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## 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.<sup>1,2</sup> Despite the pressing demand for scientific advances to improve their health, the population is understudied.<sup>3–8</sup> 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.<sup>9–11</sup> 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.<sup>12</sup> 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.<sup>11,13</sup> 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,<sup>10</sup> 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<sup>14,15</sup>: focus groups,<sup>9,11</sup> prior research,<sup>16–21</sup> 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<sup>22–24</sup> 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*<sup>17</sup> 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*.<sup>21</sup>

### *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,<sup>24</sup> 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.<sup>25</sup> 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.<sup>26</sup> 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,<sup>24</sup> 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.<sup>27</sup> Because the selected attitudinal items are not representative of the subscales of the original measure,<sup>28</sup> psychometric work on these items is not appropriate. We thematically coded qualitative data from the open-ended question, using multiple coders to bolster dependability.<sup>29</sup>

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