



technology, children, schools and families

Identity and disability: a review of the current state and developing trends

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Abstract

Currently, disability is primarily viewed from a medical model that sees it as a tragedy resulting from impairment within the disabled person. The social model of disability views disability as the barriers that society creates for people with impairment. The social model has been the 'battle cry' of the Disability Movement, challenging the medical model, and encouraging a trend toward active, vocal disabled people, many of whom perceive their disability as a part of a positive personal and social identity, and as many as half of whom, given the choice, would prefer to keep their disability rather than have it 'cured'. This paper looks at the wide range of identity issues that occur as result of a wide range of possible impairments, social and political changes relating to identity and disability, and issues around identity and disability that arise from medical and technological advancement. However whenever possible it is seeking to represent the perspective of disabled people rather than a stereotypical, non-disabled perspective, or the dominant professional perspective of disability.

The review of identity and disability draws attention to certain possibilities for the future of education, including the need for change in the structure of education, toward one that addresses disability inclusively, the need to direct focus onto the ways that education disables children and young people, the importance of listening to the voice of disabled pupils/students, and the need for developing conceptual models in education that encompass complexity, diversity and fluidity in identity and disability.

Keywords: disability, identity, society, education, young people

Introduction

The remit of this paper is to provide key information about either the current state or developing trends in the interaction of identity and disability, and where possible to make links with these and the future of education.

The paper addresses a number of issues judged to be current and important, including:

- The problems inherent in a medical model of disability, and the successes and problems inherent in the social model of disability
- The struggles of the disability movement to counter social barriers to disabled people within society, and to position disabled people as active and vocal – this trend is also seen within education
- Though technological advances may hold promise of some level of 'cure' to disabled people, research suggests that half of disabled people would not want to be cured for reasons of identity
- The importance of seeking out the viewpoint of disabled people themselves
- Constraints imposed by the use of dichotomous concepts in a range of fields
- The issue of multiple identity
- The question of disclosure of disability

These issues are linked to the future of education by signposting:

- The need for change in the structure of education, toward one that addresses disability inclusively as a matter of relevance to all students/pupils, teachers and leaders in education
- The need to direct focus onto the ways that education disables children and young people, and away from a primarily 'within-person' view of disability
- The importance of listening to the voice of disabled children and young people, and a need for increased amounts of educational research that does this
- The need for developing conceptual models in education that encompass complexity, diversity and fluidity with respect to both identity and disability

I will now provide some background information as a foundation for discussion of the papers.

The disability movement

The disability movement has been fundamental in identity formation for disabled people. The disability movement initiated a new way in which people with disabilities can represent themselves, live their lives, and campaign for their rights in Western countries, particularly the US and UK. It can be seen to follow on from other liberation movements, for example, class, race and gender, and many writers draw parallels between the disability movement and racial, women and gay/lesbian movements.

Before the disability movement, and still, currently, disability is primarily thought of as a problem within the disabled person, a perspective derived from a medical model where powerful professionals make choices for passive, needy patients. This kind of conceptualisation justifies the segregation and marginalisation of disabled people, because it asserts a biological cause that prevents disabled people from functioning normally within society. The purpose of the disability movement was, and is, to shift perceptions away from the medical model, where the problems of disability are perceived as being due to problems within the disabled person, to the idea that disability is a socially constructed barrier to a person with impairment.

The origin of this latter concept lies with The Union of the Physically Impaired Against Segregation (UPIAS) who wrote the manifesto *Fundamental Principles of Disability* which stated 'it is society which disables physically impaired people' (quoted from Dowse 2001, UPIAS 1976, p14). Academics in the new area of Disability Studies developed this idea into 'the social model of disability' (Finkelstein 1980; Oliver 1990; Barnes 1991).

The social model of disability, because it was developed to challenge the medical model, emphasises a distinction between impairment, which is within-person, and disability, which results from barriers within society. This directs focus onto social change, away from rehabilitation. This distinction between impairment and disability forms the foundation for both the beneficial impact and shortcomings of the social model of disability (Shakespeare and Watson 2001), which will be discussed in more detail later.

Problems with inadequate representation of identity and disability

The very act of searching for research related to identity and disability, fore-fronted another issue of tension and difficulty within the field of disability and identity. To find relevant research meant using categories that simplify issues of identity and disability almost beyond recognition, and can serve to perpetuate marginalisation by reifying disability and representing aspects of disability and identity as concrete and discrete. The experience of disability is better represented as a continuum that changes over time and place, and includes dynamic interplay of issues of multiple identities both within and outside categories of disability. There is a need to develop concepts that fully encompass this complexity. Had I searched looking only at identity, feminism or perhaps issues of normalisation and dichotomy, where these problems of representation are at the fore, I would have been able to present more up-to-date conceptualisations. However, the field of identity and disability is only beginning to incorporate these.

The dominant perspective from which research is carried out in disability is from a professional perspective, with the medical model's approach to disability as being 'within person'. As an example of this dominance, a recent search on EBSCO for research on dyslexia in 2007 and 2008 found 80% of research to be from the perspectives of cognitive psychologists, neuro-psychologists and geneticists, who primarily focus on dyslexia as a problem within the person, and 12% was on developing intervention within schools to enable dyslexic children to attain within 'normal' levels, which views disability from a professional's perspective. Only 8% researched the experience and perspectives of dyslexic people.

What is the significance of different impairment in relation to identity?

It would be impossible to characterise current or emerging trends in the interaction of identity and disability as a homogeneous whole. Issues of identity relate to the type of impairment experienced, and the range of impairment covered by 'disability' is huge. Though categorising disabilities is problematic, this paper will focus on three types of disability in order to demonstrate how different impairments can relate to issues of identity: intellectual disabilities, dyslexia and D/deafness.

Intellectual disabilities

A primary issue regarding identity for people with intellectual disabilities (ID) is that they are assumed to have conceptual barriers to understanding the social model of disability, and what it means to have an ID.

Intellectual disabilities are an important disability in relation to education and the future; the number of intellectually disabled children is increasing due to advances in science that mean premature infants are able to survive at a younger and younger age (Marlow, Wolke et al 2005).

At the same time, genetic counselling now results in the termination before birth of many intellectually disabled people, for example those with spina bifida or Down's Syndrome. This raises moral questions relating to identity: is it ethical for a woman to decide to terminate on the basis of a characteristic of a foetus? Stainton (2003) argues that termination is unethical if the characterisation changes the foetus into a subject. Stainton also argues that the life of an intellectually disabled person is deemed less valuable on the basis of dominant identity politics, and not 'some essential truth of science' (p537) which further questions the morality of termination due to ID. A recent article on the BBC news website, 'Many keeping babies with Down's' (2008) reported that Down's births are higher now than in 1989 when pre-natal testing began, suggesting that cultural views of Down's Syndrome by non-disabled people is becoming more positive.

Tom Shakespeare (1998) and Patricia Rock (1996) discuss the complexities of pre-natal testing. Shakespeare documents professional pressure to abort in response to positive tests for disability, and Rock insists that such advice is given by those that carry prejudice about disabled life and know nothing of the quality of life many disabled people live.

To look at the specific place of ID within wider disabilities I will be reviewing Beart et al (2005), who carried out a literature review on how people with ID view their social identity. Their main points are:

Heavy stigma in relation to other disabilities

People who are intellectually disabled are the target of stigma that is heavy in relation to other disabilities, and this stigma includes the perception, at least by others, that this is the person's dominant identity.

- For professionals a diagnosis of ID may overshadow other potential diagnoses
- This identity is likely to stay with the person over the span of their lifetime
- Families do not seek out this diagnosis for their children, in contrast to many other disabilities
- People with ID are often segregated, have few employment opportunities, are economically less well off, are less likely to marry or have satisfying social relationships, and experience fewer community leisure opportunities

Difficulty conceptualising their disability

Many people with ID may be unaware of their identity as intellectually disabled, at least on a discursive level.

- People with ID may have problems understanding the terms that are used to categorise themselves
- Parents and carers often do not talk to people with ID about their disability, but this does not necessarily prevent them from becoming aware of the stigma attached to this identity – they experience the stigma of their social identity

through their interactions with others, and this experience is often an emotionally painful one

- It is likely that intellectually disabled people experience their identity at the level of experience rather than discourse, and this should be taken into account in further research

This paper addresses the issue of personal identity in terms of systematic empirical studies, and might be criticised for placing non-disabled ideas of ID 'on' the intellectually disabled person. Other research demonstrates the development of understanding about intellectual disabilities by people with ID in the context of Self Advocacy groups, including changes toward both positive personal and group identity (Goodley 2000; Beart, Hardy et al 2004). Thus, intellectually disabled people can have a voice and a positive identity as intellectually disabled, but it is one that is vulnerable and needs facilitation.

Dyslexia

A primary issue for dyslexic people is the history of cultural scepticism with which dyslexia and other 'hidden disabilities' are viewed. Dismissive or negative cultural attitudes challenge or undermine attempts to develop a positive sense of identity. Dyslexia is an important disability in relation to education because the structure of western educational systems particularly disables dyslexic people, and dyslexic adults often have negative emotional associations with school years. The following study is an unusual study, as noted above, because it recounts the experiences of dyslexic adults rather than approaching dyslexia from a professional standpoint.

Dale & Taylor (2001) carried out qualitative research with seven dyslexic attendees to an adult studies skills course '*Learning for Life and Work*' that had been adapted so that it had a multi-sensory and experiential focus to support dyslexic learners. Using grounded theory the authors analysed transcripts from three focus groups, the students' learning journals, statements from the wider group, and classroom observation.

Dyslexia had not been recognised in most of the students while at school, and they had a history of educational failure, which they internalised as personal failure. Within the focus group, but not the wider classroom, they explored negative school experience, which was common to all the students, and included humiliation and physical punishment, and the understanding that they were 'thick' or 'stupid'.

Through life experience the adults developed a self-belief that they were able. For many it related to greater success at work in relation to other colleagues who had educational qualifications. Personal recognition of dyslexia involved re-developing a self-identity of 'able' to replace the one developed at school of 'stupid'.

The authors conclude that their purposeful role as 'peers' to the students, that as tutors they were learning also, and that one of the tutors was dyslexic, were important factors in breaking established negative educational patterns. The group functioned similarly to Self Advocacy, in that the group gave the students space to make sense of their social identity and gave a sense of control over their lives (Beart, Hardy et al 2004).

Within academic endeavours, unless dyslexia is recognised and understood, the person can experience stigma similar to ID. However, possibly because dyslexia on its own is problematic primarily in the context of academic endeavours, it is quite possible to form a positive dyslexic self- and group-identity. A positive dyslexic identity is also possible in schools; Robert Burden, in research within a special school for dyslexic boys, found overall a positive dyslexic identity, where the boys felt they were in control of their success and/or failure in school (Burden 2005).

Whether dyslexic adults disclose their disability or not is a common conundrum; the choice seems to be dependent on whether or not the context is perceived to be receptive and supportive, and on practical considerations (Olney and Kim 2001; Valle, Solis et al 2004).

Currently work is being carried out by schools, charities and the UK government to develop better support systems for dyslexic children. Theoretically, if schools support such children well, it is possible that in future there will be no such disability.

D/deafness

Tracey Skelton and Gill Valentine (2003) carried out qualitative research interviewing 15 D/deaf youth and five D/deaf lesbian and gay young people within a larger study to explore social exclusion and inclusion within varying spaces eg home, college/university, and community. This study is unusual in that it asks young D/deaf people about their experiences of different identities within D/deafness. Most D/deaf research carries out quantitative comparisons between D/deaf people and hearing people.

D/deaf refers simultaneously to 'Deaf' people – those that consider themselves a minority language, and 'deaf' people – those considering themselves 'hearing impaired', and/or those that orient themselves in an oral tradition. 'Deaf' or 'deaf' refers to these groups separately.

Deafness as minority language vs deafness as disability

Within the Deaf community there is a discourse that being Deaf is not to be disabled, but to belong to a minority language community. Within the group of young people interviewed, a number emphatically replied 'no' when asked if they were disabled; instead they saw Deafness as being about a difference between hearing and Deaf worlds. Another sub-group of young people identified with being deaf, and said they wanted to be able to hear and to speak, and be understood easily by the hearing community. The authors note that these two identities are not fixed, that they can change according to context and time.

The authors discuss the dilemma faced by young D/deaf people in choosing identity. The Deaf world tries to be independent of hearing culture, and provides huge support and positive identity for Deaf people. They do not align themselves with the disability movement, but campaign separately as a minority language. Learning British Sign Language (BSL) is often the starting point of belonging to the community.

A number of the young people that grew up in hearing families, and were discouraged to sign within oral education, commented on the power they felt when they learned BSL, that they could communicate easily and in depth, and with other people like themselves. They are part of BSL rather on the outside as they are when involved with oral language. In this way the Deaf community offers them a better quality of life.

However Deaf culture is simultaneously exclusionary and limited – for young people with other identity concerns (eg sexual, ethnic, religious) it has little to offer that is unrelated to Deafness. The Deaf world can also reject people that have links to a hearing practice, and exclude those with visual impairment due to the visual nature of BSL.

The authors point out that many students professing Deaf identities also receive Disabled Student Allowance, without noting this as a contradiction. This is understood as practicality rather than identity; their education is constructed so that to get round language barriers they need additional support. This is only one example of the fluidity

of identity demonstrated in this study. Many participants worked with hearing people, where oral communication was the only option, so at work, others credited them with the identity 'deaf'.

The authors conclude by stressing the complexities of D/deaf identity. They recommend researchers attend to the limitations imposed by binary constructions of D/deafness and deafness vs hearing.

Links to the future of education

These papers have highlighted a number of issues relating to disability and identity that can be present depending on type of impairment. The following are all issues that could be impacted more positively by the educational system in future:

- heavy stigma and/or discrimination by non-disabled people
- possibility for internalisation of negative views of non-disabled people
- difficulty conceptualising a disabled identity because of impairment
- issues of whether or not to disclose a disabled identity
- the possibility of a positive personal and group disabled identity
- the need for more research that consults disabled people
- the need for conceptualisations that encompass complexity
- the presence of disability according to context
- the presence of disability because of the structure of cultural systems.

A number of the papers suggest Self Advocacy groups are beneficial to support the development of positive personal and social identity for disabled people. Such groups adapted for disabled children and young people could be beneficial within schools. However, this would not address the core systemic problems of stigma and discrimination. The groups would single out those with a disability and bring attention to their difference, despite potential for developing positive self- and group- disabled identity.

In 2007, Sir Keith Ajegbo headed up a curriculum review entitled 'Diversity & Citizenship'. The remit was to:

- 'review the teaching specifically of ethnic, religious and cultural diversity across the curriculum to age 19
- in relation to Citizenship, explore particularly whether or not 'modern British social and cultural history' should be a fourth pillar of the Citizenship curriculum' (p14).

Recommendations by the review included the need for whole-school exploration of identity, diversity and citizenship, to be brought about through pupil voice, leadership in inclusion, training for teachers and changes in the educational systems infrastructure including development of a fourth strand in the Citizenship curriculum to be called 'Identity and Diversity: Living Together in the UK'.

The review echoes a number of areas of concern stated in this paper and in my opinion provides a possible way forward. Despite the close ties of disability with issues of cultural, religious and ethnic diversity and identity, questions of disability were not a specific part of the remit of the review, perhaps because of the common perception of disability as a medical issue, and/or under-recognised issues of discrimination.

Were issues of disability included as part of this fourth strand of Citizenship, it would provide an inclusive forum for discussion of disability along the lines of universalism (to be discussed later), where disability is viewed as something that all of us can expect to

experience at one time or another; a normal aspect of diversity. It would provide a place in which stigma and discrimination could be discussed in historical terms, a place for the voice of disabled people to be disseminated, and would have the potential to impact a number of the issues relating to disability and identity summarised at the beginning of this section.

How has identity with respect to disability changed over time with political/social changes?

Jenny Corbett and Brahm Norwich (1997) provide a reflexive account of changes since the 1980s in Special Educational Needs (SEN) due to a general social shift from passive to active. In education focus shifted from an explanation of disability in sociology and psychology to a focus on policy-making and provision. Parents changed from relying on professional expertise in educational choices to demanding the right to make choices about their children according to their individual situation. Corbett and Norwich argue against the use of simplistic dichotomies in response to these changes, eg psychological vs sociological, inclusive vs market choice, as this oversimplifies complex relationships.

Trend from passive to active

Corbett & Norwich cite an increase in legislation and policy-making within education as signposts of political/social change. For example the Warnock report, followed by the 1981 Education Act, recognised the reciprocal causal nature of special educational needs, the rights of parents to be involved in decisions about their child's education, and the right for children to be included in mainstream education. The 1993 Education Act further clarified that Local Education Authorities (LEAs) are responsible for funding SEN according to the limitations of their budgets.

The result of this legislation was a politicisation of special educational needs. Formerly disabled children were educated within specialist schools, which provided a non-political caring service similar to a medical practice. The schools changed with the above legislation to become more in line with other educational establishments, and the addition of parents in decision making introduced a 'market economy', where schools became competitors. This trend is true generally for schools, outside SEN, due to Ofsted inspections, government testing and league tables.

As LEAs became responsible for allocating funds for SEN, this process also became politicised. Fund allocation was based on a 'statement of education need' derived from diagnostic information and recommendations from professional reports, resulting in an increase in the importance of 'labelling', as the diagnostic label became a necessary route to funding. The involvement of parents in the allocation of limited funds can mean that more funding goes to the children whose parents are most able to fight for it, adding to already-present class inequalities.

The disabled movement began at much the same time as this legislation, making public individual disabled peoples' experiences of disadvantage within and resulting from attendance at special schools, which challenged professional hegemony. The idea of a positive disabled identity, that the problem was not in the disabled child but in the segregation and discrimination of disabled children within schools, contested the medical model's view of 'treatment rather than acceptance' (p382).

Dichotomous ideology

The authors argue in their paper that it is counter-productive to approach current issues of SEN from extremes such as psychology vs. sociology, or inclusive vs market-driven values. They make a case for an increase in complexity within SEN because of political, social and economic developments, which require input from a variety of perspectives to give 'richness of analysis' (p384).

The social model of disability – successes and failures

The social model of disability has been the disability movement's 'battle cry' because it provided a freeing framework for action by focusing political strategy away from rehabilitation toward removing social barriers and anti-discrimination legislation. Dowse (2001) describes the social model of disability as the disability movement's 'collective action frame', according to social movement theory.

In terms of identity, the shift away from the medical model, which places the problem of disability within the person, to the social model, which places the problem of disability within society, was emancipating. It enabled a viewpoint from which a positive self-identity of a disabled person could be constructed, and still does. The new meanings of this perspective also involve a shift from 'feeling sorry for oneself' and being passive, to feeling angry and being active. It stimulated the formation of numerous disability groups, many that developed 'identity politics', where the aspect of group identity that formerly was stigmatising is turned round to become a mark of pride (Bickenbach, Chatterji et al 1999). Thus, the social model of disability has contributed a great deal toward improving issues of identity within disability. However, the social model has also been criticised in a number of ways, both by those outside the disability movement and those within (Bickenbach, Chatterji et al 1999; Shakespeare and Watson 2001).

Conceptual limitations/inconsistencies

The social model is based on a distinction between 'impairment', a feature of a person's body or mind, and 'disability', the barriers of oppression society constructs that marginalise the person. The problem is with society, not with impairment, and the disability movement discourages gaze on impairment and encourages focus on society.

This is vital in the argument of the disability movement, because as soon as the issue of impairment becomes a focus, issues around equality also arise. If disabled people possess a biological impairment, they are in fact not equal with non-disabled people. Bickenbach et al (1999) likens this to the argument against feminism that patriarchy is biologically inevitable.

Multiple identity

The social model is narrow in that it only conceptualises issues of oppression linked with disability. Other marginalising factors (class, race, gender, sexuality, age), and how they interact with disability, are ignored. The changing and contextual nature of disability itself is also not addressed. Instead, in the social model, disability is represented as dichotomous – you either are or you aren't. The social model also does not adequately conceptualise differences between disabled people, for example, differences between social responses to physical vs mental disabilities.

Suffering

The separation of 'impairment' from 'disability' discussed above relegates issues of the body and mind, and therefore issues of pain and/or suffering, invisible in discussion of disability under the social model. This excludes essential aspects of the experience of many disabled people, for whom physical pain and/or emotional suffering following from their 'impairment' may be an everyday occurrence (Morris 1991).

Inadequate representation

In the ways detailed above, the social model fails to adequately represent the experiences of many disabled people. Bickenbach et al (1999) points out major proponents of the disability movement tend to be 'highly educated, white middle-class males with late onset physical disabilities and minimal needs' (p1181), who fall short of representing the wider issues of disability. The disability movement also fails to represent the group of people who wish to refuse the 'disability' badge, who would prefer to be non-disabled. Shakespeare & Watson (2001) cite their ongoing research with disabled school-age children, the majority of whom disliked being identified as disabled (see also Priestley, Corker et al 1999)

Possible future 'battle cries' for the disability movement

Universalism

Bickenbach et al (1999) review and critique models of disability. They put forward a model of 'universalism' to replace the social model of disability, because 'universalism as a model for theory development, research and advocacy serves disabled persons more effectively than a civil rights or 'minority group' approach' (p1173).

The authors discuss the social model of disability and the disability movement in depth before introducing universalism. They point out that regardless of the success of the disability movement over the past 20 years, eventually use of the social model of disability will have to give way for the reasons stated above, but also because the problems of disability are not only about discrimination – they are also about 'failures to provide the resources and opportunities needed to make participation feasible' (p1181), which the authors call 'positive freedom'. Problems of positive freedom revolve around distributive injustice – the unfair distribution of resources and services resulting in limited access to society. Unfair distribution is systemic; it is part of the structures of institutions and economies.

Universalism, based on the work of Zola (1989), addresses the problems of the social model of disability because it approaches disability as a contextual, ever-changing continuum that respects diversity and widens normalisation to include human variation. Disability is a universal feature of humanity, and we all can expect to experience disability in one form or another, or perhaps in many ways, over our lifetimes.

The details of universalism have not been worked out – but in terms of logical consistency and the scope to encompass the complexity of disability, universalism seems promising. One of the reasons for the extremity of the social model, though, as Shakespeare & Watson (2001) write, is the simplicity and power of its message: 'disabled by society not by our bodies' (p11). Universalism's solution to issues of logical inconsistency and its theoretical ability to represent the complexities of disability are not

likely to be quickly or easily grasped, and reasons to adopt universalism may be equally slippery to the non-specialist.

Sociology of impairment

Hughes & Paterson (1997) provide a discussion of the problems with the impairment/disability divide in the social model of disability. They propose that a combination of post-structuralism and phenomenology provide an approach with which to reframe it.

The authors discuss recent developments in the sociology of the body, which, with post-modernism, see the body and biology as social issues. The body is linked to advertising, consumerism and political struggle, and is the site of identity construction. On the other hand, the academic realms of biology, psychology and medicine, and indeed, disability studies, view the body as an object without history, without meaning, without agency, separate from the self; an object not socially produced.

The authors describe the work during the 1990s of feminists, particularly Judith Butler (1993) to rework the concept of sex-gender, from a biological-social bipolarisation to the construction of the body by social discourse.

Hughes & Paterson argue that by viewing the body as a social site, the issue of impairment can be included in the disability movement. The conceptualisations of the social model by disabled academic Mike Oliver (quoted in Hughes and Paterson 1997, p330) of impairment and disability as bipolar opposites can be dissolved by exploring disability as present at the junction between the mind, the body and society; an experience discursively produced.

Despite the advantages of a post-structuralist approach to the body in dissolving dichotomies, it also has the effect of actually dissolving the body – any sense of a real body is lost as it becomes the site of 'multiple significations that give it meaning' (p333). Hughes & Paterson therefore argue that phenomenology is needed to focus on the body as a site of lived experience. Phenomenological studies could add consciousness of sensation to issues of oppression and marginalisation in the body.

Post-structural analysis is relevant to the breadth of disability. Foucault's work has links to social production and examination of power relations, cultures, discourse and difference (Armstrong 2007), so that course seems promising, though also presents problems of its own, as detailed above. Though post-structural analysis solves many problems of the social model, it does not address the problem of physical inequality. Phenomenology seems to be particularly relevant to researching people who experience physical pain as a result of disability.

Losing disabled identity: does technological and medical advancement enhance or detract?

Technological advancement offers the disabled person the possibility of 'cure' of their disability. Cochlear implants for deaf people is one example; another slightly different example, in that it does not offer 'cure' but an external way of getting round difficulties, is computers that read and spell for dyslexic people.

Is the assumption that a disabled person would want to be cured a 'given', or is this the negative perceptions of a non-disabled society? For the disabled person who is proud of

who they are, for whom their identity as disabled has been an important part of making meaning about themselves and the people and the world they have known, the refusal of 'cure' can be the response.

Cure survey

Harlan Hahn and Todd Belt (2004) surveyed 156 disabled activists using a 7-point Likert scale exploring their responses to the question 'even if I could take a magic pill, I would not want my disability to be cured'.

Results were approximately even, with 47% not wanting to be cured, 8% ambivalent, and 45% wanting to be cured. This is supported by two prior surveys that found a majority did not want 'cure' (Weinberg and Williams 1978; Weinberg 1988).

There were two significant predictors of which disabled adults would not want to be cured. Those who had a positive sense of personal identity as disabled were significantly more likely to not want cure ($p < .001$), and those with onset of disability before age 18 were significantly more likely to not want cure ($p < .05$).

The authors speculate that disabled adults with a positive disabled self-identity do not seek cure because this would take away their source of self-affirmation. They reason that disabled adults who become disabled before they are 18 have a stronger personal sense of identity, and this prevents them from desiring a cure for the same reason stated above.

The authors conclude that these results challenge current medical practice where focus is on 'no harm' to the public, with the expectation that people will be receptive to treatment that has been shown safe and effective.

The study would have been improved if it had been possible to carry out a selection of interviews to discuss why the disabled people chose the responses they did. It is also unfortunate that the authors did not find out the nature of the disabilities of each person, as it would have been valuable to discover if the type of disability influenced whether or not the adults wanted to be cured.

The research quoted above that found that schoolchildren did not want to be disabled because they did not want to be different than their peers (Priestley, Corker et al 1999; Shakespeare and Watson 2001), is in opposition to the above research, and needs to be researched further to understand any differences in the perception of disability between children and adults. For example, is it a difference of generation or maturation? Such research is important in informing future support of disabled children in schools.

Choosing deaf children

Hallvard Lillehammer (2005) develops an ethical argument supporting the choice by a real couple, Candace and Sharon, to obtain sperm from a deaf donor in order to increase their chance of having deaf children (they indeed now have 2 deaf children). David Shaw (2008) responds to Lillehammer, arguing the couple made an unethical choice.

The table below displays one of the contrasts in their views.

Lillehammer (2005)	Shaw (2008)
'Sharon and Candace make their choice in a particular personal historical context ... Sharon and Candace would like their children to grow up and flourish as members of their own community ... Thus, they are concerned that their children grow up in an environment where they are able to communicate with their peers without feeling alienated' (p35-36)	'This argument has the hidden premise that being part of a flourishing deaf community precludes not being deaf. The couple's child could still learn sign language and be part of the community without being deaf, unless the community itself is guilty of discrimination against those who are not deaf' (p410)

Lillehammer (2005) writes against the 'conventional view', meaning he assumes most people would agree that anyone who could choose would choose that their child not be disabled. He argues that the concept of 'impartial perspective' put forward by those of a conventional view is really 'little more than the generalisation of one set of partial values to every conceivable case of a given type' (p40).

Shaw (2008) writes from the 'conventional viewpoint'. Aside from the logical arguments he makes, in his writing there is the sense that he conceptualises disability in quite negative terms. He calls deafness a disease, 'the deaf case involves the intentional creation of children who *have* a disease' (p408) and does not relate to the deaf couple's viewpoint: 'In fact, there is immediate prospect of resolving these disputes, because such philosophers are using social justice to adopt the impartial perspective of what is best for the future child, while the parents are choosing what they want without any regard for fairness' (p413). This provides an example of a stereotypical 'non-disabled' viewpoint.

These papers show the central role both personal and group identity can play in the lives of disabled people in relation to medicine, and the social and political complexities that may arise in the future in response to medical advances.

Disability, identity and the internet

Natilene Bowker and Keith Tuffin (2002) carried out interviews with 15 physically disabled participants aged 30 to 59 years who regularly used the internet, including chat rooms. The authors' aim was to explore whether or not participants disclosed their disability while online. Paterson & Hughes (1999) argue that failure to disclose works against the disability movement, as it prevents non-disabled people from being faced with contradictions to their false beliefs about disability. Bowker and Tuffin therefore were also interested, if the participants chose not to disclose, in seeking the reasons why.

The authors explored three themes in regard to disclosure: relevance, anonymity and normality. In relevance, participants chose not to disclose when the context meant this was inappropriate, however there were times they did disclose, for example if disability were misrepresented, disclosing disability gave added weight to the participant's views. In anonymity, the participants chose to withhold, disclose or invent information to present an identity, including other information besides disability. The participants enjoyed their ability to be anonymous, and felt they had a right to choose to respond privately. In normality, the participants approached the internet as a place they could be 'normal'. They choose not to disclose because they wanted to be a part of able-bodied culture, or wanted a 'break' from disability.

The authors conclude that disabled people valued their ability to choose to disclose or not on the internet very highly. Their comments about face-to-face interactions with

others suggested they did not experience non-disabled identity except online. Being online allowed them a new space to interact and form ideas about themselves; 'For those restricted to a self-description based on physical deviation from the norm, having access to other descriptions may lead to empowering outcomes' (p342).

This study offers an interesting slant on identity and the possibilities offered by the internet to people with prominent physical disability.

Conclusion

Because of the history of medical hegemony in disability and the marginalisation of disabled people, the needs and desires of disabled people are most often approached from the perspective of the caregiver and institution. Stereotypes of disabled people have been of passive, helpless people to be pitied, to be repelled by, or idealised as 'heroic' for getting round their disability. However, with the disability movement the 'voice' of disabled people has begun to be heard. A common thread appearing within research that listens to disabled people is that they can live valuable, happy lives and many do not see themselves as disabled (Watson 2002) while some (at least hypothetically) would not want to be cured. Others, when freed from the necessity of disclosing their disability, for example by being online, choose not to. This is not only because 'they have something to hide', as some have suggested but because they enjoy the control they are otherwise denied when their disabilities are visible to others.

Research that engages with disabled people themselves and tries to represent their voice, instead of theorising disability from a medical model or from conventional viewpoints, is rare, and the papers here that explore the viewpoints of disabled people were sometimes the only ones available. In respect to future education, it would be advantageous to take the viewpoints of disabled children into account in order to avoid policy and practice designed to support them that may in fact be irrelevant and/or harmful to them. Many of the problematic, systemic issues need to be addressed through structural change within education, not only for disabled children and young people, but for all pupils and students, teachers, and educational leaders. One way forward is to take a similar approach to that recommended in the Ajegbo Report, in respect to disability.

Another common thread in the research papers is related to complexity. 'Disabled' represents a huge array of impairment, and social barriers differ accordingly (Deal 2003). It cannot be viewed as representing people who share a clear characteristic, in the way race and gender do. The variation in identity between and within disabilities means that groups and individuals respond differently within the disability movement, from refusing to advocate as 'disabled' as in the case of the Deaf community, to supporting the disability movement simply by being present at meetings, as may be the case for someone with severe ID.

This complexity means that in forecasting future trends, whatever happens is likely to affect different disabled young people in different ways. For example, if, in 25 years, education is structured through home computer use, visually impaired and/or children who have difficulty with fine motor control may be marginalised, while those with a visible physical disability may be freer in their choices of identity.

Complexity is also present in the multiple identities expressed by people, in terms of sexuality, race, class, role etc in addition to disability, and indeed, as Skelton & Valentine (2003) demonstrate, there are multiple identities within a particular disability. There is also complexity in that people combine and shift identity differently in different space

and time according to context and choice. Though such complexity is commented on frequently, there is very little research done on more than one identity at a time.

Finally, the theme of bipolar concepts and the problems they cause was repeated in the research reviewed. The problem was discussed in many contexts, from opposing tensions between individual pupil rights and inclusion within schools, to the dichotomy of impairment and disability threatening the foundations of the disability movement, to the inability of a perspective from the 'conventional view' of disability to imagine it as anything other than disease, abnormality and misery.

We need to develop models that represent complexity, which can make sense of our postmodern, pluralistic culture. At the moment we are swamped by conflicting information that needs to be re-theorised in holistic, dynamic ways.

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