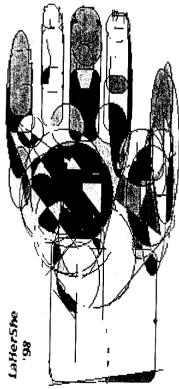


STUDYIN G DISABILITY

BY TANIS DOE

2003



CONNECTING
PEOPLE,
PROGRAMS AND
POLICIES

COVER ART BY LAURA HERSHEY

Copyright © 2003 Tanis Doe, MSW, PhD

All rights reserved. This is a self-published book. Permission was granted for use of previously published work **only** for select number of copies. Please do not reproduce or transmit in any form the material that is copywritten by others. You may use my material as long as you cite me as author or give appropriate credit. This year input will be sought on the content of this book, and it might be formally published next year. All feedback is welcome.

Cover artwork provided by Laura Hershey © 1998
You Get Proud by Practicing © 1991 available at
LauraHershey@cripcommentary.com
Other writing and poetry @ www.cripcommentary.com
Body in Trouble, from Waist-High in the World, by Nancy
Mairs © 1996 Reprinted by permission of Beacon Press,
Boston
Disability Culture Rap, by Cheryl Marie Wade
Permission granted by author.
Reassigning Meaning, from Claiming Disability by Simi
Linton, © 1998 Reprinted by permission of New York
University Press, New York

Printed by Island Blue Press, Victoria BC Canada

For more information tdoe@uvic.ca 6-1261 Goldstream Ave Victoria BC Canada V9B 2Y9

NO ISBN number at this time. Cataloguing information 1. Disability studies

Table of Contents

Acknowledgments	Page 4
Preface	Page 5
Introduction	Page 9
Chapter One:	Page 15
How Policies Impact Us	
Chapter Two:	Page 39
Pain, Peeing and other "Private" Problems	
Chapter Three:	Page 49
Body in Trouble, by Nancy Mairs	
Poem by Laura Hershey	Page 70
You Get Proud by Practicing	
Chapter Four:	Page 73
Piece of the Pie and the Wrong Tree	
Chapter Five:	Page 98
Reassigning Meaning by Simi Linton	
Poem/Prose/Rap by Cheryl Marie Wade	
Disability Culture Rap	Page 129
Chapter Six	Page 133
The Difficulty with Deafness Discourse	
What to do Basic Principles and	
A Credo for Support	Page 148
Chapter Seven	Page 155
Ambiguity, Dispute and Controversy	
Bibliography	Page 163
Recommended Readings	Page 167
_	-

CHAPTER FOUR Piece of the Pie and the Wrong Tree?

Metaphor is one of the easiest ways to understand large abstract issues. As children, we are told stories and fables to help us understand fairness and morality. As young people, we are told analogies and hypotheticals to teach us what we might have to learn the hard way otherwise. Disability can be seen as a comparatively concrete phenomenon which affects people in physical, sensory, cognitive, and emotional ways. However, accessibility is a little more difficult to understand. Accessibility is an "ideal" type, and is related to how people with disabilities interact with their universe-their communities.

Because accessibility has a meaning that people without disabilities understand, it is sometimes hard to explain the abstract concept of access as it applies to people with disabilities. For people without disabilities, having access might be permission (access to written records), legal mandate (access to children in custody battles), or even opportunity (access to a child care spot or a spot on the airplane My favourite metaphor to helping people understand the bigger picture of accessibility is using a pie. A pie is something we can generally agree is desirable, although you may decide which kind of pie. the ingredients, and the size. What accessibility means for people with disabilities is having our piece of the pie. This is not just physical access, but programmatic and financial and inclusivity. What metaphor should not do is confuse or mystify. My example is no more complicated than it appears. Pie is divided among those eating it and often, but not always, people with disabilities do not get their share.

Accessibility means that what many citizens generally desire, and have an interest in, people with disabilities should also get to desire, have an interest in, and eventually partake in. We want a slice of pie. We want to chew on life. For some people with disabilities, the only thing needed to get that piece of pie is money. Economic equality is a major force in providing accessibility. But for others, money is not the biggest barrier. Some people need assistance to physically pick up the pie, others need help digesting, and an entirely different group needs emotional support to reach for the pie safely. The main point of this is that if "everyone" wants pie, people with disabilities should also be entitled to a piece. This chapter, though, begins to question whether it is appropriate to get what "everyone" wants. When we are asking for inclusion and accommodation we might be barking up the wrong tree- there I go mixing metaphors!

I question the assumptions of what people with disabilities really "want" or need to achieve equality. I do this from my position as a woman with a disability, with a disabled daughter, and as someone who happens to be academically trained but has learned much more from living with a disability and through dialogue with others in the equality seeking movements.

I have found the most useful standpoint to use to analyze and understand accessibility is human rights. The human rights 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 and the potential to contribute to society. The rights-outcome approach draws from a variety of disciplines but frames disability issues through the lens of principles of human rights and equality of wellbeing as outcomes. (Roeher, 1996, p. 17)"

Canada's supposedly *Charter of Rights and Freedoms* guarantees equality, regardless of disability, and expresses disapproval of discrimination based on disability. If people who are different (in any substantial way), are prevented from achieving their basic human rights, they become "disabled" people. They require accessibility to regain their humanity and this accessibility is predicated upon the idea that they are being prevented from getting their piece of the pie. That prevention from access is discrimination. In the United States, the *Americans with Disabilities Act* (and several sections of the *Rehabilitation Act*) also base their regulations on this concept. Being discriminated against includes denial of access- or denial of access constitutes discrimination.

The theory of the social model presumes that discrimination against people with impairments then makes them into disabled people. This discrimination could very likely be the absence of accommodation, or the assumption that universal design is sufficient to meet everyone's needs. Day and Brodsky (1997) have articulated another problem with accommodation and the assumptions around substantive equality.

"Most important, the idea of accommodation is also fundamentally flawed at a deeper, conceptual level. In our view, the developing reasonable accommodation framework lacks the capacity to effectively address inequality and foster truly

inclusive institutions. It is flawed by its implicit acceptance that social norms should be determined by more powerful groups in the society, with manageable concessions being made to those who are "different". As long as this is the framework for accommodation, less powerful groups cannot expect much from it; accommodation means of limiting how much difference "the powerful and the majority" must absorb. (p. 8)"

What people with disabilities have been asking for, rather loudly and consistently, is fair and equal access to what "other" people have. That is, if generally people can pick up a newspaper and read it, there should be a way for a blind person or person with dyslexia to also access the information contained in the newspaper. If generally people can turn on the television and find out what people are saying or doing, then people who are deaf or blind should have captioning and descriptions provided.

If a child generally goes to the local school to get an education, then a child using a wheelchair should also have physical and educational opportunities at that same school. **Accessibility** represents the concept of fairness and equal opportunity compared to what other people have. Returning to the pie, which represents that which "everyone" wants, accessibility is generally not a question for those who can walk, talk, listen, and attendfor most people going to school, to the store, or to work is taken for granted. It is done so because being prevented or prohibited from doing these things freely would be considered a violation of human rights,

especially if it was based on colour, sex, age, or family status. When people with disabilities are prohibited from participation it becomes an "accessibility" issue, whereas I see it as a human rights issue.

Not all Pies are Created Equal(ly Accessible)

Accessibility for some people with disabilities presumes and requires that changes must be made to the way that things are ordinarily done. This is usually called accommodation (individual accommodations) and is part of the human rights argument that you cannot necessarily treat people the same to produce equality. Different people may require different routes or mechanisms to achieve their human rights. The concept of accommodation assumes, that even with careful forethought, there may be circumstances where the "needs" of an individual are not met by the structures designed for general use. This is not limited to physical structures such as doors or washrooms but to information access on the internet and on telephones.

In these cases, human rights principles being applied, the onus is on the structure to "accommodate" the person who has an impairment which makes access difficult. For example, if generally accessible bathrooms are not suitable for a person who has a wheelchair which is unusually large, a larger bathroom may need to be constructed or designated. Likewise, a job description which includes using the phone may not be suitable for a person who has no speech. A change in job duties or provision of a text telephone and new procedures for receiving or making calls might be the accommodation required. In this perspective, accommodations enables accessibility or provides

access through a different route, but the result is still access to the service, program, product, or experience that was originally entitled.

Accommodation is based on "individual" differences. Universal design, on the other hand, is not and should never be a substitute for, or exclusive of, accommodation. Universal design tries to make one size fit all. However, human variation is so diverse that one size does not fit all, and accommodation is still needed. People with disabilities are not all the same. Universal design attempts to broaden the useability of services and facilities by giving the bell curve of normality a wider berth but still relegates that either end of the bell to the margins. Accommodation, being more individual, takes into account personal variations.

Universal design and accommodation are not mutually exclusive, indeed they are both needed. But they are derived from different conceptual places. In considering the scientific and technological possibilities of "reengineering" our physical and social structures, both universality and individuality must be taken into account. The nature of universal design anticipates that, with careful forethought, most variations in humans could be fit into structures made for general public use. This is most often seen in architectural and technological structures, such as super markets and computers. It can also be used for social structures such as education or employment. The concept is that one size could fit all, or perhaps could fit most. The underlying assumption is, that by designing for multiple users, and considering differences in advance, many "impairments" could be prevented from being disabling (a.k.a. limiting).

The concept of universal design goes beyond the mere provision of special features for various segments of the population. Instead it emphasizes a creative approach that is more inclusive, one that asks at the outset of the design process how a product, graphic communication, building or public space can be made both aesthetically pleasing and functional for the greatest number of users.

"Designs resulting from this approach serve a wider array of people including individuals with temporary or permanent disabilities, parents with small children and everyone whose abilities change with age. (Welch, 1995, p. 1)"

That is, accommodation still presumes it is the "individual" difference that is the "problem". It is assumed that it is not the system, the structure, or the status quo which is the problem, but that lacking the "difference" in the individual, the status quo would serve its purpose. This assumption that currently existing universal norms are natural, just, and correct begs contesting. It also draws into the argument the whole nature of equality and, for me, the issue of disabled people as a social group.

We, people with disabilities, are very different from each other, and sometimes have conflicting needs, yet for political and analytical purposes, we are blended together to make up a socially oppressed minority. This means that when we talk accessibility, the blue wheelchair sign pops up in our minds (or at least the minds of the general public), and the parking space becomes our mascot. Curbcuts are also part of the public blurring of access issues. A few people will mention the beeping street corner alerts as examples of

access. One person I know considers the electronic eye door openers the ultimate in access. He told me, it lets everyone in- a cart, a mother with a child, a thief, a wheelchair user, and even cats and dogs. But what people forget, or have yet to learn perhaps, is that accessibility for a large majority of people with disabilities is not about physical access. There are more people with non-physical disabilities in Canada than those with mobility impairments when aggregated (Statistics Canada, 1991).

People with learning disabilities, people with bipolar disorder or schizophrenia, and people with Down's Syndrome or brain injuries may not need the curb cut or the parking place. In fact, the biggest need for access for some people with less visible disabilities is the attitudinal adjustment of those without disabilities. Accessibility, getting our piece of the pie, has to do with entitlement and convincing people we need to eat, and deserve to eat that pie, like everyone else. People with disabilities that are particularly stigmatized, like psychiatric disabilities, AIDS, and some forms of degenerative disorders like Alzheimer's Disease, face innumerable barriers to access which cannot always be demonstrated. The issues of access for these people cannot be or should not be blended together with the curbcuts, bus lifts, and accessible bathrooms. Technical aids may not yet exist that will provide access for all.

I think it is extremely important that we not think there is a fix-all that suits all people. We need to get in the habit of asking people what they need; and listening to them. Sounds simple but in reality this rarely happens. It needs to be at each level- **listening** I mean.

Socially Constructing Heterogeneity and Difference Lesbian women may experience quite different discrimination than gay men, despite both being placed in the category of homosexual, the issue of access (to jobs, benefits, programs) for each may be different. Even more complicated are issues for transgendered people or people transitioning who want their rights recognized not as gays or lesbians but as men or women (MTF/FTM).

Pooling of people happens frequently with race issues where First Peoples (known as North American Indians in the United States) are often categorized with people of colour who are Asian, African, or Hispanic, while their experiences of discrimination are often quite different. People who are "of colour" have extremely different life histories and cannot all be expected to need or want the same things to give them access to services and programs. Racism may not mean the same thing to people who speak different languages than the majority despite colour of skin. Racism might not be the only barrier to participation but becomes the central issue for those in the dominant position- easier to call it a race issue than to admit to class, economic status or other forms of oppression.

Again, for many of these people of colour, the issue is not about the door, or the bathroom, but about the attitude and sensitivity of others. Queer people, people of colour, women, and First People want pie too. But, in a moment, I will question whether or not the pie that all people want is really the same pie - maybe "everyone" is not really inclusive and we do not all want the same pie.

Deaf people and blind people and people with psychiatric disabilities may actually have less in common with each other than they do with linguistic minorities or immigrants. Most of the equality seeking groups start with the premise, that without the existing barriers, people would have a level playing ground. That is, take away discrimination in hiring, erase streaming in schools, and eliminate preferential treatment in housing or services, and oppressed minorities will be "equal". This is important to grasp at the practical level because the public often argue that they have "done enough" by prohibiting discrimination or by making curb cuts and installing electric doors. They do not get that equality and access to the general social world also involves significant attitudinal change and a "different" way of doing things.

There is also another assumption, not so much essentialist as it is postmodern, that the differences between us are all constructed, that we are all the same, but for the social world and its influence. Oh but this is so not true. I am wondering, as a researcher and as a person with a disability who happens to have significant allergies, if we might (here comes that metaphor again), want a completely different pie. I think that the people without disabilities have been eating the pie and showing us how wonderful it is for so long that we have started believing that it is desirable and that we should have it. Again by the pie I mean those things that people take for granted and value as part of daily life.

If we consider the construction of disability, and later the construction of impairment, we will see that while the "disadvantage" ascribed to being disabled may be

socially determined, the "differences" remain very real, and very lived.

I, for one, do not want the differences erased, or the experiences homogenized or sanitized. I will argue from a point of view that neither denies nor diminishes the social model and the influence of social construction, but which recognizes difference, celebrates diversity, and contests the current status of distribution of resources. Whether or not we name reality and give it meaning by interpreting it and constructing our reality, disability is a social fact and needs to be considered in the social, lived world. The nature of knowledge and its construction may be up for debate, but while the debate continues in ivory towers and cyberspace, those with disabilities continue to live in situations directly impacted by the governing metatheories and policies. Whether or not we agree with them, we are subject to them. This is where I question our need for pie.

Are we barking up the right tree?

Is equality freedom from discrimination? Is it equality of results? Is it parity or equity of income, social standing or position? Who do we want to be equal with? How does the definition of equality impact our pursuit and are we barking up the right tree? And, do we really want a tree? Do we want the pie after all? If so, why? Is equality not a construct of "normality?" Do we want to be accepted so desperately that we DO want pie?

Considering the scientific and technological possibilities of re-engineering our physical and social structures, both universality and individuality must be taken into account. The nature of universal design anticipates that,

with careful forethought, most variations in humans could be fit into structures made for general public use. This is most often seen in architectural and technological structures, such as supermarkets and computers. It can also be used for social structures such as education or employment. It can be used as a way to design inclusive programs instead of special ones.

The programs and services that people with disabilities have been asking for- self-directed attendant care, inclusive education, coaching in employment, self-employment options- all need to be designed to suit the needs of people with a range of disabilities and experiences (including differences in race, language, gender, sexuality and age). This construction of services needs a policy mandate and for this to happen people with disabilities must be seen as citizens with rights.

People with disabilities were, at one time, not considered human, but in many ways we symbolize that essence of humanity that researchers and philosophers argue about- control. Scraps of food, including pie, have been traditionally thrown to the dogs, and in past eras, to poor people and the disenfranchised. But for people with disabilities, wanting that pie may be part of the construction of our humanity. Needing a different pie, or needing the pie that everyone else has, is what makes the argument of accessibility essential. If accessibility means getting in, getting some, getting a chance to- we need to define what it is we are getting.

In Claiming Disability: Knowledge and Identity, Linton (1998) laments the problems of metaphor, the difficulty of using disability almost always in an exclusively

negative way. In literature, in media, and in conversation, blindness, deafness, and being crippled are used figuratively as much as literally. On an internet list-serve, Linton pointed out that a polio documentary did not show the positive side of being disabled. A list-serve member from the other side of the pond (Great Britain) questioned that there could be any positive associated with being disabled, because, from the British social model perspective, "disability" is social oppression. In this case, disability is *never* positive.

Impairment, which is seen as less constructed by the British scholars, might have some positives attached to it, but disability is oppression. Although North American and British theorists may agree in principle that the impairment is less socially constructed, there are newer arguments about the neutrality of this medically and functionally determined construct. These have emerged from post-modern and post-structural, primarily feminist, analysis and have been introduced at learned conferences and in graduate schools by insightful students and teachers. Linton also points out that most disability studies scholars have avoided theories of impairment.

"Disability studies theorists do need to grapple more directly with "impairment" and recognize that it is as nuanced and complex a construct as "disability". .. We have been hesitant to go in a particular direction in the development of theory-that is toward the issue of impairment itself. .. Yet it may also be the tremendous difficulty in articulating impairment in ways that do not essentialize disability or reduce it to an individual problem. (Linton, 1998: 138)"

In trying to develop a metaphor which was less destructive, and which could be used for analyzing the disability question from a social model. I used a thesaurus, my encyclopedia, and an internet search. While I did not find a "positive" metaphor for disability, I did find a useful method for analysis, based on environmentalists understanding of the "ecological foot print". For those of you unfamiliar, the footprint of a can of pop could include: the aluminum being mined. pollutants created in the process, water used, chemicals used, natural and artificial flavours, sugar brought from Africa on boats, buildings/factories built, large vehicles are used to transport the drinks, paint used to label the drinks, human resources used in manufacturing, process food consumed, and waste is created by these humans, then, of course, the left over empty cans. The exercise is used with school children to examine the impact on the environment and to consider possible ways to reduce the negative impact while retaining any benefits of the product.

If this is a potentially transferable concept, we can look at disability; and in particular people who have disabilities, and consider the ecological impact, or wheeltracks. Using this concept of wheeltracks, a Disabilitycentric version of footprint, accessibility can be seen as all those things that give people with disabilities human rights entitlement. We could conceivably look at financial costs, purchase of equipment, the need for housing which is adapted, the transportation required, human service professionals needed, and Independent Living Centers visited, as well as pensions and welfare systems. The wheeltracks made by disability (or impairment) could be quite extensive, and perhaps

expensive. A measure of cost and benefit could possibly create a deficit model for disabled people. It can be dangerous to put a price on accessibility in these times of fiscal restraint. I am not joking when I warn that this is one slope leading to assisted suicide and euthanasia as the burden of caring for people with disabilities could be too costly. We already know some parents kill their disabled children when resources are scarce or absent. Structuralist, positivist, or materialist arguments could result. But, using a social model we could also define all those barriers needing removal which would enable our participation in society. Accessibility then, could be all those things people, equipment, attitudes, and transportation which make up our wheeltracks- our proverbial marks in the sand. (Which is pretty ironic since I sink in sand in my wheelchair!)

Creating Equality Without Erasing Difference

To look at accessibility, it is important to look at inaccessibility, and the consequence of inequality. Just as disability presumes the existence of the norm (non-disabled people), and impairment presumes the existence of non-impaired, well functioning people, the social model examines our status from a perspective that it is not our impairments, but the reaction to them, that creates disability and more specifically disadvantage. This social oppression is multifaceted and pervasive, and implicit. What creates inequality? Social structures which mediate valuing of differences (and sameness, and normality, and hence abnormality). We may be organic living creatures but we exist in a world created by humans that is not at all "natural" (Sorry Darwin).

"Equal opportunity theory bases its optimal prospects principle on a theory of the group that explains how social conditions evolve toward the advantage of some and the disadvantage of others and, as a consequence, justify constrains on personal freedom to ensure optimal prospects of self determination for all... this addresses directly questions of social justice. (Mithaug, 1996, p. 50)"

Inequality is about reactions, and lack of response, to differences. It is also about structures that produce unfair distributions of wealth and resources. Taking my Black, Deaf adopted daughter as an illustration in point. it is certainly not my daughter's "fault" that she is Deaf. It is not fair that she should have to pay the "costs" associated with being Deaf or even to feel alone because of it. It is not fair that her skin colour causes her grief because of racism and adolescent taunting. And she cannot separate being Deaf from being Black. She is both- all day. However, social structures attempt to redress this through human rights legislation, tax credits, welfare payments, medical coverage and specialized intervention programs. Would equality, or accessibility to the pie, be achieved, or should equality be achieved by intervening in all these places so that my daughter would not feel depressed and alienated?

Can we erase racism? Can we create more deaf and/or black people for her to play with, live with, work with? Can we legislate captioning and interpreting in all public places? Can we eliminate all school fees and develop an inclusive curriculum? Is there a way to raise welfare rates above the poverty line and increase working peoples wages to a livable level?

Doing these things will not erase my daughter's deafness. I hope not, because we both value our deaf identity. It will not make me identify less as a disabled person.

Accessibility then, should be a way to enable people with disabilities to enjoy life rather than a way to erase difference. As access to education, employment, and transportation become critical issues to consumer advocates, there are often many areas overlooked as less important. People with disabilities are, statistically, and realistically, poor and often unemployed. We often have much more leisure time (time when we are not working) than nondisabled people, yet we have less disposable income to spend on leisure activities. Recreational programs are often only accessible if they are considered therapeutic- art therapy, music therapy, horse back riding therapy, recreational therapy, and even horticultural therapy. I am not at all arguing that these things cannot be therapeutic, but I also believe they are fun. They are enjoyable and they are enjoyed by non disabled people without having to be medically sanctioned as useful. Why is the pie (what everyone gets) only available to people with disabilities if it is for rehabilitation or treatment? Equipment is only funded if it medically necessary, and this requires meeting a strict standard of how it assists with daily activities.

As a wheelchair dancer (modern, ballroom and Latin), I am insulted by the possibility that my dancing is to "help" me get better, when really it is to enjoy life. Accessibility to recreational and non-essential programs (not health, jobs, or housing) need to be an important part of our advocacy efforts, so that we can enjoy life, and not just

92

fight for access all day long. I love dancing, even when I need to use inhalers to keep breathing after exertion. I enjoy it like some people might enjoy music or art: for fun! Perhaps the most rewarding part of my dancing has not been that I learned how to dance with a partner to a specific standard, but that now the ballroom dance society holds its events in accessible locations and thinks of me as a full member; without making "accommodations"; they simply accept me. The welcoming attitude and the chance to participate in something that I have prioritized gives me dignity and, a piece of a pie.

Beyond Wheelchairs, Ramps, and Pies

Universal accessibility should and could be a standard for all structures and will benefit both disabled and non-disabled people. As a construct, accommodation should question the normal way of doing things, rather than only making rare exceptions to the rule. We need to be disabled people with human rights, without facing discrimination based on impairment/disability. We need to have accessibility without fighting for it, without court cases, and without complaints. But more than the absence of discrimination, we also need recognition and revaluing. This is where I want to question that pie that I have been talking about as something that "everyone" wants (and usually gets).

We need to re-center or realign our theories and thinking with disability as a construct that is not entirely oppressive or negative or inherently tied to impairment. The deficit model, the medical model, may be entirely missing the phenomenological imperative of living with difference. We need to start thinking of other recipes for life.

"Descriptions which hinge upon deaf people's lack of hearing rather than on their ability to use vision in themselves become oppressive. Similarly, when blind people describe communication and information barriers relative to visual impairment, people with learning difficulties question the translatability of society's linguistic exemplars in terms of their language, or when disabled black and ethnic minority people, disabled women and disabled gays and lesbians question the language of dominant metanarratives, this sends ripples of discomfort through those who rely on these theories. (Corker, 1998, p. 48)"

I want to clarify, to preempt any misinterpretation of my point-I want to reduce barriers, create accessibility, and eliminate discrimination. I think these are necessary steps, but they are not sufficient steps. Women and their advocates have found, that even with access to the labour market, and even with better child care and sexual harassment legislation, violence still is perpetrated upon wives, workers, and children. Systemic discrimination and the experiences of poverty among women remain, world wide, despite many changes in the laws. Similarly, gays and lesbians are advocating same-sex marriage and benefits to provide "equality" with heterosexual couples, yet marriage has not substantially contributed to "equality" among opposite-sex couples; in fact, it may actually institutionalize dependence and economic inequality.

However, the fact remains that legislative change is part of the process to install newer, more responsive social expectations for people who have been previously marginalized. The expectation is that, once a law exists, the attitudes (and subsequently behaviours), will follow to comply with the new law. This is how the ecological model relates to individuals and their rights. The success (lack thereof) of Employment Equity Act in Canada (and the ADA in the US) is not a hopeful sign of this principle working in reality. So, despite my argument that we do need laws and prevention of discrimination, I think we are restricting our hopes to what able-bodied people have decided is the norm. I want us to consider that our existence as a people who have different disabilities, could be seen as a center, and as a authentic place to live. Our place to live can only be realized if we have supports, economic resources. equipment, and a change in how people respond to us. Practically, this involves revolutionizing the perception of disability itself. Revolutionalizing life.

That our equality may rest, not in being accommodated or fit into society, but in the construction/ rebuilding of structures which represent our lives, rather than those who define us as "handicapped" by our disabilities or impairments. This is why the pie is so important to accessibility concepts. Is it that we, as people with disabilities, need to get a piece of the pie, or should we collectively question the value of the pie and ask for a different pie? Or should we be asking for an entirely different product? Are we, as a people with disabilities, going to be satisfied eating from the pie of normality and the status quo or will we ask for an expanded, accessible menu from which to choose the food that meets our needs and enacts our human rights? The main point is that we do want to get what we desire, which usually means getting access to what is already there, but I am hoping we might eventually start

94

wanting more than what the status quo has to offer. Even if that pie becomes accessible, and all people (inclusively everyone) has a piece of the pie, we still might not have achieved our full human rights. The pie that we currently argue for access to was baked with ingredients of old beliefs, norms, and structures that need realligning so that our differences are not "accommodated" but embraced.

Disability- as a social construct- might become less socially constructed and more socially mediated if the suggestions for policy and service changes are heeded. However, we still will live with impairment and human variation. We need to ensure we are all part of life.

Corker, M. (1998). Deaf and disabled or Deafness disabled? Towards a human rights perspective. Buckingham: Open University Press

Day, S., & Brodsky, G. (1997). The duty to accommodate: Who will benefit? Vancouver: Dawn Canada Consultation. Linton, S. (1998). Claiming disability knowledge and identity. New York: New York University Press.

Mithaug, D. (1996). Equal opportunity theory. Thousand Oaks, CA: Sage Publications.

Roeher Institute. (1996) Disability, community and society: Exploring the links. North York: Author.

Statistics Canada. (1991). Health and Activity Limitation Survey. Ottawa: Supplies and Services Canada.

Skrtic, T. (1995). Disability and democracy reconstructing (special) education for postmodernity. New York: Teacher's College Press.

Welsh, P. (Ed.) (1995) Strategies for teaching universal design. Berkeley, CA: MIG Communications.

CRITICAL THINKING>

- 1. Is it possible to get both access to what others have and something particular to our needs as disabled people?
- 2. How can accessibility be reconceptualized to include class, race, gender, sexuality and age?
- 3. As part of other social movements- ecological, labour, feminists, socialist or other change oriented efforts- can disability be integrated into their agendas? What are the relationships between these movements?
- 4. What will equality look like when we get there?
- 5. What is stopping us from getting to our imagined ideal situation- whatever that might be?
- 6. If we cannot revoluntionize society- change it from capitalist to socialist or from individualist to collectivist, what are the other options- what else would help.
- 7. Using an ecological perspective, at the micro, meso and macro levels, how are we working towards equalitybe that a tree or a pie or something altogether different?

NOTE:

This chapter was written over time from papers and presentations at conferences, including, an editorial for Journal of Leisurability and presentation at the Roeher Institute policy and research conference. I also learned from discussions over the Internet. I think that it could stand some improvement and welcome your feedback on how helpful (or not) the writing was in understanding disability/access in social context. Next, I am pleased to share with you an important piece in the construction of disability language concepts, a chapter by Simi Linton from *Claiming Disability*.