

Cultures of disability and deafness: rethinking links between the disability movement and the deaf community

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The social model and social perspectives of disability are gaining increasing momentum within Australia. This identification of people as disabled by their environments rather than their impairment results in part in the identification of disabled people as a group marginalised and disenfranchised by the exclusions of societies and communities. Propelled by the social model, the disability movement has as one of its primary concerns the recognition of a disability culture, which is based in the shared experience of a disabled identity.

Although the general community's perception of Deaf people is associated with disability, the Deaf Community views itself as a language group. Nonetheless, the Deaf Community is politically aligned with the disability community because of such a perspective, as well as disability-based legislation which potentially assures Deaf people of their human rights.

It is argued in this paper that social perspectives of disability potentially bring the two groups into closer alliance, highlighted by the emergence of disability culture and its similarities and interactions with Deaf culture and its consequent focus on the development of a positive disabled identity.

There are also a number of trends in the way in which both disability and deafness are viewed which have a significant negative impact on the ways in which disabled people and Deaf people experience the world. These include historically medicalised views of both disability and deafness, and the current research and policy development on bioethics and prevention of disability.

Thou shalt not curse the deaf
Leviticus XIX 14

it must be emphasised that all deaf people have, in different ways, posed challenges to our thinking about disability, particularly in relation to how disability should be defined. They have also questioned whether or not existing definitions, such as those described by disability legislation or the social model of disability, can include the diversity of deaf experience in a meaningful and acceptable way without discrediting the considerable advances which have been made by both deaf and disabled people in terms of self definition, self determination and political action.
(Corker 1998:6)

There is historical distance between conceptions of deafness and disability. The dominant ways of thinking about disability – the medical and personal tragedy models – have resulted in social structures and programs which seek to treat, contain and manage people with disability. The Deaf community has been overtly political for a longer period, and it can be argued, has a far more well defined self definition as a linguistic and cultural minority group. There is, however, significant development in the disability movement of a cultural conception of disability which emphasises the structural, social and political barriers which result in the creation of disability and which locates disabled people as an oppressed minority group. It is this development which we think opens possibilities for alliance between the disability movement and the Deaf community.

It should be made very clear at the outset that we are not arguing for the development of one culture, or the incorporation or blending of the two cultures – more that there is commonality of experience and philosophy which may stand to benefit both cultures in advocacy and fighting for recognition and attainment of human rights.

In this paper, we are seeking to lay some basic ground concerning the developing nature of disability culture and Deaf culture, and consider what these changing conceptions might mean for both cultures. We also reflect on some of the emerging issues such as bioethics and medical intervention which, while offering greater choice, also form a threat to both the disabled and Deaf communities. We then close with some preliminary thoughts about what a changing conception of disability and Deafness might mean for social policy.

Interpretations of disability

Political and philosophical thinking on disability has changed dramatically over the past twenty years, shifting the interpretation of disability from a medicalised, 'personal tragedy' model or a welfare oriented charity based perception towards

social constructs that see society as responsible for disability, due to the ways in which it oppresses disabled people (Oliver, 1996).

There has been an increasing acceptance of the voice of people with disability both in their services and in research in the disability arena over the last twenty years. The paradigm largely behind this contextual change has been the social model of disability (Barton, 1996; Barnes, Mercer and Shakespeare, 1999), which places people with disability in the centre of debates about disability, impairment and handicap. This is a reinterpretation of disability which has changed the way in which people with disability are viewed and the way in which they view themselves.

In essence, the central tenet of the social model originally expressed by disabled activists and researchers was that

It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.
(UPIAS, cited in Oliver 1996:22)

During the past decade, the social model has been increasingly critiqued, tweaked and refined. It is not uncommon to hear *social perspectives* on disability or the *social relations* of disability discussed, which include recognition of issues of gender, race, socio economic status, and so on – all of which have significant impact on the barriers or opportunities which are available to people with disability. Deborah Marks' work offers a useful way of understanding the impact of disability on social relations:

Knowledge and social action go together. Thus, rather than seeing disability as being a consequence of individual differences, it can be understood as a result of perceptions rooted in social practices which mark out some differences as being abnormal and pathological. (1999:79)

Recent writing from key disability studies scholars in the UK has argued for “a multi-level, multi-dimensional analysis of disability that incorporates different paradigms along with their competing world views and methodologies” (Scott-Hill 2003:96) . Mairian Scott-Hill refers to the work of Thomson in writing “Disability studies should become a universalising discourse. Disability... would then be recognised as structuring a wide range of thought, language and perception that might not be explicitly articulated as ‘disability’” (2003:96).

It is also important not to rely solely on a focus on the oppression and discrimination against disabled people. Were discrimination to disappear, there would still remain significant barriers which prevent people with disability being fully engaged and active citizens, and “we risk trivialising the still prevalent and

often vicious stereotyping and exclusive practices by confounding them with the general incapacity of social systems to respond to individual variation.” (Scotch and Schriener 1997:5) This conception, discussed by those such as Mairian Corker (1999), Tom Shakespeare (2002) is one where disability is seen as a natural part of the spectrum of human variation which focuses on how systems respond to the variation introduced by disability.

The language we use is in itself an interesting example of the way in which understandings disability are changing. In the UK, disability activists and researchers use the term ‘disabled people’ as an indicator of the fact that people who have impairments are disabled by the social, physical and political barriers raised by the dominant modes of society. In Australia, the standard term still in use is people with disability, to reflect the person first concept. We are alternating between the two in this paper.

The disability community (as such) is at a very interesting point right now. Disabled researchers and activists are developing increasingly sophisticated ways of viewing and understanding the collective experiences of people with disabilities. Of course, there is no coherent framework or construction of disability to which all people with disability subscribe. This, oddly enough, is one of things that new understandings of disability embrace – in trying to develop understandings of the social relations of disability, it is acknowledged that there is infinite variation between people who happen to have disability (as for the Deaf community), and their experiences of disability intersect with their experiences as for example, a mother, a worker, a migrant, a student.

That being said, there is certainly a clear development of a disability culture, which is based in the shared experience of a disabled identity. One of the other key characteristics of a disability culture is a positive self identification as people with disability and a conception of disability as a natural and positive part of the spectrum of social relations.

The socially dominant culture shapes the way in which disability and impairment are viewed, and has contributed to the oppression of disabled people. At the same time disabled people have forged their own cultures as acts of resistance. Culture, therefore, is both a source of oppression and of liberation for disabled people, and is therefore central to the politics of disability.

(Riddell and Watson 2003:1)

While in the research and philosophical spheres there is a very positive and engaged changing conception of social relations of disability, there is still a long way to go in the recognition of the way that people with disability are treated by society, particularly in terms of the roles in which the general community still view them – largely as tragic victims or as needy recipients of rehabilitative services. These enduring perceptions come into direct conflict with social perspectives of

disability – for example, the usual depiction of a person with a spinal cord injury on current affairs programs focuses either on their heroic struggle to survive the terrible consequences of an accident or on a lack of specialist services such as therapies which will ‘help’ that person to rehabilitate to a point they can rejoin society. Social model understandings of disability focus on the fact that the processes of society are what is causing the exclusion, isolation and stigmatisation of the person, not their impairment.

The Deaf Community

Sign Language covers a wide range of areas in everyday life of the Deaf person. It impacts areas where language is an essential tool in the life of a person, ranging from family life through to media and telecommunications and including education, employment and community access. Sign Language is therefore the main distinguishing feature that defines a Deaf Community.

If Sign Language is rejected, the situation of Deaf people is weak and unequal. (WFD Manual 1994:41)

Auslan (Australian Sign Language) is the native language of many Deaf people who have Deaf parents and of many hearing children of Deaf parents. A research study has shown that there are almost 16,000 users of Australian Sign Language in Australia (Hyde & Power 1991. Figures used by the World Federation of the Deaf (based on World Health Organisation data) indicate that Deaf Communities around the world comprise approximately 0.1% of the population, when extrapolated to the Australian situation. With a current population of 19.5 million people in 2001 according to the Australian Bureau of Statistics Year Book Australia 2003, this translates to a figure of approximately 19,500 Deaf signing people.

The Australian Government in its National Policy on Languages has recognised the Deaf Community as a language group:

It is now increasingly recognised that signing deaf people constitute a group like any other non-English speaking language group in Australia, with a distinct sub-culture recognised by shared history, social life and sense of identity, united and symbolised by fluency in Auslan, the principal means of communication within the Australian Deaf Community. (Dawkins 1991:20)

Political representation of Deaf people

The Australian Association of the Deaf, which was founded in 1986, represents this language community at the national peak level. The international body is the World Federation of the Deaf, based in Finland and which has B consultative status with the United Nations. Hence it can be seen that there is an extensive infrastructure which represents Deaf people at the political level. Skutnabb-

Kangas categorises the Deaf Community as a minority group which is 'energetically pressing for recognition of their rights'.

Deaf people have been represented in various ways in the political sphere. The reasons for the rise and fall of the various national Deaf organisations is the basis of a Ph.D. thesis in progress, but Deaf Australians were not formally represented by Deaf people until 1986, when the Australian Association of the Deaf (AAD) was founded.

AAD was established, not only for cultural reasons, but also because of dissatisfaction with the Australian Deafness Council's ability to represent culturally Deaf people. There was a long struggle for AAD to be recognised as a peak body in which Deaf people, rather than service providers, families and hearing impaired people represented culturally Deaf people.

Deaf Culture

The social position of Deaf people has come a long way since the sixties when a text book for working with Deaf people quoted the Principal of Doncaster College of the Deaf, Dr Greenway thus:

*The deaf suffer from
Intellectual malnutrition
Social deprivation
Educational retardation
Emotional frustration
Moral and spiritual starvation
Economic limitation,
And Aesthetic impoverishment*

Reverend Firth, the author of the text book in discussion of this list actually states that 'the more one studies Dr Greenway's list, the more true one realises it to be'.

As a cultural group, the Deaf Community has a strong sense of cultural heritage. There is great significance attached to Deaf schools, Deaf clubs and regular events such as the Australian Deaf Games and Deaf Festivals, to name but a few. With the establishment (by two Deaf men, quite independently of each other) of the Victorian School for Deaf Children and the Darlington School for Deaf Children in 1860, Deaf History has been characterised by specific milestones: the Kew Deaf Cricket Club is the oldest continuously operating Deaf Sports Club in the world, having played its first interstate match in the 1890s, and some of the Deaf Societies in Australia, (established by the earlier students of the schools for Deaf children) pre-date the federation of Australia: the Victorian Deaf Society (1884) and the Royal South Australian Deaf Society (1892). Catholic Education for Deaf children commenced in 1875 (with the arrival of Sr. Mary Gabriel Hogan, a Deaf nun) in Newcastle.

Since the publication of the Auslan dictionary and the implicit acknowledgment that being Deaf was indeed a culture, there has been an increased awareness of Deafness as a culture in the Australian Deaf community, and indeed the wider community. The word 'culture' has legitimised the way of life for so many Deaf people, and the words 'linguistic minority' and particularly 'language' have also gone a long way in making Deaf people feel that their language is equally as important as English – a far cry from the days when Deaf people did not feel proud enough to be able to sign in public, or ask for community services in sign language. There has been a move from covert celebration of Deafness through the national sporting carnivals and local Rallies, to overt celebration such as the infancy of Deaf Pride Week and Deaf Festivals in the early nineties. There has been some limited media attention to the fact that Deaf people are proud to be Deaf. Analogies can be drawn with the gay and lesbian pride movement with the appropriation of the word 'pride'.

Today, Deaf Pride Week is called the National Week of Deaf People and which is held in October. The International Day of Deaf People, which commemorates the establishment of the World Federation of the Deaf is the last Sunday of each September, which unfortunately in our culture, overshadowed by the grand finals of various football codes! A more studied approach to teaching Deaf culture has unfortunately been limited to hearing students of the various nationally accredited certificates in Auslan (at VET level). It is unfortunate that this information is more readily accessible to students of Auslan than to Deaf people themselves. However the notion of a bona fide Deaf identity has leached nevertheless into the Deaf Community.

The Deaf Community is, rightly or wrongly, at a nexus between being a cultural group and part of the disability community. Never before has the Deaf Community been so politically strong; never before has the perceived threat been so pronounced.

The Future

Current research and policy development on bioethics and the prevention of disability provide a very topical area in which to consider the possible links between communities of Deaf people and disabled people. An article in the Sydney Morning Herald just two days ago raised again some of the possible outcomes for people with disability in the quest for scientific development of genetic technologies. Kristof writes, "it is difficult to draw a line where we stop 'improving' our species. Many disability activists argue that we're moving towards a new eugenics, and I'm afraid they could be right." He quotes Bill McKibben, the author of a new book on genetic science, *Enough*, as writing "Why not at least let the germ-line engineers go to work on the [people with genetic disabilities] of the world? The harm is not to the patient but to the world in which she lives" (8/7/03).

The following example clearly illustrates one of the developments of the future which stand to impact substantially on both disabled and Deaf people.

Research at the Murdoch Institute in Melbourne has resulted in the identification of the connexin-26 gene. According to Nance, environmental causes account for 50% of deafness (including prematurity, pharmacological ototoxicity, rubella, pre-natal CMV infection, post natal infection) and genetic causes make up the other 50% (syndromic deafness making up 20-30% of all genetic deafness and non-syndromic deafness, 70-80%). It is of interest that connexin-26 deafness makes up 30-40% of non-syndromic deafness. It is recessive, has a variable genotype in that it is usually profoundly deaf and contains the information for gap junction protein. In all there are approximately 400 genes which result in deafness,

The linguistic and cultural nature of the Deaf Community has led to a 17-18% increase in connexin-26 deafness over the last 200 years. The genetic basis of this threat to the Deaf Community places it squarely as an issue rooted in disability rather than in conceptions of cultural minority.

Jokkinen, from Skutnabb-Kangas states that:

It is through deficiency-based models that those in power maintain and reproduce unequal power relations. The models invalidate the linguistic and cultural capital of minority children, and their parents and communities. They make them seem like handicaps and deficiencies and glorify dominant languages and cultures as better adapted to meet the need of 'modern' technologically developed, democratic, post-industrial information-driven societies.

Is genetic manipulation of the connexin-26 gene a form of linguistic genocide? This has been argued by Jokkinen at the international level where this genocide has previously been perceived to take the form of linguistic and cultural genocide through 'prohibiting the use of language of the group in daily intercourse or in schools, or the printing and circulation of publications in the language of the group'. Jokkinen also paraphrases Skutnabb-Kangas by saying

It is practiced throughout the world. Linguistic and cultural genocide is run mainly by consciousness industry: mass media and formal schooling, along with market and other forces

As Kauppinen states:

The Deaf have common interests with language minorities and disability movements in promoting their rights. For language minorities the priority lies with human rights, especially rights concerning language. For people with disabilities, human rights and an unhampered environment are also important.

We cannot to any sort of justice to issues of bioethics and genetic science within the constraints of both the time and our level of expertise – but these are issues which need to be canvassed within the context of our paper.

Possibilities for Cultural Alliance

The medical research of the future is just one area in which an intersection of the Deaf community and Disability culture can be seen. One of the things that influences the way that disabled people and Deaf people view the relationships between their communities is the changing conception of disability and the place of theories of disability and impairment. This results in a more closely shared range of experiences as cultural minority groups and also of more philosophically aligned self conceptions.

There are many commonalities between the Deaf community and the disability movement. Corker (1998) provides a range of links between the two movements:

- A history of cultural oppression in Western society, with specific reference to eugenics, institutionalisation and genocide, for example.
- Theory is based on essentialist notions of deafness/disability, for example 'one can only be Deaf or hearing', 'disability is located in the individual or in society'
- The main specific legislations use the individual model of disability.
- Distancing from the concept of impairment
- Difficulty in dealing with pluralism and individuation
- Self-definition in terms of social identity, social movement and community
- Strong belief in self-determination
- Recognition for the linguistic minority construction of Deafness

We should, however, be very cautious about the dangers of conflating disability and Deafness. There are considerable distinctions between the Deaf community and the disability movement. For example, the disability movement has long fought for supported accommodation services, appropriate health and medical care, and so on. The Deaf community do not attach particular importance to these issues. The two movements also have very different conceptions of the value of 'mainstreaming' and 'integration', particularly in the education system. As Lane (1997) writes, "People with disabilities should no more resist the self construction of culturally Deaf people, than Deaf people should subscribe to a view of people with disabilities as tragic victims of an inherent flaw."

Lane goes on to state "It is undeniable that culturally Deaf people have great common cause with people with disabilities. Both pay the price of social stigma. Both struggle with the troubled-persons industries for control of their destiny. Both endeavour to promote their construction of their identity in competition with the interested (and generally better funded) efforts of professionals to promote *their* constructions."

What does this mean for policy?

We need to have a brief discussion about how this sort of thinking influences policy (since this is a social policy conference!)

Drawing from Lane's work (1997), we would like to outline some of the lessons that the Deaf community have learnt which could be of use in providing some parameters for thinking about how to incorporate changing conceptions of disability and Deafness into social policy.

1. changing the construction changes the legitimate authority concerning the social problem
2. changing the construction changes the how behaviour is construed
3. changing the construction may change the legal status of the social problem group
4. changing the construction changes the arena where identification and labelling take place
5. changing the construction changes the kinds of intervention

We need to recognise that there is a broader conception and self conception of disability and of Deafness, and that we can't expect people to fit neatly within a particular box marked 'disability' or 'Deaf'. Social research, policy development and development of structures need to change. Both within the welfare and social services sectors but also within the broader social, structural and political arenas in which disabled and Deaf people are conspicuously absent, there is a need to incorporate a broader conception of disability and of Deafness as removed from personal tragedy or charity, while still maintaining a practical and pragmatic understanding of the barriers which prevent the articulation of an equally valued set of life experiences and opportunities.

Finally, there is a need for alliance between disability and Deaf culture which sees both diversity and the social resistance it brings as an important means of achieving social change (Corker 1998).

Contact details:

This paper represents our initial thinking on this issue. We would value the opportunity to discuss the paper with interested readers.

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