

**UNITING DISABILITY BIOETHICS & PARTICIPATORY RESEARCH
TO
ETHICALLY ELUCIDATE PSYCHIATRIC CONDITIONS IN PERSONS
WITH
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

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ABSTRACT

BACKGROUND/RATIONALE: Persons with intellectual and developmental disabilities (pIDD) face barriers to quality health care, including psychiatric care, that result in worse health outcomes. While the mental healthcare community is increasing attention towards the psychiatric needs of pIDD, there continues to be a deficit of knowledge regarding psychiatric conditions, including suicidality. Engaging in community-based participatory research (PAR) with pIDD is the ethical way to address these deficits. An academic researcher (AR) must first educate herself on lessons from disability rights activism and disability bioethics. **OBJECTIVE:** Apply the intertwining history and principles of disability rights movements and disability bioethics to lessons learned from previous PAR with pIDD in order to propose a PAR project that aims to alleviate knowledge deficits regarding suicidality in pIDD. **METHODS/APPROACH:** Historical research will focus on landmark texts in disability rights movements and disability bioethics. Lessons learned from previous PAR is mostly obtained from reflexive accounts on behalf of the AR and outside of psychiatry. Analyzing these sources will result in a proposal of six principles that can guide the AR when ethically engaging in PAR with pIDD. **RESULTS:** The AR must understand the history of society valuing non-disabled lives over disabled lives, inclusive of pIDD, and the social model of disability as it relates to the human variation model. When engaging with pIDD, the AR can question the traditional definition of *vulnerable populations*, challenge the group to progress beyond informed consent, continually support a capacity-building approach to research and power-sharing skills, and embrace *empowerment* to enact political change. **DISCUSSION:** ARs,

pIDD, and pIDD advocates must not accept the dearth of knowledge regarding psychiatric conditions, including life-threatening suicidality, in pIDD. The medical community should prioritize PAR with persons with pIDD to elucidate psychiatric conditions in pIDD that result in more efficacious and compassionate treatment. This proposal outlines major principles through which the AR can move forward ethically by engaging in PAR with pIDD.

This thesis is dedicated to the woman living with both schizophrenia and intellectual disability who presented to the Crisis Center in need of psychiatric care for suicidality.

We failed you then, but I will always keep trying to be a better doctor for you.

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CHAPTER 1

INTRODUCTION

In this thesis, I present six principles to guide an academic researcher in engaging ethically in participatory action research (PAR) with persons with intellectual and developmental disabilities (pIDD). These principles are rooted in disability rights activism, disability bioethics, and in lessons learned from the reflections of academic researchers already working in PAR with persons with IDD:

1. Understand the history of society valuing non-disabled lives over disabled lives, inclusive of pIDD.
2. Understand the Social Model of Disability as it relates to the Human Variation Model.
3. Question the traditional definition of *vulnerable populations*.
4. Challenge ourselves to progress *beyond* “informed consent” and more truly embody equitable power dynamics.
5. Continually support a capacity-building approach to both research and power-sharing skills.
6. Embrace empowerment to enact political change.

I myself do not live with an intellectual or developmental disability. This is somewhat contradictory given the basis of PAR echoes the Disability Rights slogan *nothing about us without us*. However, I believe this thesis serves as homework for two purposes: (1) Entering into practicing ethical research with pIDD. (2) Learning a history of disability bioethics for a newly disabled person.

Rosemarie Garland Thomson is a major influence on this thesis, and she emphasizes the idea that none of us are *able-bodied*, but rather, either disabled or *temporarily non-disabled* (Garland-Thomson, 2017). I read these words when I was temporarily non-disabled, but have since been diagnosed with moderate hearing loss that requires hearing aids. Although I technically qualify as disabled, I lack the *disability cultural competence* for which Garland-Thomson advocates (Garland-Thomson & Iezzoni, 2021).

I begin with discussing why specifically psychiatric research is needed as an entry point into emphasizing the critical need for PAR with persons with co-occurring intellectual and developmental disabilities. Suicidality in persons with intellectual and developmental disability (pIDD) is a field of knowledge defined mostly by deficits in understanding and lacking applicable data to the realities of post-deinstitutionalization and a poor safety net (Moors & Faden, 2022). A snapshot, however, can be seen from a 2004 study in Canada (Lunsky, 2004). Through direct interviewing of pIDD, researchers found that among 98 people with mild to moderate IDD, 23 (23%) had suicidal ideation, 11 (11%) had had a plan for suicide, and 11 (11%) had attempted suicide. Of the 11 people who had attempted suicide, 3 (23%) of their caregivers did not rate their care receivers as suicidal (Lunsky, 2004). While this is based on a small sample size, the numbers are dramatically higher than a larger survey performed by the Substance Abuse and Mental Health Services Administration (SAMHSA) in 2014. At that time, of the general U.S. population, 3.9% had suicidal ideation, 1.1% had a plan for suicide, and 0.5% had attempted suicide (Lester et al., 2015). It is unclear if that survey included or excluded pIDD. The obvious and classic conclusion becomes *more research is needed*,

but with a more nebulous path. What does ethical research look like when investigating psychiatric conditions in persons with intellectual and developmental disability, who are traditionally considered a *vulnerable population*?

This question presents two problems. One is the relative lack of knowledge on how suicidality may present differently in pIDD, such as if different treatments are more effective than in non-pIDD or if there is a difference at all. However, given the differences in cognitive functioning between pIDD and non-pIDD as well as the formidable health disparities affecting this marginalized population, one can presume differences do exist. The second problem regards the process of research itself.

“A researcher with a ‘good idea’ and the fund and status to put it into practice enters the community, engages in information gathering and disappears to achieve the results that they intended. However they may leave the researched group feeling disempowered and frustrated.”

(Johnson & Walmsley, 2003)

This statement concisely summarizes the experience members of various communities have endured regarding being researched on. Additionally, in traditional or *positivist* research, the researcher decides how that data should be used and the results often benefit the researcher’s career without providing a tangible benefit to the community, or even be related to a topic that concerns the community. Some research has been framed as improving the life of a certain community but without the direct involvement of that community beyond serving as a data set. Like the above quote, the obtained knowledge may remain in academic silos and never directly reach the researched community.

This thesis assumes that community based partnership research is the ultimate antidote to positivist research. There is an overlap with this research movement and disability rights movements, which called for *nothing about us without us*.ⁱ The question I aim to answer in this thesis becomes: How does one unite disability bioethics and participatory action research to ethically elucidate psychiatric conditions in persons with co-occurring intellectual and developmental disabilities?

ⁱ *Nothing about us without us* is a phrase also used in movements led by people with AIDS in the 90's, advocating for research on their condition that would save lives. While this movement and the disability rights movement were co-occurring and there is overlap between the marginalization of these groups, the phrase *Nothing about us without us* is often attributed to a disability rights activist, James Charlton (Chamberlin, 1999).

CHAPTER 2

UNDERSTANDING THE HISTORY OF SOCIETY VALUING NON-DISABLED LIVES OVER DISABLED LIVES, INCLUSIVE OF PIDD

Moreno and Sisti (2014) summarize that the “scientific enterprise” of research has “been transformed from protected activities shielded by the elite status of medicine into a more transparent and publicly accountable activity” (Moreno & Sisti, 2014:186). While their discussion is more in depth, it supports the highlights of what the typical medical trainee learns as the history of bioethics.ⁱⁱ

The typical summary follows something like this: In 1947, some Nazi physicians went under trial for the horrific atrocities they performed as experiments on victims of the Holocaust. The Nazi Doctor Trials lead to the Nuremberg Code, which decreed “the voluntary consent of the human subject is absolutely essential” (*U.S. v. Karl Brandt et al. 1947*, quoted in Moreno & Sisti, 2014:187). In 1964, there was the Declaration of Helsinki, which reified this proclamation of upholding autonomous consent in a context outside of the Holocaust. In 1979 the Belmont Report came out and is most well-known for condemning the Tuskegee Syphilis Study. The US Health Service intentionally withheld treatment from about 400 Black men infected with syphilis who were told they were being treated for “bad blood” (Black et al., 2022:851). Many medical professionals

ⁱⁱ *Typical* refers to a medical trainee without a formal academic background in bioethics.

may stop here, with the implication that after this atrocity was brought to light, medical research became universally ethical.ⁱⁱⁱ

The problem with this timeline is that it is piecemeal. If researchers truly embraced the principles of voluntary informed consent in 1947, then they would have ended the Tuskegee experiments in 1947 instead of in 1972.^{iv} The fact that the typical timeline lacks major ethical proclamations since the Belmont Report implies that the medical community successfully solved how to perform ethical research. Disability rights activists and disability bioethicists developed a higher threshold of what is considered *ethical* which fundamentally changed how research is performed today.

Rosemarie Garland-Thomson, a leading bioethics scholar and activist, combines the theories of two other disability scholars and activists to define *disability bioethics*: Alicia Ouellette’s “disability principlism” and Jackie Leach Scully’s “disability epistemology” (Garland-Thomson, 2017, p. 328). *Disability principlism* is grounded in the principles outline at the United Nations Convention of Rights of Persons with Disabilities (2011) and emphasizes “non-discrimination; full and effective participation of people with disabilities in society; respect for difference; and accessibility” (Garland-Thomson, 2017, p. 328). *Disability epistemology* relates to the reframing of disability so that the person isn’t seen as *inherently* inferior but rather the world one lives in isn’t

ⁱⁱⁱ Some may add the Denver Principles in 1983. During the height of the AIDS crisis, little was known about the virus beyond its prevalence among homosexual cis-men. People with AIDS were forced to declare their rights to medical treatment as well as to participate in research about them.

^{iv} Additionally, it was discovered in 1943 that penicillin, an easily available antibiotic, cured syphilis (Moreno & Sisti, 2014).

constructed for the disabled body. The next section on the social model of disability will reinforce these principles.

The disability bioethics framework forces us to adjust our understanding of the default bioethics timeline. The core issue underlying all of these medical atrocities is no longer fragmented amidst different political contexts. The unifying violation of ethics rests in the fact that a group of people in power decide some lives are more valuable than others, specifically, non-disabled lives are more valuable than disabled lives. I see that “Nazi medicine and Nazi social and political policy merged traditional disability and illness categories with ethnic categories” (Garland-Thomson, 2017, p. 330). This transgression of human rights was repeated in multiple research atrocities across the globe, such as Tuskegee and also in Willowbrook. Willowbrook was an institution for children diagnosed with IDD. In the sixties, doctors intentionally infected these children with hepatitis to be able to test various medicines as potential cures (Moreno & Sisti, 2014).

It is now clear that the atrocities of medical experimentation go beyond issues of consent, regardless of the demographic categories of the persecuted groups. The underlying justification was based on social value: Some lives are worth living and other lives are inferior and thus not worth living. The proclamations noted as landmarks in the current history of bioethics never achieved addressing this aspect, the social valuation of medical experimentation; burgeoning bioethicists and policy makers focused mainly on consent and protection of *vulnerable populations*.

By synthesizing the ideas that Garland-Thomson and fellow disability bioethicists lay out, I expand our view on the traditional narrative of the history and development of

bioethics as a field. Tuskegee most certainly was infused with racism, *and* applying a disability bioethics lens highlights the underlying and unifying principle among all of these atrocities- the valuation, or denial of value, of one group of people's lives compared to another based on perceived disability or illness. The men in Tuskegee were told they were being treated for *bad blood*. While the Black men rightfully saw themselves as human beings worthy of dignity with a separate illness causing the *bad blood*, the white researchers were trained in a scientific environment that actually espoused the idea that certain socially racialized groups were biologically inferior to the socially racialized white group. Eugenics supported the idea that these men didn't have *bad blood* because of a common sexually transmitted infection, but that *all* people of this socially racialized group *inherently* had *bad blood*. This is akin to racializing disability/illness in the way the Nazi's transferred disability/illness to ethnic categories with Jewish people, but also disabled people, queer people, Romani-speaking people, Polish people, and others deemed *inferior*.^v

The Belmont report is often succinctly summarized as a response to Tuskegee, which itself is framed as a medical research atrocity based solely on race. However, the original report cited multiple atrocities and was one of the earlier, if not first, public document exposing and condemning 22 “ethically compromised experiments,” including Willowbrook (Moreno & Sisti, 2014, p. 188). Sure, consent is important, but if the ethical

^v What is less commonly known is that the Nazi Doctor Trials also revealed the Allies had conducted similar experiments on prison populations. This should be incorporated into the cultural understanding of bioethics as it reminds us that I can not point to the *other side* as solely committing these atrocities and reminds us Tuskegee wasn't the only racially or ethnically motivated medical atrocity. For example, similarly unethical experiments were performed on Japanese prisoners of war (Moreno & Sisti, 2014).

proclamations weren't addressing the underlying principles of valuation, then researchers could *ethically* continue this perverse treatment of fellow humans in the name of science as long as some pretense of consent was met. For example, the researchers at Willowbrook did tell parents that they would infect the children with hepatitis to help find a cure, but the institution had a long waiting list and parents who consented their children to the study were granted admission (Rothman and Rothman, 1984, referenced in Moreno & Sisti, 2014).

If the idea of valuation (that some lives are more valued than others based on illness/disability of the inferior group) as the trunk of a tree, then there are toxic branches that grow from that idea. A major branch is how disability/illness plays a role in resource allocation ethics, and is an active area of debate among bioethicists, healthcare policy makers, and disability rights advocates. Some concrete examples include contemporary issues that will undoubtedly mark the history of bioethics.

For example, the Covid-19 response in the pre-vaccine era revealed starkly ableist attitudes towards which lives were considered worth saving (Hoban, 2021). States were forced to transform implicit ideas about valuation into explicit resource allocation policies. Some states policies excluded persons with profound or severe I/DD from life-saving procedures and resources. Alabama initially explicitly stated that absolutely no life-saving resources should be spent on this population, while other states outlined that a patient's disability should be considered when determining if the resources were *worth* using on them (Lund & Ayers, 2020).

Another ongoing debate includes babies born with profound congenital variances, such as Trisomy 18. In the past, these trisomies were considered *incompatible with life*,

and babies lived at maximum a year after birth, often dying due to complications from severe structural heart abnormalities or other manifestations of the genetic variance. However, medical interventions have advanced so that invasive procedures could be performed that would correct the effect of the genetic variance, while the baby would still grow into a child and adult with profound IDD. The most recent guidelines from the American Academy of Pediatrics (AAP) supports withholding life-saving treatment when “the risk of permanent, severe neurodevelopmental and other special health care needs affect both the infant and the family and, for some parents, may outweigh the benefit of survival alone” (Cummings quoted in Weise et al., 2017, p. 5). The *benefit* relates to the *best interests of the child*, which the AAP avoids defining directly. However, a lawyer reviewing a case where life-saving care for a treatable, structural condition was withheld from an infant with Down’s Syndrome explicitly defines *best interests* as interests “in a life unhampered by physical defects, infirmities, and suffering” (Maciejczyk, 1983, p. 227).

Disability rights activists tend to disagree. A related, controversial case that showcases arguments of disability activists is that of *Ashley X*, a girl born with severe mental and physical disabilities. The parents successfully advocated for surgery to stunt her growth, remove her uterus and breast buds to prevent puberty, and generally intervene pharmacologically and surgically to keep her a child in the name of her *best interests* (Diekema & Fost, 2010).^{vi} “The implementation of the ‘Ashley Treatment’ and sterilizations on individuals with developmental disabilities also raises discrimination

^{vi} The parents of Ashley X started a blog to share her story, which can be found at <http://www.pillowangel.org/> (Parents, 2015).

issues because, if not for their developmental disabilities, this set of interventions would not be sought” (Carlson & Dorfman, 2007, p. 24).

Wolbring laments the false divide supported by these iterations of the social valuation paradigm; “the non-disabled bioethicist on the one hand and the disabled non-bioethicist on the other” (Wolbring, 2001, p. 1). Figure 1 below proposes a *disability bioethics* condensed timeline of the history of bioethics.

Figure 1: A proposed, condensed, *disability bioethics* timeline of the history of bioethics

BIOETHICS	DISABILITY BIOETHICS
<ul style="list-style-type: none">• 1947: The Holocaust → Nuremberg Code<ul style="list-style-type: none">– Must be freely consenting to research• 1964: Declaration of Helsinki<ul style="list-style-type: none">– Proactive document that wasn't directly associated with the Holocaust• 1979: Tuskegee → Belmont Report<ul style="list-style-type: none">– Tuskegee experiments 1932-1972– (<i>Why didn't they end in 1947?</i>) <p>And maybe some will know of ...</p> <ul style="list-style-type: none">• 1983: AIDS Crisis → Denver Principles<ul style="list-style-type: none">– People with AIDS are worthy of living	<ul style="list-style-type: none">• 1947: The Holocaust → Nuremberg Code<ul style="list-style-type: none">– “Disability bioethics understands that Nazi medicine and Nazi social and political policy merged traditional disability and illness categories with ethnic categories” (<i>Garland-Thompson</i>)• 1964: Declaration of Helsinki• 1979: Tuskegee → Belmont Report<ul style="list-style-type: none">– Willowbrook: 1963-1966, children with pIDD intentionally infected with hepatitis• 1983: AIDS Crisis → Denver Principles• 1990: The Americans with Disabilities Act<ul style="list-style-type: none">– Civil rights for “vulnerable” populations

CHAPTER 3

UNDERSTANDING THE SOCIAL MODEL OF DISABILITY AS IT RELATES TO THE HUMAN VARIATION MODEL

For much of recorded history, persons with disabilities were often simply isolated and hidden from society; in some cultures and time periods, babies born with obvious disabilities were killed or left to die (*A History of Developmental Disabilities*, 2023).^{vii} While this reality is barbaric, the current debate described above regarding babies born with congenital variances echoes this practice. Eventually, people with disabilities, especially those with psychiatric and/or cognitive disabilities, became housed in institutions in the first half of the twentieth century. This movement was dependent on early conceptions of what would become the *normalization* model, as these institutions were initially began to supposedly train pIDD to become normal (*A History of Developmental Disabilities*, 2023). The living conditions were often unlivable and horrific, which prompted a public response. Instead of increasing funding and resources to strengthen the social network, the federal response in the U.S. was to deinstitutionalize persons with IDD and/or psychiatric disabilities. Sisti corrects the term *deinstitutionalization* to *transinstitutionalization*, and outlines how American society has replaced institutionalizing persons with severe psychiatric disabilities (otherwise known

^{vii} *A History of Developmental Disabilities*, produced by the Minnesota Governor's Council on Disabilities, provides a detailed and disturbing timeline of how cultures in different time periods have treated people with developmental (as well as physical) disabilities. These details are out of scope for this thesis, but I strongly recommend any reader access this website to better understand how we got to where we are today in terms of how pIDD are treated in society. (<https://mn.gov/mnddc/parallels/index.html>)

as severe mental illness) in asylums with *de facto* institutionalization in prisons, emergency rooms, and hospitals (Sisti et al., 2015).

This coincided with an evolution in how social scientists viewed pIDD, which was reflected in governmental policy. The *normalization model* of disability is the idea that disabled people, with an emphasis on pIDD, should receive services that allow them to be as *normal* as possible (Johnson & Walmsley, 2003; Walmsley, 2001). This model became synonymous with the medical model, the idea that a disability is a defect of the person and the defect must be fixed to make the person as *normal* as possible. This normalcy view actually discouraged association among pIDD as a pIDD would want to associate with non-pIDD to promote *normalcy* (Johnson & Walmsley, 2003). The promotion of hiding pIDD away from society to the *full and effective participation in society* is initially explicitly valorized only if that participation is with non-pIDD (Johnson & Walmsley, 2003; Walmsley, 2001). Whether intentionally or not, collective action by pIDD was inevitably inhibited because pIDD aren't congregating with each other. The underlying concept of the normalization model reflects the same problem I see over and over in history: valuing non-disabled lives over disabled lives, and disabled lives can only prove themselves more worthy the more *normal* they become. Eventually, societal structures would support pIDD congregating with pIDD. One account describing how a group of self-advocates successfully designed and enacted their own research ideas showcase how fundamentally important collective awareness and association with other pIDD was to the individual pIDD (Williams & Swindon People First Research Team, 1999).

Disability activists of course protested this egregious *normalcy* model. Michael Oliver published a text on the *social model of disability* in 1983 (Oliver, 2013).^{viii} The social model of disability is a rejection of the medical model, and maintains a *person-first* mentality whereby the defect is with society, not the person.^{ix} This is similar to *disability epistemology*, whereby the defective society *disables* a person by oppressive measures. For example, when this theory was published, curb cuts were not a thing. This is something I am used to in 2022, where the corner curb no longer permanently rises above the street but at the corner it curves via a slope into the street. For a wheelchair user, it is difficult to transition from the sidewalk into the street with a huge drop, and curb cuts are a structural change that permit increased mobility. This is a tangible example, but the social model also requires an ideological shift that the person is valued as they are, and society disables them.

Another major event happening around this time is legal scholar Kimberlé Crenshaw coining the term *intersectionality* (Crenshaw, 1989).^x Intersectionality

^{viii} Oliver would continue to publish essays on disability rights. His more recent ones reflect how what is considered progressive at one point in time may fail to keep up. More recently, he has lamented the perceived divisions created by focusing on overlapping intersectionalities within disability, such as gender, race, class, and orientation. Paradoxically, he seems to imply a *normalcy* sentiment by saying it would be easier if I focus on the what he perceives as the most common kind of disabled person, implying a cis-white-male like himself (Oliver, 2013).

^{ix} The historical and causal relationship between the social model of disability and the *person-first* language applied to a variety of people, not just disabled people, is interesting but out of the scope of this paper.

^x In the specific legal case in which she coined this critical concept, Crenshaw represented a Black cis-woman who faced discrimination in her place of work, an mechanic shop. The employer argued they didn't discriminate because they hired women and Black people. However, the plaintiff argued that they hired only white women in the reception area and only Black men in the mechanic area. Crenshaw described this

describes the how the summation of the lived experience of multiple marginalized identities carries more weight than the discretely organized marginalized identities one may carry, that is, a Black woman faces exponentially more discrimination than either a white cis-woman or a Black cis-man (Crenshaw, 1989).

The Social Model, coined by Oliver in 1990, has evolved into the Human Variation Model, coined by Shriner and Scotch in 1997. This is the idea that *disability* “is the systemic mismatch between physical and mental attributes of individuals and the present (but not the potential) ability of social institutions to accommodate those attributes” (Schriner, 2001, p. 8). Continuing with our example, I see disability as a more fluid phenomena that incorporates reality. On paper, curb cuts are great. However, there may be a car blocking a curb cut or the sidewalk so broken up that a wheelchair user wouldn’t even be able to ride safely to the curb cut. The mismatch between actual environmental conditions and the person’s actual needs constitutes *disability*. The human variation model also concerns itself with moving away from *abnormalities* and toward *variances*. This sentiment is echoed in terms like *neurodivergent* which calls for reframing how I see autism as simply a variation of human thinking instead of a deficient model of the human brain. Using the word *cis-* as a counterpart to *trans-* also embraces the human variation model. If I were to just use *trans-* for *trans-people* but *non-trans-* people simply get to be *people*, then I reinforce an idea of people = normal, trans = not normal, and with that the potential implication for inferiority.

unfortunately common form of discrimination rested on the *intersectionality* of the Black cis-woman’s multiple marginalized identities.

CHAPTER 4
QUESTIONING THE TRADITIONAL DEFINITION OF
VULNERABLE POPULATIONS

Vulnerable populations is a formal research term that often includes persons with disabilities. In response to all of the aforementioned research atrocities, the United States Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (the National Commission) in 1974 (Levine et al., 2004). The National Commission described how these groups, often “racial minorities, the economically disadvantaged, the very sick, and the institutionalized” require boundaries in place when being researched on because of their “dependent status and frequently compromised capacity for free consent” (U.S. National Commission, 1979, p. 8, quoted in Levine et al, 2004, p. 45). This definition carries an implication that the dependent status, often ascribed to any disabled person who depends on aides or services, equates with a *lack* of independence and that non-vulnerable/non-disabled, populations possess full *independence* (Scully, 2013).

However, the populations deemed vulnerable often effectively lack the same civil rights as people deemed *not* vulnerable. The American with Disabilities Act wasn’t passed until 1990. Even with this important act, persons with disabilities still (as of 2023) lack rights under the current medical-legal system. People with disabilities that depend on disability income and health insurance cannot marry without losing their access to life-saving healthcare (Mahoney, 2022). The Civil Rights Act of 1964, technically passed before the creation of the National Commission, did not uphold rights for Black

Americans amidst the continuing War on Drugs and police brutality (Jones, 2020). Even before the official overturn of *Roe v. Wade* in 2022, growing state regulations prevented women and other people with marginalized genders from accessing healthcare that ensured their basic bodily autonomy (Totenberg & McCammon, 2022). However, people who can have sex without getting pregnant themselves have continued to enjoy this right, unbridled.

The National Commission's framing of how an individual or group exists as *vulnerable* implicitly blames the *vulnerable* person, as if they are choosing to expose themselves to being exploited. This emphasis on blaming the individual, the *vulnerable* person, in an exploitative, capitalist, patriarchal, and white supremacist system, reflects how the medical model of disability functions and persists in our conceptualization of research subjects. The problem is with the *vulnerable/disabled* individual, *not* the encompassing system in which a privileged group of *temporarily non-disabled* people, including academic researchers, is empowered *to* exploit.

This medical definition of vulnerability enables researchers, such as Iacono and supporters, to see the legally required protections for vulnerable populations as burdens to them, the academic researchers (Iacono, 2006; Ramcharan, 2006). These researchers submitted opinion pieces published in the *Journal of Intellectual and Developmental Disability* where they expressed how sick and tired they were of regulations surrounding vulnerability and informed consent, regulations that they perceived impeded their research. Iacono even complained that if one vulnerable group were required to be on advisory boards for research, then *all* vulnerable groups would have to be represented in their respective studies, and this would be “logistically impossible” (Iacono, 2006, p.

122). While they also expressed the desire to perform research to help pIDD, the paternalistic overtones that failed to embrace an analysis of their capacity to exploit pIDD potentially negated any positive benefit of said research.

Disability activists often challenge the false concept that vulnerable/ disabled populations are dependent while non-vulnerable/ non-disabled populations are *not* dependent. Independence does not mean functioning on one's own without support (Morris referenced in Williams et al. 2005). In her discussion on in/dependence and vulnerability, Scully exposes the myth of independence, stating that “ no real person has no need for the benefits of cooperation or help” (Scully, 2013, p. 216). However, the responsibility of providing the appropriate accommodations so that the pIDD *can* act and make decisions to the best of their ability lies on the shoulders of the AR (McDonald & Stack, 2016). This may include using simple, straight-forward language in research documents, transportation support, interpreters, multiple modes of communication (Johnson & Walmsley, 2003; McDonald & Stack, 2016). All of us, disabled or temporarily non-disabled, depend on accommodations. Bathrooms and water fountains are accommodations for basic human needs and other accommodations that a non-disabled person may not need, such as wheelchair ramps or microphones to enhance audio quality, are also accommodations for basic human needs (Perry, 2022).^{xi}

Now it is clear that the medical model of vulnerability reflects the problematic medical model of disability, the *person-first* framework can provide a helpful step toward developing a *human variation model* of vulnerability. In questioning the term *vulnerable*

^{xi} Kriti Sharma further explores the inherent interdependence of our society in *Interdependence: Biology and Beyond* (Sharma, 2015).

populations, I reject blaming the populations for being exploited and rather own up to our own faults as academic researchers in positions of power and our own susceptibility to exploiting others. I affirm that everyone is entitled to the same basic human rights. I vote and fight politically to ensure *vulnerable populations* enjoy the same rights and liberties as the people who traditionally compose the *exploiting* group.

CHAPTER 5

CHALLENGING OURSELVES TO PROGRESS *BEYOND* INFORMED

CONSENT TO MORE TRULY EMBODY EQUITABLE

POWER DYNAMICS

The founding principle of ethical research is *voluntarily informed consent*, that is agreeing to a research project for which a person understands the procedures being formed, the data being collected, and the associated risks and benefits. A related term is *assent*, which is when someone who is deemed incapable of giving consent still agrees to being researched, such as someone with IDD may provide assent while their caretaker provides consent.

The informed consent process involves the academic researcher dictating how the research will happen and the researched person either consents to participate or declines. It is the academic researcher who decides if someone is capable or incapable of consent. Medical professionals are more likely to deny capacity to pIDD, both in research and around decisions regarding their general healthcare. The capacity evaluation is often void of negotiation.

However, PAR aims to dissolve the boundaries between the academic researcher and the community researcher, between the medical institution and the community. The issue with informed consent, then, is not the pIDD or presumed lack of capacity to give informed consent, but the traditional informed consent process as performed in positivist research. While the underlying dedication to the bioethics principle of autonomy should undoubtedly be upheld, the informed consent, as described, inherently contradicts PAR principles. The focus of these previous researchers on a binary of informed consent,

where someone is either absolutely able or unable to give consent, still places the AR in the position of power by being able to assess capacity to consent and laying out the rules to which the CR and community-participant must oblige.^{xii}

Community agreements more wholly invites all stakeholders, in this case the academic researcher, the community researcher, and the person being researched, to the table (*Developing Community Agreements*, 2023). These groups of individuals share and most importantly, *agree* on the rules of engagement. A person may suggest a need or preference, and others respond in affirming ways that respect the needs of all individuals present. Additionally, the act of proposing a way in which community members, CR, and AR will be treated (and held accountable) indicates a secure understanding of a situation and necessitates the acknowledgement of capacity.

Community agreements can mitigate the challenges of respecting patient autonomy in the traditional informed consent process. For example, Mietola et al. approached the common situation of being unsure a pIDD fully understood the project by utilizing a multidimensional approach by requiring written consent from next of kin and evaluating consent “from the point of view of research participants” regarding “the possible stress or harm caused to them” (Mietola et al., 2017, p. 265). This approach mirrors aspects of the principles of community agreements, where the fact that humans are interdependent is respected and perspectives of all participants are taken into account.

^{xii} *Process consent* and *building capacity to be able to consent* are attempts to rectify the perceived inability for pIDD to consent to research (Dorozenko et al., 2016; Meierer et al., 2022). While laudable attempts to address the topic of informed consent among pIDD, the underlying structure of informed consent still fails to equate with shared power.

CHAPTER 6

**CONTINUALLY SUPPORTING A CAPACITY-BUILDING APPROACH
TO BOTH RESEARCH AND POWER-SHARING SKILLS**

Discussions regarding pIDD in research often use *capacity* in regards to informed consent as well as questioning the *capacity* of pIDD to initiate research questions. I utilize Amartya Sen's discussion of the *capability approach* to understand *capacity* as the ability of an individual to achieve a goal within the context of their social reality (Sen, 2008).

Some AR have uncritically embraced the idea that "emancipatory research is very difficult for people with learning disabilities to achieve" (Chappell referenced in Williams et al. 2005, p. 13). However, with a capacity-building perspective, this statement stands on shaky ground. No AR began as the principal investigator of their first-ever research project, and most likely, no pIDD will achieve emancipatory research ideals on the first attempt at research. The focus on the capacity of the community researcher also carries an unstated implication the AR's skills are fully developed. However, ARs and the institutions that regulate and fund research have been trained in a positivist tradition and need to critically develop power-sharing and collaborative skills. McDonald and Stack reported that the most significant challenge regarding sharing power and collaboration with others was experienced among the AR (McDonald & Stack, 2016). Multiple authors found the lack of control they were accustomed to in the positivist tradition a complicated and challenging endeavor (Dorozenko et al., 2016; Povee et al., 2014).

Funding agencies now often require proof that the researched community is involved in the research somehow (Johnson & Walmsley, 2003). However, there often isn't a system of accountability for this nor specific guidelines on to what extent the researched population must hold power compared to simply participating. While this is an encouraging trend within research funding institutions, larger structural barriers remain that impede power-sharing among the AR and CR. For example, paying the pIDD or CR a salary can support the pIDD holding a professional role and act as a method to hold the pIDD accountable for their responsibilities (Williams et al., 2005). However, any pIDD or person with disabilities who is dependent on disability income, which guarantees them disability health insurance that would be financially unobtainable otherwise, legally cannot earn a significant income or else they lose the necessary health insurance (Mahoney, 2022). The salary then serves a more superficial purpose.

The exact mechanisms in which researchers, inclusive of both AR and CR, enhance power-sharing and flexibility with uncertainty is an important topic but a detailed discussion would be out of scope for this thesis. However, among researchers who have engaged in PAR with pIDD there is a varied commitment to sharing power. Some agencies focused on a "power reversal," such as what is seen in mutual aid organizations (Don Weitz quoted in Nelson et al., 1998, p. 889). Other groups emphasized *reflexivity* to ensure they were more ethically engaging in PAR with pIDD (Bigby & Frawley, 2010; Dorozenko et al., 2016; Johnson & Walmsley, 2003; McDonald & Stack, 2016; Williams et al., 2005). Reflecting on the project was often implied as an opportunity to contemplate the power dynamics between the AR and CR members, assessing if the process and dissemination of knowledge truly contributed to political

change, and was even seen as a significant preventative factor against exploitation of pIDD (Walmsley 1995 quoted in Johnson and Walmsley 2003). Dorozenko et al. look to Lincoln and Guba who believed reflexivity among ARs helped “to keep the inquirer honest” while challenging biases (Lincoln and Guba 1985 quoted in Dorozenko et al. 2016, p. 309).

In the way that AR learned positivist research methods as teachable skills, I need to maintain a capacity-building approach for pIDD as well. Sometimes AR assumed that because pIDD lacked positivist research skills (such as data collection and analysis), this equated with pIDD also lacking the *capacity* or even interest in acquiring these skills (Iacono, 2006; Iacono & Carling-Jenkins, 2012; Ramcharan, 2006). However, other AR described how pIDD, acting as CR, improved their traditional research skills over time (Williams et al., 2005). It is now clear that in discussions surrounding the capacity of pIDD to execute various stages of research, I must hold a capacity-building approach. I must not hold a double standard that pIDD are the only group requiring skill-building, as AR and institutions supporting PAR both need to build their own capacity for power-sharing and collaborative skills.

CHAPTER 7

EMBRACING EMPOWERMENT TO ENACT POLITICAL CHANGE

The spectrum of participatory research often depends on two interrelated ideas: *independence* and *empowerment*. On one of the spectrum, I have **inclusive research**. Here, the community group that was traditionally researched on in the positivist tradition participates in the research process itself at some point and generally feels *empowered*. Community members are *not* necessarily involved in all steps of the process and they are *not* required to lead the charge in deciding what is researched and how the researchers interact with the community; this is in contrast to the expectations in **emancipatory research**. This particular title demands that community members *independently* direct the research process at all stages, or at least the initiation of the research question, *and* that the explicit purpose of the research is to *enact political change* (Johnson & Walmsley, 2003).^{xiii} This spectrum does not represent a dichotomy. Rather, it encompasses differing levels of how the CR or pIDD meaningfully contributes to the project and varying degrees of control (Strnadová et al. referenced in Dorozenko et al., 2016).

This thesis intentionally utilizes the title of **participatory research** as a way to encompass this spectrum (Zarb referenced in Williams, Simons, and Swindon People First Research Team 2005). Additionally, disability bioethics requires that I (1) replace the capitalist understanding of *independence* with a disability rights understanding of

^{xiii} The requirement that community folks initiate the research has met some criticism. Lay people may lack the foundational scientific knowledge to even come up with the insightful questions that create new frontiers in healthcare. Additionally, a community group may be interested in the research that the academic researcher proposes, such as cis-women, trans-men, and genderqueer people born with ovaries who may be interested in research on heart pathology that directly affects them.

independence, as described earlier, while also requiring that I (2) transform *feeling* empowered to explicitly enacting political change that directly improves the lives of pIDD. Activist and author Ijeoma Oluo skillfully argues that when discussing oppression, people must move beyond *feelings* and understand the tangible weight of oppression that directly impacts people's lives (Oluo, 2019), such as how pIDD face increased risk factors for suicidality. One CR succinctly summarizes the principles of participatory and emancipatory research: "Research is about understanding each other and that in itself will help to make things better for me, and for other disabled people" (Florence Turner quoted in Williams 1999, p. 51). Namely, both the process and results translate into tangible, political change that benefits the researched group.

Empirical reflections of academic and community researchers involved in PAR with pIDD often shared challenges that impeded the actualization of pIDD independently initiating the research process, let alone directing multiple phases of it. Therefore, the proposed PAR with pIDD most likely won't be able to attain the capitalist understanding of *independence* and may not meet the official criteria of emancipatory research. Even if some research groups aimed for full PAR or emancipatory practices, empirically both AR and CR struggled to fully attain every requirement, and one group reflected that they especially found difficulty when engaging the CR in data collection and analysis (McDonald and Stack, 2016; 205). While that experience may contribute to the perception that PAR is difficult with pIDD, the many criticisms of pIDD apply to AR as well. Data collection is tedious and computational data analysis is a acquired skill that AR had to have explicitly learned in academic settings. Even ARs in positivist research may prefer to work with a biostatistician who handles analyzing the data, so if an AR can

still be considered a researcher while outsourcing the computational data analysis, then a CR must still be considered a researcher even if they don't engage with computational data analysis. CR may be involved in aspects of the research that are more interesting to them and aligned with their skill sets. This can include being experts on their lived experience and engaging in peer to peer data collection, where a non-pIDD may interfere with the interviewing (Williams et al., 2005). Supporting the emphasis on the spectrum of PAR is that there is not complete agreement on if the CR group *must* identify the research topic at hand. Chappell (2000) claims it is acceptable for AR to identify the topic and bring it for approval to the CR group, and Walmsley and Johnson (2003) support this assertion by adding the caveat that the research topic must ultimately be owned by the CR group with IDD (Chappell, Walmsley & Johnson referenced in Povee et al., 2014).

Now that I have more critically questioned the traditional concept of *independence*, I move toward the subject of *empowerment*. Paolo Freire, who wrote the landmark text "The Pedagogy of the Oppressed," which directly influenced multiple movements, including disability rights activists, participatory research activists, feminists, and Civil Rights activists, writes: "Empowerment does not exist as the gift of few who have it to be delivered to those who do not; people can only empower themselves" (Freire 1972 referenced in Oliver 1992, p. 30). Freire's arguments relate to the idea that the underlying structure of one entity *giving* power to another renders the exchange exploitative, because why did that original group have so much power to begin with unless due to inherent power inequality?

While *empowerment* continues to be a proposed benefit of participatory research, it is not always clear what people mean when they use the term. Not all authors equated

empowerment with political change. Some defined *empowerment* as the process when “people with learning difficulties know how powerful they can be when they are doing research” (Williams et al. 2005, p. 7). This sentiment is echoed in other reflections, where the checkbox of *empowerment* is fulfilled if pIDD are able to exercise control and make their own decisions (Dorozenko et al., 2016; Povee et al., 2014).

Oliver argues that empowerment refers to a process of “self-understanding” which “is an essential pre-requisite to providing a definition of ‘the real nature of the problem’ (Oliver 1992; p. 111).^{xiv} This is the underlying argument for the social model of disability; that the system in which I live is oppressive and *disabling*. While *empowerment* is an important principle of participatory research, it is critical to understand that the process goes beyond “*feeling* empowered” and rather directly translates to examining social structures so that the research results can *change* those structures. The need to change those structures is *not* to empower people, or *gift* power to marginalized groups, but rather to stop the process of oppression so that the inherent power these groups of people embody can manifest itself without oppression.

^{xiv} Oliver directly cites Bourne, a Black Civil Rights activist, and refers to feminist movements of the time that more critically analyzed structures (Oliver, 2013).

CHAPTER 8

CONCLUSION

Figure 2: What is known, what is discussed, what is new

WHAT IS KNOWN	WHAT IS DISCUSSED	WHAT IS NEW
<ul style="list-style-type: none"> • Deficits in psychiatric research regarding the presentation and diagnosis of psychiatric conditions in pIDD, especially suicidality. • Because of this lack of attention, pIDD have unnecessarily faced/bore the burden of health inequities. • Known suicidality risk factors for the general population exist at a higher prevalence within pIDD, inclusive of mild/moderate to severe/profound, which indicates that it is critical to research the full spectrum of psychiatric conditions in pIDD in an ethical way. 	<ul style="list-style-type: none"> • Disability Bioethics and PAR movements as models for what ethical research with pIDD populations actually looks like. • Analysis of research projects performed with the goal of following PAR principles specifically with pIDD, mostly in the social research tradition. 	<ul style="list-style-type: none"> • We are not <i>protecting</i> vulnerable populations, but rather working with marginalized groups to restructure a research process that empowers these groups by enacting tangible political change. • We work toward building a world in which scientific communities no longer exploit those that have been labeled as <i>vulnerable</i> (implied by scientific communities to mean “vulnerable to exploitation”). • We respect the shared humanity between and among all groups involved in the advancement of scientific knowledge.

Persons with intellectual and developmental disabilities, their advocates, and academic researchers must *not* accept the dearth of knowledge regarding psychiatric conditions, including life-threatening suicidality, in this population. Medical professionals should prioritize participatory action research with persons with intellectual and developmental disabilities to elucidate psychiatric conditions that result in more efficacious and compassionate treatment (*see Figure 2*). Following these six principles, I can move forward in ethically engaging in participatory action research with persons with intellectual and developmental disabilities:

1. Understand the history of society valuing non-disabled lives over disabled lives, inclusive of persons with intellectual and developmental disabilities.
2. Understand the social model of disability as it relates to the human variation model.

3. Question the traditional definition of *vulnerable populations*.
4. Challenge ourselves to progress *beyond* informed consent and more truly embody equitable power dynamics.
5. Continually support a capacity-building approach to both research and power-sharing skills.
6. Embrace empowerment to enact political change.

The limitations of this thesis include the paradoxical fact that no person with intellectual and developmental disability was directly consulted on a thesis regarding participatory action research with this population. However, as previously stated, this thesis serves as homework for engaging in participatory action research with this population.

Cited sources regarding participatory action research, disability activism, and disability bioethics are almost exclusively focused on U.S. or British populations, with some influence from Canada and Australia. Logically, there are other activists in cultures and languages outside of this heavily Anglo-Saxon background. While my limitations in understanding academic texts in non-English languages and difficulty finding translations contributed to this situation, I attempted to counteract this by referencing major concepts from Black women activists. I also acknowledge the influence of Paulo Freire, a Brazilian activist and educator whose most prominent work, *Pedagogy of the Oppressed*, in 1970 itself referenced worldwide movements, such as the Cultural Revolution in China (Freire & Ramos, 1970).

Additionally, the spectrum of “inclusive” research overwhelmingly focuses on pIDD with mild/moderate disability. Folks with severe/profound IDD and/or people who don’t primarily communicate verbally are often excluded from participatory action research (Mietola et al., 2017). Academic researchers and medical providers critically need to enhance our ability to provide healthcare, inclusive of psychiatric care, to this population.

As with most academic endeavors, this thesis led to three main questions that cannot be answered by myself alone but rather in community discussions centering the voices of persons with intellectual and developmental disabilities:

1. *How do researchers address the seemingly inherent power imbalance between academic researchers and community researchers who are persons with intellectual and developmental disabilities? How does power exist equitably so that one party isn’t in the position of feeling like they are redistributing power, even though power is not a gift nor a frivolity?*
2. *What does accountability look like in participatory action research, both with and without persons with intellectual and developmental disabilities? The process of accountability (academic researchers holding community researchers accountable for promises and actions compared to the other way around) may not be equal but must be equitable. Who holds the academic researcher accountable for the shared accuracy of their reflections? While the culture in the United States surrounding accountability tends to be punitive in nature, alternative options exist such as transformative justice, which developed in grassroots organizations as a collective way of holding accountability (Carruthers, 2018).*

3. *How does the medical field in concert with persons with intellectual and developmental disabilities define the concept or diagnosis of intellectual and developmental disabilities?* The medical diagnosis has shifted from focusing solely on numerical scales supposedly correlating with intellectual capacity to a more broad definition including the level of accommodations a person requires (American Psychiatric Association, 2013). The medical definition of intellectual and developmental disability, as outlined in the Diagnostic and Statistical Manual of Mental Disorders, loses stability in the context of the social model of disability. If a person is disabled by their environment then defining a person's disability by the ways in which they need services for activities of daily living serves more accurately as an inventory of the degree to which society has disabled them.^{xv} A definition of a group would most logically be defined by the group itself, or at least in conversation with the group.

Future participatory action research with persons with intellectual and developmental disabilities can look to these six principles, steeped in disability bioethics, as a guide. However, the most ethical execution of this type of research will evolve in concert with persons with intellectual and developmental disabilities. It is possible to better serve the mental and physical healthcare needs of this population so that persons with intellectual and developmental disabilities can live unburdened by suicidality.

^{xv} The presumed incompetence placed on persons with intellectual and developmental disabilities is a prejudice that many academic researchers struggled with (Dorozenko et al., 2016). A key factor in the lack of significant research on suicidality in persons with intellectual and developmental disabilities exists in part to the persistent misconception that this population is essentially too happy because they are not smart enough to even conceive of suicide (Moors & Faden, 2022).

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