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# Clear margins: a portrait of allies - A dialogue and a map

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## Abstract

This writing and art explore the intersections between visible and invisible disability, between cancer and depression, and between a parent and child. As an advocate of inclusive education, the author has begun to trouble their own assumptions concerning practices of Universal Design, which had been based on the adage that “what is necessary for some is good for all.” Tensions between the needs of the few and the good of the many have arisen for the author as an educator, activist, and researcher. Creative non-fiction of personal life experience and artistic play are used here to find analogous ways of approaching these professional tensions. A relational word game is used to unmake a phrenological map, along with assumptions about competence that this diagram represents. By employing dialogue between reality and aspiration, and creating the conditions for serendipity, the author aims to move beyond the binaries of giving and receiving when it comes to care, inclusion, and conflicting needs.

Keywords: cancer, depression, ally, phrenology, inclusion, play

Like many art education scholars (Blandy, 1999; Keifer-Boyd & Kraft, 2003; Wexler, 2019), I am interested in Universal Design as a method of supporting inclusion in art classrooms. My teacher education taught me that Universal Design means providing supports that are “necessary for some, and good for all” (Ontario Ministry of Education, 2013, p. 33). However, I have recently been struck by the question: what if the needs of some are not good for others?

This question has arisen in my teaching practice, equity work, and research. Students come to teachers with many conflicting needs: stimulation versus silence, structure versus flexibility, independence versus support, and so on. In activist discussions, I see that demographic information is a powerful advocacy tool for people of colour, while the visibility required by demographics can endanger the employment and safety of transgender people and the invisibly disabled. Hamraie’s (2017) scholarship relates a productive dialogue between the conflicting needs of wheelchair users and visually impaired people. In the current writing, I take up the microcosm of my relationship with my mother as an entry point to these issues. In particular, I examine the experience of supporting my mother’s recovery from cancer during a relapse of my depression. I investigate how we moved through needs together.

The following section is a creative, non-fictional account of taking care of my mother, through my own need for support. This story is interspersed with italicized quotes from Anne Bishop’s (1994) *Becoming an Ally*. The result is a dialogue between my reality at that time, and my aspirational self. The final section of this essay returns to the question of conflicting needs, by way of a discussion of the artistic portion of this project.

### **Dialogue Over Lunch**

“Oh,” she says, “Do you have a health problem?” This question is embarrassing. The speaker, my mother, is being treated for cancer.

She sounds relieved when I say “Just depression.” Every time this comes up it’s like we’ve never talked about it. A Jedi mind trick: this is not the

dysfunction you are looking for.

*There seems to be a cycle of envy between visible and invisible oppressed groups. The visible resent the ability of the invisible to blend in with the mainstream ... the invisible envy [the] visible ... because they can find each other ... (Bishop, 1994, p. 79)*

For months I have been under it: “I can’t... *this*... again.” I really think I can’t, but I will. I do. Surviving depression becomes my job. Slow motion decisions. Like filling a bath tub with an eye dropper. I command myself: get dressed. How can that take two hours? Don’t judge; that makes it worse. Remember when these things were automatic. They will be again. Just wait. Talk to your mother.

*Try not to look to the oppressed group for emotional support. ... Their energy is needed for their own struggle. (p. 118)*

Since the surgery, she can’t raise her arms. She says this is hard on her husband, gets up from the table and moves toward the coffee pot.

“Don’t lift that.” I block her. “I’ll get it.”

“It’s not heavy.” Her smile is a squint. “It’s fine.” But she lets me pour her cup. “I’m fine.” And sits back down.

“If you’re gonna get sick, get cancer in Nova Scotia.” She said that to guests last week without a hint of sarcasm. “Such great care.”

But feeling flashes through pragmatism when the two of us are alone. Deep breaths through detail talk. We scour the medical report. “Incidental” is good; “atypical” is bad. Couldn’t they use another word for “invasive?” We have to look up “hyperplasia,” but we don’t speak the definition: “fast growing.”

*Support the process of unlearning oppression with other members of your own group. Do not usurp the role of communicating the experience of the oppression; that one belongs only to members of the oppressed group. (p.118)*

Five years ago, a nurse told me not to worry so much about anti-depressants. He stops his own whenever he feels better; it's not a big commitment. In the same office a doctor said that unmanaged withdrawal can cause brain damage. Three years on a waitlist brought me to a psychiatrist who said my sexual orientation is "acting out behaviour." Should I call this care?

More recently a psychologist told me to "accept depression as part of who you are." I protested. I am not a disorder; I have been invaded. She countered: "People who accept their condition don't fall as hard when they relapse." This is the first time I've heard that. It spooks me. Of course a turn is gentler if you expect it. But isn't that an invitation? An open door for the grim return. I want the opposite. Lock it out. I'm a sucker for external cues though. Is that peer-reviewed? Give me statistics, or anything to go on. Only please don't let me be a disorder.

*When we work to change these cultural oppressions, many of our tactics are ideological or cultural. They are aimed at ending shame and developing pride in those who have internalized the understanding that they have a lower value than another group.*  
(p. 82)

Can you have breast cancer without breasts? We'll know in a month. A lab technician will inspect her severed tissue and wait for cells to grow. If the sliced edges are "healthy," we'll know the surgeon got it all. That's called "clear margins." Last time the margins were "close." A millimetre and a half between lump and knife is not enough. That's when she told the doctor to take them both. Afterward, in an attempt to reassure her, a specialist called her cancer "insignificant." My mother's back was board-straight when she said, "then why am I sitting here with no breasts?"

"The worst part is the fear," she tells me now. Chemo possibilities ghost across glassy eyes. I brace myself for the visceral shut down that happens to me when my mother cries, but she doesn't. She closes her eyes and breathes in. "Having my breasts off is not bad." Eyes open, exhale, "Not yet." I don't understand but I squeeze her fingers. My usual resistance to

contact is suspended. I'm drawn in. I put my hand on her shoulder walking by, rest my fingers on her forearm while we talk. I can't stop touching her. *She's still here.*

Last week the nurse told her "you're a candidate for plastic surgery." She doesn't want it. "That won't be me," she says, "It would be like this never happened." Still, she wants to know how it will look when the bandages come off.

"I went to adjust myself," she says, "but I wasn't there. It's not bad." Hands against concave chest. "I'm just not here."

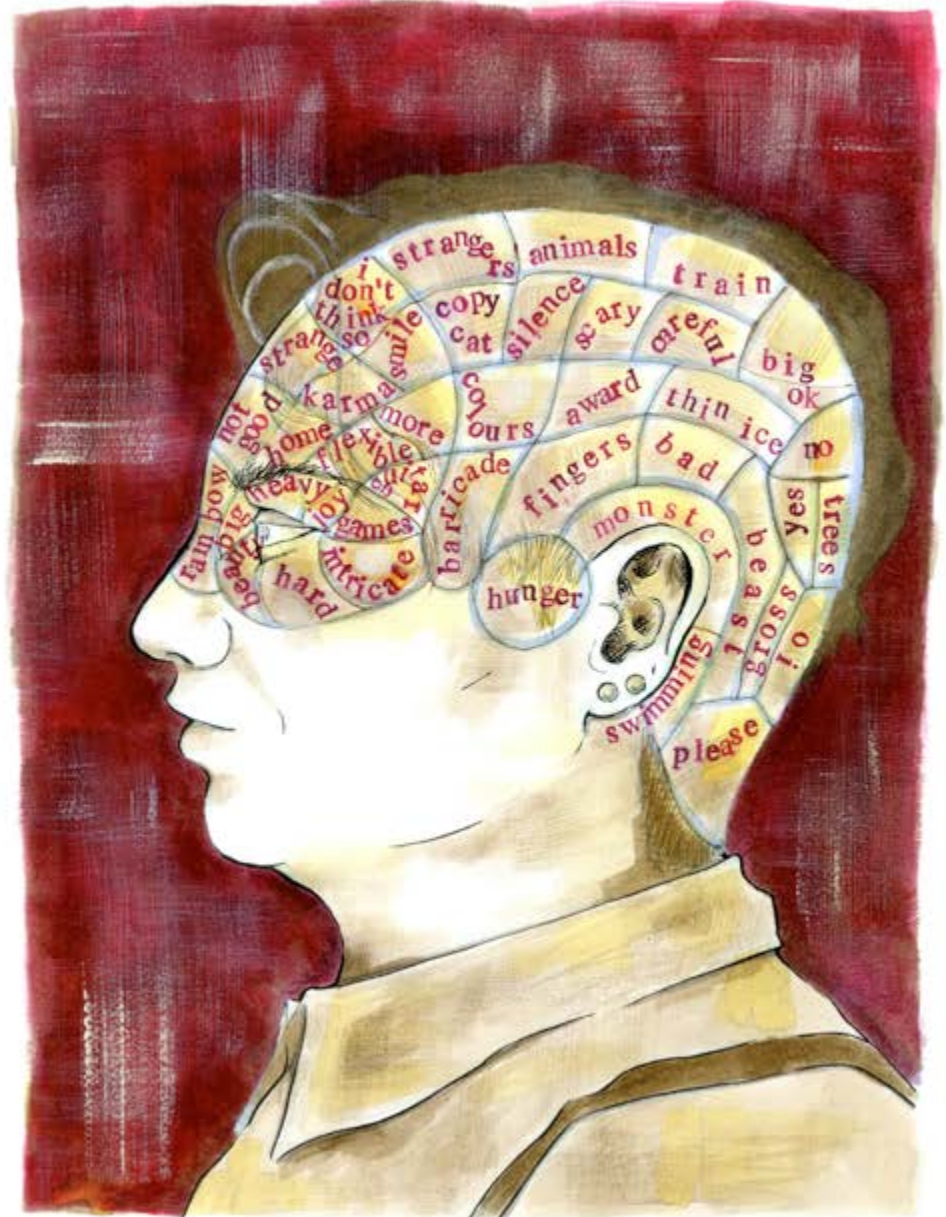
*People change. Sometimes the process involves two steps forward, one step back, or even two back, but people do change and heal and grow. People change individually and collectively... (p. 146)*

Out of nowhere an image cuts through my awareness. I can't name it. I won't describe it either. This thought-picture tells me both: "I need to feel," and "I need to never feel again." I shut it down. Unseeing my own death is where all my energy goes these days. But this will lift. Eventually depression *lifts*. Do I really have to eat though? Yes. And take positive self-talk like Aspirin. Those thoughts are symptoms. Don't believe them. False alarms make real noises. It'll be ok. Just chew and swallow.

"But how are you?" She flips the conversation back to me. Did I let the *something* cross my face? In any case, it's not my mother's custom to be the centre of things. When she called with the news, she let me talk for twenty minutes before telling me she was tested and that they found "a few, very small cells, that are cancerous."

I say, "I don't want to talk about me right now." Did that sound sharp? Be gentle. She's trying to connect. My smile is her squint. I'm afraid I'll cry if she's kind. Am I capable of connection?

*It is important to be a worker in your own liberation struggle, whatever it is. Learn, reflect on, and understand the patterns and effects of oppression, take action with others, take risks...*  
(p. 117)



## Map

At nineteen, my mother took a bus through rural Nova Scotia and sat in front of a talkative woman, who claimed to read the future in the shape of people's heads. The fortune teller put her hands on my mother's scalp and, polite to a fault, my mother allowed this. "You will have six children," the woman said. My mother had two, and later married a father of four. That makes six.

She told me this story while I stayed with her during her cancer recovery. There had been a painful disconnection between us until we spent that time together. But something transcendent occurred at the intersection of my mother's cancer and my depression. Where we both had needs, it was giving to each other that moved us forward. Sharing stories was part of that bonding.

My mother's bus story involves a discredited, nineteenth-century pseudoscience called phrenology that connects the shape of skulls to mental traits. Phrenology attributes particular characteristics to "normal" people, and states that those who lack these qualities are lesser, immoral, or dangerous (Vaught, 1902). Historically, this line of thinking has led to the institutionalization of depressive queers, like me, and the complicity of white people, also like me, in prejudice and land theft, with devastating effects on communities of colour. According to art education and disability scholar Jennifer Eisenhauer (2008), phrenological illustrations are part of a larger cultural desire to visually identify, and stigmatize, people who are mentally ill. I appropriate a phrenological map in the images here, using visual play as resistance.

My mother and I are presented as phrenological diagrams, however we are also specific individuals, intimately engaged with each other. We played a word association game, responding to the name of each phrenological category. Our answers replace the original diagram's labels. Comparing the words in analogous locations on the heads of my mother and myself, leads to found poetry. Between the two images, these words make a *necessary rainbow*, the *joy of hunger* (or perhaps the *hunger of joy*), and

other serendipitous phrases. This work maps a movement away from medicalized stigma, toward an invitation to imagine new common ground.

Returning to the question that began these explorations, when we encounter conflict between the needs of some and the good of others, dialogue and play may bring us to unforeseen new ground.

What could it mean, as educators, to offer support from places of vulnerability, and to ask for assistance from those we perceive as disabled? How can play enable relationships that are not defined by binaries of give and take?

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