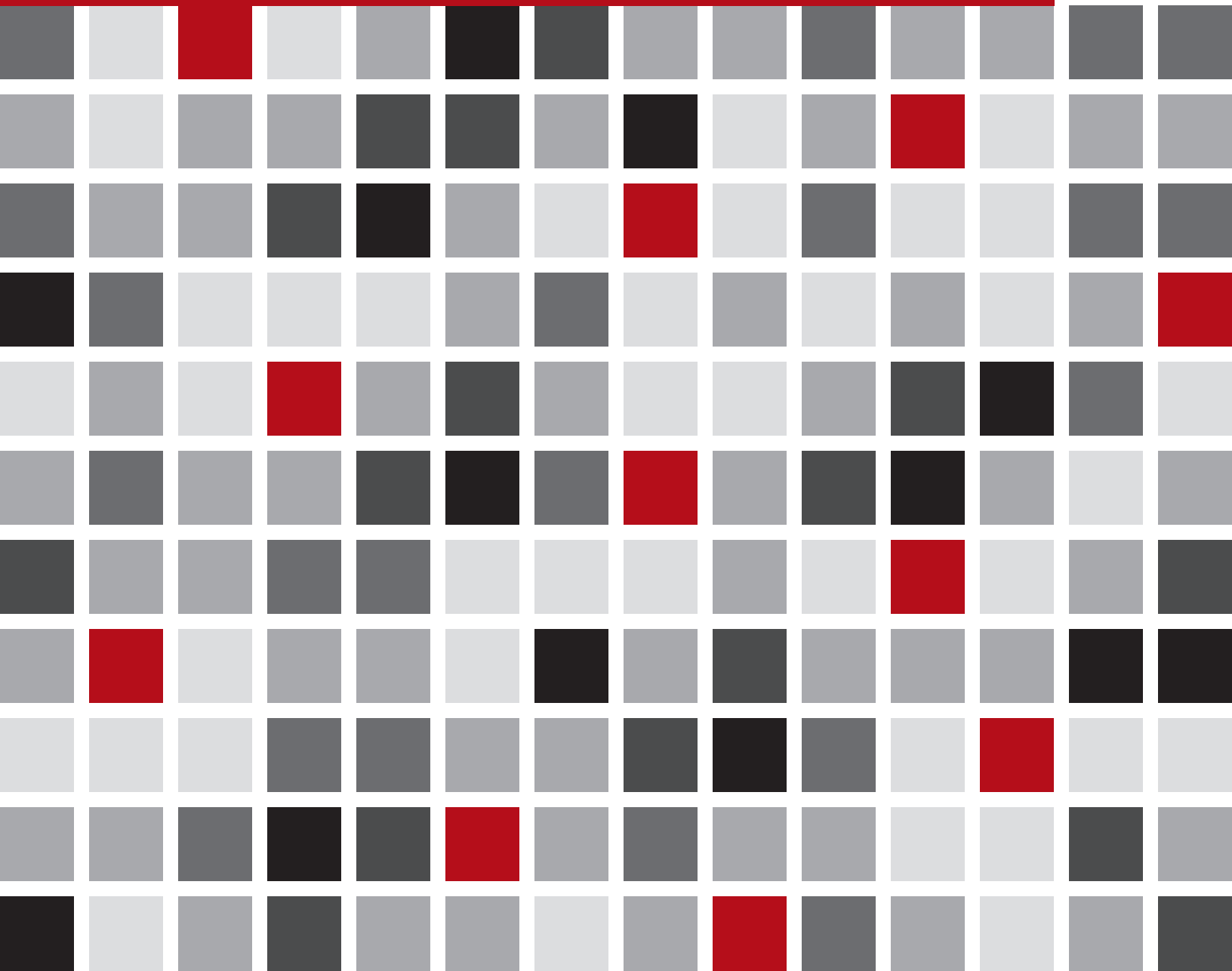
mbhp
metropolitan boston housing partnership

# RETHINKING HOARDING INTERVENTION

MBHP's analysis of the Hoarding Intervention and Tenancy Preservation Project

JANUARY 2015



# RETHINKING HOARDING INTERVENTION

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# I. INTRODUCTION

The problem of hoarding behavior plays a significant role in the housing stability of millions of people in the United States. This is particularly true of those with low or moderate incomes who do not have the economic resources to rent storage units or move to larger homes. As a result, they face the risk of eviction, housing subsidy loss, and homelessness due to their hoarding behaviors. Unfortunately, little research has been done to measure the impact of hoarding on housing stability. In the only published study on evictions and hoarding, data collected by researchers in 2010 found that 23 percent of residents seeking services from Eviction Intervention Services Housing Research Center (EIS) in New York City met criteria for hoarding. Of those, 32 percent were currently threatened with eviction and 44 percent had previously been threatened with eviction.[1]

In 2006, Metropolitan Boston Housing Partnership (MBHP), working in partnership with the Boston University School of Social Work, sought a new strategy to address hoarding with the hope of reducing the number of lost subsidies and evictions caused by the problem. Historically, cleaning out the home and time-limited mental health treatment were the only available intervention options for hoarding. MBHP chose to develop a hoarding intervention model using case management that merges harm reduction strategies with cognitive-behavioral therapy techniques. This dynamic case management approach relies on collaborations between property management, service providers, the client, and the MBHP team. The success of this initial pilot, and financial support from the Oak Foundation, led to a joint partnership with the Boston Tenancy Preservation Project (TPP), a program of Bay Cove Human Service that assists individuals and families with mental illness, addiction disorders, or developmental disabilities who are at risk for possible eviction. This joint-program became known as the Hoarding Intervention and Tenancy Preservation Project (HI/TPP).

HI/TPP had the following goals:

- Reduce the number of evictions and prevent homelessness caused by hoarding.
- Expand knowledge of hoarding and hoarding intervention techniques among housing professionals and service providers.
- Influence public agencies and policies, including the courts, state agencies, and the state Legislature to better address hoarding and guarantee program resources.
- Collect data to better understand the characteristics of clients who are "involuntarily" addressing their hoarding behaviors.

The results of HI/TPP are impressive: 98 percent of program participants referred to the program were able to maintain their housing, avoiding eviction or loss of their housing subsidy due to hoarding behavior. Initial evaluation shows participants, including those who left the program early, were able to substantially reduce the volume of clutter in their homes and maintain them in a safer fashion. In addition, HI/TPP was able to create change in the way government and judicial systems respond to cases of hoarding, working with state and local governments to identify practices and policies that could be modified or changed to better support residents with hoarding behaviors. Based on these successes, the HI/TPP model is currently being replicated in San Francisco; Burlington, Vt.; and Bedford and Burlington, Mass.

This report explores data collected from July 2011 through June 2014. When appropriate, comparisons were made between the HI/TPP data and the outcomes to those found in mental health treatment studies for hoarding. However, one factor that differentiates this study from academic research studies is that participants of the HI/TPP program are considered "involuntary"—they engaged in intervention due to a risk of eviction or housing subsidy loss.

This report highlights promising practices, recognizes challenges faced by communities seeking better options for hoarding intervention, and identifies key policy issues that impact the ability of communities to properly respond to the issue of hoarding.

**HI/TPP BY THE NUMBERS**

**175 program participants served**

**98% of program participants maintained housing**

**23: Number of communities where HI/TPP participants reside**

**1,891 professionals trained in appropriate hoarding intervention since July 2011**

**4 HI/TPP replication sites in 3 states**

# II. HOARDING OVERVIEW

## WHAT IS HOARDING?

Hoarding is a mental health disorder characterized by "persistent difficulty discarding or parting with possessions, regardless of the value others may attribute to these possessions."[2] As a result, living spaces become sufficiently cluttered so as to preclude the activities for which those spaces were intended.[3] Those with hoarding disorder have distress or impairment in functioning caused by the hoarding.[4] In the United States, approximately 15 million people (3-5 percent of the population) suffer from hoarding disorder.[5] Based on population figures for the state of Massachusetts and current hoarding prevalence data, there are approximately 20,000 to 33,500 people with hoarding behaviors in the Commonwealth.

Hoarding, when not addressed, has a chronic and worsening course. Possessions build, resulting in health and safety issues. The resident's daily activities also become increasingly impaired. These conditions can range from the mild accumulation of clutter to severe hoarding resulting in injury or death. This spectrum of severity is an important factor to consider when discussing hoarding intervention.

## ACQUIRING, SAVING, AND CLUTTER

Acquiring and saving of possessions is not unique to those with hoarding behaviors. Generally, people—even those without hoarding behaviors—place items for saving in three categories: sentimental, instrumental, or intrinsic.[6] While many people acquire and save items without developing hoarding behaviors, those with hoarding have difficulties processing information, form strong emotional attachments to objects, and avoid seeking help.[7] HI/TPP clients report to case managers that they have concerns including not having enough food or clothing, worries about the loss of identity, and a desire to have on hand important information that they may only be able to gain through their possessions.

In many ways, hoarding is similar to an iceberg. The tip of the iceberg that catches our attention in hoarding cases is the acquiring, saving, and clutter found in the home. However, just as in nature, the bulk of the iceberg lies out of sight under the water line. In the case of hoarding, what lies under the surface can include mental health challenges, neurobiological issues, and executive function issues.

Due to the complex nature of hoarding behaviors, simply removing clutter from the home will not result in sustained change. Instead, cognitive-behavioral techniques for hoarding and harm reduction strategies have proven effective in addressing both the physical home environment as well as factors that are likely contributing to the hoarding behaviors.

Two factors that play a role in the seriousness of hoarding, and therefore in the ability to address the hoarding behavior, are "squalor" and "insight." The following sections define these terms.


## SQUALOR

Squalor is defined as degradation from neglect or filth.[8] One of the common mistakes made by those assessing environmental risks in a home is to confuse hoarding and squalor. Although both place the resident of the unit and neighbors at risk, it is important to assess them as distinct issues. Hoarding can exist without squalor and squalor may exist independent of hoarding if the resident does not have the emotional attachments found in hoarding behavior. HI/TPP case managers work to assess both squalor and hoarding at intake and develop an intervention plan that addresses any squalor present in addition to safety issues cause by hoarding. Squalor was found in 33 percent of HI/TPP cases.

## INSIGHT

In addition to the complex mental health concerns, other factors play a critical role in intervention and anticipating outcomes. These factors include emotions and life experiences that contribute to hoarding, as well as the program participant's insight or awareness of the hoarding behaviors.

Generally, insight is broken into three categories as it relates to hoarding behaviors:[9]

- **Non-insightful.** Those who do not realize that the clutter is a problem.
- **Insightful but not motivated.** Those who are aware that the clutter exists but are not ready to change behaviors.
- **Insightful, motivated and non-compliant.** Those who are aware of clutter and willing to change behaviors, but struggling to move to action.

It is important to note that issues of insight are common among those with hoarding behaviors. Case managers need to use motivational interviewing and other strategies to assist clients in building their level of insight, boost motivation, and move to more active forms of engagement around their clutter problem.

# III. TYPES OF HOARDING INTERVENTION

## "CLEAN-OUTS"

In many communities, public health officials, property owners, and others are struggling to adequately address the problem of hoarding. High clutter levels create risk not only for the occupants of the home but also for neighbors and for first responders in case of medical or fire related emergencies. Commonly reported risks include substantial fire hazards, infestation, strong odors, and risk of falling.[10]

In many cases, public health officials, property owners, and social service providers rely on "clean-outs" (the removal of clutter without the resident having control over which items are discarded) to address these health and safety concerns. Despite being the first line of defense for many communities, there is little evidence to show that clean-outs are effective. One Massachusetts public health department spent $16,000 to clean out a home and store the resident's possessions. Eighteen months later, the home was cluttered once again.[11]

## EVIDENCE-BASED MODELS FOR HOARDING INTERVENTION

The first evidence-based mental health model for hoarding treatment was developed by Steketee and Frost in 2007.[12] This cognitive-behavioral treatment model takes place over 26 therapy sessions. The goal of Steketee and Frost's treatment model is to reduce the volume of clutter and rate of acquisition by addressing four specific areas: information processing, core values/beliefs, beliefs/meaning about possessions, and the role of emotions in reinforcing hoarding behaviors[13] that contribute to hoarding behaviors.

Another approach is harm reduction. Historically used to address a wide variety of public health concerns such as substance abuse, harm reduction assumes that participants will continue to engage in high-risk behavior and focuses interventions on reducing or mitigating the harm experienced due to these behaviors. Harm reduction for hoarding mitigates risk by clearing the buildup of clutter in areas such as egress paths or heat sources. Only the minimum amount of clutter necessary to achieve relative safety is removed. While it is likely that clutter will continue to build, this approach is particularly useful for reducing the risk among those with little or no insight into their hoarding behaviors, especially when continued monitoring of the environment is put into place.[14]

## A NEW APPROACH: EVOLUTION OF HI/TPP

In 2006, MBHP, working in partnership with the Boston University School of Social Work's Hoarding Research Project, began a small pilot project to address an increase in the number of Housing Choice Voucher Program (commonly known as Section 8) units that were failing annual inspections due to clutter. The success of MBHP's pilot led to the creation of the agency's Hoarding Intervention and Sanitation Initiative.

Through conversations held throughout 2008 and 2009 in each of the communities served by MBHP, it was discovered that many service providers witnessed hoarding, yet were not prepared to provide adequate assistance or referrals. At that time, task forces and educational programs about appropriate hoarding intervention were not readily accessible. As a result, a small expansion of MBHP's Hoarding and Sanitation Initiative was made to increase training options for communities interested in innovative approaches to hoarding intervention. These community conversations were a driving force in planning the HI/TPP.

## EFFECTING CHANGE IN THE COMMUNITY

HI/TPP was created to fill the gaps in direct care for those with hoarding, including building case management capacity within the Boston Housing Court and building a stronger community and policy response to hoarding in Massachusetts and other communities across the United States and Canada. MBHP and TPP felt that, in order to have a substantial and direct impact on the lives of those with hoarding behavior, any expansion of case management services in Greater Boston would have to be combined with the following initiatives.

**Increased task force support.** Task forces are one of the most common methods to address hoarding. Generally, task forces focus on community education, case consultation, or a combination of both. One challenge that task forces face is long-term stability. Funding concerns, changing membership, and the need for ongoing goal setting can contribute to the disbanding of task forces.[15]

**Training in appropriate hoarding intervention.** Hoarding intervention training is the first step for many communities who seek a more effective response to hoarding behavior. Code enforcement officers, housing providers, social workers, and first responders such as public safety and fire personnel all see the problem of hoarding through different lenses. Trainings allow multiple stakeholders to develop shared language, common assessment tools, and communication strategies to use during hoarding interventions. These trainings also help to increase the number of people trained to work directly with those who have hoarding behaviors to reduce the clutter in their homes.

**Intensive, ongoing support for cities and towns interested in investing in a case management model for hoarding intervention.** While the provision of training in appropriate hoarding intervention techniques is an important step in better assisting residents with hoarding behavior, training alone is not enough. In 2010, members of the Greater Boston Hoarding Network held focus groups with professionals at the Department

of Mental Health, Elder Services, and others about the impact of training provided by the network. In those focus groups, participants articulated the need for ongoing training to develop the skills needed for hoarding intervention, regular case consultation, and supervision from those experienced in hoarding response. Additionally, focus group participants spoke of a needed shift in agency policies that would allow staff to engage clients in sorting/discarding and other strategies to address hoarding behaviors. Without such policies, focus group participants stated they could not successfully incorporate promising intervention practices into their case management work.

The Greater Boston Hoarding Network, co-founded by MBHP, was a group of five organizations tasked with improving training and improving practices in hoarding intervention.

**Changes in public policy related to hoarding intervention.** A change in practice by professionals in a variety of disciplines is critical for successful hoarding intervention. As practices on the front lines of housing, public health, and other fields change, policies must shift to support evidence-based and promising practices.

## IV. HI/TPP INTERVENTION MODEL

In the HI/TPP intervention model, MBHP staff members combine harm reduction strategies and tools from cognitive-behavioral therapy. Meeting weekly or bi-weekly, case managers assist clients in sorting and discarding items in their home in order to meet compliance with all health and safety requirements.

In addition, any intervention attempts to address life experiences, emotions, and thinking associated with hoarding disorder, in addition to a focus on the physical environment. As a result, an emphasis is placed on helping participants learn sorting/discarding skills, develop organizational systems and strategies for reducing acquisition, understand their reasons for saving, and untangle the complex emotions tied to the objects collected. Together, these skills help participants maintain their home after the initial intervention period is complete.

The HI/TPP model also acknowledges the challenges of de-cluttering in the face of mental health challenges, physical health issues, as well as how overwhelming it can be to address large amounts of clutter. Wavering or changing insight is common among those with hoarding behaviors.

### MBHP HOARDING PROTOCOL

Generally, participants fall into one of two tracks (see Chart 1): those who actively take part in the intervention process (compliant) and those who fail to engage in the process (non-compliant). Both tracks begin with a visit to the client's home, at which point the case manager conducts an intake assessment, making note of the current state of the home. Clients then meet weekly or bi-weekly with case managers who assist in sorting and discarding items in their home in order to meet compliance with all health and safety requirements. Clients who engage in the intervention process begin to develop skills to better manage their possessions and reduce clutter in their homes. Over time, these clients are able to successfully bring their homes into compliance with health and safety codes.

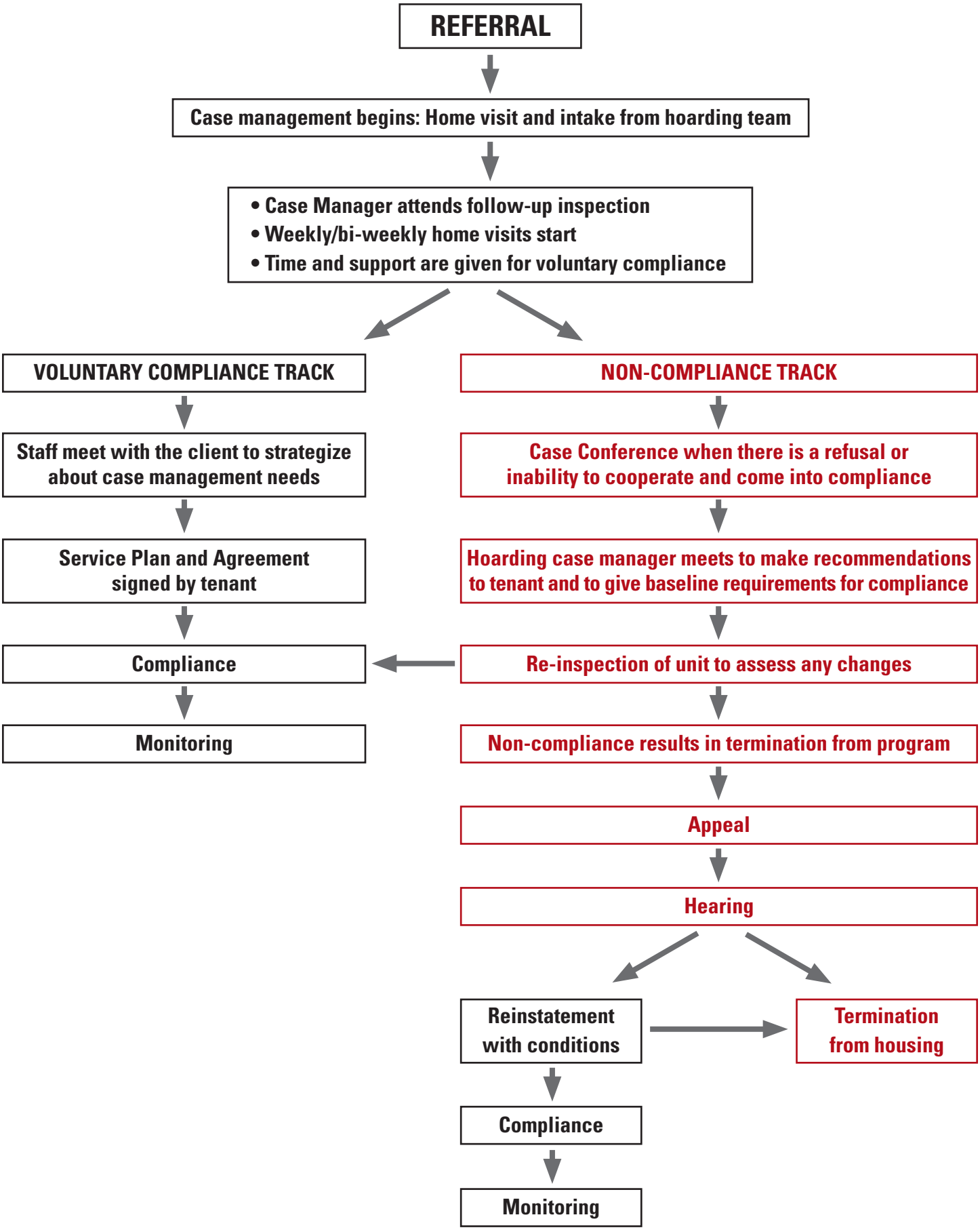
Some clients, due to lack of insight, mental health issues, or other concerns are not able, initially, to fully engage with the hoarding intervention program. As a result, the non-compliance track has several "safety nets" built into the program design. These safety nets allow case managers time to build client insight and put harm reduction strategies in place in order to prevent eviction or loss of a housing subsidy. Case conferences and hearings prior to subsidy termination or eviction help to improve communication and facilitate collaborative problem-solving before frustration levels reach the point where eviction appears to be the only available option.

### CASE MANAGEMENT FEATURES

The intake process for HI/TPP is designed to gather basic information about the participant, assess their housing risk, and obtain a sense of the myriad issues with which participants are struggling. This process informs the potential need for referrals as well as the intervention approach used to address the hoarding behaviors. Model features include:

- An individualized case management plan based on the client's stated needs, intake/assessment information, and the risk of subsidy loss, eviction, or condemnation.
- A combination of harm reduction and techniques borrowed from cognitive-behavioral therapy.
- Weekly or bi-weekly home visits that include sorting/discarding, non-acquiring exercises, and other skills critical to managing the clutter.
- Referrals to appropriate community partners for additional resources.
- Monitoring for one to two years after passing inspection (when participants allow).

**CHART 1:** MBHP hoarding protocol



# V. HI/TPP PARTICIPANTS

## HOUSING CIRCUMSTANCES

HI/TPP is unique because most participants are required to participate in the program to keep an affordable housing subsidy and/or stave off eviction. In this respect, the population in the program may differ from those who would self-refer to such a program. Also, as one of the first programs with this level of data collection, it is difficult to extrapolate the data provided here to all individuals exhibiting hoarding behaviors, but the data does provide important insights into the circumstances and experiences of those grappling with hoarding behaviors.

**Referrals.** Participants lived in 23 different towns and cities in Greater Boston, with 57 percent from Boston, 12 percent from Cambridge, and 17 percent from other towns/cities neighboring Boston. The remaining participants come from other communities in MBHP's service area. Referrals to the HI/TPP program come largely through property managers and inspectors, including many referrals from inspectors on MBHP's staff. One of the hallmarks of the program is the outreach that has been completed with a wide range of agencies, both public and nonprofit, that provide additional opportunities for households with hoarding behaviors to be identified. As a result, only 7 percent of the participants were self-referred to the program.

**Housing type.** The common image of a person who hoards is of a homeowner. In part because HI/TPP receives most of its referrals from housing inspectors and agencies working with low-income renters, only 10 percent of HI/TPP participants are homeowners. An additional 10 percent are renters in market-rate apartments, while the remaining 80 percent are living in low- and moderate-income housing, including public housing, privately-owned rentals supported by subsidies, and other supportive housing, including group homes. Given the high percentage of participants living in low- and moderate-income housing, some demographic comparisons will be made with households accessing MBHP-managed rental voucher programs and with low-income households in general.

**Threats to housing stability.** Because of the level of clutter in participant homes, high percentages were threatened with immediate eviction (50 percent) and/or the loss of their housing subsidy (69 percent).

**Length of time in the home.** Although half of participants have been in their homes for more than 10 years, there are also participants who have been in their home as little as one year (8 percent, see Chart 2). While staying in the same home for a long period can contribute to the level of clutter in a home, clutter can be a problem even for those who have moved recently.

**CHART 2:** Time in home, HI/TPP participants

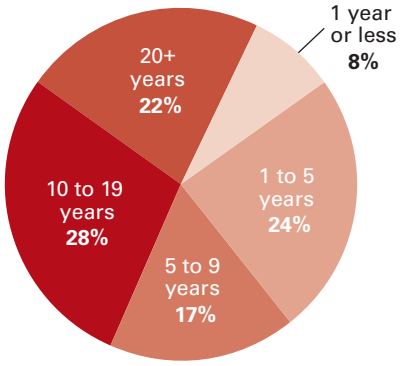
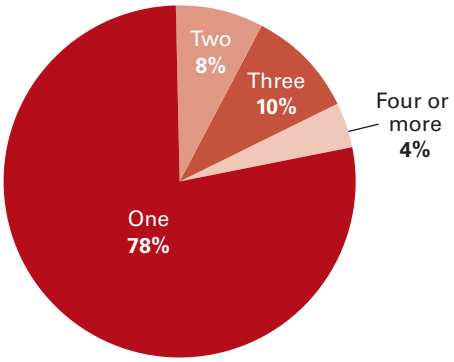



**CHART 3:** Houshold size, HI/TPP participants




**Household size and composition.** Seventy-eight percent of HI/TPP participants live alone, and 22 percent live with others (see Chart 3). In comparison, only 39 percent of MBHP rental voucher households live alone. The average household size for HI/TPP participants is 1.4 persons, considerably smaller than the 2.5 person average for Greater Boston households.[16] As only 6 percent of participants are currently in a relationship, participants are more likely to be living with other relatives, including siblings, parents, or their own children (both adult and youths). A child is present in 14 percent of households.

## PARTICIPANT DEMOGRAPHICS

**Age.** A common myth about those with a hoarding disorder is that it only affects the elderly. In fact, research has shown that for more than 50 percent of people with hoarding behavior, hoarding begins between the ages of 11 and 20.[17] While the level of clutter (and the problems created by clutter) can increase with age, the problem affects individuals at a wide range of ages. Among

**CHART 4:** Age, HI/TPP participants

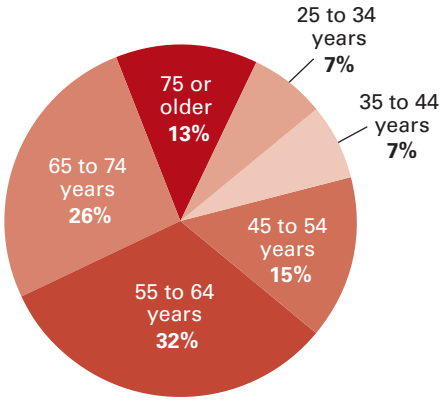
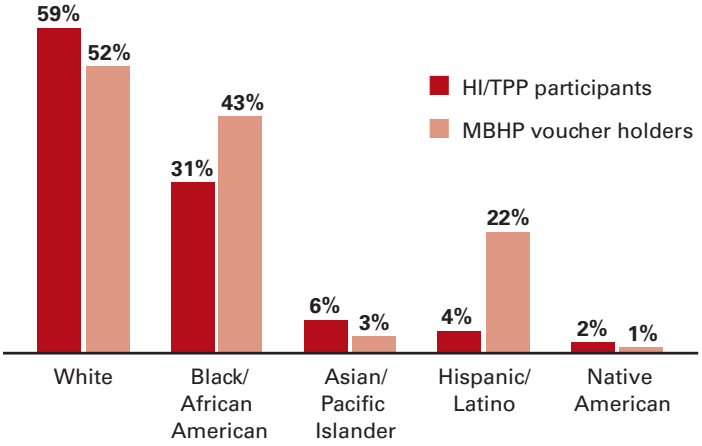



**CHART 5:** Race/ethnicity, HI/TPP participants compared to MBHP voucher holders



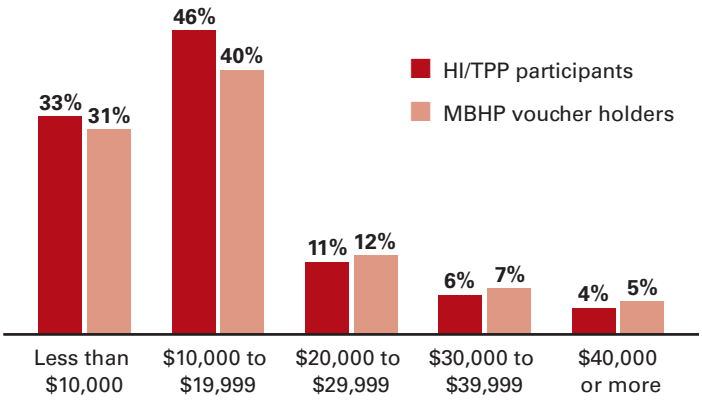

HI/TPP participants only 39 percent were 65 are older, while nearly half (47 percent) were between the ages of 45 and 64 (see Chart 4).

**Gender.** Sixty-one percent of program participants are women, and 39 percent are men.

**Race, ethnicity, and language.** Of the program participants, 59 percent were white, followed by 31 percent who were Black or African American, while 6 percent were Asian or Pacific Islander and 4 percent were Hispanic or Latino (see Chart 5). Compared to MBHP voucher-holders, white and Asian people are over-represented, while Black/African-American and Latino people are under-represented among program participants. In addition, 90 percent of participants speak English as their only language. The remaining 10 percent speak a range of languages that are generally common in the Boston area, including Spanish, Haitian Creole, Chinese, Russian, and Vietnamese.

**Work and income.** Participation in HI/TPP was not based on income. As such, some participants were not required to provide income information, and for those who did, no effort was made to confirm reported incomes. Only 13 percent of program participants reported they were employed, and of those who reported their incomes and income sources only 14 percent had wage income in the household (a family member could be working). As a result, incomes are low. Participants generally relied on SSI/SSDI (68 percent) or Social Security (29 percent). The median household income for participants was a meager $12,000 annually, just a little over the 2013 federal poverty threshold for a single individual ($11,490). The income distribution of HI/TPP participants is similar to that of MBHP voucher-holders, reflecting the fact that a high percentage of HI/TPP participants are in low- and moderate-income housing (see Chart 6). The relatively low incomes of participants highlight the need for these individuals to preserve their housing assistance.

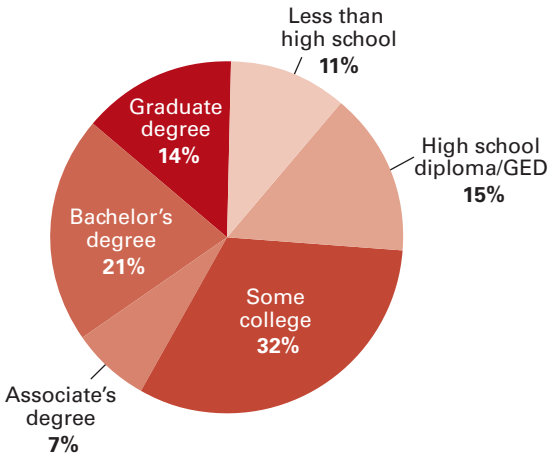
**CHART 6:** Annual income, HI/TPP participants compared to MBHP voucher holders




**Educational attainment.** Despite these very low incomes, program participants are diverse in terms of their educational attainment. Although 11 percent have not completed high school, 35 percent have a bachelor's degree or higher (see Chart 7, Page 9). Comparable data from MBHP voucher-holders is not available, but for Boston residents in poverty, only 22 percent had at least a Bachelor's Degree.[18]

The disparity between educational attainment and income among HI/TPP participants is indicative of the disabling nature of hoarding behaviors. The problem is often linked to other mental health conditions that affect people across the educational spectrum. In fact, people with hoarding have an average of seven work impairment days per month. This has a significant impact on the participant's ability to earn wages and is on par with the level of impairment found in schizophrenia.[19]

**CHART 7:** Educational attainment, HI/TPP participants




**Medical conditions and healthcare.** Only 16 percent of participants stated that they had no medical conditions, while 30 percent mentioned only one medical condition, and 54 percent stated that they had more than one medical condition. The most commonly cited health conditions were high blood pressure (18 percent) and back pain (15 percent, see Table 1). Medical conditions can be a significant barrier for participants working to address their hoarding behavior. As a result, access to additional supportive resources is often a key component of the HI/TPP case management model.

Due to the income profile of HI/TPP participants, 89 percent of participants rely on public health insurance programs, especially MassHealth (Medicaid) and Medicare. Seven percent rely solely on private health insurance, and 4 percent have no health insurance, comparable to Greater Boston health insurance coverage rates.[20]

**Mental health conditions.** Through the screening process, all participants were assessed for hoarding behaviors and only those with hoarding behavior at a threshold level became program participants. Other mental health conditions were identified by participants themselves and by service providers. Twenty-five percent had no additional mental health condition, 26 percent had one additional condition, and 49 percent reported multiple conditions. The most common mental health conditions were depression (63 percent) and anxiety (35 percent, see Table 2). There was considerable overlap between these two conditions, as 30 percent of all participants had both depression and anxiety.

**Other contributing factors.** HI/TPP staff members also asked participants about certain personal experiences that provide staff members with important clues in how to approach a participant's hoarding behavior. As these questions can be very personal, the response rate varied widely. For MBHP participants in the program, 67 percent reported a significant loss in their lives, 52 percent reported having experienced a trauma, and 36 percent reported a family history of hoarding (see Chart 8). In addition, 35 percent reported having memory issues, and 22 percent reported some history of domestic violence.

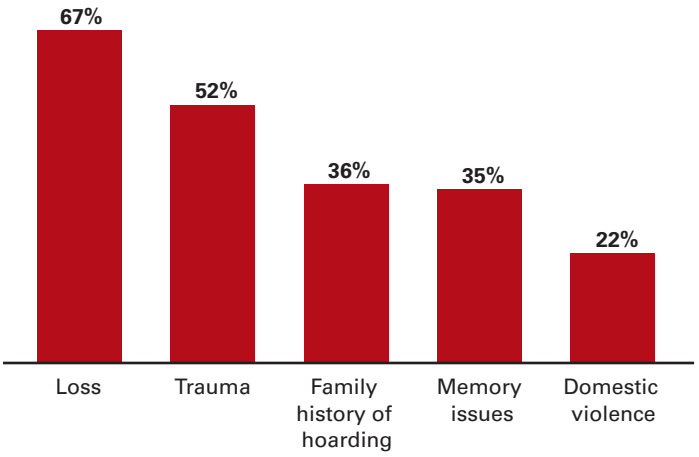
**TABLE 1:** Most common medical conditions

| | |
|---|---|
| High Blood Pressure | 18% |
| Back Pain | 15% |
| Arthritis | 14% |
| Diabetes | 12% |
| Injury (all types) | 10% |
| Feet, Leg, or Knee problems | 10% |
| Heart Condition | 9% |
| Asthma | 9% |

**TABLE 2:** Most common mental health conditions

| | |
|---|---|
| Depression | 63% |
| Anxiety | 35% |
| PTSD | 12% |
| Bi-polar disorder | 10% |

**CHART 8:** Participant has experienced (MBHP participants only)



## TYPES OF ITEMS HOARDED AND SQUALOR

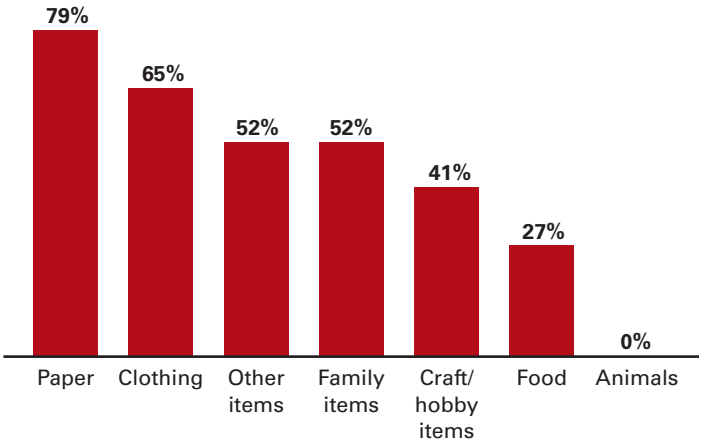
The types of items hoarded can vary widely, but staff members are able to categorize items into six groupings, while still capturing additional items in an "other" category. For program participants, the most common item hoarded was paper (79 percent), followed by clothing (65 percent), and family items (52 percent) (see Chart 9). Surprisingly, staff did not identify any participants hoarding animals, though 27 percent of participants do have a pet. Of the other items hoarded, the most commonly identified were books, furniture, toys, and electronic/computer equipment.

It is unusual for participants to hoard only one category of item. Fourteen percent hoarded one category of items, 22 percent hoarded two categories of items, while 64 percent hoarded three or more categories. In addition, program staff identified 33 percent of participants having some form of squalor, which presents additional difficulties both in terms of how it impacts the participant, neighbors, and the short- and long-terms steps needed to address the hoarding.

## HOMES MULTI-DISCIPLINARY RISK ASSESSMENT TOOL

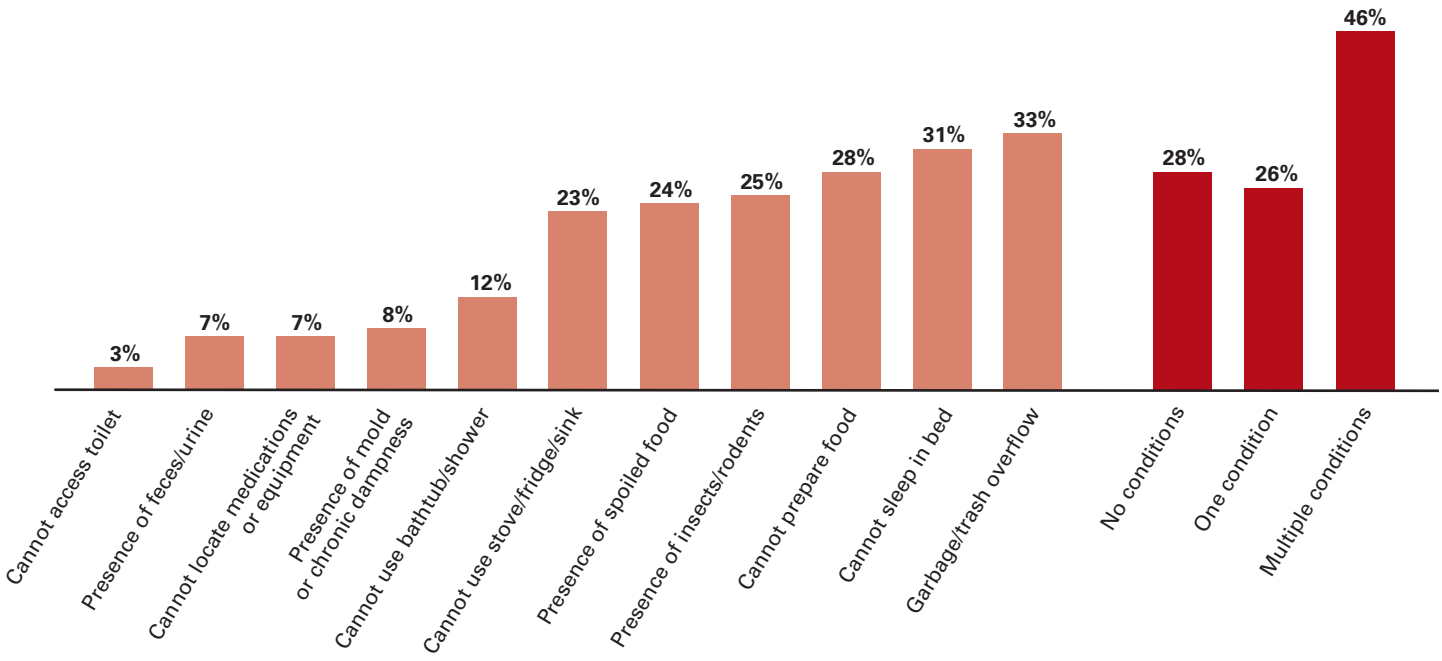
The HOMES Multi-Disciplinary Risk Assessment Tool was designed by Dr. Christiana Bratiotis for anyone who comes into contact with cluttered environments. HOMES, which stands for Health, Obstacles, Mental Health, Endangerment, and Structure, is designed to highlight the risks found in a cluttered environment, assess the insight of the occupant, and highlight potential barriers to successful intervention.

**CHART 9:** Items hoarded, HI/TPP participants




**Health conditions.** Using the health assessment portion of the HOMES Tool, staff found that 72 percent of HI/TPP participants had a condition in the home that has created a health hazard or could contribute to poor health conditions. The most common, at 33 percent, was garbage/trash overflow, followed by an inability to sleep in their bed (or with difficulty) (31 percent) (See Chart 10). The least common was the inability to access the toilet (3 percent). Only 26 percent reported having one health condition with 46 percent reporting more than one. The HOMES Tool also asks about smoking; of those assessed, 24 percent smoked.

**CHART 10:** HOMES Tool, health conditions



**Obstacles.** Clutter creates obstacles that become health or safety hazards, slow the ability of first responders to act in emergencies, or simply impedes daily life activities. Only 14 percent of HI/TPP participants had no obstacles identified, while 75 percent could not move freely or safely in the home (see Chart 11). For each of the categories in the HOMES Tool obstacles assessment, the percentage of participants with the condition was high.

**Mental health.** The mental health assessment on the HOMES tool is intended to provide an assessment of how the participant views their problems with clutter. This assessment also provides a service provider some idea as to how "ready" a participant is to work on the problem. Forty-two percent were anxious or apprehensive, and 39 percent did not seem to understand the seriousness of the problem (See Chart 12).

**CHART 11:** HOMES Tool, obstacles

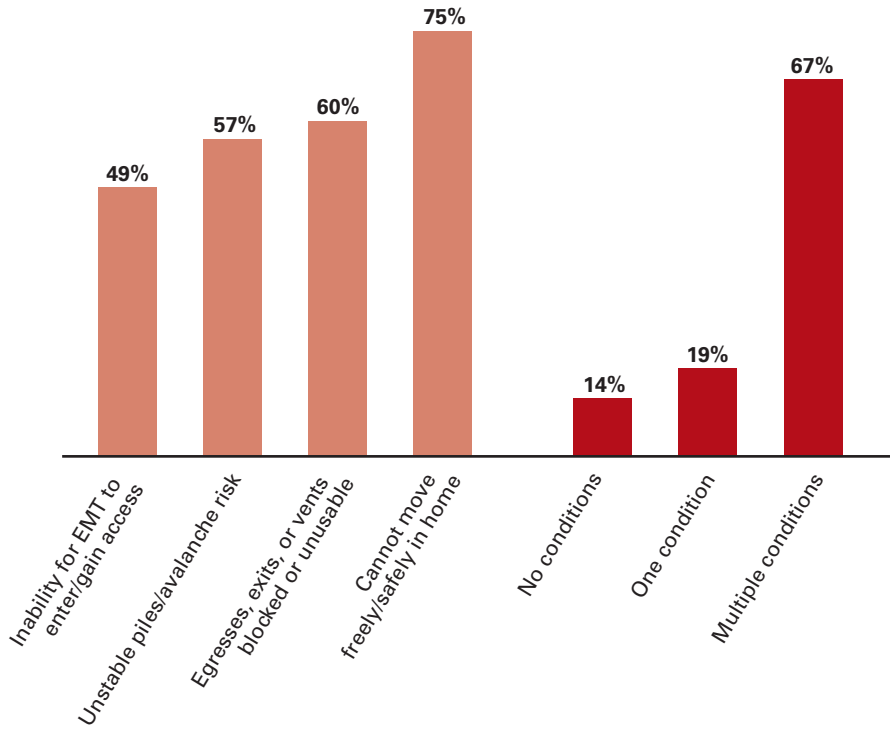



**CHART 12:** HOMES Tool, mental health conditions

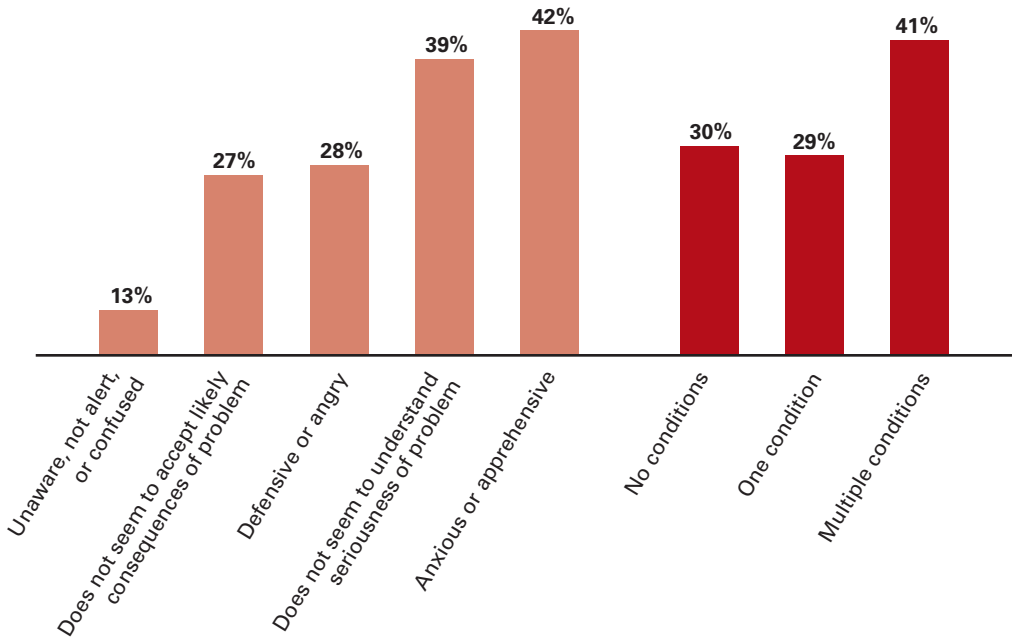


**CHART 13:** HOMES Tool, endangerment

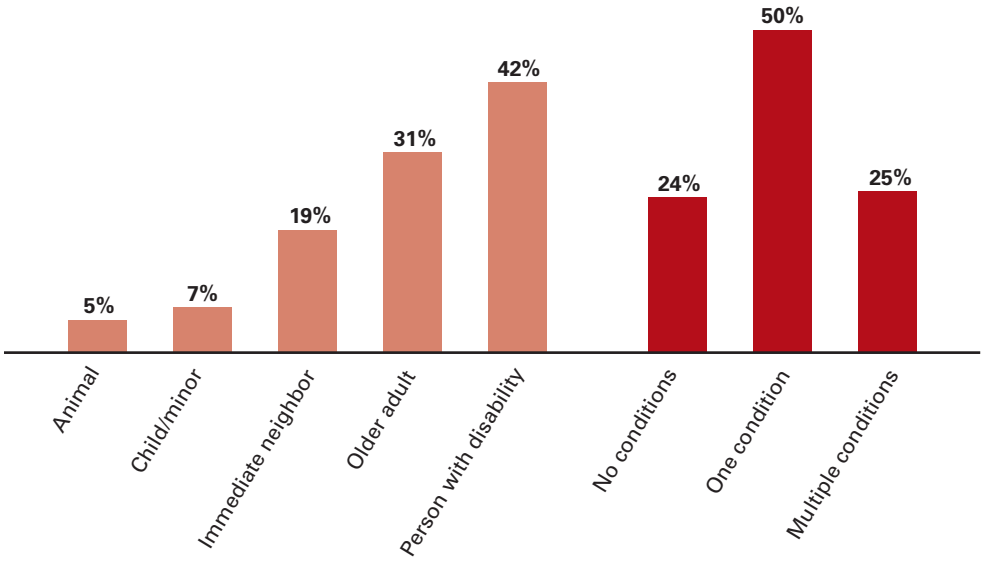
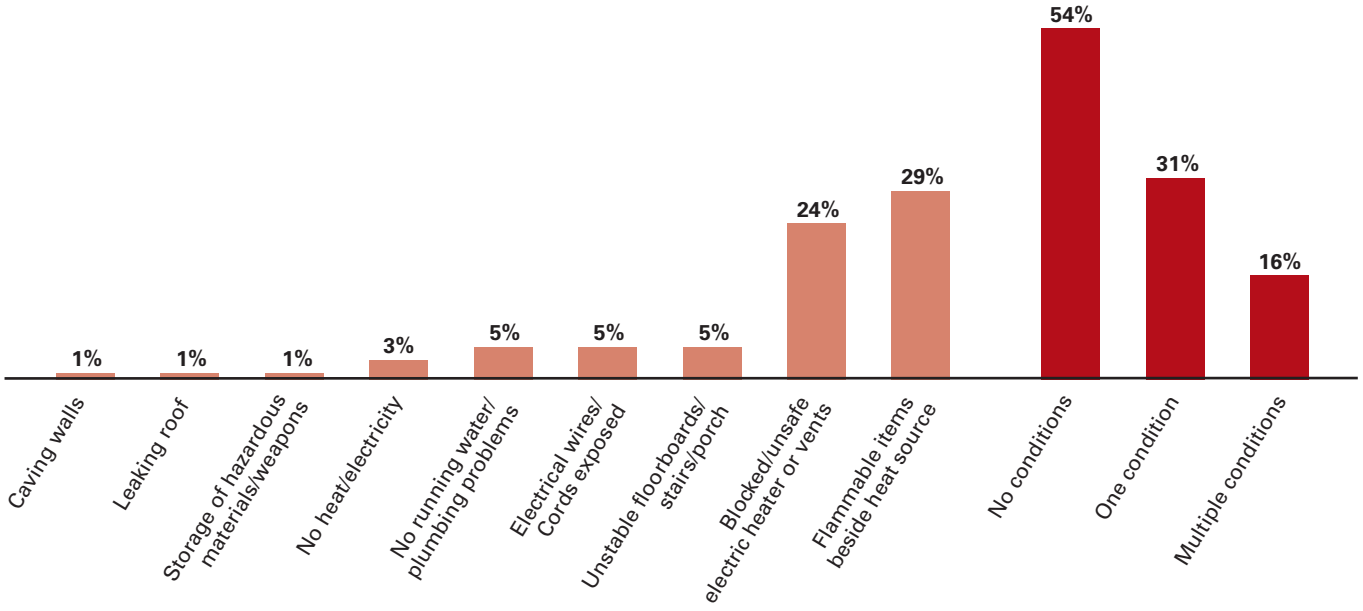



**CHART 14:** HOMES Tool, structure and safety conditions




**Endangerment.** The HOMES tool assesses the likelihood that the clutter and squalor endangers the health or safety of someone such as an elder or child in the household, including the participant themselves. In a high percentage (42 percent) of homes, a person with a disability was endangered, though most of these persons were the participants themselves, not a family member (see Chart 13). The HOMES tool also asks about risks to immediate neighbors, because many participants are living in apartments and immediate neighbors could be endangered, especially if squalor and/or an infestation is present.

**Structure and safety.** Unlike the other portions of the HOMES Tool, a majority (54 percent) of participants' homes did not meet any of the structure and safety conditions assessed (see Chart 14). A contributing factor to this outcome is the fact that 80 percent of participants are living in rental properties where a mobile or project-based subsidy (either provided to the tenant or attached to the property) is present, and therefore landlords are required to meet minimum safety conditions and inspections are frequent. For this reason, the most prevalent conditions are those that are created by a participant's clutter: flammable items next to a heat source (29 percent), and blocked/unsafe electric heater or vent (24 percent).

## CLUTTER IMAGE RATING

In addition to the HOMES Risk Assessment tool, HI/TPP staff members also evaluate the condition of the home using the Clutter Image Rating (CIR) Scale, developed by Dr. Randy Frost.[21] As the name indicates, CIR assesses the volume of clutter in a home. The CIR uses a series of nine photographs to rate the volume of clutter in each room of the home on a scale of one to nine (see inset). A CIR rating of four or higher indicates a significant clutter problem in the home. When clutter rises to this level, residents struggle to move freely in their homes or complete basic activities of daily living. As CIR levels rise, safety concerns such as fire hazards, fall risks, and potential for injury due to collapsing piles also rise. According to HI/TPP intake data, 79 percent of program participants collected large volumes of paper (see Page 10, Chart 9). As a result, property managers, code enforcement personnel, and others have placed an emphasis on addressing egress and fire safety concerns.

As the type and volume of clutter can vary considerably from room to room, the CIR is assessed for each room of the home. To summarize the overall clutter in the home, the CIR for the rooms is averaged (hereafter known as "Average CIR, All Rooms"). Generally speaking, clutter tends to be more problematic in the living room, the bedroom, and in auxiliary rooms, such as a hallway or basement, and less significant in kitchens and bathrooms. When the bathroom and kitchen are included, the overall average CIR may be close to or below the 4.0 threshold for intervention, even though, for health and safety reasons, the clutter in other rooms still must be addressed. For this reason, for this report, we will also provide an average CIR for these more problematic rooms—the living room, the first and second bedrooms, and other auxiliary rooms (hereafter known as "Average CIR, Problematic Rooms").

### WHAT IS CLUTTER IMAGE RATING SCALE?

Developed by Dr. Randy Frost, the CIR is a scale used to rate the volume of clutter in a home. Each rating shows an increased level of clutter with a CIR of 9.0 nearly touching the ceiling.

**CIR 1.0:** No clutter in the home.

**CIR 2.0–3.0:** Low level clutter.

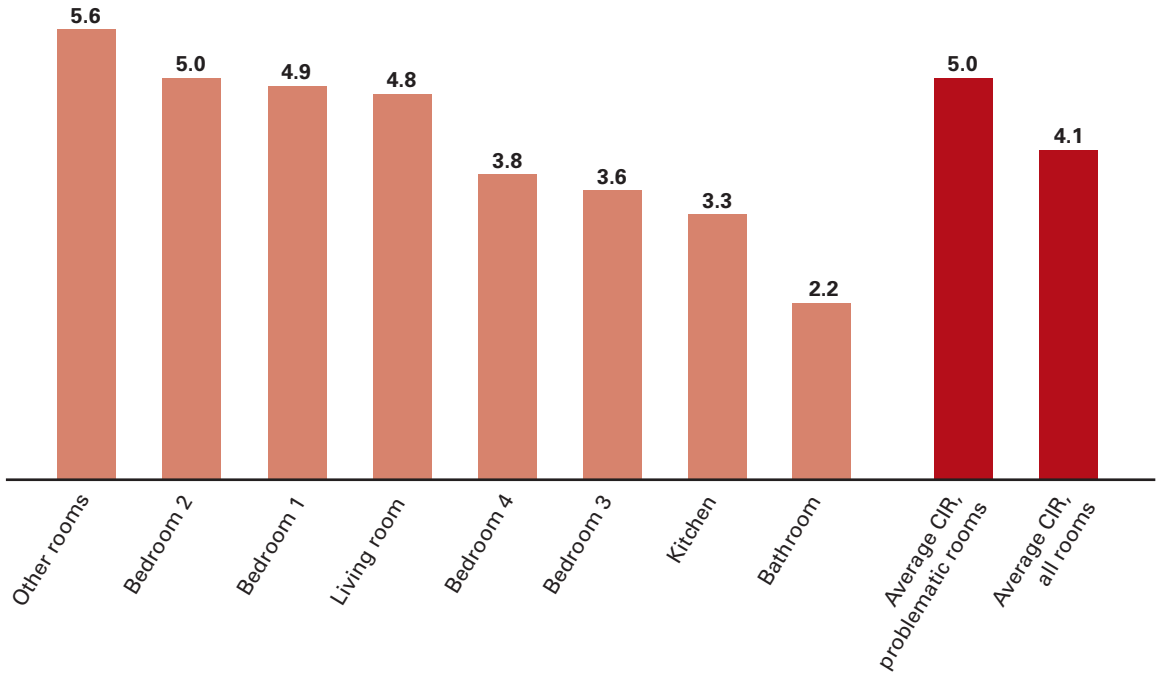
**CIR 4.0:** Clutter begins to interfere with use of space; safety hazards are found.

**CIR 5.0–6.0:** Significant health/safety concerns including blocked egress and fire hazards.

**CIR 7.0–9.0:** Severe volume of clutter; no egress.

**Level of clutter (CIR) at intake.** For HI/TPP participants, at intake, the average CIR for all rooms was 4.1. For problematic rooms, the average CIR was 5.0. Looking at specific room types, other rooms, such as hallways, home offices, or basements, had the highest average CIR at 5.6, followed by the second bedroom (5.0), the first bedroom (4.9), and the living room (4.8, see Chart 15). For those with a third or fourth bedroom, the average CIR was generally lower, and the lowest CIR could be found in the kitchen (3.3) and bathroom (2.2).

**CHART 15:** CIR at intake, by room and averages



# VII. PROGRAM OUTCOMES

## OVERALL PROGRAM OUTCOMES

HI/TPP measures program success in two ways:

1. Did the condition of the home improve sufficiently to pass inspection and move to the monitoring stage?
2. How has the condition of the home changed, as measured on the Clutter Image Rating (CIR) scale?

Participants in HI/TPP are enrolled in the program with the goal of reducing clutter and maintaining their housing. Participants who pass a formal inspection or who reduce clutter such that their case manager feels the unit would meet basic safety standards during an inspection are deemed as meeting compliance or "passing" inspection. For a variety of reasons discussed below, some participants end their program participation prior to passing inspection. These participants may terminate their participation in the program or may be terminated by their case managers for continued failure to comply with program obligations. Participants who are terminated prior to passing inspection do have the option to return to the HI/TPP in the future if deemed appropriate by project staff.

Of the MBHP participants in the HI/TPP program,* 58 percent have met compliance standards (passed) and entered the monitoring phase, while 22 percent were terminated from the program before passing. The participants who terminated from the program still contribute to the program's overall 98 percent success rate, as many were able to reduce their clutter just enough to stave off eviction, despite leaving the program early. Overall, only 2 people were evicted due to hoarding from July 2011 to June 2014. Both of those clients had severe hoarding and left the program early.

The remaining 20 percent of participants are still working toward compliance. On average, participants take 181 days between intake and passing. The program accepts new participants on a rolling basis; therefore, a number of participants are currently in the first stage of the program.

In addition to the intake process, to provide a standardized measure of change, HI/TPP staff members assess the CIR in three different circumstances:

1. When the condition of the property has improved significantly and is in compliance with health and safety codes, the CIR is assessed either in conjunction with a successful home inspection by the property manager or subsidy provider, or, where no inspection is required, by HI/TPP staff. For sake of simplicity, the property is considered to have "passed."
2. For those who have passed and are in the monitoring stage, CIR is assessed one year and two years after the initial passing data; or
3. When a participant is terminated (a "termination" from the program, either by choice of the participant or the HI/TPP program).

When examining the CIR ratings for clients who successfully brought their homes into compliance with health/safety codes (for this report, this outcome is referred to as a "pass"),** the average CIR across all rooms, including those without a clutter problem, dropped 1.3 points from an average of 3.7 to an average CIR of 2.4. When focusing on "problematic rooms," the average CIR had a 1.7 point decline from an average of 4.6 to 2.9 (see Chart 16, page 15). For comparison, in an open trial to test the efficacy of cognitive behavioral therapy for hoarding, researchers saw an initial CIR of 4.0 pre-treatment and a rating of 2.8 post-treatment.[22]

Looking at the results for specific rooms, improvement is also marked, as the average CIR for other/auxiliary rooms and spaces declined 2.7 points, from 5.8 to 3.1. CIR declines for other major rooms were not as large, but were still significant. The average CIR declined 1.9 points in the first bedroom, 1.8 points in the second bedroom, and 1.7 points in the living room.

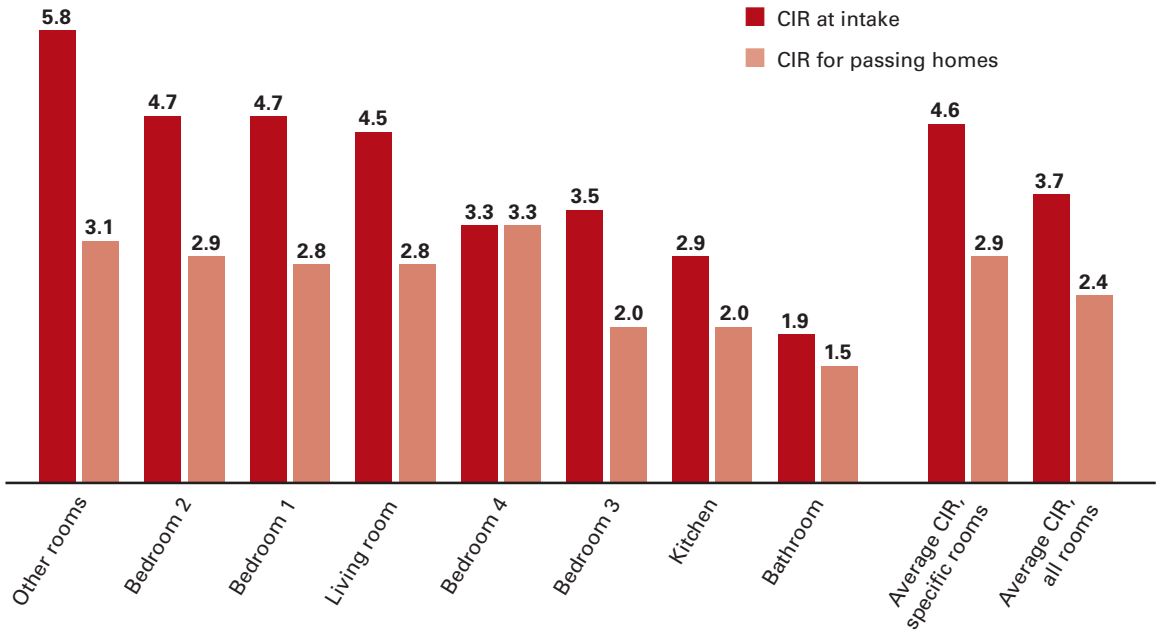
When looking at CIR data one and two years after the home has met initial compliance standards, it is hoped that participants will have maintained their homes. The data available thus far reveals that participants have been able to maintain compliance in their homes. One year after compliance, participants saw a very small 0.1 point decline in CIR. For those that have been in the program long enough, there was no change from one year to two years after compliance. Data from these one- and two-year assessments is limited, but as the program matures, HI/TPP will be able to get a better sense of the medium- to long-term success of the HI/TPP intervention approach. Although this additional long-term data is needed, this significant reduction in clutter volume data indicates that an intensive case management approach to hoarding intervention can be a highly effective strategy for those at risk of losing their housing due to hoarding behavior.

Data on homes where the participant terminated from the program is less available and therefore less reliable, but where staff members were able to collect a CIR at termination, 50 percent of the participants saw at least some improvement in CIR. For all participants that terminated, the average CIR for specific rooms at intake (6.0) was higher than for participants as a whole,

** Due to lack of data, TPP clients are excluded from this analysis. Only those participating in the MBHP program are included.*

*** This change in CIR data is only for those who had both intake and passing CIR data. As a result, the initial intake averages will differ from the intake data for all participants.*

**CHART 16:** CIR at intake, by room and averages, participants with passing homes



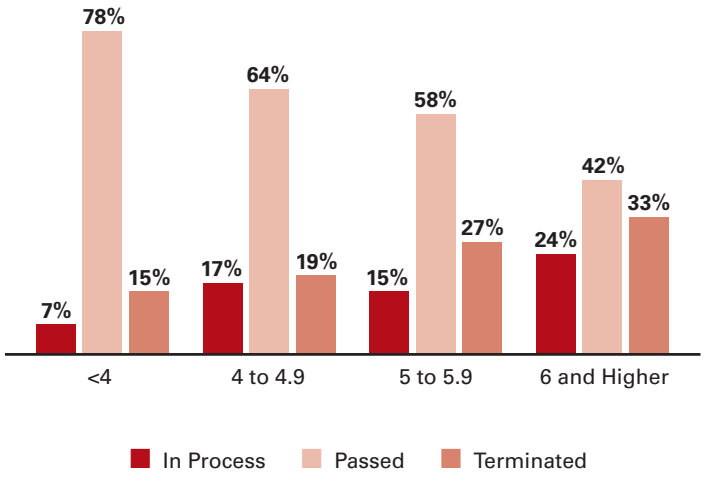

and declined one point while in the program, to 5.0. While the average CIR for those who terminated remained higher than a CIR necessary to be considered compliant (less than 4.0), the fact that only two out of the 34 participants who terminated case management services prior to passing inspection were evicted from their homes is also a success.

To get a better understanding of both the difficulties in addressing the clutter and which participants are more likely to succeed, it is helpful to take a closer look at the interplay between the initial condition of the home, participant circumstances (for example, mental health conditions or household composition), and the program outcomes.

## OUTCOMES AND INITIAL HOME CONDITIONS

Those with a lower initial CIR are more likely to pass a health/safety inspection. Seventy-eight percent of program participants with the lowest overall average CIR (less than 4.0) are able to bring their homes into compliance (see Chart 17). For these participants, the focus may have been on improving the one or two rooms that were not already in compliance. As the average CIR at intake increased, the likelihood of success declined, from 64 percent for those with an average CIR of 4 to 4.9, to 58 percent for those with an average CIR of 5.0 to 5.9. For those with a CIR of 6.0 or higher, two situations are evident. First, only 42 percent had been able to bring their units into compliance, with 33 percent having terminated participation. Secondly a higher percentage (24 percent) were still in the initial stages of interventions than those with a lower initial CIR, indicative of the longer time staff must work with those with higher levels of clutter.

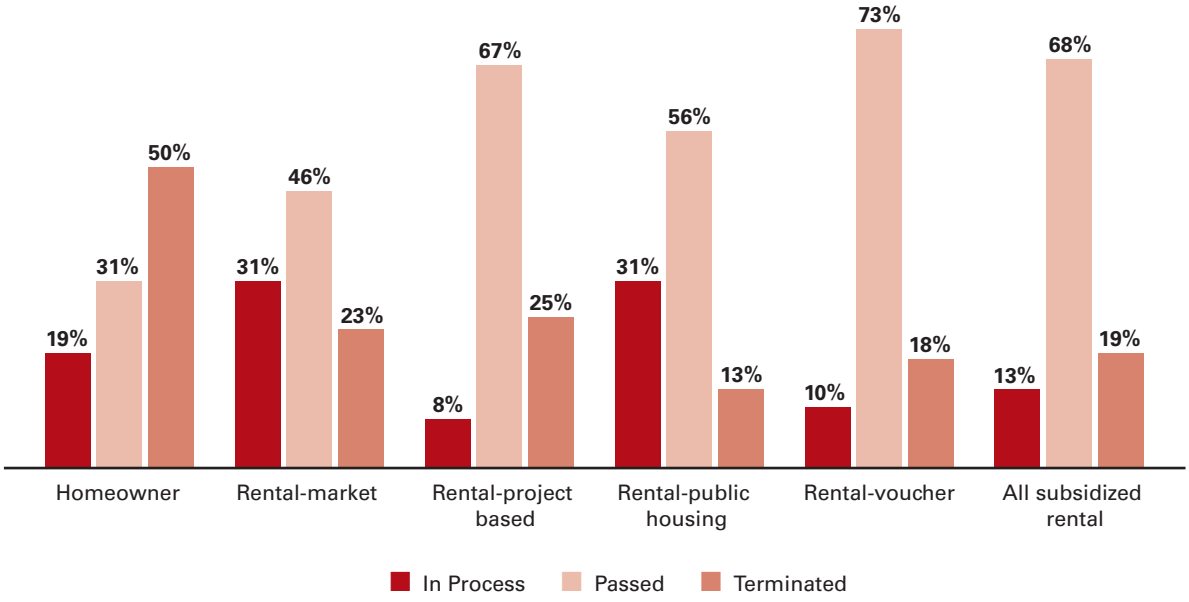
**CHART 17:** Outcome, by average intake CIR, problematic rooms




## FACTORS INFLUENCING ENVIRONMENTAL CONDITIONS AND OUTCOMES

**Housing type.** Overall, 80 percent of HI/TPP participants live in low- or moderate-income housing, which includes publicly-owned rental housing, privately-owned housing where the unit is income restricted ("project based"), and rental housing where the tenant has a subsidy ("voucher"). Of the remaining participants, 10 percent reside in owner-occupied homes and 10 percent are living in market-rate rental units (see Chart 18). When examining data collected through HI/TPP, there appears to be a correlation between housing type and the ability to bring the home into compliance with housing codes, early termination from the

**CHART 18:** Outcome, by housing type




program, and the level of clutter found in the home. State and local laws, rental leases, and subsidized housing regulations all play a role in how health and safety officials determine when the private problem of hoarding becomes a public health risk. As a result, there are different expectations for compliance time frames, clutter reduction expectations, and resources available to address the problem.

Among HI/TPP participants, 68 percent of participants with some form of housing subsidy passed inspection with 19 percent of those ending program participation prior to passing inspection (See Chart 18). When looking more closely at the compliance rates of those living in low- and moderate-income housing, it is clear that those with mobile housing vouchers, such as those found in the Section 8 program, are much more likely to remain in the HI/TPP program and pass health/safety inspection. In comparison, 50 percent of homeowners terminate prior to passing inspection with only 32 percent of homeowners successfully completing the program. The outcome for those in market-rate rental units was similar to those in rental units overall.

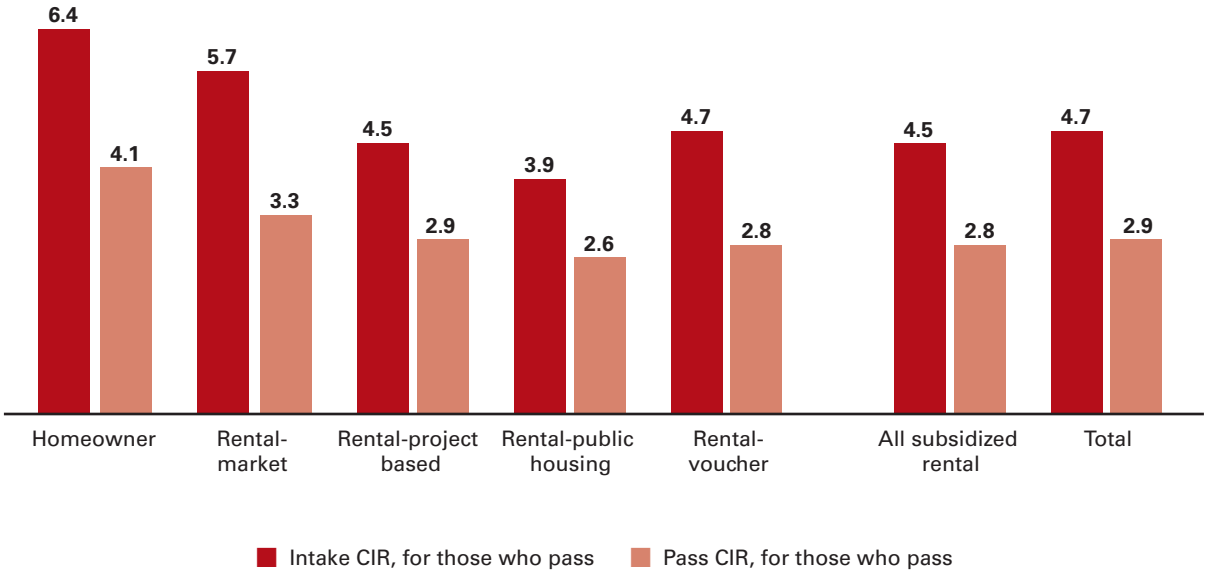
Anecdotal reports from housing inspectors, public health professionals, and other task force members tend to reflect the belief that owner-occupied homes are the most challenging hoarding cases. In these reports, professionals in a variety of fields note that homeowners tend to have a higher level of clutter than those who are in rental units and that they feel homeowners are less inclined to accept services to address their hoarding behaviors. In many cases, local health officials have little leverage in cases involving hoarding in a private home. Homeowners have the right to refuse inspection and health officers are forced to gain a court-issued warrant in order to gain access to the home. In contrast, residents in rental units may be subjected to periodic housing inspections under their lease agreement, with those in subsidized housing having a higher level of mandatory inspection requirements.

An examination of Clutter Image Rating scores by housing type sheds additional light on the differences between clients in low- and moderate-income housing and those in owner-occupied homes. When looking at the difference in CIR ratings between the homes of owner-occupied participants and those in rental units at intake, regardless of program outcome, a significant difference in the CIR rating across all rooms is found. Homeowners have an average CIR at intake of 5.6. Residents in market-rate rental units have an average CIR of 4.4 at intake and those in some form of subsidized housing average a 3.8 on the CIR scale (see Chart 19, page 17).

Based on an analysis of CIR data in combination with the risk assessment provided by the HOMES tool, clutter levels similar to those found in owner-occupied units create a variety of risks including inability to move freely or safely in the home, lack of adequate egress, and difficulty for first responders to access the home in case of emergency. As a result of the significant clutter level, mobility throughout the home is significantly impaired. Residents in these units are struggling to sleep in their beds, cook in their kitchens, or use their bathrooms.

When looking at CIR data for "problematic" rooms in units that pass inspection, the average CIR in these rooms for owner-occupied units is 6.4. This rating is 1.9 points higher than the average intake CIR rating of 4.5 found in the same rooms of those with subsidized housing and 0.7 points higher than the 5.7 rating of

**CHART 19:** Average CIR, problematic rooms, at intake and passing, by housing type




those rooms in market-rate rental units. Although the termination rate among homeowners in the HI/TPP program is 50 percent, those that do complete the program make significant reduction in clutter with an average drop in CIR rating of 2.3 points. However, further data collection is necessary before any firm conclusions about the efficacy of the HI/TPP program in working with homeowners.

Program participants in market-rate rentals had a higher CIR level at program intake (5.7) than did those in subsidized rentals (4.5). One reason for this may be that property owners of market-rate units do not annually inspect their units in the way that low- and moderate-income subsidy programs require. For those with a housing subsidy, participants have similar CIR change scores and completion rates regardless of the subsidy program type. However, those in project-based housing appear to refuse long-term monitoring more frequently than their peers in other housing subsidy programs.

**HOME health conditions.** Important indicators for participant outcomes may be found when combining CIR scores with information obtained through the HOMES tool. When examining combined data from these tools, HI/TPP participants with average CIR ratings above 6.0 also had the following risks on the health portion of the HOMES tool:

- Cannot use bathtub or shower.
- Cannot access toilet.
- Cannot locate medication or medical equipment.
- Presence of mold or chronic dampness.

The identification of these risks, especially when combined with information on CIR findings, are an important indicator of the severity of the hoarding behavior and seem to indicate that case managers may find additional barriers to client engagement and program completion. While the condition of a home's bathroom, the client's ability to locate medication, and the presence of mold in the home increase the likelihood that participants will struggle to meet basic code compliance, it is likely that other factors such as mental and physical health factors, difficulty maintaining motivation, and other issues are also contributing to the participant's early exit from the program.

**Household composition.** The composition of the household may play a role in program success. The majority (78 percent) of households consisted of an individual living alone. As a result, data on households with more than one person is limited, but still provides some insights. Initially, it appears that there is no difference in success rates between households with one person and those with two or more persons. However, comparing households with children to those with more than one adult (with no children), the outcomes differ (see Chart 20). Households with a child are more likely to pass (68 percent), while only 50 percent of households with two or more persons and no children passed, and 33 percent terminated.

A variety of factors may contribute to households with more than one adult being less successful: Both members of the household may have hoarding behaviors. One adult member may be unwilling to allow the other household members to help reduce clutter in the home or there may be burnout among those without hoarding in the home. On the other hand, households with children may have been more successful because having a child in a house with clutter increases the focus on homes with health and safety issues, creating a sense of urgency for improving the condition of the home. In fact, 75 percent of households with children in the HI/TPP program were also receiving services from the Department of Children and Families.

**CHART 20:** Outcomes by household composition

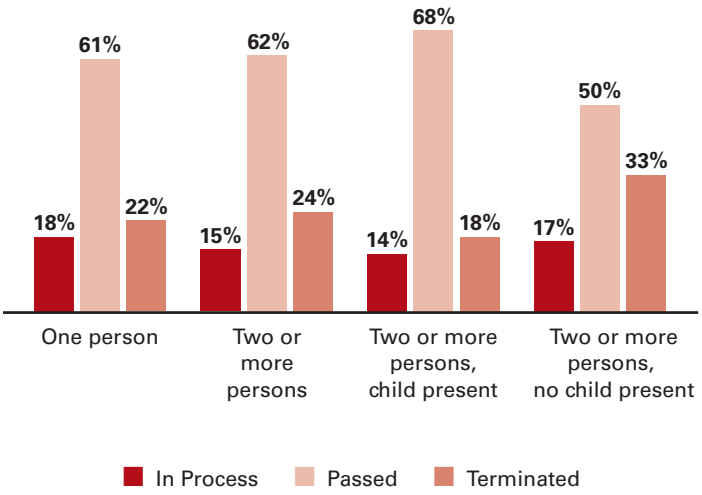
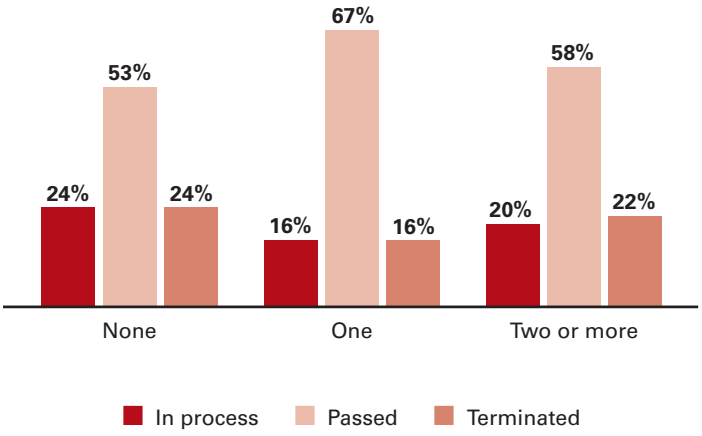



**CHART 21:** Outcomes by mental health conditions




**Mental health concerns.** HI/TPP participants with one reported mental health concern had notably better outcomes when compared to their peers with no reported concerns and multiple reported mental health concerns. Fifty-three percent of those with no reported conditions, 67 percent of those with one mental health issue, and 58 percent of those with multiple mental health issues were able to pass their inspection (see Chart 21). Termination prior to passing inspection was more common among those with multiple mental health concerns and those without any reported concerns.

There are several possible factors that are likely to impact a participant's ability to sufficiently engage in the case management process and reduce the volume in order to pass inspection: Insight into hoarding behaviors and other health issues will impact the outcome of the intervention. Lack of insight may play the biggest role in the termination prior to passing inspection for the 24 percent of program participants with no reported mental health conditions. Program participants are asked at intake if they feel that the clutter is an issue in their home. The CIR scores for participants who do not report any mental health concerns and who do not feel the clutter is a problem are higher than their counterparts with reported mental health problems. Connection to service providers in the home, executive function challenges, and high levels of burnout may also contribute to the termination rates across all participants.

## Clutter Image Rating and mental health

When examining CIR scores in each of the mental health categories outlined above, several patterns emerge. CIR ratings across all rooms are similar for those who have no reported

### CASE STUDY

Bob, 73, was 48 hours away from being evicted from public housing. His small studio apartment was filled with stacks of boxes 4 to 5 feet high. The pathway to his front door was so cluttered it was only 12 inches wide, making entering and exiting a challenge. Bob's hoarding behavior had been going on for several years and was compounded by the recent loss of multiple family members, serious medical issues, and a significant gambling addiction. Perhaps most alarmingly, Bob was so consumed with feelings of worthlessness that he refused to call 9-1-1 for medical help when needed.

Just hours after the receiving Bob's referral, the HI/TPP case manager met Bob at his home. After conducting the intake, the case manager worked with the housing provider and property manager to secure more time for Bob to improve his situation and laid out a schedule for inspections. For several months, Bob worked with the case manager on a weekly basis to develop rules and gain skills to manage his clutter. On the day of his final inspection, the pathway to Bob's door was a comfortable 36 inches wide. Piles were reduced throughout the apartment to less than 3 feet high. All told, Bob had discarded more than 50 percent of the contents in his home. He is no longer in danger of homelessness.

Through the program, Bob's sense of self-worth has improved, making him more likely to call 9-1-1 in the event of an emergency. The reduction of clutter means emergency responders can now safely enter his home to assist him, and friends were able to visit him upon his return home from a recent hospital stay. Bob continues to meet with Jesse and other service providers in the area periodically to ensure he has the support necessary to manage his hoarding and medical concerns moving forward.

## CASE STUDY

Rachel* and her family were referred to HI/TPP through child protective services. The family's home was significantly cluttered with one room completely inaccessible. Rachel had low insight into her clutter problem and did not feel that she needed any assistance in de-cluttering her home. Rachel has a history of physical and mental health problems as well as a history of loss. Her mother also has a problem with hoarding behaviors. The child protective service worker and Rachel's husband expressed concern about the safety of the children in the home and about Rachel's ability to do the work necessary to de-clutter.

After several meetings, Rachel agreed to try sorting and discarding with an HI/TPP case manager. In those meetings, the case manager attempted to work with Rachel to develop a list of items that were most important to hold onto. Rachel was argumentative and refused to engage in this process. The case manager continued to work to engage Rachel using motivational interviewing, talking about the impact of the hoarding on her children, and other techniques. Unfortunately, Rachel continued to insist that she was able to address the problems identified by protective services on her own.

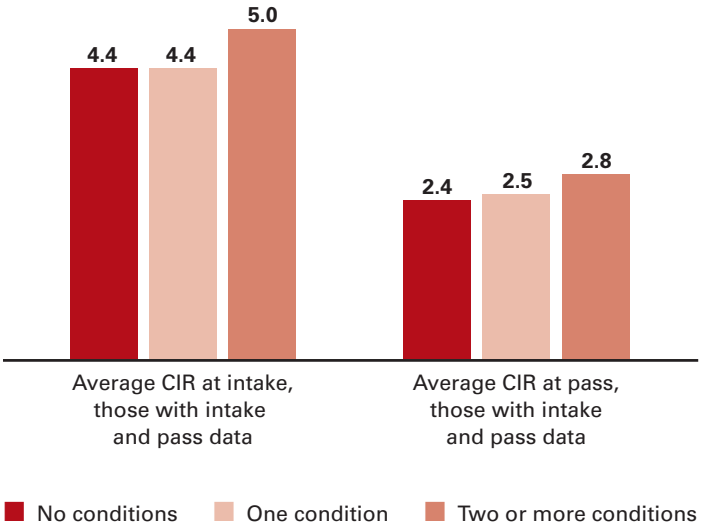
Due to Rachel's ongoing refusal to engage, low insight, hostility toward service providers working with the family, and unwillingness to work with HI/TPP staff, the case manager was forced to close Rachel's case and she terminated from the program before passing her inspection.

**Name has been changed to protect client's privacy.*

mental health concerns (CIR of 4.2) and those who have one concern (CIR of 4.1). However, those with multiple mental health conditions have a CIR of 4.9 across all rooms of the home. Upon further examination, it is clear that the kitchens of those with multiple mental health issues have a slightly higher CIR rating compared to those with one or fewer concerns. The CIR in the bathroom, however, is a full point higher on the CIR scale. This CIR indicates an increase in the severity in the hoarding throughout the home. In this respect, bathrooms with a high CIR rating are a signal that the participant is more likely to have significant problems throughout the home, including the presence of spoiled food in their home or difficulty using the stove or the refrigerator.

By isolating rooms that have consistently high clutter levels, we are able to gain further insight into the difference between these groups. Overall, those with multiple mental health

**CHART 22:** CIR mental health conditions




concerns have a CIR in these "problematic" rooms that are similar to those with no reported conditions and those with one mental health issue (see Chart 22). However, those with multiple mental health conditions have a CIR in "other rooms," such as hallways and basements that are one to two points higher than their counterparts in other groups. As previously stated, clutter levels like these substantially impede the egress during an emergency, increasing the risks associated with fire, among other safety concerns.

When we look at the relationship between the change in CIR rating and mental health conditions, the data is very limited, but the initial results provide some preliminary results that are worth noting. Among HI/TPP participants who pass inspection, there is substantial progress in reducing clutter, regardless of mental health group. Those who passed inspection reduced their CIR level in rooms such as the living room and bedroom by 2 to 2.2 points.

It appears that making improvements to the engagement process with participants with no mental health conditions or one mental health condition at risk of leaving the program prior to compliance will increase the likelihood that they will be able to effectively reduce clutter in their homes. Unfortunately, residents with multiple mental health conditions who terminated prior to compliance made little improvement on the CIR scale.

**Other contributing factors.** HI/TPP staff assessed a variety of factors that were likely to influence the hoarding intervention process, including experiences of trauma and loss, domestic violence, and a family history of hoarding behaviors. While there is no evidence that trauma and loss cause a hoarding problem, it is important to help create a feeling of safety and to work to develop systems that prevent triggering emotions that could lead to re-acquisition of possessions by the program participant after

the initial HI/TPP intervention. Learning to manage emotions attached to trauma, loss (including the fears about the loss of identity), and other life experiences are an important part of the HI/TPP intervention model. As a result, it was important for staff to better understand any factors that could contribute positively or negatively to the intervention process.

Based on the data collected at intake, none of the contributing factors above appear to contribute to the clutter image levels found at intake. However, these factors do appear to play a role in determining if a participant is more likely to terminate from the HI/TPP program prior to passing inspection. Most notably, those who reported an experience of loss were twice as likely to terminate prior to meeting compliance standards as those who report no experience of significant loss.

### Squalor

In assessing data from the HI/TPP intakes, participants with squalor had a higher CIR rating, both overall and in almost all rooms, when compared with participants without squalor (see Table 3). Those with multiple mental health conditions and squalor had higher CIR ratings when compared to participants with fewer mental health conditions. Participants with arthritis, cancer, and obesity had significantly higher squalor rates than those with other medical problems.

In cases with squalor, case managers were successfully able to develop plans to address squalor concerns and reduce the volume of clutter in the home. Given the mental and physical health issues facing HI/TPP participants, increased access to services such as group adult foster care, home making, personal care attendants, and visiting nurses would likely have a substantial impact on a resident's ability to address the squalor in addition to high clutter levels.

**Threat to housing.** Although one would be inclined to believe that a threat of eviction or loss of housing subsidy would be a substantial motivator for those in the HI/TPP program, the data contradicts this theory. Twenty-one percent of those facing loss of their housing subsidy terminated, only 13 percent with no such threat terminated, and 26 percent of those facing an eviction terminated, compared to only 19 percent of those who did not face an eviction. Such an outcome is surprising, and while there may be some explanations, further research is necessary to clarify the reasons for this outcome. Possible reasons for this difference include the fact that the HI/TPP intervention model is intended to be collaborative in nature, but there are times where property managers, court officials, and code enforcement personnel may be less inclined to collaborate and choose to instead impose deadlines without the input of others. These deadlines, particularly in combination with the complex mental health and medical issues, lack of insight, and other challenges, may play a role in why clients faced with eviction or subsidy loss find other ways to address the clutter in their homes.

**TABLE 3:** Intake for specific rooms with intake and pass data

| | Squalor | No squalor |
|---|---|---|
| Average intake | 5.1 | 4.4 |
| Average pass | 2.8 | 2.9 |

As previously stated, the HI/TPP program focused primarily on renters, thus we do not have significant data on homeowners with hoarding behaviors. Despite this lack of data, anecdotal evidence has shown us that different partners and different approaches are needed to address homeowners given that the legal tools available to address renters are not the same as for homeowners. Data from our replication projects, particularly those in Bedford and Burlington, will provide more information about the best intervention strategies for this portion of participants.

## THE IMPACT OF COMMUNITY AND POLICY CHANGE EFFORTS

As previously noted, HI/TPP staff made a significant investment in efforts to support local task forces and increase intensive support for communities building in-home support for those with hoarding, as well as efforts to develop public policies that support effective hoarding intervention practices.

**Increased task force support.** In 2008, TPP began facilitating the Boston Hoarding Task Force. Task Force members expressed a desire to re-evaluate goals, set up a plan for ongoing education, and to expand membership. Through HI/TPP, MBHP joined the Task Force and was able to use the program's training and technical assistance experience to help the task force re-evaluate their leadership structure, build an education program, and brainstorm potential new members. As a result, the Boston Hoarding Task Force formed an Executive Committee and undertook a strategic planning and visioning process. At the same time, MBHP staff partnered with the Cambridge Council on Aging to support the Cambridge Hoarding Coalition's formation of an Executive Committee, develop community education programing, and create a referral structure for hoarding cases in the City of Cambridge.

**Training in appropriate hoarding intervention.** The Boston Hoarding Task Force held two full-day trainings for professionals in Boston and raised the level of engagement among participants. In Cambridge, MBHP facilitated full-day trainings for participating agencies. MBHP also expanded training capacity to work with Pine Street Inn, MassHousing, and others to increase the number of trainings offered on hoarding intervention in Massachusetts. In total, 1,891 professionals were trained through HI/TPP.

**Intensive, on-going support for cities and towns interested in investing in case management for hoarding.** As a result of these focus groups, HI/TPP enabled MBHP, for the first time, to offer intensive training and ongoing coaching to communities. Program staff members were able to accompany staff from partner agencies on home visits to provide feedback on the intervention process. Ongoing supervision was also provided to problem-solve difficult cases. Training in combination with ongoing coaching was provided to the four replication sites in San Francisco; Burlington, Vt.; and Bedford and Burlington, Mass. In addition, MBHP partnered with the Cambridge Hoarding Coalition to provide intensive support to their effort to build hoarding intervention capacity in their community.

**Changes in public policy related to hoarding intervention.** MBHP, in partnership with the Statewide Steering Committee on Hoarding, has played a leadership role in advocating for hoarding-related policy changes. In particular, HI/TPP staff drafted legislation that mirrors an Illinois law specifying hoarding as a category of self-neglect in elder protective service regulations. If enacted, this legislation would provide protection for seniors with hoarding, as well as bring more consistency in how hoarding is assessed and addressed by elder service agencies throughout the Commonwealth.

# VIII. RECOMMENDATIONS FOR REPLICATION

## POLICY AND INSTITUTIONALIZED RESPONSE

There are few mental health issues that require a coordinated, multi-disciplinary response in the way that hoarding does. This seemingly private problem has been a challenge for communities around the globe. Increasingly, we are learning that proactively putting policies into place that support evidence-based hoarding interventions benefit both the individual with hoarding and the community agencies they work with.

MBHP has heard from housing and health officials throughout the United States that they know that clean-outs are expensive and ineffective, but they have few resources for implementing promising practices such as in-home support or case management for hoarding. To responsibly address the impact of hoarding in terms of health/safety concerns, the needs of the resident, and fiscal concerns, it is critical that housing and public health policies are crafted that support a shift away from clean-outs and use those resources for promising practices in hoarding intervention. Similarly, engaging individual donors, foundations, and government funding sources about the need to avoid siloed funding structures for hoarding intervention is also a key to ensuring that those with hoarding have access to a wide range of intervention resources.

Communities building a case management response to hoarding should start with a small number of cases, build program capacity over time, and collect data on program participants and outcomes in order to facilitate fundraising efforts. As communities look for sustainable responses to hoarding, larger systems such as public health departments, courts, and social service providers must find better ways to identify and assist those with hoarding behaviors. Similarly, mental health and medical providers can develop screening tools similar to those for domestic violence or substance abuse designed to offer supportive services before hoarding behaviors reach a crisis point.

## STAFFING REQUIREMENTS

Hoarding intervention work does not suit everyone. Case managers must have a high level of patience, be able to gain the trust of participants, have the ability to seamlessly switch between harm reduction and cognitive behavioral therapy skill sets, and have a willingness to see the problem of hoarding from a variety of different, sometimes conflicting perspectives. Case managers must be flexible in their approach, because every participant is unique in terms of the condition of their home, their personal circumstances, and their readiness to address the clutter.

Throughout the intervention process, the case manager/participant relationship is crucial to success. As a result, a caseload of 35 to 40 people per year is ideal for this intensive case management model. For agencies with a high demand for hoarding intervention services, case managers with more experience may, on occasion, be able to temporarily accommodate 50 to 65 people with proper support such as enhanced supervision, more experience working successfully with those who having hoarding behaviors, and a rich network of local service providers. Efforts should be taken to avoid such high caseloads whenever possible to prevent staff burnout and early participant termination.

Additionally, organizations using the HI/TPP intervention method must have the resources to dedicate to training and supervision for case managers. Organizations must also understand that although a rapid reduction in clutter volume may be desired, long-term safety may be best insured by making a commitment to a slower, more deliberate approach.

## COST COMPARISON

Little data has been collected about the cost/benefits of hoarding intervention strategies. The City of San Francisco's Hoarding Task Force commissioned a report that included the cost to landlords throughout the city. They found that clean-out costs alone ranged from $2,000 to $99,000.[23] As previously mentioned, Dr. Frost and colleagues found that one Massachusetts town spent $16,000 in clean-out costs only to repeat the clean-out (and the costs) 18 months later.

In Boston, eviction costs can average upward of $10,000.[24] The cost for hoarding-related evictions is likely greater due to multiple court hearings, the cost of cleaning units, and initial storage fees for tenant possessions. In comparison, based on the average case load during HI/TPP data collection, medium- to long-term case management through the HI/TPP program cost $1,799 per client. If caseloads are reduced to allow more time to assist clients with enhanced needs, this cost would rise slightly. This number does not include the cost of collateral service providers such as home makers because that data is not readily available.

## RECOMMENDATIONS

MBHP recommends the following to communities seeking to implement a case management approach to hoarding intervention in order to effectively manage costs and keep community members safe.

1. Shift away from clean-outs toward more long-term solutions.
2. Invest in ongoing training, case consultation, and supervision for all program staff.
3. Hold trainings with a variety of professions in attendance including inspectors, first responders, case managers, property owners, and other stakeholders.
4. Clearly define roles for everyone taking part in the community response to hoarding.
5. Train housing professionals, code enforcement, and others to make referrals at CIR levels of 4–5 rather than waiting until clutter levels create a crisis.
6. Establish written protocols and policies on how hoarding cases will be addressed.
7. Create and use joint-service plans for cases with multiple stakeholders.
8. Build task forces.
9. Start with a small number of cases, build program capacity over time, and collect data on program participants and outcomes.
10. Ensure that case managers have skill sets essential to working with high-needs clients.
11. Extend time standards for court cases where hoarding is the primary cause for eviction as a reasonable accommodation.

# IX. CHALLENGES

## UNDERSTANDING EARLY TERMINATION

Insight into the thought processes of those with hoarding behavior plays an important role in the success of any hoarding intervention. Unfortunately, due to the nature of hoarding, insight is frequently low in people with hoarding behaviors. When using the HOMES tool, 40 percent of HI/TPP participants who terminate services prior to passing inspection are assessed as not fully understanding the seriousness of the hoarding problem in their home and 47 percent of those terminating were assessed as not likely to accept the consequences of non-compliance. This points to a low level of insight among many program participants. Thirty-four percent of participants who did not feel that the volume of clutter in their homes was an issue terminated participation early.

Another factor in early termination may be burnout and frustration. High CIR levels and multiple risks on the HOMES tool are common for those who terminate services prior to passing inspection. Those who receive services but choose to terminate early are seeing a 1.0 point drop in CIR level. If case managers can find creative ways to maintain client motivation and engagement, there is evidence that these clients will be able to continue reducing the volume of clutter in their homes and pass inspection.

For many clients, concerns such as the emotional impact of addressing the hoarding, mental and physical health concerns, and life experiences may play a role in the decision to terminate early. Moving forward, the collection of data on the role of service providers and referrals for additional services will assist HI/TPP staff in supporting those at risk of early termination from the program.

MBHP is quite concerned about the long-term eviction risk for those who terminated early from the program. Hoarding has a chronic and worsening course; as a result, without the development of skills to better manage the clutter, these residents are likely to face eviction threats again. However, MBHP's experience has shown that clients are often more open to services when they are referred to the program for a second or third time. As we learn more about the need of these clients, we can take steps to prevent early termination.

## OTHER CHALLENGES

**Short- vs. long-term thinking.** One of the primary challenges is educating code enforcement staff, court staff, property owners, and service providers that short-term approaches such as clean-outs may reduce immediate risk, but can ultimately increase the risk to residents in the long-term. Similarly, property managers and code enforcement officers sometimes feel the need to be inflexible due to a concern that those living in cluttered homes will not take the steps necessary to bring them into compliance with housing codes. This perception that a "big stick" is needed without the willingness to engage with the program participant's case management team ultimately appears to harm the effort of the resident to comply with their obligation.

**Insight.** Lack of insight is a significant challenge for a portion of program participants. To address this challenge, case managers need to have patience, avoid being directive, and possess a well-rounded set of tools to engage the resident. Working with residents after compliance requires many of the same tools, as participants sometimes are not able to see the potential triggers for recidivism or the need to strengthen particular skills that will assist them in maintaining compliance over time.

**Access to in-home services.** Access to home-based resources such as visiting nurses, in-home mental health treatment, and home makers is a challenge for many HI/TPP participants and the staff working with them. The group adult foster care program (GAFC) that provides daily in-home services to those with MassHealth would be a great asset to most HI/TPP participants. Unfortunately, though they meet all other program requirements, the majority of participants are unable to access GAFC services because they do not live in large multi-unit buildings. Policies such as this have a direct impact on the ability of clients, particularly those with mental health and medical concerns, to access services that will assist them in properly maintaining their homes.

**Caseload.** Balancing the high rate of demand for intervention services with the time needed per client remains a challenge for HI/TPP staff. This is particularly true as the program seeks to reduce the volume of terminations from the program and reduce the time between the beginning of intervention and when the unit passes inspection. Clients with multiple mental health issues, a history of loss or trauma, and low insight likely need more time to work hands-on with their case manager each week. As a result, careful examination of program capacity and caseloads size are necessary.

# X. RESEARCH CONCLUSIONS

**The HI/TPP model of hoarding intervention is highly successful in preventing housing loss due to hoarding behavior.** Participants have a somewhat higher reduction in their Clutter Image Rating compared to those in a recent research trial using cognitive-behavioral therapy. Limited early data also suggests that clients are successfully maintaining the reduced volume of clutter after services have ended. HI/TPP will continue to follow participants to monitor clutter levels and court/eviction activity, to provide further intervention services if needed, and to gain further insight into best practices.

**The cost of HI/TPP case management is far less than the cost of a clean-out or eviction.** This is especially true when there is a desire for the unit to meet compliance over the long-term.

**Communities can successfully implement a case management model similar to HI/TPP.** In order to do so, stakeholders such as public health, housing, social workers, social service providers, and government agencies must commit to changing how they do business. Coordinated task forces, training, and ongoing coaching will enable these groups to develop the skills, practices, and policies necessary to have more human-centered and fiscally responsible intervention practices.

**MBHP is poised to take the lead on improving hoarding intervention practices.** HI/TPP staff members have played a leadership role in educating others about promising intervention techniques, not only in Massachusetts but throughout the United States and Canada. A total of 1,891 professionals have been trained through this effort and multiple communities are seeking out HI/TPP program staff assistance for building an effective hoarding response mechanism.

**More funding is needed for programs like HI/TPP.** As previously noted, the cost of HI/TPP case management is far less than the cost of a clean-out or eviction. With additional funding, partners in the HI/TPP program will be able to efficiently address program capacity challenges, including educating housing and service providers about sound hoarding intervention strategies, engagement of those most likely to terminate from the program, tracking long-term outcomes for those receiving intervention services, and addressing the need for additional policy work to support promising intervention practices.

Working with our partners, and with support from funders, MBHP is committed to:

- Expanding program direct service capacity.
- Continuing investment of training and ongoing, intensive assistance for communities building sustainable models for hoarding intervention.
- Working with local and state officials to continue developing new policies in housing, public health, and protective services to assist those with hoarding behaviors.
- Continuing data collection in Greater Boston and all replication sites to track program outcomes, refine program operations, and influence public policy related to hoarding.

In addition to expanding direct services to people with hoarding, long-term funding will allow MBHP and partners in hoarding work to continue the practice and policy changes necessary for effective hoarding intervention. This ongoing work is essential to increasing the number of providers able to work directly with those who have hoarding behaviors, as well as assisting service providers and government agencies throughout Massachusetts to develop appropriate, effective hoarding intervention policies.

# APPENDIX: NOTES ON THE DATA

For this report, MBHP relied on Hoarding Intervention/Tenancy Preservation Project (HI/TPP) program data. HI/TPP staff members asked a standard series of questions at intake and assessed the home using both the HOMES Tool and the Clutter Image Rating (CIR). Both of these tools are detailed elsewhere in this report. In addition, staff members reassessed the CIR levels at the time the property passed inspection or when a participant terminated participation in the program. Staff members also continue to monitor participants' homes, completing a follow-up CIR at one year and two year intervals after the home passed inspection.

As there is only one published study[25] on hoarding behaviors with more participants than this study (175 participants), the data from this program provides important insights into those with hoarding behaviors, the condition of their homes, and the success or failure of MBHP's assistance with these participants. Data from this report does not have the reliability of a tightly controlled academic study, however, as participants were not selected at random and no control group was established. Therefore, the reader should note this fact and take care in characterizing all those with hoarding behaviors using this data.

In general, program data must be seen in light of the difficulties that agencies have in gathering consistent and accurate data. This program is no different. For example, while every staff person receives the same training, some differences can occur in how each staff person completes the initial assessment. In addition, participants may choose not to respond to some questions, or do not provide an accurate response. For example, this data would be much richer if it were connected to participants' medical and mental health records. As it is not, HI/TPP staff members must rely on self-reported conditions, which may be incomplete or inaccurate.

HI/TPP staff members attempt to follow up with all clients to update the CIR rating, regardless of whether they have passed inspection or terminated from the program. Maintaining a relationship with a participant is difficult, especially if the participant has little insight into their hoarding behaviors and has terminated participation in the program. Even where there has been no termination, follow-up can be difficult. As a result, the number of participants with one-year and two-year follow-up data is smaller than the total number of participants. In addition, because referrals are generally from agencies and owners/managers working with low-income households, the results in this report are primarily about low-income renter households, and the experiences of homeowners are not well represented among participants.

The HI/TPP program has a rolling enrollment. As such, additional follow-up data will become available as participants reach the one- or two-year anniversary of passing inspection. With this data, MBHP will be able to revisit the data and gain more insight into both success and recidivism.

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## METROPOLITAN BOSTON HOUSING PARTNERSHIP

MBHP is the state's largest regional provider of rental housing voucher assistance, serving 9,300 tenant households and working with 4,300 property owners. MBHP serves individuals and families who are homeless, elderly, disabled, and/or of low and moderate incomes in Boston and 32 surrounding communities.

MBHP's mission is to ensure that the region's low- and moderate-income individuals and families have choice and mobility in finding and retaining decent affordable housing; all MBHP programs and initiatives are designed to encourage housing stability, increase economic self-sufficiency, and enhance the quality of the lives of those it serves. To achieve its mission and to promote efficient service delivery, MBHP works collaboratively with a broad array of service providers and neighborhood-based organizations.

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## ACKNOWLEDGEMENTS

MBHP would like to express our thanks to the Oak Foundation for supporting the expansion of HI/TPP, as well as the Bay Cove Tenancy Preservation Project for partnering with us on this effort. We also thank Dr. Gail Steketee, Dr. Jordana Muroff of the Boston University Hoarding Research Project, Dr. Christiana Bratiotis of the University of Nebraska-Omaha, and the staff at MassHousing for their continued support of our program. Our thanks also goes to our replication partners: City of San Francisco Department of Aging and Adult Services; Burlington, Vermont Housing Authority; and the towns of Bedford and Burlington, Massachusetts.

*Publisher's Note: The conclusions and recommendations in this paper are those solely of Metropolitan Boston Housing Partnership.*