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The Gatekeepers of Science:

Attitudes toward the Research Participation of Adults with Intellectual Disability

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Attitudes Scale

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Abstract

Researcher and Institutional Review Board (IRB) members' attitudes influence scientific knowledge about individuals with intellectual disability. We recruited 260 intellectual disability (ID) researchers and IRB members to develop a measure of attitudes toward the research participation of adults with intellectual disability, the *Participation in Research Attitude Scale*. Findings suggest three conceptual domains - *Opportunity and Choice*, *Help in Decision Making* and *Beneficence*. We also examined individual differences in attitudes and the relationships between general and specific attitudes. In general, ID researchers and those with closer relationships to individuals with disabilities had attitudes consistent with disability-rights principles. Some dimensions of global attitudes toward adults with intellectual disability predicted more specific attitudes toward their research participation. Implications are discussed.

The scientific knowledge base informs what we know about individuals with intellectual disability (ID) and is shaped by those who conduct research in the area and consider its ethical integrity (Lai, Elliott, & Ouellette-Kuntz, 2006). These groups, ID researchers and Institutional Review Board (IRB) members, have substantial influence. They play major roles that affect what topics are pursued, how scientists interact with research participants, and how findings are interpreted and presented to form the scientific record. In many ways, ID researchers' attitudes shape the focus, tone and portrayal of individuals with intellectual disability as these investigators write scientific literature, while IRB members' attitudes shape which individuals are allowed to participate in research and the terms of any participation. Together, these groups represent the scientific gatekeepers, or individuals who determine the type and representation of our empirically-based knowledge of individuals with intellectual disability. As such, the attitudes of these gatekeepers toward the research participation of people with intellectual disability are likely to be an important factor (Freedman, 2001; Lai et al., 2006).

Attitudes are evaluative responses to a person, a context, and a person-in-context that are informed by experiences, beliefs, and feelings (Eagly & Chaiken, 1993). Public attitudes have historically accorded less social value to individuals with intellectual disability although with time, and the work of social movements, public attitudes and relevant policies have come to increasingly reflect these newer attitudes (Dybwad & Bersani, 1996; Freedman, 2001). These attitudes – both those that limit and promote rights – inform the treatment and portrayal of individuals with intellectual disability in research. Early research practices exploited their precarious social position and physically harmful research was conducted on them, often without their consent (Freedman, 2001). As these abuses came to light and public attitudes began to shift, ways to correct the situation were devised, paying careful attention to protecting vulnerable

groups (Beh, 2002). In the USA, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (NCPHS; 1979) provided three principles to guide the ethical treatment of human research participants in the Belmont Report. *Respect for Persons* reflects the importance of respecting individual autonomy and protecting those with reduced autonomy. *Beneficence* centers on respect for individual decisions while simultaneously securing research participants' well-being. *Justice* holds that the benefits and burdens of research should be equally distributed.

Public opinion has long been divided as to whether adults with intellectual disability should participate in research and, if so, how they should be treated therein. Some favored codified restrictions on their participation as a means of protection. In recent years advocacy efforts drew on increasingly rights-based attitudes toward individuals with intellectual disability to thwart efforts to limit their research involvement (Berg, 1996). Notwithstanding these developments and the growing acceptance and affirmation of rights to participate in research among many people with intellectual disability, their family members and professionals, public attitudes often remain largely informed by perceptions of the cognitive inabilities of persons with intellectual disability (Dybwad & Bersani, 1996; Henry, Keys, Jopp, & Balcazar, 1996a). Such attitudes are part of the context that surround contemporary interpretation and application of human subjects' protections. These attitudes contribute to varied, and possibly disenfranchising, perspectives on access to research participation for adults with intellectual disability among IRB members and researchers (Lai et al., 2006). For example, inflated as well as genuine concerns regarding the cognitive and social inability of adults with intellectual disability to deliberate and act upon informed, voluntary choices about research participation persist (Freedman, 2001). Without access to appropriate research participation, adults with intellectual disability are denied

the opportunity to contribute to scientific advancements and are ill-positioned to benefit from resulting knowledge (Aman & Handen, 2006; McVilly & Dalton, 2006)

Restrictive attitudes may create subtle barriers to community inclusion: they influence the establishment of policies and influence their implementation (Antonak & Livneh, 2000).

Understanding the structure of these attitudes with psychometrically sound measures may play an important role in promoting positive attitudes that contribute to the integration of individuals with intellectual disability (Antonak & Livneh, 2000). There are few valid measures of attitudes toward this group (Antonak & Harth, 1994; Antonak & Livneh, 2000; Henry et al., 1996a, Henry, Keys, Balcazar, & Jopp, 1996b) and none that focus on their research participation, a noteworthy arena of endeavor (Lai et al., 2006). To understand and assess attitudes that affect the research participation of adults with intellectual disability, a new psychometrically sound attitude measure is needed that considers the research context (Ajzen & Fishbein, 1980). The *Participation in Research Attitude Scale* (PRAS) was developed for this purpose. We used two frameworks to inform the development of this instrument: dimensions of contemporary attitudes related to principles of the Disability Rights Movement valued by self-advocates and principles of research participation. We created items that tapped the four disability-rights focused dimensions of the *Community Living Attitude Scale* (CLAS; Henry et al., 1996a) – having say over their life (*Empowerment*), being segregated from community life (*Exclusion*), being protected (*Sheltering*) and being similar to individuals without intellectual disability (*Similarity*) – and items that reflected the three Belmont Report principles - *Respect for Persons*, *Beneficence* and *Justice* – as they relate to the research participation of adults with intellectual disability.

Once the structure of these attitudes is identified, we can begin to explore what and how individual characteristics are related to them. Previous research that examined these questions in

relation to global attitudes toward individuals with intellectual disability suggests relationships we may uncover. For example, younger individuals and those with higher levels of education espouse attitudes toward people with intellectual disability more favored by proponents of the Disability Rights Movement (Antonak & Harth, 1994; Antonak et al., 1995; Henry et al., 1996b; Henry et al., 2004). Findings related to gender difference are less clear (Henry et al., 1996b; Horner-Johnson et al., 2002; Rizzo & Vispoel, 1992). In studies where gender differences have been observed, women typically report more favorable attitudes on human rights issues than do men (Bottoms et al., 2003; Krajewski & Flaherty, 2000); although in at least one instance women had mixed attitudes (Ouellette-Kuntz et al., 2003). Additionally, staff who work with people with intellectual disability have attitudes more consistent with disability-rights principles than college students (Antonak & Harth, 1994; Henry et al., 1996b). Lastly, consistent with *contact theory* (Pettigrew & Tropp, 2006), individuals who have work experience involving individuals with intellectual disability espouse higher disability-rights based attitudes toward them (Antonak & Harth, 1994; Antonak et al., 1995; Henry et al., 1996b; Krajewski & Flaherty, 2000). These individual differences in global attitudes may be similarly related to specific attitudes.

The current research encompasses three research goals: (1) *To identify the conceptual organization of attitudes toward the research participation of adults with intellectual disability.* We anticipated that attitudes assessed by the PRAS would be organized around dimensions of attitudes about intellectual disability, around ethical principles of research participation, or a combination of the two dimensions. Given conceptual similarity between the human rights perspectives of the CLAS and the Belmont Report, we did not anticipate that 7 factors would be necessary to account for the variation in the PRAS items. (2) *To identify variables related to differences in attitudes toward the research participation of adults with intellectual disability, to*

*explore the nature of these relationships and their relative contribution to each attitude domain.*

Consistent with prior research, we expected that women, younger participants, intellectual disability researchers, and those with closer relationships to people with disability would espouse more disability-rights based attitudes. (3) *To identify whether general attitudes toward adults with intellectual disability predict specific attitudes toward their research participation.* We expected general attitudes to predict specific attitudes. That is, we expected that the CLAS scales would predict attitudes toward research participation measured by the PRAS. Since the structure of the PRAS was unknown, particular relationships were not predicted.

## Methods

### *Participants*

We used four strategies to identify scientific gatekeepers. First, we identified researchers who had published U.S.A.-based social science research with adults with intellectual disability in any of 11 journals that published these kinds of studies for a 5-year period. We also included researchers at University Centers for Excellence in Developmental Disabilities. In all, we identified 532 researchers from 151 universities, excluding those from our university. We then identified 283 IRB Chairpersons from these 151 universities. We were unable to locate reliable contact information for 144 researchers and 43 IRB members; we therefore contacted 388 researchers and 240 IRB members. We solicited participants through six personalized postal and electronic mail contacts during a six-week period (Dillman, 2000). We asked researchers and IRB members to forward the invitations to colleagues at their university/college. These recruitment efforts yielded 260 scientific gatekeepers. Response rates for direct recruitment were 35% for IRB members and 26% for ID researchers, an expected rate for active scientists.

Respondents included 116 *IRB Members*, 114 *ID Researchers*, and 30 individuals who belong to both groups (*IRB-IDRs*). Fifty-four percent of participants were female, over 65% were aged 30-59 and the majority were Caucasian (91%). Fifty-two percent of respondents indicated earning between \$50,000 and \$150,000. Almost three-quarters of participants reported holding a Ph.D., 11% reported holding a MD and 10% a Master's Degree. Eight percent noted having some form of disability. Fifty-four percent of respondents indicated a family member or friend with some form of disability. Seventy-five percent reported having worked or volunteered with individuals with intellectual disability. About three-fifths (62 %) noted having a colleague with a disability.

#### *Procedures and Measures*

We used an anonymous internet-based survey, approved by our IRB, to assess attitudes and gather demographic information. Participants were provided a definition of intellectual disability (American Association on Mental Retardation, 2002) and completed five research instruments as part of a larger study (see McDonald, 2006). First, gatekeepers completed the *Community Living Attitude Scale (CLAS) – Short Form*. The CLAS has 17-items that tap four dimensions of attitudes toward persons with intellectual disability: *Empowerment* (e.g., “people with intellectual disability can be trusted to handle money responsibly”), *Exclusion* (e.g., “people with intellectual disability are a burden on society”), *Sheltering* (e.g., “sheltered workshops for people with intellectual disability are essential”) and *Similarity* (e.g., “people with intellectual disability can be productive members of society”; Henry et al., 1996a). The CLAS uses a Likert-type scale with six response options (disagree strongly to agree strongly). We used the focal term “intellectual disabilities” in the current study. Both short and long forms of the CLAS have strong psychometric properties and construct validity (Henry et al., 1996a; Horner-Johnson,

2002) which were replicated for the short form in the current sample (see Table 2). Next, participants completed the *Participation in Research Attitude Scale - Intellectual Disability* (PRAS-ID). The PRAS was developed based on the conceptual underpinnings of the four subscales of the CLAS (31 items) and the three principles of research ethics derived from the Belmont Report (i.e., *Respect for Persons*, *Beneficence*, and *Justice*; 15 items) to appraise attitudes toward the research participation of adults with intellectual disability, a potentially vulnerable group. As administered, the PRAS has 46 unique, randomly ordered items and uses the same 6-point response scale as the CLAS. The 12 items of the impression management scale of the short form of the *Balanced Inventory of Desirable Responding* (BIDR), a psychometrically sound measure, were used to examine a tendency to respond to questions in a socially desirable manner (Paulhus, 2002). Participants also provided information concerning their personal characteristics including their age, gender, race/ethnicity, income, level and field of education, current occupation and field, percent of work week spent on research, knowledge of research ethics, and experience with individuals with disability.

## Results

### *(1) Conceptual Organization of Attitudes toward Research Participation*

To examine the conceptual factor structure of the PRAS, we performed exploratory factor analyses (EFA). To reduce the likelihood our analyses would result in uninterpretable factors, we used a variety of factor analytic procedures retaining factors that appeared across different procedures (Thompson, 2004). We used Principal Components Analysis (PCA) and Principal Axes Factor (PAF) employing both varimax orthogonal and promax oblique rotations. Across all four methods, Cattell's Scree Criterion yielded a 4-factor solution, indicating that the percent of variance accounted for levels off after 4 factors (Tabachnick & Fidell, 2001; Thompson, 2004).

Examination of factor loadings across the four methods indicated that items loaded on the same components across these four methods. Given the consistency of these results, we determined that the four-factor structure was robust and conducted subsequent analyses using PCA with varimax rotation (Thompson, 2004). We then turned to more focused issues of interpreting the fit of the 4-factor structure model and examining individual items. We systematically eliminated poor performing individual items, deleting eleven items with factor loadings less than 0.40 (Thompson, 2004). We then organized the remaining 35 items by factor and found the first three of the four components were easily interpretable, but the fourth was not. Since it consisted of three items that shared no discernable underlying conceptual relationship, we forced a three-factor solution and eliminated four items with low factors loadings and two that loaded on more than one factor (Thompson, 2004). Reconducting analyses using data with imputed missing values (viz., means) and excluding univariate and multivariate outliers yielded similar results.

In all, we retained 29 items with factor loadings greater than 0.40 and clear loadings on one factor. The resulting three factors were labeled as follows: (1) *Opportunity and Choice*, beliefs that adults with intellectual disability should be provided opportunities to participate in research and have choices about their participation (e.g., “*It is important that more people with intellectual disabilities participate in research*”), (2) *Help in Decision-Making*: beliefs that adults with intellectual disability need assistance in making decisions about research participation (“*People with intellectual disabilities need help from others to decide if they want to participate in research*”) and (3) *Beneficence*: beliefs related to protecting adults with intellectual disability from harm in the research setting (“*People with intellectual disabilities should not be invited to participate in potentially harmful research*”). The three dimensions accounted for 43% of the variance cumulatively and 19, 14, and 10 % of the variance

individually (see Table 1). Indices of internal consistency for each subscale were 0.86, 0.84 and 0.70 respectively (see Table 2). Subscale scores were computed by summing all unweighted item scores and dividing by the number of items.

We also examined evidence for the convergent and discriminant validity of the PRAS by computing correlations of the PRAS subscales with the CLAS subscales and the *Impression Management* subscale of the BIDR. For the most part, the PRAS subscales correlated significantly and in the anticipated directions with the CLAS subscales providing support for the convergent validity. As anticipated, none of the correlations between the attitude subscales and the *Impression Management* subscale of the BIDR were significant, supporting discriminant validity. See Table 2 and the last section of the results for more information.

#### (2) *Gatekeeper Characteristics and Attitude Differences*

To examine whether aspects of participants' personal characteristics, professional experience, knowledge and familiarity with research ethics and experience with disability significantly influence these attitudes, we conducted a series of Multivariate Analyses of Variance (MANOVAs), which helps control the experimentwise Type 1 error rate, evaluating each univariate test using Pillai's Trace since cell sizes were unequal (Tabachnick & Fidell, 2001). We present multivariate F statistics first for each significant effect on the composite attitude variable and then univariate F statistics for each significant effect on individual attitude domains. We also present effect sizes in units of partial *eta*-squared; the proportion of the variance in the outcome variables accounted for by each variable. When we analyzed data imputing missing values with means, no substantial discrepancies were noted. See Table 3 for means and standard deviations.

We first examined whether respondents' age, gender, income and highest degree earned affect attitudes toward the research participation of adults with intellectual disability. Only participants' gender,  $F(7, 229) = 3.91, p < 0.05$ , partial eta squared = 0.11, was related to attitudes. Gender was significantly related to *Opportunity & Choice*,  $F(1, 235) = 5.70, p < 0.05$ , partial eta squared = 0.02, *Help in Decision-Making*,  $F(1, 235) = 3.9, p < 0.05$ , partial eta squared = 0.02, and *Beneficence*,  $F(1, 235) = 4.64, p < 0.05$ , partial eta squared = 0.02. Women espoused views more consistent with rights-based and protective attitudes than men.

We then examined whether attitude differences varied according to respondents' relationships to people with disabilities. We modified Antonak and colleagues' (1995) approach to classify relationships into four categories: (1) *intimate* (e.g., self, family member and/or friend), (2) *close* (e.g., worked or volunteered with people with intellectual disability), (3) *casual* (have a colleague with a disability) and (4) *none*. Participants with both *close* and *casual* relationships were classified in the highest category (*intimate*). Participants' relationship to people with disabilities was related to these attitudes,  $F(21, 687) = 1.81, p < 0.05$ , partial eta squared = 0.05. Individuals with close or intimate relationships to people with disabilities had lower *Help in Decision-Making*,  $F(3, 233) = 3.52, p < 0.05$ , partial eta squared = 0.04.

We also tested whether participants' role, field of training, current field of work, current occupation and percent of time spent on research were related to attitudes. The role analysis included 2 covariates that varied significantly by role *and* were related to attitudes (age and relationship to people with disabilities). *ID researchers* and *IRB-IDRs* had attitudes more consistent with rights-based perspectives than *IRB members*,  $F(14, 454) = 2.18, p < 0.05$ , partial eta squared = 0.06. These differences were noted for *Opportunity and Choice*,  $F(3, 232) = 4.73, p < 0.05$ , partial eta squared = 0.04, and *Help in Decision-Making*,  $F(2, 232) = 3.35, p < 0.05$ ,

partial eta squared = 0.03. Participants' self-rated knowledge of general research ethics, familiarity with federal regulations on human research ethics, and familiarity with federal regulations on research with vulnerable groups did not explain variation in these attitudes.

*(3) Predicting specific attitudes with general attitudes.*

To examine whether *general* attitudes toward adults with intellectual disability (as measured by the four CLAS subscales) predict *specific* attitudes toward the research participation of adults with intellectual disability (as measured by the three PRAS subscales), we constructed a series of linear multiple regression equations testing each specific attitude domain with the set of general attitudes as predictors. Running analyses with and without covariates (i.e., those variables that were related to attitude differences: age, gender, role, and relationship to people with disabilities) yielded similar results: here we present results without covariates. *Opportunity and Choice* attitudes were positively predicted by *Empowerment* and *Similarity* attitudes,  $R = 0.64$ , Adjusted  $R^2 = 0.40$ ,  $F(4, 233) = 40.32$ ,  $p < 0.05$ ; *Similarity* attitudes made the larger contribution. Conversely, *Help in Decision-Making* attitudes were negatively predicted by *Empowerment* and *Similarity* and positively predicted *Sheltering* attitudes,  $R = 0.59$ , Adjusted  $R^2 = 0.34$ ,  $F(4, 236) = 31.96$ ,  $p < 0.05$ ; *Sheltering* attitudes made the largest contribution. Lastly, *Beneficence* attitudes were negatively predicted by *Empowering* and positively predicted by *Sheltering*,  $R = 0.38$ , Adjusted  $R^2 = 0.13$ ,  $F(4, 236) = 9.72$ ,  $p < 0.05$ ; *Sheltering* attitudes made the larger contribution to *Beneficence* attitudes. See Table 4 for details.

## Discussion

This research considered the attitudes of key scientific gatekeepers, ID researchers and IRB members, concerning the research participation of persons with intellectual disability and thereby perhaps their shaping of the scientific record (Lai et al., 2006). We developed a measure

of the conceptual organization of these attitudes, examined these attitudes and their relationship to other individual variables among scientific gatekeepers, and investigated whether general attitudes predicted more specific attitudes.

Results suggest that specific attitudes toward the research participation of adults with intellectual disability may be organized into three conceptual domains: *Choice and Opportunity*, *Help in Decision-Making* and *Beneficence*. The three-factor structure of the Participation in Research Attitudes Scale (PRAS) bears substantial, albeit complex, conceptual linkages to the three guiding principles in the Belmont Report (NCPHS, 1979). To illustrate, like the Belmont principle, the *Beneficence* scale of the PRAS emphasizes the need to maximize benefit, minimize harm and promote research participants' well-being. Since this attitude subscale can take the form of paternalism, readers are cautioned from interpreting high scores as necessarily positive. *Opportunity and Choice* reflects many tenets of *Justice*, or having the prospect of encountering both benefits and burdens from participating in research. However, *Opportunity and Choice* also includes items that emphasize respecting individual choice, a potentially important construct for individuals whose ability and opportunity to make such decisions may be compromised (Arscott, 1998; Ellis, 1992; Fisher, 2003; Freedman, 2001; Morris et al., 1993). These latter items share a conceptual relationship with *Respect for Persons* more than with *Justice*. *Help in Decision-Making* reflects the perspective that adults with intellectual disability require support in making decisions. This factor relates to one dimension of *Respect for Persons*: the need to provide protections to individuals with reduced autonomy. Overall, however, *Help in Decision-Making* attitudes relates more to a tendency to *protect* adults with intellectual disability by assuming reduced autonomy; as a result higher scores on this subscale should not always be positively interpreted.

The PRAS may reflect the evolving construct of *Justice*. Originally, *Justice* was focused on ensuring that marginalized groups were not unfairly targeted for high risk research with little personal benefit, with a lesser focus on including them in research with potential benefit. A contemporary framing of *Justice* may be more focused on ensuring that marginalized groups have access to respectful research participation and thus can contribute to research knowledge that applies to them and thereby receive its beneficial results (Arscott et al., 1998; Becker et al., 2004; Dalton & McVilly, 2004; Fisher, 2003; Freedman, 2001; Roberts et al., 2000). The *Opportunity & Choice* subscale of the PRAS appears to capture this contemporary perspective on *Justice*. Moreover, *Help in Decision-Making* seems to assess more traditional concerns about research participation; whereas *Opportunity and Choice* may appraise the possibility of independence and the dignity of risk (Perske, 1972), important constructs in the Disability Rights Movement. The PRAS may also convey salient guiding concerns when considering the research participation of adults from vulnerable groups, particularly those who may have questionable ability to provide informed, voluntary consent due to cognitive and social factors. To the extent that attitudes influence the behavior of scientific gatekeepers, variation may shape access to and the nature of research participation of adults with intellectual disability as well as their portrayal in science.

These findings also further illuminate our understanding of individual differences and attitudes, particularly in the research context and among scientific gatekeepers. Findings are largely consistent with prior research and predictions and suggest that these individual differences carry over from general attitudes toward people with intellectual disability to more specific attitudes toward their research participation. For example, our findings support previous research that people with close or intimate relationships to people with disabilities have higher

disability-rights based attitudes (Antonak et al., 1995; Henry et al., 1996a; Krajewski & Flaherty, 2000) and provide additional support for the *contact hypothesis* (Pettigrew & Tropp, 2006). The contact hypothesis suggests that interactions between majority and minority groups may promote dignity-based attitudes of majority groups towards minority groups at least with respect to attitudes of dignity of risk. These findings also support that women have attitudes more consistent with disability-rights perspectives than men (Bottoms et al., 2003; Krajewski & Flaherty, 2000), although they may also have more protective attitudes. These findings are consistent with findings related to gender and attitudes toward other minority groups and may be partially understood through *gender role socialization* theory which posits that women are more accepting of individuals who deviate from traditional social roles (Kerns & Fine, 1994). Lastly, particular groups of professionals more directly associated with people with intellectual disability (here, ID researchers) have, in some instances, more disability-rights based attitudes than IRB members (Antonak & Harth, 1994; Henry et al., 1996b). This finding uncovers part of what may account for tensions in how to engage adults with intellectual disability in research as ID researchers who favor dignity of risk and choice present their research for ethical review to IRB members who favor restrictions. We did not uncover attitude differences related to age and level of education; perhaps because the sample was largely middle-aged and over 80% of respondents had completed doctoral level education.

Third, the relationship of PRAS and CLAS attitude domains provides information about how general attitudes are related to specific attitudes and how these attitudes toward the research participation of adults with intellectual disability reflect principles of the Disability Rights Movement. First, it is important to note that general attitudes partially, but not completely, explain specific attitudes. Second, it appears that gatekeepers who perceive the general right of

adults with intellectual disability to self-determination also endorse their specific rights to have opportunities to participate in and make decisions about research. They also believe there is less need for others to help these adults with this decision and favor less protection of these adults in the research setting. Gatekeepers who perceive greater similarity and shared humanity between people with and without intellectual disability endorse opportunities for adults with intellectual disability to make decisions about and take part in research. These individuals also see less need for helping those with intellectual disability make choices about research. Conversely, gatekeepers who support the protection of adults with intellectual disability in general perceived a greater need for adults with intellectual disability to receive support specifically in making decisions about research participation and want to see them more protected therein. These relationships suggest that principles of the Disability Rights Movement (e.g., inclusion, choice and dignity of risk; Charlton, 1998; Dybwad & Bersani, 1996; Rioux, 1997) inform both how scientific gatekeepers frame the inclusion of adults with intellectual disability in research and how global and specific attitudes among scientific gatekeepers shape the scientific record.

#### *Implications for Research and Practice*

The findings of this research suggest important initial steps for future study and practice. Knowing the structure of attitudes toward research participation better guides our framework surrounding deliberations on the inclusion of this group in research. Second, the availability of the PRAS allows us to study the effectiveness of interventions targeted at promoting attitudes that promote the research participation of adults with intellectual disability. Interventions of this nature may be universal or with targeted groups who espouse more restrictive attitudes. These interventions can promote practices of appropriate inclusion in research for adults with intellectual disability, so that ensuing knowledge is relevant to them and scientific literature more

complete. Relatedly, researchers can continue to examine the relationship between behavior and attitudes (Zsombok et al., 1999), particularly as scientific gatekeepers consider the inclusion of adults with intellectual disability. Furthermore, we should investigate whether the three-factor solution of conceptual underpinnings of attitudes toward the research participation of adults with intellectual disability for scientific gatekeepers holds among other relevant groups (e.g., people with intellectual disability, family members, service providers, and guardians). Doing so will help further our understanding of these attitudes among the array of individuals who affect, and have an interest in the research participation of adults with intellectual disability. Lastly, further research is needed to better capture individual and other differences that account for variation in attitudes; those studied herein accounted for some of the differences; much remains to explain.

#### *Strengths and Limitations*

Among the strengths of the current study are that we: (1) assumed a conceptually driven approach to developing attitude items that we subjected to empirical assessment related to a specific domain and (2) measured these attitudes with a sample of individuals who have experience conducting and reviewing research involving adults with intellectual disability. This latter approach significantly strengthens the external validity of the research, although it is not clear how representative our participants are of the scientific community. Limitations should be noted including whether these attitude domains reflect other group's attitudes (i.e., adults with intellectual disability, caregivers, etc.) and the need to further explore the reliability and validity of the PRAS. One concern in the direct assessment of attitudes is the potential awareness of the individual that their attitudes' are being measured (Antonak & Livneh, 2000), which may contribute to a tendency to respond in a way that the individual perceives as more socially acceptable than is reflective of their true beliefs. We collected a measure of social desirability

responding and found no relationship between attitudes and social desirability responding. Furthermore, respondents participated in the research remotely via the Internet, thereby lessening any impact of social influence on attitude endorsements (Dillman, 2000). A second limitation is that the PRAS is a measure of attitudes toward a diverse group of individuals. In its current form, the PRAS does not capture attitudes that may exist towards adults with different levels of intellectual disability (i.e., mild, moderate and severe); characteristics of the referent group that have previously been found to relate to attitudes (Antonak et al., 1995; Henry et al., 1996a). Future studies could beneficially examine the effect of varying levels of intellectual disability on attitudes toward research participation. Lastly, the *Beneficence* scale may be the most conceptually complex, but least well-captured, attitude domain; as suggested by the relatively low alpha (0.70); continued development of this domain is warranted.

### Conclusion

Attitudes can help create opportunities for and barriers to full participation for individuals with intellectual disability (Antonak & Livneh, 2000). In the research context, attitudes may shape the content and nature of scientific literature that informs what we know about the lives and perspectives of individuals with disabilities. Here, attitudes that promote opportunities to participate in research and make decisions about research participation and the provision of empowering supports to adults with intellectual disability, may help generate scientific knowledge grounded in the lives of adults and increasingly informed of their strengths.

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Table 1. The *Participation in Research Attitude Scale* - Item Means, Standard Deviations and Factor Loadings.

Item	Mean (SD)	1	2	3
<b>1. Opportunity and Choice</b>				
14. People with intellectual disabilities should be given the opportunity to contribute to science by participating in research like everybody else.	5.39 (0.83)	0.78	-0.24	-0.15
32. It is important that more people with intellectual disabilities participate in research.	5.30 (0.91)	0.72	-0.11	0.03
29. People with intellectual disabilities want the choice to participate in research.	5.28 (0.82)	0.71	-0.21	-0.03
31. People with intellectual disabilities are qualified to give their perspective on issues that concern them.	5.49 (0.80)	0.62	-0.15	-0.03
42. People with intellectual disabilities want the opportunity to participate in research as much as anybody else.	4.94 (1.06)	0.61	-0.23	-0.13
19. People with intellectual disabilities have important perspectives on their lives that researchers can investigate	5.63 (.82)	.60	-.08	.21
15. If people with intellectual disabilities are not involved in research as participants, scientific knowledge will suffer.	5.02 (1.18)	0.59	-0.02	-0.03
43. People with intellectual disabilities should be provided with information about research that is understandable.	5.93 (0.31)	0.57	0.03	0.24
10. People with intellectual disabilities do not need to be involved in research on non-disability issues. *	5.23 (1.00)	-0.57	0.14	0.36
37. Researchers should treat people with intellectual disabilities as individuals capable of self-determination.	4.90 (1.25)	0.53	-0.43	0.01
33. People with intellectual disabilities' decision about whether or not to participate in research should be respected.	5.74 (0.56)	0.51	-0.19	0.25
45. People with intellectual disabilities should not participate in research. *	5.85 (0.62)	-0.49	0.05	0.24

Item	Mean (SD)	1	2	3
34. People with intellectual disabilities should not be allowed to make up their own mind about participating in research. *	5.30 (1.10)	-0.45	0.36	0.18
20. The opinion of a person with intellectual disabilities should be given more weight than those of family members and professionals in decisions about their participation in research.	4.62 (1.11)	0.44	-0.36	0.10
<b>2. Help in Decision-Making</b>				
25. People with intellectual disabilities need help from others to decide if they want to participate in research.	3.82 (1.15)	-0.03	0.77	0.22
4. People with intellectual disabilities cannot make decisions about participation in research without assistance from others.	2.62 (1.41)	-0.21	0.70	0.14
22. People with intellectual disabilities need someone without intellectual disabilities who care about them to decide whether they should participate in research.	3.13 (1.37)	-0.09	0.70	0.25
5. People with intellectual disabilities can provide consent to participate in research as well as anybody else. *	3.71 (1.41)	0.19	-0.65	-0.10
7. People with intellectual disabilities can be trusted to make up their own minds about participating in research. *	3.02 (1.23)	0.30	-0.60	0.10
12. People with intellectual disabilities cannot make a free choice about whether to participate in research.	2.12 (1.13)	-0.39	0.58	0.10
3. Family members and professionals should make decisions about the research participation for people with intellectual disabilities.	2.38 (1.26)	-0.19	0.55	0.22
9. A third party witness should always be present when people with intellectual disabilities provide consent to participate in research.	3.92 (1.53)	0.03	0.49	0.34
<b>3. Beneficence</b>				
1. People with intellectual disabilities should not be invited to participate in potentially harmful research.	2.89 (1.52)	-0.31	0.02	0.64

<b>Item</b>	<b>Mean (SD)</b>	<b>1</b>	<b>2</b>	<b>3</b>
46. People with intellectual disabilities should only be invited to participate in minimal risk research.	2.19 (1.26)	-0.42	0.00	0.62
18. People with intellectual disabilities should only participate in research when the personal benefits outweigh the potential harm.	3.71 (1.58)	-0.05	0.11	0.61
17. If people with intellectual disabilities are involved in research it is more important to address issues of coercion than it is with others.	4.92 (1.23)	0.16	0.17	0.58
16. People with intellectual disabilities should be given greater protection in research than others in similar situations.	4.89 (1.23)	0.20	0.31	0.51
11. People with intellectual disabilities should only be allowed to participate in research when their well-being can be guaranteed.	4.10 (1.58)	0.05	0.22	0.51
13. People with intellectual disabilities should always have more time than everybody else to think about whether they want to participate in a research study.	3.68 (1.24)	0.07	0.10	0.48

*Notes:* “1” indicated *Opportunity and Choice*, “2” indicates *Help in Decision-Making.*, and “3” indicates *Beneficence* attitude domains; “\*” indicates items reverse-scored to reflect their scale loadings; only items retained following the factor analysis are presented herein; numbers before items indicate order of item as originally administered.

Table 2. PRAS, CLAS and BIDR Intercorrelations, Means, Standard Deviations, and Internal Consistency.

	1	2	3	4	5	6	7	8	Mean	SD	$\alpha$
<b>1. Opportunity and Choice</b>	-								5.33	0.54	0.86
<b>2. Help in Decision-Making</b>	<b>-.53*</b>	-							3.09	0.91	0.84
<b>3. Beneficence</b>	<b>-0.24*</b>	<b>0.42*</b>	-						3.76	0.83	0.70
<b>4. Empowerment</b>	<b>0.49*</b>	<b>-0.47*</b>	<b>-0.27*</b>	-					4.67	0.78	0.69
<b>5. Exclusion</b>	<b>-0.36*</b>	<b>0.30*</b>	0.12	<b>-0.41*</b>	-				1.40	0.60	0.66
<b>6. Sheltering</b>	<b>-0.35*</b>	<b>0.51*</b>	<b>0.36*</b>	<b>-0.46*</b>	<b>0.33*</b>	-			2.84	0.98	0.72
<b>7. Similarity</b>	<b>0.58*</b>	<b>-0.40*</b>	-0.12	<b>0.46*</b>	<b>-0.50*</b>	<b>-0.36*</b>	-		5.72	0.43	0.75
<b>8. Impression Management</b>	-0.06	0.02	0.10	-0.12	-0.04	-0.02	-0.09	-	4.67	1.15	0.69

Notes: Correlations that are bolded and marked with an asterisk are statistically significant ( $p < 0.05$ ); PRAS stands for *Participation in Research Attitudes Scale*; CLAS stands for *Community Living Attitude Scale*; and BIDR stands for *Balanced Inventory of Desirable Responding*.

Table 3. Means and Standard Deviations for Significant Individual Predictors of PRAS Attitudes.

	<i>Number</i>	<i>Opportunity &amp; Choice</i>	<i>Help with Decision-Making</i>	<i>Beneficence</i>
<b><i>Gender</i></b>				
<b>Males</b>	118	5.24 (0.60)	3.22 (0.86)	3.63 (0.80)
<b>Females</b>	139	5.41 (0.49)	2.98 (0.93)	3.86 (0.84)
<b><i>Role</i></b>				
<b>IRB Members</b>	116	5.20 (0.59)	3.31 (0.82)	
<b>ID Researchers</b>	114	5.42 (0.51)	2.94 (0.92)	
<b>IRB-IDRs</b>	30	5.49 (0.40)	2.86 (0.93)	
<b><i>Relationship to people with disabilities</i></b>				
<b>None</b>	31		3.40 (1.01)	
<b>Casual</b>	9		3.81 (0.51)	
<b>Close</b>	34		3.20 (1.12)	
<b>Intimate</b>	186		2.99 (0.90)	

*Note:* Frequencies are based on the overall sample and may not reflect the number of individuals for each analysis due to missing data.

Table 4. General Attitudes (CLAS) Predictors of Specific Attitudes (PRAS).

	<i>Opportunity &amp; Choice</i>	<i>Help with Decision-Making</i>	<i>Beneficence</i>
<b><i>Empowerment</i></b>			
Beta	0.24	-0.23	-0.16
$\beta$	0.17	-0.27	-0.17
SE	0.04	0.07	0.08
t value	3.89 *	-3.59 *	-2.12 *
R <sup>2</sup>	0.04	0.04	0.02
<b><i>Exclusion</i></b>			
Beta	-0.04	0.01	-0.01
$\beta$	-0.03	0.02	-0.02
SE	0.06	0.10	0.10
t value	-0.61	0.21	-0.16
R <sup>2</sup>	0.00	0.00	0.00
<b><i>Sheltering</i></b>			
Beta	-0.08	0.35	0.31
$\beta$	-0.05	0.32	0.26
SE	0.03	0.06	0.06
t value	-1.43	5.76 *	4.44 *
R <sup>2</sup>	0.01	0.09	0.07
<b><i>Similarity</i></b>			
Beta	0.43	-0.16	0.06
$\beta$	0.54	-0.33	0.12
SE	0.08	0.13	0.14
t value	7.00 *	-2.44 *	0.87
R <sup>2</sup>	0.12	0.02	0.00

Note: “\*” indicates statistically significant predictors ( $p < 0.05$ ).