Having received an ok, 
Harold headed out the door, 
Walking down the street, 
To house three-forty-four. 
Knocking first, and entering right after, 
Harold was now in the dwelling of his elderly friend, Unbeknownst to Harold, 
His erroneous outlook would soon end. 
My boy, said the man come here, 
And bring that book to your right, 
Harold did as he was told, 
Although his hands shook with fright. 
Come with me, the man said, 
And I will show you that you are not sub-par, 
Different without a doubt, 
But lame is not what you are. 
The man led Harold to the back of the house, 
To what he called the grotto, 
In this brightly lit room, 
He opened the book, and pointed to the picture titled Tomato.

Disability as tolerable in small doses

I was hired as a Personal Support Worker (PSW) to assist a visibly disabled woman with activities of “daily living” like shopping, banking, monitoring forced aesthetic goals of losing weight, walking in a “straighter” fashion, and going on outings. These outings never included outing oneself as crip or queer. Instead, communal identities of cripness and queerness ran underground, couched in more politically correct terms like “differently abled” and “friend.” When I go out ‘with’ the visibly disabled lady that I work for, herein referred to as Rose, I am not meant to be going with her in a friendly way, but I am to go with her in a supervisory manner, so that I can apologize for her “deviant behaviour” and make others more comfortable with being presented with difference.

Tolerating disability is part of an effort to treat the visibly disabled or impaired body “just as everyone else” (Michalko 2009, p. 111). This erases or at least minimizes difference through accommodating a certain level of disability, providing that the disabled body is pleasant, courteous and grateful. Visibly disabled bodies are supposed to use humour, conversation and wit to “relieve nondisabled people of their discomfort” (Garland-Thomson 2009, p. 69). But in the case of invisibly disabled bodies, their disability does not “cancel out other qualities, reducing the complex person to a single attribute” (p. 69).

Perhaps instead of surveilling, policing, and tolerating, a support worker creates crip community with impaired bodies through welcoming disability, nurturing relationships, and creating friendships with and between impaired bodies. Crips, non-crip allies, and impaired bodies who do not (yet) identify as part of crip communities all desire communal enactments with other bodies. Perhaps this can wish can be a binding one; fuel to make us be able to do things differently.
Crippling and Queering the “Helping” Profession

Disability is normatively understood as a ‘thing in the world’ that attaches itself onto bodies. This thing called disability can be tolerated in small doses because it is politically correct to do so. In this way, disability is used to portray society as democratic and inclusive. This toleration is not done because disability is seen as a valuable, integral part of some people’s understandings of themselves and their communities. Instead, disability is tolerated because it is seen as something that cannot be accepted, and is shameful. As such, it is something that is polite to ignore (when possible).

As a white disabled PSW, I am an invisible member of crip community who is well-positioned to begin unpacking what “politically correct” tolerance of difference means to visible and invisible members of queer and crip communities.

It is unthinkable that I could desire companionship with this disabled body, that I could want to find ways to connect with Rose instead of holding power over her. How do these invisible statuses both exclude invisible members of communities through not recognizing them as members, and thus not inviting them in? How do they also give those who are non-visibly marked prestige and privilege through providing the option to choose to come out (as queer or disabled) or to pass? How does the visible whiteness of both Rose and myself influence how we encounter and/or are protected from ableism1?

The choice to come out or stay in is not available to those who are visibly marked, since they are always already brought out by others. Visibly disabled folks such as Rose are stared at and have their intelligence and very humanity questioned on a regular basis. When Rose and I go out, tellers and cashiers attempt to give change to me instead of her, they look past her as if she was not there, and pedestrians reach out to “help” her with doors and with curbs without asking her permission. Rose is treated as if she does not have feelings, a need for human interaction, or boundaries.

Understandably, Rose has learned to be very cautious and even unfriendly towards people she does not know. Her reactions to these supposedly helpful interventions by bystanders can be seen as antithetical to building community. Too easily, the onus of checking ableist assumptions can be shifted off of bystanders and onto visibly disabled people such as Rose. In contrast, invisibly disabled folks such as myself enjoy the privilege of choosing to come out, or choosing to pass. This provides the disabled individual the opportunity to move in the world, socialize with others, access employment opportunities and social services (without being overtly discriminated against) at least some of the time. This privilege comes with often being presumed as fully-abled bodied, and when we cannot fulfill all of the expectations of others, we are presumed to be lazy, disorganized, and unreliable. Consequently, visibly disabled and non-visibly disabled folks do not always get treated the same way. While the former may hope for the ability to pass and to act as if they were non-disabled, the latter may crave communal recognition within crip community. These desires are not antithetical, but they do at times rub up against one another.

Clare calls this tension, “horizontal hostility,” which he defines as the product of an interaction “between marginalized bodies from many communities [who] create their own hierarchies” (1999, p.133). In the same vein, Ejiogu and Ware (2008) observe that disability is “inextricably linked and co-created by historically informed, cultural, racial, class, gender and sexual differences” (p. 11). What can we do with this tension, knowing it always exists between communal members who are marked differently and to various extents?

Tolerating difference as an act of political correctness

My relationship with Rose is complicated, not because it is most accurately described as a friendship masquerading as a professional relationship, but because people make meaning of our relationship every time we go out “there” where things “lie in ambush” (Bauman 2003, p. 1). It is always assumed I have a duty to Rose, either because she is family or because it is a job for which I am getting paid. Commonly, it is understood there is no way an employment situation can be subverted and become a friendship. Bauman warns us of idealizing community, and getting caught up in how it feels “good to have a community” (2001, p. 1). As an invisible

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1Ableism is defined in by feminist critical race scholar and disability activist Fiona Kumari Campbell as “the network of beliefs, processes, and practices that produces a particular kind of self and body (the corporal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human” (2001, p. 44).
femmy (feminine-looking) dyke with a chronic condition and fluctuating disability status (as in I sometimes do and sometimes do not identify as disabled), I pass as both heterosexual and non-disabled. I am hardly ever identified as queer while alone, and hardly ever identified as disabled. My impairment exists somewhere between the realms of physical impairment and neurological difference (it is sometimes (n)either and sometimes both). Like Wendell, I “live between the world of the disabled and the non-disabled” (in Samuels 2003, p.240). In contrast, Rose is a visibly physically impaired and neurologically different, and has historically been a vocally homophobic woman. At first, she was first horrified that I was queer, and she let everyone in the corporate downtown coffee shop that we frequent regularly know this. But over time, Rose has grown to respect my partner and I. It is hard to say whether this newfound respect for queer folks extends to queer folks in general, or only to people whom she has already decided that she liked before she discovered they did not identify as heterosexual.

Samuels discusses how queers, unlike non-disabled crips, have developed “a variety of nonverbal and/or spoken means to signal that identity” (2003, p.241). However, femmy lesbians are not represented by these signs. Femmy lesbians are less visibly marked, could-be communal members. We could more easily blend into the norm and become part of the normate, which is “the veiled subject…outlined by the array of deviant others whose marked bodies shore up the normate’s boundaries” (Garland-Thomson 2009, p.65). The potential for blending in does not mean we are less committed to creating communities or that becoming part of the normate is inevitably desirous for non-visibly queer and disabled people.

Amanda Hamilton notes that people with nonvisible disability “are in a sense forced to pass, and the same time assumed to be liars” (in Samuels 2003 p. 242). Passing as part of normate culture through invisible markers does not mean passing subjects are less trustworthy than visibly marginalized subjects. In fact, there is potential for passing to be “a subversive practice…the passing subject may be read not as…a defiant figure who, by crossing the borders of identities, reveals their instability” (p. 243).

The invisibly queer and invisibly crip body forces communities to question who is let in and kept out. We force those engaged in creating communities to acknowledge the instability of our relationships to our bodies, as well the fluidity of identities. We provide ways to think about community outside of its ideal form. We are troublesome and we exist on the margins of queer and crip communities.

Representing Disability Differently

Disability, if it is a “thing in the world,” is a communifying thing which invites visibly-disabled bodies, invisibly-disabled bodies, and allies to come into crip community, and “dwell with disability” (Chandler 2010, para. 2). Yet we need to continually critically analyze what kinds of racialized, classed, sexualized and gendered bodies receive the invitation to participate in crip community.

In this exploration of creating crip community, it is important to remember people’s apparent resistance to doing things differently is not always a conscious decision to defy community, but sometimes comes from a lack of exposure to community and/or specific communifying practices. Since communities are cultural creations enacted differently across time and space, we need to be gentle with those who seem to be the antithesis to community, for these bodies are potentially crip. We must not privilege the visual (as does the normate) to such an extent that we assume could-be communal members are always visibly marked.

Communal enactments within a corporate coffee shop

Rose and I spend much of our time at a particular downtown coffee shop discussing the news, people-watching, and building community. Customers at this coffee shop are welcomed; they are safe in their knowledge that as long as they pay, they are free to exist in this comfortable aromatic space until the shop closes or they wish to leave. Customers believe as they sip, they can take reprieve from the hectic world “out there” (Bauman 2003, p. 1). However, they do not consider that the “outside” world with all of its discomfort is irremovable from the politically correct “comfortable” space of the coffee shop.

When Rose and I roll and walk in, people are uncomfortably reminded of the leakiness of in here and out there. Certain kinds of socially marginalized people are said to not belong in this coffee shop. If you can pass, you can come in; otherwise, you put people at dis-ease. Rose and I are breaking into
this “safe” corporate space and claiming it as our own crip space; the cripness of this space runs underground, unspoken.

Leaky bodies represent leaky boundaries between communities. Leaky bodies reveal the precariousness of “safe” spaces, as they demonstrate the ways through which spaces can be used in various ways. Breaking into a space and turning it from a space of (un)belonging to belonging is not straightforward; it is actually a rather queer and never-ending process. It must be enacted repeatedly and in different ways over time.

This corporate downtown space is not the ideal location for the enactment of community, but as no ideal space exists, this space is suitable. This space is not evidently non-accessible; there is a slope at the entrance, and the baristas are most apologetic for the stairs that descend to the bathroom. The brand of inaccessibility at this coffee shop is, I would argue, somewhat more dangerous, as this is a politically correct, non-accessible space that profits through advertising itself differently to different people.

My invisible disability allows for me to, as Garland Thomson says, “interact with the socially engineered environment and conform to social expectations” differently than Rose (2009, p. 64). This “determines the varying degrees of disability or able-bodiedness, of extra-ordinariness or ordinariness” (Garland-Thompson 2009, p.64). My body is represented as ordinary, non-disabled; it is body that enforces order, is authoritative and takes care of bodies. It is not a body which itself is disabled at times. Thus my invisibly disabled body is excluded from the “narrative of corporeal difference,” (Garland-Thompson 2009, p. 65) which enables me to be “unmarked” and “sheltered by the neutral space of normalcy” (Garland-Thompson 2009, p. 65). This is especially true when I am with Rose, since “otherness emerges from positioning, interpreting, and conferring meaning upon bodies” (Garland-Thompson 2009, p. 66). My body, juxtaposed against that of Rose, is read and interpreted as the able-body, the full-bodied body. I do not get “assigned” (Garland-Thompson 2009, p. 67) the position of the disabled body; I have the privilege to choose when and how to occupy it. My queer and crip communities can be elitist and excluding of non-visibly queer or crip bodies. It is difficult to decide when to come out “as a person whose bodily appearance does not immediately signal one’s own sense of identity” (Samuels 2003, p. 133). This means finding and/or forming crip communities that welcome non-visualy marked bodies as communal members can be difficult. Like queers, “disabled people are sometimes fundamentally isolated from each other, exist[ing] often as aliens in their social units” (Garland-Thomson 2009, p.71). This perceived isolation and lack of a given community permits and forces invisibly-disabled-crips and femmy-queers to continually redefine their communal others.

I am not read as being gay because I appear “feminine,” and since this seems to match the gender I enact, my sexuality is not questioned. While it is, in a sense, a privilege to be able to choose when to “out” myself, it is also painful to not be read as part of the community. It is painful to have to be with another woman in order to ‘prove’ that I am not actually heterosexual and to avoid “social scrutiny” (Samuels 2003, p.233), while – at the same time – being with another woman also invites social scrutiny.

In the moments when I gain queer and crip communities, I know this gain comes with “soon missing freedom” (Bauman 2002, p. 4). But for invisibly disabled crips, these moments of perceived belonging are so short that as invisibly disabled crips and a femmy dyke, I always exist on the margins of marginal communities. Rose, whose body is often read as “too disabled” and whose disruptive body is often shut out of public spaces, also exists on the margins (albeit in a different way). Thus, bodies that are regarded as insufficiently and excessively excladuable bodies are isolated within the communities within which they were said to be a part. The privilege of being able to pass as non-disabled, to fit into the world of the normate, makes it more difficult for me, an invisible member of queer and crip community to “let go of the desire to pass as nondisabled – really to be nondisabled” (Clare 1999, p.134) as invisible members are torn between two worlds, sometimes feeling at dis-ease in both. In this way, “Isolation and community tug against each other” (Clare 1999, p.134).

Garland-Thomson notes that “an invisible disability, much like homosexual identity, always presents the dilemma of whether or when to come out or pass” (2009, p.70). The decision to decide to come out is made especially difficult when one is already read as the normative ‘ideal’ body. It would be so easy to go along with assumed able-bodiedness and heterosexuality, but this would not be a way of acting that is in line with my desire to create community. I can choose to or choose not to act on behalf of crip community when I hear offensive ableist comments or notice access barriers. I choose
to counter representations of disability as excess, disability as something that is only tolerable in “small doses” and add in representations of disability as bonding.

Samuels argues that “the option of passing as nondisabled provides both a certain level of privilege and a profound sense of misrecognition and internal dissonance” (2003, p. 239). The choice to pass, to blend in within multiple communities and to be accepted by them is a supposedly desirable “privilege,” and as such, it is something supposedly self-evidently good. Yet the ability to pass can make finding community difficult, as one who can fit into either world feels forced to choose one over the other. Passing means taking refuge in a body that is read as possessing a socially acceptable level of queerness or disability. Passing, like the notion of community, needs to be troubled because we cannot pass without questioning what communifying possibilities are lost when we pass as part of the normate.

References


Amber Reid

Amber is a queer, mad-identified master’s student in Critical Disability Studies at York University. She completed her B.A. (Hons) in Equity Studies, Sociology and Women and Gender Studies (2013) at the University of Toronto. She has presented her work at the Society for Disability Studies (2012, 2013, 2014) and at the Canadian Society for Disability Studies (2014).