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Abstract There are important benefits to including adults with intellectual disabilities in research. Calls for their increased participation in research co-occur with notable discussion about how to conduct ethically strong research with adults with intellectual disabilities, a population widely considered vulnerable in the context of research. The authors systematically researched the peer-reviewed literature on ethical practices in research with adults with intellectual disabilities to identify and analyze conceptually and empirically supported ethical approaches to research in the area of research with adults with intellectual disabilities. They conducted a thematic analysis of the 37 articles that met inclusion criteria. They identified three overarching themes: (1) guiding frameworks and approaches; (2) strategies to promote accountability to ethics; and (3) making decisions about participation, including considerations for coercion, capacity to consent, surrogate decision-making, and promoting understanding. From the review, they noted diverse recommendations for ethical research practices, characterized by a lack of consensus, entrenched tensions in value orientations, and gaps in knowledge and practice. Attention to promising strands of scholarship that emphasize attention to strengths, autonomy, dignity of risk, and a contextually based framing of consent capacity may be particularly fruitful. Similarly, bringing to the forefront the role of accommodations in promoting participation, systematically studying diverse ethical aspects of research, and identifying and considering the perspectives of persons with intellectual disabilities may represent critical next steps. They suggest that research collaborations between academics and persons with intellectual disabilities present opportunities to further strengthen the ethical integrity of research in the field.

A video abstract of this article can be viewed at http://youtu.be/5Oqx02Aw3xs.

Keywords: human research ethics, inclusion, institutional review boards, intellectual disabilities, research participation

INTRODUCTION

There are important social and scientific benefits to including adults with intellectual disabilities (ID) in research, including opportunities for socially valued contributions and the reduction of persistent health, economic, and social disparities (Aman & Handen, 2006; Becker, Roberts, Morrison, & Silver, 2004; Brown & Thompson, 1997; Iacono, 2006a; Krahn, Hammond, & Turner, 2006; Lakin & Turnbull, 2005). As individuals who experience vulnerability, there are questions about how to ethically engage adults with ID in research. Even with the guidance of internationally supported ethical principles and guidelines, we grapple with understanding the best ways to responsibly address their research involvement, a unique context of community participation (Coleman, Menikoff, Goldner, & Dubler, 2005; McDonald & Keys, 2008). As the international research community worked to correct past abuses of research participants, concerns have emerged that a protectionist mind-set has taken hold contributing to more conservative practices and posing new challenges for researchers (Aman & Handen, 2006; Beh, 2002; Coleman et al., 2005; Oakes, 2002). Here, we reviewed scholarship focused on ethical research practices with adults with ID, a growing literature in recent years. This review is timely and important as concerns that overly protective expectations are placed on research with adults with ID co-occur with increasing calls for their direct participation in research. Indeed, we may be experiencing a ground shift given concurrent forces on research, including increased oversight, continued growth of the disability-rights movement, new opportunities for independence and choice, and preferences to include perspectives of adults with ID (Aman & Handen, 2006; Dybwad & Bersani, 1996; Lakin & Turnbull, 2005; Rodgers, 1999).

Research practices—or safeguards—should address research-relevant vulnerability and risk (Coleman et al., 2005). For adults with ID, vulnerabilities stem primarily from concerns about ability to make informed, voluntary decisions, the extent and nature of participation, and a de-emphasis on benefits. First, researchers have expressed concern over the amount of information individuals must grasp and their ability to weigh risks and benefits and fully understand the research, especially any consequences of participation (Aman & Handen, 2006; Arscott, Dagnan, & Kroese, 1998; Brown & Thompson, 1997; Yan & Munir, 2004). Of note, research indicates a variety of decisional capacity among adults with ID (Arscott et al., 1998; Morris,
Niederbühl, & Mahr, 1993). Vulnerability to coercion may be heightened because of communication challenges, inexperience with decision-making, coercive social contexts, and social isolation (Brigham, 1998; Cambridge & Forester-Jones, 2003; Dalton & McVilly, 2004; Freedman, 2001; Stineman & Musick, 2001). Absent informed, voluntary decisions, adults with ID may be included or excluded without their consent (Cameron & Murphy, 2006; Diesfeld, 1999), an undesired outcome.

Second, there are concerns that adults with ID may be systematically excluded from research, subjected to harmful research, or over-researched (Diesfeld, 1999; Iacono, 2006b). One reason for exclusion from research may be that researchers find adults with ID more difficult to recruit because of multiple gatekeepers who may not provide support or choose to protect rather than allow for the dignity of risk, resist participation for fear that services might be jeopardized or negatively evaluated, or believe that they know the interests of the individual (Becker et al., 2004; Brodin & Renblad, 2000; Lai, Elliott, & Ouellette-Kuntz, 2006). Lastly, there are also concerns that researchers attend too little to promoting research-related benefits to adults with ID or that they may incur harm from unfulfilled expectations of continued friendship (Malott, 2002; Stalker, 1998).

Cutting across ethical principles and research contexts is a need for strategies that safeguard individuals from harm and exploitation. There is notable debate, entrenched in a tension between balancing protection with self-determination, on how to best achieve this goal for adults with ID (Lai et al., 2006; McDonald & Keys, 2008; McDonald et al., 2009). To move forward responsible research policy and practice, we ask: From an ethical perspective, what does recent scholarship tell us about how we should include adults with ID in research? And, in what context are diverse research practices relevant and what empirical evidence is there to support the need for or value of these practices? Although theoretical and empirical attention to the ethical dimensions of research with adults with ID has expanded, to date no one has systematically brought together this literature. Here, we review research and other scholarship including accounts of research experiences and opinion that address how we ought to do research.

METHODS

To identify peer-reviewed ethical practices for research with persons with ID, together with a graduate research assistant, we systematically searched databases in the social sciences (PsycINFO, Sociological Abstracts, and Web of Science), education (Education Resources Information Center (ERIC)), and health (Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Medline), excluding databases that would have yielded redundant searches. We limited our search to English language peer-reviewed articles from January 1997 to March 2010. These dates were selected to begin after the onset of greater scrutiny of ethics committees and research practices in the United States (Aman & Handen, 2006; Coleman et al., 2005). In conducting our search, we generated a list of 43 keywords that capture language used in different disciplines and countries (e.g., ID, learning difficulty, mental retardation, handicap, vulnerable population, decisionally impaired, ethics, and proxy consent). We also hand searched the table of contents of 15 journals that publish research on ID and the reference section of all retrieved articles. We read each manuscript to identify whether it met our inclusion criteria of addressing (empirically, descriptively, or conceptually) ethics-related considerations on how to conduct research with adults with ID, including both recommendations and critiques. We excluded articles if they discussed medical treatment decisions, diverse disabilities, or children.

Our final sample included 37 peer-reviewed articles from the UK (n = 18), the United States (n = 12), Australia (n = 5), Canada (n = 1), and Sweden (n = 1). Articles came primarily from the social sciences (n = 26), especially psychology (n = 11) and social work (n = five), but also included articles from medical fields (n = 11). Over half of the articles provided perspectives (n = 20) with others equally divided among descriptive accounts of research experiences (n = 9) and empirical studies (n = 8). The number of articles has increased over time. See Table 1 for information on each manuscript.

We conducted a grounded thematic analysis (Braun & Clarke, 2006) to capture each ethical practice and related motivating concerns, mediating factors, and empirical evidence. We coded data that reflected authors’ beliefs, evaluation of research practices, or findings motivated by ethical considerations. We refined the coding framework as we examined coded text for cross-cutting themes and checked one another’s work, discussing each code and adding additional detail and structure to the codes. If we were unable to reliably differentiate codes, we combined them. At times, we created new codes to capture multidimensional constructs. All ambiguous codes were resolved through discussing and adjusting the codes and referring back to articles. We gave each segment of abstracted text the most specific code possible. The first author used this coding structure to identify a core set of higher-order codes. Several months later, the first author recoded each article without knowledge of its original coding to check the stability of coding. Codes were highly stable (Foster-Fishman & Keys, 1997).

RESULTS

We identified three overarching themes that characterize scholarship on how to ethically engage adults with ID in research: (1) Guiding frameworks and approaches; (2) strategies to promote accountability to ethics; and (3) decision-making about research participation. We describe the ideas embedded in and dimensions to each of these themes, focusing on general themes rather than those uniquely relevant to particular research designs or topics.

Guiding Frameworks and Approaches to Research

Scholars noted a variety of ethical principles and cross-cutting issues in ethical research. Addressing principles guiding research, Fisher (2002) and Diesfeld (1999) suggest that frameworks should not differ from those for persons without disabilities. McVilly and Dalton (2006) and Diesfeld (1999), however, note that researchers should recognize adults with ID as less privileged and vulnerable, thereby necessitating rigorous, ethical research, especially for those living independently, in institutional care, and in countries where rights are tenuous. Perhaps reflecting this
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<tr>
<th>Author(s)</th>
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<tr>
<td>Aman &amp; Handen</td>
<td>2006</td>
<td>Recruitment of people with ID into research</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
<td>Empirical</td>
<td>Study on the recruitment of people with ID into research, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<tr>
<td>Arooni, Brown, &amp; Hennessy</td>
<td>2006</td>
<td>Consent to psychological research by people with an ID</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
<td>Empirical</td>
<td>Consent to psychological research by people with an ID, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Becker, Roberts, Arscott, &amp; Dagnan</td>
<td>2004</td>
<td>Recruiting people with disabilities as research participants: Challenges and strategies to address them</td>
<td>International Journal of Disability Ethics</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>Recruiting people with disabilities as research participants: Challenges and strategies to address them, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Bembenek &amp; Redd</td>
<td>2000</td>
<td>Mental Retardation</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
<td>Empirical</td>
<td>Study investigating capacity to consent in adults with ID and possible strategies for addressing challenges, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Brigham</td>
<td>2004</td>
<td>The ethics of research with men who have learning disabilities and abusive sexual behavior: A â€œmindfield in a vacuumâ€</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Men with ID who have—ormight—sexually offend</td>
<td>Perspective</td>
<td>The ethics of research with men who have learning disabilities and abusive sexual behavior: A â€œmindfield in a vacuumâ€, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Brown &amp; Thompson</td>
<td>2009</td>
<td>Research ethics and the use of visual images in research involving people with ID</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>Research ethics and the use of visual images in research involving people with ID, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Cameron &amp; Murphy</td>
<td>2006</td>
<td>Ethical dilemmas in research ethics</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>Ethical dilemmas in research ethics, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Clegg</td>
<td>2004</td>
<td>Practice and intellectual ability: The ethical considerations of publishing the results of research with people with ID</td>
<td>Journal of Applied Learning Disabilities</td>
<td>Adults with ID</td>
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<td>Practice and intellectual ability: The ethical considerations of publishing the results of research with people with ID, focusing on understanding risks, ensuring voluntary consent, and improving the functioning of investigational review boards and ethics committees.</td>
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<td>Diesfeld</td>
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<td>Adults with ID</td>
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<td>Dye, Hare, &amp; Hendy</td>
<td>2007</td>
<td>Capacity of people with ID to consent to take part in a research study</td>
<td>Journal of Applied Research in Intellectual Disabilities</td>
<td>Adults with mild to moderate ID</td>
<td>Empirical</td>
<td>UK</td>
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<td>Dye, Hendy, Hare, &amp; Burton</td>
<td>2004</td>
<td>Capacity to consent to participate in research: A recontextualization</td>
<td>British Journal of Learning Disabilities</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>UK</td>
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<td>Ellem, Wilson, Chui, &amp; Knox</td>
<td>2008</td>
<td>Ethical challenges of life story research with ex-prisoners with intellectual disability</td>
<td>Disability &amp; Society</td>
<td>Adults with borderline and mild ID</td>
<td>Account of research experience</td>
<td>AU</td>
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<td>Fisher</td>
<td>2002</td>
<td>Respecting and protecting mentally impaired persons in medical research</td>
<td>Ethics &amp; Behavior</td>
<td>Adults with ID in medical research</td>
<td>Perspective</td>
<td>USA</td>
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<td>Fisher</td>
<td>2003</td>
<td>Goodness-of-fit ethic for informed consent to research involving adults with intellectual and developmental disabilities</td>
<td>Mental Retardation and Developmental Disabilities</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>USA</td>
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<td>Fisher, Cox, Davidson, &amp; Fried</td>
<td>2006</td>
<td>Capacity of persons with ID to consent to participate in randomized clinical trials</td>
<td>American Journal of Psychiatry</td>
<td>Adults with mild and moderate ID</td>
<td>Empirical</td>
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<td>Freedman</td>
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<td>Ethical challenges in the conduct of research involving persons with ID</td>
<td>Mental Retardation</td>
<td>Adults with ID</td>
<td>Perspective</td>
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<td>Gates &amp; Waight</td>
<td>2007</td>
<td>Reflections on conducting focus groups with people with learning disabilities: Theoretical and practical issues</td>
<td>Journal of Research in Nursing</td>
<td>Adults with mild to severe ID receiving mental health services</td>
<td>Account of research experience</td>
<td>UK</td>
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<td>Gilbert</td>
<td>2004</td>
<td>Involving people with learning disabilities in research: Issues and possibilities</td>
<td>Health &amp; Social Care in the Community</td>
<td>Adults with ID</td>
<td>Perspective</td>
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<td>Iacono</td>
<td>2006</td>
<td>Ethical challenges and complexities of including people with intellectual disability as participants in research</td>
<td>Journal of Intellectual &amp; Developmental Disability</td>
<td>Adults with ID</td>
<td>Perspective</td>
<td>AU</td>
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<td>Iacono</td>
<td>2006</td>
<td>Further comments on the researched, researchers, and ethics committees: A response</td>
<td>Journal of Intellectual &amp; Developmental Disability</td>
<td>Adults with ID</td>
<td>Perspective</td>
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<td>Iacono &amp; Murray</td>
<td>2003</td>
<td>Issues of informed consent in conducting research involving people with intellectual disability</td>
<td>Journal of Applied Research in Intellectual Disabilities</td>
<td>Adults with severe to profound ID in medical research</td>
<td>Account of research experience AU</td>
<td>Reviews researchers' experiences balancing law, protection, and rights in capacity to consent determinations. Concludes that providing information to gatekeepers on research, viewing capacity to consent as interactive, and involving staff in capacity determinations have advantages.</td>
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<td>Lai, Elliott, &amp; Ouellette-Kuntz</td>
<td>2006</td>
<td>Attitudes of research ethics committee members toward individuals with ID: The need for more research</td>
<td>Journal of Policy and Practice in Intellectual Disabilities</td>
<td>Adults with ID</td>
<td>Perspective Canada</td>
<td>Considers the role of attitudes that ethics review committee members may hold toward persons with ID and how those attitudes may impact decisions for research. Notes the scarcity of guidelines and direction for involving persons with ID in research and calls for more research on the topic. Discusses the morality of involving individuals with ID in research, including giving back to the individual and community once an individual is involved in research. Suggests students and faculty spend time with persons with ID to promote vested, long-term interests.</td>
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<td>Mulott</td>
<td>2002</td>
<td>Notes from a radical behaviorist: Is it morally defensible to use the developmentally disabled as guinea pigs?</td>
<td>Behavior and Social Issues</td>
<td>Adults with ID</td>
<td>Perspective USA</td>
<td>Discusses ethical issues surrounding interviewing women with ID about sexual experiences. Discusses informed consent, confidentiality and anonymity, and reciprocity between researcher and participant. Study on how 260 researchers and ethics committee members make decisions about research participation of adults with and without ID. Findings indicate that decision makers are influenced by disability status, characteristics of the research, attitudes toward involving persons with ID in research, and the participant's relationship to the research process. Study examining 260 researchers and ethics committee members' attitudes toward research participation of adults with ID. Findings indicate that attitudes are organized around three conceptual domains and that ID researchers and individuals with closer relationships to persons with ID had attitudes consistent with disability-rights principles. Study examining 199 ethics committee members and ID researchers' views on risks and benefits of persons with and without ID in lower and higher risk research. Results suggest that identification of risks and protections varied by disability status of the sample, level of risk, and role of person reviewing the study. Reaction to Iacono's article on the increasingly conservative decisions of research ethics committees in regard to involving persons with ID in research. Suggest importance of human rights perspective in considering issues related to consent and ethics committees. Discusses current approach of ethics committees to review research. Notes the lack of evidence about whether there is a need to subject research with adults with ID to greater ethical scrutiny and suggests value of promoting research participation and using circles of support for decision-making. Discusses experiences using an emancipatory research paradigm for research involving persons with ID. Addresses control of the research and the research question, consulting with persons with ID, working with an ethics committee, and extent of persons with ID involvement in the research process. Discusses ethical dilemmas of research with persons with ID in oral and archival history research. Addresses issues of ownership and anonymity when persons with ID are coresearchers. Discusses ethical and methodological issues from a study examining exercise choices by persons with ID. Considers the consent process, intrusion during data collection, relationship expectations, accountability in data analysis and dissemination, and working with research advisors.Response to vignettes on informed consent and impaired decisional capacity. Principles of autonomy, beneficence, and justice are examined for the specific population.</td>
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<td>Rodgers</td>
<td>1999</td>
<td>Trying to get it right: Undertaking research involving people with learning difficulties</td>
<td>Disability &amp; Society</td>
<td>Adults with ID</td>
<td>Account of research experience UK</td>
<td>Discusses ethical dilemmas in historical research with people with learning difficulties. Discusses ethical dilemmas of research with persons with ID in oral and archival history research. Addresses issues of ownership and anonymity when persons with ID are coresearchers. Discusses ethical and methodological issues from a study examining exercise choices by persons with ID. Considers the consent process, intrusion during data collection, relationship expectations, accountability in data analysis and dissemination, and working with research advisors. Response to vignettes on informed consent and impaired decisional capacity. Principles of autonomy, beneficence, and justice are examined for the specific population.</td>
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<td>Rolf</td>
<td>1998</td>
<td>Ethical dilemmas in historical research with people with learning difficulties</td>
<td>British Journal of Learning Disabilities</td>
<td>Adults with ID</td>
<td>Account of research experience UK</td>
<td>Discusses ethical dilemmas in historical research with people with learning difficulties. Discusses ethical dilemmas of research with persons with ID in oral and archival history research. Addresses issues of ownership and anonymity when persons with ID are coresearchers. Discusses ethical and methodological issues from a study examining exercise choices by persons with ID. Considers the consent process, intrusion during data collection, relationship expectations, accountability in data analysis and dissemination, and working with research advisors. Response to vignettes on informed consent and impaired decisional capacity. Principles of autonomy, beneficence, and justice are examined for the specific population.</td>
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<td>Stalker</td>
<td>1998</td>
<td>Some ethical and methodological issues in research with people with learning difficulties</td>
<td>Disability &amp; Society</td>
<td>Adults with ID</td>
<td>Account of research experience UK</td>
<td>Discusses ethical dilemmas in historical research with people with learning difficulties. Discusses ethical dilemmas of research with persons with ID in oral and archival history research. Addresses issues of ownership and anonymity when persons with ID are coresearchers. Discusses ethical and methodological issues from a study examining exercise choices by persons with ID. Considers the consent process, intrusion during data collection, relationship expectations, accountability in data analysis and dissemination, and working with research advisors. Response to vignettes on informed consent and impaired decisional capacity. Principles of autonomy, beneficence, and justice are examined for the specific population.</td>
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<td>Walker</td>
<td>2002</td>
<td>Autonomy, beneficence, and justice in wider context</td>
<td>Ethics &amp; Behavior</td>
<td>Adults with ID</td>
<td>Perspective USA</td>
<td>Discusses ethical dilemmas in historical research with people with learning difficulties. Discusses ethical dilemmas of research with persons with ID in oral and archival history research. Addresses issues of ownership and anonymity when persons with ID are coresearchers. Discusses ethical and methodological issues from a study examining exercise choices by persons with ID. Considers the consent process, intrusion during data collection, relationship expectations, accountability in data analysis and dissemination, and working with research advisors. Response to vignettes on informed consent and impaired decisional capacity. Principles of autonomy, beneficence, and justice are examined for the specific population.</td>
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AU, Australia; ID, intellectual disabilities; JASSID, International Association for the Scientific Study of Intellectual Disabilities; UK, United Kingdom; USA, United States of America.
perspective, a U.S.-based survey of researchers and ethics committee members suggests that scientific gatekeepers support increased protections for research with adults with ID (McDonald & Keys, 2008). On the other hand, many authors stress that an emphasis on protections may exclude adults with ID from research and thwart their ability to benefit (Aman & Handen, 2006; Arscott et al., 1998; Brown & Thompson, 1997; Iacono & Murray, 2003; Lai et al., 2006; Rolph, 1998). McVilly and Dalton (2006) note the benefits of a human rights framework that balances needs and respect for dignity. Similarly, Brodin and Renblad (2000) suggest that researchers view adults with ID as able to contribute, engage in mutually respectful dialogue, and provide opportunities to influence research. Others add that neither the presence of a disability nor the absence of capacity should exclude an individual from participation and that the participation of adults with ID in all research should be pursued (Aman & Handen, 2006; Boxall & Ralph, 2009; Dalton & McVilly, 2004; Freedman, 2001; Iacono, 2006a; Iacono & Murray, 2003; McCarthy, 1998; McVilly & Dalton, 2006; Ramcharan, 2006). Others note that there are times when adults with ID should be prohibited from participation, either as a group, as an individual, or because of the nature of the research (Clegg, 2004). Becker and colleagues (2004) suggest recruiting those with capacity (defined as those without legal guardians) whereas Lai and colleagues (2006) suggest that those without capacity may participate in research with some level of direct benefit. A study of relevant belief systems underlying attitudes toward the participation in research of adults with ID identified three dimensions of these attitudes: (1) a belief that adults with ID should have the opportunity to participate and make choices, (2) need assistance making decisions, or (3) be protected from harm. In the USA, researchers espouse attitudes more consistent with rights than ethics committee members (McDonald, Keys, & Henry, 2008).

Scholars who support participation suggest strategies to achieve this goal including promoting relationships between researchers and adults with ID. Creating collaborative relationships with adults with ID and those involved in their lives and promoting their appreciation for research may in turn promote engagement in research (Becker et al., 2004; Cameron & Murphy, 2006). Malott (2002) notes that researchers with increased investment in the lives of adults with ID may be more motivated to promote benefits of research participation. Rodgers’ (1999) beliefs and practices appear to fit well with this perspective. To facilitate relationships, researchers should be skilled at building rapport (Cameron & Murphy, 2006). Becker and colleagues (2004) add that well-trained interviewers who can answer questions may similarly promote access. Other strategies include recruiting participants through self-advocacy groups, thereby avoiding any gatekeeping by supporters (Stalker, 1998). Conversely, others note that working directly with those who are known and trusted by adults with ID, including supporters, may help them navigate engagement (Becker et al., 2004; Clegg, 2004; Stalker, 1998). Stalker (1998) cautions researchers to attend to coercion and to be aware that supporters may screen adults with ID for inclusion or exclusion. Others suggest that researchers provide support (Dalton & McVilly, 2004) and recognize that different levels of support may be needed (Brodin & Renblad, 2000). Becker and colleagues (2004) add that matching interviewers with participants’ race or ethnicity can also help promote participation. Lastly, research strategies such as visual methods may make participation more widely accessible (Boxall & Ralph, 2009).

Many scholars suggest that research needs to relate to the needs of, address topics considered worthwhile by, and benefit adults with ID (Dalton & McVilly, 2004; Diesfeld, 1999; McCarthy, 1998). Similarly, others suggest using the social model of disability to frame research (Gilbert, 2004; Rodgers, 1999), investigating questions that retain dignity and humanity (Clegg, 2004; Diesfeld, 1999), not perpetuating negative stereotypes (Becker et al., 2004), focusing on opinions and experiences (Brigham, 1998; Ellem, Wilson, Chui, & Knox, 2008; Rodgers, 1999), and being honest about the research (Brigham, 1998). Rodgers (1999) suggests that researchers develop an understanding of the information of interest but demonstrate flexibility on how it is gathered. Malott (2002) adds that researchers should provide something beneficial to participants. Similarly, Dalton & McVilly (2004) and Malott (2002) suggest that applied researchers ensure that the support strategies used in research are available to participants after the research ends. Several authors support dissemination that promotes access to findings for adults with ID, advocates, and local communities, and facilitates feedback on findings (Becker et al., 2004; Dalton & McVilly, 2004; Iacono, 2006a; Rodgers, 1999; Stalker, 1998). Stalker (1998) adds that researchers should not add words to participants’ expressions in dissemination materials.

Addressing relationships during research participation, some express a preference to promote respectful, mutually beneficial relationships between researchers and those who they study. One way to achieve this is by expecting researchers to get to know participants (Ellem et al., 2008; Malott, 2002; Stalker, 1998). As relationships develop, others note the importance of establishing the role, identity, and context of the researcher and participant (Gilbert, 2004; McCarthy, 1998). Ways to end relationships at a pace in which participants do not feel exploited are also important (Stalker, 1998). Brigham (1998) indicated that she needed to attend to these relationships before her research project could continue. Diesfeld (1999) adds that those who develop relationships with adults with ID need to live up to the trust placed in them.

Some scholars note that partnerships may facilitate ethical research. These partnerships may lead researchers to use procedures (e.g., respectful and compassionate ways to promote ability to consent, protect against violations of confidentiality, pay participants, share findings openly, and invite opportunity for interpretation) that convey an attitude of partnership and that share power (Becker et al., 2004; Brigham, 1998; Brown & Thompson, 1997; Dalton & McVilly, 2004; Diesfeld, 1999; Freedman, 2001; Gilbert, 2004; Iacono, 2006a; McCarthy, 1998; Rodgers, 1999; Rolph, 1998; Stalker, 1998). To facilitate collaboration, researchers might invite adults with ID to bring someone to support them (Stalker, 1998). Stalker (1998) believes that continued evaluations of such collaborative work are needed to determine their utility for adults with ID.

Ethical Accountability

Scholars also discuss ways to ensure ethical accountability. Many authors note the advantages of strong, knowledgeable
To minimize coercion to participate, understanding—represent the bulk of discourse in this scholar-
ship. Within this larger topic, authors consider coercion, capa-
city to consent, substitute decision-making, and promoting understand-
ing these relationships (Arscott et al., 1998; Ellem et al., 2008; Stalker, 1998). Examples of the latter approach include asking participants to explain their expectations for the relation-
ship, including expectations for continued friendship, so that there can be a negotiation of the relationship (Stalker, 1998). Similarly, some argue that researchers should modify the consent setting to decrease perceptions of inequality and concretely illustrate that services will not be compromised (Fisher, 2003), emphasize the voluntary nature of participation (Fisher, Cea, Davidson, & Fried, 2006), and ask individuals to explain their reasons for participation (Iacono & Murray, 2003). Others suggest that researchers monitor for compromised voluntariness throughout the research by attending to nonverbal cues, not assuming that a lack of objection implies consent, documenting nonparticipation, and not pressuring participants to answer specific questions (Brodin & Renblad, 2000; Brown & Thompson, 1997; Cameron & Murphy, 2006; Rodgers, 1999). Lastly, some authors note the tension between wanting to recognize and compen-
state participants, but wanting to avoid coercive incentives (Becker et al., 2004; Dalton & McVilly, 2004).

Another approach to minimizing coercion is to encourage adults with ID to consult a family member or advocate prior to agreeing to participate or to use trained, disinterested educators, advocates, counselors, or therapists to discuss the research with participants or be present during consent processes (Aman & Handen, 2006; Andre-Barron, Strydom, & Hassiotis, 2008; Dalton & McVilly, 2004; Freedman, 2001; Iacono & Murray, 2003). Engaging disinterested parties may be more strongly advised when researchers have a preexisting relationship with participants (Freedman, 2001). Some suggest not using disability service providers to recruit or support adults with ID; although they may be able to promote participation and decisional capacity, power relationships may compromise voluntariness (Cameron & Murphy, 2006; McCarthy, 1998). Support providers in Andre-Barron and colleagues’ (2008) small focus group study noted the potential for this coercion. Others disagree, believing that researchers should retain as much control as possible over recruitment (Clegg, 1999). A large survey of ID researchers and ethics committee members in the USA found notable variability in the scientific community’s perspective on which of these strategies to use (McDonald et al., 2009).

Capacity to consent Considerable discussion centers on the ability of adults with ID to provide consent. Some scholars state that the presence of ID indicates neither the ability nor lack thereof to provide consent (Brown & Thompson, 1997; Freed-
man, 2001). Other writers assert that adults with ID should be assumed capable of providing consent unless established other-
wise by formal assessment or legal determination (Becker et al., 2004; Dalton & McVilly, 2004; Dye, Hendy, Hare, & Burton, 2004). In contrast, others hold that not all adults with ID can be assumed to have capacity to consent (Iacono & Murray, 2003) and that it is a researchers’ responsibility to ensure that participants have understood and given voluntary consent (Aman & Handen, 2006; Arscott et al., 1998). Professionals in Andre-Barron and colleagues’ (2008) study agreed (although notably no participants with ID addressed the topic) while noting concerns that assessments may feel like a test and that there are no standardized tools. Research suggests that scientific gatekeepers, especially ethics

### Making Decisions About Research Participation

Decisions about research participation—including discussions related to coercion, capacity, proxy consent, and promoting understanding—represent the bulk of discourse in this scholar-
ship. Within this larger topic, authors consider coercion, capa-
city to consent, substitute decision-making, and promoting understand-
ing.

**Minimizing coercion** To minimize coercion to participate, several authors suggest that researchers recognize that adults with ID experience relationship-based power imbalances and subse-
quently establish clear relationships and assess how participants

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committee panel members, generally perceive less capacity in adults with ID, particularly in research that presents greater potential risks to participants; findings attributed to attitudes (McDonald & Keys, 2008). Assessments can ensure that those with capacity have their right to autonomy upheld (Iacono, 2006b). Of note, there are researchers who support assessing capacity while also indicating that incapacity should not be assumed (Becker et al., 2004). Other authors note that only in instances of specific concerns about capacity should researchers use psychometric assessments of capacity (McVilly & Dalton, 2006). A survey of scientific gatekeepers in the United States reflects this variability in opinion toward capacity to consent (McDonald et al., 2009). Researchers have reported challenges working with ethics committees on this matter. Rodgers (1999) was required to obtain agreement from participants’ family members and doctors, though she objected to the assumption of incompetency. Dye, Hare, and Hendy (2007) had a similar experience.

Means to assess capacity to consent include having researchers evaluate whether an individual appreciates the situation and its effects (Becker et al., 2004) or asking questions about key elements of the research to evaluate understanding (Aman & Handen, 2006; Dye et al., 2004, 2007; Ellem et al., 2008; Iacono, 2006b). Related to the latter approach, McCarthy (1998) notes that participants need not grasp opaque aspects of research such as data analysis. Asking adults with ID to consider participating in hypothetical research studies, Arscott and colleagues (1998) found that many could not accurately respond to five core questions about the research. Freedman (2001) adds that individuals’ affective state, values, and preferences should also be evaluated.

Other considerations in assessing capacity might include an individual’s previous research participation and tendency to acquiesce (Dalton & McVilly, 2004). Another approach asks service providers to provide evidence or judgments of an individual’s capacity or have a support provider confirm their decision (Andre-Barron et al., 2008; Brown & Thompson, 1997; Cameron & Murphy, 2006; Iacono, 2006a; Iacono & Murray, 2003; Stalker, 1998). After doing so, however, Iacono and Murray (2003) wished that they or a third party had been more involved. Aman and Handen (2006) add that advocates present during consent can ensure participants’ understand the study, an approach Gates and Waight (2007) support as do many surveyed in the scientific community in the USA (McDonald et al., 2009). Others favor more formal assessments of decisional capacity using objective criteria (Arscott et al., 1998; McVilly & Dalton, 2006). Assessments might be done in consultation with a psychiatrist, social worker, or psychologist or by qualified research personnel (Iacono, 2006b). Fisher and colleagues (2006) suggest that researchers explain to those found to lack capacity that it does not necessarily mean that they lack capacity to make other decisions. Dye and colleagues (2004) note that dichotomizing capacity to consent creates a threshold that can restrict participation or inadequately protect and that those without capacity can still decline participation and evidence a decision. Instead, these authors suggest considering capacity to consent along a continuum and that even those who partially understand the risks and benefits can participate.

Some scholars critique any assessment of capacity, noting that they demand more of adults with ID than for others (Freedman, 2001; Iacono, 2006b), hold them to a higher standard of rational manipulation of information (Fisher, 2003), and represent a form of paternalism (Ramcharan, 2006). Moreover, expecting adults with ID to make decisions based on a risk-benefit analysis denies them the freedom to decide based on concrete or emotional factors (Dye et al., 2004; Fisher, 2003) and can be used to justify substitute decision-making when they feel that the individual is making poor decisions (Fisher, 2003). Others have added the lack of appropriate assessment tools and that researchers may not know how to assess capacity or what indicates an acceptable threshold of performance as noteworthy concerns (Arscott et al., 1998; Iacono, 2006b; Iacono & Murray, 2003). Fisher and colleagues (2006) note that research has not found an association between total consent comprehensibility and ability to communicate a decision. Furthermore, assessments of capacity add complexity to the conduct of research (McVilly & Dalton, 2006) and may contribute to participants’ annoyance at having to answer repetitive questions as well as stress and inconvenience (Dye et al., 2007; Iacono & Murray, 2003). Iacono (2006b) adds that psychological assessment of capacity may render studies unfeasible. Cameron and Murphy (2006) and Dye and colleagues (2007) suggest future research operationalize capacity to consent to research, establish performance thresholds, and provide evidence to support assessment of capacity.

Alternatively, consent can be viewed as an ongoing, emergent process with participants’ understanding and agreement unfolding throughout the research (Brigham, 1998; Cameron & Murphy, 2006; Dalton & McVilly, 2004; Ellem et al., 2008; Iacono, 2006b; McVilly & Dalton, 2006; Ramcharan, 2006; Rodgers, 1999). Relevant here, Dye and colleagues (2004) suggest that processes, rather than individuals, be competent. Similarly, a negotiated approach to consent, inclusive of others present in the lives of adults with ID, may encourage creative solutions (Clegg, 2004; Dye et al., 2007; Freedman, 2001), suggesting that autonomy may be considered an expression of connectedness to others where others guide and help with decision-making (Fisher, 2002; Walker, 2002). Participants might use natural supports by bringing a family member, friend, or advocate to consent meetings to help review information, promote understanding, and make a decision (Iacono, 2006b; Fisher, 2003; Freedman, 2001; McVilly & Dalton, 2006; Walker, 2002). Some scholars suggest being prepared to communicate with supporters and building in time and resources to educate them on the purpose and value of research so that they can support adults with ID to make decisions (Becker et al., 2004; Cameron & Murphy, 2006). Others acknowledge that negotiated consent processes may nonetheless result in proxy decision-making but note that they may help researchers balance protecting those vulnerable to coercion or who are included without consent with including them (Cameron & Murphy, 2006; McVilly & Dalton, 2006).

Attention to context (e.g., research risks and demands, supports, past behavior, psychological condition, and experiences) is another frame through which to examine capacity to consent (Brown & Thompson, 1997; Dalton & McVilly, 2004; Dye et al., 2004; Fisher, 2003; Freedman, 2001; Iacono & Murray, 2003; McCarthy, 1998). Iacono and Murray (2003) and Freedman (2001) posit that capacity should be considered within each research project, on a case-by-case basis, framing capacity to consent as an interactive construct. In this approach, the amount...
of capacity required increases as the risk-benefit ratio decreases (Clegg, 1999; Fisher et al., 2006; Freedman, 2001). Others note that self-determination among individuals with severe to profound ID can be difficult (Iacono & Murray, 2003) and that the presence of communication disorders, dependency on others for care, social isolation, and living in institutions may render individuals more vulnerable and hence call for more rigorous procedures to ensure that consent is informed and voluntary (Diesfeld et al., 1999). Relatively, Fisher (2003) suggests that researchers be aware of each individual’s strengths and vulnerabilities. For example, consent abilities may be higher when information is personally relevant (Fisher et al., 2006).

**Substitute decision-making** When adults with ID are perceived or determined incapable of providing consent, substitute or proxy consent becomes relevant (Brown & Thompson, 1997; Dalton & McVilly, 2004; Freedman, 2001; Iacono, 2006a; Iacono & Murray, 2003; Lai et al., 2006; Rodgers, 1999). Some scholars advise care in proxy selection—perhaps leaning most on those who know the individual well, including other adults with ID—and posit that a collective decision-making process may be more effective in safeguarding individuals’ interest (Dalton & McVilly, 2004; Rodgers, 1999). Stalker (1998) advocates using psychiatrists as using family members reinforces the status of adults with ID as children. Iacono and Murray (2003) turned to their government when there was no legal guardian to provide surrogate consent. Other authors note that as substitute decision-making does not necessarily involve the individual, the individual with ID should agree to the use of a proxy and be involved in the decision-making process, perhaps by providing assent or naming a proxy (Cameron & Murphy, 2006; Dalton & McVilly, 2004; Fisher, 2002; Fisher et al., 2006; Freedman, 2001; Iacono, 2006a; Iacono & Murray, 2003; Lai et al., 2006).

When adults with ID have the opportunity to assent, authors note that researchers must consider how to handle disagreements between participants and proxies. Freedman (2001) suggests that researchers meet with surrogates and participants to review information. Brown and Thompson (1997) and Freedman (2001) posit that a decision by the adult with ID not to participant should be considered final, irrespective of whether they are considered competent. In their research, Cameron and Murphy (2006) note that three participants’ care providers declined participation and that they respected their decision even though care providers’ agreement was not required.

Stalker (1998) suggests that while proxy consent may not be ideal, it can address inappropriate inclusion or exclusion. Others disagree, because supporters’ efforts to represent the views of adults with ID might be unnecessary, overly extensive, or protective (Clegg, 2004). McVilly and Dalton (2006) suggest that proxy consent can result in denying dignity of risk and self-determination and preventing learning. Others note uncertainty about appropriate proxies (Cameron & Murphy, 2006; Iacono, 2006a; Iacono & Murray, 2003). For example, using support staff may increase compliance but not consent (McCarthy, 1998). There are also concerns about how proxies make decisions (McVilly & Dalton, 2006). Some recommend holding a series of informational sessions with participants and proxies (Iacono & Murray, 2003). Others suggest that proxies should weigh risks and benefits and make a decision based on the individual’s best interest, preferences, and/or on knowledge of the individual (Fisher, 2003; Freedman, 2001). Freedman (2001) notes that surrogates may not know individuals’ preferences and may need additional information. Others add that with proxy consent, extra caution must be exercised to address coercion (Diesfeld, 1999).

**Promoting understanding** Many authors discuss researchers’ responsibility to promote comprehension (Arscott et al., 1998; Boxall & Ralph, 2009; Brown & Thompson, 1997; Freedman, 2001), including tailoring approaches to fit individuals’ strengths and weaknesses (Dye et al., 2007; Fisher et al., 2006) and altering environmental stressors (Dalton & McVilly, 2004; Fisher, 2003). Individualized approaches might include presenting information in relationship to familiar situations and experiences and using simple, jargon-free language, symbols, concrete visual aids, and multiformat practical demonstrations, repeating information, providing information in person verbally with nonverbal communication signals, and allowing participants increased time to make decisions (Andre-Barron et al., 2008; Becker et al., 2004; Cameron & Murphy, 2006; Dalton & McVilly, 2004; Diesfeld, 1999; Dye et al., 2007; Ellem et al., 2008; Fisher, 2002, 2003; Fisher et al., 2006; Freedman, 2001; Gates & Waught, 2007; Gilbert, 2004; Iacono & Murray, 2003; McCarthy, 1998; Rodgers, 1999; Stalker, 1998). Some writers support shortening information to essential points necessary for an informed decision, including confidently and risks, even when they appear insignificant (Aman & Handen, 2006; Cameron & Murphy, 2006; Dye et al., 2007; Ellem et al., 2008; Freedman, 2001; Iacono & Murray, 2003; McCarthy, 1998). Becker and colleagues (2004) note that researchers may need training on how to develop and implement some of these strategies. These strategies may help promote adult with ID’ ability to participate in research activities (Freedman, 2001; Gates & Waught, 2007; Rodgers, 1999). In one study that employed many of these strategies, some 60% of participants were able to provide consent (Cameron & Murphy, 2006). In another, almost all were able to make a decision and evidence some capacity (Arscott et al., 1998). In a third study, while many participants could demonstrate their choice, most could not elaborate on the impact of their choice (Fisher et al., 2006). However, a study that sought to decrease demands on participants’ memory by using visual aids did not result in increased capacity (Dye et al., 2007).

Many scholars suggest that including those known to adults with ID may promote understanding (Becker et al., 2004; Diesfeld, 1999). Adults with ID and support providers in Andre-Barron and colleagues’ (2008) study suggested that adults with ID may want to discuss participation with others. Adults with ID added that peers, especially those in the same study, could also provide support. Education and experiences making research-related decisions may improve capacity over time (Freedman, 2001; Iacono & Murray, 2003).

**DISCUSSION**

A critical issue for society is how we treat those we engage in knowledge production. When research involves those from vulnerable groups, the scientific community has an increased responsibility (Coleman et al., 2005). Indeed, researchers need to be more than good scientists. We need to demonstrate sensitivity
to the ethics that permeate our work. Here, we reviewed scholars’ writings and research on how to ethically engage adults with ID in research. We are encouraged by the number of articles on the topic. This body of scholarship raises diverse considerations for framing deliberations and decisions about the ethical dimensions of research. Of concern to the field is the lack of consensus, the entrenched tensions in value orientations, and gaps in knowledge and practices. It is our hope that this review affords the opportunity to take stock of recent discourse in scholarship, challenge the field, and advance in constructive, community-supported ways the respectful inclusion of persons with ID in research.

Our analysis identified three overarching themes related to guiding frameworks and approaches, strategies to promote accountability to ethics, and how decisions about research participation are made. The balance of scholarship spotlights decision-making practices. The focus on researchers’ responsibility to ensure participants’ decisions is informed and voluntary may stem, paradoxically, from the simultaneous reality that while such decisions are the hallmark of ethical research, they are the very topics of most concern for adults with ID (Aman & Handen, 2006; Coleman et al., 2005; Yan & Munir, 2004). Although scholars are challenging traditional framings of consent, identifying acceptable solutions to the issue of capacity to consent will be critical to encouraging research inclusive of adults with ID. We are encouraged by the presence of novel, promising practices that may represent frameworks and strategies true to established ethical principles that aim to protect individuals’ rights and are responsive to unique considerations. Examples include practices that perceive strengths, retain autonomy, favor dignity of risk, and reframe consent as an interactional, contextually informed construct. However, even these practices create paradoxical conclusions and appear insufficient. For example, scholars suggest that the assent of adults with ID be sought and respected as a final decision. However, in practice this appears to be followed in one situation (when a proxy agrees to participation and the person with ID disagrees) but not in another (when a proxy disagrees to participation and the person with ID agrees). Without solutions for the latter situation, we limit individuals’ autonomy. We are also surprised by the relative lack of attention to accommodations as an ethical imperative given their relevance to promoting access and bolstering comprehension. Although strategies to promote understanding for consent purposes are often explored, they do not appear driven by nor strongly connected to what we know about promoting understanding and self-determination (Lakin & Turnbull, 2005). Accommodations are widely seen as critical bridges to equal participation and we hope that they receive increasing attention in the context of research participation (cf. Nicolaidis et al., 2011).

There may be undesirable consequences to the overriding focus on consent including marginalizing other critical discussions such as who is served by the research, relationships between researchers and research participants, how problems and populations are framed and understood, and how to recruit participants. Scholars are addressing these topics (cf. Clegg, 2004; Dalton & McVilly, 2004; Lakin & Turnbull, 2005). However, they receive notably less attention. Without more in-depth attention, we may inhibit the development and use of practices which may transform our thinking and lead to more inclusive research. For example, there is divergent thinking about relationally based sources of coercion. Largely anecdotal accounts suggest concerns that coercion to participate may limit researchers’ access to adults with ID, but we do not have an empirical understanding of whether and how coercion appears in research. In exploring how to involve or not involve others in recruitment and decision-making, future work might focus less on specific groups to include or exclude in favor of focusing on those individuals that the adult with ID wants to involve to their decision-making.

A tension in values favoring self-determination or protection undergirds perspectives on ethical research practices (Ellis, 1992). One way to categorize findings is the extent to which each practice reflects these values and the perennial quest to balance or integrate the two. Of note, research indicates that these attitudes shape determinations of access to research participation (McDonald & Keys, 2008). Formal research protections grew in response to exploitation (Coleman et al., 2005), and hence the historical concern to protect is understandable. More contemporary framings, however, may be reconsidering notions of justice in research noting the risks associated with excluding individuals from research and of paternalistic treatment toward those who are involved (Lai et al., 2006; McDonald et al., 2008). One critical question is, ultimately, whose values prevail? We note significant absence of the views of persons with ID, as well as those of who provide support to adults with ID, in the scholarship reviewed herein. To date, it is not clear to what extent prevailing ethical frameworks are inclusive of or agreeable to these critical perspectives.

The question before us is how to move forward to advance safe, respectful, inclusive research. Two steps may represent particularly fruitful avenues. First, we can add to an empirically derived understanding on how to ethically conduct research with adults with ID. We can do this by systematically studying research as it occurs, documenting and scrutinizing perspectives on and consequences of ethically relevant research practices. We can also conduct studies focused exclusively on ethical dimensions of research. For example, research can identify actual risks—as opposed to perceived risks—of research participation so that next steps are informed by genuine concerns. Our current knowledge relies heavily on small, explorative studies that largely lack the scientific rigor needed to provide an adequate knowledge base to inform policy and practice. In building this knowledge base, we would be well served to consider groundbreaking studies with other vulnerable populations. Here, we learn that many research participants, not only vulnerable populations, experience difficulty understanding aspects of research (Huntington & Robinson, 2007) and professionals do not always accurately predict perspectives of research participants (Kim et al., 2002; Roberts, Hammond, & Hoop, 2006; Roberts & Roberts, 1999; Roberts et al., 2002; Sachs, 1994; Warren et al., 1986). These studies also reveal that individuals from vulnerable populations are able to express preferences and value research participation and make their own decisions, sometimes in consultation with others (Roberts & Roberts, 1999; Roberts, Warner, & Brody, 2000; Widom & Czaja, 2005). Moreover, research participants adjust their willingness to participate according to risks (Kim et al., 2002; Roberts et al., 2000, 2006; Roberts, Hammond, Warner, & Lewis, 2004). Moreover, those judged to have greater decisional impairment express less willingness to participate in research and
individuals indicate being comfortable with being influenced by others and characteristics of the study in making their decisions (Bentley & Thacker, 2004; Kim et al., 2002; Roberts et al., 2000). Further, participants will ask for advice or supports when they perceive the need (Black et al., 2008; Kim et al., 2009). Valuing and providing resources to this type of work may further promote this goal. We might be equally inspired by the concepts explored in this external scholarship. For example, Kim (2006) raises thoughtful questions about the relationship of diminished decision-making capacity to impaired capacity to consent and ethicists now emphasize consent capacity to capture the idea that capacity “varies along a continuum and depends in part on the complexity of the decision facing the individual” (National Institute of Health, 2009). This latter definition varies notably from those that focus on capacity as a static, dichotomous variable.

A second place we can look is to disability-rights values and progress in inclusion and accommodations more generally (Charlton, 1998; Dybwad & Bersani, 1996). After all, research is a domain of community participation and hence learning from what people with disabilities say about how they want to be treated in other contexts makes a good deal of sense. Indeed, we find it curious the relative absence of the perspectives of persons with ID in extant literature. From these explorations, we might uncover preferences for treatment and new ideas such as seeing interdependence as a way to make decisions, autonomy as a function of interdependence, and that agreeing to do something because of who asked us to do it is not always undesirable provided the absolute ability to articulate or act on a genuine desire remains. Strategies such as participatory action research (Atkinson, 2004; Ham et al., 2004; Nicolaides et al., 2011; Whyte, 1990) and inclusion of persons with ID on ethics committees may help promote decisions inclusive of the perspectives of adults with ID and bring the principle of “Nothing About Us Without Us” to research. Related researchers’ relationships with persons with ID may increase their understanding and value of persons with ID, thereby fostering opportunities for research on topics meaningful to persons with ID and respectful inclusion (McDonald et al., 2008). That is to say, researchers’ relationships with their focal population may deepen their understanding of the lived experience of intellectual disability and foster their commitment to pursuing inclusive, relevant, and sensitive research.

Moving forward, it is important to attend to ways to institutionalize the conversation on research ethics including how we train researchers, how we share knowledge with ethics committee members, and how we write about the ethics of research studies. In conclusion, we remind the reader that the views available for analysis herein reflect only those who pursue scholarship on the ethical dimensions of involving adults with ID in research, with a few exceptions of those whose empirical inquiry provides a wider lens. It is uncertain the extent to which findings are inclusive of the diverse disciplines of those who conduct and review the wide ranging research conducted with adults with ID or all stakeholder groups affected. Likewise, examining how this scholarship performs vis-à-vis specific ethical frameworks or principles might yield notably different—and equally insightful—results. While such work is undoubtedly worthwhile, we note that the amount of detail typically furnished in scholarship can pose challenges to clear judgments. We further note that the heterogeneity of adults with ID may notably impact decisions about the appropriateness of specific ethical solutions. Lastly, we provide the reminder that some countries and other legal jurisdictions have legislation or policy that relates to the inclusion of adults with ID in research, particularly clinical research (e.g., the UK’s Mental Capacity Act or requirements by the Australian National Health and Medical Research Council). It is important for research occurring within these contexts to understand their responsibilities under these laws and policies and potentially critically examine the fit of these laws and policies to ethical research principles.

It is our hope that more will choose to join the group who theoretically and empirically unpack these topics that form the foundation of our work. We also hope that as individuals focused on research with adults with ID develop ethically strong research practices, they share specific strategies and resources with the larger research community. The further development of policies and practices relevant to contemporary situations may help engender benefits to adults with ID by opening up new avenues of community participation and related social contributions and scientific advancements poised to reduce persistent disparities. Examples of these practices and policies include those that attend to context and strengths, consider consent capacity as a contextually informed construct, are inclusive of the perspectives of adults with ID, allow for the right to make nonrational decisions, foster understanding between researchers and ethics committee members, and push the integration of protections and rights to autonomy. Lastly, it is equally important to bear in mind that disability status may be only one relevant aspect of potential research participants’ context and identity.

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