

Supporting People Who Hoard in Hamilton

Summary of a Service Provider Survey



**Hamilton Urban Core
Community Health Centre**
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Introduction

The need for a service provider survey regarding people with hoarding behaviours was identified by Hamilton Urban Core Community Health Centre and the Hamilton Legal Community Clinic. During the process of an intervention it became apparent to both agencies that people were experiencing problems with hoarding in various areas and that there was a lack of resources and coordination to respond to or address the needs of the individual or, in many instances, the property owner / landlord.

Hamilton Urban Core is a thriving inner city health centre and a leader in the provision of high-quality primary health care services and programs for individuals, families and groups that experience barriers in accessing the services, support and information they need. As an inner city health centre, Hamilton Urban Core receives information about people in Hamilton who are experiencing difficulties as a result of extreme hoarding. Some of those consequences include but are not limited to homelessness as a result of eviction, illness, social isolation, depression, exclusion, and family and relationship problems.

Similarly, the Hamilton Community Legal Clinic is a non-profit community legal clinic provides services to low income residents in Hamilton that includes legal advice and referrals and legal representation. In addition the Clinic is involved in public legal education, community development and law reform. As such the Clinic often sees the end result of "extreme hoarding" in their work with tenants who are facing eviction.

It is through Hamilton Urban Core and the Hamilton Community Legal Clinic working collaboratively in trying to provide support and advocacy related to hoarding that many gaps and barriers were identified. Based on this experience both agencies agreed to probe the problem further by conducting a service provider survey.

Approach

The initial approach was intended to determine if there was information, supports and resources available in the community to help people who hoard, the service providers who assist people who hoard and landlords / property owners. Given the challenges in finding the help needed it was agreed that there should be a better understanding about the coordination or lack of coordination of information, services and resources relating to extreme cluttering and hoarding.

A survey was developed and distributed to service providers across the community including housing providers in effort to ascertain the severity of the situation in Hamilton. It is understood that there are some individuals who do not meet the criteria of an "extreme hoarder" used by existing programs and services in Hamilton but who nevertheless urgently require help. The survey was also intended to identify agencies and potential partners willing to work collaboratively in developing and implementing a comprehensive coordinated community response to hoarding.

It seemed apparent that an appropriate approach to hoarding in Hamilton may involve the expansion of existing services and/or the development of new supports. Understanding the scope of the problem and the capacity or understanding of existing services was determined to be an important and necessary first step.

What is Hoarding?

Extreme hoarding has been defined by the Mayo Clinic as the excessive collection of items, along with the inability to discard them. Hoarding often creates such cramped living conditions that homes may be filled to capacity, with only narrow pathways winding through stacks of clutter. Some people who hoard also collect animals, keeping dozens or hundreds of pets in unsanitary conditions.

Hoarding is usually considered to be a manifestation of what is known as an obsessive-compulsive disorder (OCD). Relatively little research has been done on this problem despite this close association. Hoarding behaviours may occur alone or in the context of other disorders such as dementia, schizophrenia, eating disorders, and obsessive-compulsive personality disorder. Hoarding behaviours may also be found outside the context of psychiatric disorders (Steketee & Frost, 2003 & 2004).

Social phobia and depression have also been found to be closely associated with compulsive hoarding and are linked to findings of isolation and limited social networks particularly among elderly hoarders. Hoarding behavior can result in serious and even life-threatening pathology and may be an indicator for poor prognosis in the treatment of OCD.

Social Isolation and Hoarding

Some of the consequences of hoarding behaviours are the potential safety, health and fire hazards they pose. Excessive clutter can create other problems such as social isolation and relationship problems with family, friends and neighbours. People may find it difficult to move around the house, clean, manage self-care. Clutter also increases risk of injury from tripping or falling. Family relationships are often strained and many relationships are ended because of extreme hoarding. Parents can potentially lose custody of their children. In addition, people who are hoarding often do not want others to visit them. This of course inhibits their ability to connect with others increasing the risk of social isolation.

The social impacts of hoarding are not to be overlooked or minimized. Hoarding also creates a barrier for service providers and others who may be able to provide support to clients. It is often only when hoarding creates a crisis such as eviction that the hoarding problem is discovered and help at this point can be a difficult and painful experience for the client.

Good social connections and support make an important contribution to overall health outcomes. It provides people with the emotional and practical resources they need to address the behaviours. People who have less access to social supports and who are socially isolated are more likely to experience less well-being, increased depression and are at greater risk for chronic diseases and poor mental and physical health.

Pets and Hoarding

“Animal hoarding involves keeping higher than usual numbers of animals as pets without having the ability to properly house or care for them, while at the same time denying this inability. Compulsive hoarding can be characterized as a symptom of mental disorder rather than deliberate cruelty towards animals.

Hoarders are deeply attached to their pets and find it extremely difficult to let the pets go. They typically cannot comprehend that they are harming their pets by failing to provide them with proper care. Hoarders tend to believe that they provide the right amount of care for their pets. The American Society for the Prevention of Cruelty to Animals provides a "Hoarding Prevention Team", which works with hoarders to help them attain a manageable and healthy number of pets. (Wikipedia December 2010)”

Survey Results

The purpose of the survey was to gather responses from a cross-section of service providers in Hamilton regarding their experience with or understanding of problems related to hoarding behaviours amongst their respective clients. Over 40 service providers were invited to participate in the online survey of which seventeen service providers completed the survey. The survey consisted of 15 questions.

The service providers who responded to the survey represented the following organizations:

- Hamilton Urban Community Health Centre
- Hamilton Community Legal Clinics
- Able Living Services Inc.
- Mental Health & Street Outreach Services, Hamilton Public Health
- COAST
- Public Health
- City Housing Hamilton
- Ontario Works

Number of People with Hoarding Behaviours

When asked to identify the number of clients with a hoarding problem that were been seen in a one year period 28.6% of providers identified at least 1 client who is hoarding; 14.3% identified between 2-7 hoarders per year and approximately 7% of providers identified between 8-12 clients with a hoarding problem. In total approximately there were 234 known to the responding service providers who are hoarding in Hamilton.

Age

When asked to identify the typical age of the people or clients who were hoarding service providers responded with an estimate of the typical age. The highest number of individuals identified with problems with hoarding was found in the 50's age group followed by those in their 40's. Interestingly, the smallest number of hoarders was identified in the 70's and older age group.

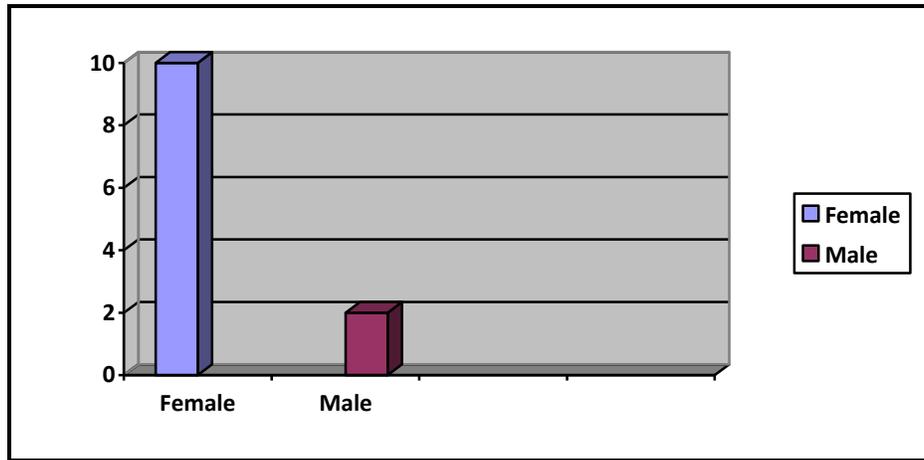
AGE GROUP	ESTIMATED NUMBER OF CLIENTS
20's	20
30's	20
40's	41
50's	75
60 - 64	36
64 - 69	25
70's	14
80's	3
90's	0
100+	0
Total	234
	Estimated known individuals who are hoarding in Hamilton amongst 17 service providers

Gender

In this survey providers identified or were in contact with primarily female clients who are hoarding. In a recent study researchers reported that within their study the female patients with OCD and hoarding behaviours were "more likely to suffer from bipolar I, substance abuse, panic disorder, binge eating disorder and had a greater severity of OCD. Male hoarders in their study had an increased prevalence of social phobia suggesting that there are gender-specific differences in the participants who had OCD and were hoarding."¹

¹ Characterizing the Hoarding Phenotype in Individuals with OCD: Associations with Comorbidity, Severity and Gender, National Institute of Health Author Manuscript; J Anxiety Disord. Author manuscript; available in PMC 2008 November 3; Wheaton, Timpano, LaSalle-Ricci and Murphy

Gender of Clients Who Hoard



Degrees of Hoarding

Providers were asked to identify the degree to which they believed their clients were hoarding from the following choices:

- Just Clutter: Things are disorganized and not in their place. There is difficulty locating everyday items such as keys or receipts. Clothing or shoes tumble out of the closet when opened. When guests arrive efforts are made to quickly hide the clutter or explain it as a bad day.
- 1st degree: Just getting behind on things they would normally manage like laundry or dishes. They are not the tidy person they once were. The little piles are starting to emerge and disorganization is affecting their life. They might feel embarrassed if someone were to see the house/ apartment but they would still let them in.
- 2nd Degree: Things are starting to get out of hand. They cannot locate normal household items like their bed, table, television or telephone, because piles have expanded to cover the items up. They have started to develop new methods of moving around their living space because normal movement is impeded by piles of stuff. They make excuses to discourage people from entering their house.
- 3rd Degree: All of the above plus they have rotting food and animal feces and/ or urine in the living space, and this is the rule not the exception. They cannot cope with the growing mess. Essential household repairs

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may not be done, because they are too afraid to let anyone in the house. The thought of anyone seeing their mess causes great stress.

The following chart illustrates the degree to which providers believe their clients are hoarding.

Degree	Number of People Identified
Just Clutter	2
1 st Degree Hoarding	4
2 nd Degree Hoarding	8
3 rd Degree Hoarding	10

Note: Number of actual responses was 24 indicating more than one response was given for some individuals.

Based on information gathered from service providers most of the client with hoarding behaviours were identified with 2nd or 3rd degree hoarding issues.

Isolation

In this survey 71.4% of the providers reported that the clients they see with hoarding problems are typically living alone. Social isolation is a determinant of health that is characterized by the lack of contact with other people in normal daily living. The Organization for Economic Cooperation and Development (OECD) defines social isolation as “both symptom and a cause for social distress.” 75% of providers surveyed believe that their clients with hoarding behaviours are socially isolated.

Hoarding Pets

According to the service providers 43% of the clients referred to in this survey have pets, generally cats or dogs, and 57% do not have pets. It is important to note however that not everyone who has pets or multiple pets is an animal hoarder. The common signs of an animal hoarder are the same as the signs for hoarders of other items including denial or lack of insight that a problem exists.

Safety

64% of the responding service providers felt that their client's hoarding was a risk to their personal safety and 21.4% identified that the hoarding behaviour was a risk to those around them as well.

Types of Things Hoarded

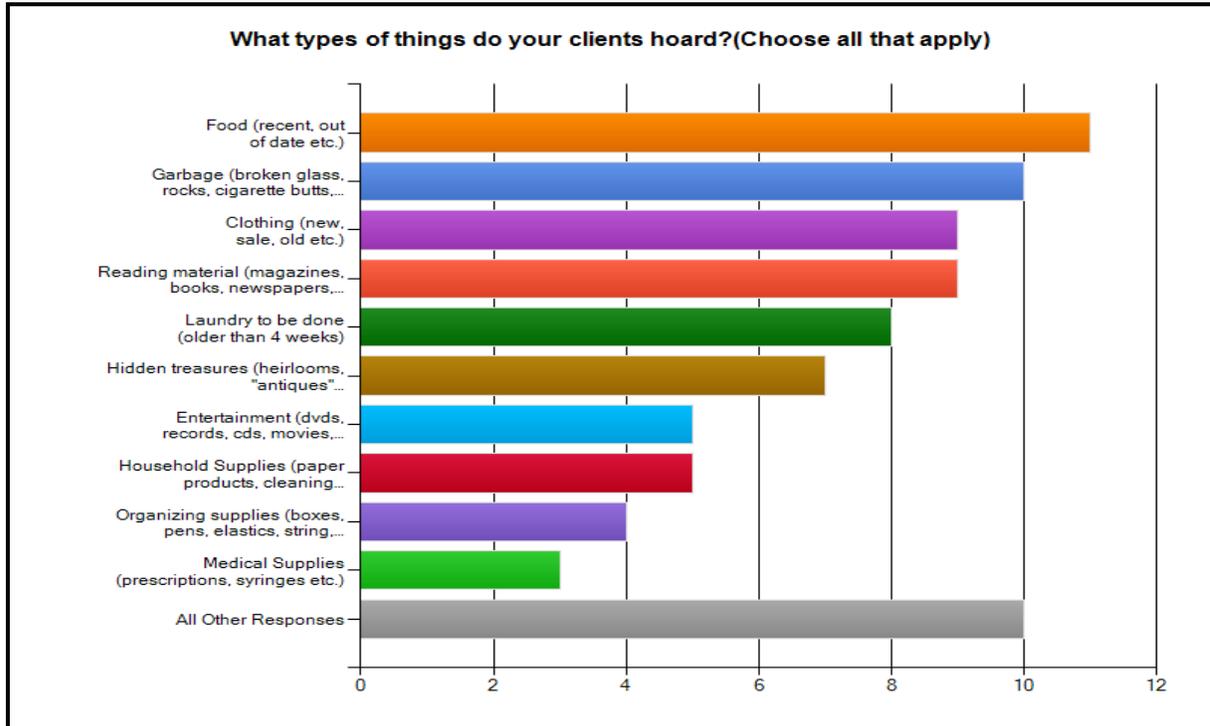
"My client collects stuffed animals; they won't let you in the house."

- Service Provider Comment

"... people with hoarding problems often become emotionally attached to items that strike the rest of us as junk, or to pieces of paper that aren't particularly interesting." Hoarders may become anxious and angry at the mere suggestion of getting rid of items that they've held onto for years. They often say that if they throw something away, they may need it someday when it will be impossible to retrieve. So they collect scraps of paper with shopping lists from years ago. They may hold on to old clothing, extra furniture, used envelopes, clothing price tags, soda cans, string, leaves, even cigarette ashes, burned-out light bulbs, used tea bags, and toilet paper cores. One woman saved wishbones from chickens because "one day they will be used for making wishes." Another collected clothes that weren't her size because she "might run into someone who needs them someday." (Richard Trubo, MedicineNet)

Based in provider responses the top five items hoarded by their clients include food, garbage, clothing, reading material (books, newspapers), and laundry to be done (dirty clothing, bedding). Other items were also noted as being hoarded to a lesser extent.

Items Clients Hoard

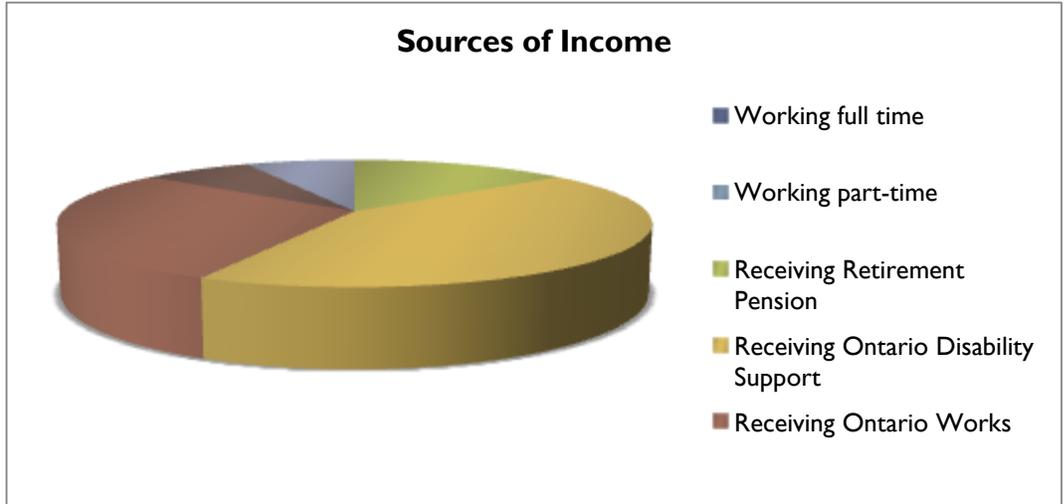


Income

There is a misconception that hoarding behaviours are synonymous with low-income or living in poverty. In fact, hoarding behaviours can be found across income groups. However, lower income individuals and those receiving social assistance may experience greater difficulty due to the lack of financial resources and supports to address the problem, particularly clean-up, or to fight an eviction order.

The service providers responding to the survey typically serve individuals who are low-income or not working. The majority of clients were identified as receiving a retirement pension, Ontario disability support or Ontario Works. A smaller portion of the clients are noted to be working either full-time or part-time.

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Service Supports

Providers were asked to identify what services and supports they felt were available for their clients who are hoarding. The following is a summary of their responses based on their understanding of whether or not services were in place or are needed.

Support Services Top 5 Responses

<i>Services that are available</i>	<i>Services that have been used for client service</i>	<i>Services that are needed</i>	<i>Not sure if the services exist</i>	<i>Services that are not available</i>
Health / mental health	Health / mental health	Financial Aid for transportation to Appointments	Cognitive Behavioural Therapy	Cognitive Behavioural Therapy
Ontario Works	Ontario Works	Social Housing / Subsidized housing	Property standards	Age appropriate services
Ontario Disability Supports	Ontario Disability Supports	Financial aid for clean-up or moving storage	Self help groups	Financial aid for clean-up or moving storage
Social Services	Social Services	Affordable cleaning and organizing services	Support groups	Affordable cleaning and organizing services
Legal clinics	Public health	Public Health	Social supports	

Summary of Service Provider Comments

Some providers felt that there may be many services available to individuals with hoarding behaviours but noted that often hoarders are isolated and withdrawn from society or family and are unwilling to accept assistance. It was also noted that hoarders are often deemed incompetent to make the decisions that are needed about hoarding which makes the solution very difficult and challenging. Providers noted that they often don't see or become involved with the hoarding problem until there is the threat of eviction.

It was also noted that the reluctance or even refusal of the individual client to participate in changing the behaviour and working with others creates additional challenges. Problems such as the client not allowing people into their home, poor follow-up, the client's lack of insight into the problem and the lack of a support system as further challenges to addressing the problem of hoarding.

Services providers were also asked about existing services that could be strengthened or supported to help clients. Responses are categorized as follows:

- Increased support and resources for clean-up including funds to pay for clean-up, removal of items, organizing, cleaning, instruction in food management and support services for individuals under age 65
- Mental health supports for appropriate problem identification and/or diagnosis, counseling, management, support and referrals
- Development of Home Management teams to assist hoarders with managing clutter and cleaning
- Better communication and coordination between service providers so that everyone has an understanding of the challenges
- Increased home interventions by a range of providers through home visits, group work and engaging others

Lessons from Ottawa and San Francisco

This preliminary survey suggests that there needs to be a coordinated response to hoarding in Hamilton. This response while unique to Hamilton does not need to be a reinvention of the wheel; fortunately there are many models and examples to draw upon.

In 2007 the Ottawa Public Health Department took steps to respond to the findings and recommendations of the Ottawa Community response to Hoarding Coalition's report "No Room to Spare". The Coalition's recommendations were described in four theme areas which are:

- Theme 1: Need for a centralized, specialized hoarding team with leadership and coordination functions
- Theme 2: Need for further education and training for “responders, politicians and the general public about hoarding of both animals and inanimate objects.
- Theme 3: Clarification and coordination of the issue of confidentiality and associated acts
- Theme 4: Need for capacity building in the areas of treatment and referrals.

Similarly The San Francisco Task Force on Compulsive Hoarding gathered data locally and found that hoarding behaviours in their communities had substantial impact on individuals, organizations and landlords. They were able to summarize the financial impact of hoarding and estimated that hoarding cost over a million dollars a year (\$1,166,105). These expenses were incurred by service providers estimated at \$502,755 and landlords estimated at \$663,350.”² The task force was not able to estimate the cost of hoarding to individuals. Overall the task force provided a conservative estimate of the cost of hoarding to service providers and landlords of \$6.43 million (US) dollars a year. They further noted that the human cost of hoarding is incalculable in the lives of families and individuals. Based on their findings the Task Force made eight (8) recommendations as follows:

Recommendations of the San Francisco Task Force on Compulsive Hoarding

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.

² (San Francisco Task Force on Compulsive Hoarding, 2009)

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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.

Developing a Model for Hamilton

The information and experiences of other groups and cities that have engaged in processes to address hoarding provides a framework for the development of a unique response to hoarding in Hamilton. The goal of a Hamilton response would be to maximize the use and coordination of existing services so that agencies and providers can work together more effectively build systemic capacity to address treatment and crisis prevention related to hoarding.

Clearly education, both client and provider, must be a critical part of the model. In addition, focusing on existing resources and creating a plan for the use of services will help in better identifying service gaps and where additional resources are needed.

Recommendations for Next Steps

The San Francisco Task Force on Compulsive Hoarding explained that “Effective treatment programs for individuals with hoarding behaviors are often seen as costly to implement. Yet as the data 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.”³

Based on the service provider survey, comments and discussion, current literature the following recommendations are made to address the problem of hoarding in Hamilton and to reduce evictions, prevent homelessness and improve the quality of life for people with hoarding behaviours. There are seven (7) recommendations in three categories: Coordination and Organization, Education and Knowledge Building; and Building Capacity in the Community. The recommendations are noted as follows:

Recommendation #1: Coordination and Organization

Implement a cross-agency collaborative network to address Hoarding and Cluttering in Hamilton. Identify / agree on a lead agency that will have responsibility for developing the network and overseeing the implementation, follow-up and evaluation of the recommendations

Recommendation #2: Education and Knowledge Building

- a) Implement a health promotion strategy to raise the level of understanding amongst clients who are hoarding, family members, landlords and community members about the supports and services available. Raise awareness amongst funders and decision makers

- b) Conduct a community scan of current needs and services for client who hoard in Hamilton and identify gaps and barriers for clients and challenges of service providers.

Recommendation #3: Building Capacity in the Community

- a) Using a cross-agency collaborative approach develop a model to address hoarding and cluttering in Hamilton using existing resources where possible and advocating for additional resources where needed.

- b) Develop or adapt tools for providers, landlords, family members and others to use in identifying hoarding or cluttering and establish a process for addressing crisis situations

- c) Create a service roadmap for people with hoarding behaviours and their families, service providers and landlords so that people know what

(San Francisco Task Force on Compulsive Hoarding, 2009)³

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- agencies to contact in different situation and have a way to identify and seek assistance.
- d) Create a multi-disciplinary Response Team that will be able to provide assessments, interventions, case management and support to individuals and groups for individuals at the different stages of dealing with their hoarding behaviour.

References

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Understanding OCD website

Appendix 1

The following are sample tools used to help providers and clients determine the degree of hoarding in two rooms: living room (Appendix 1) and bedroom (Appendix 2). These tools and workbook can be found in the book *Compulsive Hoarding and Acquiring: Workbook* Gail Steketee and Randy O. Frost, November 2006

Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



8



9

Appendix 2

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



8



9