

## **The Difficulty with Deafness Discourse and Disability Culture\***

Tanis Doe

Royal Roads University and University of Victoria. Canada

**Abstract:** This paper addresses why the Deaf Culture stance is to distance itself from disability and how this divides rather than unifies communities in common. From the perspective of a member of both the Deaf World and Disability Culture, current discourses are considered and presented for discussion.

**Keywords:** Deaf, Disability, Culture

### **My Standing (and Sitting) in the DEAF-WORLD**

Writing about this topic is both personally and politically risky for me. There are some potentially negative consequences of writing about Deaf culture and its relationship, however tenuous, to disability culture. By doing this I transgress against the dogma of Deaf Culture by questioning basic tenets. If Deaf Culture is as firm as its proponents say it is, it will withstand criticism. All worthwhile concepts deserve interrogation. I want scholars of disability studies to understand the complications and the lack of resolution in the murky issues. Let me start by positioning myself. Sometimes this is called self-locating.

I am a marginal member of the Deaf community by virtue of the fact that I can speak and was not born deaf. But I am an honored member because I have a Deaf child and have raised her within Deaf schools and the Deaf community. I am also respected for my teaching and community activism having been on the Canadian Association of the Deaf Board of Directors and worked for them in various capacities. I am marginal because I sit. I use a wheelchair (Deaf people are not disabled, See Moore and Levitan, 1993). This paper will deconstruct some of the difficulties of Deaf culture from the perspective of Disability culture (with a capital D).

My obvious use of a wheelchair is a visible signifier that I cannot be Deaf (or at least should have the dignity not to claim so). I arrived (in my wheelchair) at a table where the interpreters were positioned at an international conference in Washington, D. C. once and was told that this seating (the table) was for “the Deaf.” (*emphasis mine*) I signed. “Like me.” I was given a look of curious doubt and suspicion and then Dr. Yerker Andersen recognized me and I was allowed to stay. He is the former president of the World Federation of the Deaf and professor at Gallaudet University. He also knows me. His acceptance of my claim to the seat, to Deafness, was sufficient. But Dr. Andersen is rarely at the events I attend and I remain generally un-accepted. From this position of marginality I have a unique position of being able to live the discrimination of being disabled (socially constructed and physically impaired) in the DEAF-WORLD as well as being a part and party to it (Lane, Hoffmeister, and Ben Bahan, 1996).

For newcomers to this DEAF-WORLD, let me explain some of the language being used. When someone cannot hear there are various terms used by the public and medical professionals to signify that state. Hard of hearing, hearing impaired, late deafened, deaf and sometimes deaf-blind (although there is a true marginality in that condition as well). Being Deaf-Blind is a state of liminality that throws one out of the DEAF living room and into the Deaf but Blind too corridor. The use of the capital “D” Deaf does not describe the condition of not being able to hear. It describes a membership in a community of choice. That is you self-identify as being

Deaf by using sign language and joining with Deaf friends and sharing Deaf values. Being Deaf is far less about audiological ability to hear pure tones and more about your ability to be culturally appropriate in the presence of other Deaf people (Padden and Humphries, 1988).

Deaf culture is considered a high context culture; that is one in which communication requires a great deal of insider knowledge. The non-informed person, even with sign language skills, will have a hard time following a conversation without a sense of the topic and the participants. Deaf Culture has been compared to Israeli Culture in how it sees time and how rules of interaction are adhered to (Mindess, 1999). Similarly, it has been contrasted against the dominant hearing (white non-disabled) American culture because Deaf culture is direct and explicit and hearing culture tends to be vague and implicit (Mindess, 1999).

The concept of a Deaf culture is essential to understand if we are to understand why Deaf people do not want to be considered disabled. And then I will try to explore some difficulties in this argument based on my own experience with Disability Culture. As Cheryl Marie Wade eloquently has written, there is a Disability Culture and it is as real and as much a minority community as Deaf culture. But for Deaf people disability is not this. They see disability, in lower case, as a deficit that nondisabled, hearing people created to oppress (Lane, 1992, 1995). In his recent book on disability history, Paul Longmore identifies the problem that Deaf history scholars have constructed. “Finally and distressingly, to counter prejudice against Deaf people, Lane stigmatizes people with other disabilities. A minority model fits Deaf people; the medical model applies to other handicapped people. In fact a minority model that defines “disability” as primarily a socially constructed and stigmatized identity and that Lane so convincingly applies to the history of Deaf people also best explains the modern experience of blind people, physically handicapped people, and even most mentally retarded people” (2003:44).

### Why Deaf People Oppress and Marginalize Disabled People

I have come to believe three contributing factors about this difficulty.

One, Deaf people are raised by hearing people, put in schools run by hearing people (mostly) and live (mostly) in a society dominated by hearing values. Because of this Deaf culture has acquired, through schools and the media, most of the same negative stereotypes and understandings of what disability means. And to Deaf people, it is NOT them. They are NOT that. Not crippled, not blind, not crazy, not sick. Disability is “othered” to the extreme, at least in part because of the negative stigma it would attach to otherwise “less” oppressed Deaf people.

And this is often true. In the lower case world of impairment people who do not hear are usually not the same people who use wheelchairs or canes or who have learning disabilities. Probably at least 65% of people with disabilities are not Deaf. But there is nothing special about being deaf that prevents you from having a disability and certainly nothing magic about having a disability that prevents you from being deaf. But being deaf does not equal being Deaf.

Corker has argued that some Deaf cultural positions are devaluing disability in part because hearing values which have feared disability have been transmitted and so Deaf people do not want the label of disabled anymore than hearing people want it. I find this to be a convincing argument. Deaf people are as much a party to the social construction of what disability is as are hearing non-disabled people. I have seen it at Schools for the Deaf, at Deaf events and in relationships:

Hearing impaired people, and particularly deafened people, are often trapped between different discourses of tragedy from which there is no escape and from which they cannot develop alternative discourses because of the marginalizing effects of negative value judgments. In a sense, then Lane selects particular discourses on deafness and disability which are not directly comparable. In doing so he successfully emphasizes his main premise that Deaf people are not disabled by drawing upon the disablist discourses; he thus justifies Deaf people's claim to the right to coexist as a minority group (1998:63).

Corker, by the way, was deaf, could sign, but also talked and was positioned in a marginal status to both hearing and deaf communities in Britain. She, like I, risked her social status by arguing against the dominant Deaf discourses. She was willing to name ableism (she called it disablist) when she saw it.

Secondly, to be Deaf you must sign, respect Deaf heritage, embrace Deaf values and associate primarily with Deaf people. It helps if you do not speak and when you have Deaf children and/or parents (Evans and Falk, 1986). This is important because to really understand the Deaf perspective you must be a signer, a fluent one, and you must be immersed in history and cultural knowledge. For Deaf people, this is not about disability at all, it is about language and values.

Thirdly and perhaps most importantly, Deaf people do not see being deaf or Deaf as a stigma. They are proud of their culture and do not want it to be “contaminated” by the enormous stigma associated with lower case disability and impairment. As a movement they have made some great gains and do not want to lose this precious progress. This may seem like I am simplifying but in fact I am complicating. Deafness as Culture does not carry with it the stigma that Deafness as disability does (or could). Many Deaf people, at the grassroots and at the academic levels, really believe that hearing people (the world in general) are mistaken by seeing being Deaf as a limitation (or disability).

### Disturbing Differences of Discourse

There is significant difficulty with this discourse that creates a serious rift between and among communities. I am worried that my Deaf colleagues and my daughter who is also Deaf, are being misled by hearing people about the way they are perceived as a Culture and as a population with a deficit. My daughter is seen as limited when she goes to the store or even gets on the bus. Not because she CAN sign but because she does NOT speak. Deaf people, generally, do not get Disability (capitalized on purpose).

As a Deaf person with a disability (several actually) I claim my capital D Disability Culture status with equal pride and celebration as my Deaf status. However at disability events I am far more likely to have an interpreter provided, and to have my Deaf status recognized (maybe not understood) than have accessibility for my disability or Disability at a Deaf event. The Deaf community is at least partly built on an ableist foundation that says, “we are not them” and “they are not us”. But this divides, unnaturally, groups of people by a status that is determined medically or legally and not culturally or individually by choice. It has caused numerous Deaf people to be marginalized from their own group- other Deaf people- on the basis of access and acceptance.

Maybe some deaf (who cannot hear but are not part of Deaf culture) people do not mind how the Deaf feel about disability because for them deafness **is** disabling and since they are not part of the Deaf culture these arguments do not affect them directly. Certainly I know hard of hearing people who cannot be bothered with arguing about or with Deaf people.

But these issues do affect me. They affect me as a person, as a mother, as an advocate and as a teacher. How can I sit in a wheelchair and teach, in sign language, Deaf students about instructing sign language to hearing people? I am out of place, I do not belong. I am mis-fit. I am mis-constructed and mistaken.

How can I as a Deaf person (with a Deaf daughter) teach a Disability Studies class when Deaf culture refuses to associate itself with the literature and discourse of disability/Disability? I sometimes wonder if the Deaf leadership and membership of Deaf Culture have taken the time to read what Disabled people have been saying about Disability. Because what we are saying about Disability Culture fits in nicely with what many radical Deaf Culture proponents say. But the dialogue is missing.

Disability, in its lower and upper case forms, is LIKE deafness. It can exist on the biological plane and be physically a problem. It can be primarily an impairment or it can be primarily an identity. We seek human rights, sometimes called civil rights, as people who are citizens of nations. We are not willing to pretend to be non-disabled to get a job, go to school, have children or be on TV. We, d/Disabled people, want very much what people who argue for Deaf Culture want - status as a minority rather than status as sick, needy, dependent, and disordered.

Culturally Deaf people have struggled with not wanting to be categorized as disabled. Not struggled among each other, but against the huge special education and rehabilitation industry that puts them squarely in the category of disabled. Society, too, is guilty of considering deafness (not Deafness) to be an impairment. There are many people who acquire hearing problems in life after age 30 who agree that it is an impairment and seek out solutions. The Deaf community has little argument with them because they are really hearing people who cannot hear rather than Deaf people after all. There are double standards for the valued members of DEAF-WORLD and for those who just became deaf:

An embarrassment for the medical model of cultural deafness heretoforeward that this "pathology" had no medical treatment. With cochlear implants, however, the medical specialty of otology has been expanding its traditional clientele beyond adventitiously deafened hearing people who seek treatment, for whom an infirmity model is appropriate, to include members of the Deaf community, for whom it is not (Lane, 1992:206).

The main concern is with hearing parents, and hearing professionals (usually doctors and audiologists) who do not want deaf children to become Deaf. They want their deaf children to be as close to hearing (and Hearing) as possible. In order to approach the fixing of deaf children through current cultural and social norms it must be deemed a tragic disability and severely impairing condition. If not why would governments and medical organizations pay so much money for implants, research, interventions, treatments, and hearing aids?

Deaf people who use sign language argue for a minority status. This is in part the result of trying to distance Deaf identity from a negative deficit model. But it is also much like a white Hispanic person saying, 'I am not a person of colour' (because he is not) even if he still fits some

of the roles of a person from a minority background for language reasons. Women have had to realize that they cannot always distance themselves from their biological sex because it is part of what interacts with the world and co-creates gender but also has medical implications (such as issues of cervical and breast cancer).

The linguistic minority status that Deaf people and the DEAF-WORLD (This is another way of writing what is signed in ASL) want will not come with the same benefits as the label of disability because in North America, there is not a particularly good history of how linguistic minorities are treated. There are few if any entrenched rights and the social structures in general push for unilingual assimilation (Speak English you are in the US! or Speak French you are in Quebec!). But the formation of a positive identity as Deaf – one that is free from the negative affiliation with disability, is the first step in resisting oppression (Davis, 2002:10). The next step after having established group solidarity, is when people “are comfortable about self-examining, finding diversity within the group and struggling to redefine the identity in somewhat more nuanced and complex ways” (Davis, 2002:11). Some Deaf academics, who study Deaf Culture, have been able to look around and recognize that some groups were not at the table, and that some groups were dominating, and that some inequality existed in the purported Nirvana that was/is DEAF-WORLD (See for example Sheridan, 2001).

If culturally Deaf people can realize that they can be little ‘d’ deaf (biologically) for the purposes of educational and vocational benefits, but capital D Deaf for social purposes they can avoid the inherent conflict. Many people who are NOT disabled biologically by hearing loss want to identify as part of the Deaf community. Interpreters, hearing children of Deaf parents and people who work directly with or are partners of Deaf people. There are also some small ‘d’ deaf people who physically qualify as being disabled but who do not claim their cultural Deafness as an identity (Glickman, 1986).

Clearly there are both little ‘d’ deaf people who feel their hearing loss does need to be fixed and is "a disability" and capital ‘D’ Deaf people who are quite satisfied with their lives and do not want to be fixed. But it is not useful to pretend, or to argue, that BOTH do not co-exist. It is important for the Deaf academic position to be fortified by theory and epistemology that recognizes our social and our biological existence without denying the importance of political or cultural stances.

A socio-political model of disability, also seen as a civil rights approach, looks at disability as the consequence of how society is organized rather than biological experiences of difference. “This approach is based on the premise that disability is not a deviation or an anomaly, but that persons with disabilities are an inevitable part of the population” (Roehrer Institute, 1996:17).

One of my favorite arguments is about the Miss Deaf Pageants. In Canada, Miss Deaf Canada was discontinued when the Canadian Cultural Society of the Deaf and other Deaf organizations agreed that it was sexist and outdated to parade Deaf women around in the name of “culture”. My argument with the leaders of the pageants who claimed that this was a Deaf Cultural opportunity for leadership and recognition for Deaf women, was that this was no more Deaf Culture than breakfast. Miss Deaf Canada is directly lifted from Miss (hearing) Canada and all other such pageants. The only thing Deaf about it were the contestants but it certainly did not support or reinforce anything Deaf. It supported a sexist image of what women (hearing or deaf) should look like, act like, walk like and sign like. Deaf people are somewhat snobbish when it comes to sign; like hearing people who value speech, Deaf people value good signing. But in the U.S. there is still an event that parades Deaf women around for the title of Miss Deaf USA. I

have even seen it argued that it is MORE necessary now that a “deaf” (lowercase) woman has won Miss America. Separatism lives, but they are not supporting Deaf culture in doing this, they are supporting patriarchy and sexism. So one of my favorite arguments is an example of how the Deaf Culture has emerged as just a specific version of hearing culture and with all the faults that go along with the dominant culture and its hegemony- racism, ableism, homophobia, ethnocentrism (Anderson and Bowe, 2001). These are not Deaf attributes, but they are attributes Deaf people learned from hearing people.

What to do? (SIGNED DO-DO? WITH RAISED EYEBROWS)

Political strategies are in conflict with cultural values, and debate divides people who share linguistic needs unnecessarily. Deaf studies can learn from women’s studies and cultural studies of other people’s struggles. Women's groups struggled for 20 years with the idea that by bringing up the idea that "maybe" women are "different" from men that they would be erasing accomplishments towards equality. Now, they are realizing both sex and gender exist and that equality is only going to be achieved if both are addressed fully. In addition feminists have argued that patriarchal structures hurt some men too and so it would be good for everyone to implement (radical) social change.

Deaf people who are part of the “grassroots” of the Deaf Culture often are employed in jobs that might be considered menial or blue collar. Discrimination against Deaf people in the mainstream is still a main barrier to success in the professional fields. Deaf people are clear that while they want minority status as a Culture they want access to the majority as well. Deaf people watch TV dominated almost exclusively by hearing issues, stories and actors. Deaf people (the majority, not the professionals) work in a primarily hearing environment.

Deaf professionals, those Deaf people who have attained university education, now teaching at colleges, Schools for the Deaf, or universities, are in unique situations where the students they work with are often deaf (and/or Deaf). Deaf community leaders who work full time as directors of Deaf organizations or who lobby full time for Deaf children’s rights might be around Deaf people more regularly in their day than the average Deaf person.

But there is not enough DEAF-WORLD to go around. There are not enough Deaf spaces and Deaf jobs and Deaf cultural events to fill the needs of all Deaf people all the time. So Deaf people will join the hearing majority for part of the time. They may work at the Post Office, or at a local business, or attend a local community college instead of Gallaudet, or may even marry a hearing person instead of a Deaf person. Deaf people, despite the academic arguments of the cultural minority status, are very much a part of the mainstream of hearing/nondisabled society. And they want to be. At least they use court cases to contend that they are being discriminated against if the mainstream does not provide them with interpreters, captioning, technical aids, accommodation and access. Oh, and the discrimination is based on disability not cultural minority status.

But legal strategies are tricky. Sometimes you have to argue one way even if you do not believe it in your heart. Legal strategies around the Americans with Disabilities Act of 1990 (ADA) have included arguments that being "gender confused/dysphoric" could be a disability (a transgendered person may use this argument to defend rights that are not otherwise protected) even if being transgendered is seen as a natural and not at all a deviant status by that person.

The argument can be made that deafness as a disability does not have to be denied as long as it is recognized as the basis of accommodations such as captioning, relay services or TTYs. Cultural Deafness may not bring with it the benefits of the ADA or the Charter of Rights or political sympathy based on the deficit model, but it can bring solidarity, pride and a sense of

a future as a people that little 'd' deafness does not. Strategic identity politics might be a solution.

As Lane (1995) acknowledges, and Susan Foster (1996) discusses, if capital D Deafness is accepted as only a linguistic minority status by the governments, it would mean that most of the services and benefits that Deaf people are currently entitled to would be withdrawn. This is because they are based on the medical and disability models of what deafness means.

This has been a painful struggle for me because I was not born deaf and I was not born with disabilities. I was also not born literate or educated. It is only through my experiences growing up, going to school, raising my daughter, advocating for Deaf rights and later Disability rights that I learned what I know. I want more people with disabilities and more Deaf people to understand that we might not be so different in what we want or even in how we strategize to get it. I believe, that slowly, very slowly things are changing. This is in part because there are deaf people with disabilities and there are disabled people in the Deaf community. At the most recent World Federation of the Deaf a group of Deaf people with cerebral palsy and/or brain injury were highlighted in the daily newsletter as making important points about their need for full acceptance in the DEAF-WORLD. I was absent from that historic event but read about it on line.

The minorities in the world have a considerable history of being oppressed and exploited by the majority so the idealism of being a linguistic minority does not bring with it hope for a higher status. In fact, even the negative images of being disabled are not always seen as negative as the images of being a slave, a non-English speaking citizen, or a foreign language immigrant no matter what the skin color (Ruiz, 1988). Minorities are minorities in status, power, and acceptance. More work is needed on the issues of Deaf people who are racial/ethnic minorities but more work has to also be done on Deaf Culture (Reagan, 1990).

It is my hope that the Deaf community will come to understand that the Disability community also wants to be recognized not as deviants or broken "normal" people but as people with Disabilities in our own right. We have as much Disability Pride and Culture as Deaf people have Deaf Pride and Culture.

Deafness as a Cultural phenomenon can still be promoted for the purposes of maintaining a population of Deaf people who may, as citizens, want specific policies implemented, in the same way that religious groups, political parties or trade associations are pushing for favorable policies.

It is an uneasy alliance, to be sure, but the Disability community has begun and is succeeding in turning the previous negative conceptualizations of disability into one of pride and cultural membership. The Deaf community might even take some credit for getting a head start and giving the Disability community the idea that Disability could be POSITIVE and that membership status might be useful rather than stigmatizing. Disability dance, theatre, prose, poetry and arts have flourished at least in part because Deaf arts paved some ground to support arts and culture for people with disabilities (oh I mean Deaf).

If the Deaf community continue to distance themselves and deny any connection to the Disability movement they may lose out on a potentially politically powerful movement. This is possibly the movement to acknowledge difference, to embrace diversity but to provide for support and accommodations as a human right. Support does not need to be an entitlement per se but available because it is the right of all people to participate fully in their world as they are and not as the dominant powers that be say they should be.

**TANIS DOE**, B.A., M.S.W., Ph.D., is a Deaf activist and academic who has other disabilities and a grown Deaf daughter. She lives in Victoria, British Columbia, Canada, but also works in California, viva la Internet! Her areas of interest include technology, gender and sexuality as well as teaching disability studies.

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\* Please note that MUCH of this article appears as a chapter in Tanis Doe's self-published book *Studying Disability* (2003) It was mainly published to be used in course work at the University of Victoria- it has not been widely circulated and other than this book this chapter is brand new.