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How the Powerful Decide:

Access to Research Participation by those at the Margins

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### Abstract

How do those in power decide to include and exclude those at the margins from community life? We used simulated review of research vignettes to examine how researchers and members of institutional review boards make decisions concerning the research participation of adults with and without intellectual disabilities. Results indicate that decision-makers are influenced by the disability status of the sample, characteristics of the research in which they are engaged, and their attitudes toward the research participation of adults with intellectual disabilities as well as their own relationship to the research process. For example, decision-makers may create situations that limit the self-determination of adults with intellectual disabilities and adults without disabilities within the research context, particularly when the research poses some risk of harm to participants. Implications for theory, action and research are explored.

Key words: Community participation, empowerment, marginalization, human research ethics, vulnerable populations

## How the Powerful Decide:

### Access to Research Participation by those at the Margins

How do those in positions of power decide to include or exclude those at the margins of society? To understand the context in which members of marginalized groups struggle to participate in society, it is crucial to identify how those in power make decisions concerning their community participation or exclusion. However, community psychology studies of power and empowerment tend to focus on marginalized individuals and have rarely considered the perspectives of those in power, or how they render participation-related decisions (for exceptions see Bond, 1999; Foster-Fishman & Keys, 1997; Gruber & Trickett, 1987; Messinger, 2006). For decades, individuals with intellectual disabilities have fought to live, work and play in their communities; the influence of those with the power to promote or limit their participation in these settings has affected these pursuits (Dybwad & Bersani, 1996; Miller & Keys, 1996). Considering inclusion in research participation provides an opportunity to examine issues of power in a setting where they may be more transparent (Nelson & Prilleltensky, 2005). To explore how those in power influence access to community participation, this research explores the decision-making of Institutional Review Board (IRB) members and researchers who study people with intellectual disabilities in simulated reviews of research vignettes. Put a bit differently, the psychological empowerment of those at the margins is likely at least in part a function of organizational power. In particular, of interest here is how do those in power in organizations that affect people at the margins exercise their power to make decisions?

Current and former sociopolitical contexts influence how we conduct research (Shivas, 2004; Snow et al., 2000; Trickett, 1998): the way marginalized groups are perceived and treated by society has affected how they are engaged in research. When individuals with intellectual

disabilities had little social value, instances of abusive practices toward them as research subjects emerged (e.g., hepatitis studies at Willowbrook) (Freedman, 2001). Violations of the ethical treatment of research participants created government regulation and national debate about how to best protect them from exploitation in research (Beh, 2002; Singer, 1984, 2004). These public conversations have been particularly divisive and have serious ramifications for groups vulnerable to exploitation by researchers (Dalton & McVilly, 2004; Herr, O'Sullivan, & Dinerstien, 1999). To illustrate, perceptions that adults with intellectual disabilities are largely incompetent and in need of protection may lead to unnecessarily restrictive and/or unjust conditions (e.g., those that limit their self-determination) under which these individuals may participate in research (DeMarco, 2002; Ellis, 1992; Fisher, 2003; Freedman, 2001; Kim et al., 2004; Lindsey, 1996; Morris, 1993); alternatively, they may protect individuals vulnerable to exploitation, individuals similar to those who have been abused by scientists in the past. Such dynamics may reflect larger frameworks that restrict participation of disenfranchised groups in community life and/or that protect those vulnerable to exploitation. However, little is known about how those in positions of influence exercise their power. To understand how empowered organizations (e.g., those with influence) make decisions, it is important to understand how those individuals in power (i.e. causal agents) weigh the information before them as they make choices (cf. Zimmerman, 2000). To develop a societal awareness of how causal agents make decisions about research participation, a critical interpersonal aspect of psychological empowerment, research about the factors that may influence these causal agents' choices is needed. The current research seeks to address these needs in the empirical literature on organizational power and psychological empowerment by clearly investigating factors that may shape access to participation in research for those at the margins.

*Access to Research Participation*

Access to participation in research is a dynamic arena in which to study those who influence the community inclusion of marginalized groups. Research participation entails considerable scrutiny with respect to who may participate and under what conditions; and research participation is formalized in federal law and locally reviewed before the research can proceed (Singer & Levine, 2003). As such, there are more explicit processes for considering the participation of individuals from disenfranchised groups (Nelson & Prilleltensky, 2005). To move from exploitation and exclusion to access of marginalized groups in the research setting, decision-makers have to choose to include them in research. In choosing to exclude adults with intellectual disabilities, decision-makers are both denying this group the opportunity to contribute to scientific advances but also rendering these adults ill-positioned to benefit from ensuing knowledge gains. Since the exercise of power may become more explicit here than it is in other settings, it may be possible to ascertain some of the factors that can influence the decisions of those in authority and thus better understand the social context of research. Such understanding is needed for individuals to become more socially aware and thereby empowered in that setting (Zimmerman, 2000). For example, in the research context, decision-makers' perceptions of whether participants are able to provide competent consent, of the amount of risk posed to participants and of related needs for protections may be influential in shaping their decision concerning group member's access to research participation (Fisher, Freedman, 2001; 2003; Lindsey, 1996). In perhaps a less explicit way these considerations are relevant for many forms of community participation in other domains of life as well.

In research, there may be noteworthy differences in these decision-makers' determinations predicated on characteristics of the study under consideration and on

characteristics of the individual making the determination. In the current study, in keeping with an ecological perspective (Trickett, Kelly & Vincent, 1985), we consider both environment and person. Specifically, we examine two aspects of research studies or environment factors (the sample and the harm associated with participating) and two characteristics of decision-makers or individual factors (their role in the research process and their attitudes toward the research participation of adults with intellectual disabilities).

*Study Characteristics and Access to Full Inclusion*

*Adults with Intellectual Disabilities in Research.* Decision-makers may alter their determinations of whether (and how) individuals may engage in this aspect of community life for research that includes adults with intellectual disabilities<sup>1</sup>, a marginalized group. In part, these decisions may be related to the specific challenges adults with intellectual disabilities face as research participants related to their ability to make informed, voluntary choices, hallmarks of human subjects' protections. These challenges originate from both coercive social contexts and disability-related comprehension difficulties.

First, some adults with intellectual disabilities are located in social contexts that compromise their ability to make *voluntary* decisions (Ellis, 1992; O'Neill, 1989). Adults with intellectual disabilities sometimes have little experience making decisions, are ill-equipped with good decision-making skills, and may not be motivated to make decisions for themselves (Ellis, 1992; Freedman, 2001; Lindsey, 1996; Silvers, 2004). Moreover, social isolation may motivate them to participate in research as a means to gain acceptance or avoid disappointing or angering caregivers (Atkinson, 1988; Arboleda-Florez & Weisstub, 1997; Dybwad & Bersani, 1996; Goffman, 1963; Heller et al., 1996; Herr et al., 1999). There is also concern that adults with

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<sup>1</sup> An intellectual disability is a form of disability that develops before the age of 18 and is characterized by significant limitations in intellectual functioning and adaptive skills: an individual's functioning and skills may be promoted or limited by environmental characteristics (American Association on Mental Retardation, 2002).

intellectual disabilities demonstrate a range of abilities, from substantial to limited, for understanding information (Arscott et al., 1998; Heller et al., 1996; Morris et al., 1993). Without fully understanding the research, adults with intellectual disabilities may not be positioned to make an *informed* decision about participation. When those in power, such as researchers and IRB members, render judgment about this groups' ability to make an informed, voluntary decision, their conclusions may be driven more by nebulous criteria (including inflated concerns) that lack an empirical basis rather than fact, thereby potentially needlessly restricting their self-determination (Becker et al., 2004; Clegg, 2000; Dye et al., 2004; Ellis, 1992; Fisher, 2003; Lindsey, 1994; 1996). Moreover, these decisions may overlook how well-constructed environments can mitigate these concerns by facilitating comprehension and minimizing coercion (Clegg, 2000; Fisher, 2003). Until now, no study has examined whether and how decision-makers are influenced by the proposed inclusion of adults with intellectual disabilities in a research study.

*Harm.* Decision-makers' judgments about access to participation in research may also be influenced by the type and amount of possible harm posed to participants. The potential for social science research participants to incur harm emanates from research that may stigmatize, psychologically traumatize or expose the participating individual to legal consequences. As the potential for harm rises, investigators and regulators are advised to implement parallel increases in protections to mitigate the harm. Substantial tension persists regarding under what circumstances and in what form such safeguards should be implemented (Becker et al., 2004; Dalton & McVilly, 2004; Ellis, 1992; Freedman, 2001; Hammel, 2003; Haywood, 1977; Justo, 2004; Kellett & Nind, 2001; Kim et al., 2001; Muncie et al., 1997; NIH, 1999; Sachs et al., 1994; Warren et al., 1986). Harm may be an important environmental consideration in understanding

marginalized groups' access to community participation. How decision-makers assess potential harms in social science research remains unstudied prior to the current investigation.

*Decision-Maker Characteristics*

*Role in the Research Process.* There are two groups of individuals that carry significant influence over others' access to research participation: those who conduct the research and responsibly advance scientific knowledge and those who consider its ethical merits and ensure participants are protected. Given these interrelated, yet somewhat divergent, professional roles and sociopolitical contexts surrounding each, there has been discussion that these groups may have different perspectives on how to exercise their power over others' access to research participation. To illustrate, there is a relative lack of understanding of the type, form and implications of harm posed by social science research (Labott & Johnson, 2004; Oakes, 2002; Singer, 2004). It thereby becomes difficult to achieve a balanced appraisal that avoids trivializing real harms on the one hand and overstating perceptions of minor harms on the other (Evans et al., 2002; Fendrich, 2004; Oakes, 2002). It is here that we may see a divide between IRB members who seek to protect participants and IR researchers who want to conduct the studies. For example, some researchers feel that IRB members overstate risks in social science research and insist upon protections that may threaten their ability to conduct research and/or may be insensitive to the context of a particular study that lessens potential harm (Becker et al., 2004; Oakes, 2002). While some previous and current IRB members agree with this perspective, others emphasize the need for independent review and the empirical assessment of risk (Beh, 2002; Fendrich, 2004; IRB Advisor, 2006; Labott & Johnson, 2004). Although public discourse suggests that IRB members may render decisions about research participation that tend to place greater limitations on individuals' self-determination than researchers, no scientific data are yet

available to support or counter this claim. Moreover, the matter of who brings a more participatory perspective to the scientific enterprise, IRB member or ID researcher, has not been empirically examined.

*Attitudes.* Lastly, attitudes of those who control others' access to research participation towards marginalized groups may also influence their decisions. Attitudes inform both the conceptualization of a framework that separates right from wrong as well as how individuals apply, or resist applying, agreed upon principles (Ellis, 1992; Smith, 2000). As such, perceptions of groups may matter. For example, people who believe that adults with intellectual disabilities should be accorded the opportunity to participate in research may be more willing to promote their self-determination in research. To the authors' knowledge, to date, no investigators have accounted for differences in the attitudes of those in power when examining access to research. Yet these attitudes of those in power are posited to be of great importance in affecting opportunities for participation in community life for people with disabilities (Bond & Keys, 1993; Henry, Keys, Balcazar & Jopp, 1996; White, 2005); a socioecological orientation to disability emphasizes the ways environments, inclusive of societal attitudes, promote or limit the community integration of people with disabilities (Pledger, 2003; Tate & Pledger, 2003).

#### *Purpose*

To date there has been little research, especially from an empowerment or an ecological perspective, to inform our understanding of how those in positions of power make decisions about marginalized individuals' to community life. Within the research context, there is a strong tension between respecting self-determination and providing necessary, but not disenfranchising, safeguards for those who may have limited competence and opportunity for self-direction. Concerns have also been raised that IRB members may have a tendency to place greater

limitations on participants' autonomy than researchers feel is necessary (IRB Advisor, 2006; Oakes, 2002). On the other hand, if researchers had consistently followed ethical standards on their own in the past, the IRB process may not be necessary. This inclination for protection by IRB members may be heightened when the research participants have an intellectual disability and/or when the study presents relatively more harm to participants.

This research examined contextual and individual factors that may influence how those with decision-making power determine others' access to research participation. Specifically, using simulated ethical review, we examined: *How are different decision-makers influenced by the disability status of the sample and the amount of harm posed to research participants in making determinations of access to research participation with and without controlling for attitudes toward the research participation of adults with intellectual disabilities?*

Herein, access to research participation was represented in decision-makers' determinations of research participants' ability to provide competent consent, the degree of risk posed in participation and necessary protections to secure participants' well-being. We anticipated that the inclusion of adults with intellectual disabilities, especially in research that involves increasing harm, would be related to determinations of more restricted access, particularly among IRB members (as both main effects and interactions). This research will help shed light on how those in power make choices about the participation of a marginalized group in an important arena of community life. Thereby, this study seeks both to improve our understanding of the factors that shape the use of organization power and to provide information relevant to the interpersonal dimension of psychological empowerment for those concerned about research for people at the margins (Zimmerman, 2000)

## Methods

### *Antecedent Activities*

In order to become familiar with the phenomenon of interest, the authors engaged in several years of preparation for this study. The first author conducted an evaluation of a major university's human subjects' protection program and served on one of the university's IRBs for over 3 years. The second author has more than two decades of experience in working with university IRBs both as a researcher and a faculty advisor of studies concerning persons with intellectual disabilities and others at the margins. He has served on four college and university committees concerning human subjects' protection and has given presentations on human subjects protection issues. This experience aided the authors in identifying critical issues and methods to consider in planning this initial study of how decision makers make choices about research participation in studies of those with intellectual disabilities.

### *Design*

A three-factor mixed experimental design was used to assess the effects of Disability (No Disability, Intellectual Disability) x Harm (Low, High) x Role (Institutional Review Board [IRB] Member, Intellectual Disability [ID] Researcher, IRB Member-ID Researcher) on perceptions of likelihood of capacity to consent, amount of risk and level of protections determined necessary. Disability and Harm were within-subject factors experimentally manipulated in randomly ordered research vignettes, whereas Role was a between-subjects factor.

### *Participants*

#### *Selection*

We used four strategies to identify participants. First, we identified researchers who had recently published social science research with adults with intellectual disabilities in the U.S.A. We located these researchers by reviewing 11 journals that published manuscripts with a

substantial or exclusive focus on intellectual disability research for a 5-year period. We also included staff and affiliated faculty with research positions at a University Centers for Excellence in Developmental Disabilities. In all, we identified 532 researchers from 151 universities, excluding those from the university where we conducted the research. Once researchers were known, we identified IRB members from these researchers' universities. Through a Freedom of Information Act request, we received information about 283 of these IRB chairpersons. We were unable to locate current, accurate contact information for 144 researchers and 43 IRB members. Once universities were selected, all researchers doing studies with people with intellectual disabilities and IRB members from these institutions were eligible to participate.

### *Recruitment*

We solicited participants through personalized contacts designed to achieve a high response rate (Dillman, 2000). During a six-week period participants were contacted six times through postal and electronic communications. Researchers and IRB members were asked to forward invitations to participate to colleagues at their university/college. These recruitment efforts yielded a total of 260 participants. Response rates for direct recruitment were 35% for IRB members and 26% for ID researchers.

### *Characteristics*

Participants included 116 IRB members, 114 researchers in the field of intellectual disabilities (*ID researchers*), and 30 individuals who were both IRB members and ID researchers (*IRB-IDR*). Slightly more than half of the sample of 260 was female (54%) and almost two-thirds (66%) of the sample was between the ages of 40 and 59 (37%: 50-59; 29%: 40-49). Respondents were overwhelmingly Caucasian (91%). Almost three-quarters of participants reported holding a Ph.D. (73%), 11% reported holding a MD and 10% a Master's Degree. About one-half of

participants were trained in the Social Sciences (52%). Another 35% of participants were trained in the Health Sciences/Professions. One-half of participants were tenure-track Professors (50%), 16% were non tenure-track faculty and 12% were Research Scientists.

### *Procedures and Measures*

As approved by relevant IRBs, we used an internet-based survey to gather data to address the research questions. Respondents logged into a password protected website and, as part of participation in a larger study, completed the following three instruments:

#### *(1) Research Vignettes*

Research vignettes presented decision-makers with four fictitious research studies that either did or did not involve adults with intellectual disabilities and either presented little potential harm or more significant harm to participants. This created a 2 x 2 design of the within-subject factors. Each decision-maker completed one vignette, in random order, from each of the following categories: (1) No Disability-Low Harm; (2) No Disability-High Harm; (3) Intellectual Disability-Low Harm; and (4) Intellectual Disability-High Harm. Vignettes included information from fictitious consent forms that conveyed the study's purpose, procedures, sample, and harm posed to participants (see Figure 1 for an example). Each vignette was based on recently published research from social science journals with high visibility in community psychology, intellectual disabilities, and/or cross-disability research. This study builds on the history of using similar measures to ascertain likely behaviors in community and organizational power and empowerment research (cf. Bartunek & Keys, 1982; Zimmerman & Rappaport, 1988)

Decision-makers were asked to review each vignette either as an IRB member or as a researcher of intellectual disabilities providing ethical guidance to a more junior graduate student or colleague. Following each vignette was a series of questions that asked participants to

consider each of the following on a scale of 1-6 where higher scores indicated higher levels of the variable: the participants' likelihood of being able to provide competent consent, the degree-of-risk posed to participants, and level of necessary safeguards or protections.

*(2) Participation in Research Attitude Scale - Intellectual Disabilities*

The *Participation in Research Attitude Scale -Intellectual Disabilities (PRAS-ID)* measures the three factors (*Opportunity and Choice, Help with Decision-Making and Beneficence*) concerning attitudes toward the research participation of individuals with intellectual disabilities. The PRAS has 29 items and uses a six-point Likert-type scale where higher numbers indicated greater agreement with the item. The PRAS demonstrates good psychometric properties and construct validity (McDonald, 2006).

*(3) Individual Characteristics and Experiences*

To learn about their individual characteristics and experiences, participants completed items on their age, gender, race/ethnicity, level and field of education, and current occupation.

## Results

This study of organizational power and the empowerment of those involved with research explores how key decision-makers (i.e., members of IRBs and intellectual disabilities researchers) decide about the participation of adults with intellectual disabilities in research. Specifically, it examines how these different decision-makers are influenced by the disability status of the sample and the level of harm posed to participants in making decisions about capacity to consent, amount of risk and level of necessary protections with and without controlling for attitudes toward the research participation of adults with intellectual disabilities. To address these issues, we used a multivariate approach to mixed-factors, repeated measures analysis of variance (MANOVA) followed by using the same multivariate approach with

attitudes toward the research participation of adults with ID as covariates (MANCOVA). We evaluated multivariate and, as appropriate, univariate tests using Pillai's Trace at a Type I error rate of  $p < 0.05$  (Tabachnick & Fidell, 2001). The strength of effects were assessed with partial eta squared, and group differences were examined using 95% Confidence Intervals (CIs) and marginal means. In no case was the three-way interaction between Role, Disability and Harm significant.

#### *Capacity to Consent*

A MANOVA examining the effects of Role, Disability and Harm on perceptions of capacity to consent (likelihood) revealed significant main effects for each independent factor and significant two-way interactions between each of the three pairs of factors. The main effects of disability and harm, and their interaction, disappeared once attitudes were controlled for.

*Study Characteristics Main Effects.* *IRB Members* and *ID Researchers* paid most attention to Disability status in making judgments about capacity to consent,  $F(1, 234) = 334.07$ ,  $p < 0.05$ , partial eta squared 0.59. When the sample in the vignette did not have a disability, decision-makers judged their capacity to consent higher (Mean = 4.94) than when the sample included individuals with intellectual disabilities (Mean = 3.06). Also of note was the importance of Harm on *IRB Members* and *ID Researchers*' perceptions of capacity to consent,  $F(1, 234) = 104.23$ ,  $p < 0.05$ , partial eta squared 0.31. When research vignettes presented more harm to participants, these decision makers judged their capacity to consent lower (Mean = 3.57) than when the proposed study presented less harm to participants (Mean = 4.42). When controlling for attitudes toward the research participation of individuals with intellectual disabilities, the effect of both Disability,  $F(1, 220) = 0.80$ , ns and Harm,  $F(1, 220) = 1.49$ , ns on decision makers' perceptions of capacity to consent were eliminated.

*Decision-Maker Characteristics Main Effects.* The main effect of Role,  $F(2, 234) = 5.61$ ,  $p < 0.05$ , partial eta squared .05, had a relatively smaller yet clearly significant effect on *IRB Members* and *ID Researchers*' perceptions of capacity to consent: *ID Researchers* (Mean = 3.73) perceived significantly less likelihood of capacity to consent than *IRB-IDRs* (Mean = 4.25). This effect remained after controlling for decision-makers' attitudes toward the research participation of adults with intellectual disabilities,  $F(2, 220) = 7.61$ ,  $p < 0.05$ , partial eta squared .07.

*Study Characteristic Interactions.* Although accounting for a relatively smaller amount of the variance in perceptions of capacity to consent, the Disability x Harm interaction was clearly significant,  $F(1, 236) = 8.95$ ,  $p < 0.05$ , partial eta squared .04 (see Figure 2); all group means were significantly different from one another. While decision-makers perceived less capacity to consent for samples that include adults with disabilities than for those that do not, their perceptions of capacity to consent for samples with adults with intellectual disabilities are significantly lower for studies that present higher harm (Mean = 2.53) than for those that present less harm (Mean = 3.59). This interaction effect disappeared after controlling for attitudes toward the research participation of individuals with intellectual disabilities,  $F(1, 216) = 0.37$ , ns.

*Study and Decision-Maker Interactions.* We found a significant interaction between Disability x Role on perceptions of capacity to consent,  $F(2, 234) = 30.21$ ,  $p < 0.05$ , partial eta squared 0.21 (see Figure 3). *ID Researchers* (Mean = 4.31) perceived less capacity to consent for non-disabled samples of participants than *IRB Members* (Mean = 5.29) and *IRB-IDRs* (Means = 5.20), who were statistically equivalent. However, when individuals with intellectual disabilities were involved in the research, *ID Researchers* (Mean = 3.15) perceived more capacity to consent among participants than *IRB Members* (Mean = 2.73). *IRB-IDRs* did not differ from either group (Mean = 3.30). While all groups perceived less capacity to consent for samples with adults with

intellectual disabilities, *IRB members* demonstrated greater negative change in perceptions of capacity to consent from the No Disability to Disability conditions than *ID Researchers*. This Disability x Role effect remained after controlling for attitudes toward the research participation of adults with intellectual disabilities,  $F(2, 220) = 22.61, p < 0.05$ , partial eta squared .17.

Of further note was the significant interaction of Harm x Role,  $F(2, 236) = 4.25, p < 0.05$ , partial eta squared .04. While all groups perceived statistically equivalent levels of capacity to consent in the Low Harm condition (Means = 4.32, 4.27 and 4.67), *ID Researchers* (Mean = 3.21) perceived significantly less likelihood of capacity to consent than *IRB Members* (Mean = 3.68) and *IRB-IDRs* (Mean = 3.83) in the High Harm condition. This effect remained after controlling for attitudes toward the research participation of adults with intellectual disabilities,  $F(2, 220) = 3.05, p < 0.05$ , partial eta squared .03.

#### *Amount of Risk*

A MANOVA examining the effects of Role, Disability and Harm on perceptions of amount of risk revealed significant main effects for each within-subject factor (Disability and Harm) and significant two-way interactions between all factors. The main effects of Disability and Harm, and their interaction, disappeared after accounting for attitudes.

*Study Characteristics Main Effects.* Disability status of the participants had a significant effect,  $F(1, 241) = 53.21, p < 0.05$ , partial eta squared .18, on perceptions of amount of risk. Decision-makers' perceptions of the amount of risk posed by a study were higher when adults with intellectual disabilities were included (Mean = 3.31) than when they were not (Mean = 2.91). Harm made the largest contribution to perceptions of risk,  $F(1, 241) = 1178.97, p > 0.05$ , partial eta squared .83. Decision-makers' perceived research studies that presented Low Harm to participants as considerably lower in risk (Mean = 1.86) than research studies that presented

High Harm to participants (Mean = 4.36). The effect of both Disability,  $F(1, 224) = 1.53$ , ns, and Harm,  $F(1, 224) = 0.04$ , ns, disappeared when controlling for decision-makers' attitudes toward the research participation of adults with intellectual disabilities.

*Decision-Maker Characteristics Main Effects.* Role,  $F(2, 241) = 0.21$ , ns, was not significantly related to perceptions of risk (Means = 3.07, 3.10 and 3.16).

*Study Characteristic Interactions.* A significant interaction between Disability x Harm,  $F(1, 241) = 28.99$ ,  $p < 0.05$ , partial eta squared .11, on perceptions of amount of risk was found. There were no significant differences in decision makers' perceptions of risk by Disability status in Low Harm research studies (No Disability Mean = 1.81; Disability Mean = 1.92). However, decision-makers perceived High Harm research studies that include adults with intellectual disabilities to present more risk to participants (Mean = 4.70) than those without such individuals (Mean = 4.01). This effect disappeared when controlling for decision-makers' attitudes toward the research participation of adults with intellectual disabilities,  $F(1, 224) = 1.29$ , ns.

*Study and Decision-Maker Characteristics Interactions.* Results indicated a significant Disability x Role interaction,  $F(2, 241) = 6.41$ ,  $p < 0.05$ , partial eta squared .05. *IRB Members* (Mean = 3.39) and *ID Researchers* (Mean = 3.23) perceived more risk in the Disability condition than in the No Disability condition (Means 2.77 and 2.96 respectively), however *IRB-IDRs* perceived equal amounts of risk across disability conditions (Means = 3.32 and 3.00 respectively)<sup>2</sup>. This interaction effect remained after controlling for attitudes toward the research participation of adults with intellectual disabilities,  $F(1, 224) = 5.79$ ,  $p < 0.05$ , partial eta squared .05. Results also revealed a significant Harm x Role interaction,  $F(2, 241) = 3.21$ ,  $p < 0.05$ , partial eta squared .03, on perceptions of risk. However, there were no statistically

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<sup>2</sup> The lack of statistically significant difference for *IRB-IDRs* may be related to the small sample size of this group.

significant pairwise comparisons for the interaction and the effect disappeared after controlling for attitudes,  $F(1, 224) = 2.74$ , ns.

*Level of Protections*

A MANOVA examining the effects of Role, Disability and Harm on perceptions of level of protections revealed significant main effects for each independent factor (Disability, Harm and Role) and significant two-way interactions between Disability x Role and Harm x Role. The main effects of Disability and Harm disappeared after controlling for attitudes.

*Study Characteristics Main Effects.* The Disability status of the sample influenced decision-makers' perceptions of need for protections,  $F(1, 228) = 109.53$ ,  $p < 0.05$ , partial eta squared .32. When the research included adults with intellectual disabilities, decision-makers felt higher levels of protections were necessary (Mean = 3.48) than when they were not (Mean = 2.61). Level of Harm presented by the vignettes accounted for the largest amount of variance in decisions-makers' perceptions of need for protections,  $F(1, 228) = 596.70$ ,  $p < 0.05$ , partial eta squared .72. Decision-makers rated research studies that presented Low Harm to participants as in need of lower levels of protections (Mean = 1.92) than research studies that presented High Harm to participants (Mean = 4.18). The effect of both Disability,  $F(1, 211) = 0.02$ , ns, and Harm,  $F(1, 211) = 0.02$ , ns, disappeared when controlling for decision-makers' attitudes toward the research participation of adults with intellectual disabilities.

*Decision-Maker Characteristics Main Effects.* Role was also found to be significantly related to perceptions of level of protections,  $F(2, 228) = 3.07$ ,  $p < 0.05$ , partial eta squared .03. However, post hoc comparisons did not reveal significant group differences among decision-makers (Means = 2.94, 3.19 and 3.01). The effect remained when attitudes towards adults with intellectual disabilities were controlled for,  $F(2, 211) = 4.00$ ,  $p < 0.05$ , partial eta squared .02.

*Study Characteristic Interactions.* The interaction between Disability x Harm was not significantly related to perceptions of level of protections,  $F(1, 228) = 3.01$ , ns.

*Study and Decision-Maker Interactions.* Decision-makers' perceptions of levels of protections varied by Disability x Role,  $F(2, 228) = 18.58$ ,  $p < 0.05$ , partial eta squared .14. All groups saw a need for greater, and similar, levels of protections for research that involves adults with intellectual disabilities (Means = 3.56, 3.41, and 3.46). However, there was greater variation by Role in level of protections deemed necessary for research that does not specifically involve adults with disabilities. In the No Disability condition, *IRB Members* (Mean = 2.30) saw a need for lower levels of protections than *ID Researchers* (Mean = 3.00). Second, there was a significant Harm x Role interaction,  $F(2, 228) = 6.55$ ,  $p < 0.05$ , partial eta squared .05. All groups perceived a need for a relatively low level of protections for Low Harm protocols (Means 1.87, 1.88 and 2.00). However, *ID Researchers* (Mean = 4.51) endorsed a need of higher level of protection for High Harm research studies than *IRB Members* (Mean = 4.00). The effects of both interactions remained when controlling for attitudes toward the research participation of individuals with intellectual disabilities ( $F(2, 211) = 14.03$ ,  $p < 0.05$ , partial eta squared .12, and  $F(2, 211) = 5.81$ ,  $p < 0.05$ , partial eta squared .07, respectively).

### Discussion

In this research, we considered how those in positions of power consider contextual and individual factors to determine others' access to participation in community life. Through this study we seek to elucidate how organizations make decisions and to provide information so that others may know, at least in part, how decisions about research participation are made. Such knowledge provides important elements of the critical awareness necessary for the interactional aspect of psychological empowerment (cf. Zimmerman, 2000). Specifically, we examined how

decision-makers (IRB members, ID researchers and IRB members who conduct research with people with intellectual disabilities) respond to the disability status and harm level associated with a research study. We also studied whether and how their attitudes towards the research participation of adults with intellectual disabilities may have influenced their judgments about access to research participation. This research represents one of the few empirical investigations to examine how those in power render decisions about others' access to community life and is the first to do so in the research context. See Table 1 for an overview of these findings.

*Placing the Findings in Context*

*Study Characteristics Main Effects.* Findings that the inclusion of adults with intellectual disabilities in research decreased perceptions of capacity and increased perceptions of risk and needed protections were consistent with predictions (Ellis, 1992; Fisher, 2003; Freedman, 2001). The implications of these findings for adults with intellectual disabilities and their access to participation in research, and perhaps other aspects of community life, are less clear. On the one hand, these results are consistent with the perspective that increased caution should be exercised when engaging participants at risk for exploitation in the research context (Arscott, 1998; Berg, 1996; Ellis, 1992; Fisher, 2003; Freedman, 2001; Hammel, 2003; Lindsey, 1994; Morris et al., 1993; NIH, 1999). For example, reduced perceptions of capacity to consent are consistent with findings that adults with intellectual disabilities evidence varied, and sometimes lower, levels of understanding (Arscott et al., 1998; Morris et al., 1993). Alternatively, these findings may indicate that decision-makers create contexts that place adults with intellectual disabilities at risk of facing unwarranted discrimination resulting in exclusion or limited opportunity for self-direction (and further disenfranchisement) within the research context (Ellis, 1992; Fisher, 2003; Freedman, 2001; Hammel, 2003; Lindsey, 1994).

The findings that increasing harm decreased decision makers' perceptions of capacity to consent and increased perceptions of risk and level of protections were also predicted. These findings provide empirical evidence that the decision-makers appear likely to create different conditions of access to research according to how much harm is posed to participants and have generally accepted the principle to augment protections in parallel with increasing risks (Becker et al., 2004; Levin et al., 2004; Silverman et al., 2004). These findings suggest that decision-makers make determinations based on the individuals-in-context, as an ecological perspective suggests is appropriate (Clegg, 2000; Dye et al., 2004; Fendrich, 2004; Fisher, 2003; Kelly, 1968; Labott & Johnson, 2004; Oakes, 2002; Singer, 2004; Trickett, Kelly & Vincent, 1985).

*Decision-Maker Characteristics Main Effects.* Findings that the only overall Role-related difference was that ID researchers perceived less capacity to consent than IRB-IDRs was surprising. However, because the effect of Role is further illuminated by considering the differences among decision-makers as they examine different contextual factors, we prefer to expand our discussion of these effects. It is also important to note that Role was not experimentally manipulated and that there were demographic differences among the groups. As such, it is difficult to fully disentangle or infer causal relationships for effects involving Role.

*Study Characteristic Interactions.* Although specific predictions were not made, the findings that including intellectually disabled participants in higher harm research decreases perceptions of capacity to consent and increases the amount of risk perceived beyond simply their additive combinations are not surprising. These interactions suggest a "multiplicative risk" posed by including vulnerable individuals in high harm research (Becker et al., 2004; Dye et al., 2004; Freedman, 2001; Levine et al., 2004; NIH, 1999; Silverman et al., 2004) and emphasize the importance of the interaction of contextual factors in decision-makers' access determinations.

These findings highlight that, relative to others without intellectual disabilities, adults with intellectual disabilities may encounter more restricted access to settings that pose greater potential harm to them. However, it was surprising that this kind of interaction would not produce similar differences in desired levels of protections. Future research may shed light on this finding.

*Study and Decision-Maker Characteristics Interactions.* The finding that, in general, ID researchers changed their access determinations less than IRB members, whether or not research participants were disabled, was as expected and evidenced a strong effect size relative to other effects. We did not expect, however, that relative to IRB members, ID researchers would perceive less capacity to consent and a need for higher levels of protections for non-disabled samples. Nonetheless, these results suggest a process of “normative anchoring” by which ID researchers, through their regular contact with individuals with intellectual disabilities, may come to perceive greater similarities between individuals with and without intellectual disabilities (Ellis, 1992; Fisher, 2003; Lindsey, 1996). Specifically, their work with individuals with intellectual disabilities may lead them to give more consideration to the challenges every research participant faces and/or to the assets of adults with intellectual disabilities. These considerations may result in a “similarity effect” such that ID researchers see greater communality between people with and without intellectual disabilities. Relatedly, IRB members may be more influenced by a “vulnerability effect” that leads them to more strongly differentiate between adults with and without intellectual disabilities due to the increased vulnerability of the latter group. These findings raise potential questions related to their implications for access to research, and perhaps to other citizen roles, for adults with intellectual disabilities (Fisher, 2003; Freedman, 2001; Hammel, 2003). Making decisions with greater caution for engaging adults

with social and cognitive challenges in community life may be a reasonable response to increased vulnerability (Dresser, 1996; Evans et al., 2002; Fendrich, 2004; Kim et al., 2004; Oakes, 2002). However, these findings raise questions as to whether these responses reflect conditions of equal access or the continued discrimination, and reduced empowerment and access to community life, of adults with intellectual disabilities (Charlton, 1998; Fisher, 2003; Freedman, 2001; Lindsey, 1996). Future research may provide useful insight to these questions.

*Controlling for Decision-Makers' Attitudes.* Once decision-makers' attitudes toward the research participation of adults with intellectual disabilities were taken into account, the main effects and interactions of Disability and Harm to access determinations disappeared. These findings strongly support the practical relevance of attitudes and thus, the socioecological models of disability that highlight the importance of attitudes in defining the access afforded to people with disabilities in society. That is, subjective assessments of adults with intellectual disabilities may define some conditions for access to research (Atkinson, 1988; Ellis, 1992; Fisher, 2003; Freedman, 2001; Lindsey, 1996; White, 2005). Moreover, these findings suggest that promoting positive attitudes toward adults with intellectual disabilities may increase their full inclusion in community life and create socially just access to research for members of this group (Charlton, 1998; Nagi, 1991; Pledger, 2003; Rioux, 1997). That is, attitudes, as much as or more than impairments, may define access to community life. However, given that controlling for attitudes did not attenuate all effects, attitudes alone may only account for a portion of these determinations.

#### *Theoretical Implications*

This research provides one of the first empirically grounded forays into examining issues of marginalization through considering how those in power make decisions about community

inclusion. Empirical examination from this perspective is critical to moving forward our understanding of how key decision-makers affect those at the margins. Specifically, this research begins to build a framework of factors that influence decision-makers' differential access determinations. In general, those in positions of organizational power appear to make assessments of individuals-in-context (Dye et al., 2004; Freedman, 2001; Kelly, 1968; Kim et al., 2004). They modify their access determinations in response to both environmental factors such as study characteristics and individual characteristics such as their own position in the research process and beliefs.

First, as suggested by analyses of Disability and those that controlled for the effects of attitudes, decision-makers clearly consider disability status through the lens of their own attitudes as they determine the parameters of inclusion. These findings suggest that, in some cases, what underlies these responses to the inclusion of individuals with intellectual disabilities is beliefs about these individuals; thus findings provide support for the practical significance of the socioecological model of disability. The socioecological model of disability supports the view that both the attitudes of others, especially key decision makers, and ones' own limitations are important for determining community access for an individual with disabilities (Pledger, 2003; Tate & Pledger, 2003). Findings of this research suggest that beliefs related to individuals with intellectual disabilities, rather than their actual characteristics, may play an important, although not all determining, role in defining the terms of access to research participation opportunities as an important aspect of community inclusion. Importantly, promoting empowering attitudes toward marginalized individuals among those in power may enhance their access to community life (Foster-Fishman & Keys, 1997; McDonald & Keys, 2005). In short, an

important aspect of minimizing social marginalization may reside in helping those with more social power perceive the value of those at the margins.

Second, and somewhat surprisingly in light of previous theoretical postulations (Dresser, 1996; Evans et al., 2002; Fendrich, 2004; Oakes, 2002), it appears that ID researchers rather than IRB members are more likely to conservatively manage the engagement of nondisabled participants in research and of research participants in general in studies that pose greater amounts of harm. ID researchers appear more likely to treat non-disabled participants similar to adults with intellectual disabilities than IRB members. They perceive less capacity to consent and a need for higher levels of protections for non-disabled samples than IRB members. ID researchers reacted similarly to engaging general samples in higher harm studies. It is not clear what drives these different perspectives. ID researchers' more frequent exposure to individuals with intellectual disabilities may, in part, contribute to a more cautious stance in general and thus to these differences. Or, ID researchers may see the strengths of adults with intellectual disabilities and the weaknesses of the general population in understanding and rendering research participation decisions.

### *Practical Implications*

This research provides a preliminary framework to illuminate how contextual and individual factors shape decisions concerning access to participation in research, and potentially other aspects of community life. Disseminating this framework and helping decision-makers increase their awareness of how these factors influence their determination of others' access may work to make principles more explicit that were previously implicit. This awareness can increase the intentionality that drives the decisions of those in power and potentially mitigate previously unrecognized biases. It can make all concerned more critically aware of the factors influencing

participation decisions thereby heightening the interactional dimension of psychological empowerment (cf. Zimmerman, 2000). Guidelines of best practices for including adults with intellectual disabilities, and other vulnerable groups, can be developed that are sensitive to both the vulnerabilities of adults with intellectual disabilities and their desire for control over their lives. These guidelines may promote the respectful inclusion of adults with intellectual disabilities in research with necessary supports; thereby ensuring scientific knowledge concerning people with intellectual disabilities develops at a reasonable pace. Additionally, including adults with intellectual disabilities as research team and IRB members and/or advisors would provide expert guidance to assist other IRB members and researchers as these guidelines are considered within the context of a particular research study. These efforts could be coupled with educational and firsthand experiences for researchers and IRB members targeted to promote the respectful inclusion of adults with intellectual disabilities in social science research. Such activities may engender more positive attitudes toward adults with intellectual disabilities and contribute to a more informed treatment of them as research participants. The PRAS measure may be a useful tool in evaluating change relayed to these interventions. Similar efforts may inform how to include marginalized groups in other community settings such as education, employment and housing (cf. Miller & Keys, 1996).

#### *Future Research*

This research also highlights persistent knowledge gaps and suggests new frontiers to explore. This research provides a nascent framework for individual and contextual factors that affect the exercise of organizational power, especially with regard to decisions concerning access to research; yet it also, perhaps inevitably, leaves several gaps in our understanding of the inclusion of adults with intellectual disabilities. For example, this research indicates that the

disability status of the research participants is related to access determinations. Yet, we do not know whether these differences create conditions that unfairly discriminate against adults with intellectual disabilities, and limit their autonomy, or represent reasonable conditions given their cognitive and social vulnerabilities; further research should explore the diversity of perspectives on these issues. Similarly, future research that examines actual researcher practices and IRB deliberations and determinations with a particular sample of adults with intellectual disabilities (particularly with respect to the nature of proposed safeguards) might shed light on these persistent questions and highlight how access to other aspects of community life is similarly affected. Future research that surveys ID researchers regarding their research practices might inform the development of best practices guides specific to including adults with intellectual disabilities in research that are inclusive and yet sensitive to their cognitive and social vulnerabilities. These lines of investigation might also be undertaken to examine inclusion both in other aspects of community life and for individuals from other groups often excluded by mainstream society. Investigating IRB deliberations “in vivo” would also help illuminate how context influences access determinations and help assess the external validity of the current study. Moreover, we found that *individual* IRB members did not make more conservative access judgments. For example, it may be that when IRB members deliberate as a group, more conservative judgments are rendered than was the initial inclination of the individual members of the group; a group dynamic known as group polarization (Myers & Aronson, 1972; Williams & Toarmina, 1992). Since not all research is reviewed by a group, group polarization may differentially impact access to research participation and should be further explored.

The research vignettes used in the current research, which yielded significant and illuminating findings, could also be used in future clarifying research. For example, the current

research did not differentiate the level of intellectual disability (mild, moderate, or severe) in the sample included in the research; such qualifiers may further influence decision-makers' determinations. Moreover, this research does not identify how respondents may have been influenced in making their determinations in the absence of these descriptors. Such descriptors may further affect decision-makers' determinations and it would be useful to explore their impact in future research. Moreover, a minority of people with intellectual disabilities have court-appointed guardians. Having such a guardian may add another layer of complexity, protection and constraint to the process of making decisions regarding their research participation. It is a topic worthy of consideration in future studies. Likewise, providing fuller detail in the research vignette may better mirror the scope of information available in actual IRB reviews. It will also be crucial to include other stakeholders (e.g., adults with intellectual disabilities, care providers, and a fuller variety of researchers) in future research to explore additional perspectives on access to research.

### *Strengths and Limitations*

We believe this study has many assets; several of which strengthen the external validity of the findings. First, we developed and piloted research vignettes and other materials based on recently published social science research bolstering the plausibility of the research studies. We also piloted these research materials. Second, we experimentally manipulated two variables, surveyed occupants of three key decision-making roles, and captured auxiliary variables (viz., attitudes) that in part accounted for, altered, or better explained the outcome factors of interest. Third, we obtained a relatively large sample size of key decision-makers with an adequate response rate that represented a wide variety of geographic locations and universities.

In addition to these strengths, the study also presents a number of shortcomings and raises some issues that should be considered in interpreting results. First, we did not manipulate one of the experimental variables: Role. As such, it may be inappropriate to attribute differences related to the Role variable solely to role. Second, we presented respondents with research vignettes that contained less information about the study than they would normally have access to which may limit the external validity of the findings. However, access to fuller information about the research does not necessarily preclude the emergence of bias in the review process. Another limitation is that, unlike many instances, participants did not have an opportunity to consult colleagues in their deliberations. While perhaps reducing external validity for decisions made in groups, findings may better reflect individuals' initial opinions. Moreover, we did not recruit researchers from the wider practice of research perhaps thereby constraining the applicability of our findings to the research community that addresses issues of intellectual disabilities. However, we did capture the perspectives of those most often engaged in the making decisions about the participation of people with intellectual disabilities.

### Conclusion

In order to further the aims of social justice and promote the full community inclusion of individuals from marginalized groups, it is critical to investigate how those in positions to stifle or promote these objectives make their decisions. In this study, we studied community inclusion through considering participation in research and examined how individual and contextual factors influence how decision-makers make determinations of access to research participation. Findings suggest that decision makers' beliefs about marginalized groups (i.e., attitudes) may contribute to differential conditions of access to community life. Further research will help

illuminate how we can promote the community inclusion of marginalized groups through working with those in positions of power and influence over their access.

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Table 1. Summary of Findings.

<i>Capacity to Consent</i>				<i>Amount of Risk</i>				<i>Level of Protections</i>				
MANOVA		MANCOVA		MANOVA		MANCOVA		MANOVA		MANCOVA		
Effect	Partial eta squared	Effect Controlling for Attitudes	Partial eta squared	Effect	Partial eta squared	Effect Controlling for Attitudes	Partial eta squared	Effect	Partial eta squared	Effect Controlling for Attitudes	Partial eta squared	
<b>Disability</b>	ND > D	.59	--	.00	ND < D	.18	--	.01	ND < D	.32	--	.00
<b>Harm</b>	LH > HH	.31	--	.01	LH < HH	.83	--	.00	LH < HH	.72	--	.00
<b>Role</b>	IDR < IRB-IDR	.05	Remained	.07	--	.00	--	.00	--*	.03	Remained	.02
<b>Disability x Harm</b>	HH: More change by Disability	.04	--	.00	HH: ND > D	.11	--	.01	--	.01	--	.01
<b>Disability x Role</b>	ND: IRB & IRB-IDR > IDR D: IRB < IDR	.21	Remained	.17	IRB-IDR: ND = D	.05	Remained	.05	IDR: Less change by Disability	.14	Remained	.12
<b>Harm x Role</b>	HH: IRB & IRB-IDR > IDR	.04	Remained	.03	--*	.03	--	.02	HH: IRB < IDR	.05	Remained	.05
<b>Harm x Disability x Role</b>	--	.02	--	.02	--	.00	--	.01	--	.01	--	.00

*Note:* "--" indicates an absence of significant effect and/or pairwise post hoc comparisons. "--\*" indicates that although the omnibus F statistic demonstrated an effect, follow-up tests revealed no interaction of factors. ND = No Disability, D = Intellectual Disability; LH = Low Harm, HH = High Harm.

Figure 1. Sample Research Vignette (Disability, High Harm condition)

**Crime among Adults with Intellectual Disabilities**

The following definition may be useful in your review of this study: *Intellectual disability (ID) is a condition that develops in an individual before the age of 18 and is characterized by significant limitations in intellectual functioning and adaptive skills. It is also known by the terms Mental Retardation (MR) or Developmental Disabilities (DD).*

- This research is being conducted to examine criminal behavior among people with intellectual disabilities with no criminal record.
- You have been asked to participate because you have an intellectual disability and have never been charged with, or convicted of, a crime.
- You will be asked to participate in an in-depth individual interview and answer questions about different types of crimes that people can be involved in and your own history of criminal activity (including murder, sexual assault, and theft). You will also be asked to participate in a group interview on similar topics. Each interview will last about 90 minutes. Your name will not be connected to your answers. We will ask you to use fake names for yourself and anyone you talk about in the interviews.
- The bad thing that may happen to you as a result of your participation is that you may feel bad recalling and sharing experiences you may have had with criminal activity. Listening to other people's history of crime or having others' listen to your history may be upsetting to you. There is also a risk that someone in the group interview will not keep what is said private. All group members must promise to keep what is said in the group private and not discuss it after the group. We will provide all participants with a list of local resources. These resources may be able to help you deal with any bad feelings that come up in the interview.

Figure 2. Multiplicative Risk: The Relationship of Disability x Harm to Perceptions of Capacity to Consent.

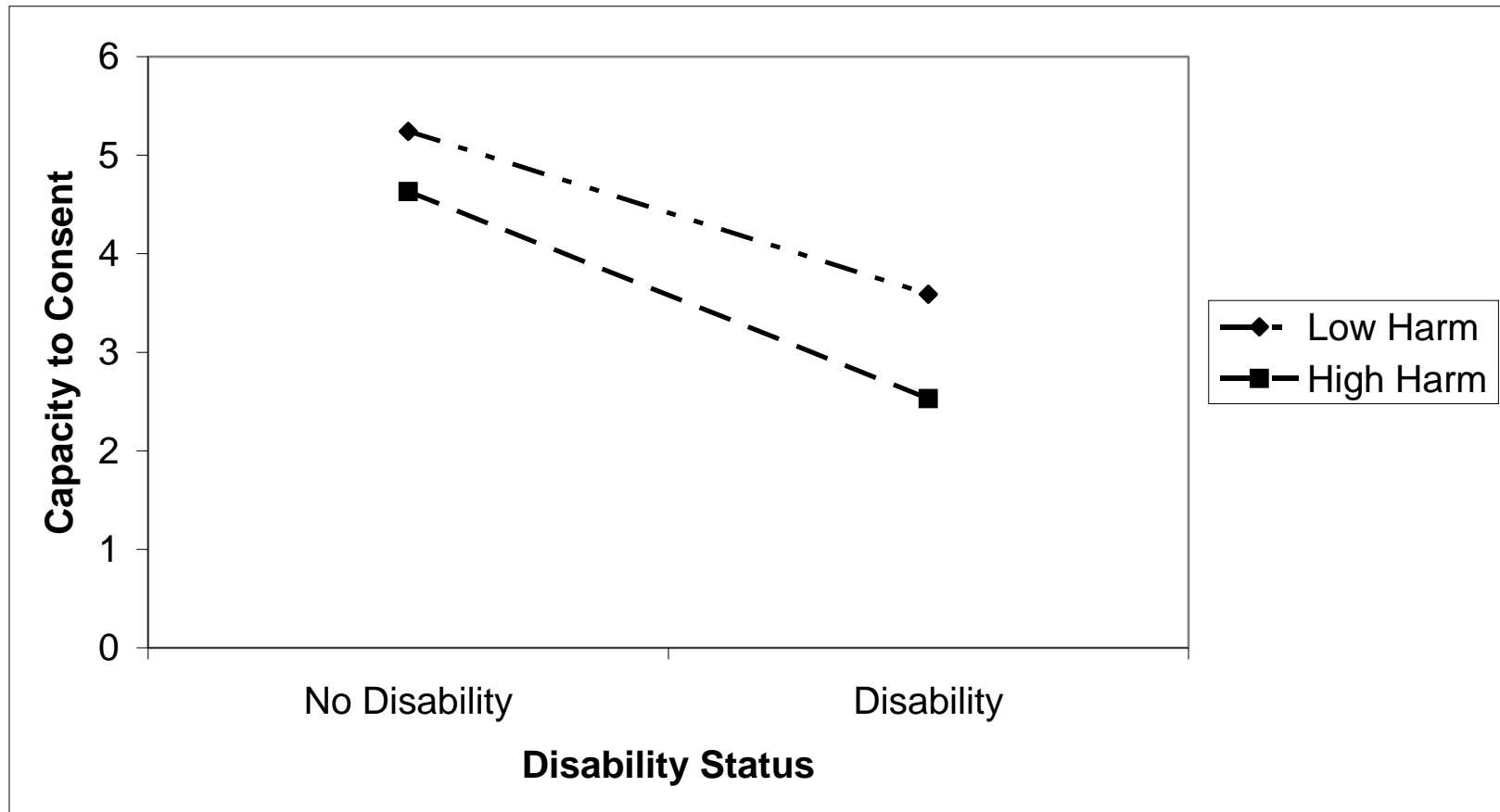


Figure 3. Normative Anchoring and the Vulnerability Effect: The Relationship of Disability x Role to Perceptions of Capacity to Consent.

