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Is it Worth It? Benefits in Research with Adults with Intellectual Disability

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Abstract

Including adults with intellectual disability in research promotes direct benefits to participants and larger societal benefits. Stakeholders may have different views of what count as benefits, and their importance. We compared views on benefits in research with adults with intellectual disability among adults with intellectual disability, family and friends, service providers, researchers, and Institutional Review Board members. We found that adults with intellectual disability value direct and indirect research benefits, and want to participate in research that offers them. Other stakeholders generally see less value in direct benefits and predict more tempered interest in research participation as compared to adults with intellectual disability. To promote respectful research participation, research policy and practice should incorporate the views of adults with intellectual disability.

Keywords

Research ethics; research benefits; adults with intellectual disability

Our society devotes considerable resources to science in order to create knowledge to benefit the greater good; individuals who participate in research may also experience more immediate benefit. Contemporary frameworks for ethical research emphasize that these indirect and direct benefits must outweigh risks associated with participation, yet this has not always been the case (Coleman, Menikoff, Goldner, & Dubler, 2003). People with intellectual disability have been subject to a disturbing history of harmful, often involuntary, research of questionable value (Freedman, 2001). Efforts to rebalance the risks and rewards

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of research participation have contributed to the exclusion of people with intellectual disability from research, and we now find ourselves in an era marked by unequal access to research benefits. Initially conceived of to protect, these practices have diminished the ability of scientific advances to promote quality of life among people with intellectual disability, and opportunities for people with intellectual disability to contribute to society via research participation. We thus find ourselves with too little information to address the pressing disparities experienced by people with intellectual disability, alongside conditions that threaten justice. To address tenacious disparities and promote human rights, we must respectfully and safely include people with intellectual disability in population-specific and general population research (Brooker et al., 2014; Feldman, Bossett, Collet, & Burnham-Riosa, 2013; Iacono & Carling-Jenkins, 2012; Northway, 2014; Welch et al., 2015). Righting past wrongs requires attention to promoting research benefits desired by community members (Dresser, 2014); importantly, like the general population, the prospect of direct and/or indirect benefits motivates adults with intellectual disability to participate in research (McDonald, Kidney, & Patka, 2012).

Including adults with intellectual disability in research can lead to benefits to individuals and society. For research participants, being in research can help adults with intellectual disability feel valued, included and worthwhile; experience equality and increased self-esteem; and provide opportunities to speak for themselves, meet people, do something new, challenge themselves, demonstrate their capabilities, contribute, and learn. At the societal level, opportunity to represent themselves in science promotes validity of the ensuing knowledge, and research that is more reflective of their views and experiences. Inclusion in research also provides researchers and society greater insight and understanding, helping to positively change beliefs about adults with intellectual disability and yielding information to promote quality of life (Heller, Pederson, & Miller, 1996; McDonald et al., 2012; McDonald, Schwartz, Gibbons, & Olick, 2015a). Given the persistent marginalization of adults with intellectual disability, in general and in scientific research, these benefits are significant.

Researchers and Institutional Review Board (IRB) members bear responsibility for evaluating and promoting research benefits. However, the concept of benefit may be differentially defined across various populations. What is beneficial is shaped by personal experience, beliefs, and values (Dresser, 2014). Hence, the perspectives of adults with intellectual disability are critically important: What they believe to be beneficial, and the relative weight assigned to different benefits, informs their perceptions of the value of research, how much they feel respected, and their willingness to participate in research. Given the important roles that family, friends, and disability service professionals play in the lives of adults with intellectual disability, their beliefs about research benefits may also impact how much they value research and their subsequent support for facilitating– or blocking – the participation therein of adults with intellectual disability (Becker, Roberts, Morrison, & Silver, 2004; Cleaver, Ouellette-Kuntz, & Sakar, 2010; Lennox et al., 2005). It is unclear whether these stakeholder groups – adults with intellectual disability, family members, disability service professionals, researchers, and IRB members -- hold similar views about research benefits. For example, adults with intellectual disability may perceive incentives as direct research benefits. However, many in the research ethics community hold

that incentives are not benefits; and some hold that incentives are potentially coercive and should be avoided. Similarly, adults with intellectual disability may place value on outcomes not usually conceived of as essential research benefits, such as opportunities to do something new or meet new people (McDonald, 2012; McDonald et al., 2012; McDonald et al., 2015a). It is possible that the scientific community underestimates the value and nature of benefits to adults with intellectual disability (Northway, 2014).

Promoting health equity through scientific advances calls for direct representation of adults with intellect disability in research, yet we grapple with how to do in ways that promote justice (Iacono & Carling-Jenkins, 2012; Northway, 2014). Insight into stakeholder views on the benefits of research can help scientists design research protocols more attentive to benefits, and in turn foster respect and greater participation by adults with intellectual disability (Dresser, 2014). To shed light on this question, we compare the views of adults with intellectual disability, family members and friends, disability service providers, researchers, and IRB members on benefits in self-report research with adults with intellectual disability. We focus on self-report research given emphasis in the field on increasing research about their thoughts, experiences, and behavior, and the more nebulous benefits associated with such research. We predicted that adults with intellectual disability would strongly endorse all benefits, especially those that improve the quality of life for themselves and others, and that these views would be strongly associated with their interest in participating in research. We predicted that other stakeholder groups would attach greater importance to indirect benefits to society than direct benefits for participants, and would predict less interest in their research participation (Dunn, Kim, Fellows, & Palmer, 2009; Heller et al., 1996; McDonald, 2012; McDonald & Kidney, 2012; McDonald et al., 2012; K. E. McDonald & M. R. Patka, 2012; McDonald et al., 2015a; Warner, Roberts, & Nguyen, 2003).

Methods

Participants

Five hundred and twelve individuals from 5 stakeholder groups participated in this study: 101 adults with intellectual disability who self-reported their disability, 98 family members and friends of adults with intellectual disability who had provided them nonpaid support in the previous year (more than 80% were family members), 109 professionals who were providing social services to adults with intellectual disability or had in the previous year, 105 researchers who conduct self-report research with adults with intellectual disability or had in the past five years, and 99 IRB members or those who had been members in the previous 2 years from institutions conducting research with adults with intellectual disability. Although some individuals fit criteria for more than one group (40%, 38%, and 12% of each of the latter groups also had a family member or friend with intellectual disability)¹, we privileged

¹Overall we found few differences for service providers, researchers, and IRB members who have family or close friends with intellectual disability. However, these service providers did perceive two of the indirect benefits as more important than service providers without family or friends with intellectual disability, and these IRB members perceived one direct and one indirect benefit as more important than IRB members without family or friends with intellectual disability. Similarly, IRB members who are also researchers perceived two indirect benefits as more important than IRB members not engaged in research with adults with intellectual disability.

professional group membership given the additional opportunities and responsibilities of employment.

In addition to these group-specific inclusion criteria, participants had to be 18 years or older, reside or work in the U.S., and have the communication and cognitive skills to make a participation decision and express opinions with or without accommodations (see below for more information on accommodations). We were able to communicate with all individuals who were interested in participating; and our inclusion criteria yielded participants from the population who would be able to participate in the research of interest (self-report research). The sample included people from all over the country. Some participants reported having additional disabilities or health conditions; mental health conditions, mobility or physical disabilities and ongoing health conditions were the most prevalent across all groups. Most participants indicated having employment, though fewer adults with intellectual disability (52.5%) and family and friends (65.3%) did. Adults with intellectual disability lived in a variety of circumstances. Most had been approved for developmental disability services (74.3%) and received Social Security (85.1%). Participants classified as family members, friends, and service providers indicated supporting people with mild, moderate, and severe intellectual disability, and some researchers and IRB members indicated that they were also family members of or friends with people with mild to severe intellectual. All groups reported most commonly working and/or having relationships with people with mild to moderate intellectual disability, or people who would likely be able to participate in self-report research. Researchers reported conducting research overwhelmingly with individuals with mild and moderate intellectual disability, though just less than one-half also do so with individuals with severe intellectual disability. Service providers held a variety of positions, and researchers and IRB members were primarily professors (52%), though some were research scientists, human subjects protections personnel, and students, who conduct mostly behavioral or social science research. See Table 1 for additional information.

Instruments

We developed the *Project ETHICS* survey using a multi-prong approach (Singleton & Straits, 1999; Willis, 2005): (1) group and individual interviews with each participant group (K. E. McDonald & M. Patka, 2012; McDonald, Schwartz, Gibbons, & Olick, 2015b), (2) prior research (McDonald, Keys, & Henry, 2008; McDonald et al., 2009; Roberts, Hammond, Warner, & Lewis, 2004; Roberts, Warner, & Brody, 2000), (3) an Expert Panel comprised of each participant group, and (4) cognitive interviews with each participant group to examine the construct validity and clarity of the survey. We provided participants with definitions of intellectual disability, self-report research, and researcher, encouraged participants to make their best choice, and explained how to answer questions. Using two parallel forms of the survey (one for adults with intellectual disability, one for all other groups), we asked adults with intellectual disability to respond from their perspective, and others to respond in reference to adults with intellectual disability. The survey also included questions on harms (McDonald, Conroy, Olick, & Panel, 2017) and safeguards (McDonald et al., 2016) in research, though we focus in this manuscript on the following data:

Benefits—We asked participants to rate how important each of 11 potential experiences or outcomes is for adults with intellectual disability or society when adults with intellectual disability participate in research², and how likely adults with intellectual disability would be to take part in research that had each experience or outcome (on a scale of 1–5, higher numbers indicated greater perceived importance and likelihood of participating). The items included 8 direct benefits to adults with intellectual disability and 3 indirect benefits to society. We also asked an open-ended question about whether there was anything else the participant wanted to share about potential benefits in research.

Views toward Research and Personal Information—We asked participants to indicate their level of agreement with the statement that adults with intellectual disability should be included in research (on a scale of 1–6, higher levels indicate greater agreement) (McDonald et al., 2008), how much they trust researchers (on a scale of 1–5, higher levels indicate greater trust) (Rubright, Cary, Karlawish, & Kim, 2011), to provide an array of personal demographic information, and whether they used support to complete the survey.

To improve accessibility, we included graphic representations to convey content, differentiate among sections and show progress towards completion; used plain language and concrete examples; and provided response graphics. We also included “do not wish to say” as a response option.

Procedures and Analysis

We received IRB approval from our university, and designed all materials and processes (e.g., the survey, recruitment and consent/assent materials, informed consent/assent procedures), with an Expert Panel. The fifteen member Expert Panel included representatives from all participant groups (about half of whom had an intellectual disability to balance power); we worked together over several months and members received stipends. We created a sampling frame of groups and organizations by and for adults with intellectual disability, family, and disability service professionals (e.g., social service organizations, advocacy groups, and social or recreational groups). We also created a sampling frame of researchers who had published self-report research with adults with intellectual disability by reviewing 7 English-language journals targeted to research with adults with intellectual disability from 2009 to 2014. We supplemented this initial list with names of researchers who had presented relevant research at one of two national conferences focused on people with intellectual disability in 2014. We identified IRB Chairpersons through a Freedom of Information Act (FOIA) request, contacting Chairpersons only those from places where we had identified researchers and asking them to forward information to their IRB members. We supplemented this list for institutions that provided publicly available IRB member rosters. We identified over 500 groups or organizations, 300 researchers, and 500 IRB members to whom we sent recruitment materials.

We recruited via postal mail letters and flyers, electronic mail, social media, in-person, tablings, and presentations, using a slightly different approach for each group. Participants

²We did not specify whether the research was focused on the general population or adults with intellectual disability.

recruited via electronic mail received multiple notifications (Dillman, Smyth, & Christian, 2009). We collected data for 4 months, closing participation for each group as it reached 100 participants. Participants provided consent or, for those with legal guardians, assent and completed the survey online, in-person, or over the telephone, with or without additional supports as desired (almost all participants without intellectual disability completed the survey online). We further promoted accessibility by using graphics in all materials, encouraging participants to take time to make their decision and to discuss it with a person of their choosing if desired, allowing participants to take a break, and providing one-on-one support in-person or over the telephone as requested (e.g., reading material aloud); participants could also access natural supports³. We (the authors and trained research assistants) emphasized voluntariness in materials and processes, and, when we had direct contact with participants, at no time did we observe anyone demonstrating subtle cues of resistance to participation or who did not understand what they were making a decision about (National Institutes of Health, 2009). All participants received a \$40 gift card.

We subjected all surveys to a data validation process (reasonable completion time, verifiable postal address, percent of survey complete, internal consistency of responses, self-reported response quality, understandability of open-ended responses, repeated IP addresses, name, or contact information), retaining those that we determined to be valid across these quality indicators. We then cleaned the data; missing data, including responses of “do not wish to say,” was <1%. For between-group comparisons, we examined several variables for inclusion as covariates (e.g., age, gender, education, attitude toward research with adults with intellectual disability, perceptions of trust, relationship to persons with intellectual disability, level of severity of intellectual disability among family members or populations served or researched, student researcher status, involvement in disability advocacy, general views toward research). Because none of these variables emerged as meaningfully associated with outcome variables, we did not retain any as covariates. Given the exploratory nature of the study, we used a cutoff of $p < 0.05$ and Tukey’s HSD test for post-hoc comparisons (Tabachnick & Fidell, 2001). We also conducted all analyses with and without imputed means; with one exception, analyses yielded identical conclusions.⁴ We report findings here with missing data. We thematically coded open-ended data, using multiple coders to bolster dependability (Braun & Clarke, 2006).

Results

Perceptions of Importance of Benefits

We examined ratings of the perceived importance of 8 direct and 3 indirect benefits. The Kolmogorov-Smirnov test and our examination of the histograms indicated data were negatively skewed, suggesting that participants perceived all items as relatively important. Nonetheless, one-way between groups ANOVAs revealed differences in perceptions among the participant groups (see Table 2).

³The only demographic variable that differentiated those who used support from those who did not was education level: Those with less education were more likely to use support to complete the survey. Similarly, only one difference in perceptions of benefits and likelihood to participate emerged: Adults with intellectual disability who used support to complete the survey felt it was less important to share their thoughts and experiences in research.

⁴With imputed means, there were no group differences on the importance of *sharing thoughts and experiences*.

Groups differed regarding perceived importance of all 8 direct benefits. Adults with intellectual disability and IRB members perceived *feeling valued or worthwhile* as less important than service providers and researchers; adults with intellectual disability also perceived this as less important than family members and friends. Adults with intellectual disability perceived *feeling in control and making own choices* as less important than all other groups except family and friends. Adults with intellectual disability and service providers perceived *feeling like you are helping others* as more important than researchers and IRB members; family members and friends also perceived this as more important than IRB members. Adults with intellectual disability perceived *sharing thoughts and experiences* as less important than service providers. Adults with intellectual disability and service providers perceived *learning new things* as more important than family members and friends, researchers, and IRB members; IRB members perceived this as less important than all other groups. Adults with intellectual disability perceived *meeting people* and *doing something new* as more important than all other groups, and researchers and IRB members also perceived these as less important than family, friends, and service providers. Adults with intellectual disability also perceived *receiving incentives* as more important than all other groups, and IRB members perceived this as less important than all other groups. In general, adults with intellectual disability perceive many direct benefits as more important than other groups.

Groups differed regarding the perceived importance of all 3 indirect benefits. IRB members perceived *researchers sharing what they learn with the community* and *the community learning about adults with intellectual disability* as less important than service providers. Adults with intellectual disability perceived *information improving the lives of adults with intellectual disability* as less important than family members, friends, and service providers; IRB members perceived this as less important than all other groups.

We performed within group ANOVAs to determine differences in perceptions of importance within groups. Adults with intellectual disability, $F(10,82) = 3.217$, $\eta^2 = .282$, perceived *feeling in control and making own choices*, *feeling like they are helping others*, and *information improving the lives of adults with intellectual disability* as more important than *meeting people*. They also perceived *feeling in control and making own choices* and *information improving the lives of adults with intellectual disability* as more important than *doing something new*. And they perceived *information improving the lives of adults with intellectual disability* as more important than *receiving incentives*. Family members and friends, $F(10,87) = 25.620$, $\eta^2 = .473$, service providers, $F(10,99) = 31.882$, $\eta^2 = .763$, researchers, $F(10,93) = 38.574$, $\eta^2 = .806$, and IRB members, $F(10,88) = 57.328$, $\eta^2 = .867$, generally saw *learning new things*, *meeting people*, *doing something new*, *feeling like you are helping others*, and *receiving incentives* as less important than other benefits, and indirect benefits as largely more important than direct benefits.

Likelihood to Participate in Research with each Benefit

We examined ratings of likelihood to participate in research for each of the 8 direct and 3 indirect benefits. The Kolmogorov-Smirnov test and our examination of the histograms indicated data were negatively skewed, suggesting that participants perceived relatively

strong likelihood to participate in research with each benefit. Nonetheless, one-way between groups ANOVAs revealed group differences in perceptions of the likelihood of research participation among adults with intellectual disability for each benefit (see Table 3).

We found group differences of predicted likelihood to participate for 6 of the direct benefits. Adults with intellectual disability expressed more interest in participating in research in which they *feel like you are helping others* than family and friends, researchers, and IRB members predicted they would. Service providers predicted adults with intellectual disability would be more interested in participating in research where they are *sharing thoughts and experiences* than IRB members. Adults with intellectual disability also expressed more interest in participating in research when they have opportunities to *learn new things, meet people, and do something new* than all others predicted they would. Service providers predicted greater interest among adults with intellectual disability to participate in research with opportunities to *learn something new* than researchers and IRB members did (IRB members also predicted less interest than family and friends), and service providers and researchers predicted greater interest among adults with intellectual disability to participate in research with opportunities to *meet new people* than IRB members did (IRB members predicted less interest than all groups). And family and friends and service providers predicted greater interest among adults with intellectual disability to participate in research with opportunities to *do something new* than IRB members did; service providers also predicted greater interest here than researchers. Adults with intellectual disability also expressed more interest in participating in research when they *receive incentives* than IRB members thought they would.

We found group differences of predicted likelihood to participate for all 3 indirect benefits. Adults with intellectual disability expressed more interest in participating in research when *researchers share what is learned with community members* and *the community learns about adults with intellectual disability* than family members and friends, researchers, and IRB members thought they would; service providers also predicted adults with intellectual disability would have greater interest in participating in research with these benefits than researchers and IRB members predicted. Lastly, adults with intellectual disability expressed more interest in participating in research when the *information learned is able to improve the lives of people with intellectual disability* than IRB members predicted.

A one-way within group ANOVA indicated that adults with intellectual disability were equally likely to participate in research that included any of the direct and indirect benefits.

Relationships between Perceptions of Importance of Benefit and Likelihood to Participate in Research with each Benefit

Among adults with intellectual disability, we examined the relationship between perceived importance of each benefit and their likelihood of participating in research with each benefit. Perceptions of importance were positively and weakly correlated to the likelihood of research participation for 1 direct and 1 indirect benefit: *feeling valued or worthwhile* ($r = .261, p < .01$) and *information improving the lives of adults with intellectual disability* ($r = .299, p < .01$). For all other benefits, perceptions of importance were positively and

moderately to strongly correlated to the likelihood of research participation, $r = .394$ to $.630$, $p < .01$.

Open-Ended Data

Participants from all groups noted that their views on benefits and their impact on participation may be driven by other factors, and emphasized the importance of including adults with intellectual disability in research. Family members and friends, service providers, researchers, and IRB members noted that it is difficult to evaluate the importance of research benefits without more context (e.g., the nature of the study and relationships among people), along with the experiences, capacities, knowledge and preferences of those participating. Service providers, researchers, and IRB members also expressed discomfort with taking the perspective of adults with intellectual disability, and preference for asking adults with intellectual disability their own views. Some family members and friends, service providers, researchers, and IRB members felt that adults with intellectual disability may be more interested in immediate benefits, and that some might not be able to understand long-term benefits. Researchers and IRB members also expressed concerns that incentives would be coercive, with friends and family members and service providers also expressing their belief that the opportunity to participate should be an adequate reward in itself.

Discussion

Scientific advances are necessary to address the persistent disparities experienced by people with intellectual disability; fostering participation in research among adults with intellectual disability helps to ensure that new knowledge is able to improve their lives, and promotes disability rights (Northway, 2014). To date, research has not always focused on promoting benefits for people with intellectual disability, particularly the benefits they most value. Infusing research policy and practice with community members' views is key to promoting ethical research and participation therein (Dresser, 2014; Lakin & Turnbull, 2005). For the first time, we asked adults with intellectual disability how important they believe direct and indirect research benefits are in self-report research, and how likely they are to participate in research with these benefits. We also compared their views to those of family members and friends, disability service providers, researchers, and IRB members. This work yields unprecedented insight; using these findings to transform research policy and practice with adults with intellectual disability may help promote quality of life for adults with intellectual disability.

Largely in-line with predictions, we found divergence of views on the importance of benefits, and beliefs about their impact on decisions to participate in research among adults with intellectual disability. Results indicate that adults with intellectual disability highly value research benefits, and are strongly interested in participating in research that provides them. These findings suggest many adults with intellectual disability have a strong sense of civic interest and are altruistic: They are motivated by opportunities to help others and to improve quality of life for all people with intellectual disability (Dybwad, 1996). The opportunity to be in research, especially when they are making the participation decision, helps them feel valued, an experience that many cannot take for granted given its

infrequency. It is worth noting that these findings also challenge some views expressed in open-ended comments suggesting that adults with intellectual disability may not understand or value indirect benefits.

However, other stakeholders, especially researchers and IRB members, may place less value than adults with intellectual disability do on some direct benefits, particularly when the benefit involves having opportunities to feel like you are helping others, learn new things, meet people, do something new, and receive incentives. It is possible other stakeholders value these benefits less than adults with intellectual disability do as they are often not the primary purpose of research (Coleman et al., 2003). On the other hand, this finding could also be driven by beliefs among other stakeholders that adults with intellectual disability do not have the abilities needed to derive such benefits from research participation, and thus they place less value on these experiences and outcomes. Future research will need to examine what factors contribute to this finding. Nonetheless, it is critical for the scientific community – researchers and IRB members – to understand their importance to adults with intellectual disability and seek ways to promote these benefits (Dresser, 2014; Northway, 2014). These benefits should be explicitly considered in designing research and in IRB review, and described in recruitment and consent/assent procedures.

Conversely, and somewhat surprisingly, compared to adults with intellectual disability other groups attach greater importance to research that allows participants to feel valued or worthwhile, be in control of their decisions, and share their thoughts and experiences (though these were still highly rated by adults with intellectual disability). It is encouraging to see this interest in showing respect to adults with intellectual disability and promoting their autonomy and opportunities for direct representation among diverse stakeholders (Iacono & Carling-Jenkins, 2012; Northway, 2014). Moving forward, the scientific community should continue to develop avenues to foster these outcomes in ways that are consistent with how adults with intellectual disability want to experience them (McDonald, 2012).

It is not surprising to see less agreement about the importance of incentives: views that incentives are not research benefits, may be coercive, or are simply unnecessary in the face of other benefits may drive beliefs among stakeholders without intellectual disability that they are less important (Coleman et al., 2003; McDonald & Kidney, 2012; K. E. McDonald & M. R. Patka, 2012). Nonetheless, the scientific community should note that adults with intellectual disability may perceive incentives as benefits. Incentives may also signal the value researchers place on their contributions. Moreover, adults with intellectual disability demonstrate somewhat less relative interest in being in research with incentives, suggesting that incentives may not carry the extreme coercive power that many fear they do, though they are motivational (McDonald, 2012; McDonald, Kidney, & Patka, 2013). That is, it is possible that incentives in research with adults with intellectual disability should be pursued equally to those in general population research.

We also found that interest in research participation among adults with intellectual disability is often stronger than other groups predicted. These findings suggest other stakeholders under-predict altruism among adults with intellectual disability, and their interest in research

that fosters direct and indirect benefits. These dynamics may also reflect their interest in protecting adults with intellectual disability from potential risks associated with research participation. Given the gatekeeping function that family members, disability service providers, researchers, and IRB members can play to facilitate or impede research participation among adults with intellectual disability (Becker et al., 2004; Iacono & Murray, 2003), it is critical that these groups understand the strong interest among adults with intellectual disability to be in research and seek to promote their opportunities to be included (Northway, 2014). Interestingly, disability service providers appear to have slightly better predictions than other stakeholders. It is possible that through long-term relationships supporting adults with intellectual disability, service providers have a strong understanding of their interests and values; they may also be particularly trusted by adults with intellectual disability (McDonald et al., 2017). Researchers may want to build on these informed, trusting relationships to further foster research participation among adults with intellectual disability.

Although this study is highly innovative, there are limitations to note. First, we focus on self-report research and provided little context: Other types of research (e.g., biomedical), additional contextual information (e.g., research purpose, procedures, risks, etc.), or alternative research approaches (e.g., hypothetical research vignettes, qualitative research, etc.), may lead to different findings. It is also possible that despite the information provided, some respondents did not correctly identify the focal population. We also had representation of student researchers: Although they represent the future of the field, they likely have more limited experience with research. And lastly, it is also possible that individuals who value research and the research participation of adults with intellectual disability were more likely to participate. However, given that there are not strong dominant cultural narratives about the beliefs studied herein, and the observed variation in responses across areas of the larger survey, we do not believe social desirability was a significant concern.

This research has important implications for policy and practice for research with adults with intellectual disability. As a guiding principle, it is essential to challenge our thinking and better listen to people with intellectual disability. There is strong community interest in research that can improve the lives of people with intellectual disability. This interest may be particularly pronounced among family, friends, and disability service providers perhaps because they experience first-hand the challenges faced by adults with intellectual disability. The scientific community should use these insights to bolster their commitment to including adults with intellectual disability in research, and to pursuing applied research and knowledge translation that can help promote health and well-being; funders should consider these interests and priorities as well. These findings can also be used to strengthen the ethical integrity of research, especially by encouraging researchers to treat adults with intellectual disability as they wish to be treated. Some research benefits are more easily promoted, and researchers should continuously seek to enhance research benefits; IRBs should learn about community views, and take them into account in their risk-benefit analysis. While all stakeholders under-estimate altruistic motivations among adults with intellectual disability to promote the good of others through research, it may be especially important for researchers and IRB members to focus more on potential direct benefits given the divergence of their views from those of adults with intellectual disability and their power

over research (McDonald et al., 2008). Accurately describing these benefits in recruitment and consent/assent processes may promote greater interest in research participation. As a result, we may see more significant representation of the population of adults with intellectual disability, more effective use of resources, and increased efforts to address disparities via scientific advances.

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Table 1

Participant demographic characteristics

Variable	Intellectual disability (n = 101)		Family/friend (n = 98)		Service provider (n = 109)		Disability researcher (n = 105)		IRRB Member (n = 99)		Total (N = 512)	
	M (SD)	%	M (SD)	%	M (SD)	%	M (SD)	%	M (SD)	%	M (SD)	%
Age	43.28 (14.66)		44.81 (14.91)		38.85 (13.41)		40.04 (12.89)		51.05 (11.72)		43.50 (14.18)	
Variable	%		%		%		%		%		%	
Gender												
Female	49.5	80.6	80.6	80.7	85.7	62.6	72.1					
Male	43.6	19.4	19.3	14.3	37.4	26.6						
Other	1.0	0	0	0	0	0	0.2					
Race*												
Amer. Indian/Alaskan Native	14.9	1.0	1.8	1.0	1.0	1.0	3.9					
Asian	0	2.0	3.7	7.6	4.0	3.5						
Black/African American	10.9	6.1	5.5	2.9	2.0	5.5						
Hawaiian/Pacific Islander	1.0	0	0.9	0	0	0.4						
White	81.2	87.8	86.2	88.6	91.9	87.1						
Other	3.0	3.1	0.9	0.9	2.0	2.0						
Latino	2.0	6.1	3.7	2.9	5.1	3.9						
Education												
Never attended school	2.0	0	0	0	0	0	0.4					
Did not complete high school	21.8	1.0	0	0	0	0	4.5					
High school diploma/GED	50.5	6.1	5.5	0	0	0	12.3					
Some college	6.9	14.3	13.8	1.9	2.0	7.8						
Certificate/Associates	7.9	13.3	10.1	1.0	0	6.4						
Bachelor's	0	24.5	35.8	7.6	4.0	14.6						
Graduate degree	0	38.8	32.1	89.5	93.9	50.8						
Disability advocacy	60.4	57.1	72.5	69.5	21.2	56.8						

Note. For items with an asterisk (*), respondents were asked to select all that apply.

Table 2

One-way ANOVA between groups differences on perceptions of importance

How important is it...	Intellectual disability (n = 101)		Family/ friend (n = 98)		Service provider (n = 109)		Disability researcher (n = 105)		IRB Member (n = 99)		F(df), η^2
	M (SD)	a	M (SD)	b	M (SD)	c	M (SD)	d	M (SD)	e	
<i>Direct benefits</i>											
Feel valued or worthwhile	4.58 (.89) ^{b,c,d}		4.83 (.43) ^a		4.86 (.37) ^{a,e}		4.84 (.46) ^{a,e}		4.61 (.68) ^{c,d}		F(4, 507) = 5.360, $\eta^2 = .041$
Feel in control/making own choices	4.55 (.91) ^{c-e}		4.64 (.60)		4.83 (.50) ^a		4.85 (.41) ^a		4.80 (.53) ^a		F(4, 506) = 4.707, $\eta^2 = .036$
Feel like you are helping others	4.60 (.77) ^{d,e}		4.32 (.82) ^e		4.42 (.83) ^{d,e}		4.05 (.88) ^{a,c}		3.84 (.99) ^{a-c}		F(4, 507) = 12.483, $\eta^2 = .090$
Share thoughts/experiences	4.53 (.82) ^c		4.71 (.63)		4.83 (.51) ^a		4.67 (.66)		4.65 (.69)		F(4, 503) = 2.758, $\eta^2 = .021$
Learn new things	4.48 (.94) ^{b,d,e}		3.71 (1.27) ^{a,c,e}		4.26 (.82) ^{b,d,e}		3.60 (1.05) ^{a,c,e}		3.04 (1.09) ^{a-d}		F(4, 506) = 30.235, $\eta^2 = .193$
Meet people	4.20 (1.18) ^{b-e}		3.34 (1.17) ^{a,e}		3.70 (.97) ^{a,d,e}		2.97 (1.23) ^{a-c}		2.54 (1.24) ^{a-c}		F(4, 506) = 31.027, $\eta^2 = .197$
Do something new	4.27 (1.08) ^{b-e}		3.35 (1.20) ^{a,e}		3.64 (1.03) ^{a,d,e}		2.92 (1.13) ^{a-c}		2.52 (1.16) ^{a-c}		F(4, 504) = 36.247, $\eta^2 = .223$
Receive incentives	4.23 (1.17) ^{b-e}		3.60 (1.11) ^{a,e}		3.59 (1.13) ^{a,e}		3.63 (1.14) ^{a,e}		2.87 (1.14) ^{a-d}		F(4, 504) = 17.875, $\eta^2 = .124$
<i>Indirect benefits</i>											
Researchers share what they learn with community	4.49 (.86)		4.42 (1.01)		4.65 (.66) ^e		4.63 (.72)		4.29 (1.12) ^c		F(4, 506) = 2.869, $\eta^2 = .022$
Community is able to learn about adults with intellectual disability	4.66 (.82)		4.68 (.55)		4.79 (.51) ^e		4.74 (.52)		4.49 (.77) ^c		F(4, 504) = 3.061, $\eta^2 = .024$
Information learned is able to improve lives of people with intellectual disability	4.63 (.74) ^{b,c}		4.87 (.37) ^{a,e}		4.88 (.33) ^{a,e}		4.77 (.52) ^e		4.43 (.77) ^{b-d}		F(4, 505) = 10.859, $\eta^2 = .079$

Table 3
One-way ANOVA between groups differences in likelihood to participate in research

	Intellectual disability (n = 97)	Family/ friend (n = 95)	Service provider (n = 107)	Disability researcher (n = 103)	IRB Member (n = 98)	F(df), η^2
How important is it...	a	b	c	d	e	
	M (SD)	M (SD)	M (SD)	M (SD)	M (SD)	
<i>Direct benefits</i>						
Feel valued or worthwhile	4.66 (.74)	4.63 (.56)	4.66 (.57)	4.59 (.61)	4.59 (.61)	F(4, 507) = .376, $\eta^2 = .003$
Feel in control/making own choices	4.60 (.86)	4.55 (.59)	4.65 (.67)	4.50 (.64)	4.49 (.63)	F(4, 507) = .984, $\eta^2 = .008$
Feel like you are helping others	4.75 (.61) ^{b, d, e}	4.42 (.73) ^a	4.56 (.64)	4.31 (.68) ^a	4.36 (.71) ^a	F(4, 507) = 7.012, $\eta^2 = .052$
Share thoughts/experiences	4.57 (.80)	4.50 (.63)	4.63 (.63) ^e	4.48 (.71)	4.35 (.69) ^c	F(4, 507) = 2.556, $\eta^2 = .020$
Learn new things	4.69 (.61) ^{b, e}	4.09 (.77) ^a	4.28 (.71) ^{a, d, e}	3.85 (.07) ^{a, c}	3.90 (.78) ^{a, c}	F(4, 506) = 18.295, $\eta^2 = .126$
Meet people	4.53 (.93) ^{b, e}	4.07 (.89) ^{a, e}	4.15 (.73) ^{a, e}	4.13 (.86) ^{a, e}	3.63 (.89) ^{a, d}	F(4, 505) = 14.077, $\eta^2 = .100$
Do something new	4.62 (.65) ^{b, e}	3.98 (.77) ^{a, e}	4.20 (.72) ^{a, d, e}	3.90 (.80) ^{a, c}	3.65 (.84) ^{a, c}	F(4, 504) = 23.699, $\eta^2 = .158$
Receive incentives	4.60 (.79) ^e	4.48 (.75)	4.44 (.81)	4.44 (.64)	4.22 (.82) ^a	F(4, 505) = 3.248, $\eta^2 = .025$
<i>Indirect benefits</i>						
Researchers share what they learn with community	4.54 (.82) ^{b, d, e}	3.97 (.95) ^a	4.29 (.80) ^{d, e}	3.93 (.94) ^{a, c}	3.71 (.97) ^{a, c}	F(4, 506) = 13.542, $\eta^2 = .097$
Community is able to learn about adults with intellectual disability	4.65 (.70) ^{b, d, e}	4.34 (.72) ^a	4.44 (.70) ^{d, e}	4.12 (.87) ^{a, c}	4.06 (.92) ^{a, c}	F(4, 503) = 9.395, $\eta^2 = .070$
Information learned is able to improve lives of people with intellectual disability	4.63 (.71) ^e	4.59 (.57)	4.55 (.74)	4.38 (.70)	4.35 (.76) ^a	F(4, 504) = 3.173, $\eta^2 = .025$