Negotiating Research Participant Consent With, for and by Adults With Developmental Disabilities in Interaction With Their Third-Party Consent Providers

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Abstract
We illuminate third-party research participant consent with, for, and by adults with developmental disabilities by examining consent as an iterative, ongoing process. We use an instrumental case study of three adults with developmental disabilities who, together with their third-party consent providing parents, participated in a broader conversation and video analysis study of how family members are part of decision-making by adults with developmental disabilities. Adults with developmental disabilities comprising our case demonstrated discomfort that left us with questions about the relational nature of third-party consent. We performed a directed content analysis of transcripts and video data corresponding to moments of discomfort, resulting in categories of one-distress, two-non-disclosure, and three-evasion. Our findings illustrate ambiguities where consent was at stake and where there appeared to be no ultimate “Yes” or “No” interpretation. We conclude that expressions of resistance to research participation by adults with developmental disabilities displayed in our data were assertions of autonomy that occurred in relation, yet ran counter to, the agendas of researchers and third-party consent providing parents. We offer recommendations for researchers in the developmental disability field and for qualitative researchers more broadly who might encounter similar ambiguities amidst the relational workings of consent. Greater analytic attention to the relational dynamics of consent has potential to expand ethical commitments of qualitative researchers beyond the limited range of meanings offered in ethics board approvals and signed consent forms.

Keywords
ambiguity, consent, developmental disability, legally authorized representative, third-party, proxy, surrogate

Introduction
As qualitative researchers, we bring ourselves to ways of being with which we may be unfamiliar and navigation of the unfamiliar has distinct significance when it involves participants who are marginalized. Rules governing ethical conduct of research with human subjects require special attention to marginalized participants through careful consideration of the principle of autonomy. Indeed, the protection and promotion of autonomy, “equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge” (Dworkin, 1989), has supplanted beneficence as the paramount value in modern bio-ethics (Childress, 1990; Root Wolpe, 1998). Autonomy is synonymous with dignity and freedom to act of one’s own accord and “consent” is a gold standard for efforts to assure participant autonomy (e.g., Declaration of Helsinki, 2008; Universal Declaration of Human Rights, 1948; Tri-Council of Canada Policy Statement, 2010). A person can consent to participate in research studies when they 1- have competence, 2- act voluntarily, and 3- are provided with, and understand, information about the nature of the study and what participation would entail. Participants not meeting these

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criteria are labeled “without capacity” and viewed as correspondingly vulnerable. Ethical guidelines include additional steps for including participants without capacity and these steps require that third parties (sometimes called legally authorized representatives, proxy consent providers or surrogate consent providers) give consent on behalf of participants without capacity. Third-party consent provokes a rethinking of how to assure participants without capacity are fully informed and acting voluntarily. The purpose of this study is to examine the relational workings of consent as an iterative, ongoing process between adults with developmental disabilities1, their third-party consent providers, and ourselves as researchers.

Third-party consent constitutes a reshaping of decision-making and requires an examination of the social contexts of decision-making as participants without capacity face risks of being overpowered by others involved in giving consent (Bach & Kerzner, 2010; Iacono, 2006). Bach and Kerzner (2010) point to the growing uptake of supported—as opposed to substitute—decision-making models towards ensuring decisions with and for people without capacity are informed and voluntary. Supported decision-making is predicated on decision making as relational in nature. Correspondingly, autonomy is socially embedded (Mackenzie & Stoljar, 2000; Westlund, 2009) and decisions by participants without capacity, such as giving consent, are achieved through a relational process. This study is motivated by the aim of better understanding the relational and iterative nature of the consent process in qualitative interviews with adults with developmental disabilities. The following review retraces the freighted history of people with developmental disabilities being treated as uncreditable research participants, and then outlines how researchers adopting a relational perspective provide a vital corrective to this history by expanding meanings of research participation by adults with developmental disabilities.

Are They Credible? Can They Consent? Tracing “What it Takes” to Include People With Developmental Disabilities in Research

Views of autonomy and consent as relational in nature are a disjuncture from longstanding assumptions regarding inclusion of adults with developmental disabilities in research. Through a largely unchallenged corpus of research, Sigelman and colleagues questioned the value of including participants with developmental disabilities in research with claims that such participants do not provide credible data (e.g. Heal & Sigelman, 1995; Sigelman et al., 1981). In their seminal study, Sigelman et al. (1981) examined whether “mentally retarded” participants provide valid answers to interview questions. Researchers interviewed institutionalized children (n=52), institutionalized adults (n=58), and community children (n=57) individually in quiet areas of institutions or schools. Participant ability to answer questions was assessed in terms of a minimally appropriate responses defined as answering yes/no or nodding. Sigelman and colleagues concluded participants evidenced systematic response bias in the form of high rates of acquiescence or “yes” answers to yes/no questions regardless of the content of those questions. Their published conclusions have been cited widely, uncritically, and recently (e.g., Barker & Pistrang, 2015) and we are troubled by how such conclusions impact how people with developmental disabilities are understood. By studying the relational workings of consent, we illuminate the multi-dimensional credibility of people with developmental disabilities as part of the evolving scholarly resistance to conclusions by Sigelman and colleagues.

Other scholars have resisted conclusions by Sigelman and colleagues by demonstrating research contributions from “learning disabled” participants in “inclusive” studies. For example, Nind and Vinha (2014) conducted repeated focus groups, that entailed use of stimulus materials as prompts, to create “vibrant interactive spaces” in which researchers with and without learning disabilities discussed what constitutes effective research processes and ideas of those with learning disabilities were central to study findings. In a similar vein, Power and Bartlett (2018) engaged adults with learning disabilities in focus group discussions and photo diary compilations to yield representations of “welcoming communities.” Thus Nind and Vinha (2014) along with Power and Bartlett (2018), illustrated content contributions and interpretation capabilities to resist claims that participants with learning disabilities lack credibility. Rapley and colleagues (1996; 2017) further resisted ideas of adults with learning disabilities as lacking credibility through their interrogation of assumptions that adults with learning disabilities are acquiescent.

Through a study of communication with adults with “learning disabilities,” Rapley and Antaki (1996) cautioned that what appears as acquiescence might instead reflect limited memory or attention span or may be a stock response to experiences that resemble test situations. Moreover, Rapley and Antaki noted that data analysis conducted on short segments of speech—such as yes/no answers to questions—strips away features of communication such as intonation, speed and pitch. Instead, researchers need to go beyond whether an answer/utterance is to be trusted and attend to the multifaceted nature of communication including the relational contexts in which communication occurs. Accordingly, Rapley and Antaki used conversation analysis to capture underlying facets of communication including the power dynamics of how people take cues from each other about what is to be said next. Through an analysis of data from interviews about quality of life conducted with eight adults with learning disabilities living in supported housing. Rapley and Antaki found participants used a range of strategies for making sense of, and responding to, questions and the context in which questions were embedded (1996, p. 224–225). Thus, rather than comprising evidence of simple acquiescence, participant agreement with the interviewer contained sophisticated elements of effort to offset their own limited understanding and facilitate the flow of communication (Rapley & Antaki, 1996).
Studies examining the intentionality of non-verbal or non-conventional communications have been part of sustaining arguments in support of the credibility of people with developmental disabilities. Antaki et al. (2017) studied particularities of how adults with profound intellectual disabilities engaged support staff. Using video records of day-to-day life of 10 participants within their homes, these researchers highlighted relational dimensions of communication by noting ways in which support staff responded to small changes evident in participants’ non-verbal behaviors including by making and testing assumptions about meanings of behaviors (2017, p. 582). Calveley (2012) elaborated on the importance of non-verbal communication through her study about people with intellectual disabilities consenting to receiving intimate care. Calveley described participants’ comfortable facial expressions and vocalizations that evidenced willingness to go along with intimate care activities and signified implied consent versus participants’ signs of distress, such as scrunching face or biting fingers, which signified withdrawal of consent. Indeed, discernment of consent in these ways is possible only through relational processes that entail participants obtaining and responding to input from others as part of the interactive flow of providing and withdrawing consent (Duque & Lashewicz, 2018). Taken together, Antaki and colleagues’ discernment of meanings expressed by people with profound disabilities, and Calveley’s illustration of people with intellectual disabilities giving and withdrawing of consent during intimate care, underline credibility and consent as fluid and negotiated relational processes.

Rapley and Antaki reflected the relational processes of data collection as they spoke in terms of “complex manoeuvres into which both interviewer and interviewee become enmeshed” (1996, p. 224). Yet studies about consent by and for adults with developmental disabilities tend to focus on obtaining third-party consent rather than on understanding enmeshed interactions related to consent. In a widely cited critique of ethical debates surrounding research participants with intellectual disabilities, Iacono (2006) discussed research participation by adults with intellectual disabilities as vital to countering protectionist and paternalistic treatment of marginalized groups. Iacono argued the importance of family members as third-party consent providers for adults with intellectual disabilities and cast the absence of consent providing family members as obstacles to inclusive research. Although we agree with the importance of family members as consent providers, we argue for fuller accounting of relational dimensions of consent through study of adults with developmental disabilities in interaction with their third-party consent providing family members.

Engaging with the complexities and ambiguity of consent as a process negotiated through relationships with family caregivers, we draw on Ochs and Taylor (1992) who studied power structures produced and reproduced through family interactions. Using dinner conversations as data, Ochs and Taylor identified the workings of power embedded in one family member introducing stories that feature another family member. The featured family member can be empowered by having their story introduced as conversation worthy. Or the family member introducing can be self-empowering, as introducing entails control over conversation topics and timing. Disability researchers examining power within family interactions found family members facilitative to the confidence of people with developmental disabilities (e.g., Lloyd et al., 2006; Nonnemacher, 2008). On the other hand, adults with developmental disabilities may be rendered compliant amidst family interactions (e.g., Pascall & Hendey, 2004; Power, 2008). Indeed, we (e.g., Salami & Lashewicz, 2015) have reported self-expression by adults with developmental disabilities as both supported and hindered by family members who provided encouragement to, yet sometimes spoke over and spoke for, adults with developmental disabilities. Moreover, these workings of family member influence on self-expression by adults with developmental disabilities are playing out in a context which, Poland and Pederson (1998) remind us, carries a requirement that participants—in our case, adults with developmental disabilities and their support providing family members—engage in some form of public self-analysis as part of research data collection. In this study of relational workings of consent, we focus on discrete moments discomfort on the parts of adults with developmental disabilities amidst family interactions and we engage with questions about the relational nature of third-party consent that these discomforts raised for us as researchers.

Methods

This study is theoretically anchored in Critical Disability Studies (CDS) focus on developing more sophisticated approaches for hearing and responding to “voices” of adults with developmental disabilities rather than on remediating communication impairments of adults with developmental disabilities. We elaborate our anchoring using a relational theory of autonomy to treat consent as a social and interdependent accomplishment achieved through iterative, ongoing processes between adults with developmental disabilities and their third-party consent providers (Bach & Kerzner, 2010). To examine consent, we use an instrumental case study of three families drawn from a broader study of family interactions and ways family members/support providers are part of decision-making by adults with developmental disabilities. Instrumental case studies have a distinct purpose of building knowledge of the case as a means of generating understandings of a phenomenon beyond the case (Baxter & Jack, 2008; Stake, 1995), and we selected our three-family case as the instrument through which to better understand the relational nature of third-party consent by research participants with developmental disabilities. More specifically, case selection was oriented by interviews that left us with discomfort about moments where consent seemed ambiguous. Our questioning of consent subsequently became the topic of
research meetings, hosted by the senior author, where video data and our recollections of the moments in question were shared. Those present agreed that the data contained evidence of participants with developmental disabilities resisting research participation, either through contradicting messages from their third-party consent providing parents, or through intentional non-engagement with researchers. Encouraged by consensus from our research team, we decided to analyze these instances of resistance more closely in service of better understanding the relational dynamics of third-party consent with, for and by adults with developmental disabilities.

Case Description and Sample Context

To be included in our broader study, participants had to be legally authorized to provide consent for an adult with a developmental disability and agree to participate in three interview-observations together with the adult with a developmental disability and other family members, friends and/or support workers interested in, and available for participation. Our broad sample is comprised of 46 participants including 14 adults with developmental disabilities and 32 of their support providing family members/friends/support workers. Our three-family case includes 10 participants and is comprised of three adults with developmental disabilities who each participated together with a third-party consent-providing family member (N = 3 mothers); two of the three adults with developmental disabilities also had other interested, available family members (N = 2 fathers) and support workers (N = 2) participate. In Table 1, our three-family case is summarized by interview-observation for each of the families represented in participation. In Table 1, our three-family case is summarized by interview-observation for each of the families represented in terms of the location, who participated, and who conducted each interview-observation.

**Participant Recruitment and Informed Consent**

Participants were recruited using an electronic call distributed through agencies providing support to adults with developmental disabilities and their families. Third-party consent providing family members responded to the call by telephone or email and were screened to ensure they understood the intent of the study and met inclusion criteria. The study intent was described as entailing three interview-observations with adults with developmental disabilities and their family members and/or friends and support workers aimed at gaining understanding about how adults with developmental disabilities communicate and make decisions amidst multi-voice interactions, and what helps and hinders adults with developmental disabilities in having their views understood. We noted that participant anonymity would be protected as participants, and people named by participants, would be assigned pseudonyms. At the same time, we cautioned that this is a relatively small study of a distinct population and as such, there is a risk that participants may be identifiable by people reading our reports, particularly people who know the participant families.

Prior to the initial interview-observation, participants provided consent in accordance with the Conjoint Health Research Ethics Board policy at the authors’ university. Participants with developmental disabilities each signed, and/or had a researcher read aloud to them, a plain language consent form that included points such as: “we are asking you to show us what your life looks like” and “we want to watch and record what you say with and to others.” Ongoing consent from adults with developmental disabilities was sought by researchers intermittently during transition points, such as talking about new or emotional subjects, or moving to a next activity. Researchers would request permission to continue in

| Adult with Disability | Third Party Consent | Interview-Observation 1 Location, Participants and Researchers | Interview-Observation 2 Location, Participants and Researchers | Interview-Observation 3 Location, Participants and Researchers |
|-----------------------|--------------------|---------------------------------------------------------------|---------------------------------------------------------------|---------------------------------------------------------------|
| Brent, age 44          | Mother Nancy; father Larry; support worker Frank             | Brent’s home with Brent, Nancy, Larry and Frank; two female researchers | Brent’s home with Brent, Nancy, Larry and Frank/travel by van to and from, and walk at, nature reserve with Brent, Nancy and Larry; two female researchers | Brent’s home with Brent, Nancy, Larry and Frank; two female researchers |
| Loreli, age 24         | Mother Jane; father John; support worker Trish               | Jane and John’s home with Jane and John; two female researchers | Jane and John’s home with Loreli, Jane and John as well as Loreli’s support worker Trish; fitness center with Loreli and Trish; two female researchers | Loreli’s home with Loreli and Jane; two female researchers |
| Diana, age 30          | Mother Cynthia                                             | Family farm with Diana and Cynthia; two female researchers | Diana’s workplace (day-care center) with Diana and her colleagues as well as coffee shop with Diana and Cynthia; one female and one male researcher | Disability support program office with Diana and Cynthia; two female researchers |
Data Collection

Mirroring the relational dynamics we sought to study, our approach to conducting interview-observations was relational and included sustained researcher engagement achieved by meeting with each participant and his/her third-party consent providing family members and interested, available friends and/or support providers three times over the course of one year. In conducting interview-observations with participant dyads or small groups, we agree with Polak and Green (2016) that collecting data from multiple participants simultaneously holds potential to illuminate tacit knowledge shared by participants. Further, our data collection team included five experienced qualitative researchers who worked in pairs to increase the likelihood of noticing and responding to subtle communications and following up and pursuing topics raised by adults with developmental disabilities. Consistent with our relational focus, one, and sometimes both, researchers remained constant across the three interview-observations.

We used friendly conversation, plain language and a relaxed pace to join and follow the energy of participants. Our initial interview-observation was 90–120 minutes in duration and aimed at building rapport and gathering background information about participant lifestyles and interests. We discussed and demonstrated how our audio and video recording devices would be used and we invited participants to move our video recorder at any point to capture images of their choosing. Approximately one month later, we returned for a “half-day” interview-observation to follow-up by asking for updates about what we had learned in our initial interview-observation such as how a holiday gathering had gone or if a new baby niece or nephew had arrived. During this lengthier interview-observation, we joined transitions and activities such as traveling to an outing, spending time at work, or meeting someone for coffee. Our line of questioning was about routines and decision-making including how adults with developmental disabilities are helped by, and provide help to, others. We reminded participants that our broad interest is in observing day to day interactions. We returned approximately six months later to share our early interpretations and inquire about changes since our previous interview-observation. We asked for participant input on interpretations such as having concluded that a participant was especially animated or comfortable in a particular setting. We asked if our conclusions sounded accurate and we invited participants explanations for why this conclusion was true, or alternatively, why researchers might have got the impression it was true. The spacing between our second and third interview-observation also allowed us to see if things had come to pass, such as beginning a new fitness program or hiring a new support worker. As well as the homes of adults with developmental disabilities, interview-observation locations included community walks, volunteer/work settings, fitness centers, restaurants, and coffee shops.

Analysis

We used directed content analysis to examine data corresponding to moments of discomfort and ambiguity related to consent (Assarroudi et al., 2018; Hsieh & Shannon, 2005). We frame our content analysis as directed rather than conventional or summative because our analytic interest in ambiguities of third-party consent was informed by provisional data analysis in the form of field notes, debriefing conversations with colleagues, and research team meetings (Assarroudi et al., 2018). Further, the content analysis was directed by our theoretical commitment to relational autonomy as we focused on how relational negotiations of third-party consent were reflected in who was allowed, empowered, and required to speak next in these discomforting interactions (Schegloff, 2007; Williams, 2011). As described below, our content analysis also draws in aspects of conversation analysis in the vein of “applied CA” (Ten Have, 2007), and recollections of firsthand experience. In this way, we incorporate “textures” of conversation analysis and “overtones” of ethnography into our use of directed content analysis and subsequent analytic claims (Sandelowski, 2000).

Analysis began with establishing context for the discrete moments of discomfort through immersion in the video data.
and verbatim transcripts of entire interview-observations centered on Brent, Loreli, and Diana. We then set parameters around transcript data corresponding to the discomforting interaction sequences and coded these sequences for conversational features of turn-taking, preference organization, and expression of authority (Clift, 2016). The convergence of these features as units of analysis (per the conversation analysis literature) did not entail the creation of Jeffersonian transcripts; nor was it motivated by explicating general rules of talk-in-interaction. Rather, we coded conversational features as evidence of if and how consent was interdependently achieved between adults with developmental disabilities and their third-party consent providing family members (Ten Have, 2007). After initial coding, we considered the latent meanings of coded sequences in relation to third-party consent by returning to our firsthand recollections, reviewing the video data, and by drawing on our sensitization to participants with developmental disabilities as potentially lacking conventional “tools” to express disagreement in interview-observations. Given that consent is an encompassing concept, we sensitized our analysis by distinguishing between consent to participate in the research study versus consent to engage with researchers during interview-observations versus consent to engage with researchers about particular topics. Category creation entailed combining manifest meanings from the coded transcripts and latent meanings based on our interpretations of video data and firsthand recollections of the interviews.

Findings

The three adults with developmental disabilities whose data we present each gave evidence of discomfort that provoked continued rounds of analysis through which we studied the workings of consent in terms of negotiating power among participants towards interdependent achievement of consent. We present these instances of discomfort as entailing evidence of adults with developmental disabilities resisting third-party consent provided by their parent(s) related to engagement with our research project, engagement with researchers, or engagement with particular topics. Resistance played out differently for each of the adults with developmental disabilities thus we present our findings by participant(s) and in terms of potential meanings for all involved in the interview-observations. For each adult with developmental disabilities, we begin with a profile of his/her living arrangements, main support relationships and interview-observation locations and key activities. We follow this with a presentation of our themes of evidence of resistance: 1- Brent’s distress; 2- Loreli’s non-disclosure; and 3- Diana’s evasion.

Brent’s Distress

Brent is 44 and lives in his own home with 24 hour support staff. He enjoys listening to music and manipulating tactile objects. Brent has little verbal communication ability—his main words are yes and no—and is visually impaired. His parents, Nancy, and Larry, live nearby and visit weekly. Nancy prides herself on understanding Brent and guiding support workers in organizing their time with Brent and keeping Brent involved. Larry has a relatively quieter style and supports Brent with comments such as: “There he is... that’s my boy.” Larry seems to let Nancy set the pace for activities yet Larry participates in activities with Brent—such as swimming—that Nancy has organized. Frank, one of Brent’s four support workers, has worked with Brent for more than seven years and was present, together with Nancy and Larry, for most, or all, of each of the three interview-observations which took place at Brent’s home with interview-observation two punctuated by an outing to a nearby nature reserve where two researchers accompanied Brent, Nancy, and Larry on a walk.

Brent prefers familiar people and activities and he values his personal space. He seems quick to feel encroached upon and we questioned Brent’s comfort with researcher presence and corresponding willingness to participate in two of the three interview-observations. Our first interview-observation at Brent’s home included Nancy, Larry, and Frank. Moments after we arrived, Brent showed signs of discomfort including by tearing at/removing articles of his clothing. Nancy explained that tearing at and removing clothing were behaviors through which Brent signals distress and Nancy noted that a safety auditor had completed an inspection of Brent’s home shortly before we arrived. Yet Nancy told us not to be concerned and that we should proceed with our interview-observation. Researchers were meeting Brent for the first time thus had no experience on which to draw in our efforts to understand the extent of Brent’s distress and how best to respond. We were heartened by Nancy’s reassurance that the interview-observation should proceed yet troubled that our presence might be causing or exacerbating Brent’s distress. We especially wished to avoid seeing Brent in a position that compromised his dignity including by removing his clothing. In an effort to balance what we perceived as disagreement between Nancy’s desire to proceed and Brent’s need for privacy/desire not to proceed, we asked some questions yet focused on abbreviating the interview-observation. Immediately following this interview-observation, the two researchers conferenced with the senior research team member about if and how to proceed with subsequent interview-observations with Brent and we concluded that we should attempt our second interview-observation but pay keen attention to signals that Brent is distressed.

Brent was much more at ease during the second interview-observation which included going for a walk with his parents and the same two researchers from interview-observation one. Yet we saw evidence of discomfort on Brent’s part which contrasted with his otherwise state of ease. During the van ride to the nearby nature reserve, Nancy and Brent sat relaxed, side by side while Larry drove and the two researchers occupied the seat behind Nancy and Brent. As part of efforts to secure ongoing consent, we reminded that our main interest is in
observing day to day interactions and Researcher 1 asked permission to video record:

Nancy: Sure if you want…

Researcher 1: Is that ok Brent?

Brent: (nodding head to music) (leans in to give Nancy a kiss on the cheek)

We viewed Brent’s head nod and kiss to Nancy’s cheek as evidence of Brent’s comfort and assent with Nancy having endorsed video recording. This instance also reinforced how Brent relied upon Nancy to help set the pace. At the nature reserve, we walked comfortably for 45 minutes as a slightly dispersed group with Brent at times walking arm in arm with Larry but mainly, walking on his own while Larry walked backwards, a few meters in front of Brent such that Larry’s presence and voice guided Brent. Periods where Brent walked arm in arm with Larry were preceded by Larry offering Brent his arm and Brent accepting. If Brent did not accept, Larry maintained his guiding position a few meters in front of Brent. Larry had cautioned researchers not to walk shoulder to shoulder with Brent as doing so could confuse and upset Brent. Late in the walk, Researcher 1 forgot Larry’s caution and came up beside Brent to ask a question. Brent stopped walking and responded definitively:

Researcher 1: Are there any activities you like to do together?

Brent: (stops walking) No.

Larry: We do lots together don’t we? Swim tomorrow.

The tone of Brent’s “no,” combined with how decisively he stopped walking, was expressive and created a moment of disorientation for the researchers. The demarcating quality of Brent stopping was such that it felt unclear whether the interview should continue at that moment. Larry’s comment about activities that he and Brent share, including swimming, suggested that Brent’s “no” response, rather than being accurate, was a signal that Brent did not want to answer or to have the researcher walking beside him. Further, Larry facilitated the conversation by filling in details in response to the question the researcher had asked Brent given that Brent’s vocabulary is small and was likely further limited by the stress of the researcher walking too near to him. Larry, who seemed to sense Brent’s need to get re-oriented, returned to walking slowly a few meters in front of Brent and using his voice to encourage Brent. After a few moments, Brent resumed walking, albeit at a slower pace.

Shortly following Brent resuming walking, Nancy intervened to point out it was time to return to the van. Nancy asked Larry to walk with Brent to quicken Brent’s pace and Larry responded by advising that, at present, Brent wanted to walk on his own. Ignoring Larry’s advice, Nancy moved to walking beside Brent:

Nancy: (from a distance speaking to Larry) You can walk to the car with him.

Larry: He didn’t want to.

Nancy: (now beside Brent) You can walk with Mom.

Brent: (stops walking and makes motions to take his pants down)

Brent’s motions of removing his clothes showed that even familiar people could provoke distress. Further, this interaction supplied evidence of the ways Larry and Nancy sometimes differed in their styles and views. Larry took a less directive approach and seemed intent on contouring his efforts around Brent’s needs for space and to move at his own pace. We saw further evidence of Larry’s less directive approach in an ensuing difference of opinions between Larry and Nancy. Once settled back in Brent’s living room, each commented about days that entail several activities as a source of distress for Brent. Nancy claimed that Brent does well with busy days.

Nancy: But you’re doing well Brent. You’re dealing well with all the people coming and going. You okay with that? Yeah.

Larry: Not really. (Chuckling)

Researcher 2: Is that ok Brent? (Brent was assembling and disassembling tactile objects/blocks)

Brent: Not really. (Chuckling)

Nancy: Yeah.

Thus Larry disagreed with Nancy’s broad point that Brent was dealing well with people coming and going yet did not elaborate when prompted by the researcher. Nancy began a response but stopped. The researcher then tilted differently by commenting about Brent’s returning to his familiar spot and using familiar objects as helping him feel calm. Overall, Brent was at ease during this second interview-observation, yet he experienced moments of discomfort and, consistent with the first interview-observation, Nancy did not appear to shift her approach in response to his discomfort. In these moments following Brent’s discomfort, we wondered if consent to participate in our study had been interdependently achieved.

Loreli’s Non-Disclosure

Loreli is 24 and was adopted as a toddler by parents Jane and John to complete their family of four that includes Loreli’s older brother Steven. Loreli is outgoing and opinionated and lives in her own basement suite with 24-hour support staff. Jane scheduled the first interview-observation at their home to include only herself and John as they wished to speak freely with researchers about their family background which included their ongoing efforts to support Loreli who they
characterized as good-hearted and loving but also defiant and a “terror on wheels.” Jane described Loreli’s disabilities as entailing limited executive functioning that leaves Loreli prone to rash decisions—such as secretly purchasing a bus ticket and meeting a boyfriend in another city—that jeopardize her safety. Jane positioned herself as managing a heavy responsibility associated with supporting Loreli including Jane’s detailed efforts with Loreli’s support staff to set expectations for keeping Loreli acting responsible and staying healthy including through healthy diet and exercise habits. We met Loreli at her parent’s home for interview-observation two where we spent a half day following Loreli in her typical activities including time at her fitness center with Trish, one of Loreli’s five support workers. The third interview-observation included Loreli and Jane and took place in Loreli’s basement suite.

We questioned the fullness of Loreli’s consent to engage with topics introduced by Jane during interview-observation three because while Loreli seemed enthusiastic to spend time with us after not having seen us for several months, she evidenced discomfort with the level of disclosure Jane expected from her. We opened this interview-observation by reminding of our goal of observing day to day interactions and asking Loreli how everything had been going since we had last seen her. Loreli responded positively saying “I’ve been really good.” However, Jane quickly interjected saying that things had not been going as well as Loreli had indicated:

Jane: (Clears her throat). The last little while…has not been good. Hmm.

Loreli: (looking down) Oh yeah…

Jane: Let’s be honest.

Loreli: I have been good (points to herself)

Jane: No…It goes both ways…there…(looking at/speaking to researchers) this is where they learn about it. Because it can’t be all just rosy all the time. If they aren’t learning anything. Right? This is what this is all about. (Looking at/speaking to Loreli) So why don’t you say what you’ve been going through?

As such, Jane shifts some researcher focus away from day to day interaction processes and toward goals for Loreli to use her mixed experiences to learn. Jane continues:

Jane: …Because it has not been good for the last little bit…it’s been ah…

Loreli: (quietly, looking at Jane) I don’t want to…

Jane: CHALLENGING (raised voice)

Loreli: that’s okay…

Jane: FOR EVERYBODY… (raised voice)

The exchange between Jane and Loreli continued with Loreli reiterating that she had been doing well and Jane asking Loreli to talk about the challenging times she had been going through.

Loreli: I don’t want to say anything.

Jane: You don’t?

Loreli: No. (shakes her head “no”)

Jane: Okay. Do you want me to?

Loreli: No. (continues to shake her head “no”)

Loreli held her position that she did not wish to share details; nor did she wish for Jane to share details on her behalf. Jane then elaborated her persuasion efforts by framing the challenging experience as universal and not entirely Loreli’s fault:

Jane: Because it’s a personality conflict Lor…it’s not all you. Okay? That’s the whole thing.

Loreli: (almost inaudible) Yeah

Jane: And that and we all have personality conflicts. You know. Throughout life don’t you know.

Loreli: (in a slightly louder voice) You don’t have to tell her what I did…they don’t need to know.

Jane: That’s up to you

Although saying “that’s up to you,” Jane proceeded to press for fuller disclosure from Loreli. Jane asked to speak to Loreli privately and Loreli agreed. Following their private conversation, Loreli shared details about a conflict with a support staff member that had entailed Loreli becoming physically aggressive. Following Loreli’s disclosure, Jane expressed her belief in the benefits to Loreli that accompany Loreli recouping difficult experiences then conveyed approval and appreciation to Loreli.

Jane: That’s good Lor…

Researcher 1: Uh hum

Jane: Thank you

Conversation about Loreli’s activities resumed but returned to Jane discussing Loreli’s relationships with support workers as entailing good days and bad days. Jane distinguished the strained relationship with the support worker that had entailed Loreli becoming aggressive and Loreli responded by softening Jane’s assessment and casting this strained relationship as an even mix of good and bad days. Jane corrected Loreli by offering the final word on this topic:
Jane: We all sort of agreed it was sort of a personality thing that just didn’t…. Loreli: There was there was the same amount of good days as there were bad days.

Researcher 1: Okay
Loreli: So not very much…
Jane: There were more bad days than good days.

Jane seemed intent on Loreli “owning up” to the dispute with her support staff and Loreli, after some resistance, complied. We were troubled that Loreli’s initial claim that researchers did not need to know about the conflict did not end up being honored. We understood Loreli’s looking at Jane while quietly voicing not wanting to share as indicating a self-conscious desire to avoid potential embarrassment of describing details to researchers. We were further troubled that Loreli had not been able to “save face” by casting the conflict in gentler terms as part of an even mix of good and bad days. Thus, we wondered if we had Loreli’s consent to engage with the topics that Loreli eventually disclosed.

Researchers turned the conversation back to inviting Loreli to comment on her interactions more broadly. Jane then raised the topic of the agency that employed Loreli’s support staff having requested that Jane intervene given a conflicted relationship between Loreli and another of Loreli’s support staff. Jane tried to engage Loreli in explaining Jane’s strategy of intervening:

Jane: (speaking to all about her parenting approach) So if you want me to come and step in it’s going to be that way. I stepped in right Lor?
Loreli: Uh huh
Jane: And ah well…tell them what I did.
Loreli: She went…I don’t remember. Might as well as refresh my memory.
Jane: Okay…I come in and I said Okay Lor. Write down everything you love
Loreli: Oh yeah
Jane: …to do. The bowling. The shopping. The going for suppers. Hanging out with me and all the fun stuff you love to do. Write it all down.
Loreli: I remember that now
Jane: And she did. And I says: “great”…I say: “it’s all gone”. (Claps her hands in emphasis) You get nothing.

Researchers turned the conversation back to inviting Loreli to share about her behaviors and the topics that Loreli eventually disclosed. Researchers followed Loreli’s conversation topics and activities, this third interview-observation was skewed towards Jane asking Loreli to recount difficult experiences and, with Jane’s direction, reinforce Jane’s consequences for Loreli’s behaviors during the difficult experiences. Our questions of interdependent achievement of consent in Loreli’s case relate to how differently Loreli’s sharing of topics may have been had Jane not been so influential in what was being shared.

Diana’s Evasion

Diana who is 30, lives in her own apartment with 24 hour support. As part of a large, blended family, Diana has several brothers and sisters, along with dogs, on the family farm where she grew up. Cynthia distinguishes their blended family as one family where biological lineage is unimportant. Cynthia said she spoke for the overall family in describing Diana as talkative and outgoing. Diana’s disability leaves her with limited vocabulary and reading comprehension along with some speech impediments. Diana has a close relationship with her mother, Cynthia who was present for interview-observation one, conducted at the family farm, and interview-observation three, conducted in a meeting room at the agency that employs Diana’s support workers. Cynthia also joined us for the second part of interview-observation two which was held at a coffee shop; this second part followed a first part where we had joined Diana at the daycare center where she works.

For interview-observation one, researchers went to the family farm where Diana and Cynthia were baking muffins and brewing coffee. Diana was welcoming and keen to give us a tour and share pictures of her niece along with stories of her favorite dog and her work on the family farm. Diana expressed pride in her knowledge of farm life including describing what needed to be done given we were in the midst of harvest season. Yet, when we met Diana for interview-observation two at the day care center where she worked, Diana was much quieter. Interview-observation two occurred one cold morning just a couple weeks before Christmas with one researcher who knew Diana from interview-observation one and a second researcher who Diana was meeting for the first time. Although the day care was festive and busy, Diana’s response to researcher presence was evasive:

Researcher 1: So you like to play with the kids?
Diana: (keeps walking and does not answer)
Researcher 1: How often do you do you come here Diana?
Diana: Uh every Wednesday morning
Researcher 1: Every Wednesday ok…
Other teacher: Diana, he likes to talk with you, can you talk with him?
Diana: Yep
Researcher 1: How is it to be auntie, are you a good auntie Diana?
Diana: Yep
On the transition to the playground Researcher 1 was confirming the access route:
Researcher 1: We are going into the playground?
Diana: Yep
Researcher 1: Is this where you go in?
Diana: Yep

Moments later, Researchers attempted more questions and prompts:

Researcher 2: Do you play basketball Diana?
Diana: (picks up basketball and tosses basketball through the net)
Researcher 1: Oh, a slam dunk
Diana: (walks away)
Researcher 1: (following Diana) So how was your morning before you came here
Diana: Good
Researcher 1: Did you get up early
Diana: Yeah

Diana moved briskly and kept her comments clipped and Researcher 1 was left feeling anxious to engage Diana. Part of Researcher 1’s effort ran contrary to data collection best practices and included Researcher 1 resorting to asking a series of closed ended questions. At the same time, Researcher 1 endeavored to assure Diana’s willingness to participate by asking Diana if she wished to stop the interview-observation. Both times, Diana replied: “no keep going.” Diana’s mixed messages (moving briskly away from researchers vs. saying “no keep going”) were likely shaped by a number of factors including interview-observation two being conducted near Christmas and, in fact, on Diana’s last work day before the holiday season. The workday setting and rhythms along with the proximity to the holiday season may have left Diana preoccupied with things that did not include topics from our previous interview-observation during which she had been talkative including by expressing eagerness for us to visit her at her workplace. Reinforcing our sense of Diana being caught up in workday rhythms, at the end of her shift, Researchers recorded Diana delivering a brief yet confident “happy holiday” message to her daycare colleagues and children.

A bit later, Diana was more talkative with researchers when we caught up with her and Cynthia at a coffee shop. However, researchers were left with a sense that their presence at the daycare center had been intrusive rather than welcome. Diana’s enthusiasm with researchers at her parents’ home and her comfort with researchers at the coffee shop versus her reticence with researchers at the daycare be tied to Cynthia’s presence. Further, both researchers conducting interview-observation two were young and one was male. Comparatively, the researchers conducting interview-observation one was both female and one was close in age to Cynthia. Whatever combination of factors may have influenced Diana’s level of responsiveness to researchers at the day care center, her evasiveness left us questioning whether Diana agreed with having consented to engage with researchers during her workday.

**Discussion**

Including third-party consent providing parents in interview-observations allowed us to examine relational negotiations of consent with, for and by adults with developmental disabilities in relation to participation in research, engagement with specific researchers and engagement with particular topics. We illustrated how consent can be driven by parents’ views and interests which may conflict with those of adults with developmental disabilities. Although researchers and adults with developmental disabilities tended to treat interview-observations in terms of documenting mostly comfortable relational processes, consent providing parents sometimes approached interview-observations as activities to be completed efficiently, or used to demonstrate and reinforce parenting goals and strategies. Of course, interview-observations occupied blocks of time in participants’ schedules and, in this sense, had an obligatory quality of something needing to be completed if not at the scheduled time, then at a future date. Indeed, parents of adults with developmental disabilities have often led lives of juggling appointments, therapies and activities for their sons and daughters (e.g., Mooney & Lashewicz, 2014; Salami & Lashewicz, 2015). Further, the playing out of parenting goals and strategies in interaction with one’s adult child with a developmental disability fit well as part of the relational data, we aimed to collect and we found support for conclusions by Lloyd et al. (2006) and Nonnemacher (2008) that parents are key to facilitating the comfort and confidence of people with developmental disabilities. At the same time, we remain concerned with how instances where parents control over timing and topics of
interactions (Ochs & Taylor, 1992) could override the comfort, and perhaps the consent, of the adults with developmental disabilities.

The determined tone of Nancy’s claim about Brent managing well with people “coming and going” seemed tied to Nancy’s parenting goals in coordinating activities for Brent. Nancy did not modify her claim even when contradicted by Larry. Parenting goals of completing activities were also evident in Nancy’s efforts to set the pace of Brent’s walking despite Brent’s resistance and Larry’s advice that Brent not be rushed. Nancy’s setting of pace mirrored our earlier experience during interview-observation one where Nancy instructed researchers to proceed even though Brent was having a busy day and acting distressed. Nancy may use an efficient style of carrying out scheduled activities to avoid needing to reschedule. Correspondingly, Nancy’s disregard of Brent’s distressed motions in favor of walking more quickly, or proceeding with an interview-observation, may reflect a parenting style of not letting difficulties interfere with plans.

Although Nancy influenced proceeding with research participation by keeping interview-observations moving along, Jane directed topics of interview-observations. Jane set a stage for directing topics by scheduling the first interview-observation to occur without Loreli’s participation. As such, Jane was able to share examples of Loreli’s poor decision-making while recognizing that Loreli would be uncomfortable listening to this conversation. Thus, researchers were given information that provided context for why third-party support with decision-making is vital for adults like Loreli. Although interview-observation two afforded researchers some immersion in Loreli’s day to day activities, interview-observation three entailed a focus on parenting goals and strategies beginning with Jane’s insistence that Loreli describe difficult experiences. Despite Loreli’s claim that researchers “don’t need to know,” Jane persuaded Loreli to share her difficult experiences. Loreli’s agreement allowed Jane to retrace, and in some ways re-establish, her own strategies of giving Loreli consequences for behaviors. On one hand, mother-daughter disconnects, and corresponding debate and reinforcement of parent rules, reflect the kinds of relational dynamics we expect to encounter while collecting data in natural settings. On the other hand, this mother-daughter disconnect entailed discussing topics that Jane, rather than Loreli, deemed important (Ochs & Taylor, 1992) and were only haltingly taken up by Loreli. Beyond differences in views and interests, Jane, understandably, may have interpreted our study aim as emphasizing the parent experience of caring for an adult with a developmental disability, and such an interpretation would be likely to run counter to Loreli’s, particularly given the phrasing of our plain language consent form, that is, “we are asking you to show us what your life looks like.” Notwithstanding the dedication to the well-being of their adult children shown by Jane and Nancy, the momentary relational tensions we observed tended to resolve in the playing out of interactions/activities that gave priority to the mothers’ goals.

Compared with Brent’s distress and Loreli’s non-disclosure, Diana’s walking away from the researcher left us wondering if the researcher’s presence, and efforts to engage, were distressing to Diana. We link Diana’s walking away with Brent’s gestures of removing his clothing and Loreli’s initial avoiding of sharing as moments of expressive resistance to the goals and priorities of others present in interview observations. Yet Diana’s signals of discomfort, including absent or clipped answers, may have been related to the different context of data collection noted in findings. Indeed, the interview-observation commenced at a different location and time of day with only one familiar researcher and without Cynthia’s participation. At any rate, when asked if she wished to stop the interview-observation, Diana instructed us to “keep going,” yet we were not convinced that we were welcome to continue. Consistent with communication studies, when an individual’s non-verbal messages (Diana moving briskly away from researchers) contradict their verbal messages (no keep going), we lean towards believing the non-verbal messages (e.g., Adler & Proctor, 2015). We understood Diana’s verbal response as a demonstration of general politeness and cooperativeness, and her overall comportment as reflecting her understanding of what it means to be observed while she is working. Yet we wondered if Diana was treating the interview-observation experience as something to be followed through given that Cynthia had welcomed researchers to their kitchen table for interview-observation one and through this hospitality, set an expectation that participation is important. Relatedly, Loreli may have accepted Jane’s persuasion given a tone set by Jane that participation is important and that disclosure of difficult experiences is part of this participation. Thus, while family values of honoring commitments and being cooperative were surely at play, we remain sensitized by researcher concern over relationships between parents and their adult children with developmental disabilities that are characterized by adult child compliance (Pascall & Hendey, 2004; Power, 2008). Whether Brent, Loreli, and Diana fully consented to what occurred in interview-observations remains an open question.

As we point out elsewhere (Mitchell et al., 2018), we are heartened by methodologists who argue for the ways in which “bad” data collection experiences can yield distinct insights (Naim et al., 2005). In our study, we remain troubled that aspects of consent by adults with developmental disabilities may be subordinated by the interests of their consent providing parents, yet such instances illuminate complexities of third-party consent as ongoing negotiations of power. Indeed, we are not presenting our case as evidence of having been convinced that consent had been withdrawn; nor do we present our case as an exemplar of types of data to be avoided or, if collected, excluded. Rather, our presentation is to illustrate ambiguities where consent was at stake and where there
appeared to be no ultimate “Yes” or “No” interpretation. The depth of ambiguity we encountered disrupts assumptions that adults with developmental disabilities are predisposed to acquiescence and reinforces thinking about communications by adults with developmental disabilities as a mix of resistance and acquiescence and rooted in relationship-driven endeavors to share meanings.

**Implications and Recommendations**

Given consent as tied to ethics, autonomy and power, we display our case data as potentially instructive for examining intricate relational workings of autonomy and consent. Most understandings of informed consent are predicated on an idea of autonomous individuals as “self-sufficient” and “self-realizing” (Clement & Bigby, 2013; Code, 1991) where the giving of consent is conceived of as a language-based, unambiguous expression. By understanding autonomy as hinging on participation from others, we focus on the relational processes through which consent is enacted. Below, we provide recommendations to help readers feel better equipped to grapple with the subtle relational workings of third-party consent in the context of developmental disability and we follow with general suggestions for qualitative researchers interested in deeper examinations of consent.

We begin by encouraging researchers to remain mindful of how histories of interventions with adults with developmental disabilities, and corresponding accountabilities experienced by their parents, may shape research participation. Researcher resemblance to interventionists may leave adults with developmental disabilities and their parents prone to complying with researchers and parents may feel inclined to showcase their “programming” with their children related to behavioral expectations and community integration. Second, aligning with our critical disability studies framing, we recommend researchers take extra care to avoid underestimating intentionality by adults with developmental disabilities. Given that research data collection, like other social processes, tends to follow—or fall into—ableist logics and practices where “the nondisabled experience and point of view” is central (Linton, 2006, p. 161), researcher uptake of subtle and multifaceted demonstrations of intentionality by adults with developmental disabilities is key to advancements that support human dignity.

Through “instrumentalizing” third-party consent as a relational process that researchers are positioned to analyze, our case study also contains lessons for qualitative researchers interested in closer examinations of consent. Firstly, we must recognize how the procedural domain of consent shapes our thinking. The procedural dimension of consent generally does not invite examination beyond its own terms which frame consent as a yes/no binary and rests on a self-sufficiency focused interpretation of autonomy. Further, the pressure for researchers to collect good data and conduct projects efficiently can promote thinking of consent as something to be secured and then banished to the static domain of approved ethics board files and signed consent forms at the earliest convenience. It follows that our own reflections on conventionally “successful” interviews will tend to draw our attention to moments of insight or richness of data rather than to the scaffolding of consent which sustained those moments of exchange. Yet consent is always there dwelling in the immediacy of social space, facilitated through the one-of-a-kind relational configuration that upholds the interview moment to moment. Discomfort can orient us toward the relational aspects of consent by drawing our attention to the discrepancy between the narrow, unambiguous meaning of consent, as documented in the paper trail, versus expansive and ambiguous meanings of consent as something that was experienced.

We are not unique in leaving qualitative interviews with a general sense of failure (Narin et al., 2004) or misgivings about the ethical ambiguity of what occurred (Lilieaas, 2013), and we offer the following recommendations for researchers looking to examine ambiguous experiences of consent more deeply. First, the decision to take lingering impressions of discomfort as a starting point for analysis should be done with the intention to reflexively confront dissonance rather than soothe it (Pillow, 2003). Second, analytic efforts should be directed to reconstituting the meanings and implications of consent in social space starting with data associated with the moments that provoked discomfort related to consent. Building on what is manifestly observable in the data, we argue that understanding the relational nature of consent requires drawing in latent meanings and researchers can do this by returning to their own recollections, field notes, and conversations with colleagues. To reiterate, our use of directed content analysis started with the coding of manifest conversation features before considering the latent meanings of coded interaction sequences in category creation. Researchers may find our approach instructive, but there are of course other qualitative methodological means of balancing manifest and latent meanings. Conversation analysis and ethnographic methods influenced our uptake of directed content analysis, and these options are likely fruitful primary methods for deep investigations of relational processes of consent (Sandelowski, 2000).

Although the developmental disability focus of our study attuned us to subtle and non-verbal expressions of resistance to research participation, we believe bringing this level of attunement into analyses of interactions with neurotypically resourced research participants would also yield insights. Indeed, there are countless ways that interviewees can pull and tug on the “argumentative fabric” of the social space of interviews in ways that are uncooperative with our aims as researchers (Wetherell, 1998). Our focus on third-party consent further shows how interviews with multiple participants find the researcher presiding over relational negotiations of consent between participants who may be positioned quite differently in terms of their goals and interactional resources for a given research encounter. Regardless of the relational
configuration, we argue that momentary fluctuations in the stability of consent do not necessarily indicate its decisive compromise. Nor is more restrictive research practice necessarily the goal of heightened awareness of consent as a relational process. Rather, studying the negotiations that occur in the relational dimension of consent will reliably reveal who shaped the research encounter according to their goals, and there is much to learn if we ask why.

Conclusion
Our instrumental case study of third-party consent demonstrated adults with developmental disabilities expressing relational autonomy through resistance to assumptions about third-party consent. Through inquiring into our own discomfort in conjunction with perceptions of the distress, non-disclosure, and evasion of participants, we found a means to interrogate the procedural domain of consent and the individualistic view of autonomy which undergirds it (Clement & Bigby, 2013). A chief strength of this study is that we were well positioned to take notice of discomfort and pursue this in an examination of consent. We entered interviews with a measure of pre-existing sensitization to the dynamics of third-party consent given the developmental disability context and the relational focus of the larger study. The availability of video data also supported higher levels of inference in our directed content analysis as we could corroborate recollections of context not reflected in coded transcripts by using features such as body language and intonation. Although the data of this instrumental case study was limited to three participant families, instrumental case studies support small sample sizes as the goal is to provoke naturalistic generalizations for readers as they combine selectively presented illustrations of data with reflections on their own experience and practice (Stake, 1995). Finally, as we continue to live with questions about consent long after interviews have transpired, we find ourselves in agreement with Frank (2005) who advises troubling and resisting tidy conclusions drawn from analytic categories. The methodological pathway to more expansive accounts of third-party consent with, for and by adults with developmental disabilities requires embracing ambiguous demonstrations of participant intent as part of the phenomena being studied.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Social Sciences and Humanities Research Council (Grant 435–2015–0997).

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Note
Developmental disability is a broad, categorical term that varies regionally and according to the health and social care providers, policy makers and researchers applying the term. For the purpose of this study, we use developmental disability to refer to conditions that are lifelong and entail some combination of intellectual impairment, communication deficit, and mobility limitation. We use “developmental disability” throughout our study yet we also reference authors who use other terms, that is, ‘learning disability’ or ‘intellectual disability’. We acknowledge the limits of disability terminology and the important scholarship advancing understandings of disability as “theoretically porous”; we join Garland-Thomson (1996) in viewing disability as a socially constructed experience that occurs in interaction with social and material contexts.

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