



Original Article

A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree?



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ABSTRACT

Background: Attitudes toward the research participation of adults with intellectual disability inform research policy and practice, impact interest in and support for research participation, and promote or discourage the generation of new knowledge to promote health among adults with intellectual disability. Yet we know little about these beliefs among the public and the scientific community.

Objective/Hypothesis: We quantitatively studied attitudes among adults with intellectual disability, family and friends, disability service providers, researchers, and Institutional Review Board (IRB) members. We predicted that adults with intellectual disability, and researchers would espouse views most consistent with disability rights, whereas IRB members, and to a lesser degree family, friends, and service providers, would espouse more protective views.

Methods: We surveyed five hundred and twelve members of the five participant stakeholder groups on their attitudes toward the research participation of adults with intellectual disability.

Results: We found broad support for research about people with intellectual disability, though slightly more tempered support for their direct participation therein. In general, IRB members and to some extent adults with intellectual disability endorsed direct participation less than others. We also found that adults with intellectual disability strongly believed in their consent capacity.

Conclusions: Resources should be directed toward health-related research with adults with intellectual disability, and interventions should be pursued to address ethical challenges and promote beliefs consistent with human rights.

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Adults with intellectual disability experience significant disparities in social determinants of health, healthcare, and health, including being at increased risk for preventable mortality and morbidity, and experiencing decreased attention to health needs, access to preventive health services, access to healthcare services, access to health promotion, and health-related quality of life.^{1,2} Despite the pressing demand for scientific advances to improve their health, the population is understudied.^{3–8} Beliefs about the research participation of adults with intellectual disability among the scientific community – including the importance of their participation, their interest in participation, and their ability to make participation decisions and safely participate in research

–inform research policy, practice, and funding. These beliefs and their consequences (for example, restrictions on or greater scrutiny of their research participation, reduced funding) can discourage research with this population, and create dynamics that limit public trust in science and decrease research participation among adults with intellectual disability. At the same time, the beliefs of adults with intellectual disability and those who support them can create interest in and support for – or the lack thereof – research participation.

Our understanding of these beliefs is in its infancy. There is initial evidence that adults with intellectual disability, family members and close friends of adults with intellectual disability, disability service providers, intellectual disability researchers, and Institutional Review Board (IRB) members – groups with key stakes in the issue – support the inclusion of adults with intellectual disability in research.^{9–11} However, these groups may hold varying

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attitudes, especially as there may be differences in their commitments to the autonomy and rights of people with intellectual disability and beliefs about their need for protection.¹² For example, family members and close friends, disability service providers, researchers, and IRB members may have more concerns about consent capacity and safety than adults with intellectual disability. On the other hand, adults with intellectual disability may more fully embrace their rights to self-determination and participation, and express more confidence in their decision-making skills.^{11,13} It is also possible that those who value the promise of research-based advances and the rights of adults with intellectual disability to full inclusion may hold beliefs more similar to adults with intellectual disability, and that those who favor safety may show more divergence from adults with intellectual disability.

Attitudes among the public (herein specifically inclusive of adults with intellectual disability, their family members and close friends, and disability service providers) and members of the scientific community (herein comprised of intellectual disability researchers and IRB members) can create opportunities to generate knowledge poised to promote the health of people with intellectual disability, or place obstacles in its way. Yet to date there has been no systematic, quantitative comparison of beliefs among these 5 stakeholder groups. This research aims to address that void in our knowledge base by studying and comparing attitudes toward the research participation of adults with intellectual disability. Because of the increasing emphasis on the value of direct participation in research, including the value of individuals themselves as a critical source of health outcome data,¹⁰ we focus on research that seeks to examine the thoughts and experiences of adults with intellectual disability. We predicted that adults with intellectual disability and researchers would espouse views most consistent with disability rights, whereas IRB members, and to a lesser degree family members and service providers, would espouse more protective views.

Methods

Instruments

We developed the *Project ETHICS* cross-sectional survey using a multi-prong approach^{14,15}: focus groups,^{9,11} prior research,^{16–21} an Expert Panel comprised of representatives of each of the 5 participant groups (none of whom were survey respondents), and cognitive interviews. The parent survey had sections on benefits, harms, and safeguards in research with adults with intellectual disability^{22–24} though we focus here on the following:

Attitudes toward research participation of people with intellectual disability

We created this section by selecting six items from the *Participation in Research Attitude Scale*¹⁷ to capture those attitudes we (the academic investigators and Expert Panel members) determined to be most essential and non-redundant with other aspects of the parent study. We asked participants to indicate their level of agreement with items related to the importance of this research, the importance of direct participation in this research, interest in participation among the population, and consent capacity on a scale of 1 (disagree strongly) to 6 (agree strongly). See [Table 2](#) (in the results section) for individual items. We also asked an open-ended question about these beliefs.

Research experience and views

We asked participants about their past research experience, including their general view of research and trust in researchers on a scale of 1–5 (higher levels indicate greater agreement). We adapted these items from *The Research Attitude Questionnaire*.²¹

Personal information

We asked participants for demographic information (including whether they had a family member with an intellectual disability), and their involvement in disability rights work.

To improve accessibility and validity, we: (1) included graphic representations to convey thematic content, differentiate among sections, and show progress towards completion; (2) used plain language, concrete examples, and defined concepts (e.g., intellectual disability, research, self-report research); and (3) provided response graphics and named anchors for extreme values for scaled items.

Data collection and analysis

We received IRB approval, and designed materials and procedures with the Expert Panel. To participate, individuals had to be 18 years or older, reside or work in the United States, and have the communication skills to make a participation decision and express opinions with or without accommodations (thereby yielding a sample reflective of those who likely could participate in the research under study: self-report research). We created national sampling frames using internet searches for community members, research published or presented for intellectual disability researchers, and a Freedom of Information Act request for IRB Chairpersons (see McDonald and colleagues,²⁴ for additional information). We recruited via postal mail letters and flyers, electronic mail, social media, and in-person, using a slightly different approach for each group. Participants recruited via electronic mail and social media received multiple notifications.²⁵ Participants completed the survey online, via postal mail, in-person, or over the telephone, with or without additional supports provided by the research team or by others in their lives.

We further promoted accessibility and broad inclusion by using graphics in all materials, encouraging participants to take time to make their participation 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. With accommodations, all individuals who were interested in participating were able to provide consent or assent and answer survey questions; our inclusion criteria thus yielded participants from the population able to participate in the type of research under study (i.e., self-report research). We emphasized voluntariness and at no time observed (when observation was feasible) anyone who seemed to be demonstrating subtle cues of resistance to participation or who did not understand the decision.²⁶ Participants received a \$40 gift card to thank them for their contribution. We collected data for 4 months, closing participant groups as they reached 100, allowing us to be sufficiently statistically powered to examine comparisons.

We conducted a data validation process (e.g., reasonable completion time, verifiable postal address, percent complete, internal consistency of responses, self-reported response quality), retaining those that we determined to be valid across these quality indicators (see McDonald and colleagues,²⁴ for additional detail). We then cleaned the data; missing data were no more than 3.9% for any single item, and using imputed means did not change findings (we report data with missing values). Given the exploratory nature of the study, we used a cutoff of $p < .05$ and Tukey's HSD test for post-hoc comparisons.²⁷ Because the selected attitudinal items are not representative of the subscales of the original measure,²⁸ psychometric work on these items is not appropriate. We thematically coded qualitative data from the open-ended question, using multiple coders to bolster dependability.²⁹

Results

Sample

Five hundred and twelve individuals from the 5 stakeholder groups participated: 101 adults with intellectual disability who self-reported their disability, 98 family members and close friends of adults with intellectual disability who had provided them unpaid support in the previous year (more than 80% were family members), 109 professionals who provided social services to adults with intellectual disability in the previous year (including primarily direct support providers, managers and other administrators, and clinicians, among others), 105 researchers who conducted self-report research with adults with intellectual disability in the past five years (about 10 of whom were students), and 99 IRB members from institutions conducting research with adults with intellectual disability in the previous 2 years. Among the latter three groups, 40%, 38%, and 12% of respondents respectively had a family member (of any age) with an intellectual disability, though they were not asked to complete the survey with reference to this person specifically and this additional experience largely did not influence findings. Some in these latter three groups also met criteria for more than one group. For the purpose of group comparisons, we classified participants into a single group, giving preference to the most inclusive professional roles as they responded to the survey from this more complex perspective (e.g., some IRB members may be intellectual disability researchers as IRBs are comprised of researchers). About one-half of researchers and IRB members were trained in health professions/applied sciences and/or social sciences (respondents could select more than one response), and overwhelmingly conducted behavioral/social science research. See Table 1 for additional information on sample characteristics.

Attitudes toward the research participation of adults with intellectual disability

Between group comparisons

We performed a one-way between groups ANOVA and found group differences on each of the 6 items about attitudes toward the research participation of adults with intellectual disability; with only one exception, adults with intellectual disability disagreed with at least one other stakeholder group on the importance of each item (see Table 2). Adults with intellectual disability more strongly agreed that *adults with an intellectual disability want to be in research studies* than all other groups; researchers expressed stronger agreement with this item than IRB members. Adults with intellectual disability also more strongly agreed that *adults with an intellectual disability can make up their own mind* than family members and friends and IRB members, and their endorsement of the importance of this was similar to service providers and researchers; IRB members expressed significantly less agreement with this item than service providers and researchers. Adults with intellectual disability also more strongly agreed that *adults with an intellectual disability need help from others to make up their mind* than service providers, and their level of agreement mirrored other groups. Conversely, adults with intellectual disability were less likely to agree that *research about adults with an intellectual disability is very important* than service providers and researchers, though their views were similar to family and friends and IRB members; researchers indicated stronger agreement with this than family and friends and IRB members. Adults with intellectual disability and IRB members were also less likely to agree that *it is very important that adults with an intellectual disability take part in research studies* than were researchers, and their views were similar to other groups. Although adults with intellectual disability did not

Table 1
Participant demographic characteristics.

Variable	Intellectual disability (n = 101)	Family/friend (n = 98)	Service provider (n = 109)	Disability researcher (n = 105)	IRB Member (n = 99)	Total (N = 512)
Variable	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	80.7	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	0.2
Race*						
Amer. Indian/Alaskan Native	14.9	1.0	1.8	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	0.4
Did not complete high school	21.8	1.0	0	0	0	4.5
High school diploma/GED	50.5	6.1	5.5	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 beliefs toward research participation.

	Intellectual disability ($n = 101$) <i>a</i>	Family/friend ($n = 98$) <i>b</i>	Service provider ($n = 109$) <i>c</i>	Disability researcher ($n = 105$) <i>d</i>	IRB Member ($n = 99$) <i>e</i>	<i>F</i> (df), η^2
Beliefs toward research	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	<i>M</i> (<i>SD</i>)	
Research about adults with intellectual disability is very important.	5.55 (.91) <i>c,d</i>	5.69 (.53) <i>d</i>	5.79 (.47) ^a	5.85 (.25) <i>a,b,e</i>	5.57 (.63) <i>d</i>	<i>F</i> (4, 506) = 6.196, $\eta^2 = .047$
It is very important that adults with intellectual disability take part in research studies.	5.36 (1.06) <i>d</i>	5.49 (.75)	5.54 (.82)	5.79 (.51) <i>a,e</i>	5.27 (.90) <i>d</i>	<i>F</i> (4, 503) = 5.833, $\eta^2 = .044$
Adults with intellectual disability want to be in research studies.	5.00 (1.26) <i>b-e</i>	4.14 (.99) <i>a</i>	4.21 (1.03) ^a	4.37 (.98) <i>a,e</i>	3.91 (.98) <i>a,d</i>	<i>F</i> (4, 487) = 14.789, $\eta^2 = .108$
Adults with intellectual disability <i>should be allowed</i> to make up their own mind about being in research studies.	5.56 (1.01)	5.48 (1.10) <i>d</i>	5.76 (.80)	5.82 (.53) <i>b,e</i>	5.46 (.77) <i>d</i>	<i>F</i> (4, 506) = 3.628, $\eta^2 = .028$
Adults with an intellectual disability <i>can</i> make up their own mind about being in research studies.	5.56 (.91) <i>b,e</i>	5.01 (1.03) <i>a</i>	5.30 (1.01) ^e	5.29 (.96) <i>e</i>	4.71 (1.10) <i>a,c,d</i>	<i>F</i> (4, 499) = 10.218, $\eta^2 = .076$
Adults with intellectual disability <i>need help from others</i> to make up their own mind about being in research studies.	4.27 (1.82) <i>c</i>	4.07 (1.41)	3.70 (1.39) ^a	3.87 (1.06)	4.12 (1.16)	<i>F</i> (4, 491) = 2.593, $\eta^2 = .021$

differ from others, researchers were more likely to agree that *adults with an intellectual disability should be allowed to make up their own mind* than family members and friends and IRB members.

Personal characteristics and experiences and differences in attitudes

We examined whether select demographic variables and experiences were associated with attitudes. By comparing group means, we found that attitudes did not significantly differ by gender, education, or age. For adults with intellectual disability, family members and friends, and researchers, attitudes also did not significantly differ by involvement in disability advocacy (yes/no). However, service providers involved in disability advocacy ($M = 5.48$) more strongly believed that *adults with intellectual disability can make up their own minds* than other service providers ($M = 4.65$), $t(100) = 3.63$, $p < .05$. IRB members involved in disability advocacy more strongly believed that *it is very important that adults with an intellectual disability take part in research studies* and that *adults with an intellectual disability should be allowed to make up their own mind* than other IRB members ($M = 5.76$ and 5.14 , $t(95) = 2.85$, $p < .001$ and $M = 5.76$ and 5.37 , $t(95) = 2.09$, $p < .05$, respectively).

Among respondents without intellectual disability, we examined whether those who have a family member with an intellectual disability (of any age) reported different attitudes than others. Those that had a family member with an intellectual disability ($M = 4.13$) were more likely to believe that *adults with intellectual disability need help making up their own minds* about research participation than those who did not ($M = 3.81$), $t(373) = 2.38$, $p < .05$.

Using a *t*-test, we also explored whether those who supported or worked with adults with “severe” intellectual disability differed from those doing so with adults with “mild” and/or “moderate” intellectual disability. Family members, friends, and disability service providers that supported adults with severe intellectual disability ($M = 5.85$) were significantly more likely to believe that *adults with an intellectual disability should be allowed to make up their own mind* than other family members, friends, and service providers ($M = 5.55$), $t(290) = 2.75$, $p < .01$. Researchers attitudes did not differ by level of intellectual disability of research participants.

Lastly, for adults with intellectual disability, we examined the

relationship between general views toward research and trust in researchers and attitudes toward research with adults with intellectual disability. Having a positive view of research in general was significantly and positively correlated with attitudes toward research with adults with intellectual disability ($r = .29 - .56$, $p < .01$), with the exception of *need help from others to make up their mind* ($r = .11$, *ns*). The level of trust in researchers was significantly and positively correlated with attitudes toward research ($r = .25 - .56$, $p < .05$), with the exception of *should be allowed to make up their own mind* ($r = .11$, *ns*).

Open-ended data

In open-ended answers participants also shared a number of factors that may impact their beliefs about the research participation of adults with intellectual disability. For example, service providers, researchers, and IRB members noted that the level of intellectual disability and other individual characteristics, as well as the nature of the study under consideration, would impact their views about the ability of adults with intellectual disability to participate in research. Participants from all groups added that trust may play an important role in whether a person with intellectual disability desires support in making their participation decision, and who they desire that support from. Some emphasized that receiving support in decision-making does not – and should not – undermine the agency of the person with intellectual disability.

Low risk studies are really where the adults with ID should be able to make their own decisions. - IRB member

It's not right to try to [take a]way the ability and the need to think for people that have ID/DD. All people with ID/DD have the right to think and talk for themselves. You do need to give them the chance to stand up for themselves[s]. This is good with having the right kind of help. It's better to ask if they need the help. - Adult with intellectual disability

Some adults with intellectual disability may need help to understand the process of what is involved, and then they should be able to make up their mind. It would depend on what the study entails and who should be involved in particular research studie[s]. - Service provider

Some only trust others to help them make decisions, some are very independent and some don't trust anyone! – Family member

Adults with intellectual disability may need help understanding the information about a research study, but once they understand that information, they can make up their own minds without help from others. However, they may benefit from being able to [d]iscuss the information with someone while they make up their minds. – IRB member

Some IRB members struggled with expressing their beliefs without having information about the individual's decisional capacity. Others added that the input of support providers is important in determining the ability of a person with intellectual disability to participate in research.

Discussion

Adults with intellectual disability experience alarming disparities in health and its social determinants; although urgent calls have been made to pursue scientific advances to reduce these disparities, ethical and social issues pose challenges to conducting this research.^{7,30} Underlying these challenges are differential beliefs about the value of this research, the value of directly including adults with intellectual disability in research, and appropriate consent practices; perceptions that adults with intellectual disability are uniquely vulnerable play an important role in these attitudes.^{10,18} For the first time, we are able to directly quantitatively compare similarities and differences in attitudes toward research about adults with intellectual disability among key stakeholders. This work sheds light on beliefs among the public – groups key to research participation who should have influence over research practice and policy³¹ – and members of the scientific community – groups who may facilitate or impede opportunities to participate in research, and set conditions for research participation which may align or not with preferences of adults with intellectual disability.

Our findings resonate with earlier qualitative work.^{9,11} We found broad support for the importance of conducting research about adults with intellectual disability and, though somewhat more tempered, their direct participation therein. Not surprisingly, IRB members espoused somewhat less support for these ideas than most other groups. We were, however, surprised that adults with intellectual disability also endorsed these beliefs somewhat less than other groups (perhaps they are less familiar with the potential benefits of research, focused on other social issues, or have some hesitation due to past violations or uncertainty about what participation involves). It is possible that although both IRB members and adults with intellectual disability strongly support this research, their more tempered support (relative to others) reflects other priorities (e.g., community change initiatives, research in other areas that affect a larger portion of the population) or, for IRB members, concerns that ethical and social issues cannot be easily addressed. This latter concern may drive reduced support for the direct participation of adults with intellectual disability in research, and potentially greater support for the ethically and scientifically questionable practice of inclusion via proxy report.³² Efforts – including policy initiatives and exposure to disability rights and advocacy – should be undertaken to challenge these viewpoints and practices in order to promote better science and efforts consistent with human rights; without such change, IRB members may place burdensome, protectionist restrictions on the research participation of adults with intellectual disability, thereby discouraging researchers from conducting this research and adults with intellectual disability from participating.^{3,12,32} Our findings,

together with earlier work, should galvanize resources (including funding) toward and encouragement for this research,³⁰ with greater attention to the value of the direct participation of adults with intellectual disability in research.¹⁰

High-quality science relies on effective recruitment, a resource intensive aspect of human participant research.^{21,33} Consistent with our predictions, we found strong beliefs among members of the population themselves that adults with intellectual disability want to be in research; other groups however, especially IRB members, expressed weaker beliefs that adults with intellectual disability would be so interested. This finding highlights potential areas of concern that should be targeted for future intervention: If IRB members, researchers, family and friends, and disability service providers think adults with intellectual disability are less interested in participating in research than members of the population indicate they are, this research is less likely to be emphasized in policy (for example, NIH does not emphasize their inclusion as they do that of women, children, and racial and ethnic minorities) and pursued. Moreover, those close to adults with intellectual disability are less likely to proactively support their involvement.^{33,34}

Also somewhat consistent with predictions, adults with intellectual disability expressed strong support that they can and should be allowed to make research participation decisions. Interestingly, adults with intellectual disability espoused this view more than others except disability service providers and researchers; family and friends and IRB members demonstrated markedly lower support for this idea. However, there was more agreement that adults with intellectual disability should be allowed to make their own participation decisions, though researchers expressed greater support for this idea than family, friends, and IRB members. Our research suggests adults with intellectual disability do weigh study-specific factors (for example, risks, benefits, and safeguards) in their approach to decision making, a core element of consent capacity^{9,11}. Conversely, there was considerably less support for the idea that adults with intellectual disability need help from others in making research participation decisions though adults with intellectual disability supported this idea more than service providers. A need of, or desire for, assistance in decision-making does not mean that adults with intellectual disability cannot retain control over their decisions.^{35,36} In fact, these findings may suggest that adults with intellectual disability understand this dynamic better than others, and further support the ethical imperative to provide accommodations to facilitate their research participation, which for some may include practices such as supported decision-making.³² It is important that future work look carefully at accommodations and opportunities to learn and develop decision-making skills with the goal of facilitating informed consent among adults with intellectual disability and dispelling mistaken negative perceptions of decisional capacity; policy initiatives may be required to support these ideas and spur changes in practice. Although our study found only one small mean difference between participants with and without family members with intellectual disability of any age, future research could further examine how membership in multiple stakeholder groups affects the views of service providers, researchers, and IRB members. More specifically, this could be useful for bridging perspectives among diverse stakeholders.

This work is not without limitations: We used a convenience sample and it is uncertain how representative our sample is; we did not include individuals who could not communicate their opinion or others members of the general public or researchers working with other populations; we measured attitudes via self-report; we asked broad questions about a heterogeneous population and activity; we were not able to conduct psychometric work; and attitudes only partially predict behavior. Although limitations of this innovative work should be kept in mind, there are many important

implications. Taken together, these results are promising and shed light on potential paths forward to further facilitate research policy and practices that can promote health equity for adults with intellectual disability. First, these findings unearth broad stakeholder support for research with adults with intellectual disability, and somewhat strong support for recognizing their capabilities and fostering their autonomy therein. However, results also indicate somewhat differential commitments and suggest potential areas for intervention. For example, it is possible that more needs to be done to help adults with intellectual disability to fully appreciate the value of research and of their participation, and to promote greater trust in science and in researchers. Promoting greater trust may be challenging given a history of prior exploitation of those with intellectual disability.^{37,38} At the same time, new approaches are needed to help others better appreciate the interests and capabilities of adults with intellectual disability, and the value of accommodations and creative study design, in order to most effectively remove barriers to self-determination, participation, and inclusion in research.³² Such efforts might be especially needed among IRB members as they hold significant control over the terms of human participant research,¹³ and demonstrate a general trend toward greater protectionism over inclusion.¹⁰ Given that IRB members likely have the least knowledge of adults with intellectual disability, intervention strategies may need to be more especially tailored to IRBs than perhaps for other stakeholders. Continued study of attitudes about research with adults with intellectual disability among important stakeholders, including development and assessment of innovative approaches to the processes of recruitment and informed consent, can and should promote research policy and practice that safely and respectfully engages adults with intellectual disability and also fosters a growing body of scientifically-based insight consonant with the goals of health equity.

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