

Back to Normal? Reclaiming Productive Citizenship - A Familiar Conversation
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Abstract: “I don’t want to be a burden!” is a statement that finds itself at the centre of familiar relationships between social actors as well as in structural relationships that frame disability and normalcy. A mother and daughter respond back, challenging its meaning as a nuanced articulation to demand citizenship rights.

Key Words: motherhood, citizenship, rights

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Introduction

“I don’t want to be a burden!” is a familiar statement woven into evening news headlines, woven into Western cultural representations of normalcy and disability and woven into the intimate spaces spent with family and friends. These words embrace our material positionality and identities as daughter and sons, as academics and everyday persons moving about the contemporary landscape as social agents engaged in meaning making. While “I don’t want to be a burden!” is infused with stinging messages of deficiency and deficit, it is also a far more nuanced articulation that challenges these meanings into a transformative statement demanding rights and respect.

As issues of power and voice are central to any research that attempts to demonstrate how individuals make meaning for themselves, the following has been framed as a conversation between two participants: Alysha (a white, working class woman in her late 20’s engaged in graduate studies) and her mother Monica (white, working class woman in her early 50’s) who negotiate their multiple roles (daughter, academic, parent, woman, persons with disabilities, heterosexual, working-class, etc) to make sense of both state mechanisms designed to “help” persons with disabilities and meanings of “burden.” The narrative below was designed collaboratively with the direct input of the participants who wished to relay the intimacy of their relationship as mother and daughter against structural relationships that frame their voices and agency. They directly respond back, speaking from their positions that do not neatly divide public from private, and academic knowledge from so called “lay wisdom.”

Respecting their input that a conversational/narrative mode might foster more flexibility in comparison to highlighted interview passages, which they felt risked the jettison of context, both contributed to this writing. In turn, this process has shaped how they desired to be presented and represented as knowledgeable subjects rather than objects of knowledge. However pseudonyms have been used to protect their confidentiality.

Writing as narrative is meant to directly address the contentious political and ethical negotiations surrounding issues of power and representation. It is a methodological approach

meant to speak back to Gesa Kirsch's (1999) question, "Whose story is this anyhow?" As Michael Marker (2003) has argued, research is often driven by the ethnographers' "interests" rather than the actual voices and experiences of the participants. What interests the participants can become ignored and silenced. If research is to become an emancipatory practice to fuel social change, listening and respecting how participants choose to contribute and desire to be represented is an opportunity for creative challenge. Research must allow for expression that is unafraid to push past conventions that govern and determine what does or does not count as "truth" or even as "real" research.

Narrative writing is in the same vein as work presented by others such as Carolyn Ellis (1995), who blend autobiography with deeper theoretical issues that link the personal and political, not as separate realms to be entered and exited, but as a seamless motion through the everyday. The personal and the political are intertwined and inseparable, the basis for ethnographic research that challenges traditions of truth that rely on impersonal objectivity to construct authority.

The purpose of generating such deeply personal texts is not to indulge in a "confessional tale" (Van Manen, 1988), nor in a narcissistic moment that only romanticizes and reinforces Western modes of story telling (Kelly, 1997). It is also not a "trick" to erase power inequality between researcher and participant. Narrative is a forum that openly engages and respects voice by challenging the conventions and divides that determine the authenticity of experience and truth.

Narrative

Often communicating via the telephone, the participants begin with a familiar statement:

"I don't want to be a burden!" responds Alysha's mother, Monica, over the telephone. Monica's voice cracks and strains with emotion. It is a response Alysha has heard echoed in academic lectures and works, a response woven into the intimate spaces shared with family and friends. Words that rush out with the pain, words that know worth is measured in I.Q. points and pay checks. Anger boils up in Alysha as thick and clean as steam off soup. She wants to pin it down, wrestle it to the mat, unravel the barbs, to lay out the ideological terrain of hegemonic normalcy and productive citizenship. But the pain disarms her. She fumbles for a speaking voice, fumbles with the impossibility of separating out her multiple selves as a daughter, as a graduate student, as a young, white working class woman struggling to make meaning of her pursuit of middle class credentials. Credentials that make her own disability as a dyslexic look like an ironic joke. "What right do I have to speak up when I 'pass' and look so darn 'normal?'," she thinks. "How can I comfort without being paternalizing? Can I speak in a way that acknowledges our authority, which recognizes the authenticity of our experiences but still respects our differences? How does disability 'interrupt' familiar narratives of mothering and of being a daughter?"

Alysha pauses knowing she cannot "talk school" into Monica's pain. Her roles as daughter and graduate student seem so distant yet inseparable from each other. There is a tension that cannot cut with a single sentence. How could her mother ever be a burden? It does and

doesn't make any sense. Alysha thinks about her mother's struggle to get out of bed in the mornings, to dress, to control both her body and mind in a seamless performance of normalcy. The effort and energy required to demand her humanity never issues a paycheck. She doesn't have a good answer for her. She is disappointed and discouraged with herself. Days later, like a splash of cold water, it hits her: normalcy is an unrecognized productive labor. Calling Monica back, she blurts out, "Okay, I think I got it Mom!"

"Oh really?" Monica replies skeptically.

"Well not the last word on the matter, but I have been doing some thinking. I've been writing down some ideas that maybe you can help me with? Here's what I've got so far: Normalcy as an undervalued and unrecognized labor needs to be foregrounded as the basis of an alternative understanding of productivity in opposition to waged work. It is an important distinction as waged work often informs neo-liberal understandings of citizenship rights that become embedded within policies aimed at offering services for the 'disabled.' These policies, based on an understanding of normalcy as productive, not only construct persons with disabilities against "the good citizen [as] male, white, active, fit and able" (Meekosha & Dowse, 1997, p. 50), but ignore normalcy as embodied effort. This deliberate neglect harmfully separates identities and treats normalcy as a stable and uncontested ideology across time and place, uprooting any material rights-based claim to public space. Although some feminist scholars have made similar arguments regarding women's unpaid domestic work this argument hasn't touched upon the pervasive assumptions of normalcy."

"What policies are you talking about?" Monica replies encouragingly.

"What about the application form you had to fill in for BC disability income assistance (British Columbia Ministry of Human Resources, 2007)? What if we applied Dorothy Smith's (1987) standpoint epistemological approach (which connects seemingly everyday happenings to their larger structural locations) to the application to see how this document embeds constructions of normalcy? I think the institutional practices behind the document ignore the contributions made by people with disabilities who are anything but burdens. I think that the people who keep telling people with disabilities to "make something of their lives" should learn a little humility and stop teaching humiliation."

"Yeah okay. I hate that form. What a piece of crap that thing is!"

"Mother! Such language!" Alysha teases, knowing "crap" is as close as Monica will ever get to actually cussing. She continues:

"Well we both know the Persons with Disabilities Designation Application states its purpose is to:

'Provide information to the ministry about the applicant's physical or mental impairments associated with diagnosed medical conditions relevant to this application for a Person with Disabilities (PWD) designation. The emphasis is on how the medical conditions and impairment affect the Applicant's ability to perform Daily Living

Activities... [and] is not intended to assess employability or vocational abilities. (Persons with Disabilities Designation Application, 2007, p. 6)'

Split into three sections the application consists of questions asking the applicant to describe the impact of their disability upon their lives, the Physician and Assessor Reports. These sections comprise a long survey of diagnostic codes and questions regarding the ability of the applicant to walk unaided, personal hygiene, housework, financial management, fluency in English, questions regarding housework, financial management, capacity to read and write and ability to maintain interpersonal relationships. Only a medical doctor may fill in the Physician Report and only a Registered Psychologist, Nurse, Psychiatric Nurse, Occupational therapist, Physical Therapist or Social Worker may complete the Assessor Report. While the applicant's signature is mandatory, only the questions to which the applicant can respond directly are optional.

Don't you think this medicalizes your relationship with your body? That it is your body doesn't matter! Your experiences are removed and are not even worth mention! But they do not stop there; removing you is also a consumerist relationship. It is the doctor's knowledge that is worth something, heck the form clearly includes rates doctor's charge to fill in the form. Don't you think this assumes a relationship that associates knowledge that matters with waged work?" Alysha storms.

"Okay I know what you're saying but I like the fact the only section I get to fill in is optional. You never know how those doctors or social workers will use what you write. Better to leave it blank. They never listen to anything I have to say anyway. Unless they think it's 'crazy' and then it's all about tinkering with my medication again. Better to say nothing at all," Monica interjects, throwing a curve ball into Alysha's theorizing.

"Yeah, you're right, but Mom, I've got a few more things to say about the form! Can I get back to that?" she whines.

"Fine Ms. Bossy, just remembered who called whom for help!"

"Okay, okay!"

"I was thinking that although the form is clear that it does not intend to use this information to 'assess employability or vocational abilities,' the way it is set up implies the opposite. It implies constructions of productive citizenship and hegemonic normalcy. Merely filling in the form implies an assessment of employability because approval is hinged upon a specific examination of daily living activities to determine the 'authenticity of one's 'inability' to engage in waged labor.

Heck, the categories used to measure disability (ability to walk unaided, maintaining personal hygiene... etc) based on a definition of disability as '... [a] severe mental or physical impairment that [in] the opinion of a medical practitioner is likely to continue for at least 2 years, and significantly restricts the person's ability to perform daily living activities...' are way too similar to language used in job wanted ads. For example the form reads:

‘For each item indicate to what degree the applicant’s mental impairment or brain injury restricts or impacts his/her functioning. Emotion, Impulse control, Insight and judgment, attention/concentration and executive skills (e.g., planning, organizing, sequencing, abstract thinking, problem-solving, calculations’ (Persons with Disabilities Designation Application, 2007, p. 16).

The same emphasis on an ability to concentrate, control emotion and apply insight and judgment are echoed get picked up in employment descriptions:

‘The successful candidate will provide administrative support to a team of Corporate Finance professionals in a fast paced and dynamic atmosphere. A positive, flexible “can do” attitude and excellent interpersonal and communications skills are required. Your attention to detail and your ability to prioritize and adapt to changing demands and pressures, in order to meet deadlines, will be essential to your success’ (David Alpin Recruiting, 2007).

Don’t you think it funny that the form concentrates so hard on proving if you can work or not, it ignores that the form provides jobs for other people who are often non-disabled? Remember you telling me how you needed to call a taxi to get to your appointment because you found it too far to walk with your brace? Funny how the form does not leave room for how you employed the taxi driver, or leaves out how the form needs to employ people to publish, print and distribute it. I think that is really ironic that the only income that seems to be supported is anyone but the person who actually has to apply. It’s like Sunny Taylor was saying (2004, p. 5), ‘People with disabilities are worth more to the Gross Domestic Product when occupying a bed in an institution than when they’re living in their own homes.’

I’m also a bit annoyed at how the form used impairment and disability interchangeably. Seems like the only embodiment that matters is a one that produces something for a wage. Thinking and feeling do not even register. It is like it is trying to divide body and mind, to say they do not have any relationship to each other. As if disability is only what you can see! What about the disabilities that do not photograph? Heck, all this medical jargon totally ignores that people live in a social world where meaning gets made. It individualizes disability as an experience and feminizes it by pushing it into private spaces like the home. So although you have to run around, really work at getting the form filled in, this gets completely ignored! You become the burden!

I think dividing people up like this into disabled verses non-disabled is hurtful for all of us. It ignores how we all have to labor to appear ‘normal.’ Just like Marilyn Waring (1988) argued about women’s unpaid domestic work that the economy would collapse without it or if people started paying for it, what if we all gave up trying to be ‘normal?’ How come this work does not count? Telling someone they cannot have full rights because they are disabled means the whole idea of having rights is based on rejecting how we really live our lives. It denies many activities we have to engage in everyday.

We really have to start thinking about how normalcy and history share the same history which has an impact on what's happening right now. For instance we know Canada has a history of settlement and displacement. We know that this has had a huge impact on how business is done and who gets to do it. But what about looking at how normalcy is part of this? I mean isn't the idea of colonization based on establishing rules about the normal way to go about doing things, about establishing a normal way to be in the world? Like L. J. Davis' (1995, pp. 26-27) was saying normalcy is a way quite literally of seeing the world that justifies invasion as objective, through morality and scientifically driven Darwinistic assumptions of survival and evolution: 'The average man, the body of the man in the middle, becomes the exemplar of the middle way of life.'

Normalcy as productive gets ignored cause it places itself as the centre from which activity gets defined. Again, like Davis was saying, "'The average man, the body of the man in the middle, becomes the exemplar of the middle way of life' or the basis for an ideological 'hegemony of the middle' that naturalizes middle-class understandings of nation, modernity, masculinity, health and sexuality; it 'justif[ies] the notion of a norm.'"

Alysha stops, listening for a response on the other end of the line eager for Monica's thoughts.

"Well, what do you think, Mom? ... Mom?"

"Huh? What? You done yet? Sorry dear, I was half watching something on TV. Yeah, yeah, I get it. Disability is a job. But nobody sees it this way, cause the world, okay the *Western* world, is too busy being normal in way that makes it not matter, makes it invisible, which means people with disabilities get read as doing nothing. Why do you gotta be so longwinded?" says Monica, slightly annoyed with Alysha's love of words and tendency to sound like an encyclopedia, yet is also deeply proud of her girl, a girl most figured would never see the inside of a university.

"But I was getting into trying to explain what you were talking about with the doctor not being interesting in anything you had to say unless it was crazy" Alysha pouts.

"Alright, alright! Let's hear it," Monica encourages, only slightly hoping Alysha would contain herself to the commercial breaks.

Alysha continuing (or is it carries on?):

"Like you were getting at, if you try to say that just because you don't have a job, it doesn't been you don't contribute, you can get pathologized through medical language as 'crazy.' A doctor is more likely to examine your head than examine history or how nations are built or busted. It's like this other person I was reading, Himani Bannerji (2003), says colonization really never leaves Europe cause it's about trying to find itself. It measures everything against itself. You only get to be a full human being depending on how closely you can literally measure up to some concept of Europe. Normalcy, backed up by colonial ideas about who is or isn't a human being, becomes objective knowledge that doctors can use to

determine your credibility. You go in there, shooting down the whole idea of what's normal and what's not, more than a few eyebrows get raised.

But we can't give up on trying to reclaim the idea of productive citizenship or challenging those ideas that give power strength. These ideas are deeper than what it means to have a disability but are about how you get positioned in the world. Hence who is disabled and who isn't has deeper meanings than who's normal and who isn't. It's about a set a privileges that locate everybody. That's why I think you can't call people with disabilities unproductive but are some of the hardest working citizens we have. It's people with disabilities helping out those without disabilities, not the other way around.

But as a strategy, although I'd love to see the look on your doctor's face if you told him that you were going to start charging for your services, we'd have to convince him normalcy isn't doing him any favors either. We'd have to point out the ways it confines who he is and how he can express himself. We'd have to show that people with disabilities demanding their rights isn't about a special interest group but is the ways in which we are all interconnected and depend on each other. It's about acknowledging all those multiple roles and labors we navigate just to get through a day."

"Okay that's a nice idea on paper but hard when I need those benefits to live on and need my doctor to fill in the form. As much as I'd love to tell my doctor to start writing me cheques, I don't think he'd be impressed" replies Monica, further challenging Alysha's book smarts.

"Yeah, okay you're right," responds Alysha, thinking about it and having to agree.

"But," Monica continues and Alysha can almost see her slow grin, "I didn't think about how I give other people jobs. The next time some one tells me to get a job; I'll tell them I create jobs instead."

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