BEYOND OVERWHELMED
The Impact of Compulsive Hoarding and Cluttering in San Francisco and Recommendations to Reduce Negative Impacts and Improve Care

A Report of the
SAN FRANCISCO TASK FORCE ON COMPULSIVE HOARDING
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**Aregawie Yosef and Belinda Lyons**
Co-Chairs, San Francisco Task Force on Compulsive Hoarding
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Compulsive hoarding is an important issue in our community. An estimated 12,000-25,000 San Francisco residents struggle with this condition. Compulsive hoarding can take a huge toll on people who hoard, their families and friends, as well as their landlords and neighbors and many public and private health and safety departments and agencies.

This report represents the extraordinary commitment and participation of a wide range of stakeholders over a 19-month planning process. It’s about time that experts, law enforcement, and public and private service providers have come together to address compulsive hoarding. There’s a light at the end of this tunnel.

In these pages you will find important recommendations for reducing the negative impacts of compulsive hoarding, including some that can be implemented at relatively low cost. These recommendations deserve careful consideration by San Francisco policy makers. I commend the Department of Aging & Adult Services and the Mental Health Association of San Francisco for this important contribution to the well-being of our City.

Tom Ammiano
Member, California State Assembly
(13th District)

The San Francisco Task Force on Compulsive Hoarding has for the first time estimated the costs of compulsive hoarding in San Francisco, and those costs are high: evictions and homelessness, fires and other threats to public safety, anxiety, depression, isolation, and broken families, and over $6 million per year in financial costs.

Many of these costs are preventable. In an era of tight funding for human services, we need solutions that achieve efficiencies through improved coordination and that save public funds by leveraging private resources. The recommendations in this report meet this test, including a single point of entry, involvement of peers in assessment and treatment, and improved coordination among public and private entities. Implementing these recommendations will reduce homelessness resulting from evictions and increase the number of San Franciscans who are able to live independently in their homes, which is one of our top public policy priorities.

We are pleased to have had the opportunity to participate in and support the work of the Task Force and look forward to the implementation of its recommendations.

E. Anne Hinton
Executive Director, San Francisco Human Services Agency, Department of Aging & Adult Services
Compulsive hoarding is a behavior that, for many, is disabling, interfering with activities of daily living such as mobility, socializing with friends and family, and holding a job. Mayor Newsom and the Mayor’s Office on Disability are pleased to see such a thoughtful and comprehensive approach to addressing this significant cause of disability and homelessness. We urge adoption of the recommendations contained in this report.

Susan Mizner
Director, San Francisco Mayor’s Office on Disability

This Report constitutes consensus findings and recommendations of a public-private partnership that reached out to and included a wide range of stakeholders affected by compulsive hoarding. The Task Force’s work was greatly enhanced by the active participation of individuals who compulsively hoard, who provided important insights into the state of the problem and solutions that can work.

DAAS and the Mental Health Association of San Francisco are pleased to have had the opportunity to facilitate this work, which outlines a clear plan to reduce the suffering and expense associated with compulsive hoarding.

Belinda Lyons
Executive Director, Mental Health Association of San Francisco
Co-Chair, San Francisco Task Force on Compulsive Hoarding

Aregawie Yosef
San Francisco Human Services Agency, Department of Aging & Adult Services
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Co-Chair, San Francisco Task Force on Compulsive Hoarding
This report is the result of the efforts of the San Francisco Task Force on Compulsive Hoarding to understand the impact of compulsive hoarding behaviors and includes the Task Force’s recommendations for improving care for individuals who hoard. Data for this report have been collected from diverse San Francisco stakeholders, including people with hoarding behaviors, service providers in both the public and private sectors, and landlords who have tenants with hoarding behaviors. The recommendations are intended to help local government, nonprofits, businesses, and individuals take effective action to reduce the risks and negative impact of hoarding and cluttering and to improve the quality of life of those dealing with compulsive hoarding.

Compulsive hoarding and cluttering is a serious and treatable behavior that is often related to several mental illnesses including obsessive-compulsive disorder and major depression. It can have significant negative effects on people who struggle with it, along with their families and communities. Compulsive hoarding and cluttering is characterized by the acquisition and retention of overwhelming quantities of objects that do not—to an outsider—seem useful or necessary and that cause the individual significant distress or impairment. Based on national estimates, the prevalence of compulsive hoarding and cluttering among adults in the U.S. is roughly 2-4%, and so we estimate that 12,000-25,000 adults in San Francisco have hoarding behaviors.

Just as people with hoarding behaviors may feel overwhelmed and not know what to do about their situation, social service agencies and landlords who try to help them to create safer, more manageable living conditions may feel overwhelmed as well. Failure to address compulsive hoarding in an effective, coordinated way can result in high-cost crisis interventions that do not address the root causes of the problem and can ultimately fail to prevent eviction or other loss of housing.

Personal communication, Steketee, G. to Eckfield, M. 11/1/05.
The San Francisco Task Force on Compulsive Hoarding gathered data locally and found that hoarding behaviors have a substantial impact:

- **Individuals** with hoarding behaviors noted that these behaviors caused them to feel isolated; impeded the development of relationships; led to concerns for safety in their homes; caused them to fear eviction; led to health problems including falls, injuries, and losing track of medications in their belongings; and caused problems in their family relationships, leading in some cases to loss of contact and even divorce and custody loss. In addition to these social and emotional costs, people with hoarding and cluttering behaviors incur financial costs that might include renting storage units, cleaning services, fees resulting from an inability to find bills, and challenges in holding a job.

- **Organizations** providing services to people with hoarding behaviors also noted an impact—including additional staff time, costs, and difficulty finding staff willing to work with clients with hoarding behaviors. One legal services attorney noted that he could successfully defend 20 non-hoarding eviction cases in the amount of time it took to resolve one hoarding case. Twenty-nine percent of agencies surveyed reported higher costs, ranging from $50 to $20,000 per client.

- **Landlords** noted challenges resulting from hoarding, including pest infestations, the need for heavy cleaning, the need to involve animal control, injuries, and fires. Costs mentioned included pest infestations ($50-$1,499), animal control costs ($200-$1,499), foregone rent ($1,000-$3,999), eviction-related costs ($2,000-$99,999), and heavy cleaning ($75-$3,999). A small number of catastrophic events (evictions costing in excess of $50,000 and a fire-related cost exceeding $500,000) were reported.

Our surveys and interviews captured actual costs due to compulsive hoarding and cluttering behaviors in San Francisco of over a million dollars a year ($1,166,105) incurred by service providers ($502,755) and landlords ($663,350). We were not able to estimate costs to individuals. This estimate is only the tip of the iceberg, and if data were available from all identified providers and landlords, we conservatively estimate that costs to service providers and landlords from compulsive hoarding are $6.43 million a year. The incalculable human cost in the lives of individuals and families adds significantly to these financial impacts.

To improve local response to compulsive hoarding, the Task Force has developed a series of recommended activities for appropriate local entities.
Recommendations

1. **Develop an assessment/crisis team** to respond to referrals about hoarding cases and coordinate appropriate next steps to facilitate meaningful, long-term improvement for individuals.

2. **Increase access to treatment** for hoarding, including in the person’s home. Treatment can include therapists, organizers, coaches, and peers.

3. **Expand support groups** available locally, including peer support groups and groups for family members, and provide training for peer support facilitators. Build on the successes of support groups by offering groups for people at different stages of dealing with their hoarding behaviors, ranging from early awareness and those just starting out to those with substantial experience working on behavioral changes.

4. **Create a services roadmap** for people with hoarding behaviors and their families, service providers, and landlords so that people know what agencies to contact in different situations and have a way to identify and seek assistance. **Establish a single point of entry** into the system of supports and resources that uses a single form for referrals, follows the services roadmap, and engages the assessment team.

5. **Develop evaluation guidelines** for landlords that are coordinated with fire department and health regulations.

6. **Provide long-term case management services** as an extension of initial assessment and treatment.

7. **Offer training** for therapists, 211/311 staff, landlords, agency staff, and families; recruit and train trainers; and provide cross-training for identification/screening/assessment across agencies.

8. **Ensure overarching coordination** and evaluation of recommended priorities (hoarding and cluttering “czar”); track implementation of priorities and evaluate success.

In the face of an estimated $6.4 million in annual costs to the City, social services agencies, and landlords from compulsive hoarding, as well as the personal costs to people with hoarding behaviors, the Task Force recommendations are designed with two ends in mind. The first is to maximize the use and coordination of existing resources and services so that they work together more effectively and efficiently. The second is to invest a modest amount (approximately $650,000 a year) in programs that both support this coordination and build systemic capacity to more effectively address treatment and crisis prevention. (Examples of possible implementation strategies and pilot projects can be found in Appendix H.) These approaches will improve the quality of life of thousands of San Francisco residents while saving the City many of the costs associated with compulsive hoarding.

In 2007, compulsive hoarding cost San Francisco service providers and landlords an estimated $6 million.
I. INTRODUCTION

This report is the result of more than 19 months of dedicated research and reflection by the San Francisco Task Force on Compulsive Hoarding, a joint initiative of the City and County of San Francisco Department of Aging & Adult Services (DAAS) and the Mental Health Association of San Francisco (MHA-SF). The San Francisco Board of Supervisors generously provided funding through DAAS to MHA-SF to support this work.

The San Francisco Task Force on Compulsive Hoarding was created in 2007 to build on innovative, effective programs that were already being developed locally and to create a blueprint for action for San Francisco. The Task Force examined existing research and the experiences of other task forces and undertook locally specific research, including a groundbreaking analysis of the financial cost of compulsive hoarding to service providers and landlords, in order to understand the case for investing greater resources to address the issue. The Task Force also launched media outreach and trainings, facilitated the coordination of some existing services, and enabled two Task Force members to jointly offer the first compulsive hoarding treatment group in San Francisco.

This report presents data collected from diverse local stakeholders, including people with hoarding behaviors, service providers who work with them, and landlords who have tenants with hoarding behaviors. It also offers the voices and stories of people in San Francisco who are struggling with hoarding and cluttering; provides an overview of research and best practices with regard to hoarding and cluttering; and makes recommendations for local government, nonprofits, businesses, and individuals to take effective action to reduce the serious risks and negative impact of compulsive hoarding and cluttering and improve the quality of life of those dealing with compulsive hoarding.
Defining Compulsive Hoarding and Cluttering

While there is some debate in the medical literature about how best to define hoarding behaviors (discussed in Appendix A), the Task Force has adopted the following definition of compulsive hoarding, based on the widely accepted work of Frost and Gross, and subsequently Frost and Hartl:

> The acquisition of and failure to discard possessions that appear to be useless or of limited value, accompanied by living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed and significant distress or impairment in functioning caused by the hoarding.2

The compulsive nature of hoarding and cluttering makes it challenging to address. A one-time “clean-out” is not sufficient; rather, recurrent behaviors must be addressed. Cluttering behavior alone, in the absence of the excessive material accumulated by compulsive hoarding, is unlikely to create the serious health, safety, and social risks that require the types of intervention and support discussed in this report. Many people have some clutter in their homes, but compulsive hoarding and cluttering is readily distinguishable from ordinary clutter, which may result from large, organized collections of objects that do not interfere with daily life or from temporary chaos accompanying a move. A key factor in compulsive hoarding and cluttering is the ongoing challenge it poses to safety and well-being.

Estimating the Number of People Affected

Estimates of the prevalence of hoarding among adults place it at roughly 2-4% of the population, or approximately 6-12 million individuals nationally.3 By way of comparison, four million people are affected by Alzheimer’s disease, according to the National Institute on Aging.4 A recent study in Massachusetts reported

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Personal communication, Steketee, G. to Eckfield, M. 11/1/05.

26.3 hoarding-related complaints over a five-year period per 100,000 residents.\(^5\)

Applying these measures to San Francisco’s adult population (633,922 based on 2006 Census estimates)\(^6\) suggests that 12,000-25,000 adults have hoarding behaviors, and that we might expect 195 complaints relating to hoarding situations in San Francisco over a five-year period.

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6  US Census Bureau, found at http://quickfacts.census.gov/qfd/states/06/06075.html accessed on 7/28/08.
Lots of people think they have clutter, but when we talk about clutter, they don’t understand that we may only have a narrow path to walk in our living rooms. Although I have a master’s degree and have had a successful career, I have almost always been embarrassed by my clutter at home. I put in extra hours at the office to be organized and successful at work, but it was as though another person lived in my apartment. I would save things like newspaper clippings and symphony programs until they overflowed the available storage space. I thought I was the only person who did this, and I tried to hide the problem. I kept up my social life away from home.

In 1995, I was diagnosed with obsessive-compulsive disorder. This diagnosis and participation in the hoarding and cluttering support group run by the Mental Health Association of San Francisco (MHA-SF) have helped me to name my hoarding problem. Initially, working with a good therapist was important. The MHA-SF support group and annual conference have been critical to my recovery because they build a sense of community among people dealing with hoarding and cluttering, overcoming isolation and fear. We don’t have places where we can talk about this. It can be potentially dangerous to talk about it at work, and it is often difficult to talk about it with family. Even healthcare providers are often ignorant.

Having support has helped me make progress—I’ve cleared clutter from my kitchen, bathroom, and living room and can now let occasional visitors into my apartment. I became a member of the San Francisco Task Force on Compulsive Hoarding because I know that building public awareness and improving services can make a real difference. Before I was diagnosed, I did everything I knew to do on my own, but I could not overcome my hoarding behavior. I tell people in the support group that we are the first generation that’s had an opportunity to recover from this. Future generations may not have to deal with the same fear.

“Before I was diagnosed, I did everything I knew to do on my own, but I could not overcome my hoarding behavior. I tell people in the support group that we are the first generation that’s had an opportunity to recover from this. Future generations may not have to deal with the same fear.”

Based on an interview with Marlo Tellschow, Task Force member, about her experiences dealing with compulsive hoarding.
Task Force Origins and Purpose

The San Francisco Task Force on Compulsive Hoarding was launched in the summer of 2007 as a public-private partnership including representatives from major city departments, non-profit housing and service providers, landlords, and individuals with hoarding behaviors. The Task Force is co-chaired by San Francisco’s Department of Aging & Adult Services (DAAS) and the non-profit Mental Health Association of San Francisco (MHA-SF).

Approximately 35 cities have active task forces addressing compulsive hoarding. Many of these task forces facilitate stakeholders coming together to consult with regard to individual cases. Some also engage in training and education for the courts, other public agencies, and the general public, and/or provide support groups for people with hoarding behaviors. An unusual feature of the San Francisco Task Force is its focus on systemic and policy issues.

This focus is possible because an array of agencies in San Francisco has already been working in various constellations to coordinate individual cases and to offer education and training as well as support groups. For example, MHA-SF, with the support of DAAS, created the Institute on Compulsive Hoarding and Cluttering in 2007. The Institute offers support groups for people with hoarding and cluttering behaviors; specialized trainings and monthly support groups for In-Home Supportive Services Consortium providers; trainings for service providers working with those who hoard compulsively; an annual conference; educational resources; information and referrals; and technical assistance. A 16-week treatment group led by a clinical psychologist from Family Service Agency (FSA) was also launched for the first time. And Adult Protective Services (APS) and In-Home Supportive Services (IHSS), both part of DAAS, along with Community Behavioral Health Services (CBHS) and the Environmental Health Section (EHS), both part of the San Francisco Department of Public Health, have been meeting regularly since October 2006, with a focus on coordination among agencies regarding interventions in individual cases.

“San Francisco is studying it [compulsive hoarding] in a meaningful way. I don’t know of another task force model around the country that has been so comprehensive.”

- Christiana Bratiotis, PhD candidate at Boston University researching how U.S. cities are addressing hoarding
In order to reduce evictions and improve the quality of life for people with hoarding behaviors, the Task Force decided to focus on the following goals:

- Assessing current needs and services
- Identifying gaps in and barriers to services
- Identifying best practices to improve coordination of services and eviction prevention
- Raising awareness among the public and policymakers
- Making policy recommendations

The Task Force identified objectives related to improving the coordination of services and reducing gaps in services and barriers to services. This included developing a mechanism for coordinating available services to address compulsive hoarding and cluttering and facilitating information exchange among various service providers.

The work of the Task Force fell into two main areas: near-term work to improve coordination, offer new services, and raise public awareness, and research to inform longer-term decision-making and investment.

A wide diversity of people are involved in hoarding cases, including police officers, home health workers, animal care and control personnel, building inspectors, attorneys, landlords, and mental health professionals. The Task Force was designed to be inclusive of these various stakeholders and to achieve consensus recommendations.

The Task Force met every other month and maintained a membership of approximately 24 stakeholders representing a range of perspectives and interests. The diversity of the Task Force’s membership has contributed significantly to the success of its efforts. Task Force members are listed on the inside of the front cover of this report.

Participating agencies and individuals acknowledge the value of the Task Force. After one year, 100% of Task Force members responding to an evaluation survey reported improved understanding of compulsive hoarding and system linkages, and 91% reported improvements in coordination of services and reduction in service gaps and barriers to services.

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**Goals of the Task Force**

- Assessing current needs and services
- Identifying gaps in and barriers to services
- Identifying best practices to improve coordination of services and eviction prevention
- Raising awareness among the public and policymakers
- Making policy recommendations

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“I have not seen anything like this in the country—San Francisco has got it right!”

- David F. Tolin, PhD, ABPP, Director, Anxiety Disorders Center, The Institute of Living, Hartford Hospital
“It can only be dealt with by me personally,” he told Oblena, who said he’d be back in a week with social workers to help out.

Oblena says Finley, like a surprising number of San Franciscans, struggles with a little-understood condition called hoarding and cluttering, which makes people strangely attached to what most people would consider junk.

Nationally, an estimated 1 million to 2 million people are compulsive hoarders. And while statistics aren’t available for just how many people in San Francisco suffer from the condition, experts say the city has become the center for study of the problem and might have more hoarders per capita than other areas.

The compact, expensive city has many SRO hotels and other small living spaces as well as an aging population that has had years to collect clutter. Dementia also can contribute to hoarding.

The nonprofit Mental Health Association of San Francisco and the city’s Department of Aging and Adult Services have teamed up to create the Institute on Hoarding and Cluttering. That group conducts training of professionals such as nurses and in-home care providers, and last summer officials launched an effort to enhance communication among city agencies that work with hoarders.

The association sees about 250 new hoarding patients a year and runs a support group for them. The Department of Public Health has two inspectors, including Oblena, who visit SRO hotels that are run by nonprofits contracted by the city to provide housing.

Mounds of stuff

The piles of trash that the inspectors often find draw bedbugs, cockroaches and rodents. If the tenant smokes a cigarette or cooks a meal using a hotplate, which is prohibited but happens a lot anyway, the whole hotel is at risk, officials said.

“Just imagine if there’s any mishap. That place would go up in flames,” said Dr. Johnson Ojo, who manages the inspectors. “Our goal is to provide safe
clean, habitable rooms for every person that lives in SROs, but we do run into these problems.”

Oblena has seen people unable to sleep on their beds because of the clutter. He inspected the room of one man who slept every night on a black metal folding chair, surrounded by mounds of clutter. The inspectors try to bring in social workers and others who can help the hoarders — both with cleaning their rooms and tackling the reasons behind the compulsive behavior.

“We give them a lot of time, a lot of chances,” Oblena said.

But if the person doesn’t comply, they can be evicted. That happens in about 10 percent of the cases, Ojo said. Some critics say these evictions contribute to the city’s large homeless population.

Once a month, those pending evictions are heard during hearings at the Public Health Department. At a recent hearing, Oblena brought in the case of Wayne Hartman, whose SRO room has been inspected numerous times over the past few months. He had made no progress in cleaning up the room, even with the help of a social worker.

“I’m humiliated by this whole thing, and I welcome all the help I can get,” Hartman, 64, said at the hearing. “I don’t want to lose my home.”

He was given until April 2 to make major changes or be evicted. After the hearing, Hartman explained that he’d been a hoarder for years. His room is filled with cardboard, aluminum foil, broken tools, newspapers and magazines.

“I’m confronted with an object, and I think I can save it, I can use it later. I can use the packaging, I can sell it, I can recycle it,” he said. “It just takes forever. I have to make a decision, and usually I’ll procrastinate.”

Chuck Dahud manages Hartman’s building and says he’s sympathetic to the problem, but Hartman won’t accept any help. “It’s really frustrating,” he said. “We just want him to live decently and clean.”

Marlo Tellschow, 68, lives in a one-bedroom apartment on Russian Hill. She has a master’s degree and held a string of administrative jobs before retiring. She has struggled with hoarding for decades. Mostly, she accumulates paper, such as a newspaper clipping that she never mailed to a friend and old programs from the symphony and opera.

“You fill the closets and the drawers, and there comes a time when there’s no more space to file it away,” she said.

She began attending a support group run by the Mental Health Association and has made progress. Her kitchen and bathroom are now clear of clutter, and she can let the occasional visitor inside.

“For most people, when they first come to the group, they feel like they are the only ones that have this problem, and that’s not true at all,” she said. “It’s supportive and comforting for people to know there are a lot of other people out there who have this issue.”

**Get involved**

A public seminar for family members of those who compulsively hoard will be held from 6 to 8 p.m. today at the World Affairs Council, 312 Sutter Street, San Francisco.

For more information about the seminar or about hoarding and cluttering, call (415) 421-2926 or visit www.mha-sf.org.
II. FINDINGS

Methodology

In order to assess the prevalence and consequences of hoarding and clattering behaviors in San Francisco, the Task Force collected information from people with hoarding behaviors, service providers, policymakers, nonprofit agencies, health and safety personnel, and landlords. We used a variety of formats for data collection, as described below. The data collection instruments can be found in Appendix D. A Data Committee made up of Task Force members and Task Force consultant Joel Ginsberg designed the data collection instruments and dissemination strategy. Wendy Max, PhD, Professor of Health Economics and Co-Director of Institute for Health & Aging, University of California, San Francisco, also provided assistance with question development and analyzed the cost data. Key themes were identified by a Research Committee made up of Task Force members. Through a series of exercises, the Task Force collectively prioritized findings and reached consensus on the recommendations contained in this report.

Focus group of people with hoarding behaviors. On February 19, 2008, MHA-SF organized a focus group of 11 people with compulsive hoarding behaviors. All of the participants self-identified as having severe hoarding behaviors, as indicated by a score of four or more on a seven-point scale in which one represents very mild hoarding and seven represents very severe hoarding. During the focus group, participants discussed eight questions relating to the effects of hoarding on themselves and their families, as well as services used and needed.

Survey of people with hoarding behaviors. During the 2007 MHA-SF annual Conference on Hoarding and Cluttering, held on October 18, 2007 in San Francisco, a survey of people with hoarding behaviors was conducted. The 60 respondents described the ways in which compulsive hoarding and clattering affects them and their families, services they have used, and the best ways to reach people dealing with compulsive hoarding. Respondents generally assessed themselves as quite severe in their behaviors: three-quarters of them rated themselves as four or greater on the seven-point scale, and a third rated themselves as six or seven.

Key stakeholder interviews. Members of the Task Force conducted interviews with 16 key stakeholders nominated by the Task Force because of their insight into existing and needed services. The stakeholders interviewed (listed in Appendix C), included police, first responders, housing providers, mental health professionals, policymakers, and social service agencies. The interviews followed an interview guide of 21 questions designed to elicit information about the diagnosis, treatment,
available resources, gaps in services, policy improvements needed, and predictors of success or failure in treatment, as well as recommendations for change. The interviews were conducted from October through December 2007. Written records of the interviews were analyzed by the Research Committee.

**Environmental scan.** This survey was designed to elicit information from a wide array of service providers who may work with people with hoarding behaviors. The survey asked about the organization and clients served, the number of clients with hoarding behaviors and the services they use, additional costs to the agency of working with these clients, coordination of services, and gaps in service provision.

The Task Force developed a list of 438 relevant agencies in San Francisco from the Department of Aging & Adult Services Network of Support, the San Francisco Behavioral Health Resource Guide (sponsored by the San Francisco Department of Public Health Community Behavioral Health Services (CBHS) and created by MHA-SF), and the Human Services Network. The Research Committee reviewed and revised the survey several times, pre-tested it, and then transposed it into Survey Monkey, a user-friendly online survey system. The Task Force was presented with drafts of the survey, gave comments and suggestions, and pilot tested the online version before it was sent out to the agencies. A letter was mailed to the CEO or executive director of each agency indicating that an e-mail invitation would arrive in a few days. Both the letter and the e-mail contained the URL for the survey. Two reminders were sent by letter and e-mail to each agency in mid-July 2008.

Between June 18 and August 4, 2008, 110 people completed some or all of the Environmental Scan survey for a response rate of 25 percent.

**Landlord survey.** A landlord survey was designed to elicit information from San Francisco property owners and managers about their experience with tenants with hoarding behaviors. It contained questions about the housing sites respondents owned or operated, the impact of hoarding behaviors on property management, and how hoarding behaviors and related needs are addressed. The Research Committee and a representative from the San Francisco Apartment Association (SFAA) reviewed the survey before it was transposed into Survey Monkey. The Task Force then sent an e-mail with the URL for the survey to a list of 1,888 landlords provided by the SFAA.

Between July 14 and August 22, 2008, 80 landlords completed the survey, for a response rate of 4.2 percent.
Findings

Local findings of the Task Force are generally consistent with existing data from other U.S. cities. Our efforts to estimate costs, however, are unique, and as we undertook this research were conscious that we were breaking new ground. Our cost estimates are not intended to outweigh the impact of hoarding behaviors on those struggling with compulsive hoarding behaviors and others around them, but are provided because they make a strong case for public investment in improved supports and systems.

Impact on Individuals with Hoarding and Cluttering Behaviors

We obtained information about how hoarding and cluttering behaviors affect individuals and about their needs through a focus group, a consumer survey, and discussions with Task Force members.

Effect of hoarding and cluttering on individuals and their families.

Individuals with hoarding behaviors described the effects of these behaviors as follows:

**Hoarding causes them to feel isolated.**
- “I can’t invite friends to visit me in my home unless they ‘understand’ the problem.”
- “I no longer give dinner parties or have people over.”
- “I socialize out of the house and am guilty about not cleaning up.”
- “[N]o one comes over, which increases anxiety.”

**Hoarding impedes the development of relationships.**
- “I do not think marriage is possible in the next 20-25 years.”
- “I can’t date women because eventually they would expect to visit my living quarters.”

**Hoarding leads to concerns for safety in their homes.**
- “I’ve tripped on my floor piles, jammed my feet [and] toes on them. I have gotten bruises on my legs and arms and had to navigate paths.”
- “I don’t want to have my appliances repaired because the repairman has to enter my house. I don’t want to let strangers enter my house.”
- “I am worried about safety—falling and slipping, bags, no clear area in which to walk.”

**Hoarding causes them to fear eviction.**
- “I have a pest control inspection every month where the property manager comes to inspect the apartment. They do a manual inspection annually. I have 3 or 4 other inspectors a year. I am concerned about being evicted from the apartment.”
• “Any landlord visit is a crisis for me to get it ‘presentable’ …”

**Hoarder causes problems in their family relationships, leading in some cases to loss of contact and even divorce and custody loss.**

• “My wife left. My adult children don’t visit.”
• “I lost custody of my daughter because of my hoarding.”
• “My family has completely abandoned me.”
• “My husband hurt himself while walking through the house…. He has no place to relax….”

**Services used and needed.** People with hoarding behaviors say that support groups, therapy, professional organizers, “clutter buddies,” and In-Home Supportive Services (IHSS) have helped them and are needed. Many also noted the value of MHA-SF’s annual Conference on Hoarding and Cluttering.

They also feel that legal services, training and education of all involved parties including people with hoarding behaviors, their family members, service providers, and landlords might be helpful in preventing eviction and homelessness among people who hoard. One person with hoarding behaviors noted a need for more services using the harm reduction model (which recognizes that people may not be able to fully stop a harmful behavior, but can mitigate its negative impact) for people who speak languages other than English, particularly Spanish. Several indicated the need for expanded treatment options, including better information about where to get treatment, more support groups, and more trained specialists. Several also noted the need for more investment in research into the causes and treatment of hoarding behaviors. Many expressed concern about the cost of hiring effective professional organizers—either the impact on their own finances or the need for low-cost organizers for those who cannot afford such services. Many also felt that print and media ads and education campaigns would be helpful to reach those who might benefit from services. Focus group participants also pointed to the need for assistance moving objects to appropriate recycling/disposal sites, and for information about resources such as cleaning services and financial resources for those who cannot afford such services. A free crisis line was also suggested.

**Financial costs to people with hoarding behaviors.** In addition to the social and emotional costs described above, people with hoarding and cluttering

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**Individuals with compulsive hoarding are asking for:**

- More support groups
- More therapy options and treatment groups
- More training for family members and service providers
behaviors incur substantial financial costs. The Task Force was unable to quantify these. They may include storage unit rental, cleaning services, and the services of professional organizers. Some people with hoarding behaviors also pay for repair costs themselves so as to avoid having a landlord or repairperson visit their units. Some noted that they experience challenges keeping up with bills because they lose them in their clutter, and that they find themselves buying things that they know they already have but cannot find. One survey respondent described how clutter impeded the ability to hold a job. This finding is consistent with other studies that indicate that people with hoarding behaviors lose more days from work and may be less productive at work than others.7

Ana’s Story

I’ve been battling hoarding and cluttering for the past five years, but it was not until two years ago that I realized I had a problem. Hoarding and cluttering is very disturbing and has changed my life drastically. It is very hard to not clutter up the house. I am always bringing things home that have no relevance to my life. I end up having too much in my house, even though I realize I don’t need more than one-third of what I already have.

Hoarding and cluttering affects all aspects of my life. My [grown] children constantly feel the effects of my hoarding. I can never have them over, and it makes me feel horrible that I can’t invite my children into my own home. They ask me for personal, cherished items and when I can’t find them, they assume I am hiding the items or just don’t want to give them away. It has caused some distance between me and my children, and that is something I am trying very hard to work on. My children are very important to me, and I will no longer allow my hoarding to come between us—they are the only ones I have left. I have no personal friends, just ones from the support groups. I am embarrassed by the chaos of my apartment and I do not allow people to come over. People think I am weird that I never allow them into my house and it strains relationships. I feel like I am a cheater in my relationships and I feel like I am missing something. I am very hard on myself.

As a hoarder, you go through a lot of feelings. Extreme self-criticism is a constant force in my life. I have a tendency to be too hard on myself; no matter what anyone else thinks, I beat myself up the most. I’ve been working really hard on not putting myself down and changing these negative behaviors that are harming my life. I am trying to reclaim myself, but this is a constant battle that requires a lot of my time and attention. I believe if I really concentrate on dealing with my behaviors I can make change, but it’s taken me almost three years to get where I am today and I still have a lot of work to do.

“Hoarding and cluttering affects all aspects of my life.”

“I believe if I really concentrate on dealing with my behaviors I can make change, but it’s taken me almost three years to get where I am today and I still have a lot of work to do.”

Based on an interview with Ana B. Gutierrez, MHA-SF hoarding and cluttering support group member.
Impact on Service Providers

The environmental scan survey and stakeholder interviews were used to determine the impact of hoarding and cluttering behaviors on service providers in San Francisco.

Organizations responding to the survey. A broad range of public and private organizations were represented, including drug treatment programs, legal services, healthcare providers, religious organizations, shelters, housing-related services, social services, and mental health service groups. Most deal with people who are low income (82% of survey respondents), have mental illnesses (82%), or are homeless (61%). That people with hoarding behaviors often interact with agencies that predominantly serve people with mental illness reflects findings from research literature, which suggests that those with hoarding behaviors often also struggle with anxiety disorders and other mental health conditions.8 The most common services offered were case management (63%), “other social services” (45%), housing assistance/support (41%), education/training for people with hoarding behaviors and their family members (40%), and mental health services (38%). On average, the responding agencies deal with 468 clients per month, although the monthly clientele ranged from six to 5,000. Fifteen respondents reported serving over 1,000 clients each month.

Clients with hoarding behaviors. Sixty-three survey respondents indicated that they currently have some clients with hoarding behaviors, with a mean of 13.9 such clients per agency. Ten agencies reported serving more than 25 clients with hoarding behaviors each month. Over the past year, 65 agencies (59% of respondents) worked with clients with hoarding behaviors, with a mean of 32.7 clients per agency. Most often, these clients are referred by other agencies (indicated by 56% of agencies) or self-referred (53%). Less frequently, they are referred by family and friends (37%) or neighbors (24%). Respondents indicated that about one-third of clients with hoarding behaviors (36%) are over age 60. Adult Protective Services notes that approximately 50% of its clients with hoarding behaviors are over 65. Clients with hoarding behaviors use a variety of types of services offered by the agencies. Most frequently mentioned were case management (72%), mental health services (63%), cleaning services (50%), meals and food (50%), and housing (48%).

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Financial costs to service providers associated with hoarding behaviors. When asked if it cost the agency more to provide services to individuals with hoarding behaviors than to other clients, 29% of respondents noted higher costs, ranging from $50 to $20,000 per client, with a mean of $3,191 per client. These additional costs resulted from additional time required to work with clients, extra hours of case management, additional pest control services, increased number of medication refills and medical supplies, and legal services. Data from the Department of Aging & Adult Services on the use of cleaning services by its clients from May 1, 2007 through April 30, 2008 indicated that in one year almost 2,400 extra hours of heavy cleaning services were authorized to In-Home Supportive Services (IHSS) clients for hoarding situations at a cost to the City of nearly $64,000. More recent data from the 12-month period October 2007 to September 2008 showed a cost of $58,000, suggesting that this is a fairly stable cost rate. Almost all of these clients had hoarding behaviors.

Respondents indicated that clients with hoarding behaviors are often more difficult to assist and more resistant to receiving help than other clients. One respondent commented that the agency has to spend more time finding employees willing to work with clients with compulsive hoarding and cluttering behaviors and has to pay more to retain them. Task Force member Tom Drohan, Staff Attorney with Legal Assistance to the Elderly, concurs that such cases often require additional hours, stating: “I could take one compulsive hoarding client and prevent that person’s eviction or I could take and settle 20 other clients’ cases in the same amount of time.” Several survey respondents asserted that while there were extra staff hours involved in working with clients with hoarding behaviors, it was very difficult to estimate the actual cost.

In order to derive a conservative estimate of hoarding-related costs, only the 15 providers that reported actual costs and indicated how many clients with hoarding behaviors they served per month during the last year were included in our calculations. These providers averaged eight clients with known hoarding behaviors in a given month and 26 unique clients with known hoarding behaviors over the last year. Based on cost per client data and the number of clients served, we estimate that these 15 agencies alone incurred an additional cost of $502,755 during the last year serving the needs of clients with hoarding behaviors, for an average of $33,517 per agency. Two providers incurred costs in excess of $100,000 last year related to clients with hoarding behaviors. The costs are based on a total of 394 clients described, but it is not known whether a given client received services from more than one provider.

“I could take one compulsive hoarding client and prevent that person’s eviction or I could take and settle 20 other clients’ cases in the same amount of time.”

- Tom Drohan, Staff Attorney, Legal Assistance to the Elderly
In estimating the cost of hoarding and cluttering behaviors in San Francisco, we asked service providers what services their clients used and how much more it cost to provide these services to clients with hoarding behaviors compared to other clients. We initially considered asking how many of their clients were receiving services as a result of compulsive hoarding and cluttering behavior. However, this proved nearly impossible to answer for those who pilot-tested our survey. Clients are often eligible for services due to age or income criteria, and the agency may not know whether the client also meets eligibility criteria as a result of a mental illness or disability. Agency staff may only learn that the client has hoarding behaviors after many months of providing services. It was not possible for agency respondents to indicate whether a client would not be using the service if she or he did not have hoarding behaviors. Thus, the estimates we have developed are very conservative in that they include only the additional costs of working with clients with hoarding behaviors compared to other clients. Even this approach was challenging, and several respondents indicated that they were unable to determine the additional costs. As noted above, some asserted that there was an additional cost, but not one that they could quantify.

**Coordination of services and quality of care.** Most respondents (67%) indicated that they work with other agencies to manage their clients with hoarding behaviors. Most frequently mentioned were behavioral health centers (72%) and the Department of Aging & Adult Services (72%). One-third of respondents (34%) said that there are rules, policies, or processes that limit their organizations’ ability to help these clients. These included attorney-client confidentiality, evictions that proceed too quickly to allow them to help the clients, client resistance and denial, piecemeal services, limited resources, and safety issues. Respondents indicated that the services most needed to address their clients’ problems were mental health services (mentioned by 57% and most often listed as the first priority) and case management (53%). Also mentioned by a number of respondents were education and training for staff (47%), cleaning services (39%), and education and training for people with hoarding behaviors and their family members (31%).

**Issues raised in stakeholder interviews.** Stakeholders noted how widespread and significant the problem of hoarding and cluttering is, calling it “fairly huge” and “massive.” As one interviewee explained, although the problem can be hidden, once one begins looking for or asking about hoarding behaviors, more cases become apparent. The Fire Department receives a call about a new hoarding case nearly once a week, and the Tenderloin Neighborhood Development Corporation (TNDC), a local non-profit housing provider serving approximately 2,500 low-income tenants in 1,800 apartments and residential hotel units, estimates that approximately 10% of their units have tenants with hoarding behaviors at a level where it is a significant
issue, and another 30% have tenants whose hoarding behaviors could become an issue. Respondents noted that the problem may be difficult to identify because people with hoarding behaviors are often reluctant to volunteer information about their condition.

Stakeholders said that hoarding is a major threat to people keeping their housing; limits individual choices; constrains people’s ability to cook, eat, sleep, bathe, or entertain in their homes; and creates health and safety risks. Families have difficulties in coping with the problems created by hoarding behaviors, and stigma is a significant issue. Property management companies and housing agencies experience financial losses due to legal fees, repairs, lost rent, and other causes. Many service providers experience frustration because the problem often seems intractable.

Stakeholder interviews identified many of the same needs as the environmental scan, and gave more texture to a number of concerns. The need for additional resources, either within their organizations or in the City more generally, was a common theme. These included the need for mental health resources, especially for people trained in cognitive behavioral approaches to treat compulsive hoarding; case managers to coordinate services; and resources specifically to help with cleaning out possessions. Several stakeholders indicated that their organization did not have clear guidelines about who should help with decluttering or clearing away items to prevent an eviction and noted that professional staff (such as attorneys or doctors) were sometimes spending time helping to clear out possessions, which may not be the most effective use of their skills. Several spoke to the need for more options for decluttering and clearing out (e.g., “clean-up crews”)—either within their own staff or from other agencies—and one noted the need for more trained declutterers who would be affordable for low-income people. One stakeholder noted a need for assisted living facilities that could address the social rehabilitation needs of individuals with hoarding behaviors.

Many stakeholders expressed the need for better coordination among agencies, indicating that some of the resource issues might be addressed through better coordination. Several stakeholders stated that they did not know what resources were available at other agencies, which other agencies were addressing this issue, or how other agencies were responding. The Fire Department in particular noted a desire to be part of a more coordinated interdisciplinary team. Similarly, there were a number of requests for a primary point of responsibility, a triage system, or some sort of case management that could coordinate the involvement of diverse agencies.

Stakeholders identified the importance of having consistent standards within and among agencies, as well as knowledge of best practices. One agency noted
that despite having a fair amount of experience responding to the issue, hoarding was always dealt with on a case-by-case basis, with no standard response or consensus about best practices among the staff. One said that it would be useful for all supportive housing agencies to have a list of all relevant housing code regulations as a clear guideline for clients with hoarding behaviors. Legal agencies emphasized the importance of ensuring that people know about the reasonable accommodation process, which can provide time to improve a situation, thereby preventing an eviction. Several agencies noted a need for more training for their staff on these matters.

One agency emphasized that early detection was important to addressing the issue effectively. Treatment on demand was identified as valuable, since timely intervention is crucial. The value of a chronic illness model, which includes patient empowerment to better self-care, coordination of ongoing care with other providers, and consistent follow-up and tracking, was noted. Ongoing intensive outreach with trained staff working in a harm reduction model (which recognizes that people may not be able to fully stop a harmful behavior, but can mitigate its negative impact) was also noted. In addition to ongoing treatment, on-site treatment—working with people in their homes—was identified as important.

### Impact on Landlords

**Housing sites.** The 80 landlords who completed the landlord survey represent a mix of large and small landlords, owning from 1 to 3,500 units. Thirty-seven respondents had only one or two units, while six had 50 or more. The mean number of tenants was 156. Twenty-five landlords indicated that they had 50 or more tenants. Almost half of the housing units represented were private (48%), but nine percent were subsidized or Section 8 housing. Most (78%) are covered by San Francisco’s Rent Control Ordinance.

**Impact of hoarding behaviors.** Thirty-seven landlords indicated that they currently have some tenants with hoarding behaviors, representing a total of 89 tenants. Most had one or two such tenants, but one indicated having 20 tenants with hoarding behaviors. Over the past five years, the respondents indicated identifying a total of 104 tenants with hoarding behaviors. Most of these tenants

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### Agencies identified services they most needed to address their clients’ hoarding behaviors:

- Mental health services
- Case management
- Training for staff
- Cleaning services
- Education for the clients and families about compulsive hoarding
live alone, in line with research from other areas. Most landlords (95%) learned of their tenants’ behaviors by visiting the units; 21% learned of the behaviors from other tenants.

Reported problems resulting from hoarding behaviors are shown on page 24. Included are pest infestations (48 incidents), the need for heavy cleaning (46 incidents), the need to involve animal control (16 incidents), and injuries (11 incidents). While most landlords had only a few tenants with these problems, one landlord indicated having 10 tenants with pest infestation problems, and one landlord had 10 tenants requiring heavy cleaning or hauling services. Landlords reported five fires and five evictions related to hoarding and cluttering. In four cases, landlords indicated a loss of rent while a housing unit was uninhabitable. All of these problems were reported as having happened within the last year.

**Financial costs to landlords associated with hoarding behaviors.** Costs were clearly difficult to estimate and only a small number of respondents were able to do so. Issues were often resolved without the landlord incurring any costs. However, this was not always the case. Costs mentioned included pest infestations ($50-1,499), animal control costs ($200-1,499), foregone rent ($1,000-3,999), eviction-related costs ($2,000-99,999), and heavy cleaning ($75-3,999). Several respondents indicated that tenants with hoarding behaviors do not report maintenance problems in a timely manner due to reluctance to have repairpersons in their apartments. This leads to higher repair costs when the problem is eventually reported. One landlord described structural damage to the floor joists and foundation due to the weight of books in a tenant’s unit. Non-quantifiable costs mentioned included dealing with odor issues and the difficulty of attracting other tenants due to unsightly clutter spilling into hallways and common areas.

There were a few reported cases of catastrophic losses. These events are extremely costly for those who experience them. One landlord indicated that eviction costs for one tenant were in excess of $50,000. Another reported fire-related costs exceeding $500,000. As serious as these incidents are for landlords, they also have significant impact on the tenants who are affected.

A conservative estimate of the cost of hoarding and cluttering to landlords was derived by simply adding up all the costs reported in our survey. Costs were reported in ranges (e.g., $2,000-2,499); to create an estimate, we used the lower end of each range (i.e., $2,000). The total comes to $665,350 during the past year. One very costly fire accounted for a substantial portion of this ($500,000). Given that the survey represents responses from only 80 landlords, this total greatly underestimates the total cost. The average cost across the survey respondents, excluding the $500,000 fire, is $2,047. Note that many of the incidents that were reported as having zero cost to the landlord may in fact have involved costs that

Many landlords sincerely want to help their tenants deal with their hoarding behaviors, but do not know where to turn.
were incurred by other parties. For example, landlords reported costs for fewer than half of the incidents in which heavy cleaning or hauling were required, but these costs may have been borne by the tenant, the Department of Aging & Adult Services, or another service provider.

**Managing tenants with hoarding behaviors.** Twenty-six landlords indicated that they have worked with various community services in connection with tenants with hoarding behaviors. Those mentioned most often were cleaning services (46%), health and safety code enforcement (35%), repairs and maintenance (35%), and pest control (27%). More than half of the survey respondents (55%) asserted that there are rules, policies, or processes that limit their ability to address hoarding and cluttering issues. Rent control or the Rent Board was mentioned most often in this context. Many landlords expressed frustration about the Rent Board’s sensitivity to tenant rights, stating that this sometimes precluded landlords from taking corrective actions that they deemed necessary. One landlord specifically mentioned calling the Fire Marshal in the hopes that an official citation would motivate a tenant to clean up the living space, only to be told that if a citation were issued and ignored by the tenant, the landlord would be responsible for complying. The landlord chose to ignore what was perceived to be

### Landlord Financial Costs

<table>
<thead>
<tr>
<th>Type of Cost</th>
<th>Number of Incidents</th>
<th>Range of Costs Reported</th>
<th>Total Cost Reported</th>
<th>Mean Cost per Incident with Cost</th>
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</thead>
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<tr>
<td></td>
<td>Total Reported</td>
<td>With Reported Cost</td>
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<td></td>
</tr>
<tr>
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<td>$100-$15,000</td>
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<td>52</td>
<td><strong>$663,350</strong></td>
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</table>
a fire safety issue. Landlords expressed great frustration with the system, and many indicated that they sincerely want to help their tenants deal with their hoarding issues but do not know where to turn. Several mentioned wanting someone else to be responsible for setting and enforcing rules regarding hoarding and cluttering behavior. Others mentioned the need for external guidance, such as a central/lead government agency or caseworker they could call. They indicated a need for services including education and training for people with hoarding behaviors and their family members, health and safety code enforcement, case management, education and training for staff, and mental health services.

In addition to the landlord survey, the Task Force also spoke directly with several landlords. David Gruber, apartment building owner and President of the San Francisco Rent Board, shared the following story about the challenges he faced in attempting to get help for a tenant whose hoarding behaviors came to light as the result of a plumbing problem:

I started five months ago with the Mayor’s Office and then proceeded to go through Adult Protective Services, the Fire Marshall, and the Bureau of Building Inspection—to see if I couldn’t get someone out there to address the issue without making it a legal issue. . . . Everybody’s been really nice with me. The problem is that no one can do anything.

Basically, it’s been told to me that unless legal action is started where there’s actually an eviction, then there’s not much that can be done. Adult Protective Services (APS) in this case has gone out. [The tenant] has told them to go away and will not let them in, or it has been determined by APS that this situation is not a priority. The Fire Marshall announced to us . . . “If he’s not letting me in, I’m not coming out.” And we asked the tenant, “Would you allow the Fire Marshall?” And he said no. . . .

I’m trying to get myself cited, [get] the building cited, because then I can get something we can advance on. . . . The bottom line is that I’ve got to start a legal action. And with the legal action, that’s when the other services can at least warn the person that they are in trouble. Now, whether they accept help at that point is another question. . . .

The problem in these cases—it’s a quality of life issue. He’s living in substandard and unhealthy conditions, but that also to me is not good in a 36-unit apartment building where I’m worried that it may affect the other tenants because of either infestation or life and safety issues. So that’s the tough part.

I’ve talked to no less than 15 people on this one over the last five
months and spent over $5,000 in legal fees . . . and the problem is that everybody’s had suggestions, but the final analysis is what I’m doing now. I just need to pursue this legal action.

Key Themes from the Data

A number of common threads—both concerns and recommendations—emerged from the responses of people with hoarding behaviors, the agencies that work with them, and landlords.

Inter-Agency Coordination: While this was primarily a priority of service providers, respondents in all groups noted a need to know which agencies to contact for help: where to enter the system and what resources are available—a services “roadmap.” A number of individuals and service providers specifically noted the need for teams able to respond to different aspects of the issue.

Mental Health Services: All groups expressed a need for more mental health services, with specific references being made to the need for more support groups, treatment groups, and more people trained in providing cognitive behavioral therapy tailored to people with hoarding behaviors. Many respondents noted the importance of investing in long-term, effective approaches rather than seeking quick fixes to hoarding situations.

Cleaning/Decluttering Services: Individuals and service providers indicated a need for more affordable in-home resources to help with cleaning, decluttering, and removal of objects. The need for declutterers or organizers who were specifically able to work with people with compulsive hoarding behaviors in a productive way was emphasized, as was the importance of ensuring that these resources were accessible to those with limited incomes.

Clear Standards: Having clear standards and guidelines about what constitutes a hazard that can lead to eviction under health and fire codes was noted by stakeholders in all groups as important for preventing eviction and ameliorating living situations.

Education and Support for Family Members: The need for education and support for family members was mentioned by people with hoarding behaviors, by service providers, and by landlords. This need is also indicated in the research literature.9

Training: Service providers indicated a need for training, and individuals with hoarding behaviors expressed a need to be able to work with people who understood their situation. Landlords also noted the importance of training.

Public Education: Expanded public education emerged as an approach of interest to many different stakeholders, since it might increase public understanding of people with hoarding behaviors, thereby reducing stigma, and reach people with hoarding and cluttering behaviors, their family members, friends, landlords, and service providers with information about relevant services.
My Story - Anonymous

I’ve been living with hoarding and cluttering my whole life; it has always been a part of me.

This is a behavior that has influenced many of my life experiences. Hoarding and cluttering takes a mundane task, such as taking out the recycling, and turns it into an impossible feat. Any small ripple becomes a tidal wave.

My apartment is so full of stuff I sometimes have to walk sideways through makeshift hallways. Much of my clutter is clean, recyclable goods but I find it difficult to dispose of them.

I have all of the intention to clean and accomplish goals but when something is out of sight, it’s out of mind. It is very easy to become distracted and move onto another task without completing the prior one.

I have always felt judged because of my possessions; I’ve been shamed my whole life. I want people to stop shaming us, because we are up to our eyebrows in shame. If I could clean everything up, I would. If I could just throw things out, I would do that too. I’ve been involved in hoarding and cluttering groups for many years and because of my involvement I am now able to acknowledge my condition and speak about it to other people. I’ve gained the strength to acknowledge that this is a life-inhibiting problem and to work on it, but it is a lifelong journey that requires understanding, and often assistance.

“I’ve gained the strength to acknowledge that this is a life-inhibiting problem and to work on it, but it is a lifelong journey that requires understanding, and often assistance.”

Based on an interview with a San Francisco resident struggling with hoarding behaviors who wished to remain anonymous.
Summary of Financial Cost Findings

Our surveys and interviews captured actual costs due to hoarding and cluttering behavior in San Francisco of over a million dollars a year ($1,166,105) incurred by a sample of service providers ($502,755) and landlords ($663,350). We were unable to estimate the financial costs incurred by people who have hoarding and cluttering behaviors. This estimate is only the tip of the iceberg. The $502,755 represents actual costs incurred by 110 service providers, only 25.1% of 439 service providers we surveyed. Thus, we estimate that costs to all service providers are at least $2.01 million annually. The $663,350 in reported costs to landlords represent one catastrophic incident that cost $500,000 and $163,350 in other costs borne by 80 landlords out of the 1,888 that we identified. Setting aside the catastrophic cost, if the remaining costs are generalized to the larger landlord population, we estimate non-catastrophic costs to landlords of approximately $3.92 million a year. Thus, overall costs to service providers and landlords in San Francisco can be estimated at $6.43 million ($2.01 million + $3.92 million + the single occurrence of the catastrophic cost of $500,000).

The costs we identified fall into two broad categories: those that are catastrophic and those that are more common but less costly. Catastrophic costs include fire and evictions. The 80 landlords who responded to the survey reported five fires related to tenants with hoarding behaviors. One fire cost the landlord over $1,000, and another cost over $500,000. Five landlords reported evicting tenants with hoarding behaviors, with reports of landlord costs ranging from $2,000 to $99,000. A respondent to the environmental scan survey also indicated that evictions cost between $25,000 and $100,000. Several consumer survey respondents mentioned the possibility of eviction. While fires and eviction are uncommon, they have the potential to be extremely costly. A recent study reported that 3.3% of people with hoarding behaviors had been evicted and another 9.4% had been threatened with eviction.\textsuperscript{10} Based on our estimate of the number of people with hoarding behaviors in San Francisco, this suggests 400-800 evictions and 1,200-2,400 people threatened with eviction each year.

A number of other expenses are incurred quite often, but are much less costly. These include pest control and heavy cleaning and hauling. Also reported frequently was the extra time needed to provide case management, medical care, and mental health services to clients with hoarding behaviors. While most of these costs range from $25 to $150 per hour, the totals can be quite large and the potential cost is substantial. It is important to recall that many agencies noted the need to spend extra time on such cases, but few were able to quantify the time and costs.

Community Costs in Context

Effective treatment programs for individuals with hoarding behaviors are often seen as costly to implement. Yet as the data above indicates, the cost of doing nothing can also be high—though the total cost is usually hidden, broken up among an array of stakeholders, or lost in an array of risks and negative impacts.

The human costs include health, quality of life, family relationships, and social networks—which are worth addressing for their own sake. The financial costs to individuals and communities include medical costs from falls, respiratory problems, and other health issues resulting from hoarding behaviors; damage to property, as from fire, pest infestation, deferred maintenance, and other hoarding-related hazards; the costs of hiring cleaners and organizers to try to prevent evictions; the legal costs of eviction processes or liability regarding safety/injury issues; relocation costs; the costs of multiple social service interventions, including those of the fire and police departments; lost wages; and other costs.

People with hoarding and cluttering behaviors may use a number of services, including healthcare services, behavioral health services, social services such as Adult Protective Services and case management, and legal services. Their behaviors may involve a number of public agencies in San Francisco, including the Department of Aging & Adult Services, the Environmental Health Section, the Department of Public Health, the housing authority, the Fire Department, the Police Department, animal control, legal aid, health clinics, behavioral health centers, and senior service agencies. They may also interact with private agencies, such as cleaning agencies, professional organizers, landlords, and medical and behavioral health programs. Use of these services result in significant costs being incurred, and have been broken down into several categories and described below.

Healthcare costs. Healthcare costs may include costs of prescription medications for addressing compulsive hoarding or co-occurring conditions, costs of cognitive behavioral therapy, and costs of other behavioral health services. Home care nurses may be impeded in conducting their scheduled visits, or may even be refused entrance to the home, potentially jeopardizing the health of person with hoarding behaviors. This can in turn exacerbate health conditions and increase subsequent costs of care.

Housing-related costs. In some cases, particularly when the housing situation of a person with hoarding behaviors is jeopardized, the services of professional organizers may be called for to try to prevent eviction. Clients may need storage services as part of the process of ensuring that they can remain in their homes. Higher than usual maintenance costs may be incurred. Heavy cleaning or hauling services may be required, and pest control may become necessary. In the case of an eviction or potential eviction, tenants’ rights attorneys may become involved.
Landlords may lose rent if a property remains uninhabited, and tenants may face relocation costs.

**Safety costs.** Hoarding behavior may result in serious safety concerns, such as risk of fire, risk of falls to occupants, and pest problems. The Fire Department may become involved if a fire hazard is identified or a fire occurs.

**Legal and police costs.** Police involvement may result from complaints filed by neighbors, family members, and others. If eviction proceedings occur, both the property owner and the tenant may incur legal costs. In the case of older individuals with hoarding behaviors, legal costs may be incurred if an individual’s capacity to make decisions or ability to live independently is questioned and guardianship is sought.

**Social service costs.** Costs to the social service system include the time of Adult Protective Services, social workers, case managers, and homemaker/chore services. Agencies may also pay a role in providing education and training for clients, their family members, and the staff who work with them. Clients may use crisis hotlines and peer support or self-help groups.

**Other costs.** Other costs may include animal rescue efforts and meals or food services. People struggling with compulsive hoarding may also miss work or be terminated from their jobs as a result of these behaviors.

### Community costs:

- Healthcare
- Housing
- Safety
- Legal and police
- Social services
- Other
Examples of Financial and Social Costs of Hoarding and Cluttering

The diagram on the following page shows four potential scenarios, each including a likely sequence of events, outcomes, and costs associated with the experience of “Chris,” a typical person who struggles with compulsive hoarding. In these scenarios, Chris has had hoarding and cluttering behaviors for some time. There is no room to walk in much of his apartment, which he rents. The fire exit is blocked and the stovetop and heater are piled with items. He no longer invites people over and rarely goes out. He is isolated and immobilized by panic and shame. He doesn’t know anything about hoarding and cluttering, does not apply this term to himself, and has never spoken with other people struggling with the condition.

In Scenario 1 (left column), Chris realizes that he needs help and moves through a process recommended by this report. The other three scenarios assume that his heater stops working, requiring entry by the building manager. In Scenario 2 (column second from the left), the building manager and Chris move through a process recommended by this report. In both Scenarios 3 and 4 (third and fourth columns from the left), the building manager, Chris, and the landlord move through processes similar to what is currently happening in San Francisco. In these scenarios, the landlord launches eviction proceedings. In Scenario 3, Chris complies with the landlord but does not receive any services beyond one-time cleaning assistance. In Scenario 4, Chris resists cleaning his apartment and is evicted.

The outcomes vary based on several factors—the community resources available to Chris, how knowledgeable the building manager or landlord is about compulsive hoarding and resources that are available, and the choices Chris makes at various stages. Text shown in bold represents services that will either be new or—in the case of support groups—significantly expanded if the recommendations of this report are implemented. Cost assumptions are based on: (1) average costs where such costs were reported in our data gathering; (2) estimates or actual costs obtained from relevant city agencies or nonprofit organizations; and (3) projected costs for new services as developed by relevant agencies.

**Scenario 1.** This scenario, shown in the left column, illustrates the benefits of early intervention and preventive services—reaching people with information and services before they experience significant health or housing problems. The majority of resources and services needed in this scenario are not yet in place, but are recommended in this report. In this scenario, Chris is exposed to public education and outreach activities and in this way learns about hoarding and cluttering and a phone number he can call for help. He realizes that “hoarding and
Examples of Financial and Social Costs of Hoarding and Cluttering*  

Stuff piles up for “Chris.” The fire exit is blocked and items are piled on the stovetop, causing a fire hazard. Chris becomes isolated. He feels panic, shame, and denial about his situation and doesn’t know what to do.

The apartment heater stops working due to heavy boxes stacked on it. To get it fixed, Chris calls the building manager. Before the manager comes, Chris cleans, but not enough to hide the clutter. The building manager enters and repairs the heater, but recognizes that there’s a larger problem with fire and safety hazards and is concerned about pest infestation.

The building manager attempts to reenter the unit to deal with the pest infestation, but Chris panics and denies entry to her.

The pest situation worsens, and the fire hazard continues.

The building manager attempts to reenter the unit to deal with the pest infestation, but Chris panics and denies entry to her.

The pest situation worsens, and the fire hazard continues.

The manager doesn’t know what to do about the fire hazard.

The landlord launches eviction proceedings.

Social services contact Chris and attempt to intervene. Chris receives legal assistance to secure reasonable accommodation.

The landlord pays for cleaning and pest control and loses rent.

The landlord pays for pest control.

The landlord pays for cleaning and pest control and loses rent.

COST TOTAL: $2,607 for one year of services

COST TOTAL: $4,316 for one year of services ($484 to landlord, $3,832 to social services)

COST TOTAL: $5,662 per occurrence ($1,484 to landlord, $4,178 to social services), high risk of repeat occurrence

COST TOTAL: $36,880 per occurrence ($26,480 to landlord, $10,400 to social services), high risk of repeat occurrence

*This example does not include animal hoarding, which requires assistance from additional agencies, such as Animal Care and Control.

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cluttering” may explain some of the challenges he is facing and decides to call. The **single point of entry** (with an estimated cost of $47 per contact) connects Chris with appropriate agencies and services. An **assessment team** (with an estimated cost of $880 per intervention) sends an Adult Protective Services (APS) worker and a trained peer responder (another consumer who is successfully managing his or her hoarding and cluttering behaviors) to meet with Chris in his home. The team helps determine what his needs are and what services he is ready and willing to access. The peer responder connects with Chris and earns his trust. As a result, Chris is willing to join a **support group** (at a cost of $430 per year). The support group helps Chris break through his isolation and slows his acquisition of new possessions. As Chris becomes more confident, he enrolls in a **treatment group** (at a cost of $1,250), developing even more skills and confidence in addressing hoarding behaviors. As a result of treatment, Chris clears the surfaces of the heater and stovetop and reduces the overall clutter, reducing the risk of fire and pest infestation. The cost for one year of services is $2,607. The cost for future years is approximately $430 per year, which is just the cost of continuing in a support group.

The remaining scenarios, which go from best case (left) to worst case (right), all begin with Chris discovering that his heater is broken as a result of clutter piled on top of it.

**Scenario 2.** Like many people with hoarding behaviors, Chris is reluctant to let people into his apartment and will do so only when absolutely necessary. But it is winter and Chris has health problems that make living in a cold apartment impossible, so he must call the landlord to have the heater repaired. He tries to clean before the visit, but is unable to hide the clutter. When the building manager arrives, he sees that there is a larger problem than just the heater (which costs the landlord about $200 to repair): there are fire hazards and signs of a possible pest infestation (which will cost on average $284 to address) as a result of the piles of newspapers and boxes around the apartment.

In this scenario, the building manager has learned about compulsive hoarding and cluttering through an education campaign led by the San Francisco Apartment Association. He accesses the **single point of entry** (at a cost of approximately $47 per contact) and is provided with **clear, written standards** about compliance with city health and safety guidelines and advice about how to present these to Chris to try to bring the apartment into compliance. If Chris also contacts the **single point of entry** ($47) for assistance, an array of resources is made available to him that will help keep him in his home and build his skills and capacity to prevent his hoarding and cluttering from reaching this level again. These include the services of the **assessment team** ($880). Chris can also secure **cleaning help** from In-Home Supportive Services (IHSS) (at a cost of approximately $1,178 per year).
based on IHSS averages) to address health and safety code violations. Through this process, Chris also joins a **support group** ($430 per year) and subsequently a **treatment group** ($1,250). Chris is able to stay in the apartment and continues to make progress in addressing his hoarding behaviors. In this scenario, the landlord bears approximately $484 in costs, and City and nonprofit organizations provide services to Chris and the building manager at a cost of approximately $3,832. The total costs in this scenario are $4,316.

**Scenario 3.** In this case, the building manager does not know what to do, and without resources available, incurs costs for repairs and pest control (estimated cost of $484) and also initiates eviction proceedings, incurring **initial legal costs** (approximately $1,000). Chris is contacted by social services (Adult Protective Services). The initial intervention involves approximately 30 hours of staff time ($1,200). He also obtains **legal assistance** ($1,000) and because his hoarding and cluttering constitutes a disability, is entitled to “reasonable accommodation” under the Americans with Disabilities Act, which gives him time to clean his apartment. In this scenario, Chris accepts further assistance from social services/APS (20 hours for a total of $800) and also accepts **heavy cleaning assistance** from IHSS ($1,178), preventing immediate eviction but doing nothing to empower Chris to change his acquiring and hoarding habits. He remains isolated and at high risk for a future occurrence. The total cost of this scenario ($5,662, $1,484 of which is borne by the landlord) could be incurred again in a matter of months. There are other costs that might be borne by Chris, if, for example, his health is adversely affected by the experience.

**Scenario 4.** Here, after initially securing legal assistance to fight the eviction, Chris resists receiving assistance and adequate services are not in place. Social service intervention attempts result in additional costs of $400 beyond those in Scenario 3, increasing these costs to $2,400. The legal assistance costs for trying to keep Chris from being evicted rise to approximately $8,000. Chris is **evicted**, at great personal and financial cost to him. The landlord’s **legal costs** rise ($22,750 on average). The landlord also incurs costs for cleaning the apartment ($996, based on average data from landlords) and lost rent ($2,250) while the apartment is not occupied. In this scenario, total costs to the landlord and city agencies or nonprofits that can be estimated from our data are $36,880, of which $26,480 are borne by the landlord. This does not include the costs that Chris incurs in relocating or potential costs to the City or nonprofit agencies if Chris becomes homeless. Because the eviction has not addressed the root cause of the problem, there is a potential for the problem to recur.

COST TOTAL: $5,662 per occurrence ($1,484 to landlord, $4,178 to social services), high risk of repeat occurrence

Scenario 3

COST TOTAL: $36,880 per occurrence ($26,480 to landlord, $10,400 to social services), high risk of repeat occurrence

Scenario 4
Michelle’s Story

Hoarding affects our relationships in so many ways. My hoarding contributed to a challenging relationship with my sister. She has almost a polar opposite relationship to possessions – with her, everything has to be just so. It was a real source of conflict between us. Finally, I asked her to come to the annual Mental Health Association of San Francisco Conference on Hoarding and Cluttering. Afterward, she changed the way she dealt with me, and our relationship has started to improve. Families need to come to the conference, and there needs to be support groups for family members.

Sometimes other people believe that we don’t mind clutter in general. But when I had a relationship with someone who was also dealing with hoarding and cluttering issues, I realized I couldn’t stand his stuff after a while. He had stuff I thought was useless. Bicycle parts, gears that smelled like oil. Don’t get me started! We can see it in other people, but it’s hard to see it in ourselves. We can clean up other people’s stuff with no problem, but we have such attachment to our own stuff.

I was fortunate to have been part of the first treatment group in San Francisco. It was incredibly useful – and in its own way, it came back to relationships. For my treatment project, I chose this huge desk that was my father’s. I didn’t realize until then that I had blocks about it. My father used to say, “Don’t touch my desk.” But I was able to clear off the top of the desk.

Ultimately, hoarding affects us deeply in our lives. Where we live is chaotic, and our lives are often chaotic. Yet I’ve learned that the more we unclutter, the more we can think clearly. As I’ve been involved in the Task Force and volunteered as a Health and Wellness Action Advocate (advocating for mental health services), I’ve been able to realize that I’m not just somebody with a problem—I can make a difference.

“[H]oarding affects us deeply in our lives.”

“I’ve been able to realize that I’m not just somebody with a problem—I can make a difference.”

Based on an interview with Michelle, a Task Force member, about her experiences dealing with compulsive hoarding.
Compulsive hoarding and cluttering is a serious and treatable behavior often related to other mental illnesses. It can take a huge toll on individuals, families, and communities. The Task Force’s findings indicate that in San Francisco there are likely thousands of people with hoarding behaviors that cause them to be socially and physically isolated, threaten their housing prospects, and make it difficult for them to function on a daily basis. Many of these people sincerely want to learn to address their hoarding and cluttering more effectively. A few service providers are already offering useful services to this group, but often feel frustrated with the lack of resources available to them and the challenges in coordinating with other providers. A number of landlords genuinely would like to be able to help their tenants with hoarding problems and do not want to evict them, but feel that their hands are tied and have no idea where to turn for help.

Against this backdrop, the Task Force calls on the City of San Francisco to take action that will help people with hoarding behaviors, facilitate the efforts of service providers, guide landlords, and reduce costs to all parties involved. In order to reduce the serious risks and negative impact of hoarding and cluttering and improve the quality of life of those with hoarding behaviors, the San Francisco Task Force on Compulsive Hoarding has identified the following priority recommendations:

1. **Develop an assessment/crisis team** to respond to referrals about hoarding cases and coordinate appropriate next steps to facilitate meaningful, long-term improvement for individuals.

2. **Increase access to treatment** for hoarding, including in the person’s home. Treatment can include therapists, organizers, coaches, and peers.

3. **Expand support groups** available locally, including peer support groups and groups for family members, and provide training for peer support facilitators. Build on the successes of support groups by offering groups for people at different stages of dealing with their hoarding behaviors, ranging from early awareness and those just starting out to those with substantial experience working on behavioral changes.

4. **Create a services roadmap** for people with hoarding behaviors and their families, service providers, and landlords so that people know what agencies to contact in different situations and have a way to identify and seek assistance. **Establish a single point of entry** into the system of supports and resources that uses a single form for referrals, follows the services roadmap, and engages the assessment team.
5. **Develop evaluation guidelines** for landlords that are coordinated with fire department and health regulations.

6. **Provide long-term case management services** as an extension of initial assessment and treatment.

7. **Offer training** for therapists, 211/311 staff, landlords, agency staff, and families; recruit and train trainers; and provide cross-training for identification/screening/assessment across agencies.

8. **Ensure overarching coordination** and evaluation of recommended priorities (hoarding and cluttering “czar”); track implementation of priorities and evaluate success.

### Implementation

Relevant city agencies and nonprofit organizations involved with the Task Force have developed preliminary proposals demonstrating how these recommendations could be implemented in San Francisco to create an effective system of care. These proposals are summarized briefly below. More detailed information is provided in Appendix H.

**Recommendation 1 – Assessment/Crisis Team:** The Task Force proposes creating a Hoarder Assessment/Engagement Team within Adult Protective Services. The core team would consist of an APS worker and a peer responder—a person with hoarding behaviors who has taken steps to address her or his hoarding and is in a position to assist others dealing with hoarding and cluttering. The peer responder would serve as a resource, building trust and helping to reduce the client’s anxiety. This core team would be dispatched to the home of an identified client with the goal of being admitted to interview the client and examine the premises. The team could arrange for assessment by a social worker from Community Behavioral Health Services (CBHS). Representatives from the Fire Department and the Department of Public Health Environmental Health Section (EHS) would also be available on a stand-by basis when needed, and could be contacted to visit the client if the team believed that this would be helpful. If the client refused assessment, the peer responder would seek permission to check in on a periodic basis, creating opportunities for the client to reconsider whether to meet with a social worker. In the pilot year, the program could work with 40 clients, at a cost of $35,200, which includes the APS worker salary and hourly costs for the peer responder. The program would be readily scalable based on the number of clients needing services.

**Recommendation 2 – Access to Treatment:** The Task Force proposes the creation of hoarding treatment groups, building on the success of the pilot treatment group organized in 2008. The 16-week treatment groups would serve up
We are not just lazy, messy people who don’t feel like throwing things away. A lot of us are bothered by it and are just in need of the tools and support to change this behavior.”

- Survey respondent with hoarding behaviors

Recommendation 3 – Expand Support Groups: The Task Force proposes expanding the array of available support groups at the Mental Health Association of San Francisco to include a support group for family members, support groups in Spanish and Cantonese, and a support group for people with hoarding behaviors who have completed a treatment group. These new groups would provide support to an additional 70 people with hoarding behaviors, bringing the total served to 150 a year plus 30 families.

Recommendation 4 – Create a Services Roadmap and Establish a Single Point of Entry: A proposed services roadmap has been created, and the Department of Aging & Adult Services Intake Screening Unit is proposed as the single point of entry to streamline services and enable people with hoarding behaviors, their families, service providers, and landlords to follow the services roadmap and access needed information and services. The Intake Screening Unit would consolidate IHSS, APS, and referral services for a single entry comprehensive community information and intake service. The unit would provide referrals and information for people with hoarding behaviors to help support their current level of independence and functioning. The intake unit would be knowledgeable in all community and institutional services for seniors and adults with disabilities, regardless of their economic status. Screening and referrals would be taken for IHSS, home delivered meals, community living fund assistance, and protective services. Other screening needs not met by the Department would be referred to appropriate community or institutional resources. To implement this, an additional FTE of staffing would need to be added, at a total cost of $116,778 per year. Training would need to be coordinated for 211 and 311 responders. (See the recommendation regarding training below.) Informing the general public and key audiences such as landlords and service providers about the roadmap and single point of entry would also be essential.
San Francisco Hoarding and Cluttering Services Roadmap

City Outreach Agencies
Outreach Home Team
Police
Case Manager

Concerned Community Members
Family Members
Neighbor
Medical Professional

Road to Services
Department of Aging & Adult Services (DAAS)
Intake Line (415) 355-6700

Legal Services
Eviction Prevention

Mental Health / Case Management
Therapists
Support Groups
Mobile Crisis
Mental Health Association of San Francisco

Abuse Prevention / Adult Protective Services (APS)
Assessment
Resource Referrals
Emergency Resources

Concerned Community Members

In-Home Supportive Services (IHSS)
(if eligible)
Caregiving/Cleaning
Ongoing Support

Police Department
Building Inspection

DPH
Fire Department
Department of Public Health

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Recommendation 5 – Develop Evaluation Guidelines for Landlords:
The Task Force proposes that the Department of Public Health Environmental Health Section (EHS) develop and disseminate “Health and Fire Code Compliance Guidelines for Property Managers and Tenants.” EHS and other Task Force partners will explore developing trainings for landlords on using these guidelines (see training recommendation below) and will determine the best methods for distributing these guidelines to landlords. The development of the guidelines is not expected in itself to incur any additional costs.

Recommendation 6 – Provide Long-Term Case Management:
The Task Force proposes that the Department of Public Health Community Behavioral Health Services (CBHS) hire two clinical social workers to provide intensive case management to a total of 35-45 clients per year at a cost of $200,000 per year. One social worker would work with the Hoarder Assessment/Engagement Team on initial assessments, and would take approximately 15-20 of these clients into intensive case management for an estimated period of one year. The social worker could be assisted by the peer responder.

The second social worker would provide therapeutic case management and supportive services to clients in their homes, after the clients had completed a period of attending a support group. The social worker would also coordinate services with a peer worker or volunteer in the community to reinforce and support the client in maintaining progress. This social worker would have a caseload of no more than 20-25 clients annually.

Recommendation 7 – Offer Training for Therapists, 211/311 Staff, Landlords, Agency Staff, and Families:
The Task Force proposes the expansion of current hoarding training programming and the development of additional educational materials on compulsive hoarding. The expanded training coordinated through a centralized training institute would fill the need for ongoing trainings for 211/311 personnel, other local service providers, family members, and landlords.

Specific trainings proposed include:

1. **Training for mental health providers:** To fill the significant need for mental health providers able to offer effective treatment for compulsive hoarding and cluttering, a one-time behavior therapy institute training with the Obsessive Compulsive Foundation is proposed to provide training to 100 local mental health providers, at a cost of $33,600.

2. **Training for landlords:** Recognizing a high need for information and training for landlords, the San Francisco Apartment Association is also exploring developing a training to assist landlords in addressing compulsive hoarding, with an estimated cost of $10,000 annually.
All of these training programs should incorporate peer trainers who have personal experience with hoarding and cluttering.

The estimated budget, including a training director, consultants, space rental, and materials, is $278,600 annually. Of this, $100,000 is currently funded by the City and County of San Francisco in a grant to MHA-SF. Thus, $178,600 in new costs are proposed.

**Recommendation 8 – Hoarding and Cluttering “Czar”:** The Task Force recommends the creation of an oversight position to coordinate the spectrum of programs addressing compulsive hoarding and cluttering; evaluate their effectiveness; and ensure that resources and services are accessible and known throughout the community. The Hoarding and Cluttering Czar would ensure service linkages among agencies providing compulsive hoarding services, convene and coordinate activities of the Task Force, track the implementation of the Task Force’s recommendations, and evaluate their success. This function was identified as key to ensuring continued coordination among Task Force members and various community stakeholders and service providers affected by compulsive hoarding and to ensuring the effective implementation of the Task Force’s recommendations.

This position would cost $100,000 per year. Most of this cost is already part of existing funding through DAAS to the Mental Health Association of San Francisco, so this proposal does not involve additional new costs.
## Summary of Recommendations, Proposed Programs, and Cost Estimates

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Cost (Year 1)</th>
<th>Numbers to be Served (if known)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Develop an assessment team/crisis team</strong>&lt;br&gt;Proposed program: Hoarder Assessment/Engagement Team</td>
<td>$35,200</td>
<td>40 clients</td>
</tr>
<tr>
<td><strong>2. Increase access to treatment</strong>&lt;br&gt;Proposed program: Offer 16-week treatment groups</td>
<td>$75,000 (of which $15,000 to come from current agency resources)</td>
<td>60 clients</td>
</tr>
<tr>
<td><strong>3. Expand support groups</strong>&lt;br&gt;Proposed program: Create new support groups to meet diverse needs</td>
<td>$77,320 (of which $20,000 is part of current agency services and resources)</td>
<td>Approximately 150 people with hoarding behaviors and 30 families</td>
</tr>
<tr>
<td><strong>4. Create a services roadmap and establish a single point of entry</strong></td>
<td>$116,778</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>5. Develop evaluation guidelines for landlords and tenants</strong></td>
<td>None</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>6. Provide long-term case management services</strong>&lt;br&gt;Proposed program: Engage clients in intensive case management</td>
<td>$200,000</td>
<td>35-45 clients</td>
</tr>
<tr>
<td><strong>7. Offer training</strong>&lt;br&gt;Proposed program: Create a training institute for local 211/311 responders, service providers, family members, landlords, others</td>
<td>$278,600 (of which $100,000 to come from current agency resources)</td>
<td>1,000 service providers, 100 family members, and 120-200 landlords</td>
</tr>
<tr>
<td><strong>8. Ensure overarching coordination</strong>&lt;br&gt;Proposed program: Create a “Hoarding Czar” responsible for evaluation, coordination, and increasing public awareness</td>
<td>$100,000 (to come from current agency resources)</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Conclusion

The San Francisco Task Force on Compulsive Hoarding has broken new ground in its effort to assess the impact of hoarding and cluttering in our community. It has identified heavy costs to individuals who suffer with hoarding behaviors—especially eviction and the threat of eviction—as well as to their landlords and the many human services and health and safety agencies that become involved in hoarding cases.

While existing programs have been building knowledge and capacity to address compulsive hoarding, the system as a whole is not sufficiently addressing the root causes of compulsive hoarding. As a result, we are more often responding to crises than preventing needless suffering and costs through early intervention.

The Task Force has proposed an array of integrated solutions designed to address this multifaceted problem. Greater coordination, new resources, and a clearer sense of how to navigate available services will help move the City of San Francisco beyond the sometimes overwhelming challenge of simply responding to the symptoms of compulsive hoarding—only to see problems repeat themselves.

This report offers hope that early intervention, proven treatment approaches, training, and coordination across agencies will reduce costs while improving the quality of life for individuals with hoarding behaviors.
APPENDICES

APPENDIX A. REVIEW OF THE RESEARCH LITERATURE ON HOARDING AND CLUTTERING

Defining the Problem and Understanding its Impact on Individuals

Focused research on hoarding behaviors and their impact has only been undertaken in recent decades and remains somewhat limited. Hoarding and cluttering has been identified as a treatable behavior often related to several mental health issues and not, for example, a reaction to a background of material deprivation. Nevertheless, the medical and psychiatric research literature reveals challenges in clearly defining “hoarding and cluttering” and determining its relationship to other diagnoses. Hoarding behaviors have been observed for many years, and while the term “compulsive hoarding” is widely used now, such behaviors have also been termed “Diogenes Syndrome,” “squalor,” and “self-neglect.” The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)—the handbook that categorizes mental health disorders and their diagnostic criteria—categorizes it under obsessive-compulsive personality disorder (OCPD), although research on the relationship between hoarding and OCPD is inconclusive and new recommendations for the classification of compulsive hoarding are likely for the 2012 edition of the manual. Most researchers and clinicians consider hoarding and cluttering behaviors a symptom of obsessive-compulsive disorder (OCD), which is an anxiety disorder. It is commonly considered to be one of the five significant sub-types of OCD.

Given these challenges, the Task Force adopted the following definition of compulsive hoarding, based on the widely accepted work of Frost and Gross, and subsequently Frost and Hartl:

The acquisition of and failure to discard possessions that appear to be useless or of limited value, accompanied by living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed and significant distress or impairment in functioning caused by the hoarding.\(^\text{12}\)

\(^{11}\) The Task Force is particularly indebted to Monika Eckfield, RN PhD Candidate, University of California, San Francisco School of Nursing, who shared this literature review from her doctoral thesis.

Hoarding behaviors can pose significant risks to sufferers and those who live with them. As hoarded possessions overtake surfaces and rooms, people may have increasing difficulty moving around their homes, be unable to use furniture, be unable to manage self-care tasks such as storing and preparing food (when refrigerators, stovetops, or ovens become blocked) and attending to personal hygiene (when bathtubs or sinks are used as storage for objects), and may have difficulty in exiting the home in an emergency due to blockage of doors and windows. Clutter increases the risk of injury from slipping and falling. Risk of fire, pest infestation, and respiratory problems may increase, and unsanitary conditions may result. In earthquake-prone areas like San Francisco, the danger of piled clutter falling on people is an additional hazard.

The social impacts are also significant. Family relationships are often strained. Marriages have broken up, and parents have lost custody of their children. Sufferers are often unwilling to have others visit their homes. This can inhibit their ability to maintain social networks, reinforce a tendency toward isolation, and make it difficult for repairpersons or staff from social service agencies to address problems in the home.

Hoarding often comes to public attention in cases when individuals are evicted or in danger of eviction because of violation of the fire code, pests, or other hygiene and safety problems noted by landlords—situations that can be devastating to those affected and costly both to them and to the community.

Prevalence

In the absence of a formal epidemiological study of hoarding, actual incidence and prevalence are not known, but based on a review of estimates and geographically-limited samples, we believe that it is reasonable to assume that 2-4% of the population, or 6-12 million adults nationally, are subject to hoarding behaviors.13

Evidence shows hoarding behaviors occurring in a wide range of ethnic and socio-economic groups. Some research has suggested that prevalence increases

Personal communication, Steketee, G. to Eckfield, M., 11/1/05.
with age,\textsuperscript{14} and age can certainly make it harder for people with hoarding behaviors to manage and remove clutter even when they wish to do so. Research on the role of gender has had mixed results, with some studies showing a higher prevalence in women and some showing a higher prevalence in men. One of the more consistent features identified is that individuals with hoarding behaviors are more likely than others to live alone.

**Causes, Symptoms, Risk Factors, and Co-occurring Mental Health Conditions**

Multiple potential causes and exacerbating factors can be identified, including increasing age, physical disability, and major life changes, as well as a range of mental illnesses.

The most obvious major symptoms include urges to save items, excessive acquisition of items, and difficulty discarding items. In addition, those with hoarding behaviors may also struggle with difficulties in categorizing, indecision, actual or perceived alteration in memory, and difficulties with concentration and focusing their attention.\textsuperscript{15} Challenges with categorization may affect the way a person organizes possessions. Problems with indecision, concentration, and focus might manifest themselves as barriers to making decisions about organizing possessions, discarding items, or avoiding acquiring new objects. While research addressing the issue of memory differences show mixed outcomes, a study by Hartl et al. in 2004 that compared a group with hoarding behaviors to a control group noted that participants from the hoarding group reported less confidence in their memory than the control group, and reported greater consequences of forgetting,\textsuperscript{16} and that those in the hoarding group also felt more strongly about keeping possessions where they could see them as reminders. A study by Grisham


et al. in 2007 found that those in a hoarding group performed worse on a test of spatial attention and working memory than both a non-hoarding clinical group and a control group.17

Emotional attachment issues, perfectionism, and procrastination or behavioral avoidance, and a strong sense of responsibility about objects are personality characteristics associated with hoarding. Attachment to objects or a sense of responsibility for how objects will be disposed of can exacerbate the difficulty of making decisions to let go of objects, while perfectionism can contribute to fear of making the wrong decision about whether to keep or discard an item. Procrastination can manifest as putting off decision-making about discarding or letting go of possessions, cleaning, organizing, etc.

Several brain studies suggest that there may be a biological basis for some of the spatial, information processing, decision-making, attention, and attachment components of hoarding.18 Other research has noted a likelihood of multiple family members with hoarding behaviors, which may signal a genetic component, and specific genetic abnormalities have been identified.19

Compulsive hoarding’s relationship to other co-occurring mental health conditions is not yet widely understood, but co-occurrence with a number of other conditions has been noted. In addition to obsessive-compulsive disorder (OCD), hoarding behaviors often occur with other anxiety disorders such as generalized anxiety disorder (GAD), social phobia, and post-traumatic stress disorder (PTSD). Studies have also shown a possible link between hoarding behaviors and dementia, schizophrenia, and depression. A small but growing body of research links compulsive hoarding with attention deficit hyperactivity disorder (ADHD). Monika Eckfield, a nurse researching hoarding behaviors and a member of the San Francisco Task Force, has noted a strong overlap between findings in the research on self-neglect among elders and research on older adults with hoarding behaviors, although not all cases of self-neglect involve hoarding and not all cases of hoarding result in self-neglect.


Researchers continue to debate whether hoarding behaviors are symptomatic of other underlying mental health issues, or whether compulsive hoarding constitutes a separate, independently occurring syndrome. The relationship of hoarding to other conditions is important for several reasons. Links to other conditions might point to new treatment approaches. The co-occurrence of hoarding and another condition may have implications for the treatment of both—for example, depression may make it harder to discard items, and being overwhelmed by possessions may reinforce depression. The co-occurrence of hoarding and other conditions may require greater coordination among diverse agencies to respond effectively, and may also point to a need for mental health personnel dealing with other relevant conditions to be aware of and attentive to potential symptoms of hoarding.

Treatment Approaches

One of the challenges noted in the therapeutic literature is that people with compulsive hoarding behaviors often refuse treatment and sometimes do not acknowledge that they have a problem. Demands on the part of family members, friends, service providers, and others that they change or that they get rid of their possessions can exacerbate conflict and resistance. People struggling with compulsive hoarding may experience ambivalence about making change: while they may see some of the negative effects of their behavior and feel intense shame about their situation, they may not be willing to part with their accumulated belongings. Finding the best way to help and support people who do not want treatment but who may be placing themselves and others at risk requires a complex negotiation of social and individual rights.

Just as there are people who are reluctant to seek treatment, there are also many people struggling with hoarding behaviors who do want help—and because compulsive hoarding is frequently a hidden problem and often not well understood, they can find themselves facing an uphill battle in seeking appropriate mental health and social services supports. Indeed, they may not realize that what they are experiencing is not a unique, personal failing, but a diagnosable and treatable problem shared by others.

A report by the University of Kansas School of Social Welfare Office of Aging and Long Term Care indicates numerous barriers to effective systems of care, including:

- The scarcity of clinicians trained to provide effective cognitive behavioral therapy (CBT) approaches (as described in more detail below).
- The time-intensiveness of effective CBT approaches, which can make them quite expensive.


- Lack of understanding on the part of the court system, which can result in legal action that is counterproductive to the efforts of other agencies working to address the situation.

- Lack of adequate funding and procedures to support inter-agency collaboration in providing multi-disciplinary team responses, which have been identified as effective.20

Until recently, traditional treatment strategies have not shown significant effectiveness. Treatment with medication has had limited success — although people with hoarding behaviors and other co-occurring mental health issues may of course benefit from appropriate medication for co-occurring conditions. Traditional cognitive behavioral therapy (CBT), and traditional CBT plus medications have similarly shown limited results.

A new CBT approach has been developed by Drs. Randy O. Frost and Gail Steketee specifically for compulsive hoarding and cluttering and is showing greater promise. It includes:

- Education
- Motivational interviewing—a behavioral health strategy to help people deal with ambivalence, recognize problems, self-motivate for change, make a plan, and take immediate steps to be effective in their new intentions
- Treatment for organization problems—including helping people to reduce the number of categories and locations for saved items, and categories for unwanted items
- Training in decision-making
- Exposure to non-acquiring and discarding—for example, “non-shopping” trips and practice discarding items
- Cognitive restructuring—a widely-used therapeutic process of recognizing, challenging, and ultimately changing patterns of faulty thinking

This is the treatment approach that MHA-SF and Family Services Agency used in their partnership to provide a treatment group locally.

Many researchers specifically caution against simply cleaning out, organizing, or discarding a hoarder’s possessions without consent except in life-threatening situations. While such action may seem like a direct solution to the problem of having too much stuff, it only addresses the symptom rather than engaging the core decision-making problems that support the hoarding behaviors and can be very traumatic for the person with hoarding behaviors. Instead, researchers strongly recommend that the person with hoarding behaviors be directly involved in and

supported in making decisions to let possessions go.

Approaches that deal with compulsive hoarding through a chronic illness management model—which addresses client self-care, coordination within systems of care, and consistent follow-up—or a harm reduction model—which focuses on managing and mitigating the negative impact rather than eradicating the hoarding behavior entirely—show promise as both respectful and effective ways of helping individuals with hoarding behaviors to improve their lives. Treatment using these approaches is not a “cure” or one-time fix, but must be continued over time.

Animal Hoarding

The Task Force has also, although less comprehensively, addressed the related but distinct issue of “animal hoarding,” which Gary Patronek, VMD, PhD defines as the accumulation of such a large number of animals that the person is unable to provide minimal standards of nutrition, sanitation, and veterinary care for them all. Animal hoarding tends to be accompanied by a failure to act on the deteriorating condition of the animals, the environment, and the person’s own health and well-being. Research on animal hoarding is limited. Animal hoarding poses serious threats to the well-being of both the humans and the animals in the household. The Hoarding of Animals Research Consortium (HARC) in Massachusetts has noted that effective solutions in animal hoarding situations are often interdisciplinary, involving coordination of a range of agencies dedicated to animal, human, legal, and health concerns.

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APPENDIX B. DEFINITIONS AND ACRONYMS

APS   Adult Protective Services, a program of the San Francisco Human Services Agency. APS provides protective services to elders and dependent adults who are unable to protect their own interests and to care for themselves.

Animal hoarding   The accumulation of such a large number of animals that the person is unable to provide minimal standards of nutrition, sanitation, and veterinary care for them.

Attention Deficit Hyperactivity Disorder (ADHD)   Usually considered a neurobehavioral developmental disorder, characterized by impulsiveness and inattention, with or without hyperactivity.

CBHS   Community Behavioral Health Services, a component of the San Francisco Department of Public Health that offers counseling and other behavioral health services to eligible San Francisco residents through a network of behavioral health programs, clinics, and private psychiatrists, psychologists, and therapists.

Chronic illness model   Developed in contrast to the model that physicians use to treat acute conditions, a chronic care model includes empowering patients to better self-care, clarifying and coordinating ongoing care within the larger system of care, using decision-support tools that assist in providing recommended care, ensuring that follow-up and tracking are part of standard procedures, and working to mobilize community resources to meet the needs of patients.

Cognitive Behavioral Therapy (CBT)   A psychotherapeutic approach that seeks to address maladaptive or distorted thinking patterns that underlie unhealthy moods and behaviors.

Compulsive hoarding and cluttering   The acquisition of and failure to discard possessions that appear to be useless or of limited value, accompanied by living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed and significant distress or impairment in functioning caused by the hoarding.

DAAS   San Francisco Department of Aging & Adult Services, which plans, coordinates, provides, and advocates for community-based services for older adults and adults with disabilities in the City and County of San Francisco.

Dementia   Not a specific disease, but a term for the loss of mental skills that may affect memory and the ability to do everyday tasks and that may be caused by a number of treatable and non-treatable changes in the brain.

EHS   Environmental Health Section of the San Francisco Department of Public Health, which strives to promote health and quality of life in San Francisco by ensuring healthy living and working conditions in the City and County.

FSA   Family Service Agency, the oldest nonsectarian, nonprofit charitable social services provider in San Francisco, offering comprehensive programs to help change the lives of vulnerable families and individuals, particularly disadvantaged children, at-risk teens, dependent and isolated seniors, and the mentally ill.

Harm reduction   A public health approach that emphasizes strategies for addressing the negative consequences of a risky or potentially harmful behavior, recognizing that people may not be able to stop the behavior completely but can reduce its harmful effects.
**Hoarding behaviors**  A term used to describe the behaviors of excessive acquisition of and/or inability to discard possessions in compulsive hoarding and cluttering.

**IHSS**  In-Home Supportive Services is a statewide publicly funded program providing personal assistance services to low-income people with chronic and disabling conditions who need such assistance to remain safe in their homes and engaged in their communities.

**In-Home Supportive Services Consortium**  In-Home Supportive Services Consortium is a non-profit agency formed in 1985 to provide homecare throughout San Francisco to at-risk older and disabled adults. The IHSS Consortium’s approach combines homecare provision, extensive home care provider supervision and trainings and community-based care coordination.

**MHA-SF**  The Mental Health Association of San Francisco, a nonprofit citizens’ organization dedicated to improving the mental health of residents in the diverse communities of San Francisco through advocacy, education, research and service.

**Obsessive-Compulsive Disorder (OCD)**  An anxiety disorder in which sufferers are plagued by recurrent, unwanted thoughts and feel driven to perform repetitive behaviors; distinct from obsessive-compulsive personality disorder.

**Obsessive-Compulsive Personality Disorder (OCPD)**  A condition in which a person is preoccupied with perfectionism, rules, orderliness, and control; distinct from obsessive-compulsive disorder.

**Post-Traumatic Stress Disorder (PTSD)**  An anxiety disorder that can develop after exposure to a terrifying event in which serious physical harm took place or was threatened.

**Reasonable accommodation**  A reasonable change in the way a housing situation is customarily handled that would enable a qualified individual with a disability to remain in housing. To be deemed “reasonable,” the requested accommodation cannot impose a fundamental alteration in the landlord-tenant relationship, nor can it impose undue financial or administrative burdens.

**Rent Board**  The San Francisco Residential Rent Stabilization and Arbitration Board implements the San Francisco Rent Ordinance, and was created “in order to safeguard tenants from excessive rent increases and, at the same time, to assure landlords fair and adequate rents consistent with Federal Anti-Inflation Guidelines.”

**SFAA**  San Francisco Apartment Association, a nonprofit organization that keeps San Francisco housing owners informed about their rights and responsibilities as rental property owners.

**Self-neglect**  A behavioral condition in which an adult lives in a way that puts her or his health, safety, or well-being at risk through failure to provide needed self-care.

**Social Phobia**  An anxiety disorder characterized by excessive anxiety and self-consciousness in ordinary social situations, with a fear of being watched and judged by others that may be severe enough to interfere with everyday life; also called social anxiety disorder.
APPENDIX C. KEY STAKEHOLDERS INTERVIEWED

Dirk Beszia
Regional Manager
John Stewart Company

Pam Cohen
Staff Attorney
Protection and Advocacy Inc.

Joyce Crum
Director
Human Services Agency

Kelly Dunn
Psych Liaison
San Francisco Police Department

Barbara Garcia
Deputy Director
San Francisco Department of Public Health

Anne Hinton
Executive Director
San Francisco Department of Aging & Adult Services

Bill Hirsh
Executive Director
AIDS Legal Referral Panel

Seth Katzman
Director of Supportive Housing
Conard House, Inc.

Priscilla Marquis
Psychologist
Kaiser Permanente

Yvonne Mere
Deputy City Attorney
San Francisco City Attorney’s Office

Aaron Peskin
President
2008 Board of Supervisors

Delene Rankin
Social Work Unit Manager
Tenderloin Neighborhood Development Corporation

Kim Schoen
Central City Older Adults Clinic

Pam Swedlow
Housing and Urban Health Clinic

Niels Tangherlini
Captain
San Francisco Fire Department

Victoria Tedder
Housing Coordinator
Independent Living Resource Center – San Francisco
APPENDIX D. DATA COLLECTION INSTRUMENTS

Mental Health Association of San Francisco
870 Market Street, Suite 928, San Francisco, CA 94102
Phone: (415) 421-2926, Fax: (415) 421-2928, www.mha-sf.org

Hoardung and Cluttering Survey
The San Francisco Task Force is a group of providers, city representatives, and consumers working to find solutions to eviction and homelessness in San Francisco. We want to hear from you! This survey is for those who have personal experience (as a consumer) with hoarding and cluttering. Thank you!

1. Do you have a problem with hoarding and cluttering?
   Yes               No

2. How do you rate the severity of your hoarding and cluttering on a 1 – 7 scale in which 1 is very mild and 7 is very severe?
   1     2     3     4     5     6     7

3. How does hoarding and cluttering affect you? What are some of the ways hoarding and cluttering affects with your social, physical, mental and/or personal life?
  __________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________

4. How does hoarding and cluttering affect your family?
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________

5. What services or resources would you like to see available for hoarding and cluttering?
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________

6. What type of support or services do you need or think are needed to prevent eviction and homelessness due to compulsive hoarding?
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
   ________________________________________________________________________________________________
7. What services do you know that are working well for compulsive hoarding and cluttering?

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

8. Who have you called to seek help from? Who has helped you? Who has not?

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

9. What do you think are the best ways to reach people who are dealing with hoarding and cluttering but may not be seeking support or services?

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

10. What do you want others in our community to understand about hoarding and cluttering?

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

11. Other things we should know?

__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

The Task Force is interested in learning more about your experience with hoarding and cluttering. Can we contact you for your ideas and recommendations? YES NO

Name: _________________________________Address: _______________________________

Phone Number: (_____) _______________________________Email: __________________________

If you would like to contact us directly to share your ideas and recommendation, please contact Frank Isidro at 415-421-2926 ext. 306. THANK YOU!

Please turn in this survey by the end of the conference and you will be entered into a $20 Safeway gift card drawing. Complete your name and address or phone number to be entered in the drawing. Winner will be contacted after the conference. Or mail to MHA-SF, 870 Market, Suite 928, San Francisco, CA 94102
1. How does hoarding and cluttering affect your family?

2. What is needed to effectively assist people who compulsively hoard in order to reduce the clutter in their homes? Think big. No idea is too big. (What programs, what services, what resources, what supports?)

3. What type of support or services do you need or think are needed to prevent eviction and homelessness due to compulsive hoarding?

4. What services do you know that are working well for compulsive hoarding and cluttering?
5. Who have you called to seek help from? Who has helped you? Who has not?

6. What do you think are the best ways to reach people who are dealing with hoarding and cluttering but may not be seeking support or services?

7. What are some ways hoarding and cluttering affects with your social, physical, mental and/or personal life?

8. Other things we should know?
Dear Community Organization:

The San Francisco Department of Aging and Adult Services and the Mental Health Association of San Francisco have assembled a City Task Force on Compulsive Hoarding to address hoarding and cluttering behaviors in our community.

Compulsive hoarding is a behavior where individuals acquire and have difficulty discarding possessions which appear to be useless or have limited value. These behaviors can lead to safety hazards, including an increased risk of injury from falls, pest infestations, fires, eviction, and homelessness. The goal of this Task Force is to understand the scope of the issue and to make recommendations about how to improve services and reduce costs.

The purpose of this questionnaire is to find out whether you are seeing clients with hoarding behaviors, what sorts of services, programs or referrals you offer those with hoarding behaviors, the costs of serving these clients, and what you think needs to be done to improve our community’s services for these individuals.

If you would like to reach the Task Force to share additional ideas or volunteer your time or services, please contact the Mental Health Association of San Francisco at 415-421-2926 x306 or hoarding@mha-sf.org. Thank you for contributing your ideas to this effort.

A few notes about this survey:

1. The survey should take about 15 minutes to complete.

2. No identifying information about you or your clients will be reported. We will report findings only in aggregate form.

3. Each agency should complete only one survey. If there are various departments that have information needed to complete the survey, the information should be aggregated in a single survey response.

4. To complete this online survey, your browser must not have cookies disabled (In Internet Explorer, you’ll find this under Tools/Internet Options/Privacy. In Mozilla Firefox, you’ll find this under Tools/Options/Privacy.)

5. You do not need to complete the survey in one session. You may return at any time to add to or edit your survey responses. To do this, however, you must access the survey from the computer at which you started the survey and you must not have cleared the SurveyMonkey cookie from that computer.

6. So as not to lose data you’ve entered, use the Previous and Next buttons at the bottom of the screen rather than the Back and Forward buttons on your web browser.

7. To encourage your participation, all survey responders will be entered into a lottery to win one $100 gift certificate at Amazon.com and one free registration for MHA-SF's 2008 conference on compulsive hoarding, to be held October 29.

Thank you for your participation.

Belinda Lyons and Aregawie Yosef
SF Hoarding Task Force Co-Chairs
**Survey on Hoarding and Cluttering in San Francisco**

**Questions About Your Organization**

1. **What is the name of your organization?**

2. **What populations does your organization serve? Select all that apply.**
   - [ ] Low income adults
   - [ ] Adults aged 18-64
   - [ ] Adults 65 or older
   - [ ] Children under age 18
   - [ ] Individuals with mental health issues
   - [ ] Individuals with dementia
   - [ ] Homeless individuals
   - Other (please specify)

3. **What services does your organization provide? Select all that apply.**
   - [ ] Animal control
   - [ ] Case management
   - [ ] Cleaning services
   - [ ] Crisis hotline
   - [ ] Education and training for consumers and family members
   - [ ] Education and training for staff who serve people with hoarding behaviors
   - [ ] Emergency mental health services (eg, mobile crisis, 5150 assessment/referral)
   - [ ] Fire protection/fighting
   - [ ] Health and safety code enforcement
   - [ ] Home making services (eg, groceries, laundry, pet care)
   - [ ] Housing
   - [ ] Housing assistance/support
   - [ ] Job placement and training
   - [ ] Legal services
   - [ ] Meals/food
   - [ ] Medical or nursing care
   - [ ] Mental health services
4. Is there any further information you would like to supply about the services you provide?

5. How many total clients/customers does your organization serve each month?
Survey on Hoarding and Cluttering in San Francisco

Questions About Your Clients With Hoarding Behaviors

The following questions explore the service needs of your clients who have hoarding behaviors that interfere with their activities of daily living. If you do not have clients who have such behaviors, please skip to the next section.

6. How many individual clients total that have hoarding behaviors that interfere with their activities of daily living do you estimate that your organization serves each month?


7. How many individual clients total that have hoarding behaviors that interfere with their activities of daily living do you estimate that your organization served over the past year?


8. From whom are clients with hoarding behaviors most frequently referred to you? If from other agencies, please specify which agencies. Otherwise, answer "yes" or "no".

#1 Other agency (specify)
#2 Other agency (specify)
#3 Family or friends of client (Yes/No)
#4 Neighbors of client (Yes/No)
#5 Self-referral (Yes/No)
#6 Other source (specify)

9. For each of the referral sources listed above, please estimate the percentage of your clients who hoard that comes from each of these sources. Be sure to match the number of the source and make sure that the percentages total to 100.

Source #1
Source #2
Source #3
Source #4
Source #5
Other Sources (#5)

10. What percentage of your clients with hoarding behaviors are 60 years of age or older?

Percentage of clients 60 years of age or older:
11. What types of services do your clients with hoarding behaviors receive? Select all that apply, whether provided by your organization or not.

☐ Animal control
☐ Case management
☐ Cleaning services
☐ Crisis hotline
☐ Education and training for consumers and family members
☐ Emergency mental health services (eg, mobile crisis, 5150 assessment/referral)
☐ Fire protection/fighting
☐ Health and safety code enforcement
☐ Home making services (eg, groceries, laundry, pet care)
☐ Housing
☐ Housing assistance/support
☐ Job placement and training
☐ Legal services
☐ Meals/food
☐ Medical or nursing care
☐ Mental health services
☐ Organizing services
☐ Other social services
☐ Paramedic/ambulance
☐ Peer support/self-help
☐ Personal care assistance
☐ Pest control
☐ Police
☐ Property management/ landlord
☐ Protective services (safety assessments and related services)
☐ Repairs and maintenance
☐ Storage
☐ Transportation

Other (please specify)
12. Does it cost your agency more to provide services to individuals with hoarding behaviors than to other clients?

If yes, please estimate the additional cost of providing service each year for a typical client with hoarding behavior, as compared to a typical client without hoarding behavior.

To arrive at this estimate, consider factors such as whether it takes more time to provide services, whether you have to provide additional services, and whether you have to provide services more frequently.

Examples:

1) If a client with hoarding behavior requires the use of pest control services, include the average cost of these services.

2) If a client with hoarding behavior has meals delivered, but it takes extra time to deliver the meals due to the need to clean the refrigerator to make room for the meal, include the cost of the extra staff time required to do that cleaning.

3) If a client with hoarding behavior receives extra mental health services because of his or her hoarding behavior, include the cost of the extra visits.

These are just some examples. Provide information about any additional costs your agency incurs because of your clients’ hoarding behaviors.

☐ No, it does not cost more to provide service to a typical client with hoarding behavior than to a typical client without hoarding behavior.

☐ Yes (enter the additional cost of providing service each year for the average client with hoarding behavior, as compared to a typical client)
13. Please describe the cost elements and approach you used to arrive at your estimate.
14. Does your organization work with or refer to other agencies in managing your hoarding-related cases or clients?

- No
- Yes

15. If yes, what are the agencies with which your organization works or to which your organizations refers in order to manage your clients who hoard? Select all that apply.

- Animal Control/SPCA
- Cleaning agencies
- Code enforcement
- Department of Adult Protective Services
- Department of Environmental Health
- Department of Public Health
- Fire Department
- Health clinics
- Home care agencies
- Mental health centers
- Police Department
- Professional organizers
- Senior service agencies
- Other (please specify)
16. Are there rules, policies or processes that limit your organization’s ability to help clients with hoarding behaviors, including issues relating to coordination of services?

☐ No

☐ Yes (please specify)

17. In your opinion, what services are most needed to address problems associated with hoarding behaviors in San Francisco? Prioritize only five items.

<table>
<thead>
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<th>First priority</th>
<th>Second priority</th>
<th>Third priority</th>
<th>Fourth priority</th>
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<td>Home making services (eg, groceries, laundry, pet care)</td>
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<tr>
<td>Housing</td>
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<td>Housing assistance/support</td>
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<td>Job placement and training</td>
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<td>Legal services</td>
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<tr>
<td>Meals/food</td>
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<td>Medical or nursing care</td>
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<td>Mental health services</td>
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<tr>
<td>Organizing services</td>
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<tr>
<td>Other social services</td>
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<tr>
<td>Paramedic/ambulance</td>
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<tr>
<td>Peer support/self-help</td>
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</tbody>
</table>
18. Do you have any other ideas or suggestions for the Task Force with regard to individuals with hoarding behaviors?

19. If you would be willing to provide further followup if requested, please indicate the best person to contact.

Name: 
Title: 
Department: 
Organization: 
Email Address: 
Phone Number: 

Thank you for your time! The Task Force will disseminate its final report to SF service providers in early 2009, including placing the report on the MHA-SF website.

If you would like to reach the Task Force to share additional ideas or volunteer your time or services, please contact the Mental Health Association of San Francisco at 415-421-2926 x306 or hoarding@mha-sf.org.
Dear Landlord:

The San Francisco Department of Aging and Adult Services and the Mental Health Association of San Francisco have assembled a City Task Force on Compulsive Hoarding to address hoarding and cluttering behaviors in our community.

Compulsive hoarding is a behavior where individuals acquire and have difficulty discarding possessions which appear to be useless or have limited value. These behaviors can lead to safety hazards, including an increased risk of injury from falls, pest infestations, fires, eviction, and homelessness. The goal of this Task Force is to understand the scope of the issue and to make recommendations about how to improve services and reduce costs.

The purpose of this questionnaire is to find out whether you have tenants with hoarding behaviors, what sorts of services, programs or referrals those tenants need, the costs to your organization associated with hoarding behaviors, and what you think needs to be done to improve our community's response to these individuals.

A few notes about this survey:

1. The survey should take about 15 minutes to complete.

2. No identifying information about you or your tenants will be reported. We will report findings only in aggregate form.

3. Each landlord should complete only one survey. If there are various departments that have information needed to complete the survey, the information should be aggregated in a single survey response.

4. To complete this online survey, your browser must not have cookies disabled (In Internet Explorer, you'll find this under Tools/Internet Options/Privacy. In Mozilla Firefox, you'll find this under Tools/Options/Privacy.)

5. You do not need to complete the survey in one session. You may return at any time to add to or edit your survey responses. To do this, however, you must access the survey from the computer at which you started the survey and you must not have cleared the SurveyMonkey cookie from that computer.

6. So as not to lose data you've entered, use the Previous and Next buttons at the bottom of the screen rather than the Back and Forward buttons on your web browser.

7. To encourage your participation, all survey responders will be entered into a lottery to win one $100 gift certificate at Amazon.com and one free registration for MHA-SF's 2008 conference on compulsive hoarding, to be held October 29.

Thank you for your participation.

Belinda Lyons and Aregawie Yosef
SF Hoarding Task Force Co-Chairs
1. How many housing sites do you own or operate?

2. How many tenants in total live in the housing sites you own or operate?

3. What type or types of housing do you own or operate?

- Private
- Subsidized/Section 8
- Rent control
- Multi-unit dwellings
- Single family dwellings
- Supportive housing

Other (please specify)
Survey on Hoarding and Cluttering in San Francisco - Landlords

Impact of Hoarding Behaviors

The following questions explore the needs and impact of your tenants who have hoarding behaviors that interfere with their activities of daily living. If you do not have or have never had such tenants, please skip to the next section.

4. How many of your current tenants have hoarding behaviors that cause problems for you or them?

Number of current tenants with problematic hoarding behaviors:

5. How many of these tenants with problematic hoarding behaviors live alone?

Number of current tenants with problematic hoarding behaviors that live alone:

6. Including the tenants mentioned above, how many tenants with hoarding behaviors have you had in the last 5 years?"

Total number of tenants with problematic hoarding behaviors over past 5 years:

7. How do you most frequently learn about your tenants who hoard? If from service agencies or other sources, please specify. Otherwise, indicate "yes" or "no".

#1 By visiting the tenant (Yes/No)

#2 From other tenants (Yes/No)

#3 From social services/public health/public safety agency (specify)

#4 From family or friends of tenant (Yes/No)

#5 The tenant who hoards tells you directly (Yes/No)

#6 From other source or sources (specify)

8. For each of the ways listed above that you learn about tenants with hoarding behaviors, please estimate the percentage of such tenants that you learned about in each way. Be sure to match the number of the source of information and make sure that the percentages total 100. Please enter numbers only, not % or other symbols.

Source #1

Source #2

Source #3

Source #4

Source #5

Other Sources (#6)
Survey on Hoarding and Cluttering in San Francisco - Landlords

9. In this question we seek to understand hoarding related problems you have faced over the past year. For each type of problem, please indicate:

1) The number of tenants that had the problem

2) The total number of times this type of incident occurred

3) The cost of addressing a typical incident (if you just have a cost figure for all incidents, divide this by the total number of incidents to come up with the per-incident cost)

<table>
<thead>
<tr>
<th>Tenants With This Problem</th>
<th>Total Number of Incidents</th>
<th>Cost Per Incident</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injury related to hoarded/cluttered environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pest infestations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Animal control issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fires</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgone rent while unit is empty and/or uninhabitable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eviction, including any related legal costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heavy cleaning or hauling services needed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. Are there any other ways in which hoarding behaviors have had a financial impact on you or your organization? If so, please describe each of these impacts and estimate the costs over a typical year. If you are able, break out the costs so we can understand the ways in which hoarding behaviors impact you or your organization financially.
11. Have you made use of any of the following community services in connection with your tenants who compulsively hoard? Select all that apply.

- Animal control
- Case management
- Cleaning services
- Crisis hotline
- Education and training for consumers and family members
- Education and training for staff who serve people with hoarding behaviors
- Emergency mental health services (e.g., mobile crisis, 5150 assessment/referral)
- Fire protection/fighting
- Health and safety code enforcement
- Home making services (e.g., groceries, laundry, pet care)
- Housing
- Housing assistance/support
- Job placement and training
- Legal services
- Meals/food
- Medical or nursing care
- Mental health services
- Organizing services
- Other social services
- Paramedic/ambulance
- Peer support/self-help
- Personal care assistance
- Pest control
- Police
- Property management/landlord
- Protective services (safety assessments and related services)
- Repairs and maintenance
- Storage
- Transportation
Survey on Hoarding and Cluttering in San Francisco - Landlords

12. Do you or your organization work with other agencies or companies in managing your tenants who hoard?

☐ No
☐ Yes

13. If yes, with which agencies does your organization work to manage your tenants who hoard? Select all that apply.

☐ Animal Control/SPCA
☐ Cleaning agencies
☐ Code enforcement
☐ Department of Adult Protective Services
☐ Department of Public Health
☐ Environmental Health
☐ Fire Department
☐ Health clinics
☐ Home care agencies
☐ Mental health centers
☐ Police Department
☐ Professional organizers
☐ Senior service agencies

Other (please specify)
14. Are there rules, policies or processes that limit you or your organization's ability to address issues related to a tenant's hoarding behaviors? An example might be confidentiality rules that limit your ability to coordinate clean-up efforts with fire department or code enforcement personnel.

- No

- Yes (please specify)

15. In your opinion, what are the two or three most important things that could be done to improve your ability to better manage your tenants who hoard, including reducing evictions?

16. In your opinion, what services are lacking for San Francisco residents with hoarding behaviors? Select all that apply.

- Animal control
- Case management
- Cleaning services
- Crisis hotline
- Education and training for consumers and family members
- Education and training for staff who serve people with hoarding behaviors
- Emergency mental health services (eg, mobile crisis, 5150 assessment/referral)
- Fire protection/fighting
- Health and safety code enforcement
- Home making services (eg, groceries, laundry, pet care)
- Housing
- Housing assistance/support
- Job placement and training
- Legal services
- Meals/food
- Medical or nursing care
17. Do you have any other ideas or suggestions for the Task Force with regard to individuals with hoarding behaviors?
18. Any additional comments?


19. If you would be willing to provide further followup if requested, please indicate the best person to contact.

Name:  
Title:  
Department:  
Organization:  
Email Address:  
Phone Number:  

Thank you for your time! The Task Force will review all of your responses and will make its final report available in early 2009. If you would like to reach the Task Force to share additional ideas or volunteer your time or services, please contact the Mental Health Association of San Francisco at 415-421-2926 x306 or hoarding@mha-sf.org.

Thank you for your time! The Task Force will disseminate its final report in early 2009, including placing the report on the MHA-SF website.

If you would like to reach the Task Force to share additional ideas or volunteer your time or services, please contact the Mental Health Association of San Francisco at 415-421-2926 x306 or hoarding@mha-sf.org.
The Federal Fair Housing Act (FHA) and the California Fair Employment and Housing Act (FEHA) provide protection to disabled tenants who are subjected to eviction proceedings by their landlords. Tenants who obtain a diagnosis for their condition from a qualified medical care provider may be able to establish themselves as having a disability. In the context of compulsive hoarding and cluttering, the applicable diagnosis will often be obsessive-compulsive disorder.

Hoarding behaviors may result in a landlord issuing an eviction notice on the basis that the tenant has created a nuisance, fire hazard, or other danger in the building. If the tenant has been previously diagnosed as disabled, the tenant may notify the landlord of the disability and request that the landlord provide a “reasonable accommodation” to enable the tenant to remain in the apartment rather than being evicted. A landlord who has doubts regarding the disability is required to request additional information from the tenant.

A landlord is not legally required to grant any accommodation requested by a tenant. Rather, the requested accommodation must be reasonable under the circumstances. Examples of reasonable accommodations might include: (1) requesting additional time to remedy the conditions inside the apartment; (2) participating in treatment groups for compulsive hoarding; (3) obtaining medical treatment; (4) requesting that the landlord provide specific and detailed information regarding the precise condition inside the apartment that constitutes the alleged nuisance; and (5) formulating a joint resolution plan with the landlord to remedy the nuisance.

Denial of a reasonable accommodation imposes serious legal problems for landlords under both the FHA and FEHA. These include precluding the landlord from prevailing in an eviction lawsuit, as well as subjecting the landlord to liability in a civil lawsuit.

22 Thanks to Task Force member Joel Liberson for writing this section.


24 See Auburn Woods, supra; Dubois v. Association of Apartment Owners of 2987 Kalakaua, 453 F.3d 1175 (9th Cir. 2006); McGary v. City of Portland, 386 F.3d 1259 (9th Cir. 2004); Giebeler v. M & B Associates 343 F.3d 1143 (9th Cir. 2003).
Across the country, cities and communities have launched task forces to address the impact of compulsive hoarding behaviors. Given the involvement of diverse agencies in addressing the situation of people with hoarding behaviors and the value often ascribed to interdisciplinary and inter-agency coordination, task forces have been a key way of attempting to build community-level understanding and responses to the challenges posed by compulsive hoarding and cluttering. The San Francisco Task Force on Compulsive Hoarding has benefited from and is contributing to the body of knowledge and best practices being developed by task forces around the country.

Nearly 50 community task forces are known to have been formed in various parts of the U.S. to address compulsive hoarding, although nearly one-third are no longer functioning or are temporarily suspended due to a variety of challenges. The task forces have been successful in a variety of areas. They have provided education to people with hoarding behaviors, their families, relevant professionals, and the broader community. They often create an opportunity for case consultation and coordination, and case intervention. Since hoarding cases are often experienced as particularly challenging by service professionals, the task forces can foster opportunities for professional support. By viewing the bigger picture, they can help communities to maximize resources, shape conceptualization of the problem, and enable a systematic response.

A much smaller number of task forces—in Dane County, Wisconsin; New York City; Fairfax County, Virginia; and Kansas (drawing on work in three pilot areas)—have developed studies, reports, or community assessments. These help the task forces directly in their own work and can be useful to task forces elsewhere as well.

The task forces are often well positioned to improve services by supporting changes in agency and community policies; creating a single point of entry and system of care for hoarding cases; supporting early identification and intervention; reducing stigma, shame, and isolation; and better using professional expertise in the community.

Task forces across the country have identified a range of community best practices for addressing compulsive hoarding. For example, having clear housing department laws and regulations can be valuable because they can provide a baseline for working with people with hoarding behaviors. If there are clear written standards about what constitutes a hazard and what kinds of conditions can result in public intervention, people attempting to ameliorate their clutter have clear benchmarks for reducing hazards.

Cross-agency coordination and/or multi-disciplinary teams are widely recognized as valuable. Many task forces addressing compulsive hoarding were developed as a vehicle for different stakeholder agencies to improve communication, better understand one another’s perspectives and roles in working with people with hoarding behaviors, and coordinate responses and resources in difficult cases. Confidentiality

requirements can sometimes be a barrier to such coordination, but models for working together effectively while protecting confidentiality do exist.

Clear systems for channeling cases, ensuring that diverse stakeholders have a clear understanding of which agencies to call for assistance, and having simple forms to enable fire and police department personnel to report cases to relevant social service providers have all also been identified as best practices. Determining which first responders are most appropriate to enter a home in which hoarding may be causing a serious hazard or violation is also important. For example, in one city, the fire department is called because fire personnel are perceived more positively than police.
APPENDIX G. TREATMENT, TRAININGS, AND PUBLIC EDUCATION – EARLY RESULTS OF THE TASK FORCE’S WORK

Even as the Task Force worked toward the development of this report, both the Task Force itself and members were using initial data and information sharing to raise awareness about compulsive hoarding and to improve coordination among providers, attorneys, private entities, and others.

The Mental Health Association of San Francisco and Family Services Agency (FSA) developed a partnership to provide an intensive 16-week treatment group, the first of its kind in the Bay Area, using a new cognitive behavioral therapy (CBT) model developed by Drs. Randy O. Frost and Gail Steketee, leading experts in the field. Demand was high—more than 50 people called about the group, which could only accommodate 10 people. At the final meeting, group members were asked to reflect on whether they had reduced their clutter since the first time they attended the group. All those present reported success in at least “somewhat” reducing the amount of clutter in their homes, and 90% answered “very much” when asked whether they received the kind of support they needed from the group.

MHA-SF continued to offer its weekly support group for people with hoarding behaviors, which engaged 88 unduplicated participants during the fiscal year from July 2007 through June 2008. Nearly 90% of participants reported in a survey in 2008 that the group had helped them to reduce their clutter.

Trainings were held in January and June 2008 for In-Home Supportive Services Consortium workers to give them a broader range of approaches for assisting their clients who compulsively hoard to declutter their residences, with a goal of helping to prevent evictions. The trainings focused on effective communication, harm reduction targets, and tangible solutions to promote safety, better health, and better comfort. Thirty-one homecare providers from IHSS Consortium participated. IHSS Consortium staff members who took part in the trainings also participated in monthly troubleshooting groups for six months following the training, and had the option of continuing in the troubleshooting groups after the six months were over. Skills learned in the trainings and the troubleshooting groups have helped homecare providers cope with their initial frustration at the resistance of clients who compulsively hoard. In an evaluative survey, 89% responded that they agreed or somewhat agreed that one of their clients with hoarding behaviors had avoided potential eviction due to clutter through the help of the homecare provider. Results of these trainings were also shared with an existing collaborative that includes the Department of Public Health’s Environment Health Services (EHS) and Community Behavioral Health Services (CBHS), and the Department of Aging & Adult Services’s In-Home Supportive Services (IHSS) and Adult Protective Services (APS), to help the agencies further their understanding of how they can help the clients they have in common.

MHA-SF hosted two additional provider trainings. “Older Adults Who Hoard: An Advanced Training for Service Providers who Serve Older Adults” was held in April 2008 and engaged 36 participants. “Training for Nurses: Strategies to Address Compulsive Hoarding and Cluttering Behaviors” was held in June and drew 11 participants. Both trainings were opportunities for professionals to earn continuing education units (CEUs).

A workshop for families, “Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring,” was held in March 2008 at the World Affairs Council with tremendous community
response—104 people attended.

In response to requests, MHA-SF also gave two trainings in June 2008 for agencies serving people with hoarding behaviors. The first, held at the Edgewood Center for Children and Families, drew 12 participants, all grandparents of children served by the center. The second was held at Bayside Elderly Housing of Chinatown Community Development Center (CCDC), and attracted 18 participants, all of whom were seniors receiving services from CCDC.

Media and public education efforts related to the Task Force resulted in the publication of several articles locally, including a front-page story in the San Francisco Chronicle on March 18, 2008, and interviews with KGO Radio and KALW. NBC Bay Area television news also covered the 2008 MHA-SF annual Conference on Hoarding and Cluttering.
APPENDIX H. POSSIBLE STRATEGIES AND PILOT PROGRAMS FOR IMPLEMENTING THE TASK FORCE’S RECOMMENDATIONS

This section includes an array of initial proposals and possible strategies for implementing the Task Force’s recommendations, including potential pilot projects and efforts to coordinate existing services. These proposals and strategies have been created by agencies participating in the Task Force in response to its findings and recommendations.

The overarching goal of these efforts is to ensure that programs that are developed provide a continuum of care from the single point of entry through an array of services and programs that productively address the needs of people with hoarding behaviors, their families, and landlords. The plans are designed to support and maximize coordination among existing services and providers so as to strengthen the effectiveness of care. For example, the single point of entry will be positioned to connect people with the proposed assessment/crisis team, which will be able to engage other services, including proposed long-term case management and support and treatment groups. Having a hoarding and cluttering “czar” in place to support coordination and assess the effectiveness of the full system of services (rather than simply focusing on the assessment of individual components by individual agencies) will improve overall efficiency and cost-effectiveness.

Program proposals follow, associated with the recommendations they are designed to implement.
RECOMMENDATION # 1

Develop an assessment/crisis team to respond to referrals about hoarding cases and coordinate appropriate next steps to facilitate meaningful, long-term improvement for individuals.

<table>
<thead>
<tr>
<th>Program:</th>
<th>Hoarder Assessment/Engagement Team</th>
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<tbody>
<tr>
<td>Annual Cost:</td>
<td>Peer Responder</td>
<td>$3,200</td>
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<tr>
<td></td>
<td>Approximately 12 hours/month @ $22/hour</td>
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<td></td>
<td>APS worker @ $40/hour</td>
<td>$32,000</td>
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<tr>
<td></td>
<td>Initial visit and written assessment and follow-up</td>
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<tr>
<td></td>
<td>4 hours + 16 hours = 20 x $40 = $800</td>
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<tr>
<td><strong>Total New Costs</strong></td>
<td></td>
<td><strong>$35,200</strong></td>
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</tbody>
</table>

Program Description

This proposed program was prepared by Adult Protective Services.

The Hoarder Assessment/Engagement Team would consist of a worker from APS and a peer counselor assigned from CBHS. Representatives of the Fire Department and DPH/Environmental Health would be available on a “stand-by” basis. APS would be the lead agency dispatching the team to the homes of identified clients.

This program leverages existing resources in that APS would identify a current worker (no new hire) to be the leader of this team and CBHS would identify a peer counselor from one of its current peer programs (no new hire) to join the APS worker when an initial client visit is scheduled.

If allowed into the home of the identified client, the Hoarder Assessment/Engagement Team would interview the client and examine the premises. If the APS worker and the peer counselor believe that there are behavioral health issues that a CBHS social worker should assess, the team would solicit consent from the identified client to schedule an additional interview so that the CBHS social worker can consider various options, including involuntary hold and/or linkage to mental health treatment. At the same time, the APS worker would assess whether it would be helpful for someone from the Fire Department and/or Environmental Health to visit the client.

In order to maintain a consistent strategy, either the APS worker or the peer counselor would always be in attendance at the visit of any other professional called into the home to assess the situation.

The budget is calculated on an hourly basis so that work order transfers can properly account for the time spent by the APS worker and the peer counselor.

The CBHS clinical social worker shall be a professional attached to the existing Mobile Crisis Team. This worker’s costs are associated with the “Long Term Case Management Services” proposal below.
If the identified client refuses to be interviewed by CBHS, the peer counselor would solicit the client’s permission to check in on the client on a periodic basis. This can continue even if APS closes the case. In this manner, the peer counselor would over time seek to see if the client would eventually allow a professional assessment. If the client ever allows such an assessment to take place, the peer counselor would contact the CBHS social worker at Mobile Crisis and make arrangements for such a meeting. The peer counselor would advise APS about the client’s change of mind regarding an assessment and it would be up to APS to either re-open the case if it has been closed (it is possible that the client’s change of mind might take months) or to keep the case closed.
Recommendation #2

Increase access to treatment for hoarding, including in the person’s home. Treatment can include therapists, organizers, coaches, and peers.

<table>
<thead>
<tr>
<th>Program:</th>
<th>Hoarding and Cluttering Treatment Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Cost:</td>
<td>Clinician (40% of FTE @ $100,000, which includes salary and benefits) plus training, clinical supervision, and administrative support $60,000</td>
</tr>
<tr>
<td></td>
<td>Psychiatrist or psychiatric nurse practitioner (10% of FTE) ($15,000, covered by existing staff, so no new cost)</td>
</tr>
<tr>
<td>Total New Costs</td>
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</tr>
</tbody>
</table>

Program Description

This proposed program was prepared by Family Service Agency.

Cognitive deficits associated with compulsive hoarding severely impact the social and economic capacities of its sufferers. Treatment prognosis for sufferers is significantly worse than for other obsessive-compulsive disorders. Medication (e.g., SSRIs) given in isolation has been shown to have very limited effectiveness. Preliminary studies have shown that rigorous, targeted cognitive behavioral therapy can be highly effective in treatment of this disease and mitigation of the harm that it causes.

The core of the service is cognitive behavioral therapy treatment groups, based upon the approach developed by Steketee and Frost at the Boston University Center for Anxiety and Related Disorders. Two groups are proposed, serving eight people each, with one group targeted to elders (ages 60+) and the other to adults (ages 18-59).

Multiple staff would be trained in this approach so that the services can be offered in multiple languages on a rotating basis. Consequently, the 40% clinical time might be divided up among several practitioners.

Groups would last for 16 weekly sessions supplemented, on an as-needed basis, by one-to-one therapy. As soon as one group is completed, another would begin, so that services would be available on an ongoing basis throughout the year. Groups alternate between various sites in San Francisco. By year two, groups would be available at least once a year in Cantonese, Spanish, and Russian. As individuals complete the group work, they would be transitioned into peer support groups.

The target population would be individuals whose lives are negatively impacted by hoarding and cluttering, with a particular focus on low-income, chronically mentally ill San Francisco residents. It is anticipated that at least 70% of these clients would have additional serious mental health and/or substance abuse conditions. Fifty percent of the clients served would be elders, aged 60 and above.

Because hoarding and cluttering is closely associated with many other co-morbid behavioral health
conditions, each participant would receive a full diagnostic assessment. Individuals with other treatment needs would be assisted to locate other treatment resources, both inside and outside FSA.

Although medication by itself does not appear to be particularly effective in the treatment of hoarding and cluttering, it can be a useful adjunct for some individuals who are also receiving CBT. Consequently, psychosocial treatment would be supplemented with medication assessment and management, where useful and desired, provided by a licensed psychiatrist or psychiatric nurse practitioner.

If carried out by FSA, the annual cost of $60,000 would be supplemented by $15,000 in agency resources. FSA could serve 60 clients per year, with an open caseload of 16-20 at any one time. FSA currently has one staff person who is trained in the proposed intervention and who has already provided two treatment groups.
Recommendation # 3

Expand support groups available locally, including peer support groups and groups for family members, and provide training for peer support facilitators. Build on the successes of support groups by offering groups for people at different stages of dealing with their hoarding behaviors, ranging from early awareness and those just starting out to those with substantial experience working on behavioral changes.

<table>
<thead>
<tr>
<th>Program: Support Groups</th>
<th>Annual Cost: Salaries and benefits, supplies, space rental, and indirect costs @ 12%</th>
<th>$77,320</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Approximately $20,000 of these costs are already part of existing budgets</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Total New Costs</strong></td>
<td><strong>$57,320</strong></td>
</tr>
</tbody>
</table>

Program Description

This proposed program was prepared by the Mental Health Association of San Francisco.

This proposal is to expand the array of available support groups to include support groups for families, support groups in languages besides English, and a support group for those who complete the proposed treatment group. A peer network or mentorship program connected to the groups, with stipends for peer leaders, might also be created.

Currently MHA-SF is funded for and provides one support group that meets weekly and serves 80 unduplicated individuals per year. The following support groups would be added:

- A family member support group (serving 30 families)
- A support group for those who have completed a treatment group (serving 10 people with hoarding behaviors)
- A support group in Spanish for people with hoarding behaviors (serving 30)
- A support group in Cantonese for people with hoarding behaviors (serving 30)

Through this expansion, MHA-SF could increase the number of people with hoarding behaviors who are served to 150, and begin serving family members as well.
Recommendation #4

Create a services roadmap for people with hoarding behaviors and their families, service providers, and landlords so that people know what agencies to contact in different situations and have a way to identify and seek assistance. Establish a single point of entry into the system of supports and resources that uses a single form for referrals, follows the services roadmap, and engages the assessment team.

<table>
<thead>
<tr>
<th>Program: Single Point of Entry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Cost: 1 FTE (salary and benefits)</td>
</tr>
<tr>
<td>Total New Costs</td>
</tr>
</tbody>
</table>

Program Description:

This proposed program was prepared by the Department of Aging & Adult Services. A proposed services roadmap has been created, and the Department of Aging & Adult Services (DAAS) Intake Screening Unit is proposed as the single point of entry to streamline services and enable people with hoarding behaviors, their families, service providers, and landlords to effectively follow the services roadmap and access needed information and services. The Intake Screening Unit would consolidate IHSS, APS, and referral services for single entry comprehensive community information and intake service. The unit would provide referrals and information for people with hoarding behaviors to help support their current level of independence and functioning. The intake unit would be knowledgeable in all community and institutional services for all seniors and adults with disabilities, regardless of their economic status. Screening and referrals would be taken for IHSS, home delivered meals, community living fund assistance, and protective services. Other screening needs not met by the Department would be referred to the appropriate community or institutional source. To implement this, an additional FTE of staffing would be needed, at a total cost of $116,778 per year. Training would need to be coordinated for 211 and 311 responders, in line with plans for implementing recommendation 7. Informing the general public and key audiences such as landlords and service providers about the roadmap and single point of entry would also be essential.
RECOMMENDATION # 5

Develop evaluation guidelines for landlords that are coordinated with fire department and health regulations.

<table>
<thead>
<tr>
<th>Program: Evaluation Guidelines for Landlords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Cost: Currently no new costs are projected. Distribution plans may involve some costs, to be determined.</td>
</tr>
</tbody>
</table>

Program Description:

This proposed program was prepared by the Environmental Health Section of the Department of Public Health.

The Department of Public Health Environmental Health Section (EHS) is developing a form entitled “Health and Fire Code Compliance Guidelines for Property Managers and Tenants.” EHS and other Task Force partners would explore developing trainings for landlords on using these guidelines (see training recommendation below) and would determine the best methods for distributing these guidelines to landlords.
RECOMMENDATION #6

Provide long-term case management services as an extension of initial assessment and treatment.

<table>
<thead>
<tr>
<th>Program:</th>
<th>Long Term Case Management Services for People who Hoard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Cost:</td>
<td>Clinical social workers (2 FTEs @ $100,000 per year, including benefits) $200,000</td>
</tr>
<tr>
<td>Total New Costs</td>
<td>$200,000</td>
</tr>
</tbody>
</table>

Program Description:

This proposed program was prepared by Community Behavioral Health Services.

The first full-time CBHS clinical social worker (housed at Mobile Crisis) specializing in hoarder case management would be the same worker who is also part of the Hoarder Assessment/Engagement Team. This worker would be called into the assessment opportunity at the request of APS and/or the peer counselor of the Hoarder Assessment/Engagement Team.

If the assessment results in the opportunity to have CBHS provide treatment, then the person who did the assessment would also provide the long-term intensive case management and treatment, assuming that the client provides consent for voluntary engagement by this worker on an ongoing basis. This worker’s caseload, in order to provide intensive case management, would be limited to 15-20 clients. This worker could be assisted by the peer counselor to ensure that assistance is provided to the client to navigate necessary community-based services. The length of time that a client could receive intensive case management would be approximately one year.

The second full-time CBHS clinical social worker would provide therapeutic case management and supportive services to clients in their residence who have completed a hoarding and cluttering support group and who voluntarily agree to continue with a case manager. This social worker would also coordinate services with a peer worker/volunteer in the community to reinforce and support the client in maintaining his/her progress. This worker’s caseload would be no more than 20-25 clients annually.
RECOMMENDATION #7

Offer training for therapists, 211/311 staff, landlords, agency staff, and families; recruit and train trainers; and provide cross-training for identification/screening/assessment across agencies.

<table>
<thead>
<tr>
<th>Program:</th>
<th>Compulsive Hoarding Training Institute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual Cost:</td>
<td>Salaries, consultants/trainers, supplies, rent/meeting facilities, and indirect costs @ 12%</td>
</tr>
<tr>
<td></td>
<td>Approximately $100,000 of these costs are already part of existing budgets</td>
</tr>
<tr>
<td></td>
<td><strong>Total New Costs</strong></td>
</tr>
</tbody>
</table>

Program Description:

This proposed program was prepared by the Mental Health Association of San Francisco; Carol Mathews, MD, at UCSF; and the San Francisco Apartment Association.

There are few professionals trained or knowledgeable about compulsive hoarding. This program would create a training institute offering a variety of trainings for therapists, human services agency staff, 211/311 staff, landlords, families, trainers, and others.

In addition to ongoing trainings for service providers and family members, trainings provided would include:

A. **Training mental health professionals in the assessment and treatment of hoarding and cluttering.**

Hoarding and cluttering is a somewhat subterranean disorder, often coming to the attention of mental health providers only in its most extreme form, making appropriate intervention challenging. In addition, the majority of mental health providers have no specific training in the appropriate assessment and treatment of this complex syndrome, which is often accompanied by obsessive-compulsive disorder, other anxiety disorders, depression, dementia, and/or psychosis. This program would provide specific and practical training to augment the already available services of mental health providers throughout the Bay Area.

There are only a few providers in the Bay Area with expertise in assessment and medical management of hoarding and cluttering and its associated co-morbidities. These providers are already at capacity or have extremely long waiting lists. Most do not accept Medi-Cal/Medicare.

This would be a one-time program aimed at training 100 mental health professionals, including psychiatrists, psychologists, nurses, therapists, and case managers in the assessment and treatment of hoarding and cluttering and the psychiatric disorders associated with it. The program is composed of two
parts: (1) a one-day conference focused on assessment of hoarding and cluttering and its associated co-
morbidities and medical management of these disorders, and (2) a three-day behavior therapy institute (BTI)
training workshop organized by the Obsessive Compulsive Foundation (OCF) focused on providing detailed
and in-depth training in therapeutic interventions for hoarding and cluttering, including cognitive behavioral
therapy (CBT) and motivational interviewing (MI) techniques.

B. Training for Landlords.

The San Francisco Apartment Association educates landlords and managers of rental housing in
San Francisco, offering classes for members and nonmembers about laws and procedures related to the
management of rental housing. SFAA recognizes the problem that San Francisco landlords have when they
are faced with the situation of having a tenant in their building who has hoarding behaviors. Not knowing
what to do, they often turn to an eviction proceeding. SFAA seeks to prevent these evictions from being so
common by educating San Francisco landlords about the correct steps to take when dealing with a tenant
with compulsive hoarding behaviors. SFAA would work in collaboration with other Task Force partners
to develop training content and materials for landlords and building managers. These would include the
guidelines that the Environmental Health Section is proposing to create (see proposal for recommendation
5) and documents that landlords could use to inform tenants with hoarding behaviors of resources and
programs, among others. The training would reach 120-200 landlords each year.
**RECOMMENDATION #8**

Ensure **overarching coordination** and evaluation of recommended priorities (hoarding and cluttering “czar”); track implementation of priorities and evaluate success.

<table>
<thead>
<tr>
<th>Program:</th>
<th>Hoarding and Cluttering “Czar”</th>
</tr>
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<tbody>
<tr>
<td>Annual Cost:</td>
<td>This would cost $100,000 per year. Most of this cost is already part of existing funding through DAAS to the Mental Health Association of San Francisco, so this proposal does not involve additional new costs.</td>
</tr>
</tbody>
</table>

**Program Description:**

This proposed program was prepared by the Mental Health Association of San Francisco.

The Task Force proposes that a centralized coordinating effort be maintained to address compulsive hoarding in San Francisco. The Hoarding and Cluttering “Czar” would serve in an oversight position to coordinate the spectrum of programs addressing compulsive hoarding and cluttering, evaluate their effectiveness, and ensure that resources and services are accessible and known throughout the community. This centralized coordinating Czar would ensure service linkages between agencies providing compulsive hoarding services, convene and coordinate activities of the Task Force, track the implementation of the Task Force’s recommendations, and evaluate their success.