“There is No Black or White”: Scientific Community Views on Ethics in Intellectual and Developmental Disability Research

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Abstract From an ethical standpoint, there are questions about the best ways to include adults with intellectual and developmental disabilities in research. Scholarship reflects divergent responses to these enduring questions and values that can be at odds with one another. To deepen our understanding of beliefs in the scientific community about how to conduct ethically strong research with adults with intellectual and developmental disabilities, we examined the views of researchers who conduct this research and ethics review board members on ethical principles and practices. We conducted four focus groups with 17 researchers and ethics review board members. We asked participants to discuss how to ethically conduct research, relevant factors to consider, appropriate ways to address ethical concerns, and the role of ethical and civil rights principles. Findings indicate support for the use of ethical principles and newer models of disability to promote inclusion in research, a focus on researchers’ interpersonal skills and relationships to participants, questions about the best approaches to recruitment, consent, and compensation, and strategies to promote participation in research. These findings reflect the socio-ecological model of disability, civil rights-based interpretations of ethical principles, the provision of accommodations as an ethical imperative, the potential benefits of promoting relationships between researchers and persons with intellectual and developmental disabilities, and the need for dialogue between researchers and ethics review board members.

Keywords: developmental disabilities, ethics review boards, human research ethics, inclusion, intellectual disabilities, research participation

INTRODUCTION

As in other contexts of community life, the inclusion of adults with intellectual and developmental disabilities in research raises ethical questions about how to promote involvement while minimizing exposure to harm. In the United States, three principles inform deliberations about the ethical conduct of biomedical and behavioral research: respecting autonomy and protecting those with reduced autonomy (Respect for Persons), minimizing harm and maximizing benefits (Beneficence), and equally distributing the risks and rewards of participation (Justice; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). These principles were developed in reaction to instances in which individuals had been exploited by researchers, and reflect concurrent attention to individual’s rights and the need to protect them (Coleman, Menikoff, Goldner, & Dubler, 2005; Freedman, 2001).

In light of the social context and vulnerability of persons with intellectual and developmental disabilities (Dalton & McVilly, 2004), the application of these principles to their research participation stimulates critical ethical questions. A recent review reveals diverse perspectives on ethical research practices (McDonald & Kidney, 2012). Most relevant to the current study, this literature considers the values that should govern research with this population, how researchers should interact with participants, and recruitment and decision-making practices. For example, many call for research that addresses the needs of people with intellectual and developmental disabilities and dissemination of findings in ways that benefit them (Dalton & McVilly, 2004; Malott, 2002). Others advise researchers to engage participants as self-determined, establish respectful dialogue, get to know them, and collaboratively define each party’s role and the duration of the relationship (Brodin & Renblad, 2000; Cameron & Murphy, 2006; Gilbert, 2004; Malott, 2002; Stalker, 1998).
Most reviews consider how to respond to concerns about whether adults with intellectual and developmental disabilities can make free, informed choices. In the interest of avoiding coercion, the scientific community debates how to conduct recruitment. In fact, there are disagreements on whether recruitment should be done by a person who is known and trusted by the participant, by researchers, or by a neutral party or advocate (Becker, Roberts, Morrison, & Silver, 2004; Clegg, 1999; McDonald et al., 2009). Researchers also grapple with how to set non-coercive incentives (Becker et al., 2004; Gates & Waight, 2007).

Related, some express concern about whether adults with intellectual and developmental disabilities can understand and evaluate information about research (Yan & Munir, 2004), with research suggesting a range of decisional capacity (Arscott, Dagnan, & Kroese, 1998; Fisher, Cea, Davidson, & Fried, 2006). This concern has led some scholars to call for the assessment of capacity, and some countries to enact legislation. Others counter that such assessments may needlessly burden participants and place barriers on research, and that available means may be inadequate (Arscott et al., 1998; Dye, Hare, & Hendy, 2007; Dye, Hendy, Hare, & Burton, 2004; McVilly & Dalton, 2006). Alternative proposals include approaching informed consent as a process that continues throughout the research or tailoring capacity expectations to the research context (Clegg, 2004; McVilly & Dalton, 2006).

When researchers believe that an individual cannot provide consent, some feel that they should be excluded from research. This response is unsatisfactory to those who note that excluding these individuals from research revokes their right to volunteer, marginalizes them, and inhibits their access to scientific advancements (Arscott et al., 1998; Becker et al., 2004). Others suggest having representatives make decisions for these adults with intellectual and developmental disabilities (Dalton & McVilly, 2004; Freedman, 2001; Iacono, 2006), advice many disagree with as the use of proxies may relegate an adult to a child’s role, lead to decisions based on proxy’s wishes, and undermine self-determination (Freedman, 2001; McVilly & Dalton, 2006; Stalker, 1998). Others focus on providing environmental modifications to improve comprehension (Cameron & Murphy, 2006; Dye, Hare, & Hendy, 2003; Dye et al., 2007; Freedman, 2001; McCarthy, 1998) or the use of participatory or collaborative methods as such efforts are thought to yield more respectfull research practices (Brigham, 1998; Dalton & McVilly, 2004; Gilbert, 2004; Stalker, 1998).

The heterogeneity of views may relate to differential commitment to values of the disability rights movement (McDonald, Keys, & Henry, 2008; Shapiro, 1994) and their use in decisions about how to ethically engage adults with intellectual and developmental disabilities in research. Researchers and ethics review board members (bodies comprised of individuals who provide independent oversight of human subjects research1) may be two groups that can reflect this divide. For example, ethics review board members may overestimate risks and have protective attitudes that lead to excessive restrictions on recruitment and consent practices (Becker et al., 2004; Iacono, 2006; Lai, Elliot, & Ouellette-Kuntz, 2006; McDonald & Keys, 2008; McDonald et al., 2008). While these groups may similarly assess levels of risks and protections, differences in the types of risks and protections perceived suggest that ethics review board members may view adults with intellectual and developmental disabilities as more vulnerable to harm and know less about them (Hayes, Hayes, & Dykstra, 1995; Kancelbaum, 2002; Keith-Spiegel, Koocher, & Tabachnick, 2006; McDonald et al., 2009).

Ethics review board members and researchers significantly influence the treatment of adults with intellectual and developmental disabilities in research. But there is a notable absence of research which provides in-depth explorations of their views. We thus pursue an initial effort to fill this void: using qualitative inquiry, we study the perspectives of these two groups on how to ethically engage adults with intellectual and developmental disabilities in the generation of knowledge. We focus on research using self-report data, providing some limit to our scope given the preliminary nature of the study. This research allows us to learn from those who routinely make decisions about research. Understanding their views on effective ways to conduct ethical research may shed light on trends, identify areas of fit and discord between the larger scientific community and those who produce relevant scholarship, and detect new ideas. This research is well-timed given calls to include persons with intellectual and developmental disabilities directly in research and the continued search for how to best do so.

METHODS

Participants

Participants included eight university faculty and staff who conduct research with adults with intellectual and developmental disabilities and nine ethics review board members (n = 17). All participants were between 30 and 69 years of age, representing each decade in between fairly evenly. Over two-thirds of participants were female and all identified as Caucasian. Three-quarters of participants held a doctoral degree, others had either a Bachelor or Master’s degree; most degrees were in the social sciences, although two held degrees in health services and two held degrees in both social sciences and health services. Almost one-half of participants were university faculty, many in tenure positions. Another six participants held research positions, two participants held university administration positions, and one held a government position.

Procedures, Materials, and Analysis

To recruit participants, we identified intellectual and developmental disability researchers in the Pacific Northwest (USA). We also identified ethics review board members, chairs, and contact persons from these universities. We sent electronic and postal mail invitations to participate, asking individuals to share information about the study with others.

We used two research instruments. The Focus Group Guide asked participants to respond to six questions about engaging 1In the USA, these bodies are federally mandated to review federally funded research, although many institutions use them to review all research with human subjects, irrespective of funding source.

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adults with intellectual and developmental disabilities in research using self-report data (e.g., how to conduct research, factors to weigh, ways to mitigate concerns, the role of dignity, respect, self-determination, inclusion, and well-being). We also included a definition of intellectual and developmental disability (AAIDD, 2012). The Participant Survey asked about participants’ personal and professional background.

We conducted four focus groups: the first two were with either ethics review board members or researchers, the second two included mixed groups. We sent participants consent documents and interview questions in advance. We held the focus groups, which lasted about 90 min, in private rooms and provided snacks. The first author facilitated three focus groups, and a graduate research assistant (RA) facilitated a fourth. Participants provided consent to participate. We audio-recorded all focus groups, and a RA took notes during each group and checked notes for completeness and accuracy.

We took an inductive approach to coding. First, we conducted within-case analyses for each focus group (Miles & Huberman, 1994). After the fourth focus group, we noted no new major themes, indicating that we had achieved theme saturation (Lincoln & Guba, 1985). We then reviewed each focus group, creating codes for each discrete segment of data. We met to review initial codes and agree on a final set of codes. Next, we collaboratively developed a relational coding structure, identifying conceptually linked codes and creating higher-level coding categories. Lastly, we each applied the coding framework to the four sets of data. Throughout the analysis, we discussed any disagreements about code labels, definitions and placements of codes and data segments until we reached agreement on all coding determinations.

FINDINGS

We identified three principal themes that characterize views of the scientific community on ethical research with adults with intellectual and developmental disabilities: guiding values, researcher qualities, and research practices.

Guiding Values

Participants spoke about the values that should guide research with adults with intellectual and developmental disabilities. At times, these values reflected context-specific interpretations of the Belmont Principles (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). As one participant (an ethics board member) noted: “...you really can hardly go wrong by going back to the Belmont Report and thinking about the principles ... we show respect for people by not excluding them; we show respect by including them ... it’s a justice issue not to exclude a population.”

A researcher exemplified the agreement on the importance of inclusion: “There’s been kind of a tendency to protect people with [intellectual disabilities] ... [the] assumption then is that people ... should not be forced to do things but there hasn’t been a reciprocal understanding that people should have the opportunity to do things ... we don’t give them many opportunities to say ‘yes.’ I think it’s balancing those and making sure that we’re not doing things to people and forcing things on them but also make sure we’re not deciding for people that this isn’t appropriate for them or that they shouldn’t have a chance to decide whether or not they want to do it.” Participants also noted that exclusion from general population research is equally problematic, and that the sensitivity of the research and risk-benefit analysis are also important to evaluate.

Similarly, participants noted that values embedded in definitions of disability and personal beliefs inform views and can subsequently limit or promote inclusion in research. Some participants felt that research should be framed in terms of capabilities and that the diverse experience and abilities of adults with intellectual and developmental disabilities should be considered. Some participants feel that researchers should connect personally with adults with intellectual and developmental disabilities and have interests beyond scientific publications, although some (as this ethics board member) noted that there can be ensuing complications emerging from these interests: “It’s a human thing. It’s a humane thing and I don’t mean that in a way of pity ... are you engaging people in your project, in your research in a way that really shows that you’re not just looking to publish an article ... There’s an intent that goes beyond what you can put on paper ... I think each individual researcher has to tap into in some way and I often times find myself connecting with people that I am working with ... I think having an investment in [it], sometimes that creates a problem ’cause you lose ... that ... perspective ... it’s something I always weigh, what is my ultimate objective here.”

As a result of valuing and using these beliefs, participants envisioned research stimulated by the needs and preferences of adults with intellectual and developmental disabilities. A few participants indicated that one way to achieve this is to use participatory action research (PAR). Participants felt that PAR lead to more ethical research, in part because of the true inclusion of those affected. One researcher noted: “I try to embody participatory action research. That’s ... what I see as ethical ... true inclusion of the people that you’re working with instead of acting on them, acting with them.” Participants noted that other ways to identify priority needs include communicating with members of the population, attending conferences, and reading. The same researcher explained that “Those of us who really do this kind of research need to spend ... ongoing time with people and understanding the issues and reading the websites, going to conferences ... Research questions are being driven by what’s true today ... not what’s been in the textbooks, you know, five years ago or ... necessarily what’s coming up in journals ... being applied researchers ... you really need to be out there and living and breathing and sitting next to people.”

Researcher Qualities

Participants also discussed the interpersonal skills they felt that researchers should possess. First, some participants reported that researchers should know and understand the diverse life contexts and experiences of adults with intellectual and developmental disabilities, especially since lack of knowl-
edge may lead to misconceptions that exclude them from research. Relatedly, some participants felt that researchers should always be aware of what they are doing and whom they are serving. Participants also noted the importance of good communication skills, including effective oral communication skills for diverse research participants. One researcher discussed the benefit of community partners teaching researchers how to work effectively with adults with intellectual and developmental disabilities. Participants also noted that researchers need to be flexible in the provision of supports to promote participation and throughout data collection.

Research Practices: Inclusion, Coercion, and Comprehension

Participants discussed practices that they felt led to more ethical research. These practices reflect value-driven, contextual considerations, and illustrate the tensions among inclusion, coercion, and comprehension. Of note, ethics review board members stressed that they can assist researchers as they plan their research, although some were less aware of population-specific ethical challenges. First, many participants noted competing demands—and ensuing ethical dilemmas—in recruitment. One way researchers handle recruitment is to ask agencies to share information with clients. However, some perceive this strategy as imperfect, noting that providers may select who to inform about the research as they rationalize why participation would be inappropriate or impossible for some. This practice feels paternalistic to some researchers who noted that when approached directly, these same persons express interest. One researcher explained: “It seems like service providers and often parents have a lot of reasons why this wouldn’t be appropriate for a particular individual . . . they wouldn’t be capable of doing that . . . times when we’ve had opportunities to talk to individuals themselves they’ll be very interested. So that’s been a big frustration of trying to figure out how to reach people more directly because we keep running into so many closed doors with gatekeepers. Because they are trying to protect people, which is an appropriate thing to do . . . But it kind of swings too far [and] becomes, I think, disrespectful in the other direction.” Other researchers preferred reaching out to individuals directly by using client listings or working with self-advocacy groups who may be more trusted by the community.

Many researchers noted attending to coercion. One researcher noted that recruiting puts researchers in educative roles, as they must help adults with intellectual and development disabilities and their supporters understand research in general, as well as the specifics of the research study in question. Participants disagreed, however, about whether a researcher assuming these roles is desirable. Some feel that it is unavoidable, noting that individuals who make decisions independently may be similarly assumed capable to make decisions about research. This is exemplified by this comment from an ethics board member: “Consider . . . constraints there may be on the ability to give voluntary consent. You need to consider it, you don’t need to deny somebody participation in research because of it. What’s known about this population? What is the level of disability? What else do they do for themselves in daily life? . . . and we make a decision on how much extra protection we need to provide based on some of those answers.”

One core question for those who need assistance with decisions, captured by one ethics board respondent: “is [the participant] protected given his/her ability to control and forecast what implications of participation might be?” One measure participants discussed was that they may need a caregiver to help make the decision: “If you need the oversight of a guardian to execute . . . activities of daily life, consenting to research should have a guardian’s input” (as noted by another ethics review board member). While some participants felt that it might be appropriate to use guardian consent in medical studies, others expressed concern that those who do not have legal guardians may end up excluded from research given misunderstandings about guardianship.

Participants agreed that when guardians are present, it is important to consider their role. For example, some participants

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feel that researchers should evaluate participants’ relationship with the guardian; if a guardian tends to respond for the participant, that may indicate that the guardian is making the decision. Some participants felt that when this happens, the researchers should exclude the individual. One ethics review board member noted that they must rely on researchers to evaluate these interactions. Several participants noted that they sometimes perceive a bias among carers that adults with intellectual and developmental disabilities cannot make decisions, leaving the guardian responsible. For those with legal guardians, participants noted that researchers can provide separate documents to indicate that each individual has a distinct decision, provide all information to each party, and allow time for the decision. This approach helps ensure that adults with intellectual and developmental disabilities participate meaningfully in the process. Participants left unresolved the question of what happens when the potential participant appears to understand and wants to participate but the carer disagrees. Participants added that allowing opportunities to withdraw at any time allows the decision of the participant to be flexible. Illustrative is this comment offered by one researcher: “[There need to be] procedures in place for everybody to get ample opportunities to withdraw or decline to participate throughout.”

Another consideration that participants addressed was how to determine whether an individual understands, with agreement that those who do not understand should not participate. One ethics review board member added that assessments of understanding are only needed for higher-risk research. Some participants talked about informal, project-specific means to make these determinations such as asking participants a series of questions, and reexplaining topics for which an individual initially responds “I do not know.” Participants noted the complexity of this situation; according to one ethics review board member, “the investigator has to, very quickly, come to a couple of critical decisions.” These situations leave some researchers wondering whether their efforts to bolster understanding result in undue pressure to participate.

While many participants indicated support for some form of assessment of comprehension, others noted concerns that doing so is paternalistic and unfair. One researcher explained that “Folks I work with . . . say don’t treat me like a child and don’t make assumptions. There’s not a lot of understanding in part because it is a diverse group. . . . There’s a large diversity of folks and most folks can do just fine . . . I may have the same issues understanding that consent as if I had that label.” Concerns also persist about appropriate standards: what quantity of correct responses is necessary? Other concerns noted include that individuals with limited literacy may be excluded. “Maybe they can give verbal consent . . . they just can’t read very well, but they can understand to make a decision” was one comment offered by a researcher. Some participants felt that it was important for researchers to set straightforward standards and for institutions to write clear policies.

Participants also discussed the importance of making consent processes and materials understandable, including lay language documents to guide conversations with participants and the need for low reading levels, while also noting how rare it was to encounter such materials. A researcher explained, “It’s a difficult thing because you really want to make sure that everybody understands] . . . using as simple language as possible.” Other strategies participants described include providing multiple explanations and links to everyday examples, having participants go through exercises for complicated topics such as what will happen if confidentiality is breached or confidentiality in focus groups, coupling visual and verbal materials, answering questions, using clear language, and breaking information into discrete chunks were also discussed. A researcher responded to us: “[I do] a whole bunch of work on designing the informed consent forms and trying to make visuals . . . Trying to compare it to everyday examples, public and private information, and all of that. But I think giving people all the time they need to process something and then what you’ve said and then to process what they say back is one important piece.”

Having researchers work directly with adults with intellectual and developmental disabilities to assist with wording on materials, having a nonresearcher explain information, or consulting an ethics review board may help as well. To help participants differentiate between program participation and research, one researcher has participants put on hats during data collection activities to mark the change. Participants also shared that providing consent materials and information before an individual needs to make a decision helps, although they also noted that this rarely happens. An ethics review board member emphasized the importance that participants be aware of all risks; one researcher wondered whether some statements unduly alarm people.

Researchers described the importance of consent as an ongoing process (e.g., reminding participants they are in research, that participation is voluntary, the limits of confidentiality) and the utility of having different individuals collect data than those who deliver an intervention. A researcher explaining that “One way that I consistently do that is at each stage . . . remind them ‘this is still a research study, do you remember what that means?’ It’s going through it in very lay terms and reminding them that at any time they can leave . . . and reminding them that their information is confidential.” Researchers also discussed compensation noting tensions among wanting to offer incentives that are attractive, fair, and noncoercive. Valuing compensation equal to other populations, one researcher said: “We shouldn’t necessarily pay them less because they value it more than someone else” Another added: “One thing that I struggled with wanting to provide some kind of compensation for research participation so that we’re just not asking them to give their time freely but at what point does it come coercive that people are just getting into the research project to get their gift card or whatever . . . and trying to find an appropriate point where it is enough . . . but it’s not they’re only getting to the study for that and that they’re maybe staying involved longer than they would otherwise want to just so that they can get their money. I haven’t come up with a good answer to that yet, but I think that that payment and what it represents to people is an ethical issue.”

Participants also spoke about ethical issues that emerge during data collection. For example, participants, especially researchers, reported that they felt that it was a researcher’s ethical responsibility to provide adequate supports and accommodations, including flexibility around the length of time it takes to participate. One researcher noted that grant-related pressures may present unrealistic timelines to complete research
appropriately. Researchers noted the importance of emphasizing that, as appropriate, there are no right or wrong answers but that they want to hear individuals’ perspectives. Researchers also noted the importance of maintaining participants’ interest and reported using interactive assessment tools, limiting the length of questions, and providing breaks during which they might discuss unrelated topics. Researchers also spoke about having data collection in areas that are accessible by public transportation and in buildings and rooms that are accessible, and that researchers should pursue financial support for removing barriers to participation such as transportation. Moreover, providing transportation may help lessen dependence on supporters for assistance, and hence lessen some of the supporters’ hesitation to encourage research participation.

Some researchers felt that it was inappropriate to hand an adult with intellectual and developmental disabilities a survey and expect them to complete it. Instead, they felt that interviews provided opportunities for expression, and, in the case of group interviews, a setting where they may feel more comfortable and empowered and make new friends. Alternatively, some researchers noted that having supporters present to explain information and help the researcher understand the participant may help. However, participants also noted that this solution raises concerns, particularly when the research is sensitive as the presence of supporters may challenge confidentiality, privacy, and voluntariness. One suggestion to mitigate this concern is to send materials to participants in advance and suggest that they review them with someone. One respondent (a researcher) explained that “The key is flexibility . . . on what we’re doing, to make sure that we know that we’re getting what we’re supposed to be getting . . . In addition to giving extra time I think, ensuring the individual has the supports they need to participate is critical . . . One of the ways that’s been useful, that we’ve adapted [in] our study . . . is send some of [the research materials] in advance of coming to an orientation . . . Sending those in advance and letting people know it’s okay to have somebody help you with that and that’s fine and we anticipate that. But also letting folks know that when they come in person there will be plenty of time and there will be people there ready to assist them as well. Building in extra layers of flexibility is helpful.”

Lastly, one researcher emphasized the need for researchers to proceed with caution since one negative experience can have consequences on subsequent participation. To inform future research, an ethics review board member suggested that researchers ask participants, “What could we have done to make your participation easier?” and “What did you find offensive?”

DISCUSSION

We conducted an exploratory qualitative study to examine the beliefs of researchers and ethics review board members on how to conduct ethical research with adults with intellectual and developmental disabilities, with a focus on self-report research. Findings indicate support for the use of ethical principles and newer models of disability to promote inclusion in research, a focus on researchers’ interpersonal skills and relationships with and knowledge of persons with intellectual and developmental disabilities, questions about the best approaches to recruitment, consent, and compensation that balance self-determination, respect, and safety, and strategies to promote participation in research.

In general, researchers and ethics review board members endorsed beliefs and practices that favor participation in research as a right and reflect a strengths-based, socio-ecological model of disability (Pledger, 2003). For example, participants focused on altering the environment to promote inclusion, rather than on individual deficits. In so doing, they framed accommodations as an ethical imperative, a framing not frequently explicitly employed, although many attend to how to improve comprehension (Fisher et al., 2006; McDonald & Kidney, 2012). These findings support prior work on attitudes toward research with this population; these beliefs may be increasingly focused on how to respectively and safely promote participation in research as a matter of justice and respect, signaling movement away from exclusion as a means of protection (Lai et al., 2006; McDonald et al., 2008). It also suggests that researchers may need to learn about effective accommodations (or partner with those who have this expertise) and a potential review criterion for ethics committees to consider.

This focus on the right to participate, present in many scholars’ work (Iacono, 2006; Lai et al., 2006), parallels values of the disability rights movement that call for full participation in all facets of society, including those which present risk (Shapiro, 1994). Attention to these societal shifts may help create more numerous and effective access ramps to research participation, which may in turn promote the production of knowledge able to positively impact the lives of persons with intellectual and developmental disabilities. Given differential support for the value of inclusions and rights (Iacono & Murray, 2002; Lai et al., 2006; McDonald et al., 2008), researchers, professors, and persons with disabilities and their allies may want to invest in promoting understanding of disability rights so that research principles and their application can increasingly reflect these values. In so doing, we note the value of treating others as they want to be treated (Alessandra, n.d.). That is, we might consider infusing research practices with the preferences and needs of persons with intellectual and developmental disabilities in order to promote respect and accountability (Kitchin, 2000; McDonald, Kidney, & Patka, 2012). One way to achieve this goal is through the use of participatory research models which reflect the disability rights mantra of “Nothing About Us Without Us” (Ham et al., 2004; Nicolaidis et al., 2011). We were surprised that few participants identified participatory methods as a tool to promote ethical research. This finding may reflect the uneven uptake of commitment to perceiving the capabilities of this population and the need for models and resources to carry out such work. We hope these commitments grow, and that we identify ways to help members of ethics review boards understand and appreciate the role of these values in research ethics.

Less expectedly given relative emphases in scholarship, participants paid notable attention to the sensitivities, skills, and knowledge of researchers who conduct this research. These views suggest that researchers who study individuals from marginalized groups may need exposure to specific paradigms and experiences in order to engage in research with greater ethical integrity. That is, researchers may need more than scientific training. Instead, we may need to attend equally to developing
researchers who have had opportunities to develop positive relationships with people with intellectual and developmental disabilities (McManus, Feyes, & Saucier, 2011). These relationships may help researchers learn from persons with disabilities and provide researchers with a deeper understanding that they can then apply to their research. Moreover, if researchers develop personal investments in the well-being of persons with intellectual and developmental disabilities, they may also increasingly value pursuing in research of benefit to them (Brodin & Renblad, 2000; Malott, 2002; Stalker, 1998). Unfortunately, textbooks typically fail to include discussions relevant to marginalized populations (Aldridge, 2007). We recommend that graduate programs institutionalize opportunities for new researchers to develop these relationships. Another benefit is that researchers may be better positioned to help ethics review board members understand the context of their research. We emphasize the value of exchanges between the two parties that would allow for critical co-learning. This finding may also suggest a new criterion of merit for ethics review boards to use in evaluating researchers.

Unexpectedly, participating members of the scientific community spent less time focusing on consent than anticipated given its dominant place in scholarship. This finding may indicate that when they consider ethical issues in research with persons with intellectual and developmental disabilities, their framework broadens to question the values and sensibilities of those who engage in this work and the role of accommodations. Nonetheless, their discussion mirrored others as they considered how to promote comprehension, handle informal and formal guardians, assess competency to consent, maintain ongoing consent, and appropriately set incentives (McDonald & Kidney, 2012). Participants expressed support for researchers’ responsibility to modify their approach to bolster understanding, determine that an individual understands the research, and, especially for researchers, sensitivity to dynamics of coercion and paternalism that can occur in the consent context. These findings suggest that researchers proactively and on the spot address these issues in research, coming to solutions that appear to be best for each project and individual. As such, researchers demonstrate adaptability, attention to context, and an eagerness to continually learn how to better conduct research. They also express somewhat divergent opinions on what is best and a general sense that even the best approaches are imperfect. This finding again highlights the importance of exchanges between researchers and ethics review boards to facilitate critical discussions that may help both meet their priorities. In particular, ethics review boards may augment researchers thinking on the topic and thus improve ethical analyses that inform researchers’ decision making.

Of note, some ethics review board members seemed less familiar with persons with intellectual and developmental disabilities. For example, they were less aware of gatekeeping that researchers may encounter from service providers and family members and accommodation strategies that promote inclusion. As a result, ethics review board members may be less aware of practices that may be received as paternalistic, including the importance of promoting rights and inclusion in research (McDonald et al., 2012). These findings emphasize the value of collaborations between researchers and ethics review board members to design research with high ethical merit and high-light the unique perspective and knowledge each contributes to such exchanges. Mutual respect and trust are critical ingredients to the human subjects’ process in order to facilitate open channels of communication and contribute to ethically strong research. It is thus essential for researchers and ethics review board members to recognize the value of each other and work together to promote much-needed research that is respectful to those it engages in knowledge production. Including self-advocates and allies on ethics review boards may build capacity of ethics review boards (DeRenzo, 1997). Collectively, these dialogues can create learning communities and space for ethical dialogue (Clegg, 2004).

These findings should be interpreted with caution. We conducted an exploratory qualitative study in order to explore views in greater depth than other methods allow. It is important to consider that our sample was small, geographically homogenous, and comprised of persons largely conducting social science and health services research who were willing to share their beliefs in a group. It is possible that participants represented those who favor the inclusion of marginalized populations in research or that participants felt pressured to respond in particular ways given the group context of data collection. Given the variance in some views and the fact that we did not perceive any shared group beliefs, we do not think that social desirability responding was a significant concern. Nonetheless, the extent to which our findings may be more broadly applicable is not clear. Moreover, future research will need to examine the accuracy of these views. We also limited our inquiry lens to self-report research. While this decision allowed us to focus discussions on research in which adults with intellectual and developmental disabilities are asked to express themselves, it may also have led participants to focus on a subsample of the population who may experience less severe forms of disability and/or fewer challenges providing consent. Future research can more fully consider how the diversity of the population and the nature of the research impacts views on ethical research practices.

In conclusion, we note the ethical minefields that researchers navigate in the quest for knowledge that can benefit adults with intellectual and developmental disabilities. Participants raised many questions. In the words of one participant, “there just is no black or white”; instead there are numerous gray zones. Not only did many participants wonder how to best conduct research, but they also appeared to have an incomplete knowledge of relevant policy and law, including how to handle issues of informal and legal guardianship. Most participants expressed support for trying every approach possible to include as many individuals as possible, only succumbing to exclusion when other alternatives have been exhausted. In the end, each decision is a careful tradeoff between promoting the benefits of participation with the need for protecting. Despite these best efforts (which represent a departure from decisions to exclude from the get-go), there is a sense of nagging uncertainty and discontent with imperfect practices. Of note, scholarship is no more unified and certain (McDonald & Kidney, 2012). These gray zones cover the research landscape and cast shadows on the line between what is right and what is wrong. To bring clarity to these decisions and push forward ethical research, we can create communities of practice where the scientific and nonscientific communities come together to discuss shared
interests in the ethical conduct of research; these multiple viewpoints can spur thoughtful, inclusive dialogue and mutually agreeable decisions about research ethics. We can also generate inclusive scholarship that sheds light on the topic, including data to allow us to evaluate the veracity of views expressed by participants in this study.

REFERENCES


