

# Recruiting and Retaining People With Disabilities for Qualitative Health Research: Challenges and Solutions

Qualitative Health Research

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## Abstract

There are 56.7 million people with disabilities (PWD) living in the United States; yet, PWD are significantly underrepresented in health research. Even when researchers purposively seek to include PWD in studies, challenges emerge related to recruitment and retention, leading to inadequate representation and surface understandings of this population. This in turn contributes to the perpetuation of implicit and explicit health disparities that are already experienced by this population. Grounded within a qualitative, community-based participatory health research framework, we highlight challenges associated with recruiting and retaining PWD in health research, including a critical analysis of the research enterprise structure, how this disables accessible research practices for PWD, and leads to continued skepticism among PWD regarding the value of participating in research. Finally, we propose solutions to create and maintain a culture of access and inclusion as well as long-term collaborative and equity-focused partnerships.

## Keywords

qualitative research; quantitative research; health research; people with disabilities; community-based participatory research; recruitment and retention; qualitative; literature review; North American

## Introduction

With an estimated 56.7 million Americans (18.7%) living with physical, cognitive, sensory, and mental health impairments, people with disabilities<sup>1</sup> (PWD) have been called the largest minority group in the United States (Brault, 2012; Brucker & Houtenville, 2015). Despite this, PWD are one of the largest unrecognized health disparity groups (Krahn, Klein, Walker, & Correa-De-Araujo, 2015). Notwithstanding federal and international policies that enshrine PWD's rights to full and equal participation in all aspects of society, this group experiences disadvantages across numerous social determinants of health, including access to employment, education, and stable housing, as well as high rates of poverty, violence, and social deprivation (Yee et al., 2018). The disability experience is a unique juxtaposition such that PWD are simultaneously at high risk for health and participation disparities while also being high-volume and high-cost users of health care and social services.

Regardless of the importance placed on understanding demographic, economic, and social justice issues related to addressing health disparities among PWD, this group is ironically underrepresented in the very clinical, public

policy and research agendas that are specifically aimed at reducing health disparities (Williams & Moore, 2011). There is a critical need for a comprehensive research agenda that is based in the rich, varied, and complex lived experiences of PWD as well as the environmental factors that shape their lives. Such an understanding can lead to the development of community-informed solutions to address these disparities. Yet, even when research agendas promote the inclusion of PWD, researchers frequently encounter challenges with recruitment and retention. The purpose of this article is to highlight these challenges and offer potential solutions particularly as they relate to qualitative health research. Adopting a social justice lens, we draw on disability-focused literature and our own qualitative community-based participatory research with the disability community.

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## The Problem

Addressing the health disparities that affect PWD requires a critical and emancipatory approach. According to Smith-Chandler and Swart (2014),

Critical and emancipatory research is designed by advocates to attend to the perspective that through the research process, individuals with disabilities will be in the unique situation not only to empower themselves but to emancipate others from existing oppressive structures that preclude full and equal participation in society. (p. 426)

Qualitative health research methods are well suited to this approach in that they are more likely to adopt a “life-as-whole” data collection and analysis approach that begets a narrative that sheds light on the barriers PWD experience in their day-to-day lives (Atkinson, 1998). However, the structure of the research enterprise, inaccessible research practices, and skepticism about research leads to inadequate representation of PWD both in disability-specific and “mainstream” health-related research. Be it to assure a more accurate representation of the general population (which consists of both people with and without disabilities) or to conduct research specifically with PWD, there is value in understanding the factors that influence successful and ethical recruitment and retention of PWD into qualitative health research.

### Inadequate Representation

The United Nations Convention on the Rights of Persons With Disabilities (CRPD; 2006) indicates PWD shall be ensured full and equal rights and freedoms and with respect for their inherent dignity. These rights include *equal* and *appropriate* opportunities to participate in health-related research. However, barriers to recruitment and retention of PWD can confound the research process before and after it has begun, leading to inadequate representation of PWD.

Although qualitative research embodies a more holistic approach to understanding problems, representative participant pools are required if qualitative health researchers seek to positively impact the disability population as a whole or a targeted subset within the disability population. Rugkåsa and Canvin (2011) highlighted two important reasons why the underrepresentation of a population in health research is a problem. First, when certain groups of people are excluded from research, it limits the ability to fully understand population health issues in all of their richness and diversity. Second, from a social justice perspective, the failure to include from research members from a given population risks social exclusion and marginalization. For example, when PWD are excluded from health

research, medical model interpretations persist that situate disability as a problem within the individual that needs to be fixed or cured by way of professional intervention (Oliver, 1990). Such curative models fail to account for the role that physical, sociopolitical, and economic environment factors play in shaping the disability experience (Oliver, 1990), thus widening the inequalities they experience in health care access, quality, and outcomes.

### Why Inadequate Representation Is a Problem for Qualitative Health Researchers

Disability cuts across all ages, races, gender identities, and socioeconomic statuses (Institute of Medicine, 2007). As a category, disability is fluid and is one of the only minority groups that people can join throughout their lives. Indeed, there are few people whose lives will not be touched by disability. When PWD are excluded from health research, it can threaten the trustworthiness of the work and the contextualization of the findings, which are widely recognized markers of rigor in qualitative research (Creswell & Miller, 2000; Levitt et al., 2018). In the absence of well-targeted samples of PWD, researchers potentially miss out on the opportunity to better understand and to positively impact a population who already lives with a thinner margin of health (Pope & Tarlov, 1991). In addition, while PWD experience the same health conditions as the general population (e.g., cancer, diabetes, and cardiac disease), most research about these conditions does not include PWD. Consequently, we do not know how the findings relate to and intersect with the experiences of PWD (Williams & Moore, 2011). Therefore, health practitioners and policy makers are likely to make judgments about the acceptability of interventions (e.g., medications, services, or regulation) without the personal feedback of PWD (Lennox et al., 2005). In this way, PWD essentially become missing data, compromising the development of evidence-informed clinical interventions, resource allocation, and policy decisions.

### Deep-Seated Barriers to Research Participation Among PWD

Challenges in recruiting and retaining PWD for research exist for a number of reasons, including structure of the research enterprise, accessibility of research, and skepticism about research. We recognize each disability affords its own set of challenges and is impacted by different factors in different ways; however, to reach the broadest population of researchers, we focus on disability in the broad sense without emphasis on any one type. So, in this section, we describe the most common factors that can impede recruitment and retention of PWD.

**Structure of the research enterprise.** Research funding and regulatory guidelines can impede research before it has begun or exclude individuals with more severe or specific types of disabilities. Other disability research issues related to the structure of the research enterprise is the lack of PWD represented in it and time and resource constraints. Although these factors are not restricted to qualitative health research, awareness of how they impact broad inclusion of PWD is essential to understanding data limitations and advocating for solutions.

**Research funding.** Research funding, both federal and foundation, tends to be organized diagnostically. This organization may limit the ability to secure funding that examines the cross-disability experience and identifies the interrelationships between social determinants of health and the disability experience. Overly strict, but often poorly justified, exclusion criteria may omit people with complex disabilities or multiple comorbidities from participating in the research. In turn, this can limit the ability of research to develop nuanced understanding of the lived experience disability within and across diagnostic groups.

**Regulatory guidelines.** The designation of PWD as a vulnerable population, while necessary to ensure that decision-impaired individuals are not coerced or harmed in research, can lead to exclusion. Regulatory body guidelines can render ethics committees unable to approve disability research from happening in the first place. A person must be able to understand relevant information, to appreciate the current situation and its consequences, to manipulate information rationally, and to communicate his or her choice (Code of Federal Regulations, 2009). Unfortunately, guidelines intended to protect individuals' rights and autonomy can result in excluding and discriminating the groups those guidelines are trying to protect (Smith, 2008). Moreover, paternalistic attitudes about the need to protect PWD may lead to an overemphasis on research risks without recognizing the potential benefits to individuals with disabilities and the disability community at large (Boxall & Ralph, 2011; McClimens & Allmark, 2011).

**Lack of PWD in research.** As a whole, there is lack of PWD working in the research enterprise. Consequently, there is potential for nondisabled researchers to misrepresent and to misinterpret disabled people's experiences and interests because they themselves have never experienced what it is like to be disabled (Stone & Priestley, 1996). Even when PWD are active in the planning and implementing of research, they infrequently play the lead role (Puyalto, Pallisera, Fullana, & Vila, 2016; Strnadová, Cumming, Knox, & Parmenter, 2014; White &

Morgan, 2012). Tregaskis and Goodley (2005) contended the lack of researchers with disabilities is due to a society that perpetuates the idea that dependence on care and support is shameful and/or undesirable or a built environment that does not support their participation. Indeed, discrimination and structural barriers within academia can further limit disabled researchers from engaging fully in the process (Miles, Nishida, & Forber-Pratt, 2017; Sheldon, 2017). When PWD are not able to take leadership questions in the research design process, important questions can go unasked and unexplored. However, Sheldon (2017) problematizes assumptions that positionality as a person with disability automatically grants the researcher an emic perspective. Rather, Sheldon asserts that researchers with disabilities can help to destabilize dominant understandings of disability.

**Time and resource constraints.** Researchers' own lack of time and resources is an antecedent to recruitment challenges. It is also one of the reasons for over-samplings of convenience or of easier-to-reach individuals. Participant recruitment, particularly in the absence of direct access to a population, can require more time and resources than anticipated to achieve saturation (Becker, Roberts, Morrison, Silver, & Taub, 2004; Nary, Froehlich-Grobe, & Aaronson, 2011). However, funding timelines are often rigid, failing to accommodate changes in methodology when a given approach is not working. When flexibility is not given, "corners" are cut and the quality of the research suffers (Barnes, 2009). Similarly, the time span from funding announcements to application deadlines too often are brief; therefore, they do not accommodate the extra time needed to obtain ethics approval (a stipulation for some funding agencies) in a way that attends to regulatory body's concerns about working with vulnerable populations or that supports community-based participatory approaches (Gustafson & Brunger, 2014).

**Accessibility of research.** Qualitative research practices and conventions are highly structured and systematized to promote transparency, rigor, and adherence to regulatory requirements. Some of these practices and conventions may overshadow the access and accommodation needs of people with a broad range of physical, sensory, cognitive, and behavioral impairments. In this subsection, we highlight where and how this may happen early in the research process, during the recruitment and data collection stages.

**Recruitment processes.** In spite of the prevalence of disability throughout society, PWD are a hard-to-recruit population. Some reasons include their geographic and social dispersion (PWD usually are not clustered in particular communities or family units), the social devaluation of disability (which makes some people unwilling to

self-identify as disabled), and the heterogeneous nature of the disability community (which makes it challenging to clearly define sampling parameters) (Ellard-Gray, Jeffrey, Choubak, & Crann, 2015). In addition, recruitment materials may render research inaccessible before recruitment has begun. These materials can be text-heavy, which may disadvantage people with reading disabilities, visual impairments, or low literacy skills.

A digital divide also might prevent recruitment materials from reaching a broader disability population. Citing financial difficulties as the most common barrier, PWD have less access to technology (Abascal & Civit, 2000; Davidson & Santorelli, 2009; Kane, Jayant, Wobbrock, & Ladner, 2009; Keating, Nagai, Hadder, & Kowalsky, 2007). When they do have access, smartphones tend to be their only technology device and due to economic disadvantage, experience more cellular service disruptions. These disruptions and singular technology access point lessens the likelihood that PWD will learn about digitally promoted research opportunities.

**Data collection.** Data collection can be exclusionary even before it has begun. Consent material often contains academic language and jargon that is difficult for some PWD to understand. As a result, they may not join a study simply because they do not understand its purpose. Some regulatory bodies permit a third party (e.g., a family member, physician, or legal caretaker) to provide consent on behalf of the person with the disability; however, there are times in which that person is unknown, overburdened, disinterested (Lennox et al., 2005), or refuses access to the participant (Goldsmith & Skirton, 2015).

Also, while qualitative research data collection methods are broad and encompassing, without accommodations, they can be exclusionary. Some data collection methods, such as interviews, privilege the perspectives of people with strong verbal and communication abilities (Becker et al., 2004). Given Denham and Onwuegbuzie's (2013) finding that 71% of empirical articles over a two-decade span in *The Qualitative Report* relied on interview data collection, there is just cause for concern that many of these studies, without intending to do so, excluded potential participants due to a lack of planned accommodations.

On-site requirements for data collection can exclude viable participants, as well. Lack of accessible transportation, buildings, and transitions (e.g., sidewalk), as well as weather, geography (urban, rural), and topography (e.g., hills, ground cover, etc.) can complicate movement. Also, for people with cognitive, social, and/or emotional impairments, factors such as noise, air quality, and crowds can impede initial or continued participation. Although digital and phone technology may offer an alternative to on-site data collection (e.g., phone interviews and video conferencing), these methods may be cost prohibitive for

some individuals as it uses vital and costly data (for those individuals with only a mobile phone) or requires technology that they might not be able to afford (e.g., computer or tablet connected to the Internet) (Chadwick, Wesson, & Fullwood, 2013; Hoppestad, 2013).

Finally, data collection methods requiring excessive amounts of time or that occur at repeated intervals can make extended participation challenging, thus impacting retention rates. PWD spend tremendous time and energy coordinating services, managing health and health care, and self-advocating in a society rife with physical, social, and financial barriers to participation and social inclusion (Hammel et al., 2015). In addition, issues of fatigue, comorbidities, and mobility challenges can make participation difficult (Ellard-Gray et al., 2015). As a result, PWD, in the face of other life stressors, may deprioritize research that does not address their immediate needs or that they perceive does not directly relate to their lives (Provencher, Mortenson, Tanguay-Garneau, Bélanger, & Dagenais, 2014).

An outcome of these collective barriers is researcher's oversampling of more accessible disability communities (Kroll, Barbour, & Harris, 2007) and of PWD who have more resources/supports and thus may have more capacity to participate in research (Bigby, Frawley, & Ramcharan, 2014). Kroll et al. (2007) referred to such participants as "professional subjects." The concern with oversampling is that these individuals, compared with other PWD, may be better connected to resources and support networks, know more about their condition, and might show greater assertiveness in expressing their views, needs, and experiences (Becker et al., 2004). In addition, when the same individuals are repeatedly asked to participate in research, they may develop research fatigue, limiting their willingness to participate (Kroll et al., 2007). Given the nature of some qualitative methods, such as narrative inquiry or ethnography, in which there may only be a few participants, recruitment that most accurately illuminates people's stories or describes shared experiences is essential.

**Skepticism among PWD about research.** In addition to access barriers, recruitment and retention of PWD into research is influenced by legacies of mistrust and power differentials. This mistrust stems from a variety of sources, some of which we describe below.

**Misuse of research data.** Per Barnes (2003), some mistrust stems from politicians, policy makers, and the media's misuse of research data. To some extent, this is because contributions are not returned back to the disability community and public, or to the governmental bodies, volunteer agencies, and service providers who serve PWD, in a way that is beneficial or addresses raised



issues. This is disenfranchising to those individuals or organizations the research seeks to represent.

**Inaccessibility of academic text.** Related to contributions not being returned is the inaccessibility of academic texts, denying PWD the opportunity to act on the findings or to request funding to support research outcomes (Kitchin, 2000). Participants who do not see results of the research in which they participated or in a way accessible to them may feel cheated. Researchers might neglect this step due to limitations in time and resources, or simply that they are unaware of or do not acknowledge the importance of the results to participants and their support network (Iacono, 2006).

**Power differentials.** Mistrust in research also may stem from power differentials that exist between PWD and health researchers. PWD have been medicalized, scrutinized, and surveilled by researchers and service providers who judge who is “disabled enough” to deserve supportive services and resources and who are “capable enough” to enjoy full and equal participation in all aspects of society (Magasi, 2012; Magasi & Hammel, 2009). As a result, PWD may see academic researchers, regardless of their philosophical or epistemological orientation, as one more person passing judgment or profiting off their experiences.

**Lack of existing relationships.** In other instances, it is the lack of existing relationships (e.g., between the researcher, the PWD, and/or gatekeepers) that contributes to these power differentials. Without relationships, some PWD feel “mined” by researchers (Duran, Wallerstein, Minkler, & Foley, 2012; Kitchin, 2000) or uncomfortable with disclosing personal information to someone they do not know (Bell et al., 2008). In part, some of this is due to past situations where trust was broken (McDonald, Schwartz, Gibbons, & Olick, 2015) or where there was fear of retaliation if they were to share undesirable information (McDonald et al., 2015).

**Gatekeepers who are hard-to-reach, disinterested, overburdened, or skeptical.** Another challenge in the recruitment and retention of PWD is gatekeepers who are hard-to-reach, disinterested, overburdened, or skeptical. Gatekeepers can be both formal (e.g., administrator of a care facility, physicians, community leaders, insurers, etc.) and informal entities (e.g., support staff and family members). Regarding formal gatekeepers, large organizations may have tiers of management through which researchers must wade before reaching the person who can approve recruitment (Lennox et al., 2005). Also, service providers may lack the resources to fulfill their roles within research projects (Crook, Tomlins, Bancroft,

& Ogi, 2015) or they may delegate the responsibility to support staff who themselves have no time, interest, or incentive to assist (Becker et al., 2004; Stoneman, 2007).

Like formal gatekeepers, informal gatekeepers, such as family members and caregivers, might not have the time or energy to participate and thus perceive research as an optional, additional load (Lennox et al., 2005). Some caregivers are concerned about the loss of medical benefits for their care group if they participate (Becker et al., 2004) or their care group’s choice to participate (Goldsmith & Skirton, 2015; McDonald et al., 2015). In many instances, though, the reasons for gatekeepers blocking access to patients is unknown (Nary et al., 2011), thus making this challenge, along with others presented in this section, difficult for researchers to overcome.

## Solutions

Contemporary scholars with understanding of disability can offer insight and solutions to make research more inclusive. In reviewing the literature for solutions to the problems presented, we adopted a critical and emancipatory research approach. Per Smith-Chandler and Swart (2014), this means that the researcher(s) not only considered the perspectives and experiences of PWD throughout the research process, but in a way that empowered them. To make the breadth of these solutions readily accessible to the reader, we summarize them in a table format (see Supplementary Table 1). Also, as a supplemental file, we demonstrate how we employed many of these solutions in our own practice (see Supplementary Table 2). Although we did not include all solutions (and would not expect any one researcher to do so!), our goal was to create a culture of access and inclusion based on the development of long-term collaborative and equity-focused partnerships.

## Conclusion

Participation in research aimed at supporting others and sharing experiences can be empowering (Crook et al., 2015). Over the last two decades PWD are demanding a greater role in research as well as greater benefits (Stone & Priestley, 1996). However, there remains a need for a greater and more comprehensive research agenda that solicits qualitative health research that aims to understand the rich, varied, and complex lived experiences of PWD and the societal and environmental factors that shape their lives. Preference and support for collaborative, participatory, and emancipatory research designs that seek to rebalance power differentials between research participants and “expert research professionals” and that support researchers who do research *with* PWD rather than

about PWD is critical to reducing the health disparities experienced among the disability community.

As evidenced in this article, there are solutions to overcome the factors that preclude PWD's participation into research. Examples of this include improved communication with regulatory bodies, the employment of reasonable accommodations to obtain consent, diversifying and making recruitment more accessible, building accommodations into data collection, taking steps to foster trust, and making research easier and more appealing to gatekeepers. In some instances, technology is facilitating these efforts by making information and participation more accessible. Despite these advances, there remains much need to form supportive pathways for PWD to pursue careers in academia/research, to identify means by which to include PWD to whom research is currently inaccessible, and to reduce the societal barriers that hinder PWD's participation in both mainstream and disability-specific research. PWD already live with a thinner margin of health (Pope & Tarlov, 1991) than their nondisabled peers. Failure to include PWD in research only perpetuates the health disparities of an already underserved population. As qualitative health researchers, we can continue to learn about the factors that contribute to this outcome and take steps to generate research that improve health-related quality of life of PWD.

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### Supplemental Material

Supplemental Material for this article is available online at journals.sagepub.com/home/qhr. Please enter the article's DOI, located at the top right hand corner of this article in the search bar, and click on the file folder icon to view.

### Note

1. In this article, we focus on people with disabilities (PWD) in the broad sense, rather than any one diagnostic group or disability type. To guide our understanding of disability, we use the United Nations Convention on the Rights of Persons With Disabilities' (2006) definition: "Persons

with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." This definition integrates concepts from a social model of disability. This model emphasizes that disability is not a flaw in the individual, but rather emerges when people with bodies or minds that function different from the norm encounter barriers in the built, social, and economic environment.

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