



Accessible & Participatory Methods for Involving People With Mental Disabilities in Housing Discrimination Testing

Study of Rental Housing Discrimination on the Basis of Mental Disabilities:
Short Paper 4



ACCESSIBLE & PARTICIPATORY METHODS FOR INVOLVING PEOPLE WITH MENTAL DISABILITIES IN HOUSING DISCRIMINATION TESTING

STUDY OF RENTAL HOUSING DISCRIMINATION ON THE BASIS OF MENTAL DISABILITIES: SHORT PAPER 4

Prepared by

Katherine McDonald

Syracuse University

Tia Nelis

Joy Hammel

Janet Smith

University of Illinois at Chicago

Prepared for

U.S. Department of Housing and Urban Development

Office of Policy Development and Research

Submitted by

M. Davis and Company, Inc.

August 2017

Disclaimer

The contents of this report are the views of the contractor and do not necessarily reflect the views or policies of the U.S. Department of Housing and Urban Development or the U.S. government.

Contents

Abstract.....	1	Preparing and Supporting Testers: Use of Companion Testers as Ongoing Supports.....	12
Introduction and Literature Review: A Summary of Involving People With Intellectual and Psychiatric Disabilities in Research.....	2	Documenting Differential Treatment and the Role of the Companion Tester.....	15
Methods.....	6	Recommendations for Expanded Testing in the Future.....	16
HUD Study of Rental Housing Discrimination on the Basis of Mental Disabilities.....	6	Recruitment and Training.....	16
Debriefing Focus Groups.....	6	Data Collection.....	17
Results and Discussion.....	8	Testing Implementation Data.....	19
Proactive Commitment to Inclusion.....	9	Recommendations and Conclusions.....	20
Strategies for Tester Recruitment, Selection, Retention, and Matching.....	9	Recommendations.....	20
Preparing and Supporting Testers: Initial Training.....	10	Conclusions.....	21
Preparing and Supporting Testers: Ongoing Support During In-Person Testing.....	11	References.....	22
		Appendix: Debriefing Questions.....	25

Abstract

Scientific pursuits inclusive of community members bring benefits for science, community members, and society. Although a growing literature addresses how to involve people with intellectual and psychiatric disabilities in research, these methods have yet to be used in housing discrimination testing research, particularly in conducting in-person testing with people with intellectual and psychiatric disabilities (referred to as people with mental disabilities by the U.S. Department of Housing and Urban Development [HUD]). We conducted summative focus groups with people with intellectual and psychiatric disabilities, testing trainers and testing research team members who were

actively involved in a pilot study of market rental housing discrimination to evaluate the testing experiences. We review key findings and recommendations to determine how to effectively, respectfully conduct housing discrimination testing with testers with intellectual and psychiatric disabilities, including implications for recruitment, training, data collection, and knowledge translation of findings back to disability communities and policymakers. We pay specific attention to accommodations and supports that contribute to high-quality, accessible, and inclusive in-person housing discrimination testing with testers with intellectual and psychiatric disabilities.

Introduction and Literature Review: A Summary of Involving People With Intellectual and Psychiatric Disabilities in Research

In response to a history of exclusion and discrimination, the disability rights movement emphasizes the importance of involving people with disabilities in all matters that affect them. Inclusive approaches drive society from deficit-based thinking and marginalization to strengths-based thinking and human rights for people with disabilities (Charlton, 1998). These values provoke new ideas for research. Many argue that involving people with disabilities in the conduct of research is a moral mandate that can prevent research from having negative consequences, including further exploitation and stigmatization, and promote human rights (Beresford, 2002; Dubois et al., 2011; Duckett and Fryer, 1998). By conducting research *with* people with disabilities (and not only *on* or *about* them), scientific pursuits become informed by individuals' lived experience. Insider views may help to create knowledge that more fully and accurately reflects reality, provide more informed evidence to guide policy, and encourage change that can improve the lives of people with disabilities (Beresford, 2005; Duckett and Fryer, 1998; Telford and Faulkner, 2004). Moreover, evidence is emerging that conducting research with people with disabilities leads to innovative research questions and designs, effective interventions, enhanced recruitment and participant retention, accessible data collection, valid data, and greater trust in science among community members (Bigby, Frawley, and Ramcharan, 2014b; Bonham et al., 2004; Crawford et al., 2011; Dubois et al., 2011; Telford and Faulkner, 2004).

Evidence is also growing that community members involved in the conduct of scientific research encounter significant benefits. Community members often appreciate being able to share their perspectives, contribute, and meet new people; and they may make gains in knowledge, self-esteem, and confidence. They may also gain employment opportunities and skills such as how to use technology or how to conduct a formal test, think about and execute research, work as a team, use public transportation, and advocate for themselves and their community (Beresford, 2007; Bigby, Frawley, and Ramcharan, 2014b; Bonham et al., 2004; Conder, Milner, and Mirfin-Veitch, 2011; Dubois et al., 2011; Duckett and Fryer, 1998; Flood et al., 2013; Ochocka, Janzen, and Nelson, 2002). These gains can all improve the lives of people with disabilities and their participation in society.

A variety of approaches can be used to conduct research with people with disabilities. Although somewhat distinct from one another, they are united by shared commitments to bringing community members and professional researchers together to conduct research to promote positive community outcomes, valuing lived experiences, and equally appreciating the distinct contributions of community and professional researchers (Beresford, 2005; Bigby, Frawley, and Ramcharan, 2014a, 2014b; Ochocka, Janzen, and Nelson, 2002). Approaches vary, however, on the extent of power sharing between community and professional researchers. In this paper, we use the term *community-engaged research* to broadly capture input into the conduct of the research from community members. Many posit that community-engaged research requires support from funders and policy-makers (Carrick, Mitchell, and Lloyd, 2001) and professional researchers committed to the inclusion and empowerment of people with disabilities (Conder, Milner, and Mirfin-Veitch, 2011; Duckett and Fryer, 1998; Walmsley, 2004a), an assumption that was evaluated in this project. Related to the latter point, community-engaged research demands that professional researchers change their traditional approach to research and attend to interpersonal and political dynamics in research (Nelson et al., 1998); they may also need to demonstrate greater flexibility and creativity (Bigby and Frawley, 2010; Bigby, Frawley, and Ramcharan, 2014a; Conder, Milner, and Mirfin-Veitch, 2011; Dubois et al., 2011; Stevenson, 2014).

Community-engaged research with people with intellectual and psychiatric disabilities represents a relatively small, but growing, approach to research that is also called for by disability communities (Beresford, 2005; Ochocka, Janzen, and Nelson, 2002; Stack and McDonald, 2014; Telford and Faulkner, 2004). What research that does exist primarily explores topics with which these communities have direct experience and uses qualitative methods (Stack and McDonald, 2014; Walmsley, 2001). We are still, unsurprisingly, learning how to conduct community-engaged research with people with intellectual and psychiatric disabilities. Fortunately, many researchers are writing about their experiences and the success and challenges they encountered along the way. In this paper, we review these practices, with a focus on the involvement of people

with intellectual and psychiatric disabilities in data collection, including the activities that lead up to data collection (that is, project design and preparation for data collection).

Surprisingly few authors discuss the selection of community researchers. Those who do describe the value of having community members apply for community researcher positions and undergo a selection process to identify fit between their skills and interests and the needs of the project (Bonham et al., 2004; Delman, 2012; Dias et al., 2012; Hutchinson and Lovell, 2013; Stevenson, 2014; Timmons et al., 2011). Some add that a similar process can occur as the research progresses into new activities by matching team members' skills to specific tasks (Ochocka, Janzen, and Nelson, 2002).

Many researchers write about the need, after teams are formed, to develop explicit policies and practices to develop personal relationships, share power, provide disability-related accommodations, and train community researchers. Often these processes help to build trust, while also increasing the social validity of findings. For example, some existing literature stresses that professional researchers must create settings that enable positive relationships to develop (Nelson et al., 1998). Getting to know people, using first names, sharing personal information, and celebrating personal events can all help team members develop personal, positive relationships with one another (Beresford, 2007; Bigby, Frawley, and Ramcharan, 2014a; Björnsdóttir and Svendsdóttir, 2008; Dowse, 2009; Dubois et al., 2011; Duckett and Fryer, 1998; Gammon, Strand, and Eng, 2014; Nelson et al., 1998; Ochocka, Janzen, and Nelson, 2002; Richardson, 2002).

Establishing positive relationships also involves deliberate attention to transforming societal power dynamics so that power is shared between community and professional researchers (Clements, 2012; Delman, 2012; Nelson et al., 1998; Ochocka, Janzen, and Nelson, 2002). Acknowledging power differences; including community members on research teams and advisory boards; codeveloping principles and practices for working together; and sharing power by contributing to meeting agendas, alternating meeting chairs, listening to each person, negotiating with one another, discussing all major decisions, and clearly agreeing about roles and responsibilities are all recommended strategies for achieving power sharing (Abell et al., 2007; Beresford, 2007; Bigby and Frawley, 2010; Bigby, Frawley, and Ramcharan, 2014a; Burke et al., 2003; Chapman, 2014; Dowse, 2009; Dubois et al., 2011; Duckett and Fryer, 1998; Flood et al., 2013; Gammon, Strand, and Eng, 2014; Hutchinson and Lovell, 2013; Maddock, Lineham, and Shears, 2004; Mirza et al., 2008; Nelson et al., 1998; Ochocka, Janzen,

and Nelson, 2002; Rose et al., 2011; Timmons et al., 2011; Walmsley, 2004a; Ward and Trigler, 2001; Williams, Simons, and Swindon People First Research Team, 2005). Providing computer or other technology access and maintaining ongoing communication so that each team member is apprised of project developments and has opportunities to provide input may also help equalize power (Bigby, Frawley, and Ramcharan, 2014a; Ochocka, Janzen, and Nelson, 2002; Rose et al., 2011), as can formally hiring community researchers, although employment can be complicated for those who receive government benefits (Beresford, 2007; Bigby and Frawley, 2010; Bigby, Frawley, and Ramcharan, 2014a; Dubois et al., 2011; Duckett and Fryer, 1998; Maddock, Lineham, and Shears, 2004; Nelson et al., 1998; Northway, Howarth, and Evans, 2014; Telford and Faulkner, 2004; Timmons et al., 2011). Securing resources—including adequate time—and reflective practices may also promote power sharing (Atkinson, 2005; Beresford, 2007; Bigby, Frawley, and Ramcharan, 2014a; Dubois et al., 2011; Flood et al., 2013; García-Iriarte et al., 2009; Ochocka, Janzen, and Nelson, 2002; Walmsley, 2004b).

For people with intellectual and psychiatric disabilities, a key component of community-engaged research is the provision of disability-related accommodations to promote environmental, sociocultural, and communication access (Beresford, 2007). In general, teams including people with intellectual disability appear to emphasize the need for a wider array of accommodations than teams with people with psychiatric disabilities. Many researchers emphasize that supports should be individualized and change over time with the needs of the project, and they also underscore the value of keeping in mind that everyone, not only team members with disabilities, may need accommodations (Chapman, 2014; García-Iriarte, O'Brien, and Chadwick, 2014; Morgan, Cuskelly, and Moni, 2014; Ochocka, Janzen, and Nelson, 2002; Telford and Faulkner, 2004; Walmsley, 2004b).

Some of these accommodations require “working across differences” (Nelson et al., 1998) by timing meetings differently, having breaks during meetings (for respite from cognitive engagement), and being willing to accept behavior and language less common in professional settings. Others involve helping community researchers with transportation, as many people with intellectual and psychiatric disabilities do not have a driver's license or private transportation, may not use public transportation independently or need assistance learning new routes, or need financial assistance to cover costs of transportation (Bonham et al., 2004; Flood et al., 2013; Nelson et al., 1998; Williams, 1999). Others create accessibility by pursuing

research questions and methods (typically qualitative or photographic) more readily understood by community researchers, having meetings that involve more informal group discussion, providing short summaries of previous research (sometimes in audio or video form), and communicating using plain language (one idea per statement), bullet points, photos, symbols and graphics, and with a speed that works for everyone (Abell et al., 2007; Atkinson, 2004; Beresford, 2007; Bigby and Frawley, 2010; Björnsdóttir and Svendsdóttir, 2008; Burke et al., 2003; Chapman, 2014; Conder, Milner, and Mirfin-Veitch, 2011; Crawford et al., 2011; Davidson, 2009; Dias et al., 2012; Dowse, 2009; Flood et al., 2013; García-Iriarte et al., 2009; García-Iriarte, O'Brien, and Chadwick, 2014; Jurkowski and Paul-Ward, 2007; Kramer et al., 2011; March et al., 1997; Nelson et al., 1998; Paiewonsky, 2011; Richardson, 2002; Walmsley, 2001, 2004b; Williams, 1999; Williams et al., 2010; Williams, Simons, and Swindon People First Research Team, 2005).

Many teams working with people with intellectual disability emphasize the value of human support to help community researchers access and share information; in fact, some teams believe community-engaged research is not accessible to people with intellectual disability without such support (Björnsdóttir and Svendsdóttir, 2008; Chapman and McNulty, 2004; Walmsley, 2001; Williams, Simons, and Swindon People First Research Team, 2005). This support often involves reading information aloud in conjunction with using the practices described previously. Support may be provided by research mentors or personal assistants (Bigby and Frawley, 2010; Chapman and McNulty, 2004; Flood et al., 2013; Schoeters et al., 2005; Timmons et al., 2011; Walmsley, 2004b; Williams, 1999; Williams, Simons, and Swindon People First Research Team, 2005), or it may be provided by individuals already supporting the person with intellectual disability. In these latter cases, these individuals are also able to help the community researcher stay in communication, attend meetings, and take part in data collection (Burke et al., 2003; Conder, Milner, and Mirfin-Veitch, 2011; García-Iriarte, O'Brien, and Chadwick, 2014; Walmsley, 2004b). Some observers emphasize the importance that community researchers themselves be involved in the selection of support providers (Flood et al., 2013). Others note that community researchers with greater literacy and comprehension skills can provide support to those who have greater challenges accessing information and that experienced community researchers can help train and support new community researchers, taking on roles as peer mentors and navigators (García-Iriarte, O'Brien, and Chadwick, 2014; Morgan, Cuskelly, and Moni, 2014).

To accommodate community researchers during data collection, teams have used pictorial interview guides or surveys and color-coded questions and communication devices to administer surveys (Bigby, Frawley, and Ramcharan, 2014a; Bonham et al., 2004; Flood et al., 2013). Others have paired community researchers with professional researchers, or had professional researchers available during data collection to assist as needed (Bigby, Frawley, and Ramcharan, 2014a; Bonham et al., 2004; Chapman, 2014; Hutchinson and Lovell, 2013; March et al., 1997; Mirza et al., 2008; Ochocka, Janzen, and Nelson, 2002; Timmons et al., 2011), and some teams have found that community researchers can take increasingly independent roles as they develop relevant skills (Williams, Simons, and Swindon People First Research Team, 2005). Some teams debrief immediately after data collection to both troubleshoot for future data collection and to begin to reflect on findings and their meaning (Bigby, Frawley, and Ramcharan, 2014a; Chapman and McNulty, 2004; Conder, Milner, and Mirfin-Veitch, 2011). Because community researchers have direct experience with topics under study, which may involve difficult topics such as abuse or discrimination, some teams work with community researchers to develop plans and supports for any emotional upset they may experience (Dowse, 2009; Dubois et al., 2011; Flood et al., 2013; Northway, Howarth, and Evans, 2014).

Support for involvement in data collection may also be provided via ongoing, project-specific training, sometimes incrementally offered based on project phase (Clements, 2012; Delman, 2012; Dubois et al., 2011; Hutchinson and Lovell, 2013; Maddock et al., 2004; Nelson et al., 1998; Ochocka, Janzen, and Nelson, 2002; Perry and Felce, 2004; Telford and Faulkner, 2004; Ward and Trigler, 2001). This training typically involves the entire team and provides opportunities to watch and practice research activities such as collecting data or sharing findings via role plays and skits and via individualized feedback on performance (Abell et al., 2007; Bonham et al., 2004; Chapman, 2014; Dias et al., 2012; Flood et al., 2013; García-Iriarte, O'Brien, and Chadwick, 2014; Jurkowski and Paul-Ward, 2007; March et al., 1997; Northway et al., 2014; Paiewonsky, 2011; Perry and Felce, 2004; Walmsley, 2004a; Ward and Trigler, 2001; Williams et al., 2010).

Recent policy and legislative changes suggest that the number of people with intellectual and psychiatric disabilities accessing the rental market will markedly increase over the next several years, yet we know little about the extent of housing discrimination against this protected class. What little research has been conducted on housing discrimination on the basis of mental disability has not employed a community-engaged research

approach in a large-scale, in-person housing discrimination testing effort completed with and by people with intellectual and psychiatric disabilities themselves. The recent HUD-funded *Study of Rental Housing Discrimination on the Basis of Mental Disabilities* offered an opportunity to pilot this approach, supporting the conduct of 101 in-person housing discrimination tests that were conducted in two separate metropolitan areas. The goal of the testing was not only to measure discrimination against people with intellectual and psychiatric disabilities, but also to test a variety of testing methods with the goal of demonstrating a potentially feasible approach to nationwide testing.

After the completion of the in-person testing task, a series of focus groups were held with project leaders, testers with intellectual disabilities, testers with psychiatric disabilities, and companion testers. This paper documents the feedback, observations, and lessons learned from the focus group participants regarding the overall in-person testing experience and recommendations for future researchers who may seek to conduct larger-scale housing discrimination research employing a community-engaged research approach.

Methods

HUD Study of Rental Housing Discrimination on the Basis of Mental Disabilities

HUD recently sponsored a pilot study of housing discrimination experienced by people with “mental disability.”¹ The project had several major components, including the establishment of an Expert Panel to provide guidance to the research team and HUD over the course of the project; a series of short papers on relevant topics related to housing discrimination on the basis of mental disability; and pilot testing to measure housing discrimination against people with mental disabilities using a variety of methods, including e-mail testing, telephone testing, and in-person paired testing.

The study employed a community-based, participatory research approach to actively involve people with intellectual and psychiatric disabilities in the following aspects of the project.

- Initial focus groups to identify potential housing discrimination experiences and preferred ways to disclose mental disability during a test from the consumer perspective.
- Membership in the project Expert Panel that monitors and gives recommendations across project activities.
- Initial tester training session (1 day) with companion testers and followup practice tests in the field as a pair.
- In-person testing, data collection, and documentation.
- Post-testing debriefings with testing coordinators.
- Final summative focus groups with testers to evaluate how the testing experience went, positive strategies used to support them, and recommendations for potential expanded testing outside these two sites in the future.
- Co-authors on HUD short papers to reflect the consumer voice and implications for taking information learned back to disability communities represented.

The initial literature review and focus groups, input from the Expert Panel, and a small set of exploratory in-person tests served as preparatory steps to working with in-person housing discrimination testers with intellectual and psychiatric disabilities. These efforts were designed to provide key insight into housing discrimination experienced by this population and ideas for how to involve community members as in-person housing discrimination testers, including the recruitment, selection, and training of testers and the data-collection process. A total of 101 in-person paired tests were conducted, with each pair consisting of an individual with an intellectual or psychiatric disability and a companion without a disability.

This project represented the first time people with intellectual and psychiatric disabilities served as in-person testers on a multisite, larger-scale basis in housing discrimination research; therefore, this pilot project was also assessing—

- The feasibility, reliability, and fidelity of testers from these groups.
- The use of paired companion testers as a support to these testers.
- The accessibility of training, testing, and data collection materials to enable these testers to fully participate in this project.

To this end, many reasonable accommodations were utilized to proactively support testers, many of which are discussed and evaluated in the following debriefing focus group results.

Debriefing Focus Groups

To evaluate the inclusion and active participation of people with intellectual and psychiatric disabilities as housing discrimination testers, we conducted four summative focus groups with key participants and stakeholders involved in this housing discrimination pilot study. These focus groups were with—

¹ *Mental disability* is defined as “(1) having a mental or psychological disorder or condition that limits a major life activity, including working; (2) any other mental or psychological disorder or condition that requires special education or related services; (3) having a record or history of a mental or psychological disorder or condition which is known to the employer or other entity covered by this part; or (4) being regarded or treated by the employer as having, or having had, any mental condition that makes achievement of a major life activity difficult” (*Foster v. City of Oakland*, 2009 U.S. Dist. LEXIS 70094).

1. **Project leaders.** The team who designed and carried out the project, including the two principal investigators, two testing coordinators from regional sites, and four project team members involved in training and research protocols.
2. **Testers with intellectual disability.** Three testers with intellectual disability from the Chicago and Washington, D.C. sites.
3. **Testers with psychiatric disabilities.** Four testers with psychiatric disabilities from the Chicago and Washington, D.C. sites.
4. **Companion testers.** Five people who were trained and conducted in-person tests with testers with intellectual and psychiatric disabilities from the Chicago and Washington, D.C. sites.

In all, four focus groups, including 20 individuals involved with the in-person paired testing, were held. The focus groups were held in the weeks immediately after the completion of in-person testing and data collection so participants could reflect on their testing experiences over time. Individuals participated in the focus groups in person in Chicago at Access Living Center for Independent Living and via teleconference in Washington, D.C., connected via the Equal Rights Center (ERC). All participants, except those on paid project positions, received a \$50 gift certificate to reimburse them for their time, and, in cases where needed, received transportation funding. Participants also signed consent forms and the University of Illinois at Chicago Institutional Review Board approved the research.

The focus groups were facilitated by two people: (1) a member of the project Expert Panel with extensive academic and research experience in participatory action research with people with intellectual disabilities and (2) a member of the project Expert Panel who is a leader and disability advocate in the intellectual disability community and who self-identifies as an individual with intellectual disability. Both facilitators had previous experience conducting qualitative focus groups; neither was directly involved in conducting the in-person testing.

The facilitators asked broad questions with specific probes to delve deeper into areas of interest identified by project team members, participants, and HUD (see specific group guides in Appendix A of this paper). Peer mentors in these communities reviewed questions for the testers with intellectual disabilities and psychiatric disabilities to ensure they were accessible and easy to understand. All groups were asked to describe their experience with the in-person testing (including whether they felt respected), what went well and what challenges were encountered, what was learned over the course of the project, whether companion testers were necessary, whether people with intellectual and psychiatric disabilities can be testers, and ideas for making the project better and doing this work on a larger scale. For the project leaders, we asked additional questions about how they designed and implemented the project (including tester recruitment and selection, training, and data collection) and what strategies they used to include testers with intellectual and psychiatric disabilities. Testers were also asked whether they would recommend being a tester to other people with disabilities. Lastly, both testers and companion testers were asked whether they knew what to do if they encountered a problem during the in-person testing.

A real-time captioner was used to document the focus groups and create verbatim transcripts for each group. Research assistants then checked these transcripts using notes taken during the focus groups. The first author, using an inductive data reduction process, conducted a thematic analysis to identify key themes and meaningful patterns among themes. All authors critically reviewed the themes, and revisions were made until agreement was reached (Braun and Clarke, 2006). Themes were then member checked, or audited, by the lead facilitator with intellectual disability to ensure they accurately portrayed the experiences of testers with disabilities and could be relayed back in an accessible format. After they are finalized, results of the focus groups will also be shared with all focus groups participants.

Results and Discussion

In general, testers, companion testers, and project leaders enjoyed working on the project, and valued the opportunity to be part of what they saw as important work.

I enjoyed the project. (tester with intellectual disability)

My experience was great. (tester with intellectual disability)

Testers felt respected by others and felt that trust was gained as a product of receiving accommodations to support their involvement. Many testers wished the project lasted longer or that they could do more testing than their financial situation would permit (because of the receipt of benefits). Testers also felt they benefited from their work because they learned how to conduct apartment searches, take notes and complete forms, and evaluate potential housing discrimination issues and access needs.

I got to see other areas of noncompliance ... where things didn't work so well. (tester with intellectual disability)

The experience I got is how to look for an apartment and learning how to show I.D. and stuff. How to ask for applications. How to take it home and get a business card. That's how you look for a job but it is a different experience. (tester with intellectual disability)

The process of even filling out a report. I've never done it before. (tester with psychiatric disability)

They also had a chance to meet new people, go out in the community, and see new types of apartments and areas of their community.

I got to meet new people I haven't met before. (tester with psychiatric disability)

It was kind of nice to get out. (tester with psychiatric disability)

I got to see apartments I wouldn't have seen. (tester with psychiatric disability)

As companion testers witnessed potentially differential treatment toward testers with disabilities, they came to better appreciate the value of the project; these experiences also strengthened their commitment to the work.

You know, the things I learned this time around is if you do it by yourself for so long, you're a lot more removed from the process of what you're doing. You know what you're doing and you know this is good stuff you're doing. But when you have that person right there with you [referring to tester with disabilities with them at tests], there's a different type of investment. On my part, there is a different type of investment. It is—it hit home that I was doing something important. (companion tester)

Companion testers also had opportunities to observe the capabilities of people with intellectual and psychiatric disabilities.

Another major thing I learned is just how capable these people are. I had worked with some people with these challenges in the past, these mental disabilities and I had, you know, some feel for how they worked at an ordinary job. Again, the dedication I saw on the part of the two people I worked with and also just how capable they were. They really didn't need help in terms of being able to memorize what was required. No help at all. I learned to have all the more respect for people who have these so-called mental challenges. (companion tester)

The only frustrations testers and companion testers expressed involved instances in which landlords did not show up for appointments (and, hence, they felt disappointed that time was wasted and initially uncertain about how to handle the situation), apartments shown by maintenance or janitorial staff who could not answer questions or provide a meaningful experience, and apartments far away from public transportation. One tester reported knowing a landlord from church.

When I walked in the door and saw the woman, I kind of knew that I knew her. And then when she looked at me and she looked at my name and she said oh, you're [name]? And I said yes, ma'am. And she just gave me this look like I know you, too. And it really kind of freaked me out and I just kept, I stayed with the role and when she asked for my phone number or e-mail address, I just fumbled. ... I tried to ... throw her off and stuck to my script ... it turned out fine. (tester with psychiatric disability)

Proactive Commitment to Inclusion

Project leaders felt that their interest and excitement in working with people with disabilities, their commitment to including testers with intellectual and psychiatric disabilities, and their proactive approach to recognizing that accommodations would be critical to promote the successful inclusion of testers with intellectual and psychiatric disabilities. For example, project leaders worked with focus-group participants and the project Expert Panel, which included many members with disabilities, to proactively identify potentially needed accommodations to make in-person testing possible and accessible to testers with disabilities. These processes helped the research team and testing coordinators design training and testing protocols responsive to the accommodation needs of testers with intellectual and psychiatric disabilities (described in the following section).

I would say that from the very beginning, you know from the research design planning on the data collection planning, you know, we had in mind and identified areas where we might need to adapt our typical tester recruitment and training and maintenance in order to accommodate using testers who actually have intellectual or psychiatric disabilities. And there were really helpful members of the study team as well as Expert Panel members who assisted in identifying the kinds of things that we might need to incorporate or address or be aware of. (project leader)

I think the first thing we did was the inclusion of a companion tester ... someone to support testers to remember details and to help in documenting experiences. (project leader)

We would just kind of check in with them about what they needed. ... Do you want me to read it to you? ... What's their preferred method of contact? (project leader)

Strategies for Tester Recruitment, Selection, Retention, and Matching

Testing coordinators from the two metropolitan areas broadly recruited potential testers, typically by calling (often multiple times) a variety of community groups and organizations in which people with intellectual and psychiatric disabilities actively participated or from whom they received housing or community living services. Because of widespread employment disparities among this population, some people with intellectual and psychiatric disabilities were found to be more available to work as testers; however, this fact may also have limited the recruitment of testers with full-time jobs or busy schedules.

Testing coordinators also communicated extensively with potential testers to discern if testers could complete the essential job duties. In these interactions, testing coordinators talked about the value of providing potential testers a candid and thorough description of the project and their expected role (including emphasizing the responsibilities akin to other jobs), assessing how the potential tester understood his or her role, and the potential tester's comfort with "pretending" to be searching for an apartment and disclosing their disability during the housing search process. All these issues were proactively covered in the initial training.

The team maintained flexibility in the tester training protocols, simplifying and limiting background information and lecture. Instead, the team focused on mini practice exercises and open discussions about questions to enable the testers to gain comfort with doing a test and working with a companion tester. Testing coordinators and trainers acknowledged that these adaptations to improve the usability and accessibility of the training materials could be useful in other discrimination testing and training projects with protected classes other than people with intellectual and developmental and psychiatric disabilities.

For some project leaders, initial training helped test coordinators make a final determination about a potential tester's involvement in the actual in-person tests.

We did some pretty extensive interviews with people and not that they were these formal interviews but more of kind of longer conversation. So I think each time we met with a new tester candidate, it probably took about an hour that we spent with each person ... just completely being very honest and frank about what the project's going to look like. Assessing their comfort levels ... we asked a number of questions and really tried to feel out if they understood what this was about. (project leader)

I tried to get people to come to the training because I figured in the practice test, it would become obvious whether or not they were able to do the study. (project leader)

One of my big struggles is many people didn't feel comfortable disclosing their disability. So there were a lot of people who were interested and said oh, well, I'll be the companion or I just don't want to be involved because they didn't feel comfortable disclosing their disability. On the MI [mental illness] side, that was I think one of the biggest struggles recruiting there ... but we did get enough testers. (project leader)

Testing coordinators also noted that they needed to allocate significant time to the recruitment process, needing to initially recruit about three times the number of testers needed. For example, in some cases—most notably among potential testers with intellectual disability—availability and reliability were issues (for example, getting training scheduled, not showing up for scheduled training, the availability of reliable transportation, and the need to navigate a new transportation route without support). This challenge of time was especially difficult given the need to coordinate testers with intellectual disabilities with companion testers for initial training, practice testing and for each in-person test.

Getting and keeping people who had intellectual disabilities engaged was one of the hardest things in terms of reaching out, I reached out to a lot of different organizations, a lot of different people. I had people who, you know, put me in contact with specific individuals that they thought would be great. And I just couldn't get them in for training. They would have conflicts. I would call that week to remind them and they had scheduled something else. (project leader)

Despite challenges, testing coordinators from the two participating community agencies were able to recruit the necessary number of testers given their extensive contacts and constant networking with community groups and people with disabilities, something that could not have been done by an agency that was not familiar with and embedded within disability communities. The use of these community-testing organizations, Access Living and ERC, were constantly identified as a critical component of the project and a key to success in actively supporting people with intellectual and psychiatric disabilities during the in-person testing effort.

Testing coordinators also noted it was important to identify people who would be good companion testers, and ensuring a strong rapport between a tester with disabilities and his or her companion tester was key to the tester's comfort and to the quality and efficiency of testing. Coordinators also noted that it was especially important that testing coordinators regularly monitor how that match was experienced by both testers and companion testers throughout the testing assignment, including assessing this fit during the initial training, in which the team purposively built in many opportunities for pairs to get to know each other and become comfortable with each other during practice tests.

Testing coordinators and testers agreed that pairs should be rematched if one of the members was not comfortable and that tester choice of companion was very important to the comfort and fidelity of the tester and data collection.

I enjoyed working with [companion]. I think we work real well together. (tester with intellectual disability)

The energy just wasn't there [referring to relationship between tester with psychiatric disability and her first companion match]. She was on a totally different page ... she was more in thought and in words about what she was doing as far as her own personal business was concerned. ... I'm not saying she didn't do what she was supposed to do but the thing was that first of all, she did not know how to provide the information that was necessary. She could remember it but she kept jumbling it up. The other thing was that she didn't necessarily want to give me a copy of it. I just kind of became very forceful and just called her out directly and said you cannot write like this. This is not about you. But that's just my attitude. So I was kind of uncomfortable with her. ... I did inform staff here that I would prefer not to work with that individual. (tester with psychiatric disability)

We worked around that and we found that some of the testers worked well with certain companions of their choice. (project leader)

Preparing and Supporting Testers: Initial Training

Project leaders worked to design tester *training* to effectively engage testers with intellectual and psychiatric disabilities and actively support their learning. For both groups, training materials deemphasized complicated text, reduced the number of ideas presented at one time, and incorporated graphics, photos, and images to illustrate more abstract points, such as civil rights. The trainings also included opportunities to observe testing skits performed by testing coordinators and project staff first, and then for testing pairs to actively engage in several different testing scenarios through role plays (moving from working in pairs with an assigned project staff to role playing in the front of the whole group and getting feedback afterwards) and frequent breaks to take in information learned. Based on initial insights from consumer and stakeholder focus groups and discussions with the Expert Panel at the start of the project, project leaders delivered the training differently for each group to maximize their learning. For example, testers who had an intellectual disability had the information broken into smaller units followed immediately by opportunities to practice a small skill first and then build up to practicing a full test, and finally moving on to an actual practice test in the field. Testers with psychiatric disabilities received initial information in one sitting and then practiced different scenarios.

We structured trainings so that we train testers with intellectual disabilities and separately so that each of the sort of three categories of testers, the control testers, the testers with intellectual disability and the testers with psychiatric disabilities were trained separately so the content wasn't different in the trainings but the delivery might be a little bit different. The companions for the protected testers were trained together with the protected testers ... this helped to make them feel like partners or a testing team. (project leader)

In developing the presentation for the training itself ... [we] simplified the Power Point presentation pages so they weren't overwrought with information on one page. We tried to keep it to you know, two to three bullet points per page. So that we were providing the information but providing it in a way that wasn't so overwhelming to any of us. And I think—I also tried to put in some artwork. Some color, some graphics. So that it wasn't just a monotonous white background with a border. We tried to keep it interesting and accessible to that group. (project leader)

We did role playing which was very, very helpful [emphasis given]. We did an initial role play with the staff members and then we had the individuals do small group role plays of a scenario being out in the field. And then we reflected as a group and this brought up lots of great questions on testing. And that was something we don't normally do in our training. And was very, very helpful. (project leader)

We created skits to make these trainings more engaging. I personally thought that was a really effective—a little bit more enjoyable for both ends. Some showed a best case scenario and some showed a worst case scenario so they could see a range of what might happen. So that testers could better understand what we're asking them to do before they even started the role plays themselves. And we also allowed time for frequent breaks which probably was helpful as well for many of the testers coming in. (project leader)

Testers felt that these experiences—particularly the opportunity to practice and receive individualized feedback—helped them learn their responsibilities and feel prepared for their role.

I think I was really equipped doing the training. (tester with intellectual disability)

The training was fine in terms of like kind of prepared you for worst case scenario. (tester with psychiatric disability)

What I felt worked well are the people that I worked with here that was in charge. [The testing coordinators] all of the project. They took so much time to work with the testers. They invested a lot in role playing before we went out on tests. (companion testers)

Some testers noted that when there was significant time between training and testing in the field, it was beneficial to have opportunities to brush up on their skills and debrief about how they were doing. Project leaders felt that providing a significant amount of time during training that would be devoted to hands-on learning was essential.

Preparing and Supporting Testers: Ongoing Support During In-Person Testing

Project leaders also supported testers during *data collection* in ways that testers and companion testers found helpful. Project leaders provided scripts and checklists to help testers remember the personal information they would need to provide during testing. They also provided reminders via e-mail, telephone, or both (cell phone communications were used frequently before, during, and after testing) and were readily available to respond to questions and assist with unanticipated problems.

And so there was always somebody to answer the phone [at testing coordination site]. So it was never like an organization that you can't get back to. They are here. They were there. And they were supportive. (tester with intellectual disability)

The agency itself here [testing coordination site], they've been extremely open. It seems to have an open door policy. So it's like well can you stop in at so and so I can't make it at that time. Can I come at such and such a time. Yes that'll work. They've been here to be supportive as well. (tester with psychiatric disability)

If I had any questions about anything, I either e-mailed [the testing coordinators] or whatever or if I needed to know like say if I'm on my way there or the day before that, okay, what time is it? I would call them and they were very helpful with that. (tester with psychiatric disability)

We allowed a lot of time, a lot of extra time for the briefings and debriefings than we normally do for testing. (project leader)

Many project leaders and testers agreed that being able to debrief with the testing coordinators immediately after each test (either

per the telephone or in person) was very helpful. The project design intentionally had this debriefing occur within 48 hours of the actual test and, in many cases, testers completed debriefing immediately after the test or within 24 hours.

For some, being able to complete the forms at the testing coordination agency allowed them access to onsite computers and to the testing coordinators in case they had questions; these factors helped them submit completed forms quickly and accurately.

We always came back and used the computers here [testing coordination site]. That was useful for two reasons. First, it was immediate. Second of all, I have a patchwork of computers and I've had a variety of difficulties with them. So it was really nice to use the computer here. Use their downloading system. And when we had a question about the questionnaire and there were some confusing questions, [testing coordinator] was right there to tell us what she wanted. So I think that was really important because in the past, I have waited—when I was testing on my own or with someone else, we've waited awhile to do the narrative and the questions. But that was so helpful, I think to the tester and to me to get it done right then and get it where you had help. I thought that went really well. (companion tester)

Project leaders felt it was important, whether for training or data collection, to ask testers what they need assistance with (for example, writing, reading, or a quiet room to complete forms in) and to be flexible in responding to testers' emergent needs. Many noted that support decreased over time as testers increased their skills and comfort. Although some testers initially felt nervous, they reported becoming increasingly comfortable as they gained experience.

I did pretty good. I got nervous on a few tests but after that, I got the hang of it. (tester with intellectual disability)

Thus, supporting a key group of testers was important so they could do multiple tests and feel comfortable in doing so, rather than trying to have a large pool of testers who might conduct only a single test.

Preparing and Supporting Testers: Use of Companion Testers as Ongoing Supports

Companion testers also provided support to testers during data collection. For example, when testers forgot to ask a question of a landlord, “got off track,” or “froze,” companion testers were able to naturally prompt the tester or provide a response.

The agent asked me how much did I make? And that's the first time I froze on that. Practiced with [testing coordinator], research team. When they finally asked that question, I froze ... but [my companion tester] jumped right in and talked me through it. (tester with intellectual disability)

There's times I can stutter. And then you know, I go and I look up. He [companion tester] would prompt me. (tester with intellectual disability)

I was with three different companions and they all had done this before. They knew okay, what to look out for. They could think on their feet. Which is good because sometimes I forgot something and they brought it up. (tester with psychiatric disability)

And from my standpoint, it was slightly easier because I was in the background observing as opposed to having to lead the test asking the questions with the other person who would, you know, be asking the things. Occasionally, if they [tester with disability] would not bring something up, that would need to be brought up, then I would poke up. Oh, you wanted to ask about what lease lengths. (companion tester)

Companion testers also reassured testers and helped them feel less nervous during data collection or in a new area of their community.

He said it is okay to be nervous but after that, you'll get the hang of it. Just be yourself. Just say why you're here and then just tell why I'm here to help. After we did all of that then we were role playing. After we got out of the car, it worked out well. (tester with intellectual disability)

The person I was paired with was really awesome and he had done these types of things before so having somebody who had experience I thought was really helpful in terms of just like pointers and making me feel calm because I felt like if we had two people who had never done this before, we could have blown it or forgotten something. (tester with psychiatric disability)

I think I took pressure off the main tester. They didn't have to remember everything nearly as much because I was there like keeping track. But at the same time, they would often need at least a little prompting. They would forget a question or two. And I would be there to be able to say oh, weren't you curious about this? And they would say oh, yeah, that's right. If I hadn't been there like that part of the test could have easily been forgotten. (companion tester)

Companion testers were also able to provide assistance by taking notes, organizing and remembering information, helping out when unanticipated situations arose, and in some cases with transportation.

She helped me with role playing with [testing coordinators]. And to help organize my notes before we went on each test. (tester with intellectual disability)

I think that it is important to have a companion when you're going out because your eyes just cannot catch everything. Your ears cannot hear everything. And your mind will not hold everything. (tester with psychiatric disability)

Even having somebody to talk to like the times that we did take the public transportation together and having them be there and say oh, you know, don't forget you wanted to ask—which was fine because in my story, part of my disability was forgetting to ask things. So he could openly remind me and it wasn't weird at all. Oh, this is great. So that really helped me a lot because sometimes they would really want to sell the apartment. They would be talking and talking and I would forget one or two things so he could remind me. So I think those three things, it was nice. I really got to know my partner and I had the same one throughout the whole thing. So it was just nice having somebody there. It was like meeting up with a friend to go do it so that helped a lot. (tester with psychiatric disability)

The companions ended up being really, really helpful in getting that filled out in a timely manner and also capturing a lot of details because you know, they were taking notes. (project leader)

Many testers and companion testers felt that companion testers may have helped some testers feel less stressed because immediate support was available, that testers and companion testers complemented one another during data collection by offering different ideas, and that working as a pair made the experience more enjoyable. Testers and companion testers noted that the support provided by companion testers during data collection may have added credibility to the disclosure of a disability by testers.

I think we were very believable. We were very believable when we were there. He would reinforce to them that you know, she has a disability. ... I'm here to take the notes. (tester with intellectual disability)

I think it kind of backed up my claims a little bit. I guess kind of add more proof to whatever story I was throwing out there. (tester with psychiatric disability)

I feel like having the companion backed up the claim. If I just went out there, I have a disability, I do have memory issues. But having that person backing you up, it made it more real. (tester with psychiatric disability)

For when it was the case where the main tester would have a developmental disability that made it hard for them to remember things and thus I was there to take notes, that provided such a perfect excuse for me to take notes in the background. And it was great. I appreciated that. It made things just a lot easier. They didn't bat an eye to see me in the background scribbling down things the whole time the test was going on. That worked well for me. (companion tester)

On the other hand, some companion testers wondered whether their presence tempered potential opportunities for differential treatment by landlords.

A lot of times, they would say that partially looking at me. I knew they were sort of saying that because they know I'm recording this. They say yeah, well, you know—one guy say well I think people with disabilities, they should have just as many rights as other people. He's looking at me. I just think that if I weren't there, that response wouldn't have been there. ... I won't go as far as to say less discrimination but it was more—they didn't rush us through it. They were more respectful. They were more engaging. So I don't know if it was—I don't know what the end result would have been. That's why I don't know if I go as far as saying they were less discriminatory. (companion tester)

I have to agree with that because on at least a few of the tests, I feel like if I hadn't been there, they probably would have treated the person differently because they were clearly uncomfortable that the person had the disability but they would look at me and you could tell they were holding their tongue. I can't say for certain but I got that impression on a number of the tests. I think my presence there did cause them to treat the person with the disability differently. (companion tester)

Most participants felt that companion testers were most effective when they saw their relationship with the tester as a partnership. That is, when companions understood that they were there to support testers, not to be testers themselves.

There was a mutual respect before a narrative was sent over to the office, we both reviewed it no matter who the primary writer was. Particularly with [my companion tester], we would sit in the car. Do you think I need to put that in? I said yeah, put that in! (tester with intellectual disability)

Because I was a lot better typer than my partner, companion. What we did is I would type it up. He sat next to me so we would go through—we both took notes and then we would go through and make sure that our notes jive or he might have something I forgot to take down and we would go through and fill out the questions first that we would use and then do the narrative. We wrote the narrative together and I would say it out loud and then double check with him. It was like a team effort. (tester with psychiatric disability)

The first one I did, that was kind of stressful. Because of the companion I was with and with the narrative, she just started typing everything up without even telling me anything that she was typing or even telling me what she was—so I was just sitting there. She's like I did this, I did this, I did this. [Tester with psychiatric disability] did this and I did this and I did this. That kind of frustrated me. So after she had done that, and plus there was stuff left out and stuff that—so I just—I retyped like most of it because a lot of stuff wasn't in there and a lot of stuff that was said in there. Then basically, I had to leave. I had finished signing it and she had just waited for the companion to come back and look at it and sign it. The second person I was with, basically, it went a lot better. Because they explained it that since I was the person doing the test and the companion would look over it and I would ask is there anything else I should put or what else should go in here and stuff like that. Then she would look over it and then it was all done. (tester with psychiatric disability)

I had to keep in mind that it was a partnership. (companion tester)

To achieve this outcome, companion testers need to be flexible to tester's needs and preferences.

I had to be more patient because I'm used to just doing it all on my own and I really had to make sure I gave my partner room because he—my partner had the answers and I did, too, and mine were waiting to be blurted out. . . . I had one partner . . . he talked and talked. If he got off track, I had to sort of get in there. Another partner went at a totally different place on the other side and I had to find out when he actually needed prompting because he navigated it differently. And then I had another partner, I mean, partner of partners. It was like golden. So you know, just dealing with the different personalities or the way people navigated differently. (companion tester)

The dynamic of successful relationships evidenced itself when testers and companion testers had discussed and agreed on who would do what, had good communication before and after data collection, and both contributed to the completion and approval of reporting forms. It may take mentoring, training, and role playing to help companion testers excel in these supporting roles.

I think the biggest—one of the biggest things that we did was to—from the start of testing was to not make assumptions about what testers could or couldn't do. So this came up especially in terms of who—which person in the pair was going to be taking on the role of writing up the test report and the narrative and that there was no assumption made that one or the other was going to do it. Kelly and I both were really involved in facilitating, figuring out, among each pair, after each test, figuring out who was going to take on that role. And what that was going to look like and what the other person might be doing at the same time. Like who was going to be taking on the actual typing up, writing, that kind of stuff. And I think this was obviously important in terms of people with disabilities feeling respected but also modeling that for the companion. So modeling it for the people without disabilities, for them to be isn't how we're going to treat each other and you know to really respect that we all have different strengths and limitations so I think that was one of the biggest things. (project leader)

This observation may be especially true for companion testers who had been testers themselves in other discrimination tests. Although their previous experience provided great knowledge and insight, they also had to transition to playing a supporting rather than primary role.

I had to learn to sit back a bit and let somebody else carry the ball more. (companion tester)

When directly asked whether companion testers are needed, nearly everyone agreed that most testers with intellectual disability would need a companion tester to complete data collection. Many participants felt that most testers with psychiatric disabilities, however, and perhaps some testers with intellectual disability, could initially use a companion but could then do testing on their own as they gained experience.

I would not have been able to do that without a companion. (tester with psychiatric disability)

But if it had been longer, a year or seven months or something, I felt that by the time I eventually—we didn't have time to keep going up but I felt by that time, I probably

could have done it by myself. . . . But having the partner there is like having training wheels. (tester with psychiatric disability)

I feel I would have been able to do this on my own if I had done this before and I mean I'm a lot different than a lot of other people or whatever. I don't mind going anywhere in the city. (tester with psychiatric disability)

I think a couple of my partners could have did it totally on her own if it were about going right up to it and it happening but if you go right to it and it doesn't happen right then and there, that's where you get that—you know, those things that might happen that you don't know how to take care of. (companion tester)

I think most of our testers with MI had an incredible ability to recall all of the questions. I feel like they could have done these tests on their own. And we had—one of the testers with the developmental disability who also I think could do these tests on his own. (project leader)

Documenting Differential Treatment and the Role of the Companion Tester

Lastly, some testers reported that landlords treated them differentially and that the companion tester helped to document and handle that treatment. For example, one tester was asked repeatedly whether they had a criminal background, what their income was, and whether they could afford the unit.

The resident managers kept wanting me to say that I had a criminal record. She went over that a few times. Are you sure? Because we're going to look. I said no, I'm a person with a disability. You tell me now, I can take that into account. She asked me three times. The first "no" should have been sufficient. I answered her three times. (tester with intellectual disability)

Another tester felt the landlord was suggesting she may not be intelligent enough to live in the building, and another was told the landlord would pray for her.

One guy was very nice. He prayed for me. He hoped that my mental illness got better and he was praying for me [tester smiles and shakes head]. He was very nice about it though. (tester with psychiatric disability)

Other testers reported landlords acting distracted (talking on the telephone or looking at their watch), being abrupt in interactions, refusing to provide an application (likely because an application had been received earlier in the day), or simply "giving attitude."

Generally people greeted you. They greeted you politely. But there is an attitude. And there was nothing in the training or in the process to put in the attitude. The attitude is not something that they say. But you feel it. (tester with intellectual disability)

We had one person—I guess he was the realtor that refused to give us an application to an apartment. It was like okay. He was going to give us a business card. Just abrupt with us. Someone had put in an application that day. Figured I'm done. . . . We had another lady, she wasn't rude. I feel like if she had a watch, she would be looking at it every 10 seconds. (tester with psychiatric disability)

Companion testers had the sense that testers appreciated having someone with them to witness and validate this treatment, and to member check their documentation of it.

I mean the fact that I was able to see it, I think made them feel a little better because after some tests, they would say did you see when they asked me that? I said yeah, that was something they would have never asked me. So having someone acknowledge that, yes, this is going on, I think probably at least made them feel a little better as unpleasant the discrimination obviously made them feel. (companion tester)

Recommendations for Expanded Testing in the Future

Although the testers understood the scientific value of the current testing approach and its focus on one specific disability group (for example, intellectual or psychiatric disability), many protected-class testers wished the project could be broadened to better reflect the lived experience of disability, especially because many people with disability experience more than one functional limitation. For example, some people with intellectual disability also were anticipating some future physical access issues and wanted to be able to document those as well. They also thought it would be illuminating to study the qualities of “accessible” housing, particularly what that means and looks like for people with intellectual and psychiatric disabilities.

Widen the scope. We dealt with intellectual disabilities but developmental disabilities, they run neck and neck. Being able to get in a building and get out of a building safely. Noticing the differences. ... So just widening the scope of things so we can mention in a narrative that if you see a problem, you know, because like you said, discrimination ... if there is a difference in treatment and in placement, that's discrimination. I see where that exists. I see where that exists. That whole thing about where the ramp is. How do you get in? Where the steps are. Apartments that don't have elevators. How do you accommodate? They'll say well, it's okay to live here but you don't have an elevator. Just widening the scope. So it would be easier to identify the discrimination. (tester with intellectual disability)

There are certain properties that are HUD or affordable properties that persons with disability because of their ability to pay. Their real ability to pay. We went into this role having a good salary and a trust. In reality, persons with disabilities don't have that financial means. And the buildings that they live in weren't included in the study. And some of those buildings are HUD funded. And they are substandard. And that's it. So again, it's like make it a little more real for persons with disabilities. (tester with psychiatric disability)

I would include more people with props. Wheelchairs, walkers, you know. More visual effects. Maybe you know button your shirt up wrong. (tester with intellectual disability)

This type of detailed experiential information was gained in this project by adding qualitative focus groups, before and after the testing, with people with intellectual and psychiatric disabilities, and it is recommended in the future that qualitative methods, such as focus groups and potentially participant observations and accessibility audits be included.

When considering expanding this work at a larger geographic scale and across more sites, project leaders, testers, and companion testers had many recommendations. For example, project leaders felt that having an experienced, centralized oversight team would be important for making sure that the in-person testing efforts are standardized across the sites (including training), facilitating ongoing communication among sites, and providing ongoing support and accommodations as needed.

Recruitment and Training

Project leaders further confirmed the importance of additional strategies that were used in this pilot project, such as the need for housing organizations to partner closely with organizations run by people with disabilities within testing regions, to succeed in this work. They also stressed the importance of providing adequate time for the recruitment, training, and ongoing support of testers with intellectual and psychiatric disabilities, with some suggesting initially recruiting about three times as many testers as originally needed. Holding training in places that are familiar to potential testers, such as at disability and community organizations, could help attract testers with intellectual and psychiatric disabilities because they are more likely to trust these sites.

If I was to design the study, I would design it and build in with the time and the resources to work with this particular population to get them in, be able to, you know, work around their schedule a little more, maybe do trainings in a place they're already going to be. (project leader)

Many project leaders emphasized the importance of *not making assumptions about what testers can and cannot do* when preparing testers and companion testers for data collection. They also agreed that experienced testers with intellectual and psychiatric disabilities and companion testers might be well-equipped to train future testers, and their role as peer mentors and trainers should be considered in future trainings (perhaps with the aid of videos that they could be involved in producing).

It would be good to have an old tester come in and you know, just share the experience. (tester with intellectual disability)

Project leaders again emphasized the value of building in time for mentoring and one-on-one training. Everyone agreed on the benefits of ensuring that everyone has an opportunity to role play and complete a practice test with feedback.

We were the first selected to do the role playing so we had a lengthy period of role playing and that was very helpful. But we did not do a practice test. That probably would have been more helpful. (companion tester)

Some testers added that having everyone engage in more than one practice test may be advantageous.

Because the revised training specifically designed for this project is more engaging and participatory than traditional tester training, some project leaders thought it might be effective to use for other housing discrimination projects too.

Although recognizing that each person is unique, some companion testers suggested that training should include up front some general information about intellectual and psychiatric disabilities in a respectful way that acknowledges the considerable heterogeneity of people with intellectual and psychiatric disabilities. This type of training could be developed in partnership with peer mentors. Project leaders added that trainers can readily model respectful behavior and ways to acknowledge the strengths of people with intellectual and psychiatric disabilities to further support companion testers.

Data Collection

For data collection, some testers recommended that they receive a checklist detailing everything they should do before a test (including practical information such as using the restroom). Some testers also expressed a desire to do tests in areas where their personal characteristics match those of the local community and in areas that feel safe.

I know if I go to certain neighborhoods, they're going to be wondering why a white girl is looking for an apartment here, unfortunately. So race does become a problem. (tester with psychiatric disability)

Testers and companion testers felt it might be best to ensure that apartment viewing appointments are with leasing agents and not maintenance personnel.

I never met an actual landlord. Always a maintenance guy or a real estate agent. (tester with psychiatric disability)

Some testers also added that testers should also be involved in making calls to arrange apartment viewing appointments because some of the testing information is requested at that point of contact.

We had a situation where a lot of the questions would be answered by the companion as they were making the appointment phone call. (tester with psychiatric disability)

I think the hardest part of this for me, I've done quite a bit of testing in the past and nothing very similar to this in the past but maybe the hardest thing for me about this particular assignment was making the phone calls. Because several times, you would have the person you were talking to start asking well, is this apartment for you? It got tricky trying to steer them away or saying you were short on time. (companion tester)

Some project leaders wondered how they could ensure that testers receive support for any emotional reactions they may have during data collection. Many encouraged future teams to allow testers and companion testers to return to the testing coordination agency after each test to debrief and complete reporting forms, and this time would also be a potential time to support them emotionally and give them additional resources, if needed.

I would have them come in so that I could help them almost do the debrief while they're writing the narrative to make sure all of the information is being caught as opposed to sending them off on their own to fill out these crazy forms. (project leader)

A few testers noted that the clarity of the forms could be improved so that testers and companion testers might have fewer questions for testing coordinators and that testers might benefit from being connected to disability advocacy and community groups when they are not already so connected.

I feel like some of the questions were worded in a way where you had two options and none of it fit. (tester with psychiatric disability)

There was a few questions that I couldn't even understand the way they were written. (tester with psychiatric disability)

I think maybe some of the forms would have to be changed for the IDD people. It is so much information. It is so wordy. (project leader)

Some testers asked whether alternative payment options could be used so that those who receive benefits could more fully participate without having their subsidized disability income be at risk.

I guess I would have liked to do more of these but it would have affected my social security being reported, the amount of money. So I don't know. Instead of—I don't know if they would get reported with gift cards but or like say prepaid cards or whatever. But it might have been better like with that in my situation because I would have liked to do more of these because I had a really good companion and everything. (tester with psychiatric disability)

Finally, several focus group participants added that everyone should have the chance to reflect and debrief at the end of the project in focus groups with a small sample of testers and staff, similar to what was undertaken during this project. They felt the focus groups allowed for them to validate their feelings, revisit their experiences and make sense of them, reconnect with other testers and companion testers, and validate their contributions and role in the overall project. Having a thank you celebration after the testing also provided this validation and a chance to continue social networking with fellow testers.

Testing Implementation Data

In addition to the protected-class testers with mental disabilities and the control testers who typically constitute a matched pair test, companion testers were recruited and trained to accompany testers with mental disabilities on the in-person visits. Discussions with the Expert Panel, the study team, and HUD established the credibility and benefit of someone posing as a family member or friend to accompany the tester with a mental disability to provide support and assistance during the test and in preparing the test report forms. Companions were able to reduce the stress of conducting the test for the testers with mental disabilities, prompt testers to remember questions to ask and profile information, keep test visits focused, ensure that test reports were complete and accurate, and reinforce the reveal of the mental disability.

The use of companions added some costs to the in-person testing. Each test required the use of three people (protected-class tester, companion, and control tester) rather than two people, with the additional challenges of coordinating the schedules of three people for each test, which took more time and generally required longer intervals between tests. The costs of training, tester fees, and travel expenses for the testers and the additional companions were about 30 percent higher. In traditional paired testing, 101 completed test visits would require 202 person-contacts (number of tests x number of testers); the use of

companions resulted in 303 completed person-contacts. The costs and the scheduling were manageable challenges; the in-person testing was completed on time and within budget.

Not all testers with mental disabilities would necessarily require companions if doing this repeated testing over time, particularly after they become accustomed to the testing process. Some of the testers would be excellent testers on their own; others would have more difficulty conducting the tests and preparing the test reports without the support and assistance of the companion. Because of the importance of ensuring the consistency of test protocols and test reporting and the range of needs for assistance of testers with intellectual and psychiatric disabilities, however, having companions for all protected-class testers is appropriate and justified the additional costs.

Three trainings for testers were held in Chicago in June and July of 2014 for 27 participants, of whom 23 actually conducted tests. Three trainings were also held in Washington, D.C., in April, June, and August of 2014 for 21 testers; 17 conducted tests. We did not experience more attrition of testers with disabilities than would be expected in any tester pool. Testers with mental disabilities needed longer pretest briefings, particularly in the beginning, and a longer time for debriefing after the test, although this factor was partly because the tester and the companion both participated in the debriefing, which lengthened the conversation.

Recommendations and Conclusions

Recommendations

Based on our experience in implementing this housing discrimination testing with people with intellectual and psychiatric disabilities, review of relevant literature, and findings from the focus groups, the following recommendations are made to ensure high-quality, accessible, and inclusive in-person housing discrimination testing with testers with intellectual and psychiatric disabilities.

1. Project leadership and design.
 - Project leadership is deeply experienced by, and important to, people with intellectual and psychiatric disabilities. Embedding testing coordinator sites within local disability and housing rights communities was especially valuable in supporting testers with disabilities. Many of the testers were interested and excited about working with the project team in the future to become more formal members of the team through, for example, roles such as peer mentors and trainers.
 - Testing sites and all project members need to actively foster commitment to, and belief in, the inclusion of people with intellectual and psychiatric disabilities at all stages of research projects. They could potentially model how to transfer this process to new sites that have not explored these concepts or train communities to implement these approaches in future testing research. Several testers also expressed that HUD leaders could potentially learn from testers with intellectual and psychiatric disabilities to gain more experience in inclusive and participatory strategies and research design in all aspects of housing research, housing policy, and accessible design.
 - Having an inclusive project requires the fostering of coleadership in which the research and community colead and collaborate together to design and conduct this type of discrimination research.
 - Inclusion also means bringing housing discrimination experts together with people with personal experience of disability to fully and accurately understand the lived experience of finding and keeping rental housing.
 - Future testing should use these experienced testers in future protocol development and training, using pilot project testers as peer trainers and mentors in a train-the-trainer model.
2. Recruitment and selection of testers.
 - Reinforce responsibilities and expectations of participation with potential testers to encourage increased reliability and validity of findings.
 - Provide time, needed resources, and expertise to recruit, select, and support team members with intellectual and psychiatric disabilities.
 - Have a sustained, informed selection process for testers and companion testers that involves time to build relationships and develop a match.
 - Involve experienced testers with intellectual and psychiatric disabilities in recruitment and selection for any future testing, as they also have key contacts throughout communities to assist in recruiting and could be a vital support to new testers.
3. Training and data collection.
 - Be proactive and flexible in accommodating team members with intellectual and psychiatric disabilities in training and data collection, including specific attention to strategies to make participation more accessible and inclusive to these target groups.
 - Match supports to individual needs and reevaluate the need for supports as testers gain experience. Have a choice and range of supports and accommodations available to testers.
 - Provide person-centered support with choice, including having a choice on whether to stay with a specific companion tester or to choose another who is a better fit.
 - Examine whether companion testers are needed long term or not—between the added credibility and validity added to the testing versus the potentially unanticipated effect that their presence may actually decrease or buffer differential treatment.
 - Use and design plain-language materials, pictures, role plays, and videos in all training and data collection instructions and forms.
 - Use technology to enable people with intellectual disability to take on increasingly independent roles in testing, such as voice-operated smart phone or tablet documentation.

- Structure trainings tailored to specific community needs (for example, provide all the information and then practice for testers with psychiatric disabilities, but organize information into smaller segments followed by many practice opportunities for testers with intellectual disability).
- Attend to emotional aspects of testing in training and provide needed supports and resources via testing coordination debriefings and referrals.
- Discuss attitudes that may be encountered during tests in the initial training and consider how to capture attitudes and treatment in more detail in reporting.
- Ensure everyone has time to role play, practice, and receive individualized feedback during trainings.
- Support companion testers as they learn and practice how to provide positive, effective support to testers with intellectual and psychiatric disabilities in a respectful, person-centered, and directed way.
- Build in ongoing support and training, including ensuring that testers know whom to talk to regarding concerns, questions, or issues.
- Anticipate need for additional time to coordinate in-person testing schedules and transportation accommodations, and potentially use this information during the matching of paired testers.
- Add in adequate time for testing coordinators to debrief with testers after the actual test and to assist them in accurately completing full reports.
- Continue to provide immediate payments for work with no upfront costs to community members so they can easily participate.

Conclusions

This research effort hypothesized that people with intellectual and psychiatric disabilities could be viable testers within housing discrimination research. To date, very few studies have actually involved this protected class in housing discrimination research, and, within them, did so on a very small basis such as small-scale pilot tests to show initial potential. This project actively involved people with intellectual and psychiatric

disabilities in the implementation of 101 in-person tests within real rental housing situations. The team was successful in realizing this inclusion and participation, which is a significant milestone and a new finding for housing discrimination testing research.

This success was predicated on the use of many accessibility and participatory strategies that were proactively built in to the design of the overall study.

- The inclusion of disability and housing rights agencies in testing trainers and coordination.
- Accessible training that could be flexibly adapted to meet different tester needs and to enhance the match between testers with disabilities and companion testers.
- The use of companion testers to support testers with disabilities in a respectful partnership.
- Built-in opportunities to debrief and ask questions throughout the testing.

All the aforementioned strategies were cited as critical to supporting the active participation of people with intellectual and psychiatric disabilities in the testing.

Specific challenges that were identified during testing included the need for (1) longer and more extensive time and energy to recruit potential testers with intellectual and psychiatric disabilities and to address issues if testers dropped out or were not available because of other life issues, (2) more customized and ongoing training and practice sessions for testers, and (3) a longer timeframe and the supports needed to debrief and complete testing reports. Accommodating all these challenges required a longer period of time in the field for actual testing; this extended timeframe was built into this specific research effort and would also need to be implemented in any future larger-scale testing.

Not only did people with intellectual and psychiatric disabilities participate in the testing, but they also were actively involved in the study design, the evaluation of study forms and ways to document experiences, supporting each other and new testers throughout the project, and evaluating their experiences and member checking findings after the testing. Such community-engaged research was cited as valuable, and in fact critical, to the successful implementation of this housing discrimination study and to any future expanded studies of housing discrimination with people with intellectual and psychiatric disabilities.

References

- Abell, Simon, Jackie Ashmore, Suzie Beart, Peter Brownley, Adam Butcher, Zara Clarke, Helen Combes, Errol Francis, Stefan Hayes, and Ian Hemmingham. 2007. "Including Everyone in Research: The Burton Street Research Group," *British Journal of Learning Disabilities* 35 (2): 121–124.
- Atkinson, Dorothy. 2004. "Research and Empowerment: Involving People With Learning Difficulties in Oral and Life History Research," *Disability & Society* 19 (7): 691–702.
- . 2005. "Research as Social Work: Participatory Research in Learning Disability," *British Journal of Social Work* 35 (4): 425–434.
- Beresford, Peter. 2002. "User Involvement in Research and Evaluation: Liberation or Regulation?" *Social Policy and Society* 1 (2): 95–105.
- . 2005. "Developing the Theoretical Basis for Service User/Survivor-Led Research and Equal Involvement in Research," *Epidemiologia e Psichiatria Sociale* 14 (1): 4–9.
- . 2007. "User Involvement, Research and Health Inequalities: Developing New Directions," *Health & Social Care in the Community* 15 (4): 306–312.
- Bigby, Christine, and Patsie Frawley. 2010. "Reflections on Doing Inclusive Research in the 'Making Life Good in the Community' Study," *Journal of Intellectual and Developmental Disability* 35 (2): 53–61.
- Bigby, Christine, Patsie Frawley, and Paul Ramcharan. 2014a. "A Collaborative Group Method of Inclusive Research," *Journal of Applied Research in Intellectual Disabilities* 27 (1): 54–64.
- . 2014b. "Conceptualizing Inclusive Research With People With Intellectual Disability," *Journal of Applied Research in Intellectual Disabilities* 27 (1): 3–12.
- Björnsdóttir, Kristin, and Aileen S. Svendsdóttir. 2008. "Gambling for Capital: Learning Disability, Inclusive Research and Collaborative Life Histories," *British Journal of Learning Disabilities* 36 (4): 263–270.
- Bonham, Gordon S., Sarah Basehart, Robert L. Schalock, Cristine B. Marchand, Nancy Kirchner, and Joan M. Rumenap. 2004. "Consumer-Based Quality of Life Assessment: The Maryland Ask Me! Project," *Mental Retardation* 42 (5): 338–355.
- Braun, Virginia, and Victoria Clarke. 2006. "Using Thematic Analysis in Psychology," *Qualitative Research in Psychology* 3 (2): 77–101.
- Burke, Anne, Jane McMillan, Lorraine Cummins, Agnes Thompson, Watson Forsyth, James McLellan, Linda Snow, Anne Fraser, Mary Fraser, Charity Fulton, Elizabeth McCrindle, Lorraine Gillies, Shelley LeFort, Gail Miller, John Whitehall, John Wilson, Janet Smith, and David Wright. 2003. "Setting Up Participatory Research: A Discussion of the Initial Stages," *British Journal of Learning Disabilities* 31 (2): 65–69.
- Carrick, Rachael, Annie Mitchell, and Keith Lloyd. 2001. "User Involvement in Research: Power and Compromise," *Journal of Community & Applied Social Psychology* 11 (3): 217–225.
- Chapman, Rohhss. 2014. "An Exploration of the Self-Advocacy Support Role Through Collaborative Research: 'There Should Never Be a Them and Us'," *Journal of Applied Research in Intellectual Disabilities* 27 (1): 44–53.
- Chapman, Rohhss, and Niall McNulty. 2004. "Building Bridges? The Role of Research Support in Self-Advocacy," *British Journal of Learning Disabilities* 32 (2): 77–85.
- Charlton, James I. 1998. *Nothing About Us Without Us: Disability Oppression and Empowerment*. Berkeley, CA: University of California Press.
- Clements, Karen. 2012. "Participatory Action Research and Photovoice in a Psychiatric Nursing/Clubhouse Collaboration Exploring Recovery Narrative," *Journal of Psychiatric and Mental Health Nursing* 19 (9): 785–791.
- Conder, Jennifer, Paul Milner, and Brigit Mirfin-Veitch. 2011. "Reflections on a Participatory Project: The Rewards and Challenges for the Lead Researchers," *Journal of Intellectual and Developmental Disability* 36 (1): 39–48.
- Crawford, Mike J., Dan Robotham, Lavanya Thana, Sue Patterson, Tim Weaver, Rosemary Barber, Til Wykes, and Diana Rose. 2011. "Selecting Outcome Measures in Mental Health: The Views of Service Users," *Journal of Mental Health* 20 (4): 336–346.
- Davidson, Ann-Louise. 2009. "Community and Residential Integration, and Paid Employment Go Hand-In-Hand—A Collaborative Inquiry," *Journal on Developmental Disabilities* 15 (2): 27–37.

- Delman, Jonathan. 2012. "Participatory Action Research and Young Adults With Psychiatric Disabilities," *Psychiatric Rehabilitation Journal* 35 (3): 231–234.
- Dias, John, Malcolm Eardley, Elizabeth Harkness, Louise Townson, Chloe Brownlee-Chapman, and Rohhss Chapman. 2012. "Keeping Wartime Memory Alive: An Oral History Project About the Wartime Memories of People with Learning Difficulties in Cumbria," *Disability & Society* 27 (1): 31–49.
- Dowse, Leanne. 2009. "It's Like Being in a Zoo.' Researching With People With Intellectual Disability," *Journal of Research in Special Educational Needs* 9 (3): 141–153.
- Dubois, James M., Brendolyn Bailey-Burch, Dan Bustillos, Jean Campbell, Linda Cottler, Celia Fisher, Whitney B. Hadley, Jinger G. Hoop, Laura Roberts, Erica K. Salter, Joan Sieber, and Richard D. Stevenson. 2011. "Ethical Issues in Mental Health Research: The Case for Community Engagement," *Current Opinion in Psychiatry* 24 (3): 208–214.
- Duckett, Paul S., and David Fryer. 1998. "Developing Empowering Research Practices With People Who Have Learning Disabilities," *Journal of Community & Applied Social Psychology* 8 (1): 57–65.
- Flood, Samantha, Davey Bennett, Melissa Melsome, and Ruth Northway. 2013. "Becoming a Researcher," *British Journal of Learning Disabilities* 41 (4): 288–295.
- Gammon, Deede, Monica Strand, and Lillian S. Eng. 2014. "Service Users' Perspectives in the Design of an Online Tool for Assisted Self-Help in Mental Health: A Case Study of Implications," *International Journal of Mental Health Systems* 8: 2.
- García-Iriarte, Edurne, John C. Kramer, Jessica M. Kramer, and Joy Hammel. 2009. "Who Did What?: A Participatory Action Research Project To Increase Group Capacity for Advocacy," *Journal of Applied Research in Intellectual Disabilities* 22 (1): 10–22.
- García-Iriarte, Edurne, Patricia O'Brien, and Darren Chadwick. 2014. "Involving People With Intellectual Disabilities Within Research Teams: Lessons Learned From an Irish Experience," *Journal of Policy and Practice in Intellectual Disabilities* 11 (2): 149–157.
- Hutchinson, Andre, and Andrew Lovell. 2013. "Participatory Action Research: Moving Beyond the Mental Health 'Service User' Identity," *Journal of Psychiatric and Mental Health Nursing* 20 (7): 641–649.
- Jurkowski, Janine M., and Amy Paul-Ward. 2007. "Photovoice With Vulnerable Populations: Addressing Disparities in Health Promotion Among People With Intellectual Disabilities," *Health Promotion Practice* 8 (4): 358–365.
- Kramer, Jessica M., John C. Kramer, Edurne García-Iriarte, and Joy Hammel. 2011. "Following Through to the End: The Use of Inclusive Strategies To Analyse and Interpret Data in Participatory Action Research With Individuals With Intellectual Disabilities," *Journal of Applied Research in Intellectual Disabilities* 24 (3): 263–273.
- Maddock, Julia, Deidre Lineham, and Jane Shears. 2004. "Empowering Mental Health Research: User Led Research Into the Care Programme Approach," *Research Policy and Planning* 22 (2): 15–22.
- March, Justine, Betty Steingold, Susan Justice, and Paula Mitchell. 1997. "Follow the Yellow Brick Road! People With Learning Difficulties as Co-Researchers," *British Journal of Learning Disabilities* 25 (2): 77–80.
- Mirza, Mansha, Andrea Gossett, Nathan K.C. Chan, Larry Burford, and Joy Hammel. 2008. "Community Reintegration for People With Psychiatric Disabilities: Challenging Systemic Barriers to Service Provision and Public Policy Through Participatory Action Research," *Disability & Society* 23 (4): 323–336.
- Morgan, Michelle F., Monica Cuskelly, and Karen B. Moni. 2014. "Unanticipated Ethical Issues in a Participatory Research Project With Individuals With Intellectual Disability," *Disability & Society* 29 (8): 1305–1318.
- Nelson, Geoffrey, Joanna Ochocka, Kara Griffin, and John Lord. 1998. "Nothing About Me, Without Me': Participatory Action Research With Self-Help/Mutual Aid Organizations for Psychiatric Consumer/Survivors," *American Journal of Community Psychology* 26 (6): 881–912.
- Northway, Ruth, Joyce Howarth, and Lynne Evans. 2015. "Participatory Research, People With Intellectual Disabilities and Ethical Approval: Making Reasonable Adjustments To Enable Participation," *Journal of Clinical Nursing* 24 (3–4): 573–581.
- Ochocka, Joanna, Rich Janzen, and Geoffrey Nelson. 2002. "Sharing Power and Knowledge: Professional and Mental Health Consumer/Survivor Researchers Working Together in a Participatory Action Research Project," *Psychiatric Rehabilitation Journal* 25 (4): 379–387.
- Paiewonsky, Maria. 2011. "Hitting the Reset Button on Education: Student Reports on Going to College," *Career Development for Exceptional Individuals* 34 (1): 31–44.

- Perry, Jonathan, and David Felce. 2004. "Initial Findings on the Involvement of People With an Intellectual Disability in Interviewing Their Peers About Quality of Life," *Journal of Intellectual and Developmental Disability* 29 (2): 164–171.
- Richardson, Malcolm. 2002. "Involving People in the Analysis: Listening, Reflecting, Discounting Nothing," *Journal of Intellectual Disabilities* 6 (1): 47–60.
- Rose, Diana, Jo Evans, Angela Sweeney, and Til Wykes. 2011. "A Model for Developing Outcome Measures From the Perspectives of Mental Health Service Users," *International Review of Psychiatry* 23 (1): 41–46.
- Schoeters, Ludo, Patrick Schelfhout, Griet Roets, Geert Van Hove, Louise Townson, Rohhss Chapman, and Ian Buchanan. 2005. "Partnership Working Between University Researchers and Self-Advocacy Organizations: 'A Way Forward for Inclusion?' in England and 'Fine Feathers Make a Fine Bird' in Flanders," *Journal of Intellectual Disabilities* 9 (4): 345–357.
- Stack, Erin, and Katherine E. McDonald. 2014. "Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up?" *Journal of Policy and Practice in Intellectual Disabilities* 11 (2): 83–91.
- Stevenson, Miriam. 2014. "Participatory Data Analysis Alongside Co-Researchers Who Have Down Syndrome," *Journal of Applied Research in Intellectual Disabilities* 27 (1): 23–33.
- Telford, Rosemary, and Alison Faulkner. 2004. "Learning About Service User Involvement in Mental Health Research," *Journal of Mental Health* 13 (6): 549–559.
- Timmons, Jaimie C., Allison C. Hall, Jennifer Bose, Ashley Wolfe, and Jean Winsor. 2011. "Choosing Employment: Factors That Impact Employment Decisions for Individuals With Intellectual Disability," *Intellectual and Developmental Disabilities* 49 (4): 285–299.
- Walmsley, Jan. 2001. "Normalisation, Emancipatory Research and Inclusive Research in Learning Disability," *Disability & Society* 16 (2): 187–205.
- . 2004a. "Inclusive Learning Disability Research: The (Nondisabled) Researcher's Role," *British Journal of Learning Disabilities* 32 (2): 65–71.
- . 2004b. "Involving Users With Learning Difficulties in Health Improvement: Lessons From Inclusive Learning Disability Research," *Nursing Inquiry* 11 (1): 54–64.
- Ward, Karen, and Jordan S. Trigler. 2001. "Reflections on Participatory Action Research With People Who Have Developmental Disabilities," *Mental Retardation* 39 (1): 57–59.
- Williams, Val. 1999. "Researching Together," *British Journal of Learning Disabilities* 27 (2): 48–51.
- Williams, Val, Lisa Ponting, Kerrie Ford, and Philippa Rudge. 2010. "Skills for Support: Personal Assistants and People With Learning Disabilities," *British Journal of Learning Disabilities* 38 (1): 59–67.
- Williams, Val, Ken Simons, and Swindon People First Research Team. 2005. "More Researching Together: The Role of Nondisabled Researchers in Working With People First Members," *British Journal of Learning Disabilities* 33 (1): 6–14.

Appendix: Debriefing Questions

Session 1 with Testing Trainers/Coordinators

8:30–10:30am (Central); 9:30–11:30 (Eastern)

Led by Katie

1. **Introduce yourself (slide has your picture)**
2. **Ground Rules**
 - Speak one at a time.
 - Speak your name before talking.
 - When you are done talking, say “done”.
 - We will go around the room to get everyone’s feedback.
 - It is ok to skip a question.
 - There are no right or wrong answers.
 - Everyone’s thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
 - What is said in the room, stays in the room (respect confidentiality)
 - Anything else for today’s focus group?
3. **Getting consent on recording the session**
 - Is it okay to audio record the session?
4. **Introduction**
 - Name
 - What you did for this project
5. **Questions**
 1. Describe how you designed and carried out the training and testing so that testers with intellectual and psychiatric disabilities could carry out their responsibilities and feel respected?
Focusing on the reasons why things were designed and carried in a particular way, think about this for:
 - a. *Recruitment and selection of testers, including companion testers*
 - b. *Training protocol*
 - c. *Testing protocol*
 - d. *Ongoing support for testers during testing*
 2. What strategies did you use to effectively, respectfully include testers with intellectual and psychiatric disabilities?
 - a. Strategies used with the group of testers with psychiatric disability
 - b. Strategies used with the group of testers with intellectual disability
 3. Was there anything that wasn’t working well and got in the way of effectively, respectfully including testers with intellectual and psychiatric disabilities?
 - a. *Did you make any changes as a result?*
 - b. *What did you think went well after the changes?*
 4. Do you think these two groups are/can be good testers? Why and/or why not?
 5. What did you learn from being a part of this project?
 6. If we were going to do testing on a larger-scale, are there any different or additional strategies you would use?
 - a. *Are there any challenges to effectively, respectfully including testers with intellectual and psychiatric disabilities that you feel you weren’t able to successfully address?*
 - b. *Can you identify any potential solutions to them?*
 7. Is there anything else you would like to share?
6. **Thank you for your participation**

Session 2 with Testers with Intellectual Disability

10:30am–12:00pm (Central); 11:30am–1:00pm (Eastern)

Led by Tia

1. **Introduce yourself (slide has your picture)**
2. **Ground Rules**
 - Speak one at a time.
 - Speak your name before talking.
 - When you are done talking, say “done”.
 - We will go around the room to get everyone’s feedback.
 - It is ok to skip a question.
 - There are no right or wrong answers.
 - Everyone’s thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
 - What is said in the room, stays in the room (respect confidentiality)
 - Anything else for today’s focus group?
3. **Getting consent on recording the session**
 - Is it okay to audio record the session?
4. **Introduction**
 - Name
 - What you did for this project
5. **Questions**
 1. Describe your experience working on this project. *How does it feel to be part of this project? What have you learned? How were you changed?*
 2. What worked well during the project? *What helped you be a part of this project? Think about:*
 - a. Training
 - b. Doing the testing
 3. Could you have done the testing without a companion tester? How did your companion tester help you?
 4. Did you feel respected and that you were able to contribute to the project in your role? *Give examples of each.*
 5. Did you know who to go to if you had a problem or needed help? *What happened?*
 6. What do you think can be done to make this project better? *Are there any different ways or supports that would help you to be a better tester?*
 7. Would you recommend being a tester to other people with intellectual disability? *Why or why not?*
 8. What advice would you give if we were going to do this project across the country?
 9. Is there anything else you would like to share?
6. **Thank you for your participation**

Session 3 with Testers with Psychiatric Disability

1:00–2:30pm (Central); 2:00–3:30pm (Eastern)

Led by Tia

1. Introduce yourself (slide has your picture)

2. Ground Rules

- Speak one at a time.
- Speak your name before talking.
- When you are done talking, say “done”.
- We will go around the room to get everyone’s feedback.
- It is ok to skip a question.
- There are no right or wrong answers.
- Everyone’s thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
- What is said in the room, stays in the room (respect confidentiality)
- Anything else for today’s focus group?

3. Getting consent on recording the session

- Is it okay to audio record the session?

4. Introduction

- Name
- What you did for this project

5. Questions

- Q1. Describe your experience working on this project. *How does it feel to be part of this project? What have you learned? How were you changed?*
- Q2. What worked well during the project? *What helped you be a part of this project? Think about:*
- a. Training
 - b. Doing the testing
- Q3. Could you have done the testing without a companion tester? How did your companion tester help you?
- Q4. Did you feel respected and that you were able to contribute to the project in your role? *Give examples of each.*
- Q5. Did you know who to go to if you had a problem or needed help? *What happened?*
- Q6. What do you think can be done to make this project better? *Are there any different ways or supports that would help you to be a better tester?*
- Q7. Would you recommend being a tester to other people with psychiatric disability? *Why or why not?*
- Q8. What advice would you give if we were going to do this project across the country?
- Q9. Is there anything else you would like to share?

6. Thank you for your participation

Session 4 with Companion Testers

2:30–4:00pm (Central); 3:30–5:00pm (Eastern)

Led by Katie

1. **Introduce yourself (slide has your picture)**
2. **Ground Rules**
 - Speak one at a time.
 - Speak your name before talking.
 - When you are done talking, say “done”.
 - We will go around the room to get everyone’s feedback.
 - It is ok to skip a question.
 - There are no right or wrong answers.
 - Everyone’s thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
 - What is said in the room, stays in the room (respect confidentiality)
 - Anything else for today’s focus group?
3. **Getting consent on recording the session**
 - Is it okay to audio record the session?
4. **Introduction**
 - Name
 - What you did for this project
5. **Questions**
 1. Describe your experience working on this project. *How did it feel to be part of this project? What have you learned? How were you changed?*
 2. What do you think about this project is working well? *What is helping you be a part of this project, and specifically to be a companion tester?*
 3. Do you think you were needed as a companion tester? *What role did you serve as a companion tester (what did you do)? What did you learn about being a good companion tester? Are there any strategies or supports that would help you better be a companion tester?*
 4. Did you know who to go to if you had a problem or needed help? *What happened?*
 5. For those of you have done housing testing before, what did you learn about housing testing with people with intellectual and psychiatric disabilities? *What did you bring from your past experience to this project?*
 6. What advice would you give if we were going to do this project across the country?
 7. Is there anything else you would like to share?
6. **Thank you for your participation**