

Connecting Disability Equality to Citizenship Education

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Declaration

“I certify that this work has not been accepted in substance for any degree, and is not concurrently being submitted for any degree other than that of PhD being studied at the University of Greenwich. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised another’s work”.

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Abstract

This thesis argues that the invisibility of disabled people in the Citizenship curriculum is no longer tenable. In analogue to race and sex discrimination, I use legal case analyses, together with empirically framed case studies within an international perspective, to systematically explore different aspects of citizenship. Citizenship elements range from 'legal', 'constitutional context', 'political participation', 'human rights', 'community', 'socio-economic' to 'identity and belonging'. Through a *mash-up* methodology of running voices of disabled people themselves over various themes of citizenship, the contributions, barriers and achievements of disabled people are embedded in the analysis. This includes often apparently conflicting or contradictory voices and cross-cultural discussions.

Disabled people's experiences are constitutive of, not additional to citizenship values. The work confirms that a paradigm shift is taking place in our understanding of disability, which profoundly challenges traditional models of citizenship and leads to uncertainties in professional practice. I propose a three-pillar model of inclusive citizenship, underpinned by the social model of disability, a socio-legal framework of rights-based anti-discrimination, and recognition of struggle as a political manifestation of contested ideologies. Each pillar is associated with concomitant shifts not only in individual but also in institutional behaviour, which extends to a critical examination of the law, the role of the state, social and institutional practices.

The extent to which curriculum development on Citizenship, policy ideas, resources and practices are inclusive of and accessible to disabled people, and how programmes of study at key stages 3 and 4 reference disabled citizens, is critically discussed. This leads to an outline of practice with potential that connects disability equality to Citizenship education.

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Note on presentation

As a clear print document, and incorporating principles of inclusive communication (ADEPT Transcription), this thesis seeks to reach a wider audience. The RNIB's clear print guidelines have been followed (RNIB 'See it Right' updated 2008). This means that, at times, specific guidelines in the Research Student's Handbook of the University of Greenwich (2007) have been overridden by considerations for disability and wider access. For instance, blocks of capital letters, underlined or italicised text are all harder to read. To avoid stylised typefaces, Arial font rather than New Times font is used, italics and underlining text have been avoided, headings are not centred, and pages are numbered to the right. One exception is that original text in German is written in italics, followed by plain font translation in English.

The bibliography follows similar guidelines. Italics and underlining are avoided, as are footnotes, which make it difficult to follow text. References for (a) books, (b) journal article, and (c) internet links are presented in the following way:

Barton, L. (eds) (2001) *Disability, Politics and the Struggle for Change*, David Fulton: London

Burchadt, T. (2004) 'Aiming high: the educational and occupational aspirations of young disabled people', in *Support for Learning*, 19(4), 181–186.

Full links to webpages are given immediately following the book reference, for easy of access:

Archbold, S. (2000) President of the British Association of Teachers of the Deaf, at the NCIUA Forum in Cardiff in November 2000
<http://www.nciua.demon.co.uk/kids.htm>

Oliver, M Barton. L (2000) The emerging field of disability studies: A view from Britain, paper presented at Washington DC October 2000
<http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/Emerging%20field.pdf>

Chapter 1

Why, who, what, and how?

“... there was increasing anger, hostility and suspicion among organisations of disabled people that much that passed as ‘disability research’ was nothing more than a ‘rip-off’.”

Oliver, in Barnes and Mercer (2006)

Why?

On Friday 2nd July 1999, I attended a conference at Goldsmiths College, University of London entitled ‘Preparation for Adult Life: coherent education for personal and social development?’ Much of the day was concerned with the implications of the Secretary of State’s proposals for pupils’ personal and social development and Citizenship within the revised curriculum. With a professional background in law and personal engagement in disability politics the potential for raising disability equality issues in the National Curriculum seemed obvious to me and filled me with great excitement. But the hostility to the idea that the conference topics had anything to do with disabled people left me doubting whether I had any grasp on reality. Delegates, speakers and workshop leaders, Head-teachers, Local Education Authority Advisers, Initial Teacher Trainers, all would explain in one way or another that ‘SEN’ was a specialist area. They expressed concern that everyone wanted to jump onto the bandwagon of Citizenship and stressed the importance of tightening the remit to avoid overloading the subject. “It must achieve clarity, coherence and manageability”, I was told. I felt it loud and clear, the message that disabled people and Citizenship in the curriculum did not go together. This left me wondering: What was the position of disabled people in society? And who knows? What models of citizenship are there and what does it mean to disabled people? Was disability equality relevant to Citizenship in the curriculum? And how might it be taught?

Controversy over the inclusion of equality issues or other ‘causes’ continues to date: ‘Everyone with a fashionable cause wants a piece of the curriculum.’ and ‘The school curriculum has become a battleground for zealous campaigners and entrepreneurs keen to promote their message.’ and ‘Those advocating citizenship education have cobbled together a list of unobjectionable and bland sentiments that have been re-branded as values.’ (Furedi, 2007).

Disability issues have entered academic and professional debate in education, not least due to changes in the law that require an action plan to be published, similar to Race Equality Schemes and Gender Equality Schemes. However, as Oliver and Barton (2000) note about the impact of feminist perspectives, ‘the very point when women’s studies was accepted as a legitimate academic discipline in its own right was precisely the point at which it seemed to lose its radical cutting edge.’ Whilst I believe that disability equality is a long way off from being accepted into the mainstream academic thinking and professional practice, a note of caution is nevertheless applicable. The authentic nature of disability equality is therefore explored in this thesis by listening to the voices of disabled people themselves, by unscrambling traditional ideas and examining new perspectives and ways of thinking about disability as shaped by the disability movement in Britain and world-wide. I have called this changed pattern of ideas *Denkmuster* – a term I shall use throughout - and organised it into three key principles, which together with concomitant shifts in individual and organisational behaviour - form pillars for inclusive citizenship. This model of inclusive citizenship exemplifies an uncorrupted, authentic perspective of disability equality and offers guidance on how it can be embedded into practice.

Who?

This thesis is concerned with ‘disabled people’ as understood by the social model of disability, with ‘disabled people’ as defined in UK anti-discrimination law, and with ‘disabled people’ as used by organisations of disabled people internationally. I intend to marshal existing ideas on the social model of disability (Oliver, 1990) to yield new insights in the context of a rights-based approach to citizenship and Citizenship education (the National Curriculum subject is in capital letters). Chapter 2 will explore competing understandings

of 'disability', and Chapter 3 will introduce the extended legal definition of a disabled person within the Disability Discrimination Act 1995 as amended by the Special Educational Needs and Disabilities Act 2001. My focus is on 'disability equality' and not on inclusion or exclusion, not on widening participation, not on diversity generally, and not on special educational needs provisions.

What?

This thesis sets out to connect Disability Equality to Citizenship Education. I will argue that it is not only possible to make that connection, but that without doing so the very core of Citizenship education fails to be addressed. Writers have positioned groups of people in relation to citizenship by means of a 'politics of difference', which categorises people into different groups, such as women (Lister, 2003) older people (Craig 2004) same sex relationships (Donovan, 1999) or identity (Isin and Wood, 1999). No research has yet been undertaken, however, that connects disability equality and citizenship education. Kerr (2003) examined teacher's understanding of citizenship, whilst Greenfield (1996) and Hudson (2006) are concerned with teaching and implementing citizenship education in an English comprehensive school and in a secondary school community respectively. However, they neither explicitly address disability equality issues nor include the voices of disabled people. Garbutt (2003) and Becket (2005) connect citizenship and disabled people, but not to Citizenship education. Both deal with limited elements of citizenship, Garbutt in relation to professionals' attitudes to disabled people, Becket as a struggle in social movement theory, and neither is connecting this to the constitutional legal context. In a discussion paper prepared for the Disability Rights Commission, Morris (2005) outlines three concepts that are essential in the meaning of citizenship for disabled people. I have taken account of those ideas on self-determination, participation and contribution, but have expanded the range of citizenship concepts and values as relevant for disabled people to include justice, fairness and intrinsic worth or 'the right to be different'.

In order to gain a picture of disabled people as citizens, I will first map the material disadvantage of disabled people in different spheres of life, in particular with reference to education and employment. These experiences

are linked to aspects of citizenship and a case is made that disability discrimination is endemic and systemic in our society. Disability discrimination is a 'social evil' equivalent to other forms of discrimination. Social injustice and unfair treatment based upon the irrelevant characteristic of having an impairment is as discriminatory as treatment based upon irrelevant characteristics of age, ethnicity, religion, gender, sexual orientation, marital status, nationality or race. As Citizenship education addresses 'social evil', disability discrimination cannot be left out.

I intend to establish a line of argument that leads to the view that

- Disability discrimination exists in various forms, is unacceptable, endemic and widespread.
- Society generally, and the education sector specifically, have a responsibility for action to achieve disability equality.
- Citizenship education itself needs to discharge its duty for disability equality if it is to meet its overall aim and purpose.
- The active involvement and voices of disabled people and the disability movement are essential in this process.

The concept of citizenship adopted in this thesis is loose and flexible. On the one hand, philosophical thinking about the individual and the state, about the nature of society, or about meanings of fairness, equality and justice inform the debate. On the other hand, the outcome of consultation, workings of committees and democratic processes within the specific context of the National Curriculum as applicable in the UK, draw a practical boundary around philosophical abstractions. In 1998 the 'Crick Report' (Advisory Committee on Education for Citizenship and the teaching of democracy in Schools) identified three inter-related components that should run through all education for Citizenship.

- Social and moral responsibility:
Pupils learning - from the very beginning - self-confidence and socially and morally responsible behaviour both in and beyond the classroom, towards those in authority and towards each other.
- Community involvement:
Pupils learning about becoming helpfully involved in the life and

concerns of their neighbourhood and communities, including learning through community involvement and service to the community.

- Political literacy:

Pupils learning about the institutions, problems and practices of our democracy and how to make themselves effective in the life of the nation, locally, regionally and nationally through skills and values as well as knowledge - a concept wider than political knowledge alone.

Attention has been paid in this thesis to select content areas for analysis that provide a point of contact to the content areas of the subject and teaching of Citizenship in the National Curriculum in England and Wales. Consequently, elements of Citizenship that are explored in the next chapters range from 'political', 'legal', 'social', 'economic', 'participation', 'community', as well as 'identity and belonging'. Essential, however, is the explicit inclusion of perspectives and lived citizenship experiences of disabled people themselves. Within the current debate, the rights and responsibilities of citizens as individual actors within a western democratic society appear privileged. However, this thesis provides layers of analysis beyond the individual by examining the role of the state, social institutions and social structures.

Despite different strands, Citizenship is primarily a legal concept linked to a constitutional framework for nations. These contain the ground-rules of government, of how the state can exercise its power and the role of citizens in this regard, how money is raised and prioritised for spending. Constitutions elaborate on rules and principles of living together in a civic society and the nature of these rules change over time. This can be exemplified by the Treaty for Establishing the Economic European Community (as amended) in 1957, which not only created a trading community but also established Citizenship of the Union (Article 8) where citizens 'shall enjoy the rights conferred by this treaty and shall be subject to the duties imposed thereof'. In this economic context, the rights of workers and duty of the state to protect those rights have traditionally been fore-grounded. For example, passive smoking kills 79,000 people in the European Union EU every year. In order to protect the Health and Safety rights of workers the European Commission - made up of ministers from all member states - has passed a Directive (2002/10EC) to

member states to protect their workers accordingly. All 27 EU countries have already introduced varying levels of restrictions. In March 2004 Ireland became the first country to pass a total smoking ban in its pubs and bars. On 30th January 2007 the European Commission called for a total smoking ban in public places across its 27 member states. This extends the economic remit of offices and workplaces into a social sphere or public spaces and illustrates that constitutions are 'living instruments': they are developing and reflecting changed relationships between citizens and the state within and across nations. Disabled people have organised themselves to have a voice in Europe. The European Disability Forum EDF, for instance, has as its aim 'to represent disabled people in dialogue with the European Union and other European authorities' and its mission is 'to promote equal opportunities for disabled people and to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the European Union.' (EDF)

Listening to voices, acting upon those views and involving different people in decision-making is a cornerstone of western democratic citizenship. This fails if disabled people are left out.

"Nothing about disabled people without disabled people is the motto of our movement, but also a basic principle of democracy. We will therefore continue to work at all levels to make sure that civil dialogue becomes a permanent reality in the region. It is a right we are asking for, not a favour". Yannis Vardakastanis EDF President, 19 March 2006

Basic human rights are enshrined within the first nineteen Articles of Germany's constitution: 'The dignity of man shall be inviolable. To respect and protect it shall be the duty of state authority' (Article 1 *Grundgesetz* GG). To this extent, Article 3 (3) GG deals with equality before the law 'No one may be disadvantaged or favoured because of his sex, his parentage, his race, his language, his homeland and origin, his faith, or his religious or political opinions.' It was not until 1994 that this provision was amended to include disabled people '*Niemand darf wegen seiner Behinderung benachteiligt werden*' ('no-one must be disadvantaged on the basis of impairment/disability'). This provision has been interpreted by disabled activists as meaning '*Menschen mit Behinderungen ein Leben ohne Barrieren zu*

ermöglichen 'to enable people with impairments a life without barriers' (Hermes, 1994; Heiden, 1996 ; Degener, 1995; Dahesh, 2000; 2004). Article 3(3)GG is phrased in such a way as to allow for positive discrimination and more favourable treatment for disabled people, as the phrase 'or favoured because of' in the first sentence has been removed. As to access to democratic participation France defines this in reference to national sovereignty, which is said to 'belong to the people'. 'All adult French citizens of either sex who enjoy civic and political rights are entitled to vote' (Article 3). The United States constitution lays down that 'The right of citizens of the United States to vote shall not be denied on account of race, color or previous condition of servitude' (Article XV) which was later amended to include 'on account of sex' (Article XIX). No specific mention is made of disabled people's access to vote.

In contrast to written or codified constitutions, the constitution of the United Kingdom is indeterminate, indistinct and unentrenched (that means its rules can be changed by a simple majority in parliament). There is no single document containing constitutional arrangements. The British constitution can be found in customs and traditions, sourced from the Magna Carta of 1215 and the Acts of Settlement in 1701, in decisions laid down in case law, in treatise of constitutional experts, such as A.V. Dicey, and in documents to which the UK is a signatory, such as United Nation Convention on the Rights of the Child 1989 or the Treaty of the European Union (as amended). It deals with broad issues such as law-making, parliamentary rules, central and local government decision making. A key principle of the British constitution is 'The Rule of Law' which means that the rights of individuals are determined by legal rules and not by arbitrary acts, or a failure to act, by people in authority. Britain is unique in Europe for having enacted individually enforceable anti-discrimination laws that protect disabled people in different spheres of life, such as employment and education. The framework for the teaching of Citizenship in schools has limited ability to refer to codified constitutional instruments, such as the Human Rights Act 1998. As such, emphasis is placed on legal-political values and behaviours that are indicative of the relationship between the individual, communities and the state, as outlined in western democratic constitutions. The Advisory Committee on Education for

Citizenship and the teaching of democracy in Schools outlined the aim and purpose of citizenship as follows:

“The aim and purpose of citizenship education in schools and colleges is to make secure and increase the knowledge, skills and values relevant to the nature and practices of participative democracy; also to enhance the awareness of rights and duties, and the sense of responsibility needed to develop pupils into active citizens...”

(Crick, 1998)

This thesis will critically discuss the ‘legal’ aspects of citizenship in relation to disabled people. Attention is paid to law-making and the developing legal framework in the UK of anti-discrimination as opposed to traditional legal responses of entitlement and welfare. Traditional statutory provision in education laid down informal and formal assessment or bureaucratic processes within a ‘special educational needs’ framework, which then entitle so identified pupils to additional resources or ‘special’ arrangements in order to meet learning needs. Since the passing of the Disability Discrimination Act 1995 (as amended) emphasis is placed upon duties to remove barriers to participation and a strengthening of individual rights of disabled people to fair treatment. The implementation of this rights-based law, a gradual expansion and re-definition of the definition of a disabled person and the meanings of discrimination, ensuing case law, comparison with other anti-discrimination measures, concepts of direct and indirect discrimination, of legal comparator, of reasonable adjustment and legal justification, and the relevance of the Disability Discrimination Act to the education sector are being charted.

Analysis turns to the role of the Law, underlying philosophy, inconsistencies in statutory instruments and resulting uncertainties for professional practice. A fresh perspective on the meaning of equality for disabled people and implications for action are examined. A second strand related to legal aspects of citizenship concerns Citizenship and human rights. This will be explored in relation to actual and potential redress to the Human Rights Act 1998 that disabled people can have. The ‘political’ dimension of citizenship explores disabled people’s participation in formal and informal democratic processes as well as organised political struggles and resistance. In line with citizenship

values of self-determination and respect, emphasis is placed upon organisations **of** disabled people rather than organisations **for** 'the disabled'. 'Community and belonging' directs attention to the dichotomy of interacting with disabled people as 'needing help', 'a burden on common good' or 'dangerous' on one side, and as citizens with positive contributions to make, on the other. 'Identity' and Citizenship raise issues surrounding labelling and descriptions of disabled people, categorisations and procedural responses to people with impairment, on the one hand, and questions of the self-perception of disabled people, meaning of a 'disabled identity' and coming-out as a 'disabled person' on the other. Examples will be given of how competing definitions and contradictory legal frames of references, combine with institutional discriminatory practices, and thus lead to uncertainties in professional and personal relationships between disabled and non-disabled people.

How?

All research is political (Hatch, 2002) and it is important to make theoretical and epistemological foundations clear. This thesis applies the social model of disability (Oliver, 1990; Mercer Barnes, 2005) to citizenship. Epistemologically I draw on and blend a range of traditionally distinct academic fields and construct meaning by examining multiple realities through disabled people's own voices and positions. Empirically-framed case analyses provide the key methodology in this research. These are introduced in the next section. Overall, I adopt a critical theory stance (Kellner, 2003; Scott Usher, 1999; Young, 2007) that explores the lived citizenship of disabled people. Unlike the positivist, scientific method which understands itself to be neutral or objective, a critical approach recognises that values, in particular citizenship values as outlined above, are guiding this research.

'Critical theory integrates the values of social justice into the practice of research and focuses on the manner in which injustice and subjugation shape people's experience and understanding of the world.'

LaNear, 2007: 90 referring to Endres, 1997

Likewise, Kellner (2003) regards critical theory as encapsulating the aim of social justice and an attempt to conceptualize the totality of a given field, and 'importantly make connections and articulate contradictions, overcoming

idealist or reductive theories of the whole.’ (Kellner, 2003). As originally developed by the ‘Institute für Sozialforschung’ at the University of Frankfurt in the 1920s and 30s, critical theory (Held, 1992; Habermas, 1992) that integrates political, cultural, economic, structural and psychological aspects of analysis is applied in this thesis. To achieve this, I intend to present a ‘mash-up’ of perspectives in order to understand the depths of social oppression as experienced by disabled people.

Mash-up methodology: creating a new song by use of empirically framed case analyses.

‘Mash-up’ is a Jamaican Creole term originally meaning ‘to destroy’, and in Hip Hop music this term refers to music made up entirely of different songs, different styles or genres usually considered to be incompatible. A ‘Kylie Minogue versus New Order’, or ‘Chris Isaak versus Eminem’ for instance, where one song’s vocals run over the other’s musical lines, resulting in, for instance, ‘Papa had a Rodeo’. Mash-up has been described as ‘the highest form of musical re-contextualisation’ and ‘pulls out the song’s inner essence’ (Cruger, 2006). In this thesis, I wish to pull out the ‘inner essence’ of disabled people’s voices and run these over different elements of citizenship, so that they remain continually fore-grounded. The voices are provided by using evidence directly from disabled people or disabled people’s experiences. This is achieved through the development and use of different forms of case analyses, such as embedded case study (Yin, 2003), case law analysis, and case scenarios, which are run over a multiplicity of situations and circumstances exemplifying or illuminating particular elements of citizenship. A mash-up unsettles, is unexpected, implies no previous connection, at least to the minds of people who ‘know’ the dominant melody. They know it so well. People who are ‘expert’ in their traditional well-rehearsed systems are invited to change *Denkmuster*. A mash-up version seems wrong, awkward, challenging: almost threatening. It is in this unsettling, challenging edge that mash-up methodology is akin to applying critical theory. To the purist of tradition (in music as elsewhere) the mash-up version does not appear to fit together, such as hearing the distinct voice of Annie Lennox over a drum’n’base musical line, or the ragged EMINEM over loved Beatles melody. However, the present

generation listens to the song as **one** creation, one entity, one complete whole new sound. Mash-up implies something new has been created. In this way I seek to present a new song that includes disabled people. Mash-up methodology produces a perspective with changed *Denkmuster* that is completed by the fore-grounding of disabled voices. If, in Citizenship Education as elsewhere, we don't hear that voice on every page, then the complete 'whole' version of the song has been corrupted.

To illustrate corruption that occurs in traditional citizenship discussions which fail to run disabled voices over its themes, a brief example is offered. In this introductory chapter I write about constitutions, but within mash-up methodology I need to run disabled voices over the theme of 'constitutional legal rules'. I cannot talk about the European Union Article 8 without mentioning the European Disability Forum in their own voice. I cannot look at German non-discrimination clauses Art. 3(3) GG (*Grundgesetz* Basic Law) without citing disabled people who give meaning to this legal provision. The emerging picture is more than the two parts of 'constitutional legal rules' on the one hand and 'disabled people's responses or perspectives' on the other, it tells a fuller version of citizenship in the European Union, one that shows disabled people as constituting and actively engaging, first left out and later inserted in official text, as citizens struggling and campaigning in political discourse of the 'European Union'. Thus mash-up methodology hears disabled voices not as additional ones to existing tunes, but as a constituent of a new and different song. Without it, there is no 'pure' or neutral or objective approach to citizenship, such as to constitutional issues of the European Union, only a corrupted one. There is no 'European Union' without disabled people, there is no Citizenship Education without disability equality. My proposition is that to talk of citizenship issues in an abstract space without considering its full diverse mix of people, issues and experiences of different citizens, is unsound. The picture is not so much incomplete as false. In this way, mash-up methodology employs a 'critical unmasking of dominant, hegemonic discourse' (Moore, 2007: 26), but goes beyond deconstruction in that it presents a new song on the theme of citizenship rather than merely a 'different perspective' or standpoint perspective from disabled people's point of view.

Case analyses: preparation and mapping exercises

In the preparation of the design and application of case analyses, the 'inner essence' of disabled people's voices has been mapped by (a) an extensive literature review in the fields of disability studies, philosophy, sociology, education, law and citizenship education, (b) visits, conversation and participation over three years (and ongoing) with disabled people, organisations of disabled people and institutions for disabled people in Britain and Germany, and (c) a review of equalities case law (race and sex), comparative legal provisions (in common law and civil law countries) and monitoring of developing disability discrimination case law in Britain and human rights law in Europe. This preparation has been a considerable, time-consuming task, 'given that no aspect of community life is irrelevant to citizenship' (Copeland, 2005).

Ethical dimensions have been observed throughout and research was conducted in a manner that respected all participants (DRC, 2006). Disabled people's voices are polyphonic, discordant, and international. They range from disabled academics (including Abberley, Aspis, Barnes, Booth, Degener, Ewinkel, Hermes, Morris, Mason, Oliver, Rieser, Shakespear), to 'ordinary' disabled people of different ages and backgrounds, cultural practices, religious beliefs, sexuality, and with different levels of political activism (for ethical reasons they remain anonymous unless specifically agreed to be included by name). They include individual disabled people (such as Chapman, Devenney, Finch, Fitzgerald, Grieveson, Puresh, Ward) and organisations of disabled people (including Adept, the Association of Young People with ME, BAG Selbsthilfe, the British Council of Disabled People, the British Deaf Association, Club '82, Disability Awareness in Action, the European Disability Forum, the Federation of Deaf People, Greater London Action on Disability, Direct Action Network, DP Consulting, Lebenshilfe, Trade Union Disability Action, the Association of Disabled Professionals, the United Kingdom's Disabled People's Council), disabled politicians (including Lord Ashley, President R.D. Roosevelt, Dr. Manfred Schmidt, Volker Langguth-Wasem), disabled teachers and trainee teachers. Illustrative material from Germany and other international contexts is presented to complement the

picture at a European and more global level. The voices are taken from both published material and unpublished material, as written voices and oral evidence, such as views collected during the 'Access To Leisure And Services' ATLAS project, conversational interview data of disabled students in Higher Education, and responses during Disability Equality Training sessions (see Chapter 2 'At the Schoolgate' for details).

In an effort to *connect* disability equality issues to Citizenship education, searches have been undertaken to find freely available and accessible authentic voices of disabled people and their experiences, rather than creating more data of such voices. Disabled people have been 'speaking for themselves' for years, but the necessary connections have not always been made. Particularly fruitful in this regard are websites of organisations of disabled people, in Britain, Germany and internationally, the online accessible Disability Archive UK (Centre for Disability Studies, Leeds) and 'soft' data which had been collated through research diaries during extensive networking activities and in my role as Disability Equality Consultant. Furthermore, voices in qualitative and quantitative research that has been conducted by the Disability Rights Commission (such as Hunter et al, 2007; Lewis et al, 2007; Stanley, et al 2007), voices on 'Speaking for Ourselves', and other organisations that operate from a social model perspective are permissible, but disabled people's reported views, if not quoted directly, as for instance summarised in Disability Equality Schemes, are approached with caution, as are disability experiences as reproduced in judicial reasoning, or by professional 'experts', since neither of them is a first-person account or authentic voice.

Case analyses: case study, case law analysis, and case scenario

In this thesis a 'case study approach' is not simply equated with 'qualitative research', since both quantitative and qualitative elements are used to frame and run disability voices over themes of citizenship. I apply three varieties of case study method in a 'teleological' sense, primarily to illuminate, to reveal not so much inadequacies, but a different picture. The aim is to *connect* disability equality to the concerns of educational practitioners in Citizenship Education. A dichotomy of quantitative and qualitative methods is not helpful

as it fails to provide a meaningful distinction when finding out about disabled people's lived citizenship experiences. Commissioned to examine Australian policy and research on 'access', Yates notes that:

'Questions have been raised as to whether 'participation and access' can be assessed simply by counting who is in school or whether these relate also to the experiences of students in schooling – in one sense a qualitative matter, but a matter whose existence is demonstrated in measurable differences in post-school careers of different groups.'

Yates, 1990:1 quoted in Yates, 1997: 490.

Therefore, in Chapters 2 and 3, I focus on aspects of citizenship in employment and education with qualitative data on the material position of disabled people, such as access to education and employment opportunities, to health, housing or support networks, level of income and poverty, setting the scene for the case examples. In the AA Centrica case discussion, disabled people's action is embedded in a broader context of employment structures. Several stories are concurrently presented. Disabled people's voices, of those who are exercising political citizenship through protest and demonstrations, organised forms of disabled people's voices through the Disability Rights Commission and Trade Unions, as well as disabled people's action in taking recourse to the law, are run over the expanding and contracting economic 'pulse' and context of the business (AA Centrica). The case analysis is expanded by reference to disabled academic voices in their critical writing (e.g. Abberley, 2002). Equally, in Chapter 5 the question is raised: how are people with learning difficulties enabled to fulfill their citizenship duties as parents? It is not enough to count how many disabled people have their children taken away, although the fact that this empirical evidence is available and the stark numbers provide the British context for the Kutzner case law analysis.

Following Yin (2003) the 'embedded case study is an empirical form of enquiry appropriate for descriptive studies, where the goal is to describe the features, context, and process of a phenomenon'. A critical analysis, however, and the rigorous application of the social model of disability, go beyond description and begin to make sense of facts, narratives and case presentations. The scope of my thesis does not allow for great detail on each

single case study. These are of necessity narrowed or sketched in outline, in order to present a disability voice over a *particular* citizenship theme, such as the theme of 'useful economic participation', 'political engagement', 'democratic participation' or 'identity and belonging'. However, the totality of single and embedded case studies together with voices of disabled people from a very broad range of empirical sources performs the function of triangulation and thus increases the validity of the study. This richness provides persuasive evidence of both the need for and a method of connecting disability equality to Citizenship Education. The main methodology of this thesis can thus be characterised as 'critical thinking' with the active involvement of disabled people.

Mash-up methodology and the role of law

Case law analysis is a specialised form of case study conducted by way of a text-based critical discourse analysis of legal reasoning and its impact within the educational context. Reported legal cases are not easily accessible. I have used open access summaries provided by the Disability Rights Commission, but mainly accessed case law through Lexis/Butterworth data bases (online <http://www.butterworths.co.uk/> and <http://www.lexisnexis.co.uk/>). Three main legal case analyses are presented in this thesis. The first one deals with case law as text and examines the traditions imported by the common law method of *stare decisis* and the application of a *ration decidendi*. The second case law analysis deals with a seminal decision that illustrates the meaning and interpretation of welfare legislation for disabled people. It concerns a case brought by Mr. Barry against Gloucestershire county council regarding their interpretation of 'assessment of need' under the National Health Service and Community Care Act 1990. As with AA Centrica, this case also provides a view of how the 'pulse' of contracting and expanding economic condition affects the legal definition of welfare needs, and in this way adversely impacts upon citizenship themes of self-determination, respect and capacity. A third case law analysis, in Chapter 5, examines the working of a particular legal provision. The 'case' under discussion concerns the role of the state as enabling or constraining individual capacity regarding citizenship responsibilities. The meaning and interpretation of Article 8 of the Human

Rights Act is examined as an embedded case study in the context of the experiences of the family Kutzner in Germany, who are disabled people with learning difficulties whose children had been taken into care. Furthermore, case decisions from the developing Disability Discrimination Act as they relate to education are examined in Chapter 4. In these examples, the 'case' is a particular decision or legal rule and the analysis draws out and decodes underlying messages about disabled people and dilemma or conflict in current professional practice. The cases have been selected on the basis of legal significance. They demonstrate notable developments in new legal provisions as enacted by the Special Education and Disability Act 2001, and for that reason several cases were supported by the legal team of the Disability Rights Commission.

In all legal case analyses, I question the role of law and present a critical perspective to the idea that law evolves progressively into a successful tool to achieve disability equality. In teaching Citizenship, the law and legal aspects will have to be covered (Thorpe, 2007). My approach to Citizenship Education is a socio-legal-political analysis. These case studies show that a 'neutral' approach in presenting the law is problematic. I agree with LaNear (2007) that: 'traditional historical narratives can serve to mask injustices that exist beneath a celebratory surface of statistics, legislative enactments, and judicial decision-making that may present an impression of continuous progress.' (LaNear, 2007: 89)

Finally, the tool of a case scenario has been employed in order to show the extent to which disability equality is similar to and distinct from anti-discrimination laws in race and sex discrimination. Drawing on actual decided cases and relevant case scenario material, I am arguing by analogy to institutional racism and indirect discrimination as experienced by women. Equally, based upon a series of actual cases brought before the courts, the dilemma of 'equal treatment' has been abstracted into a 'Winston' case scenario (developed from Adept material), which is then run over philosophical citizenship themes of 'fairness' 'equality' and 'justice' in order to connect disability equality to Citizenship.

Rehearsal and final design stage

Initial ideas about connecting disability equality to the concerns of educational professionals had been presented to an international audience in Belgium, The Netherlands and England (INSPIRE project by University of Greenwich, Bill Goddard). This experience shaped in particular Chapter 4 on the history of oppression and resistance in education. Consequently, I developed a very clear focus on disability equality rather than 'special needs' or 'inclusion'. Following a review of initial stages of the implementation of Citizenship in schools, I decided that the overall approach of my writing should model how existing data and accessible disability voices can be connected to the aspects of Citizenship Education. All of the case study approaches can at best be generalised to theory and not to particular 'subjects' (Yin, 2003: 10). Unlike ethnography or life-histories, my case studies do not have 'disabled people' as their subject, but have disabled voices as their context. I model mash-up methodology on themes of citizenship, which are immediately transferable to educational practice, such as on the themes of bullying, issues of abortion and pre-natal testing, school uniforms, elections and voting, school council, role of the media, identity and what it means to be British, community involvement, active citizenship and different forms of political action. Evidence about disability voices is presented in multi-modal fashion with the inclusion of or reference to a small number of photographic or pictorial representations (such as images of the various statutes of President R.D. Roosevelt, Alison Lapper), reference to a DVD ('TALK' by the Disability Rights Commission with 93% disabled cast), poster campaigns ('Are we taking the DIS?' as part of the disability debate) and interactive internet resources designed by young disabled people (such as the Youth Web and VERVE) or online access to video talk of people with cerebral palsy in their own voice (Speaking for Ourselves) as well as personal stories of disabled athletes in the Paralympic team (Ability vs Ability). In combination this results in a rich tapestry of disabled people's own voices, which empirically draws together a wide range of data sources and provides a context for clear thought on citizenship issues.

Chapter 2

Disability Models in Education

As with any social science concept, there are competing understandings and meanings of key terms, and 'disability' is no exception. In recent years, the politicisation of disabled people has brought this difference, a sense of grievance, and growing conflict over perspectives to the fore. Struggles extend not only to the social meaning of disability, but also to its application and relevance to policy and practice. In particular, the developing legal framework as relevant to the field of education is witness to this struggle over perspectives. The field of 'education' remained outside the reach of anti-discrimination legislation, even six years after the original Act was passed (Disability Discrimination Act 1995). It was not until further political action and grass-root agitation from disabled people themselves that the incorporation of an amendment in form of the Special Educational Needs and Disability Act 2001 was achieved.

This chapter begins by outlining the traditional view of disability and explores its impact on disabled people, their families and friends, schools and the wider society. The scene is set by a short narrative vignette. The technique of visualising a particular scene, as directed by a training facilitator, and imagining responses to that scene, has been employed in disability equality training with a range of clients, including teachers, young people, parents and educationalists. This data is drawn from training events over a period of four years (Greater London Action on Disability with Adept, ATLAS project 1999 - 2003) reaching an audience of over 6500 people. An analysis of typical responses (collected on flip charts and in research notebooks) to the scenario 'At the School Gate' forms the basis for discussion of dominant understandings and images of disability.

Having explored 'typical' gut-reactions, the Disability Equality Training session moves through layers of re-contextualising 'disability' to reach a level of understanding that corresponds to the 'social model'. These techniques are not reproduced here. Instead, the social model of disability is introduced through the voices of disabled people. It has its roots in the disability movement and is thus associated with disabled people's own perspectives. With reference to the international disability movement and its activities in Britain, together with published voices from disabled academics the challenges of the social model of disability are detailed.

Whilst I am aware of various critiques of 'the social model', both from disabled thinkers and non-disabled academics, I am primarily concerned with moving away from a functionalist account of disability towards a recognition of material inequalities, which are reflected in and sustained by institutional structures of oppression. The impact of a social model understanding on the experiences of disabled people is illustrated, in particular, in relation to self-perception and identity. A preliminary conclusion about the social model of disability and its relevance to Citizenship in schools is drawn. Rather than a complete conception of 'disability' the social model is seen as a tool for achieving conditions for full citizenship of disabled people. The chapter closes with a brief overview of the Disability Rights Commission Citizenship Pack (2000), but ends with a cautionary note about 'hidden' barriers that require further analysis.

At the School Gate

In order to set the scene of how traditional thinking defines disability and anticipates its impact, a short scenario is given below (adapted from Eileen Finch, Adept). The reader is then taken through a series of typical responses given by delegates. These responses are critically discussed. They illustrate a strong dominance of the traditional (individual-medical) model of disability. This is the scenario which is used to trigger responses and delegates are asked to picture this: "Parents and children at the school gate, chatting during the usual morning and afternoon pick-up times. This social scene is replicated up and down the country, at many different schools and in

diverse communities. Imagine a context closest to your own situation. “Your neighbour Aisha, who is eight months pregnant, drops off her ten-year-old boy Sanji. As usual, she stops to chat with you and other parents at the gate. Sanji is friends with your daughter, Lilly. (pause) One morning, Aisha did not arrive at the school gate. Instead, Aisha’s partner Elizabeth took Sanji to school. On arrival you asked why Aisha did not come herself and were told:

‘Aisha had to go to hospital.

She has had the baby early.

The baby is disabled ‘. “ (pause)”

What do people say, think or feel about this event?

Disability Equality Training run by disabled people themselves has followed a standard methodology since its early beginnings in the 1960s (BCDOP; Campbell and Gillespie-Sells, 1991; commentary from Eileen Finch at Adept, 2001) in order to activate change processes both for individuals and within organisations. In common with other anti-discriminatory professional development work a first step is to ‘unpack’ commonly held views and attitudes. As a training consultant for Greater London Action on Disability (GLAD) with Adept, I have employed the school gate scenario at the beginning of Disability Equality Training (DET) in order to elicit traditional responses to disability as prevalent in society. As part of an interactive training approach the activity seeks to engage the affective aspects of a whole person rather than merely call for an intellectualisation of issues. Typically, DET training is conducted as a one-or two day event with a group of up to 12 delegates (cf. Adept running DET for GNER railways, 2002 – 2004; Greater London Authority, 2003 ongoing), although it can reach larger audiences (such as Conferences, Cranfield University 2001). Delegates drawn from industry, leisure, public and private sectors, as well as education engage with disabled facilitators. DET has proven to be particularly effective in attitudinal change with disabled trainers, who have a less obvious impairment (Tooke, 2002: 19-20). I will also draw on evidence from a small number of MA students in Education Studies taking modules, which I have facilitated, such

as 'Special Educational Needs' or 'Inclusion'. The group size was much smaller, but left more space for discussion of personal and direct experiences. Using 'brainstorming' techniques (Osborn, 1953), characterised by a laissez-faire approach free from evaluation and judgement, fast responses and one word answers were invited without censoring. I have not moved into 'thought shower' or 'mind map' or 'blue sky thinking' but prefer the descriptive term of brainstorming. People with epilepsy through their organisations have not shown offence by the use of 'brainstorming'. In a survey in 2005, 93% of respondents with epilepsy did not find the term offensive (Epilepsynse, 2005). Epilepsy Action notes:

"Our view is that it depends upon the context: if the word is being used to describe a meeting where participants are suggesting ideas, then its use is not offensive to people with epilepsy."

The issue may have been 'hijacked' by concerned non-disabled people, as one disabled person reports:

"I am a member of the British Epilepsy Society and the consensus there is that there was no pressure from the community to challenge the term, yet someone has taken ownership of this concern somehow thinking they know better than the community concerned." (TES, 2005)

For this training activity, the question to be addressed in each case was: What do people say, think or feel about this event? With the inclusion of 'thinking' and 'feeling', both cognitive and affective responses are sought, and in contrast to 'saying' the unspoken world of 'thinking' and 'feeling' looks beyond the immediate public sphere of what can be observed to the private sphere of what else might shape peoples' responses. Every contribution was noted on flip chart in the language used by delegates themselves. The following summary is based on an analysis of feedback collected from over 6250 delegates. This is not intended as a 'scientific analysis' into society's attitudes, but rather serves to map dominant, recurring themes.

A typical list of key word responses can be represented as follows:

Shock

what's **wrong** with it?

What a shame.

Why did it happen **SORRY** how can I help Devastating
Who will look after it? **Embarrassed** isolated **FEAR** **Unsure**
Blame the mother did she smoke? How **badly** damaged is the baby,
People stare **feel angry** What's wrong? How disabled is the baby?
I am glad it's not me! Is the mother alright? Empathy. *ever so sorry.*
What a pity! **Don't know what to do or say to her,** feel upset
Avoid seeing Aisha Cross the road when I see her coming.
Bullying at school **l o o s e** his friends *many* years of difficulties
Sad **helpless** hopeless (...pause...) **Sanji will be neglected.**
go to a special school Sanji may develop behaviour problems
Emotional support. **Need social worker** need psychologist
Can you operate on the baby? they will struggle **Have to change school**
One child is normal needs many things, needs **to fight** to get them
Is there a cure? **God** is punishing the family for sins ...
 What is the child's name? Will mum have to give up her job?

Fig.1: Typical set of responses to 'At the School Gate'

Dominant understanding of disability: Tragedy

What are the first words that come to mind? Without fail in every training session delegates quickly listed responses of key words which fell within a tragic framework. 100% of the flip charts display this perspective, exemplified by words such as 'shame', 'sorry', 'shock', 'sad', 'devastating'. Delegate's own facial expressions and tone of voice often accompanied these responses in line with the perceived personal tragedy that has struck.

In around a quarter of training sessions, there was a member of the audience with personal experience of having been told that their child or grandchild was disabled. Their stories confirmed these negative images of disability as a personal burden to be borne, something to be ashamed about and to be hidden. Every parent who shared what happened when they found out that

their child was disabled had very similar stories to tell in respect of their relationship with medical and hospital staff.

For reason of confidentiality specific details are not reproduced here, but their initial experiences can be illustrated by published example. A particular instance given by Carmen Ramirez, describes an interaction with medical staff leaving her with a sense of guilt, a compulsion to keep her baby 'out-of-sight' and outrage at the changed relationship with the world around her :

"About two hours after Danny was born, the neo-natalogist came into my room and told me I had a 'Mongoloid son'. I didn't take it very well. My husband Alfredo and I went out to the nursery to look at Danny.

The nurse thought she was being well intended and said "Do you want your son at the window where everyone can see him, or do you want him away from all the other babies where nobody can see him?"

(Mason, 2000: 34-35)

Delegates, who were parents of a disabled child or occasionally grandparents, told of the coldness and sterile nature, the looks of sadness and sympathy that were displayed towards them when the message had been delivered, and many recalled a string of medical terms they did not understand, explanations culminating in predictions of dim future prospects for the health and well being of the child, as well as having received unsolicited advice about giving the baby up for adoption.

Parents of children with learning difficulties, children who may have Down Syndrome or brain injuries or other impairments, reported early conversations with medical consultants who did not see a future for their son or daughter beyond a certain age. Some parents felt very frightened as they had no contact with or experience of children or adults who were disabled and did not know what to expect. A current initiative by SCOPE (Speaking for Ourselves) is seeking to find out the experiences from the disabled children's (now adults) own point of view. Jill, for example, mirrors the concerns which parent delegates had shared during the training:

"When I was born with cerebral palsy, the consultant advised my mother to put me away in an institution and to have another baby and forget about me." (BBC news, 12th Feb 2005)

“My mum was told very bluntly that I had brain damage and it was highly unlikely that I would grow up to recognise my parents, that I would never walk.” (SCOPE, Joan Ross)

On two occasions delegates stated that they had been advised to withhold medical intervention, which would be given as standard to any other baby. Recent legal history has been made by cases going to the House of Lords where parents and medical experts disagree over what is in the best interest of a disabled or seriously ill baby. This struggle is played out in the legal arena as well as the media. The BBC, for example, reported that Dame Elizabeth Butler-Sloss, president of the High Court Family Division, ruled that doctors can withhold treatment if baby Luke Winston-Jones' condition worsens (BBC news, 22nd Oct 2004). The case followed that of Charlotte Wyatt, where doctors and the family also disagreed over what was best for the baby. In Charlotte's case, the High Court equally backed the doctors treating the 11-month-old baby, who wanted permission not to resuscitate her as they judged her quality of life as so poor as not be worth living.

The reporting of such cases in the media is firmly rooted in language of the individual model of disability focusing on ‘what is wrong with baby Luke?’ and using language of pity, deficit and severity of impairment. The articles describe conditions as ‘severe chromosome abnormality’, ‘growth deficiency, and ‘low-set and malformed ears’, giving details of clenched hands, bone abnormalities, hernias, skin mottling, heart defects, feeding and breathing problems in infancy and learning disability, and the effects of serious cardiac defects. Independent advocates need to be appointed in hospitals to act in the interest of premature babies (SCOPE, 2005). A charity, which represents people with cerebral palsy, fears some babies are being denied life-saving treatment and is concerned that doctors and parents may be using statistics on the chances of extremely premature babies developing an impairment or condition to withdraw basic medical care from them (BBC news, 30th July 2005). Currently available data suggests that just under 50% of premature babies may be developing an impairment, or what in the media has been termed ‘mild to severe disability’ (Epicure, 2005). The study has been following the lives of 300 extremely premature babies over six years and has found that just under half have developed impairments including cerebral

palsy and autism. The debate has gathered pace and arguments which deem these disabled lives as 'not worth living' have reached a crescendo. The question of what constitutes 'life worth living', of who should have the power to decide and conflict over allocation of resources was essentially what delegates shared when reporting their experiences. Medical experts would stress problems and difficulties, and paint a rather bleak future. Mason (2000) summarises the collective experience of parents in these circumstances:

'Many parents of disabled children talk of the moment of disclosure – the time they were told that their baby had an impairment. They talk about being isolated from the rest of the ward, curtains, embarrassment, clinical language they did not understand, an aura of sadness, disappointment and commiseration. Then they are sent off home to come to terms with their tragedy.' (Mason, 2000: 36)

Further responses reveal that the perceived personal tragedy is extended, by proxy, to the immediate close relatives and friends. In this regard, concern soon turned to the mother, and how she must be sad and disappointed and experience a sense of 'loss' of the 'normal baby' she should have had.

Overall, there were 35% of delegates who regarded themselves as disabled, however only around 1 in 25 of these delegates offered an early contribution which disclosed their status. Disabled people often remained silent.

Delegates, who did speak up and were themselves disabled, shared many personal experiences which affirm the ideas and dominance of 'a personal tragedy theory of disability' (Oliver, 1990: 1) together with the dominant role of medical experts in much of their life. Virtually all of the disabled delegates had acquired their impairment rather than having been born with it.

'Adjustment' to this unforeseen or sudden event and the diverse ways of 'coping' identifies aspects of the tragic perspective for disabled delegates themselves. Many of the key words, such as 'shock', 'victim of', 'loss', 'no longer able to do' symbolise their initial confrontation as a disabled person. Various psychological theories concentrate on how an individual adjusts to loss and change (Kubler Ross 1965; Hopson Adams, 1976; Bridges, 1995). Hopson and Adams (1976), for example, concentrate on how the changes impact upon an individual's self-esteem, and have suggested seven phases of transition. Their argument is that all individuals go through similar experiences

when confronted with loss, which can be represented in a cycle of transition. Initially a sense of being overwhelmed and unable to act takes over, characterising the stage of immobilisation. This is followed by stages of denial and depression. According to Hopson and Adams (1976) a frequent reaction to a crisis is to deny that it is happening. This label of 'being in denial' has often been applied to disabled people, who simply want to get on with their life, who want to work or want their disabled children to attend mainstream schools. A further associated and necessary phase, according to the psychologists, is one of 'letting go' and 'accepting reality'. In this stage the individual in transition is required to let go 'of their old state of being'. When experts, such as educational psychologist or teachers, adopt this kind of thinking and apply it to disabled people the interaction can be premised on the idea that it is necessary to accept the reality of what is happening, 'come to terms with their disability'. If they don't, disabled children and adults alike might be labelled as 'having a chip on their shoulder' resulting from their impairment, for example because they can't get used to being blind, are embarrassed for having a speech impairment, or can't walk 'normally'. Aspirations, ideas, expectations, assertion can thus be crushed by defining the disabled person's responses as 'being in denial' 'unrealistic' 'unmanageable'. At school, for example, disabled children have experienced career advisers who essentially told them not to expect too much, that someone with cerebral palsy cannot study psychology (Devenny, 1992), that the girl with one arm cannot become a nurse, that her friend with short arms, or the other one wearing callipers, will probably never get married and have children (Ewinkel and Hermes, 1996). Disabled school children have repeatedly been told that their dreams of becoming a football star, a doctor, a hairdresser, a pop idol were unrealistic, (O'Mahony, 2001; ALLFIE conversations) in contrast to children who are not disabled. These children tend to be encouraged to dream of becoming Prime Minister, a famous lawyer or brain surgeon. Usually children are allowed to expand their imaginations in play-acting fantasies becoming a fire fighter, beautiful princess, a famous writer, astronaut or saving the world as superhero (Chapman, 2002), but the 'application' of psychological models of loss and transition within an individual

conception of disability acts to reduce both independence and opportunity for disabled children. Aspirations are stifled.

Models of grief when applied to the situation of disabled people also assume the tragedy position in that it is taken as a fact that there has been a 'loss' of some kind and that the reduced opportunities that a disabled person may experience in life is as a result partly of that loss and partly of their individual way of coping with that life change.

Dominant understanding of disability: Blame

Initial responses within the tragic perspective, although never subsiding completely throughout the day (even after the school gate activity had been concluded), generally gave way to consideration of the role of the mother and her and the baby's position in the community. Messages, though, bore a double edge; concern on the one hand and blame on the other. Under the first message came responses, such as 'poor Aisha', 'how will she cope', 'is the mother alright?', 'what can I do?', 'does she have anyone to help her?', whilst the second set of messages was searching for blame 'why did this happen?', 'did she smoke/ drink alcohol/ take drugs?', 'is it because they were in a lesbian relationship', 'did she have a healthy lifestyle/ healthy diet?', 'where is the father?', 'punishment from god'.

Message of blame and the message of 'evil' can be discovered in Judaeo-Christian belief systems, and has equivalent manifestations in other religious thinking. I argue that despite an increasing secularization of society and evidence of a reduction in religious practices with a decline of religious belief and worship in contemporary western society (see for instance Bruce, 1995; Davie, 1994, quoted in Thompson and Woodward, 2004: 66 - 67), the underlying roots of knowledge about human experiences and its ethical content still shape ideas, fears and behaviour. In his brief history of discrimination against disabled people Barnes (1991) points out that the *Malleus Maleficarum* of 1487 declared that disabled children - 'changelings' or 'the devil's substitute for human children' - were the product of the mother's intercourse with the Satan.

These legitimated beliefs within powerful religious establishments were by no means restricted to the middle ages. The creation and perpetuation of knowledge about disability within religion continues through time. Barnes

(1991: 12) confirms that 'only lately have people with learning difficulties been allowed to receive some sacraments in the Roman Catholic Church'. Winzer (1997) informs us that John Calvin preached that people with learning difficulties and those with impairments such as slurred speech, hearing impairment or cerebral palsy, which were taken to indicate a 'feeble mind' at the time, are possessed by Satan. He refers to Kanner, who searched for characteristics of Autism (1946):

'Martin Luther was of the opinion that such a child is merely a mass of flesh (*massa carnis*) with no soul (Kanner 1964). Luther further subscribed to the belief that the Devil is the father of idiots; he denounced the mentally handicapped as "filled with Satan" (Barr, 1913: 26) and even suggested that one child be taken to the nearest river and drowned (Kanner, 1964).' (Winzer in Davies, 1997: 94)

Delegates from diverse religious and ethnic backgrounds, including delegates who do not see themselves as practicing religion, offered examples of powerful cultural influences on how disabled people are viewed, and thus what people might say, think or feel as a response to the school gate scenario. Sometimes delegates would seek to speak to the facilitator at break time to share what they saw as particular barriers in their particular culture. One delegate, who was a head teacher in a south London secondary school, reported her religious beliefs in some detail. This included seeing many of her pupils (who were identified as having special educational needs) as 'possessed by evil' or 'having lost their souls' (1999).

Some societies have placed a person with an impairment 'closer to God', whilst others have seen strong association with Satan. Oliver (1990: 19) reports on the findings of Aall-Jilek's study in 1965:

'Epilepsy is for them something dramatic, frightening and inexplicable. It must therefore be a spirit who has taken possession of the patient. Some epileptics may be regarded with a certain degree of respect on this account. They even can become a *mganga* should they not be too much affected intellectually. But mostly the spirits possessing them is supposed to be evil.' (Aall-Jilek, 1965: 64, quoted by Oliver)

A further theme is that of retribution or punishment for the sins of the father or mother or the kinship family. An example is given where evil and impairment

are associated by the Masai people of Kenya. Talle (reported in Ingstad and Whyte, 1995: 62) explains: 'A term sometimes used with reference to a deformed child is engoki (sin), meaning a child with 'bad luck'. The term implies that there is some kind of inherited sin within the family.' Perhaps spurred into action by the International Year of Disabled Persons in 1981 and the United Nations Decade for Disabled Persons in 1983 anthropologists had begun to research and write about disability in diverse cultural contexts. In 1990 the journal 'Social Science and Medicine' devoted a special issue on cross-cultural perspectives on disability. Researching attitudes towards people with learning difficulties in non-Western cultures, Egerton (1985) has been quoted as finding great variations, 'from negative discrimination, to acceptance, and even to the positive attribution of supernatural powers' (Ingstad and Whyte 1995: 4). Whilst religion or reference to a higher power represented only around 2% of the responses on flip charts, once an opportunity for discussion was given and contributions were invited the subsequent statements, feelings and opinions were strongly held, hotly contested and vigorously defended.

There was a considerable number of responses which blamed the mother's behaviour, such as smoking, eating the wrong food, drinking too much alcohol, asking for and using prescribed drugs, or consumption of illegal drugs. Her moral code of conduct, sexuality, religion was also questioned; including having a lesbian relationship, not being sociable or not going to church. In each case, her failure to display an adequate level of individual responsibility is said to have led or contributed to the event.

One particular type of response questioned whether she had undertaken all the relevant pre-natal tests. Discussions on choosing to continue with a pregnancy once it is known or likely that the baby will have an impairment were generally agreed to represent irresponsible personal decisions. The overwhelming impression was one of avoiding any form of disabled life, if possible, although once a baby with, for example, Down Syndrome, was born, it should be welcomed. A disabled life as 'a life not worth living' is also a message hidden in some ante-natal screening practices. Disability Awareness in Action (1997, 2000) has reported consistently on the increasing pressures being put onto parents to ensure that the pregnant mother is undergoing all

relevant checks so that any 'defects' and forms of impairment might be detected. Current debates in the disability movement and Deaf community vehemently oppose the proposed changes to the Human Fertilisation and Embryology Bill, because

"It restricts the reproductive liberty for citizens who possess specific characteristics, including deaf people. (and) It prevents the birth of certain kinds of people, including, but not limited to deaf people."

(British Deaf Association, 2007)

In particular, this concerns Clause 14, section 4, number 9 (Lines 23-30, Page 10), which reads:

'Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—

(a) a serious physical or mental disability,

(b) a serious illness, or

(c) any other serious medical condition,

must not be preferred to those that are not known to have such an abnormality.'

Frequently, the reported narratives by delegates were accompanied by pressure to terminate pregnancies where a disabled foetus had been confirmed.

'Perhaps the most intrusive, violating and invalidating experiences, for disabled people, emanate from the policies, practices and intervention, which are justified and rationalised by the personal tragedy view of disability and impairment. The tragedy is to be avoided, eradicated or non-disabled (normalised) by all possible means. Such are negative presumptions held about impairment and disability, that the abortion of impaired foetuses is barely challenged.'

(Swain and French, 2000: 153)

In contrast to individual responsibility, there were no recorded responses which attributed the event to 'bad luck' 'one of those things' or other general reason, all blame - if mentioned - lay at individual action and individual choice. Similarly, no response offered a cause for celebration of the event, such as stating that it was 'good luck', 'an opportunity', 'a gift'.

Dominant understanding of disability: Charity

In Western culture, charity has grown as a response to disabled people having been rejected by families and communities and living at the edge of cities begging for alms. Delegates felt it important to consider how to offer support to Aisha and her family, they wanted to feel better about what had happened by helping, but also felt personally overwhelmed and helpless under the circumstances. There was general agreement that some kind of welfare approach would be useful and an acknowledgment that it might be very difficult to get the required resources, such as specialist speech therapy if that was what was needed.

With the dominance of a bio-medical understanding of the 'tragedy' of disability, the social response is linked to established charitable activities, with organisations for disabled people usually being divided into separate impairment categories (such as for the blind, for deaf, for people with learning difficulties). This institutional representation of a traditional view of disability is seen as a hindrance to the citizenship of disabled people themselves.

Disabled people become the objects of pity rather than the subjects of citizenship rights, they become recipients of special resources rather than contributors to the production of wealth.

'Instead of enabling us to participate on an equal basis in our communities, charities separate us out into categories based on medical definitions of what is 'wrong' with us. Charitable organisations are founded on an unequal relationship. Money is raised on our name, through the creation of feelings of pity or fear, and it is spent on things which non-disabled people deem to be 'best' for us. (Morris 1992: 8)

The disability movement adopted a slogan of 'Rights not Charity' (BCDOP) in order to draw attention to the view that disability invokes a range of civil rights issues. However, organisations run by disabled and non-disabled people also fight for equal rights (cf. Time to Get Equal campaign, Scope). Coyle (2005) argues that pressure of disability as a rights issue, rather than a concern only for charity or pity must continue to be applied to politicians and decision-makers, especially in light of the establishment of a single equalities commission. These follow early concerns over the question of distribution of

resources on grounds of charity and entitlement rather based on rights, which requires fundamentally re-orienting priorities on how our capabilities and resources are used.

'With the cutting back of public service, charities have become more important. There is an increasing reliance on charitable benevolence to provide very basic services and opportunities. This is the 'charity trap': we are forced to plead poverty and suffering, forced to beg for our share of the money that is raised in our name, forced to collude with undignified images of our lives.' (Morris, 1992: 10)

Within this perspective, a charity approach to disability is a barrier to full participation and citizenship for disabled people since it is based upon patronising and condescending behaviour patterns and has removed democratic rights to equally valued independent participation. Disabled people also make a distinction between organisation for and organisation of disabled people, with the former being 'charitable' in nature and the latter linked to 'self-determination', a central facet of citizenship.

Dominant understanding of disability: Bio-medical condition

Responses that concerned the baby directly were generally in the second half of the feedback time. Delegates turned their thoughts to the baby directly, but often only after a short pause, after re-reading what had been put on the board thus far. Questions were then directed at the baby's condition, with the responses displayed on 100% of flip charts falling broadly under 'What is wrong with it?' and 'How disabled is it?' The issue here is that delegates framed the enquiry in language that focuses on the biological and medical aspects traditionally associated with disability. The concerns indicated that the baby was somehow 'falling outside the norm', 'having something wrong with it', 'having some kind of medical condition', 'lacking in function and ability', and that the level or severity of its condition can be measured, in fact that it is somehow important to know 'how much' of it there was. The messages also confirmed that the baby was 'not one of us', and more generally, that it was 'a disappointment'.

'Where is the child in all this? – the unique individual who came into the world expecting a fanfare and champagne, only to find tears and disappointment?' (Mason, 2000: 37)

There was a keenness to know just what and how much was 'wrong' with the child, and this was often expressed under the guise of therefore being better able to help, 'if the epilepsy is not so bad they have medication for that', 'it makes a difference whether only the finger or the whole arm is missing', 'with mild cerebral palsy conductive education has been very successful and they can walk almost normally', 'some children with brain damage are only vegetables and not much can be done'.

Vic Finkelstein reminds us that the way a disabled person is viewed, and views themselves, influences the way they are treated and services are organised (1993).

'Seeing oneself as suffering because of an impaired body or function could lead to demands for assistance to become as 'normal' as possible.' (Finkelstein, 1993: 9)

In this way medical intervention, rehabilitative or educational support can be viewed as a form of social control by masquerading as being in the interest of disabled people. This is exemplified by experiences reported by disabled women in Germany in a book by disabled women about disabled women (Ewinkel and Hermes 1992):

"Damit wir trotz unseres körperlichen Defekts ästhetischen Vorstellungen nahekommen und unsere Mängel nicht auf den ersten Blick sichtbar sind, muß alles Negative und Unerwünschte gut versteckt werden." (1992: 47) (So that we approximate aesthetic conceptions despite our physical defect of deformed bodies and so that our impairments are not visible at first sight, everything negative and unwanted must be well hidden.)

They talk about "perverse fashion" of simultaneously wearing long black leggings and a skirt, having to hide their callipers with the long leggings, whilst at the same time having to appear feminine and wearing a skirt. This is demanded so that despite the physical impairment a sense of beauty can be achieved by covering up the negative, undesirable aspects of the body. Other examples include heavy, unsightly prosthetics which get in the way of playing, strapping on artificial legs for a woman double-amputee wheelchair user where the legs serve no useful function other than to appear more 'normal'.

The national charity for 'spastics' and physically disabled people in Germany (*Bundesverband für spastisch Gelähmte und andere Körperbehinderte e.V.*) published an essay with the aim of providing a theoretical foundation as well as practical advice on make-up strategies for disabled girls designed to make them appear feminine and to distract from their impairment (Seebaum, page 34 quoted in Ewinkel Hermes 1992: 47). Disabled women have raised a recurrent critique that the social model fails to fully address the role of the body, whilst others examined socio-cultural perspectives (Albrecht, 1992; Rioux, 1994; Davie, 1995; Wendell, 1996). In this thesis I promote a shift from 'impairment' to 'access' not as a means to *deny* impairment differences, deny the pain caused by conditions, or deny other physical/biological differences related to ascribed impairments, but as a means of focusing on the type of action in the social environment that enables elements of citizenship. Undoubtedly, Frida Kahlo (1907 – 1954) has 'suffered' pain, both physical and mental distress, directly caused by injuries she sustained in a bus accident. However, she is widely reported to have worn long colourful Mexican dresses, apparently in order to distract from her 'thin leg' due to polio and other physical impairments. Flamboyant hairstyles and Tehuana headdress further moves the eye up, away from the defective physical aspects in social contexts. 'The full skirts, shawls, braided hairstyles, and heavy jewellery that she adopted were worn in part to please Rivera, and in part to conceal her physical ailments. Yet it was also a political statement in support of an authentic and independent Mexican heritage.' (Tate, 2005)

Relationships and behaviour

Following further facilitation about what might happen to 10-year-old Sanji, or next time we see Aisha, both at home and at school, delegate responses were invited, which place the immediate family into a social context. Without exception, a changed relationship was reported in all spheres of life discussed, at home, with the children, with the partner, with family and friends, in the local community, at school, in the playground, at work, on the bus, in the shopping centre. To begin with, the boy Sanji might not be asked about his brother or sister as would usually be the case with a newborn baby, for fear of having to talk about 'bad news' and difficult feelings.

Theory of presentation of selves

The feedback presented a picture of uncertain relationships. Behaviour changes that were reported are assumed to take place in a scene put together by unfamiliarity and inexperience. In order to remain comfortable in the presentation of oneself (Goffman, 1975) scripts are played out within an agreed scene, which each participant is 'sufficiently attuned to one another so that open contradiction will not occur' (1975: 20). The initial setting of the scene is important as 'the individual's initial projection commits him (sic) to what he is proposing to be and requires him to drop all pretences of being other things' (1975: 22). According to Goffman, scripts are played out in the social arena, where people generally know 'their place' within the definition of a scene. So, for example, in the scene of a general practitioner's consulting room, there is a generalised 'doctor-patient-script' which is being followed. The 'agreed' expert is the GP, whilst the patient is the one listening to the advice given. If a patient was to question the GP's expert status, for example by disagreeing with x-rays and requesting a referral to aromatherapy instead, or by starting the consultation with stating their own experience as a physiotherapist, the consensus of the scene is threatened. Within the psychology of interaction, Goffman argues that people have a need to maintain a consistent front after the initial projection of a scene. Thus, the greatest opportunity to influence a scene is when we first define and project ourselves into a social context. After the initial opening for Aisha, for example as a mother with soon two children relating to another mother with children at the same school, it is difficult to change the definition of the scene to a mother with a disabled child.

Analysing Goffman's scripts

Delegate feedback showed a need to avoid conflict. Following Goffman, the initial definition of the scene had been set some time ago, and delegates demonstrated the need to avoid challenging the consensus by saying or doing something 'wrong' or 'offensive'. In that quest it might be best to reduce contact all together, by 'crossing the road', 'probably not going around to visit', 'no longer able to come to coffee morning', all of which avoided changing the script. As a result, Aisha's opportunity for social interaction was greatly reduced, but so were the opportunities of Aisha's friends interacting with her.

Scenes which can restrict opportunity not only arise out of a psychological need to avoid confrontation, but as Michalko (2001: 351) explores in 'Blindness enters the classroom', relate to institutional organisation and production of knowledge as well. In his analysis of interactions as a blind lecturer, he reminds us of the importance of interrelating scenes. Quoting Butler's definition of 'scenography' (1993: 28), he argues for the need to interrogate the ways in which the scene is put together, staged and socially constructed (2001: 351).

The context of a range of scenes in the field of education will be explored further in Chapter 3 with a discussion of the meaning of disability discrimination, and specifically in Chapter 4 in the context of inclusive education. For the moment, however, it is important to note an immediate dilemma. If it is the 'inexperience' in terms of the sight of and contact with a disabled person that contributes to the uncertainties in the definition of the scene, and if as a result of that inexperience, the delegate responses point to a further avoidance of future shared scenes leading in effect to segregation - how then can the uncertainty ever be resolved for the future?

Research into teacher's beliefs about working with disabled pupils has consistently shown that the more direct the experiences of inclusive practices, the more flexible attitudes of teachers would be (Marshall 2002, Zambelli 2004). According to that research, teachers with disability experience, on the whole, were more positive about the possibilities of shared relationships.

In a similar fashion, delegate responses pointed to changed relationships with Sanji, for example that he might get bullied, such as name calling for having a disabled brother or sister, involving play-acting that assumes that 'disability' was something you could 'catch' and get by association, or might simply be treated differently, with 'kid gloves' so as to avoid upsetting him. The impact of such behaviour shows that segregation and bullying appear to re-enforce each other, as Vlachou (1997: 1) observes:

'During my early socialisation process, disabled children were not children to be friends with. Whenever, accidentally, they happened to be around they were targets of jokes, objects of curiosity and pity, and provokers of fear for the 'unfortunate tricks that life can play.'

Delegates also expressed concern that Sanji might get neglected as a result of having to give so much attention and time to the disabled sibling. As a result, Sanji might develop emotional and behavioural problems, and in a way become disabled himself.

Personhood

Fewer than 2% of responses offered any positive term associated with personhood, such as the question 'what is the baby's name?' When such contributions were given, over 80% of these came from delegates with personal experience either as a disabled person themselves, or as a significant other (parents, spouse, partner, grandparents) of a disabled person. A further 15% originated from 'professionals' who saw themselves as having adopted a 'person-centred approach' and often prefaced such responses with statements that they 'ought' to be said. 'We normally ask how heavy the baby was and what name it has been given. We should do the same.'

Discussion of Findings

Ensuing ethical debates too easily presumed a 'right' and a 'wrong' answer. There are a number of research studies examining the attitude of this or that group towards disabled people. The task for disability equality training, and, as I shall argue, for practitioners in education, is not so much finding out what attitudes are, but identifying and acknowledging the fact that we base our behaviour and structure our institutions on sets of ideas and notions of disability arising from tradition. Ideas, thoughts, feelings and responses left 'closely wrapped' and 'unopened' can form a powerful barrier to change. To this extent, this thesis adopts a Weberian approach which acknowledges that interactions are based upon both beliefs and experiences. In his analysis of four paradigms for the study of social phenomena Priestly (1998) outlines position 2 which covers those approaches which value knowledge derived from the experiences, beliefs and interpretations of individual actors (1998: 77). Taking this point further, it can be argued that people do not interact directly with the disabled person and surrounding situation, but with imaginations of their intentions and actions. I am not merely concerned here

with an issue of 'attitude' but with sets of ideas which bind together and form ideologies. The essence of ideologies has been described as

'A second nature ... history congealed into habit, rooted in the very structure of need.' Giroux 1984: 317

The history that is congealed into habit is a history of oppression of disabled people (detailed discussion of its manifestations is explored in subsequent chapters). We carry this history around with us in our (subconscious) minds, reinforced through daily practices and continually shaped by our actions and the action of others. These actions, in turn, are reflected in, legitimated and reproduced by social institutions, with dominant ideologies operating at every level. The collection of delegate responses to the school gate scenario is symptomatic of dominant ideologies surrounding disability. It is the collective nature of ideas as manifest in society's organisational response to impairment that is at issue.

To illustrate this point further, I demonstrate the collective nature of ideas through critical observations on the interplay of ideas as evident in language, tradition and power within a key institution in secular society – the law. Whilst it can be argued that religion has lost much of its importance in western society, even the thinking of the judges in the highest court of the land in the UK shows evidence of references to God or higher ethical questions in relation to disability. Mr Justice Hedley, for example, in the case concerning baby Charlotte ([2004] EWHC 2247 (Fam) FAMILY DIVISION, 7 October 2004), contemplated a common psyche of humanity:

"This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism." Justice Hedley, at para 21.

Similarly, Lord Hoffman in the Court of Appeal case of Bland (Airedale NHS Trust -v- Bland [1993] AC 789) contemplates these questions, which are woven into a textual fabric that represents disabled people as pitiable, tragic almost 'inhuman' lives. At page 826 Lord Hoffman says this:

“I start with the concept of the sanctity of life ... [W]e have a strong feeling that there is an intrinsic value in human life, irrespective of whether it is valuable to the person concerned (sic) or indeed to anyone else. Those who adhere to religious faiths which believe in the sanctity of all God's creation and in particular that human life was created in the image of God himself will have no difficulty with the concept of the intrinsic value of human life. But even those without any religious belief think in the same way. In a case like this we should not try to analyse the rationality of such feelings. What matters is that, in one form or another, they form part of almost everyone's intuitive values. No law which ignores them can possibly hope to be acceptable. Our belief in the sanctity of life explains why we think it is almost always wrong to cause the death of another human being, even one who is terminally ill or so disabled that we think that if we were in his position we would rather be dead (sic). Still less do we tolerate laws such as existed in Nazi Germany, by which handicapped people (sic) or inferior races (sic) could be put to death because someone else thought that their lives were useless.”

Lord Hoffman at page 826 (op. cit.)

The application of case law with previous cases being referred to, examined and applied is characteristic of English common law principles. In contrast to European legal systems, the doctrine of precedent imports 'tradition' and stability into the law. Karl Marx recognised the burden of tradition and the difficulties of challenging dominant ideologies:

‘Men make their own history, but they do not make it just as they please; they do not make it under circumstances chosen by themselves, but under circumstances directly encountered, given, and transmitted from the past. The tradition of all the dead generations weighs like a nightmare on the brain of the living.’ (Feuer, 1969: 360)

It is not so much important to know where attitudes come from, but to realise that there are dominant understandings of 'disability', which have a powerful emotional grasp operating at a subconscious level and which are produced and re-produced through institutional settings.

As current legal history is being made on the right to medical care, the legal process re-produces assumptions about the quality and value of disabled lives, through the legal doctrine of *stare decisis*, binding precedent, use of language and dominant ideas. Referring back to a case some twelve years earlier (Court of Appeal in *In re J (a Minor) (Wardship: Medical treatment)* [1991] Fam 33) Mr Justice Hedley in the Charlotte case seeks guidance from published legal opinion:

“We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life ... even very severely handicapped people (sic) find a quality of life rewarding which to the unhandicapped (sic) may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child’s, and mankind’s, desire to survive.”

Lord Donaldson of Lynton MR at p.46-47, (case op. cit.)

Lord Donaldson is referring to disabled people in outmoded, and to many disabled people, insulting language, the image of personal tragedy is reinforced by terms of ‘suffering’, ‘severely’ and ‘intolerable’, a life with ‘no commensurate benefit’. Mr Justice Hedley states that he finds ‘considerable assistance’ in these words (at para 24), thus, twelve years later and through laying down his own judgement in a key judgement speech for future reference, he further perpetuates the underlying model of disability, cementing the textual representation of disabled people as pitiful objects.

In their policy statement on assisted dying, the Disability Rights Commission (Coyle, 2005) acknowledges the slow progress that is being made in shifting attitudes regarding disabled life as life worth living.

‘Legalisation of assisted dying in any country reflects and impacts upon its view of disability, impairment and terminal illness. The DRC strongly believes that the UK does not yet hold a mature enough attitude towards disability, terminal illness and disabled people’s lives. The media and medical profession in particular still portray disabled people

as weak, passive recipients of society rather than as active contributors to it.' (DRC, 2005)

In building a typology of responses and belief-systems about disability this chapter has shown that the individualised tragedy model is very powerfully operating at cognitive and affective levels. However, the ideological grasp goes further and reaches deep into social structures, such as the law and education. Chapter three outlines and further analyses disability discrimination in relation to the law, whilst chapter four explores disability discrimination and the meaning of inclusion in education. The exploration of both the legal and educational context is important in gaining a fuller understanding of citizenship issues as they relate to disabled people.

Challenging definitional content

Disabled people have raised epistemological questions rejecting claims of universal truths about disabled people's lives and argued for contingent social construction in place of what may appear 'natural. Oliver (1987: 10) reminds us why meanings attached to disability and definitions are important:

'From the politics of minority groups. From the 1950s onwards there was a growing realisation that if particular social problems were going to be alleviated or removed, then nothing more or less than a fundamental redefinition of what the problem actually was, was necessary. Thus homophile groups, black people and women set about challenging the prevailing definitions by attacking the sexist and racist biases in the language used to underpin these dominant definitions and creating, substituting or taking over terminology in order to provide more positive imagery.'

(Oliver quoted in Vlachou, 1997: 12)

Findings from training sessions demonstrate that 'gut-feeling' responses, which avoid detailed cerebral analysis before they are set free, indicate powerfully the negative, medically oriented personal tragedy view of disability and the fear and uncertainties associated with it, such as the ones referred to by Lord Hoffman of becoming 'terminally ill or so disabled that we think that if we were in his position we would rather be dead '. At this point I wish to recognise this view as dominant and deeply embedded. It is not a statement that such a view is inevitable, nor that it is a sole determining factor in creating

the position, changed social relationships or experiences of disabled people in society.

This traditional view of disability can be summarised as problematising the body and seeking solutions that avoid or minimise a perceived personal tragedy. Oliver (1996) argues that at the core of traditional disability lies a mistaken causal connection between the person's impairment and social impact. He argues:

'There are two fundamental points that need to be made about the individual model of disability. Firstly, it locates the 'problem' of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability.' (Oliver, 1996: 31)

It is that causal connection which fuels the image of the tragic, awful life events of a disabled person. Oliver (1996: 32) continues:

'These two points are underpinned by what might be called the 'personal tragedy theory of disability' which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals. Of course, nothing could be further from the truth.'

Thomas (2002) agrees with Oliver on the importance of the physical and mental deficit in constructing the traditional meanings of disability:

'Biomedicine has as its focus individual deviation of body and mind from socially recognised norms. Impairment per se is of central concern – its detection, avoidance, elimination, treatment and classification.' (Thomas, 2002: 40)

From a historical perspective, Barnes et al (1999) summarise the traditional model of disability in relation to knowledge:

'At the beginning of the twentieth century, the individual approach to disability – which sees its diagnosis and solution in medical knowledge – was securely entrenched. The focus is on the bodily 'abnormality', disorder or deficiency, and the way this in turn 'causes' some degree of 'disability' or functional limitation.'

(Barnes, Mercer and Shakespeare, 1999: 21)

Taking the view that such a perspective of disability is neither inevitable nor a priori the question of what determines the social position of disabled people

remains. Analysis of the responses shows that there is variation in different social contexts and change over time. The argument here is not that the very thoughts and ideas create the experience of disability, but that connected thoughts and ideologies dialectically relate to the social institutions which create and perpetuate disability. Oliver (1990: 20) warns against simplistic reductionism arising out of anthropology. He agrees with Abberley that we must avoid 'seeing societies as, in the final analysis, the embodiment not of social and economic relationships, but of thought systems' (1988: 306). However, within a dialectic that connects patterns of thought with the material position of disabled people, it is necessary to note that powerful themes are embedded in our cultural history. I argue that it is an important first step to acknowledge such dominant ideas as part of a shared heritage, and then to develop strategies which will expose disabling themes in all their various oppressive disguises when they present themselves in education. In this sense, it is the structural nature of thoughts and ideas rather than individual attitudes per se that I am concerned with.

I agree that not all societies regard disabled people as inevitably positioned at the margins and this alerts us to the social, political and economic dimension of stereotypical images. Ingstad and Whyte have examined the social status and participation of disabled people in cultures from the Tuareg, Masai people of Kenya and Songye people of Zaire among others (1995). One of the researchers to this collection of studies offers insight about the Masai people, quoted earlier in relation to seeing disability as given by God or nature and not as a source of individual blame:

'Physically impaired persons marry, become parents, and participate in all communal activities to the best of their abilities.' (Talle, 1995: 69)

To Oliver (1996: 31) the individual model includes a medicalisation of disability issues. The insidious 'drip drip' of a traditional perspective of disability is most readily evident in a bio-medical approach to health, well-being and independence, where medical and welfare institutions operate within power structures that are informed by and in turn inform traditional sets of attitudes. Power is exercised through formal and informal, structural and agency construction of knowledge and practices:

'The medical model has dominated perceptions of and policy on disability ... since society is steeped in the medical model ... its professionalism informs the perceptions of a wide range of people. This includes those with formal power (politicians, legislators, administrators), in a wide range of arenas and practices, including social workers, psychologists, rehabilitation counsellors and teachers ... as well as those with informal interpersonal power over the lives of people tagged as disabled'

(Fulcher, 1989: 44, quoted by Vlachou, 1997: 18)

With these two viewpoints, one that stresses the structural and material elements that create reduced life opportunities for disabled people, the other that emphasis culture and representation, and locates disability in society as socially constructed, disability theory has been placed into two separate 'camps'. I argue for a combination of the two. Such a model of disability is necessary to achieve political change within education; a model of disability that focuses on structural creation of disability but acknowledges the cultural history and the role still being played by ideological attitudes.

Social Model Challenge

During the time of the American Civil Rights movement in the 1960's disabled people began to think of themselves as 'being oppressed'. Just as feminists have challenged the individualised nature of women's position and their negative health experiences, for example due to the role expectations placed upon them as mother and housewife (Oakley, 2005), disabled people have rejected the individual blame attached to their position and formulated ideas of internalised oppression:

'Our anger is not about having ' a chip on our shoulder', our grief is not a 'failure to come to terms with our disability'. Our dissatisfaction with our lives is not a personality defect, but a sane response to the oppression which we experience.' (Morris, 1991: 9)

In Britain, one of the first essays on the subject, entitled 'A Critical Condition' had been written by Paul Hunt (1966, quoted by Light 2003: 131) expressing dissatisfaction with the individualised responses to disability. Hunt observed that views held about disabled people were linked to the prevalent economic

attitudes of an expanding capitalist Western society. These views included seeing disabled people as 'unfortunate' and thus unable to enjoy a comfortable material world, or as 'useless' and thus unable to contribute towards generation of wealth, and as 'in need' and thus requiring compensation for their disability. Compensation in form, for example of welfare provision, is seen as taking away resources from the wider community, thus reducing what is available for the well being of the community. In this way disability presents an economic burden to society. In its extreme form Nazi Germany employed the image of the 'useless eater' in a Prussian advertising campaign seeking support for reforms in the education system in 1937. The poster detailed the extra cost of education required for pupils with learning difficulties and other impairments. Propaganda such as this may have found its way into the subconscious of people and softened their attitudes towards the eventual killing of disabled people. This history may have contributed towards the formation of a cultural tradition which 'still weighs like a nightmare on the brain of the living'. In the modern Germany of the year 2002 hundreds of disabled people were living in fear. In the former East Germany, Deutsche Demokratische Republik DDR attacks on disabled people, together with attacks on other minority groups, had risen dramatically (Mut Gegen Rechte Gewalt, 2002). As can be seen, an economic agenda linked to the idea of scarce resources within our free-market system enables a view of disability as unfortunate and useless to the overall good of society. It is these structures in society which restrict opportunities for disabled people. It is the structures which disable. The recognition that social, economic factors restrict lives and aspirations of disabled people was articulated in Britain by a group of physically disabled people. Following Hunt's thinking, an organised group of disabled people in the mid-seventies formed an alliance as the Union of the Physically Impaired Against Segregation (UPIAS). The key bone of contention was that of having to live segregated lives and UPIAS advanced their interpretation (Finkelstein, 2001) of disability in these terms:

'(Disability is) the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of

people who have physical impairments and thus excludes them from participation in the mainstream of social activities.’ (UPIAS. 1976)

Disability Awareness in Action defines disability within a social construction view of society as ‘the social consequences of having an impairment’ and

‘While the academic community may view it differently, for the disability movement the social model provides a way of thinking about disability that accords with our experience of being disabled people – that disability is caused by the attitudinal, physical and communication barriers imposed on us rather than the effects of our impairments.’

(Light, 2003: 133-134)

International disability movement

The challenge to traditional ideas of disability and development of new thinking was part of a wider international movement of politically active disabled people. In 1981 Disabled People’s International drew attention to a fundamental distinction to be made between ‘impairment’ and ‘disability’. This was partly to negate the traditional view of disability, which conflated both ‘disability’ and ‘impairment’ as essentially meaning the same, and was partly in response to the World Health Organisation’s triple definition of impairment, handicap and disability (WHO 1980). Within the WHO’s definition a necessary causal connection is made between a person, who has an impairment and that person having a disability in terms of not being able to perform an activity considered normal for a human being with the resulting handicap of not being able to perform social roles deemed normal. Oliver (1990: 4) and others have criticised this causal link implicit in the WHO definition of 1980, essentially arguing that the individual’s impairment is causing their disadvantaged position in society. The WHO definition has now changed, due to political pressure of disabled people, and, as I shall argue, due to incongruities in thinking that no longer ‘make sense’ of the ‘old’ view. The international disability movement argued that a priori link cannot be established, since in their mind the following two ideas have to be dealt with as distinct:

‘impairment’ refers to the loss or limitation of physical, sensory or mental function on a long-term basis, and crucially

'disability' the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from participation in the mainstream of social activities.'

DAA, Social Model based upon Hunt (1966)

Since the 'problem' of disability was conceived of as an individual problem, located within that person's impairment, the solutions to this problem were also conceived of within an individual perspective. The social model challenges that approach by arguing that disability is either socially created, through the responses of a society unthinking of the requirements of disabled people and evident in its structures and organisation, or socially constructed through the language, ideas and processes within which power is exercised, resources are allocated and social goods are distributed. If the 'problem' to disability lies within society, then the solution must equally be located in society. This is achieved, for example by placing duties onto society to remove the barriers which stop disabled people from fully participating as equal citizens in all spheres of life.

Definitions accepted in policy documents and legislation

The Department for Children, Schools and Families (2007) in its Disability Equality Scheme 2006 - 2009 details the following definitions to be used:

"In this scheme we follow the social model of disability and we use the words disability and impairment to mean different things:

Disability: the disadvantage experienced by individuals as a result of barriers (attitudinal, physical, and so on) that impact on people with impairments or ill health.

Impairment: impairment is a long-term characteristic of an individual which affects functioning or appearance and may give rise to pain, fatigue, communication difficulties, and so on

This thesis argues for a shift in thinking, and one pillar of this paradigm shift concerns the essential issue of separating 'impairment' from the experience of barriers in society, i.e. disability. This is at the heart of a social model

understanding of disability. In relation to citizenship discussion, such a shift further entails a focus on 'access' issues (discussed in relation to the concept of discrimination in the following chapters). The government department responsible for education at school level refers back to earlier government policy, the design of which was heavily influenced by disabled people themselves, who are pushing for a broader understanding of the meaning and impact of the social model of disability. 'We take those definitions from page 26 of *Improving Life Chances*, published by the Cabinet Office in 2005'.

Later, the same document puts it like this:

'Two main barriers are evident across all aspects of disabled people's lives: in where they live; their personal relationships; their opportunities for education, training and employment; access to healthcare; access to leisure activities; and participation in the life of their community and in wider society. The support which society makes available to people with a wide range of impairments is generally not fitted to the person. Instead disabled people are expected to fit into services. Support is organised and delivered according to different policy, professional and service boundaries, resulting in unnecessary bureaucracy, a fragmentation of disabled people's lives and often a failure to meet their needs adequately. Policies and practices do not pay enough attention to enabling disabled people to be active citizens, or supporting disabled people to help themselves. There is instead a focus on incapacity, inability or risk associated with impairment or mental health needs. Responses to needs are often more likely to create dependency than enable people to participate in their local communities, fulfil their family responsibilities or be economically independent.'

(Prime Minister Strategy Unit, 2005: 72)

This emphasis on what has to be in place for disabled people to be 'active citizens' is discussed in relation to the socio-legal context of citizenship in later chapters. In this thesis, I am applying a 'socio-political-legalistic' model of disability, that is an interpretation of disability in the social model fashion, but within the legal context of rights and citizenship, as democratic participation 'having a say' of disabled people.

Disabled people's experiences of the social model

In many ways a re-interpretation of the problem of disability in social terms has liberated disabled people from feeling personal failures and seeing themselves as to blame for difficulties in life. Andrew Hubbard describes his experience of the world around him before he discovered the social model as saying 'You are blind, the world is sighted. It's your problem. The responsibility is yours' and as a response to these messages he developed a strategy of complete denial: 'I wanted to be normal. I wanted other people to treat me as normal. And I thought I was actually capable, strong enough certainly, and clever enough to cope as though I didn't have any problems' (Hubbard, 2002: 169). He discovered the social model while training with the RNIB as a Disability Equality Trainer and taking the message on board was a difficult journey:

"The course leaders seemed to be rather radical: You are all disabled people, they said. ... I was faced with a great dilemma because I had repressed my disabled identity for the last twenty-four years. Suddenly that was being challenged. ... I did not think I could change to see myself as a disabled person. I had absorbed all of society's standards, beliefs, images, everything... I did not want to mix with disabled people. I wouldn't join a blind club or anything like that. I was afraid to identify with disabled people." (Hubbard, 2002: 172)

The pressure to 'pass' as non-disabled is vividly conveyed by Theresia Degener (in conversation 2002) and echoed by Carol Thomas (2003: 11):

"I was born without a left hand, an impairment which I began to conceal some time in my childhood. This childhood concealment strategy has left a long legacy: I still struggle with the 'reveal or not to reveal' dilemma, and more often than not will hide my 'hand' and 'pass' as normal. But concealment carried, and continues to carry, considerable psychological and emotional costs and has real social consequences."

Disabled people share the experience of living with the individual model of disability as oppression and discovering the social model thinking and lifestyle as liberation. Shakespear Watson (2002) compared this to a consciousness-raising coming-out of empowered disabled people.

“My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.” (Crow, 1996: 206)

A key difference in perspectives on disability is that the social model regards all disabled lives as worth living, whilst ultimately individualised medical, within-child deficit models aim to screen out, reduce, remove, hide, cure, treat, and segregate people with impairments. There would be a world without impairments, such as spina bifida (Tanni Grey-Thompson), genetic disorders (Professor Hawkins), sensory impairments (Ray Charles, Beethoven), cerebral palsy (Ade Adepitan) or physical deformity (Matt Fraser, Professor Theresia Degener).

Changing Perspectives: seeing it from the other side

The film ‘TALK’ created by the Disability Rights Commission ‘to bring disability issues into the mainstream’ (DRC 10 December 2001) has been widely distributed, and over 10,000 people had requested copies in the first year. This uptake is encouraged by the fact that the resource is available free in a range of formats including British Sign Language BSL, captioned, subtitled, audio-description, or a combination of these (contact DRC). TALK has been used in Disability Equality Training by adept, TUC, local councils, NASUWT, Arriva, British Airways, the BBC, Channel 4, Halifax, Lloyds TSB, Morrisons supermarkets, the Police Training Board Scotland, Virgin Atlantic and WH Smith, as well as Ford Motor company in England, Spain, France and Germany, in Russia and Nepal, and has been shown to the Welsh Assembly and the Scottish Parliament. In 2002 as part of the national curriculum inclusion of Citizenship, TALK had been distributed to the nation’s secondary schools.

TALK video: content

The TALK video is an award-winning short film of the trials and tribulations of living in an ordinary world. With a running time of just 12 minutes it deals with ordinary areas of life, such as employment, business, leisure, social activities and transport, as experienced by the central character ‘Robert’, played by

Jonathan Kerrigan. Kerrigan plays a business executive, whose negative preconceptions of disability are dramatically shattered. He enters a world of 'role-reversal' where he experiences a range of barriers to participation in a world designed and run by disabled people. 95% of the film's cast members are disabled people, such as actor and writer Matt Fraser. For the purpose of the video 'Robert' can be regarded as the disabled person, disabled by attitudes, behaviour, policy, systems and procedures designed for people who have impairments. The underlying model of disability is the social model.

TALK video: story line

The audience is drawn into the story by the opening scene, filmed in grey, at a board meeting or planning meeting, which represents any typical business meeting. A bubble of voices spurting out the latest slogans 'innovative', 'fresh', 'dynamic' indicates traditional business priorities. Just as the meeting is about to close, the chair is reminded of the Disability Discrimination Act and the question of what to do about it. A brief discussion ensues and concerns are raised about cost, image and compliance, with phrases such as 'these ramps make damn good PR' and 'don't get me wrong, my cousin is disabled, I know what it is like for them'. The character Robert is nominated to go on a fact-finding mission and report back at the next meeting. Before Robert leaves the meeting, he turns to his colleague to say 'I've got the interview' to which she replies 'You are leaving us then?' This illustrates how in the ordinary world as we know it, a man in Robert's position, white, male, non-disabled, in paid employment, is assumed to move up in his career, he has aspirations and everyone expects him to succeed.

The video then progresses through a series of scenarios, in full colour version, where Robert finds himself in a world designed for and by disabled people. A powerful tool of role-reversal takes the viewer through the experience of frustrating barriers created by people and organisation. Robert becomes the outcast, and in that world, for example, he has great difficulties reaching the interview on time, is not expected and welcomed by the prospective employer, is given a Braille form to fill out and in the final analysis does not get the job. He says 'It is as if they weren't even listening'. The social model of disability as applied in this video demonstrates how opportunities are reduced and aspirations scaled down when it comes to career options for

disabled people. Other scenarios illustrate barriers in transport, leisure, services and facilities. The viewer is confronted with assumptions and experiences the adverse impact of behaviour based upon assumptions and decisions lead by impairment concerns.

Supporting Citizenship Education

A first step in reaching pupils and teachers on the issue of disability equality is to introduce the arguments of the social model of disability and perspectives of disabled people. With that the notion of discrimination as based upon individual and group actions, or failure to act, is challenged (DRC, 2002). In other words, disabled people do not face disadvantage because of their impairments but experience discrimination in the way we organise society, or as Oliver (1996) put it, in the way society responds to impairment. This disabling response includes failing to make education, work, leisure and public services open, inviting and accessible, failing to remove barriers of assumption, stereotype and prejudice and failing to outlaw unfair treatment in our daily lives. The DRC Citizenship Pack (2000) challenges disability discrimination and promotes a particular model of disability. However, translating these ideals of citizenship education into professional daily practice is problematic. This thesis argues that the actual application of teaching material, such as the DRC's Citizenship Pack, in the classroom is filtered through a plethora of hidden barriers. Reasons for this include the enduring conflict of traditional views of disability, structural oppression in education settings, and the humanistic assumptions underlying the concept of citizenship. I will now turn to the concept of disability discrimination. This will be examined further in the next two chapters. Chapter 3 outlines the legal framework and Chapter 4 analyses structural disability discrimination in education. Models of citizenship and political engagement are discussed in Chapter 5, whilst Chapter 6 examines the curriculum and school context of teaching Citizenship.

Chapter 3

Disability Discrimination: Legal Framework

The analytical aim of this chapter is to establish the philosophical and legal principles of disability discrimination, which will be applied to the context of education in Chapter 4. The narrative focus of this chapter is the experience of disability discrimination for disabled people and its cumulative effect on citizenship. The narrative will supply case scenario contexts of active citizenship issues and dilemmas, which will be further analysed in Chapters 5 and 6. I argue that disabled people are materially, socially and politically disadvantaged by structural, institutional and behavioural arrangements in contemporary western societies, such as Britain. The chapter explores in particular the sphere of employment, but will also examine political activities, legal processes, leisure and education. Particular attention is paid to democratic practices which illustrate citizenship as the site of political struggle, and in this context the impact the law has had on broadening, constraining and defining choices open to disabled people in each of these spheres. The premise is that the legal framework, including the processes, application and impact of the law, is characterised by its capacity to either constrain what individuals can do or enable their active participation as citizens. In discussing the tension between the structure of the law and the agency of individuals, patterns of discrimination against disabled people are outlined. In order for the concept of citizenship to be inclusive of all citizens, it is important that the meaning and impact of disability discrimination in our society is understood.

In Britain, discrimination based on less favourable treatment has been acknowledged in respect of sex and race, with the implementation of the Race Discrimination Act and Sex Discrimination Act in the mid 1970s. Disability discrimination, by contrast, is still being contested. Testimony to this struggle lies in the fact that the parliamentary passage of anti-discrimination laws in respect of disabled people in Britain took over thirty years and was expressed in eighteen defeated private member's bills until the eventual passing of the Disability Discrimination Act in 1995. However, the question of disability discrimination is still not settled, as the DDA continues to be amended, with recent extensions under part 4 to include Education (Special Educational Needs and Disability Act 2001), implementation of physical access clauses and extension of duties to include the public sector.

To begin with, facts and figures set the scene and illustrate the material disadvantage of disabled people in all spheres of life. The inter-relationship of a range of forces within a broader economic context is illustrated by a case study detailing the impact of decisions taken by business on the lives of disabled people. Then, in the first part, this chapter will apply the concepts of social construction and social creation of disability, as discussed in the previous chapter to the legal context. I will show that the law has been instrumental in the creation of disability (Gooding, 1994; Stone, 1984). A brief historical overview is offered to illustrate the creation of dependency of disabled people through traditional welfare legislation. This is linked to the tragic model of disability and its view of disabled people as dependent. The challenge as mounted by the social model, which asks the law to recognise independent living and choice of disabled people, will be outlined. The locus of the disability problem, i.e. that which stops disabled people from taking an active and equally valued position in society, is moved away from the individual impairment or condition to social arrangements and structures. Traditional welfare-based laws form part of the structures which constrain independent living choices of disabled people, and it is these structures which create disability.

The second part of this chapter explores the impact of institutional structures on disabled people by contrasting traditional legal approaches of entitlement

with more recently won civil rights-based legislation. This section illustrates a particular problem with entitlement legislation, which by its nature is discretionary and thus 'entitlements' can be taken away. Boundaries drawn to map out who is and who is not entitled can be shifted to account for changed economic or political realities. This is illustrated in detail by examining the judgments in the House of Lord 'Barry' case. Welfare legislation is to a large extent linked to the creation of dependency of disabled people. Analysis of this case forms the basis for a contrast of entitlement approaches with rights based laws. Anti-discrimination legislation protects rights, which are inalienable, universal rights of equal treatment, and cannot be given nor taken away, unlike entitlements. The aim of anti-discrimination law is to protect specifically targeted groups of people from discriminatory behaviour and policy. Anti-discrimination is not about giving something extra, or providing special treatment. This will be explored by looking at the parliamentary passing and current struggles concerning the Disability Discrimination Act 1995 (for further details see Leeds Disability Archive, DDA 1995).

Within employment, an overview of the developments of anti-discrimination laws in the past thirty years is offered. The chapter compares the development of different legal provision concerning race, sex and disability with reference to employment rights and duties. The legal meaning of discrimination in the field of employment is explained with examples of less favourable treatment by direct and indirect means. It is argued that the law has the potential to enable fair and equal participation of disabled people. Pertinent legal concepts, such as less favourable treatment, are explained and a comparison made between different legal provisions in respect of race, sex and disability. In the sphere of employment the legal definition of discrimination is explored in detail using the analysis and reasoning of the seminal Post Office case, which established indirect discrimination principles. The chapter then discusses the reluctance of the British legal establishment to examine indirect and institutional discrimination, and the reluctance of transferring these principles into anti-discrimination laws for disabled people.

Living at the edge

Disabled people are living at the margins of society and their structural social position and material reality is one of disadvantage (Oliver, 1996:64). This

claim has long been supported by research into affordable housing (Borsay, 1986; BCDOP, 1986; Rowe 1989, 1991), employment pattern and working conditions (Labour Force Survey, annually, 2006; Martin, White and Meltzer, 1986; Prescott-Clarke, 1990; Thornton 2005; UNISON 2008; Fullick 2008) access to health and personal services (Oliver, 1996; DRC Report 2004; DRC DVD 2006) use of mainstream leisure services (ATLAS team, 1999 – 2003; Tooke 2003) and educational provision or schooling (Barton, 1988; Barnes, 1991; ALFIE 2002; Burchardt, 2005). In the sphere of employment, 6.8 million people of working age (or nearly 20% of the working age population) self-declare as disabled. Of the 6.8 million disabled people of working age, 3 million (approx) are in work .13% of the UK workforce are disabled (Employer's Forum on Disability, Overview).

The Labour Force Survey (Spring, 2005) presents a more detailed picture:

- Nearly one in five people of working age (6.9 million, or 19%) in Great Britain are disabled
- There has been an increase in the number of working age people reporting a disability; from 6.2 million in Spring 1998 to 7 million in Spring 2005
- Only about half of disabled people of working age are in work (50%), compared with 80% of non disabled people of working age
- Almost half (45%) of the disabled population of working age in Britain are economically inactive i.e. outside of the labour force. Only 16% of non-disabled people of working age are economically inactive
- Nearly one third of disabled people who are economically inactive say they would like to work (28%), compared with less than one quarter (24%) of non disabled economically inactive people
- Employment rates vary greatly according to the type of impairment a person has. Disabled people with mental health problems have the lowest employment rates of all impairment categories at only 21%. The employment rate for people with learning disabilities is 26%.
- Disabled people are more than twice as likely as non-disabled people to have no qualifications (26% as opposed to 10%)


- The average gross hourly pay for disabled employees is £10.31 compared to £11.39 for non disabled employees.

For London this means that disabled Londoners are twice as likely to be unemployed as non-disabled people. Young disabled people and black disabled people are further disadvantaged. In London, 28% of disabled people want to work but do not have a job, compared to 11% of non-disabled people (London Household Survey, GLA 2004). These figures and research findings demonstrate that disabled people remain at the edge of engagement. As a result, disabled people were found more likely to be living in poverty, to be leaving school with fewer qualifications, to be out of work or on lower income. Incomes of households with at least one disabled person are 20-30% lower than the incomes of all households (op.cit.). That situation of lived discrimination led to a poster campaign organised by disabled people for the Disability Rights Commission, as part of the disability debate (ongoing):

**I'LL NEVER
GET A SEAT ON
THE BOARD.
I'VE GOT THE
WRONG CHAIR.**

**ARE WE TAKING
THE DIS?**

Have your say at disabilitydebate.org

 Disability Rights Commission



Asian female wheelchair user employee working at her desk.

“I’ll never get a seat on the board.

I’ve got the wrong chair. ”

Are we taking THE DIS?

Have your say at disabilitydebate.org

The government has accepted that disabled people currently have very limited opportunities to participate in and exercise full citizenship rights in all spheres of life (IPPR, 2007). Two spheres of social engagement examined in this thesis include employment and education. These areas are closely linked. On the one hand, attainment in education opens opportunities in employment, whilst, on the other hand, skill requirements in the employment sector influence the product of education. Successive governments have been shifting emphasis from one direction to the other, from education to skill and back, as evident in their frequent name changes (Department for Education and Science, Department for Education, Department for Education and Employment, Department for Education and Skills, Department for Children, Schools and Families, Department for Innovation, University and Skill). Disabled people's position, requirements, rights and aspirations have in the past been completely absent when policies in education and employment were drawn up, as 'disability' was seen to be a medical or health issue. Within the traditional welfare response to disabled people, with a key concern about functional ability and 'normal', healthy biomedical conditions, the focus of experts has often been the impairment of disabled people, rather than their access to educational or economic opportunities. Key questions for policy development, for people in decision-making positions, such as employers or teachers, was to inquire into the medical dimension of the person's impairment, how severe, what type, what pattern, how and when the condition manifested itself. With a focus on the individual's impairment, policy development failed to take notice of aspirations and possibilities. The failure to include into our thoughts disabled people's participation in paid employment is exemplified in the fact that up to 1971 education provision for disabled pupils in special schools were under the control of the Department of Health and Social Services, not Education (Barton, 1995). The failure to include into our thoughts disabled pupil's participation in equally valued educational activities is rooted in idea that educational resources could be obtained only through a process of mapping impairment, by 'statementing' special educational needs which described, medically certified and

psychologically approved the special condition of individuals as related to their impairment (more in Chapter 4).

Around 770,000 (7%) of children in the UK are disabled. Disabled children and young people currently face multiple barriers which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education. 29% of disabled children live in poverty. The educational attainment of disabled children is unacceptably lower than that of non-disabled children and less than 50% of schools have accessibility plans. (Every Child Matters, 2004). Disabled young people aged 16-24 are less satisfied with their lives than their peers and there is a tendency for support to fall away at key transition points as young people move from child to adult services. Families with disabled children report particularly high levels of unmet needs, isolation and stress. A report by the Audit Commission in 2003 found that there was a lottery of provision, inadequate strategic planning, confusing eligibility criteria, and that families were subject to long waits and had to jump through hoops to get support. The prevalence of multiple forms of impairment is increasing.

For over two decades, disabled academics have argued that disabled people are made dependent, both financially and socially, through what has been termed 'institutional discrimination' (Oliver, 1986; Barnes, 1991:8). Bauman (1997) observes that people who are lacking in educational attainment and living in poverty are regarded as 'irrelevant' to the economic needs of society. They can no longer be drawn into the economic processes of production, as needed by fluctuating economic demands. Disabled people who are dependent in that way cannot even function as the 'reserve army of labour' (Marx, 1977: 602) which provides a flexible pool of people to draw on, who can be included or excluded at times of economic need. A combination of factors leads to their exclusion. Since this means that disabled people tend to be long-term unemployed, poorly educated and of low aspiration, with the assumption that they have little to offer even at times of sustained economic growth, disabled people can easily be drawn into a negative spiral of disadvantage. A poll commissioned by the Disability Rights Commission (2002) revealed that one in six (15%) young disabled people said they had been turned down for a paid job, and told it was for a reason related to their

impairment or health problem. 41% of disabled people of working age have no educational qualifications in comparison to 18% of non disabled people (Disability Follow-up to Family Resources Survey 96-97). The additional cost of living in a disabling society and the relative lower living standards are well documented and analysed (Zaidi, 2005). Bauman illuminates such conditions as resulting in the 'newly poor' who are seen to be 'fully and truly useless and redundant, and thus become burdensome others who have outstayed their welcome' (1997: 5). If disabled people who are poor, live in inferior or inaccessible housing, have reduced mobility through inaccessible transport systems, lower educational attainment, are also out of work then the negative impact upon their lives increases exponentially. The barriers to full citizenship experienced by disabled people are compounded.

Disabled people are underrepresented in all areas of paid employment. When they do find work, it is likely to be poorly-paid, low-skilled and low-status jobs, which is described by Barnes as 'underemployment' (1991: 65). 93% of impairments are acquired by people of working age (Adept 2004). Once in work, or if becoming disabled whilst in work, disabled people are more likely to be dismissed. These harsh realities, together with various factors that shape the experience of disabled people in the labour market are highlighted in the following case study.

AA Centrica

Protests by GMB union members and disability activists at AA Basingstoke attest to these concerns (July, 2005). Demonstration have been organised outside the Banqueting House in Whitehall SW1 2ER where 400 guests were to attend the gala dinner. These protests drew attention to 'the AA's targeting of its disabled patrol drivers in a 431 job cutting exercise last month' (GMB Union). The Disabilities Rights Commission was investigating some of the cases. The demonstration also protested at the further sacking of another 300 staff announced by the AA from facilities in Maidstone, Kent and Basingstoke, Hampshire.

Whilst formal protests had been lodged with the Disability Rights Commission, complaining that the company was targeting disabled staff to bear the brunt of

job cuts, the AA rigorously denied these claims. Martin Sawkins, HR director at the AA, said:

“Any employee with a disability has full access to a range of occupational health support and assistance. This includes positive adjustments to their working practices, conditions, equipment, and performance targets to reflect their individual circumstances.”

It is clear that in order for disabled people to benefit from planned redeployment, as suggested, the infrastructure of the company needs to be disability-friendly in attitude, accessible in design and accommodating in diversity of working methods, as may be required to enable a disabled worker fully effective in one area to transfer to another.

These job cuts at the AA are not isolated, but form part of a pattern following the merger and £1.75bn take-over. In July 2004 the AA was sold by Centrica to venture capital firms CVC Partners and Premira. Just 3 months later it was reported that the AA was to cut 1,300 jobs - 10% of its workforce despite membership increasing by about 5.5 million under Centrica's ownership. AA employs about 1,000 staff at Newcastle and about 650 in Cardiff. The AA recently announced that a site at Maidstone in Kent, which employs 154 staff answering emergency breakdown calls, will close, while work will transfer from Basingstoke in Hampshire, which deals with administration, to Cheadle, leading to some 129 job losses (BBC news, 15th August 2005). This appears to signal a severe economic downturn for this company as a result of which job losses are inevitable. In such circumstances disabled people are at the most vulnerable.

It was a different story only five years earlier. Centrica then recruited around 40 disabled people as part of a 'Welfare to Work' project in Manchester, for example. The DRC included Centrica's initiatives as an example of good practice in recruitment:

‘From 1998 to 2002 Centrica worked in partnership with Carers UK, the Employers' Forum on Disability and Jobcentre Plus on a recruitment initiative to create new employment opportunities for family carers and disabled people. Through the project-led Recruitment Initiative, a model and a process has been developed that has resulted in over 180 people being recruited, 45 per cent of whom are people with a disability

or health condition. Centrica has benefited from a pool of highly skilled and motivated new employees that it otherwise would not have attracted.

(DRC 'Making it Work' employment guide to the DDA, 2002).

Originally around 300 job candidates from the north-west of England were referred by Jobcentre Plus, the government-run employment service.

Following a telephone interview for permanent positions at British Gas call centres, successful candidates attended a two-day workshop run by career counsellors Capita Grosvenor to prepare for the final interview. Centrica subsequently offered contracts to around 50 interviewees, some of whom had not worked for many years, and 80% of which were disabled (Ethical Performance, 2001). Whilst Barnes might regard these job opportunities at call centres as 'underemployment' (1991: 65), the Human Resource director Richard Bide said that Centrica planned to continue to employ disabled people because it had seen the following benefits:

'....motivated and high-performing staff, reduced staff turnover, a workforce which better reflects its customer base, raised awareness across the company of issues affecting disabled people.'

Centrica also recognises further actual or potential benefits of having disabled people in your workforce:

' ... managers are more skilled in recruiting and managing a diverse workforce, enhanced corporate reputation, and business benefit, which entails the personal performance of disabled people using traditional measures of efficiency and productivity , the general performance of the company that recruits, retains and develops disabled employees, particularly through better people management systems, the long-term business impact of reputational gains and the positive impact of employing disabled people on other employees' morale and motivation.

(Unlocking the Evidence, 2001)

And a few months later, Centrica promptly won the 'Realising Ability' award as part of the Business in the Community (BiTC) Awards for Excellence programme 'for their substantial investment in disabled people as employees and customers' at a ceremony, where businesses reward themselves for good business practice. Human Resource Management International (2003, Vol. 11

(4) 15ff) reported this success story as an example of inclusion into the world or work of groups of people, who traditionally are difficult to find jobs for.

“UK conglomerate Centrica has successfully recruited carers, long-term unemployed, lone parents and people with disabilities to contact-center jobs – and tackled assumptions and prejudices head on.

Centrica touches the lives of millions of Britons through its well-known consumer brands such as British Gas, Scottish Gas and the Automobile Association. Its business success depends on being able to understand the changing needs and expectations of its customers.”

The reality for disabled people, however, looks very different. The AA employs Sales and Service Advisors in Customer Service Contact Centres located in three sites across the UK and their resourcing team at Centrica (the AA's parent company). They commissioned external consultants to conduct ‘profiling’ of existing sales and service advisors to help ‘inform recruitment and development activity in the future’, or in other words assist in the decision-making on redeployment and redundancies. They have looked at approximately 70 Customer Sales Advisors and 70 Customer Service Advisors across all three of their sites (Cardiff, Newcastle and Cheadle). The process included use of personality and motivation profiling using two psychometric questionnaires. They constructed ‘Danger Zone profiles’ for service and sales roles to indicate the score ranges on particular scales that may cause concern. There are many issues concerning the fairness and application of such tests to disabled people (to any person, in fact). Suffice to raise the issue of making such tests accessible, providing accommodation and reasonable adjustments in access. Barriers to fair interviewing may include issues such as attitude of assessor, mode of communication, timing and method of application, timing and spacial arrangements, avoidance of fiction and stereotypes in interpretation of interview data, and dealing with past disability discrimination of the disabled candidate.

The outcome had been reported as a success story for a psychometric assessment consultancy, which carried out this project (ASE) and, indirectly at least, contributed to the identification of job cuts. Other performance reviews had also been carried out, and they also identified people who should be made redundant. The company argued, for example, that whilst the

majority of AA patrols meet or exceed the company's expectations, a minority fall short of achieving the required performance levels. The above mentioned disabled people protesting in Basingstoke were part of that minority group. Furthermore, British Gas, a part of £18bn group Centrica, which was the parent company of the AA, revealed plans to cut 1,450 jobs as part of a drive to cut costs (BBC, 2004) and a year later again cut 2000 jobs (BBC, 2005). Jobs being targeted were mainly at managerial and support levels. This includes the posts, where previously disabled people on 'Return to Work' programmes were recruited into. It also claimed that redeployment and reduction of vacancies means that the actual number of redundancies will come out closer to 850 (BBC, 2004), which again raised the question of possible accommodation for disabled people in terms of work routine, equipment, work load, flexible timing, accessible communication, additional training and practical assistance.

The following facts are reported in August 2005 at World Markets Analysis: The overall business context was that in February, Centrica announced an operating profit for last year of \$1bn – a rise of 14% on the previous year's £870m. And the British Gas business had increased turnover by 2.4% to £6.2bn, helped by a rise in market share, higher prices and growth in its home services business. Centrica is the UK's fifth-largest producer with gas production of around 10.8 Bcm. Through its gas sourcing division Centrica Energy, the group has been securing access to gas assets through licensing deals with upstream operators. The division generated turnover of £914 million and operating profits of £512 million in 2004 (World Markets Analysis, 2004). For the six months ended 30 June 2005, Centrica plc's turnover increased 16% to £6.78B (Reuters, 2005). Another year later, in 2006, the day after British Gas announced its biggest price rise for consumers, Centrica revealed record profits:

“Centrica's operating profits rose 11% to £1.51bn last year. The announcement triggered angry protests from consumer groups and unions.” “Centrica's profits from gas production rose 31% to £1.02bn, while its profits from gas storage more than doubled to £154m.” (Evening Standard, 2006)

The bigger picture shows how disabled people are in positions of material disadvantage, reduced bargaining power, struggling to retain employment within systems of systemic disability discrimination and conflicting business priorities - fuelled by, what some have described as, 'obscene' profits. Disabled people are caught up, and loosing out, in the expanding – contracting pulse of the economy. However, the bigger picture also shows forms of resistance, albeit at a reduced sphere of influence, and illustrates an instance of organised and political activity of disabled people asserting citizenship rights of freedom of speech, freedom of assembly, and the fact that some legal advances in the protection of disabled people have been won in that grievances can be taken to the Disability Rights Commission. These are all important democratic processes.

Impact of systemic disability discrimination

In addition to the economic conditions outlined above, surveys show that there are a significantly higher proportion of disabled people who retire early as compared to the non-disabled workforce (Labour Force Survey, annual). The impact of this combined economic reality for disabled people and their families is not only lack of income, but also a reduction in opportunities, in the variety and extent of the ways disabled people can relate to, form friendships and build social or business connection with other people. It limits choices available for leisure activities and impacts upon human relationships, with fewer opportunities for disabled and non-disabled people to meet within the same sphere of influence or activity. Non-participation in economic activity, for whatever reason, so Oliver contends, is likely to lead to difficulties in securing the essentials for a healthy life, but also in 'establishing satisfactory relationships' (1996: 85).

An analysis of these facts leads to the view that disabled people are systemically oppressed. Whilst Abberley agrees that a main mechanism of disabled people's oppression is the exclusion from social production, he warns of drawing the conclusion that the only way to overcome this is by working towards a wholesale inclusion into existing forms of economic productivity (1997: 35). Abberley also recognises the principle of the 'reserve army of labour' and concedes that 'society may be willing, and in certain

circumstances become eager, to absorb a proportion of its impaired population into the workforce' - as was the case, for example, shortly after the second world war, and as appears to be so within Centrica. However, a large proportion of people with different or multiple impairments, or in circumstances not conducive to finding paid work, will become more and more reliant on welfare support. There may be a danger of a bi-partheid system developing, one for disabled people who, as and when required, can join the labour market, albeit at inferior conditions, and the other for disabled people who are unable to remove barriers of expectation and lack of access. The concern is that inclusion of some disabled people may have the effect of further distancing the remainder population of disabled people. As a way out of this, Abberley argues, a new theory of oppression needs to be developed, which 'avoids this bifurcation, through a notion of social integration which is not dependent upon impaired people's inclusion in productive activity'. Following on from this line of argument, the model of citizenship thus implied looks at imagining a changed relation of people and the productive contributions they make to society, moving the focus away from a purely economic contribution to include broader social or cultural elements. This thinking also leads to a different conception of independence, which is a key requirement in promoting active citizenship. Disabled people have fought for self-determined living choices, which are seen to run counter to the traditional conception of the 'dependent' disabled person in need of assistance. A dependent person is thus less able in taking up active citizenship responsibilities. The idea of independent living requires further exploration, and will be discussed below.

These patterns of exclusion from the labour market, reduction in opportunity for meaningful relationships and lowering of the standard of living can be described as systemic disability discrimination, because different systems work together to produce an accumulative effect. This means that the current system of organising the production and distribution of goods and services, of distributing advantages and opportunities, of social and economic relation works to the detriment of disabled people. Disability discrimination results from unchanging working systems, systems based upon business priorities over human need, systems perpetuating fiction and stereotypes and systems

creating barriers to participation for disabled people. Oliver (2004) notes that there is universal agreement that disabled people do not have the equal job opportunities and is critical of the structural context for this. Increasingly concerns have been raised about the productivity of disabled people and their contributions to the national economy. Successive government initiatives put emphasis on work, detailed surveys analyse the labour market experience of disabled people (Smith and Twomey, 2002, see Disability and Employment reading list from DRC) resulting in projects, a 'new deal', Return to Work schemes, and increased training opportunities (Department for Work and Pension, 2006), whilst at the same time reducing welfare 'handouts' and direct provision of services by agencies, such as social services departments. However, there is little evidence that these policy initiatives have managed to reduce discriminatory barriers for disabled people (Sapey, 2005). Piggott, Sapey and Wilenius (2005) report on research findings into the employment strategies of local authorities aimed at increasing the participation of disabled employees. The Local Public Service Agreements (LPSA) of two district council areas with targets to increase the number of disabled people returning to work were examined. Despite these initiatives to get unemployed disabled people back into paid employment research found that there was not one additional disabled person in employment despite the help offered. For as long as the underlying ideology remains focused on the individual impairment rather than the organisational change required, barriers to participation will remain. Disability discrimination needs to be tackled at the systemic level. Oliver (2005: 21) notes that 'government policies are, by and large, targeted at equipping the impaired individual for the unchanging world of work rather than changing the way work is carried out in order that more people can access it'.

Independent Living Choices

As a consequence of a restructuring of the welfare state over the past decades, disabled people have not only experienced reduced levels of funding, but a changed relationship with the state. In the context of low active participation in the labour market, greater reliance on state support is inevitable. Barnes observes that 'the overwhelming majority of disabled people and their families are disproportionately reliant upon social security

arrangements for their livelihood' (1991: 121). Traditionally, dependency on benefits is explained by reference to the inability of individuals to look after themselves and problems in securing paid employment which could sustain them adequately (Oliver, 1996: 65). It is their individual deficit, lack of ability caused, perhaps, by a missing limb, physical or sensory impairment, learning disability, mental health issue or a long term health condition that is seen to restrict their independent living and economic activity. The concept of disability discrimination, by contrast, requires an explanation that takes account of systemic patterns and barriers to active participation in social life which is rooted in the way society organises itself rather than the individual impairment.

With the introduction of the 'market logic' following the National Health Service and Community Care Acts 1990 disabled people have become 'consumers' of services, clients and service users. In their research on the behaviour patterns of health and social service users Baldock and Ungerson (1994) are critical of the market logic as a solution and advocate greater effective participation by 'needy' (sic) people. Their findings show that the growth of consumerism within a market model has had a slow start. Whilst there are service users who see themselves as consumers, with a view that they expect nothing of the state but instead actively select and buy from the available mixed market (health, social, voluntary, private sectors) or provide services out of family and household resources, these examples remain relatively few. The researchers state, that 'clearly, this is a view which is easier to hold if one has enough money to pay for what one wants' (1994: 267). Disabled people by nature of the structural oppression outlined above would not easily fall into this category. Disabled people have advocated direct control by disabled people themselves over the use of resources, rejecting the role of passive recipient of care. Disabled people are happy to take on the role of consumer if two conditions are met. Firstly, disabled people themselves must be in charge of funding and resources and secondly, they make their own decision on the type, level and method of service provision, whether by direct or indirect means. This form of personal and social services had been termed 'Independent Living' (Askheim, 2005; Morris, 1993; Oliver and Barnes, 1998; Zarb et al 1996). Rather than relying on dependency-creating welfare services (Priestly, 1998) disabled

people have lobbied for independent living arrangements which enable their active participation as citizens. The development of a legal and policy framework that eventually allowed for a user-focused perspective of 'need' and how best to meet it is illustrative of changing attitudes towards citizenship rights of disabled people. Given the long struggle for independent living laws, this area is also indicative of the difficulties in overcoming systemic discrimination against disabled people.

The Role of the Law: creating disability

Having explored the reality of disability discrimination, this section raises doubts as to the law's impartiality in responding to and dealing with disability discrimination. The first part illustrates how the category of 'disabled people' is socially constructed, that shifting definitions create both more dependency and a greater number of disabled people, whilst the second part argues that the law itself continues to create disability by the interests it is set up to protect. In understanding the role of law it is imperative to appreciate the social context within which legal rules operate and to examine the impact on the lives of disabled people.

Doyal (1994) contends that the reform of disability civil rights laws had been made more difficult by problems in identifying a 'disabled person' and in measuring 'disability'. In his discussion on the need for demographic information he agrees that 'the disabled population will vary according to the threshold definition of disability and the purposes of the survey in question' (1994: 3). This pinpoints the fact that 'disability' is a contested concept, whereby definitions and classifications may include or exclude large sections of the population. Definitions and threshold criteria have been expanding or contracting over time.

Traditional policy responses to disability have been through welfare and entitlement provisions. Many academics in the disability studies field argue, that the particular category of 'the disabled' did not exist until the late nineteenth- early twentieth century (Barton 1997; Barnes, 1991; Oliver, 1996). It is with the rise of capitalism that many disabled people were unable to compete in the newly emerging forms of standardised production, factory work, enforced discipline, time-keeping, a one-fits-all routine, standard-height workbenches, normed methods of production at set speeds. Ryan and

Thomas (quoted by Oliver) observe that 'all these were highly unfavourable changes from the slower more self-determined, flexible method of working' that existed previously for all workers, and into which disabled people were more easily included (1980: 101). Oliver concludes that 'the arrival of industrial society created particular problems' for the continued productive inclusion of many disabled people (Oliver, 1996: 85). The category of 'disabled person' was thus someone who for reason of impairment required a different norm to going about one's work, and since that was not in line with developing business priorities, disabled people were created, classified and categorised. That group of people now required a policy response. 'Disabled person' is thus the product of a discriminatory relationship between an impaired individual and a given society.

Society's response to the identified 'disability problem' had been to re-distribute some of its goods to needy and deserving people according to strictly laid down criteria, in form of 'entitlements'. The key organising principles for welfare entitlements for disabled people is 'need'. The origin of the welfare state dates back to the Beveridge Reports in the late 1940s. The National Assistance Act 1948 was drafted to provide powers for the direct provision of services, but specifically disallowed monetary help given directly to disabled people. Under s 29 of the National Assistance Act 1948 as originally enacted, local authorities had the power to make arrangements for promoting the welfare of disabled persons. Disabled people were fighting for rights to services and succeeded in lobbying successfully for the passing of the 1970 Act, which under s 1 of the Chronically Sick and Disabled Persons Act 1970 for the first time, placed local authorities under a duty to inform themselves of the need for making arrangements for disabled persons within their area. The impact of shifting definitional boundaries can be demonstrated by closer examination of entitlement laws in health and social services. By entitlement laws in this context I mean legal powers, duties and obligations which give rise to provision in form of human, financial, or material resources.

Following the introduction of the NHS and Community Care Act 1990 the way services were coordinated between agencies radically altered with the introduction of a market ideology and the principles of care management. No

new entitlements to services were given and reference had to be made to previous legislation, dating back as far as the beginning of the welfare state in the late 1940s.

Who is defined as disabled is laid down in section 29 of the National Assistance Act 1948. In that original piece of entitlement legislation, disabled people are depicted as vulnerable, dependent and 'in need'. They are entitled to services if they fall within impairment-focused definitions of disability:

'Persons aged eighteen or over who are blind, the deaf or dumb, or persons suffering from mental disorder of any description, and other persons aged eighteen or over who are substantially and permanently handicapped by illness, injury, or congenital deformity or such other disabilities as may be prescribed.' (Section 29 NAA 1948)

This description is firmly based upon individual bio-medical model of disability (Oliver, 1990) locating the 'problem' of disability within the individual deficit, as discussed in previous chapters. It leaves little room, therefore, to consider social and environmental arrangements, resources or policy decisions in the construction and creation of disability.

In respect of people thus defined, not infrequently de-personalised, labelled by category and referred to as 'Section 29 clients' and 'Section 29 service users' (see, for example, legal textbooks used for lawyers and social work students Brayne & Martin, 1997: 280-282; Cull, 2001: 43), the local authority has duties under section 2 of the Chronically Sick and Disabled Persons Act 1970. These duties are listed as specific services such as day care, meals-on-wheels, or home help, which at the time were perceived to assist dependent disabled persons. Framed from a paternalistic perspective this duty is about arranging services 'for' people, rather than enabling disabled people do it themselves, 'enabling disabled people to meet their own needs' (Oliver, 1996: 68) as would be the case under independent living arrangements.

The wording of the 1970 Act clearly lays a duty upon local authorities regardless of available budget. The combined effect of the requirement to assess for the need under section 47 of the NHS and Community Care Act 1990 and the duty to provide services under section 2 of the 1970 Act is that once 'needs' have been identified, services must be provided and arranged for regardless of available resources. The problem with entitlement legislation

is that these 'entitlements' are linked to available resources. Significant resource implications have arisen as a result of the operation of the NHS and Community Care Act 1990. There were no parliamentary debates to discuss the event of available resources being outstripped by 'demand' as created by assessments under section 47. Without legislative amendments, the law was required to find a solution to the problem of identifying greater level of need than existing services were able to meet within their current definitional framework. This is achieved by developing the law on a case-by-case basis and setting precedence at the highest court, the House of Lords.

Mr. Barry and law's impact

In order to illustrate the operation of the law in respect of entitlements for disabled people and to provide the foundation for further discussion, the seminal case of Mr. Michael Barry will be reported in detail. This case arose in 1994_(R v Gloucestershire CC, ex parte Barry[1997] 2 All ER 1, [1997] AC 584, [1997] 2 WLR 459, HL.). The facts of the case were summarised by Lord Lloyd of Berwick, reproduced here to set the scene:

"Mr Michael Barry lives in Gloucestershire. He was born in 1915, so he is coming up for his 82nd Birthday. In the summer of 1992 he spent a short spell in Gloucestershire Royal Hospital suffering from dizzy spells and nausea. He was told he had suffered a slight stroke. He has also had several heart attacks, and cannot see well.

After discharge from hospital, he returned home, where he lives alone.

He gets around by using a zimmer frame, as a result of having fractured his hip several years ago. He has no contact with any of his family. But two friends call from time to time to do things for him.

On 8th September 1992 Mr Barry was referred to the Social Services Department in Gloucestershire County Council ('the Council'), and on 15th September his needs were assessed as follows: 'Home care to call twice a week for shopping, pension, laundry and cleaning. Meals-on-wheels four days a week.' The Council arranged to provide these services.

Nearly a year later, on 3rd August 1993 Mr. Barry received a routine visit from the Social Services Department. His needs were being assessed as being the same. Then on 29th September 1994 Mr. Barry

received a letter from the Council regretting that they would no longer be able to provide Mr. Barry with his full needs as assessed. Cleaning and laundry services would be withdrawn. The reason given was that the money allocated to the Council by central government had been reduced by 2.5 million and there was 'no-where near enough to meet demand'. It is only fair to add that the letter was sympathetic in tone."

The issue was whether, when deciding what services it was bound to provide under s 2 of the 1970 Act, the council could properly have regard to its resources. By a majority of 3 to 2 the House of Lords held that it could. The outcome of the case was that the court allowed local authorities to reduce or withdraw services to disabled people after re-assessment. The justification was that the local authority must be allowed to take account of their changed financial position. Consequently, the financial position of the local authority in effect re-defines what is classified as 'need' for disabled people. Eligibility criteria were set and access to services tightened as a result. To reiterate the point made earlier, the difficulty with entitlement laws is that entitlements can be taken away depending on external, economic and political factors. The problem for the courts was that to have decided otherwise would have meant making the government responsible for funding local authorities at a higher rate, potentially at a cost of billions. The impact on disabled people of shifting definitions and the introduction of eligibility criteria is clear: fewer services, less assistance, reduced independent living, greater uncertainty, increased dependency on existing provision. Following the decision of the Divisional Court on the narrow question, the council reassessed some 1,500 people in receipt of services under s 2 of the 1970 Act. As a result of the reassessment the number was reduced to 1,060.

Entitlement provision, definition of disabled people and policy approaches are all cast from within the framework of paternalism. Lord Berwick's sympathy for the claimant Mr. Barry was evident, for example, in his use of language that underlined how much Mr. Barry had suffered, and in his legal reasoning Lord Berwick dissented from the majority judgment. He recognised that issues of finances should not influence the decision of whether or not a person has a 'need' for services. He states:

“The council now appeals to the House. The Secretary of State for Health is joined in the appeal. It is as well that he should be for it is the failure of central government to supply the funds necessary to enable the council to carry out what I regard as their statutory duty which departing from the fine words contained in the government White Paper *Caring for People: Community Care in the Next Decade and Beyond* (1989) (Cm 849), has put the council into what the Divisional Court called an impossible position; truly impossible, because even if the council wished to raise the money themselves to meet the need by increasing council tax, they would be unable to do so by reason of the government imposed rate-capping.”

In the context of inadequate resources, or a fixed perception of how resources are prioritised, the 'way things are done' was thus under discussion. However, the decision of the law came down on the side of the status quo protecting interests of fiscal policy rather than disabled people in need of re-distribution of resources to enhance equality of outcome. The law cannot suggest a substantial re-definition on how resources are used. Jones (1995), however, argues for exactly that: a recasting of the definitional framework. He observes that within Wiltshire, for example, the social services department had a financial turnover of £75 million in one year and Jones raises the question of how this money, staff resources of 3500 and locality resources of 110 is being spent (1995: 110). For example, if money spend on running a day centre does not satisfy the actual independent living needs of disabled people, then much of that budget is wasted to keep existing buildings and staff services. The welfare state as conceived of by Beveridge rests on full employment, insurance principles and male breadwinners. Oliver (1996), however clearly argues, that this - from cradle to grave - idea of anticipating services for all citizens had failed disabled people. The analysis of the Barry case leads to the same conclusion.

Entitlements – what entitlements?

The *R v Gloucestershire County Council, ex parte Barry* (1997) case is an indication of increasing conflict over resources, which sets disabled people's requirements for independent living in direct conflict with other groups of people. Disabled people's needs are seen as additional, costly and a burden.

Existing fiscal, social, political and economic arrangements remain unchallenged. Disability discrimination arises out of the fact that existing arrangements, existing priorities are left intact. It is these arrangements which create dependency. They are not designed with disabled people in mind from inception, but include 'needs', such as health and social care needs, as an 'expensive' afterthought. The way society organises its resources fails to include all disabled people as citizens. A model of inclusive citizenship is therefore needed. This shows how the law has created disability by categories of 'need' and 'eligibility', has remained partial by enforcing processes of assessment and the legal principles created in case-law which leave disabled people at the margins. At times of economic constraints the law thus serves to significantly reduce opportunities for disabled people.

The development of more direct control over resources by disabled people is a positive step towards the removal of disability discrimination. Prior to the Community Care (Direct Payments) Act 1996 (as amended by Health and Social Care Act 2001, s 67(2), Sch 6, Pt 3) there were no provisions in the legislation, which enabled local authorities to pay money directly to persons requiring services under s 29 of the 1948 Act so that they could buy-in the services themselves rather than merely accepting the services supplied in kind by the local authority. The employment of personal assistants (PAs) by disabled people as employers rather than the supply of carers, home services or meals-on-wheels by agencies, such as voluntary organisations or social services, heralds a shift not only in language (from care to assistance) but also in decision-making powers (from expert/professional knowledge towards disabled person's own control). Direct payments have been framed in terms of support (not illness or incapacity); this means ensuring that people can have what support is needed and when it is needed. Rather than having to accept a place in a day centre as traditionally provided for by local authorities, for example, the support needed for a disabled person with direct payment may be assistance in getting to and using the local community centre, the library, local college, a place of worship or sports centre. Rather than going to a respite home for two weeks, the disabled person can use direct payment resources to arrange for an accessible holiday, a weekend cottage in Devon or assisted stay with a friend. The development of direct payment illustrates

how the law has been used to enable greater citizenship power, self-determination and flexibility in the lives of disabled people. However, the struggle over independent living has been played out over the past thirty years and continues to be shaped by the resistance and resilience of organised disabled people. Undoubtedly, though, Direct Payments and the growth of tailored, flexible services is a first step in removing disability discrimination.

The Role of Law: anti-discrimination provisions

Disability discrimination as a legal concept is now enshrined in the Disability Discrimination Act 1995. Before I consider the drafting and application of this Act in more detail, a brief overview of the origin and meaning of anti-discrimination measures is offered. During times of civil unrest in the United States of America in the 1960s civil rights campaigns agitated for equal treatment for Black Americans, as triggered by Rosa Parks' refusal to give up her seat on a bus to a white man in 1955. Mrs Parks was the first black woman to challenge the law. It took several years before equal treatment laws were passed. Anti-discrimination measures can be traced back to the concepts of 'disparate treatment' and 'adverse impact' as developed in the common law of the US Supreme Court in *Griggs v Duke Power Company* 1971/401 US 424. In the next section the legal principles of British anti-discrimination laws are explained. Different forms of discrimination and how they have been developed in law are illustrated in both race and sex discrimination cases focusing on employment. Established legal principles are then critically examined and comparison is made to provisions in the Disability Discrimination Act (as amended).

Direct and indirect discrimination

The British race and sex discrimination legislation details two forms of discrimination, direct and indirect discrimination. The application of direct discrimination requires a comparator. If, under similar circumstances, a person from a protected class, as defined in law, is treated less favourably than the comparator is or would have been treated, and if this treatment is due to their 'race' or 'sex' then the behaviour is discriminatory and thus unlawful. The Race Relations Act was originally passed in 1975 and Sex Discrimination Act in 1976, both with subsequent amendments as recently as

2002. To treat someone less favourably than their comparator applies dually, this means that both men and women can sue, as can any member of a 'race' as defined in law, including white (Caucasian) people. Examples of direct discrimination might be the outright refusal of a service, or the decision not to shortlist a qualified candidate.

Indirect discrimination is a little more complicated. It concerns the apparent equal application of a condition or requirement to all. However, the condition or requirement in question cannot be met by the protected class in as high a proportion as it can be fulfilled by members of the pool of comparators. To illustrate this development and show how indirect discrimination is legally identified, the seminal case of women postal workers will be examined. The concept of indirect discrimination was included in the Sex Discrimination Act 1976 section 1 (b) as a result of *Steel v Union Post Office Workers* (1977) IRLR 288.

The issue arose out of a dispute concerning promotion opportunities for women postal workers as compared to their male colleagues.

“Mrs Steel had been employed as a post woman since November 1961. However, due to a Post Office rule that women could not achieve “permanent full-time” status, she did not achieve permanent status in the job until September 1975 when an agreement between the Post Office and the Union of Post Office Workers provided for the abolition of this rule. Under the terms of this agreement, her seniority as a permanent full-time post woman ran only from 1.9.75, though she had served continuously as a temporary full time post woman since November 1961. Seniority is important in this job for a number of purposes, including the allotting of “walks” or rounds. In March 1976, Mrs Steel applied for a vacant walk. On the basis of the seniority rule, however, this walk went to a Mr Moore who had become a permanent full-time postman in July 1973 and was therefore senior to Mrs Steel, though he had less continuous service in the job.

Mrs Steel subsequently complained to an Industrial Tribunal that she had been discriminated against on grounds of sex. During the course of the Tribunal hearing, she explained that she had no complaint against the Post Office but that her complaint was against the union

which had negotiated the agreement of 1975. The Industrial Tribunal dismissed Mrs Steel's claim on the ground that she was making no complaint against the Post Office and that her complaint against the union was misconceived. According to the Tribunal, matters such as seniority "are entirely for the union, its members and the General Post Office". Mrs Steel appealed against this decision."

Depending on their seniority, all postal workers were given greater freedom in choosing their walks. The condition for this freedom was seniority' and was applied equally to all postal workers. However, women postal workers were less able to meet this condition than their male counterparts. This was due to the fact that they were not able to build up seniority as they were largely employed as temporary workers or on a part-time basis.

"The requirement or condition that a successful applicant for a walk must be the most senior in the roll of permanent full time postmen was a requirement or condition such that the proportion of women who could comply with it was considerably smaller than the proportion of men. Moreover, the requirement or condition was to the detriment of the appellant because she could not comply with it. Though in time the discrimination would be phased out, the time to consider whether the requirement operated to the appellant's detriment was when the requirement or condition had to be fulfilled.

Thus, the appellant was entitled to succeed in her claim against the Post Office."

So, while no direct discrimination in form of behaviour which disadvantages the position of any particular individual woman postal worker existed, women were nevertheless discriminated by indirect means. The general rules, the organisational context, under which the women competed for seniority were stacked against them from the start, and the freedom to choose walks beyond reach, was merely a theoretical rather than actual possibility.

The tribunal members also considered possible justifications on the side of businesses. They stated that 'in approaching the question of whether indirect discrimination is justifiable, a number of considerations must be taken into account'. The Employment Appeals Tribunal, however, warned against the application of the criterion 'necessary in business' as an easy justifications.

The judgment instead is now asking organisations to consider alternative methods of achieving their aim:

“A distinction must be made between a requirement or condition that is necessary and one which is merely convenient. A practice that would otherwise be discriminatory cannot be justifiable unless its discriminatory effect is justified by the need — not the convenience — of the business. For this purpose, it is relevant to consider whether the employer can find some other non-discriminatory method of achieving his object. In the present case, therefore, it would be right to enquire whether it is necessary to allot walks by seniority or whether some other method is feasible; to consider whether the seniority rule could not be revised so as to give women some credit for their previous service; and to consider the extent of the disadvantage which women suffer under the present system in terms of numbers and likely duration.” (op.cit.)

It does, therefore, appear that business objectives and business requirements can, in certain circumstances, trump the equality dimensions of fair and equal treatment. It is not about weighing-up two equal sides, but deciding whether a genuine business necessity exists, and if so, then, and without question, the law will protect it.

This British definition of indirect discrimination is narrower than the American concept of adverse impact. The US Supreme Court termed the discrimination *inherent* in the very fabric of society as ‘in-built headwind’ *Griggs v Duke Power Company* 1971/401 US 424. Bourne & Whitmore (1996: 63) interpreted this to mean ‘anyone who is not a member of that group which has traditionally been expected to take part in a particular activity’. The concept of adverse impact has enabled the American laws to achieve significant inroads into reducing institutional discrimination.

Indirect discrimination, in contrast, has ‘not been as useful in challenging systemic discrimination in Britain’ (Clarke, 1995: 9) but has nevertheless proved useful in combating some more obvious forms of race and sex discrimination. Dickens reviews thirty years of Equality Legislation and Britain

and observes widespread systemic institutional discriminatory practices (2007). Employment tribunals remained reluctant to discuss 'indirect discrimination' and few formal investigations by the Commission for Racial Equality CRE or the Equal Opportunities Commission EOC would address institutional indirect discrimination (Bourne & Whitmore, 1996: 64). There has been a distinct reluctance to pursue the idea of institutional discrimination and of extending the parameters of equal treatment to include issues which would require changes to processes and procedures. The law initially protected 'business as usual'.

Law's reluctance

The reluctance to tackle indirect discrimination points to powerful forces concerned with, interested in and protective of the very fabric of society. There is a strong reluctance to change. In Britain, for example, the subject of institutional racism had been explored from as early as 1981 by publication of the Scarman Report. McCrudden (1982) and Jenkins (1989) equally explored institutional racism, but the term became an issue for public debate only following high profile reporting of the murder of Stephen Lawrence on 22 April 1993. It took several years of inquiry until eventually in 1999 a committee decided that 'the police force in London made too many mistakes in their investigation' (Dialogue Works). The term 'institutional racism' gained currency and seventy recommendations to combat racism in the police force were published by MacPherson (1999). It is therefore surprising, disappointing and perhaps worrying, that five years later, the Commission for Racial Equality launched a further inquiry (2004) into police racism. This report was published in March 2005. The findings were very depressing, since it appears very little progress towards eradicating institutional discrimination had been made. The report found, for example, that police forces and several police authorities had been so poor at cracking down on racism within the ranks that the CRE is now threatening legal action. Out of 15 police forces chosen at random, 14 had failed to meet legal requirements. The report also criticised training for probationers, found that tests designed to detect racist officers were more likely to catch Black and Asian recruits than whites. Ethnic minority officers were also more likely to be targeted for disciplinary action by their

forces, whilst episodes of racial hatred by white officers against ethnic minority colleagues were detailed. Black officers, for example, told the inquiry team that the trainers, supposed to play a vital part in eradicating prejudice among officers, were often hostile to race equality themselves.

In order for institutional and indirect discrimination to be removed, the organisation itself needs to change. However, institutional change was slow, and the report called middle management in the police force the 'ice in the heart of the police'. There was concern that despite willingness to change at the top, this did not translate into action lower down. Sir David Calvert-Smith, who led the investigation, however, presented a very interesting perspective. He said institutional racism was not necessarily the cause. Rather, many managers did not have the necessary people management skills as they were selected almost exclusively on their operational abilities. 'When [managers] are appointed they are not given the training necessary to understand the new problems that they will face as managers so they are ill-equipped to deal with the sort of problems that arise' said Calvert-Smith. However, how can there be a 'willingness at the top' if recruitment procedures, job specifications and training priorities are decided without addressing racism? Surely, it is an organisational issue and thus a clear example of institutional discrimination. Institutional discrimination is a term originally developed to increase the scope of what can legally be covered as 'race discrimination'. McCrudden (1982) outlines legal uncertainties in relation to the term 'discrimination', which had developed until that time. He was concerned that there were 'a number of conceptions of what constitutes discrimination and considerable disagreement as to its meaning', indicating that in the centenary that had passed since the first attempts to protect civil rights in Britain, the question of how exactly protected classes (legally defined groups of people) are discriminated against, remained unresolved. McCrudden continues to ponder the issues: 'To what extent, firstly, should we distinguish between discrimination and prejudice? Prejudice may be regarded' he moves 'as neither a necessary nor a sufficient component of discrimination' (1982: 304). This is an important point, discriminatory behaviour can exist even in the absence of prejudice. Recognising dominant patterns of organisational and social relations McCrudden explains how adjectival use of 'institutional' or 'structural' before

'discrimination' or 'racism' became common to describe the exclusion of Black and ethnic minority people from housing and employment. The level of explanation is structural not individual. In the United States it had long been the view that institutional discrimination is not dependent upon prejudice nor on choices made by any particular individual within the organisation, such as personnel managers, employers, team leaders, or head teachers, nor indeed middle managers in the police force. Knowles and Prewitt explain:

'The rules and procedures of the large organisations have already pre-structured the choices. The individual has only to conform to the operating norms of the organisation and the institution will do the discriminating for him (sic).' (1969: 143)

Whilst this analysis serves to illuminate how policy and procedure can do the discriminating for you, it fails to address the fact that individuals with decision-making powers, such as the senior officers of the police force, sit together in the first place to draft those very rules.

British legal and political thought had great difficulty accepting any form of institutional or group level analysis. Until the influence of the European case *Bilka-Kaufhaus GmbH v Weber von Hartz* (1986) ILRL 317 British tribunals have been adding 'intention' as a requirement of indirect discrimination. However, indirect discrimination, by its very nature, need not be animated by direct prejudice on the part of those with decision-making powers, since the issue is not intention, i.e. whether the discriminator meant to treat a group of persons less favourably, but the impact or effect on the lives of that group of people that is decisive. Indirect discrimination operates to provide an 'in-built headwind' for some, whilst it serves to create barriers to equal participation for others.

Thus the basic legal principles of anti-discrimination are direct and indirect discrimination of a protected class (such as women or men) based on the idea of equal treatment. It is significant how the protected class is defined and how far the net is cast. This will be discussed in detail in respect of disabled people. For the moment, the Aristotlean notion of 'fair treatment' requires further analysis (Aristotle Ethics). In order to benefit from any of society's goods people in similar positions are to be treated in similar ways, while the

treatment of people in dis-similar positions has to be modified in proportion to their particular dis-similarity ensuring that no irrelevant differences are taken into account.

To illustrate this principle of anti-discrimination within the Race Relations Act, for example, a sign outside a pub displaying 'No dogs, No Blacks, No Irish' would be unlawful. This implements the idea of fair treatment by making it unlawful to discriminate against a person in similar position (visiting a public house to have a drink) on the basis of irrelevant differences (colour of skin, religious belief). Anti-discrimination measures dealing with sex discrimination covers equal treatment between men and women in similar situations, such as recruitment and selection for employment. For example, it is prohibited to ask women of their intention to marry and have children before offering a job on the assumption that women might be off work for pregnancy, leave her job to look after children or be less reliable employee because of child care commitments. Such questions would be termed 'less favourable treatment' as compared to a man in the same position. Even if both men and women were asked the same questions, the impact of such a question is different for men and women. Asking such questions remains unlawful since they treat women less favourably, because they are more likely to be responsible for child care arrangements. This form of discrimination is 'indirect'. It is never a good enough argument to say 'we are all treated the same', 'we are all asked the same question' and with this the presumption that no discrimination exists. It is in fact the failure to recognise relevant dis-similarity, which often leads to discrimination. In the above scenarios, the material position of women and men is dis-similar in that women in the main are regarded as primary carers for children.

Less favourable treatment, whether by direct or indirect means, on the basis of race and sex is thus prohibited in law. With anti-discrimination principles firmly in place for the past forty years, it is somewhat puzzling to think that 'disability issues' and the irrelevant difference of impairment took over thirty years to pass into legislation, which would protect disabled people against discrimination on the same basis.

The Role of Law: Parliamentary law-making

Despite the success of early anti-discrimination laws, disabled people were not so protected and they fought for recognition of anti-discrimination measures. It took seventeen attempts to pass private members bills in parliament before, in 1995, a compromised version of a civil rights bill and anti-discrimination measures finally passed into the statute books.

The struggle of disabled people to resist systemic discrimination, to fight for equal citizenship rights and to demonstrate political will and strength encompassed civil disobedience, direct action demonstration, lobbying of parliament as well as commissioning research and providing academic debate (Barnes, 1991; Barnes and Oliver, 1995). Democratic principles and methods of participation do not easily support the voice of minorities. Within democracy and a notion of majority-rule, safeguards and protective procedures are required in order to enable minority perspective, rights and active participation. Political and legal processes were for a long time 'closed' to the question of anti-discrimination for disabled people. This can be attested by running through the chronology of attempts to pass anti-discrimination legislation. Despite common currency in the field of race and sex, the idea that disabled people are discriminated against and require political will and legal measures, was not accepted by people in power. The conceptual difficulties, which acted as a barrier and lead to a flawed understanding of disability issues, will be discussed shortly.

The passage of time

In 1982 the Rt Hon. Jack Ashley MP introduced the Disablement (Prohibition of Unjustifiable Discrimination) Bill, under the Ten-Minute-Rule. Whilst it was given an unopposed first reading, it was lost at the end of business. Then, in early 1983, the same Bill was being presented as a Private Member's Bill, introduced by Mr. Donald Stewart. However, the Bill failed to secure the required 100 votes for the Closure, even though it reached 77 votes in favour with no votes against. Therefore the Bill could not be given a second reading as a necessary step in passing legislation. In November that same year, a completely different Bill was being debated. The Chronically Sick and Disabled Persons (Amendment) Bill sought to introduce anti-discrimination into Part 1. Again, this Bill failed to reach the second reading stage. Despite

that fact that it exceeded the required 100 votes to 164 for, a government whip ensured defeat by 210 votes against. Nevertheless, the idea of prohibiting discrimination against disabled people and of fighting for full civil rights had gained groundswell. In the same night, on 18 November 1983 Lord Longford took the Bill into the House of Lords as Bill no. 2. The support was enormous and the Bill passed all stages into the third reading. However, on the motion that the Bill do not pass, it was defeated by 68 votes to 49. This second Bill advanced the disability equality agenda in that it sought to make discrimination against disabled people unlawful and to set up a commission similar to the Equal Opportunities Commission to investigate instances of discrimination and promote and police disability equality, for example by formal investigations and by publishing guidance. Further attempts to achieve individually enforceable civil rights for disabled people were made by Mr. Wareing, Lord Campbell and Mr John Hughes. They were all unsuccessful, amidst some spectacular political manoeuvring.

The final Parliamentary passage did not inspire disabled people to put trust in their political leaders when it comes to ensuring comprehensive, individually enforceable citizenship rights. The Disability Discrimination Bill was presented by the then Secretary of State for Social Security, Mr. Peter Lilley. It received its first House of Commons reading on 12 January 1995 and was steered through the House of Commons by the Minister for Social Security and Disabled People, Mr William Hague, as succeeded by Mr. Alistaire Burt, who saw the Bill through the House of Lords until October. There had been a total of 13 sittings between 31 January and 28 February 1995 as the Bill was given detailed scrutiny in Standing Committee E, a process which resulted in a number of Government amendments, each of which reduced the outright protection for disabled people. The second House of Lords reading initiated detailed debates and the Bill was committed to a Committee of the Whole House, which considered it over a period of three days on 13, 13 and 27 June 1995 (HL Deb Vol 564, cols 1640-1718, 1723-1284, 1895-1954 and 1975-2054; HL Deb Vol 565, cols 608-680 and 686-744). As a consequence, the government introduced a number of extensive and substantive amendments and additions to the Bill. This, almost new Bill, was reported to the House of Lords for consideration with amendments as HL Bill 120. The reading took

place on 18 and 20 July 1995. A further amended HL Bill 135 emerged, but did not have time for a Third Reading before the House rose for summer recess on 21 July 1995.

When the Bill was re-considered by the House of Commons, it disagreed with one of the substantive amendments made by the House of Lords and made additional amendments. This action is very unusual and indicative of the then government's overwhelming majority and decision-making powers. The House of Lords finally accepted and the Disability Discrimination Act 1995 (Chapter 50 of 1995 legislation) received its Royal Assent on 8 November. By the end of parliamentary passage, unequivocal Civil Rights for disabled people were knocked out of the Bill. Thirty years after UPIAS first agitated for full citizenship rights, disabled people in the UK were disappointed, angry and aggrieved by the introduction of the Disability Discrimination Act in 1995. There were several reasons for this. Primarily, the Act was seen as a watered-down compromise and fell short of the expected recognition of full citizenship rights in all spheres of life. There was disagreement over the definition of 'disability' and the meaning of the protected class, and anger at legally sanctioned discrimination.

Still waiting

Furthermore, the fact that the Act was implemented in stages was seen a major injustice. Why should disabled people have to wait even longer for their rights? Many areas of ordinary life were left untouched, such as education and transport. This meant that disabled people were still waiting for fully enforceable civil rights and equal treatment to the same degree that is legally enshrined in terms of race and sex discrimination. The latest amendment to extend disabled people's protection against discrimination passed Parliament and received Royal Assent on 7 April 2005. However, even then disabled people were kept waiting, many of the most significant parts became active in mid and late 2006, and for positive Disability Equality Duties in schools in 2007 and 2008.

A key critique concerned the legal principle of fair treatment. In stark contrast to other anti-discrimination legislation, the Disability Discrimination Act allowed certain forms of justification. To justify discrimination in effect means

to accept discrimination against disabled people by allowing it to be overridden by some other concern or qualification in pursuit of some competing objective. The rights of disabled people to active participation are legally constrained, whilst the interests of others are legally promoted over and above the rights of disabled people. A further difficulty with the law concerns its application and interpretation, in that the proportional and reasonable use of legal powers regarding 'reasonable adjustment' is not clearly defined and thus subject to the exigencies of competing political, social or economic interests.

One of the reasons why disabled people had to wait so long for anti-discrimination measures was the widespread belief that there is no such thing as disability discrimination. It was argued that if disabled people were not interviewed for a job, for example, or refused entry to a restaurant, that this treatment was due to their having an impairment and not due to discrimination. 'Disability' was seen as a justifiable reason to treat people less favourably, often with added assumptions that 'disabled people simply cannot work productively', 'they need so much assistance' or 'disabled customers are messy, risky and their presence is unfair on other customers'. The problem was perceived to lie within the sphere of the individual to whom negative characteristics are attributed by reason of their impairment. House of Commons debates (as recorded in Hansard) testify to the idea that anti-discrimination measures were both unnecessary and irrelevant. Instead, a voluntary code of practice by employers was promoted and a general education and awareness raising initiative supported, falling short of accepting disability discrimination as a fact.

In contrast, disabled people have argued that society discriminates against them in all areas of life by failing to take account of impairment when designing and organising civil society (Barnes, 1991; Degener, 1995; Barton and Oliver, 1997). Activities of civil life range from school to sport, housing to paid employment, from marriage to campaigning, cinema to bakery to polling station and shopping centres. A law was needed to protect disabled people from discrimination in all these areas with the aim of increasing participation in the mainstream of society. Scope conducted research to show how disability discrimination limits employment opportunities of disabled people. Barnes

(1991) made a convincing case for Anti-Discrimination Legislation by detailing the extent of disability discrimination in different spheres. Research, facts and figures, as well as personal stories were presented to make a case.

Continued lobbying by disabled people and their allies finally lead to the presentation of the Civil Rights (Disabled Persons) Bill in May 1994. Mr Roger Berry MP said in support of his proposed legislation:

“It is not about charity, being paternalistic or being nice to disabled people. It is about rights. The Bill’s purpose is to ensure that the disabled (people) have the same rights as everyone else in employment, housing, education, public transport and the provision of goods and services.” (Hansard, 20 May 1994; col 520)

Mr. Berry acknowledges traditional policy responses to disability, mainly charity and special (nice) treatment. This overview of the history of anti-legislation legislation in Britain brings into sharp focus the conflict between competing groups and interests, between traditional and social model approaches to disability, between status quo and change. More importantly, though, it gives support to the lament that anti-discrimination legislation had been a ‘last resort’ for the government who under repeated pressure from organised groups of disabled people and their allies had to deflate that pressure by diluted concessions, repeated amendments and compromises scheduled over several years of implementation.

The Role of Law: Structure of the DDA

Having detailed the ongoing struggle of establishing legal protection based upon anti-discrimination, rights-based, individually enforceable civil rights for disabled people, this section will outline and critically discuss the structure of the Act. Three questions will be addressed: What areas of civil life are covered, or in other words who has duties under the Act? Who falls within the protected group, how is a ‘disabled person’ defined, thus who can bring a case under the Act? And thirdly, what is the meaning of discrimination, what behaviour and which circumstances are unlawful under the Act?

The Disability Discrimination Act (DDA) was passed with the stated aim to end the discrimination that many disabled people face. It sets out to protect disabled people in key areas of social life, in both private and public sectors:

- employment

- access to goods, facilities and services
- the management, buying or renting of land or property
- education, from school to post-16, including qualification boards
- transport
- public sector duties to promote disability equality

Part I of the Act deals with the definition of who is protected under the law part II outlines provisions in employment, whilst part III covers service providers, any services and facilities that disabled people may wish to use. Education has only been incorporated into part IV with the passing of the Special Educational Needs and Disability Act 2001 (SENDA). This delay and clash of conflicting legal principles are discussed in more detail below. Further parts deal with transport, housing and the Disability Rights Commission.

The legal approach to the protection of rights for disabled people is first to establish whether or not a person is a disabled person. The next question is whether or not the provider, particular service or employer has duties under the Act. And the third question is whether there has been any discrimination. As already noted, disabled people face many barriers in the labour market, one aspect of that barrier is their lack of qualifications with disabled people in positions where they are less likely to have recognised vocational or academic qualifications. The barriers to obtaining and retaining paid employment are obvious. Since October 2002, the employment provisions in part II of the Act have been extended to cover organisations that confer qualifications, renew or extend professional recognition or trade qualifications. It is unlawful to discriminate against a disabled person when awarding, renewing, extending or withdrawing such qualifications (Employment Studies).

Definition of a 'disabled person'

The Disability Discrimination Act 1995 in part I defines who is a member of the protected class, since only 'disabled people' can bring a case. To date, a relatively small number of cases failed on definition, that is where the court or tribunal disagreed with the person bringing the case that they classify as 'disabled' (Institute of Employment Studies Statistics, annual). It is useful to remind ourselves of the purpose of this Act: It is to protect from discrimination. The DDA is not a welfare piece of legislation, which would entail giving benefits or entitlements as an extra benefit to specially qualified groups of

people. Whilst with welfare legislation the definitional boundary is usually drawn narrow, to reduced the number of claimants and thus keep tight control of expenditure, anti-discrimination measures, in contrast, aim to protect a wide range of people, and thus the definition is drawn more generously. The new definition has a very strong residual mode of thinking about disabled people as 'requiring charity and handouts', which presents challenges to principles of anti-discrimination. Frequently, disabled people with 'hidden' impairments, such as heart conditions, asthma, progressive conditions and disabled people who have varying mental health, episodes of depression or anxiety, had only a fifty : fifty chance of being recognised as disabled by employers or service providers. By contrast, people with cerebral palsy or people who have hearing impairments, or have epilepsy have no difficulty being accepted as 'disabled' under the Act. The problem with the definition of disability in the DDA is that it perpetuates, even promotes myths and common-sense stereotypes about disabled people. This is because the definition and guidance at first sight remains firmly rooted in individualised deficit model of disability. The Employment Tribunal in 1989 exemplifies this problem in their approach in the case of *Goodwin v The Patent Office* (EAT 57/98):

“What the Act is concerned with is the effect of an impairment on the person’s ability to carry out normal activities (...) The focus of attention required by the Act is on the things that the applicant either cannot do or can only do with difficulty, rather than the things the person can do.”

This leaves a difficulty and paradox for disabled people. On the one hand, the disabled person needs to show that they are 'substantially affected by impairment' in what they cannot do in ordinary day-to-day activity, whilst at the same having to show that they are capable of doing the job by showing what they can do. Since the definition of disability is meant to be broad enough to cover all people who are at risk of discrimination, a closer look at the interpretation of relevant sections is required. The DDA states in sections 1 and 2 who classifies as a disabled person.

1. Meaning of 'disability' and 'disabled person'.

(1) Subject to the provisions of Schedule 1, a person has a disability for the purpose of this Act if he has a physical or mental impairment which

has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities.

(2) In the Act 'disabled person' means a person who has a disability.

2. Past disabilities.

(1) The provision of this Part and Parts II to IV apply in relation to a person who has had a disability as they apply in relation to a person who has that disability.

(2) Those provisions are subject to the modifications made by Schedule 2.

Disability Discrimination Act 1995 (c. 50)

In plain English, the meaning of these provisions cannot easily be determined. A key problem is that the legal definition confuses 'impairment' with 'disability' (see section 1(2) which reads 'a person who has a disability'). This section uses language reminiscent of bio-medical model approaches. For example, human resource managers or local education authority advisers may look at this definition and imagine the traditional model of disability - that is a person who has some deficit or difficulty. In order to decide whether an applicant or service user is protected by the Act, a false interpretation may be given to the words 'has a substantial and long-term adverse effect'. For observers still thinking within the bio-medical model of disability this requires someone to be 'really' disabled, to have a 'serious' impairment, to be 'quite incapacitated' before they can claim rights under the Act. In that way, there is a danger that policy, practice and procedures are developed based upon a false understanding of who is covered under the Act. This is particularly dangerous if the judiciary and members of tribunals have not received adequate instruction and training on disability equality issues.

The Act does not specify what is meant by 'substantial adverse effect, and thus whether an impairment has a substantial adverse effect cannot not be gleaned directly from the wording of the DDA. However, the Government has debated the issue and shared the intention that even quite minor impairments are included, but that trivial conditions should be excluded. Hansard discussions and legal development show that 'substantial' simply means 'more than minor' and aims to distinguish an impairment from, for example, a scratch (HC Deb Standing Committee E, col 114 by Mr. W. Hague; HC Deb

vol 566, col 174 by Mr A. Burt). The meaning of any provision in the Act is supplemented by regulations (Disability Discrimination (Meaning of Disability) Regulations 1996 SI 1996/1455) and statutory guidance issued by the Secretary of State under section 3, which states that 'guidance on matters to be taken into account in determining questions relating to the definition of disability'. This means that the definition of disability is flexible, and the law has a role to play in both extending and reducing its scope. Currently, in line with other anti-discrimination measures, the breadth of the protected class continues to grow. The Government has issued guidance and whilst this does not in itself impose legal obligations on an employer or service provider, a tribunal or court must take into account all available guidance when considering a complaint about discrimination. The recent extension of who falls within the protected class is testimony to the fact that disability discrimination is slowly being recognised as an issue to be addressed more widely in society.

To illustrate the need to extend the definition, I shall briefly look at people who have cancer. Cancer itself is not an impairment, and whilst many people with cancer would be protected from unfair treatment, others simply would not meet the legal requirements. In *Cox v Bells Toyota* (1700896/98), for example, the applicant had cancer of the jaw. This caused his face to swell, impaired his speech and made it difficult for him to swallow. The tribunal did not think that this alone was enough to satisfy the statutory test. However, it found that the applicant had a disability because it recognized that his condition would be very much worse but for the courses of chemotherapy and radiotherapy he was undergoing. It also noted that the illness was likely to become more serious (DCR, 2003).

In contrast to this, there are many cases of cancer where the person may be unable to establish that they fall within the Act. Thus they fail to be protected from discrimination, particularly if the cancer is in remission. Whilst the law deduces the effect of treatment, this applies only for as long as the treatment persists. Thus, if treatment has ceased, the individual's condition must be assessed without discounting the previous medical treatment. This can lead to rather inequitable results as the following case illustrates.

In *Hay v Highdorn Co Ltd* (2201755/98) the applicant had returned to work part-time following successful treatment for breast cancer, but was subsequently dismissed for refusing to return to fulltime working (which she would have found too tiring). She was unable to produce evidence that the cancer was likely to return or that it would recur if she stopped her medication. There was no evidence of an ongoing adverse effect at the time of her dismissal and so the tribunal found that she was not a disabled person at that time (DRC, 2003). Whilst it is plainly obvious that some form of unfair treatment has taken place, the law as it stood did not protect the applicant. This has now been remedied. With the implementation of the Disability Discrimination Act 2005 – ten years after it first fought its way through parliament – the definition of disability has been extended to cover people who are HIV positive, have cancer, or multiple sclerosis from the moment of diagnosis. There is no need to establish impairment or adverse effect. The DDA 2005 also amends the definition of disability for people with mental health issues, since it removes the requirement that a mental impairment should be clinically well-recognised. So, whilst people with agoraphobia, for example, would have found no problem coming under the protected class, newly developing mental health issues might have posed a barrier. Finally, it is important to note that only disabled people are able to claim rights. This means that an employer or service provider can take steps to specifically include disabled people, as non-disabled people cannot claim less favourable treatment caused by positive action or positive discrimination.

Meaning of discrimination

At the core of anti-discrimination measures lies the question of what practices, behaviour, rules, policy and procedures are unlawful and what barriers to disabled people's full citizenship rights and to active participation need to be removed. The pejorative meaning of discrimination is 'differential legal, social or economic treatments of persons which is motivated by irrelevant consideration' (Concise Oxford). The experience of disability discrimination takes two main forms (i) less favourable treatment and (ii) a failure to remove barriers.

Less favourable treatment

The first form of discrimination is somewhat comparable to direct discrimination in race and sex discrimination laws. The DDA gives the meaning of discrimination to include organisational behaviour by employers and service providers that

‘...discriminates against a disabled person if for a reason which relates to the disabled person's disability, he treats him less favourably than he treats or would treat others to whom that reason does not or would not apply;’

This approach to less favourable treatment requires a comparator, a person with whom the disabled person in a particular situation is compared and (a) who does not have the same impairment and (b) who would be treated differently. The comparator can thus be a disabled person with a different impairment or a non-disabled person. In bringing a case for discrimination the disabled person does not have to show that there is actually someone who was treated better, but a hypothetical comparator will suffice.

A key part of the definition of less favourable treatment is the requirement ‘for a reason related to that person's disability (as defined in part I of the DDA)’. The working of the law will be illustrated with a case scenario based on one of the early cases brought under the Act. It also reflects the experiences of disabled Londoners:

“How would you feel if you were asked to leave a restaurant because you had a learning difficulty? ... I was so angry I could have punched him but I kept my cool. In fact, at the time, I was so shocked I just walked out.” Faisal Yousef (GLA)

The scenario that follows raises the legal question: Has the landlady discriminated against Winston on the basis of less favourable treatment related to that person's impairment?

“Winston has learning difficulties and as part of his condition shouts from time to time. He has invited a group of friends to the pub to celebrate his birthday. The landlady approaches the group and asks Winston to leave. One of his mates tells her that he has learning difficulties. The landlady replies that she would ask anyone to leave who shouts.”

Cases of blatant and direct discrimination against disabled people do exist, such as a refusal of a service because that person has an impairment, uses a wheelchair or is blind. Direct discrimination tends to involve some form of 'intent', whether an intent to treat less favourably, or an intent to protect the disabled person 'in their best interest'.

As a matter of fact, there have been a series of cases involving disabled people being refused access to a pub, all across Britain.

A landlord in a Scottish case, for example, refused to allow an assistance dog into premises to accompany a deaf client (DRC/02/5986). The landlord said he did not want the dog in the pub because food was served. The disabled woman tried to explain the situation but was told not to bother by the landlord. The landlord then said that he did not believe she was deaf and her friend had to explain that she could lip read very well. They then had to leave the pub.

In North Wales resident Gareth Foulkes was visiting The Albion Inn with friends. He was told by bar staff that he would only be served if he and his friends agreed to be segregated from other customers due to Gareth's hearing dog, Hiro. Dr Kevin Fitzpatrick, DRC Commissioner for Wales, said:

"It is shocking to find that Gareth would be served if segregated from other customers. Disabled people have the right to have a social life, just like anyone else, and businesses should be aware of how to treat disabled customers. It is no longer acceptable for disabled people to be treated as second-class citizens. The law now says so and it will be enforced."

A further case, reported by the Disability Rights Commission (2002) concerns a young woman with learning difficulties. "Mary McKay and her befriender Frankie, from the charity Uniting Friends, had gone for a quiet drink at the Ye Olde Valentine pub, in Gant's Hill, Essex, before they went to see 'Chicken Run' at the local cinema. When they entered the pub Mary gave a little skip because she was in a good mood and looking forward to a night out. The doorman of the pub, run by national brewery chain Scottish and Newcastle, told Mary's companion to "keep her in order". Soon after, the landlord came over and became abusive. He then turned and, across a crowded pub, shouted to the bar staff that Mary and Frankie shouldn't be sold any more drinks. Mary was very humiliated and upset by the experience and has since

found it difficult to go out. This is not the first time that people with learning difficulties have been barred from Ye Olde Valentine pub. In evidence, two other young people with learning difficulties also recounted similar experiences.”

These cases illustrate the endemic nature of the experience of disability discrimination, which leads to segregation, isolation and the humiliation of being treated as a second-class citizen. All cases succeeded under the DDA, with Mary being awarded £3000 in damages for injury to feelings and costs were also awarded against the defendants to the tune of £14,000. Despite these successes, cases under Part III (Service and Facilities) are relatively few, and the uptake by people with learning difficulties is particularly low. The whole legal process, the court system, hearings and particular procedures can be very intimidating. To bring a case can be daunting, especially without the advice of expert legal support, therefore, many potential claimants would be put off by this (Department for Education and Employment’s Research Brief No. 119).

Returning to the Winston scenario, deep rooted threats to freedoms as an equal citizen can be highlighted. At first sight the ‘less favourable treatment’ requirement does not appear to be met and the landlady might be seen to be acting fairly, since she says she would ask anyone who shouts to leave. However, the principle of fair treatment requires consideration of similarity and difference, with an adjustment of the treatment (organisational behaviour) in proportion to the dis-similarity of one person in the same position as another (comparator). So, for example, assistance dogs for Deaf and hearing impaired people have been specifically trained and must be treated differently, as they are dis-similar from ordinary pets.

This means that the landlady needs to have regard to Winston as one of a range of diverse people who come to her pub, as someone who has a learning difficulty and shouts from time to time. This person is compared to a person to whom that impairment does not apply, i.e. someone using a wheelchair, a non-disabled person or perhaps someone who is blind. Does she treat Winston, having due regard to his difference, less favourably than any of the comparators? She says she would ask any of the comparators to leave if they shouted. Even though it may be doubtful whether she would

actually do this, regard needs to be had to the phrase 'for a reason related to that person's impairment'. Why does Winston shout? It is part of who he is. He gets kicked out of the pub for who he is, whilst others get kicked out for what they do. They can change what they do, Winston cannot change who he is. And, applying the social model of disability, nor should he change who he is, be 'cured' or 'specially trained', but the external factors of exclusion need to be addressed.

This scenario is an example of how formal equal treatment that does not distinguish between individuals, but assumes a standardised 'norm', can be discriminatory. The landlady's behaviour, therefore, needs to distinguish; her treatment needs to change in proportion to Winston's dis-similarity so as to ensure that she treats him equally and fairly. Dworkin (1978) identifies two concepts of equality, the right to equal treatment which he considers to entail the right to an equal share of valued social goods (such as freedom of movement, enjoying a drink with friends), or equal access to opportunity or resource (such as every citizen having the right to participate in democratic processes) as well as burden (such as contributing to the economy through work). Dworkin's second concept of equality (1978) emphasises the right to be treated with the same respect and concern as others. This is a higher level of equality principle, derived from the first, and requires that the particular individual circumstances of a person are taken into account. This idea of differential treatment will be of particular relevance to the second form of disability discrimination within the DDA.

Failure to make reasonable adjustment

In stark contrast to traditional anti-discrimination measures, the DDA accepts a social model perspective of 'barriers to participation'. Disabled people are prevented from taking part in socially valued ordinary activities by the way society is organised and thus creates or reinforces barriers. Instead of looking for medical interventions, cure or other changes to the impairment, the disabled person can expect society to remove the external barriers. The second form of discrimination under the DDA exists if there has been a failure to do so. 'Reasonable adjustment' is thus a duty in law placed on employers (in part II) on service providers (in part III) and on educators (in part IV) to

remove barriers by making reasonable adjustments. Two questions immediately come to mind: Adjustments to what? And what is reasonable?

Principles of Reasonable Adjustment

An employer discriminated by refusing a job interview to an applicant on the basis that that person has a hearing impairment and communicates through a sign language interpreter using British Sign Language BSL. This is less favourable treatment and as such unlawful. It does not matter what motivated that refusal, whether the employer thought the person less able to do the job, whether they thought it best to spare the embarrassment for the disabled applicant, or whether it was due to some administrative issue, such as lack of space or time for another person in the interview room. Equal opportunity principles dictate that the Deaf person is to be given the same opportunity to display knowledge and skills as applicants to whom that impairment does not apply. The Deaf person, applying Dworkin (1978), needs to be treated with respect and concern. To show respect for this applicant requires treatment at an equal level, neither patronising nor dismissive. It requires an interaction with disabled people based on fact and not fiction (Behavioural Change Model, Adept 2003), thus eliminating stereotypes and misconceptions, or fiction such as 'Deaf people cannot work safely' or 'cannot use a telephone'. This is only part of the process, though. The principle of equality also requires concern shown by the employer. This is not to be confused with charitable or philanthropic concern, since that would not meet the first of the two elements (respect at an equal level). To treat the Deaf applicant with concern requires action on behalf of the employer. Employers have a legal duty to remove any barriers and to enable participation on an equal footing. Thus, in order for the Deaf applicant to demonstrate what they know, arrangements for a sign language interpreter need to have been made, additional time allowed in the interview schedule to give equal time to the applicant by allowing extra time for translation, appropriate seating arrangements for applicant, BSL interpreter and the interview panel to have been agreed between the parties so that the sign language in use will be effective. All of these arrangements would be deemed 'reasonable adjustments' as compared to the standard arrangements in this case. However, an employer would fail to make reasonable adjustment if, for the next Deaf applicant, the same arrangements

would automatically have been made, since the second Deaf applicant (in this given case scenario) does not use a BSL interpreter, but uses a hearing aid. In that case the barrier to communication, and thus to the applicant's opportunity to convince the panel, lies in the acoustics of that particular interview room. This barrier could be removed by providing a loop-system and relevant microphones, for example, and by changing the location to a quieter room. Of course, the employer shows concern by ensuring that the loop system is working, that the panel members know how and when to use microphones, and that the loop-system symbol is clearly displayed. A third Deaf applicant has a hearing dog to assist. This requires yet different forms of accommodation to enable access.

The access issues dealt with in these scenarios relate to auditory (loop system), visual (signage), environmental (location), language (BSL interpreter), time (adjusted to accommodate translation) and physical/spacial (seating, room lay-out) adjustments. They are not concerned with individual impairment, with how much the applicant can hear or whether they were born deaf. An interaction based on finding out about impairment, in this case 'hearing impairment' in all three examples, does not assist in finding solutions to access issues and thus knowing what adjustments to make.

The principle of 'reasonable adjustment' places the responsibility of change onto employers, service providers and education providers. It requires an interaction with disabled people based on fact and it is thus important to ask, clarify and inform about access issues. Arrangements will need to be in place, which shows both respect and concern for the person involved.

Access to Justice and Reasonable Adjustment

Bringing a case under the DDA can be very difficult for many reasons. Employment tribunal and court proceedings are not renowned to be the most user-friendly of places. With additional barriers to participation for disabled claimants these processes can be particularly challenging. The Disability Rights Commission DRC has been developing a range of strategies to address this by working with disabled people on their proceedings. People with a learning difficulty and people with a hearing impairment can find proceedings especially daunting because of access issues concerning communication. In an effort to remove barriers, the Group for Solicitors with

Disability GSD and the Bar Council have called for voluntary assistance from colleagues with 'practical experience of, as well as an active interest in' the provision of such legal services; GSD agrees that:

'there are pressing problems of access to legal services for people with a hearing (impairment). This is in the context of court rooms, tribunals and every place where a member of the public has the right to advice from qualified lawyers' (GSD, 2004)

The Human Rights Act 1998 incorporates the European Convention on Human Rights, which in Article 6 requires that in the 'determination of his (sic) civil rights and obligations or of any criminal charge against him (sic), everyone is entitled to a fair hearing'. For disabled claimants, a fair and equal hearing is only possible if access issues have been successfully addressed. Consequently, a voluntary code of practice, being 'nice' to disabled people, or having merely 'an active interest in' does not suffice. There is a right to a fair hearing with corresponding duties to make the process accessible. A practical example is provided, which illustrates the successful negotiation in this process.

Reasonable adjustments in practice

Mary McKay v 1. Bryn Thomas & 2. Scottish & Newcastle Plc Case No IG100989

'Ms McKay has learning difficulties, hearing and visual impairments. She visited the defendants' pub with a friend and within minutes was asked to leave and was told she would not be served any more drinks. The DRC became aware of another two individuals with learning difficulties who had also been asked to leave or refused entry to the same pub. All three gave evidence at the hearing. To ensure the witnesses and Ms McKay understood the purpose of the proceedings a local voluntary service for people with learning difficulties was contacted to provide extra support to the individuals involved. Contact was also made with the day centres and residential homes used by the individuals so that family friends and staff members involved in the three individuals' lives were familiar with the proceedings.

Correspondence was made accessible using a variety of methods. Each letter had a picture of the legal officer at the top so the individual knew whom it was from and that it related to the court proceedings. The letters were written

using simple language and structured so they could be easily understood. Correspondence with two of the individuals was sent in half inch font and Ms McKay was also sent a copy spoken onto a tape. Copies of correspondence were also sent to the individuals providing support who could then discuss the letters with the three individuals and contact the Commission with any questions arising from them.

Information regarding Ms McKay's impairment and its effect on her daily life had been provided to the defendants in order for them to be able to understand the reasons why requests for adjustments may be made.

The witness statements contained questions that had been asked to the witnesses to assist them in providing details of the incidents. All three statements were produced in regular and large print and both formats were included in the trial bundle. One statement was also recorded on to tape for the witnesses' own use.

There is no provision in the Civil Procedure Rules for individuals with learning difficulties to sign a witness statement if they cannot read it themselves. A representative of the DRC read the statements to the witnesses and signed, and the witnesses confirmed they understood the content.

At the Case Management Conference the court was given information on Ms McKay's impairments and how they affected her. It was also requested that a court with an induction loop be used and a conference room be available so that the hearing could be adjourned for a short time, if necessary. This was to allow the proceedings to be explained or summarised to enable her to understand the case. A request was also made that the case be listed first so the witnesses with learning difficulties were not caused extra distress by having to wait long periods before giving evidence.

The court readily agreed to these suggestions and was happy to assist the witnesses if necessary. The issue of adjustments to enable Ms McKay to bring her claim was also raised with the defendants, who were happy to assist. Prior to the hearing counsel met with the witnesses to gain an understanding of their access requirements and to explain the way the court worked and outline what would happen. Arrangements were made with the court clerk to enable the witnesses to enter the courtroom. They were given a

chance to practise being on the witness stand, taking the oath, answering questions and had the role of the judge and barristers explained.

During cross-examination of the witnesses it was accepted that questions needed to be kept simple, to the point and only addressed one point at a time so the witnesses could understand what was being asked. The claim was successful. Ms McKay was awarded £3,000 in compensation and the judge declared that the actions of the defendant amounted to unlawful discrimination (DRC, Case Reports).

For reasonable adjustment to be effective ongoing consultation with the disabled person concerned is helpful, as are diverse mechanisms for feedback and consultation, both with the specific disabled person and with disabled people more generally. Giving the person a 'voice' through advocates, personal assistants or training enables the realisation of basic civic rights. A willingness to imagine changed arrangements is essential, to prepare in advance, to change, diversify, expand the 'standard' procedures. For example, a simple move to provide printed material as standard Arial in 14 font with 1 ½ line spacing would increase access to the printed information and enable independent use of that material by many people without having to declare their access need individually; people with a visual impairment, people with memory or concentration issues, people with learning difficulties, older people with deteriorating sight, people with depression, people affected by side effects from medication, people in a hurry, can all benefit.

These considerations and processes are additional to clarifying access issues in terms of auditory, visual, environmental, time and language, and making practical changes as a result. Furthermore, the workforce within organisations requires respect and concern in terms of reasonable adjustment. Whilst it is recognised that generally the participation of disabled people in employment is low, and within the law even lower, with just 2% amongst solicitors, for example (GSD, 2005) the Department for Constitutional Affairs DCA has recognised the importance of accommodation, in particular in a context acquiring an impairment whilst at work:

We have made improvements to the working lives of judges, such as more flexible working arrangements and better support for serving judges, over recent years to better meet the needs of a diverse

judiciary. ... Reasonable adjustments are made for disabled judges, both on appointment and in respect of impairments which develop while a judge is in post. (Department for Constitutional Affairs, 2005)

Whilst improvements have been made to the proportion of female judges, which runs to about 10% women as High Court Judges and Lord Justices of Appeal and 49% as female Justices of Peace (DCA May 2005), as well judges from ethnic minorities (DCA) figures for the proportion of disabled judges are not available. The department regrets

‘While there are promising signs of greater numbers of women and minority ethnic lawyers entering the judiciary, and of the removal of barriers to the full participation of disabled people at every level of society, the current make up of the judiciary does not reflect the UK population or the legal profession from which judges are drawn. There is still more to be done to increase the diversity of the judiciary at all levels.’

In 2004 the Equal Treatment Bench Book (ETBB) addressed itself to the issues of equality before the law. However, defining what is meant by discrimination this guide only referred to direct and indirect discrimination (page 5). This fails to fully encapsulate disability discrimination, which can be experienced as a failure to make reasonable adjustments. Legal professionals, including judges, are initially advised to obtain impairment information from their clients, rather than ascertaining what access issues need to be addressed:

‘Do make a point of obtaining, well in advance if possible, precise details of any disability or medical problem from which a person who is appearing before you has’. (ETBB 2004: 7)

But uncertainty over how best to interact with disabled people continues with:

‘ Do allow more time for special arrangements, breaks, etc. to accommodate special needs at trial’ and ‘Do give particular thought to the difficulties facing disabled people who attend court – prior planning will enable their various needs to be accommodated as far as possible.’

And later the advice is specific, focusing on access not the impairment reasons for that access requirement, and thus much clearer in terms of individual and organisational behaviour that is required:

'Do encourage the availability of court documents and advance information in different local languages and alternative formats e.g. Braille, large print, audiotape, etc. and do encourage the provision of access to interpreters and signers.' (ETBB 2004: 8)

Conclusion

Disability discrimination cannot be taken in isolation but has to be examined in the overall political, economic and social context paying due attention to inter-connected spheres of influence. The law does not operate in isolation. The drafting and application of entitlement or civil rights legislation, for example, are products of a particular society at a particular time. Althusser (1972) sees law as capable of forcefully implement dominant interests and values.

Together with Gramsci (1971) Althusser maintains that the legal system is part of a repressive and ideological state apparatus protecting the interests and values of capitalism. Ideology – a set of ideas, values and beliefs, provides the impetus for social cohesion.

In the context of law, Cotterell (1992) views consensus as an act of a minority of people:

'There are 'dominant' ideas or values which consistently influence law and government more powerfully than others seems more plausible. In this perspective the consensus that determines the way law operates can be seen as the consensus of an elite – an influential minority – or a number of elite.' (Cotterell 1992: 101)

Disability discrimination in Britain, whilst having the legal recognition within the Disability Discrimination Act 1995 (as amended), is less forceful a concept than comparable discrimination based on race or sex. Change has been painfully slow, and change in fact may mask continuities under the guise of tackling disability discrimination. For example, by stating that the law now recognises unlawful disability discrimination, it is also the case that the law has for the first time authorised discrimination against disabled people. The negative meaning of discrimination as a form of avoidable, unlawful, social evil has been diluted. Legal definition and principles of justification narrows the concept of disability discrimination, and as a result less of it exists. Taking account of 'reasonableness' factors, business necessity, lawful

justification means that less disability discrimination is acknowledged in law. Hence, the application of law and the material reality of disabled people are only partially coincident and as such tell two different stories.

The law, at best, sets minimum standards and by itself is not enough in ensuring fair and equal access to socially valued opportunities. Thirty years of the Equal Pay Act 1970 has made little impact upon actual differential pay between women and men for jobs of equal value. In reviewing ten years of the Americans with Disabilities Act (ADA1990) statistics are unspeakably depressing. According to the American Bar Association, 96.4% of cases brought under the ADA were won by the employer. A review of 50 key cases promotes the view that 'Better understanding of ADA can help employers both avoid costly litigation and take advantage of a segment of the US labor market that has not yet been fully utilized.' (Erdos et al 2006). However, there is a glimpse of hope. Since this was largely due to a narrowing of disability definition, the British legislation at least recognises that definitions need to be drawn widely if anti-discrimination (as opposed to welfare) measures are to succeed. In that sense the passing of time – forty years all told – at least had some benefit.

It must be recognised that the law has no objective meaning but will be brought to life by particular sets of values and beliefs. Dicey (quoted in Cotterell, 1992: 10) thought of law as the consensus opinion of 'the majority of those citizens who have at a given moment taken an effective part in public life' (1905: 10). Since disabled people, as a group, have been excluded from much of public life, consensus over legal matters cannot be assumed to exist. Disabled people are still struggling to be heard, their voices quietly or marginally represented within the legal framework. This chapter has argued that the law is an instrument of the state apparatus either mediating between conflicting interests, aiming to achieve equilibrium of interests or indeed of furthering the interests connected with the exigencies of western capitalist mode of production and globalized economic forces.

Chapter 4

Disability Discrimination: Inclusive Education

The analytical aim of this chapter is to establish the meaning of disability discrimination in education and to explore citizenship elements of equality, community, identity, democratic participation and 'having a say'. Particular attention is paid to structure and agency issues between individuals and authority. This analysis is framed within the philosophical and legal principles of (i) the social model of disability with (ii) a rights-based approach to (iii) political struggle in the context of education. The narrative focus of this chapter is taking a long historical view of the lived-citizenship experiences of disabled people in education and its cumulative effect on future life choices. The first part of the narrative has, as Finkelstein put it, 'something to say about the historical context in which attitudes are formed' (1980: 8 quoted by Borsay, 2002). Sources drawn on include published opinions of disabled academics, historical text (legislation, records, newspaper articles, written reports), disabled people's own stories, empirical facts and legal case law. Whilst overall confined to a few sources, thus not comprehensive in its coverage, the narrative tapestry is nevertheless valid if read within a wider socio-political context (Borsay, 2002: 107). Stubborn historical continuities can thus be illustrated.

This Chapter will apply the meaning of disability discrimination as established in Chapter 3 to the context of education. Principles of anti-discrimination, which incorporate Dworkin's (1978) equality principles, together with national and international legal requirements, provide a rights-based approach to the

discussion of disabled people's participation in education. Historically, legal approaches to disability in education were based upon care and control, welfare or 'special' treatment. The role of law in devising categories resulted in labels for disabled children, which either open or close doors for educational opportunities.

To begin with, facts and figures will again set the scene and illustrate the educational disadvantage of disabled young learners. The second part of the narrative offers a brief historical overview, charts the development of legal measures to the recent changes, which focus on anti-discrimination, and examines developing case law. As a major shift in thinking takes place uncertainty and political struggle come to the fore. Inherent contradictions in policy and law are played out in an educational context.

For example, within different pieces of legislation there are conflicting perspectives and underlying assumptions in responding to disability, one set focusing on (i) impairment ('identifying pupil's special educational needs', the other on access (school accessibility plans, reasonable adjustments, positive disability equality duty), the first set of measures are (ii) allocating resources according to classification of 'entitlement to something extra', whilst the second protect individual rights to fair treatment and non-discrimination, and with (iii) decision-making by experts in stages of an administrative assessment process in the first, compared to duty to involve disabled people in the second. Whilst part IV of the DDA as amended by the Special Educational Needs and Disability Act 2001 broadly represents a rights-based anti-discrimination approach, it has incorporated remnants of 'old' thinking and language of 'special educational needs'. An increase of 800% of complaints brought to SENDIST tribunals (LEXIS/ Butterworth) with 172 claims (2002 – 2004) indicates the strength of competing interests involved.

Underlying the concept of citizenship are human rights values (dignity and self-determination) and human rights principles (full and equal participation). United Nations Convention on the Rights of the Child 1989 asks Nation States in Article 23 to ensure that disabled children have 'a full and decent life in conditions, which ensure dignity, promote self-reliance and facilitate active participation in the community.' The analysis of citizenship rights in education

for all goes beyond a debate over inclusion of disabled pupils. Kunc (1992) speculates that 'when inclusive education is fully embraced, we abandon the idea that children have to become 'normal' in order to contribute to the world'. He foresees a particular kind of citizenship:

We begin to look beyond typical ways of becoming valued members of the community, and in doing so, begin to realise the achievable goal of providing all children with an authentic sense of belonging.

(Kunc, 1992: 38, cited in Lipsky and Gartner, 2000: 20)

Similarly, Barton (1998: 84) associates the notion of inclusivity with citizenship in that it (inclusivity) 'places the welfare of every citizen at the centre of consideration.' This chapter recognises exclusionary processes within education in relation to disabled people and the challenge this poses to the concept of citizenship. It poses the questions of how citizenship education can be implemented to include disabled people. Particularly, if the business of education in its culture, practice, policy and procedures fails to embody the full citizenship rights of all participants, especially disabled people, how can it be a credible site for the dissemination and education of citizenship principles?

Facts and Figures

In *Every Child Matters* (2003) the government has established that the educational attainment of disabled children is unacceptably lower than that of non-disabled children. Barnes (1991) previously researched educational opportunity for disabled children both in segregated special schools and within mainstream provision, and found it wanting. This affects a great number of children, however 'disability' is counted. One in twenty children are disabled within traditional impairment measures, which represents a rise of 62% between 1975 and 2002 (Contact A Family, press office).

Every 3.5 minutes a parent is told that their child has a serious medical illness, health defect, physical, mental or sensory impairment (Barrett et al, 2003). The income of families with disabled children is 23.5% below the UK mean income of £19,968 and 21.8% of families have income that is less than half the UK mean. In the winter of 2007, one in ten families with a disabled child had their fuel cut off (Contact A Family, press office). As the difference between high earners and lower income is growing year on year, the impact

of having a much reduced income is exacerbated. This means that over half of all disabled children grow up at the margins of poverty (Gordon and Parker, 2000). Disabled children are often educated in segregated schools, specialist departments and exposed to a different curriculum. The overall experience is one of social exclusion (Burchardt, Le Grand, Piachaud 1999: 230; ALLFIE) and 'one of exploitation, exclusion, dehumanization and regulation' (Barton 1986: 276). Additionally, they experience a high level of specific exclusion. One in five children with autism, for example, is excluded from school at some point (Barnard, 2000; 2002). SCOPE (1994) found that over 40 per cent of those interviewed who were educated in both special and mainstream schools felt that their abilities had been underestimated. This situation has hardly changed in the past decade. Disabled children's experience of education is of a lower quality than that of their non-disabled peers (DRC, August 2005; Lewis, 2007). In particular:

- One fifth said that they had been discouraged from taking GCSE's .
- A quarter of disabled children said they were discriminated against at school
- 34% of disabled students said that they did not get the support they needed from teachers and other staff.

These findings support the argument that disabled children experience discrimination in terms of accessing equal educational experience as compared to their non-disabled peers.

Educational inequality has long been discussed in terms of gender, ethnicity, class background and poverty, as, for example, a focus on children whose attainment and abilities are seen as below average, the Department of Education and Science admitted that our education system is failing a large section of pupils (DES, 1991: 2). A problem is that 'special needs' is often conflated with 'low ability'. Government inspections of special schools has come up with a similar picture when examining the quality of academic teaching, access to all areas of the curriculum and basic facilities and accommodation (Barnes, 1991: 43-46; DES, 1989: 14; Ofsted, 2004). Pupils in special schools were denied access to a range of educational opportunities. Mainstream schools equally fail, only 23% of primary schools and 10% of

secondary schools are fully accessible (Audit Commission, 2002). From whatever standpoint, educational inequality is accepted as an issue affecting our education system. In the context of political interest in reducing social inequality and renewed debates on citizenship, disability discrimination in education draws into sharp focus a changed relationship between the state and its citizens. Armstrong and Barton argue that inclusion requires 'the removal of the material, ideological, political and economic barriers that legitimate and reproduce inequality and discrimination in the lives of disabled people' (Armstrong, Barton 1999: 214).

History of oppression and resistance

This section explores the history of segregated education for disabled people, not from dominant perspectives (Swain, 2005: 787) but agrees that 'contrary to some accounts, this has not followed an orderly and progressive pathway or been planned according to rational principles' (Armstrong, 2003: 63). Whilst I acknowledge that voices of disabled people's experiences can only be sought from the recent past, analysis of a range of historical sources will nevertheless raise critical questions (Reid Walmsley, 2006). The language adopted will correspond with the language used at the time for reasons of authenticity and to illustrate changes over time. The story of segregated education is intertwined with social, economic, commercial and scientific developments of the time and is testament to complexities of social relationships, policy development and contested interpretations of meaning. Whilst a sketched historical overview can illuminate significant changes in how society has responded to people with impairments, it also serves to illustrate stubborn continuities of sets of ideas on disability and related political struggles. With reference to citizenship, in the telling of history, particular attention is paid to infringements of civil rights of disabled people and growing political organisation of disabled people themselves, who have challenged dominant ideas.

Segregation by impairment and questions of access

Early categorisation of learners followed impairment labels. The first special school was set up in Liverpool in 1791 and was designed for the 'instruction

for the indigent blind'. Thomas and Loxley (2001: 22) inform us that during the nineteenth century such special schools emerged and were set up according to impairments, with philanthropists offering their support and later in 1834 the government stepping in to provide relief for the deserving poor. Early special schools included the Worcester College for Blind Children, Sons of Gentlemen, which opened in 1866 with the intention to offer education to 'blind children of opulent parents' (cited in Tomlinson, 1982: 37). Tomlinson points out that schools for children with sensory impairments 'blind' and 'deaf' were established as business ventures (Hodgson, 1953, cited in Tomlinson, 1982). The category of 'mental defective' existed in 1846 when the first private school opened in Bath. A further label was added when the first asylum for 'idiots' opened a year later. By the time of early compulsory education in 1870 this number had grown to five establishments admitting over 500 children and adults with that label (DES, 1978).

Segregation by impairment was necessary and thought to be 'in the best interest of the children, since 'the best form of education' could be applied. For example, following an influential International Congress in 1889, three resolutions were passed outlining the best method of education for deaf and dumb children, two of which are reproduced here:

1. The Convention, considering the incontestable superiority of articulation over signs in restoring the deaf-mute to society and giving him a fuller knowledge of language, declares that the oral method should be preferred to that of signs in the education and instruction of deaf-mutes.
2. The Convention, considering that the simultaneous use of articulation and signs has the disadvantage of injuring articulation and lip-reading and the precision of ideas, declares that the pure oral method should be preferred.

Likewise, a Royal Commission was issued in 1885 to examine the best method of education for blind people with the ultimate goal of employability and usefulness to society. The full brief read:

"to investigate and report upon the condition of the blind in our United Kingdom, the various systems of education of the blind, elementary, technical, and professional, at home and abroad, and the existing institutions for that purpose, the employment open to and suitable for

the blind, and the means by which education may be extended so as to increase the number of blind persons qualified for such employment." The Commission was extended in 1886 to include the deaf, dumb and other cases where "special circumstances would seem to require exceptional methods of education". Segregation by impairment labels has thus been associated with special education methods for each group of learners. Statutory categories of impairment in the UK have been socially constructed and re-defined over time (Barton, Tomlinson 1984). These categories and labels serve to identify and marginalise groups of people. As they developed, even 'experts' disagreed over their precise meaning, and on occasion would acknowledge that disability categories serve as administrative tools (Gooding, 1997). It is therefore necessary to interrogate where, when, how and why these social constructions have taken place and the impact on disabled people. Armstrong (2002) advocates use of a range of historical sources, whilst Reid and Walmsley (2006) found disappointingly little evidence of disabled people's own voices until very recently. Early examples of categorisation can be found in the Idiots Act of 1886, which differentiated between idiots and imbecile in terms of the kind of care and control required. Mental deficiency was seen as a social problem, leading to idleness or pauperism and as such would violate against the value of self-sufficiency and as such might grow into a social or economic burden on the state.

The reach of workhouses

A philosophy of utilitarianism (Mills on Bentham 1871) is one of the stubborn continuities which shape thinking, in particular from the eighteenth century workhouse to twenty first century concerns with citizenship, as the thread is an agenda of usefulness, social contribution and avoidance of non-deserving burdens. Legislative roots for dealing with potential burdens to productive society go back to the fifteenth century:

"In 1494, the Vagabonds and Beggars Act (11 Henry VII c.2) determined that: "Vagabonds, idle and suspected persons shall be set in the stocks for three days and three nights and have none other sustenance but bread and water and then shall be put out of Town. Every beggar suitable to work shall resort to the Hundred where he last

dwelled, is best known, or was born and there remain upon the pain aforesaid." Worse was to come — the Statute of Legal Settlement (1 Edw. VI. c.3) enacted that a sturdy beggar could be branded or made a slave for two years (or for life if he absconded). The Act condemned "...foolish pity and mercy" for vagrants. On a more positive note, cottages were to be erected for the impotent poor, and they were to be relieved or cured." (Workhouses)

This demonstrates two key approaches of care and control, the application of which has shown little regard to what is now recognised as basic human rights. The care element for the impotent poor (which presumably included many disabled people) was based on an individual, bio-medical understanding of its causes aiming to relief and cure. The control elements were strongly framed in terms of stripping citizenship rights, food, shelter, freedom of movement, freedom of assembly, and freedom per se. A series of Poor Laws developed in order to deal with the question of resources, taxes, responsibilities, policy and social practices. These laws remained on the Statute books for hundreds of years, for example the 1601 Poor Law Act was not finally repealed until 1967, and the influential 1662 Settlement Act remained until 1948. The Act passed in 1697 also required the official identification and categorisation of people to be easily recognisable by everyone as citizens of a lower class. Paupers were to wear in red or blue cloth badges on their right shoulders showing the letter of their parish and the letter 'P' indicating the status of being a person in receipt of poor relief.



Pauper's badge for Ampthill parish (Workhouses)

Inmates of workhouses would wear uniforms made of coarse material for durability rather than comfort. Large institutions, such as workhouses, asylums, long-stay hospitals or residential schools, are characterised by a lack of basic citizenship principles, such as privacy, personal dignity, autonomy and personal choice. Inmates are separated, isolated both physically and symbolically from the rest of society.

Symbolic messages are no longer carried in form of badges, or yellow stars, but young people still 'feel the badge', for example as names of special schools or charities printed in large letters on the side of minibuses, or a slot on the local leisure centre's programme that reads 'swimming for the disabled' or 'The Charlie Chaplin Adventure Playground for disabled children' (ATLAS research 1999 -2003) or disability pass in Germany with a 'B' printed on denoting *Begleitperson* (the disabled person is entitled to bring a personal assistant for free or at a reduced rate, for example when travelling on public transport).

Goffman (1961) identified four factors which lead to institutionalisation: Batch living characterises that a group of people are treated as a homogenous whole, taking meals at the same time, following same routines according to fixed rules. Binary management is where the two worlds of inmates and management are strictly kept separate, with staff taking decisions affecting inmates. The inmate role characterises the state of affairs where inmates lose their sense of belonging, their sense of identity and become 'the inmate' 'the pauper'. There is a break with the past as inmates lose all their former roles. Finally, with continued living in institutions the process leads to the inmate adopting an 'institutional perspective', by which Goffman understands a loss of self, loss of aspiration, and acceptance of the power of the institution over one's personhood.

Workhouses as institutional legacy

Disabled people ('the chronic sick', 'lame', 'handicapped', 'epileptics') were also sent to the workhouses. Their experiences are indicative of institutionalisation throughout the century involving the stripping of citizenship rights. Workhouses are part of the history of oppression against which the independent living movement (Morris, 1991; Chapter 2) has protested in

recent years. The stripping of personhood was achieved by a myriad of methods, including the wearing of uniforms. Mabel Cooper is active in self-advocacy. When she was young she lived in a children's home and later in a long-stay hospital. Her story (Mabel Cooper, online) shows how people with a learning difficulty experienced life in institutions:

"The worst thing was, I couldn't wear my own clothes, you had to wear other people's. You never got your own because the beds were too close together, so you didn't have a locker or anything, you just went to this big cupboard and helped yourself. There might be six piles of dresses in this big cupboard." Mabel Cooper, online

Both batch living and binary management are easily evident in Mabel Cooper's story, which took place only about fifty years ago:

"We all ate on the ward together, but not with the staff. Food was vile, I didn't like it. They used to bring dinners up at 11 o'clock and they used to sit and talk till 12 or half past. The dinners were horrible. There was no choices. My friend Eva, she used to be one of the nurses, she used to heat it up for us." Mabel Cooper, online

Similar institutional processes have taken place in segregated education, where many children who attend special schools also reside (Reid Walmsley, 2006). As with any residential establishment, residential special schools, which are often located away from the original community of the child, tend to display a range of factors pointing towards Goffman's elements of batch living, binary management, inmate role and institutional living. Modern inspection reports continue to reflect the overall impression of institutionalisation with phrases such as 'shabby and unkempt', 'in serious disrepair', 'drab and dingy', 'run-down and poorly heated', 'of bleak exterior', 'barren and uninviting' (quoted in Barnes, 1991: 43; Audit Commission, 2002). As a specific example, basic hygiene and toileting arrangements showed lack of space, poor design and staff handling routines which resulted in lack of privacy for the children. This indicates binary management power in form of one set of principles for staff (privacy) and another for the children (surveillance), and results either in an acceptance of the inmate role by disabled children, who resign themselves to having their most private aspects and functions on public display, or in challenging behaviour and resistance. Barnes (1991) further found that

physical access, contrary to what might be expected from a specially designed 'special school', was generally poor. Staying with the same example, hygiene and toileting provisions were too small and inaccessible, often requiring children to ask for additional assistance when otherwise they could have managed independently, sometimes having to leave doors wide open to allow for transfer, additional staff in cubicle or limited wheelchair access. On occasions doors would be routinely removed so as to provide better surveillance for staff (ATLAS). Batch living is also evident in these most intimate human needs where many special schools have set times for 'toileting' en mass, for example before/ after lunch (Greenford Cowgate Centre, 1999; Lebenshilfe 2003). Institutional experiences sown from workhouses continue to shape disabled people's lives today. Survivors of special schools and residential living bear witness from within (SCOPE Speaking for Ourselves). Because of a focus on impairment rather than access, a reluctance to accept difference, professional's persistent failure to listen, significantly reduces participation in the 'lived-citizenship' of disabled learners.

For example, a failure to enquire about and to accept the communication method (non-verbal and eye contact yes/no responses) as **that** disabled child's preferred, self-determined access requirement, combined with the school's focus on what the child is unable to do (impairment), as expressed in their insistence on her learning to use 'more socially acceptable' tactile communication (pictures, pointing to board, using switches) a young woman had been labelled with 'profound communication difficulties' and had not had access to effective communication, to 'having a say', by the time she left school even though she was able to do so (Morris, 2001: 20).

Workhouses and educational legacy

Furthermore, workhouses have contributed to the development of educational responses to disabled people. Markus (1993) (quoted in Armstrong 2003: 56) asserts that 'the seeds of many educational practices' were sown in the eighteenth century workhouses. This refers particularly to the dual concerns for ensuring 'order and work'. Workhouses would both contain the poor, and with it many disabled people, as well as providing workers in form of on-site

labour. Training was given in production processes of weaving, knitting and spinning (particularly for girls), and basic instruction in arithmetic, reading and writing as required by future factory workers. 'Education' became those skills thought necessary for a useful application to enhance productivity according to the interests of influential people and economic need of the time.

The workhouses exemplified the changing relationship between individuals and the State in that they replicated modes of production now required in the developing industrial age. In the early twentieth century emphasis continued to be given to relevant skills and handicrafts, especially if children or young people were regarded as 'ineducable'. Mabel Cooper witnessed this:

"There was no school there, they only let you use your hands by making baskets and doing all that sort of thing. That's all you did. In them days they said you wasn't able enough to learn so you didn't go to school you went to a big ward and they had tables.

You just went there and made baskets or what-have-you. Because in them days they said you wasn't capable enough to learn to do anything else, so that's what you did.

So in St. Lawrence they never went to school. They went and made baskets. If you didn't do that you went to one of the work places or the laundry, or stayed in the ward doing nothing." Mabel Cooper, online

Even in the late twentieth century 'workhouses' persisted in form of Adult Training Centres, Rehabilitation Centres or Sheltered Workshops, the link between education and usefulness remains. People with learning difficulties, blind young people or others who attended these centres, would work in an assembly line fashion to create piece work for local factories, make dust masks or put nails into pre drilled holes ready for the next stage of dissembled production processes. Sheltered workshops provided on-site cheap labour under the guise of 'training and education'. Complicated welfare laws made it unlawful to pay the recommended wage.

The final inmate role adopted means that aspirations remain low. The close link between education, poor relief and incarceration in many large institutions 'provided a kind of productive ecosystem'. This was observed by Armstrong (2003: 57) in relation to workhouses, but continues to ring true for modern design of rehabilitation, education and training for many disabled people. In

Germany, for example, over 80 % of vocational training for disabled people is offered by way of rehabilitation centres, which are almost always based on residential living. Despite social and economic changes towards an information society, these rehab-centres remained stubbornly loyal to outdated modes of production. Training in computer skills was being offered, but progressing very slowly, whilst large numbers of training places are available in the declining metal working industries (1997) (*Bundesminister für Arbeit und Sozialordnung*; for details on the German system of rehabilitation with case studies *Fallreihen* based upon insider contributions (Vonderach, 1997). Even the name of the ministry responsible is reminiscent of the workhouse ethic, namely the 'ministry for work and social order'. Armstrong (2003) comments that :

'The current return to an insistence on the importance of technical and vocational skills as a key part of the curriculum in schools for some pupils, harnessed to the moral agenda of 'citizenship' and 'family values' are a reinterpretation of earlier rationalities linked to social usefulness and economic productivity.' (Armstrong, 2003: 58)

Armstrong concludes that historical accounts of the institutionalisation processes, of dehumanising regimes and bleak experiences of life in special schools and institutions for disabled people from these early days to current times emphasise not education, but 'the restrictive, harsh and un-stimulating regimes' of care and control (2003: 62).

Tangled web of histories

Readings of history do not offer a hegemonic picture of simple facts (Reid Walmsley 2006). On the one hand, it can be seen that disabled children were being instructed, trained and educated. However, Wright (2001: 191-192) discovered that attitudes in Victorian England, and with it, policy response had shifted from a philanthropic understanding that training idiot children is necessary and possible, so that they can take their full place in society, to a more pessimistic view that these children and young people needed to be contained. The objectives were to control their movement and ideally to limit procreation, so as to reduce future social failure. Rather than looking for a

continuum of single discernible facts, understanding the past requires close examination of diverse perspectives and struggles.

Care and control

At issue is the relationship of certain individuals (variously described as idiots, imbecile, feeble-minded, defectives, epileptics) within productive community and dominant values. If such individuals are seen as a burden in relation to the State or as reducing competitiveness of the nation as a whole, then the state is required to secure its continuation and future success by controlling the negative impact that flows from having these individuals live amongst its citizens. In that sense people with these labels are not classed as full citizens, and are seen as objects that require some form of intervention. Within the optimistic, philanthropic outlook the focus of this intervention is on identifying and then remedying the deficit of the individual, and thus reducing the negative impact on society as a whole by emphasising what contribution they could make. This was often described as being in 'the persons' best interest', as protecting the vulnerable from the harsh realities of life. The extent to which the fullest possible contribution can be achieved also marks the degree of their citizenship. This means that the emphasis is on protection, while the decision-making processes over the person's life remains inaccessible to the individuals concerned since decisions are in the hands of the State and later various 'experts'. In that sense disabled people failed to live as autonomous citizens. Overall, a limited membership, a reduced form of citizenship is granted.

Within the pessimistic outlook, in contrast, such efforts of training and protective measures were seen as futile and costly, since such (disabled) people were overall seen as dangerous and a threat. Therefore, in the long term, this perspective seeks to segregate, control and eventually eliminate such individuals altogether. They may be seen as a threat to the progress of others, a threat to social cohesion, a danger to themselves and to others' productivity (cf Report of the Metropolitan Commissioners in Lunacy to the Lord Chancellor 1844; The Lunacy Commission, MDX resource provided by Andrew Roberts).

During the optimistic phase schools would be opened, such as Mary Dendy's school for the feebleminded in 1902 as a forerunner to special schools. The school in Manchester was recognised by the Board of Education as both the first and the most complete residential provision for the 'feeble-minded' in England. At that time the Royal Commission on the Care and Control of the Feebleminded (1908) was looking for solutions to the social problems created by 'the feeble-minded'. In practice, it is not easy to determine whether a school or institution fell within an optimistic or pessimistic belief system. There is no easy delineation between these two perspectives, since ideas remained contested throughout this period. So, for example, despite an optimistic rhetoric at the time of a Christian duty to care for less fortunate, these institutions have often been run as commercial venture and indicated the more pessimistic outlook in their objectives. An advertisement for Heigham Retreat in Norwich illustrates keenly the appeal to the middle and upper classes of having their off-spring taken away:

“The proprietors think that the means now offered to the upper and middle classes will be eagerly seized. No parents having the misfortune to possess such children (imbecile and idiotic children), can fail to perceive how injurious it is to them to mix with boys of stronger powers, who can make no allowance to deficiencies they cannot discern; consequently the weak are annoyed and oppressed in all schools, public and private. Nor is the mode of education common in schools suitable for the imbecile, who require a system of training adapted to the animal frame, as well as to the capacity of each individual case, pursued with patience, perseverance, and kindness.”

(Manchester Guardian, 11 January 1851, cited in Sheehy et al 2004:15)

Rationales for segregation

The poster reflects attitudes of the time. The need for segregation was based on a number of interlinked assumptions: that the disabled person suffered from an individual deficit, that they were vulnerable to risk and potential objects of bullying or abuse, that the correct educational response was one of training a lesser human being, 'the animal frame', that individual capacity was reduced compared to 'normal' children, and that that training called for a

different curriculum. These assumptions were cemented by the belief that all this required specialist attention by expert staff in places away from the mainstream of social activity.

“With these intentions, the proprietors have provided a matron, nurses, and attendants, to enable them to carry their views into operation in the manner most advantageous to the young children.”

(op.cit.)

Barton details further historic justifications for segregated provision supported by reflective voices of disabled people (Barton 1995: 28 – 31). Of those there are several continuities of ideas in modern arguments, for example the idea that it is best for disabled children to be in segregated settings since that reduces the possibility of bullying and abuse.

"I myself am a special school survivor," says Simone Aspis of the British Council of Disabled People (BCODP). "I know that many special schools today are no different from the one I went to. I experienced bullying by the head teacher and the pupils." And on the argument that special settings are protective, she refers to the fact that such institutions are not necessarily the safe places as envisaged, and equally she refers to the weakness of the argument itself: "If someone complained that Black children or Jewish children were being bullied and the answer was to put them all in their own schools, there would be an uproar. Why then is it all right to do this to disabled children?" Simone Aspis.

Prevailing ideas, thoughts and fears of the past provided fertile ground upon which policy decision were made. Mary Dendy (1855 – 1933) was a key expert witness and became the first paid commissioner under the Board of Control when the Mental Deficiency Act was passed in 1913. Her views, ably plotted by Wright (1996) represented much of Edwardian society's fear and ideas of the threat of the "unfit" and the virtues of the "lethal chamber" at a time when in Whitehall, Home Secretaries pondered the merits of sterilisation of "mental defectives", but decided to introduce segregated institutions instead. A hundred years later, in June 2005, the Mary Dendy Unit was opened as part of a secure hospital for adults with mental health problems. The naming symbolises agreement with and recognition of her pioneering work for residential establishments. This new unit at Nether Alderley doubled

in size to cater for patients who might otherwise be sent to Rampton high security hospital. The legacy of Mary Dendy's control in dealing with people regarded as a threat to society is still present.

A further reduction in 'lived-citizenship' concerns the element of control. This had a strong foothold in deciding on pedagogy, content and method of educational instruction. With a (i) focus on impairment of not being able to speak orally rather than self-determined access of using sign language, and (ii) in disregard to a right to be different that instead is perceived as a threat to the common good, and (iii) in silencing their voices by use of power, Deaf people have experienced and resisted a particular kind of oppression. Based on the fear, for example, that deaf children might rebel, organise and act subordinatedly against the establishment British Sign Language was banned in schools in 1888 (BBC voices). This meant that children were forced to adopt the 'oral' approach, and as a direct result of not signing they missed important parts of the communication and left school with lower reading ages and lower qualifications (MLA, Deaf History). Deaf young people no less able than their non-disabled peers left school with an average reading age of 8 years. Deaf adults were barred from entering the teaching professions – even to teach Deaf children – until recently.

The element of control is equally present in dealing with some working class issues. Simpson (2002) notes that the Charity Organisation Society in 1871, whose main aim was to distinguish the deserving from the undeserving poor, thought that 'the removal of an imbecile member of a struggling working-class family' was a necessity. It follows that to be classified 'deserving' does not necessarily accord with social value. Simpson states the prevailing view of the time as understanding that 'with the best will in the world, the defective holds back the progress of the family and of society; consuming valuable resources and contributing nothing in return.' Not everyone agreed with a 'soft' charitable approach. Tizard (1958, quoted in Lacey 2004: 3) suggest two reasons for the shift to the more pessimistic view. First science and genetics had developed, and second ways of measuring intelligence were being experimented with. The findings of the influential Royal Commission in 1908 were that feeble-mindedness was a deficit primarily caused by faulty inheritance and often associated with anti-social behaviour, crime, promiscuity and general

degeneracy (BOPCRIS). Philanthropy and Christian Charity alone were no longer seen as successful in combating these social evils. Society's response to difference was to 'curb and control' so that economic conditions could be established that enabled 'progress'. Change in society could not be allowed to be held back by struggling working-class families, but their defective offspring had to be taken away and segregated from 'good-stock'. Fear about 'our social rubbish' (Sir James Crichton-Browne Royal Commission, quoted in Cole, 1989: 44) extended to people who might 'pose as normal' and may 'lurk within the general population' (Radford, 1991, quoted in Atkinson, 1997:99).

Measuring deviance: politics of knowing

Further examples of these developments can be discerned from early tests for human intelligence. Following the findings from the Wood Committee Report 1929, which concerned itself with measures of human intelligence and corresponding allocation of educational resources, categories of mental ratios formed the basis for decisions as to who should receive what kind of education. The relationship between chronological age and mental capacity was quantified to establish who should be educated in separate institutions. Three main categories into which to assess 'defective' children were, at the lowest level, the idiot with a ratio of less than 20, then the imbecile with a ratio of between 20 and 40, and finally the feeble-minded with a ratio of more than 50. Feeble-mindedness was defined as 'one who is capable of earning a living under favourable circumstances, but incapable from mental defect from birth, or from an early age, (a) of competing on equal terms with his normal fellows, or (b) managing himself or his affairs with ordinary prudence' (Tredgold, 1908: 75, quoted in Lacey et al 2004:2), imbecile as one, who 'for reason of mental defect was incapable of earning his own living, but capable of guarding himself against common physical dangers'. In this way the issue of disability was dealt with from an essentialist perspective, as a condition pertaining to and inherent within an individual. This identifying criteria was seen as resulting from biological rather than social causes. In terms of learning difficulty these essentialist ideas would later be embodied by words like 'intelligence', which were taken as given. Intelligence, or forms of intelligence, were thought of as existing and simply requiring an expert, such

as a psychologist or educationalist, to discover and unlock that potential in each child. At the time when compulsory elementary education was established (Foster's Education Act 1870 and Mundela's Education Act 1880, see Museum of Childhood online) class sizes were very large with a pupil: teacher ratio of 60: 1 in 1870 and 48:1 in 1891 (Board of Education 1901: 105, quoted in Copeland, 2002). Common forms of pedagogy were rather regimented and geared towards exam preparation (cf. Smith, 1931: 254 61; Wadle, 1976: 68 – 89, referred to by Copeland, 2000) since at that time schools received their funding by results following Robert Lowe's Revised Code of Practice (Copeland, 2003: 44). It is thus no coincidence that two Royal Commissions would be announced, one that looked into the working of education in terms of the Education Acts, and the second for blind, deaf, dumb and other exceptional children who seem to require 'exceptional' methods of education. Different methods of accessing knowledge and learning were required. Clearly the large class sizes, methods of instruction and inflexible testing were prohibitive of success for disabled children. But rather than adjusting to different access methods, the focus was on impairment and impairment categories.

Transforming uncertainties into knowledge

Thomas and Loxley (2002: 22) argue that special education has had many reasons for growing, in particular through the way knowledge is constructed and reproduced, or as they said the 'setting of certain knowledge on a pedestal', which 'has created a false legitimacy' for theories or justifications underlying segregated and special education. One hundred and forty-three witnesses presented evidence to the Royal Commission on the education of blind, deaf and dumb children, whilst only seven spoke about idiot, imbecile and other exceptional children (Copeland, 2003: 45). Experts, such as Dr George Shuttleworth, who was Medical Superintendent of the Royal Asylum for Idiots and Imbeciles at Lancaster, spoke of 'intellect' as if this was a self-evident truth, a norm against which 'idiocy' could be measured. Shuttleworth never offered a definition or description of intellect, nor was he asked to do so. Similarly, idiocy and other terms could not easily be defined. Competing and contrasting opinions of Shuttleworth and Warner (Copeland 1997: 713)

exemplify this difficulty. Francis Warner was a professor of physiology and a paediatrician in a London hospital, and his evidence included the recognition that children with irregular hearing or eyesight, disease of the heart and lungs, and others were often unable to cope with elementary education. He estimated that one in twenty children would fail in the education system of the time, which included sometimes cruel and brutal methods of correction (Copeland, 2003: 46). Warner's emphasis for this failure lay on the method and organisation of instruction (access issues), whilst Shuttleworth regarded the individual deficit of intellect as root cause (impairment), the former more akin to disabled people's modern day perspectives of the social model, and the latter representing an individualised, bio-medical deficit model. The latter model framed thinking and policy responses for decades, whilst the former was historically silenced.

A preoccupation with measuring, quantifying and classifying led to the rise of psychometric testing and Terman's first use of the term 'intelligent quotient' for IQ testing in 1916. Cyril Burt, an 'enthusiast of Social Darwinist thinking' was the first psychologist in London three years earlier. He whole heartedly embraced methods of psychometric testing and rode on a wave of prolific and well-received publications when all seemed to be coming crashing down.

Thomas and Loxley explain that Burt's 'fondness of psychometrics and his commitment to the idea that intelligence was inherited and more or less immutable all combined to give great stimulus to a segregative education system based on the categorisation of the child.'

(Thomas, Loxley 2002: 32)

However, his research evidence was brought into disrepute by discovery of fraud and falsification. The pressure of success and the desire to turn up with new discoveries led Burt to fabricate research findings, construct data about twin research, and invent peer reviewers (see Kamin, 1977; Hearnshaw, 1979). Thomas and Loxley assert that the bigger problem is not so much the fraud itself, but the underlying desire to prove what appears a self-evident truth about 'intelligence' and innate human abilities:

'More interesting than personal psychology in this chapter of deceit is Burt's conviction in the legitimacy and correctness of the cause for which he was contriving evidence. Here was a man who had the

highest respect for science, yet was prepared, it seems, to put conviction in a deeper truth, (...) above it'.

(Thomas, Loxley 2002: 33)

In this argument the system of segregated special education developed largely built upon ideas of essential differences. Uncertain knowledge seeking status continued as Kanner (1943), Asperger (1944) and Wing (1979) (referred to by King, 2006) all struggle with describing what is meant by 'Autism', and psychologists arrive at tentative conclusion of 'probably autistic' (King, 2006) and psychiatrists ascribing various mental health labels in search of true knowledge, diagnoses.

Morality

A fourth category was openly labelled 'moral imbecility'. This was 'a person who displays from early age and despite of careful upbringing, strong vicious and criminal propensities, on which punishment has little or no effect.'

(Tredgold, 1908: 76, quoted in Lacey et al 2004:2). To belong to this last category was not as a result of any intellectual impairment, but dependent upon a person's social conduct considered socially and morally defective.

Again, the root-causes were assumed to lie within the biology of the individual upon which social factors, such as 'good upbringing' have no effect. It is likely that people with a learning difficulty might have been included as people easily influenced by immoral and criminal elements in society.

Behaviour contrary to accepted social norms causes problems for authorities throughout the century. In recent years, the idea that people with a learning difficulty may live independently has gradually gathered strength. However, motherhood remains hotly disputed. Mabel Cooper's reflections illuminate these difficulties:

"In them days if you had learning difficulties or anything that's where they used to put you. They didn't say, 'Oh you could go into a house and somebody would look after you'. They would just say 'You, you've gotta go into a big hospital' and tha's it. Years ago, if you wasn't married and you had a baby that was a disgrace and they would say, 'Oh the mother goes to a workhouse or a loony bin' as they had in

them days, or the mother went into a workhouse or a loony bin and the child was put in care. I think that's why there was more women."

(Mabel Cooper, online)

Wolfensberger (1972) quotes a passage written in 1915, which indicates the increasing threat that some people were perceived to pose to the proper order of things, such moral values of decency, proper behaviour of time keeping and adherence to standardised work routines in a developing industrial society:

'For many generations we have recognised and piled the idiot. Of late we have recognised a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace to society and civilisation; that he is responsible to a large degree for many, if not all, of our social problems.' (1972: 34)

There is broad agreement in both historic and modern views that 'morally defective' behaviour threatens the cohesion and citizenship of the general population. Anti-social behaviour is a process that challenges a common citizenship idea within UK's diverse population, since it is behaviour that is 'anti' the particular 'social' arrangements, expectations and values. For children ascribed Autism, 'has an autistic spectrum disorder' 'is autistic' 'suffers from ADHD', 'looks normal' but has 'deviant behaviour' and is regarded as anti-social in that their 'variability and unpredictability' in their behaviour 'means that there is no easy solution to the problems that they present to the education system' (King, 2006: 6).

Labels and categorical approaches

In this way, the labels attached to certain individuals usually had a negative impact. Meaning changed over time with developing official uses and application of these terms. The labels of the 1913 Mental Deficiency Act were modified slightly, but remained until the 1959 Mental Health Act. The law then abolished terms such as 'imbecile', 'mental defective', 'feeble minded' and 'idiot' to describe people with a learning disability. However, to use Oliver's (1992: 23) description: 'while the language has changed, the same group of professionals are doing the same things to the same group of children as they were doing before'. This continuation reflects elements of Goffman's binary

management as a growing number of professionals and diverse range of specialisms wield power and control over disabled people. In the early 1960s, the demand for segregated institutions had far outstripped availability, as 35,000 special school places were available for the 84,000 children thought to need places in Britain. It was in the 1970s when Britain's first special needs teacher training courses opened at Westhill College of Education, Birmingham - the first time teachers had been specially trained to teach people with a learning disability. This emphasises the idea that experts have the knowledge on disability issues, not the disabled person themselves, and that professionals are in the best position to provide relevant interventions. It also separates special teacher from regular teachers, with a range of connotations attached to that, not least that the business of disability is not one of ordinary teachers, but has to be referred to the specialist for treatment and intervention, whether medical or educational. All of these developments took place over a period when early and late industrialisation spread across the nation, with increasing numbers of manufacturing and commercial developments, and the later subsequent decline in manufacturing in Britain. Collectively this resulted in changes in the process of production and changed relationships between individuals and the centralised state. Responding to a categorical approach based upon impairment is thus directly related to the economic and political context (which includes level of willingness to address relevant access requirements) within which it takes place. Rather than an essential 'given' flowing from within the individual concerned, the socio-political context shaped the lived-citizenship experience of disabled learners. Developing industrialisation is but one of these contexts. For Hong Kong, colonisation and traditional Chinese cultural beliefs provided the economic and political backdrop within which segregated education along impairment lines developed. Lewis (1999) reports that Hong Kong's educational response to young disabled people was to provide a range of special schools based on personal and categorical deficits. By 1996 the number stood at 2 'blind' and 4 'deaf' schools, 7 'physically handicapped', 7 schools for the 'maladjusted', and a staggering 42 schools for the 'mentally handicapped' (National Archives). He further informs us that all Hong Kong special schools are managed by charities or community-based voluntary groups, whilst the

government had not provided any official educational response to disabled children:

‘The reasons for this situation might partly be explained by the long accepted links between charity and disability in traditional Chinese culture, although in mainland China the overwhelming majority of special schools are provided by government.’

(Lewis, 1999: 44)

However, the real reasons might be found in the attitude of the British colonial administration. Whilst compulsory education in Australian colonies was introduced by the end of the 19th century, the Hong Kong administrators appear to have put little value on the education of Hong Kong people and introduced compulsory education not until the 1970s. Lewis refers to Postiglione and Lee (1997), who noted that at that time the European Economic Community was concerned about competition of cheap child labour and exerted pressure to remove this unfair economic advantage in the international labour market (Lewis, 1999: 45). Lewis identifies that the ‘correct way’ of doing things in response to disability was conceptualised and acted upon according to the ideas of those who ruled rather than those who were being ruled over and resulted in essentially western duplicates underpinned by a western set of beliefs (Lewis 1999: 47).

Disabled children and adults have been ascribed an identity with recurring themes of ‘being of less value’ and ‘clogging up the system’. As ‘the defective’ in society, who add ‘an inert mass...a dead weight which encumbers the school’ provided the impetus for removal from mainstream education (Binet and Simon, 1914:18, cited by Simmons, 2003). Tomlinson (1995) asserts that ‘The history of special education is largely one of exclusion – the more students in mass education systems have failed to learn and behave in a manner deemed appropriate to mainstreams schools, the more they have been squeezed out of the schools or the mainstream curriculum.’ A historical perspective thus illuminates the complex context within which segregated education for people with impairments has developed. In order to describe, identify and respond to disabled people different historical epochs have employed relevant language. Foucault described how in the middle ages disabled people of all kind were part of ordinary street scenes, ‘insanity’ and

'idiocy' part of everyday life, 'fools and mad men walked the streets' (quoted in Armstrong, D 2003: 9) and throughout the ages, disability was of no particular concern, not viewed in a special way, nor excluded or organised, 'it is simply there, part of the general human lot of misery'. The category 'special educational needs' did not exist at the time of Victorian and Edwardian England, nor during the first and second world wars, since it was only introduced with the Education Act following the Warnock Report in 1978. Language carries symbolic meaning which changes according to the context and purpose for identifying particular groups of disabled people.

Grass root language of power

To illustrate political activity of disabled people, a particular struggle over language will be examined. Language relates to the 'identity' element of citizenship. Several changes occurred in the description of people with a learning difficulty, from idiot, moron and imbecile, mentally handicapped, which later differentiated between severely, or moderate or mild degrees of impairment. A precise meaning of these terms can not easily be gleaned. Even amongst 'experts' there is no settled understanding of what various descriptions mean. Early struggles include the contrasting view of Shuttleworth and Wagner to the Royal Commissions in the late nineteenth century. Shuttleworth located the problem as within the individual child and defined imbecile accordingly. The medical connotation of the term 'mental handicap' changed again to one that emphasises the ability to learn, as described by 'learning difficulty' or 'people with a learning difficulty'. These changes were due to the pressure exerted by people with learning difficulties themselves as documented in 'Altogether Better' (1993). People First, a self-advocacy group of people with learning difficulties, charted their international struggle in changing the name from mental handicap to learning difficulty. A spokesperson from People First explained that to be called people with learning difficulty is preferred by their members, since that indicates that they **are** able to learn, albeit in a different manner, and it takes focus away from the medical descriptions of 'what is wrong with us'. Members of People First in Canada achieved this recognition ahead of their British, North American and European counterparts. The slogan 'label bottles not people' was worn on T-

shirts and press conferences were given. In fact, many European countries are still lagging behind by using terminology predominantly concerned with degrees of impairment and, in particular, names of eminent practitioners, such as John Langdon Down (1828-1896). John Down was the son of a village grocer from Cornwall. Following his medical degree he was appointed medical superintendent of the Royal Earlswood Asylum for Idiots in Surrey. It was there that his interest in classification resulted in him taking numerous photographs and deciding that a group of people could be classified as 'Mongolian idiots'. This was based on his understanding of racial characteristics and interpretation of measurements of the diameters of the head and of the palate from the series of clinical photographs he took. Mongolian idiocy became a widely used term and remained popular, with minor modifications to mongoloid or such, until 1961, when the editor of *Lancet* chose Down's syndrome from four alternative names suggested by a group of geneticists. With the World Health Organisation endorsing Down's syndrome, and renowned expert professional journals reproducing it, the term achieved world wide almost universal acceptance. In this way, 'Down's Syndrome' is embedded in the production and dissemination of knowledge itself, and as such it is not an easy task to challenge and change existing terminology without also challenging dominant knowledge and processes of 'knowing'.

Resistance to a simple name change prevailed not only within medical and professional circles, but was also evident from within the voluntary sector, charity organisations and organised pressure groups consisting mainly of parents and friends, such as The Organisation for the Protection of the Mentally Handicapped (now MENCAP). At a heated committee meeting (All Together Better, 1993) parents were voicing their opposition to a change of terminology to 'people with learning difficulties' as detracting from the central mission that their organisation is charged with, namely fundraising. Further, it was mooted that people with learning difficulties could not themselves come to a reasoned position on this. However, change was eventually achieved and MENCAP changed not only terminology, but its own name. Still, essentially it remained an organisation **for** people with learning difficulties, rather than **of**. The national self-advocacy network of People First now defines itself as:

“People First (a voice for People with Learning Difficulties) is an organisation run by and for people with learning difficulties to raise awareness of and campaign for the rights of people with learning difficulties and to support self advocacy groups across the country.”

“At People First (Self Advocacy), when we talk about people with learning difficulties, we mean ‘people labelled as having a learning difficulty’. This is one of the labels that society puts on us to mark us out as not being able to understand things the same as other people. At People First we do not think in terms of medical labels like ‘autism’ or ‘Down’s syndrome’. We don’t look at what doctors say is ‘wrong with us’. “ (People First)

MENCAP and People First are organisations that have different objectives, different funding systems, different organisational structures, divergent long term aims and significantly, continue to be in conflict over terminology.

MENCAP describes itself as the UK's leading learning disability charity working with people with a learning disability and their families and carers.

Whilst People First emphasises the campaigning activities by stating:

“We campaign for the rights of people with learning difficulties and support self advocacy groups across the country with information, advice and training.”

In contrast to MENCAP the term ‘learning disability’ is rejected outright:

“At People First (Self Advocacy) we believe that people labelled as having a learning difficulty are disabled by society. We choose to use the term ‘learning difficulty’ instead of ‘learning disability’ to get across the idea that our learning support needs change over time. With good support we can become more independent and do more for ourselves.”

(People First, Why learning difficulty not learning disabilities?)

A charity approach to disability has been rejected by disabled people, who instead saw civil rights and citizenship as issues to be fought for. By the 1970s they organised themselves into pan-impairment organisations and ‘Rights not Charity’ marches were first organised in 1988. The history of segregated education can be characterised as a history of oppression, which denies disabled people self-determination, full participation and basic civil rights. In response to oppression, with a view to realising ordinary citizenship

rights, there has been a growing political movement **of not for** disabled people. Benford and Hunt (1995: 85, quoted in Campbell and Oliver, 1996) stated that 'the very existence of a social movement indicates that differences exist regarding the meaning of some aspect of reality.' However, the history of segregated education is not one where disabled people passively became victims of dominant ideologies, rather they have organised and actively fought for their rights. Thus, with the devastating events of Milan in 1888, dissatisfied Deaf people and their allies resisted, and the first organisation **of** Deaf people came into being, the British Deaf Association formed in 1890. Equally, following the impact of the Royal Commission and potential disadvantages in the labour market for blind people, the National League **of** the Blind was formed as a Trade Union in 1899. It was not until the 1980s that the political movement of disabled people started to have a wider impact on understanding disability. Campbell and Oliver (1996: 19) observe that the first decade saw a transformation in political movement, with disabled people seeking to ensure the full economic and social integration as required by the United Nation Declaration of the Rights of Disabled People 1975. Here it was for the first time written that voices of disabled people should be heard when it comes to decisions that may affect them. Section 3447.12 of the Declaration states:

'Organisations **of** (emphasis added) disabled people can be usefully consulted in all matters pertaining to the rights of disabled persons.'

United Nation Declaration of the Rights of Disabled People 1975

During the 1990s the growth of the disability movement was evident both in terms of numbers of organisations and of impact on understanding disability as a civil rights issue. A paradigm shift in thinking is said to have taken place. The success of these collective self-organised counter-currents to traditional thinking was even more remarkable when considering the broader context of continual under-funding, political inertia and lack of willingness to take ideas directly from disabled people, who traditionally were seen as passive recipients of care. Among these organisations is the British Council of Disabled People. BCODP is the UK's national organisation of the worldwide Disabled People's International (DPI) Movement. It was established in 1981

by disabled people to promote their full equality and participation in UK society. BCDOP now represents some 126 groups run by disabled people in the UK at national level. The BCODP, says Simone, supports the 2020 campaign by the Alliance for Inclusive Education. This aims to have achieved entirely mainstream education by the year 2020. "We appreciate that mainstream schools do not work for some children," says Simone. "But that's because of a lack of commitment - not because they can't work."

Look who is talking: insider perspectives

Armstrong, D. (2003) argues that insider perspectives are of central importance in understanding experiences of special education. Irrespective of whether or not 'special education' is seen to work, the lived experiences of individuals who came through the segregated system offers insights about separate-ness, being treated as of lesser value, experiencing loss of family and friends, institutionalisation, reduced opportunities and overall a reduced citizenship (Mason, 1990; Aspen, 2005). The tangled web of historical readings in the previous section points away from the question of competent and committed special educationalists. Alternative readings of history present the question not so much of whether segregation works, but why it came into being and whether we would - behind a veil of ignorance (Rawls, 1972) - choose or be content with the experiences as presented by disabled people - and thus place ourselves voluntarily in that position, one of segregation or oppression as is the lived-citizenship of many disabled people. Would we choose that place? An example is offered by Oliver (2000) when visiting a group of students with learning disabilities in Holland he notes that 'the group home itself was like group homes all over the modern world, clean, comfortable and well designed. But it failed my own personal test of acceptability; I wouldn't have been prepared to live there so I don't think other people should be forced to either.' This is echoed by children with dyslexia and their parents in a study comparing segregated and inclusive provisions. They reject the term 'special class' in favour of 'reading unit' (Nugent, 2007). Whatever the rationale for special education, the lived experiences accumulate to build a picture of oppression as detailed above, and I would conclude that whatever the rationale, rights trump utility (Dworking, 1978).

Paradigm shifts

The argument in reverse is that 'inclusion does not work', with writers, such as Feiler and Gibson (1999: 148), promoting the view that there is an 'alarming lack of empirical evidence' and a failure to underpin arguments with 'research'. The kind of knowledge promoted is scientific knowledge, empirical and statistical and objective. Pressure on that kind of knowledge has led to falsification, as discussed in the case of Cyril Burt, and with recent examples of the South Korean researcher 'inventing' research data to support his DNA cloning research.

'South Korean researcher Hwang Woo-suk resigned from his position as a university professor on Friday after his school said he had damaged the scientific community by fabricating the results of at least nine of 11 stem-cell lines he claimed to have created.'

(CBS news)

Thomas and Loxley (2002: 22) view this kind of knowledge as having been put on a pedestal. They argue of its danger in that

'It is our contention that the putative character of this knowledge (...) has created a false legitimacy for the growth of special education and the activities of special educators.'

Foucault (1982) discusses social practices which deal with the way in which groups of people, such as disabled people, undergo a process of 'objectification'. He identifies three key aspects of this, one of which is how language, concepts and vocabulary are used to give ideas the status of science (1982: 298). A particular component of the elevated status of certain scientific methods is a set of underlying, binding, reinforcing, unchallenged 'truths' that form a 'paradigm'. Giddens (1993) explains the notion of paradigm as referring to 'taken-for-granted, unexplained assumptions shared by communities of scientists, who confine their attentions to small-scale puzzle solving within the bounds of those assumptions' (1993: 149).

The narrow focus of a 'small-scale puzzle' can be illustrated by the following argument about social inclusion of disabled children. The taken-for granted assumptions reflect a focus on the disabled child as the object of analysis and as having the deficit. The starting point for this perspective is unquestioned, the problem is rooted in or within the individual deficit. Attention is then drawn

to the small-scale puzzle of the 'absence of specific skills' on the part of the disabled child, reinforced by an impressive published research tradition:

'Research in the inclusion movement suggest that the ability of children with a disability to establish and maintain social relationships is central to their social acceptance and social integration in the inclusive setting (Fujiki & Brinton, 1994; Guralnick, 1990, 1992; Guralnick et al., 1995; Odom, McConnell & McEvoy, 1992; Odom, McConnell, McEvoy, Peterson, Ostrosky, Chandler, Spicuzza, Creighton, Favazza, 1999). These studies have revealed that the absence of specific skills will effect interaction with peers. According to Odom et al. (1992) these deficits in social interaction may be a result of one or more developmental domains. These are communication, interpreting auditory and visual information, attending, and organising information and the knowledge gained from the environment. Cognitive models or frameworks measuring social competence continued to lead the research on the origins of social skills deficits in children (Ladd, 1999). At the core of these frameworks for social competence are underlying social cognitive competencies such as language and cognition (Leffert & Sipperstein, 1996).'

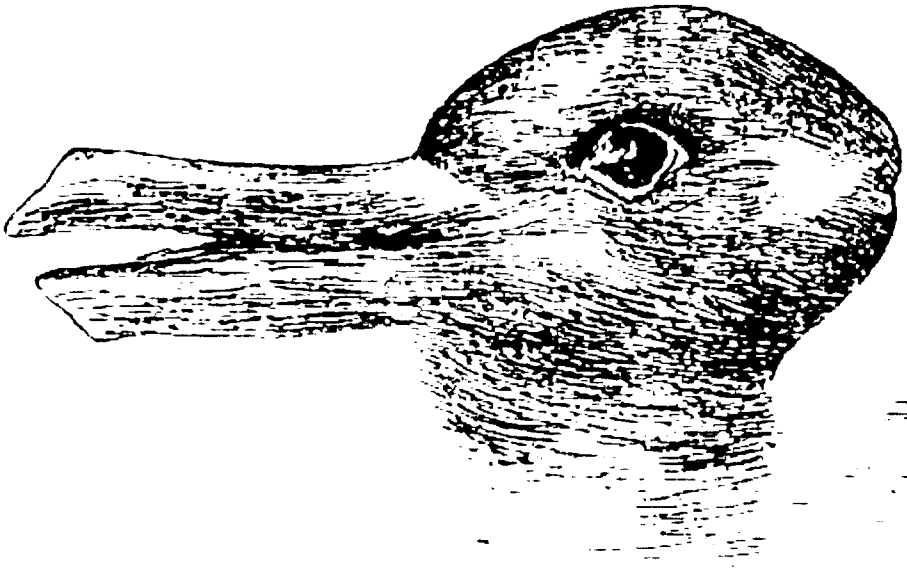
The framing of this research provides a particular gaze onto an issue, which leads to prioritising what are deemed worthy and relevant pursuits, whilst others are suppressed (Cheek, 2000). The priority for the above enquiry lies in the cognitive models and origins of social skills deficit. However, a simple reversal of perspective would challenge the fundamental assertions: Why is the focus on the disabled child and not on their non-disabled peers? What skills can non-disabled peers bring into the equation to enable social inclusion? The researchers continue to ask, what are arguably the 'wrong' questions; questions with a focus on inability of disabled children. Whilst stressing the importance, for example, of 'gaining successful entry into a group during play' as a fundamental task for children, they fail to consider the reversed perspective, which is to ask how individual group members, settings and environments, cultural practices, values and beliefs enable entry and accept play contact among children with impairment differences or other differences.

'Peer group entry is not an easy task to master during most play activities and it appears that almost 50% of initial attempts to enter a group are rejected or ignored.' (Corsaro, 1981).

In the social sciences Laudan (1977) defined the paradigm of enquiry as 'a research tradition' - a way of doing things in the correct way amongst scientists, a tradition which consists of 'a set of general assumptions about the entities and processes in a domain of study and the appropriate methods to be used.' Insider perspectives and emancipatory research (Barton 1996; Oliver 1997; 2002) challenge these traditional methods. Disabled academics and researchers argue that for too long disability issues have been suppressed. This is evident in education by scientific assumptions inherent within the special education system (Barton 1997; Corbett, 1996). Arguments about special education or inclusion presented without the voices of disabled people (Clough and Barton, 1995 & 1998; Moore, 2000; Reid Walmsley 2006), without acknowledging the political struggles (Campbell and Oliver, 1996) and without connecting disability issues to broader social picture are thus seen as vacuous, irrelevant and at worst damaging in that they can perpetuate the oppression already experienced by disabled people.

A paradigm shift is said to take place when new 'truths' are discovered which do not fit into traditional mode of thinking and which undermine the very foundation of old ideas. In an attempt to understand the changing history of science, Kuhn (1962, 1970, 1977) analysed thought patterns, which form into paradigms. He asserted that these taken-for-granted assumptions were not simply dominant current scientific ideas, but reflected and supported a particular 'correct' world view. 'Kuhn used optical illusions to illustrate how the same set of information can be viewed in totally different ways' (wikipedia). A paradigm shift thus indicates a process whereby old, trusted ways of seeing are gradually or rapidly replaced by new, radically different ways.

Understanding the history of special education can provide a context which invites a paradigm shift.



What animal is this?

Duck or Rabbit?

(Wikipedia, Duck-Rabbit_illusion.jpg at Paradigm shift)

In order to build up and maintain a picture of a particular world-view, irregularities, not-fitting facts can be brushed aside whilst leaving the overall understanding intact. This is increasingly no longer possible when confronted with the reduced citizenship experiences of disabled people, with facts and figures of oppression and voices of disabled people. Oliver (2000) addressed these issues in the following way:

“This idea of the replacement of one paradigm by another through a knowledge revolution is helpful in understanding our current experience in special education; in Kuhn's terms we are moving from a special to an inclusive education paradigm. In my view the anomalies in the special education paradigm are becoming so numerous that we are approaching paradigm incommensurability, by which Kuhn meant that the particular worldview was falling apart, was becoming unsustainable.”

(Oliver, Keynote address ISEC 2000, Manchester)

A closer examination of historical developments and struggle bring into the open anomalies which the existing view cannot sustain, it offers the option to

shift the view 'from the duck to the rabbit' (Kuhn, 1977 3rd ed: 114). It can no longer be right to separate and segregate individuals based on irrelevant characteristics such as impairment, or blame disabled people for their lack of inclusion. Twenty-five years ago, Tomlinson (1982) saw the cracks appearing. She asked questions about systemic patterns of segregation by race and class, questions about who benefits from a segregated and special educational needs system. Oliver summaries her attack in terms of a paradigm shift 'that the special education paradigm serves the interests of a variety of groups, organisations and institutions, only one of which are the children so labelled. So there remains yet another crack in the paradigm; special education is not just about meeting the educational needs of 'special' children.' The paradigm is cemented by advantage of interested groups and unequal power relationships.

Learning from history: Recognising British Sign Language

History tells us that exclusion is the product of unequal power relations with inherent processes of 'social othering' (Bauman, 1997) which identifies and then excludes those 'not one of us', 'strangers ... are the people who do not fit the cognitive, moral or aesthetic map of the world' (1997:17). In a keynote speech at Manchester's Conference 'Including the Excluded', Slee (2000) is talking about taking back the power, and emphasises that:

'exclusion is not the random outcome of natural and meritocratic distribution as was argued by Hernstein and Murray (1994) in their 'spectacular and ugly' (Kincheloe and Steinberg, 1996) treatise on racial and class inferiority 'The Bell Curve', or in Robert Nozick's (1994) grandiloquent defence of the Hayekian opposition to civic responsibility and concessions to distributive justice.'

(Slee, 2000)

This section demonstrates how, rooted in 'otherness' British Sign Language was a site of struggle to achieve inclusion and basic citizenship rights. British Sign Language as an alternative form or first choice of communication has a positive impact on the educational experiences of Deaf children. Traditional forms of power are difficult to dislodge, even when using democratic processes and grass-root campaigns. From the early days of prohibition in

1888, British Sign Language gradually freed itself from the shackles of hearing people's control. With the promotion of oralism as an instruction method allowing sound and lip-reading only, sign language was pushed underground. Children who continued to use sign in schools would be classed as indolent and badly behaved. In a speech given in 2003 the importance of the events in 1880 was emphasised and details explained. A summary of the speech is reproduced in full to give voice to Deaf people themselves:

“Deaf people were around in the pre 17th century but they were seen as being 'uneducable'. However, around the 1750's, people started to notice that Deaf people could be educated via sign language. From the 1780's onwards, Deaf people were having no problems with education and they were even writing books. There is also evidence that Deaf people were successful lawyers, artists and politicians.

In 1880, the situation for Deaf people started to take a turn for the worse. It was at the International Congress on the Education of The Deaf in Milan that sign language was almost destroyed by the delegates who all were strong oralist supporters. At this Conference, held on September 6 -11, a declaration was made that oral education was better than (sign) education. A resolution was passed banning sign language. The repercussions to the resolution and declaration had a knock on effect of the decline of Deaf people. Deaf teachers lost their jobs; sign language in schools reformed to the oral method; hundreds of oral schools were set up; the quality of Deaf education decreased dramatically and Deaf children were leaving schools with little qualifications and social skills.”

(Federation of Deaf People, 2003)

Similar repercussions were felt in Japan in the 1920s. Takada (2004) reports that ‘the government's education policy took a decisive turn in the direction of oral education in the early days of the Showa Era (1920's), and many Deaf teachers lost their jobs.’ This influence continued even after World War II when educationalists in Japan adamantly adhered to oralism. Takada points the finger at the conservative attitude of the administrative sector and an attitude of ‘business-as-usual’ as key sources for resistance to change.

Institutional behaviour based upon these attitudes prevented sign language from winning recognition as a language in Japan.

Sign Language recognition was achieved by passing relevant legal measures in New Zealand in October 2003. Disability Issues Minister Ruth Dyson thought that the bill would give sign language equal status to that of spoken languages, for example by giving people the right to use sign language in any legal proceedings. It was acknowledged that the New Zealand Deaf Association fought for official recognition of their language for 20 years. The impact of an education system that does not recognise one's language and culture (British Sign Language and Deaf culture) on the self-esteem and confidence of affected children has been variously documented (Deaf Equality Forward). Again, the basis for living as full citizens with rights to participation and self-determination is undermined by a policy that prohibits key aspects of that citizenship. It took decades of struggle by Deaf people before finally Sign Language became not only allowed but recognised as one of the official community languages. A closer look at this struggle reveals how difficult it is for oppressed groups (such as disabled and Deaf people) to regain a power balance which allows the promotion of their viewpoint, the realisation of wishes, elements of autonomy and choice, or in other words basic citizenship rights.

Encouraged by United Nations development, the struggle over Sign Language took place globally, from Japan to New Zealand, Canada and North America, in Europe and in Britain, everywhere Deaf people were asking for 'recognition' of their language and culture, regarded as key elements of citizenship. The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, adopted in 1993, state that:

'Consideration should be given to the use of sign language in the education of deaf children, in their families and communities. Sign language interpretation services should also be provided to facilitate the communication between deaf persons and others.'

(UN Rule 5, Accessibility, 20th December 1993)

In the UK the campaign was co-ordinated and promoted by Deaf people themselves through organised groups and networks. The Council on

Deafness, which included many deaf organisations, such as the British Deaf Association BDA and the Federation of Deaf People lobbied the government on the issues. As a result the government asked the Disability Rights Commission DRC in May 2000 to examine how recognition could be achieved. In turn, the DRC consulted and commissioned deaf organisations, in particular the British Deaf Association, to establish a national taskforce on BSL. The arguments in favour of recognising BSL were summarised in terms of citizenship rights, as follows:

‘It is estimated that British Sign Language is the first or preferred language of between 50,000 and 70,000 people in the UK. Deaf people who use BSL are united by a shared culture, community and history; BSL is fundamental to their self-esteem and social well being. For those who find spoken language more difficult to access than sign language, provision of information and education in BSL is especially important. ‘

‘UKCoD (United Kingdom Council on Deafness) believes that official recognition of BSL would bring clear benefits to many thousands of Deaf people in terms of improved access to information and services. Recognition would also promote better knowledge and understanding of the language in society as a whole and formally acknowledge the status of BSL as one of the UK's four most widely used indigenous languages - along with English, Scottish Gaelic and Welsh.’

(UKCoD, 3rd October 2000)

This issue was taken to the European Parliament. Change through political activity and democratic mechanism is a very slow and often frustrating process. The European Parliament passed two resolutions calling on member states to recognise their respective national sign languages, one in 1988 and another in 1998. However, only four states had done so by 2000.

In Britain the final phase took over three years, despite the prevailing support and an international climate inclined to accept Deaf culture. Not happy with simple representations from Deaf people, Maria Eagle, the Minister for Disabled People, was asked in December 2001 to organise a meeting with leaders of deaf organisations so that she could find out the meaning and practical impact that Sing Language recognition would have for Deaf people.

Apart from political representation, lobbying and democratic processes, the law can be used as a tool for social change. Frustrated with the slow progress by the government and given the uniform support from Deaf people themselves the only recourse seems to ask for changes in the law. However, as the implementation history of the Disability Discrimination Act 1995 shows, this also is a path fraught with obstacles and delays (Chapter 3).

Finally, on March 18th 2003 Andrew Smith, the Secretary of State at the Department of Work and Pensions, and Maria Eagle, Minister for Disabled People, made a joint statement that the government recognises British Sign Language to be a language in its own right. This was accompanied by allocated resources and an action-plan, for example for official training of interpreters.

BSL challenges for education

Political engagement of disabled people in the fight for the recognition of ones language is one thing, getting it accepted in practice is another. The Framework of Action accompanying UNESCO's Salamanca Statement on Special Needs Education, to which Britain is a signatory, states that:

'The importance of sign language as the medium of communication among the deaf...should be recognised and provision made to ensure that all deaf persons have access to education in their national sign language.' (Framework for Action (1994), para 21)

However educational provision for deaf children varies greatly between education authorities. Some LEAs are not offering bilingual programmes and had very few schools or resource bases for deaf children offering any formal teaching of BSL. It was observed that since a lack of access to BSL learning can adversely affect the language development of some deaf children, this will also impede their subsequent learning.

"The report, "At the Heart of Inclusion: the role of specialist support for deaf pupils" conducted by RNID (...) demonstrates that although the Special Educational Needs strategy (SEN) has shown successes, there is a significant variations in the level of specialist support provided for deaf children in mainstream schools across the country. Currently 44% of resource centres do not have fully qualified staff." (RNID, 2005)

The issue of recognition and use of British Sign Language illustrates one challenge to inclusive education in the way schools are organised and education is provided. The shift required is (i) away from a focus on the impairment 'deafness' to the access requirement 'British Sign Language', and (ii) accepting a right to be different, a right to equal access to educational provision, which (iii) requires changed priorities, political engagement, positive action, such as provision of BSL interpreters. For d/Deaf learners inclusive citizenship is built upon a shift in these individual and organisational behaviours. In achieving such changes, struggles over resources and political action is ongoing. Indicative is this question raised by the UK Deaf Council:

"To ask the Secretary of State for Education and Skills which further education colleges are offering Council for the Advancement of Communication with Deaf People (CACDP) British Sign Language beginners courses at Level One and Level Two in the 2006-07 academic year; and how many such colleges have stopped providing CACDP British Sign Language beginners courses at Level One and Level Two since his Department withdrew funding for British Sign Language classes." (Hansard, 17 January 2007)

A legal framework which acknowledges rights for disabled people rather than entitlement moves the issue firmly into anti-discrimination with concomitant duties of education providers. Education law has moved in that direction and, on the face of it, is capable of opening up full citizenship participation for disabled people. However, further barriers are presented by (a) an ethos of 'parental choice' where parents insist on an all oral teaching environment, whilst the Local Education Authority allocated a mixed oral/signed school, and (b) allowing resource consideration to influence school placement decisions.

'Special Needs' meets 'Disability'

The law provides parameters for the way society understands, responds to and behaves towards children and adults with impairments. These parameters have been re-drawn over the years due to pressure by disabled people, making 'acceptable' behaviour, 'adequate' language, 'helpful' arrangements of the past unacceptable, unhelpful and unlawful in the present.

The traditional response to disability has been in form of welfare-based laws. In the UK, particularly following the second world war, a range of non-contributory social security benefits for disabled people and carers began to be introduced. The Chronically Sick and Disabled Persons Act 1970 strengthened entitlement to a range of social services, and gave more prominence to the rights of disabled people, with practical entitlements such as meals-on-wheels, or parking badges for people who have a mobility impairment. Education laws focused on mechanisms for getting resources allocated to individual children following particular processes of entitlement (procedures for acquiring a statement of individual special educational needs which will trigger additional resources that follow the child). These processes are mediated through the professional expertise paradigm, effected by means of 'othering' through identification, classification and allocated on principles of 'most in need'. Overall the process of 'statementing' results in competition over perceived scarce social goods. Welfare entitlements are based on the idea of the deserving poor and depend upon economic and policy priorities. Entitlements, as discussed in Chapter 2, are relative and can be taken away. Rights, in contrast, are inalienable. In this context, anti-discrimination rights include the right not to be discriminated against, that is to be treated less favourably by reason of some irrelevant characteristic, such as impairment, sexuality, gender, religious practice, age, class, marital status, ethnic background, trade union activity, employment status, language or race. A traditional entitlement approach to disability is reflected in the special educational needs framework as developed following Warnock in 1978. This welfare-based approach clashes with an anti-discrimination framework of the Disability Discrimination Act 1995, and amended in 2001, 2005.

Education Policy and implementation of Laws

The shape of the education project, of curriculum priorities, pedagogy, aims and objectives, organisation and resource application appears in a perpetual state of metamorphosis. Thomas (2005) notes, that education policy is not monolithic (quoting Carlson, 1993). Education policy sends a range of multi-layered messages and consists of over-lapping discourses (quoting Grundy, 1994). As a concomitant, I would add that the legal measures, codes of

practice and developing 'compliance' of education and anti-discrimination laws engender diverse responses, all of which aim to achieve 'best fit' and embed 'the law' into the many layered education policy (Taylor, 1997). Ball (1993) reminds us that policy discourses define not only what can be said or thought, but also whose voice is to be heard and with what authority. Policy discourse on disability equality in education, within the rhetoric of inclusion and citizenship, define what is meant by key terms and who can speak with authority on the issues. Research in Australia (Keffe, 2005) into head teacher's understanding of disability equality legislation and inclusion emphasises that the developing inclusive education paradigm to date remains sufficiently undefined, lacks boundaries and clarity, and consequently results in a large degree of uncertainty on leadership, practice and local policy development. The emerging picture in Britain, as evident in case law development, appears to confirm these processes.

Period of rapid changes

Rapid changes had been introduced in early years education from the late 1990s, when the government published its Green Paper 'Excellence for All Children: Meeting Special Educational Needs' (1998). A Programme of Action (1998) followed which focused on enhancing the statutory framework of allocating resources and responsibility under the special educational needs procedures. This was further enhanced with the introduction of legislation in 2001, when special educational needs procedures and anti-discrimination measures in education came within the Disability Discrimination Act 1995. In addition, the government is tackling working across agencies, such as early years initiatives of 'joined up working' with the production of the Green Paper Every Child Matters (2003) and Removing Barriers to Achievement (DFEE, 2004). These changes are characterised by shifts in thinking and struggles over resources. Evidence of increasing arguments over resources can be found in the rise of Disability Tribunal hearings which have as their subject matter a conflict between parents and local education authorities over allocation of appropriate educational resources and school provision. This is particularly stark for children on the autistic spectrum. Between 1995/6 and 2001/2 there was a 620% increase in SEN and Disability Tribunal hearings

concerning children with autism, indicative of the growing conflict over school provision (SENDIST annual reports). Since anti-discrimination is not about giving something extra, or providing special treatment, a behavioural and attitudinal change is required. Without such a shift responsible authorities (schools, head teachers, courts and tribunals, parents and advocates) may remain within a deficit model and confuse emerging disability discrimination laws with entitlements. Such confusion is evident in a case involving a girl with cerebral palsy, where the school failed to provide reasonable adjustment necessary to enable access to education on the basis of an assumed lack of available resources. The SENDIST tribunals have been characterised as 'on a steep learning curve', struggling to implement legal principles relevant in employment law also into the education context (Silas, Wolfe 2005).

Rights-based approach to resources, not welfare allocation of need

The facts of the case are that a 17-year old girl, who attended a mainstream school, had been provided with two full-time assistants. These were funded through her statement of special educational need by the local authority. However, whilst not being responsible for funding, the school was required to put their mind to recruitment and to adopt a policy that creates a reasonable prospect of continuity of cover. This they failed to do, thinking that the provision of support staff is a question of resources as arranged through the local education authority. As a consequence the client was required to provide the support herself and her daughter had been excluded from classes and left without food and water for several hours. Two mechanisms operate, overlapping, complementary and in conflict: 'special educational needs' a welfare approach, which attracts additional resources and anti-discrimination, which requires existing resources to be used to the benefit of all. Confusion over resources and responsibilities is also an issue in the following case. Although ostensibly the issue of discrimination is masked by concerns over health and safety, a common device to categorically exclude disabled people from public life, the barrier to participation was one of resource failure.

Anthony Ford-Shubrook (by his litigation friend) -v- St. Dominic's Sixth Form College (reported by the DRC and in case citation)

This case illustrates resource failure as a barrier in terms of planning and organisation of the resource, rather than as a lack of resource all together.

'The client is 16 year old boy who is a wheelchair user and has been denied a place at his local sixth form college. He has chosen this college because it is close to his home which enables him to travel without relying on someone else to transport him and it offers the A-level courses he wishes to follow. He has visited the college and was able to access all the necessary facilities on the ground floor but unable to access a classroom on the 1st floor. He is making arrangements to purchase a stairclimbing wheelchair to enable him to access the first floor. However the college have refused to admit him on the grounds that as a wheelchair user he will present a health and safety risk to himself and other students.'

As an early case brought under Part IV of the Disability Discrimination Act (SENDA) it set case law clarification of duties that education providers have towards working for the inclusion of disabled people. This case falls firmly within the 'fiction' of general health and safety considerations, so often used against disabled people when people are concerned with risk due to impairment, rather than facts. The outcome resolved the funding issue, but as the case was settled it does not provide legally binding answers in future cases. The outcome is reported as follows:

'Proceedings were issued and the Commission applied for and obtained a mandatory interim injunction compelling the college to admit the client as an enrolled student in September 2003 and the full trial hearing was expedited to take place in November 2003. The College decided to appeal against the granting of the injunction, but prior to the appeal hearing they agreed to settle the case on the basis that the Learning and Skills Council agreed to fund the cost of a temporary accessible classroom for all IT lessons to be used until the lift was installed at some point in time between Easter and Summer 2004.'

(DRC, 2004)

Anti-discrimination

Essential in anti-discrimination measures are concepts of equality, fairness and justice. As discussed in Chapter 3 formal equal treatment by way of same

treatment for all can be discriminatory and thus less favourable as it does not distinguish between individuals, but assumes a standardised 'norm'. The landlady's behaviour in the Winston case example failed to distinguish; her treatment required proportionality in relation to Winston's dis-similarity so as to ensure that she treats him equally and fairly. Dworkin (1978) identifies these two concepts of equality: the right to equal treatment, which he considers to entail the right to an equal share of valued social goods, or equal access to opportunity or resource, as well as equal burden. Dworkin's second concept of equality (1978) emphasises the right to be treated with the same respect and concern as others. This is a higher level of equality principle, derived from the first, and requires that the particular individual circumstances of a person are taken into account. This idea of differential treatment as a means to achieving equality rather than as a traditional welfare response is a key challenge in education.

McAuley Catholic High School v CC and others (2004)

In a case concerning a pupil with Tourettes Syndrome and as having been identified with Attention Deficit Hyperactivity Disorder ADHD ([2004] 2 All ER 436) the issue of differential treatment was raised. The Disability Rights Commission supported the case since they saw the school's behaviour as punishing the boy for impairment related behaviour:

'The client's 13 year old son IC has Tourette's Syndrome and co-morbid ADHD and attends a mainstream school which has excluded and punished him on several occasions for behaviour which was related to his impairment. In addition the school has failed to make reasonable adjustments and have excluded him from a school trip.'

This is an important case as it provides an example of a mainstream school failing to recognise the consequences of cognitive impairment and so treating the boy's impairment-related behaviours as disciplinary matters. These incidents, however, should elicit a more informed response. As such, this case goes to the heart of how Part IV should be applied in practice in a mainstream setting. The case was reported in All England case citation and detailed extracts will be used to illustrate specific legal, inclusion and citizenship issues. One particular legal question raised by this case is: who

should be the comparator in terms of the less favourable treatment? The parents alleged that by virtue of s 28B(1) of the 1995 Act the school had discriminated against IC, namely that for a reason which related to his impairment, it treated him less favourably than it treated or would treat others to whom that reason did not and would not apply, and that it could not show that the treatment in question was justified, contrary to s 28A of the Act. Who are these others to whom that reason does not apply?

In applying Dworking's equality principles, if a girl was excluded and a boy was not excluded for the same behaviour, the comparator is clear. As race and sex discrimination acts upon less favourable treatment 'on the ground of' or 'because of' a simple reversal gives the comparative position. Disability discrimination is distinct from that. The protection is 'for a reason related to impairment' and thus the comparator is not as the school argued, non-disabled children who behave badly, but the school population as a whole, which does not misbehave.

The school argued that the correct comparator was to establish whether a child without any impairment but manifesting the same behaviour would have been excluded permanently from the outset, whilst the parents argued that it was the children who did not have Tourett's syndrome and behaved appropriately. This view was affirmed by the Tribunal. They referred to the Code of Practice accompanying the Disability Discrimination Act, where it was said that in the case of a pupil with Tourette's syndrome, who was banned from a school trip because of her abusive language, the comparison had to be made with others who did not use abusive language.

The parent's saw the issue of the boy's behaviour in a bigger context and argued that barriers in the arrangement of the school curriculum and environment meant that he was put at a substantial disadvantage. The parents' claim against the school was allowed solely on the issue of lack of pastoral support with the result that the school was ordered to produce an action plan to deal with the specific needs of children on the autistic spectrum or who had alternative communication requirements and that a mentoring system be also established. A similar case was settled at the hearing stage with the school agreeing to apologise, to include the pupil in any future school trips and to make the necessary reasonable adjustments to enable the pupil

to be fully involved in the school. Both cases illustrate a shift in thinking that is necessary to enable an essential element of citizenship, that of social participation. The issue of 'behaviour' can no longer be seen to be a result of individual deficit, but an interaction in a social context. It also shows how schools and the education system generally have social responsibilities in making inclusion happen and have duties in removing particular barriers.

Duty to include

Anti-discrimination measures, as discussed in Chapter 3, have been in place since 1995 and for schools already cover the sphere of employment in part 2 of the Act, which should enable more disabled teachers to practice in schools. In previous legislation the Local Education Authority LEA had a duty to choose mainstream schooling, if 'the school was suitable to the child's age, ability or aptitude or to his SEN; the attendance of the child at the school would be compatible with the provision of efficient education for children with whom the child would be educated; and the attendance of the child at the school would be compatible with the efficient use of resources.'

This left the school with a 'resource-driven' get-out clause:

'In relation to the 'efficient use of resources', case-law had already determined that the costs of a special school place were to be treated as 'sunk costs' for the LEA - the special school place having already been funded on a place basis, whereas those of a mainstream school place were not - the mainstream school place being funded on a pupil basis. This heavily militated against s 316 being used to secure a mainstream placement in practice.'

(Silas, Wolfe, 2005: 3)

However, the focus has dramatically shifted. The Disability Discrimination Act 1995, as amended by the Special Educational Needs and Disability Act 2001, now places a duty in three respects:

- a duty not to treat disabled pupils less favourably, without legally valid justification, for a reason which relates to their impairment;
- a duty to make reasonable adjustments so that disabled pupils are not put at a substantial disadvantage compared to pupils who are not

disabled (but there is no duty to remove or alter physical features or provide auxiliary aids and services); and

- a duty to plan strategically and make progress in increasing accessibility to schools' premises and to the curriculum, and in improving the ways in which written information provided to pupils who are not disabled is provided to disabled pupils.

(House of Lords, Explanatory Notes, 7th December 2000)

The latter duty, the accessibility plans, ran initially over a period of 3 years. A key aim of the planning duty is to address the accessibility of schools for disabled pupils in physical environment, access to information, access to the curriculum and all educational services. The Disability Discrimination Act 2005 further emphasizes disabled people's rights to full participation by placing a duty on all public authorities, including schools, to promote disability equality. Both planning and promoting duties require specific action at school level.

Accessibility Plans

“Because if you're down there in (that) area right, you've got to go up all the way up three ramps to get to science, but in that area there's like a set of steps that you just go straight up, and you're at science.”

(Craig, reported by Priestly, 1999: 100)

Schools are required to produce accessibility plans for their individual school and LEAs are under a duty to prepare accessibility strategies covering the maintained schools in their area. Accessibility plans and strategies must be in writing. The Code of Practice acknowledges that the precise nature and content of plans will vary according to the size of school and the resources available to the school. These plans have been in place since 2002, DfES guidance states that schools must produce their own accessibility plans, whilst LEAs must produce accessibility strategy; a plan to increase the extent to which disabled pupils can participate in school curriculum, improve the physical environment of schools to improve the extent to which disabled pupil can take advantage of education and associated services, improve the delivery to disabled students of written information which is provided to pupils who are not disabled. Guidance further stipulates that this should be done within a reasonable period of time and in a format which takes account of the

views expressed by the pupils or parents about their preferred means of communication. The basic idea is to shift from impairment concerns to access action, with concomitant duties placed upon education providers. These requirements as encapsulated in legislation and guidance further symbolise a shift in governance. The process of developing accessibility plans requires a changed relationship with disabled people, whether parents, pupils or local disabled people. The first issue is that schools will have to address their minds to the question of inclusion in terms of enabling better access for disabled people. In developing plans schools are advised to use expertise from disabled people, parents and pupils. Interestingly, the guide fails to mention disabled staff (as if to assume that there are none or that their role is irrelevant) but does mention specialist staff as a source of expertise, such as traditional Special Educational Needs Co-ordinator, thus underscoring the traditional 'professional expert' – 'disabled person' divide.

The Office for Standards in Education (Ofsted) has the task to monitor accessibility plans. Ofsted inspectors have to address inclusion and participation of disabled people by finding criteria against which they assess the relevance and effectiveness of accessibility plans. It is crucial that inspectors have received disability equality training which places access issues in the broader context of a school environment and ethos within the social model of disability. However, there is concerns over how effective inspectors are in adequately addressing the full range of access issues. For example, a special school inspection report (2002) simply states 'The school reports under the Disability Discrimination Act. All areas are now fully wheelchair accessible', whilst a report in 2005, also concerning a special school, failed to address any access issues at all (Ofsted, 2005).

Further indications of a lack of emphasis on broad access issues is in a school report for children aged 11-16. The inspectors made 16 references to access, all referring to access to the curriculum generally with over a third of comments relating to access to information technology or computers, but failed to address any other physical, environmental, communication or inclusion access issues (Ofsted, 2005). Access to the computer was interpreted narrowly to mean number of terminals and allocation in timetable. Access to computer did not include consideration of adapted keyboard,

alternative interface or internet web site accessibility standards (cf Hayward, 2006). Early research indicated that less than 50% of schools had accessibility plans. Planning duty and disability equality duties are anticipatory, and thus include actual and prospective pupils. There are thus several levels of accessibility duty within Part IV of the Disability Discrimination Act 1995 (as amended by the Special Educational Needs and Disability Act 2001):

- access to the physical environment
- access to communication and information
- access to the curriculum.

The traditional association of 'disability access' with a typical wheelchair user in mind leads to considerations of 'ramps and lifts' (TALK, 2000). Physical environment and physical access are indeed important, however, general inclusive design, provision and use of aids and adaptations, diversity and range of ICT equipment, including photocopier, keyboards, loop system, choice of seating, seating arrangement, furniture, lighting, sound quality, room space, allocation of rooms, are all equally important factors in enabling access to the physical environment, and ultimately to the curriculum.

However, in themselves, even if fully addressed, these access issues are only part of the picture and can be undermined by other barriers within the school context, such as barriers rooted in attitude, individual and organisational behaviour that disenfranchise disabled people. A case brought under the Disability Discrimination Act may, on the face of it, concern access to classrooms by a wheelchair user, but underlying barriers are that of lack of commitment, addressing oneself to finding solutions, hiding behind 'fiction' and fears such as 'health and safety' concerns, or making broad generalised judgements about ability or impact upon the disabled child and other pupils. For the access issues of communication and access to information an equally bigger picture is needed. Communication and information access in the first place requires the provision of alternative formats, responsiveness to preferred means of communication, whether it is Braille, large print, audio-visual, tape, pictorial, Easy Speak, electronic information or facilitated communication. However, it is also necessary to demonstrate commitment,

provide relevant and ongoing training, to have systems and procedures in place to support individual staff responsiveness to particular access requirements. Do we know what to do in response to a specific access requirement, say Easy Speak or British Sign Language? How does the system make this happen, who is responsible? Are these responses triggered by individual requirements or do we have systems in place that expect, anticipates a diversity of learners, diverse methods of communication, diverse access requirements? Do we expect disabled people to be part of, constituent of 'the community' or additional to?

As a basic illustration of this point the recruitment of trainee teachers onto a Post Graduate Certificate of Education programme, or onto the school-based Graduate Teacher Programme pathway offers a range of dilemmas. To begin with, the traditional recruitment process does not ask access-type questions but remains in bio-medical model thinking by asking impairment questions, such as 'do you have a disability', 'do you use a wheelchair', 'are you blind', 'do you have any special needs'. Within the social model of disability a person does not 'have' a disability but is disabled by barriers in society, and is a person who has an impairment or condition. If a potential trainee should say 'yes' to being blind, for example, what does this information that focuses on the impairment or condition tell the recruiting institution about that person's access requirements? Access requirements focus on the barriers created and removable by society. Access requirements for a blind person may be as diverse as requiring large print written communication, colour contrast in the physical environment, using a guide dog, occasional use of a white cane, requirement to re-allocate duties of playground supervision, wearing dark glasses to deal with light sensitivity issues, use of ICT in classroom teaching, employing a personal assistant, requiring clear auditory communication in meetings and additional time to access reports. If an applicant did state that she required written communication in large print size 24, how would that information get translated into action? Are organisational responses triggered by individual requirements when they appear, or do we have systems in place that expect a diversity of learners, and therefore ask about access issues and offer alternative methods as an integral part of recruiting new students?

Who are we talking about?

A report on the First Round of Accessibility Strategies was produced in Scotland (The Scottish Government, 16th December 2003) and the results showed some uncertainty as to who is treated as being a disabled person, and as such, covered under the provisions. In other words, who are disabled pupils in terms of access, planning duties and disability equality, as opposed to pupils who have special educational needs? These uncertainties are evident in the behaviour of schools and attitude of tribunals. On 28 April 2004 the Disability Rights Commission supported a case that concerned a complaint of disability discrimination on ground of access to education provision. However, since the law adopts a four-step approach to disability discrimination cases, whereby each question addressed needs to be answered in the affirmative before moving on to the next, this case fell at the first hurdle. When considering a potential case of discrimination, courts and tribunals clarify these points:

1. Is the person bringing the case a disabled person as defined in part 1 of the Act?
2. Does the particular authority (school, college, service provider, employer) have a duty under the Act?
3. Has there been any discrimination, either
 - in form of less favourable treatment? or
 - failure to make a reasonable adjustment?
4. Is the discrimination justified by specific criteria within the law?

On the question whether the disabled child on whose behalf the case was brought was disabled as defined by the Act, the Tribunal concluded that as she did not have a mental illness she was not covered by the definition of disability under s 1 of the DDA. The client's claim of discrimination was therefore struck out. Early SENDIST cases have struggled with the definitional shift (cf **A v HM School**) as anti-discrimination envisages a wide definition of the protected group, where 'substantial' in law means 'more than trivial' (Chapter 3).

The definition of disability in section 1 refers to a mental or physical impairment. However, guidance clearly spells out that this should be interpreted most widely and should include, for example, sensory impairment and learning difficulties. The difficulty for the tribunal was the wording of 'mental illness', which according to available guidance at the time needed to be 'a clinically well-recognised condition'. This requirement has since been removed (DDA 2005), but at the time the tribunal struggled with combining the issue of mental health and the description of dyslexic and dyspraxic tendencies. The person clearly required a range of alternatives to access learning. It is my contention that the tribunal failed to address the question of who is a disabled person. The child concerned need not have to be seen to fall within the scope of 'mental health' impairment. The child was described as having 'general developmental delay with dyslexic and dyspraxic tendencies'. This clearly falls within an 'impairment', a term that encapsulates all forms of impairment in law such as a sensory, physical, learning and mental impairments. Parliamentary discussions evidence that the interpretation of 'impairment' was to be given its widest possible meaning so not to exclude people who require the protection of the law. The description of the impairment appears to affect several of the eight legally specified areas of ordinary life, such as communication and concentration. Therefore, the child easily falls within the meaning of a disabled person under the DDA (more than trivial). The point of the legislation is to protect groups of people from discrimination and enable active participation and inclusive citizenship.

This illustrates how anti-discrimination measures under the Disability Discrimination Act define the protected group widely, and that such an approach contrasts with the more narrow definitions applied to entitlement laws, with which the tribunals traditionally are more familiar and had been applying under successive special educational needs Education Acts over the past thirty years. To find that the child concerned had special educational needs if due to his developmental delay with dyslexic and dyspraxic tendencies 'he has a significantly greater difficulty in learning than the majority of children of his age' seems easier for practitioners, than to grasp the message that a person is a disabled person without necessarily displaying the stereotypical 'badly handicapped' severity or degree of impairment. For many

tribunal members a mind shift is required and training in disability equality issues, if not in the application of legal principles, in order to avoid any confusion. In anti-discrimination law the focus is on access (duty to make reasonable adjustments, non-discrimination principle) and not on impairment.

Understanding of the scope of the strategies: who is covered?

The legal definition of disability continues to be contested as Scottish research further illustrates uncertainties over who is the protected group:

13. The majority of local authorities referred in their strategies to the definition of disability in the Disability Discrimination Act 1995, as amended (see Annex A for more details). Whilst some listed specific groups of children who would be covered by the accessibility strategy, it was noted that groups of children with non-visible disabilities were sometimes not listed.
14. Strategies often referred to the overlapping category of children with special educational needs/additional support needs and the link between the accessibility strategy and the authority's support for learning or inclusion strategies.
15. A number of strategies also included children with social, emotional and behavioural difficulties, and some authorities made clear links between their accessibility strategies and their behaviour support strategy.

The overlapping definitions go back to sections 312 to 336 of the Education Act 1996. A child with special educational need is defined in a circulatory manner:

312. –

(1) A child has "special educational needs" for the purposes of this Act if he has a learning difficulty which calls for special educational provision to be made for him

(2) Subject to subsection (3) (and except for the purposes of section 15(5)) a child has a "learning difficulty" for the purposes of this Act if-

- (a) he has a significantly greater difficulty in learning than the majority of children of his age,

(b) he has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area of the local education authority, or
(c) he is under the age of five and is, or would be if special educational provision were not made for him, likely to fall within paragraph (a) or (b) when of or over that age.

(3) A child is not to be taken as having a learning difficulty solely because the language (or form of the language) in which he is, or will be, taught is different from a language (or form of a language) which has at any time been spoken in his home.

Classification illustrated: British Sign Language user

It can be difficult for practitioners, head teachers and others in schools to understand how a child should be classified. How might a child, for example, who uses British Sign Language be classified? And to what effect? Does she have special educational needs? And/or is that child a disabled person under the DDA? Within the special educational needs framework section 312 of the Education Act 1996 will be applied. One obvious stumbling block is the phrase 'has a disability which either prevents or hinders him from making use of educational facilities of a kind generally provided for'.

The child, within the social model understanding of disability, has a sensory impairment or within a cultural model is a Deaf person regarding herself as a member of a language and cultural minority. If we take 'has a disability' in section 312 as meaning 'has an impairment' then the first element of the definition is satisfied, and in that regard she may be classed a child with 'special educational needs'. The second limb of that definition looks at how schools are ordinarily organised, what is generally provided for, and the way that it is usually provided. Since British Sign Language is not (yet) an additional language of instruction in school, and not usually provided for as of choice, or generally available in schools, this second limb is also met. Our child can thus be seen as having special learning difficulties under section 321 of the Education Act 1996. In essence this is the result by virtue of using BSL in an unchanged school context.

Subsection (3) of that same section may, however, indicate a different approach. It states that a child would not have special educational needs solely because the language (or form of the language) in which children are taught is different from the language (or form of a language) which has at any time been spoken in the child's home. With the recognition of BSL as an official language, and with the adoption of a cultural perspective of many Deaf people, the issue can be regarded as one of language, in which case the processes of 'statementing' and with it of securing additional resources to meet a special requirement will not be triggered. The issue then becomes one of language rights and welcoming cultural diversity.

With the incorporation of education into the anti-discrimination framework in 2001, the child, who is using British Sign Language can also be regarded as a disabled person under section 1 of the Disability Discrimination Act (as discussed in Chapter 3). The child, who is using sign language is thus entitled to protection against discrimination. Schools have disability equality and accessibility duties placed upon them, and within those duties are required to avoid putting the child at a disadvantage as compared to other children and a duty to make reasonable adjustments. Access to information, communication and the curriculum are specifically covered.

Anti-discrimination puts a duty on society to remove disabling barriers, and in contrast to special educational needs thinking, anti-discrimination expects that the school context will have to change.

Curriculum access

It is further reported, that there was little evidence in the strategies to show that authorities had considered how to improve access to specific subject areas within the curriculum or had considered providing advice to schools on how to do this. 'While the expectation is that schools would undertake this in relation to individual pupils, authorities should consider developing guidance on how schools can make all courses and programmes more accessible to pupils with specific access requirements, for example, pupils with learning difficulties, sensory impairment or mobility impairments.' The report goes on to state that many, but not all authorities addressed the need to improve access to extra-curricular activities, both during the school day, such as educational

excursions, and after school. 'This is an area where the right to access and full participation and particular access requirements of pupils with a range of impairments can be overlooked. It is recommended that authorities ensure that extra-curricular opportunities are reviewed, and, if necessary, addressed in future strategies.'

Disability Discrimination in Education

In 2003/4, the Disability Rights Commission DRC has received 6,476 calls to its helpline from parents and disabled students about unfair treatment they have experienced in the education system. All cases are brought as parents or advocates of disabled people, young disabled people themselves and disabled teachers have serious concerns over basic infringement of citizenship rights. The DRC reports that 'complaints range from the refusal of help to administer medication; not being allowed on school trips; poor physical access on school premises; refused attendance at after school clubs; exclusions and a lack of help with transport to and from school.' The non-discrimination duty extends to all school activities, from admissions, provision of formal and informal educational opportunities, assessment and testing, to exclusions.

Disability discrimination cases – pupils less favourable treatment

In a case reported in February 2006 a school that excluded a six year old with diabetes because of his condition has been forced to apologise to the boy and reimburse his school fees. Rupert, who was a pupil at Sunninghill Preparatory School in Dorset from the age of two, has Type 1, insulin-dependent diabetes. Rupert's parents, Kai and Peter Knell were told by the school that following a risk assessment and consultation with staff and governors, Rupert could not continue at the school without paying for a full-time carer. The school did not invite Mr and Mrs Knell to discuss their concerns and gave no notice to Rupert and his parents before the exclusion.

The DRC reports the details of the case like this:

'Rupert's parents had agreed a protocol with the school which meant Rupert, under supervision, would test his blood sugar levels several times a day and staff would provide him with a snack, if needed, after the test. Rupert's insulin injections were administered by his parents at

home. Rupert's consultant paediatrician recommended self-testing as he thought it would lead to a better chance of detecting a hypoglycaemic episode. However, on Friday 11 March 2005 when Mrs Knell arrived to pick Rupert up from school, she was told that Rupert would have to leave Sunninghill. The school had already packed Rupert's personal belongings. The following Monday, the Knells received a letter from Sunninghill stating that without full time support Rupert could not continue at the school. The Knells were told that this decision was made following a risk assessment and consultation with staff and governors. As Sunninghill is an independent school, Rupert's parents would have had to pay for a full time carer for him.

Rupert's father Peter Knell said: "What made us angry was the shameful way in which Rupert was excluded from school – with no notice and no time for Rupert to say goodbye to his friends. We weren't consulted about the exclusion or given any reason why he needed a full time trained carer. If we'd been invited in to discuss the school's concerns before the exclusion we could have avoided legal action. "But I'm pleased the matter has now been resolved and Rupert is happy in his new school. I hope that Sunninghill honours its promise to review its procedures so that other children don't suffer the same humiliation as Rupert." DRC, February 3, 2006

Several issues become apparent in this scenario. Firstly, schools have a duty of care towards all pupils and in exercising this duty may jump to conclusions about risk when confronted with impairment-related matters. To exclude on the basis on diabetes seems so out-of-step with the realities of risk management for that individual living with diabetes, and this appears to show how traditional medical model approaches rear their ugly heads. Again a shift in attitude and behaviour is required. A mind set that accepts disabled people as active members with citizenship rights will address inclusion mechanisms, otherwise agencies may be rather 'too quick to show the door' (Massie, 2006). An understanding that disabled people live productive lives and successfully 'risk-manage' themselves on a daily basis is essential in understanding the position of disabled people as having material rights as citizens and multi-level active participation in citizenship processes. The

education context is no exception and schools dealing with impairment-related issues of exclusion need to adopt a 'can-do' attitude to fully realise these rights. Such an approach requires that any potential barriers to inclusion are fully addressed before a decision is made.

Mr and Mrs Knell challenged the school's decision under the Disability Discrimination Act (DDA) and were supported by the DRC. Solicitors, who represented Mr and Mrs Knell in their DDA claim, pointed out that Rupert's treatment by the school was clearly unlawful under the DDA. This case is one of many that illustrate how many schools seem unaware of the requirements of the legislation. As a positive outcome of legal action, the school Sunninghill has promised to review its procedures. However, that knowledge and resultant possibilities of inclusive practices remain within the individual school and within case law reporting. Ten years on from first coming into force the Annual Report of the Anti-Discrimination Commission in Queensland, Australia (2002) asserted that disability equality claims were rising, increasing both in numbers and in complexity year on year. Knowledge gained from disputes and learning on inclusive practice resulting from disability discrimination cases fails to receive attention in wider circles and thus best practice fails to be disseminated accordingly.

Rights, human rights and mind sets

The concern that schools may be unaware not only of the letter of the law but of the meaning of legislation to their policy, practice and procedure has been echoed by research in Australia, where anti-discrimination legislation in education had been implemented since the 1990s. Keffe (2005) examined the qualitative perspectives that head teachers and principals in schools had of the disability discrimination legislation. The study found a reduced level of knowledge of the disability discrimination legislation and vague, ineffectual inclusive education policies contributed to leadership and management problems. Whilst the initial response to the legislation was positive, at least in terms of creating a momentum for change, this had quickly waned to a state of affairs that 'deals with' disability equality only when absolutely necessary by

way of 'waiting for contentious issues to arise before accessing and scrutinizing the legislation, policy documents or legal expertise for advice'.

Disability discrimination cases – pupils reasonable adjustment

This case (also reported by DRC) concerns what appears to be a simple reasonable adjustment, to allow the use of a lap top computer. However, attitudinal and organisational barriers to inclusion are evident:

“The client’s submitted a DDA claim to Special Educational Needs and Disability Tribunal SENDIST that the respondent school had failed to make a reasonable adjustment for her disabled son. Her son has dyspraxia and she was requesting that the school allow him to use a lap-top for written school work. The Tribunal considered the claim and a hearing took place in 2003. The client presented her claim in person and re-iterated the written claim that she considered the school had failed to comply with their duties under S28C of the DDA to make reasonable adjustments to prevent her son as a disabled pupils being placed at a substantial disadvantage.”

(Disability Rights Commission, case work team)

Here the basic four-step legal approach was not followed. The Tribunal only considered the school’s duties under S28B of the DDA and determined that there had not been less favourable treatment, but they should have addressed the next question as well, that of making a reasonable adjustment (or in other words, the duty to remove disabling barriers):

1. Is the person a disabled person as defined in part 1 of the Act?
2. Does the particular authority have a duty under the Act?
3. Has there been any discrimination, either
 - in form of less favourable treatment? or
 - failure to make a reasonable adjustment?
4. Is the discrimination justified by specific criteria within the law?

The case demonstrates how the legal process itself failed to assist and deal with disability equality issues. The Tribunal failed completely to deal with the reasonable adjustments aspect of disability equality, and as such exhibits lack of understanding of disability equality in terms of the social model and in

terms of inclusive citizenship rights, in relation to the assertion that society has a duty to remove barriers. The rule not to allow use of lap top is a barrier to inclusion, but the failure to address reasonable adjustment by the Tribunal fills me with anger over the continued denial of basic participation of disabled people in the very context which is set up to ensure legal citizenship rights for disabled people.

Inequality in legal presentation also meant that the client would not have been able to challenge the Tribunal's decision without the help of the Disability Rights Commission. The appeal was eventually conceded by both the Tribunal and the school, and the original decision had been struck out.

Reasonable adjustment, assessment and educational standards

A particular contentious issue in relation to removing barriers to participation is when 'reasonable adjustment' has to be balanced with competing agenda, such as 'standards' or 'excellence'. This can be illustrated with a case of a 10-year old boy with Chronic Fatigue Syndrome, ME.

The child, who applied for a place at his local grammar school, tires very easily and can only concentrate on school work for approximately 20 minutes at a time. His parents approached the school and asked for the 2 hour exam to be split into 20 minutes sections. With concerns over standards and equity in relation to other students, the school refused to make any adjustments to the 11+ examination, primarily on the grounds that it would be unfair to other pupils.

This was one of the first claims to Special Educational Needs and Disability Tribunal under Part IV of the DDA. The case was supported by the Disability Rights Commission. Again, rather than forming part of legally binding case law, even though the case had good prospects of success, dealing with key issues of reasonable adjustment to examinations and assessments and the potential conflict with academic standards, no precedent was formed. The case has been settled. The school agreed to split the exam into three sections to be sat on three separate days. Under Part IV of the Disability Discrimination Act examinations and assessments are services in the provision of education where disability discrimination due to less favourable treatment or failure to make reasonable adjustments has to be avoided. Anti-

discrimination legislation does not require compromise to academic standards, in the same way that anti-discrimination in employment still seeks the best person for the job. Despite this, 'academic standards' have been invoked as a justification for the failure to make changes to the method, mode, timing or otherwise traditional way of assessing, by way of reasonable adjustment. Such justification is legally available in a limited number of scenarios, but only if in that case there may be a compromise to core academic standards. Consequently, core academic standards should be specific, clearly defined and well publicised. The school did not want to be seen to treat a disabled child more favourably, nor to compromise on 'academic' excellence. This allowed little scope for reasonable adjustment. Similar concerns over diluting academic excellence are apparent in the following example drawn from a University, where students hand in regular assignment to their tutors for comments. Despite this institution's mission statement of widening participation and 'openness', the actual experience of requesting a reasonable adjustment appeared to fly in the face of diversity, as the institution seemed to find it difficult to reconcile academic standards with practices that would fall within the flexibility required by reasonable adjustment. A blind student requested a regular 'allowance' of up to seven days for submission of written assignments. The student reported that this request was made for the past four years of study. Each time it was eventually agreed, but each time the student needed to go through a series of explanations and justifications, starting with the tutor and working the way up to the managers. In fact, the student stated that s/he would engage in negotiations as soon as s/he had details of the new tutor, ahead of course start date, thus having a less favourable experience in getting started on the course than other students, who do not have to make this reasonable adjustment request. The initial responses from the tutor, from their teamleader and from the manager of the programme were often negative. A set of underlying assumptions included that it was in the student's own control to hand in on time: 'it is in your own best interest to ensure to give your work in on time', 'we do not want you to fall behind in your studies', 'regular extensions would not be fair to other students'. It took persistence and power of persuasion to convince, year-on-year, that the 'extension' of allowing an

additional seven days for submission is, as a matter of fact, not an extension, but a reasonable adjustment. The student produces the answers to written assignments on tapes. These tapes need to be sent to be transcribed and then to be up-loaded and submitted electronically. This procedure of sending tapes and subsequent transcription takes a minimum of seven days. In other words, the student has the same amount of time as other students to complete the task, but the transcription into a format accessible to the tutor marking it takes extra time. To understand that it is extra time for transcription and not extra time for the student seems difficult in a context preoccupied with academic standards.

It is interesting to note that that same institution is able to offer flexibility in terms of end of course examinations, with excellent provisions of amanuensis, allowance of break time, home exams, additional time or examinations split over two half days. However, this positive organisational behaviour is not embedded and 'automatic'. Pockets of positive practice may be due to the Quality Assurance Agency (QAA) code of practice, which lists such arrangements, and partly due to the fact that the law school autonomously decides on extensions while examinations are dealt with as part of a wider university practice. The QAA states that institutions should consider implementing procedures for agreeing alternative assessment and examination arrangements when necessary that:

- are widely publicised and easy for students to follow;
- operate with minimum delay;
- allow flexibility in the conduct of the assessment;
- protect the rigour and comparability of the assessment;
- are applied consistently across the institution;
- are not dependent on students' individual funding arrangements.

The QAA further informs education service providers that they may wish to consider the following adjustments:

- flexibility in the balance between assessed course work and examinations; demonstration of achievement in alternative ways, such as through signed presentations or viva voce examinations;

- additional time allowances, rest breaks and re-scheduling of examinations;
- the use of computers, amanuenses, readers and other support in examinations;
- the availability of examinations or the presentation of assessed work in alternative formats (eg modifying carrier language);
- the provision of additional rooms and invigilators for those using alternative arrangements.

The concept of reasonable adjustment is not new in that it features in primary legislation of the Disability Discrimination Act since 1995. Schools and Higher Education establishments are familiar with its provisions in terms of employment and in terms of service provision (parts 2 and 3). It challenges practitioners to develop policy and practice with imagination and flexibility in order to achieve active participation, inclusion and equality for disabled people. Reasonable adjustments creatively applied can thus include 'proof reading support for dyslexic students writing dissertations, assistant to carry out manual tasks in practical laboratory assessment and production of a three dimensional model as alternative to two dimensional diagram' (The Scottish Disability Team).

Raising standards is a perpetual driving agenda for school management and governing bodies, curriculum development, extended learning, and all educational services, including assessment.

The government's information on standards allows visitor to focus their search (DfES, online) by offering areas of particular interest and subdivision. These areas include: a focus on achievement for minority ethnic groups, gender and achievement, gifted and talented, but they do not include disabled pupils.

Instead, standards are addressed for 'special schools'. This division and use of language underscores the perception that disability and standard may be in conflict, and may also confirm a perception that an equalisation approach, as with gender or race, is not relevant, necessary or appropriate for disabled pupils. The code of practice at paragraph 4.27 requires practitioners to remember that the academic standards reason should not be used spuriously.

' Where elements are not central core to a course, they are unlikely to provide

a reason to justify discrimination based on academic standards. Nor can academic standards be used as justification for barring whole groups of disabled people from courses or services. Any justification has to be relevant to the academic standards of a particular course and to the abilities of an individual person.' However, disabled people have experienced a history of fiction and prejudice which links having an impairment with not being able to do something, with needing help and requiring assistance. Traditionally the response to impairment related access was one of 'special concessions' or 'special consideration'. Now disabled people are asking to be regarded as full citizens with equal rather than special rights. In place of a welfare approach, the language moves to reasonable adjustment, which is, in essence, the removal of barriers placed there by the way society responds to impairment. In terms of examinations and assessments questions need to be asked as to what is being assessed and how this knowledge, skill or ability can be demonstrated in a variety of ways.

Reasonable adjustment – to what extent?

The case of the boy, who has Torretts Syndrome, and the circumstances that concerned behavioural issues as they arose in an unsupportive school context ([2004] 2 All ER 436) demonstrates that the social model approach to understanding disability, with its emphasis on removing barriers arising in the social, school organisation context, is also key to avoiding discrimination and potential cases being brought against the school under the DDA. A social model approach to disability helps to clarify what kind of adjustments might be necessary. Section 28C(1) of the 1995 Act requires a school to--

'take such steps as it is reasonable for it to have to take to ensure that ... (b) in relation to education and associated services provided for, or offered to, the pupils at the school by it, disabled pupils are not placed at a substantial disadvantage in comparison to pupils who are not disabled.'

Practitioners frequently bemoan the legal 'chewing gum' phrase 'reasonable adjustment'? What is reasonable appears to some the same question as how long is a piece of string? The following case illustrates some of the difficulties.

Research as part of the 'Reasonable Adjustment Project' sought to clarify issues, which set as its aims:

"This project was jointly funded by the Department for Education and Skills and the Disability Rights Commission and was developed on our behalf by Disability Equality in Education [DEE]. The aim of the project is to promote good practice in making reasonable adjustments for disabled pupils." (Disability Equality in Education, DEE)

McAuley Catholic High School v C_ and others - [2004] 2 All ER 436

Question of Reasonable Adjustment/ resources:

The case as reported in All England Law Reports reminds us that the tribunal considered this point in para 6 of its reasons. It considered three forms of reasonable adjustments that the school needed to undertake in order to give IC a chance to learn and reduce the possibility of challenging behaviour. We know from Mrs. Lawrence:

' that the transition from year 7 into year 8 is quite a challenge for many pupils as they move from mixed ability groups into sets for each subject. The children were also set in their forms which meant that IC was in groups of lower ability children, which had the advantage for them of being small in size. A disadvantage of the setting system was that it became impossible to replicate the buddy system that had worked so effectively for IC in year 7 as there were no children of the right calibre in IC's sets in year 8 to carry out such a sensitive task. The three children who had previously performed that role had all moved into different classes from IC in year 8. In addition, IC's groups did not always consist of the same children and there were accordingly additional changes of fellow pupils for him to adapt to and cope with.'

(DRC, case work; reported [2004] 2 All ER 436)

Therefore, possible adjustments consisting with the provision of support for IC during unstructured times (paras 9 and 10 of its reasons) and the making of arrangements to assist IC in the transition from year 7 to year 8, which included provision of a mentor and active pre-planned management of his behaviour (para 10 of the reasons). Since this was not provided for and the

school did not address the issues as arising out of the existing school organisation ('business-as-usual' attitude, can't change our procedures to fit in for one boy) the tribunal concluded that the School had failed to take reasonable steps as were required by s 28C(1)(b) by failing to give IC the necessary personal guidance and support within the context of the School pastoral system. A failure to provide reasonable adjustment which enabled curriculum access is illustrated like this:

'IC had particular difficulties with science. The method of teaching at the School required the children to work in groups; IC found it hard to cope with this method as he had a tendency to wander around the room and to touch the equipment and chemicals on the teacher's desk while the teacher was trying to help the other pupils. For those reasons, he had been removed from science lessons on two occasions as it was felt that he was presenting health and safety risks. He was then taught by the head of science on his own but this regime was perceived as a punishment by IC and by his parents.'

(DRC, case work, reported [2004] 2 All ER 436)

Overall, the court decided that disability discrimination was evidenced in a range of matters for reasons of less favourable treatment, failing to provide curriculum access and serious failure to make arrangements for reasonable adjustments. The judge summed up three key issues under reasonable adjustment:

'In my view, there was ample evidence on which the tribunal was entitled to conclude as it did that first, 'more active pre-planned management of [IC] would in our view have helped and made a difference', second, that IC 'was not given the necessary personal guidance and support within the context of the School pastoral system as he required' and third that 'the problem [for the School] was not so much one of resources but of planning and organisation'.

(DRC, case work, reported [2004] 2 All ER 436)

'Reasonable' in law primarily means an arrangement that works, an adjustment that deals with the access issue or that removes the barrier. A

reasonable adjustment is anything that the school can do to remove barriers to physical, social, school culture, curriculum and communication access by an action taken or a measure implemented to change the school context. The school's action in this regard is effective if it takes into account the interests of all possible stakeholders, the pupil concerned, parents, teachers, other learners and school aims and objectives. It is important to note that, as we move towards realising citizenship rights for disabled people and a more inclusive society, the standards of what is an acceptable balance of interest and what is reasonable may change over time.

McAuley Catholic High School v C_ and others - [2004] 2 All ER 436

Question of bullying:

A further institutional barrier can arise in the way that policies are drafted and implemented. The relevant policy here is on bullying.

'The tribunal recorded that IC was 'capable of concentrating and producing good work in lessons on some days [but that] there did not appear to be any particular pattern to his behaviour'. He had LSA support for the equivalent of 16 out of the 25 hours of lessons that he received each week and he was usually taught in small groups with 'work being differentiated for him'. The School arranged for a number of LSAs to support IC as it was considered important that he did not develop a dependency on any one particular individual.'

(DRC, case work, reported [2004] 2 All ER 436)

This section introduces the pupil and shows the kind of reasonable adjustments which enabled participation in education. Learning Support Assistants LSA during each lesson are to support the individual child and not substitute individual teaching. We do not know how the LSA was employed in this instance. It was also very helpful to aim to ensure continuity and training several people to take on that particular function. However, there is still a school culture of not accepting difference, of 'othering', stigmatising and bullying, all which undermined IC's positive engagement with education.

'In spite of these efforts by the School to support IC in lessons, his parents were becoming increasingly concerned for his safety and

welfare as he was reporting more bullying incidents, which were causing him a great deal of distress and anxiety. On 18 September 2002, IC had been found by a member of the staff in the playground during the lunch break curled up in a ball and he refused to move until his elder sister, who was a pupil at the School, came to assist. IC claimed that he had been attacked and kicked by another pupil. He said he was tired of being kicked and his mother described him as 'very upset after this incident'.

(DRC, case work, reported [2004] 2 All ER 436)

The situation deteriorated further and contrasts the early picture of what the boy was capable of, since he was initially described to the tribunal as a 'well behaved child who can be quiet and hesitant [but] he was observed to have only a limited group of friends and interaction with a wider peer group is difficult for him.' This raises questions about disability bullying and how to tackle this in the school context.

Bullying, harassment as disability discrimination

Disability bullying is a wide spread phenomenon, ranging from comments written on dirty vans 'This van is being cleaned by David Blunket', a comment which is then briefly discussed on a BBC Radio programme (Sarah Kennedy, Radio 2). Name calling, put-downs and exclusionary behaviour in schools permeates the daily experiences for many disabled pupils (Aspen, 2002). Bullying is inflicted on less powerful persons from people in more powerful positions and can either be overtly exercised, such as through overt behaviours that intimidate, offend, degrade or humiliate and generally belittle the disabled person. Bullying and harassment can, of course, also take a more vicious form, where a disabled person is beaten, kicked and subjected to physical and mental harm.

More indirect and subtle means of bullying relate to exclusionary school practices and culture at both individual or organisational levels, with, for example segregated allocation of space, where information is withheld, a person is isolated, where decisions are made without involving that person and where the disabled person is effectively excluded from activities generally undertaken by peers. In this case IC did not experience a safe school

environment, one which tackled bullying effectively. As a direct consequence of the impact of persistent disability bullying his personal well-being, his access to the curriculum and his general coping behaviour deteriorated even further.

'Another incident occurred on 2 October 2002 when IC claimed that he had been attacked by other boys in the toilets who pushed his head down a lavatory. In consequence, he ran out of the School to a local park and he eventually made his way home at 6.00 pm. The School only informed IC's parents of his disappearance at 3.30 pm. The School carried out an investigation into this episode but were unable to reach any conclusion as to who was responsible for the incident.'

(DRC, case work, reported [2004] 2 All ER 436)

Further bullying attacks were recorded and his behaviour seriously deteriorated. Observation notes pointed out the difficulties that IC was having in conforming to the requirements of what the school deemed acceptable behaviour in the classroom. His behaviour, if seen as a consequence of bullying, may be regarded as ineffective coping mechanisms. However, if seen as behaviour either purely within his control, or purely due to his impairment, is seen as unacceptable behaviour in the class room. He was humming, making clicking noises, being distracting and annoying to other pupils, as well as often being unable to join in group work.

Significantly, IC was also observed to be solitary and to be unable to interact with other children in physical education classes, at lunch time and at break times. These observations correspond with a view of more subtle disability bullying, which consist of exclusionary practices and experiences. The descriptions in court focused on the deficit if IC, such as 'IC appeared unable to initiate communication in a positive manner'. In the corridor between classes, he was observed roaming up and down, searching and latching onto familiar faces and then barging others into corridor walls whilst laughing inappropriately. Recognising that the school could provide reasonable adjustments in order to remove barriers to social inclusion, Mrs Robinson's report suggested that IC's behaviour might be moderated if he was moved into a teaching group pairing with other children, who might set him a better example and if there was 'positive reinforcement of any successes'.

Rather than tackling the issue of bullying, with concomitant themes of respect, tolerance and celebration of difference, the pupil IC was pathologised (Foucault, 1974) within an individual deficit model of disability. The statement of special educational needs – a concept which runs counter to anti-discrimination principles – for IC referred to the need for his school to have access on an ad hoc basis to an educational psychologist and a teacher for pupils with communication difficulties who would provide information and advice on meeting IC's needs. IC became a pupil at the School in September 2001 and his transition initially 'seems to have taken place without undue difficulties' as there was no evidence of any particular problems for him during the Autumn term. However the situation had seriously deteriorated as a result of unchanged school context, a failure to remove barriers, a failure to tackle disability bullying and continued individualised deficit thinking, which led to a deterioration in his well-being and eventually to his exclusion. An effective policy on disability bullying needs to be both proactive with preventative strategies and responsive to incidents, which have already taken place. Disability Now (September, 2005) reports that, whilst most schools now have anti-bullying policies, the government is concerned that a significant number of schools either had no policy on bullying or had not directly addressed disability bullying as an issue. There are a range of different strategies that have been employed, from buddying to giving extra responsibilities to lunchtime supervisors, from video, workshop and training activities to peer councils and mentoring schemes at schools. The National Autistic Society (2002) promotes buddy systems, which can give bullied children a sense of belonging, security and better self-esteem. Each school has the flexibility to draw up their own policies and make use of local resources. Disability Now also illustrates how the ongoing 'special' treatment that disability bullying receives locates the solution with 'experts' rather than within mainstream practice: 'Petula Ftory, head of advice and advocacy at the National Autistic Society (NAS), says parents who call them with concerns about bullied children are often advised by helpline staff to contact the school's special education needs co-ordinator to discuss what anti-bullying policies are in place.' Whilst it is helpful to be directed to enquire about anti-bullying policies, it is unhelpful to locate this issue within a segregated 'special

needs' framework. Where do other parents go, who wish to find out about a school policy? Research into disability bullying found that at least one in three disabled children is bullied at school, both in mainstream and in special schools (DN, 2005). The incidence of bullying increases in non-structured situations. 'One issue to consider, Ms Ftory says, is that bullying often happens when children are not in class, but on school transport or when moving between classes. "Clear communication channels are needed with everyone involved, not just the key people, but the administrative staff and the dinner ladies, because a lot of bullying happens at break times," she says.'

The case of IC's experience when changing school and moving up to higher levels demonstrates how a schools' policy on bullying becomes an issue of active pre-planned management of what might work for an individual pupil. This policy would work within the provision of necessary personal guidance and support as part of the context of the School pastoral system. It was acknowledged that the school's failure to enable respect for IC was not so much one of resources but of planning and organisation. The court found that 'the tribunal considered that there had been sufficient information for the School to have made the necessary adjustments and thus it rejected the question of resources as not a substantial reason for the failure'.

Barriers to inclusive education

In the 1950s segregated education in the US between black and white children was made unlawful through the application of human rights principles in the judgment of the groundbreaking case of *Brown v Board of Education* 347 US 483. The court decided that the segregation of children according to ethnic categories of the time (coloured and white) had an adverse impact upon the relationship between them, and in particular was stigmatising, dehumanising and degrading for black children. The judges recognised that segregated education resulted in an unequal educational experience for black children, one characterised by feelings of inferiority, low aspiration and a much reduced level of attainment. In Australia, several cases referred to the principle that children should have access to mainstream regular schools, and that segregation was discrimination. This chapter has recognised persistent disability discrimination in education, and has argued that a mind-

shift is required in order that full citizenship rights can be realised for disabled people. The necessary paradigm shift moves away from segregated education for disabled pupils to inclusive settings. Inclusion becomes a civil rights issue for disabled people in the same way it had been for black children in the 1960s America. Slee (2000) notes that Mel Ainscow (1999:218) has described inclusive education as 'elusive', a project that continues to struggle against processes and practices of schooling that erect barriers that compromise the participation of some students. Ofsted (2004) inspectors in Britain recognise this inflexibility: 'For some schools rigid timetabling, inflexible staffing and lack of inventiveness were handicaps to effective developments.' Whilst I agree with the general sentiment that school organisation can erect barriers to inclusion, there is an issue of language that I wish to address. It is interesting to note that Ofsted's language refers to an outmoded and offensive phrase 'handicap' in the context of disability equality. This is particularly confusing, since Ofsted write in the context of 'inclusion'. It appears that disability equality and appropriate language did not enter their minds as relevant to a discussion of inclusion.

For the Disability Rights Commission, inclusive teaching 'relies on teachers being able to ensure that they and classroom support staff have the resources to assist students with additional requirements'. How existing resources are being used is indeed contentious. However, this description of inclusive teaching may be seen as locating the problem as within the individual child of 'having additional requirements' and as a problem of 'resources' rather than planning, organisation and management. It is interesting that this excerpt is part of the introduction to the Disability Rights Commission's Resources Pack (2000) for teachers on Citizenship Education with a disability focus (DRC, Inclusive teaching). As such the reference to resources can be read in the context of having little or no teaching resources that include disability equality into the citizenship agenda at schools. However, there is no favourable explanation of the phrase 'students with additional requirement'. This phrase appears to have been used in place of 'special educational need', which still identifies a particular legal category of pupils.

Inclusive education is not simply moving disabled children into unchanged school contexts, but removing barriers to inclusion by making reasonable

adjustments, as discussed above. Recognising equalisation measures, it is not about 'mainstream dumping' nor, as Barton put it:

'... about assimilation or accommodation of individuals into an essentially unchanged system of educational provision and practice. It is not fundamentally concerned with the inclusion of categorised pupils such as disabled pupils.' (Barton, 2003: 12)

The barriers that need to be removed can be organised into attitudes, behaviour, physical design, communication and institutional obstacles. Some key attitudinal barriers discussed include attitudes of teaching staff, who, for example,

- Think dyslexia is a myth; people do not have it; it does not exist (Disability Equality training sessions, 2005)
- Assume children's requirements are in conflict with other children's requirements (DRC case notes)
- Are concerned about the 'burden' of impairment (Education and Skill Reports, House of Commons)
- Feel unable to teach children with visual impairments unless specifically trained

Barrier attitudes of parents may include:

- Holding on to 'special education' as a fight over resources, assume disability equality takes resources away
- lack of tolerance difference in behaviour of other children in class
- protection, labelled unrealistic, not coming to terms with their child's impairment

To realise inclusion and citizenship for disabled pupils the two key issues to be addressed are attitudes and institutional barriers, such as discussed above. A further illustration of how institutional barriers reduce disability equality is given with two cases brought in 2002 under the Disability Discrimination Act 1995.

Institutional rules as barriers: school uniform compliance.

This case concerns a 6 year old boy with eczema who had been advised by his GP and consultant to wear 100% cotton clothing (DRC/02/6592). The school he attended had a school uniform policy which required all pupils to

wear a particular type of trousers that were not 100% cotton. Clearly he was unable to follow this rule since due to his condition he would have had a very severe eczema attack, so he attended school in his cotton trousers. The school told him that he should not wear them and must wear the specified uniform trousers. Following meetings with the head teacher, his mother decided to remove him from the school and he now attends another school where he is allowed to wear 100% cotton trousers. The school claim that they did not know that the boy had eczema and therefore did not discriminate against him. The boy's mother has asked for an apology from the school, a change to school uniform policy and staff training in disability equality issues. Having brought a case under Part IV of the Disability Discrimination Act the case was settled before the hearing to everyone's mutual satisfaction, and no further details are known. However, it shows how a lack of understanding of disability issues and a failure to ascertain access requirements of pupils can lead to discriminatory behaviour. In particular, a rigid adherence to school policy means that the school may fall foul of anti-discrimination laws by failing to make reasonable adjustments to their rules.

In a second case concerning the rules about school uniform, a 12 year old girl with a physical impairment that prevents her from walking long distances, standing for long periods or participating in strenuous physical activity, experienced the effects assumptions and of adhering to rigid rules. The girl wears special built up trainers as one leg is longer than the other. The school she attends is failing to make reasonable adjustments in three ways, first they did by not allowing her to wear non-uniform footwear, use the lift and be excused from PE. Since the claim was submitted the Special Educational Needs and Disability Tribunal the pupil had been subject to further discriminatory treatment including being shouted at by school staff for making a claim.

The Disability Rights Commission reports that 'this is a sustained and blatant course of discriminatory treatment, and it appears that there may also be victimisation. Since the case explores the extent of the critical duty upon mainstream schools to take reasonable steps to avoid substantial disadvantage and thereby is pertinent to current DRC policy work in this area.'

The wearing of a school uniform, so it is argued, contributes towards good behaviour and discipline of pupils. The uniform represents a 'symbol', that is an object that signifies something else. For the school the significance attached to the prescribed school uniform links to discipline, belonging to a common school community and respect for the values that the uniform represents. Often, school uniforms reinforce the message by adding further symbols on their cloths, such as badges or school crest.

However, clothes can also be seen as an individual's choice in taking up an identity. Through symbols we share with other people our identity and represent to whom or what we belong, whilst also distinguishing us from others. We can choose an identity by the choices we make about our wardrobe. Williams (1986: 91) describes

'I am not merely faced with a choice of what to wear, I am faced with the choice of images: the difference between a smart suit a pair of overalls, a leather skirt and a cotton skirt, is not one of fabric and style, but one of identity; you know perfectly well that you will be seen differently the whole day by what you put on.'

In that sense rules about the school uniform constrain the choice we have over expression of identity, and contravening uniform rules is seen as reasserting that individual's identity against the collective. Furthermore, the governing body has a general responsibility for pupil conduct at school and for the promotion of good behaviour and discipline (sections 38 and 61 of the School Standards and Framework Act 1998) any clamp down on deviation may be understandable. It is the head teacher's job to implement governing body uniform policy.

Professional guidance provided for teachers reminds practitioners to have regard to equality issues. However – crucially – this guidance fails to include disability equality issues. It reads, for example:

Equality issues

School governors should have regard to their responsibilities under the Sex Discrimination Act 1975, the Human Rights Act 1998 and the Race Relations Act 1976. In addition, from May 2002 the Race Relations Amendment Act requires schools to have a race equality policy. This

requires them to assess the impact of all their policies, including uniform or dress codes, on children.

(Teacher Net)

This is in stark contrast to guidance offered by disability organisations, such as the education guidance published by the muscular dystrophy organisation, which gives examples of when and how the school uniform policy needs to be applied flexibly. This gap in knowledge underscores the importance of listening to the voices of disabled people themselves, and of establishing consultation processes, beyond the need to learn about the impact of disability equality legislation on school policy. All of these are thus barriers to inclusion: lack of consultation mechanism, rigid school policy and failure to consider disability equality issues in everyday tasks.

Disability discrimination of disabled teacher

In order to further illustrate the systemic nature of disability discrimination as it relates to the idea of citizenship in education the focus of this section is the experience of disability discrimination of a teacher, who has become disabled in the course of her working life at school. About 93% of impairments are acquired, rather than born with, with most of these occurring during working age (Adept, 2004). Employment contexts, such as schools, need to be responsive to a changing workforce and have systems in place that anticipate the accommodation of a range of impairments with flexible, responsive planning and organisation of resources.

This case concerns a disabled teacher, Mrs Meikle, who began working in 1982 as a part-time teacher, becoming full-time in 1990. Since 1985, she worked at Gedling School. In January 1993 her eyesight began to deteriorate with a visual condition that resulted in lost of sight of one eye and her eyesight in the other eye also deteriorated. The case went to the appeal court and raised a number of issues involving employment and discrimination law. The first issue was whether the respondent established that she had been constructively dismissed by her employer, and whether constructive dismissal amounted to a "dismissal" within the meaning of the Disability Discrimination Act 1995; Mrs Meikle also had a reduction in sick pay by fifty per cent after one hundred days absence from work and claimed that this amounted to

discrimination under the DDA. To appreciate the full extent of legal arguments, the following extract of the court judgment (2004) is reproduced in some detail. The court, in the speech of Keene, LJ, found:

“On each of these issues the Employment Tribunal found for the employer, but was reversed by the Employment Appeal Tribunal. The employer, Nottingham County Council, now appeals from that decision. As I shall describe, the employee, Mrs Gaynor Meikle, was successful before the tribunal on a large number of complaints which she brought against the NCC of unlawful discrimination under the DDA, and those were not the subject of an appeal to the EAT.

The Main Facts:

3. Mrs Meikle began working for the NCC in 1982 as a part-time teacher, becoming full-time in 1990. Since 1985 she worked at Gedling School. In about January 1993 she began to suffer from a deteriorating visual condition, and as a result she lost the sight of one eye and her eyesight in the other eye deteriorated. That meant that reading made her feel tired, but she found it easier to read if the printed word was enlarged.
4. She found that she had a particular problem at the school with a document produced each morning showing which teachers were required to cover other teachers' classes. This daily cover timetable was printed in very small print. From about May 1993 she explained to the Head Teacher, Mr Lamb, that she needed an enlarged copy of this daily timetable but no arrangements were ever successfully made over following years for her to be provided with an enlarged copy.
5. Some other steps were taken to assist her, but because of noise and other problems it was suggested in March 1998 that her textile teaching (one of four subjects she taught) should be moved to a room designated as DT6. That was located at the other end of the school from another classroom where she regularly taught. She asked that her timetable be adjusted so as to allow for the problems created by this physical separation, but no adjustments were made even though, as the tribunal found,

"it would have been practicable to do so".

6. The tribunal also found as a fact that the NCC did not consider her needs when drawing up the 1998/1999 timetable. One of the adjustments she sought to her working arrangements was an increase in what were called "non-contact" periods, essentially periods when the teaching of pupils did not take place, so that she could do more of the necessary preparation and other work during daylight hours rather than after dark. The tribunal found that she was given fewer such non-contact periods than could have been achieved.

7. Because of her eye-strain, Mrs Meikle had a number of absences from work. In particular she started a period of absence on 13 June 1999. In a report to the NCC in August 1999, a Consultant Occupational Health Physician, Dr Thompson, referred to her distress "as a result of continuing delays and difficulties in implementing the advice given to facilitate her continuing duties" and added that

"the main problem in the past has been her visual impairment but in view of the factors noted above, the effects the situation has had on her general health now appears to be a significant concern."

By now Mrs Meikle had instructed solicitors to act on her behalf, and on 23 July 1999 she presented the first of her two originating applications, alleging disability discrimination.

8. On 10 September 1999 Mrs Meikle was told by an officer of the NCC that she was suspended because of her absence. This was done under the terms of a Department for Education Circular which had in fact been superseded in May of that year. The new Circular in force at the time of the suspension provided that such a step should only be carried out on the advice of an appropriately qualified medical adviser. In due course the tribunal found that this suspension was irrational and unjustified.

9. Mrs Meikle was put onto half-pay as from 17 December 1999. This was the result of a policy of the NCC whereby an

absence from work for more than one hundred days resulted in a reduction of sickness benefit. She did not apply for the NCC to exercise its discretion against making such a reduction.

10. Various negotiations then took place during the early months of 2000. A further Consultant Occupational Health Physician, Dr Platts, reported on 29 February 2000 that Mrs Meikle had quite good distance vision, so that she would have no great difficulty in seeing pupils in her classes, but that it took her much longer than her colleagues to carry out routine reading, preparation of coursework and marking pupils' work.

11. On receipt of that report, her solicitors wrote on 8 March 2000 to the NCC, setting out "the main reasonable adjustments requested by our client". There were eight adjustments requested, including

"1. enlargement of all written materials, especially the daily cover timetable and notices for departmental meetings", and

"9. (sic) additional non-contact time to allow our client to mark work during daylight hours at school and to do less marking at home in the evenings."

In its response the NCC commented that it would be difficult to reduce her contact time further but that the enlargement of written materials was "not a difficult issue". Mrs Meikle's solicitors replied to this by letter dated 15 May 2000, in which they went through each of the eight items in detail, dealing with the comments made by the NCC in its response. On the issue of non-contact time, it was said by her solicitors that there was another member of staff, not disabled, who had more non-contact time than she did, and they did not agree that more non-contact time could not be made available if the NCC wished.

12. By a second letter of the same date to the same officer of the NCC, her solicitors referred to a meeting which had taken place to assess what reasonable adjustments were required to enable Mrs Meikle to return to work. The letter continued:

"For the sake of clarity we confirm that the reasonable adjustments our client is seeking are as set out in our letter to the County Council dated the 8th

March 2000 (copy enclosed). If our client is able to return to teaching textiles in the old Textiles Room, only the reasonable adjustments numbered 1 and 9 in our letter dated the 8th March 2000 will need to be made."

Keene, LJ, in the case of 'Nottinghamshire County Council. v Meikle' [2004] EWCA Civ 859.

These facts illustrate the complexities of disability discrimination issues. On the face of it, the initial issue concerns a straightforward request for communication access, namely that of providing large print information. If a school had in place mechanisms by which to anticipate a range of communication access requirements, then a request for large print would make no particular demand to the 'normality' and the 'business-as-usual' of the running of the school, whether that concerns information for pupils, for parents or for teachers. In meeting employment-related duties the school would benefit as this also enables them to meet other equality duties under the Act, such as accessible services under part 3 and access to communication under Part IV. Employing disabled teachers can enable schools to adopt best practice, which goes beyond the strict requirements of the law and can enhance the overall school management experience for all staff, as staff engage in a responsive, consultative and democratic management style rather than a top-down, autocratic one.

Under part 2 of the Disability Discrimination Act, which applies to schools since 1995, schools are under a duty to consider reasonable adjustments which might include re-arranging tasks and re-allocation of duties. One of the adjustments that were sought by Mrs Meikle was an increase in "non-contact" periods, essentially periods when the teaching of pupils did not take place, so that she could do more of the necessary preparation and other work during daylight hours rather than after dark. However, the school's working practices illustrated that time-tabling was organised 'as usual' and this led to further impairment-related issues that put Mrs. Meikle at a substantial disadvantage. As with previous disability discrimination cases involving disabled pupils, Mrs Meikle was pathologised and her requests for reasonable adjustments were denied. Unless these adjustments would be in place, she was unable to return to work. Whilst it is important to assess an individual teacher's fitness to

teach, guidance reminds us to ensure that all relevant reasonable adjustments have been addressed:

'DfEE Circular 4/99, Physical and Mental Fitness to Teach of Teachers and of Entrants to Initial Teacher Training, makes it clear that schools' assessments of 'fitness to teach' must be made within the provisions of the DDA. Schools should assess a person's ability to work effectively with any necessary and reasonable adjustments in place: 'a person's physical capacity to manage his or her work may be enhanced with appropriate technical or human support or advice and institutional arrangements' (page 6, paragraph B2.2).

Overall, treating the disability issue as one stemming from an individual deficit led to a self-fulfilling prophecy in that Mrs. Meikle was unable to fulfil her employment tasks for a long period of time. Her rights to active participation and valued contribution to employment life were denied. The benefits of employing disabled teachers have been variously discussed. The Department for Education and Skills (2000) notes, for example, note that:

'Another reason to employ disabled teachers is because children benefit from opportunities to learn from a variety of people, as they will have to do in their future lives. A realistic awareness of disability can be developed before prejudice has had time to set in.' (DfES, 2000: 6)

The National Union for Teachers agrees that the contribution disabled teachers can make enhances the message of disability equality in education, in particular in the 'becoming of a citizen' of disabled pupils:

'Disabled teachers are an essential resource. They are role models for disabled pupils. Like other teachers, they are a valuable source of experience and expertise. Disabled adults in our schools help to prepare all students for life in a diverse society.' (Scope/NUT, 2001: 1)

Skill Scotland notes that disabled graduates were currently under-represented in the teaching profession, as found by research in 2003 which showed that 7% of disabled graduates in work entered teaching compared with 7.9% of non-disabled graduates (AGCAS, 2003).

In summary, attitudinal barriers that disable teachers with an impairment range from assumptions about ability, assumptions about health and safety, assumptions about the burden of adjustment to outright hostility, fear and

insecurity. A recent shift in thinking, an attitudinal shift concerning health and safety, is evident in this excerpt from Skill Scotland regarding medical screening of teachers:

'Skill Scotland strongly welcomes the deletion of the medical standards for admission to teacher training courses and registration with GTCS, and recognises that circumstances have changed considerably since the medical standards provisions were first introduced. In particular, there is greater recognition of the civil rights of disabled people. Attention is increasingly given to removing the barriers which 'disable' a person, as described within the Social Model of disability. In light of this, the medical examination is an unnecessary and discriminatory barrier for disabled people who want to pursue a career in teaching.'

(Skill Scotland, medical standards)

Recognising that disabled people remain an untapped or underused potential of new teachers the General Teaching Council set up a taskforce in November 2005 to eliminate barriers and create opportunities for disabled teachers (18 November 2005). The taskforce has not fully understood or adopted the social model of disability, as evident in language that describes a person as 'having a disability' rather than 'having an impairment'. Teachers with impairments are disabled by barriers in the attitudinal, behavioural or organisational environment. However, the taskforce acknowledges the importance of disabled teachers as role models, but in common with other organisation's supportive statements, restricts this idea of positive role model to disabled pupils:

"In building inclusive schools, we need to ensure not only the inclusion of pupils with disabilities but also teachers with disabilities who can be their role models."

(Professor Barry Carpenter, Chair of the taskforce)

As the taskforce met in spring 2006 they seem to have their work cut out if full inclusive practices are to be addressed, disability equality issues from disabled people's perspective of the social model and policy and practices in the education system so that disabled teachers can take their place as active, productive, contributing citizens.

Disability discrimination, whole school context and citizenship values

This chapter has argued that the business of education in its history, culture, practice, policy and procedures fails to embody full citizenship rights for all. Shifts in thinking are taking place. Uncertainties and debates in how to teach, where and what to teach young disabled learners, how to relate with disabled people professionally, legally and socially, how to define and respond to impairment, how to listen and involve disabled people in an ongoing struggle over contested ideologies. These uncertainties raise a further question: how can schools be a credible site for the dissemination and education of citizenship principles, when through attitudinal, access and institutional barriers this is denied to disabled people? In the next chapter, the concept of citizenship is explored. Drawing on a range of theories the meaning of full citizenship rights for disabled people will be examined. Building upon duties to remove barriers as explored in educational case law, the next chapter also addresses the State's role and civic duty of everyone towards 'access':

“I think and feel that oppression in any form should be the concern of everyone. The reality tells me that people mostly settle for the status quo. I feel if you are not for it you are against it. There is no middle ground. Translate that into disability: if access is not available and people accept that as the way it is, they are actively saying they don't want change.” (Sandy Slack, *Disability Awareness in Action*)

Chapter 5

Citizenship

The previous chapters have made a case for action to combat the patterns of inequality experienced by disabled people, have outlined the history of oppression and illustrated the complexities of disability discrimination.

Whatever meaning is given to 'citizenship' the discussion thus far has argued that disabled people are at the margins of society and fail to enjoy full citizenship. It was argued that a paradigm shift is taking place as regards the position of disabled people in society, and that for this to have an enduring impact, both an individual and organisational behaviour change has to take place that involves disabled people as active citizens.

This chapter analyses the concept of citizenship in terms of its theoretical and philosophical foundations. Following the discussion of infringements of political and civil rights of disabled people in previous chapters, the growing political organisation of disabled people themselves, examples of democratic mechanisms of how disabled people have fought for equality in employment, campaigned for anti-discrimination legislation and promoted equality of access in education, the first element of citizenship to be explored is 'political'. Other elements include 'social', 'economic', 'participation', 'community', as well as 'identity and belonging' aspects of the concept of citizenship. The chapter aims to posit disabled people's perspectives, experiences and contributions within the broader analysis of the concept of citizenship, in particular by recognising processes of 'social othering' (Bauman, 1997) and individuals' ability for 'sociological imagination' (Mills, 1959).

Disability Politics and Citizenship

This section argues that despite formal political equality of franchise for disabled people, persistent barriers to their realization remain. Traditional

concepts of citizenship encapsulate universalist claims expressed in terms of inalienable human rights, equal political status and concerns, equality in democratic processes, equality before the law. As a basic starting point 'citizenship' refers to a status and set of political rights and responsibilities. Formally, every British citizen automatically enjoys the status of being a citizen. There are no longer any official competing status categories, such as 'a woman' (who in the past did not enjoy the status of citizen) 'slave' or 'freed slave'. However, despite the formal recognition, the reality for disabled people still means that, despite significant improvements in recent years, equal status of being a citizen cannot be enjoyed across all sections of the community. The Government recognises that disabled people are not yet equal members of the group of people referred to as 'citizens'. The Strategy Unit report 'Improving the Life Chances of Disabled People', published in January 2005 set out their vision and acknowledged existing disability discrimination:

"By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society".

Disabled People themselves broadly approved of the report. The British Council of Disabled People welcomed the report as a historic step forward in the right direction where official thinking about disabled people is firmly rooted in the Social Model of Disability – for the first time in an official government document. In this way disabled people are moving closer to gaining citizenship status in the political arena, in the way policy responses are designed and priorities given. However, significantly this report appears to legitimise political inequality for a further twenty years under a veil of 'working towards' inclusion and respect.

Personal is political

The slogan from the women's movement of the 1960s 'the personal is political' challenged the presumption that each woman's personal situation was just that, personal and not of public concern. This can equally be applied to the context of disability politics. Here I argue that meaningful participation in public life is grounded in a thorough appreciation of the social model of disability, both at public and private levels. Since the traditional, common

sense understanding of disability regards impairment as a 'personal' tragedy, related thought patterns feature a range of associated ideas about the capability of disabled people, such as where they should live or how they should be looked after.

In order to illustrate how right across Europe these thought patterns are being challenged, the next session describes developments that relate to the political participation of disabled people in Germany. Locating itself within the international disability movement, the German disability movement equally argues forcefully for self-determination (*Selbstbestimmtes Leben*), and for a qualitative change in thinking (*eine wichtige qualitative Änderung von Denkmustern*), to effect what in Britain is known as the social model thinking of disability. As long as disabled people are conceptionally regarded as 'residents' in care homes, who need to be 'looked after' their participation in public life is literally *un-thinkable*, since the thought patterns are that of the old paradigm. *Schwerbehinderte Menschen werden noch immer, insbesondere solche mit geistigen Behinderungen, konzeptionell als „Heimbewohner“ angesehen, die in entsprechenden Einrichtungen „versorgt“ werden.* (Severely disabled people, especially with a mental impairment, are still conceptionally regarded to be a care-home resident, cared for by appropriate institutions.) (BAG Selbsthilfe, 2006)

Following the elections (*Bundestagswahlen*) the national federation of organisations of disabled people (BAG Selbsthilfe, Dachverband der Selbsthilfeverbände behinderter und chronisch kranker Menschen) met ministers and members of parliament in Berlin to push disability issues up on the political agenda. In their statement released in March 2006 BAG published its perspectives on disability politics. As in other European countries, in Britain, Australia, North America and right across the globe, there is an increased emphasis on political organisation of disabled people, and on the need to change patterns of thinking (*Denkmuster*). BAG states that in the current debate about public responses to disability issues, in particular the revised legislation concerning welfare support, the concept of paradigm shift, adopted from the social sciences (Kuhn, 1971), is crucial in understanding disability politics.

BAG received cross-party support at a well-attended evening on *'Perspektiven der Behindertenpolitik'* with ministers and key figures ranging from Franz Thönnies, parlamentarischer Staatssekretär beim Bundesminister für Arbeit und Soziales, die Patientenbeauftragte der Bundesregierung Helga Kühn-Mengel und die behindertenpolitischen Sprecher aller im Bundestag vertretenen Parteien, Hubert Hüppe (CDU), Markus Kurth (BÜNDNIS 90/DIE GRÜNEN), Jörg Rohde (FDP) und Ilja Seifert (PDS).

In der Diskussion um die Einführung und das in Kraft treten des Sozialgesetzbuches Neuntes Buch (SGB IX) ist der Begriff des Paradigmenwechsels in der Behindertenpolitik geprägt worden. In den Geisteswissenschaften wird mit Paradigmenwechsel eine wichtige qualitative Änderung von Denkmustern bezeichnet. Dass dieses Ziel mit der Neuausrichtung des SGB IX verfolgt und im Verhältnis zu den klassischen Rehabilitationsträgern auch zu einem guten Teil verwirklicht werden konnte, ist eine erfreuliche Tatsache.

(During discussions about the introduction of new social security laws the concept of a paradigm shift was established within disability politics. The social sciences define this as a substantive qualitative change in patterns of thinking. We welcome that this aim is being pursued in this legislative revision and that traditional service providers of rehabilitation are responding positively to make this a reality.)

In order to reach the goal of full inclusion, access and acceptance right across society, BAG argues that a paradigm shift in thinking of officials and within the general public has to embrace the social model of disability. BAG doubts that good progress is being made on this front and argues that the public authorities have a crucial role to play in modelling new thinking. To this extent, solidarity with disabled people and opportunities for full participation in mainstream activities of life is only possible once this change in thinking has taken place. This requires changes in attitudes and assumptions (such as 'disabled people need help and are dependent') and changes in resulting behaviours, both individual and organisational.

Dass dieses Ziel auch in der gesamten gesellschaftlichen Breite erreicht werden konnte, muss jedoch bezweifelt werden. Die Solidarität mit behinderten Menschen und ihre Möglichkeit zur Teilnahme am

Leben in der Gemeinschaft werden durch den nach wie vor nicht vollzogenen Wechsel im Bewusstsein der Bevölkerung und die dies nicht verhindernde Legislative erheblich beschränkt.

(To achieve this goal in a broader societal context remains doubtful. Solidarity with the idea that disabled people have equal participation in the life of the community is hampered by the barrier of lack of public awareness, and by the failure of these legal proposals to address this.)
(BAG Selbsthilfe, 2006)

When raising disability issues, however, 'the personal is political', as Volker Langguth-Wasem emphasised. When dealing with political change and in an attempt at influencing political decision-making often the very personal stories of disabled people's disenfranchisement carries political persuasion:

Es sind die ganz persönlichen Beispiele, die die Menschen erreichen, wenn es darum geht, Missstände aufzuzeigen und deutlich zu machen. Und da unterscheiden sich Politikerinnen und Politiker auch nicht von anderen Bürgerinnen und Bürgern. Um die diskriminierenden Auswirkungen der zunehmend neuen Lesart des Merkzeichen B in Schwerbehindertenausweisen vor allem den neuen Parlamentariern klar zu machen, half die ganz persönliche Geschichte des stellvertretenden Bundesvorsitzenden der BAG SELBSTHILFE, Volker Langguth-Wasem.

(It is the very personal examples, that reach people, in an attempt to illustrate where things go wrong. That is no different for politicians, especially the new ones. In order to illuminate the impact of the new rules on having a 'B' stamped on the severely disabled pass the very personal story of our vice-chair Volker Langguth-Wasem).

(BAG, Selbsthilfe, 2006)

Volker Langguth-Wasem told of his experience at the Frankfurt Erlebnisbad (public swimming pool). He wanted to buy tickets at a reduced price and showed his disability pass (*Schwerbehindertenausweis*), which in Germany has a 'B' printed on denoting *Begleitperson*, that is that the disabled person is entitled to bring a personal assistant for free or at a reduced rate, for example when travelling on public transport. However, indicative of attitudes towards disabled people as 'helpless', and assumptions of 'higher risk', the cashier

refused entry to Volker, since he interpreted the 'B' to mean that you **must** rather than **may** bring a helper with you, and in any case it was he who was ultimately responsible:

'Es ging nicht um dürfen, sondern müssen. Schließlich trage er die Verantwortung, und deshalb dürfe Volker Langguth-Wasem das Bad nicht ohne Begleitperson besuchen.' (It is not a question of may but of ought to. He was responsible, therefore Volker Langguth-Wasem was refused entry without a helper.)

Personal stories are political in that the collective of these stories illustrates more than a collection of stories, but the actual experience of disabled people, as narratives reveal patterns of attitudes, behaviour and discrimination across society. Disability Capital Stories (GLA 2003, 2004) reveal similar attitudes:

"All I did was ask the staff at Wembley Park Tube station to help me get my wheelchair down to the platform and it all kicked off! ... I had already bought my ticket and the man at the barrier asked me repeatedly, "Can't you walk?" I told them I had made this journey many times, in reverse from Liverpool Street, where the staff were really helpful. So why couldn't I do it going from Wembley Park? They told me the staff at Liverpool Street were wrong. They also told me I was a fire hazard. I felt really angry and humiliated." (Angela Smith, London)

The interpretation of the *Schwerbehindertenausweis* as a means to further reduce participation of disabled people in public life is a phenomenon across Germany. The individual resolution for Volker was that he promptly turned to a Youth waiting in the queue and invited him to attend the *Erlebnisbad* - nominally as his 'helper' for free. Creatively and with determination he employed skills of lateral thinking to bridge their contrasting positions. Such diametrically opposed views about participation in public life, played out in the interaction between disabled people and public officials, has not only relatively recently surfaced. It is when disabled people begin to see themselves as equal citizens with equal rights that the conflict of perception *Denkmuster* appears.

The concept of citizenship as a political status thus needs to be extended to cover citizenship as political activism and citizenship as a political identity of disabled people themselves. These processes involve conflict and

controversy. Kevin Donnellon explains how he discovered his political identity, central to which is an understanding of the social model of disability.

'His passion for disability politics only developed recently. "Until the late 1990s, I tended to avoid disabled people like the plague. I used to say to people, 'I am not disabled, I can do everything for myself.'" Then, in 1996, a friend who was also a Thalidomide survivor invited Kevin to a meeting about the social model of disability. "I said 'get lost' at first, 'if it's full of wheelchairs I don't want to go', but it's one of the best things she ever did for me." After the social and medical models of disability were explained, I was like, '**wow**, why didn't I get this years ago, it's so obvious'. Before, I would get carried upstairs in clubs by bouncers. I used to be apologetic, thinking I was a nuisance getting carried everywhere. I didn't realise access was a political issue, even though I have always been political - it's strange." (DN)

Kevin Donnellon recognises that his private trouble (Mills, 1959) of having to be carried upstairs is in fact indicative of a public issue woven into the structures of civic society. He has been denied access and equality. Rather than any personal failing, not being able to walk up steps, and generally making a nuisance of himself, Kevin identifies social structures as creating, both external and internal, barriers to participation. Internalised barriers refer to associated ideas about displaying a 'disabled identity'. This attempt at moving the private, personal aspect of disability into the political domain is also recognised at an international level. Arguing for contextualising political struggles and recognising cultural, historical and economic specificity, Kay Schriener considers the situation of political disability activism in a country, such as Saudi Arabia:

"Disability is considered a family issue and women bear the responsibility of caring for other family members who may have disabilities. Disability is largely an issue of the private sphere, not the public sphere. In a government where the monarchy rules with almost complete autonomy, the 'interests' of disabled people must find their way to power through traditions of royal authority, family lineage, and religious influences that are unfamiliar, and perhaps perplexing, to many Westerners."

“This example illustrates that studying the political influence of disabled people requires a country-specific approach. It would be difficult to assess the status of persons with disabilities in Saudi Arabia without a through grounding in its history and contemporary situation.”

(Disability World, 2001)

In this example of sociological imagination (Mills, 1959) Kay Schriener connects remote social and political forces, and seemingly unconnected historical circumstances in order to connect an individual's personal situation at the level of public influence. The concept of citizenship in its political dimension thus has universal elements that apply to every human being with the status of 'citizen' and it has particular elements that arise in specific socio-political contexts. Traditional conceptions of citizenship encapsulate universalist claims at the expense of particular differences, as in 'Citizenship for everyone, and everyone the same qua citizen' (Young 1999: 263). The ideal of a universal citizenship concept relies on collective identification of individuals whose political life, whose independent actions, whose similarities, according to accepted characteristics, is taken for granted (Wagner 1981: xv on collective symbols). Traditionally, disabled people have been excluded from such thinking.

Electoral participation and public office

A key element of political participation in Western democracies is electoral involvement and access to political institutions, with meaningful participation in democratic processes. Access to the full range of political process, however, remains limited for disabled people, despite formal equality. This is exemplified by looking at the right to vote in elections. Polls Apart is a campaign organised by SCOPE to make Britain's democracy accessible to disabled voters. At each General Election since 1992 disability campaigners have filled in a short access survey when they vote. Their findings form part of Scope's Polls Apart evaluation of disabled people's access to the democratic process (Polls Apart, 1992, 2005). Polls Apart reports that on Election Day 2005 campaign volunteers surveyed over 2,000 polling stations and found that 68% of polling stations were inaccessible to a disabled person. In regional reports Polls Apart highlight the regional differences in accessibility

and consider access in the context of specific regional circumstances. In London, for example, it was reported that 96% of polling station staff were helpful and friendly, which is an important attitudinal condition to assist all voters including disabled people and to remove disabling barriers.

Positive was also the fact, that 74% of polling station in London had low-level ballot booths compared to 68% nationwide. Low-level ballot booths are one of the simplest ways to improve access and are easy to install. They guarantee privacy for wheelchair users, people with arthritis and other health conditions who need to sit down, and a range of disabled and older voters who prefer to sit down to vote. However, only 65% of polling stations in London had a large print notice of the ballot paper on display while only 54% provided a tactile voting device. The campaign report details that this is compared to nationwide figures of 70% and 68% respectively. Consequently, blind voters or people with coordination impairments cannot mark their ballot paper independently and therefore cannot cast their vote in secret.

A similar picture emerged in recent elections in Germany. Each district and local municipal was required to give public information on disability access to polling stations (*Wahllokale*). Whilst access in Germany was generally good, there was recognition that access (*Zugang*) was restricted in many areas and not all polling stations allowed democratic participation for disabled people. There is a difference between access (*barriererfreier Zugang und Nutzung*) which allows independent access to and use of a service or facility, which is classed as *behindertengerecht* (literally translated 'right & fair for disabled people'), and assisted access to a service, denoted merely as a disability-friendly service *behindertenfreundlich*.

Fully independently accessible



behindertengerecht

Accessible with assistance:



behindertenfreundlich

In 1999 only half of all polling stations were accessible with easy assistance *behindertenfreundlich* (Berlin Statistik, 1999). Through persistent pressure and lobbying by disability organisations, this improved radically. For example, by 2005 in the Stadt Lüneburg only four out of 60 *Wahlbezirke* were inaccessible.

Für die Vorbereitung der Bundestagswahl 2005 steht wenig Zeit zur Verfügung, das macht sich auch bei der Suche nach Wahllokalen bemerkbar: Nicht alle 60 Wahllokale in Lüneburg sind für Behinderte erreichbar. (There is little time in preparation to the general elections 2005, noticeable in the search for polling stations. Not all 60 are accessible for ‚the disabled‘) (Lüneburg, de).

Disabled people in Lüneburg, who could not access one of those four polling stations, were advised to take advantage of postal voting. However, this puts disabled people in a less favourable position, since they have to decide ahead of other voters whom to vote for, and this does not allow for last minute changes of mind. Furthermore, the advice stated that on the reverse of the letter every voter received there was an application for postal voting. This form, however, was not made available in alternative formats, and the procedure for postal voting also puts disabled people at great disadvantage compared to people who can attend their local polling station:

Ein Briefwahlantrag findet sich auf der Rückseite der Wahlbenachrichtigungskarten, die alle Wahlberechtigten erhalten haben. Mit diesem Antrag können im Briefwahlbüro im zweiten Stock des Bürgeramtes, Bardowicker Str. 23, Briefwahlunterlagen beantragt werden. Dort kann auch gleich die Stimme abgegeben werden. Die Wählerinnen und Wähler müssen dafür ihre Wahlbenachrichtigungskarte und ihren Personalausweis oder Reisepass mitbringen.

(Postal voting details are on the reverse of this voting card, which were sent to everyone entitled to vote. Go with this form to the civic offices Bardowickerstreet 23. There, on the second floor, you can apply for a postal vote and register your vote. You need to bring you passport and entitlement to vote card.) (Lüneburg, de)

Disabled people were advised to complete the form on the reverse, and by a specified date to appear in person. No specific access information to the building was provided. Again, these arrangements, however well-meaning, have the effect that the disabled person experiences less favourable conditions for their active participation in political elections. Despite legislation and formal rights, disabled people remain disadvantaged in their access to electoral participation. The failure to provide accessible polling stations is in

direct contravention of law. Such adjustments are legal requirements under the Representation of the People Act, and under service sections of the Disability Discrimination Act. This means that beyond a restriction in political participation, the very foundation of the democratic political process, the rule of law, is compromised when it comes to disabled citizens.

Political voices of disabled people

Legislation has recently been extended to cover public bodies, all administrative, legislative and executive strands of government and agencies, which can be construed as an 'arm of government'. The new duties place disability equality on the agenda and require public bodies to promote the full inclusion of disabled people in all activities and decision-making. The political map thus now includes formal equality for disabled people in decision-making processes. In practice this means considering the impact decisions may have on disabled people, and crucially, setting up accessible, relevant consultation mechanisms by which the voices of disabled people can be heard, of which the *BAG Selbsthilfe Parlamentarierabend* is an example.

A further example of disability consultation has been reported by the BBC (23 May 2006): 'Dozens of disability groups are being asked to help the Conservatives redraft their policies at a series of seminars. Conservative leader David Cameron and shadow disability minister Jeremy Hunt have launched the first of these looking at health and social services. Mr Hunt says he wants organisations for disabled people to be at the forefront of policy making. Future events will focus on benefit reform, housing, education and transport.' However, the political issues raised as involving disabled people are not the environment, global warming, more police, fewer taxes, cleaner hospital, business development, or school discipline, but appear instead firmly rooted within traditional 'disability' concerns on the impairment as a 'burden' on health and the welfare support services. In order to truly realise political participation, it is important that each minister considers disability issues under each of their headings, so that disability issues and the voices of disabled people permeate every ministerial brief. This need has been recognised by the government when it set up the Office for Disability Issues in

2005 a cross-parliamentary department aiming for real equality by bringing voices of disabled people into the heart of government and placing responsibility for action within each department. A House of Lords debate (Hansard, 6 February 2006, column 419) confirmed this commitment.

In this sense, political dimensions of citizenship as a status and a set of rights entail the articulation of interests and active involvement of disabled people in decision making process. Historically, struggles have taken place for recognition and participation. This struggle is exemplified across the globe:

- by the Independent Living Movement that originated in Berkley (USA),
- by struggles across the world for the Deaf community recognition of Sign Language,
- by eighteen unsuccessful attempts at passing disability equality legislation in Britain and its the passage through parliament,
- by a fifty-year delay of extending the non-discrimination Article in the Basic Laws of the German constitution,
- by the move towards self-determination across Europe, such as *Selbstbestimmtes Leben durch Bundesverband Körperbehinderte* in Germany,
- and by the Independent Living movement and disabled people as individual budget holders rather than passive recipient of care under Direct Payment Legislation in Britain.

Disabled people do not, of course, speak with one voice. Assumptions about universalism can be as damaging as assumptions about individual tragedy views of disabled people. Calling upon a wide range of organisations and individuals will undoubtedly produce diversity and uncertainty. Among those who took part in the Conservative Party seminar were the Disability Rights Commission and representatives from many of the UK's leading disability organisations such as Scope, the Royal National Institute of the Blind, Leonard Cheshire and British Council of Disabled People (BCODP). Mr Hunt himself said that he wanted 'organisations for disabled people to be at the forefront of policy making'. As has been illustrated in Chapter 4 in the discussion about the struggle for recognition of British Sign Language and

People First, there is a crucial political difference in consulting with and involving organisations **of** and organisations **for** disabled people. In Britain, as the first country in Europe to tackle discrimination against disabled people by means of individually enforceable anti-discrimination legislation has as its watchdog the Disability Rights Commission (DRC). With a majority of disabled people on the board, this organisation *of* disabled people campaigns strongly for political participation of disabled people. In a recent legal challenge to the government, the DRC enhanced human rights in form of electoral rights for people with mental health issues. Access to the electoral system has been a priority for disabled people for a number of years, and small successful steps towards equalisation of this citizenship right continue to be taken:

“Currently people detained in psychiatric hospitals (under civil powers) may vote by post or by proxy, but not in person. Advised by the Mental Health Act Commission and other experts, we challenged this blanket ban as being incompatible with the Human Rights Act. People could be given leave to go shopping but not to vote! The Government amendment to the Electoral Administration Bill has removed this blanket ban so that patients may vote in person where they are granted permission to be absent from the hospital. We also challenged the discretionary nature of the Bill's provisions for accessible voting. As a result, the Government has amended the Bill so that information and guidance for voters must be provided in a range of accessible formats. This applies to postal voting as well as voting in polling stations.” DRC (June 2006)

Citizenship as a status thus links to an individual's competence of exercising all that pertains to the status of being a citizen, including electoral participation. However, as people with impairments are disabled by barriers of access, attitude and behaviour, as exemplified above, they possess civil and political rights to vote, but are 'denied to become a competent and fully fledged member of the polity in the first place' (Isin and Wood 1999: 4). The political element of citizenship as a status and the sociological perspective of citizenship as the actual ability to practice, which sees citizenship as competent membership (Turner, 1990, 1997), are part of each other.

Citizenship status and citizenship membership are thus 'constitutive' (Isin and Wood 1999) of an understanding of citizenship that reflects the experiences of disabled people. It is recognised that citizenship rights and duties are exercised within existing structures and it is those very structures that act to oppress disabled people - unless changed to reflect an inclusive citizenship.

Political office and disabled candidates

Citizenship issues arise at the interface of individual political identity and disability politics. Political identity is raised as potential candidates for public office project their own identity as a disabled person onto the political map. Particular views on their own position as a disabled person, whether underpinned by the social model understanding or not, can either remove barriers to participation or reinforce traditional stereotypes.

Political candidates who have physical impairments have been found to be 'better off', politically speaking, if their condition was as a result of military service. During the 1996 Republican National Convention, Robert Dole, the senior Senator from Kansas and Presidential aspirant, was introduced by his wife as proudly bearing a "badge of honour". This badge of honour was a war injury, which he sustained in 1945. Recent reporting emphasises this 'tragedy' and how he bravely overcame it: 'He was awarded two Purple Hearts for his war injuries, as well as the Bronze Star for bravery for crawling out of his foxhole in an attempt to rescue his platoon's radio man. Wounded by German machine-gun fire, Lt. Dole lay paralyzed for nine hours on an Italian battlefield before being evacuated. Three years and nine operations later, he would walk again, but never regain use of his right arm.' (Washington Times, 18th March 2005)

Newspapers reported that, in Senate speeches, Dole compared today's political climate with that of another era: "Fifty years ago, we had a president, Franklin Roosevelt, who could not walk and believed it was necessary to disguise that fact from the American people. Today I trust that Americans would have no problem in electing as president a man or woman with a disability." (Washington Post, 1996).

Similarly, Senator Max Cleland of Georgia, is another American politician who is disabled and received his injuries in the war. He is a Democrat, and a

former U.S. Senator, who uses a wheelchair as a result of having both legs amputated following a grenade explosion. He regularly emphasises in his biographical reports and press statements that his injuries were received as a US Army soldier during the Vietnam War, and he wrote a book on the '12 Principles on Living Life to the fullest', implying a personal tragedy that is being overcome. If a candidate has been treated for a mental illness, in contrast, there are potentially serious consequences, as was true for Arizona Senator John McCain. In 2000 he made a bid for the Republican presidential nomination. Senator McCain, who had spent years as a prisoner of war in North Vietnam, found it necessary to release his medical records to combat the charge that his lengthy confinement had made him mentally unstable. However, whether or not true, these stories still surface now that he is a serious potential candidate for the presidential elections in 2008. Behaviour under scrutiny is reported as 'associated with Posttraumatic Stress Disorder (PTSD), which afflicts many of our combat veterans, especially those that suffered terribly as prisoners of war.' This comes in light of the fact that recent research confirms the rise in Post Traumatic Stress Disorder PTSD, especially among war veterans. At the Washington Conference in February 2006 the report revealed that around one-third of Iraq war Veterans will suffer from some degree of Post Traumatic Stress Disorder (PTSD) (US Medicine). Antonette Zeiss, deputy chief consultant for mental health services at the Department of Veterans Affairs, said that up to 40,000 soldiers returning from Iraq and Afghanistan show symptoms of PTSD, 31 percent of all veterans being reviewed for possible mental health disorders. PTSD, which commonly arises from prolonged exposure to combat and the ongoing threat of death or serious injury, is characterized by recurrent thoughts of trauma, reduced involvement in work or outside interests, hyper alertness, anxiety and irritability. Alcoholism and drug abuse are also common among Veterans, who display symptoms of PTSD.

At a broader level of concern, the World Health Organisation WHO regards people with mental health issues as 'denied citizens'. WHO estimates that 450 million people worldwide are affected by mental, neurological or behavioural problems at any time, and one in four patients visiting a health service has at least one mental, neurological or behavioural disorder but most of these

conditions are neither diagnosed nor treated (2006). Confirming common stereotype and myths surrounding Senator McCain, the WHO outlines that:

‘People with mental disorders are some of the most neglected people in the world. In many communities, mental illness is not considered a real medical condition, but viewed as a weakness of character or as a punishment for immoral behaviour.’ (WHO, Mental Health)

Above campaigning experiences of candidates associated with disability issues shows how in the United States running as a ‘disabled’ candidate for public office works better in some circumstances than others. The person with the war injury certainly has an advantageous effect as compared to someone with a mental health condition. Neither of the above two presentations of disabled identity and constructions of impairment, however, is founded upon social model principles. I argue that citizenship is contextualised and particularised within culture and to be effective, ‘perhaps what is required above all is a broader change to the cultural value attached to disabled people – a paradigm shift in the way in which disability is understood.’ (Gooding, 2000: 549). Until public attitudes change toward the shift as debated in Germany – that of a radical change in thinking pattern (*eine wichtige qualitative Änderung von Denkmustern*) - disabled candidates will continue to manage information about their impairment to achieve the most media-savvy impact and political advantage, but fail to raise their personal situation as a political issue concerning all disabled people. In this sense they lack the necessary sociological imagination, which views disabled people as full citizens.



Fig.1 President FD Roosevelt, (1997)



Fig. 2 Roosevelt and his granddaughter



roosevelt in france with his son, elliot

Fig. 3 Supported by his son

(Franklin D. Roosevelt, Presidential Library and Museum and Roosevelt Library, photos accessible online).

Franklin Delano Roosevelt

Perhaps one of the best known politicians and yet initially not widely known as a disabled person was President Franklin Delano Roosevelt (FDR). In terms of citizenship, an examination of FDR's historical and political impact offers a way of understanding the interaction between an individual's agency and social structures, such as culture, media, language or democratic institutions:

'Neither the life of an individual nor the history of a society can be understood without understanding both.' (Mills 1959:3)

The role of a disabled identity as part of 'being a citizen' and of 'acting as a citizen' is brought into sharp relief by social structures that deny impairment to enter into the public sphere. Even current official White House biographical information about the Roosevelt family either fails to mention disability and impairment, or reinforces a personal tragedy perception. For FDR there is a brief reference to polio, which serves to describe the man in tragic terms, focusing on the fact that he was relatively young, lost the use of his legs, that this event is life-changing, immeasurably tragic and requires personal courage by a brave individual to be overcome: "In the summer of 1921, when he was 39, disaster hit-he was stricken with poliomyelitis. Demonstrating indomitable courage, he fought to regain the use of his legs, particularly through swimming."(White House, Presidents).

Following in the footsteps of his fifth cousin, Theodore Roosevelt was himself described as 'struggled--against ill health'. However, as if in an effort to counteract any perceived weakness, the site describes that he 'vigorously led Congress', and 'mastered his sorrow' about his wife's death'. (White House, Presidents) .The site hails him as 'one of the most conspicuous heroes of the war.' Anna Eleanor Roosevelt's entry is credited with lines, which simultaneously serve to underscore FDR's personal tragedy and put her in her rightful place as a carer: "When he was stricken with poliomyelitis in 1921, she tended him devotedly." (White House, First Ladies).

In this way the White House website contributes towards the political education of its visitors and offers a particular presentation of history, one that removes disability as an issue in one area and offers language deeply rooted in tragic models of disability in another.

Franklin D. Roosevelt contracted Polio in 1922, aged 39. When he campaigned to become President, the United States of America was a war-torn country in the grip of economic depression. His task was described during the 1997 FDR Memorial celebrations by Kwame Holman: "To millions of Americans Franklin Delano Roosevelt was an intimate symbol of strength, hope, and the renewal of a nation."

The president needed to project as a healthy, strong leader who could be trusted to put things right. This image conflicts with the traditional image of someone using braces and a wheelchair who, literally cannot stand on his own two feet. Roosevelt appears to have made a tacit agreement with the press that he should not be photographed as a disabled person. He is hardly ever shown in a wheelchair. When travelling to places where he gave public presentations, he would arrive hours early to speeches and events and set up behind the scenes. Roosevelt controlled his image by allowing no photographs of his wheelchair and using his bodyguards and his sons as crutches (Fig. 3 above) so he could stand while delivering speeches.

Nevertheless, President Roosevelt did translate his personal situation into political momentum and endeavoured to equalize opportunities for disabled people. In 1934, President Franklin D. Roosevelt set up the Committee on Economic Security (CES). The committee had the task of studying the need for an economic security system to provide income for older people and

disabled citizens. Whilst recognising that support for people unable to work was traditionally provided by women in families, Roosevelt knew from his own experience and from political opinion he had formed that there was also a need for a national system. In January 1935, the CES publicised a report to President Roosevelt outlining a plan for a national program of economic security. This plan ultimately became the Social Security Act (SSA), which was passed by Congress on August 14, 1935. Three years prior to creating the CES, in February 1931, he gave a Radio Address on a 'Program of Assistance for the Crippled'. FDR was looking at his own experience and promoted the New Deal ethos of early intervention, education and training, together with enhanced rehabilitation programmes that would enable a return to work (or 'useful life', as it was described in those days). He clearly self-identified as a disabled person (cripple, sic):

“People know well that restoring one of us cripples--because as some of you know, I walk around with a cane and with the aid of somebody's arm myself--to useful occupation costs money. Being crippled is not like many other diseases, contagious and otherwise, where the cure can be made in a comparatively short time; not like the medical operation where one goes to the hospital and at the end of a few weeks goes out made over again and ready to resume life. People who are crippled take a long time to be put back on their feet--sometimes years, as we all know.” (Roosevelt, NPR 1931)

President Roosevelt addressed an audience of both disabled and non-disabled people asking for political support on this issue, thus treating the disabled person as having a political identity and citizenship qualities of the same value as others:

“From you who are crippled and you who are absolutely normal we shall have help in furthering this great purpose.” (Roosevelt, op.cit.)

Despite the personal conviction on issues of disability equality and the desire to improve the social and economic position of disabled people, the President's individual agency is evidently constrained by prevailing social structures, such as prevailing political discourse, sets of ideas, culture and use of language. However, his position, the family tradition of political activity, the financial security, educational opportunity and social connection are

structural forces which enable individual agency and provide opportunities for action. The socio-economic context of a particular time both constrains and enables opportunities for individuals to exercise political citizenship. For a different example of the influence of FD Roosevelt on early ideas of independent living at Warm Springs in Georgia, see Holland (2006).

Citizenship has to be understood as individual capacity brought into play under particular socio-political conditions. FDR was in a unique position to have an influence on public life, of course, and as a testament to his skills of working effectively with others is the fact that he was re-elected for four terms. In order to realise citizenship an individual needs to possess capacity and a set of skills, as well as an opportunity to exercise these citizenship skills. President Roosevelt's influence in politics and impact on disability politics continues to the present.



When America's memorial to President Franklin D. Roosevelt was dedicated on May 2, 1997, FDR was not shown in his wheelchair. His impairment and disability was hidden. This was partly justified by presuming what FDR himself would have wanted.

Fig. 1: President F.D. Roosevelt (1997)

At the Memorial opening, Lawrence Halpin refuted criticism of covering up historical truths: "Obviously, we're not disable-antagonistic at all. This was designed for disabled people. We tell the story that he is disabled carved in the granite; this statue in this location is--portrays him in an exact replica of the chair that he normally used when he went and joined the people. And we thought that we were covering it the way he would want us to have covered it." Now, a statue of FDR in his wheelchair appears at the FDR Memorial, dedicated by President Clinton on January 10, 2001. Following a five-year campaign to reach congressional approval and secure private finance, the National Organisation on Disability NOD was finally informed by the White House in December 2000 that a monument would be dedicated to FDR.

The life-size bronze statue shows Franklin D Roosevelt seated in his wheelchair. The President of the NOD, Alan Reich, proclaims this dedication as 'a great victory for people with disabilities'. He hoped that 'the statue will be an inspiration to people worldwide, disabled and non-disabled alike' and affirmed a widely held view, that the FDR's Memorial 'finally acknowledges his significant disability experience'. The Chairman Michael Delan, whilst summarising the significance of this successful outcome of the campaign, acknowledges the fact that a disabled identity can play out more favourably in some situations than others:

"While Roosevelt hid his disability from the public during his lifetime, believing that the country wasn't then ready to elect a wheelchair-user as President, he nonetheless stayed in his chair when it was uplifting to particular audiences, such as when touring veterans hospitals.

It's wonderful that the whole world will now know that President Roosevelt led this country to victory in World War II and through the Great Depression from his wheelchair. FDR's successful leadership proves for all time that it's ability, not disability that counts."

(International Centre for Disability Resources on the Internet)

The larger than life statue of President Roosevelt in 1997 (Fig.1) had been a source of controversy since the opening of the memorial. The statue is reported as 'portraying a war-worn seated Roosevelt' and as having 'drawn criticism for its failure to show the President as he was... physically challenged. Opponents of the statue believe that the cape draped Roosevelt purposely hides this historical truth.' (Roosevelt, NPR, 2004).

In contrast, today's statute no longer hides a disabled identity:



Fig. 4 Bronze statue of President Franklin Roosevelt, unveiled 2001

Citizenship identity, individual capacity and structural factors combine into forces which enable the status of 'being a citizen' to flourish into one of 'acting as' and 'being seen as' a citizen. Historically and traditionally social structures deny impairment to enter into the public sphere, but recent social change, pushed for by disabled people themselves, persistently challenges these structural barriers.

Disabled Politicians and 'the disabled community'

Recent political history in 2004 illustrates how disabled people as citizens continue to be differentiated into a homogenous subgroup, denoted by the term 'the disabled community':

'Although he has yet to take his place in the House of Commons, Canada's first quadriplegic member of Parliament is already having an impact. His supporters say Steven Fletcher, the newly elected Conservative MP from Winnipeg, has energized the hopes of the disabled community across the country.'

(Canary Sun, 5th July 2004) see also Steven Fletcher.

By differentiating disabled people into a 'disabled community' at least two subgroups of a citizen-community are constructed, the disabled community and the non-disabled community. The description emphasises the homogeneity of 'the disabled' as within a community of their own. The term 'disabled people', in contrast, is used within the social model of disability (Oliver, 1983, 1990) as people with impairments, who are disabled by barriers of attitude, behaviour and contexts (Reichart, 2006). Other than in this experience, this shared reality of barriers there is no inference of commonality in the expression 'disabled people'. In the German language this commonality would be best expressed by the term *Gemeinwesen*:

'Community as *Gemeinwesen* is the underlying reality in men (sic) which drives them towards some common goal through the formation of society. It is the very being of man (sic) as social, an existential being, rather than an ideal that lies beyond, a *present* human and humanizing factor, rather than a not-yet-existent end. *Gemeinwesen* is men's (sic) **being (wesen) together (gemein)** –ness with other men (sic)' (Mahowald, 1973: 480)

Disabled people can therefore be seen as autonomous individuals, or groups of people who may come together to organise themselves along a range of self-selected or ascribed qualities and interests. Citizenship in its original form did indeed delineate between 'those who are' and 'those who are not' part of some common society, community or *Gemeinschaft* (Tönnies 1887, translated 1957 and 1963). In the German language, early writings on citizenship differentiated between several expressions all translated into 'community',

such as *Gesellschaft*, *Gemeinschaft*, *Gemeindewesen*, *Gemeinde*, and *Gemeinwesen*. However, by referring to 'the disabled community', inclusive citizenship needs to be understood as 'multi-communal', with disability characterising but one such community rather than constituting the 'other' community. A broader, inclusive community becomes necessary. In this sense, *Gemeinschaft* is what disabled people are striving for, where every individual is free to cultivate their talents in all directions, since 'only in *Gemeinschaft* is personal freedom possible' and that in a real community, as opposed to an illusory (as at present) individuals obtain their freedom in and through association' (Marx Engels, 1960: 76, quoted by Mahowald, 1973: 482). Based upon Böckmühl's assertions, only when humans have become substantially and essentially social do we have a citizenship community: '*Wenn der Mensch wesentlich sozial geworden ist, ist Gesellschaft = Gemeinschaft*' (Böckmühl, quoted by Mahowald, 1973 : 482). The different forms of 'community' and 'citizenship' are thus merely various stages in this overall endeavour, as 'the present state of affairs *Gesellschaft* is quite obviously not *Gemeinschaft*.' (Mahowald, 1973 : 482).

In the European context, community citizenship refers to 'the possession by members of a community a range of social and cultural rights and responsibilities by virtue of their membership of that community as a distinct element of their national citizenship rights' (Phillips Berman, 2001). The focus of identity in these discussions is on ethnic, national and cultural characteristics. Prototypes of community citizenship are introduced by Phillips Berman (2001) as follows: a) full community citizenship; b) partial, undifferentiated community citizenship; c) partial, differentiated community citizenship ('ethnic citizenship'); d) 'discriminated citizenship' where notional formal access to national citizenship is granted to members of all communities but is negated by institutional discrimination. As established in Chapter 2, and detailed in Chapter 3, the socio-economic situation of disabled people as compared to the life of non-disabled people is less favourable. Disabled people can be members of the 'disability community' as weak or as strong members. Following Peled (1992) membership in a weak community is voluntary as this community is open and inclusive, but members exclude

themselves if they do not regard themselves as a disabled person belonging to that community, and they exclude themselves by not participating actively as part of the disability community, or the disabled people's movement. Some disabled teachers, for example, exclude themselves from the 'disabled community' by not regarding themselves as disabled or by failing to disclose their impairment (Stanley, 2007). In contrast, in a strong community, membership is not wholly voluntary and disabled people may belong to that community by virtue of having been ascribed characteristics, roles or socio-economic conditions that leave little choice or autonomy.

Rights Now and British Council of Disabled People BCDOP

Indicative of the fact that there is no one 'disability community' is the history of organised disabled people's struggle for comprehensive, enforceable civil rights legislation. A campaigning group 'Rights Now' was formed in 1985 consisting of a membership of nearly 80 disability organisations and trades unions and over two thousand individual members. This collection of interests and groups represented a spectrum of disability politics, from organisations of disabled people, active radicalism, to parliamentary lobbying and the 'Big 7' charity organisations for disabled people. On the road to anti-discrimination legislation (discussed in Chapter 3) the campaign reached a peak when Roger Berry's Civil Rights Bill went through Parliament. The 'disability community' organised protests culminating in a mass lobby by disabled people at Westminster. With such broad representation and loud voices the Conservative Government at the time appeared to have conceded and realised that they had no choice but to do something. As a result, the Disability Discrimination Bill was drafted. However, since it included justifications that made discrimination against disabled people legal, as well as a raft of other legal loop-holes with no enforcement agency equivalent to Race and Equality Commissions, many disabled people regarded it as second-rate and unacceptable. It was at this point that the disability community split, the umbrella of support under 'Rights Now' fragmented. The British Council of Disabled People BCDOP remained focused on the more radical agenda of repeal and achieving fully enforceable individual civil rights, whilst charity organisation, in contrast, moved to support the government's Bill. This major disagreement was widely reported in the media,

and debated by disability interest groups, for example in the BBC magazine 'Ouch' (BBC news, OUCH 11th March 2004)

Within the disability movement the BCDOP reported as follows:

“There was a debate within Rights Now as to whether to accept this as the best on offer or to continue to pressurise to get proper Civil Rights legislation. It was at this point that the “Big 7” pulled the rug from under the Movement by agreeing to work with the Government on the DDA, rather than reject it and call for its “repeal”, and that is still their current policy. It is believed the “Big 7” had a number of reasons for this, including possibly economic ones – there was money in work associated with the DDA.” (BCDOP)

Disabled people are members of both weak and strong communities, with multiple interests and as a collection of stakeholders are far from forming a homogenous subgroup of citizens. With an emphasis on self-determination, self-identification and political awareness the international network of disabled people, Disability Awareness Action (DAA), defines disability as ‘the social consequences of having an impairment’. DAA adopts a weak community membership accordingly:

“DAA’s work is driven by an inclusive view of the disabled community - defined quite simply as those people who choose to identify as ‘disabled’. We are aware that not all groups of disabled people adopt such an inclusive approach, sometimes using both formal rules and informal sanctions to discourage people who are not seen as belonging to ‘their’ group, but such difficulties are caused by the individuals involved, not the social model!” (DAA)

Kay Shriner (2001) considers challenges in the comparative study of disability politics and remains uncertain on the question of disability community:

“If there is a community of people who have disabilities, who admit to having disabilities, and who identify themselves as having a set of common interests that can and should be represented in the political system, then a disabled candidate is much more likely to make specific appeals to this group of voters. And, that candidate is probably more likely to represent this group in the policymaking process if he or she is elected. “(DAA).

Lord Ashley, d/Deaf and disability communities

In Britain the most enduring disabled politician is Lord Ashley. First as an MP and then as a peer, Jack Ashley had been raising disability issues as a political issues since he was elected Labour Party Member for Stoke on Trent South in 1966. It was not until the age of 45, following a routine ear operation, that he became deaf. He founded Deafness Research UK in 1986 in a belief that science would be able to find many answers to 'deafness problems'. Lord Ashley's view of impairment and its impact is thus primarily within the individual / medical domain and membership to the 'deaf community' is strong, since he regards people who are deaf or hearing impaired as having no choice in the matter. Lord Ashley is known to have campaigned tirelessly and won cross-party support in his endeavours to enhance the life of deaf and disabled people. His wife's death was reported by the BBC accompanied by glowing 'overcoming tragedy' terms about Lord Ashley:

"The former Labour MP commands enormous cross-party and public respect for his vigorous campaigning for disabled rights and his inspirational personal struggle to overcome the effects of deafness."
(BBC, news, 4th November 1999)

Lord Ashley and his wife had set up Deaf Research UK. In line with bio-medical approaches to disability a key research endeavour of this charity has been to 'cure' and 'make deaf people hear again'. Campaigners hail technical and scientific advances of cochlear implants as a success in this regard. A Cochlear implant is a small, complex electronic device with a microphone, speech processor, transmitter and electrodes that is implanted under the skin behind the ear. Whilst this implant cannot restore hearing, it does give the wearer auditory information about their environment and can assist in understanding speech. In contrast to a hearing aid the implant does not magnify sound, but works in place of the damaged hearing organ of the inner ear. Adults like Lord Ashley who have lost their hearing later in life can often benefit from the implant, as they can associate the sounds that the implant makes with sounds they remember from their hearing days. However, children as young as 2 years have also been given cochlear implants, and some experts, such as the National Institute on Deafness and other Communication

Disorders argue that early implantation is better since children aged 2 to 6 can learn to associate sounds with environmental information (NIDCD).

Cochlear implantation is a controversial issue. Discussions about the ethics and usefulness of cochlear implants have been strong. Whilst these implants can give children access to spoken language, some experts argue that children should not be exposed to unnecessary operations in situations which are not life threatening, and that there are unacceptable risks, such as meningitis. However, the knowledge that moves within current expert institutions (Foucault, 1980), such as university, government research projects or refereed academic journals, vigorously supports progress with cochlear implantation and indeed calls for further research into other cures, such as stem cell (Archbold, 2000; Hashino, 2005; O'Donoghue, 1999; Rivolta, 2004). Members of the **Deaf** community, in contrast, are on the whole against cochlear implants, since to them they are culturally **Deaf**. Regarding oneself as a member of the **Deaf** community is akin to belonging to a cultural, ethnic, language minority, and cochlear implants are seen as unnecessary, or in fact a hindrance, in a community that uses sign language. These disagreements go beyond a division between experts and deaf disabled people, but run deeply within the group of d/**Deaf** people, who can be further divided into the **Deaf** community and deaf people, and each sub-community has people who are born deaf or have acquired their impairment in later life. Deaf people, therefore, cannot easily be drawn into one community and be treated as a homogenous subgroup of citizens.

Lord Ashley brings his own personal position to bear, reflecting the views of the time as he grew up in the 1920s and 1930s through to a time when he became deaf, employing skills of diplomacy, negotiation and influence amongst others, and projecting the resulting disability identity onto the public political map. However, it cannot be said that he represents the d/**Deaf** community, since there are multiple positions of individuals who have a hearing impairment, with two diametrically opposed viewpoints on their identity and belonging: culturally **Deaf** people identify as members of a language minority (weak membership), while deaf people often look for medical and technical advances to enhance their position in the hearing world (strong membership).

Furthermore, to what extent can it be presumed that Lord Ashley speaks for 'the disabled community'? Undoubtedly, he actively supported many campaigns and projects to enhance the social and economic positions of disabled people. He is known to have campaigned on many issues:

"... most of them affecting under-privileged people and matters of palpable injustice. He played a leading role in the Thalidomide campaign which led to increased compensation and improvements in drug safety. He has also campaigned on similar compensation issues, such as vaccine damage, and the arthritis drug, Opren. He is a campaigner for women's rights, being the first MP to raise the issue of domestic violence in Parliament. He also pressed for changes in the law relating to rape which were subsequently introduced. Disability has been a major interest, and he has campaigned over the whole field with emphasis on employment and social security."

(Deafness Research)

Specific issue on deaf-access and communication have also been successfully campaigned for. When the Communications Act 2003 was introduced it appeared merely to regulate satellite and cable television channels. However, in considering the impact of the law and what the resultant individual and organisational behaviour may have on d/Deaf people, Lord Ashley realised that action needed to be taken. He was instrumental in securing major amendments to the Act, which now obliges satellite and cable television channels to subtitle 80% of their programmes over the next ten years. Lord Ashley further 'secured a significant amendment - introducing a five year target of 60% - thus accelerating improvements to television access for deaf and hard of hearing viewers' the deaf council reported. Lord Ashley did not stop there and campaigned for two further amendments - one requiring broadcasters to publicise subtitled programmes, the other requiring digital electronic menus to specify subtitled programmes. 'He also secured an amendment to ensure that OFCOM, the new regulator, widens the availability of communications equipment for disabled people' (Deaf Council). And in this regard he can be seen as forcefully representing the interests of d/Deaf people.

However, in recent years Lord Ashley clearly championed a paradigm shift in thinking in line with social model principles. This is very much what the disability movement in Britain, Europe and internationally is struggling for (DPI disabled people international; DAA disability awareness in action). A key concept in citizenship for disabled people is independence, which is viewed as encompassing choice, self-determination and autonomy. Lord Ashley represents these aspirations of disabled people by calling for a far-reaching re-think on independent living, for example. In 2005 he raised the issue of Independent Living in the House of Lords (Hansard, 6 June 2005, column 667), and a year later a most radical proposal with cross-party support, driven by disabled people themselves, had reached an important legislative stage: the introduction of the Disabled Persons (Independent Living) Bill on Thursday 8th June 2006. Speaking at the Disability Rights Commission, Lord Ashley emphasised the following citizenship issues:

“Throughout my Parliamentary career, I have fought for all disabled people to have the same choice, dignity, freedom and control as every other citizen. These are the central principles of ‘Independent Living’. Independent Living is not simply disabled people doing everything for themselves. It means ensuring that disabled people have the same freedom to choose as every other citizen and are supported in that choice, in order that they may lead the lives they want to lead.”

(DRC, 2007)

This discussion has shown up difficulties with the concept of ‘community’ or ‘communities’ and in particular has raised questions about the extent to which a ‘disabled community’ can be represented. I have suggested a complex web of interconnected identities, which are hailed and interpellated (Althusser, 1971) in specific contexts. Belonging to one community is often seen as exclusionary, thus a choice has to be made as to where one’s allegiance lies. For deaf Asian people, for example, cultural and family ties can be seen as a potential conflict with a strong d/Deaf identity:

“Many people have asked about deafness and Asian identity. Families feel that the deaf member of the family will be disregarding their background if they gain a stronger deaf identity.” (Deaf Hampshire)

Autonomy

Following above discussions, I propose that 'exercised citizenship' or 'lived citizenship' is how people actually experience and realise themselves within given structural constraints and opportunities and experience the impact that social practices pertaining to citizenship have in their daily lives. Liberal traditions, which admittedly give little regard to structural forces, see individual action as involving choices, decisions and individual freedom to act autonomously. This has been denied to disabled people. Morris (2005) argues that impairment and disabling barriers impose limits on an individual's capacity for independent action and thus she argues that positive steps are required in order to deliver opportunities for self-determination.

A strong legal framework is necessary to protect and enable full citizenship. This emphasis on legal aspects of citizenship is promoted by Degener (1995) and she argues it will challenge the serious human rights violations of disabled people across the world. Degener further sees participation as key to realising citizenship, and the role of organisation of disabled people as well as representing politicians is to increase the pace of change towards such enabling laws (Swain, 2003:154). The Independent Living Bill introduced by Lord Ashley addresses these enabling requirements, for example by ensuring that disabled people have access to communication support and by placing duties on local authorities to provide services that enable. Consequently, a principle of inclusive citizenship is the combined realisation of autonomy and independence, choice and control, which go beyond a simple liberal understanding of individual action, 'doing it for themselves'. Instead, inclusive citizenship appreciates that we all live in reciprocal relationships with each other, with more or less pronounced levels of inter-dependency, and that disabled people have been disabled by society's response to impairment, such as traditional welfare laws. Building on an Etzionian (1995) view of individuals as essentially socially constituted rather than free-standing individuals, I argue that since social beings are perpetually infused by culture and shaped within socio-economic contexts - autonomy is fundamentally a social concept.

Rule of Law

Within the idea of political citizenship is the notion of the rule of law and equality before the law, underscored by the idea that rights apply equally to all irrespective of social position, gender, cultural background, religious practice, and whether or not they are disabled. In this regard, the concept of citizenship has a legal dimension and is posited within western democratic principles. This next section will explore the meaning of this principle for disabled people by detailed legal analysis of a case concerning the protection of the child of parents with learning difficulties.

Equality before the Law

This principle is enshrined into European law to which Britain is a signatory. Article 20 corresponds to this principle which is included in all European constitutions and has been recognised by the Court of Justice as a basic principle of Community law (Case 283/83 Firma A. Racke of 13 November 1984, Case C-15/95 EARLE de Kerlast of 17 April 1997 and Case C-292/97 Karlsson of 13 April 2000). Therefore, everyone is equal before the law means that the law has to apply equally to all, irrespective of irrelevant differences, such as gender, age, buying power, locality, religious practices, sex, race or impairment. In principle, thus, rights and responsibilities enshrined or protected in law apply equally to disabled citizens.

In order to examine the extent to which this principle fails or works for disabled people, I will discuss the right of people with learning difficulties, who are parents, under Article 8 of the Human Rights Act 1998, 2000. Of all parents with learning difficulties, 50% have their children taken into care (DRC, 2006). I am examining the legal steps if a hypothetical applicant with learning difficulties was taking a case under the Human Rights Act, and analyse the decision of the Kutzner case from Germany. Whilst several Articles may be relevant, I shall focus on the working, interpretation, application and impact of Article 8 of the Human Rights Act.

Article 8 of the Human Rights Act (HRA 1998, 2000)

This Article states that:

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise

of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The rights guaranteed under Article 8 include a person's private life, the right to enjoy family life, the right to privacy of one's home and correspondence.

For parents with a learning difficulty, the right to enjoy family life, to be parents and bring up their children is thus covered, and in bringing a case under the Human Rights Act, Article 8 is engaged.

This right was incorporated into domestic law by the Human Rights Act 1998, which came into force on 2 October 2000 and has no retrospective effect.

When asking the question whether parents or children have suffered a violation of their right under Article 8, the law will adopt the following stages:

1. Is Article 8 engaged (does it apply)?
2. Is there an interference (violation of right)? If yes ...
3. Is the interference 'in accordance with the law'? If yes ...
4. Is that interference in pursuit of a legitimate aim listed in Article 8(2)?
5. Is the interference 'necessary in a democratic society'?

In principle, then, what rights does the parent with learning difficulty have?

Article 8 is a negative duty by the state not to interfere. In that sense it prevents unjustified infringements by the state (and public bodies acting as an organ of the state). Social workers, health professionals and other experts would fall within members of the state and their infringements would be covered. However, Article 8 also imposes positive obligations on the state to respect family life. 'Respect' means that steps have to be taken to ensure that these rights are realised in practice, so that disabled parents, such as parents with learning difficulties, have the opportunity to enjoy family life and have that experience respected. Of particular relevance here is the positive duty affirmed by the European Court of Human Rights in *Kutzner v Germany* (2002) (Application no.46544/99), where the Court stated:

"Where existence of a family tie has been established, the state must in principle act in a manner calculated to enable that tie to be developed and take measures that will enable parent and child to be reunited."

1. Is Article 8 engaged (does it apply)?

As a general rule, 'family life' for the purposes of Article 8 covers the relationship and tie between parent and child, even where the parents are not married and do not live together (*Kroon v Netherlands* (1995) 19 EHRR 263). Case law determined that the mutual enjoyment by a parent and child of each other's company constitutes a fundamental element of family life (see *W., B. and R. v UK*). Parents with learning difficulties have a fundamental right to be with their children, as do the children to be with their parents. Simply being blood related would, however, not suffice, so for the parent bringing a claim there must actually be a family life in practice, with contact and social ties (*Fawad Ahmadi & Anor v Secretary of State for the Home Department* [2005] EWHC 687).

2. Is there an interference with Article 8?

The law understands family life to have an essential ingredient: to develop ordinary family relationships. When a decision has been made, to remove the child and to place that child in care or with foster parents, then that basic right to ordinary family life has been interfered with. Generally, the law sees this as a very serious interference, as was confirmed in *Olsson v Sweden* (No.1) (1989) 11 EHRR 259, where the European Court of Human Rights noted that 'it is an interference of a very serious order to split up a family.' In legal proceedings of this kind, where the child is taken away from the parents with learning difficulties, the court will regard this removal as an interference under Article 8.

3. Is the interference 'in accordance with the law'?

Human Rights law, as an example of universal legal framework, aims to balance interests of the individual citizen with interests of the community. It lays down specific rules when an interference can be regarded as 'within the law'. This is to avoid arbitrary decisions and ensure equality before the law. Following these rules, so it is assumed, guarantees a fair application of general legal principles irrespective of differences, such as parents with learning difficulties. Consequently, an interference will only be 'in accordance with the law' if:

- there is a legal basis in domestic law;

- the law or rule in question is accessible; and
- the law or rule in question is formulated with sufficient clarity to enable those likely to be affected by it to understand it and to regulate their conduct so as to avoid breaking the law (see *Sunday Times v UK* 1979-1980 2 EHRR 245).

In care proceedings, Social Services are required to act according to relevant law and policy. The legal basis can be varied, and in the UK this usually involves the Children Act 1989, 2004, and while there are some issues of interpretation, generally the legality of this source cannot be faulted. In Germany paragraph 1666 of the Civil Code (*Bürgerliches Gesetzbuch*) lays down that the guardianship courts are under an obligation to order necessary measures if a child's welfare is jeopardised (*Gefährdung des Kindeswohls*). 'Measures' means steps that the state has to take in order to protect the child. The first sub-paragraph of 1666a provides that measures intended to separate a child from its family are permissible only if it is not possible for the authorities to take any other measure to avoid jeopardising the child's welfare.

4. Is the interference in pursuit of a legitimate aim listed in Article 8(2)?

Having made a decision, invoking a recognised legal source, that decision to place a child in care must be justified under Article 8(2). The usual justification advanced is 'to protect the rights and freedoms of others' (the child), which in the UK is stated in the Children Act as 'in the best interest of' the child and as a need to protect the child's welfare. This justification is likely to be accepted by the Court as the legitimate aim of taking children into care.

5. Is the interference 'necessary in a democratic society'?

This appears to be the crucial question. It was considered in a similar case, where the applicants had learning difficulties and the state (*das Sozialamt*) removed their children in *Kutzner v Germany* (2002) (Application no.46544/99). However, in this case the state further restricted rights protected by Article 8 in that the parents were ordered not to have any contact with the children subsequently. The state removed all parental responsibility and placed the two daughters in foster homes without visiting rights.

This decision was based entirely upon the belief that they would be unfit parents. There was no allegation of neglect or ill-treatment of the children or

within the family unit, nor any specific incidence to raise these concerns. The family doctor together with health and social care professionals came to the conclusion that parents with learning difficulties were as 'a matter of fact', meaning essentially or intrinsically, emotionally, intellectually and physically unfit to be parents. In the Kutzner case the European Court of Human Rights found a violation of Article 8 on the basis that the reasons relied upon by the state were insufficient to justify such a serious interference with family life. In reaching this decision, the Court came to the conclusion that the reasoning adopted by the state was too broad.

Reasons have to be considered in particular circumstances to make them relevant and proportionate in weighing up competing interests in civil society. Relevant circumstances are based upon fact and not assumptions and proportionate means that a whole range of options and alternatives have been considered before those steps were taken that best deal with all the circumstances. The underlying consideration for citizenship is that each citizen merits equal consideration and respect. The Court stated that

'in order to determine whether the impugned measures were "necessary in a democratic society", it has to consider whether, in the light of the case as a whole, the reasons adduced to justify them were relevant and sufficient for the purposes of paragraph (2) of Article 8'.

Clearly, the relevance can only be taken from the specific facts of the case.

Facts, context and the working of the law

The basic facts of this case as summarised in the European Court judgement were that the applicants, Ingo and Annette Kutzner, who had learning difficulties, were married and have two daughters: Corinna, who was born on 11 September 1991, and Nicola, who was born on 27 February 1993. The applicants and their two daughters had lived since the children's birth with Mr Kutzner's parents and an unmarried brother in an old farmhouse. The applicants had attended a special school for people with learning difficulties. The court found it relevant to elaborate that 'owing to the parents' late physical and, more particularly, mental development, the girls were examined on a number of occasions by doctors.'

Case details in the judgement indicate a great concern on the side of the state over various risk factors. As discussed in relation to the thought patterns *Denkmuster* about the attitude and treatment of disabled people in Germany, who carry the *Schwerbehindertenausweis B*, a common approach of health, social care and educational professionals is a heightened perception of risk, which is triggered when dealing with people who have an impairment. This is equally prevalent in the UK and has been described by Social Services Inspectorates as an 'overzealous approach to the assessment of risk' by childcare social workers and other experts in the UK (1999).

The children had received early educational support and the parents were given assistance. However, on 27 May 1997 the Bersenbrück Guardianship Court withdrew the applicants' parental rights over their two daughters and ordered their placement with foster parents, notably on the ground that the applicants did not have the intellectual capacity required to bring up their children, but also on the ground that the girls were very late in their mental and physical development and the applicants had failed to cooperate with social services.

As to the first element, Booth (2001) noted in his research that key features of professional practice in child protection proceedings in relation to parents with learning difficulties are 'a presumption of incompetence' which regards these parents as innately incapable and unfit for parenthood, and 'a deficiency perspective', a tendency to always focus on what they cannot do instead on building on their strengths. In a judgment of 29 January 1998 the Osnabrück Regional Court, relying on two expert reports, one highlighting the parents' mental retardation and the second their emotional underdevelopment, upheld the Guardianship Court's order for the girls' placement. The girls were placed in separate, unidentified, foster homes and restrictions were imposed on the applicants' visiting rights. The applicants were not permitted to see their children during the first six months; thereafter they were given visiting rights in the presence of third parties initially of one hour monthly, subsequently increased to two hours monthly. Commentators on Kutzner agree that the court regarded the conduct of the professionals as 'overzealous':

„...wird deutlich, dass das Gericht das Vorgehen der deutschen Behörden als überzogen einstufte“. (It is evident that the European

Court regarded the behaviour of the German authorities as excessive.)

The second element, the applicants' alleged failure to cooperate with social service, is indicative of a strained client-expert relationship. This comes to the fore when disabled people, traditional passive recipients of care, adopt a consumer approach to their services and develop strong characteristics indicative of a wish for self-determined living. The person whose job is to assist the parents in raising the children, Frau Klose, had clear ideas as to what was best for the children and how things should be done. Her ideas would most likely have been based upon a long tradition of academic discourse dating back to 1844 (Karl Mager), since to qualify in Germany as *Diplom-Sozialpädagoge/-pädagogin (BA)* she needs *Abitur* the equivalent to A-levels followed by a three-year training where knowledge is obtained through the higher institution of education. Davis (2003), a professor of social work at Birmingham University, outlines the transformation from an ordinary person to becoming a social worker in attitude, approach and skill. The aim of professional training is:

Sozialpädagoginnen und Sozialpädagogen begleiten, unterstützen, fördern und erziehen Menschen, die - aus welchen Gründen auch immer - ihren Alltag nicht allein bewältigen können und professionelle Hilfe brauchen. Die Berufsleute nehmen direkt teil am Leben ihrer Klientinnen und Klienten und gestalten mit ihnen den Alltag. Ihre Arbeit hilft den Menschen, sich in die Gesellschaft integrieren zu können.

(Socialworkers and Educational Psychologists to support, assist, promote and educate people, who for a variety of reasons are classed as unable to cope with daily living and because of that deficit, they need professional help.) BFF, Bern

It is understandable then, that rather than offer advice and act at the request of the parents, Frau Klose, on occasions, acted as an independent expert in her own right, which is described by Sapey and Hughes (2005: 294) as:

'On entering a profession, people express an allegiance to the knowledge base and codes of ethics of that profession. They become part of what Kuhn (1962) referred to as 'normal science'.'

As a consequence, the relationship between parents, who feel themselves 'in charge' of the children and who have ideas of their own, and the professional can easily be strained. Conflicting approaches, disagreement with expert opinion, and a sense of having one's own viewpoint disregarded in the first place may lead to behaviour on the part of the parents with learning difficulties that is not in accordance with a view of a 'working in partnership'. This breaks the agreed 'script' as analysed by Goffman (1971).

In communicating professional ideas particular communication and access requirements need to be in place, such as easy-speak, avoidance of jargon, support of an advocate, adjustments of timing or organisation, avoidance of value judgements. A failure to provide these combined with affirmation of professionalism can lead to labelling the recipient of assistance, in this case the parents with learning difficulties, as uncooperative, irrational, unrealistic and obstructive, even aggressive.

Zwischen Oktober 1995 und Mai 1996 betreute Frau Klose, eine sozialpädagogische Familienhilfe, die Beschwerdeführer offiziell zehn Stunden pro Woche an ihrem Wohnsitz. Die Beschwerdeführer behaupten, dass es sich in Wirklichkeit nur um drei Stunden gehandelt habe, da ebenfalls die Zeit für die An- und Rückfahrt zu berücksichtigen sei. Das Verhältnis zwischen ihr und den Beschwerdeführern war rasch konfliktgeladen, was den Beschwerdeführern zufolge dazu führte, dass ein sehr negativer Bericht über sie verfasst wurde.

(Between October 1995 and Mai 1996 Frau Klose, a family educational psychologist, supported the claimant officially for ten hours a week. The claimant disputes this as being only three hours, as the remaining time was for travel. The relationship between the claimant and the support worker quickly became confrontational, with the consequence that the claimants received a very negative report from the authorities) (Kutzner, Menschenrechtsgerichtshof, 2002)

The relationship between Frau Klose and Ingo and Annette Kutzner has been described as able to readily be inflamed. It is entirely feasible that this has been created by professionals' responses to a desire for autonomy, as disabled parents assert their autonomy as 'capacity to make informed choices

about what should be done and how to go about doing it' (Doyal and Gough, 1992: 8). Crucial to personal autonomy is 'the opportunity to participate in the social roles of production, reproduction, cultural transmission and political authority' (Lister, 1997: 7), such as being a parent. Bert Massie, chair of the Disability Rights Commission commented on research findings from Bristol University (2006) and observed that underlying some of these cases are discriminatory attitudes, summed up as 'people with learning difficulties cannot be parents'. In addition to disabling attitudes, the Kutzner case is also characterised by a conflict between the views of the applicants, parents with learning difficulties, and the professionals, who supported them. Booth (1997) termed such an approach 'confidence-inhibiting-support'.

It is a recognised legal principle in European and domestic courts that family cases are decided in terms of the best interest of the child (*TP and KM v UK* (2002) 34 EHRR 2). Expert witness reports would have been drawn on both sides of the arguments, and in the hypothetical case as indeed was in the Kutzner case, professionals and the family would present evidence against the points brought forward by the state, thus opposing the removal of the children. This interference with family life is regarded as very serious and in *K and T v Finland* 151 ECHR 2001 it was held that it was not enough for the state to argue that the child could be placed in a more beneficial environment for their upbringing, the Court required other circumstances to exist, pointing to the "necessity" for such an interference with the parent's and children's right under Article 8. Whilst the law ostensibly applies these legal principles uniformly and equally to all, the interpretation of key legal terms as adduced from actual observations in Ingo and Annette Kutzner's life heavily relies upon the interpretative framework of experts. It is a shift in some of the expert's thinking, both professionals giving evidence and judges upon hearing this evidence applying the law that enabled these parents with learning difficulties to have their children returned to them. The belief 'could be placed in a more beneficial environment' combined with ready perceptions of risk might have been the thinking *Denkmuster* when dealing with disabled parents in the past.

A positive duty

In the question whether the rule of law has been applied equally, and particularly whether Article 8 of the Human Rights Act had been violated, the

court will have regard to the obligation which the state has in principal to enable ties between parents and their children to be preserved. In its judgement the court noted the welfare concerns, but thought that the state had not discharged its duty to act positively in order to 'respect' family life:

"The Court recognised that the authorities may have had legitimate concerns about the late development of the children noted by the various social services departments concerned and the psychologists. However, it found that both the order for placement in itself and, above all, its implementation were unsatisfactory.

It appeared that the children had benefited from an early age – and at the applicants' request – from educational support and that the situation had become acrimonious as a result notably of a conflict between the applicants and a social worker who submitted a very negative report to the Osnabrück Youth Office. Further, the opinions of the psychologists consulted at various stages of the proceedings before the domestic courts were contradictory if not as regards their conclusions then at least as regards the reasons relied on (one psychologist referred to the parents' lack of intellectual capacity while the other referred to emotional underdevelopment that made them incapable of contributing to the development of the children's personality).

Moreover, other psychologists who had been retained as expert witnesses by the German Association for the Protection of Children and the Association for the Defence of the Rights of the Child and family doctors urged that the children be returned to their family of origin. They emphasised in particular that there was no danger for the children's welfare and that the applicants were entirely fit to bring up their children both emotionally and intellectually. They said that the children should be given additional educational support. Those conclusions could not be disregarded simply because their authors were acting privately.

Lastly, at no stage was it alleged that the children had been neglected or ill-treated by the applicants. Accordingly, although the educational support measures taken initially subsequently proved inadequate, the

question arose whether the domestic administrative and judicial authorities had given sufficient consideration to additional measures of support as an alternative to what was by far the most extreme measure, namely separating the children from their parents.”

Therefore, the state is also under a duty to give sufficient consideration to additional measures of support as an alternative to the “most extreme measure, namely separating the children from their parents.” (Kutzner above). The court stated that ‘in addition there is a positive obligation inherent in an effective “respect” for family life. Thus, the key judgement is “Where the existence of a family tie has been established, the state must in principle act in a manner calculated to enable that tie to be developed and take measures that will enable parent and child to be reunited.” The court supported its reasoning by reference to other cases (among other case authorities cited by the court: Eriksson, pp. 26-27, § 71; Margareta and Roger Andersson, p. 30, § 91; Olsson v. Sweden (no. 2), judgment of 27 November 1992, Series A no. 250, pp. 35-36, § 90; Ignaccolo-Zenide, § 94; and Gnahoré, § 51). However, none of these refer specifically to the kind of support that may enable parents with learning difficulties to self-determine the upbringing of their children with assistance.

This issue of taking positive steps to ensure inclusion or active participation or the fulfilment of human rights, in essence, is core for disabled people’s realisation of equality before the law. The kinds of measures taken by the state, and society generally, the range of support and assistance that may enable parenthood are generally considered ‘under-developed’ in member states (Andron & Tymchuk, 1987; Booth, 1998; Dowdney & Skuse, 1993; DRC, 2006; Llewellyn, 1990; Sheerin, 1997). This has led to calls for support services, for accessible easy-to-understand information, for advocacy and self-advocacy systems for people with learning difficulties (such as Change Campaign, 2006). This means that the legal principle, that the state must act in a manner that supports family life, has been enshrined and forms part of the rule of law, but disabled parents have historically been absent in its interpretation and practical application. It is perhaps indicative of the ‘novelty’ of the issue of equal rights that this is the only case brought to date under Human Rights legislation that seeks to establish equality before the law for

parents with learning difficulties. As in other citizenship areas, such as political life, the contribution and participation of disabled people has to a large extent been invisible. The approach in the Human Rights Act as laid down in law and followed by European as well as domestic courts appears uniform and to comply with the rule of law:

‘An interference with the right to respect for family life entails a violation of Article 8 unless it is “in accordance with the law”, has an aim or aims that is or are legitimate under Article 8 § 2 and is “necessary in a democratic society” for the aforesaid aim or aims. The notion of necessity implies that the interference corresponds to a pressing social need and, in particular, that it is proportionate to the legitimate aim pursued.’

Yet, the actual application of key legal principles is open to interpretation and embedded in social and cultural practices. Building on Doyal and Gough, and agreeing with Lister, this case illustrates an element of lived citizenship for disabled people as ‘critical autonomy’: able to situate, criticise and challenge rules and practices. Ingo and Annette Kutzner have done so in their relationship with professionals, such as Frau Klose, and by using legal representation bringing their case first in domestic court and then to the European court and to this extent the rule of law has been effective. The Kutzner case had repercussions across Europe, not least in Germany where it originated from. On the positive side it is clear, that if a parent or parents have their child taken into care, and the only reason advanced is the learning difficulty or other impairment of the parent(s), applying the rule of law, this may now be considered an unjustified interference. The extent to which supporting evidence can be drawn from other professionals, who agree or disagree with the removal of the children, evidence of the effect on the children’s welfare and whether other alternatives have been considered will all be relevant in determining whether a claim would be successful.

Rights and Responsibilities

Exercised citizenship pertains to the enjoyment of rights and the fulfilment of responsibilities. The discussion of the rule of law with citizenship involving ‘critical autonomy’ so far has three dimensions: citizenship as competence

regulating behaviour between individuals (accessible communication with parents with learning difficulties; putting point of view forward, disagreeing with professionals), citizenship as governing the relationship between individuals and the state (taking a case against state; state's paternalistic and enabling responsibilities; application of legal rules to particular facts by judges), and, thirdly, citizenship as a set of principles in weighing up competing interests between individuals (parent – child; expert – disabled citizen) and their community (family life).

A recent study entitled 'Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children' (Tarleton et al, 2006) carried out by Bristol University's Norah Fry Research Centre, found that, in the context where an increasing number of adults with learning difficulties are becoming parents, adequate assistance and support is often not available. The study outlined a range of barriers to finding appropriate support, which would assist people with learning difficulties to fulfill their citizenship responsibilities as parents, as well as enable the enjoyment of citizenship rights for both parents and children.

In addition to the barriers of 'presumption of incompetence', 'deficiency perspective', and 'competence-inhibiting-support' (Booth, 1998) discussed above, Carson (2006) reporting on the research found that 'many parents with learning difficulties are classed as "too able" to qualify for the services they need and end up having their children removed because they receive support too late'. People with learning difficulties can often be 'good enough' parents, following their own rather than professional's fixed ideas about what should happen, given adequate, relevant, appropriate and timely support. The report outlined that different professionals 'often had different conceptions of parenting against which parents were assessed'. In the above Kutner case such disagreements led to an assessment of 'uncooperative behaviour', a damning report and ultimately interference with their basic human right to family life. But the research indicates other behaviour options, such as distancing oneself from professional help for fear of having their children taken away, or disengagement with services because they had a negative view of them as parents and people. These processes of internalised oppression undermine citizenship skills and lead to disengagement and exclusion, thus

further reducing capacity for inclusive citizenship, which entails rights and responsibilities. Disabled people can become responsible citizens, but may require positive action by the state in order to enable competence and capacity. Positive duty - if focused on the removal of attitudinal, behavioural and contextual barriers - assists in creating the socio-political environment for inclusive citizenship.

In July 2007 the UK Parliament announced a public evidence session into the Human Rights of Adults with Learning Difficulties. These meetings are open to the public and further details are available online, and the details of the press announcement have been made available in an accessible format for people with learning difficulties themselves, Easy Read, in addition to having extended the deadline for written submissions, thus aiming to make this parliamentary democratic process as accessible as possible. This envisages adults with learning difficulties as active participants in this process rather than merely passive recipients of the outcome of such discussions.

(Parliament, UK Documents, Human Rights 2007)

Principles of inclusive citizenship

The concept of citizenship is contested (Beiner, 1995; Kymlicka and Wayne, 1994; Shafir, 1998; Steenbergen, 1994; Tilly, 1996; Turner, 1993). It has been understood to mean a legal or political status, but has raised questions about the kind of society we live in and want to live it (Mouffe 1992: 25). Citizenship has meanings across different disciplines, such as the law, sociology, social policy, geography, history, psychology, and politics.

I have argued that despite the formal recognition, the reality for disabled people, notwithstanding significant improvements in recent years, is one of disadvantage and less favourable treatment rather than equal status of being a citizen. Inclusive citizenship is built upon 'social quality' for disabled people, in that it requires not only formal equality but equality in social practices. In 1997 European social policy developed the idea of social quality. Essentially, the idea encompasses subjective and objective factors pertaining to the social participation of citizens, 'the extent to which citizens are able to participate in the social and economic life of their communities under conditions which enhance their well-being and individual potential' (Beck, 1997: 3).

Furthermore, opposing views about participation in public life are played out in the interaction between disabled people and public institutions. Beyond citizenship as a political status, I have promoted the concept of citizenship as political activism and citizenship as a political identity of disabled people themselves. The political element of citizenship as a status and the sociological perspective of citizenship as competent membership (Turner, 1990, 1997) are 'constitutive' (Isin and Wood 1999). Since citizenship issues arise at the interface of individual political identity and disability politics, citizenship is multi-dimensional, with overlapping, intersecting elements that come into play under particular socio-political conditions. In this regard, citizenship has to be understood as individual capacity unfolding in particular contexts. Citizenship identity, individual capacity and structural factors combine into forces which may enable or disable the status of 'being a citizen' to flourish into one of 'acting as' and 'being seen as' a citizen. The role of the state to be pro-active, with duties in society to identify and remove disabling barriers, is of paramount importance for an exercised citizenship that pertains to the enjoyment of rights and the fulfilment of responsibilities for disabled people.

Historically and traditionally social structures have denied impairment to enter into the public sphere, but recent social change, pushed for by disabled people themselves, persistently challenges these structural barriers. A concept of inclusive citizenship, which recognises multiple subject positions, has to acknowledge such struggles. In this sense, I agree with Dahrendorf (1994: 17), who regards combinations of identity at the heart of civil and civilised societies and exclusion as the enemy of citizenship. Inclusive citizenship considers individual citizens as perpetually infused by culture shaped by socio-economic contexts and engaged in reciprocal, social rather than self-interested relationships. If in society levels of consciousness are raised, so that we all, including disabled people, can maintain a dignified identity within several common *Gemeinwesen* (that sense of together-ness), develop a global, interdependent not self-interested, *Gemeinschaft* from which to derive structures in our *Gesellschaft*, which at the point of full inclusion is when *Gemeinschaft* equals *Gesellschaft* and becomes inclusive citizenship.

Chapter 6

Education for Citizenship Citizenship Education

“The hard reality is this. Society in every nation is still infected by the ancient assumption that people with disabilities are less than fully human and, therefore, are not fully eligible for the opportunities which are available to other people as a matter of right.”

Justin Dart, Disability Rights Activist 1992

Previous chapters have established a particular view of disability, namely one that is rooted within the social model (Chapter 2). The thesis then explored the meaning and lived experiences of discrimination for disabled people in the wider social sphere generally (Chapter 3) and in education in particular (Chapter 4). I have argued that a paradigm shift is taking place in our understanding of disability which challenges traditional models of citizenship (Chapter 5). Throughout the discussions a central dichotomy remained acute, with disabled people as active, independent, self-determined persons on the one hand, and disabled people as objects of pity, passive recipients of care or in need of special treatment or specialist services on the other. This dichotomy has been analysed in terms of the legal framework (Chapters 2, 3 and 4), equality principles (Chapters 3 and 5), citizenship as the site of political action (Chapter 5), and the concepts of social construction and social creation of disability (Chapters 2 and 3). These issues were discussed in relation to lived experiences in employment, politics, family life and education. Each of these areas is directly related to the concept of citizenship, and thus the understanding gained of the wider picture for disabled people in society leads to the argument that inclusive citizenship is built upon ‘social equality’

for disabled people, in that it requires not only formal equality but equality in social practices. To this extent this chapter now offers a critical evaluation of citizenship education in British schools. The analysis is based on three key principles: the social model principles, an anti-discrimination approach and recognition of struggle as a political manifestation of contested ideologies.

Key principles of inclusive citizenship

Firstly, the social model principles as elaborated in previous chapters can be summarised as a process that has at its core the identification and removal of barriers to participation. For disabled people, such barriers are created by society's response to individual impairment and consist of attitudes, behaviour, institutional arrangements and the physical design of the environment. The second principle turns to the developing legal framework that is characterised as a rights-based rather than entitlement-based approach, and thus applies equality and diversity principles known from other anti-discrimination legislation (race, gender, sexual orientation, age) to people, who have an impairment and are classified as disabled within the law. Finally, the principle of contested ideologies, which manifests itself in and recognises a continued struggle by disabled people to live as full and equal citizens, both in the participation in political processes and in active, equally valued participation in the social life of the community. This sense of active engagement is crucial in an inclusive concept of citizenship for disabled people.

Taking a macro view of education for citizenship, I argue that the site of citizenship education, the theoretical and definitional framework, method of dissemination, actual content and social practices are all interlinked within the 'project of citizenship education'. Teaching Citizenship as a 'product', thus, cannot be separated from the actual practice of modelling or living citizenship in schools, citizenship as a 'process'. What and how citizenship education is taught in schools must be seen in the context of the whole school and the broader education experience. Within the analytical parameters established in previous chapters, the aim of this chapter is to critically examine the impact and relevance of citizenship education for disabled people and the role that the education sector plays in relation to this.

In particular, Chapter 5 argued that inclusive citizenship or 'lived citizenship' is how people actually experience and realise themselves within given structural constraints and opportunities. This includes how people experience the impact that social practices have upon their daily lives. This chapter now extends the discussion by examining the literature on the development of Citizenship as a subject, by critically evaluating a sample of Citizenship resources, by exploring pedagogical tools and by analysing particular personal accounts in Higher Education settings. These discussions and experiences emphasise the idea, first introduced in Chapter 5, that society has a positive duty, which - if focused on the removal of attitudinal, behavioural and contextual barriers - assists in creating the socio-political environment for inclusive citizenship. Barriers, as illustrated in Chapters 3 and 4, established that disabled people are systemically disadvantaged and live at the margins of society. Specific examples in this Chapter offer an insight into the kind of institutional and systemic barriers that combine to make inclusive citizenship and valued participation unreasonably difficult even in an environment which rhetorically welcomes diversity, or where in its written policy the 'social model' had been adopted.

In addition to examining systemic discrimination, Chapter 4 specifically argued that the business of education in its culture, practices, policy and procedures fails to embody the full citizenship rights of all participants, especially disabled people. Within this backdrop, the question initially posed in Chapter 4 is now extended and embraced by means of a critical analysis:

1. How can schools be a credible site for the dissemination and education of inclusive citizenship?
2. What barriers to inclusive citizenship need to be tackled?
3. How can education establishments meet their positive duty?

Citizenship education into the curriculum

The Revised National Curriculum (2002) has three key aims for the education of all pupils: setting suitable learning challenges, responding to pupil's diverse learning needs and overcoming potential barriers to learning and assessment. Relevant guidance suggests that teachers use all available senses and experiences of pupils. The government's overall strategy is to enable every teacher to expand their repertoire of inclusive skills in 'Removing Barriers to

Achievement (DfES, 2004)'. In order to meet these standards, account must be taken of disability discrimination issues.

"Young people who would have been considered 'uneducable' 30 years ago, before the policy change brought about by the Warnock Report and the 1981 Education Act, are now thriving as independent citizens, often in employment or volunteering and contributing greatly to society as a consequence of their enhanced educational opportunities."

DRC, Special Schools Debate, July 2005

As noted in Chapter 4, categories of learners with impairments have changed over time. Under the 1944 Education Act, disabled children were categorised by their impairments and defined in medical terms. Many children were excluded from educational experience altogether as they were considered to be 'uneducable', 'maladjusted' or 'educationally sub-normal'. As demonstrated in research of the Greater London Authority's Disability Capital surveys (2003, 2004), entitled 'Another Planet?', experiences of discrimination and exclusion in light of major barriers to equal participation for disabled and Deaf Londoners sets disabled people apart from the mainstream of society 'as if from another planet':

"The aggressive stuff is more easy to deal with somehow - it is just a shock when somebody crosses the street to spit in your face. When people dismiss you and exclude you and treat you like you are from another planet, that is when the veneer cracks and tears flood inside."

"Another Planet? presents a stark picture of discrimination in London and compellingly shows that discrimination, disadvantage and exclusion are common and everyday experiences for disabled and deaf Londoners in 2003." GLA Disability Capital Survey, 2003, 2004

The House of Commons report (2006) likewise, notes that disabled children were often treated 'as a race apart':

'The various Acts and legislation that have followed demonstrate the progress in attitude that has taken place since the Warnock report towards the aim of trying to include all children in a common education framework and away from categorising children with SEN or disabilities as a race apart. This has been representative of a broader international trend.' (HC Education and Skill, Third Report, 2006: para 10)

Despite many advances towards inclusion, disabled learners continue to experience discrimination and disadvantage in education, as outlined in Chapters 3 and 4. In discussions about where disabled learners are educated, whether special education and segregated education provision will continue, or whether disabled and non-disabled children are educated together, the argument has been promoted that we must consider the issue of citizenship for all. These issues are usefully analysed 'through the lens of a long-term aim of disabled people establishing equal citizenship in our society and the role schools play in relation to that objective as agents of change in society.' (DRC, 2005).

For the past two decades the debate about 'citizenship education' has been growing. The history of teaching citizenship in schools has been ably plotted (Batho 1990; Brown 1991; Heater 1999, 2001, 2004; Kerr 1999; Oliver and Heater 1994), but fails to make any reference to disability or impairment or disabled people or disability discrimination. Likewise, the teaching of controversial issues equally has long been established (Clarke, 1992; Carrington and Troyna, 1998), but with limited inclusion to date of issues affecting disabled people and within a questionable 'medical' framework, such as discussions about abortion, euthanasia, social care and voluntary work for disabled people in need.

A first attempt to consolidate different ideas about citizenship in the classroom was offered in 1990 Curriculum Guidance Paper 8 *Education for Citizenship* (NCC, 1990), which unanimously recommended that citizenship education should be put on a statutory footing and made compulsory for primary and secondary pupils. The Secretary of State at the time did not accept the idea that citizenship education is of value or feasible in primary education. Initially, there was no sign of learning outcomes in the QCA's guidance papers and the DfEE Citizenship Order. At that time the curriculum was designed into Key Stages and organised around measurable learning outcomes, with some heavy prescription of content and learning in core curriculum subjects.

Citizenship Education has become a statutory subject since September 2002 for Key Stages 3 and 4. Breslin and Dufour (2007) argue that this signalled a key shift in the status of Citizenship as a curriculum subject. These

researchers say that Citizenship 'has shifted from the margins of schools, where it was taught by enthusiasts, to the core with the imprimatur of government support and enshrined in law as an official National Curriculum subject.' The content was to be developed from three strands following the PSHE cross-curricula themes, covering political literacy, social and moral responsibilities and community involvement. Learning outcomes are formulated in the Citizenship Order. Despite this, the content of citizenship education remained very much contested and unclear. Five years after the first guidance paper in 1990, a head teacher outlining the process of whole-school curriculum development, quoted in Beck (1998: 96) was clear on four of the 'cross-curricula themes' but stated; 'As for the other one – when someone tells us what education for citizenship is, I'm sure that will trigger a response'.

Citizenship is a widely contested concept, one that is 'unstable' throughout history (Isin & Wood 1999: 6) and widely debated in academia as well as political spheres (Crick, 2000; Delanty, 2000; Isin 2000; Kymlicka 1994; Shafir 1998; Steenbergen, 1994; Tilly 1996; Turner 1990, 1993, 1997). Whether we agree or not that 'The new citizenship is a creative synthesis of politics and social studies' (Crick, 2000: 13) the roots of citizenship ideas can be found in academic subjects as diverse as sociology, politics, psychology, social policy, economic theory, legal studies, philosophy, history and even geography. There is no agreed approach to or understanding of this concept, nor on how to teach it. The history of teaching citizenship education as explored by Heater (1991) identified three main periods of citizenship education in schools during recent decades, whilst models of education for citizenship proposed by Starkey and Osler (2005: 79) are grounded in human rights with the idea of a 'cosmopolitan' citizenship, all of which is illustrating current disagreement and uncertainties among politicians and education practitioners alike. Others argue that human rights and citizenship rights need to be distinguished: 'While human rights are regarded as innate and inalienable, the rights of citizens are created by States' (Isin and Turner, 2007).

Within this debate, however, the voice of disabled people and the argument for an inclusive citizenship that encapsulates the lived experience of self-determined disabled people, as argued in this thesis, has been largely silent.

For disabled people Citizenship must be conceptualised as involving more than one academic discipline since questions are raised at an individual level and at an inter-subject level, questions are located within the community and directed at political or institutional structures. These questions concern the political life and the nature of human beings living together, family life and work, how best to organise society and its resources, and the realisation of personal dignity, equal value and active participation when learning to value each other's differences, such as the physical and mental differences presented by or ascribed to disabled people. Citizenship has to reach across traditional boundaries of academic thought, reach different levels of analysis and be inclusive in its lived experience. Inclusive citizenship is when people who have an impairment can be enabled rather than disabled as citizens in every sphere in society.

Not only is there no common understanding or acceptance of 'inclusive citizenship', but of what Citizenship as a curriculum subject entails. These uncertainties about Citizenship as a subject are reflected in practice. When Ofsted undertook to review pilot provisions of citizenship education (2004 – 2005) they found that there was a key problem of definition:

"In one case, two of the three arms of a citizenship programme undertaken by a school did not meet the QCA objectives; there was no shared understanding on the part of the staff of what citizenship means, or how the elements of the programme fitted together. This raises a question of the training needs of the staff involved, as well as the need for effective guidance and support for young people so that they understand the place of citizenship in their curriculum."

And in 2006 the Ofsted report 'Towards consensus?' noted that 'significant progress has been made in implementing National Curriculum citizenship in many secondary schools. However, there is not yet a strong consensus about the aims of citizenship education or about how to incorporate it into the curriculum.' Research findings and current developments underline that what is being taught and how it is being delivered is far from obvious or natural, but is a result of debate and contested ideas. Citizenship itself is essentially contested in nature (Gallie, 1955 referred to in Beck 1998: 97). The critique of this thesis is that, to date, such debates have had very little inclusion of the

position of disabled people as citizens. Furthermore, their struggles as disabled people failed to be taken into account when making decisions and coming to determinations about citizenship education in schools.

An absence of disabled voices can be illustrated in the early developments of citizenship. With the decision to push ahead with the idea of citizenship in schools New Labour set up the Advisory Group on Citizenship and the Teaching of Democracy in Schools. This group was to determine the nature and purpose of citizenship education in schools with an overview of what good citizenship education would entail both within the formal and informal curriculum. Key academics in the field of citizenship, such as Kerr (1999) noted the 'carefully chosen, balanced membership' of the advisory group with reference to practitioners in citizenship education and people offering professional expertise in the wider political field, with an emphasis on the non-partisan approach (1999: 276; membership is detailed at page 5 in 'Education for Citizenship and the Teaching of Democracy in Schools' 1998, commonly known as the 'Crick Report'). Disabled people, disabled experts and disability equality issues - if present - were invisible, not noted or commented upon, and thus effectively absent by all accounts.

A similar absence of disabled voices in citizenship literature has been noted in Australia. Meekosha and Dowse (1997) promote the idea that 'A citizenship which acknowledges disability is fundamental to re-imagining local, national and international collectivities.' The extent to which schools provide a context in which disabled people are valued as equal citizens, one which enables disabled learners to fully participate and reach their potential, and one which builds a society where disabled people have a voice, belong and are self-determined is under scrutiny.

This next section will examine English education policy, curriculum documentation and internet-based Citizenship web resources, and address the school context in four ways: 1) describe developments in Citizenship as a subject in the curriculum, focusing on key players, both individuals and organisations, who shaped and influenced its realisation and the extent to which this includes disabled voices; 2) offer a critique of resources available to educators in terms of its inclusivity for and to disabled people; 3) outline programmes of study at key stages 3 and 4 with reference to disabled citizens

and inclusive citizenship for disabled people; and 4) examine examples from practice by outlining the potential of teaching Citizenship with a disability dimension in other curriculum subjects.

Developing Citizenship

There had been a long struggle towards recognition of Citizenship in the curriculum. Momentum was gained when three key institutions came into existence and regrouped over time. They work to assist in developing content and shape to this area of the curriculum. Three more central, and often referenced (Breslin Dufour 2007: 7; Huddleston Kerr 2006: 227-8), organisations are the Citizenship Foundation, the Institute for Citizenship and the Centre for Citizenship Education. From its early beginnings in the Law in Education Project, which was influenced by the work of Lord Phillips, the Citizenship Foundation was established in 1989. As such, the Citizenship Foundation is true to its roots focusing on the education of teachers and young adults about law, democracy and society, with the aim to empower individuals. Professor Ken Fogelman was the founder of the Centre for Citizenship Studies in Education when it came to life in 1991 at the School of Education at the University of Leicester. A further non-governmental organisation was established a year later in 1992 as concerns over youth disaffection and political disengagement rose (Speakers Commission). The Institute of Citizenship aims to promote 'informed, active citizenship and greater participation in democracy and society through a combination of community projects, research, education and discussion and debate' (Institute of Citizenship online).

Active citizenship

The Quality and Curriculum Authority (QCA) defines in its glossary of terms the concept of 'active citizenship':

'In an educational context, citizenship learning through participation in school- or community-based activities. See also citizen and citizenship. Under the national curriculum in England, pupils at key stages 3 and 4 engage in participative activities as part of their citizenship curriculum. Ways this might be done are given in the QCA schemes of work. Guidance is also available from organisations specialising in citizenship education.' QCA online - Glossary

Whilst at first sight the notion of 'active citizenship' appears laudable, there are several notes of caution. Concerned with the underlying message about the role of the state Beck (1998) raises party political issues. He sees voluntary involvement in the community as possibly reinforcing the view that: 'active citizen who tacitly at least supports the New Right agenda of severely cutting back on public expenditure and public provision of welfare in favour of a mixture of privatised and voluntary provision, and who accepts a personal obligation to contribute time and energy to such voluntary activity' (1998:101). With New Labour in power since 1997, the emphasis then shifted to a communitarian understanding of community involvement, where individuals are caring people, sensitive to the needs of others, interested in getting involved, connected and motivated to contribute positively in social life. For disabled young people research revealed that 74% said they did not feel they were 'active citizens' in their local communities, they were not treated as 'equal citizens' and they felt that the Government had limited awareness of the issues concerning them and that public authorities rarely listened to their views (Prime Minister Strategy Unit, 2005). In terms of disabled citizens this thesis is arguing for a shift from traditional responses to the issues of disability as a welfare/ entitlement issue, to individual and organisational behaviour, which is underpinned by the social model approach and framed by rights in terms of anti-discrimination. A failure to include disabled people, disabled young people and disability equality issues in 'active citizenship' on those terms will be detailed below. The social model approach requires a focus on access not impairment, whilst 'rights not welfare' constitutes the second pillar of the overall paradigm shift in thinking (Kuhn, 1962 in Chapter 3; *Denkmuster* in Chapter 5). The changes in *Denkmuster* and concomitant action are multi-layered and inter-connected. When both, a failure to shift from impairment to access and from entitlement to rights, are present, then the discriminatory impact upon disabled people is compounded, and disability discrimination embedded in the very fabric of institutions.

The definition of active citizenship 'working with others to make a difference' is open to interpretation. Dominant ideas about and responses to disability, although gradually shifting in limited ways, remain firmly rooted within an individualised bio-medical mode, as is evident, for example, in 'At the School-

gate' responses over seven years of Disability Equality Training (detailed in Chapter 2) traditional legal framework (e.g. NAA 1948 and definition of disability in DDA in Chapter 3: 62; 80 – 82; poor laws in Chapter 4: 104) or charity responses (Deaf Research UK in Chapter 5: 203). The broad public is lacking a 'sociological imagination' (Mills, 1959) and in that regard 'the public imagination conceives of most people with disabilities (sic), especially women, as passive citizens' (Meekosha, 1997: 50) who are ideal *objects* for active citizenship. Ofsted inspection results indicated that students had not sufficiently shifted from those traditional ideas. Therefore, it can be seen that 'while some students engage in responsible action on behalf of others, this is more concerned with altruism than citizenship' (Ofsted 2005). In contrast to this position, a social model understanding of disabled people promotes not so much living for the interests of others, but a mutual recognition and learning from each other. Bob Findlay, writer and disability rights campaigner, reinforces this point:

"There is an old saying: Never judge a book by its cover. I think that's the answer. We should take (disabled) people as they come, listen to them, accept them as they are and be prepared to learn **from them.**"
(Findlay, 2006)

In contrast to this understanding of disabled people as self-determined, what is seen as 'worthwhile' in current Citizenship practice in schools includes fund-raising, voluntary work, charitable events **for** disabled people as sufferers and victims afflicted by personal tragedy. With students continuing these activities in their own time, habits are formed that not only determine individual interactions with disabled people based on pity, but also present long-term barriers to a shift in mindset. Ofsted characterises the most successful citizenship activities as:

'The activities undertaken by students are wide ranging and worthwhile, although some did not fit the project definition of citizenship. Activities included fund-raising and voluntary work. Students are also expected to identify, research and make a presentation on a citizenship issue. This activity takes place partly in tutorial time and partly in students' own time and is intended to benefit the school community. Examples include: a newspaper written by and

for other students; a day's charitable event to involve all students.'

(Ofsted, 2005)

The strand of 'active citizenship' poses particular challenges in terms of working towards an inclusive citizenship that recognises disabled people not as mere objects, but as active citizens as imagined by Crick in this much quoted passage:

'We aim at no less than a change in the political culture of this country both nationally and locally: for people to think of themselves as active citizens, willing, able and equipped to have an influence in public life.'

(QCA, 1998: 7)

Within the bio-medical, individual, and traditional responses to disability the phrases 'willing, able and equipped' may be related to a deficit approach caused by individual impairment, where a disabled person because of their impairment is either not willing, not able or not equipped to participate, and therefore needs help from others. Within traditional thinking 'active citizenship' activities help others from a deficit perspective **for** the helpless, dependent person, rather than, for example, directed **by** the disabled person themselves as illustrated by the Independent Living Movement (Chapter 3: 54; 67). The social model of disability, in contrast, focuses on access issues in the social environment. The kind of 'help' needed is to identify and remove individual and institutional practices that create disabling barriers and reduce opportunities to have an influence in public life (e.g. budget priorities and business behaviour in Chapter 3: 58ff; access to schools, curriculum and learning in Chapter 4: 108; 143ff; access to political life, democratic participation, voting in Chapter 5: 189; 195 - 198; right to private and family life as disabled parents in Chapter 5: 218; 223 - 231). To what extent are disabling barriers in the school context and a failure to shift from an impairment perspective to one of 'making access happen' reducing disabled people's opportunity to be 'willing, able and equipped' to participate in active citizenship? A positive attempt at addressing access and participation within active citizenship was reported by the Citizenship Foundation (Press Release, 30th March 2007). However, professional uncertainty, for instance over the use of language and the location of the 'problem' (impairment or access), is also evident in this example:

“Students from two schools will be coming together next week to assess the accessibility of the Welsh coastline for young people and people with special needs / disabilities. ... By assessing the accessibility of the coastline, the students will help the National Trust to ensure that the countryside can be an educational and recreational space for young people of all abilities.”

(Citizenship Foundation, Press Release 2007)

The report seems uncertain over what to call the students who attend from Kings Mill, described as ‘a special needs school in Driffield, Yorkshire’. Do they have special needs or disabilities or both or either? Are they constituent of or additional to ‘young people’? Are these students not able or differently able or less able? Able, willing and equipped...? Does lack of access to the countryside arise because of their ‘special need’ or particular form of ability?

Citizenship objectives: objects and subjects

Beyond the meaning of active citizenship, a closer look at the three organisations in the development of Citizenship mirrors a degree of variation as to what Citizenship should be about. The mission statement of the Centre for Citizenship Studies in Education is indicative of broad, general strands in the field of Citizenship:

‘The Centre for Citizenship Studies in Education promotes research and education for citizenship, human rights and the teaching of democracy in schools. The Centre is committed to developing more democratic and inclusive approaches to education, based on the principles of freedom, equality, justice and peace. It aims to support schools as model communities, in which there is respect for the individual and for difference, and for equality of rights. There is a particular need to reaffirm democratic values in the face of violence, intolerance, and racism and to enable young people to see how they can achieve change through democratic participation.’

(Centre for Citizenship Studies, online)

At first sight the issue of disability equality is not directly addressed in any of these three internet resources and associated web pages or centres for the development of Citizenship. In stark contrast, one particular equality

dimension, that of racism, features prominently. The Quality and Curriculum Authority QCA asks 'What is the potential in PSHE and citizenship curriculum for valuing diversity and challenging racism?' In the schemes of works referred to on the standards site of the DfES Unit 3 of KS4 specifically deals with 'Challenging Racism'. Pupils are expected to learn 'what racism is and how the law protects citizens who are victims of racism.' Standards for the outcome of learning envisage that children and young people 'reflect on different situations in which they might see or hear about racist behaviour or actions' and that 'they devise strategies to help challenge racism, discrimination and stereotypes, and recognise the importance of mutual respect and understanding within a diverse society' (DfES, standards online). The Citizenship Foundation promotes 'Show Racism the Red Card' an 'anti-racist education campaign, which aims to end the presence and toleration of racism in football' for Citizenship teaching at KS3. Equivalent explicit references to disability discrimination (Barnes, 1991; Gooding, 1997) or disablism (Miller et al, 2004: 9; SCOPE) are absent in general mission statements and further web pages. It can be argued that principles underlying the general mission statements in Citizenship of, for example, 'developing more democratic and inclusive approaches to education' are equally valid with reference to disabled people, so that disabled children experience more democratic and inclusive approaches to their education, and so that non-disabled children learn about democratic and inclusive approaches of disabled people in their education. Equally valid appear also the issues of human rights, and other principles raised in the mission statements. The question arises whether disability issues are subsumed within the universalist claims of 'citizenship' and consequently, whether disabled people by inference or assumption are included in 'all', or whether disability issues are seen as separate and not immediately relevant to discussions of citizenship, and because of that are not specifically mentioned. What are the features that distinguish disability discrimination or disablism from racism in British society, and what makes disability issues appear less immediately relevant? Are there justifications that set racism apart to be given not only a status of relevance and urgency, but also of deserving particular attention in the field of Citizenship with regular references to it?

A third option is that disability issues are neither automatically included nor irrelevant to the discussion of Citizenship, but are *conditionally* relevant, that is only within a distinct homogenous sub-group of 'the disabled' or of people differentiated into a segregated group according to impairment categories. This applies to schools or educational contexts, where pupils are differentiated into the subgroup of 'the disabled' (for example in terms of 'special educational needs children') and educated away from their non-disabled peers, with varying labels such as 'having multiple and severe disabilities'. Citizenship issues have become relevant for or in reference to this 'special' group of people.

Conditionally relevant and special

Describing disabled pupils as if belonging to one homogenous mass is a wide-spread practice in educational writing, in the media, academic press or amongst 'experts'. Within a social model understanding, the term 'disabled' is used to refer to a group of people. However, whilst the phrase 'disabled' recognises that children who have impairments are *disabled by* a range of barriers, such as lack of alternative communication strategies, timetable constraints, budgeting priorities or attitudes of peers, the phrase 'special educational needs' or 'special needs child' locates the problem within the individual child and raises the assumption that extra resources are required to meet some extraordinary requirement caused by the child. A recent report into the working of the statementing process in primary schools (TES April, 27, 2007) emphasises that children are waiting for one or even two years for this 'extra' support. In a social model understanding the focus would shift to schools and to the overall allocation and distribution of resources and the mechanisms for doing so, such as the fact that local authorities are both responsible for allocating funding to enable disabled children and for assessing particular requirements (for further details see House of Commons Third Report on Education and Skills, 21 June 2006. In slowing-down the process by which requirements are identified (the statmenting process), this administrative process serves to reduce the speed by which resources have to be made available on an individual child basis.

Fundamentally, the failure to include diversity at the outset of planning and in the thinking about delivering education leads to exclusion. These issues of diversity include the fact that disabled children have a range of learning styles, physical access requirements, and diverse communication methods. As they have not been thought of sufficiently, and thus not been thought of as differences that should be equally valued, a system is designed into which only *some* children fit comfortably. Such design has been described by Tomlinson (1995) as an 'out-dated and dysfunctional organisation called school'. My argument is that the learning requirements of children with impairments are not fundamentally different from those of other learners. They are not *special*, but, as any child, children with impairments have basic physical needs, safety, emotional needs, affiliation and esteem, and self-actualising needs (based upon Maslow's seminal hierarchy of needs, 1943). These translate into the same 'need' as every child: A need to be able to get into school, to make themselves understood, to get to their desks or learning spaces, access the learning materials, sit comfortably, relax at playtime, make friends, be safe, be heard, benefit from relevant and rewarding learning experiences, achieve, grow in confidence... The needs are no different, but how they can be realised are. The children, whose *learning access requirements* are different from standard forms, such as accessing not printed but taped material, having to take more frequent breaks in order to enable learning, using alternative communication methods, requiring personal assistance at meal times, are no different in their basic needs (Maslow) but require different responses in institutional design: curriculum design, pedagogy, environmental and organisational design. If these requirements are not being met at the outset, later 'corrections' or add-ons often incur additional costs, which is what makes 'special educational needs' expensive.

If these learning access requirements are not being met the children, in the meantime, suffer and experience reduced access to education. Tomlinson (1995) describes the special education system itself as 'a failure of the schools as an organisation to adapt and change to accommodate all pupils'. Ten years later, Osler and Starkey write about cosmopolitan citizenship and

argue that 'schools as institutions need to adapt to the learners in order to guarantee a right to education for all' and that 'it is by upholding these rights that schools will be genuinely inclusive, respecting difference and promoting equality' (Osler Starkey 2005: 59), all of which are pre-requisites for citizenship. Osler and Starkey are not writing about disabled children, but are considering issues of racism. Exclusion and failure to adapt is not only relevant to issues of racism, as signified by the following facts on discrimination and educational exclusion, or gender or social class, with which educational practitioners are familiar, but also by reason of impairment and relevant to disability access requirements.

'African Caribbean boys are up to 15 times more likely to be excluded from school than white boys. In 2003, roughly 70 per cent of African Caribbean pupils left school with less than five higher grade GCSEs or their equivalents. This represents the lowest level of achievement for any ethnic group of school children.'

(Discrimination Law Review, 2003; 2006)

The TES article repeatedly uses the phrase 'special needs pupils' which, like other terms, such as human rights 'rolls effortlessly off the tongue, predigested' (Armstrong Barton 1999: 214), it appears to regard this group of children as having a common identity or a common denominator. It is as if there is some self-evident truth and we all know what we are talking about and who these children are. As Baroness Warnock admitted in a recent interview:

"one of the major disasters of the original report was that we introduced the concept of special educational needs to try and show that disabled children were not a race apart and many of them should be educated in the mainstream... But the unforeseen consequence is that SEN has come to be the name of a single category, and the government uses it as if it is the same problem to include a child in a wheelchair and a child with Asperger's, and that is conspicuously untrue."

(The Guardian, 31st January 2006)

The fact is, that children who have been ascribed the label 'special educational needs' are defined in relation to the school context. For example, the child has special educational needs if 'he has a disability which either

prevents or hinders him from making use of educational facilities of a kind generally provided for children of his age in schools within the area of the local education authority' (Education Act 1996; Chapter 4: 147-148).

Educational facilities 'of a kind generally provided' means that children are defined in relation to what the school provides, how the school functions, thus in relation to 'business as usual', and as recent debates attest, in relation to 'extensive evidence of the overlap between education and social/economic needs' (Dyson 2001; Emerson and Hatton 2005).

By this reasoning, all children who use British Sign Language (BSL) have 'special educational needs' unless, of course, they attend a school where teachers and pupils also use BSL, where BSL is the 'norm', is a regular method of school-based communication, or where they have BSL interpreters in class. If the school context changes then the special educational need of children with an impairment disappears (see history of BSL in Chapter 4: 113; 129 - 135). A child using a wheelchair to get about will have 'special educational needs' until the school environment is designed for easy access (Chapter 4: 107; 130; 143-145; Barnes 1991 on special schools; DDA case of Antony Ford-Shubrook; accessibility plans). A student at university with dyslexia, in contrast, no longer has 'special educational needs', as the legal definition only applies to schools. That student remains disabled, however, as long as her communication and learning access requirements are not being met. What would be helpful, for example, is the provision of lecture notes and reading material in advance or lecture notes to be accessible via the intranet, power point slides to visually support the spoken presentation, but for slides to be read out rather than relying on the audience to read, or the recording of lectures or seminars instead of relying on hand-written notes. This not only removes the 'special educational need' but is welcomed by other students, who appreciate the independence through self-directed learning, which these advanced provisions can provide. Noticeable, however, are 'hidden' barriers beyond that of inaccessible printed matter, which have been reported by disabled students and academics alike (Healey, quoted in THES, 20 August 2004; oral evidence from disabled students; contributions in DET at HE settings 2002-2006; Fitzgerald, 2006). The term 'dyslexia' is contentious and

often met with professional suspicion (Stanovich, 1996; British Psychological Society 1999) and there is no consensus view (Nugent, 2007).

In a discussion about educational values Norwich and Corbett's (2000) understanding of dyslexia access issues are indicative of one aspect of 'hidden' barriers, that is regarding disabled people's access requirements as either selfish or a burden on the common good. Critical of parents pursuing their 'individual entitlement' and market choice, they observe:

'In relation to dyslexia parents are usually happy to have their child labelled 'dyslexic' and may not be concerned with the resource-worthiness of their child in relation to other children. This epitomises the market values of individualism and self-interest, regardless of community needs.' (2000: 104)

Hidden barriers come in many forms and act specifically at a systemic level. One such barrier includes an institution's apparent concern with 'intellectual property rights'. This has an impact not only on students with dyslexia, but any student who has alternative access requirements to the recording and recalling of class-based information.

Business-as-usual

The concern expressed in HE institutions with intellectual property rights will be briefly expanded as an example of a 'hidden barrier' to participation and learning. This is a controversial concept, as the term 'intellectual property' imbues mental or cognitive effort and output of the intellect, or ideas with the same characteristics as physical property and possessions. It gives some exclusive rights over intellectual work, the most common forms of which are copyright, patents or trademarks and industrial design. However, in a learning context the key issue of intellectual work lies in a critical engagement with a range of different ideas and what seems paramount in order to 'protect' intellectual property is to acknowledge where ideas come from or who developed them, and not presenting those as one's own. An illustration of combined structural barriers is given in recent advice to academic staff by the Open University on recording face-to-face tutorials (Snowball, July 2007). It states: 'In some circumstances students with specific learning needs may be

unable to take notes in a tutorial and may wish to record it instead. The guidelines point out that the content of tutorials remains the intellectual property of the university...'

In our relationship with disabled people uncertainty is created when we remain focused on impairment rather than shift into access. The Open University sample guidelines to resolve this dilemma or challenge mirrors a general uncertainty in professional relationship about dealing with access requests of the recording of lectures (see for example NATFHE , DRC and SKILL combined advisory note (2003) 'Compliance with Part IV of the Disability Discrimination Act – Recording of Lectures by Disabled Students'). The OU article, which is by no means alone in its approach, describes disabled students within a deficit model as 'unable to take notes in a tutorial' rather than recognising access differences, whereby impairment-related differences in access methods, such as recording notes or having a scribe, are different but equally valid and valued. The impairment-reasons for this difference are irrelevant. Various guidelines (Skill 2003, OU 2007, The Higher Education Academy and Equality Challenge Unit 2006) firmly point out that the content of tutorials remains the intellectual property of the university. This advice applies only to tape recording of tutorials. Students who access and record potentially the same 'intellectual property' in written form by hand or by memory recall are not so reminded. Emphasis is thus placed upon the different method of recording, with the non-standard form giving rise to concern and alert. Diversity in the method of recording causes uncertainty as standard practice and 'business as usual' is challenged. The fear is that a valuable possession may be reproduced and passed on to others. Further barriers to learning in the form of accessing and later recalling information are placed upon disabled students by the additional requirement that they seek consent from all staff and students, who in turn have a right to refuse! An equivalent requirement to seek consent to produce a written record of what is being said does not exist. Intellectual property, in any case, requires acknowledgment, engagement and good referencing, not differential access to it in the first place. It is 'business as usual' that remains a powerful barrier in reducing educational access, not any 'special need' ascribed to a learner. Treating disabled learners as a 'special', homogenous group outside the

'norm' contributes towards their reduced citizenship status, one that emphasises 'being a burden' or a 'threat' to the common good.

Inconsistencies: good practice – bad example

An example of how disabled pupils may be conditionally relevant to Citizenship is given by a link from the DfES website to the Teacher Net, describing a case study of a successful Citizenship project. The following discussion will show, that there are inconsistencies with a concept of Citizenship that applies only conditionally to an excluded or differentiated group away from mainstream educational contexts. Despite some good practice within the special school, the positioning of pupils and of disabled people as separate from the norm (GLA 2003, 2004 'Another Planet?') and by inference as less valued rather than equally valued, runs counter to conceptions of citizenship. For instance, the headline reads 'School Council in a Multiple Disabilities Special School'. Students at Victoria School, who are described as 'children with multiple disabilities aging from 2-19 years old' and for some of whom 'verbal communication is either very difficult, or impossible' have been given a student voice. The school has achieved active participation of disabled pupils in school affairs. Following Arnstein's (1969) 'Ladder of Participation', which has been developed by Hart (1992) for UNICEF into 'Ladder of Children Participation - From Tokenism to Citizenship' it is recognised that there can be a danger of tokenism in consultation. It has also been recognised, for example, in Northern Ireland when involving disabled children and young people in children services planning (2002), that there is a range or scale of participation from no involvement to tokenism to actual full empowerment. The report from Victoria School informs us, that pupils 'who wish to be council members create campaigns through posters, video, and discussion, suggesting why they would be good advocates for their class'. Indeed, some practical solutions to lunchtime issues have been debated, and steps taken which resulted in changes in pupil's immediate environment. However, following discussions in Chapter 2 it is apparent that the language adopted in this website fails to reflect a social model understanding of the difference between impairment and the disabling environment created by society. The description of children with verbal communication difficulties underlines the causal connection between the pupil's impairment and the lack

of communication. In contrast, a social model approach looks to barriers in society that need to be identified and removed in order to achieve 'communication' and thus inclusion. The children have an impairment, but are disabled by the failure of mainstream education to take account of their differences. This can be exemplified by reference to difference in communication methods. The problem is located within the individual as a bio-medical problem of 'difficulties in verbal communication' rather than one of requiring a range of or alternative communication methods. If the communication problem is located within the social and organisational context, then the responsibility for solving it lies with the school, its staff and the way resources are allocated. In this instance we are informed that 'assigned specific council advocates' would meet them in lunch times 'to communicate in alternative ways so that all student views in the upper school are fully included'. This is indeed a positive example of taking account of the voices and views of pupils with impairments, who continue to be disabled by the lack of appropriate and accessible methods of communication in education settings. However, the fact that this takes place within a segregated, special school setting, emphasises the isolation or exclusion experienced by these pupils from the mainstream education context overall. As long as not all schools are geared up for alternative communication methods as a matter of course, disabled pupils and their voices are not equally heard and thus not equally valued. As a result, whilst this web page reports a positive case study, the underlying messages about disabled people's place in society and how their difference is less valued undermines the concept of inclusive Citizenship.

Reporting a positive, but segregated, example of a Citizenship project, in the language rooted in the bio-medical model of disability, has the effect that this out-dated model is reinforced and perpetuated. Inherently, disabled pupils as subjects in Citizenship are relegated to the edge of educational experiences, rather than its mainstream. Teacher Net, through its link from DfES internet pages, provides a limited view of disabled pupils' role in active Citizenship. The positive message of involving disabled pupils and listening to their voices is further reinforced as the report of the project also features in the professional press, such as the Journal of the Association for Citizenship

Teaching. Whilst there is a very positive message about including and listening to the voice of disabled pupils, the broader context, the language and underlying assumptions surrounding this project create a real danger of reinforcing outmoded ideas rather than assisting educationalists to shift into the new paradigm (Chapters 2: 39; Chapter 4: 130 – 133; 135 - 139 and Chapter 5: 190 – 192; 203).

Web-based Resources for Citizenship

In light of the Ofsted report (2004) which noted increasing reliance on internet websites as sources for the teaching of Citizenship, the content and design of these web pages and importantly their link to other internet sites, shape and reinforce particular ways of thinking about the subject of Citizenship.

Therefore, if these resources and internet links do not include the voice and the concerns of disabled people, from a social model perspective, and if no direction is given to sites that do, then practitioners in the field are far less likely to shift their own *Denkmuster* into the new disability paradigm, let alone provide opportunity for the learner to explore that direction. In their review of Initial Teacher Training (2004) Ofsted noted that web-based learning and information is invaluable in this particular subject area of Citizenship. Ofsted recognises that generally teachers' subject knowledge is limited in relation to Citizenship and that the knowledge-gap can be bridged by use of the internet and web-based learning opportunities, advice and discussion forums:

'Citizenship-specific web-based facilities are used very well in nearly half of the courses inspected. They enable tutors and trainees to offer and obtain support, share resources and discuss controversial issues relating to the teaching of citizenship. These resources play an important role in meeting trainees' subject knowledge needs in a curriculum area that is still being recognised and where there are fewer resources than for more established subjects.' (Ofsted, 2004: 2)

A starting point might be the department for education and skills' website on Citizenship 'What is Citizenship' is explained according to three strands identified in the Crick Report (1998) as (i) social and moral responsibility, thus concerning issues at an individual level, (ii) community involvement, which is locating citizenship at the inter-subject and group level, and (iii) political literacy, which is looking at institutions and political processes of democracy

and decision-making. These components, the DfES advises, should run through all education for Citizenship teaching.

From the social model of disability perspective, the question arises to what extent disabled people are included in discussions about and the learning of topic descriptions as presented on the website. For instance, how are disability issues included with reference to three key aptitudes and behaviours that the DfES describes in citizenship education? If the curriculum is designed to encourage 'self-confident behaviour in and beyond the classroom, towards those in authority and towards each other', how does this reflect and refer to disabled people's experiences? The Citizenship Foundation claims that 'It helps them to develop self-confidence and successfully deal with significant life changes and challenges such as bullying and discrimination.' To what extent does this apply to disabled pupils and to non-disabled pupils in dealing confidently with disabled pupils or disabled adults? (Chapter 4: 120 – 122; 172ff on bullying; Chapters 3 and 4 on discrimination).

Likewise, in the second strand of community involvement, how are disabled people positioned in the context of 'pupils learning about becoming helpfully involved in the life and concerns of their neighbourhood and communities, including learning through community involvement and service to the community'? How can this be realised for disabled pupils, and reach the Citizenship Foundation's goal that Citizenship education 'enables them to make a positive contribution, by developing the expertise and experience needed to claim their rights and understand their responsibilities, and preparing them for the challenges and opportunities of adult and working life.'? How do disabled people feature in the opportunities of adult and working life? (Chapters 3: 55 - 67 employment and Chapter 5: 218 – 232 family life). And finally, what do pupils learn about the role and impact that institutions have on the lives of disabled people as citizens locally, regionally and nationally? The Institute for Citizenship emphasises the active engagement necessary: 'they should be encouraged to think critically about their role in society and their potential as agents for change.' With reference to the Advisory Group on Citizenship's 1998 report, the Institute for Citizenship concurs that the main aims of Citizenship education is 'for people to think of

themselves as active citizens, willing, able and equipped to have an influence in public life' (Education for Citizenship and the Teaching of Democracy in Schools' para 1.5). To what extent are pupils inspired to think critically about disability equality issues and actively engage as agents towards change in reducing disabling barriers in their school context and the wider community? How is the active participation and involvement in real experiences in the school and wider community connected to the experiences of disadvantage or success of disabled people? To what extent does this include disabled people as active agents for change?

Ashley School in Widnes, Cheshire

Reference is made in this regard to a positive project of a two-year pilot in Ashley School in Widnes, Cheshire. A mixed-age and gender group formed an anti-smoking campaign ACT in 2002. Working both within the school and outside the school the group engaged in several activities, including a visit to the House of Lords where they met Lord Jack Ashley. Apart from the obvious link to Citizenship in the political process of informing him about their ACT campaign and in finding out what the Government's position is on the smoking issue, this event provides opportunity to make a range of disability equality issues explicit, as discussed in Chapter 5 in relation to the d/Deaf community, parliamentary campaigning of disabled people, the importance and meaning of independent living for disabled people. Such disability equality dimensions can be touched upon as the students interact with a disabled person in authority and someone with a long history of campaigning for the rights of disabled people.

Diversity

In May 2006 the DfES set up the Diversity and Citizenship Review Group with a former head teacher Sir Keith Ajegbo in the chair. The findings fed into the current Review of the National Curriculum on Diversity and Citizenship. The concept of 'diversity' in this report is largely based upon 'race' and key proposals are that citizenship education in secondary schools should address community cohesion, shared values and the subject, a fourth theme, of 'Identity and Diversity: Living Together in the UK'. However, as before, the experiences of oppression by disabled people and their active struggles toward achieving change have had no space in that review.

The review itself has attracted much publicity and has apparently been 'welcomed by educationalists and the public alike' (DfES). Posted as an online article, readers are referred to another internet link for a full copy. Significant inter-referencing of web sites on Citizenship creates a close reader community in relation to a common endeavour. Knowledge structures are formed, reinforced and perpetuated in ways that shape the process of 'knowing'. In fact, key internet web sources for Citizenship (DfES, Citizenship Foundation, QCA, Association for Citizenship Teaching and 'teachernet') all reinforce the positive message and broadly agree with the particular views presented. For instance, Tony Breslin, Chief Executive at the Citizenship Foundation said:

"We welcome Sir Keith's suggestion that a fourth strand, 'Identity and Diversity: Living together in the UK' should inform future curriculum models as well as his call for an approach to citizenship education that is informed through the lens of history. This approach brings a welcome focus to the role of issues such as immigration, universal suffrage, the legacy of slavery and the EU, in forming the Britain that we are today and in shaping our multiple identities and our shared values." (Citizenship Foundation, 25 January 2007)

ACT applauds Alan Johnson, Secretary of State for Education and Skills, who said: 'I think that this report marks the coming of age of Citizenship as an important part of the national curriculum.' The key recommendation of his report involves the teaching of identity and diversity as a new element of the secondary curriculum for Citizenship education, something which Mick Waters, Director of Curriculum at the QCA, agrees:

"QCA welcomes the publication of Sir Keith Ajegbo's report into diversity and citizenship. It draws attention to the need to promote better understanding in our schools and in our society about diversity and citizenship across the curriculum. We at QCA have already taken steps to give citizenship and diversity a greater prominence in schools and are continuing to look at ways in which diversity can become more embedded into the curriculum. All recommendations are covered in the revised secondary curriculum which is due for consultation in February." (QCA, 25 January 2007).

Circles of Knowledge

Whilst I concur with much of the praise about such matters as giving greater prominence to Citizenship in schools, looking at ways in which diversity can become more embedded into the curriculum, or teaching identity and diversity as an issue relevant to Citizenship, I remain concerned that disability issues, disabled identity, and diversity as it relates to people with impairments, are at best only conditionally referenced. In that way, practitioners are learning about Citizenship teaching by becoming members of 'communities of practice' (Wenger 1998, 2001), but disabled people as citizens remain excluded in their discourse. Educationalists looking for guidance, sharing ideas and contributing resources to the teaching of Citizenship are creating and sustaining a particular knowledge of the subject matter.

'Over time, this collective learning results in practices that reflect both the pursuit of our enterprises and the attendant social relations. These practices are thus the property of a kind of community created over time by the sustained pursuit of a shared enterprise. It makes sense, therefore to call these kinds of communities: *communities of practice*. (Wenger 1998: 45)

Given the prominence of internet sites in terms of the production of knowledge and process of knowing, closer attention is paid in this next section to the resources that are either available or referred to online. All trainee teachers are reminded of their responsibility towards Citizenship, and that information again privileges certain routes of information over others (TTA, 2003), thus contributing towards an 'inner circle of knowledge'. The Institute for Citizenship particularly promotes the teaching of Active Citizenship:

'For this to occur, Citizenship education needs to be thought provoking, inspiring and actively engage students with the political, social and moral issues of the world around them. It is recognised that such learning cannot be purely abstract and classroom based but also requires young people to learn through active participation and involvement in real experiences in the school and wider community. To this extent, one of the key elements of the National Curriculum Citizenship Programme of Study is aimed at developing students' skills of participation and responsible action.'

It states that support for these activities in teaching Active Citizenship can be found from a wide range of organisations and they offer 'a selection'.

Members of this growing community of practice are invited to add resources and are asked to contact the organisation with their ideas. The page of resources and organisation links lists of government bodies, citizenship education organisations and miscellaneous as detailed in Appendix A (accessed throughout 2006 – 2007; recent update May 2007).

Despite such extensive external links on the broader issue of Citizenship, disabled people's perspectives appear to be largely absent. Disability equality issues, then, are not directly addressed in any of the resources or links. A concern with disability is found as a conditional reference to Citizenship only, that is: when disabled people are positioned as 'Young People with Special Educational Need', for example. This particular resource refers to a year-long project of developing activities in a number of schools, which were written up by eleven teachers. The website describes that 'the activities are specifically targeted at pupils with severe and profound and multiple learning difficulties (SLD and PMLD) between the ages of 11 and 16 but are suitable for a wider ability and age range'. Whilst remaining within a segregated, special educational needs perspective and language, the project appears to indicate the potential for the use of this resource in schools away from segregated settings and within mainstream education encompassing a diverse range of learners. The only specific disability reference to disabled people as citizens found on this resource list is to the BBC pack 'Focus Citizenship: Minorities. 'Through drama, documentary and personal testimony these programmes consider the themes of disability, skin colour and refugees.' However, because this resource is not available for free and is not referenced in the 'inner circle of knowledge', it thus remains at the margins. Furthermore, disabled people are not themselves in control of the content and past history of the media leaves critical disabled academics suspicious (Oliver, 2006). In developing a 'shared repertoire of resources' (Wenger, 1999) members of the developing community of practice around Citizenship education re-affirm their domain, establish a community and develop practice by exchanging their 'experiences, stories, tools, ways of addressing recurring problems—in short a shared practice' (Wenger, online).

From Disabled People's Perspectives

One resource that has no direct internet reference within this shared community of knowledge but is explicitly connecting disability equality issues with citizenship education is the 'Citizenship Pack' from the Disability Rights Commission. In March 2003 the pack was launched and made available to schools across England, followed in February 2005 for Scotland and March 2006 as a bi-lingual resource for Wales. Over 5000 packs are in schools in England and Scotland alone. This classroom resource consisting of the award-winning short film TALK (introduced in Chapter 2; free copy available from DRC), eight lesson plans with interactive activities, trigger photographs and fingerspelling cards, has been matched to KS3 and KS4. This pack for the teaching of Citizenship is designed to address disability equality issues within the national curriculum subject of Citizenship and strands of PSHE. However, resources do not speak for themselves. Having packs in schools alone does not translate into connecting disability equality to Citizenship education.

Likewise, the availability of positive or challenging internet resources alone, such as the link to the DRC micro site or the Paralympics site of 'Ability vs Ability' is not sufficient to effect a shift in thinking. 'Ability vs Ability', for example, provides a wide range of interactive resource material

'interviews with new generation Paralympic athletes; a media bank of photos of athletes in action and Olympic video material; FrameGrabber tool to freeze, caption and save images from videos; six fun Paralympic quizzes; ten activities for young learners aged 9–16; fact files about the Paralympic movement; hotlinks to a wide range of related websites; and support guidance for teachers'.

Ability versus Ability: Nothing else

However, the extent to which this can assist in opening up the debate towards new thinking and a change in *Denkmuster* is contingent on a range of factors. This challenge will be illustrated in the next section.

'**Ability versus Ability ... Nothing else**' introduces Paralympic Athletes and offers the learner interview data in order to meet and get to know the person better. Sascha Kindred and Clare Strange are two of the twelve athletes with

interview clips. In response to the question 'When did you begin swimming?' Sascha explained that he was eleven years old, which is quite late to start swimming. He elaborated that 'because of my disability my mum was reluctant to let me go into the water'. We find out that his brother, who is not disabled, was allowed, and that Sascha wanted to do what he did. When asked about his first competition event, Sascha explains that it was along time ago at a 'CP Gala' for people with cerebral palsy and that his impairment was right sided Hemiplegie. Sascha goes on to detail an impressive range of positive achievements, including winning gold medals in Sydney and Athens. Left as it stands and without guidance there is a danger that learners fall back into traditional, tragic and charity models of disability as is evident in the 'At the Schoolgate' scenario in Chapter 2, when interacting with some of the information provided by this resource. Disabled people themselves do not necessarily see themselves as 'disabled' within a social model understanding. To present reasons for the exclusion from swimming in terms of 'because of my disability' fails to give due regard to social and institutional arrangements, to the attitudes of experts or people in charge when making judgements about the aspiration of disabled children (as discussed in Chapter 2; facts and figures in Chapter 4: 108 – 110; final inmate role, aspirations and institutionalisation in Chapter 4: 114 - 117).

Similarly, Clare Strange provides interview data that has the potential to reinforce tragic conceptions. When asked how long she had been playing wheelchair basketball, she said eight years, ever since an accident in 1997 left her paralysed. The follow-up question of 'What age were you when you started?' gave further opportunity to reinforce this event as cruel, unexpected and life-changing as Clare states she had just turned 18 and was in the middle of her A-levels when the accident happened, and that 'it was all a bit crazy'. As if to underscore the idea of the need for adjustment (Oliver personal tragedy 1990; adjustment theories in Chapter 2) the interview data provides evidence that Clare initially took up the sport of wheelchair basketball as a rehabilitation activity (cf. New Deal, rehabilitation and return to work FDR in Chapter 5: 206). Clare admitted that in her view teachers struggled when she went back to school. 'They could not treat me as Clare ... and started mothering me' she complains. As with Sascha, Clare also firmly advocates to

follow one's dreams and the idea of personal best: 'Really follow your dreams and go after it 100 percent' (Ability v Ability online).

Aspiration in Citizenship

There is a concern that teachers inherently subscribe to a restrictive notion of citizenship as an 'ideal citizenship against which achievement can be measured and towards which aspirations can be directed' (Marshall, 1950: 29). The danger is that the aspirations, hopes and dreams of disabled young people are marginalised. In an American study Alston, Bell and Hampton (2002) examined the attitudes of 140 parents and 323 teachers of students with ascribed learning difficulties, who wished to enter science or engineering careers. The researchers examined the perception and concerns of parents and teachers in eight 'attitude-areas' of (a) access, (b) reasonable adjustment (accommodating difference), (c) role models, (d) teacher understanding of student needs, (e) length of learning time, (f) students aptitude and educational preparation, (g) career guidance, and (h) employer attitudes. Unsurprisingly, they found that parents thought teachers overall lacked commitment and were reluctant to support students with learning difficulties, and that they did not make the necessary effort to effect reasonable adjustments. Employers in the engineering and science field were found to be reluctant to consider disabled trainees and in particular were reluctant to hire someone with a learning disability. Irrespective of the 'objective truth' about teacher's attitudes, such as their actual approach to finding accommodation (reasonable adjustments) for disabled pupils, it is in the subjective lived experience of parents that the reality of citizenship for disabled pupils has been mirrored. For even if the young person's entry into science careers is thwarted by a *perception* of unhelpful teachers, rather than their actual reluctance, young people's sense of citizenship rights of belonging, of respect and valued contributions are not realised as long as this perception persists. The attitude and advice of adults, of teachers and parents is important in young people's choices and plays an important role in determining career options (Dick Rallis, 1991). Whilst it is significant that the views of disabled students themselves were left out in this particular research, the substantive findings are nevertheless echoed in the UK by research undertaken by the Disability Rights Commission (2002, 2005), by first-person accounts of

disabled people (disabled athletes in 'Ability vs Ability'; disabled young people in ATLAS; disabled older people in SCOPE 'In our own voices') or are supported by Ellis and Porter (2005):

'Their findings suggest that the teachers of the core subjects, English, mathematics and science, had less positive attitudes than their colleagues. Further, pupils with special educational needs made least progress in science where teacher attitudes were the least positive.'

Ellis Porter (2005)

The experience of quashed aspirations is echoed by Thomas Quasthoff, a base baritone and thalidomide survivor. His aspiration in the mid 1980s was to become an Opera singer (Quasthoff, 2004), but despite his talents and shortly before the entrance exam the music school decided not to interview him as 'he would never be able to complete the academic requirements of the music degree', which included the requirement to play an instrument. Quasthoff, who since worked with Sir Simon Rattle, Daniel Barenboim, Seiji Ozawa, Christian Thielemann and others, has twice received the *Deutsche Grammy* award, titled his biographical film 'the dreamer' and the world premier of the film took place at the Vienna state opera, where he succeeded and performed as an Opera singer. Any music curriculum would be enhanced by *Lieder* or jazz songs performed by Quasthoff and with it connect disability equality with citizenship values as it is in Quasthoff's own voice and illustrates barriers experienced as a person with an impairment and the resourcefulness of disabled people in this ongoing struggle of active engagement. The film was produced without any sponsorship of music companies or TV-coorporations and awarded as 'Best Documentary 2005' it could be used in Film and Media studies. Furthermore, since it is bi-lingual in English and German, excerpts of the film could feature in German language classes.

Citizenship and teaching competence

In the context of inclusive citizenship, the question, therefore, arises as to the willingness, the extent and knowledge and effectiveness of teacher's delivery of disability equality issues within the curriculum. I argued earlier in this section that resources do not speak for themselves. I shall shortly promote the idea that resources need to be framed by teachers through an emancipatory

approach (Geelan, Taylor, Day, 1998) if they are to be effective in encouraging the imagination of learners towards a shift in perception of disabled citizens. This argument is extended, in that teachers require the necessary baseline knowledge in Citizenship and inclusive citizenship values. For disabled people these values involve respect, self-determination, valued participation and an open attitude or willingness that allows changes to 'business as usual'.

The teacher zone for 'Ability vs Ability' provides generic approaches to teaching, for example on 'Direct Teaching' strategies adapted from 'The Framework for the Teaching of Mathematics' and in the 'Connecting the Learning' guidance. These support materials for teachers build upon what is generally accepted as good teaching practice, but they remain so generalised as to show only bones and no flesh. What does it mean in the teaching of Citizenship that addresses disability equality issues, for instance, when the teacher is advised to 'give accurate and well-placed explanations' or to 'listen carefully to pupils' responses and responding constructively in order to take forward their learning'? Such advice assumes a good baseline knowledge surrounding disability equality in the first place. A Paralympic Resource Pack (2000 – 2005) is also available via the teacher zone with pdf-teacher information cards. Two cards are firmly connected to Citizenship in the national curriculum. Card 15 outlines the statutory requirements, including the teaching of Citizenship, whilst Card 16 details Citizenship learning objectives and what this means in relation to Paralympics:

'Pupils should be taught about human rights issues including those for the disabled person, such as

- barriers to participation
- access to facilities
- transport arrangements or facilities

They should be taught to identify social justice issues and respect the need for democracy and where appropriate be able to take an active role in local community activities and public life, including the support and provision of sport and leisure opportunities for the disabled.'

The National Association of Schoolmasters Union of Women Teachers
(2002)

Citizenship education is regarded as a human rights issue and the fact that disabled people experience barriers to participation is equated with human rights. This understanding of human rights falls within individually enforceable rights against other individuals or organisations, such as covered by the Disability Discrimination Act, or against the State as covered by Articles in the Human Rights Act. However, the language of homogenising 'the disabled', the practice of conditionally referencing disability issues into Citizenship for the disabled, and by regarding disabled people as objects rather than subjects of citizenship activities, confirms the struggles that even a well-intentioned, well-informed resource has in getting shifted into new disability paradigm. The guidance offers much positive evidence of a social model potential, but ultimately fails to fully embody inclusive citizenship.

Connecting disabled people to Citizenship

A further complicating factor for the inclusion of disability equality issues into Citizenship resources is a perspective that covers 'disability awareness'. Even when a resource can be found, albeit not referenced in the 'inner circle of knowledge' for Citizenship teaching, that resource will not automatically improve inclusive Citizenship that respects and values the contributions of disabled people, one where teacher and learners are shifted into a social model, anti-discrimination approach, with active engagement. Citizenship resources for key stage 3 and 4 of the curriculum that have been successfully piloted. York or Leicestershire, for example, list a range of activities and include some with reference to disability (Institute for Citizenship Education, Introduction to Disability Awareness, online). Emphasis is given to the fact that these resources feature disabled young people and are developed with the input and real life experiences of disabled young people. Clearly, such approaches are commendable in terms of acknowledging disabled people as active citizens.

However, the theme is often of 'disability awareness' rather than disability equality. Sometimes children are given specially adapted glasses or a wheelchair 'to see what it is like not being able to walk, or not being able to

see properly' (teacher, anon), or exercise that ask to imagine how they would feel as a disabled child or how children 'with special educational needs' sometimes feel (exercise 9 and 12 Institute for Citizenship). These types of activities are in danger of reinforcing impairment and with it the loss and tragic perspective. They do little to draw attention to access barriers. It would be better to construct activities where children recall or experience their own barriers to participation (not impairment), from which to reach into Citizenship values. In that way they can emphasise with what it feels like to experience barriers, be discriminated against and excluded. I will use one set of positive images of disabled young people and the resource their internet site provides as a basis for my argument that teachers themselves need to understand and be committed to a social model understanding of disability in order to advance disability issues within the teaching of Citizenship. Well intentioned resources and 'Awareness' is not sufficient.

Youth Web

This web link does not feature in the 'inner circle of knowledge' in the developing community of practice around Citizenship education. However, it is an example of a free resource that is informed by the voice of young people. The Youth Web claims that 'it allows young people in Leicestershire to communicate directly with peers and those responsible for their education 'on a range of issues, including crime, sexuality, friendship, multi-culturalism, diversity, personal safety'. But will they – adults and people in authority - listen? Whilst disability issues, as argued in this thesis, can be read into all of the subjects, specific reference is made at Youth Web to 'disability awareness' and 'independence'. The latter resource has been created by young adults from the VERVE Independent Living group and features nine narratives and first person accounts of disability experiences. VERVE stands for variety, equality, respect, values and enjoyment and thus aims to encapsulate the essence of what Osler and Starkey (2005) call 'cosmopolitan citizenship'. Sixth form pupils from Ashfield Special School provide three photo-stories and an online questionnaire with the aim to raise 'disability awareness'.

First person accounts by disabled people as represented in photo-stories or picture enhanced short text narratives are 'raw' resources that do not speak

for themselves. They can be employed in a range of contexts and used in a variety of ways. A twelve-picture story of Yolanda in VERVE, for instance, shows a young woman, who is a wheelchair user, living independently in her own home. She likes chatting, meeting friends and a couple of photos show her out and about. The narratives behind the pictures do not reveal themselves as an abstract, 'correct' version through its visual and written text alone. Text cannot reach its audience purely by looking at it, but requires decoding by either conscious or subconscious understanding. Such understanding is acquired by exposure to and engagement with language, text and art-form, and in reference to a shared cultural heritage. Louw (1993) argues that subconscious understanding develops over time and 'is build up of our previous experience' of word associations, for instance (Maybin 1996: 171). Chapter 2 explored the word associations in response to the 'At the school gate' scenario, and research data showed that the responses were overwhelmingly rooted in a bio-medical, charity model ideas and thinking pattern of disability. Therefore, if resources are used in a way that simply recalls or implicitly relies upon our common cultural understanding of, say 'the meaning of disability', out-dated modes of thinking are likely to be affirmed and through the process of teaching 'disability awareness' such ideas are likely to be reinforced, perpetuated and remain within the old meaning despite the new context of Citizenship. What is required is that the learner (both teachers and pupils) are provided with an opportunity to challenge their thinking and to explore the new paradigm of disability. This can only be successful if thoroughly grounded in a social-model understanding of disability (Oliver, 1990), the first principle that frames this chapter, and through emancipatory participation by disabled people themselves, the third of this chapter's principle (political struggle). Concerned with values education in schools, which is what Citizenship as a National Curriculum subject separates from traditional subjects, Fisher (2000: 64) connects creative thinking, imagination and moral reasoning:

'The link between creative thinking and moral reasoning is summed up in the need to encourage imaginative reasoning. ... this is necessary if children are to come to see themselves not only in relation to others in

the present world, but also in the world that could be ... transcend the present to construct an understanding of what could be.'

The VERVE photo-story uses 'foregrounding' of the person by placing Yolanda as a cartoon-drawn figure into the photographic setting.

Foregrounding unsettles the reader's expectation by presenting a 'fresh perspective' (Maybin 1996: 163). Attention is drawn to the disabled person in her context, and the reader is challenged to look again from a different perspective. In a photograph one would expect everything to be represented as a photo-reproduction. To suddenly see the person Yolanda as a drawing positioned into the frame of the photograph has the effect of surprising the reader. In this way the resource subtly, but powerfully underscores the theme of a paradigm shift and change in *Denkmuster*. The reader is challenged to look afresh at the disabled person not as a passive recipient of care and being looked after, but as an active person in her own home, washing up, making a cup of tea, chatting on the phone, calling an accessible taxi, ordering drinks at the bar and sitting with friends in the pub.

A connecting pedagogy

A range of teaching techniques and activities are employed in the teaching of Citizenship. In relation to disability equality issues, a similar range of techniques have been developed. It is, however, imperative that pedagogic approaches involve challenges to traditional disability models. Therefore, when using first person accounts, the input of disabled people themselves, stories or narratives, real life experiences, media reports, pictures, visits to establishments, fund-raising activities, teacher-pupil exchanges in the classroom and within the broader school environment, IRF (initiation, response, feedback) sequences in classroom interaction, guiding questions in group work, specific tasks or community activities as part of teaching Citizenship, it is important to 'recruit children's imagination' (Bruner, 1980; 1983; 1986). Imagination about difference is a first step in learning about disability as more than a tragic, sad, sympathy invoking unchangeable condition of poor sufferers, but of disabled people as actively participating citizens. Democratic teaching styles lend themselves better to this 'awareness- and imagination-raising' outcome than traditional ones (McKinney, 2005). The IRF exchanges (Sinclair and Coulthard, 1975)

between teachers and pupils in classrooms have been critically observed, whereby teachers are the primary initiators, whilst pupils rarely do. Gary's page at VERVE (enter Gary's page and 'ask Gary') appears to reverse this. He introduces himself with a brief text and invites the reader to engage in a question and answer session. A classroom cartoon of pupils and Gary himself, invites the reader to use the mouse/ direct the cursor to 'prod' one of them (the pupils) to ask a question and see Gary's answer appear on a speech bubble. The design of the webpage and the virtual interactions that are possible replace or complement the physical teacher in the actual space, but the teaching and learning function remains the same. Gary's web page takes the place of the teacher and the fact that the questions are given means that the web page is *initiating* the sequence of interaction. And this interaction itself may take place as a classroom activity, where the teacher continues with feedback and enables further IRF exchanges. Mercer and Swann (1996: 123) report Dillon (1988) and Wood (1992) amongst others, who have 'suggested that teachers' questions tend to suppress pupils' contributions to classroom talk, because they are usually designed just to elicit one brief *right* answer'. There is a danger that the VERVE interactive resource equally treats disability issues as having just one *right* answer.

This can be further illustrated by the example, where prodding of one particular student on Gary's web page elicits the question 'How long have you been disabled?' to which Gary, who is a wheelchair user, answers 'All my life'. Left as it stands students' learning about disability equality may get the wrong impression, or reinforce traditional ideas that people are born with their impairment. One of the first responses of young people to the question 'what is a disabled person' is the image of a wheelchair user (Chapter 2 research), whilst less than 6% of all disabled people are wheelchair users. Equally, a frequent assumption is that disabled people are born with their impairments, but over 83% of impairments are acquired later in life, only 17% of disabled people were born with their impairment (Institute for Public Policy Research, 2003). These, and other facts presented in Chapters 3 and 4, seem crucial to a teacher's baseline knowledge and understanding in order to be equipped to discuss inclusive Citizenship in relation to disability. The internet support available and resources to hand within the Citizenship discourse community

fail to offer baseline knowledge and cannot adequately support teachers and learners.

Teachers may generate a whole series of initiations and children learn to reply only to the last one, as Graddol (1994: 212) reports 'children operate the rule that they only answer the final one'. Whilst children generally participate readily in IRF sequences (Willes, 1983; Edwards, 1992; reported in Mercer, 1996: 124), study of Aboriginal conversational styles in Australia found that children there 'failed to perform their appointed roles in the discourse' (Malcolm, 1982: 129 reported by Mercer *ibid*). However, the language structure of IRF exchanges can be used for more than one type of function. In the teaching of controversial issues there are rarely any *right* answers. McKinney (2005) explores specific dilemmas arising from a critical pedagogy approach and refers to Weiler (1991: 462) for the need to make explicit the teacher's and student's own subject positions, and in particular 'making the teacher more visible'. The particular context of language, culture, disability and other experiences together with teachers' value systems has to be acknowledged. In the same way that teachers with racist or sexist or homophobic attitudes and values are unsuitable for enhancing children's imagination about difference, teachers who remain 'traditional' in their responses to disabled people are likewise a barrier to the teaching of inclusive Citizenship.

Teacher self-perception

The extent to which a teacher is or is not grounded in the social model of disability becomes an important determinant for the way children's imagination can be recruited and their understanding of disability equality enhanced and thus of inclusive Citizenship. It is a relevant but not a conclusive condition that the teacher has an impairment and is disabled themselves, but the extent to which they themselves have shifted into the new paradigm is a necessary condition. The question, therefore, is not whether a teacher is disabled, but which perspective or understanding that teacher brings with them, their 'emancipatory' self based upon espoused values, with which students should engage, as described by Geelan et al (1998). Engaging with values is not to be confused with agreeing with them.

Recent research of professionals with hidden impairments examined their own training and working experiences (DRC, 2007), some disabled teachers (e.g. Teacher 1) noted a shift in thinking in terms of 'times were changing and that wider societal understanding and acceptance of disability and impairments, including mental health problems, could be found' (DRC 2007: 36), others (e.g. Teacher 2) positioned themselves still as a disabled person within the 'deserving poor' perspective (Chapter 4, 144 - 145), whilst others (e.g. Teacher 3) noted ongoing barriers to the active participation of disabled teachers in professional life:

"Up to recent years I wouldn't have used them at all, I think it is a very much case of the minds of people have moved on, the acceptance of certain usage of words have become more familiar and accepted, and the social aspect has become more accepted. Depression was never talked about openly." Teacher 1

"I sometimes feel like if I say I'm disabled I'm being a bit of a fraud because I see people around me who are much worse off." Teacher 2

"I think there's still a stigma with some people who think ... if I say to anyone that I've got ME, they think it's all in my mind and you know and that's why a lot of people don't talk about it openly." Teacher 3

These examples show how the self-knowledge of teachers varies and is not solely determined by or depend upon having an impairment themselves. For a positive use of recourses that addresses disability equality issues within Citizenship, self-knowledge that is grounded in the social model of disability is helpful. However, the institutional context might make such a perception difficult. Over 53% of impairments can be described as 'hidden' in that they cannot easily be seen or are not immediately obvious to others. To disclose or not to disclose unseen impairments has left many disabled people unsure of how to present their public disabled identity. One option is not to see oneself as disabled, another is to 'pass' as not having an impairment, a third is to 'selectively disclose' and a fourth is to 'stand proud'.

Not seeing oneself as falling within the definition of 'disabled person' as framed within anti-discrimination legislation, is partly related to lack of knowledge about the law, partly to what has been learned about the meaning of 'disability' over the years, and partly to negotiating particular contexts and

social relations. Reflecting on researching disability and higher education Alan Hurst, writing in 1996 - the same year that the Disability Discrimination Act received Royal Assent - stated that 'unlike some of the contributors to this book I do not have a disability'. He then goes on to detail some of his impairments, which by the sound of it might well fall within the legal definition, such as the Asthma he mentions (1996: 124). People with Asthma may fall within the definition of the DDA. Given certain circumstances on how the impairment impacts on daily life, Alan Hurst, then, may be a disabled person in strict legal terms under the DDA, but he is most likely not a disabled person under Incapacity Benefit legislation. He is neither seeing himself as a disabled person - at least not as a 'real' disabled person when he says 'I cannot claim to have experienced the hostility, prejudice and oppression felt by others (other 'properly' disabled people) - nor are other people typically likely to regard him as such.

In an attempt to support disabled students, the University of Oxford has provided a series of information packs, one of which deals with Asthma (Oxford University, 2004). The University recognises that students may not see themselves as disabled 'If you have a medical condition such as Asthma, you may not consider yourself to be disabled, but you may need support or special arrangements in Higher Education'. Only after having read two pages of impairment-focused information, about the bio-medical circumstances, symptoms, causes and diagnosis, how an attack is triggered and such, does the student enquirer find access-information about what the University can do to enable successful study. The disabled student is spoken to as someone almost identified with their impairment and not as a citizen 'willing, able and competent' to fulfil duties and responsibilities as a learner. At page three of the document the University helpfully points out that reasonable adjustments can be made, although the language is not that of 'access' and 'rights', but of 'welfare' and 'care'. So, rather than sharing information about 'alternative' examination arrangements, the booklet refers to 'special' or 'separate' arrangements. The discussion of the workhouse ethos (Chapter 4) comes to mind, where the twin concerns of 'care' and 'control' dealt with disability issues. Special arrangements were made if you were a 'deserving poor' and separate arrangements 'in your own best interest' or 'for your own protection'

or to protect others. Furthermore, rather than in dialogue with relevant officers at the University, the University asks the student to make an appointment with a medical expert, as medical referral and letter of evidence is required before arrangements can be made. A shift into a rights-based approach, in contrast, understands that disabled people fall within the definition not to qualify to get something extra or additional, but to be protected against being treated unfairly. It would be unfair to expect a student to demonstrate particular subject knowledge in test circumstances that may trigger an Asthma attack. Better to remove those negative conditions to properly ascertain how much the student has actually learned.

With this emphasis on impairment and deficit no wonder 'successful' academics are reluctant to bring themselves within this label. In the process of identity formation people are hailed into subject positions, what Althusser (1971) calls interpellation:

"I shall then suggest that ideology 'acts' or 'functions' in such a way that it 'recruits' subjects among the individuals (it recruits them all), or 'transforms' the individuals into subjects (it transforms them all) by that very precise operation which I have called interpellation or hailing, and which can be imagined along the lines of the most commonplace everyday police (or other) hailing: 'Hey, you there!'"

Althusser, 1971: 174

However, disabled students and disabled staff who do not regard themselves as 'disabled' appear to reject this ascribed inferior identity: 'do they mean me?'

Connecting disabled identity to Citizenship

Whether or not the person adopts a 'disabled identity' depends upon a range of issues and contexts, which can lead to a multi-layered approach in taking up an identity in one context whilst rejecting it in another. Identity is confirmed in relation to others, it is 'a concept that presupposed a dialogical recognition of the other' (Isin and Wood 1999: 19). Keeping a disabled identity hidden and out of the public domain through non-disclosure reduces that person's participation and citizenship. In their discussion about sexual citizenship Isin and Wood draw a similar parallel:

“Once again, understanding of the relationship between space and citizenship is crucial.... gay rights are also about access to public space.... Public space is about visibility and access for the citizenry and central to the idea and the *performance* and *practice* of democracy (Berlant, 1997; Grube, 1997). This access to public space concerns not the performance of sexual acts in public, but the right to participate in public processes as a *sexual person*, even if that sexuality is homosexuality.” (1999: 85)

The ‘coming-out of the closet’ for disabled people as a person, even if that person is a person of difference, is a political process in itself and essential in the political democratic practices of lived citizenship.

“It’s a bit like coming out of the closet, it’s something you’re constantly doing, you don’t just disclose it once... because you’re going on a placement, when you are on placement you might go and spend a couple of weeks with another institution, so each new place you go to, actually means is that you’re disclosing all over again ... it’s not just you fill in a form and you’ve disclosed it, that just tells the University ...”

Trainee teacher (DRC 2007: 43)

In the employment context of teachers, nursing or social work professionals disclosure of impairment or health conditions carry a number of risks, not least the perception that teacher’s contribution and work will automatically and detrimentally be affected by their impairment or condition. Fears include being judged as inferior (Blankfield, 2001), as not coping or as less able (Stanley et al 2007). As to ‘fitness to work’, the Disability Rights Commission found over 70 separate regulations and pieces of guidance across these three employment sectors, none of which took account of the anti-discriminatory objectives envisaged by various provisions in the Disability Discrimination Act. In 2004 the Social Exclusion Unit expressed particular concern over stigmatising effects of living and working with a mental health condition, as one in 4 of the UK population will at some point in their lives be affected by a serious mental health problem (MIND). The DRC concluded that:

‘This means that disabled teachers, nurses and social workers are in danger of experiencing discrimination if they disclose their impairments

or long-term health conditions, both at the point of entry when they undertake training and also later on, once they start working.'

(DRC, 2007: 34)

If the institutional climate is not conducive to accepting and responding constructively to disclosed impairments, then disabled people not only feel unsafe, but of lesser value. This is not a climate that lends itself to the teaching of inclusive citizenship values. Advances in the anti-discrimination framework have had some positive effects on trainee teacher action, as the DRC reports:

'Professionals felt confident that they could disclose disability and described themselves as being more assertive in their attitudes as a result of knowing that the legislation was there to provide 'back up' or clout: It gives me clout, it gives me something to say, 'will you do this?' and if they say, 'no', I'll say, 'well look you're going to have to do this because I'm entitled to it'. Student Teacher (2007: 31)

Despite these positive comments, only 2% of the academic workforce in the post-16 sector, Further and Higher Education have disclosed an impairment or health condition (HESA statistics), whilst around 20 - 25% of staff are estimated to be disabled (DRC 1996; UCU UNISON 2007: 14; 42). Low disclosure rate is also evident in other sectors, with 60% of staff in Thurrock Council, for instance, expressing some fears about speaking out about concerns on disability discrimination or avoiding identifying as a disabled person for fear of dismissal (December, 2006). As discussed, under-disclosure may be related to people not seeing themselves as belonging to the protected group of disabled people within current British anti-discrimination measures. The Equalities Challenge Unit (2007) notes that over 50% of Higher Education staff, who would meet the Disability Discrimination Act definition do not regard themselves as a disabled person. A fifth of disabled professionals interviewed in the recent DRC survey had only partially disclosed their impairments and health conditions. Some professionals may see it as irrelevant to disclose as they see themselves as 'coping fine' (SKILL, 2007). Furthermore, disclosure 'was experienced not as a single event, but as a series of negotiations' (DRC, 2007: 6) pointing to the importance of establishing a dialogue between the disabled person and the organisation.

The law has defined who is a disabled person in very broad terms, in contrast to narrow definitions of traditional welfare-based criteria of a person entitled to disability benefits of some form or another (Chapter 3). Two shifts in *Denkmuster* that enable better disclosure are: (i) conceptualising disability not as a welfare-issue but as one of human rights, shifting into a rights-based understanding, and (ii) rather than delving into impairment questions, put access arrangements in place. Furthermore, not only does fear or misconceptions about disclosure place barriers to exercised citizenship rights, lack of or inappropriate organisational response further disables people. This means that an organisation needs to have policy and procedures in place to enable effective disclosure, thus enabling a dialogue followed by appropriate actions. Institutional arrangements and organisational behaviour in response to disclosed impairment equally raises questions as to the extent to which this will enable rather than disabled the participation and inclusion of disabled professionals. These questions of definition are compounded by a legal system that runs within two contradictory models of disability.

These issues of self-perception and disclosure are relevant in the teaching of Citizenship if the context of the school and the lived experience of disabled people are to be taken into account. An environment that in its perception or lack of action is hostile to the recognition and inclusion of people with hidden impairments presents barriers to the realisation of inclusive citizenship for all. In these post-modern times, when the terms 'disabled person' and 'disability' are still perceived by many as being the most stigmatising of descriptions, and professionals associate being a disabled person themselves with 'feeling inferior', 'made to feel inferior', as if 'you aren't able', or 'not full human beings', or being 'one of the weaker members of society' (Stanley 2007: 36), then education for Citizenship in a school context that includes disabled people on an equally valued basis remains a big challenge. The government has accepted that steps need to be taken to tackle misunderstandings, misconceptions and low levels of knowledge amongst the general public in relation to disability issues (Disability Equality Scheme, DfES 2006). One of the pillars argued in this thesis - that of shifting from identifying impairment as a problem to action on access issues - is also accepted, as the department

DfES points to the need to address and promote a better understanding of the difference between individual impairment on the one hand, and disabling social barriers on the other (DfES 2006: 12). Skill (2007), in response to that statement, argues that

“It will be necessary in doing this to ensure employers create a better climate for disclosure of disability and discussion of reasonable adjustments and promote positive attitudes amongst employees towards disabled people.”

In this chapter so far I have argued that in developing Citizenship as a curriculum subject circles of knowledge appear to exclude or marginalise disability equality. Whilst text, media and community-based resources and especially web-based resources are infused with the anti-racist messages, they remain mostly silent on disability equality. The debate on Citizenship Education at best only *conditionally* references disabled people. One of the reasons for this has been related to the discourse and broader structure of education, part of which still includes labels, systems and procedures of ‘Special Educational Need’, which Fulcher (1989) termed ‘the politics of special needs’ and Corbett (1996) referred to as ‘bad-mouthing’. These result in ‘special arrangements’ as well as language, perceptions and behaviour that emphasises impairment-based deficit descriptions. The relative low value attached to ‘special education’ has been illustrated by Norwich and Corbett (2000: 106) by looking at the training of teachers, which they describe as a marginalising process: ‘preparing teachers to understand and relate their practice to a wide range of needs is hived off in separate options, modules and day presentations.’ General teaching requirements now address inclusion as teachers are required to provide effective learning opportunities for all pupils. Guidance detail expectations and offer examples of meeting access learning requirements, such as diversity in formats, allocation of time, structure of lessons. Barber and Turner (2007) criticise Government guidance on initial teacher training ITT as becoming progressively more descriptive, an attitude which in itself could pose a further ‘hidden’ barrier to participation and inclusive citizenship.

Even positive, emancipatory resources do not speak for themselves but are qualified by contextual matters, such as teachers’ own subject knowledge on

disability equality, and implementation depends upon a democratising, participative and inclusive pedagogy. The 'best' knowledgeable and enabling teachers are not necessarily teachers who have an impairment themselves, in the same way that racism can be challenged by teachers with different ethnic backgrounds. Nevertheless, the visibility of disabled teachers is important. I have demonstrated that coming-out as a disabled person is essential in modelling citizenship, and that both internalised barriers as well as institutional ones reduce individual agency and the range of potential subject-positions that disabled professionals can take up. For disabled people to experience socio-cultural citizenship (Pakulski, 1997) means to have a right to be different, irrespective of impairment, impairment-related lifestyle choices or difference in learning access requirements; that right is linked to a necessity in society, and thus in education, to 're-value stigmatised identities, to embrace openly and legitimately hitherto marginalised lifestyles and to propagate them without hinderance. ... Full citizenship involves a right to full cultural participation and undistorted representation' (Pakulski 1997: 83). In the legal context and moving towards anti-discrimination approaches this necessity has been translated into a range of duties placed upon individual and social actors, such as employers, schools or colleges. This right to be different and concomitant necessity to re-value diverse identities is acutely applicable in the context of Citizenship Education with reference to disabled people. The emerging picture, however, is one where Citizenship Education is rarely touched by 'real' disability issues, and where disability equality does not connect to Citizenship Education. This next section examines the National Curriculum with reference to points of connection for disability equality and inclusive citizenship.

Connecting disability equality issues to Citizenship education

The National Curriculum sets out three areas of Citizenship teaching. Here I would like to emphasis not only that disability equality issues are capable of being connected to Citizenship, but that without doing so the objectives inherent in Citizenship education cannot be fully met. The National Curriculum on Citizenship should ensure that 'knowledge and understanding about becoming informed citizens' are acquired and applied when 'developing skills of enquiry and communication', and 'participation and responsible action'. The

first of these will be represented in full and examples of disability equality issues that fall within this description will follow together with references to relevant topics and Chapters in this thesis where these issues have been discussed. The National Curriculum on Citizenship is supplemented by suggested Schemes of Work, Unit 3 of which concerns Human Rights. Disability Equality will be 'read into' this unit as an illustration. A full mapping exercise has not been undertaken.

KS3 Knowledge and understanding about becoming informed citizens.

The National Curriculum requires pupils to be taught about:

1. the legal and human rights and responsibilities underpinning society, basic aspects of the criminal justice system, and how both relate to young people
2. the diversity of national, regional, religious and ethnic identities in the United Kingdom and the need for mutual respect and understanding
3. central and local government, the public services they offer and how they are financed, and the opportunities to contribute
4. the key characteristics of parliamentary and other forms of government
5. the electoral system and the importance of voting
6. the work of community-based, national and international voluntary groups
7. the importance of resolving conflict fairly
8. the significance of the media in society
9. the world as a global community, and the political, economic, environmental and social implications of this, and the role of the European Union, the Commonwealth and the United Nations.

Previous chapters have given ample material on disabled people as citizens and their actual lived experiences, which connect to each of the above National Curriculum headings for Citizenship: legal and human rights of disabled people; experiences of young disabled people refused in pubs and clubs; diversity in national identities; working of public services, such as provision of day services in contrast to independent living arrangements, the operation of the law and the impact on individual agency and opportunities for

disabled people; parliamentary debate and law-making, how the Disability Discrimination Act came to be passed; voting and the electoral system, access to voting, lobbying by disabled people and the impact of disabled politicians; conflicts of interests and examples of organised struggle by disabled people, conflict resolution and issues of bullying; reporting in the media; global developments towards disability equality, such as economic conditions, the recognition of BSL, the colonial impact on the development of special schools, and detailed European dimensions with comparative examples from Germany. This list is illustrative and not exhaustive.

To further illustrate connections, material in learning to think about central and local government (KS3 point 3 above) might incorporate use of internet resources and ICT in general. In terms of Deaf and disabled citizens, pupils might examine how the local authority attempts to include a diverse range of people in their decision making and planning, how public bodies reach out to Black and Ethnic minority communities, how they consult and listen to young people and how they involve Deaf and disabled people. Information material about their service or invitation to public consultation meetings provide much stimulus for analysis. Three regional examples will illustrate how they could be used within a social model perspective: Great Yarmouth Borough Council, Kingston, and Inclusion Scotland'.

Council asks Disabled Citizens for their Advice

Great Yarmouth Borough Council is inviting disabled citizens and their carers to a forum to discuss the kind of issues that matter to them.

The Council, working closely with Great Yarmouth Disability Forum, has arranged an open meeting for members of the public and organisations to give their views on how easy they find access to Council services.

"We need to know what people want, to enable us to improve our services," said Communications and Diversity Officer Karla Symonds. "Do they have problems physically accessing Council owned buildings, or making contact through email or the telephone?" 17. October 2006

Kingston Disabled and Older People's Forum

'Kingston Disabled and Older People's Forum is a new way for disabled and older people to be involved in the development of local

services provided by the Council, Kingston Hospital and Kingston Primary Care Trust (PCT). It is led by the Council. The first focus event for the Kingston Disabled and Older People's Forum was held on 30 June 2006. About 25 disabled and older people attended and were asked for their opinions on local Council and health services. We were particularly interested to know of any difficulties they had in accessing services because of their disability.' Kingston, LB 2006

In these excerpts, the disabled person is positioned into particular social roles. Great Yarmouth BC is inviting disabled people 'and their carers' to participate. This reflects the common sense idea that disabled people are dependent upon helpers. However, within the social model understanding of disabled citizens, disabled people are seen as capable of making choices and determining their own life. In that sense, many disabled people employ personal assistants. As people engage in these forums, both the council staff and the disabled person can be said to adhere to their respective subject positions (Fairclough 1989) as having accepted roles as the leader (the one who sets out the agenda, organises, who directs and asks questions) and follower (the disabled person with their helper, who responds appropriately when asked to do so). In this way these 'scripts' (Goffman 1971) contribute towards the formation of an identity, becoming a disabled citizen in that particular council context. There is little room to manoeuvre once a scene is set. The roles are relatively fixed.

Furthermore, over time an expectation has build up, which serves to maintain this institutional relationship, and each time an exchange takes place as part of the forum discourse, subject positions are reinforced. In the early 1980s disabled people in care homes refused to be hailed into (Althusser 1971) subject positions as the objects for care and they broke the scripts of the 'being-cared-for' and the 'dependent person' by agitating for independent, self-determined living (Morris 1993). This gave impetus to the disability movement in Britain and eventually led to legal changes which allowed personal assistants (not carers) to be employed by the disabled person directly (cf. Direct Payment Act 1996). The disabled person became the 'expert', who then was in charge of what and when and how things needed to

be done. The power has shifted from the 'expert' professional care-giver to the 'in-charge' disabled person.

Consultation and involvement of disabled people in local and national government raises a range of issues relevant to Citizenship. In order to realise democratic participation, local authorities have a duty to give due regard to disability equality. This includes the duty to assess the impact any decision might have on disabled people. They are required to promote equality and encourage disabled people to play a full part in public life (Disability Discrimination Act 2005, Disability Equality Duty). Over 45,000 public bodies, including education institutions, across Britain are covered by the Disability Equality Duty. The idea is that disabled people are part of the thinking from the outset and that social/ organisational barriers are removed. The Disability Rights Commission guidance for schools on how to meet this positive duty states: 'Involvement is a more active concept than consultation, and requires schools to engage with disabled children and adults from the beginning and use their views throughout the process of developing a Scheme, designing a policy or reorganising a practice.' DRC (2006)

To present several strands of the argument as well as the voice of disabled people and to enhance the understanding of the social model of disability for the learner additional source material can be introduced by reference to internet sites of disabled people, such as 'Inclusion Scotland'. This is a consortium of organisations of disabled people and disabled individuals. The website or the text of their manifesto can be the source material for analysis. Emphasis is placed on barriers 'that exclude us' rather than the wording of councils in the third person 'do they have problems' or 'any difficulties they had' in accessing services.

"Through a process of structured development we aim to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect our everyday lives as disabled people in Scotland. Now that there is a duty for public bodies to meaningfully involve and engage with disabled people, this updated manifesto is a call to politicians and policy and decision makers in both the public and private sectors to work in partnership with us to establish mechanisms where we can address and redress the barriers that exclude us."

Inclusion Scotland (2005)

The results of council forum activities are reported on their websites. Pupils could go to find out what had been said and what, if any, action the council is taking. In Kingston (2006), for example, one area of feedback concerned schools, and pupils could be encouraged to debate controversial issue of inclusion.

Schools

- Lack of educational provision for youngsters with visual impairment (one Forum member had to go to school in Kent) and funding issues.
- Lack of equipment available for visually impaired pupils in mainstream schools

To present a balanced view on controversial issues, opposing views have to be included, and the voice of disabled people needs to be represented. In the QCA guidance on teaching of controversial issues, teachers are reminded of their statutory obligation in this regard (2001: 47). The Education Act 1996 section 407 places a duty on teachers to take all reasonable practical steps to ensure that where political or controversial issues are brought to the pupil's attention, they are offered a balanced presentation of opposing views. This can only be achieved if teachers include disabled people's perspective (on abortion, on consultation, on media representation, on education) from within the social model movement. It is not sufficient, for example, to present views for and against inclusion, if these views do not include disabled people, and more over, do not include the political aspect of the disability movement (Campbell and Oliver 1996). This is exemplified in recent debates about Special Education. Barton (2005) offers a response to Warnock (2005), who appeared to go back on earlier ideas about inclusion. He criticises, among other issues, the fact that not one reference was made in her submission to the growing literature by disabled academics nor to disabled people and their allies supporting inclusive education, such as the Campaign by ALLFIE to end segregated education by 2020. I concur with Barton in that we must recognise the central role that disabled people play in this struggle and to leave their voices out of academic or political debate is academically unsound, and for the educational experience in schools plainly unfair. A balanced presentation

of controversial issues in schools, equally, can only be achieved if and when such voices are actively heard.

Cross-curricular approaches

Citizenship issues can be raised within non-Citizenship subjects, such as History, Geography or Drama. The National Curriculum provides cross-references under relevant headings, such as for KS3 (1) 'the legal and human rights and responsibilities underpinning society, basic aspects of the criminal justice system, and how both relate to young people' reference is made to two aspects of the History curriculum. The National Curriculum provides cross reference to History in this way :

Britain 1750-1900

10) A study of how expansion of trade and colonisation, industrialisation and political changes affected the United Kingdom, including the local area.

A world study after 1900

13) A study of some of the significant individuals, events and developments from across the twentieth century, including the two World Wars, the Holocaust, the Cold War, and their impact on Britain, Europe and the wider world.

DfES (Standards on Citizenship)

Again, previous chapters provide material that is relevant, such as the trade and economic conditions outlined in Chapter 3, or in Chapter 4: 101ff about the history of special education, the influence of the workhouse ethos, the struggle for recognition of BSL, or in Chapter 5 discussions of disabled politicians and their influence, such as Lord Ashleys work in Britain, F.D. Roosevelt's attitude to coming-out as a disabled person, the debate about the visibility of the wheelchair in his memorial statutes and examples of early implementation of independent living in his project at Warm Springs, Georgia (Holland, D 2006). Additionally, the disability organisation Scope has launched a new free DVD and teaching pack of its ground-breaking oral history project "Speaking for Ourselves. The aim for this two year oral history project is 'to communicate the living heritage of disabled people to a wider audience'. In line with an emancipatory approach Scope trained 16 disabled

volunteer interviewers to record life story interviews with people with cerebral palsy who are over 50. The fact that disabled interviewers remain unpaid and the message this sent about valuing disabled people's contribution, 'under-employment' and reduced educational opportunities discussed in Chapter 3, could form a topic of discussion with pupils. The interviews can be accessed online, both as written and spoken stories. However, Oliver (2006) warns against losing control as disabled people over the production of knowledge on disability history. Radio 4 (19 April 2006) discussed three disability history projects: "English Heritage is funding one history project run by a group of disability rights campaigners in Manchester. The University of Leeds Centre for Disability Studies has collected the writings of activists and their supporters. And the charity Scope is part way through an oral history of the lives of over 50 people with cerebral palsy, it'll eventually be held by the British Library." Oliver: "We cannot leave it to organisations that purport to speak on our behalf, like Scope, we cannot leave it to the media - they still deal in stereotypes. So if we are going to do it we have to do it ourselves."

Drama

There is a growing understanding that 'the experiential nature of educational Drama can animate Citizenship issues' (Foreman, 2006: 45). Whilst drama methods are interactive and varied, the use of empathy is particularly valued' (Formeman: 46). In 2001, a theatre company in South London offered drama-based workshops for young people as a means to engage with Citizenship themes. The learners were provided with detailed background information on complex and controversial subjects, such as the use of CCTV or refugees in Kosova, for instance. Facilitators and teachers worked together and presented themselves in particular roles, such as a victim of ethnic cleansing or a representative of a multi-national company or a local community leader. The project's internet site is no longer accessible, but the Citizenship Foundation in 2002 noted the possibility that disabled citizens might feature in these gameplays. They explained:

'The starting point for these games is looking at Citizenship from the point of view of how we define what is a citizen, or the possibility that

some may be regarded as more of a citizen than others, e.g. convicted prisoners, disabled people, asylum seekers.’

Citizenship Foundation (2002)

As with ‘disability awareness’ there are concerns with an approach that addresses disabled people’s perspective in roles played by a non-disabled person. Foreman (2006) emphasises the need ‘to feel what others feel’ in developing teenagers’ emotional intelligence. However, without guidance from a social model stance, what students may engage with is what it feels like to have an impairment and the effects of that, e.g. being unable to walk or see or communicate or being in physical pain. The understanding that needs to be gained, however, is of what it feels like to be presented with barriers; barriers which are removable given the willingness and action of people and organisations.

In practical terms, this means drawing on one’s own experiences, not imagining those of others presented as ‘separate to us’. It means empathising with feeling as a person who **is able** to get from A to B, though not by walking but by other means obstructed to them, or by a method (walking with two sticks or using a wheelchair or a white cane or an assistance dog) that is different but not equally valued. A person who **is able** to make choices but is not being listened to. To create such an experience, not simulation of impairment but of barriers to participation is crucial. Echoing Forman (2006: 47) it is important to set targets and outline clear objectives to ensure success of drama within Citizenship. This entails clear aims and objectives on understanding disability discrimination, with a knowledge on how to distinguish disability discrimination from other forms of discrimination (such as direct and indirect discrimination in relation to age, gender, homosexuality, race, religion, cultural practices, marital status). To experience disability discrimination on the basis of failing to make reasonable adjustments, barriers need to be placed so that the young person finds it difficult or impossible to complete a given task. For example, being given written instructions on paper in tiny point 3 font that reads: Find three ways of involving people that have differences, such as red hair, different coloured skin, have asthma or amputated legs

and in a context where all furniture is removed, the room is darkened, loud noisy music is playing and it is forbidden to sit down ‘for health and safety’

reasons, and with the facilitator's patronising verbal and non-verbal language that exemplifies little is expected of them, but that they just do their best, and so forth (adapted from Adept barriers activity in Disability Equality Training). Attitudinal, environmental and organisational rules barriers are placed, which make it difficult or impossible for the pupils to complete the task. This simulates barriers akin to disability discrimination, rather than having their eyes covered with a blind fold, or imagine what it must be like being in a wheelchair to simulate impairment. The point is: the barrier of the small font, the rules, the negative attitude, the darkened room, the noisy background, or whatever barriers were placed, can be removed. The Disability Rights Commission TALK video in the Citizenship pack, with 95% of its cast being disabled actors, firmly focuses on societal and attitudinal barriers, not on impairment, since in the world designed and organised without consideration for people like the central character Robert, he is disabled (treated differently, refused entry to the restaurant or bus, assumed to require help, not listened to, discriminated against, not welcomed) but does not have an impairment. Experience of barriers and an understanding of disability discrimination can also be brought to learners by disabled people's own voices and by listening to their own experiences.

Scheme of Work Unit 3: Human Rights

Within the scheme of work, individual units provide specific ideas on how to teach the requirements laid out in the National Curriculum. The issue of disability equality, though not specifically mentioned, can be implied, and 'disabled citizens' read into, these schemes. Failing to address issues from disabled people's perspectives serves to exclude their experiences. Disabled and non-disabled learners are given an incomplete picture of, for example, 'basic rights for every person in the UK' if disabled people are not explicitly regarded as citizens. Resources that deal with explaining the Human Rights Act to learners need to be accessible and made available in a range of formats in order to both reflect intrinsic values and reach a wider range of audiences. An early effort by the Citizenship Foundation to 'reach' 'engage' 'stimulate' learners is called 'Welcome to the Human Rights ImpACT' (1999). The information is presented in a multi-modal booklet. Multi-modal refers to

the use of more than one semiotic channel of communication within the same text, such as words and pictures suggesting speech, which is less formal than written English. The reader is presented with several columns of print, different typographical devices, style and size of type face, changing fonts, underlining small section of text, photographs and pictures suggesting people are actually speaking, and with text running level, slanted or diagonally across the paper as if several voices could be heard simultaneously. This publication is popular and has recently been made available as a pdf-file downloaded at Citizenship Foundation. Goodman (1996) referring to Fairclough's argument that professional encounters as becoming 'conversationalized' (1994) is observing that 'institutions, such as the state, commerce and the media, are increasingly using less formal, more conversational styles so that people understand and participate in interactions more easily.' In this way young people are being recruited into the subject of the Human Rights Act by making it less 'stuffy' than traditional teaching on constitutional issues. This more informal style seems to open up a more friendly, accessible route to the subject. However, Goodman is also concerned that 'it also allows those people in positions of authority to imply the existence of a friendly relationship where no such relationship actually exists. It could therefore be seen as manipulation' (Goodman 1996: 142). The pdf-file suggests best reading at 150%. Despite this advice, the presentation of information is not accessible if we seek to reach a broad range of learners, including people with a range of impairments. No alternative formats seem to be offered. As discussed in Chapter 4, access to information is now enshrined as an individually enforceable right, and a failure to anticipate a range of access formats fails this duty and thus discriminates against disabled learners. A leaflet written by the Commission Legal Services CLS on the Human Rights Act (2007) not only has the clear English standard, but also advises that this leaflet is available in Welsh language, Braille and audio formats. It is perhaps far less 'exciting', photographs of different people's portraits are presented in a neat row from left to right on the front page, and every person has their mouth closed (thus no speech or conversation implied). There are no other pictures or changes in font, so the leaflet may appear less engaging but is very much clearer and accessible.

In terms of the content, Citizenship Foundation's information resource on the Human Rights Act includes only two brief references relevant to disabled people: '...failure to provide access to polling stations' and 'a woman suffering from breast cancer'. The first could be used to alert the reader to the issue of access as an anti-discrimination issue, and the second to expand disability understanding as involving people with the impairment of cancer in its considerations. Whilst the CLS leaflet contains no details other than a general reference to the anti-discrimination principle of Article 14 applying to disabled people.

For Human Rights the DfES SUnit description reads:

"In this unit, pupils learn about human rights and responsibilities, relating their learning to their own experiences. They examine the role of the Human Rights Act (1998) in protecting basic rights for every person in the UK. They consider circumstances in which the rights of individuals could conflict with those of another individual or with the collective rights of a community, and learn that most human rights are not absolute. They examine situations in different parts of the world where people's rights have been infringed, and investigate the experiences of refugees. They develop an understanding of human rights and responsibilities within a local, national and global context. Many of the concepts and issues about human rights that are introduced in this unit are complex and will be developed further in citizenship at key stage 4 and beyond."

DfES, Standards for Citizenship

In a survey by the Disability Rights Commission DRC (2006) it was found that over 70 per cent of the British population were unable to name any of their human rights. Bert Massie, Chairman of the DRC, says:

"Human rights are vital to achieving dignity and a fair deal for all of us. Disabled people have successfully used Britain's Human Rights Act to fight injustice and to protect even their right to live." DRC (2006)

The critical examination of the Kutzner case (Chapter 5) connects with these suggestions as it details the working of Article 8 of the Human Rights Act 1998 with reference to disabled people, disabled parents and children, the role of people in authority, the role of the state and the conditions within which

rights can be achieved. A British example of the effect of Article 8 is in the case of two disabled sisters: In *A and B v East Sussex County Council* (2003) Mr Justice Munby remarked that: ‘the other important concept embraced in the ‘physical and psychological integrity’ protected by Article 8 is the right of the disabled (sic) to participate in the life of the community...This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not so circumscribed and so isolated as to be deprived of the possibility of developing his (sic) personality’ (DRC, 2007). Article 6 covers the right to a fair hearing and the case of Mary McKay as well as relevant guidance published to judges, the Equal Treatment Bench Book (Chapter 3) outlined organisational barriers that disabled people experience and how the legal process removed them.

On a positive note

Given the political will, enthusiasm, imagination and leadership, as well as sufficient core and long-term funding, democratic action that involves disabled young people can become a reality. A positive case study called ‘Democratic Action for Bath and North East Somerset Youth’ DAfBY, cited in 2005 by the National Youth Agency NYA and in 2006 by the Quality Improvement Agency. One of the key issues for involvement of young people in rural areas and disabled young people was lack of accessible transport, so to support its inclusive ethos transport is provided whenever the group meets. This does not tackle transport access problems intrinsic to the current public transport infrastructure, so the young people, including disabled young people, took the issue up with the UK Youth Parliament. It is reported that the group membership is inclusive:

‘The overall age range is 13 to 19, with young people aged 16 to 18 making up about a quarter of the membership. There is an equal gender balance and representation from gay and disabled young people.’ NYA 2005

This project follows guidance from the framework for citizenship learning QCA ‘Play Your Part’ (2005). Furthermore, Bath and Somerset Local Strategic Planning groups have had direct input from organisations of disabled people,

such as West of England Coalition of disabled people. Inclusive Citizenship in action is when the focus is on access issues, when disabled members have equal rights and when disabled people are directly involved.

In conclusion

This chapter has applied the three key principles of inclusive citizenship to the wider context of Citizenship education. Framed by a social model and an anti-discrimination approach, I have highlighted the lack of disabled people's voices in Citizenship education and drawn attention to caveats in relation to practice that may at first sight appear to connect disability issues to Citizenship education. I have examined the development of Citizenship as a subject, and critically evaluated a sample of Citizenship resources. These discussions - as supplemented by disabled people's experiences - further emphasised that education practitioners have a positive duty to address and remove attitudinal, behavioural and contextual barriers. Often, a stubborn insistence on impairment issues hinders access to learning and to a positive formation of a disabled identity. Only when a shift in attitude and behaviour values disabled people from the outset, and when institutional rules and procedures reflect this shift throughout its practice can the socio-political environment be created for inclusive citizenship. This entails a shift towards understanding disability equality as an anti-discrimination issues with a history of acts of resistance and involvement of disabled people themselves. Without the active participation of disabled people and without disabled people's voices and experiences, the teaching of Citizenship is internally inconsistent and unable to reach its goals, contained in the three 'Cs': 'Citizenship in the curriculum; Citizenship in the culture of the school; and Citizenship in terms of the school's relationship with its surrounding community' (Pattison and Barnet, 2005). Both disabled and non-disabled learners would lose out.

Conclusion

“As Jamie reminds me daily, both deliberately and unwittingly, most Americans had no idea what people with Down Syndrome could achieve until we'd passed and implemented and interpreted and reinterpreted a law entitling them all to a free appropriate public education in the least restrictive environment. I can say all this without appealing to any innate justification for human dignity and human rights, and I can also say this: Without a sufficient theoretical and practical account of disability, we can have no account of democracy worthy of the name.” Bérubé, M (2003)

What I have found

Citizenship education is a multifaceted, complex, contested and pervasive undertaking not confined to the classroom. The subject of Citizenship in the National Curriculum itself connects political ideology with education ideology, where ideology means:

‘A framework or values, ideas and beliefs about the way society is and should be organised and about how resources should be allocated to achieve what is desired. This framework acts as a guide and justification for behaviour’ Hartley (1983: 26-7).

Through the ‘inner essence’ of disabled people’s voices, drawn from academic to teaching professionals, from children, young people and adults, from grass-root activists and ‘ordinary’ disabled people, the meaning of disability equality crystallizes by way of enhancing certain features of citizenship ideology, such as values of self-determination, dignity and respect, self-worth and the right to be different. This emphasises and requires a changed relationship of people with impairments with the way society is and should be organised and about how resources should be allocated. However, the shift into anti-discrimination remains painfully slow and incomplete with wide-spread lack of clarity on forms of disability discrimination.

The disabled voices used in this research are by no means speaking in unison, at least not to the untrained listener. However, I do believe they tell one story. Disagreement and difference within disabled voices in relation to Citizenship themes is equivalent to musical dissonance: essential in painting the overall *Klangqualität* quality of sound. Citizenship education covers controversial issues, requires empathy with a diverse range of people, whereby education for tolerance is a central aim (Article 29 of the Convention of the Rights of the Child; Grover 2007:60) and explores a range of political forms of active engagement. In this research, the mash-up methodology produces polyphonic voices over controversial themes, such as issues of pre-natal testing, abortion, cochlear implants, finding a cure to deafness or the use of BSL, where disabled people do not agree with each other. There is a mash-up of perspectives over how to understand or use the social model of disability, ranging from feminist, materialist to interactionist standpoints. Running over the Citizenship theme of active citizenship are disabled voices involved in or promoting a broad spectrum of political campaigning methods from protests, political lobbying, education and persuasion, poster campaigns, democratic participation, voting behaviour, self-organisation, internationalism, recourse to the law, to direct action and civil disobedience. There is no 'one' voice or 'true' voice. In the same way as dissonance, a note or chord outside the prevailing harmony, is vital in understanding the overall tonal and harmonic quality of music, apparently conflicting or contradictory voices are necessary in completing the mash-up of perspectives over a theme of Citizenship. The picture that emerges tells us more about the structural forces in society than any one of these voices could do by themselves. For instance, by hearing both sides of the disability 'Rights-Now' campaign which splintered following the implementation of the Disability Discrimination Act 1995, and how each fraction understands and lives their citizenship participation differently, a dissonance is produced that offers some deeper insight into structural forces. In this instance, the state eventually changed its position on the passing of the DDA. In doing so, the government managed to pacify the broader masses of discontent with apparent concessions of legislation, but legislation that for the first time imported 'justification' into anti-discrimination law. Rather than achieve a radical change as the 'Rights Now'

campaign had agitated for, the democratic process resolved itself into pluralism with piece-meal changes at best, whilst an 'effective' reading of legislative history (Hook, 2005) understands this outcome as a dangerous new potential for injustices at their worst. Therefore, even though the law now offered concessions in aspects of citizenship, such as limited rights within employment, it did not substantially alter the status quo. This is evident, for example, by a very long lead-up within staged implementation periods, flexible interpretations of the meaning of 'reasonable' and outmoded definitions of a 'disabled person'. Enacting the DDA, whilst not meeting the full aim of equal civil rights, pacified some within the political disability movement. This acted as a concession, which led to a splintering of the powerful wave of protest into several groups, whose interests were set against each other, whilst the overall status quo and 'business-as-usual' largely remained intact, with business priorities as dictated by the 'pulse' of economy protected.

Data and evidence in support has frequently drawn on work from the Disability Rights Commission, which is easily accessible to any practitioner seeking clarity, but also referred to legal case law through Lexis/Butterworth. In the debate whether or not human rights issues are part of citizenship this thesis has confirmed the link and extended the understanding of human rights from disabled people's perspectives. I have systematically explored different aspects of Citizenship, from 'legal', 'economic', 'community', to 'identity' and shown the contributions, barriers and achievements of disabled people. I have shown that a well-developed resource, such as the Disability Rights Commission 'Citizenship Pack' (2000), is insufficient in connecting Disability Equality to Citizenship education. Attention must be paid to achieve shifts in *Denkmuster* that translate into changed praxis which enhances not only the lived citizenship of disabled people, but also reduces non-disabled people's uncertainties in professional and private relationships with disabled people.

New Knowledge

In examining the lived experiences of disabled people, this thesis has defined inclusive citizenship as a process whereby people who have an impairment can be enabled rather than disabled as citizens in every sphere of life. To this extent, I have represented connected ideas in a three pillar model. I have brought together knowledge from different strands of 'academia' and ensured

that disabled people's voices were presented and listened to throughout. In doing so, I have made existing ideas on human rights values more robust by adding additional perspectives about the impact on disabled people. In applying anti-discrimination legal principles to the education context, I have sought to relate the social model of disability to the broader context of teaching Citizenship in school. This has involved the transfer of knowledge gained from practice as a Disability Equality Training and a University lecturer, to pedagogical approaches relevant for Citizenship teaching. I have included comparative material from Germany.

Model of inclusive citizenship

Inclusive citizenship for disabled people is underpinned by three principles running through this thesis, encompassing citizenship values of justice, fairness, intrinsic worth and self-determination. A model of Citizenship that makes these a reality for disabled people requires a paradigm shift in thinking *Denkmuster* followed by appropriate action concomitant to each principle.

This can be represented in three pillars for inclusive citizenship:

1. the **social model**, which requires a shift from impairment to access as first mooted by Oliver (1990: 7-8) when he changed impairment questions into access questions: from 'What complaint causes your difficulties in holding, gripping or turning things?' into 'What defect in the design of everyday equipment like jars, bottles and tins, causes you difficulty in holding, gripping or turning them?'
2. **anti-discrimination**, which requires a shift from welfare, entitlement or 'special' responses to action concerned with legal duties in removing barriers. This is a rights-based approach that takes account of people with impairments from the outset. This legal framework moves away from an entitlement-based approach towards accepting equality and diversity principles that are applied to age, gender, race, ethnicity, religious practice, marital status or sexual orientation.
3. recognition of disability as **political struggle** and of contested ideologies, which entails a shift away from dependence-creating structures to those controlled by disabled people; this requires more than consultation, but real involvement of disabled people and representation of the disability movement.

Implications for practice

Knowledge about the first principle is now widespread. However, the actual individual and organisational shift from impairment focus to access is often missing. The social model may have found widespread rhetorical acceptance, but the reality for disabled people in education contexts, as detailed in this thesis, contradicts this intention. A quick survey of Disability Equality Schemes (DES) in universities, for examples, indicates a wealth of good intentions stating that the DES 'is informed by the social model', 'uses the principles of the social model', 'is applying the social model', 'underpinned by the social model', 'promotes the social model', 'supports the principles of the social model'. In contradiction to this, on application forms university students continue to be asked about their 'special needs', declare whether they have 'a disability' and asked to tick boxes that focus on impairment, such as 'dyslexia', 'blind', 'deaf', 'wheelchair user', 'autistic spectrum disorder', 'mental health difficulties'. They are asked to enter the appropriate code 'if you have a physical or sensory disability which might in some way affect your studies at the institution or may require special facilities or treatment'. Moving tentatively towards addressing access issues are application forms that indicate 'the university needs to know the nature of your disability if it is to provide you with the best possible support' and students are asked again to tick impairment categories. However, as discussed, a dialogue that seeks to find out about impairment does not advance clarity about access issues. This has been variously illustrated in:

- Chapter 3: 99 - 104, focusing on ascertaining access requirements for Deaf applicant and the principles of reasonable adjustment; with the dilemma further illustrated by McKay access to legal proceedings;
- Chapter 4: 166 – 169, 176 - 181 with the idea of asking impairment questions in postgraduate education courses, diverse access requirements for same impairment, and by examining systemic responses to impairment questions.
- A detailed examination in the case scenario of the disabled teacher Mrs Meikel in Chapter 4: 181 – 187.

- Chapter 6 responses to the impairment of Asthma rather than tackling access to examination).

Awareness is not enough. We need to enter into a dialogue with disabled people, asking, clarifying, providing information, listening to disabled people about what we can do differently, about when and what kind of access requirement come into play. This is relevant to all staff, from admissions officers, administration staff, teachers and lecturers, subject leaders, Equality Officers, staff in the canteen or visiting Professors. As Citizenship is linked to the whole school ethos (QCA, 1999; Chapter 4: 188) and by way of remaining congruent, the shift from impairment to access needs to permeate the whole institutional context in consistent and embedded ways.

The law is necessary, but not sufficient for change. Conceptual confusion has arisen amongst some educational practitioners who are connecting human rights with substantive universal individual rights. This thesis has clarified the anti-discrimination framework relevant in the private sector in dealings between individuals or organisations, and rights derived from international conventions, such as the incorporated European Convention on Human Rights, in the relationship between individuals and the State. Anti-discrimination law alone cannot affect a shift in praxis as inconsistencies in legal provisions blur the boundary between entitlement and rights-based approach to disability equality. In educational practice, a differentiated approach, which recognises and values relevant differences, not 'business as usual' is required. The shift in *Denkmuster* involves crossing an assumption barrier into fact, from seeing disabled people as unable to do things, as in need of 'special' resources as 'burden' or a 'threat' into facts ascertained by dialogue and involvement. Empirical facts indicate that many different people engage in social spaces and have an equal right to do so, therefore we need to be geared up for it from the outset; this requires changes to 'business as usual' at individual, organisational and government level. This includes a review of allocation of resources that takes account of disabled people's difference in how 'business as usual' is designed.

The three pillars of inclusive citizenship are mutually interdependent and together connect to Citizenship. Citizenship has the potential to include

disabled voices and permeate education. The Department for Education and Skills DfES own Disability Equality Scheme DES (2006) acknowledges:

‘Involving disabled people in the creation of the Department for Education and Skills DES has given us a direct insight into their priorities for change. The DES contains no subject specific guidance in any subject, but notes concerns over invisibility of disabled people in the curriculum.’ (DfES 2006: 26).

Recommendations

The issues outlined in this thesis are very complex and my findings do not lead to simple solutions. A range of broad recommendations for actions offer several ways of making progress towards connecting disability equality to Citizenship education.

For each recommendation it is assumed that action is underpinned by the three pillars of inclusive citizenship. Recognising that ‘accepted ways of thinking and acting’ among education practitioners not only influence policy flows, but ‘act as a filter in the policy-implementation process, shaping the interpretation and negotiation of policy’ (Trowler, 2003: 146), attention needs to be paid to teacher training and ongoing professional development that emphasises the inclusion of disabled professionals. The Training and Development Agency (TDA) should consider practical ways of training more disabled teachers, and of ensuring greater ‘visibility’ in the presentation of self. Education institutions need to review employment, interview, selection, training, appraisal, and management systems with a view to supporting a dialogue with disabled staff based upon access not impairment. Apparent conflicts between ‘academic excellence’ and ‘reasonable adjustments’ raise uncertainty among education professionals and need to be settled in favour of flexibility and diversity that does not compromise but enhances excellence. Likewise, these institutions need to review education service provisions, application procedures, curriculum content, teaching and assessment practices with a view to supporting a dialogue with actual or potential learners that is based upon access not impairment. Formal and informal learning opportunities that involve people from the disability movement can deepen Citizenship teachers’ understanding and confidence in connecting disability equality issues.

In terms of resources for Citizenship, two processes would connect disability equality: (a) To collate and update disability equality resources, including websites, that adhere to the three inclusive citizenship principles, and (b) link (those) disability equality resources/ websites directly to 'circles of knowledge' of government and professional discourse. In this context, it would be helpful to find out what happened to the Disability Rights Commission 'Citizenship pack' (2000) in each school and suggest practical ways to improve its application and reach. Given the importance of human rights issues to the subject of Citizenship and to disabled people, I would recommend the design of an information leaflet/ brochure on human rights, which specifically includes a range of examples relevant to disabled people. To bring resources to life as tools for connecting disability equality to Citizenship, it is essential to review pedagogy and best practice in the teaching of Citizenship (a) to include empowered selves of disabled voices, and (b) to anticipate and respond to diverse learning requirements. This means aiming to permeate disability equality issues, concerns, case studies, facts, examples and narratives into teaching material and activities (a) for Citizenship and (b) across other NC subjects. It is also necessary to ensure that disability equality is not 'swallowed up' by race or general diversity concerns, but its unique forms of discrimination, the wider meaning of direct discrimination, discrimination as reasons related to impairment and the failure to make reasonable adjustments, are all adequately addressed.

Barton and Armstrong (2003: 43) regard the question of language and labels as a 'national challenge reflected in the official document policy of both government and professional bodies'. In order to connect disability equality to Citizenship, language, 'gaze' and discourse remains incongruent and internally incoherent as long as it relates to 'special educational need' or other categories of impairment. It is, thus, essential to remove discriminatory language that only *conditionally* references pupils with impairments in the context of Citizenship. Until the full removal of 'special educational needs' language, I recommend the removal of these terms if they are used to identify pupils; instead clarify that 'special educational needs' language is describing administrative or procedural measures in obtaining resources, and not people.

For the whole school ethos to reflect disability equality, we need to ensure whole school policies, such as bullying, local community activities, and forms of active citizenship, are undertaken within the three pillars of inclusive citizenship, the social model, anti-discrimination and active involvement of disabled people. In finding ways of involving disabled people, the lead should be taken from the disability movement.

My Contribution

This thesis is a contribution to the developing understanding and practice of the teaching of Citizenship in England. I have developed a mash-up methodology that sees disabled voices running over themes of citizenship in a research activity that 'creates a rich dialogue with the evidence' (Yin, 2003: 59). Empirically framed case analyses have contributed to the developing understanding and practice of the teaching of Citizenship in England. I have revealed several levels of incongruity and uncertainties. Applying insights of direct and personal disability experience, together with practical knowledge and skills of 12 years as a Disability Equality trainer in the private and public sector, including work in schools, Further and Higher Education setting, I have presented the argument that Citizenship education that fails to take direct account of disabled people is internally incoherent to stated Citizenship values, learning goals and outcomes. The invisibility of disabled people in the Citizenship curriculum is no longer tenable. Disabled and non-disabled learners lose out.

Through my teaching and academic experience at Universities in diverse departments, such as Health and Social Welfare, Law, Education, and Social Sciences, I have been able to enrich the debate on Citizenship education by drawing from across traditional subject boundaries and traditions. I have displayed particular clarity in presenting the working of the Law with a keen focus on the meaning of anti-discrimination in the context of disability.

Furthermore, institutional and systemic disability discrimination undermines control, individual agency, self-determination and choice by disabled citizens. I have marshalled evidence that these failings can be redressed by a policy and practice standard with social model principles that goes beyond the rhetoric, but ensures the active involvement of disabled people at all levels.

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Appendix A: Online Resources and Links for Citizenship Education

Government Bodies

Department for Education and Skills (DfES): www.dfes.gov.uk/citizenship

- Sections for teachers, pupils and parents and governors.
- 300 resources for teaching Citizenship.
- Virtual Teachers' Centre for sharing ideas.

Qualifications and Curriculum Authority (QCA): www.qca.org.uk

- Citizenship schemes of work and planning guidance.

Citizenship Education Organisations

The Association for Citizenship Teaching (ACT):

www.teachingcitizenship.org.uk

- Information about the professional association and magazine *Teaching Citizenship*.
- Reviews of Citizenship education resources.

Centre for Citizenship Studies in Education: www.le.ac.uk

- Information about teacher education courses at the Centre.

The Citizenship Foundation: www.citfou.org.uk

- Information about own resources for schools.
- Teaching support section with list of support organisations and websites.
- Active learning ideas, for competitions, speakers and solicitors in schools.

Community Service Volunteers (CSV): www.csv.org.uk

- Information about volunteering for young adults.

The Hansard Society: www.csv.org.uk

- Citizenship education programme with activities like MPs in schools.

School Councils UK: www.schoolcouncils.org

- Resources with advice for developing school councils.
- Citizenship section.

Development Education Association (DEA): www.dea.org.uk

- Schools section with information on guidance booklets for global dimensions of learning.

Appendix A: Online Resources and Links for Citizenship Education

- Link to www.citizenship-global.org.uk - the site for ideas and resources for learning global dimensions of Citizenship.
- List of member organisations.

Miscellaneous

Active citizens: www.activecitizens.org.uk

- Advice and project experiences for extra-curricular Citizenship activities.
- List of support and funding organisations for working with young people.

Get Global: [Get Global:](#)

Learning Through Landscapes www.ltl.org.uk

YouthNet UK: www.thesite.org

The Young People's Parliament (YPP): www.ypp.org.uk

BBC Online: www.bbc.co.uk/schools/citizenx

- Picture stories, movies and tasks for Key stage 3 Citizenship.
- *Get Involved* site with examples of active citizenship from schools.

Changemakers: www.changemakers.org.uk

- Information and publications about active involvement projects for young people.

Channel 4: www.Channel4.com/learning

Citizenship in secondary section offers "World of difference" awards for globally active citizenship.

Comment:

Other organisations likewise offer links to resources. This may be borne out of practical consideration in terms of what has worked (e.g. in Hertfordshire schools <http://www.thegrid.org.uk/learning/citizenship/resources/list/>) or born out of a professional concern with 'meeting the needs of teachers' (e.g. Institute of Citizenship . <http://www.citizen.org.uk/education/resources.html>). No direct reference has been made to disability organisations, disabled people themselves (see **Bibliography** for contact details and examples).