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## What Is Disability Culture?

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I have been asking (and being asked) the title question for at least the past dozen years. I have identified and shared example after example to demonstrate the existence of disability culture, but it is much more difficult to define the phrase. There are many reasons for this. The words, "disability," and "culture" are each value-laden, charged with emotion in every culture I have encountered. Almost all of us identify with more than one culture. Growing up I knew, for example, that I was male, that I was a Midwesterner (United States), that I was Jewish, that I was middle class, that I was white, and probably many other things I am forgetting as I write this paragraph. The point is that each of these examples could be considered cultural. I was also a person with a disability during most of my youth, but it was much later in my life that I identified myself that way.

Moving to an international perspective the word "disability" has different connotations to diverse cultures just as the word "culture" does. The definition of disability that may have become the most known is that of someone who has a major life impairment preventing them from participating easily in a major activity such as walking, seeing, hearing, thinking. But that definition is one of only dozens in the United States alone. Worldwide there may be hundreds, if not thousands, of definitions of disability and I would venture the same applies to the idea of culture. Any word that has such historical and contemporaneous significance will create controversy and interest.

In the past two years I have been asked to describe and stimulate discussion about disability culture on two websites. As a result of these efforts I have sought quotes about disability culture from sources around the world. The bulk of this paper will consist of other people's words with some (hopefully) descriptors about why these particular quotes are being used. One note about style and language. I have attempted to maintain the styles I found these words first formatted in out of respect to the authors and their wishes. In the same vein, I have kept the language in its original spellings.

I begin quoting myself from Investigating a Culture of Disability: Final Report published in 1994 after receiving the first monies from the Department of Education to do research about disability culture. This paragraph was first used in my proposal to the National Institute on Disability Rehabilitation Research (NIDRR) to start this work:

The existence of a disability culture is a relatively new and contested idea. Not surprising, perhaps, for a group that has long been described with terms like "in-valid," "impaired," "limited," "crippled," and so forth. Scholars would be hard-pressed to discover terms of hope, endearment or ability associated with people with disabilities. (Brown, Investigating a Culture of Disability)

The following quote I found online while searching for descriptions about disability culture from other countries. I know nothing about the author:

Disability can be represented as a culture, though the range of differences among the disabled is enormous. The disabled community is the most divers[e] there is. It is therefore important to include self-reflection and self-criticism in disability studies programmes. Some difficult questions have already been asked: have these differences been used as a means of division and separation? Are people with severe developmental disabilities or learning disabilities regarded as full members of the club? Or is the expression 'physical disability' a disguised strategy for drawing a line, even if it is common knowledge that (develop)mental disabilities have physical markers too? (Ine Gevers: Non-Symbolic Cultures, <<http://users.bart.nl/~5star /N/about.htm>>)

Harlan Hahn, perhaps the first scholar to write about disability being beautiful, wondered, "Have you ever thought about going to McDonald's as part of your cultural heritage? He says for people with mobility disabilities fast food restaurants are a cultural icon." (VSA arts New Mexico website: <<http://www.vsartsnm.org/>>)

Understanding Disability Culture (New Zealand)

A New Zealand website I found included many links to disability culture and focused, as does much of the world, on employment.

Encouraging and educating the public so society is informed and understands disability culture. One way this can be achieved is by ensuring a disabled person is included on employment interview panels. Ensuring the rights of disabled people are promoted and upheld. This can be achieved by ensuring a complaints process is understood by disabled people using particular services. Providing employment opportunities for disabled people. This can be achieved by ensuring employment criteria does not disadvantage disabled people. Foster leadership by disabled people. This can be done by ensuring disabled people are invited to training and education courses with other staff. Support quality living in the community for disabled people. One way to achieve this is to offer a choice of living and support options for disabled people. Increase the collection and use of information about disabled people, issues and services. Promote participation of disabled Maori. This can be done by ensuring that they are included in discussions on policy

development and service delivery. Promote participation of disabled Pacific Peoples. This can be done by ensuring disabled Pacific People can be involved and contribute to various organisations. (The Implementation of the New Zealand Disability Strategy Auckland Regional Forum)

#### Celebration of Disability (South Africa)

A South African Minister identified "disability culture" as a way to celebrate disability:

The struggle for inclusion is going to be a long one as the evolution of "disability culture" is still in an infant stage in our country. A key function of "disability culture" is the celebration of the uniqueness of disability. It is my belief however that it will blossom as people with disabilities increasingly identify with each other and begin to express themselves more artistically and participate in the cultural life of society as a whole. (Speech by the Minister of Arts, Culture, Science and Technology, Dr Ben Ngubane at The Celebration of Disability Awards 25 November 2000, Durban, South Africa)

#### Disability in the Arts, Disadvantage in the Arts (Australia)

An Australian website includes a multi-tiered plan to utilize the arts, disability culture, and disability pride to focus on people with disability contributing to Australian society. Below is a small sampling of what's on their website:

People with a disability should have the option of identifying themselves in the context of a named 'culture of disability' which is a positive development, because society as a progressive force has a good deal to gain from the notion that people with a disability are contributing members of society, the arts providing a particularly appropriate vehicle for such a contribution. Arts In Action, South Australia Eddie Bullitis describes disability culture as having evolved from a range of ingredients; issues with which people with a disability have always been grappling, such as segregation, tolerance, celebration, unity, common experience, oppression and barriers.

To some people the very notion appears dangerous because it implies a return to past eras of segregation and separation and might be a cause of fear and confusion. However, one of the powerful objectives of identifying a cultural movement is to be able to bring about positive changes of attitude, systems and laws, through shared thought and action.

Disability culture offers people with a disability another framework of possibility or choice.

Sally Chance states that the idea of belonging to a culture of disability is offered to the members of Restless, within the specific context of the company, as a possible means of forging individual identity. Often this is a means of

counterbalancing the views of some members of society. It is a choice among many possible choices of a means of identifying oneself.

#### Visibility and Identity:

Disability culture is about visibility and self value. As with many groups in society, recognition by others only comes with self awareness within the group of the groups' differences and strengths. Disability culture offers ways for people with different disabilities to pursue their own, as well as shared goals.

Tony Doyle suggests the following outcomes from naming disability culture:

debate is stimulated[,] myths are challenged[,] cultural contributions are made, which shatter the image of people with a disability being only "needy" and the reality is reinforced that people with a disability are not only consumers of services but have something to give.

Disability culture is already being advanced by developments in technology, which are facilitating communication in ways unheard of in recent times. Bulletin boards have been a standard form The concept of cultures of disability lends the drive towards these outcomes political clout, leading to opportunities for creative involvement at a community and professional level.

A confident and forward thinking disability culture perspective is a powerful mechanism with which to voice the issues, legitimise our collective claims within health and sociopolitical contexts, as well as the arts, and gain support.

A disability culture movement can move the thinking behind the artistic practice, social relations and service provision by, with and for people with a disability beyond the simplistic notion of people with a disability being 'included' in these structures rather than driving them.

The future of networking and sharing information for some years while the internet can only develop this form of communication. South Australia based Heather Rose was able to create the scenario and screen play for the movie Dance Me To My Song, realising her own artistic skills due to developments in adapted technology.

#### An Australian Model of Disability Culture

Above all, this paper proposes that an Australian model of disability culture is emerging, exemplified by the High Beam Festival, and worth consideration and discussion by artists with a disability, artists, people with a disability, their families and friends, professionals and volunteers working in the disability sector and people working in community

cultural development, because it is open and flexible, attracting people through their interest. An event has a disability cultural emphasis because of its spirit and energy not because the movement has stipulated, for example, that 50% of its participants are people with a disability.

The disability culture movement's basis in the arts ensures that the issues are voiced in ways which allow the imagination of our fellow human beings to be touched.

The disability culture movement is dynamic, responsive and developing as greater numbers of people with a disability are able to contribute to its progress. The movement provides a powerful medium for the voice of people with a disability to be heard with dignity, in a spirit of collaboration with people with and without a disability, pointing to a future direction not merely based in social justice and redressing inequalities but in the pursuit of common goals.

For more information or to contribute to the discussion contact: Tony Doyle at Arts In Action on phone 08 8224 0799, fax 08 8224 0709 Sally Chance at Restless Dance Company on phone/fax 08 8212 8495 or at <restless@adam.com.au>; Eddie Bullitis on phone 8201 3358 or fax 8201 3210; the DADAA network can be contacted via DADAA National Network Coordinator on phone 02 9251 6844 or fax 02 9251 6422 or email <@one.net.au>.

#### Disability Culture and Disability Rights (Japan)

Osamu Nagase first contacted me while he was in Europe working on a Master's Thesis about disability and especially deafness in Japan. One chapter was about disability culture. I found his entire thesis on the internet and include that chapter below. (It is reprinted with Nagase's permission.)

If I am what I am today, you know, deep inside, the way my mind works, it is because of disability. Disability has enriched my life. -B. Venkatesh, India

[D]isabled people are forming distinct culture based on our own unique life experiences and history. -Steven Brown, USA

[W]e want something more than integration into mainstream culture. -Sian Vasey, UK

Just don't make me walk.... I'll lose my job. -Ed Roberts, USA

In this chapter, I will discuss disability culture as an emerging movement to "take pride in disability" (Brown, 1994: 10). A disability culture acknowledges life with a disability as a way of life, which means that the life of disabled people is not necessarily tragic or devalued. The creation of a disability culture is a basis for the establishment and implementation of disability rights - a requirement for equality - without creating or deepening

"dilemma of difference". This is to say, the establishment of disability as a way of life ensures disability-conscious social organizations. Within this approach, Deaf people, with their distinct culture and language, could make a significant contribution. Disability culture is a creation of new values.

## Disability Culture

A disability culture movement (Brown, 1994), which takes pride in disability is emerging. Brown, co-founder of Disability Culture Institute, explains that disability culture is "to exclaim pride in the condition of disability" (1994: 10). In the preceding chapter, a statement by a Deaf person asking "what is positive about being disabled?" (original emphasis, Harris, 1995: 148) was quoted. Indeed this is a soul-searching question. One way to show what disability culture is, is to answer to this question, which is undoubtedly shared by the wider society, which has viewed disability so negatively, as discussed in chapter one. There are a number of disabled people who do answer to this question.

The following is from Venkatesh, a blind director of an NGO in India:

Q: So does that mean that blindness is part of your identity which you feel quite happy with?

[Venkatesh:] If I am what I am today, you know, deep inside, the way my mind works, it is because of disability. Disability has enriched my life as a person.

Q: How has it enriched your life?

[V:] What gives worth to this life? It's not what you have or what you don't. It's the ability to enjoy what you have, no matter what.... Because being disabled is nothing wrong. (Coleridge, 1993: 14)

Brown, who has spoken on topics such as "Why I like my disability", also answers:

The notion of disability being affirming first came to my attention several years ago when a friend exclaimed that losing his leg was the best thing that had ever happened to him. He went on to explain that prior to his accident he was unfocused, joy-seeking person who gave little thought to what he would do with his life or how his actions might impact anyone other than himself. (Brown, 1994: 94)

If I were given the choice of a new life without a disability I would not take it. My disabling condition is one of the many characteristics which has contributed to the person I have become. Without a disability I would be different. And I have no desire to be someone else. I am happy with myself. (Brown, 1994: 96)

Asaka, a disabled activist in Japan, who had been exposed to Aoi Shiba, responds; "My disability is my

identity" (Asaka, 1993: 80, my translation) and "I, not only myself I think, don't really care whether I have a disability or not, in my next life, if there is no social disadvantage and if there is no discrimination" (1990: 94, my translation.)

These views might be considered as "compensation", just like a sign language is considered as an inadequate compensation for the hearing loss. A woman with a disability counters this as follows;

Not all of us view our disability as the unmitigated disaster and diminishment that seems expected of us. We know that what hurt, anger and distress we have felt was not generated by the condition itself but by the obstacles and offensive assumptions that society heaps upon it. If we dare express the view that it has brought spiritual, philosophical and psychological benefits, it is suggested that we are making a virtue of necessity, repressing our pain, or glorifying suffering. Such certitudes generally issue from those whose experiences of necessity, pain or suffering is considerably less than our own and who, above all, have no personal experience of our condition. (Morris, 1991: 187)

Morris says;

[T]he emergence of a disability culture is difficult but tremendously liberating. Such a culture enables us to recognize the pressure to pretend to be normal for the oppressive and impossible-to-achieve hurdle which it is. Most importantly, this culture challenges our own prejudices about ourselves, as well as those of the non-disabled culture. (Ibid: 37)

Morris adds "A number of the women I interviewed for this book [Pride against Prejudice] see disability as a positive thing to have happened to them" (Morris, 1991: 187). For the development of disability culture, history of disabled people has an important role to play. History occupies a significant place in the formation of group identity. However, until recently, history of disabled people has been ignored (Driedger, 1989; Oliver, 1990) or only the medical aspect of disability has received attention. It is, therefore, encouraging to note the growing interest in history of disabled people. For instance, a prominent Japanese author, Hanada, has produced an extensive writings on the history of disabled people in Japan, with particular emphasis on artists with disabilities (1975, 1978, 1980, 1985, 1990). Growing list of literature deals with, among others, independent living movement in USA (Levy, 1988; Treanor, 1993), history of DPI (Driedger, 1989), "medical solutions" to disabled people (Gallagher, 1995). History of deaf people, obviously for their cultural and linguistic aspects, is receiving a particular attention, resulting in the establishment of societies on the history of the deaf in some countries and an international society

on deaf history, Deaf History International was founded in 1991. Heroes, defined as "people who do something out of ordinary" (Brown, 1992: 227) and mythology are essential concepts for all cultures, including disability culture. Brown contends that "almost all people with disabilities have performed heroic activities because of the pervasive discrimination encountered by each individual with a society" (1992: 227). Carrying the argument further, Brown promotes mythology, which is "universal language" and is "a set of symbols placed in a context which anyone can understand" (1992: 232), demonstrated by heroes with disabilities. In fiction, Horwood, a writer and a father of a disabled child, successfully created a legend of a hero with cerebral palsy, who was forced to live in an oppressive institution for decades but never gave up hope (Horwood, 1987). Artistic activity is also an essential area for the development of disability culture. The cultural representation of disabled people through literature, poetry, music, TV, plays, cinema (Norden, 1994) in the past has been instrumental in creating a powerfully negative imagery of disability and of people with disabilities. Not only metaphor of illness (Sontag, 1977) but metaphor of disability has been powerful and infinitely negative. Disabled people themselves have an essential role to play to change the cultural representation of disability. Morris states that "we need to explore our own identity as disabled people. We need to explore what physical and intellectual limitations mean to us, what illness and death mean to us. And we need to explore the experience of oppression common to people with all sorts of different physical and intellectual disabilities. (Morris, 1990: 113)

Another woman with disability says;

through the arts we can make discoveries about what we have in common and place the emphasis on those things rather than on our differences, thus countering the traditional charitable model of disability that has historically kept us separate from each other (Vasey, 1989 quoted in Morris, 1991)

Summarizing his own argument as well as developing preceding paradigms, including that of DeJong (1979), Brown has established a disability rights/culture/pride paradigm as follows;

DISABILITY RIGHTS/CULTURE/PRIDE PARADIGM  
COMMUNITY ASSISTANCE/MEDICAL/CHARITY PARADIGMS  
DISABILITY RIGHTS CULTURE/ PRIDE PARADIGM  
DEFINITION OF PROBLEMS  
Physical or mental impairments; lack of socio-economic, political, educational, and cultural skills  
Dependence on professionals, family members, and others; hostile attitudes and environments; lack or legal protections or recognition of inherent worth of disabled people  
LOCUS OF PROBLEMS  
In individual (who is broken or sick needs fixing and curing)  
In socio-economic, political, educational environments and perceptions  
SOCIAL ROLES  
Patients, clients, charity

recipients, non-existent Family and community members, customers, coworkers, advocates, same as anyone else SOLUTIONS TO PROBLEMS Professional and volunteer interventions and treatments Equitable socio-economic, political, educational, and cultural options WHO CONTROLS Professional and/or volunteer Individual or group of individual's choice DESIRED OUTCOMES Maximum self-care; No social misfits Pride in unique talents and attributes of each individual and positive disability identity (Brown, 1995b)

#### Disability Culture and Deaf People

From disability culture perspective, the achievement of Deaf people, including the creation and development of a distinct language and culture, is a blessing and exemplary. While Bienvenu asks "[h]ow can we fight for official recognition of ASL and allow ourselves to be labeled "communication disordered" at the same time?" (Bienvenu, 1989: 13), there is no denying that sign language was born because of deaf people's disability. But that does not mean sign language is "primitive" or it has not developed into a full-fledged language. Disability can be a beginning. It is true, society views impairment and disability very negatively. But that does not mean whatever produced or developed from disability is negative. None other than Deaf people have proved this by their language and culture. And Deaf people are not alone. After all, impairment and disability are natural part of life. I personally would like to invite Deaf people to be at the forefront of disability culture movement. Deaf people are perhaps most qualified to be the vanguard of this. Within the disability culture framework, Deaf people will have a special place. Deaf people, if they wish and choose to do so, can be leaders in this blossoming new movement. From being deaf and Deaf, they have produced sign language, which is a rich cultural contribution not only to the disability culture but to the overall culture of humans. In this framework, the maintenance of a sign language can be supported by other disability groups. The enhancement and expansion of "normal" will be shared by all, hearing or deaf, disabled or non-disabled. Deaf people may miss this precious opportunity if they insist they don't belong to disability culture. The selective denial of particular impairment will not lead to a society created for all. The Deaf community can choose to pursue its own path, disclaiming disability, which runs the risk of "collaborat[ing] with non-disabled people in oppressing those with disabilities" (Ladd, 1990: 4). On the other hand, Deaf people may become an integral part of the disability culture movement, which presents a precious opportunity to open up a wholly new path of liberation, in solidarity with other disability groups. It is up to the Deaf community.

#### Difference, Equality and Disabled People

Our younger daughter, who is two years old, has

strabismus (crossed eyes). My wife and I do not want her impairment to develop into eye coordination problem, a disability. We want her to use both eyes properly. She already had one surgery. It seems that she needs to have another one. Difference, in this instance, disability, is often not desirable from the perspective of the individual concerned as well as their guardians as in the case of children. Historically various social forces have viewed them very negatively with serious consequences for disabled people. Because of particular difference, namely disability, their total existence, even their life was denied. But we have to be careful and avoid over-generalization. A number of disabled people, including Deaf people, are proving that disability is not necessarily unwelcome. On the other hand, it can be a blessing. Prevention will never be able to eradicate all impairments and it should not. While there are preventable impairments caused by social, economic and political reasons, many are part of natural human conditions, such as aging. Also, some disabled people, notably Deaf people, decide have children with the knowledge that their children will have an impairment, as discussed in chapter four. Rehabilitation cannot restore all functions. In consideration of one's overall life, some people choose not to restore certain physical functions. After all, it is up to each individual to decide if it is worthwhile to have rehabilitation (Tsuchiya, 1994). Asaka (1993) and Brown (1992, 1994, 1995a), among others, say that disability is positive and affirming. At times, it can be true and it is true. But is it necessary to make a value judgement? As Tateiwa (1992b, 1990) argues, disabled people should not be forced to make a judgment if their disability is positive or negative. Disability has been identified as the negative difference by society and by non-disabled people. At times this was also internalized by disabled people themselves. As a reflex, disabled people may be tempted to claim that disability in general is affirming (Tateiwa, 1990). Disability can be affirming and it is at times but not in general. As mentioned earlier, many impairments are caused by political, social and economic reasons (Abberley, 1987; Helander, 1992; UNDP, 1993). Just to think of 150,000 men and women, adults and children, who have survived but have been disabled from mines in Cambodia (UNDP, 1993) suffices. What is affirming, though not without difficulties, is life with a disability. To live with a disability is not less valuable than to live without it. To live with a disability, can be life-affirming. Many disabled people, including Asaka (1993), Brown (1995, 1994), and Venkatesh (Coleridge, 1993) say it is and there is no reason not to believe them. A number of Deaf people, though differently, testify to this. Their life is NOT life worth not living. But again, disability itself, does not necessarily have to be affirming. In this respect, I find Morris convincing, when she states;

I would still rather walk than not be able to walk. However non-discriminatory the society in which I lived, to be able to walk give more choices and experiences than not being

able to walk. This is, however, quite definitely, not to say that my life is not worth living, nor is it to deny that very positive things have happened in my life because I became disabled. I can therefore value my disability, while not denying the difficulties associated with it. (Morris, 1991, 71).

Abberley expresses a similar view;

Impairment must be identified as a bad thing, insofar as it is an undesirable consequences of a distorted social development, at the same time it is held to be a positive attribute of the individual who is impaired. (Abberley, 1987: 9)

There are others such as Hahn (1988), Brown (1992, 1994, 1995) Asaka (1993) and Matsukane (1994), who emphasize enabling aspect of disability. Their overall contribution is a new cultural meaning of disability, which has been fixed as the representation of "the other" and a devalued status. Though life with a disability is valuable, what makes is difficult is handicap. The priority, therefore, should be on the removal of attitudinal, social, economic, educational, linguistic and cultural barriers and disadvantages our societies have created against disabled people. For too long, these oppressive aspects have not been taken seriously, if not completely ignored. As discussed in earlier chapters, disabled people themselves as agents have taken the bold and historic initiative of changing the paradigm of disability from "the medical", charity and tragedy to rights, culture and pride. At the international level, the adoption of the Standard Rules is just one small but significant step towards recognitions of these social barriers which prevent disabled people from full participation and equality. Our society has been excluding certain people, including people with disabilities, when we plan and organize our society. The starting point should be the clear recognition that our society has discrimination against disabled people. The implementation of the Standard Rules at the local, national and international level is an essential factor for the realization of rights of disabled people and the creation of equal society. If their implementation is not satisfactory, disability rights movement may choose to propose an adoption of a more powerful instrument, a convention. If that necessity arises, the disability rights movement should be well prepared, learning from the discussions of the UN General Assembly particularly in 1987. There are a lot of lessons to learn from them. The homework includes the governmental recognition of disability rights, reasonable accommodation, and equality concept for disabled people. Most national governments need to be made aware that social planning and organization which exclude disabled people or which does not provide reasonable accommodation is discriminatory. Disability presents one of the most fundamental "difference". In other words, successful creation of equality for disabled people is likely to benefit other

socially disadvantaged groups. One of such an attempt is "a society for all" concept, which originates from disabled people's movement (Lindqvist, 1992; Wiman, 1994). The Social Summit in Copenhagen in March 1995 adopted "a society for all" as an umbrella concept for social integration in its final document (UN, 1995b, para. 66), which states that "[t]he aim of social integration is to create "a society for all", in which every individual, each with rights and responsibilities, has an active role to play. Such an inclusive society..." In this paragraph, there is no reference to disability or disabled people.

#### Difference as Celebration: Disability Culture

Now a mental exercise. It is 2XXX and all the countries in the world have achieved the implementation of the Standard Rules. Imagine a society without handicap, without social constraints, without prejudice against disabled people. Jobs, schools, support services such as personal assistance, access to information and communication, access to the physical information, opportunities for marriage and the rest are all in place. In that kind of environment, disability and its implications will be quite different from how they are today. As some argue, it may be true that disability will no longer matter (Shapiro, 1993) in that environment. On the other hand, this kind of "integrationist dream" (Ibid: 103), in which disability does not matter, may never realize and in fact may not be welcome. Difference is celebration. The purpose of the above exercise is to visualize what we are trying to achieve and where we are going. It is not enough, even though essential, to remove socially-created barriers. A creation of new value is vital. Through the establishment of disability culture, which is a creation of new value, difference emerges as celebration. Without this development, most likely the establishment of disability rights will end up creating or deepening the dilemma of difference. Also the implementation of disability rights "only" leads to equality, either formal equality or material equality, and not further. As French (1993) and Morris (1991, 1993) argue, middle ground certainly remains. In this respect, "disabled people are experts on disability" as advocated by disability rights movement, including independent living movement, is an expression of disability culture. The uniqueness of disabled people is their personal experiences of disability. These personal experiences are assets of disabled people. To apply these so far less utilized experiences to disability issues is a creation of a new value. The precarious situation of human rights of disabled people (Despouy, 1993) presents disabled people paradoxically an opportunity to be socially and politically active. Hahn sees "a unique chance to become involved in a historic struggle to extend and expand the definition of human rights" as well as "greater meaning and purpose in life" (Hahn, 1988: 31). For Hahn, therefore, disability "can also become an important source of empowerment and a major potential for promoting the increased acceptance of human differences" (Ibid). Brown also acknowledges that "my

disability have enabled me to play a significant role in one of the greatest human rights movements of my time" (Brown, 1994: 95). Disability begins as difference, as defined by others (non-disabled people); then goes through equality, with disability rights and reasonable accommodation; and ends as "difference as celebration", this time seen from those with disabilities. In this process, the focus on disability as difference runs the risk of stigmatization. To avoid stigma and to go beyond equality towards emancipation, which is "primarily about social creativity, introducing new values and aims, new forms of cooperation and action" (Nederveen Pieterse, 1992: 13), disability culture is essential. The establishment of disability rights and the parallel development of disability culture are two wheels.

Many voices of disabled people have been quoted in this paper. The following is the final one.

We need courage to say that there are awful things about being disabled, as well as the positive things in which we take pride. If we feel strong enough to do this, we can truly challenge the way non-disabled people make judgements about our lives because in so doing we will take charge of the way in which disability is defined and perceived. (Morris, 1991: 71)

We can celebrate, and take pride in our physical and intellectual differences, asserting the value of our lives. And while confronting the very real difficulties that physical and intellectual differences involve, we can fight against discrimination and insist that the needs created by those differences are met in a way which enhances the quality, and our control, of our lives. (Ibid, 189)

Disabled people are increasingly more confident and proud of themselves through the development of disability culture. Disabled people are not victims. Disabled people have chosen to be agents of change. The establishment of life with disabilities as a distinct and valuable way of life also provides non-disabled people an alternative vision of life and society in the sense that they do not necessarily take their way of life as given. This is a truly exciting time to witness this revolutionary change and, if one wishes, to be an active part of it.

(Osamu Nagase, December 1995; this paper was submitted in partial fulfillment of the requirements for the Degree of Master of Arts in Politics of Alternative Development Strategies at the Institute of Social Studies, the Hague, the Netherlands. The material above was reprinted with permission.)

Growth of the Human Condition (Sweden)

Adolf Ratzka, often referred to as the founder of European independent living, is frustrated by the frequent focus of

disability culture on the arts. In correspondence with me he expressed how disability culture holds meaning for him:

As far as I am concerned, disability in the arts is uninteresting. I am more interested in culture in its sociological or anthropological definition as the sum of experiences, thinking and findings that one generation passes on to the next one. Culture then becomes a vehicle, one of several ones, of one's identification and socialization. The experience of disability impacts people in many ways depending on a lot of factors such as the type, extent, duration, onset of disability and, more interestingly, the interplay of one's disability with the majority culture they are living in. So any attempt coming from disabled people themselves to improve their position in their respective society must necessarily involve getting people with disabilities organized. This effort will be easier, if there is a perceived common interest, a communality among the group, a sense of community, *Gemeinschaft* (in sociologist Tonnies' words). The common experience of disability - to the extent that some of it is shared with other disabled people within one's majority culture and these experiences are universal among other majority cultures - can be the glue to get and to keep people together across disabilities, classes, geography and national boundaries. Political action to be effective requires organizing. Therefore I see a value in the theme of disability culture as an organizing tool. Apart from that, on an individual level, the shared experience of disability can be a tool in coming to terms with one's disability, in promoting one's personal growth and in reducing one's bewilderment towards the human condition. (Adolf Ratzka, Institute on Independent Living, <<http://www.independentliving.org>>)

To conclude with my own thinking, here is my one paragraph definition, the shortest I can come up with, published in a 1996 issue of MAINSTREAM magazine that I still use:

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities.

Those of us working the field of disability culture probably all agree on several basic points. First, disability culture is not the same as how different cultures treat different disabilities. Instead disability culture is a set of artifacts, beliefs, expressions created by disabled people ourselves to describe our own life experiences. It is not primarily how we are treated, but what we have created. Second, we recognize that disability culture is not the only culture to which most of us belong. We are also members of different nationalities,

religions, colors, professional groups, and so on. Disability culture is no more exclusive than any other cultural tag. Third, no matter what the disability or location of the person with the disability we have all encountered oppression because of our disabilities. Fourth, disability culture in the southwest of the U.S. may be very different than in the northeast U.S. or Europe or Africa, but all of us have the similarities described in the first three points. Finally, we who have worked, researched, studied and written about disability culture have most often begun in the arena of cross-disability culture, meaning all disabilities and cultures. We are aware they are may be nuances, or even larger differences between some of us, but we have had to start somewhere.

If we consider all the possibilities of all disabilities and all cultures it is probably more accurate to say that there are "cultures of disabilities." Why is any of this important? I believe there are two significant factors.

First, how will we or anyone else know how to relate to us if none of us are aware of our cultural background. For example, many disabilities come with some sort of pain and/or fatigue. How will mainstream society ever be able to incorporate us into itself if neither we nor it recognize pain and/or fatigue as part of who we are.

Secondly, and maybe even more importantly, for years we have discussed integration like it was our business to fit in with mainstream society. As we become more aware of our own unique gifts some of us have also become more convinced that this is a backwards perspective. It is absolutely not our job it fit into mainstream society. Rather it is our destiny to demonstrate to mainstream society that it is to their benefit to figure out that we come attached to our wheelchairs, our ventilators, our canes, our hearing aids, etc. and to receive the benefit of our knowledge and experience mainstream society needs to figure not how we fit in, but how we can be of benefit exactly the way we are. That is disability culture, at least from one person's perspective. What do you think?

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