



Getting Into and Maintaining Housing in the Private Rental Market: Experiences of People With Mental Disabilities

Study of Rental Housing
Discrimination on the Basis
of Mental Disabilities:
Short Paper 2



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STUDY OF RENTAL HOUSING DISCRIMINATION ON THE BASIS OF MENTAL DISABILITIES: SHORT PAPER 2

Prepared by

Joy Hammel

Janet Smith

Danbi Lee

University of Illinois at Chicago

Prepared for

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Abstract

Research shows that people with mental disability (MD), including people with psychiatric disability (PD) and people with intellectual or developmental disability (I/DD), face significant barriers to obtaining and retaining housing. Although this issue is of particular importance in light of the Fair Housing Act, the Americans with Disabilities Act, and the Olmstead Decision, it remains unclear exactly what these barriers are and in what stage(s) of the process they exist for people with MD. This study used a qualitative research design to capture the lived experiences and voices of people with PD and I/DD. Six focus groups (four consumer groups [n = 25] and two stakeholder

groups [n = 15]) were conducted to understand rental housing search and discrimination experiences of people with MD and the perspective of key stakeholders who often serve as intermediaries to connect people to community housing. Findings point to two key areas: (1) barriers and potential discrimination experienced during the process of accessing rental housing, and (2) the supports and accommodations needed to remain in rental housing long term. This report summarizes these first hand perspectives and implications for housing discrimination research, practices, and policy.

Introduction and Literature Review

The federal Fair Housing Act (Title VIII of the Civil Rights Act of 1968) as amended in 1988 prohibits discrimination on the basis of mental and other forms of disability in the rental, sale, and financing of housing, or other housing-related transactions (HUD, n.d.). Although the U.S. Department of Housing and Urban Development (HUD) has played a major role in the enforcement of this law, discrimination against people with mental disability (MD)¹ within the private housing market continues to be a pervasive issue (Housing Discrimination Law Project of Vermont Legal Aid, 2012; Pratt et al., 2005). Two major groups affected under this umbrella of MDs are people with psychiatric disabilities² (PDs) and people with intellectual or developmental disabilities (I/DDs). Previous studies have shown that discrimination occurs both covertly and overtly for these groups, ranging from inconsistent and differential treatment during the application process to the denial of requests for reasonable accommodations and modifications (Fair Housing Council of Suburban Philadelphia, 2009; Huss, 2005; Kanter, 1993; Seattle Office for Civil Rights, 2011). Further, discrimination occurs during all phases of the process, including finding and applying for housing and remaining in housing long term (Fair Housing Council of Suburban Philadelphia, 2009; Seattle Office for Civil Rights, 2011). These experiences of discrimination can make it difficult for people with MDs to find, obtain, and retain rental housing. In addition to living with the challenges of an MD, these individuals often face additional challenges, such as living in poverty or on income subsidies, which further affect market rental housing searches, applications, and long-term housing sustainability.

Although a growing body of research surrounding housing discrimination for people with MDs is emerging, the voices of these consumers are not readily apparent within most of the research, and, indeed, people with MDs are often excluded from research. For example, people with I/DDs have long been excluded from data analysis and interpretation (Koenig, 2012), although the results of this research can have a significant impact on their lives. Within housing discrimination research, people with MDs have sometimes been involved in the data

collection phase of testing, but they have not been as involved in the developmental and exploratory phases in which research questions are developed nor in the translation of findings back to the community for everyday use. It is more common for people with PDs to be involved in data analysis and interpretation development than their counterparts with I/DD, although this active involvement in housing access and discrimination has been very limited. This lack of involvement has led to a movement on behalf of people with PDs and I/DDs to gain more control throughout the research process (Schneider, 2012; van Draanen et al., 2013). This movement prioritizes the need for community-based participatory research approaches that actively involve people with PDs and I/DDs in the research process, particularly in identifying specific sources and types of potential discrimination experienced within market rental housing, the resulting impact on obtaining and maintaining community-based housing of choice, and long-term ability to maintain living in that rental housing over time when disability and accommodation needs change.

Within housing discrimination research, strategies to include consumers with disabilities can include the use of interviews, focus groups, member checks, and peer facilitators/key informants. Interviews and focus groups can be used at the beginning of a study to determine issues of importance to participants, thus serving to shape the research process (Corrigan et al., 2003; Gaizauskaite, 2012; Nelson and Earls, 1986; Nelson et al., 2007; Patton, 2002; van Draanen et al., 2013). In other words, they can be used to understand the experiences that people with MDs have had when searching, applying for, and living in private market rental housing. Focus groups can also be used as a type of needs assessment in which a group of people with first-hand experiences outlines issues that need to be addressed (Krueger and Casey, 2009; Nelson and Earls, 1986). Further, conducting disability-specific focus groups, potentially co-led by a peer facilitator or key stakeholder, can serve to create a safe space for discussing issues and ensuring access (Nind and Vinha, 2013; Woodring, Foley, and Rado, 2006). Finally, member checking, during which researchers review developing analyses and seek

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).

² In this paper, we are using the term *psychiatric disabilities* interchangeably with *mental illness*.

verification from participants with disabilities, can be used at various phases of the research process, such as during focus groups and data analysis (Mertens, 2010). Using member checks and key stakeholders/peer facilitators during focus groups can serve to involve people with MDs in data collection, analysis, and other aspects of the research process from which they have been traditionally excluded (Irvine, 2010; Mertens, 2010). This member checking can also improve the social validity and trustworthiness of the data and interpretations made.

Research shows that people with MDs face significant barriers to obtaining and retaining housing (Corrigan et al., 2003; Nelson and Earls, 1986; NCD, 2010; Nelson et al., 1998). Although this issue is of particular importance in light of the *Olmstead*

Decision,³ it remains unclear exactly what these barriers are and in what stage(s) of the process they exist. More fully involving people with MDs in housing research can serve to inform and support the research process, thus improving its credibility and ensuring that the project is meaningful and useful to this population (van Draanen et al., 2013; Walmsley and Johnson, 2003). This research aims to fill the gap in the literature by involving people with MDs throughout the process through the use of a participant-directed approach, such as Nelson and Earls (1986) and Nelson et al. (2007) used. This research also builds on the work of Nelson et al. (2007) by learning from participants *how* the specific sources and types of discrimination experienced are leading to barriers in obtaining and maintaining housing.

³ In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that unjustified segregation of people with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act.

Design and Methods

This research effort used a qualitative research design to capture the lived experiences and voices of people with disabilities. Six focus groups (four consumer groups and two stakeholder groups) were conducted to understand housing discrimination experiences of people with MDs and the perspective of key stakeholders who often serve as intermediaries by helping to connect people with MDs to community housing. Consumer participants were recruited through community agencies using purposive and snowball sampling. Recruitment flyers and invitation letters were distributed to community agencies and MD organizations across two large cities, Chicago and Washington, DC. We invited people with PDs or I/DDs who had direct experiences with potential housing discrimination in the rental market and who were interested in sharing those first-hand experiences. In addition, key community stakeholders were recruited for separate focus groups based on their expertise in housing issues. Invited stakeholders included peer mentors and advocates, staff from the Center for Independent Living, disability organizations involved in housing searches with people with MDs, protection and advocacy/legal organizations involved in housing discrimination lawsuits, and housing policymakers and funding agencies. All participants consented to participate in the focus groups via approved procedures from the University of Illinois at Chicago Institutional Review Board.

All focus groups were conducted in person, with the exception of one stakeholder group that was run through teleconferencing to accommodate key stakeholders from different parts of the country. Focus groups used a structured guide with open-ended questions, strategies to elicit full and equitable participation by different participants, frequent paraphrasing and summarizing of emerging themes, and use of a white board to note themes and validate observations with participants (Krueger and Krueger, 2009). The length of each focus group ranged from 90 to 120 minutes, and each group consisted of four to eight participants.

Discussion topics included examples of housing discrimination situations personally experienced by people with MDs (PD and I/DD) and key points in the housing search process during which discrimination may occur and disability may be disclosed (either purposefully or inadvertently) during the housing search

process. Housing stakeholders were also asked to comment on these experiences across the many people with MDs they served across myriad market rental housing searches. Both groups were also asked to describe types of reasonable accommodations that may be needed and requested by people with MD during the housing search process that may further complicate housing access.

The consumer groups were split into two groups, with two forums for people with I/DD and two forums for people with PD, to make participation fully accessible and to gain as much participation as possible. Under the direction of a consumer peer mentor from the I/DD community, focus group questions were adapted for participants with I/DD to make them more accessible and understandable. Each participant was offered a gift certificate as an honorarium for his or her time, transportation assistance, a personal attendant, and other accommodations, such as food and drinks.

The focus group discussion was documented via real-time, Internet-based captioning that also enabled the discussion to be captured as a verbatim transcript. These data were then analyzed using a grounded theory approach to embed the findings in the lived experiences of people with MD (Huberman & Miles, 1994; Krueger & Krueger, 2009; Strauss & Corbin, 1994); that is, verbatim quotes from people with MDs and key stakeholders were identified and then organized into key themes related to market rental housing experiences. The results were then “grounded” in the voice of people with MDs themselves, a key strategy called for in previous literature and from the disability communities. After removing all personal identifiers (for example, names of people, landlords, or organizations) from the verbatim transcripts, the transcripts were coded and triangulated by a team of three researchers and were member checked by two participants with MDs. This process enabled the researchers to verify key themes and results, not only among fellow research team members, but also among people with MDs. The analyses and interpretation were completed using an iterative, constant comparative method to identify themes with corresponding quotations and examples; that is, after each round of analyses, the team met to build consensus and further interpret findings given different perspectives of different reviewers.

Results and Findings

Participants

Participants in the focus groups included 25 consumers and 15 stakeholders (see Table 1 for more detail about the consumer focus groups).

Out of 25 consumers, 15 had a PD and 10 had an I/DD. The sample reflected the diversity of the two large urban communities from which people were recruited, with greater participation by African-American people, people living in poverty or on significantly limited incomes, and people with less than a college degree of education. Several participants

had recently moved out of institutional settings (for example, nursing homes, institutions for mental diseases (IMDs), and intermediate care facilities) to the community and were living in and searching for market rental housing, representing an Olmstead group⁴ in that they had recently made the transition to least restrictive community living settings via state Medicaid initiatives, and shared this experience. The demographics of this sample are the result of the strategy of recruiting through local community agencies involved in housing support and may not represent the general population or other communities (for example, rural, other geographic areas).

Table 1. Demographics of Consumer Focus Groups and Interview Participants

Characteristic		Frequency	Percentage
Type of disability	PD	15	60
	I/DD	10	40
Sex	Female	15	60
	Male	10	40
Racial background ^a	African-American	17	68
	Caucasian	8	32
	Hispanic	2	8
	Native American	2	8
Education	Less than high school	6	24
	High school/GED [®]	8	32
	Some college	6	24
	Associate's/bachelor's degree	3	12
	Master's degree	2	8
Marital status	Single	19	76
	Divorced/widowed/separated	5	20
	Married	1	4
Annual income	Less than \$12,000	12	48
	\$12,000 to 20,000	8	32
	\$20,000 to 30,000	2	8
	More than \$30,000	1	4
	Did not disclose	2	8
		Mean (SD)	Range
Age		47 (7.99)	21–62

GED[®] = general educational development. I/DD = intellectual or developmental disability. PD = psychiatric disability. SD = standard deviation. n = 25.

^a The sum of racial background percentages exceeds 100 percent because participants were permitted to check all racial backgrounds that applied.

⁴ An Olmstead group refers to the group of people with disabilities who qualify to receive state-funded supports and services in the community rather than institutions based on the *Olmstead v. L.C.* decision.

Findings

During the focus groups, participants with PDs and I/DDs discussed the steps involved in accessing rental housing, separating their comments into two phases of the process: (1) the barriers and potential discrimination experienced during the process of accessing rental housing, and (2) the supports and accommodations needed to remain in rental housing long term. The following section describes experiences shared by focus group members related to both housing search and retention and delineates similarities and differences in how they were experienced by people with PD and I/DD.

The Housing Search Process

Participants discussed an often lengthy process to search and apply for rental housing. Because of a lack of available or adequate units or because of the need to move or to find a new unit following a crisis, hospitalization, or institutionalization that resulted in a loss of housing, they repeated this lengthy process many times. The following participants' comments summarize this complex process.

It took me over 3 years to get my apartment and live on my own. I tried so hard the first time and no one would rent to me. And then I landed up in a nursing home for a while and lost track of everything and had to start all over again. Every time I feel sick or think I'm getting worse I cringe—I might lose my place and have to start all over ... that's scary and really depressing to think about.

There's not a lot out there for people like me [with I/DD], like you know, to live on your own. Every time we [participant and family] tried, nothing worked. Nobody would take me. ... My mom died and left me some money. X [developmental disability community agency] helped me find a place and now I'm on my own and I'm good at it ... I know a lot of people [with I/DD] who want to get out and live on their own and it takes a really long time to do that.

Approximately one-half of the participants with PDs completed this search on their own and had to learn by trial and error how to find landlords that would "accept them." One participant said—

... the ones who are not so fast to judge you because of your mental illness. You've got to find those and sometimes it takes a long time before you do. You didn't ask to be this way. It's something that just happened. But if they won't work with you, you can't get in the door.

Other participants reported that during the search process they brought along a friend or family member, whom they described as a positive support and an advocate during the process.

I didn't have family so I asked a friend to come with me. And I told her to watch out for me and let me know if she thought I was being taking advantage of, or to take notes and help me remember. It really helped me a lot cause we talked after. I felt safe with her.

Overall, people who brought along another person as a support reported feeling safer and more comfortable in the housing search process; however, both groups reported that they still experienced potential discrimination by landlords during the process. One participant said—

I've gone out by myself and gotten negative reactions to me and my disability, and I've gone out with a friend and still had problems with landlords reacting to my disability. It's just when I'm with a friend at least I can check back after if they caught the same problem I did. It's like having a safety backup just in case.

The other half of the participants with PDs and most of participants with I/DD completed their search with a community agency that served as a more formal liaison with landlords and housing agencies. Two participants described this experience.

X [mental health community agency] knew a landlord that would take chances with people with mental illness, and he did and he didn't just stop with those, and I feel really grateful to know this man because he gave us a chance, an opportunity to have a place. He didn't do a background check, he just accepted us to live there. He still deals with [agency name], so there needs to be more people like him and agencies like [agency name] to help broker that deal.

The case manager is the best person I have ever met ... she helped me with everything. ... She helped just get my foot in the door.

In several instances, participants described working with "housing locators," including peer mentors with an MD who had gone through the housing search process and could support them in a unique manner.

Yes I got hooked up to Sue [name changed] who was one of those consumer mentors, they called her a housing locator. X [mental health organization] hooked me with her and she helped me search for places on line, and figure out what to say in advance, like a kind of script and set of questions to ask. She also met me at places so we could

look at them together. She was great in pointing out what to ask about or there were certain features to think about. She also helped me compare different places after. But what was best is she'd been through all this herself, she had a mental illness too. I trusted her.

Barriers to Rental Housing: Getting in the Door

The first step of moving into the community requires gaining access to rental housing on the open market. Focus group participants raised issues that people with MDs experience when seeking housing, including issues relating to—

- Searching and finding information about housing availability.
- Viewing and assessing apartments in person with managers.
- Formally applying for units and receiving notification on whether that application was accepted.
- Finalizing the move into the apartment (from the time the application is accepted to the time of move in and changes during that time).

Participants with MD identified the following main challenges.

- Disability disclosure and stereotypes related to MD.
- Landlords not understanding or responding negatively to reasonable accommodation requests as part of an application.
- Landlords imposing additional fees without explanation (for example, additional or more expensive background checks, additional deposits).
- Landlords denying or not encouraging applications based on factors other than disability, such as income or background history.

Issues with disability disclosure and stereotypes. The first challenge, disclosure of an MD during the housing search process, occurred in many different ways. Sometimes, people with MDs told property managers and landlords about their disability outright, not necessarily knowing they had a right to not disclose. In many cases, providing this information led to negative treatment, as one participant with a PD described.

The first time I did this I just blurted out that I was mentally ill. Now I know I don't have to do this, it's my right not to tell them. Now I'd wait and I coach people not to tell people you have a disability. There's way too many attitudes about it and they'll close the door on you right away.

For several people with I/DD, however, disclosure was a way for them and family/supporters to screen if the landlord was

receptive to people with I/DD and if the unit and landlord overseeing it were perceived as a “disability friendly” place and situation. One family member noted the following.

We always say it up front that Joe [name changed] has a developmental disability, and then we wait to see how people react. We've coached Joe to say that he can take care of himself and live on his own too so if they ask questions, he can say that back. It's kind of like a test to see how people react when we say that, and if it's worth it to even apply there.

In some cases, an MD was assumed by landlords and managers based on how the person talked, looked, or acted on the phone or in person. One participant described this situation.

Sometimes, you know, it's just how you talk or look. They can tell right away something's wrong, you're different. The more I talk, the more they figure it out. Then they start to make a lot of assumptions—that I'm crazy or not right or I'm drunk or on drugs or something, or I can't take care of myself or will hurt them.

In many cases, people with MDs conducted their housing search in collaboration with a mental health organization, involving mental health professionals, case managers, and housing locators as liaisons during the process. Although consumers were educated on their rights to not have to disclose their disability during the housing search process, mental health staff and community organizations working with people with MDs sometimes disclosed small pieces of information, such as affiliation with this mental health organization, previous living situation, or background history, that could lead landlords to infer MD and potentially react. Two mental health stakeholders involved in housing provision said—

That if they saw, for example, here, in the [MI hospital] was the last place they lived, they would know that's a place where people with mental disabilities live, and they might say, well, I don't want somebody who lived at X to live in my apartment.

I would say that persons with serious mental illness and IMDs, the naming is very significant to the landlord when they learn that name, and the statutes for IMDs ... defines residents as inmates, as mental patients.

Participants also reported that landlords and managers sometimes asked outright about their disability, including questions pertaining to diagnoses, behaviors affiliated with a given disability, treatment they were or were not receiving, and the individual's overall safety and judgment. Participants reported their experiences as follows.

I had one guy that just said ‘what’s wrong with you? Are you OK?’ I told him it was just my psychiatric disability and he looked at me oddly and said, ‘What’s that? Are you taking any meds? Who’s your doctor?’

A lot of people ask me if I can take care of myself, or if I’m safe. Or they say, you can’t live by yourself.

As participants repeatedly described, many of the questions and reactions by landlords reflected common stereotypes and attitudes about MD and its relationship to competence and safety in community living. Participants with PDs discussed these stereotypes and their impact on finding rental housing.

Landlords don’t let you rent to—that word they use, “crazy,” they don’t want to rent to people who are crazy ...

I think the assumption we are to make is that folks who have mental illness are dangerous to others and will be dangerous to the landlord and the property. They’re not working so they can’t live independently, they won’t be able to keep the place clean, and they’re worried what will happen if they go off their meds.

Landlords’ experiences with previous tenants also shaped their attitudes toward new applicants with MD. Participants said—

If a person in the building has had a mental illness in the past and got kicked out, they probably wouldn’t let the next person in.

Somebody might have, for example, a past eviction for non-payment after they became disabled and couldn’t work anymore. They might have even something a little more problematic, like they had a manic episode and were evicted for nuisance or something like that. ... And people are very, very unwilling—even low-income landlords are very, very unwilling to make the accommodation of disregarding less-than-wonderful stuff in the person’s tenancy history.

Focus group participants with I/DD also reported dealing with landlords’ attitude and stigma related to their disability; however, stereotypes attached to people with I/DD focused more on their competence. One participant described such attitudes.

One area we were talking about, other factors where I think there is a distinction between intellectual and psychiatric disabilities is assumptions of violence and how that could play into it. In the general public and the assumptions that are made about particularly with respect to schizophrenia as an example as opposed to an intellectual disability. I have found that to be true, that the supposition of violence with mental illnesses or some

kinds of mental illnesses and the more common supposition I found with intellectual disabilities has been just that the person can’t handle the demands of being a tenant, not that they will do anything violent, but that they can’t cope.

These attitudes and stigma often prevent people with an MD from securing a housing unit from the very first step. From the first call, potential tenants are being screened and assumptions are being made about the potential renter’s competence related to community living. One participant described this situation from personal experience.

Sometimes you don’t even have to identify. It may come over on the phone. They may not get to first base to get an appointment to see the unit. So you might have a person who speaks in a way that would make them think they have a mental disability. ... That, right there, ... they don’t get past that first phone call.

The assumptions about competence and stereotypes about a given disability, which may be held by a particular landlord, can then lead to the consumer learning, or not learning, about any available units, or to the consumer being steered toward specific units or a particular location based on an assumed disability. This type of steering was perceived to be intentional segregation, as participants and stakeholders reported—

There was a situation where I applied for an apartment, nice, but it was part of, I guess the low income housing, so apparently they didn’t like something about my application, but at the end they ended up telling me we have a sister complex which is that you might fit in there, and I really got offended. I got offended because if I can use the same information to get in there, how come I can’t get in here?

For people with I/DD, they never even thought about them being on their own in their own place. They don’t have any concept of what that might look like or that it might work. They ask why they aren’t living in one of those homes, like a nursing home or institution. Or it’s NIMBYism as in Not in My Backyard, not wanting people with I/DD in the neighborhood. Sometimes it’s pretty subtle and you don’t even realize it til after you’ve left that they steered you away from their place.

Lack of understanding regarding reasonable accommodation requests. The second challenge related to getting into rental housing involved reasonable accommodation requests. Focus group participants with MD described many different types of accommodations that might be needed to live in the community and in a rental apartment. These included—

- Cognitive supports for safety, judgment, memory, attention, organization, decisionmaking, and problemsolving. Such supports include environmental modifications; technologies such as alarms, sensors, and emergency response systems; signage; cueing; and human or personal assistance with tasks such as apartment management, budgeting and money management, scheduling, and food shopping and meal preparation. From a housing perspective, such an accommodation might require the need for additional keys, security access, or parking for support personnel. Cognitive assistance may also include the use of support and service animals.
- Emotional, behavioral, and social supports. These supports include the use of live-in or drop-in personal assistants, drop-in volunteers and check-in services, and support animals. From a housing perspective, such an accommodation might include a request for specific units or features within them to feel safe, to not disturb others or self, or to limit or manage social interactions with other people.
- Physical supports to accommodate additional physical and chronic health conditions, aging, deconditioning, mobility and coordination, and long-term side effects of medications. From a housing perspective, such an accommodation may include a request for physically accessible unit features or placement within a building, environmental modifications, grab bars and other access features, accessible parking, and use of or space for assistive and mobility technologies.
- Environmental features and modifications related to sound/noise, sensory, temperature, air quality/chemical sensitivities, and unit placement.
- System and policy accommodations related to completing applications and paperwork, bill payment timing, or handling policies. From a housing perspective, such an accommodation may include a request for alternative communication of important information or advance notice on any in-unit communication or maintenance, alternative forms of information access, policies to protect privacy and safety, extensions on payments, or holding a unit during an emergency or crisis.

Some of the accommodations described could be legally considered “reasonable accommodations,” while others describe supports that would not involve or need a formal request but might be perceived as “special requests” by landlords. Regardless, participants reported feeling that landlords have little understanding about reasonable accommodations for people with MDs, why they are needed, or an individual’s right to request them. One participant said—

Compared to people who use a wheelchair, I don’t think landlords get mental disability or any accommodations needed. It might be really important for me to live on a certain floor, or to have someone come into the place to help me with remembering and organizing or paying my bills, or I need advance warning about anyone coming into my place, whatever. But this looks different than say wheelchair access. They don’t get that I need these things because of my disability or they say things like ‘we can’t offer that to you cause we don’t do it for anyone else’ ... It’s almost like reverse discrimination—they’re using fair housing to deny me what I need because they don’t get the disability accommodations part of it, especially for someone with a mental illness.

Although many of these reasonable accommodations did not require any or very limited costs, landlords perceived them as not necessary or not reasonable. Stakeholders described these misperceptions.

She had found an apartment, secured it, but in order to move into the apartment, she needed to move in away from the bushes up front—there were bushes that were along the route to the back door, and she felt unsafe, and so she was asking to let her move into the front door, but they were refusing. So she just wasn’t able to move into the apartment and didn’t get that rental.

I had someone who needed a particular unit or floor, they might need a third-floor unit versus a first-floor unit if they have issues with safety, paranoia about other people, or a past history with violence or abuse in their lives ... they (landlords) think it’s just a personal preference or for the view, but it’s not. It’s a reasonable disability request.

This lack of understanding also applied to requests to have in-home assistance or the equivalent of a live-in personal assistant for cognitive and psychosocial reasons rather than physical support. A stakeholder described one such situation.

One issue we had was for a location that had a lease with one person, the individual needed to have someone there to provide other types of help to enable the person to stay living in the community ... like medication management, paying bills, coping with stresses, etc. And they were told the other person had to leave.

Participants with MD also reported confusion regarding the use of support animals, particularly for emotional support. One housing stakeholder said—

We actually have gotten quite a few cases about landlords refusing to allow emotional support animals to people with

mental illness and then the person doesn't want to move in because they cannot bring their support animal. ... There's a lot of confusion too on support animals, service animals, and companion animals and what that means for rental housing or what is considered reasonable.

Reasonable accommodations related to support animals also proved to be challenging for landlords. One family stakeholder said—

Even for the pets, you know, do you allow pets? Well no, we don't. Well, mine's a service animal. I just had this experience myself, just myself, and I said well, there's a one pet rule. Okay, well I have three tortoises and a parakeet. Well, you're going to have to get rid of the tortoises, and I'm like okay, well they're service animals. Oh really, do they help you read? What services do they specifically perform? Well, they help with my daughter's PTSD, so I would have to go before an appeals board.

Participants may also need physical accommodations. One participant described her need as follows.

I'm getting older myself. It's not easy to get around and I can't walk long distances anymore. I can't carry my groceries up 3 flights. Sometimes my balance is off and I could use some grab bars in the bathroom so I don't fall. ... But I'm scared to ask for anything else cause I'm afraid they'll use it as yet another excuse to throw me out.

Additional requirements and fees. The third challenge that focus group participants faced as they sought to access rental housing was the confusing and complex list of additional fees and requirements imposed on them during the housing search and application process. Participants discussed this issue as follows.

When you go to apply for a rental, you know, another thing to check is nonrefundable fees. People call me all the time, and say I got an apartment, but I have to pay a deposit plus I got to pay an application fee, and stuff for credit and criminal check and a laundry list of other fees. It's not just the deposit. Its additional fees and its nonrefundable. ... You can go and fill out the paperwork, and they know when you're filling it you're not going to get it. So that's extra money that they got.

I have no idea if this is even legal, or if they are charging me the same thing they do everyone else, or if it's because I'm disabled and they don't want me there. It's all these extra fees and no one charges the same. There's no rhyme or reason what they'll charge you. In one place it's \$25 for credit check, in another it's \$100 and not refundable. That doesn't make sense.

Participants said that they felt taken advantage of by housing providers, but they also felt that they could not prove that they were treated unfairly. Many participants reported that they did not complain about this treatment because they wanted their own place, and they worried that they would not be able to rent the unit without paying all of the requested fees. One participant said—

This happens all the time to me but I don't say anything. I complained once and it just backfired on me, they pulled the unit away from me cause I questioned all the fees. Now if I'm looking and they have a lot of fees, I usually don't even apply cause I know they don't want me there.

Participants from I/DD and community stakeholders groups reported that landlords would take advantage of people with I/DD in a different way. As an example, one participant reported how a landlord falsified the paperwork without informing her, assuming that she would not notice.

Well, because I found out later what they did inside where I signed up for blah blah blah and agreed to pay extra for blah, blah blah, and then when my mother went and got the paper, because my mother knows my handwriting, and she said that ain't even your handwriting.

The focus group of people with I/DD also pointed out that the paperwork required during the application process can be very complex and difficult for people with I/DD to see, read, and understand. One participant said—

They have these big long legal contracts that people with I/DD can't read and they don't know what they are signing unless you have someone with them and then you're pretty much letting the disability out of the bag and hoping it doesn't backfire. It's really easy to take advantage of them, or to bring it back later to hold against that person and evict them later.

Finding other reasons to deny housing. The fourth challenge that participants with MD described relates to landlords using reasons other than the presence of a disability to deny housing, such as income, credit, or criminal background. Participants described this issue as follows.

Categories that allow for housing providers to discriminate so in addition to the disability, you have the income, the criminal background, the substance abuse, you have no job, pick the one you want if you want to deny an apartment. That's the challenge.

Yeah, if you have a criminal background, then you have another strike against you. You have your mental illness,

and then, you know, sometimes people judge a book by its cover. It's just, you know, there's so many different things to go against us. Like I say, if you've got a criminal background, they'll be like well they've got too many problems, and then you have a mental illness, so they find a way to discriminate.

The credit being the most dominant basis for denial when persons have been living in an institution with \$30 a month in net income, and may have very old credit exposure or evictions for third-party credit reports, bad credit, boom, you're denied. ... Landlord's initial willingness to master lease or do some sort of work-around of people's absence of credit or bad credit, and then changing their mind and saying, oh, by the way, we're no longer going to accommodate.

Economic status and the use of rental subsidies, such as a housing choice voucher, were also perceived as a source of denial or differential treatment. Participants described their experiences with vouchers as follows.

Not enough vouchers so you can't afford anything, you have to be on these waiting lists over and over and over again. Or when you get one and are lucky enough to do so, the landlord won't take it. They'll rent to someone else who doesn't use a voucher.

I recently had a situation where I went to an apartment complex, and I applied and I do have a housing choice voucher and after I paid the money, you know, the application fee and the deposit and they gave me my address. But when other people came in with 'jobs', better jobs, they took my apartment back, they took it away after they approved it.

Barriers to Rental Housing: Staying in Housing Long Term

In addition to barriers to getting into rental housing, people with MD also described barriers to staying in, maintaining, and sustaining rental housing for the long term. One stakeholder addressed the issue of sustaining housing—

Where do landlords turn us down for renting or turn down a tenant? It happens much more on the retaining of housing than the acquisition of housing. It's easier to get people in. The challenge becomes when things become difficult in terms of the maintenance of the apartment, what you do there, or the loss of a voucher, or other things happen.

Focus group participants raised issues faced by individuals with an MD as they sought to maintain a rental unit in the community, including the following five issues.

1. Ongoing events and situations that landlords used to evict tenants with MD.
2. Breaches of confidentiality and privacy.
3. Monitoring tenants with MD but not monitoring others.
4. Inadequate apartment maintenance and repairs.
5. Inhospitable, unsanitary, and unsafe living conditions.

Ongoing events and situations used for eviction. Participants reported that landlords and management staff did not have an understanding of the changing nature of their disability and, therefore, the changing reasonable accommodations that might be needed. Two stakeholders discussed this issue as follows.

It's not just finding housing, it's staying in that housing and keeping it over time. We can help people find a place but so often it's more about being able to live there after they get in, and not getting thrown out or forced out. Sometimes this happens right after they move in; sometimes it's after the person has something happen to them or there's an emergency or crisis, or they lose a big support in their lives. Sometimes their benefits get cut or they can't afford their medications and have troubles. It's the long-term haul that's the problem, and so many people end up moving from place to place and starting over.

We've seen cases where landlords have rented initially, but then, you know, based on some behaviors, which are not dangerous, but may not be typical, refused to renew the lease, and in the worst case, did eviction proceedings.

Focus group participants with MD also experienced medical emergencies and other crises that resulted in late rent payment. This type of situation provided landlords with excuses to evict rather than work with the individual to accommodate their return to the unit. One participant described an experience with a medical emergency and lost lease.

Sometimes life gets out of control. Like when I needed to be hospitalized and landed up in a nursing home for a while. It wasn't my fault but I lost my lease and my apartment, and had to start all over again.

Without adequate supports or because of the loss of supports over time, people with MD experienced life changes that made it difficult to maintain management of their housing, putting them at constant risk for losing housing. One participant described the risks for people with MD.

What makes the issues of affordable housing when you get involved as a tenant is they have rules and guidelines that maybe a mental person with a disability like me, we can't

keep up and we get penalized by the housing, and we will end up homeless eventually because there's only so much a person with disabilities can do, like keeping your house clean, making sure that you go to events that they have, or making a payment when your disability payments are cut. You know, there are a lot of things that can prevent you that you accidentally can break the rules and you get penalized.

Confidentiality and privacy. Participants also reported many issues related to choice, control, and privacy that threatened their ability to remain in their apartment. Focus group participants described situations in which landlords or management staff would come into the apartment without permission in the name of “inspection.”

I could be laying in my bed asleep, and I could hear someone coming in, and they say our rules say we can come in within 24 hours of notice. But it also says you must let me know. I got a trauma. I used to get raped and beaten. And if I wake up and someone is standing over me, it's terrifying ...

When they come to exterminate, they exterminate the whole building. They go through your drawers, shirts, underwear, I mean, like that's their home, and that's an issue because you have to respect privacy of the tenants.

A participant with I/DD reported how his landlord harassed him with constant reminders on rent due dates.

The lady keep bugging me every time. She keeps bugging me about, “you know, don't forget, you've only got a week, so I'm gonna see you?” She'll knock on my door and say it again and again—you know, lady, you've got to stop doing that. I know, tell me once, not two days, not three days, every day.

Monitoring tenants with MD but not monitoring others. Many participants described situations after moving into a unit in which their disability was not only disclosed to the landlord, but also to other staff and even to other tenants, which then started a cycle of constant surveillance and monitoring of their activities. Two participants described such situations as follows.

They figure that's because you've got a disability [I/DD] and everybody knows you have a disability, they think they can take advantage of you. It makes you very upset, because they know you work and all that so they should treat you like any other renter. Instead they watch your every move and think it's OK to go into your space without your permission to check up on you. They say it's a safety check.

And they'll watch you more. Yeah, every little thing that go wrong and the person don't even have to have nothing to do with it. They put a label on that person, oh, she's got a mental disability [I/DD]. She did it, we can put it on her, and they blame her for it. Doesn't matter if she did anything, she'll get blamed.

Inadequate apartment maintenance and repairs. In addition to landlords not informing tenants about regularly scheduled maintenance, they blame or hold accountable renters with MD for any issues in the unit, even if they resulted from regular wear and tear. One participant said—

You have a responsibility to report damage that occurs. And then if you don't report it, some people are afraid to report things that are wrong in their building, the plumbing or whatever else. Then they say, oh, I had these crazy people in my property, and they tore it up. Well, they didn't tore it up. They were living there for 15 years, and in 15 years it didn't have another paint job or needed new plumbing or whatever. That's the thing. You're penalized because of your psychiatric disability.

Inhospitable, unsanitary, and unsafe living conditions. For many participants, repair needs in the unit remained unaddressed over time, resulting in unacceptable living conditions. Several participants discussed such conditions.

The landlord where I was living knew that most of the people there had mental health problems. We got free furniture and the landlord says it was brand new, and what happened was bed bugs were in my apartment and I reported it to the landlord, and then they wouldn't do anything for a whole month. So I called DCRA (housing inspection agency). And they sent out someone. They got cited and said they had 30 days to fix it. Here it is almost seven more months after, and they have not fixed it. So what I'm I have to do now is I've lost all of my clothes and all of my furniture, and I have a daughter and she couldn't understand. She had mental health issues too and it's really tough on her.

I had bug infestations a bunch of times, including bedbugs; I had bites all over my body. I complained and complained but they didn't do anything. I filed a complaint and even they said, why don't you just move? As if that's possible? Do you know how hard it is to find a place when you have a mental illness? You'll put up with a whole lot just to be in your own apartment. But sometimes the conditions are really bad.

Many participants reported needing to bring in an outside advocate to troubleshoot and intervene with landlords regarding inadequate living conditions before actions to address them were taken. One participant with IDD said—

Yeah, I used to have a hard time like if I needed something fixed in my apartment, they used to take forever. Until Quality Trust (legal protection and advocacy group) had to step in, and once they discovered who Quality Trust was, and I guess they had to look it up on the Internet, then they finally did something. My mother done all we could and we couldn't get nowhere, once Quality Trust stepped in, then they started doing what they were supposed to do. What about people who don't have somebody like Quality Trust?

Several focus group participants reported that when they complained about the condition of the unit, the building management staff told other tenants that the problem was due to the person's MD, not the apartment conditions. This set off another cycle in which fellow tenants and the social community created an inhospitable living environment. A participant described one such situation.

I used to live in a place and had they what they call a socialization room... I would go in that room occasionally and socialize with people and all I would hear would be people talking about [mental health agency name] and how those people with mental illnesses were crazy and they were damaging the building and why did they let them live here. It's tough to live in a place when you hear that kind of thing.

Discussion and Conclusions

Like Nelson and Earls (1986), Nelson et al. (1998), and Corrigan et al. (2003) demonstrated in their qualitative and participatory research with people with PDs, directly involving people with MDs in housing and community living research is needed. This focus group research was co-facilitated by people with MDs, including people with PDs and I/DDs. Their first-hand experiences bring to the forefront the specific issues they faced in searching for, applying for, moving into, and staying in market rental housing.

As reflected in the results, people with MDs experience many barriers to getting into and staying in rental housing in the private market. Although individual experiences differed, focus group participants with I/DDs and PDs experienced similar patterns in potential housing discrimination in the private rental market in the two major urban housing markets represented in this research, and they experienced these issues in all stages of the housing process: before, during, and after the search and application process. Both groups struggled with issues of disability disclosure and, when disclosed, or even assumed, experienced pervasive stigma and stereotypes about MD that influenced their housing access and control. Nelson et al. (2007) found that perceived choice and control over housing were positively correlated with the quality of life of people with PDs in Canada. By better understanding the types of discrimination, where in the housing process they occur, and why they lead to barriers in obtaining and maintaining housing, we may be able to better understand housing discrimination and strategize these community living opportunities with people with psychiatric and I/DDs in the United States.

Participants in this research also discussed the lack of knowledge and understanding on the part of landlords and housing providers about the housing and reasonable accommodation needs for people with MDs as compared with those for people with more visible physical disabilities. This lack of understanding then led to many false assumptions or misguided beliefs

about whether accommodation requests were reasonable as related to the disability or not. For example, although support animals are increasingly used for emotional and cognitive assistance, landlords told many participants that these animals did not qualify as reasonable accommodations. In addition, participants perceived that landlords and housing managers did not understand what reasonable accommodations may look like for people with PDs and I/DDs, particularly those related to cognitive and psychosocial accommodations. They expressed a need to better educate housing providers about reasonable accommodation strategies and how they might be expressed by people with MD and then implemented within private market rental housing.

From previous studies, particularly with people with PDs in Canada and other countries, we know that discrimination occurs during the housing process. Through this study, however, we learned from people with MDs in the United States about their specific experiences of private market rental housing discrimination, the types of discrimination that occur, and the stage(s) of the housing process during which they experienced these forms of discrimination. Thus, we better understand what private market rental housing issues and discrimination may look like for people with PD and I/DD, and this knowledge can inform efforts to develop mechanisms to mitigate these discriminatory practices.

Housing discrimination against people with MDs, however, can be complex, subtle, and hard to prove. Qualitative focus groups feature first-hand experiences and perspectives of people with MD related to potential discrimination, but they do not provide the evidence to demonstrate actual discrimination in everyday practice. Therefore, follow-up, rigorous discrimination testing with large samples of people with MDs continues to be needed to provide this evidence. This qualitative focus group research, however, highlighted many specific examples and situations that can inform large-scale discrimination testing design and delivery.

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