From If I Can't Dance Is It Still My Revolution:

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Defining Disability

There are and have been a lot of ways to define disability. Typically, disability has been defined through the <u>medical model</u>, <u>charity model</u>, <u>rights model</u>, <u>social model</u> and <u>radical model</u>. And these perspectives sometimes overlap or even compliment each other (for example, many people who work under the rights model are also proponents of the social model and the charity model and medical model often work to reinforce each other).

Most people think it is easy to define disability. They think it is some sort of loss or abnormal physical or mental functioning.

What about the groups of people who live on the margins of the definition, such as psych-survivors, psych-consumers and people with mental health issues, people with intellectual disabilities, deaf people, those with minor physical or intellectual disabilities, people with non-apparent physical disabilities, and those with chronic illnesses, among others. Are these people disabled?

who is and who is not disabled has become an important social question, particularly for legislators. They seek to define disability in order to provide (in)access to civil rights and provide income support to those who cannot work (their definition).

Typically, when there are real or substantial benefits for disabled people, government excludes many, if not most of us. When the legislation is unenforceable or pays lip service to the rights of disabled people it is wide reaching, as those in power will lose nothing by allowing an inclusive definition.

For example, the Ontarians with Disabilities Act (ODA) states that: 'disability' means, (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness...(b) a condition of mental impairment or a developmental disability, (c) a learning disability...(d) a mental disorder...

The ODA is a relatively meaningless piece of legislation that is supposed to ensure access for disabled people.

The *Ontario Disability Support Program Act* (ODSP), on the other hand, provides income supports to disabled people. It defines a person as being disabled if:

- (a) the person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
- (b) the direct and cumulative effect of the impairment on the person's ability to attend to

his or her personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and (c) the impairment and its likely duration and the restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications.

Where people benefit, the definition of disability is very restricted and adheres to the <u>Medical Model</u> of disability. Where people benefit little or not at all, the definition of disability is very broad.

Medicalization and the Medical Model

Medicalization, is defined by Cathrine Reissman as:

The term medicalization refers to two interrelated processes. First, certain behaviours or conditions are given medical meaning - that is, defined in terms of health and illness. Second, medical practice becomes a vehicle for eliminating or controlling problematic experiences that are defined as deviant, for the purpose of securing adherence to social norms. Medicalization can occur on various levels: conceptually, when a medical vocabulary is used to define a problem; institutionally, when physicians legitimate a programme or a problem; or on the level of doctor-patient interaction, when actual diagnosis of a problem occurs.

In the disability context it means that our identities are medicalized everything that we are or will be is seen through the medical scope. Under the medical model or approach to disability, we become our disabilities and our disabilities are seen only as negative or bad because that is how the medical profession sees them.

This plays out in a lot of different ways in our daily lives. Some of them are:

Biased, Discriminatory Medical Care: Our entire medical treatment is filtered through our diagnoses. This is problematic because doctors often attribute all of our symptoms to our disability and do not necessarily investigate fully or properly. This means someone could go into the doctor complaining of a serious problem and essentially be patted on their head and sent off because this is a symptom or progression of their disability when it could be something else entirely. This means that when many disabled people seek out medical care they do not get as thorough treatment as non-disabled people. This is especially the case when it comes to psychiatrized people and psych survivors as their physical symptoms may be disregarded and attributed to 'psychosis' when they require treatment.

Similarly, when a fat person goes to the doctor with knee pain, the doctor will likely tell the person to lose weight. But if a thin person goes to the same doctor with knee pain, they doctor will likely examine them and do tests. Both people could have the same condition and the same amount of pain but because fat people are medicalized, they are not treated with respect and their complaints are not investigates.

Perception of Low Quality of Life: As disabilities are defined solely as bad by medicine, our disabilities are counted only as negatives in our lives - which isn't the case for many disabled people. Further, it has been found that doctors routinely value our quality of life lower than disabled people do. The most dramatic illustration of this is when disabled people try to seek medical treatment and are denied it because doctors view them as being 'better off dead'. There was at least one case where a disabled person had to fight to get life saving treatment because the doctors felt that they would be doing him a disservice if he continued to live.

We Are Defined as Dependent Patients: Disabled people are not seen as agents of their bodies, rather as patients who have things done to them and who are dependent on doctors to cure or treat us. This is not what disabled people's lives are actually like.

The reality is that whatever medical diagnoses a disabled person may or may not have tells you nothing about who they are. It is a common pet-peeve among many visibility disabled people that non-disabled people are constantly asking "what do you have" or "what is wrong with you" (the second being a slightly more offensive version of the first). If you ask someone what they "have" and they tell you that they have CP, spinal muscular atrophy, fibromialgia, schizophrenia or lupus, what does that tell you about what they think about the world? What does it tell you about what kind of music they like or what they do with their free time? What does it tell you about who they are in love with or what they hope for the future? It tells you nothing about who they are.

Disability Is Individualized: the medical model of disability individualizes disability, paints it as an individual tragedy, and does not account for social barriers. Western medicine positions disability between the doctor and the patient (disabled person) where the patient has the disability and the doctor has the tools to 'cure' the patient. Where the doctor is unable to 'cure' the patient, the doctor then treats the disability. If treatment is unsuccessful (in the doctor's view of success) the doctor then fills out forms to allow the patient to seek income support if the patient is physically or mentally unable to find and keep employment.

Doctors Have Power Over Our Daily Lives: Doctors are asked to provide medical information that is translated into non-medical resources (such as housing, food and transportation). As doctors are not necessarily skilled in the delivery of these services, they can misrepresent the needs of disabled people. Doctors are often lacking a true understanding of poverty because they are rich and they may not work to ensure their patients get access to the resources they deserve because they do not understand what many disabled people need and how badly they need it. Just one example of this is that some doctors refuse to fill out any forms for people on social assistance even if they are paid to do it and even if their patients could get hundreds of dollars a month extra to live off of.

Not Searching for a Cure

Contrary to what may people believe, most disabled people do not want a cure.

In fact, many disabled people actively resist funding going to cure their disabilities. If you are not disabled, this may be really difficult to understand. If you aren't disabled, imagine for a moment that you live in poverty, that you cannot get a job even though you are qualified and you want one because no one will hire you, that most public spaces and almost all private homes are inaccessible to you and that every year millions of dollars are raised and spent so that you can be cured while you get little or no support to live you life and to combat ableism.

If you are disabled, you know this situation very well. You also know how it feels to constantly have your entire existence undermined and devalued by the pursuit to ensure that people like you will not exist.

However, disability will always exist and is an inevitable part of life. So why spend billions of dollars trying to eradicate it when the project to accommodate disabled people and help provide people with adequate standards of living is far less expensive and far more humane.

The Charity Model

The Charity approach to disability viewed as being in the 'best interests' of disabled people but it does not consider disabled people's experiences and knowledge as necessarily valuable or essential. This approach is about well meaning 'do-gooders' acting on our behalf without us. Because we aren't in control of the process little good, or even harm, is often the result.

In the past decades, people who follow the charity model have not so much tried to define disability as they have tried to redefine it. These attempts to redefine or rebrand disability have largely failed because they have been made by people, while well meaning, who are largely not disabled and who have a negative and paternalistic view of disability.

One example of the rebranding of disability through the charity model is the term handicapped. The word *handicapped* replaced *gimp*, *crip/crippled*, and *lame*. Handicap is an offensive and unacceptable term as it is derived from a gaming term which means to equal out a disadvantage by, for instance, spotting points or playing with one hand tied behind your back. The word handicap implies an inherent disadvantage that undermines the quality of disabled people's lives. Handicapped later became *differently-abled*, which establishes, by definition, what normal is and that we aren't it.

Similarly, *retard* was transformed into *slow* and then to *developmentally delayed* or *developmentally disabled*. Again, these terms establish a norm, which is problematic. These terms also embed the concept in them that there is one line of development for people. They imply that people with intellectual disabilities have somehow stalled in their "development" and are fixed at a spot in time where their lives will be forever unfulfilled.

They don't have room for the plethora of meaningful experiences that people with intellectual disabilities undergo.

Challenged is another term adopted by others on our behalf as a way of describing our lives. Where the medical model inserts diagnostic labels that are individualizing and define people's entire identities, politically correct liberals individualize our oppression by calling us challenged. This label tells us that all obstacles we face are because of our own minds and bodies, not because of social inequities and inaccessibility.

Furthermore, *challenged*, like *developmentally disabled*, *differently-abled*, and *handicapped* does nothing to change our lives, it doesn't build ramps, or housing; it doesn't provide interpreters or personal support workers; it doesn't bring equality or autonomy; and, it doesn't abolish segregation or discrimination. The attempts by well meaning liberals to establish "politically correct" terms to define disability are just that, attempts to dictate how things change for our benefit. In this case, nothing changes but the label.

The entire charity approach is designed to ensure that no real change ever occurs. It is about people doing good for others, it is not about change, it is not about liberation, it is about the agents of charity - the do-gooders feeling better about themselves and the world they live in.

It brilliantly co-opts the language of resistance talking about "fighting," "resisting," and "beating" disabilities.



Charities, however, identify our disabilities as the things that oppress us, not social barriers, not systemic issues - our bodies, our minds (the things that give us life and make us who we are).

ARTHRITIS FIGHT IT!

The things to be resisted are those are our disabilities and no fundamental social change should ever occur under this view. This is in itself an oppressive view and why the <u>social model</u> and the <u>radical model</u> have worked to reclaim and redefine disabled people's points of resistance and fight for social justice rather than the elimination of disability.

Rights Model

The rights model is primarily a fight for access to the privileges people would otherwise have had if they were not disabled. A focus on rights is not a struggle for fundamental social change; rather, it strives to make changes within the existing system.

The idea behind disability rights is that:

A human rights approach to disability acknowledges that people with disabilities are rights holders and that social structures and policies restricting or ignoring the rights of people with disabilities often lead to discrimination and exclusion. A human rights perspective requires society, particularly governments, to actively promote the necessary conditions for all individuals to fully realize their rights.

This is the definition of <u>DRPI</u> (<u>Disability Rights Promotion International</u>). According to this group and many other rights groups, "As full citizens with equal rights, people with disabilities are entitled to: access to education, equal rights to parenthood, rights to property ownership, access to courts-of-law, political rights such as the right to vote, equal access to employment"

However, the rights approach does not address fundamental flaws within the system that disabled people are seeking inclusion in. For example, the rights model recognizes the right of disabled people to own private property but does not question fundamental injustices attached to property ownership. Further, it does not necessarily address colonialism which has resulted in much of the property ownership in many parts of the world to be a direct result of racism and theft.

It is important to acknowledge that much of the access and privileges that disabled people have today is a direct result of the people who struggled and continue to struggle for disability rights. Many people have fought very hard for disabled people's inclusion in society and these struggles need to be recognized and celebrated. However, we need to do more than fight for rights within society as it is structured now, we need to fight for social justice for everyone and that means restructuring society.

Social Model

The *Union of Physically Impaired Against Segregation* (UPIAS) separated the idea of disability from the idea of impairment in 1976. They said:

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society.

by this definition requiring a wheelchair is the impairment where the inability to enter certain buildings is the disability. This definition sent shock waves through the disability rights community.

This definition set impairment as the physical or mental "limitations" apart from the social barriers that are disabling.

<u>Michael Oliver</u>, a disabled British academic and author of <u>Understanding Disability:</u> from Theory to Practice a disabled British academic, expanded on this idea, saying:

It is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are taken in to account in its social organization.

The separation of impairment and disability was a revolutionary idea at the time. It took the discussion away from disabled people's own bodies and minds and made it about social conditions, access and oppression.

The social model has become the broadly accepted view of disability by most disabled activists and academics.

They have promoted it because it puts forward the position that there are fundamental problems with the way that society approaches disabled people. While this is very much the case, allowing this dichotomy reinforces the ableist notions that there are problems with or flaws in all disabled people's bodies or minds rather than acknowledging that disability is an aspect of basic human diversity.

The social model establishes or reinforces what is <u>normal</u> and people with "impairments" as being outside of that.

At the time, the social model was a revolutionary idea. But now, it is limiting and outdated.

Tom Shakespeare and Nicholas Watson have argued that, like the sex/gender dichotomy that was used by feminists to advance their goals in the past, the impairment/disability duality is both socially constructed and limiting to contemporary disability discourse. They state that:

The words we use and the discourses we deploy to represent impairment are socially and culturally determined. There is no pure or natural body, existing outside of discourse.

The idea that disability is socially constructed and impairment is a biologically reality, as promoted by the social model, only serves to reinforce ableist notions. Like disability, **impairment is also a social construct.** This is why the <u>Radical Model</u> is a far better way to view disability.

This doesn't mean that there are no biological factors; rather, our social perceptions inform how we relate to those functions and place social value on states of being that may otherwise be neutral.

The Radical Model - The Way Forward

This approach to disability looks at disability entirely as a social construct and does not separate impairment from disability like the <u>social model</u>.

Radical disability activists acknowledge that we do not control the definition of disability - that it is defined by those with power to their benefit.

Women, queer people, trans people, racialized people, poor people and other marginalized people were all considered disabled at one point in history, largely under the umbrella of feeble-minded and/or degenerate.

Radical disability activists are very critical of certain groups' attempts to get more privilege by defining themselves as other than disabled. Members of the Deaf and psychiatrized communities have attempted to distance themselves from other disabled people by saying essentially "there is nothing wrong with us. We are a linguistic minority or we think and experience the world differently but we are not disabled. There is nothing wrong with us."

The radical disability model says there is nothing wrong with *any* of us.

We argue that disability is simply defined as those who are externally identified as disabled and those who self-identify as disabled.

To us, disability is not a point of individual or social tragedy but a natural and necessary part of human diversity. The tragedy of disability is not our minds and bodies but oppression, exclusion and marginalization.

We do not need to be <u>cured</u>. We do not need <u>charity</u>. We need respect, equality and access.

What is normal?

Normal is relatively new.

According to Lennard J. Davis, in Enforcing Normalcy: Disability, Deafness and the Body:

A common assumption would be that some concept of the norm must have always existed. After all, people seem to have an inherent desire to compare themselves to others. But the idea of a norm is less a condition of human nature than it is a feature of a certain kind of society.

...this concept 'normal,' 'average,' 'abnormal' - all entered the European languages rather late in human history. The word 'normal' as 'constituting, conforming go, not deviating from, the common type or standard, regular, usual' only enters the English language around 1840. (Previously, the word had meant 'perpendicular'...)

We are taught that normal is good, disability is not normal and, so, disability is bad.

However, normal functioning is simply a line drawn arbitrarily. Normal itself is frequently held out in authority when it is an abstract concept that fails to provide an adequate definition of the human existence. Are people who are born with one arm or who have low IQ test scores abnormal? It depends on the set of criteria that one uses. By some standards one could say that these groups of people are rare in the general population. However, by others, if you look at how many people have one arm or low IQ scores, you will find that there are a great many of them, which may make them normal. Indeed, one could say that they are probably not typical or average. However, speaking of someone's probable lack of typicalness in respect to one aspect of the person's mind, body or identity does not ring with the same authority as saying that someone is not normal.

Even if one could establish what normal is or isn't in relation to disability/impairment, there are other problems with normal. For instance, autistic people are commonly described as having "peaks of ability." There are some things that many autistic people are very good at and other things that they cannot do. Michelle Dawson, an autistic woman takes issue with this view, saying in a Quirks and Quarks interview:

it isn't that we have these sort of peaks and valleys it is that we are fundamentally different. The processes that we apply to these various tasks are different, our brains will do things differently...if you have normal as a baseline it will produce this result of peaks and valleys that isn't a collections of excesses and deficits attached to a normal person it is just that it's the product of a fundamental difference in how our brains process information

As Dr. Laurent Mottron, a psychiatrist who works with Dawson, put it in the same interview, "you do not describe a dog as a negative of a cat and we still do neuroscience research of autism by describing autism as defects of typical mankind". In other words, you cannot take what is normal behavior for a cat (or an autistic person) and say it is abnormal because it is not what dogs (or non-autistic people) generally do. The same can be said of many groups, while some groups of peoples' minds and bodies act differently

than some other groups of people that does make them inferior, simply different. You cannot use the same scale to measure people in these groups as you do to measure people who are not members of those groups.

Being An Ally

Non-disabled individuals must become allies. They must become personally committed to supporting disable people, to helping us have a place at the table, to have our ideas respected, to make things accessible for everyone, and to call people on their shit. It is the role of the ally to educate oneself and others, to take leadership from disabled people and work in their own communities towards creating change. While allies should always be in support roles, that should never keep them from asking questions or deserting to know why things are being done in a particular way.



However, I also have difficulty believing that it is possible. As a disabled person I have found myself often believing that allies do not exist. I have been let down, angered, heart broken, profited off of, undermined, sabotaged, aggravated and used by people who call themselves allies. I have come to understand that no matter how great and ally one seems, that their failure as an ally is inevitable. As a white person, however, I have to believe that allies can exist. I am committed to being an anti-racist ally and I cannot accept that I and others like me cannot fight alongside people of colour towards an anti-racist and just society. The compromise between these two positions is to accept that we will all fail as allies and that is, indeed an essential part of being one.

Indeed, my perpetual disappointment in so-called allies is a result of a number of disturbing to devastating experiences. I didn't believe allies existed until I met people who specifically identified as non-disabled allies and who did work that revolved around

disability issues. These people, I believed, were truly allies and they gave me hope that we could create a movement of t.a.b.s and gimps united.

While disabled people deserve allies, it is important for disabled people to recognize that most of us have some sort of race, class, gender, sexual orientation, or other form of privilege. We also have to be allies to each other. Because the disabled community is so broad, there have been many instances where certain disabled people work to obtain privilege by defining themselves as something other than disabled. We have to work to be allies to each other as well, recognize where we are granted privilege when other disabled people are not and work to change that.

In many ways, it is much easier to identify what not to do as an ally then what you should do as an ally because there are so many negative experiences of allies. however it is important to make a concerted and continuous effort and constantly reflect on your own role as an ally.

What Not To Do As An Ally

There are a number of kinds of so-called allies that, while they may have good intentions and even may be doing some good work, are actually doing a lot of harm and not being good allies.

Note: these are written for people who are being allies to disabled people, but disabled people need to avoid doing these things when they are being allies to other people and communities.

Here are a few types of allies that you should avoid being:

The Profit Maker: and an ally you should never present yourself as an expert or profit from your role. There is a difference between being paid enough to survive and profiting; however, non-disabled people should not be paid organizers or writing books around disability issues, and they should not be taking positions where they are in the spotlight because there are always disabled people who would be better positioned to be in those roles. If an ally is approached with a project that they would be editing the disabled opinion or profiting from their role as an ally, they should always pass that responsibility on to a disabled individual.

There are so many people who profit off of disabled people: the medical industry, manufactures of personal support devices, the pharmaceutical industry, attendant services, etc. I don't think there is much difference between someone who makes a profit off of disability who calls themself an ally but doesn't put the money back into the community and someone who calls themselves a business person and does the same thing.

The Expert: It is never the job of an ally to speak for disabled people, only with us. It is the responsibility of an ally not to take the stage but ensure that the stage has a ramp and an interpreter. Kike Roach, in *Politically Speaking*, said:

It gets really tiring for us to be the only ones to speak out about it. But what you cannot do if you want to be an ally is to speak for other people. You can't say how other people should conduct their struggles or what they should be doing. You shouldn't try to dictate to them. But that's very different from speaking out against the barriers these people face.

Frequently, non-marginalized people are asked to speak about other people's oppression and struggle. In part, this is because of our education system which actively discriminates against marginalized people so there are fewer of us with the credentials to be considered experts. Of course this is an incredibly offensive viewpoint because who better is there to speak about a group's oppression than people who have an in-depth and intimate understanding of that oppression.

More importantly, we are excluded because we are less palatable. We might be angry. We might call people out how they are being offensive. And we might be offended by their oppressive behavior. Thus, it is easier to bring a non-expert expert. However, if an ally has the privilege to be asked, they need to use that privilege to ensure others that opportunity.

The Poser: Allies need to be very clear with others as to who they are. They need to constantly ensure people know they are allies, not disabled people. It is essential that allies never let on that they are disabled. When they do, it is likely for one of two reasons: to claim an oppression to not have to address their privilege or, more likely, to be able to speak with greater authority on the issue. That not only gives those people the power to speak for us, but also to speak things that they have no personal experience with as if they do.

The Identity Politician: These are people who usually have privilege coming out of their eyeballs who make it an important part of their political identities to be allies to everyone. Some of these folks do really good work and are allies. Others, however, are publicly allies but never follow through. That is, they take the credit for ally work but they do not do any of the hard work, the real work of being an ally. The work of being an ally is never glamorous, it is almost always behind the scenes, it is quiet, it is thankless. If you find this isn't the case for your ally work, you are probably a bad ally.

The Leader: A fundamental component of being an ally is having the understanding that you don't actually know what it is like to be part of the affected community. Even if you think you know, you really don't. That is one of the reasons it is important to *take* leadership from the communities you are working with. Sometimes you won't agree with the approach and that is okay. Sometimes you will have questions and that is okay. What isn't okay is for you to not to bother to find out what people want or to know what people want and to do something else. As David Gilbert said in No Surrender:

I was in transition from a liberal, who wanted to 'uplift' the oppressed (to make them more like me) to a revolutionary, who realized that oppressed people like themselves must become the arbiters of their own destiny.

If you aren't taking leadership, it is because you have a paternal liberal belief that you know better. You don't.

The Leadershopper (Leadership Shopper): Similarly to someone who does not take leadership, the shopper uses their knowledge of the divisions in a community to find people who will "lead" in the way they want to follow. In any marginalized community, oppression works to divide people. Some people are co-opted, some people are scared, some people have internalized oppression, etc. You can find anyone who will agree with you if you look hard enough and then you can say you are taking leadership. However, this isn't honest and it isn't real leadership.

Resistance

We are not living, to be sure, in mountain times, in revolutionary times, and that is as it is. We live in valley times - times of uncertainty and confusion, times of endemic hopelessness and deepening despair. These are times to stay awake and aware, to gather strength, to study and build our projects, to make whatever modest contributions you can, to blow softly on the embers of justice - and to remember - Bill Ayers, Fugitive Days: A Memoir

Right now, "blowing on the embers of justice" means fighting individual cases, building relationships, being allies, fighting to win back victories that were won by past movements and slowly chiselled away at until they were skeletons, or gone completely. "To remember" is to <u>learn history</u> and to learn from history.

Those in power control the majority of the resources and almost all of the military strength. We are poorly armed, if we are armed at all. What we do have is numbers. If we can demonstrate to the people who are actively oppressed and exploited by those in power that we really can win, that things really can change, more will join in the fight to win freedom and dignity.

Disabled people have fought back. We have locked down. We have occupied. We have marched. We have organized. We have won battles. And we can keep fighting until we get what we need.