“We Want Respect”: Adults with Intellectual and Developmental Disabilities Address Respect in Research

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Abstract

Respect is central to ethical guidelines for research. The scientific community has long debated, and at times disagreed on, how to demonstrate respect in research with adults with intellectual and developmental disabilities. To illuminate the voices of those most affected, the author studies the views of adults with intellectual and developmental disabilities on respect in research. Findings are consistent with disability rights’ ideas and indicate that adults with intellectual and developmental disabilities have much to contribute to the discussion, that they value participating, and that they agree with calls to focus on human rights and dignity. Notably, participants spoke at lengths about the nature of interactions between researchers and participants. Implications are discussed, including how to infuse research standards with community-supported values and preferences.

Key Words: respect; research participation; inclusion; people with intellectual and developmental disabilities

In the United States, principles for ethical research include respect for persons (respecting individual autonomy and protecting those with reduced autonomy), beneficence (securing well-being), and justice (equally distributing the risks and rewards of research participation). These principles are expressed in informed consent, analysis of risks and benefits, and sample selection (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979), with considerable attention given to questions of whether individuals are able to make informed, voluntary decisions; whether they will be exposed to harm; and whether sufficient protections are in place (cf. Dye, Hendy, Hare, & Burton, 2004; Fisher, 2003). For sociopolitical minority groups with individual and collective histories of mistreatment and marginalization, the concept and expression of respect in research may bear distinct meanings. It therefore becomes critical to understand stakeholders’ perceptions of research practices in order to devise practices experienced by participants as respectful (Iacono, 2006; Roberts, Hammond, Warner, & Lewis, 2004). Unfortunately, this foundational work on community-supported practices has infrequently been pursued.

Values embodied in the disability rights movement (Charlton, 1998; Dybwad & Bersani, 1996; Miller & Keys, 1996) hint that individuals with intellectual and developmental disabilities may hold important beliefs about whether research practices are respectful. However, they have had little opportunity to offer their perspective, particularly within scientific discourse. Systematically studying these views is thus the goal of this research. This research may be particularly timely given calls to conduct more research with adults with intellectual and developmental disabilities to address pressing disparities (Aman & Handen, 2006; Turnbull & Lakin, 2005). However, ethical complexities in conducting research with adults may contribute to the relative lack of research with this population. This research is thus posed to potentially illuminate effective strategies and promote much needed research; it may equally shed light on perspectives relevant to research with children with intellectual and developmental disabilities.
As people with intellectual and developmental disabilities advocate for their rights and society responds, the scientific community is attending to the negative consequences of excluding them from research, how to balance inclusion in research with protections, and devising protections experienced as respectful (Aman & Handen, 2006; Iacono & Murray, 2003; Lai, Elliott, & Ouellette-Kuntz, 2006). These shifts in discourse elevate ethical principles in research participation to focus attention on respect for a person’s dignity—not only their autonomy—that is consistent with human rights frameworks (McVilly & Dalton, 2006). Although a somewhat elusive concept, respect is embodied in an attitude and behavior that conveys acknowledgment of, attention to, and value for a person (Dillon, 2010)—treatment that many people with disabilities have long been unable to take for granted (Charlton, 1998).

To date, the scientific literature, largely through researchers’ experiential accounts and commentaries, and to a lesser degree in empirical study, has examined an array of issues related to research ethics and adults with intellectual and developmental disabilities. Most relevant to the current research, this scholarship considers inclusion in research, research focus and methods, and relationships between researchers and research participants. On the first topic, opportunities for adults with intellectual and developmental disabilities to participate in research, scholars emphasize three core ideas: avoiding using the presence of disability to preclude participation; viewing adults with intellectual and developmental disabilities as able to contribute to research; and encouraging their participation in research more generally, not just in research focused on adults with intellectual and developmental disabilities (Aman & Handen, 2006; Iacono, 2006; Iacono & Murray, 2003; McCarthy, 1998; McVilly & Dalton, 2006). On research foci and methods, some scholars advocate that research should address topics that adults with intellectual and developmental disabilities perceive as worthwhile. Likewise, some scholars suggest that research should relate to the needs of adults with intellectual and developmental disabilities and benefit them directly (Dalton & McVilly, 2004; Diesfeld, 1999; Malott, 2002; McCarthy, 1998). Others recommend that research aims be informed by the social model of disability (Gilbert, 2004; Rodgers, 1999) and investigate research questions that promote dignity and humanity (Clegg, 2004; Diesfeld, 1999). Scholars also advise avoiding perpetuating negative stereotypes about people with intellectual and developmental disabilities (Becker, Roberts, Morrison, & Silver, 2004) and focusing instead on their opinions and experiences (Brigham, 1998; Ellem, Wilson, Hong Chui, & Knox, 2008; Rodgers, 1999). Others add that researchers should be honest about the research (Brigham, 1998), use participatory and visual methods (Boxall & Ralph, 2009), and provide supports to participants (Brodin & Renblad, 2000; Dalton & McVilly, 2004).

Last, relationships between researchers and research participants have also received attention, with some scientists emphasizing the need for honest, respectful, and mutually beneficial relationships. Relationships with these qualities might be achieved by expecting researchers to get to know participants (Ellem et al., 2008; Malott, 2002; Stalker, 1998) and establishing the roles, identities, and contexts of both researchers and participants (Gilbert, 2004; McCarthy, 1998). Ending relationships at a pace in which participants do not feel exploited may equally achieve this goal (Stalker, 1998). Similarly, collaborations with people with intellectual and developmental disabilities may help researchers design research that conveys an attitude of collaboration and that shares research more fully with them. Resulting research practices might include providing protections against violations of confidentiality, paying participants for their contribution, inviting opportunity for feedback on findings, and sharing findings more readily outside the scientific community (Becker et al., 2004; Brigham, 1998; Dalton & McVilly, 2004; Diesfeld, 1999; Freedman, 2001; Gilbert, 2004; Iacono, 2006; McCarthy, 1998; Rodgers, 1999; Rolph, 1998; Stalker, 1998). Some note that while such relationships may promote ethical research, they may also demand critical relational skills of researchers (Becker et al., 2004; Cameron & Murphy, 2006).

In the last decade or so, the scientific community has emphasized these aspects of ethical research because people with intellectual and developmental disabilities have often been treated poorly in research (Aldridge, 2007; Ferguson, 2004). Also of note, there are persistent tensions in values and preferences for research practices linked to how they reflect efforts to preserve autonomy or primarily offer protection.
from harm (McDonald & Kidney, 2012; McDonald et al., 2009). And despite some researchers’ recommendations, their ethics committees may insist on contrary research conditions, including practices that researchers believe are needlessly protective and thus do not promote the dignity of individuals with intellectual and developmental disabilities (Dye, Hare, & Hendy, 2007; Lai et al., 2006; Rodgers, 1999).

One way to reconcile these tensions is to consider community members’ perspectives, with the goal of creating research practices experienced as respectful by the population of interest. Although we know less about the views of adults with intellectual and developmental disabilities, initial evidence suggests that they want to be included in research (Ham et al., 2004; Heller, Pederson, & Miller, 1996; Iacono, 2006). They also advocate that researchers focus on their abilities, conduct research relevant to them, value their contributions and time, display patience, and provide accommodations (Andre-Barron, Strydom, & Hassiotis, 2008; Ham et al., 2004; Heller et al., 1996). Though informative, this research does not specifically focus on respect in research, a critical principle of the disability rights movement and in research ethics. Moreover, this knowledge derives from researcher accounts and small sample research on views on collaborations for training and research (Andre-Barron et al., 2008; Fisher, Cea, Davidson, & Fried, 2006). I focus on facets of research not directly related to decision making (e.g., recruitment and informed consent). To my knowledge, this is the first time the concept of respect in research from a human rights perspective has been systematically studied among adults with intellectual and developmental disabilities. It is unclear to what extent the perspectives of adults with intellectual and developmental disabilities will mirror those of the scientific community and those promoted in the disability rights movement; it is reasonable to expect that research practices that promote inclusion, dignity, and strengths-based perspectives will be favored.

Method

This exploratory research took a multimethod, qualitative approach. With two graduate research assistants (RAs), I conducted 16 individual interviews with adults with intellectual and developmental disabilities to explore their perspectives in depth. To explore emergent findings not addressed in each individual interview and check findings and interpretations with participants, we subsequently conducted four focus groups to solicit feedback on key findings from the individual interviews.

Participants and Measures

Sixteen adults with intellectual and developmental disabilities with prior experience as research participants took part in the research. Participants were not under legal guardianship and were able to and interested in participating. Of the 16 participants, 5 were men and 11 were women. Four participants were between 19 and 29 years old, 2 participants were between 30 and 39, 4 participants were between 40 and 49, 2 participants were between 50 and 64, and 3 were over the age of 65 ($M = 44.69$ years, $SD = 17.75$ years). Eight participants identified as White, 7 participants identified as Black, and 1 participant identified as Asian or Pacific Islander. No participant identified as Latino. Six participants had less than a high school education, 5 had some high school education, and 5 had completed high school or the general equivalency diploma. At the time of the individual interviews, 13 participants were unemployed and 3 participants worked part-time. Finally, 13 participants reported participating in one prior research study, while 3 participants...
reported having been involved in three prior studies. One half of participants had been involved in behavioral intervention research; one quarter had been involved in individual interviews; and one quarter had participated in focus groups.

We created and pilot tested all materials with the assistance of two research advisors who had intellectual and developmental disabilities. To explore individual experiences and perspectives in depth, we created the semistructured Individual Interview Guide to ask about a recent research experience. We then asked about opinions of experience and views on inclusion, recruitment, decision making, safeguards, risks, benefits, and respect. The interview guide also included demographic questions. We conducted an initial analysis of the individual interviews to identify core themes. To examine emergent findings from individual interviews and check our findings and interpretations with participants (i.e., to engage in member checking), we created the presentation-based Focus Group Guide to ask participants for reactions to core findings (i.e., finding out about a study, informed consent, and positive and negative things about research), including their accuracy, completeness, and relative importance.

Procedures and Analysis
I hired two advisors with intellectual and developmental disabilities to ensure the appropriateness of research strategies and materials. More specifically, I hired them to help ensure that the research materials and practices conveyed respect to participants and were understandable. The research advisors also helped devise accommodation strategies. Together we created documents (e.g., recruitment materials, consent forms, and interview and communication guides) that included clear language and informative images. The communication guides included a participation schedule for the consent process, individual interview, and focus group; a break guide so that participants could indicate that they would like to take a break or stop the interview; and an interview progress guide that indicated questions completed and questions remaining. We also pilot tested all materials and received institutional review board (IRB) approval.

We sent flyers via postal and electronic mail to regional self-advocacy groups, nonprofit and government service organizations, and researchers. We also spoke to those who had questions about the research. We asked people to share the flyers with adults with intellectual and developmental disabilities who (a) had participated in research, (b) were not under legal guardianship, and (c) were interested in and able to participate in interviews. Many people shared flyers with their peers, clients, or research participants in individual or group meetings or through postal mail. We recruited 16 individuals through case workers (n = 9), disability researchers (n = 2), personal communications (n = 2), and participant referrals (n = 3). When participants contacted us, we spoke to them about the study and assessed their eligibility and interest. Together we decided when and where to meet to discuss the research and answer questions. We also offered assistance with travel (including reimbursement for travel expenses) and emphasized the voluntary nature of participation. We told participants that they could bring a friend or support person if they wanted to; none decided to do so. With one exception, all individuals who contacted us to express their interest in the study participated (one person declined to participate after choosing to take the offered waiting period before making her decision).

We then scheduled individual interviews (although in some cases, the individuals decided to participate right away) and planned how to meet participants’ specific needs and preferences (Heller et al., 1996). At all times, we read materials with participants. We conducted interviews in locations that were convenient, comfortable, and private for participants; these included homes, coffee shops, a case manager’s office, and our office. We reviewed consent information, answered questions, and asked participants to explain the purpose, risks, benefits, and procedures of the research in their own words. To be selected for the individual interview, participants did not have to agree to take part in the focus group. All participants demonstrated an understanding of the research and agreed to participate and have the interview audio-recorded. Interviews ranged from about 20 to 71 min, with an average duration of 40 min.

A few months later, we conducted focus groups. All participants were invited; 12 of the 16 participants were reachable, interested, and available. One individual did not participate because she does not like sharing her opinion in groups, another did not have a working phone number, and two were out of town for an extended period. We selected participants for each group based on
characteristics and experiences that appeared to account for differences in perspectives and their availability (Woodring, Foley, Rado, Brown, & Hamner, 2006). We conducted focus groups in private rooms at our university. At the beginning of the group, we reviewed the research and ground rules and answered questions. All participants indicated their willingness to participate and have the focus group audio-recorded.

We moderated interviews by following the natural progression of dialogue with appropriate follow-up questions and, for the focus groups, solicitation of different perspectives. Participants received compensation for travel costs and a $40 gift card for each interview. Focus groups also included a meal. Trained RAs completed verbatim transcriptions, and another RA reviewed them.

We created case summaries of each individual interview to examine individual perspectives (Miles & Huberman, 1994). We then conducted a thematic analysis across cases to identify initial themes for the focus groups. These initial themes centered on finding out about a study, informed consent, and positive and negative things about research and touched on subthemes of trust, clarity of information, the roles of others, treatment by researchers, and emotional experiences. Our analysis indicated that we had achieved data saturation as no new information relative to the findings reported here emerged after we had conducted about two thirds of the interviews. After the focus groups, we proceeded to a deeper analysis using data from the individual interviews and focus groups (Lincoln & Guba, 1985; Miles & Huberman, 1994). We developed the coding framework by randomly selecting transcripts to read independently. We met to discuss emergent themes and their relationships until we came to agreement. We repeated this approach until we had read all transcripts and agreed on a coding framework. As with the initial analysis, early versions of the coding framework covered core components of research stages and included subthemes related to participants’ prior experience, evaluation of prior experiences, and views on how research should be conducted. We then created higher order themes linking initial themes to one another. Examples of these higher order themes include inclusion, respect, trust, and improving quality of life. Under my supervision, two graduate RAs then applied this framework to all data using Atlas.ti (Atlas.ti Scientific Software Development, 2009). We discussed all coding discrepancies until we reached consensus; we similarly agreed to modifications to the coding framework. Early on, there was greater discrepancy among the RAs as we refined the coding framework. As we clarified the meaning and structure of codes, interrater reliability improved and eventually culminated in perfect agreement. Several months later, I assessed the stability of coding by recoding all interviews; I did not find any discrepancies.

Results
I identified three overarching themes in research that account for the views of adults with intellectual and developmental disabilities on respect. I describe each theme and provide illustrative quotes (all participants’ names have been changed).

Research Designs
Participants spoke about how research designs accord respect to persons with intellectual and developmental disabilities. First, several participants noted the importance of conducting more research with persons with intellectual and developmental disabilities, especially since they are frequently excluded from research. Participants said that researchers should specifically reach out to people with intellectual and developmental disabilities to get them involved and open up research participation to everyone, regardless of their literacy level: “Get more people involved … try to get more people in more of the studies” (Felecia). Even when they are invited to participate, participants cautioned that being randomly assigned to a control group can feel like rejection: “I didn’t like it … they didn’t keep me very long … they kicked me out … they told me not to come back” (Grace).

In discussing respectful research aims, many participants suggested that researchers conduct studies focused on their strengths and abilities or that provide opportunities for them to learn and improve their lives:

People with disabilities … can learn a lot from research. They can learn where it can help them go and what they can do. Especially if it will help them with their everyday thing … their everyday life … their job, the community they live in … [to] speak up for themselves when they need to speak up … it will give that person kind of an edge. … Persons with disabilities right now … are a community out there that need guidance. (Alice)
Noting that many of them are socially isolated, a few participants want researchers to provide them time to interact with other participants:

You don’t get a lot of time to talk to [other participants] and really get to know ’em. … [i]t’d be fun to get to know the other people. … If you always have somebody to talk to, if you’re not just by yourself … if you make friends in the study … that makes it fun too, which is nice. (Ashley)

Other participants indicated wanting to engage in fun activities, including outings.

Addressing research procedures, a few participants noted that they prefer research that allows them to freely express their opinions and feelings with open-ended questions: “I liked how [in a] lot of these researches I gave my opinion. … Throw out the questionnaires, ask us and we’ll tell you” (Rick). Others indicated that they prefer that researchers avoid lengthy surveys with too many or repetitive questions:

I didn’t like doing it over and over again, the same answers … the same ones over and over again, the yes or no answers, and I couldn’t understand why the hell they wanted the same questions over and over again and I didn’t like that. … It was too long and I probably got tired but I didn’t get mad. I wanted to get it done. (Charles)

Participants added that they may become tired, confused, frustrated, develop headaches, or lose interest when research is too lengthy (even when they understand why researchers might use this strategy):

Sometimes … they just go over the same question just with different words and they get me really confused. … It’s still the same question … but they just reword it. … I think what it is, is making sure that you pay attention to the words … but … [I] find it confusing. … I be like okay, I’m tired … it just be like too long, then I lost my interest in it. (Charissa)

One participant stressed how important it is that studies take place in a private setting where service providers or others cannot overhear: “We should [do the] study at a coffee shop … because nobody from your home can hear you. … I don’t like when they hear what I share” (Grace). Of note, although at least one participant expressed discomfort with research that labels individuals as disabled from the outset, another noted feeling uncomfortable with group-based research that might involve participating with those without disabilities: “I don’t want to go to a group where everybody was on a higher level than what I was on” (Roselyn).

Participants felt that researchers can also show respect by compensating them for their contribution and time. Participants reported that they liked receiving compensation: “Give them discounts at [a] movie theater” (Ashley). Others noted that many persons with intellectual and developmental disabilities lack fiscal resources, and thus compensation may be needed. Several participants felt that researchers also show respect by providing feedback to or sharing findings with participants: “[You want to] see if you did ok. … You want to say, ‘Did I do ok?’” (Alice).

Many participants also noted that it was important for researchers to portray people with intellectual and developmental disabilities in a positive light when they share research findings. And last, participants wanted researchers to help others learn about people with intellectual and developmental disabilities by disseminating research findings and to not take findings out of context or use them for purposes they do not support and feel may have negative consequences.

Providing Accommodations

More than one half of participants noted that people with intellectual and developmental disabilities need accommodations and supports to participate in research. Participants felt that, to show respect, researchers should be aware of and plan for individual needs: “[Be] aware what their needs are” (Joan). Participants also wanted researchers to make sure the participants know where to go and whom to contact in case of any problems. They also request that researchers conduct research in places accessible by public transportation so that they can independently get to the location: “[My case manager] had to take me all the time. … I wanted to take the bus” (Grace). Participants also felt that researchers should take the time to read and explain everything, talk slowly, and repeat information when asked to: “Teach them … if it has a lot of reading in it … and they don’t understand the words … take the time and respect that person and read it slowly to them and then they’ll understand it and that’s respect” (Alice). Participants also indicated that researchers should allow them plenty of time to answer questions and help them complete paperwork and surveys: “Help ‘em fill out the papers” (Virginia). Some added that they become frustrated when that support is absent or that they become concerned when they
do not understand the information. One participant added the reminder that people with intellectual and developmental disabilities may have other forms of disabilities, such as visual disabilities, that require accommodations.

**Researcher–Participant Interactions**

All participants described the ways researchers' treatment of them conveys respect and emphasized the importance that they feel respected in these interactions. Many also noted that when they feel respected, they in turn respect the researcher: “Respect the disability community ... you don’t respect one person, you don’t respect any of the disability persons. ... We want respect, you don’t show us respect, we don’t wanna respect you” (Rick). Participants described wanting to be treated well by researchers, which included treating them in a way that was age appropriate: “Treat us like an adult” (Grace). They also wanted to be treated as equals, listened to, have good things done for them, and be recognized as people, like everybody else: “Disability people are not just disability people, they [are] their own people too. ... They’re Americans. Just like everybody else without disabilities” (Claire).

Participants reported wanting researchers to sit down and talk with them, sometimes in advance of participating in the research, so that the researcher could get to know them and help them feel at ease, “by talking and gettin’ to know that person ... and making that person feel comfortable to talk to that person” (Roselyn). These exchanges might foster mutual understanding and knowledge and promote researchers’ awareness of the needs of adults with intellectual and developmental disabilities: “It helps you to understand us and respect us as people” (Alice). Participants noted that this might include increased understanding of widespread limited literacy among people with intellectual and developmental disabilities and also noted that needs will vary among individuals.

Participants also described wanting researchers to ask them whether they want to talk, need help, or have questions: “They [should] care about their needs ... by sitting down to talk to them ... making sure they have their needs and making sure that they are comfortable” (Joan). Participants also wanted researchers to pay attention to people with intellectual and developmental disabilities and to respect that they have opinions and things to say that matter: “Just because they’re disability doesn’t mean they don’t have things to say” (Claire). Specifically, participants believe that researchers should ask for participants’ opinions: “Just listen … and let ’em know their opinion do matters” (Roselyn). They also want to be addressed directly, even when they bring a person to support them in meeting with researchers: “It felt to me that was the inappropriate way to talk to [my case manager] and not me, because I was there to do the study” (Alice).

Participants used many adjectives to describe the behaviors they feel should characterize researchers’ interactions with people with intellectual and developmental disabilities: “Be on your p’s and q’s ... always speak positive ... come with a clean, nice attitude ... always be extra friendly ... [the researchers’] attitude is very important” (Charissa). These included having researchers be honest and direct with participants: “Shoot square, no fun, no games, just shoot square ... [give] the honest, God truth ... tell the truth, don’t hold nothin’ back. ... Be nice, and act like yourself” (Raymond). Participants also wanted researchers to act politely toward them: “Be polite ... when research is mentioned” (Alice). And they prefer that researchers be friendly, nice, positive, direct, humble, relaxed, welcoming, and professional: “Being ... nice, humble, not being tense ... it makes a person feel at ease” (Andre). Participants expressed a desire that researchers “[be] patient” with them (Joan). Last, they wanted researchers to smile and make eye contact: “Respect them and get eye contact” (Claire).

During participation in research, a few participants noted that they believe researchers should provide help if they feel sad (e.g., by listening to experiences and opinions) or stop the research if the person feels badly: “If you feel they’re getting upset or agitated, don’t leave the room ... work with somebody ... ’til they take a deep breath” (Alice). A few participants also thought that researchers should provide snacks or drinks to boost participants’ comfort: “If you thirsty, they have somethin’ to drink, if you need somethin’ to snack on it was there ... they try and make you feel as comfortable as possible” (Andre). In some cases, doing so may meet significant needs in the community:

Tell them to buy pizzas and cookies and pops and ice creams and bananas and things and bring it to the places. ... That
way people will know … it ain’t just that you’re doing your job, it’s that you guys understand disabled peoples … you guys [are] out to help ’em. … Some disabled people barely eat food. (Lorraine)

Other participants described wanting to receive affirmation that they had done well, to be thanked for their contribution, and to be informed about what was going to happen after the research: “Another way to show your respect is that you look at all of them and say, ‘I think you done a very, very beautiful—we had a very good day and I respect you all for that” (Alice). Receiving expressions of appreciation after participating in research let them know that the researcher was still thinking of them and appreciated their contribution: “They’ve sent me stuff in the mail saying thanks for participating in the study. … I liked getting them in the mail … that they’re still thinking of me. … That makes me feel important” (Charles).

Many participants also spoke about how they did not want researchers to treat them. These comments included not wanting researchers to be pushy, make mean statements, or stress them: “They don’t push me to do something I don’t want to do, which is nice … not say mean things to any people that have disabilities” (Ashley). Participants also want researchers to not make fun of them: “Don’t make fun of them ‘cause they’re different, or, like, don’t make fun of the way they speak” (Claire). They also do not want researchers to get mad at them: “Don’t get upset if you say the wrong thing” (Alice). Other participants added that they want researchers to keep their word, maintain confidentiality, and not hurt them.

Participants talked about the positive consequences of researchers treating them with respect. Interactions of this nature allow participants to feel not only respected but also that the researcher genuinely cares about them, thereby helping them feel more comfortable with the researcher and in participating in the research: “I felt like, you know, someone really cares” (Felecia). These interactions help the participant stay positive and in a good frame of mind to continue to want to participate: “She’s straight on a lot of things, like, when she’s talkin’ to ya, she didn’t beat around the bush. She told ya how it was. I like that … and I liked what she said, so we stuck with her” (Raymond). One participant added that when she does not like how she is being treated by a researcher, she will not participate in the research: “I walked out on that one … researcher kept getting mad at me” (Elizabeth). Other participants described how taking the time to get to know the person and showing they care will allow researchers to get more complete, honest responses from participants: “This person really cares, I’m really gonna give it my all” (Charissa).

Discussion

In the quest to conduct responsible and respectful research, the scientific community must strive to infuse research practices with the values and preferences of those most affected by the research (Clements et al., 1999; Iacono, 2006; Roberts et al., 2004). Achieving this goal improves not only the ethics of research but can simultaneously benefit its quality (Viswanathan et al., 2004). In this study, I explored the perspectives of adults with intellectual and developmental disabilities on respect in research. Overall, findings suggest that adults with intellectual and developmental disabilities have much to contribute to the conversation and that they value research. Of note, they also agree with calls to expand the discussion of respect in research from one primarily focused on autonomy and protections to one that elevates the focus to consider principles of human rights and dignity as overarching goals (McVilly & Dalton, 2006). Participants’ views on respect in research center on research that includes them, promotes their well-being and social value, provides accommodations, and is conducted by people who demonstrate positive regard for them.

Findings are largely consistent with ideals embodied in the disability rights movement and call for practices consistent with those that favor inclusion, rights, and respect (Charlton, 1998; Dybwad & Bersani, 1996; Heller et al., 1996; Miller & Keys, 1996). For example, adults with intellectual and developmental expressed desire to be included in research. They are most interested in research that allows for equal opportunity, their voices to be considered, their strengths to be illuminated, their lives to be improved, and their rights to privacy and confidentiality preserved. They also want to be acknowledged for their contributions. Moreover, adults with intellectual and developmental disabilities want accommodations throughout the research process, not uniquely for understanding information in consent processes, so that genuine paths to inclusion and full participation can be achieved.
Particularly noteworthy in the context of a group who has long faced marginalization and mistreatment (Charlton, 1998; Dybwad & Bersani, 1996; Miller & Keys, 1996), adults with intellectual and developmental disabilities spoke at lengths about one of the less focused-on areas of research ethics: the nature and tone of interactions between researchers and participants. Here, participants called for interactions that should be present in contexts in which they are respected and valued. Specifically, adults with intellectual and developmental disabilities desire being treated as deserving human beings and as adults with worthwhile opinions, they want to have the opportunity to get to know researchers and discuss their needs, they want to be treated positively, and they would like to receive sustained appreciation for their contributions. Unfortunately, adults with intellectual and developmental disabilities cannot take such interactions for granted (Dybwad & Bersani, 1996; Ferguson, 2004; Heller et al., 1996). Indeed, when people with intellectual and developmental disabilities are displeased with research participation, their displeasure appears to be notably related to the nature of interactions with researchers rather than with the research itself. Adults with intellectual and developmental disabilities also ask that research findings be used to educate others about their values, needs, and abilities and to help improve the lives of individuals with intellectual and developmental disabilities. Collectively, these emergent, grounded findings support views of respect inclusive of attitudes and behaviors that convey value and care and the need for ethical frameworks that embody a human rights perspective (Dillon, 2010; McVilly & Dalton, 2006).

Incorporating these ideas into research guidelines and practices can be straightforward, although they receive less focus in the education and socialization of researchers and discussions of research ethics. Moreover, attitudinal barriers may exist that challenge their uptake (Aldridge, 2007; McDonald, Keys, & Henry, 2008). Indeed, many of these requests are easily implemented (e.g., compensating participants, providing snacks, avoiding lengthy data collection sessions, sending thank you notes following participation). Others ask the scientific community to reenvision frameworks for research ethics and the relationships between scientists and those they engaged in knowledge production. The scientific community is called on to deepen their understanding of people with intellectual and developmental disabilities, to seek to include individuals with intellectual and developmental disabilities in research more generally, and to build in opportunities for participants to benefit directly and learn from research. The scientific community is also summoned to build in accommodations to research practices and budgets and to provide opportunities for people with intellectual and developmental disabilities to express their experiences and opinions. Researchers are also asked to share findings with participants and to consider how research aims and the characterization of findings further stigmatize or convey respect to people with intellectual and developmental disabilities. It is worth emphasizing that adults with intellectual and developmental disabilities may better respond to methods involving open-ended questions that allow them to freely express themselves. As such, researchers should consider methods that use wholly or in part open-ended questions (in surveys, interviews, or other formats). Indeed, such questions orally administered might be experienced as more respectful while also being more accommodating and thus enable greater inclusion in research and understanding of research questions.

By taking the time to learn about people with intellectual and developmental disabilities, seeking financial support for research, and including discussions of these less tangible facets of research practices in the education and socialization of new researchers and with those who review the ethics of proposed research, the scientific community can develop research standards in line with a human rights framework and that convey respect to research participants congruent with their values and preferences. However, in striving to promote rights and dignity in research, it is critical to note the heterogeneity of views found herein; researchers may need to personalize their approaches and/or pursue multiple options so that all participants can feel respected in the research process. Indeed, these findings recall the value of reflective practice (Clegg, 2004), which pushes researchers as individuals and as a community to critically examine their scholarship vis-à-vis displaying respect for those they engage in inquiry.

These findings should be interpreted in light of relevant limitations. Although I recruited a diverse sample and provide the first targeted study
of the perspectives of adults with intellectual and developmental disabilities on respect in research, this study is exploratory, and participants may vary from others in meaningful ways. Here, participants were not under legal guardianship, had prior research experience (largely with behavioral research), and were willing to share their opinions. They may also possess greater value for research or have had more positive experiences with research. It is difficult to discern how these characteristics may color findings; findings related to accommodations, particularly those that make use of assistive technology or other support strategies, may intensify with a different population. Although this research included only adults, these results may equally illuminate key issues in respect in research for children. In research with children, respect for autonomy, research focused on their needs and the topics they value, and research that seeks to include their voice may be particularly important. Future research can help illuminate these persistent knowledge gaps by including more diverse samples with respect to age, communication abilities, and experience with research.

In conclusion, I emphasize the value of using a human rights framework to elevate the focus on respect in research ethics (McVilly & Dalton, 2006). A human rights framework views accommodations as an ethical right and considers how research aims and interactions with and portrayal of research participants convey respect and dignity. Spotlighting interactions between researchers and research participants illuminates more subtle ways that individuals can be harmed or derive benefit from the important and valued role of research participant that are less procedural and may not be captured in an ethics committee review process. Knowing and responding to the views of adults with intellectual and developmental disabilities on how they want to be treated reflects a critical means to more fully meet the ideals of guiding ethical principles in scientific inquiry. Pushing this idea further, genuine partnerships with adults with intellectual and developmental disabilities developed through research approaches such as participatory action research may equally represent an important way to augment the ethical integrity of science and fully embody the mantra of the disability rights movement, “Nothing About Us Without Us” (Charlton, 1998; Nicolaidis et al., 2011).

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Respect in research