

“Nothing About Us Without Us:” Ethnography, Conscientization, and the Epistemic Challenges of Intellectual Disability

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ABSTRACT

As the number of Christian theologians engaging ethnographic research increases, there have been several scholarly conversations about how the power and privilege of the researcher impacts knowledge and relationships in fieldwork. These challenges are particularly potent in the case of doing fieldwork among people with intellectual and developmental disabilities. This essay examines these questions by revisiting the conceptual underpinnings of the “epistemic privilege of the poor” within Latin American liberation theology. I argue that the epistemic privilege cannot be understood apart from the process of conscientization, as established by Brazilian philosopher Paulo Freire. However, embedded within Freire’s framework are presumptions about conceptual capacities and theological anthropology that potentially exclude people with IDD. The essay concludes by examining strategies that have been used by theologians doing ethnography to address inherent power imbalances, such as solidarity, accountability, and participatory action research, in order to open up space for further conversation about promoting the agency and flourishing of marginalized communities, especially those who may not share our conceptual frameworks.

In the United States, the strongest call for the use of ethnography has come from theologians with liberatory commitments, who justify ethnography not only as a way of gathering additional data, but as a formative practice in itself. They insist that the situatedness of a theologian is integral to the production of her work. Naturally, questions of privilege, power, and epistemology have been frequent topics of examination for theologian-ethnographers, even within this very journal. In the ongoing process of critical reflexivity, numerous theological ethicists have written about how they navigate their positions as “outsiders” of relative privilege vis-a-vis the communities in which they work: Melissa Browning, Christian

Scharen, and Aana Marie Vigen, among others. As a theologian and Christian ethicist myself, I re-engage these conversations for two reasons: first, to thicken our conceptual understanding of the “epistemic privilege” that is so essential to liberation theologies; and second, because the context of my own ethnographic work, among people with intellectual and developmental disabilities (IDD), poses questions of power and agency that complicate many “best practices” of accountability. My fieldwork among people with IDD places old questions for ethnographic research into sharper relief, but it also raises new questions about the processes and products of our work.

To begin, in the first portion of this essay I set up the tension that intellectual disability can create for liberationists: several theologians of disability have shown resistance to liberation theologies of disability, contending that a liberationist emphasis on “self-determination” and “self-representation” excludes people with profound intellectual disabilities, who have limited capacity for communication and even in some cases symbolic thought. These criticisms of liberation theologies raise questions about the role of the “epistemic privilege of the poor” in doing theology. Epistemic privilege is a valuable but under-theorized concept among liberationists; the next part of the essay examines this concept within its primary progenitors, Latin American liberation theologies. I find that the epistemic privilege of the poor is actually reliant on the concept of “conscientization,” as developed by Brazilian philosopher and educator Paulo Freire. Yet, when we attend to Freire’s influential work, we also find assumptions about human nature and cognitive capacities that implicitly exclude people with intellectual disabilities from processes of social change. Thus, taking a closer look at conscientization raises challenges that call for further reflection on key practices that theologians engaging ethnography use in mediating differences of power and privilege. The latter portion of this essay examines solidarity, accountability, and participant action research with specific concerns for how these practices might work among IDD communities. I do this in the hope of opening up space for further conversation about how to promote the agency and flourishing of marginalized communities, especially for those who might struggle to engage the conceptual frameworks that have shaped liberation theologies.

OUTSIDERS AND LIBERATION THEOLOGIES

I first came to ethnography because I saw in it a tool to approach new experiences, new “data” that I felt was missing from theological discourse: namely, the voices and experiences of people with IDD. When I began my research, I was searching for a way to do a “liberation theology” derived from the experiences of the IDD community. I have found that ethnography does offer a valuable way to engage experience, that necessary source of theology, in a careful, considered, and critical manner. Nonetheless, it was in the very process of reflexivity, so essential to ethnographic work, that I began to struggle with questions about just what it is we mean by the “epistemic privilege of the poor,” often intertwined with the justification for this method.¹ This is not a new question for those engaging ethnographic method in Christian theology, but the particularities of working with people who have intellectual disabilities put questions about the epistemic privilege in sharper relief — in particular, the fact that many liberation theologians insist that the epistemic privilege of the poor is constituted by conscientization, first. A troublesome word

to translate from its original Portuguese (*conscientização*), conscientization requires that people enduring oppression commit to a certain level of reflexivity themselves. This means the oppressed must be able to recognize structural oppression and desire social justice and transformation.²

Yet, epistemic privilege has proven to be a dividing issue within theologies of disability. Nancy Eiesland's book *The Disabled God*, a foundational text for theologies of disability, is liberationist in nature, and is driven by a commitment to her own concept of epistemic privilege, which she often expresses through the disability rights slogan, "nothing about us without us."³ Yet, Eiesland and other liberationists have been critiqued for a theology that does not, even cannot account for all kinds of disabilities — especially intellectual and developmental disabilities.⁴ Theologians focused on intellectual disability, such as John Swinton and Hans Reinders, argue that the act of self-representation integral to "nothing about us without us" excludes people with IDD. Liberation theologies, they argue, can have valuable political impact, but are theologically insufficient for understanding the Christian obligations towards people with IDD.⁵

On one level, this divide indicates differences in what liberationists and their critics think that theology ought to be. Swinton and Reinders both seek to emphasize a shared humanity, and for them the particular is less important than the universal. And yet particularity — in identities, in communities — is essential to liberation theologies. It is true that most liberationists emphasize the theologian's self-identification with the community from which she speaks: Latin Americans write from and for Latin American base communities; women write feminist liberation theologies; Eiesland writes a liberation theology for the physically disabled.⁶ However, Reinders and Swinton mistakenly assume that a shared identity is required in the production of a liberation theology, and that is why they resist the possibility of a liberation theology of intellectual disability. As they understand it, someone with IDD (who cannot engage in self-representation) would be unable to either advocate for themselves politically or produce a theological work stemming from their own experience. Therefore, when it comes to theologically engaging experiences of IDD, the work will always have to be done by someone without an intellectual disability, which means it would not be a proper liberation theology (as they understand it).

In truth, shared identity and self-representation are only part of doing liberation theology, but solidarity presents another essential element that creates space for "outsiders" to play a role. Nonetheless this generates a difficult question for understanding the role of epistemic privilege. In terms familiar for an ethnographer, this amounts to asking: what is the role of insiders and outsiders in producing a liberation theology, both concerning the drive for social transformation and the production of theological work itself? In the following section, we look at Latin American liberationists and how they understood the epistemic privilege of the poor. While emphasizing that the epistemic privilege of the oppressed is not unique to Latin American theologians, they are often considered the progenitors of epistemic privilege's significance to theology. Yet the concept is often somewhat under-theorized in liberationist work, as Latin American theologians tend to implicitly rely on the framework established by Freire. Therefore, understanding both conscientization and the epistemic privilege of the poor and oppressed also requires a return to Freire's work, *Pedagogy of the Oppressed*.

EPISTEMIC PRIVILEGE IN LIBERATION THEOLOGIES

Freire's influence on Latin American liberationists is extensive. He appears in Gustavo Gutiérrez, Clodovis Boff, Juan Luis Segundo, Ada María Isasi-Díaz, and more.⁷ Liberation theology shares a basic outline with Freire's work: a unity of theory and praxis, liberation as "humanization," and the role of conscientization. Most importantly, the unity of theory and praxis must begin with the experiences of those who are poor, oppressed, and relegated to the margins. Liberation theologies engage theoretical work, such as social analysis and scriptural hermeneutics, but it is always oriented towards the practical transformation of the world, which includes both the elimination of social oppression and the conversion of persons away from sin. These goals, for both Freire and liberationists, are connected to self-determination, sometimes referred to as the process of "humanization," of people recognizing their agency and subjectivity in the world.⁸ Gutiérrez, for example, phrases the definition of liberation as the process of nonpersons becoming persons who "can live with dignity and be agents of their own destiny."⁹ Gutiérrez's definition — "nonpersons" becoming persons — serves as the cornerstone for many others.

Essential to this process of humanization is conscientization, which is where Freire's influence on the liberationists comes through most clearly. Indeed, Gutiérrez openly gives Freire much of the credit for developing and exploring the best methods of conscientization:

But in order for this liberation to be authentic and complete, it has to be undertaken by the oppressed themselves, and so must stem from the values proper to them. Only in this context can a true cultural revolution come about. From this point of view, one of the most creative and fruitful efforts implemented in Latin American is the experimental work of Paulo Freire, who has sought to establish a "pedagogy of the oppressed." By means of an unalienating and liberating "cultural action," which links theory with praxis, the oppressed perceive — and modify — their relationship with the world and with other persons. They thus make the transfer from "naive awareness" — which does not deal with problems, gives too much credit to the past, tends to accept mythical explanations, and tends towards debate — to a "critical awareness" — which delves into problems, is open to new ideas, and replaces magical explanations with real causes, and tends to dialog. In this process, which Freire calls "conscientization," the oppressed reject the oppressive consciousness which dwells in them...¹⁰

In a sense, conscientization operates as a kind of safety-check in the process of liberation: it prevents theologians from naively adopting a perspective of the oppressed that might result from the internalization of dominant ideologies. However, the process (and potential pitfalls) of conscientization go unexamined by many liberationists. While Gutiérrez affirms that the poor themselves have to make the option for the poor, the quote above is the most attention he gives to what the actual process might look like. Boff is able to describe what ideological — and ergo idolatrous — theology is, but has limited words on what an appropriately conscientized theology might look like.¹¹ Segundo goes so far as to take conscientiza-

tion away from the poor, arguing that conscientization originates not among the oppressed “masses,” but as a result of an enlightened “minority,” who are able to critically deconstruct the ideologies to which the masses may be susceptible.¹²

On the one hand, this ambiguity concerning conscientization could be a result of the commitment to the epistemic privilege itself: there is no fully “conscientized theology,” argues Clodovis Boff, because the process of questioning is ongoing, and only ideological theology refuses to question itself.¹³ Moreover, if the oppressed are meant to be the leaders of their liberation, professional theologians (who often benefit from privileges of education and class) ought not to be the primary sources of the substance of these theologies. Yet, on the other hand, it must be admitted that in practice professional theologians are often the gatekeepers when it comes to liberation theologies. Books from Gutiérrez, Boff, or Segundo are read because of the credentials of their authors. There are limited ways in which an impoverished member of a Latin American base community could be heard amongst academics. As gatekeepers, theologians adjudicate (whether explicitly or not) the content of the theologies they encounter among the oppressed.

One strategy for addressing the implicit, but under-examined divide between academic theologians and marginalized communities emerges in the *mujerista* theology of Isasi-Díaz. In many ways, Isasi-Díaz is actually closer to recapturing Freire than others, in large part because her work is grounded in an ethnography focused on storytelling and everyday life experiences, rather than larger economic theories, such as dependency theory, that earlier liberationists initially favored. Isasi-Díaz values her method precisely because it empowers women to name and share their experiences. In fact, she challenges Gutiérrez’s description of liberation theology as a “reflection on praxis” because she finds the distinction between theology and praxis itself to be problematic: “We do not believe that our theological enterprise is a ‘second step,’ or a ‘second reality’...the doing of *mujerista* theology [is] a liberative praxis, as a matter of fact.”¹⁴ In light of this, it is unsurprising that Isasi-Díaz is also critical of divisions between theology as an academic profession and the theologies that come from the women in her ethnographic work:

Our understanding of *mujerista* theology as a liberating praxis is a refusal to reduce theology to a formal, disciplinary discourse in which adequacy has to do with certain intellectual criteria formulated by those who control the cultural and academic apparatus and which are quite foreign to the day-to-day struggle of Latinas to survive.¹⁵

Here, Isasi-Díaz recognizes the gatekeeping function of the academy, and sees *mujerista* theology as a rejection of it. Theology as “orthopraxis” – or right action – democratizes the production of theology: everyone is a theologian.

While she blurs the lines between praxis and theology, academic and grassroots theologians, Isasi-Díaz also insists on conscientization for all involved in *mujerista* theology. The preferential option for the poor is not a result of “their being morally better, or more innocent;”¹⁶ rather, “opting for Hispanic woman means that we, as Hispanic Women, engage in the difficult and painful task of getting rid of the oppressor within, of the internalized oppressor.”¹⁷ On the importance of conscientization, Isasi-Díaz draws quite directly from Freire and his use of “limit situations.”¹⁸ When Hispanic women are directly confronted

by injustice, by social structures beyond their control which defy their desires for survival and liberation, they find “the spark of suspicion that will move them to a liberative praxis.”¹⁹ Therein lies the dialectic that grounds the epistemological privilege of the poor: in the acceptance of freedom and responsibility to work for liberation in a world that constantly seeks to frustrate that freedom and deny liberation.

Yet it must be said that Isasi-Díaz can only blur the lines between the professional theologian and the grassroots theologian because of how closely she can identify with the women she works with — which she is very much aware of:

But I have had to accept the fact that I am both an insider and an outsider in the community of Hispanic Woman. I have struggled to distinguish what I hold in common with the respondents (because I am a woman and Hispanic) from what is different, that is, class, age, role, degree of formal education, and so forth. It is important to recognize that identities are always complex and multifaceted, and, therefore, no researcher is ever totally an insider.²⁰

Similarly, Gutiérrez, Boff, or Segundo may let the differences between theologians and their communities go unexamined because of how much they share in common. Moreover, there is a certain kind of anthropology that these liberationists can assume, one which uses the terms agency and self-determination without pause: they hold no doubt that the oppressed, once having gone through conscientization, can reclaim the agency the world has denied them. While this is not an individualistic agency (given the importance of community to liberation theologians), it is an agency that relies on voices being heard, on ideas, hopes, and dreams being expressed in ways that the rest of the community understands.

Such a form of agency presents a challenge for people with intellectual disabilities; indeed, it might seem that Reinders and Swinton are accurate in their critiques. Do liberation theologies ultimately prioritize a political sense of agency that people with significant IDD cannot participate in? If agency is only concerned with political effectiveness, that answer might be affirmative. Yet, that is a shallow reading of the liberationists; rather than effectiveness, they seek humanization, to work for “nonpersons becoming persons.” This is why conscientization is essential to the epistemic privilege of the poor. Nonetheless, there are tensions to be explored here — and for that, we must dive more deeply into the work of the architect of conscientization, Paulo Freire.

FREIRE, CONSCIENTIZATION, AND BEING HUMAN

Freire wrote his famous book, *Pedagogy of the Oppressed*, as a result of his experiences teaching literacy among impoverished adults in Brazil.²¹ Critiquing “banking” models of education, in which knowledge is given out to students like loans from a bank (and the bank ultimately always maintains control over that knowledge), Freire’s approach placed the oppressed in the role of co-teacher. Agency of the oppressed is essential for Freire’s social revolution, since liberation cannot be paternalistically “gifted” to

the oppressed by the oppressor without merely reinscribing the power dynamics that define oppression in the first place. Herein lies the importance of Freire's conscientization to the epistemic privilege itself: "Who are better prepared than the oppressed to understand the terrible significance of an oppressive society? [...] They will not gain this liberation by chance, but through the praxis of their quest for it, through their recognition of the necessity to fight for it."²²

The alternative to the banking model is "problem-posing," a model that Freire describes as a kind of dialog.²³ Given the context of literacy education, Freire locates "the word" at the heart of this dialog: the word, Freire argues, is where reflection and action exist together, because "to exist, humanly, is to name the world, to change it." That is to say, humankind engages the world through the process of naming, which continues to shape and alter what has been named, which then prompts further reflection, and so on.²⁴ Reflection and action need one another, as reflection without action is merely "idle chatter," and action without reflection "negates the true praxis and makes dialog impossible."²⁵

Freire's concept of "word" constituted by praxis and reflection is connected to an anthropology that places a strong boundary line between human persons and animals.²⁶ That boundary is the capacity of a person to "to treat not only his actions but his very self as the object of his reflection," or reflexivity.²⁷ Unpacking this, Freire asserts:

Unable to decide for themselves, unable to objectify either themselves or their activity, lacking objectives which they themselves have set...animals are ahistorical...Animals are not challenged by the configuration which confronts them; they are merely stimulated. Their life is not one of risk-taking, for they are not aware of taking risks.²⁸

Essentially, this difference between persons and animals comes down to their capacities for conscientization. The "limit situations," which in Isasi-Díaz's argument developed conscientization for Hispanic women, are at the heart of the problem-posing methodology that Freire uses in literacy education. Freire also sees limit situations as critical to human consciousness: "critical perception is embodied in action [...] which leads men to attempt to overcome the limit situations."²⁹ The ongoing struggle against limit situations and the cycle of reflection and praxis they invoke is foundational to how the oppressed will ultimately transform the world. Animals, lacking a capacity for objectifying the world, cannot participate in its transformation: they cannot enter the process of conscientization.

Freire is not laying out a comprehensive human anthropology, nor is he making assertions about cognitive psychology or linguistic developments. His broad-strokes outline of the importance of "the word" in human nature is not original: he draws on assertions that have been made about personhood across centuries, and in a variety of disciplines. Nonetheless, I make this foray into Freire's underlying anthropology because, intentionally or not, the anthropological framework of his model for social change leaves out people with IDD, particularly people with profound intellectual disabilities. Throughout history people with IDD have been denied their personhood on precisely these grounds: their limitations in rational thought, the difficulties in communication, the perceived lack of language. Once again, we encounter the problem set forth by Swinton and Reinders: if liberation requires conscientization, and conscientiza-

tion requires reflexivity, does this process ultimately leave behind people with intellectual disabilities?

Some clarification needs to be offered, here. First, many people with intellectual disabilities can and do communicate with relative ease. And many people with IDD have been able to engage in critiques of social structures: to name and struggle against the limit situations that surround them. Evidence of this is seen in self-advocacy organizations such as People First, or Self Advocates Becoming Empowered (SABE).³⁰ Nonetheless, even in these examples it must be pointed out that the structure of something like People First relies on the presence of nondisabled social workers and allies.³¹ And even for those whose language is limited, it behooves us to take an epistemically humble position concerning the intellectual capacities of people with disabilities who might simply have trouble expressing themselves.³² Nonetheless, we cannot ignore that a great many people with intellectual disabilities will have a limited capacity for the kind of reflexive work Freire is calling for. Those who are capable of reflexivity will likely find such processes facilitated by the nondisabled.

Even as I point out these tensions with Freire's underlying anthropology, we may recognize that many of these challenges are not restricted to the IDD community. Freire's educational model integrates experts from outside the oppressed community as dialog partners who may pose the problems and limit situations on which the group reflects. Furthermore, given the ongoing, open-ended nature of conscientization, it cannot be assumed that all members of an oppressed community will be at the same level of awareness. It may be that the potential challenges of seeking conscientization among the IDD community are different only in degree, not kind. I bring this to attention not to discard Freire and those who have been influenced by him; rather, I pull this forward because of Freire's own commitment to an ongoing examination of the connection between theory and praxis. Are the limitations of Freire's anthropology also expressed as limitations of his method and praxis? And more specifically for the task at hand: are these limitations recognized and reflected on by the theologians engaging this framework?

One of the ongoing themes of conversation among theologians who do ethnography (and especially those who take part in participatory action research) is how to make sure that our participants and collaborators have agency in the work. We are still in the process of figuring out what it means to take seriously the epistemic privilege of marginalized communities, as well as our own role as (privileged) researchers within that community. In the following section, I offer an overview of the strategies currently being used to engage epistemic privilege, and the places where those strategies might run into the limits and tensions of agency and conscientization that I have indicated in Freire and liberationists above.

BRIDGING THE GAP: ETHNOGRAPHIC STRATEGIES

In my own fieldwork, which took place over three years at nonprofit service provider for adults with IDD, I found myself hyper-cognizant of my status as an outsider. I was an outsider not only among the people with IDD who were my informants, but also within the broader structures of the nonprofit that helped facilitate my research. While the nonprofit had been extremely helpful in both moving through their internal review process and supporting me through my university's IRB, there still were multiple delays, specifically over the informed consent process I was proposing. Since very few of the clients with

IDD were literate — and even the ones who were tended to be shy about trying to read — I had proposed an oral informed consent process. I wrote out the exact script I would use when speaking with clients, with multiple check points for comprehension. Though I would not be asking them to sign anything, I did specify that I would give them a copy of the script for future reference, just as if I was giving them a copy of the consent forms they signed. Even once I was through the IRB process, actually starting the work became another issue. Getting in touch with staff members entailed long games of phone tag and confusing emails about who was accountable to what in my research process. None of it malicious, just the standard signs of struggle for a non-profit in the midst of a large-scale transition — this PhD student from theology who for some reason wanted to do research at Payton Industries was at the bottom of a very long to-do list.³³

So when I was finally able to start doing my observation, I was eager to engage informants directly. One of the first men I spoke with was Tim — a middle aged man with thick, wire-rimmed glasses and the energy level of someone a fifth of his age. When excited, he would give you high-fives that actually kind of hurt. We sat down and went through the informed consent script together, and he verbally agreed (with a high-five). The rest of the afternoon, however, I watched him show whoever would listen the copy of the script I had given him in exchange for his consent. As I watched, I found myself blushing every time he showed it off to an unsuspecting staff member. I worried that his bragging would make other clients feel excluded, or that my presence was already causing a distraction, getting in the way of the normal tasks in the workshop. I even wondered if the staff members would question the document, written at a third-grade level. Though following the rules of the IRB, I was concerned about seeming “official” enough. As I have continued to reflect on my discomfort in that moment, I realized it came from more than concerns about the consent script. It was Tim’s enthusiasm that discomforted me. His pride at being asked to help was a status symbol he felt compelled to show other people. For weeks, I had been frustrated by phone tag and ambiguities, feeling like I had no social standing at the nonprofit. But to Tim, I had an awful lot. As both theologian and ethnographer, I remain deeply aware of the differences between myself and the IDD community — differences in power and privilege that at times seem unbreachable. I am not alone in this, as many have written reflexively and academically about the ways their own privilege marked them as “outsiders” in their fieldwork. Three important strategies for addressing this difference while preserving agency — and human dignity — have emerged in the conversation: solidarity, accountability, and participatory action research.

SOLIDARITY

It is uncontroversial to state that ethnography-as-theology entails an act of solidarity on behalf of the theologian.³⁴ Yet, the meaning of solidarity remains frustratingly diffuse, invoked across a variety of contexts, including labor organizing, the Catholic social tradition, and liberation theology. Isasi-Díaz articulates the problem:

The true meaning of solidarity is under serious attack and runs the risk of being drastically changed. The proof of this is how fashionable its usage has become,

how easily it rolls off the tongues of all sorts of speakers, how unthreatening it is. If the true meaning of solidarity were understood and intended, visible radical change would be happening in the lives of those who endorse it with their applause.³⁵

Solidarity is invoked freely, but without depth. The lack of meaning that Isasi-Díaz complained about applies just as easily to us, today. And yet solidarity does a great deal of work within liberation theology, particularly concerning the role of the oppressor in relationship to the oppressed. For example, Gutiérrez defines solidarity as something which must “manifest itself in a specific action, a style of life, a break with one’s social class;” it is required in order to work for the liberation of the poor.³⁶ Gutiérrez offers an example of this kind of break: voluntary poverty, “a poverty lived not for its own sake, but rather as an authentic imitation of Christ.”³⁷ Gutiérrez is not defining solidarity as voluntary poverty, but raising voluntary poverty as a prime example of what solidarity ought to look like: a sacrifice of the privilege that someone who is not poor enjoys. This sacrifice is what allows the oppressor to join the revolution led by the oppressed: or, how an outsider gains a position among insiders. It is no surprise that solidarity plays an essential role for theologians doing ethnography.

Nonetheless, Isasi-Díaz’s questions about what constitutes the actual content of solidarity must be taken seriously. She presumes more of an insider status to doing *mujerista* theology, though she is not unaware of the differences between “professional theologians” and the rest of the *mujerista* community. Engaging the difference of professional and grassroots theologians requires seeing theology as dialogical, seen in her advice for those researchers who are more “outsider” than “insider”: “The less the professional theologian is an insider, the more she must be immersed in and stand in solidarity with the community. In other words, she must allow herself to be deeply engaged by the community so that she can, as much as possible, come to understand the community from within.”³⁸ It is in understanding the community “from within” that solidarity is generated, which according to Isasi-Díaz operates like a conversation between the oppressed and oppressors. Even though the conversation is often started out of mutual interest, “the first word in this dialog is uttered by the oppressed.”³⁹ A “friend” of the oppressed responds with critical self-examination, and their “response is born of the critical consciousness of those who allowed themselves to be critiqued and who take responsibility for their own consciousness.”⁴⁰ Confessing one’s own complicity as oppressor helps the oppressed continue their own process of conscientization, but in framing this as a response, not the first step, Isasi-Díaz leaves the oppressed as leaders in their own processes.

From this we can identify four major features of solidarity in relationship to ethnography: (1) it requires a commitment to the wellbeing of the community in which we engage; (2) this commitment manifests as some kind of “break” with a theologian’s positions of privilege; (3) it preserves the agency of the oppressed; and finally (4) the theologian dialogs with the community, but must do so while engaging in an ongoing process of humility and reflexivity. The question that my work with the IDD community raises is the question of that “break” with my own social class. How can I voluntarily sacrifice my abled privilege? What does crossing the boundary of that social divide look like? Even as I question this from the perspective of working with the IDD community, there are numerous other social divisions and injustices in which a similar problem arises: I cannot easily shed my white privilege, nor my heteronormative

privilege, or numerous other invisible ways in which I have benefited from structural injustice. Isasi-Díaz's model of dialog for solidarity can help this dilemma to some degree, but this may be one way in which working among people with IDD poses a unique challenge, especially given a long social history of infantilization and "learned helplessness" among people with IDD.⁴¹ I think of Tim's reaction to being included in my research. I must be aware of how his eagerness to be included, eagerness to please, may affect the way he interacts with me in our conversations, those of solidarity and otherwise. This is not to say that people with IDD are never assertive, challenging, or confrontational. Rather, I mean only to draw attention to a breach of power and privilege that must be carefully considered before believing any progress has been made in building a bridge to cross it.

ACCOUNTABILITY

Much of the more recent work on ethnography and theology comes from theologians openly wrestling with their outsider status among the communities they engage in their fieldwork, and accountability plays a large role in being attentive to difference. For the purposes of this argument, I will focus on the practical and concrete suggestions made by Vigen, both in her individual research and collaborative work with Christian Scharen.⁴²

In many ways, the suggestions for accountability continue the image of "dialog" that Isasi-Díaz offered for solidarity. On the most basic level, accountability calls for structuring our research in a way that facilitates trust and maintains the integrity of participants: it lets them speak "the first word" in the conversation. Vigen has also called on ethicists to preserve the agency of their informants by de-centering the academic, theoretical presumptions that we "experts" might bring into the field. She also expresses a preference for the term "collaborators" as a sign of this agency:

Language matters. Is the participant your teacher or an object of study? Hopefully, and most likely, the white scientist who uses the term 'subject' does not think of or treat individuals with whom she is working in any way similar to a lab rat. Yet the choice of terms may indicate whether or not one thinks that the participant has a role in helping them to define what is important to learn.⁴³

Vigen goes on to define accountability with four elements: (1) a commitment to following-up with informants and avoidance of misappropriation and misinterpretation (which Isasi-Díaz also promotes); (2) the obligation to offer descriptions that are rich, honest, and complex; (3) placing the collaborators first; and finally, (4) that the research itself "ought to matter in some way to the positive transformation of society."⁴⁴

Of course, these practices of accountability have limitations. In a response and reflection on Vigen and Scharen's book, Mary McClintock Fulkerson admits to not bringing her own ethnographic research back to the church where she did her fieldwork, Good Shepherd. She argues that she was using an interpretive framework to describe the dynamics of the church which many of the informants would not have had access to, prompting her to question:

...have I crossed the line of 'accountability'? If so, should every interpretation by the ethnographer require assent/collaboration? But these questions are connected to the inevitable re-framings that come with theological/ethical employment of ethnography. Even to 'interpret' what folks without language are communicating, if one had the skills of reading nonsymbolic communication, would be a reframing that could not be safely or adequately confirmed.⁴⁵

Such questions about accountability resonate with my own work. It is broadly accepted that doing ethnographic research entails acts of translation and interpretation, in multiple senses, but what does it mean to translate something into a language that the community of our fieldwork does not speak? Fulkerson's question about people without language, such as people with profound intellectual disabilities, is pertinent to how all people communicate: the nonsymbolic is always at play, not just among people with profound intellectual disabilities.

In their response, Vigen and Scharen admit to the temptation wherein "the researcher might err on the side of too much caution and timidity—in the name of respect and reflexivity— and resist claiming as much expertise, knowledge, or normative authority as he/she ought."⁴⁶ One manner of navigating this comes with the recognition that accountability is not merely about verification: "'bearing witness' does not equate with—or validate as 'Truth'—every/any-thing that informants tell ethnographers."⁴⁷ Vigen expresses this in her earlier work as well: "the point is not to tell every story, but to tell a few with care and attention to detail."⁴⁸

I have spent a lot of time thinking about what shape accountability ought to take for my own project. On one level, there is institutional accountability: promoted by processes like the IRB, and through ongoing conversations with the nonprofit that served as my field site. But how am I accountable to the clients — to Tim? In the time since I went through the consent process, my relationship with Tim has developed enough that I sense he would be unlikely to challenge or correct me in any of the interpretations that I might offer in doing my ethnographic work. Telling his story, "with care and attention to detail" seems to be the very least I can do, but it also feels unsatisfying. Is telling stories, honestly and in all their complexity, enough of a contribution to the social transformation that Vigen calls for?

PARTICIPATORY ACTION RESEARCH

Participatory action research (PAR) is the most direct strategy for connecting ethnographic research to social transformation; while PAR has a couple of different genealogies, at least one of those relates back to Freire himself.⁴⁹ Broadly speaking, PAR involves the community within the design of the research itself: this can involve everything from setting the goals for the research, to changing the questions,

to developing themes that become a part of qualitative interviewing. Though it has been around for nearly half a century, it still does not have a large foothold within either the social sciences or theological disciplines, although practical theology has a greater affinity for action research than other subdisciplines.⁵⁰ PAR makes an appealing partner for liberative theological projects precisely because of its emphasis on the agency of collaborators in fieldwork; moreover, as Browning recently observed, the research is structured such that “solidarity with one another was what came naturally in the project [...] it offered an educational research model that made room for both the insider and outsider.” As Isasi-Díaz called for, it frames the research as a conversation; for the outsiders involved in the research, as Browning identifies herself, the “methodology itself was a reminder that as the researcher, I could never hold the epistemological privilege in the project.”⁵¹

Examples of PAR among people with IDD — theological or otherwise — are few and far between. Social scientists have already been reflecting on the particular challenges that arise in trying to use this model in collaboration with people with IDD.⁵² Some of the questions involve transparency about the actual level of participation and involvement of people with IDD; with appropriate structures of support to facilitate involvement; and with “the extent to which participation in the project has changed the lives of participants.”⁵³ Currently, PAR is often done through partnering with a service provider; but said service providers may also create limits or restraints on the work.⁵⁴ I could not have completed my research within the timeline of my degree program without the nonprofit I partnered with: it provided me a community and connected me with informants who were already invested in issues of disability and community inclusion. To have tried to recruit all those participants on my own without the legitimacy of partnering with the nonprofit would have taken a prohibitive amount of time. Nonetheless, as I indicated in my story above, maintaining appropriate contact with the nonprofit was a struggle, and the tightly bound schedules of the clients I worked with, like Tim, restricted my time not only for observation, but also for interviews and other forms of data collection. Even so, these kinds of structural challenges may be applicable to PAR research in general, not just people with IDD. As I have been asking throughout this section, are the differences of doing ethnographic research among people with IDD ones of degree, or of kind? Is it merely that they need more forms of community support to engage this kind of research, or that the support structures themselves need to be re-thought?

At the center of such a question is the same problem I identified in Freire’s work: whether action research requires a certain set of conceptual capacities that not all people with IDD will have. As one social scientist asks: “if people with intellectual disability need non-disabled allies in the research process how can the integrity of their account be maintained [...] how can we prevent the non-disabled researchers from assuming a dominant role in the research process?”⁵⁵ If the answer to this question is that we cannot prevent the non-disabled from taking a dominant role, that would seem to undercut the essential process of conscientization, and could imperil our ability to engage the epistemic privilege of people with IDD in any sincere way.

One suggestion, made by Christine Bigby, Patsie Frawley, and Paul Ramcharan in their 2014 review of inclusive social science research, has to do with the kind of academic work actually produced:

By working at various levels of abstraction, with multiple layers of analysis and concepts, and producing different types of outputs, the frustrations expressed [...] at the inability to share abstract skills with people with intellectual disability and to produce deeper analysis as part of inclusive research are to some extent resolved. It becomes legitimate, for example, to produce both a stand-alone life story as well as a more analytical and inaccessible interpretative account.⁵⁶

The benefit in a suggestion like this is that it shifts the focus away from what people with IDD cannot do and to questioning what it is we produce, as researchers, that we might be taking for granted. Must the final product of a theologian's work be articles like this very one, steeped in abstraction? This question prompts continued reflexivity about what the end goal of our theological projects might be.

Still, it is not clear that this actually resolves the issues raised by conscientization (although it ought to be said that conscientization is not nearly as integral to action research in social science as it is in liberation theologies). Despite the prompt to consider alternative means of communicating ideas, we are pushed further still to consider the challenge that Fulkerson raised: how to both hear and communicate what is learned from people without language, or more precisely, without a language that we can understand. We must seek a version of participant action research in which their agency (limited and contingent though it may be) is respected, in which their epistemic privilege is taken seriously. The epistemic privilege of the oppressed, by its nature, wants to be received by a listening community filled with insiders and outsiders alike.

This is not an easily resolvable dilemma. Nonetheless, I bring these questions forward because they are important to ask, because they reveal another growing edge for ethnography and theology. Participatory action research holds great possibilities for building on the need for solidarity and accountability in ethnographic work; but in the interest of ongoing critical reflection on our theories and practices alike, we must be aware of the places where the theories underpinning our praxis might continue to exclude. Conscientization is essential for liberation theology methods, and conscientization is, per Freire, reliant on a certain level of conceptual reasoning. For people with intellectual disabilities, communicating to researchers in that register may be very limited, and in some cases, it may not be practically possible. Naming this challenge is the first step towards generating creative solutions.

I still firmly believe that ethnographic fieldwork creates invaluable opportunities for engaging the experiences of people with intellectual disabilities, for bringing them more fully into theological conversations in which they have long been ignored. When theologian-ethnographers speak of the importance of solidarity, accountability, and even mutuality and participation, we must be willing to continually re-imagine what agency, communication, or even knowledge of the world looks like. That is what it will take to keep developing ever more inclusive theologies.

ENDNOTES

1 Christian Scharen and Aana Marie Vigen, eds., *Ethnography as Christian Theology and Ethics* (New York: Continuum, 2011): 60-67; Emily Reimer-Barry, “The Listening Church: How Ethnography Can Transform Catholic Ethics,” in Scharen and Vigen, eds., *Ethnography as Christian Theology and Ethics*, 98; Ada María Isasi-Díaz, *En La Lucha = In the Struggle: A Hispanic Women’s Liberation Theology* (Minneapolis: Fortress Press, 1993): 80-87.

2 Paulo Freire, *Pedagogy of the Oppressed*, Myra Bergman Ramos, trans. (New York: Seabury Press, 1970): 19n1.

3 Nancy L. Eiesland, *The Disabled God: Toward a Liberatory Theology of Disability* (Nashville: Abingdon Press, 1994). Several other major works in theology and disability claim a similar perspective: Sharon V. Betcher, *Spirit and the Politics of Disablement* (Minneapolis: Fortress Press, 2007); Kathy Black, *A Healing Homiletic: Preaching and Disability* (Nashville, TN: Abingdon Press, 1996), and Jennie Weiss Block, *Copious Hosting: A Theology of Access for People with Disabilities* (New York: Continuum, 2002).

4 This is true, and something that Eiesland readily admits to: “To be sure, it would be a worthwhile and much-needed project to examine the experience of persons with intellectual, social, or emotional disabilities within the church. However, such endeavors are outside the scope of this work.” If Eiesland does not intend her work to speak for people with IDD, it is precisely *because* of her dedication to her method, “nothing about us without us.” As someone who does not share the experience of having an intellectual or developmental disability, Eiesland would betray her own convictions in claiming to speak for them.

5 Hans S. Reinders, *Receiving the Gift of Friendship: Profound Disability, Theological Anthropology, and Ethics* (Grand Rapids, MI: William B. Eerdmans Publishing, 2008): 159-169; John Swinton, “From Inclusion to Belonging: A Practical Theology of Community, Disability and Humanness,” *Journal of Religion, Disability & Health* 16, 2 (2012): 172–90.

6 Granted not all who have written liberation theologies of disability have identified with having a disability. Kathy Black’s book, *A Healing Homiletic*, claims a liberationist label, though Black herself does not identify with the Deaf community that she engages in the text. Even as a critic of liberation theologies of disability, John Swinton claims a liberationist agenda in *Resurrecting the Person* (Nashville: Abingdon Press, 2000) and draws from Gutiérrez’s work. Neither author, however, addresses the question of identity in relationship to writing a liberation theology.

7 Clodovis Boff, *Theology and Praxis: Epistemological Foundations* (Maryknoll, NY: Orbis Books, 1987); Gustavo Gutiérrez, *A Theology of Liberation: History, Politics, and Salvation* (Maryknoll, NY: Orbis Books, 1973); Ada María Isasi-Díaz, *En La Lucha = In the Struggle: A Hispanic Women’s Liberation Theology* (Minneapolis: Fortress Press, 1993); Juan Luis Segundo, *Liberation of Theology* (Maryknoll, NY: Orbis Books, 1976).

8 Freire, *Pedagogy of the Oppressed*, 27-28.

9 Gutiérrez, *A Theology of Liberation*, xiv. *Ibid.*, 57. Boff, *Theology and Praxis*, 35-45. Segundo, *Liberation of Theology*, 208-237. Boff, *Theology and Praxis*, 36. Isasi-Díaz, *En La Lucha*, 180. *Ibid.*, 181. *Ibid.*, 202.

- 10 Ibid., 57.
- 11 Boff, *Theology and Praxis*, 35-45.
- 12 Segundo, *Liberation of Theology*, 208-237.
- 13 Boff, *Theology and Praxis*, 36.
- 14 Isasi-Díaz, *En La Lucha*, 180.
- 15 Ibid., 181.
- 16 Ibid., 202.
- 17 Ibid.
- 18 Isasi-Díaz developed this from Freire’s “generative themes” as tools to promote conscientization. Generative themes are roughly defined as “the issues that are important to the person [...] [t]he deep feelings, the emotions around an issue incite the person to actions; they motivate her to take initiative and move out of her apathy.” Ibid., 162.
- 19 Ibid., 164.
- 20 Ibid., 88.
- 21 Freire, *Pedagogy of the Oppressed*, 19-25. It is also worth noting that for Segundo, at least, Freire’s origins with literacy education raise significant questions about the application of conscientization. Segundo argues that conscientization is not the same as literacy: literacy makes one’s life easier, conscientization makes life far more difficult. The motivation for the former will be easier than the ongoing motivation needed to engage the latter. Segundo, *Liberation of Theology*, 210.
- 22 Freire, *Pedagogy of the Oppressed*, 29.
- 23 Ibid., 74.
- 24 Ibid., 75.
- 25 Ibid., 75-76.
- 26 Ibid., 87.
- 27 Ibid.
- 28 Ibid.
- 29 Ibid., 89.
- 30 Both People First and SABE fall under a broader “self-advocacy” umbrella. There are many different forms of self-advocacy groups, with varying levels of influence: People First, for example, has chapters across the US, but other groups stay more localized. For further information on history and for finding local organizations,

see the SelfAdvocacy.Net website: <http://www.selfadvocacy.net>

31 For a description of how People First integrates the nondisabled into their advocacy process, see Joseph Shapiro, *No Pity* (New York: Three Rivers Press, 1994):184-210.

32 The Deaf community offers a historical example of this: until education in Sign was widely available, people born deaf were frequently also labeled “dumb,” simply for lack of language. Once Sign was able to spread through the community, the medical community realized that the Deaf community had the same spread in variation in intellectual abilities as the Hearing community. Hannah Lewis, *Deaf Liberation Theology: Explorations in Practical, Pastoral, and Empirical Theology* (Burlington, VT: Ashgate Pub., 2007): 39-60.

33 The name of Payton, and of Tim, have both been changed to preserve privacy.

34 Todd Whitmore has also made the case for solidarity as a virtue within anthropology as a discipline, which tends to prioritize relativism as its primary moral commitment. See: Todd Whitmore, “‘If They Kill Us at Least the Others Will Have More Time to Get Away’: The Ethics of Risk in Ethnographic Practice.” *Practical Matters* 3 (2010), 1-28.

35 Ada María Isasi-Díaz, “Solidarity: Love of Neighbor in the 1980s,” in *Feminist Theological Ethics: A Reader*, Lois K. Daly, ed., (Louisville, Ky: Westminster John Knox Press, 1994), 78.

36 Gutiérrez, *A Theology of Liberation*, 172.

37 Ibid.

38 Isasi-Díaz, *En La Lucha*, 89.

39 Isasi-Díaz, “Solidarity,” 82.

40 Ibid., 83.

41 Learned helplessness actually has a wide and varied use among cognitive and behavioral psychological theory, but for people with IDD it generally means that the more someone is told “you can’t” do something, the more that person internalizes those beliefs, and judges the self accordingly. Thus, it points to a particularly potent form of assimilation to a dominant ideology that infantilizes most adults with IDD. For a brief historical overview and lengthy list of studies, see: Bruce Overmier, “On Learned Helplessness,” *Integrative Physiological And Behavioral Science: The Official Journal Of The Pavlovian Society* 37, 1 (March 1, 2002): 4–8.

42 Aana Marie Vigen, *Women, Ethics, and Inequality in U.S. Healthcare: ‘to Count among the Living’* (New York: Palgrave Macmillan, 2006). Vigen and Scharen, *Ethnography as Christian Ethics* (2011).

43 Vigen, *Women, Ethics, and Inequality in U.S. Healthcare*, 90.

44 Ibid, 95-96.

45 Mary McClintock, Fulkerson, “Roundtable on Ethnography as Christian Theology and Ethics: Ethnography: A Gift to Theology and Ethics,” *Practical Matters* 6 (2013), 5.

46 Christian A. Scharen and Aana Marie Vigen, "Roundtable on Ethnography as Christian Theology and Ethics: Ethnography Audacious Enough to Witness," *Practical Matters* 6 (2013), 2.

47 Scharen and Vigen, "Ethnography Audacious Enough to Witness," 2.

48 Vigen, *Women, Ethics, and Inequality in U.S. Healthcare*, 108.

49 Glassman, Michael, Gizem Erdem, and Mitchell Bartholomew, "Action Research and Its History as an Adult Education Movement for Social Change." *Adult Education Quarterly* 63, 3 (2013), 272–88; Melissa Browning, "Epistemological Privilege and Collaborative Research: A Reflection on Researching as an Outsider," *Practical Matters* 6 (2013), 8-9.

50 "Theological action research" has made headway in the U.K., particularly through the work of Clare Watkins. As a whole, this approach is oriented towards working within faith communities, in contrast to many of the ethicists included this paper (as well as myself), whose fieldwork took place within communities that did not necessarily have an explicitly unified Christian identity. Nonetheless, Watkins's argument in favor of action research resonates with the integration of theology and praxis that Isasi-Díaz spoke of: "[theological action research] is not simply saying that practices provide data for theological reflection; or that they are, in some vague way, 'theological,' open to theological interpretation. Rather, the fundamental conviction of our theological action research is that, before we even look at practices, they are, of themselves, embodiments of faith seeking understanding: they form a theological voice, or authority, which needs to be listened to as such." Clare Watkins, "Practising Ecclesiology: From Product to Process Developing Ecclesiology as a Non-Correlative Process and Practice through the Theological Action Research Framework of Theology in Four Voices," *Ecclesial Practices* 2, 1 (2015), 35.

51 Browning, "Epistemological Privilege and Collaborative Research," 10.

52 Christine Bigby, Patsie Frawley, and Paul Ramcharan, "Conceptualizing Research with People with Intellectual Disability," *Journal of Applied Research in Intellectual Disabilities* 27, 1 (2014), 3-12. Jennifer Conder, Paul Milner, and Brigit Mirfin-Veitch, "Reflections on a Participatory Project: The Rewards and Challenges for the Lead Researchers," *Journal of Intellectual and Developmental Disability* 36, 1 (2011), 39-48.

53 Conder et al., "Reflections on a Participatory Project," 40.

54 Ibid., 42.

55 A.L. Chapell, "Emergence of Participatory Methodology in Learning Difficulty Research: Understanding the Context," *British Journal of Learning Disabilities* 28 (2000), 41.

56 Bigby et al, "Conceptualizing Research with People with Intellectual Disability," 9.