

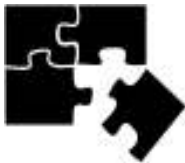
Survey of Key Stakeholders in Hoarding Behaviour Treatment

Final Report #2

Prepared for:

The Ottawa Community Response to Hoarding Coalition

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1. Introduction

Standing in a grocery store line provides one with an opportunity to browse popular magazines about what is capturing the attention of North Americans in today's society. Five out of seven covers during the summer of 2007, when this study was conducted, highlighted various articles about "clutter".

Service providers in Ottawa have been collaborating since 2003 to address this issue as the ***Ottawa Community Response to Hoarding***. A strategic plan was developed in 2006 that identified the knowledge and skill development of treatment and support workers as a priority in assuring appropriate interventions in preventing and/or controlling hoarding behaviour.

The literature¹ identifies interventions that positively impact the internalized process of change behaviour as essential to avoid repeated relapse. Repeated relapse is a hallmark of hoarding behaviour which causes a cyclical and repeated risk of eviction or loss of accommodation due to fire or other housing crises. Top international experts² agree that treatment for the reasons people hoard holds the best chance for long term success in promoting change behaviour, stabilizing housing, and reducing the risk of homelessness.

Research funding to further explore the knowledge and skill development needs of treatment and support workers was made available to the Coalition in 2007 by Human Resources and Social Development Canada, Homelessness Partnering Secretariat. The findings of the study: *Survey of Key Stakeholders in Hoarding Behaviour Treatment* - form the basis of this report.

Additional information from a study completed in 2006³, about the profile of hoarders, as well as the nature and types of hoarding activity, has been added to this version of the report - *Final Report #2*. This additional information, plus expanded descriptions of the 2007 study findings, will help readers who are unfamiliar with "hoarding" better understand the issue.

¹ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding (Literature Review). Ottawa.

² Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding (Literature Review). Ottawa.

³ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding (Literature Review). Ottawa

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1.1 What is Hoarding?

Cluttered living space to the point of precluding use of the kitchen, bathroom and bedroom is known as hoarding. People who hoard put their own health and safety, and the lives of their neighbours at risk. Fire hazards abound and rodent and insect infestations can create a neighborhood nuisance and provide a medium for infectious diseases.

Hoarding is usually considered a manifestation of Obsessive Compulsive Disorder (OCD)⁴. It may occur alone or in the context of other disorders such as Dementia⁵, Schizophrenia⁶, eating disorders, mental retardation, and Obsessive-Compulsive Personality Disorder (OCPD)⁷. Relatively little research has been done on this problem despite its close association with OCD. Social Phobia⁸ and Depression⁹ have also been found to be closely associated with compulsive hoarding and are linked to findings of isolation and limited social networks among elderly hoarders. Hoarding behavior can result in serious and even life-threatening pathology and may be an indicator of poor prognosis in the treatment of OCD.

⁴ A psychiatric anxiety disorder most commonly characterized by a subject's obsessive, distressing, intrusive thoughts and related compulsions (tasks or "rituals") which attempt to neutralize the obsessions.

⁵ An acquired loss of cognitive function that may affect language, attention, memory, personality and abstract reasoning.

⁶ A mental illness characterized by delusions, hallucinations, disturbances in thinking and withdrawal from social activity.

⁷ A personality disorder that is characterized by a general psychological inflexibility, rigid conformity to rules and procedures, perfectionism, moral code, and/or excessive orderliness. OCPD is often confused with (OCD). This could be due to the more commonly known OCD and the similarities in name of the two disorders; however the mindsets are typically different and unrelated.

⁸ An anxiety disorder characterized by overwhelming anxiety and excessive self-consciousness in everyday social situations. Social phobia can be limited to only one type of situation — such as a fear of speaking in formal or informal situations, or eating or drinking in front of others — or, in its most severe form, may be so broad that a person experiences symptoms almost anytime they are around other people.

⁹ A common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration.

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There are 3 defining features of compulsive hoarding:

1. The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value;
2. Living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and,
3. Significant distress or impairment in functioning is caused by the hoarding.

These features distinguish hoarding from the collecting of objects generally considered interesting and valuable. Collecting is not considered pathological unless accompanied by extreme clutter. Clutter in the homes of those who hoard is extremely disorganized and valuable objects are commonly mixed with trash.¹⁰

Other terminologies commonly used in the literature and related to hoarding are: Diogenes Syndrome (DS); self neglect; excessive collecting; and excessive cluttering. DS, self-neglect, age reclusion, social breakdown of the elderly, and squalor syndrome are synonymous and refer to a situation in which an elderly person living alone is not able to provide him or herself with the services necessary to maintain an adequate level of physical and mental health¹¹.

Individuals who hoard may be generalists or specialists. The generalist tends to retain everything that comes into their possession. The specialist tends to retain one type of item or a limited class of items. People who gather large numbers of animals or newspapers are specialists while the generalist will have every piece of mail, every newspaper, all the food wrappers and containers, etc. that ever came into their home. In the extreme, the generalist will hoard all their excrement, their shed hair, used bandages, and so on¹².

¹⁰ Steketee, G. Frost, R. Kim H-J. (2001). Hoarding by Elderly People. National Association of Social Workers. CCC Code: 0360-7283/01

Steketee, G., Frost, R. (2004) Cognitive Behavioral Treatment Manual for Compulsive Hoarding & Addendum.

¹¹ Reyes-Ortiz C. (2001) Neglect and Self-Neglect of the Elderly in long-Term Care. Annual of long Term Care: Clinical care and Aging 2001; 9(2):21-24

¹² Dane County (2001). This Full House.
www.co.dane.wi.us/aging/elderabuse/pdf/hoardingtaskforcereport.pdf

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More specific sub typing of hoarding¹³ uses the following terminology:

- 1) *Common Hoarding* of items similar to all items people save. Sometimes it is accompanied by other OCD symptoms;
- 2) *Diogenes Syndrome (DS)* involving self neglect, domestic squalor and hoarding of items often considered trash;
- 3) *Animal Hoarding* involving the accumulation of a large number of animals and failure to:
 - Provide minimal nutrition, sanitation, and veterinary care;
 - Act on the deteriorating condition of the animals or the environment;
 - Act on or recognize the negative impact of the collection on their own health and well-being.

1.2 What Causes Compulsive Hoarding?

Although the ultimate cause of compulsive hoarding is unknown, Steketee & Frost¹⁴ have proposed a Cognitive Behavioral Model of Compulsive Hoarding. This model suggests that hoarding is based on the following interrelated deficits or problems:

1. *Information processing* - Anecdotal observations linking Attention Deficit Hyperactivity Disorder¹⁵ (ADHD) to hoarding have been noted which may contribute to the disorganization difficulties seen in hoarding. Difficulty with decision-making, complex systems of categorization and inaccurate judgments about the importance of things can also be evident.
2. *Beliefs about and attachments to possessions* - This involves sentimental attachment and control over objects, consideration of possessions as part of their identity, and comfort derived from possessions when they are seen

¹³ Steketee, G., Frost, R. (2004) Cognitive Behavioral Treatment Manual for Compulsive Hoarding & Addendum.

Patronek, G., The Hoarding of Animals Research Consortium. (2001) The problem of Animal Hoarding, Municipal Lawyer, May/June 2001 pages 6-9, 19, Washington, D.C.

¹⁴ Steketee, G., Frost, R. (2004) Cognitive Behavioral Treatment Manual for Compulsive Hoarding & Addendum.

¹⁵ A syndrome (a group of symptoms or signs) that is usually characterized by serious and persistent difficulties resulting in: inattentiveness or "distractibility", impulsivity, and hyperactivity.

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as a safe and secure environment in a dangerous world. It may be excruciating to have others touch or use their belongings.

3. *Emotional distress and avoidance behaviours* - Resisting acquiring items or attempts to discard possessions is associated with a feeling of loss not unlike what people experience when losing a loved one. On the other hand acquiring items can be associated with positive emotions, even a “high” feeling.

1.3 Barriers to Addressing Hoarding¹⁶

In many North American communities, if a hoarder resists recommendations to improve conditions, the only recourse may be through the legal system. Besides being inefficient and expensive, this moves what may be a mental or public health issue into the criminal justice arena, which can impede timely recognition of important health issues and delivery of needed services.

Some communities have passed laws that attempt to place the burden of paying for clean up and animal care on to the hoarder, but this approach fails to address many other problems related to human health and well-being and is moot when the hoarder is destitute. Existing laws also tend to prevent elderly people from being easily ousted from their homes.

The range of agencies involved may pose difficulties when a model of service delivery is not in place. Namely, whose problem is it, and who should take responsibility for sorting it out? Arguments may ensue about whether the client is mentally ill, extremely eccentric or plain bloody minded. Other barriers evolve from professional training orientations, administrative procedures, and eligibility rules. Service agency staff are typically trained in rather narrow, specialized fields such as mental health or criminal justice services, and may not feel comfortable dealing with other issues or working within an interagency framework. Bureaucratic procedures often obstruct collaborative efforts because agencies may insist on following their own intake and case processing procedures, and confidentiality requirements may limit their ability to share information about clients. Siloed public and private funding also perpetuate single-issue programs. As long as legislatures and funders structure programs to address specific problem areas, single-issue programs will continue to have difficulty making their services available to populations not specified by their mandate.

¹⁶ Dinning, L, (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding (Literature Review). Ottawa.

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2. Purpose of the Study

This study was designed to begin the identification of skill and knowledge needs amongst licensed health care practitioners and support workers that could lead to the development of successful interventions for hoarding behaviour. The study was also designed to produce qualitative data and anecdotal information valuable to building effective strategies in offering people help with the reasons they hoard.

Expected deliverables were:

- A user-friendly report of the results of the primary data collection activities that identifies:
 - The needs of hoarders with respect to treatment options and access to community resources;
 - The information needs of licensed health care practitioners and community service providers;
 - The preferred methods of information transfer to practitioners and service providers; and,
 - The willingness of practitioners and service providers to work together to increase the awareness of issues related to hoarding behaviour.

- Produce questionnaires and resources that can help Ottawa stakeholders continue to monitor and respond to the needs of those who hoard or provide services to those who hoard; and other communities wishing to conduct a similar survey.

Recommendations regarding the prevention of eviction and homelessness due to hoarding have been added to this second version of the report.

2.1 Methodology

A qualitative approach was taken to conduct the survey of key stakeholders in hoarding behaviour treatment. The consultants worked closely with representatives of the Ottawa Community Response to Hoarding Coalition to finalize the overall design for the survey, identify sample sources and strategies, and finalize the data collection instruments and overall research protocol such as protection of respondent confidentiality. The coalition included approximately 35 representatives from both the community service provider constituency as well as the medical and clinical community during the period this project was undertaken.

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Member organizations of the Ottawa Community Response to Hoarding Coalition in 2007 are listed in Exhibit 1. In addition, consumers (clients who hoard) occasionally participated in the Coalition.

Exhibit 1 – 2007 Member Organizations of the Ottawa Community Response to Hoarding Coalition

Canadian Mental Health Association - Ottawa	City of Ottawa
Carlington Community Health Centre	• Ottawa Fire Services
Centretown CHC	• Ottawa Public Health – Health and Social Crisis Program & Health Inspection
Community Care Access Centre	• Ottawa Property Standards and Bylaw Services
CRC basse-ville	• Employment and Financial Assistance - Ontario Works
Eastern Ottawa Resource Centre	• Ottawa Police Services
Geriatric Psychiatry Community Services of Ottawa	• Home Help Program
Good Companions Centre	Children's Aid Society
Housing Help	Elizabeth Fry of Ottawa
Human Resources Social Development Canada	Gem Healthcare Services
Nepean CRC	Ottawa Hospital –Mental Health Crisis Unit
Nepean Housing	Ottawa-Carleton Association for Persons with Developmental Disabilities
Options Bytown	Project Upstream
Orleans-Cumberland CRC	Royal Ottawa Hospital
Ottawa Community Housing	St. Joe's Women's Centre
Ottawa Humane Society	The Glebe Senior's Centre
Pinecrest-Queensway CHC	Visiting Homemakers Association
Sandy Hill CHC	Western Ottawa Community Resource Centre
Shepherds of Good Hope	Yearwood Efficient Solutions
South East Ottawa Centre for a Healthy Community	
Vanier Community SC	

Other organizations connected through an electronic distribution list included:

Action Logement	Causeway Clubhouse
Ontario Ministry of Agriculture	Faith Groups
Minto Management	Family Services of Ottawa
Queensway Carleton Hospital	Help the Aged
Senior's R Us	Home Management Services
Service d' Entraide	Ontario Ministry of Agriculture

Representatives of these organizations, in turn opened the doors to obtaining a representative sample of local community service providers and licensed health practitioners, as well as persons with hoarding behaviour.

To obtain as representative a sample as possible of persons who hoard, plus treatment & service providers, a multiple sampling strategy was used.

The strategy included:

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- Collaborating with community service providers including community resource centres, senior centres, etc.;
- Posting notices about the study in strategic locations including doctors' offices, senior centres, etc.;
- Telephone calls to identified local Psychiatrists, Psychologists and Physicians;
- Sending a flyer seeking key informants to:
 1. The Coordinator of the Ottawa Community Based Psychiatrist's Continuing Education Series for distribution to the membership of Ottawa's Community Based Psychiatrists;
 2. The Coordinator of Continuing Education for Psychiatrists between Ottawa University Medical School and the Royal Ottawa Hospital;
 3. Key stakeholders in community and hospital based medical and mental health treatment;
 4. Consumers who have in the past contacted the Coordinator of the Ottawa Community Response to Hoarding Coalition for consultation (Flyer was adapted for this group).

The survey employed several modes of data collection, depending on the respondent group and purpose, including: face-to-face interviews, telephone interviews, self-administered questionnaires and focus groups. The content of the various data collection instruments was designed to address the objectives of the study.

Telephone and face to face interviews were conducted with individuals exhibiting hoarding behaviour. Each interview took about 30 minutes. In total, 10 persons with hoarding behaviour, of the 13 contacted, agreed to participate in the study.

Telephone and face-to-face interviews were conducted with licensed health care practitioners. In a few instances, respondents preferred to complete the questionnaire on their own time and thus a self-administered instrument was designed to accommodate those individuals. The telephone survey was about 20 minutes in length. In total, 16 licensed health care practitioners agreed to be interviewed from the 30 contacted directly by the consulting team.

Two focus groups (one in English and one in French) were conducted with community service providers to obtain their input. The groups were about 90 minutes in length and were facilitated by an experienced focus group moderator. Several individuals, who were unable to attend, sent responses via e-mail to the focus group questions. A total of 24 community service providers participated. All members of the coalition and its associates (representatives of 35 plus organizations) were contacted with an invitation to participate.

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Appendix A provides a copy of the instruments used in the survey including the:

- Survey for persons who hoard;
- Telephone survey for medical practitioners;
- Self-administered questionnaire for medical practitioners;
- Focus group moderator's guide;
- Field instructions and tips for others wishing to conduct similar research.

As with all survey research of a more sensitive nature, this study was not without its challenges. Key to the final results of the study was the sudden loss of leadership to the coalition when the Coordinator's position was eliminated due to an internal reorganization at her agency. The resulting instability of the coalition led to decreased attendance at the final focus group for community support workers, and a loss of commitment by those workers to identify clients who hoard and health practitioners to be interviewed.

Other challenges included: the willingness of identified individuals who hoard to be interviewed; convincing busy professionals to participate in yet another study; scheduling focus groups at a time when the maximum number of persons can attend; and completing a study of this nature in a relatively short time period including summer holidays.

For the most part these challenges were met through collaboration among representatives of the Ottawa Community Response to Hoarding and the consultants. One agency allowed their coalition representative to become the liaison with the consulting team when the Coordinator role was lost; while the consulting team sought additional health professionals to interview to meet the requirements of the study.

The most important lesson learned was the confirmation of strong community commitment in Ottawa to addressing the issue of hoarding – a commitment that overcame the change in project leadership and allowed for the continuance of the coalition a year later when the second version of this report was released. This study would not have been completed without the dedication of coalition members and the former Coordinator, who continued working on the project as a volunteer after her employment ended.

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3. Results

In order to further inform the training and information needs of licensed health care practitioners, community service providers and individuals with hoarding behaviour; relevant information collected during the development of the coalition's strategic plan in 2006¹⁷ has been incorporated into the results section of this report.

3.1 Interviews with Individuals Who Hoard

Interviews conducted with individuals with hoarding tendencies were conducted for both the 2006¹⁸ and 2007 studies. In both instances, considerable time was needed in convincing contacts to follow through with interviews.

In general, respondents as a group had little experience with one-to-one treatment or support providers. Those that did seek assistance found little value in the experience with some commenting on the lack of knowledge about hoarding exhibited by their treatment or support worker. Assistance from families was also shunned by most.

Most looked to self help sources such as web sites for support if they were interested in help. Although none had any experience with self help support groups, some expressed interest in this form of help.

The following sections provide more details about the interview results from both studies.

3.1.1 Respondent Profile

Thirteen individuals were identified by members of the Ottawa Community Response to Hoarding Coalition as being willing to be interviewed by the consulting team in 2007. Ten individuals were eventually interviewed for this study.

Respondents to this study were predominantly middle aged single females living on their own in either rented (50%) or privately owned (50%) homes. Seven were

¹⁷ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding.

¹⁸ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding.

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female; two were male, and one transgendered¹⁹ (male to female). Nine lived alone at the time of the study, while one lived with her husband and two children.

One respondent was under the age of 25, seven were between the ages of 45 & 64, and two were older than 65. Nine respondents were born in Canada and one in the Bahamas. Eight felt most comfortable speaking in English. The mother tongue of two respondents was French but they were willing to be interviewed in English.

Three respondents described their health as good. Another three described their health as very good. None described their health as excellent, while one described poor health. Three respondents who were working at the time of their interview described their health as affecting their ability to work.

Sixty percent of the respondents were working full or part time at the time of their interview. Of the three respondents employed full time, one worked out of her home and one professional expected to leave work shortly due to her health. Of the three working part-time, one owned her own business. Of those not working: two respondents were retired, while two respondents were on disability or too ill to work.

Six individuals described their hoarding behaviour as preventing them from doing the things they like on a daily basis. Another three respondents described their behaviour as *sometimes* preventing them from doing things they like on a daily basis; while one said it did not affect her daily activity.

One individual expressed the following concern, "*I can see a family trait of hoarding emerging in myself*". Service providers in describing clients during focus group sessions for this study noted similar family histories.

The profile of respondents for this study mirrors that of respondents who hoard interviewed for the development of the coalition's strategic plan in 2006 and the profile of individuals who hoard described in the literature review for that study²⁰.

2006 Study

Of the five people interviewed for the 2006 study, all were single or divorced, living alone, well educated and middle aged or older. Two of the five were employed in professional positions. One worked from home and another rented out part of her home for income. Three of the five individuals were women.

¹⁹ Appearing as, wishing to be considered as, or having undergone surgery to become a member of the opposite sex

²⁰ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding. Ottawa.

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Similar to those interviewed for the 2007 study, most were experiencing a decline in their physical and mental health and spoke of a lack of energy and motivation. Two had been injured due to clutter in their homes. One was not eating regularly as he was no longer able to use his kitchen.

Other insights into the profile of people who hoard can be drawn from the literature review conducted for the 2006 study. According to the literature, hoarding may be more prevalent in the elderly; or it may be that more elderly hoarders are identified. Within this group, one study identified 44% as having mental illness; nearly 66% demonstrating difficulty with self-care, and; 80% physically in danger due to their hoarding. The severity of hoarding appears to increase with age.

A low rate of marriage and high rate of divorce among people with compulsive hoarding is noted in the literature. Most elderly hoarders are female, unmarried, and live alone. Never married status is associated with more severe hoarding, greater impairment and possibly worse intervention outcomes.

Those who hoard were often described in the literature as having led successful professional and business lives with good family backgrounds and upbringing. Other frequently used descriptors include: independent, unfriendly, stubborn, obstinate, aloof, aggressive, suspicious, secretive and quarrelsome. An additional descriptor notes that more than 75% of hoarders have at least one 'pack rat' among first degree relatives. Family members may influence motivation for treatment if they condone or engage in the hoarding.

3.1.2 Treatment Experiences and Interests Related To Hoarding Behaviour

Respondents interviewed in the 2007 and the 2006²¹ study described limited experience with and desire for treatment.

Five respondents for the 2007 study had had some form of professional treatment (that being on a one-to-one basis). Those five individuals described their one-to-one treatment for hoarding as being provided by a Social Worker (4 individuals), a Psychologist (2), and by a Psychiatrist (1). One received multiple referrals to the various professionals listed from a Community Care Access Centre (CCAC) worker.

Two of the five individuals receiving one-to-one professional treatment said the treatment helped. One individual living in supportive housing noted that a monthly fire inspection requirement, information about how to sort belongings, a

²¹ Dinning, L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding.

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letter outlining requirements to prevent eviction, and opportunities to talk to his housing worker (a Social Worker) about his hoarding behaviour all helped him to keep on track. The other respondent felt one-to-one treatment provided an opportunity to talk to professionals about his hoarding behaviour and possible solutions.

Three of the respondents receiving professional help stated they did not find one-to-one treatment helpful, although two of these individuals described some benefits. One woman stated, *“Even though there have been slight improvements, by looking at my apartment it is now worse than before. But I know what questions to ask myself, such as – do I need this?”* Another respondent felt she had to respond no because she had just started working with a social worker and was unsure if it was going to help. She was, however, finding the phone contact somewhat helpful in understanding why her hoarding behaviour started. She also disclosed that she was being treated for depression and that her situation had somewhat improved. The third individual stated that the Social Worker assisting her did not know how to approach the issue. *“He was too pushy and made any interaction very stressful!”*

One respondent described a family intervention as a form of (non-professional) treatment. This intervention was led by the family itself and helped as the family was able to assist with cleaning when the respondent was not mentally able to accept help from others.

Positive assistance could not be attributed to any one particular group or profession of treatment providers. One individual with hoarding behaviour, and service providers in one focus group, described experiences with a one-to-one approach using a coordinated team of professionals as being very successful.

None of the respondents had been involved in a group treatment session.

3.1.3 Suggested Improvements to Treatment

When asked about how the treatment they had received could be improved, one respondent to the 2007 study noted a preference for support by phone, one for treatment in his home, while the others preferred a hospital or community setting.

One respondent said his preference was not to include family members in any treatment approach while another was interested in such an option as long as the session leader was knowledgeable. One man described attending an information session for the general public on hoarding that he found helpful. Another expressed concern about the knowledge level of the individual working with him in regards to hoarding. At the time of the interview, he felt he could have done better on his own with medication prescribed by a Psychiatrist. One woman

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commented; *“I should have gone more often – my appointments were every couple of months, not weekly or bi-weekly which would have been my preference”*. A team approach is needed according to another respondent.

Group treatment with a moderator was suggested by three respondents. One said, *“We would learn from each other”*. *“Participants could include people who hoard, people with and without hoarding behaviour, and other family members”*, according to one respondent. A community setting was recommended by all for group treatment.

A professional organizer was also suggested but that respondent commented, *“You need to be at the stage where throwing stuff out is acceptable”*.

3.1.4 Treatment Preferences for Those with No Treatment Experience

Half of the ten people interviewed in the 2007 study stated they had not received any professional treatment. Of these five, four would have liked to have had some help. The other respondent did not see her hoarding as a problem, but said her family did.

Those wishing they had had professional treatment made the following comments:

- *“I know I need treatment but I don’t know how to get started in addressing my hoarding behaviour.”*
- *“I can see a family trait of hoarding emerging in myself.”*
- Two respondents described themselves as becoming more isolated from friends and family due to their hoarding.

Three of the four respondents never having received treatment, but interested in treatment, expressed interest in both one-to-one treatment, and a group treatment approach led by a professional. The fourth respondent, who had had no treatment, and was somewhat ambivalent about the need for treatment, indicated she would consider treatment provided by someone on a one-to-one basis; *“As long as it was not a Social Worker”*. She would also be interested in hypnotism, but not ‘talking’ treatment. *“A family group session was not of interest”*, she stated. *“My mother just wants to empty my house.”*

Two of the three respondents interested in one-to-one treatment would consider assistance from a Psychologist. The third respondent indicated interest in assistance from a Psychiatrist, a Psychiatric Nurse or a professional organizer/declutterer. Two would consider treatment in their home while the other preferred a treatment provider’s office.

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Of the three individuals willing to consider group treatment, two preferred participants to be only people with hoarding behaviour. The other was willing to also meet with people who did not have hoarding behaviour, including family members: *“Participants could include people who hoard, people with and without hoarding behaviour, and other family members”*. Interest in internet on-line self help groups was also expressed by one individual. Respondents indicated a preference for a community or hospital setting for group treatment. No preference was stated for who should lead a family session.

Individuals interviewed for the 2006²² study also expressed interest in self help techniques that could be accessed via the internet and through support groups.

3.1.5 Experiences in Seeking Treatment

The five respondents in the 2007 study who had not received treatment were asked about their experiences (if any) in seeking treatment.

One stated he didn't try very hard because he was worried about losing control over his belongings. The other four didn't know where to start, couldn't find anyone trained in this area, didn't know treatment was available, or didn't see hoarding behaviour as a problem.

3.1.6 Suggestions for Others Who Hoard

Both the 2007 and 2006 study respondents provided suggestions and comments for other individuals who hoard, and for coalition members about how they could assist those with hoarding behaviour:

- *“It is helpful to be prompted and to have a check list to follow e.g. have a clear path to another exit.”*
- *“The website Fly Lady <http://flylady.net/> is helpful in maintaining day to day structure”*. Several other websites and self help resources were suggested by a 2006 study respondent:

<http://www.ocfoundation.org/1005/index.html>

<http://clutterless.org/>

<http://spaceclearing.com/>

<http://nsgcd.org/>

²² Dinning. L, (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding. Revised by L. Bonnie Dinning Consulting Services & Christine Davis, Social Data Research Ltd
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Making Peace with the Things in Your Life – Cindy Glovinsky
Overcoming Compulsive Hoarding – Fugen Neziroglu
Organizing from the Inside Out – Julie Morgenstern
Stop Clutter from Stealing Your Life – Mike Nelson

- *“Don’t punish yourself for not controlling hoarding. I won’t allow myself to go out because I have not dealt with cleaning my home and this isn’t good. This is all related to self esteem.”*
- *“Don’t live alone. Meet with people who understand hoarding and others with the same problem.”*
- *“Let them know they are not alone and that there are treatment opportunities”*
- *“It causes disinterest in finding help for yourself.”*

3.2 Interviews with Licensed Health Care Practitioners

Sixteen of the thirty Licensed Health Care Practitioners contacted regarding this study agreed to be interviewed.

Thirteen of the practitioners interviewed were Psychiatrists. Of these, nine respondents were working in the community, three were working in hospitals and one was retired. One of the hospital based Psychiatrists also worked in the community.

Two community based Psychologists were interviewed. Of these, one was also hospital based. Only one Family Physician of the ones approached agreed to be interviewed.

For the most part those interviewed expressed limited experience with and knowledge of hoarding behaviour. Information about treatment options was the most cited need. Practitioners were also interested in knowing how to coach clients regarding their hoarding behaviour, or where they could refer clients for such support.

The following sections provide more detail about the results of interviews with licensed health care practitioners.

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3.2.1 Experience with Clients Who Hoard

Community based Psychiatrists, including a retired Psychiatrist, cited more years of experience in treating clients with hoarding or possible hoarding behaviour (10 or more years on average), than hospital based Psychiatrists (less than 6 years). A third of the community based Psychiatrists qualified their responses regarding their number of years experience in treating hoarding as responding to the number of years in practice during which they treated mental illnesses thought to be associated with hoarding.

Both interviewed Psychologists had less than 7 years experience in working with clients who hoard. The one responding Family Physician cited her years of experience in treating clients as 0 because she had not encountered “hoarding” during her 28 years of practice.

3.2.2 Hoarding Behaviour Knowledge

When asked to rate their knowledge with respect to hoarding behaviour by using a scale of 1 to 10 where: *1 = could use a lot more information, and 10 = I'm very confident about my level of knowledge about this disorder*, respondents replied as follows:

- The hospital based Psychiatrists rated their knowledge within a range of 5 to 8 with an average of 7.3.
- The community based Psychiatrists rated their knowledge within a range of 3-9 with an average of 6.3. One commented, *“I would rate my general knowledge about the disorder as 5 but my knowledge of treatment as 0”*.
- The retired Psychiatrist rated her knowledge as 3.
- The community based Psychologists rated their knowledge within a range of 6-8 with an average of 7.
- The community based Family Physician rated her knowledge as 0.

3.2.3 Information Needs

In general, the health care practitioners interviewed for the 2007 study were consistent in identifying their key information needs. The most frequently cited information need across all groups was for more evidence based treatment

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options including both cognitive-behavioural approaches²³ and behavioural intervention strategies²⁴. In particular, hospital-based psychiatrists raised the need for information related to evidence based treatment of OCD hoarding including the Role of medication and Psychotherapeutic interventions. *“Hoarding is perceived as a very hard disorder to treat, yet it is so pervasive and such a negative influence on quality of life and Comorbidity”*²⁵.

Other areas of information need where there was general agreement among the different types of practitioners interviewed were:

- Epidemiology²⁶ of hoarding behaviour with a focus on prevention, early identification and differences about hoarding behaviour and treatment requirements for different diagnoses such as Asperger Syndrome²⁷, mental retardation/developmental disability and Schizophrenia;
- An understanding of how to deal with individual risks associated with hoarding such as: safety issues that might arise for hoarders in their homes including the danger of fire, falls or other injury due to accumulated items; competency considerations for the individual who is hoarding regarding their ability to make sound decisions about belongings; legal issues that need to be considered in establishing mental incompetency or accessing private property; and physical health issues that could arise for the person who hoards due to poor sanitation, self neglect and zoonotic disease²⁸;
- Easy to access practical resources for health care practitioners, family members and people who hoard such as a listing of local services designed to help de-clutter, clean and organize a hoarder’s home; as well as educational handouts and information about other resources including websites related to the identification and treatment of hoarding behaviour; and,

²³ Cognitive-behavioral therapy is an action-oriented form of psychosocial therapy that assumes that maladaptive, or faulty, thinking patterns cause maladaptive behavior and "negative" emotions. (Maladaptive behavior is behavior that is counter-productive or interferes with everyday living.) The treatment focuses on changing an individual's thoughts (cognitive patterns) in order to change his or her behavior and emotional state.

²⁴ There is a broad variety of interventions from which to choose. Both personal preference and severity of discomfort will influence the choice or combination of “talk therapy”, medication, participation in self-help groups, or inpatient treatment

²⁵ The term "comorbid" refers to a disease or disorder that occurs at the same time as another disorder but is not related to it.

²⁶Information on causes, controls and patterns

²⁷ Asperger Syndrome or (Asperger's Disorder) is a neurobiological disorder. It is presently described as an autism spectrum disorder

²⁸ Pertains to diseases transmittable from vertebrate animal to humans

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- Access to information on preventing hoarding and the impact of hoarding on the community

Some areas related to the need for information did not cut across all types of practitioners. For example, community-based Psychiatrists were more interested in gaining more knowledge about things such as the management of hoarding behaviour including treatment & medication options and motivation of clients as well as gaining access to research results about different diagnoses associated with hoarding. This group of respondents also mentioned the need for learning more about the reasons why people hoard and how to recognize the signs and symptoms to help identify hoarders in early stages and prevent more serious consequences for both hoarders and the community at large. Having access to helpful screening tools such as a set of standardized scales to assess and rate hoarding behaviour to help predict appropriate therapeutic interventions was also seen as important by community-based psychiatrists.

The Psychologists interviewed in the 2007 study were more interested in gaining information about treatment protocols and approaches (those established as empirically based best practices) including both cognitive-behavioural approaches and behavioural intervention strategies; how to encourage individuals to work on hoarding when in therapy for other related mental health issues; an assessment tool to be used by multiple disciplines in community-based and office-based settings; and access to “user friendly” fact sheet information related to different aspects of hoarding behaviour for use by agencies and clients.

Although only one Family Physician was interviewed in the 2007 study, this respondent did raise some interesting questions related to the need for more information. These were:

- Is there any evidence that screening individual patients by family physicians is helpful in determining whether or not a patient hoards?
- Is there any evidence that once a Physician is aware that a patient hoards that this knowledge by the Physician will be useful in changing a patient’s behaviour?
- Are there effective treatments to stop people from hoarding?
- What is the recidivism rate?
- Is there a screening device available for Family Physicians to use in their offices?
- In a family practice using only electronic medical records, is there a screening tool that can be used by the Physician (such as the Folstein score for dementia, or a depression score) that can be incorporated into the computer database?

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3.2.4 Tools and Resources to Improve Skills and Knowledge

Health care practitioners in the 2007 study were queried about their interest in a variety of information topics, tools, resources and training opportunities to improve their skills and knowledge. As responses were very similar, and no significant variations could be linked to any particular professional group, they have been combined in the following sections. As not all provided an answer for each question, the numbers responding to each question vary.

“How To” Information Topics

In the 2007 study health care practitioners were presented with a series of “How To” topics related to the care and treatment of people who hoard and asked to indicate their interest in knowing more about each of these topics for the purpose of their own practice.

Almost all (at least 14 of the 15 health care practitioners interviewed) indicated an interest in knowing more about the following topics:

How to help their clients:

- Improve their decision-making skills for possessions
- Learn problem-solving skills
- Organize their possessions to make them more accessible & more easily maintained in an uncluttered way
- Increase appropriate use of their space
- Reduce their compulsive buying or acquisition
- Remove (discard, recycle, sell, give away) unneeded possessions
- Evaluate their beliefs about organizing, acquiring, and discarding
- Prevent future hoarding
- How to link and work collaboratively with local on site de-cluttering coaches

Most health care practitioners (13 out of 15) also expressed an interest in knowing where to access evidence based prevention and treatment related resources. As well, respondents expressed interest in learning more about the differences in hoarding and its treatment in different diagnoses such as Asperger Syndrome, mental retardation and OCD, or a combination there of. A suggestion was made to look for possible models of treatment elsewhere to apply to hoarding, such as the addiction’s treatment model.

One respondent wanted information about how to approach the subject, taking into account the client’s anxiety, while another wanted to know how to help clients work with families wanting to help.

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Information Dissemination Methods

To learn more about the best way to disseminate information to health care practitioners, respondents were given a list of different types of common learning modalities. The most favoured approach (14 of 15 respondents indicated their interest in this approach) was attending short term intensive training sessions given by leading experts in the field. Most respondents (at least 10 of 15) would also have an interest in: attending an annual conference on hoarding related topics; having access to a dedicated interactive website on the topic of hoarding; and, receiving regular culturally appropriate²⁹ fact sheets or newsletters by Email.

Fewer, but still more than half of the health care practitioners who responded to the 2007 study would also value having access to DVD's/videos on particular topics that they could watch at their own leisure and share with others.

There was far less interest (5 or fewer respondents) in information dissemination methods such as: attending a "train the trainer" workshop so that information could be transferred to others; attending occasional workshops - perhaps 3-4 times a year - on specific topic related to hoarding; or, attending an ongoing course or courses (i.e., weekly classes) on a particular subject.

Resources Related to the Treatment of People Who Hoard

The 2007 study also explored the level of interest among health care practitioners regarding content-related resources that might be helpful in the treatment of people who hoard. Once again, respondents were presented with a list. In this instance, they were asked to rate each item on a scale of 1 to 3, where 1 = very helpful, 2 = somewhat helpful, and 3 = not helpful. Respondents were unanimous in one area – having access to a list of community resources, support groups and self help tools related to the treatment of people who hoard. All 15 respondents indicated that this resource would be very helpful to them in their practice.

The majority of respondents (at least 11 of 15 health care practitioners) would also welcome a "culturally appropriate" screening tool that could be administered to clients to help identify whether hoarding may be a problem; and having access to a list of other providers that could be used for referral purposes.

Respondents were less interested (only 8 respondents rated this resource as 'very helpful') in having access to a culturally appropriate intake tool once the client has agreed to start treatment to help document the client's history, current behaviour and other relevant background information. As well, only a few (4

²⁹ Available in at least English and French for the interviewee and interviewer; and respectful of differing cultural values and mores of the interviewee.

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respondents) would value having a comprehensive health assessment and referral tool to help you identify which treatment course would be most helpful?

Respondents were asked for other suggestions in terms of helpful resources and tools. Added suggestions included a tracking or monitoring tool to follow client progress, a website with self help tools for those with hoarding behaviour, and a buddy system for those who hoard. An interest in access to statistics on the relative frequency of various DSM's³⁰ in individuals with varying levels of hoarding, on types of safety issues and on relapse was also expressed.

3.2.5 Other Comments Related to the Needs of Health Care Practitioners

Each health care practitioner interviewed in the 2007 study was given an opportunity to provide open-ended comments and suggestions at the end of their interview regarding other tools or resources needed to address the issue of hoarding in this community. Several expressed appreciation for the attention to the issue of hoarding this study was creating in Ottawa.

The additional open-ended comments and suggestions provided by respondents mirrored some of the check list items presented earlier but also lent some additional insight into what is needed in Ottawa to more effectively address the issue of hoarding. In general, a lack of information on this subject and an interest in receiving information was noted. Some specific suggestions included the need for more information on: how to detect hoarding in patients who may present initially with other complaints, how to treat the disorder, and who is the Public Health contact regarding public health concerns. One Psychiatrist identified a need for an agreement that there is more than one type of hoarding. *"When hoarding is identified it needs to involve a diagnosis (it is not just OCD) or the aetiology of symptoms. This can help identify which of several treatments may be appropriate."*

The lack of information particularly for Family Physicians was recognized by 2 respondents. *"Hoarding behaviour is not an issue to which Family Physicians are sensitized. There is nothing in family practice journals and there has never been any presentation on this in Continuing Education Courses. It has never been suggested as a topic. I suggest having someone write about hoarding behaviour in a peer reviewed family medicine Journal. Another source of information for Family Physicians in Ottawa is the Public Health Dept. Newsletter."* Other respondents suggested alerting the Ministry of Health, provincial medical organizations and magazines such as the Medical Post and CMAJ to this issue.

³⁰ Abbreviation for the "Diagnostic and Statistical Manual of Mental Disorders," a comprehensive classification of officially recognized psychiatric disorders
Revised by L. Bonnie Dinning Consulting Services &
Christine Davis, Social Data Research Ltd
June, 2008

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The need for specific resources such as a scale to measure improvement, a de-cluttering team (nurse, Occupational Therapist, counsellors, etc.) who can interact with a number of practitioners, a list of clutter coaches, a group therapy option, and support and information for the families of those who hoard, were also mentioned.

3.3 Focus Groups with Community Service Providers

Twenty-four community service providers participated in two focus groups. One group involving 12 Francophone participants was conducted by a member of the Ottawa Community Response to Hoarding. The Anglophone focus group was conducted by the consultants and involved 12 individuals. Three respondents participated by responding to the Anglophone focus group questions via e-mail.

3.3.1 Hoarding Situations Encountered

Anglophone participants cited a wide range of 0 to 30 years of experience with this client group. When asked about the frequency of their interaction with clients who hoard, one participant said her agency dealt with hoarding cases about twice a month, another working with developmentally disabled individuals cited 11 or 12 individuals with hoarding behaviour in their agency's 150 client residential program, while yet another described 3 of 80 clients with mental illness having a hoarding problem.

Respondents in both the Anglophone and Francophone focus groups provided descriptors of the situations they had discovered. For Anglophone respondents these included: medications hoarded for 20-30 years; hoarded dead animals; a need for rehousing; hoarding behaviour involving more than one family member, and; an association with sexual abuse, disability, discrimination and life experiences of not being able to defend one's self.

Francophone respondents described several similar situations including: the discovery of a hoarding situation during a fire emergency where several services had to be mobilized to force a move; a hoarding situation involving 10 encounters and a client who could not throw anything away he deemed of value; the stockpiling of food; the emptying of one home by Public Health for health reasons; a women living in an apartment with the water shut off; a woman who did not bathe or shower and accumulated everything; a mother and daughter who hoarded items such as string for "crafts", and; an individual who accumulated newspapers in every room. In summing up, participants in the Francophone focus group identified debt, the accumulation of items and inability to discard, the loss of ability to solve problems, unresolved personal issues and hoarding as a recurring problem - as common elements associated with the disclosure of hoarding behaviour.

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3.3.2 Elements of Success

Participants in the Anglophone focus group provided a few success stories involving their encounters with individuals who hoard. One participant described a client who attempted suicide and began to hoard after the loss of a family member. Bereavement counseling helped and the individual was able to, with assistance, identify important mementoes that could be used in creating a quilt to take with her to a retirement home. Others described successful situations such as one individual who was helped when adult children agreed to take some mementoes after he was able to work through memories associated with them; a good assessment as a result of a referral from the Royal Ottawa Hospital for someone with schizophrenia - and a quick response from the agency receiving the referral, and; a team approach developed with the assistance of a Public Health Nurse, a CCAC worker, and a Psychiatrist who made home visits.

Specific techniques described as being helpful were: use the 3 second rule – *“Toss it or make a decision where item will be kept”*; support workers should work in pairs to avoid potential accusations (such as stealing) being made by clients; sort items into containers; use Motivational Interviewing techniques.

Several participants noted some success in using strategies that follow the de-hoarding guidelines outlined in the 2006³¹ study such as helping the person to remain focused, providing emotional support, helping the person with decision-making, being a cheerleader, helping with hauling, and accompanying the person on non – acquiring trips.

Support workers from the Canadian Mental Health Association described having some success in supporting clients in crisis situations, but not in prevention - as time and community supports were not available.

3.3.3 Gaps and Challenges

Collectively, service providers (both Anglophone and Francophone) described the gaps and challenges they face in addressing hoarding in Ottawa. According to participants in both focus groups, there is a lack of dedicated staff and individual agency ability to provide the required long term investment of time to address hoarding as hoarding, per say, is not an issue for which public funding is

³¹ ³¹ Dinning, L. (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding. Ottawa.

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provided. Worker safety is also a concern due to fire, public health and other hazard possibilities in the homes of people who hoard.

Preventing hoarding, getting clients to accept help and the cost of clean up are major challenges according to participants in the focus groups. This can involve long term, repetitive hoarding by more than one family member, serious mental illness, addictions, and health and aging issues. In addition, closing 'no kill animal' shelters (often ways for people to hide their animal hoarding behaviour) often raises public ire.

Other issues include the absence of screening and assessment tools that are simply not available, and few opportunities to share and get useful information, e.g. case conferencing. There is also insufficient treatment options and limited knowledge about the issue amongst treatment providers such as Physicians & Psychiatrists. A lack of knowledge amongst by-law officers, emergency personnel, support workers and the general public was also identified.

Although the Ottawa Community Response to Hoarding Coalition has a strategic plan to address hoarding it is unable to undertake a coordinating role due to the incapacity of participating agencies to put time into this initiative.

3.3.4 Tools and Resources to Improve Skills and Knowledge

Similar to the licensed health care professionals, service providers from both focus groups expressed interest in strategies to help clients improve their decision - making and problem solving skills, how to assist clients to organize or discard possessions, increase or maintain appropriate use of living space and work with de-cluttering coaches. Francophone participants identified consultation access to knowledgeable professionals or action teams and an opportunity for case study reviews as being desirable.

Specific tools and resources of interest for Anglophone participants were culturally appropriate intake, assessment, and referral tools, a list of community resources for clients, a check list of items to address with clients, and a list of treatment and service providers for referrals.

Anglophone participants indicated interest in a wide variety of education and training possibilities such as websites, e-groups, workshops, conferences, printed material, DVDs, and access to a dedicated library. Francophone participants suggested training during working hours or evenings.

Other needed information and skill development tools and resources identified by Francophone participants included: more information on how to assess the signs of excessive accumulation, crisis intervention, where to start, what helps and

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what obstructs progress as specific training topics. As well, Anglophone participants were in total agreement that having more information about the following topics would be useful in their practice to help people who hoard: helping clients to create more living space and planning for its enjoyment; helping clients to increase appropriate use of their space; improving the decision-making skills for possessions of clients; organizing their possessions to make them more accessible & more easily maintained in an uncluttered way; reducing their compulsive buying or acquisition, removing (discard, recycle, sell, give away) unneeded possessions; evaluating their beliefs about organizing, acquiring, and discarding(and relationships with possessions); learning problem-solving skills; and how to prevent future hoarding. Additional topics of interest to some participants in the Anglophone group included animal hoarding and how to care for one's self as a support worker.

3. 4 Interest in Participating in a Community Response to Hoarding

Health care practitioners and community service workers who responded in the 2007 study were queried about their interest in participating in a community response to hoarding strategy.

Five Psychiatrists indicated an interest in adding their names to a list of practitioners (for referral purposes) being compiled by the Ottawa Community Response to Hoarding Coalition.

Eight Psychiatrists and one Psychologist indicated an interest in partnerships with a decluttering coach. Of these, seven Psychiatrists and one Psychologist were willing to have their names made available to the Ottawa Community Response to Hoarding Coalition for further exploration on this possibility.

Three Psychiatrists indicated an interested in joining the Ottawa Community Response to Hoarding planning table to help decide the best course of action related to increasing Ottawa's capacity in the hoarding area.

Eight service providers indicated interest in joining (or continuing to work with) the Community Response to Hoarding Coalition to help decide the best course of action related to increasing its capacity to address hoarding behaviour.

Ten service providers indicated interest in having their name added to or continuing to be on a list of service providers who serve clients with hoarding behaviour.

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Service providers attending the Francophone focus group were not canvassed about their interest in the Community Response to Hoarding Coalition.

The names and contact information of interested practitioners and community service providers were forwarded to a representative of the Ottawa Community Response to Hoarding at the end of the study in 2007.

4. Conclusions

4.1 Hoarding is a Cause of Homelessness

Data is very limited about the prevalence of hoarding and the resolution of reported cases. One American study reported a 5 year prevalence of hoarding related complaints to 88 Public Health departments of 26 per 100,000. 40% of 58 of the reported cases refused to cooperate at all and had some or all of their possessions removed. For nearly half of these, the buildings were condemned or the tenants evicted.³²

In 2005 Ottawa Public Health staff alone identified 94 cases of hoarding behaviour³³. Based on the American statistics in the absence of Ottawa data, 19 may have had their homes condemned or been evicted. It can be surmised that several became homeless and have most likely continued to encounter homelessness due to the cyclical nature of hoarding behaviour. This estimate would certainly spiral upwards if additional 2005 statistics had been available from the approximate 35 other organizations in Ottawa who have self identified as interacting with clients who hoard.

Canadian provincial and federal siloed approaches to funding specific issues exacerbate this problem because an assigned mandate to address hoarding behaviour does not exist. As a result, data related to hoarding behaviour becomes lost within statistics about eviction or housing loss due to financial woes: inappropriate interventions are then applied which fuel the cyclic nature of both hoarding and homelessness.

³² Frost, R.O., Steketee, G., Williams, L. (2000) Hoarding: A Community Health Problem. *Health and Social Care in the Community*, 8(4),229-234

³³ Dinning, L. (2006). "No Room to Spare" Ottawa's Community Response to Hoarding. Ottawa.

4.2 Treatment Providers, Support Workers, Individuals Who Hoard and Their Families Need Information about Hoarding

Previous to this study, The Ottawa Community Response to Hoarding Coalition had already taken giant steps in addressing the knowledge and skill requirements of service providers and professionals on the topic of “hoarding”.

Well attended conferences, workshops and information documents on the topic have been provided over the past few years placing the Ottawa coalition at the forefront in addressing hoarding in Canada. Implementing the recommendations of this study will further enhance the quality of service delivery and treatment in this community and others.

An initial list of knowledge and skill development topics for service providers was identified in the 2006 study³⁴. The 2007 study identified the need for continued development on many of the same topics, in particular:

- Evidenced based treatment and support options
- Lists of community service and treatment options including treatment professionals able to take referrals
- Coordinated case management with established policies and procedures
- Better ways to engage ambivalent, non-compliant clients
- How to identify and prevent hoarding
- Self help groups and self help techniques for those who hoard
- Health and safety issues for those with hoarding behaviour
- Multi cultural approaches

The 2006 study also identified the need for a workshop or resource on privacy/confidentiality and on ordinances applicable to hoarding³⁵. Such information is crucial to ensuring consistency in approach by support and emergency personnel, especially during a crisis intervention.

In adding the voices of licensed health practitioners, this study emphasizes the similarity in knowledge and skill development needs of all potential members of a treatment/support team, including families wanting to help relatives who hoard. And, by combining the results of the 2006³⁶ and 2007 studies a clear acknowledgement of the lack of treatment and support services in Ottawa, and

³⁴ Dinning. L, (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding.

³⁵ Dinning. L, (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding.

³⁶ Dinning. L, (2006). “No Room to Spare” Ottawa’s Community Response to Hoarding.

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the lack of clarity about roles within the existing treatment/support structure emerges.

New information is provided by the 2007 study about how information and skill development could be provided. Short term workshops, conferences, websites and other internet options proved of most interest to treatment/support providers, with the requirement that they be provided or created by those with recognized expertise in the field. Those with hoarding behaviour and their families also want access to information. Websites seemed to be particularly popular with respondents exhibiting hoarding behaviour in this study and the former 2006 study³⁷.

Tools to assist in the treatment and support of individuals who hoard were also identified throughout the 2007 study. Of particular interest are lists of community resources, referral options, self help tools and groups, screening and assessment aids, and case conferencing opportunities.

Interest in collaboration remains strong in Ottawa as evidenced by those willing to add their names to lists to help with planning and treatment options. And, according to coalition representatives, other initial outcomes such as those listed below are already being recognized and attributed to the activities undertaken for this study:

- An increased base within the Francophone professional community and community service providers has been achieved due to a Hoarding Awareness Workshop in French and the Francophone Focus Group
- There is an increased awareness of hoarding behaviour and the risks associated with it such as homelessness
- More consultations occurred with the Coordinator of the Ottawa Community Response to Hoarding Coalition concerning "at risk" patients.
- Increased linkages have been initiated with community based treatment professionals (Psychiatrists, and Social Workers).

4.3 A Community Approach to Addressing Hoarding Behaviour is Needed

The 2006 study³⁸ clearly established the benefits of a community response to hoarding.

³⁷ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding.

³⁸ Dinning. L, (2006). "No Room to Spare" Ottawa's Community Response to Hoarding.

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Communities can spend thousands of dollars to clean out a home that is the site of hoarding, only to discover the same individual and situation a few months later. An attempt to capture the Ottawa 2005 public health staffing costs associated with 94 hoarding cases produced an estimate of \$133,328.00. What is not included in this figure is the time of fire, police, and by-law officers, or community support workers; nor does it include the cost of clean up itself!

Cooperation of a broad spectrum of municipal agencies and social service organizations can optimize the resolution of hoarding cases. In this way, the problem can be attacked on all fronts and with greater leverage. Such an approach leads to reduced frustration and costs and improved cooperation and outcomes for hoarders and their families.

Communities should consider the establishment of a coordinating body that includes representatives of public/community health, fire, police, housing, zoning, mental health, aging, adult protective services, child welfare, and animal welfare/control/veterinary organizations. Joint planning can produce decision trees to address identified problems, strategies to streamline reporting, and common assessment, and intervention procedures. Cross-disciplinary training and direct communication among multiple service agencies are other possible benefits.

The Ottawa Community Response to Hoarding Coalition is demonstrating the benefits of such an approach even in the absence of funding directed at coordinating activities to address hoarding behaviour. Much of its current success can be attributed to its ability to raise awareness of the issue through training and information sharing opportunities. However, this study reinforces the need for other activities such as: the development of screening and assessment tools; opportunities to share and get useful information; and, training in particular for licensed health practitioners to insure the availability of treatment options.

5. Recommendations

5.1 Recommendations to Human Resources and Social Development Canada, Homelessness Partnering Secretariat

The following recommendations are made to the Homelessness Partnering Secretariat as the funder and one of the direct recipients of this study. The Secretariat links with communities, provinces and territories, partners in the

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private and not-for-profit sectors and Aboriginal partners, with the goal of aligning federal/provincial/territorial investments to prevent and reduce homelessness. In carrying out this role, it is recommended that the Secretariat:

- Provide community planning bodies addressing homelessness with information about hoarding behaviour and the potential impact it may have on their community's services and supports
- Convey information about the link between hoarding and homelessness to provincial policy makers responsible for funding to address homelessness
- Request that the Canadian Public Health Association investigate hoarding behaviour as a public health issue
- Contact the Canadian Medical Association about the findings of this study and their member's need for information about hoarding behaviour
- Contact the Canadian Association of Municipal Administrators about the findings of this study as it pertains to the costs (time and money) incurred by multiple municipal service areas to respond to hoarding situations in municipalities.

5.2 Recommendations to the Ottawa Community Response to Hoarding Coalition

The Ottawa Community Response to Hoarding Coalition should move quickly to capitalize on the momentum created by this study. Its next steps in order of priority should be:

- Immediate follow-up with those health practitioners and community service providers interested in supporting a coordinated response to hoarding in Ottawa
- Initiate regularly scheduled case conferences for the purposes of developing plans for specific situations, assembling de-cluttering teams and sharing learnings
- Establish working groups or identify agencies to develop workshops, information tools, screening & assessment tools, and information sharing mechanisms such as list serves and web sites.
- Clarify the roles of professionals such as Family Physicians and Psychiatrists in addressing hoarding
- Identify an agency willing to develop and provide support groups for those with hoarding behaviour
- Identify an agency willing to develop support options for families of those with hoarding behaviour
- Contact the Ontario Medical Association with an offer to provide a session on hoarding behaviour as part of the Family Practice and Psychiatric Continuing Education in Ottawa

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- Develop articles for submission to journals reaching Family Physicians, Psychologists, Psychiatrists, Nurses and Social Workers such as the Medical Post, CMAJ, and Canadian Journal of Public Health
- Develop articles for the general public and placing them in community newspapers

Attachments:

Appendix A – Questionnaires and Focus Group Guide