

Conducting Research with Individuals Who Have Intellectual Disabilities: Ethical and Practical Implications for Qualitative Research

Abstract

Despite the acknowledgement that individuals with intellectual disabilities are the experts on their own experiences, these individuals have been largely omitted from the disability discourse. Research in the field of disability has typically been done on individuals with disabilities, rather than with them, disempowering this already vulnerable population. Qualitative methodologies, such as Participatory Action Research (PAR), can be employed to involve individuals with intellectual disabilities in the research process. A review of the literature revealed a number of ethical (e.g., obtaining informed consent and assessing capacity) and practical challenges (e.g., recruitment, data collection, analytic strategy, researcher interpretation) that interfere with researchers engaging in PAR. These challenges must be overcome in order to empower persons with intellectual disabilities to participate in research.

Despite the acknowledgement that individuals with intellectual disabilities (ID) are the experts on their own experiences, these individuals have been largely omitted from the disability discourse (Kitchin, 2000). Research in the field of disability has typically been done *on* individuals with disabilities, rather than *with* them, disempowering this already vulnerable population and taking away their voice. For example, positivist research, such as research conducted in the medical field, has often diminished and silenced the voices of people with ID and has often degraded them as “psycho-medical curiosities” (Dowse, 2009, p. 142). Conducting research, particularly qualitative research, *with* individuals with disabilities is therefore essential, yet limited research has appeared to address the issues or concerns surrounding doing so.

Although qualitative methodologies have gained popularity within the past few decades, both the quantity and quality of qualitative studies conducted with people with ID still remains low compared to the general population (Irvine, 2010; Lloyd, Gatherer, & Kalsy, 2006). Research in the field has been predominantly quantitative in nature, giving little portrayal of what the lived experiences of individuals with disabilities are really like (Bollard, 2003; Irvine, 2010; McDonald & Patka, 2012). However, the need for qualitative research in this population is particularly relevant as qualitative research “has much to tell us about the complexity of the disability experience that other types of research do not capture” (O’Day & Killeen, 2002, p. 12).

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Keywords

intellectual disability,
qualitative research,
consent,
capacity,
participatory action
research

According to Wallerstein and Duran (2006), Participatory Action Research (PAR) is “an orientation to research that focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment, and incorporates community theories, participation, and practices into the research efforts” (p. 312). The key to PAR is that it utilizes both action as well as participation to frame the basis of the methodology (Walter, 2009). The term *action* refers to the fact that research should be more than just seeking information and that research should also involve a component that aims to promote social change (Walter, 2009). Action is achieved where participants are influential in collecting and analyzing data, and determining which actions should subsequently follow, resulting in a reflexive cycle between the researcher and the community (Baum, MacDougall, & Smith, 2006).

Furthermore, the participatory nature of the research project requires an equal and collaborative involvement from the community of interest (Walter, 2009). A crucial component of PAR is the open collaboration between the researcher and the community of interest, involving the community of research interest with the research objectives to promote practical and meaningful outcomes. PAR also advocates for power to be shared equally between the researcher and the research community, preventing unequal power relationships (Baum et al., 2006), and developing a relationship where the researched become the researchers. Additionally, because PAR originates with the community of interest, the community (e.g., an individual with a disability) is provided with the opportunity to identify problems that are important to him/her, and research topics are not determined from the outside (e.g., from the researcher). Therefore, PAR is characterized by a strong and active involvement from the researcher or research team, in addition to the vigorous and in-depth participation from those with the research objective (e.g., the community) (Walter, 2009). The value of conducting PAR research is in the fact that through community partnerships, both academics and community members have the opportunity to contribute their strengths to a more comprehensive research process (Blodgett et al., 2011; Wallerstein & Duran, 2006).

The aim of this paper is to provide a selective overview of the literature with regards to the

challenges associated with conducting qualitative research with individuals who have ID – in particular, in using PAR. Recommendations are also provided for how to address identified challenges.

Methods

For the purposes of this paper, we conducted a literature search to identify studies and review articles through various sources. Databases such as PsycINFO, PsycARTICLES, Annual Review of Psychology, BioMedical Sciences, Annual Review of Sociology, ProQuest Nursing and Allied Health Source, JSTOR, and PubMed were searched. Articles were selected on the basis of their relevance and appropriateness to both the framing within a PAR perspective, as well as their applicability to the specific research issues within the ID population (e.g., ethical issues, practical issues). Key words such as “intellectual disability,” “learning disability,” “qualitative research,” “consent,” “participatory action research,” “ethical challenges,” “practical challenges,” “methodological challenges,” “communication issues,” “involvement in research,” and “inclusion strategies” were used in the literature search. As the literature on ethical and practical challenges specifically within qualitative research for individuals with ID remains relatively sparse, articles were also identified from reference pages of key articles in the field.

Findings

The review of the literature identified a number of ethical and practical challenges to conducting qualitative research with persons with ID.

Ethical Challenges

Qualitative research can lead to new discoveries that are difficult to portray in other methodological approaches (O’Day & Killeen, 2002); however, researchers often face ethical challenges even prior to obtaining relevant research findings. In particular, issues of consent and capacity determination are discussed below.

The Consent Process

According to Article 3.2 of the Canadian Tri-Council Policy Statement (TCPS2; Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC), 2010), consent to participate in research shall be informed. Researchers must “provide to prospective participants, or authorized third parties, full disclosure of all information necessary for making an informed decision to participate in a research project” (CIHR, NSERC, & SSHRC, 2010, p. 30). In order for consent to be informed, potential participants must be able to grasp the information that was provided, as well as have an opportunity to ask questions, discuss, and consider whether they would like to participate. The key to obtaining informed consent is that potential participants comprehend the information being conveyed to them by the researcher; however, for individuals with ID, the capability to provide full and informed consent has been described as a dilemma (Andre-Barron, Strydom, & Hassiotis, 2008; Lloyd et al., 2006).

According to McCarthy (1998), there is a misconception surrounding obtaining informed consent, whereby it is “implied that problems regarding informed consent can all be overcome, if handled in a sensitive enough manner” (p. 143). For example, in the case of individuals with ID, they may feel obliged to consent to be interviewed because they feel pressure from outside sources, such as their parents or workers (Irvine, 2010). According to Roberts and Illardi (2003), vulnerable populations, such as individuals with ID, are more prone to coercion than any other research participant. Until very recently, there have been few publications in the literature with regards to the issue of obtaining informed consent for individuals with disabilities (e.g., Arscott, Dagnan, & Kroese, 1998; Dye, Hare, & Hendy, 2007; Stalker, 1998; Swain, Heyman, & Gillman, 1998). Furthermore, consent to research participation has rarely been studied empirically within this population (Arscott et al., 1998; Dye et al., 2007).

Arscott and colleagues (1998) sought to examine the ability of individuals with ID to consent to research participation and found that, although all participants agreed to take part in the larger research study, none of their participants

answered their five questions regarding consent correctly. Questions regarding the advantages and disadvantages of taking part in research were the most difficult to answer. Additionally, participants in their study appeared to not understand that they could withdraw from the study at any time. Dye and colleagues (2007) conducted a similar study to assess the capacity of individuals with ID to consent to take part in research using three experimental conditions. Despite using different strategies that are often recommended by other researchers, such as having consent information broken down into sections or consent information accompanied by photographs, the authors found no differences in the ability to consent to research across groups, and only 5.9% of their sample were deemed able to consent.

The implications of Dye and colleagues’ (2007) study are particularly important because they suggest that alternative methods such as pictures are not helpful in developing the ability to consent. However, for decades researchers have been advocating for the use of videotapes, graphics, vignettes, storybooks, and other inventive methods of information disclosure to obtain consent (e.g., Dresser, 1996; Fisher, 2003; March, 1992; Matysiak, 2001). Researchers continue to suggest that it is essential to document individual informed consent using alternative methods within this population because many individuals with ID may be unable to read or write (Andre-Barron et al., 2008; Molyneux, Wassenaar, Peshu, & Marsh, 2005). For example, Cameron and Murphy (2006) outlined the importance of using a variety of supports to make language accessible, such as using symbols, simple language, bullet points, and repetition of information. As Matysiak (2001) states: “It is well and good to speak of informed consent and to have respondents sign consent forms, for example, but how is that relevant for someone who does not read and has difficulty understanding lengthy sentences?” (p. 193).

Although Dye et al. (2007) showed no empirical evidence for using alternative methods to obtain consent, one important issue has often been neglected in the literature. While researchers frequently comment on the use of alternative methods for individuals with disabilities in general, no published article, to the authors’ knowledge, has discussed implications for obtaining consent for *specific* disability populations.

Fetal Alcohol Spectrum Disorder (FASD) is an example of a condition that might present challenges to obtaining consent. Individuals with FASD often have deficits in expressive and receptive language abilities (McGee, Bjorkquist, Riley, & Mattson, 2009). Furthermore, individuals with FASD often have difficulties with memory, and therefore often need to “over-learn” a concept. The implication of this ability discrepancy means that, although researchers may believe individuals with FASD have consented to participate in an informed manner, they may not fully comprehend or understand what they are being asked to do. Individuals with FASD may seem to understand the study requirements and their ability to withdraw from the study at any time because they are able to use their expressive language abilities to appear more knowledgeable. Therefore, the researcher may believe that the individual with FASD has understood the advantages/disadvantages and potential risks/benefits of the study, but it is likely that the individual with FASD lacks comprehension of these requirements for consent.

Examples that may affect the capacity to give consent are Down syndrome and Fragile X syndrome. Individuals with Down syndrome or Fragile X syndrome both have learning challenges; however, individuals with Down syndrome often do well when they can learn sequentially, whereas individuals with Fragile X syndrome have cognitive weaknesses with sequential processing (Dykens, Hodapp, & Finucane, 2000). Individuals with Down syndrome may also have sensory deficits that can impact the consent process. For example, hearing loss may be prevalent in approximately 66 to 89% of individuals with Down syndrome, and ophthalmic conditions, such as strabismus, may be prevalent in approximately 60% of individuals (Dykens et al., 2000). Therefore, methods of obtaining consent may differ for these populations because visual or auditory presentation of information may be irrelevant.

Determining Capacity

Capacity refers to one’s cognitive ability to make a specific decision at a specific point in time (Surrey Place Centre, 2011). In order to have full capacity to make a decision, an individual must be able to understand and retain information

relevant to the decision, as well as the ability to weigh the information (e.g., risks and benefits) in the decision-making process (Calveley, 2012). Capacity is not static, but rather changes over time and requires distinctive abilities depending on the nature and complexity of the decision to partake in a particular research project. Determining one’s capacity should take place before obtaining and documenting consent because some individuals with ID may be incapable of giving consent. For example, patients with mild to moderate ID will likely be able to provide consent, whereas those with more severe to profound ID may not have that capacity (Calveley, 2012; Surrey Place Centre, 2011). Steps may therefore need to be taken to involve others who know the individual best, such as family members or paid caregivers, when assessing capacity and obtaining informed consent.

Determining one’s capacity has particular relevance for qualitative methodologies. Persons with mild to moderate ID are often able to consent to participate in research, and as researchers have noted there is an identifiable and consistent pattern of involving participants who have the ability to articulate their views in a clear and coherent manner (Lloyd et al., 2006; Paterson & Scott-Findlay, 2002). However, those with ID who have difficulties expressing themselves verbally are included less often in qualitative research, particularly interview research, due to the generalized misconception that individuals with ID have little or no insight and often lack capacity to provide coherent responses regarding their life experiences (Matysiak, 2001; Turner, 1980).

Practical Challenges

In addition to the ethical challenges discussed above, researchers often face a number of practical, or methodological, challenges when undertaking qualitative research projects with individuals with ID. Three of these challenges, communication, data analysis, and power differentials are presented in the following discussion.

Communication: Asking Questions and Assessing Credibility

Many individuals with ID have difficulties with communication, including grammar, expressive language, pronunciation, articulation, and uneven or unpredictable rates of speech (Dykens et al., 2000). For example, individuals with Down syndrome tend to have difficulties in many aspects of language and communication (Roberts, Price, & Malkin, 2007). Specifically, individuals with Down syndrome often have impairments in their grammatical abilities, with many individuals not progressing beyond a level of 3 years old (Dykens et al., 2000; Fowler, 1990). Furthermore, individuals with Down syndrome also have weaknesses in their expressive language, perhaps impeding their ability to express their concerns or queries regarding the research project or to give appropriate responses.

Similarly, individuals with Angelman syndrome have minimal or absent word usage, so non-verbal communication is best. Although this lack of language appears in almost all cases of Angelman syndrome, only a handful of studies provide measurable information about expressive and receptive language abilities in these individuals (Summers & Pittman, 2004). Despite minimal verbal word usage, there appears to be a greater variability in cognitive abilities in these individuals than was once thought (Summers & Pittman, 2004).

Although conducting qualitative research with individuals with Angelman syndrome would be extremely challenging and time consuming, augmentative and alternative communication approaches may provide a feasible option for individuals with Angelman syndrome. Such approaches may include manual sign language, for those who are able, or symbols, such as real objects or photographs, and picture communication (Summers & Pittman, 2004). Selection of appropriate communication approaches should be lead by the contemplation of several factors, including the individual's current skills and communication needs, the individual's ability to use symbols, and the individual's functional limitations (Summers & Pittman, 2004). This example is certainly not meant to serve as a means of how to go about conducting qualitative research with these difficult study

populations, but rather as an example of the challenges that researchers face in trying to represent individuals who are more severely affected in the disability discourse. As Lloyd and colleagues (2006) point out, "the only way to attempt to truly capture their perspective is to ask the individuals to express it directly" (p. 1388). These authors go on to recommend gaining information regarding the experiences "of individuals with expressive language difficulties, given the strong possibility that they might have problems making their voices heard in everyday life" (p. 1388).

It is for these reasons that some researchers have questioned the credibility of interview responses given by individuals with ID, including factors such as poor or inconsistent memory of events, difficulty in responding to abstract or reflexive questions, and confabulated or meaningless responses (see Lloyd et al., 2006 for a summary of relevant research studies). Researchers have also found a tendency toward acquiescence when more direct questions are asked (e.g., Heal & Sigelman, 1995; Sigelman, Budd, Spanhel, & Schoenock, 1981), which has important implications for the types of interview questions that are asked and the way in which these questions are asked.

Open-ended interview questions frequently result in inadequate answers, with many individuals with ID being either incapable of answering or providing little information (Lloyd et al., 2006; Sigelman et al., 1981). As previously discussed, individuals with ID have been shown to frequently acquiesce when asked yes or no questions. Sigelman and colleagues (1981) found that although slightly fewer of their participants could answer either-or questions compared to yes-no questions, responses to either-or questions were more consistent. Furthermore, responses to either-or questions from participants were somewhat more consistent with responses given from other informants, such as caregivers or parents (Sigelman et al., 1981). Therefore, asking questions that are structured and concrete may provide more clarity to the participants, resulting in more in-depth and rich responses. By engaging in PAR projects, co-researchers with ID can assist in developing questions that are relevant to them, consequently aiding in the quality and depth of interview responses.

Data Analysis: Difficulties Involving Individuals with ID

Gilbert (2004) has identified the collection and analysis of data as the most challenging aspect of undertaking research with individuals who have ID. Although researchers have advocated for participatory and emancipatory research projects, examples of research where individuals with ID have been involved in data analysis remain hard to find (Koenig, 2011; Kramer et al., 2011; Nind, 2008). The lack of involvement in the data analysis process is particularly troublesome, because research projects may strive to be participatory in nature, but may in fact be disempowering to participants.

Concerns regarding the data analysis procedure have been raised by Walmsley and Johnson (2004), who contend that there must be a place for theorizing in qualitative research that is carried out without the involvement of persons with ID. At the same time, there must be a commitment on the part of the researcher to make their theoretical findings comprehensible to their participants (Walmsley & Johnson, 2004). Thus, the implication is that individuals with ID are “barred from the critical area of analysis and theorizing that allows us to make sense of research findings” (Koenig, 2011, p. 2).

However, other scholars, such as Tuffrey-Wine and Butler (2010), argue that it may be possible for researchers with ID to make additional analytical input, but that extra effort and expenditure for spending time and providing training must be taken into consideration. Other authors speak to the “added value” (Koenig, 2011, p. 8) of including individuals with ID in the analysis of qualitative data, because findings can be grounded in interpretations of the individuals’ lived experiences. Kramer and colleagues (2011) have identified similar strengths of incorporating individuals with ID in the research process. By implementing a PAR project, Kramer and colleagues (2011) presented numerical data in three visual formats for analyses to the participants, where a two-step process was used to analyze and interpret the data. All participants in their study were actively engaged in the first stage of the analytical process, which involved analyzing bar graphs as a group. However, the second stage of the process, which involved interpreting the data, was not fully inclusive.

Despite not being fully inclusive, the findings of their study highlight two outcomes that the group experienced: empowerment and awareness. Regardless of the challenges with interpretation and dissemination, this study provides an excellent starting point for developing appropriate strategies to use when attempting to analyze and interpret qualitative data with individuals who have ID.

An important component of the data analysis process is the researcher’s interpretation. PAR projects are ideal because individuals with disabilities have the opportunity to interpret the qualitative data framed within their own experiences and knowledge. However, when just the researchers interpret qualitative data, there is a possibility of imposing their own assessments and outlooks on the accounts of participants, which may compromise the aim of the qualitative interviews if the final analysis reflects the researcher’s concerns and interpretations, rather than those of the participants (Lloyd et al., 2006).

Therefore, researchers need to be highly reflexive to make it clear to the reader how they have analyzed their data. However, as noted by Dowse (2009), theorizing about how one’s own understanding of individual biases might influence the findings has been notably absent from the literature. Therefore, there is a need for PAR projects with individuals who have ID that allow them to assist in all stages of the research project, including the data analysis and interpretation stage. For researchers not engaged in PAR projects, member checking provides a way to ensure representativeness of the data (Irvine, 2010). Additionally, researchers can strive to respect the voice of the participants by using direct quotations in manuscripts and reports produced from qualitative studies.

Challenging Disempowerment: Difficulties with Power Relationships

Disability discourse has been, and to a sizable degree still is, predominantly controlled by people who do not have a disability (Bollard, 2003; Kitchin, 2000). For this reason, disability scholars have contended that the vast majority of published articles are not representative of people’s experiences and knowledge

(Oliver, 1992) because existing literature is researcher-oriented and based on the agendas of researchers without disabilities (Calveley, 2012; Kitchin, 2000; Sample, 1996). Therefore, scholars have struggled with the notion that existing disability research is disenfranchising to those whom they seek to represent (Kitchin, 2000) and further reinforces the misrepresentation of individuals with ID. These arguments clearly provide a framing for the criticism of existing positivist research, and are the basis for why qualitative methodologies, and particularly PAR, have been called to the forefront by a number of scholars (e.g., Bollard, 2003; Brown, 2007; Kitchin, 2000; Kramer et al., 2011; McDonald & Patka, 2012; Walmsley, 2001; Walmsley & Johnson, 2004).

Because researchers have argued that current disability literature is not representative (Kitchin, 2000; Oliver, 1992), issues surrounding differences in the power relationship between academics and individuals with disabilities is clearly a challenge. The researcher is viewed as a person of importance, which can be intimidating for many participants, and in particular those with ID (Irvine, 2010). Irvine (2010) argues that researchers need to try to find ways to rectify this power imbalance by finding ways to empower participants. She suggests that such empowerment can be done through the choice of location of the interview, which allows the participant to feel comfortable and provides a feeling of familiarity. However, involving the participant in making minor choices does not actively involve them in the research project. In order to give participants a voice in the project, individuals with disabilities need to be actively engaged in all stages of the research project.

Individuals with disabilities have spoken on their own behalf and have argued that by employing individuals with disabilities as consultants in the research, research findings can be more representative of the population (see Kitchin, 2000). With participants as consultants, academics would retain control over the research process and the questions being asked, but the participants would be provided with the opportunity to correct misinterpretations and impact the course of the research (Kitchin, 2000). Although involving participants as consultants is a good start, truly equal partnerships, or co-researcher involvement,

will allow research to become more demonstrative and reflexive because the issue of unequal power relationships would be addressed. By involving individuals with disabilities as co-researchers, we acknowledge their expertise of their own circumstances and their own lived experiences. As Dowse (2009) states, "the emphasis on mutuality and the co-construction of research agendas, interpretative frames and meanings is a method that has rarely been seen in research practice in intellectual disability" (p. 151). By using such an approach, the skills and knowledge of both the researcher and the researched can merge and create a process of integrated inquiry and reflection (Dowse, 2009).

Recommendations

Participatory and emancipatory research frameworks have been recommended for conducting research with individuals who have disabilities for a number of reasons. As Balcazar and colleagues (1998) note, individuals with disabilities themselves have the opportunity to articulate the problem and participate directly in the process of defining, analyzing, and solving their own problem. This direct involvement in the research process enables a more precise and genuine analysis of their social reality, and the procedure of partaking in PAR can increase awareness among individuals with disabilities about their own potentials and strengths. Furthermore, the PAR process itself can be empowering to people with ID, because they have the opportunity to raise awareness of their situation and express a desire to change said situation if they find it unsatisfactory (Kramer et al., 2011). In order for the results to be relevant and empowering to those with ID, it is essential that the process itself is also empowering (Matysiak, 2001).

The implication is undoubtedly that individuals with disabilities need to be more involved in the disability discourse, including the research process. However, the question then remains, how do academics and researchers go about ensuring that individuals with ID are actively involved in *all* steps of the research process? Special considerations must be made regarding assessing informed consent as well as capacity, plus researchers should consider the effect of specific disabilities on the research process.

Researchers need to pay particular attention to issues involved in obtaining consent for research from individuals with ID (Arscott et al., 1998). Researchers need to spend more time when obtaining consent, which needs to be accounted for in the initial planning of the qualitative research project (Cameron & Murphy, 2006). Additionally, information sheets and consent procedures need to be adapted appropriately for specific disability populations.

For example, as was previously discussed with assessing consent for individuals with FASD, researchers should break instructions into component parts, as well as complement auditory instruction with written or visual instruction. Researchers should also provide one on one instruction regarding the requirements of the study, as well as use language that is familiar to the individual. Additionally, like in all cases of obtaining informed consent, the researcher should check for comprehension. Furthermore, when assessing consent with individuals with Down syndrome or Fragile X syndrome, different considerations may need to be taken into account. For example, breaking consent information into small components and continually building on the previous chunk of consent information may be particularly helpful in obtaining consent in individuals with Down syndrome, whereas individuals with Fragile X syndrome may more easily understand what they are being asked to consent to in the study if consent information is provided visually, alongside verbal instruction with frequent breaks and frequent repetition of information (Dykens et al., 2000). Despite difficulties with sequential processing, individuals with Fragile X syndrome often have cognitive strengths in long-term memory for learned information and in recognizing visual information (Kennedy, MacGregor, & Rosenfield, 2004).

Finally, consent should also be viewed as an ongoing process (Cameron & Murphy, 2006; CIHR, NSERC, & SSHRC, 2010). Researchers often assume that their ethical obligations are completed once consent to participate has been obtained (Freedman, 2001). However, because individuals' preferences and concerns regarding the research project may change over time, researchers should continually communicate with their participants and obtain consent throughout the duration of the research.

Revisiting the consent process throughout participation, frequently referred to as "process consenting" (Munhall, 1989), allows participants to play a collaborative role in decisions regarding their ongoing participation. Process consenting allows both the researcher and participant to assess consent throughout the research process, an approach that provides more protection and freedom of choice for participants because unforeseen issues inevitably arise and risk can never fully be anticipated. Process consenting allows the participant the freedom to withdraw from the interview or study at any time and ensures that the participant has a say in confidentiality throughout the research process.

In addition to participant communication challenges, interviewers also need to be aware of how their own communication styles and interview guides can affect a participant's response. Interviewers need to be flexible when conducting qualitative research with individuals with ID. For example, it may be necessary to have someone present who is able to assist in interpreting the language and meaning of a particular response (Irvine, 2010). Flexibility is also required to ensure maximum involvement for those whose language abilities are less articulate (Lloyd et al., 2006). Such flexibility may involve conducting interviews with the aid of other techniques to enhance understanding and allow participants to respond in different ways. For example, participants who have little or no verbal abilities may respond to questions using sign language. Interviewers should also consider the wording of their questions and how interview questions may need to be specifically tailored to each participant depending on their individual strengths and weaknesses.

Conclusion

This paper highlights the ethical as well as practical challenges and considerations that researchers must account for when conducting qualitative research with individuals with ID. It is important to draw attention to these challenges in order to improve the research process and fully include individuals with ID in the research setting.

Altogether, in order to engage individuals with ID in the disability discourse, researchers must recognize the expertise of individuals with ID

and the substantial knowledge they are able to bring to the research setting (Irvine, 2010; Kitchin, 2000; Mactavish et al., 2000). Although involving individuals with ID in research, especially those with severe or profound disabilities, can be challenging, researchers can obtain findings that provide new insights to the disability experience. By engaging in participatory or emancipatory research projects, individuals with disabilities can be active contributors in defining their own social issues or problems and become vigorous agents in initiating social change.

Special considerations need to be made to accommodate individuals with ID in the research process (Irvine, 2010), and these can present a number of ethical and practical dilemmas. The population of individuals with ID is complex and diverse, which means tailoring methods that are specific to each individual with regards to both ethical and practical guidelines. The key to success when conducting qualitative research with individuals who have ID requires the researcher to be flexible, both in adapting methods appropriately and modifying their expectations accordingly. Debates continue with regard to the most effective ways of including people with ID in the research process, as well as ensuring the credibility of research findings and interpretations (Mactavish et al., 2000). Although research publications continue to address the challenges and considerations presented in this paper, more research is needed that includes individuals with disabilities in the research process, particularly in the data analysis procedures.

Key Messages From This Article

Persons with disabilities: You deserve to be involved in all stages of the research process and to have your voices heard. Researchers should acknowledge that you are the experts on your own experiences and that you have valuable contributions to make to the field of intellectual disabilities.

Professionals: Researchers should be aware of strategies and the accommodations needed to provide a more inclusive research experience for individuals with intellectual disabilities. Researchers should be aware of the value of conducting Participatory Action Research (PAR) projects.

Policymakers: Policymakers must make certain that adequate protections are in place to ensure the safety of individuals with intellectual disabilities when participating in research. Ethical practices for research based on the Tri-Council Policy Statement (TCPS2) guidelines need to be followed.

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