CANADIAN JOURNAL OF
Disability Studies
Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Consent-as-Method: Capacity to Consent of Cognitively Disabled People and Research Ethics Review

Le consentement en tant que méthode : capacité de consentir des personnes ayant une déficience cognitive et examen de l'éthique de la recherche

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Abstract

Informed consent is a core ethical principle informing research conduct. Yet, normative consent culture–often grounded in ableist understandings of capacity, rationality, and independence–exclude people with cognitive disabilities. The adjudication of consent capacity in research can be a source of harm, requiring researchers to enact lateral ableism against research participants and, potentially, themselves. As anthropologists conducting ethnographic research with intellectually and developmentally disabled participants in Canada and the U.S., we argue for the creation of an anti-ableist consent culture in the context of research. In exploring alternative ways of doing consent, we turn to the etymology of "feeling-with"–the collaborative, multi-sensory, and embodyminded experience of giving, getting, and living consent–as this can inform more ethical and anti-ableist notions of consent.

We propose "consent-as-method" as part of a larger conversation about the methodological challenges and potentials of doing research *as and with* people with non-normative bodyminds. Drawing on our research and lived experiences of cognitive ableism, we theorize consent practices that consider disabled people's felt knowledges of denial of consent capacity and coercion to inform anti-ableist, relational ways of doing consent. We focus on capacity because it structures the kinds of bodyminds that are seen as capable of being consenting subjects. We build on existing scholarship that considers how critically engaging with disability as a lived experience and orientation fundamentally crips our methodological and ethical commitments. Attending to consent capacity through consent-as-method treats consent as not only a means to an end but as an anti-ableist research ethic.

Résumé

Le consentement éclairé est un principe éthique fondamental qui guide la conduite de la recherche. Pourtant, la culture normative du consentement – souvent fondée sur une compréhension capacitiste de la capacité, de la rationalité et de l'indépendance – exclut les personnes ayant une déficience cognitive. La décision sur la capacité à consentir à la recherche peut être une source de préjudice, obligeant les scientifiques à adopter un capacitisme latéral contre les participantes et participants à la recherche et, potentiellement, contre leur propre personne. En tant qu'anthropologues menant des recherches ethnographiques auprès de participantes et participants ayant une déficience intellectuelle ou développementale au Canada et aux États-Unis, nous plaidons en faveur de la création d'une culture anticapacitiste du consentement dans le contexte de la recherche. En explorant d'autres façons d'obtenir le consentement, nous nous tournons vers l'étymologie du « sentir-avec », c'est-à-dire l'expérience collaborative, multisensorielle et incarnée consistant à donner, obtenir et vivre le consentement, car cela peut alimenter des notions plus éthiques et anticapacitistes de consentement.

Nous proposons le « consentement comme méthode » dans le cadre d'une conversation plus large sur les défis méthodologiques et les potentiels de la recherche avec des personnes dont le corps et l'esprit sont non normatifs. En nous appuyant sur nos recherches ainsi que nos expériences vécues en matière de capacitisme cognitif, nous théorisons les pratiques de consentement qui prennent en compte les connaissances ressenties par les personnes handicapées en matière de déni de la capacité à consentir et de coercition pour façonner des manières relationnelles et anticapacitistes d'obtenir le consentement. Nous nous concentrons sur la capacité parce qu'elle structure les types de corps et esprits considérés comme capables d'être des sujets consentants. Nous nous appuyons sur les savoirs existants qui considèrent à quel point l'engagement critique envers le handicap en tant qu'expérience vécue et orientation rend fondamentalement crip nos engagements méthodologiques et éthiques. En nous intéressant à la capacité de consentir via le consentement comme méthode, nous considérons le consentement non seulement comme un moyen pour parvenir à une fin, mais aussi comme une éthique de recherche anticapacitiste.

Key Words
Consent; Capacity; Research Ethics; Intellectual and Developmental Disability; Cognitive Disability; Autism; Cognitive Ableism; Research Methods

Mots clés
Consentement; capacité; éthique de la recherche; déficience intellectuelle et développementale; handicap cognitif; autisme; capacitisme cognitif; méthodes de recherche

Introduction

"I would like for them to articulate to me what exactly they are afraid of." This is the wish Long posed to Quinn after meeting with an administrator from their Institutional Review Board in March 2022. "They asked me if I was aware that not all autistic people can consent to research," Long texted. "I would love for them to explain that to me in detail," Quinn replied; "Ask them: 'Can you be more precise? Under what conditions?' Honestly, they probably don't really know what they're talking about, unfortunately." As scholars conducting research involving intellectually and cognitively disabled participants, conversations such as this one were frequent as we navigated the way our universities responded to research involving participants with cognitive disabilities.[1] Granted, hand-wringing over the consent capacity of cognitively disabled people and their subsequent ability to participate in research is rooted in histories of scientific exploitation and worries about participant vulnerability (Iacono 2006; McDonald and Kidney 2012) . Nonetheless, these concerns require researchers to engage in ableist practices towards themselves and participants.

Critical disability studies scholars have a responsibility to challenge ableism, including in the institutional spaces that shape the possibilities of our research. We write as anthropologists conducting ethnographic research with disabled participants. Quinn's fieldwork takes place in Montreal, Quebec with intellectually disabled participants, their caregivers, and staff at a day centre to explore how normative consent culture often serves to regulate the sexual lives of intellectually disabled people. In turn, she examines how this regulation of sexuality regulates

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[1] "Intellectual and developmental disabilities" is a term used across our field sites, in both person-first and identity-first variations, which we alternate throughout the piece. Following McKearney and Zoanni (2018), we analyze our specific research encounters through a theorization of 'cognitive disability' to bring together a variety of intellectual, mental, and learning disabilities such as Down Syndrome, autism, dementia, and brain injury. Through using cognitive disability as an umbrella term, we do not reify a mind-body distinction, but rather work to draw attention to how cognitive ableism shapes ideas about capacity to consent.

other spheres of intimate life, such as friendship, parenthood, and cohabitation. She uses the language of ‘anti-ableist consent culture’ to explore how disabled people challenge presumptions of incapacity. Long uses knitting as a creative research strategy to expand representational practices of autism in the context of the autistic self-advocacy movement in the United States. They work to materially represent autistic adulthood in the face of the existential erasure of autistic people. While our projects differ in many ways, we share concerns regarding the cognitive ableism we encountered, directly and indirectly, as it relates to the ethics review process and informed consent.

Our experiences suggest that consent is an important methodological and theoretical arena, particularly with regards to conducting research with people with cognitive disabilities. While we recognize that critical disability studies researchers come from different disciplinary paradigms, we encourage a shared orientation to thinking about how ableism travels through our institutional spaces to shape research participants that allegedly “lack consent capacity.” These participants face cognitive ableism, “a prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the potential for them) against those who are believed not to actually or potentially possess them” (Carlson 2001, 140). If a critical disability methodology “seeks to radically disrupt the multiple sociopolitical ideologies that assign more value to some bodies and minds than to others” (Minich 2016, para. 11), then critical disability studies researchers must reckon with determinations of consent capacity.

Doing research is doing consent. We cannot do research without doing consent. And there are many ways to *do* consent. In Canada and the United States, university-based researchers are subjected to standard sets of requirements for obtaining informed consent from research participants. Most commonly, doing consent in research looks like a signature on a protocol form or a verbal statement that one has reviewed information about the study, including potential benefits and risks, and agrees to participate. Presumably, consent is revisited throughout the research project and can be retracted. Recognizing how cognitively disabled people are excluded from normative consent cultures more broadly, we propose doing consent in research differently. We examine consent through etymological roots of "feeling-with,"–the collaborative, multi-sensory, and embodyminded[2] experience of giving, getting, and living consent–as this can inform more ethical, anti-ableist notions of consent. The durational implications of "feeling-with" stress that consent is ongoing beyond simply revisiting an informed consent document throughout the length of the project. Rather, an anti-ableist culture of consent imbues the broader research relation. In turning away from the eventfulness of informed consent as a document, a bureaucratic portal into a research relation, consent-as-method situates consent as relational from the start. However, this consent relationship is pre-emptively limited by institutional ethics boards through ableist assumptions about capacity. Thus, the bodyminds allowed to engage–and how they engage– in the research/consent relationship are foreclosed before our institutions even acknowledge our research has begun.

In viewing consent as foundational to methodology, we propose "consent-as-method" as part of a larger conversation about the methodological challenges and potentials of doing research as and with people who have non-normative bodyminds. We contend that consent-as-method fundamentally shifts expertise about the determination of capacity to those who have profound experience of being denied access to consenting relations. Rather than assuming institutional ethics reviewers' capacity to adjudicate the consent capacity, consent-as-method

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[2] Embodyminded is a term used by Sara Acevedo Espinal (2020) who writes "from the perspective of an autistic writer who lives with chronic illness, this spinoff aims to signify the somatic experiences of neurological embodiment–in a way, this is to represent the soma of a brain that is the body and a body that is the brain" (268).

takes the institutional ethics exchange as an opportunity to "crip" ableist assumptions about consent. By this, we mean proposing methods that meet the access needs of researchers and participants, making consent capacity possible. Attending to consent capacity through consent-as-method treats consent as not only a means to an end but as a research ethic. Though informed consent is often treated as an ethical imperative, a consent paradigm rooted in ableist requirements of capacity can cause harm. As we discuss elsewhere, denying the capacity to consent is violence, and informed consent as enshrined in ethics protocols often requires "researchers to enact ableist protocols against our disabled participants and ourselves" (Quinn and Long 2022). Thus, consent-as-method works alongside "cripping ethics," that is "orienting to disabilities, not as differences that delimit or confound ethical processes, but as complex embodiments, including visible and invisible mind-body attributes, which, through challenging the normative standard of the human undergirding conventional ethical frameworks, expand possibilities for ethical conduct by opening the field of decision making in research" (Mykitiuk, Lamarre, and Rice 2018, 258).

Consent-as-method contributes to broader conversations about how we do disability studies research, and even research more broadly. As Temple Jones notes in their recent article about the harms of research ethics review: "the presence of disability in research, and disabled people as (and alongside) researchers, has the potential to reshape, and even crip, qualitative work by continually heightening standards of accountability in the field" (2021, n.p.). At stake is not simply how to "include" disabled participants in our existing research protocols but how critically engaging with disability fundamentally alters our methodological and ethical commitments. As Price and Kerschbaum (2016) argue in the context of qualitative interviewing, "disability crips methodology." In other words, disability and access needs—both of the participants and researchers—expose and challenge normative research frameworks. Our methodologies–how we engage research questions with participants–are mediated by institutional norms. Prior to discussing these norms, it is helpful to examine the ableism that underlies consent relations more broadly.

Consent and Ableism

Quinn approaches informed consent and research relations through theorizing about infrastructures of intimacy and sexual (in)access in the lives of intellectually disabled people. Quinn links questions of interpersonal consent to a broader set of concerns about consent culture(s) and ableism at societal level, within the institutions disabled people frequent, and in addition to sexually intimate relations. In recent years, particularly since the #MeToo movement, the giving and getting of consent has been central to how we understand good and bad sexual relations giving way to what some scholars have deemed the ‘age of consent’ (Fischel 2016, 2019; Gilbert 2018; Beresford 2014). “Yes means yes” models of consent are increasingly centered in discourses around what constitutes legal, moral, and ‘good’ sex—and legal, moral, and ‘good’ social relations in general.

Consent is not only an interpersonal act that delineates legal from illegal sex; it is a foundational concept at the heart of western notions of sociality and co-existence in opposition to trespass and coercion (Miller 2010; Kleinig 2010; Drakopoulou 2007). The moral force of consent to transform unwanted acts and relations into wanted ones is grounded in a genealogy of morality centered on autonomy and competence, stemming from social contract theories of Thomas Hobbes and John Locke (Drakopoulou 2007; Kleinig 2010; Beauchamp 2010). Consent theorists have previously addressed the way that the subjects of consent relations are presumed to be male and white, revealing how the ethics of consent depend on racialized and heteronormative presumptions (Mills 1997; Pateman 1988). The consenting individual is presumed to have decision-making capacity and be engaging voluntarily as a sovereign self, free from coercion. In short, Quinn argues that the consenting subject is presumed to be non-disabled. Situating consent culture within this lineage makes the limits of a consent culture more visible, showing how it is grounded in conditions that elide interdependence and neglect the coercive power of systemic ableism.

Cognitively disabled people frequently live at the intersection of unmitigated surveillance and coercion. These experiences range from fierce protectionism from caregivers and hired aides (Shuttleworth et. al. 2012; Kulick and Rydström 2015; Carey and Gu 2014), to the slow wearing down of one's resolve and self-confidence that (can) come from years of supported decision making (Hollomotz 2014). The harm of coercion, at its most extreme, manifests in eugenic procedures in practices, such as the forced sterilization of disabled people (disabled women especially) (Kittay 2011; Desjardins 2012; National Women’s Law Center 2022) and the forced segregation of cognitively disabled people into institutions (Ben-Moshe 2020; Ben-Moshe, Chapman, Carey 2014). Existing research and Quinn’s ethnographic findings suggest that, even when living in community settings, cognitively disabled people are often unable to access their own bank accounts, transportation, or extracurriculars without direct support and permission by a caregiver, personal attendant or service worker (Avery 2019; Kulick and Rydström 2015; Levinson 2010). While these overt examples of coercion evidence the inaccessibility of consent culture to intellectually and developmentally people, there are more covert–though still insidious–ways that their consent capacity is denied due to ableist presumptions.

In Quinn’s fieldwork, caregivers rarely operate from a place of malice, and the decisions reached tend to benefit the disabled adult. Nonetheless, this results in a slow wearing down of the cognitively disabled person's access to consent culture and the full realization of their capacity to make decisions. Quinn observed numerous instances of informed consent being glossed over by staff and caregivers at a day centre, presumably to speed up bureaucratic processes and ensure access to services or funds. Staff support clients with coordinating a variety of internal and external services that support daily living. In one instance, a private paratransit company notified a client that their pickup time after work would be changed by a half an hour. The client's approval was needed to confirm this change. According to a staff member remarking on the need to complete paperwork quickly for the disabled client's sake: "She needs this service, she knows that, we all know that. The deadline is tomorrow so there's no time to go over it with her. I'll just sign her up and we'll figure it out." Those with authority over day centre clients argue that the need for expediency and efficiency in the face of bureaucracy justifies the harm of uninformed consent. Staff approve the schedule changes knowing that, fundamentally, the disabled client has little choice and requires transit to maintain their employment. Some staff evaluate the risk of missing out on services to be of a higher priority than obtaining informed consent for every signature–which in this case amounts to decisions-making about bodily autonomy and mobility.

The harm caused by the quick turnaround times for consent-getting demanded by service bureaucracy is further exacerbated by legal and practical gray areas around the obligations and responsibilities pertaining to the informed consent of the disabled individual who is under a protection regime.[3] Ambiguity and legal confusion around the extent to which a person under a protection mandate has the right to make decisions of daily living effectively results in an assent model of decision making. As such, their decision-making capacity is cast in doubt and assigned

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[3] We use the term "protection regime" to refer to the variety of legal mechanisms in place that limit the autonomy and decision-making capacity of intellectually and developmentally disabled people in the United States and Canada such as conservatorship, guardianship, and curatorship.

to an authority figure with presumed capacity. To be clear, these decisions are often necessary to navigate the systemic demands of caregiving that prioritizes the expertise of parents and other caregivers over the wants and desires of the disabled person (Carey, Block, and Scotch 2020).

There is no normative consent culture for people who are presumed to be incapable of making decisions or whose access needs are in friction with the ableist demands of institutions. This is not to say that cognitively disabled people are not living and relating consensually (Gill 2015; Campbell et. al. 2020; O'Connell 2019) – but the doing of that consent will be different for people who are non-verbal, who do not conform to "compulsory able-bodiedness" (McRuer, 2006), and whose ways of processing information and responding to the world do not align with compulsory able-mindedness. Attending to the ableism imbued in how we understand consent and the consenting individual allows us to ask how the chronic lived experience of coercion, presumed incapacity, and dependence might make way for an anti-ableist consent culture.

Consent Capacity in the Context of Research Ethics Review

Ethical possibilities for research, particularly with human participants, are constrained by various levels of policy, interpreted, and applied at the institutional level by entities such as Research Ethics Boards (REB) and Institutional Review Boards (IRB)[4]. These ethics boards review proposed research protocols for compliance with ethical norms, namely *respect for persons, beneficence/concern for welfare,* and *justice*. Conceptions of research risk and benefit guide the evaluation of research, with the detail of review tied to the level of perceived risk. The review process may require that researchers amend elements of their proposed research protocol, a process which can be lengthy. Particularly for junior researchers who are on tight timelines and

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[4] For the purpose of this paper, we will refer to REB and IRB collectively as institutional ethics boards or simply, ethics boards.

have limited access to funding, the repeated revisions can pose a significant barrier. This may result in research projects being unable to proceed as envisioned, or at times, unable to proceed at all without major modifications that fundamentally alter the research goals and commitments of the researcher. As Santinele Martino and Fudge Schormans note (2018), the proposed amendments may involve not talking to disabled people at all. Thus, while ethics boards are by no means the only gatekeepers in academic research, their role in adjudicating ethical standards can prove a major hurdle and dictate what types of research programs and relationships are allowable. While many of our peers bemoan the cumbersome, bureaucratic processes that poorly align with the on-the-ground realities of conducting research with human subjects, we are especially concerned with how these processes treat research with disabled participants, particularly those with intellectual and developmental disabilities.

In doing so, we add to a critical literature that approaches ethics review as a process whose purpose is not necessarily primarily to protect the wellbeing of so-called “human subjects” but "to shrink the vistas of legitimate research to those forms that support the tenets of neoliberalism itself: the positivist, the quantitative, the experimental” (Chin 2013, 201). As a space for shaping research to institutional values, ethics review becomes a site of academic ableism. Including disabled people in any part of research, especially those with cognitive disabilities, challenges normative institutional ethics (Temple Jones 2021, Santinele Martino and Fudge Schormans 2018; McDonald and Kidney 2012). We take seriously the importance of determining benefits and risks associated with any research program, as well as the potential for harm and exploitation. Yet we investigate the degree to which, “ethics review frameworks remain rooted in biomedical epistemological biases that best serve researchers and lead to barriers in including intellectually disabled people in research about themselves" (Temple Jones 2021, n.p.).

It is of course possible to include cognitively disabled research participants ethically and consensually (e.g., Hughes and Santinele Martino 2023; Cascio and Racine 2019; Jones 2008; St John et. al 2018; Cameron and Murphy 2006; Coons and Watson 2013; McCarthy 1998). Together, this body of scholarship suggests best practices for those working with intellectually and developmentally disabled people. For example, protocols should allow for access needs for both researchers and participants, such as considering that access workers may need to be involved in the research relationship and that consent forms might be better understood in an easy read or plain language format. However, it is noteworthy that institutional permission is required to enact these steps in the first place. Because of the highly bureaucratic and opaque nature of institutional ethics review, it is tempting to understand it as simply a university insurance policy–a checkbox to be achieved prior to the commencement of the *actual* ethics of research on the ground. And while undoubtedly ethics review cannot account for the nuance of lived ethical relations as they unfold, we contend that institutional ethics review is a crucial site for anti-ableist efforts and education.

In Canada, the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2022) is the standard for ethical research practice. The statement is a joint policy drafted by the Interagency Advisory Panel on Research Ethics, formed in 2001 by the three research funding agencies of the Government of Canada.[5] Any institution that receives federal funding from these agencies is required to comply with the TCPS2. The policy outlines (in)appropriate inclusion and exclusion guidelines with special considerations for research

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[5] The Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC)

involving women, children, the elderly, and participants who lack decision-making capacity, defined as those who cannot consent for themselves, such as children or people with cognitive impairments. Generally, the inclusion of those who are unable to consent "should generally be limited to research of minimal risk" (TCPS2 2022, chapter 4, article 4.6). While disability identity alone should not trigger full board review (TCPS2 2022), anecdotal evidence from researchers across Canada working with disabled participants suggest it often does, particularly when the disability in question is perceived to entail mental incapacity. While the policy intends to prevent inappropriate exclusion, the recommendations and framing set up researchers to avoid research populations, themes and questions that might be assessed as high risk. In Quinn's case, the combination of population and topic (cognitive disability, sexuality, intimacy, consent) triggered a full board review.

Researchers should be honest and accountable for conditions that cause risk; categorically treating a research project as inherently more risky simply because it involves disabled people is stigmatizing. "Minimal risk" in both Canada and U.S. policy is defined as no more risk than is encountered in one's daily life; however, Long's institution described this in terms of the risks encountered by a "normal healthy person." This unfortunate phrasing gets at a likely unintentional point: disabled people may encounter a significant level of risk in the context of their lives, including the harm that stems from the denial of capacity in the first place. This does not mean, of course, that disabled people should be subjected to unnecessarily high risk in research; however, we suggest that disabled people be allowed the dignity of risk in situations that create consent capacity (Perske 1972; Wolpert 1980).

In the U.S. context, the major policy guiding ethics for human subjects research is known as the Common Rule, a set of regulations adopted across U.S. federal agencies. The Common

Rule is based upon the recommendations in the Belmont Report (1979) that outline the basic ethical principles for biomedical and behavioral research and guidelines for implementing them. The Belmont Report notes that mental disability may impact one's ability for self-determination and may limit one's ability to comprehend the risks and benefits of research. Until 2018, the Common Rule noted that "mentally disabled persons" require special consideration as research participants because they are "vulnerable to coercion or undue influence" (U.S. Department of Health and Human Services 2009, §46.111). This blanket designation of vulnerability, as well as the term "mentally disabled," were criticized, including by disability studies scholars (Patterson and Block 2019), and the current version of the Common Rule instead refers to "individuals with impaired decision-making ability." In Long's experience, this new category maps closely onto disability through ableist presumptions of capacity.

Ethical guidelines such as the ones we encounter in our Canadian and U.S. contexts result from of histories of exploitative research, including research with disabled people. As Teresa Iacono puts it, "Knowingly or not, every researcher submitting a proposal to a research ethics committee does so in the shadow of the Willowbrook study and other similarly infamous experiments conducted with individuals who were vulnerable because of their limited cognitive capacity and/or being in a powerless position" (2009, 173). This history has resulted in a protectionist stance that often leads to unnecessarily cumbersome layers of protection and the exclusion of cognitively disabled people from research (Martino and Fudge Schormans 2018), along with the institutionalization of the doctrine of informed consent (grounded in compulsory abled-bodied/minded ways of being) as the singular way of doing consent (Bell 2014).

Consent and Capacity

Though it has been vigorously critiqued, informed consent is a core ethical principle informing research conduct. Yet, normative consent culture excludes disabled people. To argue for the creation of an anti-ableist consent culture in research, we focus on how capacity structures the kinds of bodyminds that are seen as capable of being consenting subjects. Enduring anxiety about the capacity of intellectually disabled participants limits participation in democratic society (Clifford Simplican 2015), an argument we extend to normative research ethics. For example, in describing informed consent, the Belmont Report (1979, Part C Section 1) notes that: "Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them." This principle of respect ties informed consent to judgment of capacity. As noted above, recent policy changes in the U.S. have shifted from blanket categorizations of disability as vulnerability to the language of "decision making capacity." While some scholars welcome this change, arguing that "the focus on *capacity to consent* and *power to resist manipulation* are more helpful dividing lines, not disability or impairment categories" (Patterson and Block 2019, 73), we argue that "capacity to consent" remains closely shaped by ableism. Able-bodiedness depends on and coalesces with able-mindedness and a notion of the capable mind that can reason and reflect in normative ways (Egner 2019). Our experiences lead us to be suspicious of "capacity" as an equally ableist neoliberal strengths-based reframe of "vulnerability."

Long encountered the determination that their participants potentially lacked consent capacity solely on the basis that they were autistic. Once this suspicion was raised, Long was forced to complete an initial section of the application on "adults lacking capacity to consent," which asked how and why subjects may lack consent capacity. "Because the ethics reviewer said so,” was a tempting response to the circular logic that expected the researcher to repeat the institution’s concerns back to them. Instead, pragmatics required explaining how Long’s proposed participants did in fact have capacity, an argument that left unchallenged the initial assumption that autistic (and other people with intellectual and developmental disabilities) inherently have suspect consent capacity.

Notably, the blanket suspicion of consent capacity was applied exclusively to research participants. Long could not help but wonder how, if involving autistic research participants required special approval to vet their consent capacity, autistic researchers were considered able to assess consent capacity or even be allowed to conduct research at all. This irony became especially pronounced when, after revision, Long’s approved method for determining participants’ consent capacity was to question participants about the research protocol to double-check understanding. The ethics board was satisfied that if Long’s participants could accurately repeat facts from the consent form signed prior to the interview, such as the approximate duration of the interview, they were providing adequately informed consent. What we want to highlight in sharing this detail of the review process is that Long’s cognitive capacity (as an autistic person) to administer this proposed pop quiz at the beginning of each interview–much less their ethical desire to actually do so–went unscrutinized. To actually follow through on the pop quiz amendment would have made Long complicit in lateral ableism against fellow autistic people under the guise of ethical informed consent.

How ethics boards approach these types of research proposals will vary; however, it is our experience that researchers are encouraged to consider studying alternate groups of people (e.g., non-disabled parents and caregivers of disabled people rather than disabled people themselves) or are forced to justify that the proposed research participants do indeed have capacity (Santinele Martino and Fudge Schormans 2018; Santinele Martino 2022). “Capacity,” then, operates as the dividing line that allows for cognitive ableism. The move from blanket designations of “vulnerability” that encompass all disabled people to blanket suspicions of incapacity for those with intellectual and developmental disabilities creates a hierarchy of disability. This hierarchy is furthered by the requirement to argue for the capacity of intellectually and developmentally disabled research participants. The fear of intellectually and developmentally disabled people’s presumptive incapacity forces researchers to argue that participants are not disabled or at least, “not that disabled,” reinforcing the specter of a threshold of “severe disability” beyond which participants are no longer includable. In order to receive ethical approval, the researcher becomes complicit in enacting lateral ableism by reinforcing prejudice towards one group of disabled people for the sake of another. Cognitive disability is associated with a lack of reason and coherence, a lack of capacity for symbolic thought, incompetence, and irrationality which marks cognitively disability subjects as childlike, as “on the outermost limits of human existence” (Erevelles 2002, 7).

Whereas “vulnerability” is immeasurable, “capacity” is likewise vague and yet evokes an authoritative medical and legal judgment that can be determined through established norms. Determination of capacity is a form of institutionalized power operating through the imposition of the researcher’s authority. The researcher is tasked with the violence of deploying an individualized judgment. The capacity of cognitively disabled people is brought under scrutiny when they are positioned as research participants; however, the decision-making capacity of those within the research institution, including the ethics reviewer, is unmarked and unquestioned. Positioned within the supposed cognitive superiority of the institution, the researcher is asked to make decisions regarding the decision-making capacity of participants, yet the researcher’s capacity to do this is assumed simply by virtue of their academic location. We note this not to argue for capacity assessments of researchers, but to point out how researchers are positioned as cognitively superior to research participants. Such a distinction is especially harmful in contexts where “researcher” and “participant” are located within the same communities. The research ethics review of capacity requires researchers to enact ableism against research participants and, potentially, themselves.

While certain bodyminds are inherently assumed to be capable, other bodyminds have their capacity subjected to a much higher degree of scrutiny. “Capacity” offers a nebulous, malleable term that can be applied in ableist ways throughout research ethics review. While the capacity of research participants among the general population is rarely questioned, even though this population is by definition neurodiverse, research specifically including participants who are identified as cognitively disabled will often raise concerns about consent capacity. Here, the ethical imperative put forward by disabled self-advocates of “nothing about us without us” (Charlton 1998) hits a roadblock.

Consent as feeling-with

The mutuality suggested by the adage “nothing about us without us” (Charlton 1998) can suggest ways of doing consent that counter ableist logics of coercion. Revisiting the Latin etymology of the term 'consent' is instructive here, opening new possibilities for theorizing and doing consent across cognitive differences. The prefix *con*, meaning ‘together’, joins with *sentire,* or ‘feel’. Side by side, these root words tell us that doing consent might be about feeling together. Given this possibility, consent-as-method requires mutual attention to the felt sense of giving one’s approval or permission to proceed. Or rather, the embodied knowledge that comes with feeling ignored. In ethics protocols, consent has largely been reduced to a written and/or spoken (dis)approval to participate. How might consent be understood through feeling together, instead of, or in addition to, particular modes of thinking together? Embodied forms of knowledge are generative elements of a disability epistemology, without being subsumed by a hierarchy of knowledge types. An intellectually disabled person's capacity to consent might also be rooted in a deep and extensive embodied awareness expertise about how giving and getting consent feels.

Through consent-as-method we are asked to consider what consent to research feels like. Intellectually and developmentally disabled people are accustomed to being touched and prodded by doctors and specialists, with functional touch, as opposed to desire-based touch that feels good (Erickson 2007). In order to access services, they are required to share and reshare intimate details of their lives and mental states. Their feelings are overridden in favor of eternal expertise, if considered at all. "Forced intimacy" is "the common, daily experience of disabled people being expected to share personal parts of ourselves to survive in an ableist world" (Mingus 2017, para. 1). Under these conditions that deny consent opportunities, people with intellectual and developmental disabilities have developed a felt sense of transgression and trespass. As one of Quinn's participants explained, "I hate doing stuff that feels bad," pointing to the ways that intellectually and developmentally disabled people are often coerced into a perpetual state of feeling bad and doing it anyway.

Consent-as-method is about actively creating ways to apply the felt knowledge of coercion and cultivate space for good feelings around consent. For Quinn, consent-as-method required identifying concrete examples of consent and coercion in the lives of potential research participants. In weekly focus groups with participants, Quinn asked participants to provide synonyms for 'consent' and discuss what each of those terms felt like. "What does it feel like to be listened to? To be respected?” “What does it feel like when your feelings are not considered? When Quinn asked participants what consent is and is not, the group talked about what consent, or the transgression thereof, feels like. One participant recalled an ‘icky feeling’ whenever the driver of her adapted transport vehicle would complement her, or when he touched her lower back as she climbed onto the bus, or told her in explicit detail about his weekend exploits as they drove to her medical appointment. Another participant talked about the sick feeling in her stomach every time she was reminded to take her psychiatric medication, the medication she was not interested in taking, the medication she was taking because the therapist said that her ‘outbursts’ were disproportionate and disruptive to the other occupants of her group home. Quinn and her interlocutors developed a shared language around consent but especially a felt sense that they could draw on to identify when they were approaching their boundaries, feeling uninformed, or at worst, feeling coerced.

Quinn worked with participants during weekly social groups to identify terms and feelings that individuals were already using to explain when their consent had been honored and denied. Participants noted their familiarity with bad (non)consent compared to the infrequency of feeling heard, safe, respected, considered. Despite fewer opportunities to feel what affirmative and even enthusiastic consent feels like, the intensity of the associated feelings was easy to express and participants did this through visibly releasing tension in their bodies, stimming, smiling, wrapping their arms around themselves, and sighing with relief. One participant, while blowing over her lasagna at the weekly community dinner, said that giving consent when you really mean it feels like a warm hug.

Focusing on moments of disabled joy, even minor moments, re-shape knowledges of disability that are dominated by the “suffering slot” (Robbins 2013). Tired of reading descriptions of autistic people as having disordered emotion, Long's fieldwork sought to find ways of feeling-with autistic people that opened new representational possibilities for autistic experiences. Aware of the ableism and violence that inflects so much of autistic people's lives, Long chose to focus on autistic interests and passions. They wanted to highlight moments of autistic joy that exceeded diagnostic descriptions of what it means to be autistic. Long decided to turn their own passion of knitting into part of their research method as a creative way of representing autistic livingness. Connecting with participants to share each other's interests, celebrating enthusiastic info-dumping, and learning about new passions resulted in modes of feeling-with that challenged conventional narratives of autism.

While engaging in their research felt good, Long's efforts to get their institution's consent to engage in research felt decidedly bad. Despite initial meetings with the IRB to explain that this research was not a behavioral intervention on autistic people and to smooth over any other misunderstandings prior to submitting the research protocol, Long's protocol was returned without further review on the grounds that their participants were vulnerable because of the potential to lack consent capacity. Though not intended to be a project about consent, per se, ableist notions of consent and capacity shaped the early stages of implementation and invited further theorization of institutional ableism.

***Doing* Consent-as-method**

While critical disability studies approaches to capacity sharply trouble consent beyond critiques of autonomous individuals, it remains that consent is something that must be done. For those of us in academia doing research with people whose cognitive capacity is challenged, there is little choice but to find ways to exist within institutional requirements and definitions of "ethics" that elide anti-ableist practices. Though a "best practice" of consent may rarely be possible in these conditions, we do believe that there is space for better practices through the enacting of consent as a methodological commitment.

First and foremost, we emphasize that denying the capacity to consent is violence; we must create alternatives that are less harmful. Consent-as-method is a research ethics practice based in anti-ableist consent culture. Consent here is thus more than an exchange, contractual or otherwise, but a way of being together. It is understanding the research encounter as a relationship wherein we come together with histories of coercion, extraction, and harm–and with expertise, knowledge of pleasure, and capacity. Moving away from consent as an exchange and instead as a relation allows us to consider the embodied and felt sense of ongoing informed consent.

By attending to felt senses we do not intend to imply that consent is either experienced as good or bad. Entrenching this binary further serves existing normative consent culture that suggests an enthusiastic yes is the only affirmative mode of giving and getting consent. An anti-ableist consent practice acknowledges feelings of ambivalence, confusion, and ambiguity. In Quinn's field site, feelings of ambivalence were treated with care, as a gut signal that those involved in the consent relationship might be feeling uninformed or incapable. Rather than taking that as an indicator of incapacity to consent, it became an opportunity to slow down, step back, re-explain and make more-concrete the topic or discussion at hand. For Long, it meant recognizing how stories of autistic joy also referenced violence. Sometimes this violence was spoken (or typed), and sometimes it was glossed over. Respecting consent meant allowing participants space to tell stories of feeling bad, while also acknowledging when the bad feelings went unmentioned. These moments deepened our knowledge of each other's capacities and made gauging whether discussion felt safe and comfortable easier over time. Making opportunities to feel and stay with ambivalence and uncertainty is crucial to how we understand consent-as-method.

Our experiences evidence of alternative practices for doing consent. In assuming capacity and disability expertise (Hartblay 2020), we align consent-as-method with Black and Indigenous discussions of anti-racist methodologies that create alternative modes of relationality through attending to how knowledge is made in contexts of ongoing violence and dispossession (Liboiron 2021, McKittrick 2021, Smith 2012). Starting from the belief that consent is possible resists reinscribing the disabled bodymind as already deficient and incapable. While critical disability studies closely attends to ableism, we want ways of doing research that go beyond detailing violence. Research with disabled communities has been both damaging and damage-centered. “In a damage-centered framework, pain and loss are documented in order to obtain particular political or material gains” (Tuck 2009, 413). Feeling-with allows us to go beyond strategic uses of pain and loss to think about different sources of capacity that can inform more ethical relationships. In keeping with critiques of damage-centered research, we offer our experiences here not with a focus on the harms we have encountered but with the hope of providing generative examples of consent practices that reduce harm when conducting research with participants labeled with cognitive disabilities.

As researchers, we are put into positions where we argue for the capacity of our research participants, and thus acknowledging the need for accommodations can feel as though we are adopting the institutional viewpoint that our participants pose a collection of “challenging-to-work-with” deficits. We can recognize that disability impacts people’s lives in real ways while also resisting infantilizing, ableist stereotypes. Critical disability studies teaches us not to shy away from disability and acknowledge our shared vulnerability and interdependence. From this perspective, we contend it is not ableist to acknowledge access needs. When we start with assuming that consent capacity is possible, we can shift our focus to supporting consent capacity and reducing the harm caused by normative consent culture. Consent-as-method involves accounting for the access needs of everyone involved in the research project. This position fundamentally challenges the presumption that ethics reviewers and researchers are not disabled. We are all participants in the research process with changing and variable expertise around consent capacity.

Consent-as-method orients us to the knowledge of those with lived experience of having their consent capacity denied, those who have the expertise to help us think about doing consent differently. We propose that the expertise of those very people be centered in determining consent capacity and how consent to research will be achieved, negotiated, and retracted. Through their exposure to and imbrication in histories of coercion and presumed incapacity, cognitively disabled people have significant insights that should inform how institutional ethics boards theorize and adjudicate consent protocols. These protocols should be based on participants' existing strategies and practices. This not only requires familiarity and time on the part of the researcher, but the institution's willingness to explore consent relationships outside of established norms. In our fieldwork, this involved attending to gestures, expressions, fleeting comments, bodies-in-space, and stims, all of which served to express a felt sense of our consenting relation–feeling together. Consent-as-method makes space for these established relational dynamics, as well as relationships with those providing care or services to the disabled participants.

Consent-as-method can offer possibilities beyond simply including intellectually and developmentally disabled people as research participants. We see consent-as-method as part of a methodological toolkit that is able to respond to the demands for research that meets the needs and priorities of disabled communities and researchers. Though our critique is set in the context of universities and their doctrine of informed consent, consent-as-method can be taken up in spaces outside of the institution as well. Consent is relational and treating consent-as-method allows us to create more accessible and just relationships one step towards creating less ableist spaces for working and learning.

Research is a relationship. Consent-as-method is a way to think capaciously about capacity as part of the continuum of relations that make up the research project. It acknowledges the ways we feel our way through sometimes sticky and sometimes exhilarating research encounters. It is through an analysis of capacity that we come to understand the ableism that underlies consent culture, and the bodyminds considered able to consent. Capacity is not static. Like consent, it is ongoing and more-than-contextual. Capacity is felt and done together.

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