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Reflections of a community-based participatory researcher from the intersection of disability advocacy, engineering, and the academy

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Abstract

This article uses an evocative autoethnographic approach to explore the experience of being an insider-researcher in a community-based participatory research setting. Taking a holistic perspective and using the form of narrative story-telling, I examine the dynamics between the typically marginalizing (but sometimes empowering) experience of being an autistic woman and the typically privileging (but sometimes oppressive) experience of being an engineering professional, during a time of career upheaval. Themes of motivations and mentors, adversity from social services and the academy, belonging, the slipperiness of intersectional positioning, feedback cycles of opportunity, dichotomies of competence and inadequacy, heightened stakes, and power and resistance are explored through the narrative. While primarily leaving the narrative to speak for itself per the qualitative approach taken, the article concludes with a discussion of how the personal experiences described relate both to the broader work of insider-researchers within disability-related fields, and to misconceptions about self-reflection and capacity for story-telling in individuals on the autism spectrum.

Keywords

Autoethnography; insider-researcher; community-based participatory research; critical systems thinking; autism; intersectionality

Introduction and methods

It's winter, 2015, and my dissertation manuscript is complete sans this article, which is to be an evocative autoethnography (Ellis, Adams, & Bochner, 2011; Ellis & Bochner, 2006) reflecting on, and analyzing, my experience as an “insider-researcher” in a community-based participatory research (CBPR) group. I'd forgotten, until a committee member reminded me today, that I am a student. I am – of course I am – I'm working on my dissertation manuscript. But how could a thin, transient identity like “student” compete with

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the blaring lighthouse-glare of the rest of me? I've filled senior engineering roles for two decades, worked as an academic scientist for one, and been an autistic woman¹ my whole life. Plus, I'm fixated right now on that very crossroads of scientist/self-advocate/engineer because it's the experience I'm exploring in this article. What is the experience like? What does it mean to me? What might it mean for others similarly positioned, as well as for CBPR researchers, or for individuals on the autism spectrum, more broadly?

It is from this crossroads of advocacy, engineering, and the academy that I co-direct a CBPR group, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE). I co-founded AASPIRE from the community side nine years ago, angry about how poorly autism and autistic people are represented in research, angry about oppression in my own life, and wanting to leverage science for social change. But my positioning is complex. With my MS in systems science, current career in academic research, and previous career in software engineering, I also exist as a part of the academy and am used to the relative respect and privilege afforded senior technology professionals – even if they happen to be female and disabled. As I work deeper into my doctorate and deeper into the academy, these intersections of marginalization and privilege shift, dance, and, at times, assault each other.

My dissertation topic is on building an interactive web site with the autistic community using a hybrid critical systems thinking (Flood & Jackson, 1991) and CBPR (Israel et al., 2003) approach. Both of these approaches to inquiry draw heavily on critical theory and are philosophically and pragmatically rooted in concerns of power, resistance, and emancipation (Flood & Jackson, 1991; Minkler & Wallerstein, 2003). Therefore, engaging in critical self-reflection, exploring non-reductive/holistic methods of analysis, and challenging dominant discourse are key components of my work. Of holism from within the context of critical systems thinking, Jackson writes, “Holism puts the study of wholes before that of the parts. It does not, therefore, try to break organizations, or other entities, down into parts in order to understand them . . . (Jackson, 2006)” On intersectionality, Hulko writes,

Researching and writing about intersectionality and interlocking oppressions often require a blurring of any remaining lines of distinction between the personal and the professional because identity, oppression, and privilege are not solely abstract concepts; they have real, complex, and often-disputed meanings in our daily lives. Moreover, it can be difficult to comprehend what these meanings may be and the dialectical relationship between the personal and the political from a purely structural level analysis. Consequently, feminist, antiracist, and disabilities scholars have urged researchers and practitioners to engage in explorations of the subjective realm of oppression to gain a better understanding of the personal impact of structural relations of domination.

(Hulko, 2009)

Regarding autoethnography (Ellis et al., 2011), the method of holistic inquiry with which I have chosen to explore my intersectionality, Ellis writes in a dialogue with a friend,

¹I use identity first language (autistic person) in this article rather than person first language (person with autism) because being on the autism spectrum both an important part of my identity and the chosen language of the autistic community. See Sinclair (1999) for a detailed rationale.

Autoethnography shows struggle, passion, embodied life, and the collaborative creation of sense making in situations in which people have to cope with dire circumstances and loss of meaning. Autoethnography wants the reader to care, to feel, to empathize, and to do something, to act . . .

and

Instead of being obsessively focused on questions of how we know, which inevitably leads to a preference for analysis and generalization, autoethnography centers attention on how we should live and brings us into lived experiences in a feeling and embodied way . . . We take people into these ethical domains through story, characters, emotion, and dramatic and narrative plot.

(Ellis & Bochner, 2006)

In that winter of 2015, completing my dissertation, I re-read my PhD research log, which spanned January 2012 through January 2015. Copying the reflexive passages into a separate document, I rearranged them under themes. I thought about the events of my dissertation work, and about the events that got me to those events. I paired the themes from my reflections with the events of my life and began writing this narrative, modifying identifying details to protect confidentiality where needed. Although presented somewhat linearly through time and organized under themes, the lived experience itself can only be understood non-reductively, as a whole. Themes simultaneously influence each other much as the personal and the universal, the political and the scientific, and the intersection of privilege and marginalization; the whole is a restless dynamic.

After I completed the analysis, I shared my findings with the AASPIRE research team and with four similarly intersectional researchers for member checking and verification (Rossman & Marshall, 2010). Not only did they triangulate my experiences, they brought up other ways in which intersectionality has played a similar role in their lives along lines of ethnicity, sexuality, and belonging to a religious minority. While my experiences are uniquely mine, the broader themes and narratives may have transferability to other settings. Those themes uncovered were motivations and mentors, adversity from social services and the academy, belonging, the slipperiness of intersectional positioning, feedback cycles of opportunity, dichotomies of competence and inadequacy, heightened stakes, and power and resistance. While primarily leaving the narrative to speak for itself per the qualitative approach taken, I found my personal experiences related both to the broader work of insider-researchers within disability-related fields and to misconceptions about self-reflection and capacity for story-telling in individuals on the autism spectrum.

Motivations and mentors

Winter, 1986. It's Maine, so it's cold. The ground is so frozen that they have to stash the dead in crypts until the spring thaw, and that won't come till April. I'm on the floor again, knees tucked under me as a stack of books slough over. Index cards scatter, unnoticed, my disorderly attempt to conform to the teacher's instructions long-abandoned; keeping track of a chaos of index cards is more work than an entire research paper four times over. Do the

real work first, then make it look like I did what the teacher wanted after the paper is written. Hide the evidence that I just can't do anything the normal way.

The Underground Railroad. Civil Rights in America. Segregation in the 60 s. I thread through the story of oppression and resistance as though it were my own. Which is ridiculous, I'm a white, Italian-American from a recently-immigrated family; there's no reason for it to resonate. Yet in my bedroom, a half-assembled robot and a Commodore 64 co-exist with the Civil Rights movement. Cool mathematics and flaming social justice. Private rebellions and mental malfunctions. "Am I strong to live with these difficulties I have, or am I weak to have them at all?" I trace the question with obsessive precision in my journals beside suicide dreams and blueprints for systems change.

Passion keeps me going most days, but when it's not enough I continue on because of Mrs G, the English teacher who taught me how to write, and Miss W, the history teacher who yells, "IT ALL INTERRELATES," isn't allowed in Congress because of past civil disobedience, and slips me *Anatomy of a Revolution* (Brinton, 1965) on the side. Mrs G and Miss W don't care if I use index cards when I write my research papers. They care that I learn something. Their caring makes me cry. I do not want to let them down.

Some days mentors aren't enough either. Glass breaks, the world fragments, the shrapnel of peer-abuse and functional impairment piles into a rage of self-hate, and nothing makes sense. There are no anchors here. Always too loud, too bright, eyes and mouths I don't recognize, and no matter what I do it's never the right thing –and I never know why. Senses scrambled. Word salad. Communication disconnect, static on the radio. Some days I can keep organized within the mess; other days I can't. I'm labeled "disturbed," but no one knows why.

Winter, 2014. It's Oregon, so it's raining. The ground is so wet it can steal your boot. I'm on the floor again, knees tucked under me as I try to extract the book I want without toppling the stack. *Power/Knowledge* (Foucault, 1980). *Disability and the Internet* (Jaeger, 2011). *Critical Systems Thinking* (Flood & Jackson, 1991). Social justice stacked beside books on programming languages, dynamical systems, and fuzzy logic – plus a healthy collection of robot parts. My passion for narratives of oppression and resistance makes sense to me now; doesn't matter how white or educated I am, I don't pass for non-disabled any more than I pass for a man. Being different makes me marginalized, especially in male-dominated engineering fields. Being marginalized makes me angry. Anger I can channel into social justice.

Or self-destruction.

I am savvy about self-destruction too these days. When hope isn't enough hate will have to do. They both get the job of systems change done. For the past three years, I've combined my dual passion for engineering and social justice into building an interactive online healthcare tool kit for autistic adults, supporters, and healthcare providers (AASPIRE, 2014). There are still no anchors in my sense-scrambled world, but at least now I have a diagnostic term – autism – for why I fail at basic things.

Other days neither hope nor hate is enough, so I continue on because of Christina N., Katie MD, and Laurie P. They are my friends, peers, mentors, challengers, and champions. They have given me opportunities I must honor. I would not be on the floor working on my dissertation without them, nor would I have gotten the education that enabled me to write in my reflexive journal the previous autumn,

Midgely's sacred and profane systems boundaries (Midgley, 1992) is really interesting for this paper too, since my intersectionality places me in both the sacred and profane categories simultaneously. What comes of the margins when one occupies space in the entire system?

Adversity from social services and the academy

Winter, 2008. I am desperate for work. I'd let myself be lulled into a false sense of privilege. I thought I could have a house and a future and a modicum of respect; the delusion came easily during my decade as a senior engineer. I was in charge of a department, responsible for the company's internal information systems, respected, gifted with a beefy paycheck. Of course, the fantasy fell apart when my office moved five miles south because difficulty coping with change one of the criteria that can define autism (American Psychiatric Association, 2013). Now the loss of my daily routine has taken with it most of my functional speech and I can't find all the rooms in my house, but I've been denied disability benefits because I can bend and lift and have a work history. Naturally, I can clean toilets along with the rest of my kind.

Except I can't. Cleaning toilets, like most "simple" things, is something I've never been able to manage.

So what can I manage? I can program computers. I can write well. I can learn almost anything that doesn't involve navigating the sensory world. I'm clever with science, particularly in nonlinear or "wicked problem" (Churchman, 1967) areas that don't yield well to traditional analytical methods, such as human-computer interaction, process analysis, and communications. I need a career that builds on my engineering skills, gives me control over my schedule and environment, and is willing to ignore the double-whammy of sex and disability. In 2010 and 2011, white women comprised only 18% of scientists and engineers, women more generally only 15% of engineers and 23% of computer scientists, and, in addition to experiencing higher rates of unemployment, only 65% of scientists and engineers with a disability were employed compared with 83% of non-disabled peers (National Science Foundation, 2013). Perhaps I could do something in academic research?

I think my posse of social workers would be happier with the toilet-cleaning plan.

I sit with my mouth shut, eyes on the spaces between the tiles, as they tell me I am expensive and difficult, and roll their eyes in joint sympathy over having to endure me. But my Individual Employment Plan includes a master's degree in Systems Science with a focus in computational intelligence and modeling, which I've nearly completed. It's clear that they are not going to help me find a job. Anything I can do is so outside of what they understand

that they don't even know how to start. My past professional privilege bites me on the throat again.

I find a researcher working with assistive devices for autistic people.

"Why would I want to talk to people with autism about my work?" She asks without irony.

I swallow my feelings and reply. "Well, first because it's important to involve end-users in technology development," (Adam & Kreps, 2009; Brajnik, Yesilada, & Harper, 2011; Federici et al., 2005; Friedman & Bryen, 2007; Jaeger, 2008; Kelly et al., 2009; Kennedy, Evans, & Thomas, 2011; Mirchandani, 2003) I say, "but second, I'm not coming to you as a 'person with autism' but as an engineer with relevant expertise looking for a research internship. My lived experience is simply added value."

A long, uncomprehending stare.

I find another researcher, and this one wants me! She wants me to apply cutting-edge technology to problems of accessibility. Yes!

A month idles by. I remind, "You're paying me. I have a wide range of skills, programming, databases, user interface design, technical communications –"

"Check this research assistant's paperwork for mistakes."

I'm disappointed there's no technology component, but at least it's something to do. I finish fast, it's a trivial task.

"Actually, I don't need you right now," the researcher confesses. "Perhaps you can help my colleague make her web site more accessible."

"Sure, that's one of my specialties." A week later, I present my assessment of the changes needed for the site to meet minimum accessibility standards.

The client says, "No."

"No?"

"The navigation and layout stuff is great, but leave the text alone."

"I'm not recommending we modify the text of the legal documents. Just supplement them with lay-language summaries."

"No."

"But the purpose of the site is to help people obtain assistive devices. They can't do that when the information is at a post-graduate reading level and the concepts completely abstract. You're shutting out the very people you're trying to benefit!"

"Good bye."

Maybe I am setting my sights too high. Maybe I am letting the privilege I once enjoyed get in the way of whatever dues I need to pay to the academy before it will have me. “I will do this work you need without pay,” I offer to another researcher.

He accepts, and is thrilled with my product.

“Maybe you could pay me for future projects?” I whisper.

He coughs around the offense I have just given. “You’re an autistic self-advocate, not a member of my research team. Paying you would be unethical.”

“But,” he adds, “feel free to continue to volunteer.”

I stare down the barrel of a group home. No money for the mortgage. Freedom lost.

Belonging

Fall, 2009.

“We got the OCTRI grant!”

I co-founded AASPIRE in 2006 because of social justice, writ large. Not everything about the crisis that cost me my engineering job was bad; it encouraged me to connect with the large, international community of autistic people. For the first time, I met others who knew the dissonance of feeling stupid and smart at the same time. Who knew what it was like to experience the world through a whirl of sensory chaos, to be pushed to the margins by ableist oppression – and to delight in and leverage a unique cognitive-sensory experience too. I learned about the autistic civil rights movement through writings in online community resources like Baggs (2005):

Self-advocacy is fundamentally about *true* equality, respect, and power, and about recognizing and changing the current imbalances in all of those things. Whether it is going through the legal system to close an institution, fighting back physically against intolerable surroundings, talking back to staff, sabotaging the power of staff over the lives of disabled people, being listened to when we communicate in non-standard ways, learning that it’s okay to have a voice and make decisions, or passively resisting the dominance of others over our lives, real self-advocacy will always upset the status quo in some way.

As social workers and academics destroyed my self-confidence, my peers taught me to take back my power.

It was through engagement with the autistic community, too, that I met Christina N. We met to discuss autism research, segued swiftly into how science contributes to oppression, and ended up discussing ways CBPR can address these issues. A form of action research developed within public health, CBPR seeks to create equitable partnerships between marginalized communities and academic institutions to conduct research desired by the community (Israel et al., 2003; Minkler & Wallerstein, 2003; Nicolaidis & Raymaker, 2015). We – Christina N, myself, and founding members from the autistic community – formulated

AASPIRE's mission as science for social justice with the autistic community (Nicolaidis et al., 2011; Raymaker & Nicolaidis, 2013).

But the universal social justice issues experienced by the autistic community are also the personal social justice issues of my daily life. As Hulko pointed out in her earlier quote, the dynamic between identity, oppression, and privilege plays out as messily as anything in the real world (Hulko, 2009). There is no easy delimiter between the personal and the universal, between the political and the scientific. Real lives don't divide so neatly.

AASPIRE was a love-labor, a gamble. It was the safe space I had carved with mentors and peers I trusted where I could belong. It was the one thing I cared about enough to do for free – although it was also my last hope for employment before I passed into the murk of no return.

"We got the OCTRI grant!" Christina N and I jump and clap, giddy, and grinning.

We got funding to collect preliminary data for our healthcare intervention plan. And I got a pay check and an opening into academia as the community principal investigator (PI).

Slipperiness of intersectional positioning

Fall, 2011.

"We got the healthcare toolkit grant!" Another cause for jumping and grinning, this time higher and broader. AASPIRE got its intervention funding; we are going to create an interactive, online toolkit of healthcare resources for adults on the autism spectrum, and I am going to be community PI, project director, and lead web developer. Occupying intersectional space makes me economical – I am self-advocate, scientist, and engineer all-in-one. Academics like working with me as a community voice because I am easy and save time. (Although Katie MD remarks, "I think 'we' like working with you because you are also smart and willing to collaborate (K. E. McDonald, personal communication, 2015);" like any model, story-telling necessarily oversimplifies.)

On the other hand, I am not representative. Sure, I know the sick lurch-and-grind as the social worker blackmails me by withholding my bus pass and I am forced to hand her all my power. But I also know the satisfaction of walking into a room of high-powered professionals and having them listen to, and act upon, my recommendations. I do not know the oppression without the privilege. Which is why AASPIRE includes a whole team of autistic people with different experiences from mine.

As the project opens, those collaborators push back. Who is doing the work? Who made these decisions? Where is the transparency? Why did I not get a say in X?

Comfortable in my autistic identity, my foot in the community, I forget that I am made suspect by my intersection with the professional and scientific. This hurts; I withdraw, unsafe in my own community space.

But really, do I not have the same reaction to people in authority? They have blackmailed me with bus passes, denied me needed services, pushed me into poverty, and dismissed the idea that an autistic person could have anything of value to contribute to a research project.

I unbristle, swallow, and acknowledge I need to re-earn trust in this new context. I reveal: this is the work I do, here is a FAQ, these are the important decisions we make together, and these are the boring, busy, techy decisions that are a waste of your time. I do my job of implementing the team's decisions and recommendations, and take deep breaths into the passage of time where actions can prove the sincerity of words. In a confidential check-in conducted by Katie MD, in spring, 2012, team members overall say they trust the process of working together, enjoy the project, and feel they are contributing at a desired level (McDonald, 2012).

Opportunity begets opportunity (or privilege begets privilege?)

Summer, 2012, I travel to Autreat, one of the autistic community's oldest and biggest cultural events. I've always wanted to go, and this project is what gives me the resources to get there. Friends online become friends at the lunch table; we blow bubbles and I spin and trill in their iridescent fairy-shine. I present on AASPIRE's work and get important feedback about the web site's accessibility. Most importantly, for three days, I am somewhere I belong.

I return and get back to work. I program the web application, work with the AASPIRE team on content and design, and work through the end-user engagement studies to test the intervention's usability and acceptability (Raymaker et al., in press). I write oceans about health and healthcare (AASPIRE, 2014). Christina, N. encourages me to go for my doctorate. The project has given me enough financial stability, and enough of a meaty study with aspects under my direction, to make that possible. I feel the feedback between my community status, my professional background, and these academic opportunities like an unstoppable machine. If I hadn't had professional skills, I wouldn't have been trusted with these project roles; if I hadn't been an autistic person, I wouldn't have been privileged as a co-PI with only a master's degree; if I hadn't been given that first co-PI opportunity, I wouldn't have this project to carve out a section for my dissertation work. One of the basic systems archetypes – a generalized model of nonlinear feedback in a particular class of situations – is “success to the successful” (Senge, 1990). In this model, the more success a person has, the more others perceive them as able to take advantage of opportunities, thus the more opportunities are presented, and the more the person is able to demonstrate their ability to succeed: it is a virtuous cycle. I think uncomfortably about my friends who were never given an opportunity for that initial success.

I pass my comprehensive exams in spring, 2013. My dissertation will consist of three papers on intersections of CBPR, critical systems thinking, and the techier aspects of the toolkit web site development. In order to meet the requirement of at least one sole-authored paper (AASPIRE's CBPR process requires an offer of co-authorship to all partners), I plan to conduct an autoethnography of my experience as an intersectional researcher working on the project. I begin a reflexive journal.

Dichotomies of competency and inadequacy

In spring 2014, my mentors nominate me for the student award from the American Association of Intellectual and Developmental Disabilities, and I receive it. In my reflexive journal I write,

Intersectionally, I co-exist as all of these identities, as a whole person with overlapping facets. But sometimes, the overlays separate and . . . none of the pieces fit. I've won an award for my research but am incapable of executing any of the steps to attend the ceremony to accept it [because of my disabilities]. I'm doing work that should see me involved in a professional organization, but . . . being totally unable to execute any steps to make use of a membership or attend any of the conferences [because of my disabilities], there's little point . . . I haven't been paid since December because my necessarily job-carved world doesn't fit with what the academic administration can cope with . . . My ability to do anything besides the core of the research work is dependent utterly on colleagues. On tagging along with them to a conference, on them introducing me to others and facilitating the conversation, on their kindness in hiring me even though, I have no real position, no legitimate claim to the work I do . . . I can manage to succeed at the science, but I can't manage anything that being successful brings with it.

A week later, I add,

But realistically, there's a ton of ways in which my intersectionality makes things hella [lot] easier and stronger than they would have been otherwise. I don't have to go to consultants to check something about the community or about what having an autistic perspective is like. I don't run as much of a risk of making faulty assumptions and erroneous conclusions. In many ways being a member of the community/population of interest removes a degree of bias because I'm not having to work with a mental model of an alien culture/experience. Insider status might introduce some biases like knee-jerk responses about power, but it also relieves other biases like around what the community/population 'should' be like or do. It also helps me to properly contextualize the community/population without having to do a ton of anthropological study. There are tons of benefits.

Someday, maybe, I will have an office in which to hang that award. (At which point, reading an early draft, Katie, MD reminds me I'm a student and students do not get offices, which leads me to acknowledge the entitlement I feel because my first career privileged me with offices, so less is a step back – unlike traditional students who have yet to begin.)

Heightened stakes of success or failure

Winter, 2014. My dataset stares icily. I wish it would give me a hint as to what it contains, some means to brace myself against failure. Back in December, someone in the community called the project "silly," amongst other hurtful things. In my journal, I wrote,

If people don't like something, I listen carefully, ask questions, and then make determinations about whether or not I feel the comment requires action . . . where

that breaks down – but for a different reason [than ego] – is when people within the community reject . . . the work that . . . me and my team actively tried really, really hard to account for. That type of thing hits me hard . . . because I care so much about (1) helping my community and (2) my peers in my research team. It's not just my hard work that's getting thrashed, it's THEIR hard work too. The community side of my work has an entirely different investment in it than the academic/professional sides, and I really struggle there.

Later I wrote, "I sometimes feel like I hide in my academics because I can't cope with what I really care about on the community level." Research results have loaded meanings when acceptance and rejection by one's own community hinges on them. Botching this project could mean loss of social support, friendship, access to the comfort of shared culture and belonging; I've an ethical obligation to report the truth. When I look at the results of the toolkit web site evaluation, will I find vitriol?

Not to mention, I've few sustainable options for a fall-back career. Where else would I go, what else would I do? Back to begging at the feet of academics who see little point in working with someone like me? Back to a corporate office where any change could send me into catatonia again, like when I lost my engineering job because of a minor office move (assuming a corporation would have me)? I can't let down the people who believed in me either, who gave me this opportunity – what if I find I acted irresponsibly with their trust in my skills when no one else would touch me? These data represent the edge between maintaining professional privilege and being pushed further into the margin.

My palms prickle. I run the statistics first. Good, old, friendly quantitative numbers; perhaps my data can give me a hint as to what it contains after all.

Easy to use: 97%. Easy to understand: 95%. Useful: 96%. Would recommend to a friend: 92%. Would recommend to a healthcare provider 95% (Raymaker et al., in press). Deep breath. It's safe to dig deeper.

The qualitative data are spare but encouraging. There is no hate. The suggestions for improvement make sense. In the "anything else you'd like to tell us" box, one person said, "This was a terrific experience. It helped me identify and solidify in my thinking the areas in which I have difficulty. . . . I enjoyed being a part of this study. Thanks for the fun experience." Another said, "I think it is wonderful you are using the community to make your tools better – it is empowering." I am going to be OK.

Power and resistance

Late spring, 2014, I write,

Engaging in the academic system as a peer makes me feel powerful in a way that's never been open to me as an advocate. I can rant all I want about stigmatizing research, about lack of focus on whatever area I care about, etc. And on a policy-level sometimes it does get through a bit, shifting focus here, encouraging someone to include the community in their work there. But that is not the same type of power at all as when I review a paper or a grant proposal, or publish a paper that

gets cited and used in classrooms, or discuss something with a student, and know that what I have done has shifted whether something gets published, funded, or considered by others when s/he goes back out into the world or develops his/her career. It's a top-down vs. bottom-up impact/influence on science. Am I the outsider urging people to change the structure of their system to produce different behavior? Or am I the insider restructuring the system with my own hands . . . ? . . . As an advocate I often leave situations frustrated even if they have been successful, having banged up against the enormity of something that may or may not implement [systems change] in a way that makes a difference. As a scientist I leave the situations satisfied; even if my recommendations are not taken I was a part of a larger process that, for all its flaws, was set up exactly to allow for new voices, new discoveries, and change in the landscape of knowledge . . . As a systems person, I've always felt more comfortable finding and fingering the leverage points myself than asking someone else to influence them for me.

In retrospect, I recognize that it's easier to get things done from the privileged position of a scientist than the marginalized position of a self-advocate.

10 December, 2013, two days before my dissertation proposal defense, I write: "The very act of you doing this research is an act of resistance vs. Foucault's normalizing power (Foucault, 1980). It is a small subversion from within."

10 December, 2014, one year later as I prepare my final manuscript I find that quote next to a photograph of a page from a CBPR textbook: "'Doing research' is not, in itself, a goal. Research is only a method to achieve these broader goals [of systems change]." (Minkler & Wallerstein, 2003, p. 203)

I will be ashamed of neither my marginalization nor my privilege.

May they make the way easier for researchers with disabilities to come.

Broader implications

I have avoided presenting too much explicit analysis of my experience in an effort to both avoid reductionism and to stay true to Ellis' approach to autoethnography as a means to "open up conversations about how people live, rather than close them down with a definitive description and analytical statements about the world as it 'truly' exists (Ellis & Bochner, 2006)," and story-telling as "an 'activity which reveals meaning without committing the error of defining it' (Arendt, 1973, p. 107)" (Ellis & Bochner, 2006). However, there are two broader implications I wish to make explicit. First, this article has connections to the larger body of work examining the experiences of researchers with disabilities in academia. Lack of inclusion of insider perspectives in scientific inquiry has been criticized as presenting significant ethical problems, a situation CBPR aims to address (Israel, Eng, Schulz, & Parker, 2001, 2005; Minkler & Wallerstein, 2003; Oliver, 1992; Raymaker & McDonald, 2013; Raymaker & Nicolaidis, 2013). Disability studies also calls for individuals with disabilities to work within the field (Linton, 1998; Oliver, 1992; Raymaker & McDonald, 2013). However, the topic of insider-researchers is not without dilemmas, such as potential

for harm via the research process itself or by rejection from the larger academy (Mogendorff, 2013; O'toole, 2013; Rinaldi, 2013; Vernon, 1997), or via rejection by one's own disability or advocacy communities. The decision to "out" oneself as a disabled disability researcher (in so much that remaining hidden is avoidable to those of us who do not "pass" or who have established political identities) is a political act in itself which may ultimately shift ableism within the academy (O'toole, 2013). On the other side, being an "out" researcher within a community which is suspicious of researchers may help to build trust toward scientists.

These ideas around insider research and being disabled in academia were echoed by other autistic members of AASPIRE during my member checking. One person stated,

I am also an insider researcher and have considered the benefits and risks . . . I see many benefits but do worry about harm via the research process and rejection by the academy or disability/Autistic community. I have been taken advantage of in academic settings, including from autism researchers, and it's hard to know much is people being assholes or my being particularly vulnerable.

Another recalled how poorly the academy was set up to support graduate students with disabilities,

One thing I really remember from when I was [in graduate school] is that disability services were well equipped to deal with issues that a disabled undergrad might experience but had much less of a clue what to do with a disabled graduate student. They could help with academic stuff, sure, but the things I needed the most help with were all non-academic things, many of which either weren't applicable to undergrads at all (e.g. all of the social stuff with academic conferences and thesis work), or were solvable in other ways for undergrads (e.g. amenities that were available in undergrad dorms but not graduate housing).

I hope that my experience, as well as AASPIRE's longevity and success, reinforces the value of insider-researchers within disability-related fields and contributes to the growing body of work about our experiences. I hope that the risks taken by myself and others of my generation – including by my colleagues in AASPIRE who also walk in both worlds – push that political shift forward.

The second implication is with respect to the characterization of autism as involving impaired capacity for story-telling and self-reflection (e.g. Goldman, 2008; Kennedy, 2006). One of AASPIRE's early attempts to fund the toolkit received the following comment from a reviewer with respect to including autistic people as co-researchers and study participants:

It is assumed that high-functioning individuals on the spectrum have the ability to reflect on their own experience and that they can give a valid assessment of what they need. Yet there are studies which indicate that lack of self-reflection is one of the limitations of those individuals. In short, there is not adequate evidence that the self-reports of individuals on the autism spectrum are valid or reliable.

(Anonymous, 2010)

This notion likely comes from a large body of work led by autism researcher Firth and her students, which postulates that lack of “theory of mind” is at the core of autistic behavior (Firth, 1993) and has permeated the broader social consciousness; for example, one BBC news article titled “People with autism have ‘problem with self-awareness’” states “Sophisticated scans showed the brains of people with autism are less active when engaged in self-reflective thought” and “research has shown the problem is people with the condition have trouble thinking about, and making sense of, themselves” (BBC News, 2009).

Autistic individuals, however, frequently tell a different story. Jim Sinclair (1993) writes,

I have an interface problem, not a core processing problem. I can’t always keep track of what’s happening outside myself, but I’m never out of touch with my core. Even at worst, when I can’t focus and I can’t find my body and I can’t connect to space or time, I still have my own self. That’s how I survive and how I keep growing . . .

This is echoed in the documented lived experience of many of us, and has led to a strong critique of the prevalent literature (Lindsay, 2012). During member checking, one of AASPIRE’s community members remarked,

[lack of capacity for self-reflection] is one of those frustrating assumptions that I keep dealing with. In fact, I think this [reflexive paper] is something that needs to be read by autism researchers precisely because of that. It continues to amaze me how many people who study autism for a living don’t get it, when it comes to things that I’ve not only experienced but commiserated with other autistic people about!

Conceptualizing people on the autism spectrum as incapable of self-reflection is of great concern within the autistic community, because it risks dehumanization or dismissal of our thoughts and opinions. If nothing else, let the fact that my reflexive writing exists at all play some small role in changing that dangerous discourse.

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Biography

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