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Problematizing Reflexivity, Validity, and Disclosure: Research by People with Disabilities About Disability

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Abstract

In this article, I explore the potential for people with disabilities to conduct research about disability in education. Drawing upon Rasmussen (2006), I consider whether merely sharing one aspect of identity with participants is enough to gain an emic (insider) perspective when doing research. I argue that not only should we problematize our own identity, but that research should change the researcher's own identity and that the degree to which research promotes this change is an essential aspect of formal validity of the research. Finally, I propose some practical implications and offer some advice for researchers conducting research on disability.

Keywords

Queer Theory, Emic Perspective, Disabled Researchers, Non-Disabled Researchers, Validity

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Problematizing Reflexivity, Validity, and Disclosure: Research by People with Disabilities About Disability

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In this article, I explore the potential for people with disabilities to conduct research about disability in education. Drawing upon Rasmussen (2006), I consider whether merely sharing one aspect of identity with participants is enough to gain an emic (insider) perspective when doing research. I argue that not only should we problematize our own identity, but that research should change the researcher's own identity and that the degree to which research promotes this change is an essential aspect of formal validity of the research. Finally, I propose some practical implications and offer some advice for researchers conducting research on disability. Keywords: Queer Theory, Emic Perspective, Disabled Researchers, Non-Disabled Researchers, Validity

In the course of my decade of working in the field of Special Education, I have rarely encountered a teacher, let alone a researcher, with a visible disability, either physical or mental. More generally, I have rarely encountered researchers in the field of education with any kind of visible deviant personal characteristics, whether it be disability, gender, sexuality, weight, or other ways in which bodies are marked and shaped. Discrimination and other structural barriers combine in a way that marginalizes researchers with disabilities, particularly when it intersects with race, class, gender, and sexuality.

Similarly, it is also uncommon to encounter work in the field of Special Education that critically interrogates how the researcher's positionality influences their work. Allan and Slee (2008) discussed this problem and wrote that "too often, there is an apparent unwillingness by researchers of inclusive education to reveal their positions, where they are coming from, by specifying the foundations of knowledge and assumptions about the nature of reality on which their work based" (p. 1). This lack of critical interrogation leads to a situation where much of the field of Special Education is comprised of writing about those with disabilities, with little understanding of how researcher identity impacts one's research.

The consequences of this marginalization are devastating; the discipline of Special Education has become insular; ignoring the critiques offered by researchers in disability studies (many whom identify as disabled), researchers in Special Education persist in the "standard and widespread use of damaging labels and deficit-driven medicalized conceptions of conceptions of disability that undeniably contradict[s] the views and life experiences of many disabled people" (Connor, Gabel, Gallagher, & Morton, 2008, p. 445). Moreover, efforts by those wishing to bring disability studies into the field of Special Education are often pushed to the margins due to the fact that "most special education publications and organizations seem [are?] philosophically and methodologically conservative and monolithic" (Brantlinger, 1997, p. 430).

In this article, I want to consider the idea of disabled persons being able to do their own research on disability. Rather than valorize this idea, however, I want to both explore the possibilities raised by this approach as well as the potential pitfalls that researchers with disabilities can fall into when writing about disability. By raising both these possibilities and pitfalls, I offer guidelines for what makes for quality research within the study of disability. I draw extensively on my own work on queer methodology (for example, Sheldon, 2010a) in order to bring a queer lens into the study of disability, although I make an effort to avoid simple

analogy in favor of a more complex analysis of the relationship between queer and disabled identities.

I also offer suggestions in this paper for those researchers who may not identify as having a disability themselves; their voices and ideas matter to the discourse around disability, but they cannot and must not be offered in lieu of people with disabilities being able to conduct their own research and define their own questions. This article, therefore is directed at both disabled and non-disabled researchers as well as towards those who sponsor, fund, and utilize research. Although the examples given are primarily from the field of education, it should be of interest as well to those in other fields who perform and utilize qualitative research. It also may potentially be of interest to quantitative researchers, although my area of expertise is in qualitative research methodology and the examples in this paper will be primarily qualitative.

“Nothing About Us Without Us!” From Research with Disabled People to Research by Disabled People

I begin my inquiry into methodology by exploring the idea of research with disabled people. A slogan that has become popular in the disability rights movement is “Nothing About Us Without Us” (Charlton, 1998). When applying this principle to research, it suggests that disabled people need to be intimately involved in the processes of research on and about disabled subjects. One suggestion that has been offered is that we need to conceptualize this as the shift from doing research about disabled people to doing research with disabled people. In models such as participatory action research, research is planned and constructed “with those people whose life-world and meaningful actions are under study” (Bergold & Thomas, 2012). Keeping with Charlton’s concept, disability cannot be studied without working closely with disabled people and allowing them to be intimately involved in the process of research.

In participatory research, it is about the conversation between researcher and participant; “knowledge is co-constructed relationally and through dialogue” (Springett, Atkey, Kongats, Zulla, & Wilkins, 2016). Springett et al. proposed that the quality of this sort of research is judged by the degree in which the study incorporates the ethical value of participation in the study. In this paper, I want to build upon their idea of participatory research and to argue that people with disabilities creating and doing their own research on disability, with the disabled person as the primary researcher, is the epitome of participation and that researchers such as Springett et al. have too limited a vision of what is possible in terms of participation.

The Erasure of Disabled Teachers and Researchers from the Discourse¹

In Sheldon (2013), I argued that the logics of rehabilitation within Special Education entirely erase disabled teachers and researchers from the discourse around disability. I cited Reid and Valle (2004), who provocatively asked:

What questions might researchers who grew up labeled with LD [Learning Disabilities] pursue? How might those questions differ from those that are now being addressed? Do teachers identified as having LD teach differently? How would they reorganize schools if they were given the liberty to do so? (p. 472)

¹ I use discourse in the sense of that Hunter (n.d.) uses it: “Foucault’s reformulation of the concept of discourse derives from his attempts to provide histories of knowledge which are not histories of what men and women have thought... they are reconstructions of the material conditions of thought or ‘knowledges’” (as cited in Kendall and Wickman, 1999, p. 35).

Reid and Valle suggest that researchers with LD might consider different topics of inquiry, ask different questions, and be able to shape a different vision for schooling. Some people might (incorrectly) infer from this that Reid and Valle intend for people with LD to study only LD issues and likewise for only people with LD to study LD issues.

I believe that Reid and Valle (2004) intended their statement to be much broader in scope; they are proposing a major shift in how we do research around disability. Reid and Valle sought to challenge the power structures that “define truth”, “determine what constitutes knowledge”, and “authorize some people—but not others—to speak” (p. 472). Challenging these power structures head on, Reid and Valle proposed an inversion of these power structures in order to “modify what counts as current knowledge” (p. 472) and generate new knowledges that challenge the erasure of disabled teachers and researchers from academic discourse around disability. In doing so, they sought to challenge the ways in which disability is constructed under medical and scientific models and to instead create a platform for disabled people to define their own identities and speak on their own behalf.

Disability and “The Closet”

This exclusion of researchers with disabilities from Special Education is reminiscent of the situation described by de Castell and Bryson (1998); writing about LGBTQ (Lesbian, Gay, Bi, Trans, and/or Queer) education researchers, they state that “only heterosexual or faux-heterosexual people are usually welcome to do school-based educational research” (1998, p. 247) because of the homophobia that exists in schools and the difficulty of gaining access to school sites. There are similar issues, I propose, for people with visible disabilities who choose to research on disability.

Coming out as disabled is of course different from coming out as LGBTQ, but there are similar issues with disability; some people with disabilities can attempt to hide their disability but there is a lot of discrimination against people with disabilities who attempt to conduct educational research. (I return to this question of the “closet,” identity management, and disability later in this article). In addition to outright discrimination, there are many practical barriers for disabled people who seek to do their own research on disability, which I address in the next section.

Barriers to Doing Research

There are also significant potential challenges for disabled researchers in terms of academic careers; many disabled researchers face issues in the academy. Some of the barriers to full participation in academic career that have been observed by disabled scholars include: difficulty being productive enough to earn tenure (Chouinard, 2010; Ghiaciuc, 2013), discrimination on the grounds of disability (Chouinard, 2010; Price, 2013), accessibility of the faculty hiring process and perceived cost of accommodations during that process (Smith & Andrews, 2015), salary discrimination (Chouinard, 2010), excessively high teaching loads (Chouinard, 2010); inaccessibility of conferences (Price, 2013), difficulties integrating into the culture and politics of their campuses (Smith & Andrews, 2015), exclusion from social events and faculty meetings (Chouinard, 2010); lack of interpreters for impromptu meetings (Smith & Andrews, 2015); difficulties keeping up with the typing demands of the job (Garland-Thomas, 2013), inaccessibility of campus services (Samuels, 2013) and academic articles and books not being available in accessible formats (Oswall, 2013). These obstacles, combined with more overt discrimination, represent a significant barrier in terms of having research that is for and by people with disabilities.

Are Disability Studies Exempt from These Barriers?

What, one might ask, about the relatively new² field of Disability Studies? Disability studies is an interdisciplinary field with a growing presence in the humanities and which has also gained some traction in the social sciences. It is, though, not the same as Special Education, has a very different object of study; Special Education, as a “a technical field, located within a positivist framework, concerned with issues of diagnosis, assessment and causes of disability and appropriate forms of treatment” (Rizvi & Lingard, 1996, p. 10) is concerned with the practical problem of educating children with disabilities, while disability studies proposes a much broader lens, looking at how we come to be disabled by society (Shakespeare, 2013), the history of disability, and the ways in which disability is socially constructed.

Many of the same barriers that I describe about Special Education, though, still exist in disability studies. Disability studies privileges a highly analytical, academic language (which can sometimes be a challenge to those with learning disabilities and intellectual disabilities); non-disabled scholars still have an easier time getting published and building academic careers, and conferences and organizations within disability studies are not always accessible. Moreover, these conferences are challenging for less financially privileged people to attend, particularly those that may incur extra costs due to their disabilities.

The Relationship Between Disability Studies and Special Education

Some of the ideas of disability studies do cross over into Special Education, but they sometimes get distorted in the translation; witness, for example, how concerns about ableism and stereotyping raised by people with disabilities has in the field of Special Education turned into a hegemonic practice of person-first language, with special educators and other non-disabled advocates often insisting on using person-first language even when the people they work with prefer identity-first language (Brown, 2012).

Person-first language is when you say a “person with a disability” rather than a “disabled person” in order to privilege that the person comes first and the disability is not the defining characteristic. Identity-first language argues that when you yourself identify as having a disability, it may be such an important characteristic that you might choose to put your disability first rather than treat it as a mere characteristic that you possess (Brown, 2012; Dunn & Andrews, 2015). I use both in this article, depending on which perspective I am emphasizing at the time.³

The pushback from disabled people against person-first language has been gradually building. Smith and Andrews (2015) noted that “the deaf community embraces the idea of being deaf as inseparable from their identity.” (p. 1522) and consequently prefers the term ‘Deaf person’ rather than ‘person with Deafness’.

Facing a relatively insular Special Education field, disability studies researchers who study topics related to education have attempted to establish the field of “disability studies in education.” This “nascent field [is] grounded within the broader province of Disability Studies (DS)” (Connor, Gabel, Gallagher, & Morton, 2008, p. 441) However, to the dismay of these scholars, there has been a significant problem with scholars in Special Education trying to claim

² I am making a comparison here between disability studies and similar fields such as sociology; sociology dates back to the early 19th century, while disability studies dates approximately to the early 1980s, with the Society for Disability Studies being founded in 1982

³ The teacher of the first class I took in Special Education after being admitted to my credential program would have given me an automatic “F” if I failed to use person-first language on a paper.

they are doing “disability studies in education” without a sufficiently critical analysis of disability; Connor, Gabel, Gallagher, and Morton (2008) observed that:

...the term “disability studies in education” was invoked by a disconcerting number of novelty seekers looking to add a veneer of distinction to their decidedly conventional special education research, inadvertently interpreting DSE as a trendy new term signifying “special education with a makeover.” (p. 446)

Disability Studies in Education has, however, given disabled people a platform within the field of Education. Although non-disabled people certainly do research and write in the area of DSE, it was clear to me from attending the DSE Special Interest Group meeting at AERA and when I went in 2013 that Disability Studies in Education was far more welcoming to people with visible disabilities than my own field of Special Education ever was. This idea that disabled researchers can do critical work around disability was particularly important to me, and served as a major inspiration for writing this article.

Do Disabled Researchers Have an Emic (Insider) Perspective When Studying Disability?

In considering the idea of disabled people doing their own research on disability, I do want to offer a cautionary note. I want to raise some skepticism about the proposition that someone with the same disability as their subject automatically gains an emic (insider) perspective into the life of someone else with that same disability. When considering one’s identities through a lens of queer theory⁴, it becomes complicated, socially constructed, and fundamentally unstable.

Consequently, a researcher needs to constantly interrogate and have an attitude of skepticism towards their own identity, and to consider the impact of multiple identities on the work that they do. Ramussen (2006, as cited in Sheldon, 2010a) observed that researchers need to deconstruct even their own identities: positionality is in some sense just a “chimera” despite having real impacts on our research (p. 38). Rasmussen argued that we both need to include our own personal biographies in our research but to simultaneously “destabilize unified understandings of identity” (p. 38).

Researchers also need to consider the history and context of their own identities, not just of those that they study; the call to destabilize identities is not just about recognizing the socio-historical construction of one’s subjects but also includes one’s own identity. Claiming an identity without a critical analysis “slide[s] into claims of essential difference, neglecting to critically examine the social context in which they are formed,” warns Mayo (2007, p. 84).

This requirement for considering the construction of identities does not just apply to non-disabled researchers. This critical analysis is still important, in fact, I believe, all the more important if the researcher is themselves disabled. As a researcher, I must resist the temptation to merely think that because I identify as disabled, I therefore have some special insight into disability and therefore no longer need to deconstruct my own identity. Through the process of deconstructing identity and examining social context, I propose that we can problematize the whole category of “disability” altogether and move from superficial understandings of disability and can begin to look at how this concept is socially and historically constructed.

⁴ Jagose (1996) wrote of queer theory: “Queer theory’s debunking of stable sexes, genders and sexualities develops out of a specifically lesbian and gay reworking of the post-structuralist figuring of identity as a constellation of multiple and unstable positions” (¶ 4). I am using queer theory here to interrogate identity in a broader sense, not just sexual and gender identity.

Studying a Disability Other Than One's Own: Some Potential Pitfalls

More than just studying one's own disability, however, disabled researchers often address disabilities other than their own. Consider my situation as a person with a psychiatric disability; does it give me any kind of special knowledge about someone, with, say a physical disability or a learning disability? Positionality is a complex thing, especially when it comes to disability, and it cannot be reduced to a simple binary of disabled/not-disabled. My own research, for example, focuses primarily on verbal learning disabilities, and not being someone with a verbal learning disability, it places me in a complex position; clearly, having familiarity with disability in terms of gaining accommodations and working with the system to access resources gives me a broader perspective even when studying a disability other than my own.

Is Sharing One Aspect of Identity with Participants Enough?

On the other hand, I find it easy to jump to conclusions and to assume that a research subject's perspective is the same as mine merely based on sharing some aspect of identity with them. It is important not to fall into that trap and to consider the full complexity of identity even when you believe you share an identity with your subjects. Let us consider some examples from research about sexual orientation and about race to see why this is important.

Rasmussen (2006) explored the complexity of shared identities by discussing Kennedy and Davis (1996)'s experiences doing research when both they and their subjects shared a lesbian identity. Contrary to the naïve view that sharing an identity makes research easier, Kennedy and Davis instead observed that:

...the common bond of lesbianism and familiarity with the social context did not make positioning ourselves in relation to the complex and powerful forces of class, race, and gender oppression—not to mention homophobia—easy. (p. 173, cited on Rasmussen, p. 47)

Kennedy and Davis found that the complexity of intersectionality means that merely sharing a single characteristic is not enough to (automatically) understand the perspective of your subjects. Similar to Kennedy and Davis' findings about lesbian identity, similar issues exist with race; "researchers from the same racial background as their participants do not necessarily have an unproblematic relationship with them because of the heterogeneity of individuals who identify with a given racial group" (McDonald, 2013, p. 130). Because of the other characteristics that influence identity, perspective, and history, you do not automatically gain an emic perspective merely because you share the same racial identity.

More generally, as Rasmussen (2006) argued, "a shared biographical fragment...does not necessarily translate to shared interests and a greater possibility of empathetic understanding or sensitivity between researcher and participant" (p. 47). Rasmussen is not saying that lesbians should not do research on lesbians and that people of color should not do research on people of color, but rather that we need to consider the complexities of both our own identities and our subjects' identities and how they are formed. Tying this back to disability, I offer an example from my own research: as a person with a disability, I believe in the importance of building a more accessible world, and so it makes logical sense for me to study disability, but I cannot simply impose my own experiences on my participants because of us being both disabled, even if we both have the same disability.

This leads into the next question, that of the validity of research, something that becomes increasingly foregrounded when a researcher studies something that they have a

personal stake such as research on/in/about disability; can research in which you have this kind of personal investment in still be “valid” in the formal sense of research validity?

Validity of Openly Ideological Research

In light of perspectives such as postmodernism, I find it tempting at first to dismiss research validity as an outmoded positivist social science concept. Queer scholars have called for the rejection of paradigms that involve objective truth (e.g., Gamson, 2000; Honeychurch, 1996) and validity at first glance appears to be something we should reject outright as well. Upon further study, though, I reached the conclusion that validity does have considerable utility in the study of disability and in other social justice-informed research. Moreover, validity, even though queer scholars may take issue with it, is an important part of what makes for quality research, if we want to be able to “distinguish ‘good’ and ‘poor’ research” (Springett, Atkey, Kongats, Zulla, & Wilkins, 2016). Objective truth, under the perspective of queer methodology, may be a mirage, but that does not mean that everything is subjective; and we still need to have a coherent, detailed definition of research quality. To do so, we need to redefine a lot of the terms used by positivist researchers in ways that meet our research goals.

Lather (1986), in her article about openly ideological research, suggests that although researchers should seek to give up claims to neutrality and objectivity, this does not necessarily mean that we should give up on the concept of validity in regards to our research. She insists, rather, that the validity is a key component of doing value-based research in which we seek (with our research) not merely to interpret the world but to change it (to paraphrase Marx, 1888). Lather offers and then reinterprets three standard criteria for validity: triangulation, construct validity, face validity, and then adds one non-standard criterion, catalytic validity.

Triangulation

The idea of triangulation, Lather (1986) suggested, should be expanded from using multiple assessment measures to including multiple data sources, multiple methods, and the idea of using multiple theoretical schemes to frame and analyze one’s data. Multiple theoretical schemes is something key when doing research on disability; rather than, for example, using only disability studies as your framework, a researcher should consider looking at their research from multiple theoretical schemes. Some examples of theoretical schemes given by Lather include Neo-Marxist Research, Feminist Research, and Freirerian Research. My own research into disability draws upon paradigms such as critical theory, critical pedagogy, and queer theory in addition to disability studies. It is important, though, to not rely just on one theoretical orientation in one’s work and to constantly ask what your data and theories might look like under a different theoretical framework. One should not only use disability studies to inquire into disability and only use queer theory to inquire into queerness, but rather, you bring many different theories to bear on your research and look at the interaction between the theories in order to develop your own. When doing so, it is important to preserve the unique character of the tools you use and not engage in a formulaic synthesis (Atkinson, 2005).

Construct Validity

Construct validity, in a traditional framework, is about whether your instruments measure what they purport to be testing. Lather (1988) writes that we live in a post-positivist

era⁵, in which “foundational views of knowledge are increasingly under attack” and where we no longer have absolutes despite our “lust” for such absolutes (p. 570). Keeping in mind Lather’s post-positivist framework, she is less interested in how accurately your “scientific” instruments measure your constructs. Instead, she redefines construct validity; she is interested in how a researcher’s theories are changed by the “ceaseless confrontation with the experiences of people in their daily lives” and that one’s “a priori theory” becomes changed through the researcher’s engagement with “the logic of the data” (1986, p. 67). This focus on the people you work with and their lived experience is an important part of any kind of meaningful research involving disability; all too often, the focus in research becomes instruments and data collection rather than our participants (and the researchers) lived experiences.

Face Validity

Face validity, in traditional research, is about checking your data with the participants, to make sure you are quoting them accurately. Lather suggested that in addition to checking the data with participants, we need to recycle “analysis back through at least a subsample of respondents” and “refine them in the light of the subject’s reactions” (p. 248). We need to do this in a thoughtful and meaningful way; this is not just a “box to be checked” but something that involves a serious attention and care to what the people involved consider. Rather than just finding the very things we predicted in theory, we need to revise our theories based on what we learn from our engagement with others and based on their own self-understandings that they gain as a result of research, which I discuss more in the next section

Catalytic Validity

Catalytic validity, the nonstandard criterion that Lather adds, is probably the thing that has resulted in the most debate when I raised it to researchers that I work with. Lather contended that an important criterion of validity is that the study should have transformative value for participants. Researchers should seek to design research that enables participants to gain new, socially-transformative understandings of themselves. The research process, Lather contended, needs to “reorient, focus, and energize” participants so that they “gain self-understanding, and ideally, self-determination through research participation” (p. 67). This is particularly important when doing research with disabled subjects; all too often they are treated as a mere object of study and are not given meaningful opportunities to learn about themselves during the research process. I explore further the potential for catalytic validity for researchers in the next section.

Learning from Autoethnography

Autocatalytic Validity

Thinking about Lather’s theories on validity, I notice that her theories are about how a researcher’s theories are transformed by interacting with participants and about how participants are transformed in their interactions with researchers, but there is one important component missing; how the researcher is themselves transformed by the process of research—an *autocatalytic validity*, to coin a new term. Autocatalytic validity works hand in hand with

⁵ Lather is declaring that we are in a post-positivist era in 1998, yet 18 years later, the field of Special Education is still mired in positivist paradigms.

catalytic validity; as participants learn to “read” and transform the world, the researcher’s own conceptions of the world change.

As participants gain new understanding of their identity, so does the researcher. McDonald (2013) wrote about Rooke (2009)’s argument that researchers need to “let go of an ontology that presumes that a researcher’s sense of self is stable and will stay the same in the course of a given research project” (p. 132). McDonald believes that we need to treat a researcher’s identity as something that can change in the process of research. More than just acknowledging that this can happen, I am arguing that the researchers’ own sense of self (as well as participants) *needs* to change in the process of research for the research to be considered valid (in the formal sense of validity).

McDonald (2013) refers to this process of researchers and participants changing as a result of research as self-reflexivity; he argued that “self-reflexivity requires researchers to attend to the implications of their research not only to them but also on their research participants” (p. 128). Where my concept of autocatalytic validity differs from self-reflexivity is the focus on validity; like Lather’s catalytic validity, autocatalytic validity argues that research is less valid, in the formal sense, when it fails to transform the researcher. More than just stating a fact about researchers being transformed and proposing that they consider this, it argues that this is a necessary element of research which seeks to transform the world.

To further consider how to design research with autocatalytic validity and to consider this process of transformation that a researcher goes through, I explore next the methodology known as autoethnography to see what it can offer us for our research on disability.

Autoethnography and Critical Reflexivity

Autoethnography as a research method proposes a sort of critical reflexivity, an interrogation of our own values, beliefs, paradigms, and methodology. Adams and Jones (2011) proposed that interrogation “involves a rigorous call for reflexivity- to reflect not only on the self, how the self works, and how others are implicated by the self and the self’s desires, but also on how we represent – in writing, performance, film, and so on—the process and challenges of reflection” (p. 111). Thus, they suggest, autoethnography calls for us to pay close attention to the process of implication and representation.

Much like Lather’s concept of triangulation, Adams and Jones (2011) saw the process of critical reflexivity as being one of diversity; that you have to view your research through many different lenses. They wrote that “a commitment to diversity – of media and knowledges, subjects and subjectivities, standpoints and relationships – foregrounds the use and importance of critical reflexivity” (p. 111). In doing autoethnography, you have to look at yourself, at others, at your views, at your relationship to self and other; applying autoethnographic techniques to your research is not mere solipsism as some have alleged, but rather about applying this principle of critical reflexivity to the work that you do.

Critical reflexivity does not presuppose any particular research technique; rather, it is a basic principle that we can draw on when doing research. It is not solely a strategy used by disabled researchers; it can be used by non-disabled researchers who are studying disability; making sense of one’s subjectivity as an able-bodied person (or as is often said in disability studies, a temporarily able-bodied person, since most people’s life trajectories end in some form of disability, even if only from old age) can be just as important as a disabled researcher making sense of their subject position as disabled. Critical reflexivity does require a certain amount of self-disclosure, though, which in some situations and contexts can be problematic or even dangerous for researchers. I discuss issues of self-disclosure in the next section.

Can You Have Critical Reflexivity When Using Techniques of Identity Management?

The problems with self-disclosure become apparent when one starts to apply critical reflexivity; in disclosing our identification with marginalized identities, are we left at the whim of those who subscribe to oppressive ideologies? Must we consent to being “outed” as queer and/or disabled at all times, or can we use strategies of “identity management” in order to achieve control and agency about disclosure? In this section, I will use my two Master’s degree projects, one on the topic of queerness and one on the topic of disability, in order to explore issues of “coming out” and identity management as they relate to critical reflexivity.

Identity Management in My Study of LGBTQ Teachers

In Sheldon (2010b), my unpublished Master’s thesis, I explored the concept of the idea of identity management in the context of doing research on LGBTQ teachers:

... questions of identity and identification are central in taking a queer approach to research. Diana Fisher (2003) sees coming out as a strategy of identity management and control over one’s life rather than as a simple question of whether you are in or out of the closet. Even when studying a GLBT⁶ organization in which it is reasonable for me to be out as a gay man, there are still numerous questions about how I should present my identity. When the check-in question at a caucus meeting asks about your identity, should I say “gay” or “queer?” To what extent do I attempt to conceal my identity as a leatherman: obviously I wouldn’t wear leather cuffs or pants, but need I drop the leather jacket? The leather backpack?

Identity management is something that has always been critical for LGBTQ teachers, and is even more important to LGBTQ researchers in the context of their research. To reflect the full nature of one’s personality and identity can be potentially risky in the context of schools. Long (1993) suggested that readers imagine his paper being presented

by a small, mustachioed man wearing a gold lame cocktail dress, black pumps with three inch stiletto heels, a raven wig, and a beaded cloche with peacock feathers. (p. 79, cited in Honeychurch, p. 348)

One can only imagine if that man walked in to meet with a principal about doing some research in their school; needless to say, the interaction probably would not go well. This is not just a problem for femme gay men; I have definitely encountered issues doing research and teaching in schools when wearing more masculine items of clothing such as a leather jacket and pants. Both the hyperfeminine and hypermasculine can both be issues when doing research in a school setting. I use this example of queer identity management in order to introduce a parallel situation that exists for disabled researchers.

⁶ GLBT stands for Gay, Lesbian, Bisexual, and/or Trans; the order of the acronym and what letters should be in it is a matter of long-standing debate; it is now generally preferred that the “L” come before the “G” in the acronym. In this writing I was using GLBT since the organization I was studying has “GLBT” in their organizational name.

Identity Management in My Research about Disability

Identity management is crucial to disabled researchers, particularly those with non-visible disabilities; should one, for example, disclose their history of mental disabilities such as schizophrenia or bipolar when doing research in sensitive settings like schools? Even if you are researching, for example, children's mental health, you might lose access to your research sites if these kind of personal histories were disclosed. What does this mean for the ability to engage in critically self-aware and self-reflexive inquiry if you are not even "out" as having a disability in the contexts in which you do research?

In my second (unpublished) Master's degree project (Sheldon, 2014), I chose to disclose my own mental health history and how it related to my understanding and perspective of disability, but only to readers of the project rather than to the teachers that I worked with. This is in many ways a strategy of identity management, even as it attempts to introduce a critical reflexivity. Must critical reflexivity and disclosure go together? Are they equivalent? This is what I will explore in the next section.

Disclosure and Critical Reflexivity

This is the crux of the question that I want to raise about disabled people doing research on disabled subjects; must you disclose being disabled (or queer, or being from a non-majority religion, or any other axis of non-obvious difference) in order to be reflexive in your work? And who must you disclose to – your participants? Your colleagues? Your readers? It may not always be safe to disclose a disability, much like it is not always safe to disclose a queer identity.

On the other hand, strategic disclosure may enhance the catalytic validity of the research; conversely, it is hard to offer tools to transform reality when you are hiding a significant portion of your identity from your participants. This is illustrated in my critique (Sheldon, 2010a) of Pascoe (2007)'s research on gender and sexuality with high school students; she chose not to come out to the gay and lesbian students that she encountered in the school in order to gain more access to the more sexist and homophobic portions of the school and in order to investigate the dynamics of heterosexism and sexism within the school. Sears (1996) likewise proposes the idea of "covert queer research" (as cited in Capper, 1999, p. 6) in order to use invisibility to gain access to research sites within schools, but even if you can successfully pull this off it comes at a price; you lose the opportunity to enact your identity and the opportunity to explore how your enactment of identity impacts your subjects.

Identity management and selective disclosure gives you a certain power, but often at the expense of those without the ability to avoid such disclosure. An autistic person, for example, is unlikely to be able to "hide" their differences in behavior in the way that someone with, say depression might be able to. Several of my friends with cerebral palsy work in fields that require significant intellectual competence; they have varying degrees of mobility aids that they use in different contexts, and when not using such aids, someone might merely think they are merely temporarily injured rather than disabled⁷. Given the long-standing stereotype about cerebral palsy and intellectual disability, it might be logical to choose to hide this disability, but at any moment someone might "discover" the "truth" and out them at their work or while they are trying to secure employment. Being LGBTQ as well as disabled makes strategies of hiding potentially even more risky; they have multiple, interlocking axes of identity management going on, each with their own risks and potentialities.

⁷ One relevant thread of research within disability studies is the difference between injury, illness, and disability. (See, for example, Serlin, 2006, p. 54).

For LGBTQ folks there is also another aspect to identity; the spectre and charges of “recruitment” hang over any efforts to work with LGBTQ students. For disabled youth, this becomes all the more apparent; the social construction of people with disability as being non-sexual makes it difficult to meaningfully address and create programming for LGBTQ youth with disabilities. Thompson (2008) proposes that the “reluctance to recruit [might be] simply internalized homophobia” (p. 49); he states that we have to overcome our own discomfort and fears when developing resources for LGBTQ youth with intellectual disabilities. Effort at identity management, thus, become even more challenging when you are proposing to work with LGBTQ youth; this example is one of the complexities of queer research, and when you add the element of disability it becomes all the more transgressive to teach about LGBTQ issues, and makes it even more difficult to do research on these topics.

Disability Vantage Points as Catalyst for Social Change

The final section of the article concerns a concept that I term “vantage points;” the idea that having a disability affords one a unique viewpoint when writing about and researching disability. In Sheldon (2014), I contextualized my final project for my Special Education degree by discussing my own history of attempting to access disability accommodations and how this motivated my own work in the area of universal design. The goal of the project was to utilize principles of universal design in order to create a framework for a classroom that minimized the need for individual accommodations and then to teach this framework to math teachers and to reflect on this process of teaching in order to revise the workshop. In this project, I explained this as follows:

This vantage point [of a person with a disability] is key for this present project – as I have both seen the system from the point of view of someone with a disability attempting to access services but also from the point of view of a special education teacher who’s had to evaluate students for services. I’ve seen, too, how the labeling that might be so useful to get an accommodation on the college level can be very detrimental to a student in their earlier years. And how the paradigm of special education often prevents us from making the very changes we need in K-12 education; much like how the paradigm of accommodations in higher education creates a band-aid that keeps paradigms like universal design from taking hold in higher education classrooms.

I want to propose, therefore, that disabled researchers need to use their subjectivity, their view of looking at the world, as a catalyst for transforming the experiences of other people with disabilities. As I mentioned previously, this is not a simple relationship; it requires thought, historicization, deconstruction, and exploration of both one’s own identity and the identities of others.

It also requires careful attention to the way in which we treat those that we work with; the goal is not to take advantage of others in order to write our dissertation or our book, but rather, to find a way to better their lives in the moment, even if all we do is listen and create a space to affirm their stories.

In the next section, I address some potential problems with this theory of vantage points, looking at the ways in which it might reify fixed identities.

Problematizing Vantage Points

This discussion of vantage points needs to be nuanced. Non-disabled researchers can still produce research that challenges ableism, much like how heterosexual researchers can still produce research that challenges heteronormativity. Allen (2010), while conceding the importance of a researcher's biography to the knowledge they produce, asks us to "'play' with the suggestion that who we are does not determine which knowledge we produce." (p. 161). Queer theory's questioning of stable identities applies here; "shatter[ing] the idea that some accounts are inherently more authoritative and accurate than others" (McDonald, 2013, p. 133).

Keeping in mind (as I discussed earlier) the ways in which non-disabled researchers are privileged within academia, I propose that they still have something important to contribute in the study of disability. My argument for creating a space for disabled researchers within the field of education is not an argument that the "temporarily able-bodied" (and able-minded) researchers should never contribute to the discourse around disability. Rather, it is more about the able-bodied/minded being willing to lift up voices of researchers who are marginalized within the discourse, to offer financial support and mentorship to those who are underprivileged within the academy. In doing so, we must remember that power dynamics are "fluid and constantly being (re)negotiated" (McDonald, 2013, p. 133) and that we cannot see oppression as a static entity. Much as we can shift between ability and disability as we move between contexts and through time, so can the nature of power dynamics in academia; we need to become aware of these and seek to make structural challenges, but the goal is not to "call out" particular able-bodied researchers but rather to change the structural relationships within the academy.

Summarizing the Implications for Researchers

In this section of the paper, I offer a brief summary of the concrete implications of the ideas in this paper for researchers doing research about disability.

Summarizing the Implications for Disabled Researchers

When doing research as a disabled person studying disabled subjects, it is important to consider your own identity and how it influences your research process. Research should have catalytic validity and be a transformative process for participants, but it must also have autocatalytic validity and be a transformative process for yourself by challenging, questioning, and problematizing your own identity and experiences. Simply studying your own disability does not give you a magic insight into the experiences of others, and likewise, to tell your own story requires engaging with others' experiences in order to understand your own, to move from mere autobiography into critically reflexive autoethnography.

Summarizing the Implications for Non-Disabled Researchers

When a researcher who does not identify as having a disability is studying disability, it is still important to have self-reflexivity. One can still tell their own story, although it is important to make sure that stories of able-bodied people do not overshadow that of people with disabilities; you can tell the narrative of how you came to know about disability, but this requires a critical engagement with those who do identify as disabled and face discrimination and challenges due to this identification. Research should be designed in such a way that it creates transformative experiences for those with disabilities, and likewise, creates paradigmatic shifts within the researcher as they encounter the stories and experiences of those

with disabilities. Ultimately, researchers that are “non-disabled” should come to realize how their own identity is fluid, not just in terms of ability, but in terms of the many axes that form their identity.

A Concluding Note

I have been working on the theoretical framework for a queer research methodology for many years, and have worked in Special Education for the past decade, but this project is the first time that I have brought together my interest in queer methodology with my interest in disability. This project has been one of significant autocatalytic validity, in that I have had to reflect both on my own experience of identity and how it has affected my research process. I hope that what I have offered here is of use to other researchers in reflecting on their practice, of interest to disabled people who choose to participate in research, to those seeking to improve their educational practice with those with disabilities, and to consumers and funders of research. In doing so, we can move from merely asserting “Nothing about us without us” to becoming our own producers of knowledge and research practice and create rigorous, reflexive, and quality-filled research that brings our selves, both disabled and non-disabled, into our research practice.

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