

“You Can’t be Cold and Scientific”: Community Views on Ethical Issues in Intellectual Disability Research

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Abstract

Perceptions, attitudes, and ethical concerns related to conducting research with adults with intellectual disability hinder scientific innovation to promote health. Yet we lack an understanding of community views on effective research policy and practice. To address this knowledge void, we qualitatively studied the views of adults with intellectual disability and those who provide them support regarding research participation of adults with intellectual disability. We found substantial support for their inclusion, particularly given the possibility of benefits to adults with intellectual disability, researchers, and society. We also found concerns for potential harm and differing ideas on how to promote safety. Our findings emphasize the importance of their inclusion in research, and the need for policies and practices that promote respect and safety.

Keywords

research ethics, intellectual disability, disability rights

Recognizing the key role public perceptions play, early efforts to establish a framework for ethical science included non-scientists in the process (Coleman, Menikoff, Goldner, & Dubler, 2005; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). Nonetheless, professionals have largely retained control over decisions affecting policy and practice (Dresser, 2014). Understanding perspectives of the public is as relevant today as ever as we seek to enhance trust in the research enterprise, promote representation in research, and understand risks and safeguards in the face of a changing society and scientific innovations (Dresser, 2014; Roberts, Warner, Hammond, & Dunn, 2006). Similar to other groups who experience marginalization, people with intellectual disability have experienced exploitation at the hands of scientists (Freedman, 2001). Subsequent efforts to safeguard their well-being may have contributed to overprotection and greater exclusion from direct participation in research (Brooker et al., 2014; Feldman, Bossett, Collet, & Burnham-Riosa, 2014; Northway, 2014); importantly, these safeguards may not effectively address or reflect community views.

Today, fueled by the disability rights movement and evolving public attitudes, people with intellectual disability have greater access to community life (Charlton, 1998; Dybwad & Bersani, 1996). With the drive for greater participation throughout society comes increased emphasis on directly including people with intellectual disability in

research. The argument for inclusion recognizes that new knowledge may inform and address health disparities far too common among this population (Krahn, Hammond, & Turner, 2006), and rejects historical assumptions of incapacity to make voluntary, informed decisions (Viecili, Lunskey, & Strike, 2009). These changes also give rise to new questions about ethically strong approaches to scientific inquiry (McDonald & Kidney, 2012). As we seek to address emerging questions, attending to community members’ perspectives should once again prove fruitful. Stakeholders’ perspectives contribute significantly to, for example, devising research practices that are experienced as respectful and safe. Incorporating their views may foster greater trust, and therefore greater inclusion in research, not to mention better science (Dresser, 2014; Iacono & Carling-Jenkins, 2012; McDonald, 2012; McDonald & Raymaker, 2013).

Intellectual disability is characterized by a low IQ and difficulty with everyday skills; and individuals with intellectual disability may have less control over their lives and less experience making decisions (Dybwad & Bersani,

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1996). The features and experiences of people with intellectual disability contribute to ethical and social concerns related to including them in research, and consensus on how best to address these challenges eludes the scientific community (McDonald & Kidney, 2012; McDonald & Patka, 2012). The scientific community tends to focus most on questions of risk related to recruitment and on valid informed consent. For example, there are questions about whether different recruitment strategies contribute to undue influence or inhibit access to research participation, and whether adults with intellectual disability can make informed and voluntary decisions (McDonald & Kidney, 2012; Ramcharan, 2006). Possible strategies to improve or ensure informed decisions include, among others, providing disability-appropriate accommodations, involve substitute decision makers, and conducting an individualized assessment of decisional capacity. In practice, such “solutions” to ethical concerns can raise as many questions as they answer. For example, how can privacy and human rights be promoted when people who provide support to adults with intellectual disability are influencing decision making and are present during data collection? Responding to these concerns may also add complexity to the research process (McDonald & Kidney, 2012), which may further discourage researchers from engaging adults with intellectual disability in research (Becker, Roberts, Morrison, & Silver, 2004; Lai, Elliott, & Ouellette-Kuntz, 2006).

There are no easy answers to how to pursue science that is safe and respectful (McDonald & Raymaker, 2013). Attention to complex concerns from multiple perspectives is beneficial. Affected community stakeholders include not only adults with intellectual disability, but also those who provide them with support and services. Members of this latter group are particularly important given their frequent role as gatekeepers between researchers and people with intellectual disability, as well their potential ability to facilitate understanding and inclusion (Iacono & Murray, 2003). We have some insight into the perspectives of people with intellectual disability with prior research experience: They value inclusion in research given the possibility of direct and indirect benefits, and want to be treated with respect and have control over their research participation decisions. They also demonstrate decision-making skills and want to receive accommodations to facilitate participation (McDonald, 2012; McDonald, Kidney, & Patka, 2012). We have less insight into the views of people who provide adults with intellectual disability with support, including disability service providers, family members, and close friends, though their perspectives on other aspects of community life provide some clues. It is likely that some of these individuals may stress the importance of including adults with intellectual disability, especially in research that can improve quality of life and is focused on strengths. Some may also favor maintaining autonomy even when

capacity is questioned (Becker et al., 2004; Iacono, 2006; Woodring, Foley, Santoro Rado, Brown, & Hamner, 2006). Nonetheless, it is also possible that for some support providers, concern to protect individuals in the face of real or perceived vulnerability and harm may incline them toward more restrictive views favoring exclusion from research, particularly research that poses greater risk, and more stringent limitations on control over participation decisions (Clegg, 1999; McDonald, Keys, & Henry, 2008).

Understanding community members' viewpoints is key to guiding policies and practices which may encourage research and, in the long-term, promote health. To shed light on this knowledge vacuum, we sought to explore the perspectives of key community stakeholders. Specifically, we qualitatively studied the views of adults with intellectual disability, professionals who provide social services to adults with intellectual disability, and family members and close friends of adults with intellectual disability on the participation of adults with intellectual disability in self-report research (i.e., research that asks what individuals are feeling, thinking, and doing). Our focus on self-report research that aims to study the thoughts and experiences of adults with intellectual disability reflects the field's increased emphasis on direct representation in such research and the less clear risks this research may bear. We studied community members' general views, as well as their views on research benefits, harms and safeguards, trust and respect, and major aspects of research participation.

Method

Participants

We conducted focus groups with 57 adults from three different stakeholder groups: adults with intellectual disability ($n = 24$), people who provide social services to adults with intellectual disability ($n = 21$), and family members and close friends of adults with intellectual disability ($n = 12$). We invited adults with intellectual disability who did not have prior experience as an adult research participant. Participants self-reported their disability and were from an array of circumstances including those with and without court-appointed guardians, those living independently in the community and in group homes, those with and without intimate partners, and those working and not working for pay, though most received Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). We also invited professionals who currently provide, or have in the past 12 months provided, social services to adults with intellectual disability, directly or through management roles (e.g., direct care providers, case managers, benefit coordinators, inclusion specialists, program directors, and executive directors), and family members and close friends of adults with intellectual disability who provided unpaid

Table 1. Participant Demographic Information.

	Adults with intellectual disability	Professionals	Friends/family members	Totals
Gender				
Male	6	3	4	13
Female	18	18	8	44
Age				
18-19	—	2	2	3
20-29	1	3	1	5
30-39	9	1	2	12
40-49	4	2	2	8
50-59	6	11	3	20
60-70	1	1	1	3
70+	—	—	2	2
Not reported	3	1	—	4
Race				
White	21	16	11	48
Black or African American	1	4	1	6
American Indian/Alaska Native	1	—	—	1
Mixed race	—	1	—	1
Not reported	1	—	—	1
Ethnicity				
Latina/o	2	—	—	2
Education				
Did not complete high school	6	—	1	7
High school diploma or GED	15	4	1	20
Attended college	—	5	1	6
Associate or bachelor's degree	1	9	4	14
Graduate degree	1	3	5	9
Not reported	1	—	—	1
Total participants	24	21	12	57

support to at least one adult with intellectual disability in the past 12 months. Family members, close friends, and service providers supported adults with various levels of intellectual disability. For all groups, we invited individuals who were aged 18 or older, had sufficient communication skills to make a decision and express their opinion (with or without accommodations), and who were in the greater Syracuse, NY (United States) area. See Table 1 for additional information about participants.

Instruments

We created a semi-structured *Focus Group Guide* based on the first author's prior research and review of relevant literature. Using open-ended questions coupled with graphics, we queried participants on their general views about participation of adults with intellectual disability in research, as well as their perspectives on benefits, harms, safeguards, respect, and trust. We also asked about their views on how research studies are conducted, including important topics to study, the role of people who provide support to adults with intellectual disability, recruitment, decision making,

and dissemination. We asked each of the three participant groups the same questions, with shifts in framing to reflect their position, and used a moderator's version of the guide with additional probes to foster deeper exploration of initial responses. We also asked participants to complete a *Personal Information Survey* to collect demographic information, and we maintained *Field Notes* throughout recruitment, data collection, and analysis.

Procedures

We received human subjects' approval for this study. To promote accessibility and cultural sensitivity, we created materials from those the first author had previously developed with people with developmental disabilities (Kidney & McDonald, 2014; Nicolaidis et al., 2012). We partnered with The Self-Advocacy Association of New York State—Central Region to recruit participants, sharing information about the study widely throughout the community via postal mailings, emails (to individuals and listservs), social media, newsletters, posted flyers, a project website, and in-person meetings with and tablings at organizations, groups, and

community events by or for adults with intellectual disability, their families, and/or service providers.

We worked with adults with intellectual disability to address supports needed to participate, including individual planning of transportation and (if desired and for those with legal guardians) the involvement of another person as they learned more about the research and made their decision. We designed our consent or assent form to promote understanding by minimizing text and using plain language and informative graphics, and included a communication guide to provide a visual depiction of consent choices. We held individual consent meetings with adults with intellectual disability to foster individualized access to the information and time for decision making (Heller, Pederson, & Miller, 1996; Kidney & McDonald, 2014; Woodring et al., 2006), and reviewed consent information again at the focus group, emphasizing choice and the right to decline answering questions throughout the focus group. For service providers, family members, and friends, we conducted the consent process at the focus groups; most participants received a copy of the consent or assent form in advance of the focus group.

We held 16 focus groups, all in private locations, at our university or local organizations, beginning with adults with intellectual disability and disability service professionals; we held the first focus group with family members and friends about 1 month later. Our ongoing analysis suggested that we achieved data saturation (Lincoln & Guba, 1985), and thus we ended recruitment just shy of our anticipated enrollment of family members and friends. We kept each group relatively small (7 participants or less) to allow for deeper exploration of the phenomenon of interest and ensure conditions that would foster access for those with intellectual disability. We provided participants with a short version of the questions, which included each broad question and its related graphic and we projected information on a large screen. This information also included a visual depiction of progress through the interview questions using the graphics associated with each question. The first author moderated all focus groups, speaking all information out loud and following the natural progression of the discussion. Not including the break, focus groups lasted about 1.5 hr. We audio recorded each focus group, and a research assistant (RA) took detailed notes. We provided participants with a meal, reimbursement of travel costs, and US\$40 to thank them for their participation.

Analysis

Data collection and analysis overlapped: We debriefed immediately following each focus group and in regular meetings, noting emergent themes and implications for subsequent focus groups. RAs transcribed each focus group verbatim; a different RA then checked transcripts for completeness and accuracy. Our qualitative analysis preserves participants' voice and was informed by multiple traditions (Braun &

Clarke, 2006; Lincoln & Guba, 1985; Miles & Huberman, 1994; Strauss & Corbin, 1990). We pursued an inductive data reduction process starting with within case analysis facilitated by focus group summaries. Using both transcripts and summaries, we continued to identify key themes and meaningful patterns among themes. In our analysis, we refined codes and used procedures to strengthen credibility, including investigator triangulation, thick descriptions, reflexivity, and an audit trail (Krefting, 1991; Lincoln & Guba, 1985). We used NVIVO to organize and manage the data.

Findings

Our analysis identified key themes related to community perspectives on inclusion in research, as well as benefits, harms, and safety associated with research participation.

Inclusion in Research

Participants expressed strong support for the research participation of adults with intellectual disability in both research specific to intellectual disability as well as general population research; support for the former was somewhat stronger. Beliefs that support their participation in research include beliefs that adults with intellectual disability have equal rights to participate, that they have often been left out (and as a result, people without intellectual disability have had little opportunity to learn from them directly), and that their participation may help to improve quality of life for people with intellectual disability.

We're part of the community . . . everybody has something to give . . . why should people be excluded because there's something wrong with their legs or something wrong with their arms or something wrong with something else. Why should it matter? Everybody should . . . have the chance . . . to be part of something. (adult with intellectual disability)

I think it's a good thing if it's going to . . . helps meet their needs. (service provider)

I think it can be always beneficial to their lives. (family member and friend)

Not only should adults with intellectual disabilities be participating in research focused on adults or children with [intellectual disability] but all standard population studies . . . I think that is a necessary part of improving the situation as it is. (friend)

However, some participants subsequently expressed hesitation, or noted circumstances that would decrease their support for research participation. Family members, friends,

and service providers noted they might not want to include individuals who cannot provide informed consent, or that they might not support research on sensitive topics, without direct benefits, or which might produce opportunities for harm, confusion, or misunderstandings including research on topics with which adults with intellectual disability may have less experience (e.g., sex and sexuality):

I think [my sister] would sign the form if someone was telling her to, but I don't think she would comprehend what she was actually doing. (family member)

Some things they might not already have an opinion about. And, I've seen some people be influenced . . . good or bad. . . unnecessarily. (service provider)

Understanding sexuality would be an area that I think depending on the person's ability to . . . understand those concepts . . . I don't know that that would be a wise area. (service provider)

Participants with intellectual disability indicated they might decline to take part in research that they felt was too private (e.g., romantic relationships or parts of their pasts they find embarrassing or upsetting), of greater risk and uncertainty (e.g., medication trial), or if they did not feel adequately accommodated or did not know the researcher well: "I think some topics might be a little . . . awkward for some people . . . [some topics are] private" (adult with intellectual disability). Service providers added that they felt participating in research may not be positive or possible for all adults with intellectual disability (e.g., those with "behavioral challenges," those without support in their lives), adding that these determinations should be made individually. Family members expressed the most mixed views, and service providers appear to feel the strongest that the research should directly benefit people with intellectual disability.

Benefits of Research Participation

Participants emphasized the importance of multi-level benefits associated with the research participation of adults with intellectual disability. They described benefits for people with intellectual disability including psychosocial benefits such as increased self-esteem and an opportunity to demonstrate their worth and value, along with a sense of equality, contribution, motivation, confidence and belonging, opportunities to challenge themselves and do something, speak for oneself and meet new people, learn, and, more immediately or down the road, experience improved quality of life:

I think it's because I enjoy doing it and it's something that . . . makes new challenges for me and maybe help end up being something that's gonna . . . change something. (adult with intellectual disability)

I think they wanna help and they wanna be part of something that could change stuff . . . feel like you're part of something, that you're doing something, not feeling worthless. (adult with intellectual disability)

My hope would be that it would generate enough interest and support for more funds to be allocated to reduce disparities, especially in healthcare. . . . Folks with disabilities can be invisible. (service provider)

I think it's important . . . because they've been neglected as far as research goes and I think it would really help especially with making rules and regulations because a lot of people have no idea whatsoever about how their lives are. (family member)

Some adults with intellectual disability emphasized being in research as a part of their efforts to speak up for themselves and grow through new experiences; they also expressed appreciation for incentives, though many indicated incentives were not the primary reason for their participation and that they may participate in the absence of an incentive. Participants also talked about the benefits researchers can encounter as they learn directly from adults with intellectual disability and experience what they can do, therefore sparking greater insight and understanding. Participants described benefits that society might experience as similar to those researchers might encounter. For many participants, benefits to researchers and society were especially important given that adults with intellectual disability have had less opportunity to directly represent themselves and that increased understanding of their perspectives may challenge prior assumptions:

I know people . . . don't really understand us. . . . They don't know the life we have and what we struggle with. (adult with intellectual disability)

It's gonna open so much understanding for other people. (adult with intellectual disability)

To allow them to articulate their barriers and their discriminations because a lot of times, you know, we're standing outside the box looking in. We can only assume but to just get an idea of . . . what they go through day to day. (service provider)

It helps with awareness. . . . [people in the community] don't understand, it's almost like they're afraid. So the more it's out there . . . about how they want to be treated and stuff and just in general, will help the average person. (family member and friend)

In general the public sees disabled people as different and I see them more the same than different, and so I think for that kind of reality to become universally accepted would be a major change. (family member)

Harms in Research Participation

In considering the research participation of adults with intellectual disability, participants described harms that might emerge at different phases of research. At the recruitment and consent stages, family members, friends, and service providers described concerns that adults with intellectual disability might be susceptible to undue influence and feel that they have to participate when asked by certain individuals. This dynamic was of particular concern when those relationships are characterized by power differentials such as may be the case with service providers, because of the incentive level, or because they trust too readily:

Some individuals have some vulnerability and their decisions can be influenced. (service provider)

I could see [my sister] trusting really easily. (family member)

Adults with intellectual disability, however, noted that they may have a hard time trusting others because of past experience with broken trust from a variety of sources, including family members, service providers, and peers; some family members expressed the same view: "I often worry that if people will keep their word or not. . . . it's hard to have trust. I have trust issues toward people" (adult with intellectual disability). Many adults with intellectual disability also noted times when they would decline participation, including as a result of interactions with researchers or because the research is held in an unfamiliar location: "If you just decided you didn't feel comfortable" (adult with intellectual disability). Adults with intellectual disability indicated that when finding out about a project, it can be difficult to identify whether it is legitimate, or a scam; service providers expressed concern over whether adults with intellectual disability can successfully make such determinations:

You never know what [mail] is. . . . It could be a scam. (adult with intellectual disability)

A lot of people with disabilities rely on us to be that trust filter. . . . I think . . . adults with disabilities . . . whether they either can't learn, or haven't been taught or haven't been taught properly they don't almost have that some of them have that ability to say this is a person I can trust. (service provider)

With respect to decision making, support providers noted concerns about including adults with intellectual disability who do not understand information about a project, though some service providers suggested this alone should not lead to an individual's exclusion. Service providers added that some adults with intellectual disability have had less opportunity to learn and practice making decisions; this may be a factor driving increased risk in research with this population: "A lot of them are . . . thirty or however old but their parents would say no and some of them wouldn't even speak up to say yes this is somethin' I would want to do" (service provider).

In considering interactions with researchers, adults with intellectual disability expressed concern that researchers might treat them disrespectfully:

I think just be . . . not criticized because I think criticism is one of the worst feelings and it just, it makes you self-conscious. . . . Criticism is I think one of the most hurtful things . . . just to be . . . respected and . . . to feel like you're like everybody else. (adult with intellectual disability)

Relatedly, support providers described their concern about whether researchers have appropriate skills to work with people with intellectual disability: "If the researcher's not skilled . . . [the participant] may leave feeling worse than they came in" (service provider). All participants talked about the potential harm if people with intellectual disability are treated as a disability or a label, rather than as a person, and are made to feel inferior:

You don't ever want to put them in a situation, either, where they're feeling, um, inferior, or they're feeling like something can make them feel like they're not as smart as somebody else. (service provider)

It can become a problem if they're only seen by their disability and that they're not valued as a person. (family member)

Similarly, support providers discussed the potential for psychological harms (such as questions triggering emotions), misunderstandings, or adverse reactions to food (if available); fewer adults with intellectual disability noted the potential for misunderstandings or hurt feelings unrelated to treatment by researchers. However, some adults with intellectual disability noted the potential downside that they might

disclose something they had previously held inside, though they might subsequently experience relief following their disclosure. Some family members wondered whether they might feel bad about the disclosure later; they also wondered about any potential negative impact of researchers coming in and out of the lives of adults with intellectual disability.

Adults with intellectual disability also expressed concern that they might experience backlash from support providers (support providers agreed that this is a concern), especially if confidentiality is broken. They noted it can be hard to be certain that their information will not be shared with others: “A lot may be scared. . . . You don’t know if it’s going to . . . translate to the staff or anything so it’s really hard” (adult with intellectual disability). Support providers talked more about their concern that people who provide support may sometimes prevent adults with intellectual disability from learning about opportunities to participate in research, and also noted the potential for the incentive to be taken from the adult with the intellectual disability by the support provider. All participants agreed that the presence of support providers might keep adults with intellectual disability from fully disclosing their thoughts and experiences with researchers, or might influence responses. Family members added that service providers may actively influence responses to avoid disclosure of information that may be damaging to the service provider; service providers noted adults with intellectual disability may want to please others, and therefore try to provide responses that will be well-received. Last, support providers noted that findings might be misused or have damaging impacts on people with intellectual disability, or that no improvements might come as a result of the research.

Safety in Research Participation

Participants identified a variety of ways to prevent or reduce harm that might come from research participation, and emphasized the importance of safety. Some service providers added that increased protections may be needed for some people or for some projects, and other service providers added that it can be challenging to balance risks, safety, and rights:

People who have an intellectual disability, they have vulnerability. . . . While completely respecting them as a human person also recognizing that vulnerability. (service provider)

It’s a double-edged sword sometimes . . . while you know you have to be really careful . . . and . . . make sure that they have informed consent and all of the safeguards, you . . . don’t want to restrict. (service provider)

Adults with intellectual disability stressed that researchers should treat them with respect by being honest and

viewing them as competent adults able to make their own decisions, use respectful disability-related language, ask for their permission and talk directly to them:

Don’t treat them like . . . you’re better than them. (adult with intellectual disability)

Treating them with respect. (adult with intellectual disability)

Always have faith in them. (adult with intellectual disability)

Adults with intellectual disability often noted that feeling respected helped them feel that they could trust the researchers. They also expressed interest in researchers who did not pressure them to participate or answer a particular question, and readily allow them to stop if desired. Some support providers agreed and also stressed that researchers should avoid making false promises: “You have to be really sensitive, and come with an open mind. . . . So that you won’t offend their feelings and not invalidate what they’re feeling” (service provider). Many linked feeling respected with feelings of safety. Support providers advanced such ideas further: They expressed interest in scrutiny of researchers, and wanted to see that researchers received training and have experience with people with intellectual disability. They felt such experiences would ensure that researchers could communicate respectfully and effectively with people with intellectual disability (e.g., being non-judgmental or condescending, demonstrating high expectations and patience, and asking concrete questions), as well as have a more informed sense of their lives:

I think some bad things that can come out of it is not knowing who you’re researching well enough and the researcher being versed in working with individuals with . . . intellectual disabilities. (service provider)

You gotta hire really the right people to do the research. . . . It’s definitely a skill and something that not everybody’s good at. (service provider)

The researchers have to be comfortable with silence, comfortable with waiting, know themselves, comfortable with differences and no um assumptions about speed of language versus . . . intelligence. (service provider)

Somebody has to be watching the researcher. (family member)

Related, participants noted that providing accommodations, and helping participants feel comfortable, can reduce harm and increase feelings of safety. Participants felt

accommodations such as plain language, pictures and videos, examples and demonstrations, opportunities for questions and answers (especially during decision-making processes), adequate time to reflect and respond, and emphasis on individual choice can facilitate decision making about participation:

I think to let them . . . speak at their own time or don't hurry 'em. (adult with intellectual disability)

Make it more accessible. . . . We're American citizens and . . . we should like be able to go where we want and do what we want and be able to get it and feel safe. (adult with intellectual disability)

Some adults with intellectual disability noted there are times when they prefer to consult with another person such as a friend, service provider, or family member, as they make decisions, though all stressed it was important the decision be theirs:

It's my life. . . . You can give your opinion . . . if I ask for it's that's fine, if you're just going to blurt things out just because, no. (adult with intellectual disability)

I talk to somebody about [my decision]. (adult with intellectual disability)

Support providers stressed that researchers need to take an individualized approach to providing accommodations, and adults with intellectual disability emphasized the importance of asking the person what they need:

I might do things slower than you, I might need other assistance . . . and if you don't know them ask 'em. (adult with intellectual disability)

Read it to people because I know sometimes a lot of people have a hard time reading. Um ask them . . . what would make it easy before they come. (adult with intellectual disability)

Support providers also talked about the value of skilled researchers who effectively attend to nonverbal cues and power, use respectful language, do not set incentives too high, and get to know participants prior to participation to build a professional rapport. They also stressed researchers' responsibility to make sure participants can give informed consent (e.g., asking questions about the research or the individual's interest in participating, querying support providers on whether the person understands), and felt that

exclusion of adults with intellectual disability, as a population or specific individuals, was sometimes necessary: "You'd have to have some proof that the person understands . . . by either just saying it back to you or some kind of . . . process where you're sure the person understands" (service provider). Adults with intellectual disability expressed desire for informal time to get to know researchers, and opportunities to take a break if they get upset; family members agreed that getting to know researchers informally is important, and added that researchers should be clear about the expected length of the relationship. Several participants also noted the benefits of conducting the research in safe and familiar locations. Collectively, participants noted these strategies may help adults with intellectual disability to feel comfortable fully expressing themselves, subsequently also improving the quality of the research data: "Creating an atmosphere where folks feel safe. That's huge if we want honest answers from folks" (service provider).

Many support providers felt they could play a role in keeping adults with intellectual disability safe, though they also wanted researchers to be aware that not all adults with intellectual disability have adequate supports in their lives. For example, some support providers felt that researchers should first talk to them, and that they can help assess whether an individual would be suited for participation and what supports are needed for safe research participation; some family members felt that they should be approached first and provide permission for researchers to talk with disability service providers supporting their family member with intellectual disability:

Most service providers are going to know about the safeguards. So they're going to know . . . what might be a good um a good fit . . . there's some people that it would be great for research stuff and then there's some people that it might not be so good for. And you would want me, being in that field, I would want to protect that person. (service provider)

It's important that there's somebody there who knows about behaviors, behavior plans, triggers, and stuff like that. (service provider)

Support providers also felt they could provide encouragement and assistance that might help adults with intellectual disability feel comfortable, understand, and be able to participate in research:

During the research like interview, you could have like . . . their support staff with them to like just maybe like read their nonverbal expressions to make sure that they're feeling comfortable and just like tend to any needs that they have at that moment. (service provider)

Some people that I can think of they actually would need somebody with them not to ya know tell them what to say or anything but to um support the like um ya know it's okay to say what what you really think . . . cause just talking to them before they went in I don't think that would be enough. (service provider)

Many added that support providers should be present throughout participation, though some saw observing through a one-way window or absence during data collection as more appropriate, and noted it might depend on the nature of the research and/or the preferences of the person with intellectual disability:

I truly believe that with a little bit of help anybody can be included more but I also see the downfalls to having the support staff there. Because I know that sometimes people act differently . . . hold back on what they're saying. (service provider)

There's people in support personnel most of the time have are looking out for the best interest at least in their opinion of the person they assist, uh but they also have an influence on how they respond to things or how they react to environments, discussions . . . their presence even there can be problematic. (friend)

Some service providers felt that the presence of support providers might actually increase risk: "There's the risk of whoever is accompanying being paternalistic, you know and making decisions for the . . . person with disabilities" (service provider). Adults with intellectual disability stressed that the involvement of others can be complicated, and some indicated desire to not have staff involved in their research participation. For example, some noted that staff have been mean to them, or that staff do not provide them with desired privacy, though they may be open to the involvement of staff whom they trust (this may be a stronger preference among those who describe themselves as shy), and who may help them feel comfortable and safe, better understand information, and remind them of things they have forgotten:

She's been with me so long so she knows I'm pretty independent, so um a lot of times I like people there because some things I forget. And she'll you know remind me or something, so it's just a good support and safety. (adult with intellectual disability)

[If staff were with me during research, I would feel] a little nervous. (adult with intellectual disability)

You might not feel comfortable with staff in the room You'd want them to step out and have YOU answer the questions and then have them come back in. (adult with intellectual disability)

Support providers agreed that their involvement can be complicated given dual possibilities of sometimes serving as "trust filters" for adults with intellectual disability, and sometimes as a source of hurt and distrust. Some noted they should not speak for people with intellectual disability or that researchers should not ask for participation decisions in the presence of the support provider. Several participants emphasized the importance of the researcher directly addressing the adult with intellectual disability when a support person is present.

Discussion

Our findings shed much-needed light on community views of ethical issues in the research participation of adults with intellectual disability, and bear important implications. Generally, our findings suggest strong community support for research with adults with intellectual disability, though with concerns, preferences, and unresolved questions for how to minimize harm while maximizing respect and safety. Though largely not surprising, these findings unearth important views for the scientific community to consider and address as they pursue ethical policy and practice in research with adults with intellectual disability.

In line with disability rights, community members voiced robust interest in including adults with intellectual disability in research (Charlton, 1998; Dybwad & Bersani, 1996). Like many others, adults with intellectual disability are altruistic and want to contribute to society, and encourage opportunities for improvements for themselves and their community (McDonald et al., 2012; Roberts et al., 2002). Community members also felt that access to research participation should be an equal right, and that living involves some degree of risk that all of us have the right to accept and experience (Iacono & Carling-Jenkins, 2012; Perske, 1972). In prior literature on this topic, some have questioned the ethics of including "vulnerable populations" in research, and have made attempts to classify people with intellectual disability as a protected class (Dresser, 1996); critical commentary points in particular to concerns about capacity to consent and the risks of psychosocial harm. While stakeholders in our study voiced these concerns as well, our findings suggest community members nonetheless favor inclusion; their views should spark new thinking about notions of vulnerability and inclusion (Northway, 2014).

Although this innovative research unearths key insights, there are important limitations to consider prior to exploring their implications. First, our findings may reflect regional perspectives: We only recruited throughout our region and had a strong response from adults with intellectual disability who are involved in disability rights advocacy. Second, our findings may best reflect the views of those who support research to such an extent that they are willing to take part in research about research, and who are

comfortable sharing their views in a focus group. Third, as we focused our inquiry on self-report research with adults, it is unclear what community views toward other types of research may be, as well as toward research with children, though many of our findings may be more broadly applicable. Nonetheless, the level of invasiveness of the research and the nature of involvement required of a research participant may alter these views significantly. Last, our sample over-represents women: Women may hold more disability-rights informed views alongside more protective tendencies (McDonald et al., 2008).

Best Practices

The strong support for inclusion in research among participating community members can spur new thinking about vulnerability and inclusion, and resonates with increasing attention to human rights (Iacono & Carling-Jenkins, 2012; Northway, 2014). The scientific community can respond by encouraging direct participation in disability-specific inquiry and general population research; Institutional Review Boards (IRB), researchers, and funders should be aware of these preferences and objectives. Given strong interest in benefits that may be associated with the research participation of adults with intellectual disability, researchers should cultivate direct and indirect benefits in designing research, including opportunities to learn (across multiple dimensions) and develop relationships, and experience psychosocial benefits and improvements in quality of life (immediately or over the long term); IRB members may be particularly effective collaborators in helping researchers identify and encourage such benefits. IRB members can also help researchers maximize benefits as they pay careful attention to benefits in reviewing research with adults with intellectual disability. Researchers who clearly communicate these benefits in recruitment and consent processes may be particularly effective in attracting interest in research participation among adults with intellectual disability and those who may promote or impede researchers' access to them.

Our findings also bear important implications related to risks and safety in research. The scientific community must attend to views on research risks and protections that are viewed as effective and respectful. We must devise ways to navigate trust and distrust, respect, understanding, and relationships with support providers; working with trusted friends of adults with intellectual disability—including those with and without disabilities—may reduce the impact of relationships characterized by greater power imbalances. Not surprisingly, many adults with intellectual disability have “battle scars” from direct experience with abuse and violations of trust (Kennedy, 2014); the impact of these wounds carries over into new relationships with researchers, making trust—a key factor in research participation

decisions (Rubright, Cary, Karlawish, & Kim, 2011)—important and challenging to promote.

Collaborations with community members, especially adults with intellectual disability and the groups and organizations they run, can assist these efforts and indicate developments in relevant policies and practices; such features of proposed research studies may be important for IRB members to attend to, though they may need professional development to augment their understanding of these dynamics and be able to assess their presence in individual protocols. Approaches to consider also include building the capacity of researchers to understand the population, and skill in establishing sensitive and respectful interactions, perhaps through positive personal relationships and explicit opportunities during graduate school (McManus, Feyes, & Saucier, 2011). These experiences may help researchers, for example, encourage participation while creating interactions that promote respect and emphasize genuineness. Building in accommodations and paying attention to the heterogeneity of the population may also prove fruitful in this endeavor; as we do this work, colleagues in communication, inclusive education, and related fields may provide valuable insight and resources. On the other hand, the involvement of support providers and incentives will need greater scrutiny to ascertain community support for their use. We may arrive at consensus on the need to involve support providers in ways that do not jeopardize autonomy or privacy. If we do, we will also need to educate them on their role vis-à-vis research participation, including how to balance interests in protection with interests to promote human rights and quality of life. We also need to shape standards for researchers to maintain confidentiality so as to minimize the risk of backlash from service providers and explore the value of new models of decision making that emphasize capacity and agency such as supported decision making (United Nations, 2014; Kohn & Blumenthal, 2014; Vecili et al., 2009). As we identify effective, respectful strategies to include adults with intellectual disability in research, we must ensure that IRBs are aware of these developments, and are more informed about the lives of adults with intellectual disability; representation of adults with intellectual disability on IRBs could aid this goal.

As we improve ethical policy and practice for research with adults with intellectual disability, key among our priorities is determining how to earn and merit the public's trust: Experience with broken trust among adults with intellectual disability coupled with widespread pseudo-science and politically- and consumer-motivated polling and outreach pose constant challenges to scientific inquiry. It is possible that greater sharing of what scientists do to be qualified to conduct research and the role of IRB approval may help foster greater trust in research among the public; expectations and accountability of scientists may go a long way as well. Researchers who work with trusted networks and clearly

identify their university affiliations, funding sources, and/or collaborating groups or organizations may convey key information about project legitimacy. Paradigmatic shifts to seeing the public as partners in science, rather than subjects of science, may bear fruit in increasing interest in research participation (McDonald & Raymaker, 2013). Ultimately, research participants should be empowered: Community members should be involved in setting ethical policy guidance (Dresser, 2014) and should have genuine authority over claims that research policy and practices are safe and respectful. Such bottom-up, community-grounded approaches may be especially well-received by those interested in disability rights. One policy and practice that receives strong community support involves drawing from ways to promote “procedural independence” so that adults with intellectual disability retain control, even when they receive assistance from others (Kohn & Blumenthal, 2014).

Research Agenda

Additional research can better address methodological limitations of this study, and shed light on key questions generated by it. For example, future research with more diverse samples using different methods can help identify any possible bias associated with the limitations described above, particularly as establishing ethical research policy and practice is challenged by the heterogeneity of people with intellectual disability. Future research can also identify whether these views hold up to larger-scale empirical scrutiny, and better isolate factors that account for variance in perspective. Key areas meriting future empirical attention include isolating real risks—and not just perceived risks—in research with adults with intellectual disability (including whether undue influence exists), identifying how we can make use of innovations such as supported decision making (Kohn & Blumenthal, 2014) and ideas of sliding thresholds for consent capacity (Fisher, 2003; National Institutes of Health, 2009), establishing what information people want to know and how they want to receive that information in making participation decisions (Andre-Barron, Strydom, & Hassiotis, 2008), and examining whether accommodations effectively promote understanding and reduce undue influence.

Educational Implications

These findings lead us to ask important questions about researcher readiness to conduct safe, respectful research with adults with intellectual disability. Undoubtedly, researchers’ experience, knowledge, values, and interpersonal style matter. How do we educate, socialize, and support researchers to have integrity, display sensitivity to community needs and preferences, anticipate and provide for diverse accommodation needs, and communicate effectively and respectfully with adults with intellectual disability? This question

demands that we rethink graduate education and related learning experiences; it also emphasizes that it may take greater resources, time, and effort to pursue research with adults with intellectual disability. Supporting communities of practice for researchers and funding levels and timelines that adequately support ethical research practices may be especially important. Identifying ways for IRBs to accurately assess researchers’ qualifications in these areas may also be needed. Educating community members—in this case, adults with intellectual disability and those who provide them supports and services—may be equally important so they more thoroughly understand issues that give them pause to participate, or encourage participation. For support providers—and perhaps some researchers and IRB members—it may also be critical to help them expand their ideas of who can participate in research.

Conclusion

Our long-term interest is in encouraging science that is sensitive to the ethical and social dimensions of conducting research with adults with intellectual disability. We hope that this work, in conjunction with other efforts, yields an informed, contemporary understanding of how to pursue research inclusive of people with intellectual disabilities with greater attention to its ethical dimensions. Some strategies for pursuing research that is safe and respectful are fairly straightforward, others are less clear cut and will require further inquiry, innovation, and resources to effectively address. We hope to make sustained contributions in this vein. As immediate next steps, we used these findings to work with a multi-stakeholder Expert Panel to design a large-scale survey to more fully explore the ideas uncovered herein. We look forward to sharing insights from this next stage of *Project ETHICS* soon.

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