Evaluation Tradecraft

Evaluation Tradecraft presents short articles about the art of evaluation in housing and urban research. Through this department of Cityscape*, the Office of Policy Development and Research presents developments in the art of evaluation that might not be described in detail in published evaluations. Researchers often describe what they did and what their results were, but they might not give readers a step-by-step guide for implementing their methods. This department pulls back the curtain and shows readers exactly how program evaluation is done. If you have an idea for an article of about 3,000 words on a particular evaluation method or an interesting development in the art of evaluation, please send a one-paragraph abstract to marina.l.myhre@hud.gov.*

Person-Centered Evaluation Surveys With People With Disabilities: Lessons From the Field

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Abstract

A critical mechanism for advancing health equity is the design of programs that are person-centered and aligned with the goals of the individuals they serve. For evaluators, it is critical that the work is grounded in the perspectives and values of those individuals (Logan, Witgert, and Hersey, 2022). This article describes the processes the study team developed and the lessons learned about collecting information from residents of the U.S. Department of Housing and Urban Development's (HUD) Section 811 Project Rental Assistance program and Project Rental Assistance Contract properties that may inform other efforts to meaningfully engage people with disabilities in evaluation research.

Introduction

The Project Rental Assistance (PRA) program aims to expand access to high-quality, affordable housing and voluntary, community-based services so that eligible people with disabilities can live successfully in the community. From 2015 to 2020, Abt Associates evaluated the PRA program to assess the effect of the PRA program on residents' housing tenancy and use of home and community-based services, the quality of properties and neighborhoods where assisted residents live, and residents' healthcare outcomes, relative to traditional Project Rental Assistance Contract (PRAC) properties typically delivered in group homes or small assisted properties designated to people with disabilities. It is critical to successfully engage the people a program most affects in its evaluation. Doing so ensures evaluations are grounded in what matters most to participants and provides agencies and funders with a more concrete understanding of how programs affect the communities they serve (Logan, Witgert, and Hersey, 2022). To gather residents' perspectives on the PRA program directly, the study team developed and conducted an in-person resident survey to determine residents' use of and experience with the services they receive in their homes, opinions about their housing and neighborhood, and perceived health and quality of life.

Residents' perspectives were critical to a comprehensive assessment of the PRA program. The study team adopted several practices to collect the perspectives and opinions of program participants. Asking questions about sensitive, private health concerns and the social and emotional well-being of program participants with developmental, intellectual, and mental health disabilities raised several considerations. For example, the study team took steps to design survey questions that resonated and could be reliably understood, provided training and support for survey staff, coordinated with property management and supportive services staff to recruit residents who were interested in completing a survey, established informed consent and cognitive screening procedures that take into account a wide range of disabling and mental health conditions, and researched the legal requirements regarding mandatory abuse and neglect reporting and legal guardianship.

Background: Overview of the Section 811 Project Rental Assistance Program and Evaluation

Authorized under the Frank Melville Supportive Housing Investment Act of 2010 (hereafter referred to as the Melville Act),[1] the Section 811 PRA program provides project-based rental assistance to nonelderly people with disabilities with extremely low household incomes.[2,3] The program responds to the goals of the Supreme Court's 1999 decision in *Olmstead* v. *L.C.* to allow people with disabilities to live in the least restrictive settings possible that meet their needs and preferences.[4] The Section 811 program allows persons with disabilities to live as independently as possible in the community by providing rental assistance with access to appropriate supportive

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[1] Frank Melville Supportive Housing Investment Act of 2010 § 42 U.S.C. 8013 (P.L. 111-374).

[2] "A person shall be considered to have a disability if such person is determined, pursuant to regulations issued by the Secretary to have a physical, mental, or emotional impairment which (A) is expected to be of long-continued and indefinite duration, (B) substantially impedes his or her ability to live independently, and (C) is of such a nature that such ability could be improved by more suitable housing conditions."

[3] Households are eligible for PRA program housing that have incomes at or below 30 percent of area median income.

[4] *Olmstead* v. *L.C.* (98-536) 527 U.S.581 (1999).

services (HUD, 2023). The 811 PRA program funded a new type of housing subsidy that is different from the traditional Section 811 Capital Advance and the PRAC program that has been operating since 1991. The Section 811 program offers two types of housing subsidies. Exhibit 1 notes the major differences between these two types of housing subsidies.

Exhibit 1

Major Differences Between the Two Types of Section 811 Housing Subsidies

Project Rental Assistance Contracts	Project Rental Assistance
• Provides interest-free capital advances and operating subsidies to nonprofit developers of affordable housing.	• Provides project rental assistance to state housing agencies partnering with state health agencies to allocate to owners of affordable housing developments built with other federal or state funding.
• Requires 100 percent of units to be set aside for people with disabilities. • Often operated as group homes or small assisted properties designated for people with disabilities.	• Requires a maximum of 25 percent of units to be set aside for people with disabilities.
• Residents are nonelderly people with disabilities in very low-income households (defined as less than 50 percent area median income).	• Residents are nonelderly people with disabilities in extremely low-income households (defined as at or below 30 percent area median income).
• Nonprofit owners of PRAC program housing ensure that residents have access to voluntary, community-based services.	• Residents must be eligible for Medicaid-funded home and community-based services[a] or similar Medicaid services to help them live independently.

PRAC = Project Rental Assistance Contract.

[a] Home and community-based services enable people with disabilities to live in the community. They can include personal assistance services, transportation, home health, case management, adaptive equipment, respite care, and other services.

The PRA program started as a joint initiative between HUD and the U.S. Department of Health and Human Services' Centers for Medicare & Medicaid Services (CMS). The PRA program aims to expand access to high-quality, affordable housing and voluntary, community-based services so that eligible people can live successfully in the community. To assess the implementation and outcomes of the PRA program approach, the Melville Act required an evaluation.

Abt Associates evaluated the PRA program between 2015 and 2020, focusing on 6 of the 29 state housing agencies that had received PRA program funding at the start of the evaluation. These states were selected because they housed the largest numbers of PRA residents when the study's research design was finalized in 2017, giving the evaluation the best chance to detect program outcomes for PRA residents. One goal of the evaluation was to assess the effect of the PRA program on residents' experiences with their homes, services, and neighborhoods and self-assessed health status and quality of life relative to PRAC program housing. To achieve this goal, the study team developed and conducted an in-person resident survey to help answer the study's research question: *What is the early evidence on how PRA program residents fare relative to similar individuals in the PRAC program in terms of quality of life, housing and neighborhood characteristics, housing tenure, health, and service utilization patterns?*

The study team completed the resident survey with 403 individuals living in either PRA- or PRAC program-funded housing. All survey participants were individuals with physical or developmental disabilities or mental illness. Prior to receiving housing assistance through the PRA program, most PRA residents were experiencing homelessness, residing in an institutional setting, or at risk of homelessness or institutionalization without access to affordable housing, and most PRAC residents lived in a group home or private residence.

Conducting Surveys With People With Disabilities

The principle of "nothing about us without us" is the central tenet to communicate the idea that a representative should not decide on any policy without the full participation of the group members that the policy will affect (Charlton, 1998).[5] A comprehensive assessment of the PRA program required including the perspectives of those the program affects the most and who are the most knowledgeable about its effect on resident experience. Residents provided their perspectives on key program domains, including the tenant application and placement process, housing quality, neighborhood quality, community inclusion, quality of life, and the adequacy of supports. Although efforts have been made to include people with disabilities in evaluations of federal demonstration programs serving individuals with disabilities (Nichols, Hemmeter, and Engler, 2021), they have often been left out of research on healthcare experiences and health outcomes (Krahn, Walker, and Correa-De-Araujo, 2015; Rios et al., 2016). Often this omission is due to rigid inclusion and exclusion criteria for research studies and the design and execution of data collection procedures that make participation in research studies inaccessible for individuals with disabilities. Designing research studies to make sure individuals with disabilities are able to participate fully is important for all types of research, but maybe more so for studies in which individuals with disabilities are a high-priority population.

Collecting data directly from people with developmental, intellectual, and mental health disabilities and asking sensitive and private questions about health and well-being requires additional considerations beyond those that may exist for collecting data from the general public. These considerations include designing survey questions that resonated and respondents could reliably understand, providing training and support for data collectors, coordinating with property management and supportive services staff to recruit residents who are interested in completing a survey, establishing informed consent and cognitive screening procedures that take into account a wide range of disabling and mental health conditions, and researching and understanding the legal requirements around mandatory reporting and legal guardianship.

To design the resident survey instrument and develop data collection procedures, the study team took the following steps to ensure that individuals with disabilities would be able to participate: (1) Allowed for multiple avenues of resident recruitment and consent; (2) conducted interviews in person and on site at resident properties rather than electronically or via phone; (3) allowed residents to respond with a proxy, caregiver, or family member on hand to help with responses; and (4) designed a short survey instrument with primarily closed-ended items to reduce the burden on respondents. Further details on the design and execution of the Section 811 evaluation resident survey follow. This article highlights the strategies the study team used to capture resident perspectives and ensure that people with disabilities could fully participate in the evaluation.

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[5] "Nothing about us, without us" is an overarching principle of disability research, underscoring the necessity of meaningful participation of people with disabilities throughout the research project lifecycle.

Survey Questionnaire Design

The study team designed the resident survey instrument to capture resident perspectives about their housing and neighborhood, daily life, and access to the services and supports. The survey was designed to capture information about quality of life and service receipt (or lack thereof) that residents of PRA and PRAC program properties can uniquely provide. The study team drew from existing survey instruments and adapted items from three survey instruments that have been validated with people with relevant program experience: the Money Follows the Person Quality of Life survey (Sloan and Irvin, 2017),[6] the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community-Based Services Survey (AHRQ, 2016),[7] and HUD's (2009) Customer Service and Satisfaction Survey.[8] The resulting 75-item, in-person, verbally administered survey took between 20 and 45 minutes to complete.

The study team worked with the property managers at six PRAC program properties to each identify one to two residents interested in participating in cognitive testing. Property managers provided the study team with individuals' names and contact information at their properties who were interested and their preferred date and time. The study team conducted in-person cognitive testing with six residents on site at their respective properties. Each cognitive testing interview took approximately 1 hour to complete. The survey staff administered the resident survey and used a series of embedded probes to assess whether questions were easy to understand and whether residents interpreted the questions as the study team anticipated. A notetaker documented interviewees' responses and notes about the interview process. The study team provided residents with a $75 gift card who completed the cognitive testing interview.

Lesson Learned: Cognitive testing is a valuable step in the design phase of any data collection effort. During the course of the six cognitive testing interviews, the study team revised questions and response options for clarity, updated the response options to make sure they were mutually exclusive, added additional response options, and updated the wording of questions to better align with the goals of the questions. For example, the original draft of the survey included the question, "Do you have trouble getting around your neighborhood?" During the cognitive testing process, the study team learned that residents interpreted trouble as a bad thing and associated it with not following the rules or getting in trouble, so the study team updated the wording to, "Do you have problems getting around your neighborhood?" Similarly, a five-point Likert scale that included "fair"

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[6] This survey has been used in numerous states as part of the implementation and evaluation of the Money Follows the Person demonstration since the demonstration launched in 2007. The survey primarily draws on items from the Participant Experience Survey (Version 1.0 of Mental Retardation/Developmental Disabilities 2003, MEDSTAT Group, Inc.) and selected items from the following instruments: ASK ME!, Cash and Counseling, National Core Indicators® survey, Quality of Life Enjoyment and Satisfaction Questionnaire–Short Form, and the Nursing Home Consumer Assessment of Health Plans Survey. The survey can be found at https://files.nc.gov/ncdma/documents/files/MFP_QOL_Survey_12_2018_0.pdf.

[7] This cross-disability survey for adults receiving long-term services and supports from state Medicaid Home and Community Based Services (HCBS) and supports programs was developed with funding from CMS and is available for states to use on a voluntary basis. Survey development included formative, cognitive, and field testing with people with disabilities. The National Quality Forum endorsed 19 measures that are calculated using HCBS CAHPS data in 2016. The survey can be found at https://www.medicaid.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html.

[8] HUD developed this survey with input from housing industry representatives and resident leadership groups. The survey can be found at https://www.hud.gov/sites/documents/DOC_17223.PDF. More information is available at https://www.hud.gov/program_offices/public_indian_housing/reac.

and "poor" as response options elicited examples related to equity and fairness and lack of money. As a result, the scale's options were revised to *Excellent, Good, Okay, Not so Good,* and *Bad*. The cognitive testing process was a critical step to fine-tune questions and response options and ensure the resident survey meets the goals of the evaluation. It provided an important opportunity to make sure residents have an opportunity to contribute to the evaluation design.

Staff Training

The study team assembled an interdisciplinary group of survey staff comprising staff with expertise in health care and Medicaid and those with expertise in housing policy. The study team conducted training in three parts to provide background on the PRA and PRAC programs and Medicaid services for people with disabilities, develop familiarity with the survey instrument, and role-play survey scenarios.

The study team began by cross training all survey staff, providing an orientation to the Section 811 PRA program and to the concepts that underlie it, which are community integration of people with disabilities, permanent supportive housing, and Medicaid long-term services and supports. A senior housing policy researcher led a discussion about appropriate person-centered language when talking with and about people with disabilities and interviewing people living in poverty. The study team gave special attention to human subject protections and informed consent, mandatory abuse and neglect reporting guidelines, and ensuring privacy and personal safety when conducting surveys in residents' homes. These topics are important for all research involving human subjects, not limited to people with disabilities, but additional nuances may present when engaging people with disabilities (see the following Informed Consent and Resident Safety sections).

Next, experienced researchers trained all survey staff on the survey instrument. The study team described the design and validation of the survey tool, explained how survey results would be used as part of the overall evaluation, and reviewed survey sections. Two researchers then role-played administering the survey, which training participants discussed afterward. The study team leaders encouraged survey staff to practice the survey instrument in pairs to become comfortable with the survey questions, flow, and length.

Third, survey staff gathered for a group learning session focused on scenarios that could occur when third parties are present during surveys with people with disabilities. For example, a property manager, service provider, or family member could inappropriately attempt to answer for a resident or indirectly influence the resident's responses. Each researcher drew a card describing a scenario, read it aloud, then described how they might respond to politely explain that the goal is to provide respondents with privacy and to gather residents' responses in their own words. Senior researchers provided feedback and suggestions. This exercise gave survey staff the opportunity to practice responses to potentially awkward situations and to consider how to best gather participants' own opinions.

Lesson Learned: Talking through scenarios was just as important to making survey staff feel prepared as practicing with the survey instrument. For most survey staff, conducting in-person surveys with low-income people with disabilities was a new experience. In addition, few survey staff had experience meeting residents of HUD-supported housing in their homes. The scenario training helped survey staff think through possible unanticipated situations and develop culturally and linguistically appropriate responses in advance. Practicing the scenarios in a training setting helped dispel anxiety about etiquette for interacting with people living in poverty and communicating with people with various disabilities.

Outreach and Participant Recruitment

Historically, people with disabilities have often been excluded from participation in research (Banks et al., 2022). The survey staff used a multipronged outreach and recruitment method to engage as many PRA and PRAC program residents that were interested in the survey, regardless of their disability type. First, the survey staff conducted direct outreach to residents by mail. Second, the survey staff conducted facilitated outreach efforts through property managers and service providers who have ongoing relationships with residents. Finally, the survey staff recruited residents on site and offered a $40 gift card incentive to residents who completed a survey.

Prior to beginning resident outreach, the survey staff notified property managers by mail and e-mail 6 weeks before each survey visit. The notification explained the purpose of the study, alerted property managers to the planned direct outreach to residents, and asked for their assistance in determining the best way to schedule and conduct surveys with residents at each property. Developing a relationship with property managers was crucial to ensuring access to buildings. Property managers also assisted with outreach (see the following paragraph) and, at times, secured private meeting spaces in common rooms or offices where survey staff could meet with residents to conduct surveys.

Direct Outreach

About 4 weeks before each site visit, the survey staff mailed PRA and PRAC residents in selected properties letters inviting voluntary survey participation. The letter, written at a seventh grade reading level, stated that the survey staff would ask questions “to learn how you feel about your housing, your neighborhood, your daily life, and the services you may receive.” The letter asked those who might be interested in completing an in-person survey to call toll-free. The letter also requested that legally authorized representatives for any residents who may have a legal representative or guardian contact the survey staff regarding a resident’s possible participation. Two weeks before each site visit, the survey staff mailed reminder postcards to residents who had not responded to the letter, reiterating the opportunity and again providing a toll-free number.

Facilitated Outreach Through Property Managers

Recognizing that response rates to mailed invitations were likely to be low, the survey staff engaged property managers to assist with recruitment. The survey staff called property managers to request that they publicize surveys and provided a flyer and consent-to-contact form, which recorded residents’ permission for survey staff to call to schedule a survey, for property managers’ use. The survey staff called property managers weekly to securely receive contact information for interested residents, then followed up with those residents directly to schedule a survey time.

Facilitated Outreach Through Service Providers

Because PRA program residents are eligible for Medicaid home and community-based services, the survey staff also leveraged service providers to assist with outreach. Six weeks prior to visits, the survey staff e-mailed select service providers information about the survey and a consent-to-contact form. The e-mail asked service providers to call the scheduler with interested residents' contact information, and the scheduler then followed up directly with interested residents.

Onsite Outreach

Despite these outreach efforts, many survey staff began onsite visits with a less-than-full schedule. Thus, the study team developed processes and tools for onsite recruitment. Once on site, survey staff supplemented the scheduled interviews by offering ad hoc interviews to additional Section 811 residents at each property. In most cases, survey staff knocked on doors or rang buzzers to apartments Section 811 residents occupied to offer them survey participation. If residents were not at home, survey staff left a flyer with contact information. In a few cases, the opportunity to participate in a survey and receive a gift card spread by word of mouth through a property while survey staff were on site, and residents sought out survey staff to volunteer their participation. Prior to beginning a survey, survey staff verified PRA program residents' participation in the Section 811 program and conducted a brief cognitive screening with both PRA and PRAC residents to ensure their capacity to meaningfully consent to survey participation.[9,10]

Lesson Learned: Property managers can facilitate access to buildings and bridge introductions to residents. A practical advantage of conducting surveys with PRA and PRAC program residents is that all the properties the survey staff visited employed a property manager who was based at the property at least part-time, and many properties employed an onsite service coordinator. Many property owners that administer Section 811 housing are not-for-profit organizations with missions of serving low-income populations and were supportive of the research goals. Making connections with property managers facilitated survey staff's access to buildings and residents.

Lesson Learned: Onsite outreach can supplement scheduled interviews to engage residents with disabilities. People with disabilities may experience a variety of barriers to keeping scheduled survey appointments. For some residents, scheduling healthcare and social services appointments must take priority. Unreliable transportation to and from such appointments can wreak havoc on schedules. For other residents, advance scheduling may be challenging. Many residents have "good days and bad days" and may, thus, decline advance scheduling or opt out of participation in the moment. Onsite outreach allowed survey staff to reach as many residents who wished to participate as possible.[11]

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[9] This program verification was not necessary at PRAC program properties, because all residents at PRAC program properties are program participants.

[10] The Informed Consent section provides more information on cognitive screening.

[11] The surveys were completed before the COVID-19 public health emergency. Abt Associates developed and is continuing to update guidelines for in-person data collection that protect the health of interview or survey staff and respondents. The staff follow all federal-, state-, and local government- and individual property-issued health regulations.

Lesson Learned: Not all volunteers were eligible for survey participation. Because the PRA program requires that no more than 25 percent of apartments at a property are set aside for PRA program residents, most residents at a property were *not* eligible to participate in the survey. This distinction was sometimes challenging for survey staff to explain to individuals who were enticed by the gift card incentive but were ineligible to complete a survey.

Informed Consent

Obtaining the informed consent—agreement to participate based on an understanding of participants' rights and risks—of people with developmental, intellectual, and mental health disabilities may require additional steps to ensure their ability to consent to participate in the research.

Survey staff screened all respondents for the cognitive ability to complete the survey independently and obtained participant consent (and consent of legally authorized representatives if applicable) prior to conducting the survey. The study team also developed procedures for use of a proxy to assist in survey completion when necessary and for obtaining informed consent from residents with legally authorized representatives.

Cognitive Screening

Prior to scheduling or conducting a survey, the survey staff conducted a brief cognitive screening with all potentially interested survey respondents to ensure their capacity to meaningfully consent to survey participation. To engage as many residents as possible in the survey, potential respondents who could not accurately answer three cognitive screening questions were asked to identify a proxy, that is "someone who could meet with us and help you answer questions about your housing, the services you receive, your health, and your daily life."

The survey scheduler (when scheduling in advance) or surveyor (when recruiting on site) briefly described the survey's purpose to each potential respondent. The scheduler or surveyor explained that participation was voluntary and that the information respondents provided would be kept confidential. The scheduler or surveyor then asked potential respondents to explain three key elements of informed consent in their own words:

1. Can you tell me in your own words what the survey is about?
2. When I say your participation is completely voluntary, what does that mean to you?
3. When I say that your answers will be kept confidential, what does that mean to you?

Of the 403 residents surveyed, this process deemed 6 to require a proxy to consent to the resident's participation and assist the resident in completing the survey. When a proxy was needed, the resident was also asked for assent to participate in research and given the opportunity to decline.[12]

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[12] Assent is the agreement of someone not able to give legal consent to participate in a research activity.

Research Participants With Legally Authorized Representatives

Some individuals with developmental and intellectual disabilities or mental illness have another person who is legally authorized to act in their behalf in certain health, financial, or legal situations, including participating in research (exhibit 2). The study team researched federal and state legal guardianship consent laws to better understand where and how often they might encounter legal guardians or representatives among survey participants (for example, is it more common for people with specific types of disabilities or conditions or in specific states?) and to determine when and how to involve guardians or legally authorized representatives in data collection.

Exhibit 2

Legally Authorized Representatives

According to the U.S. Department of Health and Human Services' regulations for the protection of human subjects in research, if an adult lacks the capacity to consent as result of their health or cognitive conditions, only the legally authorized representative for that adult can give consent for participation in research, unless the Institutional Review Board waives the requirement to obtain informed consent (45 CFR 46.116(c)(d)). A legally authorized representative is "an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research" (45 CFR 46.102(c)).

The laws regarding guardianship and whether consent is needed for individuals to participate in research vary by state. Most of the study states had no law specifically addressing the issue of consent in the research context outside of consent for medical procedures or treatment. Requirements for legal guardianship or for a legally authorized representative may also vary according to the specific needs and circumstances of the individual. To ensure consistency in processes across states, the study team elected to follow guidelines from California's Research Subject's Bill of Rights, which applied the most restrictive policies and requirements regarding legal guardianship. The study team also trained survey staff about state-specific guardianship terminology as it varied by state.

The telephone recruitment script asked potential respondents, "Do you have a legally authorized representative or someone else you need to talk to before taking the survey?" If the answer was yes, survey staff were instructed to obtain the legally authorized representative's contact information, obtain informed consent from the representative, then call the resident back to proceed with cognitive screening and scheduling an interview. The determination of a legally authorized representative and cognitive screening are independent processes. Not all individuals who have a legal guardian require a proxy to complete the survey, and not all individuals who require a proxy to complete the survey have a legal guardian.

Lesson Learned: Legal research may be necessary. The study team consulted with Abt Associates' Institutional Review Board (IRB) and legal counsel to clarify the state and federal laws that addressed consent of legally authorized representatives and were potentially applicable to the study. Study IRBs may wish to consult with legal counsel when deciding how researchers can best engage program participants who have a legally authorized representative.

Resident Safety

People with disabilities are at a higher risk of abuse, neglect, and being victims of crime than people without disabilities (DRC, 2023).

Mandatory Reporting of Abuse and Neglect

The study team researched mandatory reporting requirements for each of the six study states to determine whether the study team would have legal responsibilities to report potential cases of abuse or neglect of individuals and the procedures for reporting this information. The study team reviewed mandatory reporting policies from the National Adult Protective Services Association (NAPSA) and state department of aging and social services websites. The study team identified both the definition of who mandatory reporters are in each state and how to report suspected abuse or neglect for both mandatory reporters and the general public (exhibit 3).

Exhibit 3

Mandatory Reporters

Mandatory reporters are required by law to report any suspected neglect or abuse of populations such as people with disabilities, older adults, and children. Mandatory reporters often include medical professionals, social workers, teachers, police officers, and other professions that interact with vulnerable populations or in positions in which they are more likely to observe abuse or neglect. State legislatures establish mandatory reporting requirements and the state department of health or social services or adult protective services agencies govern them.

Lesson Learned: Resources are available for reporting possible abuse or neglect. The research on mandatory reporting proved valuable to the study team by identifying reporting standards that the study team could use for this study and others. The typical standard for reporting is when the reporter has a reasonable suspicion that a situation causes abuse or neglect of an individual. Most of the study states have a toll-free number and an online messaging system to report potential abuse or neglect. The NAPSA website provides an up-to-date listing of all states' mandatory reporting requirements, definitions of types of abuse and neglect, and guidance on when individuals should consider making a report.

Reporting Adverse Events

Reporting adverse events is required for all human subject data collection, and survey staff were required to report all incidents of adverse events or unanticipated problems research subjects experienced to Abt Associates' IRB administrator as soon as possible and no later than 48 hours after the event occurred. For the resident survey, adverse event training and reporting requirements were put in place to ensure that survey staff understood what constitutes a reportable event and to ensure the safety and well-being of the respondent and survey staff during the data collection process.

Although the survey staff did not encounter any concerns regarding suspected abuse or neglect of residents, the study team followed up on several instances—with the knowledge of affected residents—with property management or services staff, HUD, or state Medicaid agency contacts regarding information survey respondents provided during data collection or via the toll-free survey scheduling line. Residents' complaints about housing were forwarded to HUD or the property manager, depending on the nature of their concerns. Resident concerns or complaints about property management were routed to HUD's Office of Multifamily Housing, which administers the Section 811 Project Rental Assistance and Project Rental Assistance Contract programs.

Lesson Learned: Identify points of contact and a reporting process before data collection starts. Given that our survey respondents were living in HUD-assisted properties, and most were receiving health care and supportive services through Medicaid, the study team had some avenues for reporting concerns about residents' safety and well-being beyond the state agency toll-free numbers and websites.

The study team reported concerns about residents' safety or health to either the resident's case manager, if known, or the study's point of contact at the state health or social services agency. These individuals were able to contact the residents' assigned case manager to follow up directly with the resident about concerns or needs.

Lesson Learned: Provide multiple avenues for study participants to provide feedback or report concerns. All outreach materials and the written consent document included contact information for Abt Associates' project director for the evaluation and for HUD's contracting officer. The consent document included toll-free numbers for HUD's Office of Multifamily Housing if residents wanted to report concerns about housing.

Survey Staff Safety

Field staff mainly conducted surveys in one-on-one meetings in residents' apartments. To ensure the safety and well-being of survey staff who were often working alone and potentially hearing about challenging health and quality-of-life issues from survey respondents, the study team created the role of "safety officer." These senior members of the study team were available to support the field staff as needed. Survey staff were asked to keep safety officers apprised of their whereabouts while at the property, and safety officers were required to be available by cell phone or text message throughout the entire days they were on call. Each individual field surveyor was required to check in with their safety officer at the end of every day of a field visit after all scheduled interviews were completed. Survey staff could also reach out at other times during the day if needed. Safety officers were available to talk through any challenges or incidents that may have occurred during the day and help determine whether further actions were required.

Lesson Learned: Safety officers provided support and reassurance to field staff. This additional role and safety protocol were valuable additions to the data collection protocol. Survey staff appreciated having a designated point of contact with whom to discuss any challenging situations as they arose.

Conclusions

The best way to understand a participant's experience with an intervention or program is to ask them. Rather than relying solely on secondary data or interviews with staff implementing a program, collecting data directly from participants provides valuable insight into program impact and what matters most to participants (Logan, Witgert, and Hersey, 2022). In addition, centering equity in research demands that researchers engage the people the programs most affect. The study team's experience conducting in-person surveys with Section 811 residents demonstrates both the feasibility and importance of including residents' perspectives in the evaluation.

Some evaluation findings were only available through the resident survey. For example, residents' experience with their neighborhood, apartment, and home and community-based services can only be measured directly. Similarly, residents' reporting of any unmet needs cannot be measured with secondary data. In addition, the resident survey added a perspective that helped the study team contextualize other evaluation findings. For example, the evaluation used a publicly available index from the U.S. Environmental Protection Agency to assess neighborhood access to public transit and found that Section 811 neighborhoods score higher than average. Correspondingly, less than one-fourth of survey respondents reported problems getting around their neighborhoods. The survey further elucidated common reasons for challenges getting around the neighborhood such as lack of money for transportation, transit trips taking too long, and neighborhood accessibility (Vandawalker et al., 2020).

A critical mechanism to advancing equity is the design of federal programs that are person-centered and aligned with the goals of the individuals they serve. As evaluators, the study team believes that it is equally critical that the work is grounded in the perspectives and values of those individuals. Participants' lived experience is their expertise, and engaging participants with lived experience meaningfully in evaluations provides a foundation for equitable evaluations (Logan, Witgert, and Hersey, 2022).

Acknowledgments

The authors gratefully acknowledge the assistance of colleagues at HUD and Abt Associates who provided consultation and guidance, reviewed drafts, and offered support throughout the development, writing, and publication of this article: Marina Myhre and Teresa Souza of HUD and ZeAmma Brathwaite, Sara Galantowicz, Susan Longley, Debi McInnis, Brenda Rodriguez, and Michelle Wood of Abt Associates.

The authors also acknowledge colleagues who collected, analyzed, and reported survey data, the PRA and PRAC property managers who facilitated access to residents, and the residents who generously gave their time to complete the survey.

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