

# “No Room to Spare”



## Ottawa's Community Response to Hoarding Plan

Prepared for:

*The Ottawa Community Response to Hoarding Coalition*

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Image from [www.shoal.net.au/~sandra/WIF8.html](http://www.shoal.net.au/~sandra/WIF8.html)

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*“The best things in life are not things,  
but moments with loved ones,  
moments with nature,  
moments of spirituality,  
creativity, growth, success, romance,  
or, discovery for the sake of things  
– or so it seems.”<sup>1</sup>*

**When asked “What has been most helpful to you in dealing with your hoarding situation?” one individual responded; “*Reading this phrase*”!<sup>2</sup>**

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<sup>1</sup> *Making Peace with the Things in Your Life* by Cindy Glovinsky

<sup>2</sup> Client interview conducted for the Ottawa Response to Hoarding Coalition, 2005.

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## **“No Room to Spare”**

### **Ottawa’s Community Response to Hoarding**

#### **Executive Summary**

Today’s reality and talk TV shows are abuzz with quick fixes for individuals whose cluttered homes are offered up to the voyeuristic TV watching public. Sadly such sensationalistic shows usually portray little understanding of the possibility that the individual under scrutiny is a compulsive hoarder.

Such individuals experience difficulty discarding large numbers of possessions often considered useless by others. In some instances, animals such as dogs and cats are hoarded.

Cluttered living space to the point of precluding use of the kitchen, bathroom and bedroom can put the health and safety of the individual who hoards and neighbours at risk. Fire hazards abound. Rodent and insect infestations can create a neighborhood nuisance and provide a medium for infectious diseases.

The Bottom Line is also a concern. 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. Financial disaster, eviction and homelessness for that individual are frequent outcomes.

An attempt to capture the public health staffing costs associated with 94 hoarding cases in 2005 for the City of Ottawa produced the staggering total 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!

Service providers in Ottawa have collaborated to address this issue locally. With the assistance of a consultant, a strategic plan has been developed that focuses on governance, service delivery, knowledge & skill development, and social marketing.

Specific activities of the plan include:

- Establishing a centralized hoarding unit
- Developing common guidelines and protocols for use by collaborating agencies
- Establishing a comprehensive integrated service delivery system inclusive of intake, assessment, case management, and voluntary/involuntary interventions
- Identifying treatment options consistent with the values and principles now established by the Ottawa Community Response to Hoarding
- Developing and implementing a training plan for service providers
- Establishing a website and e mail list serve
- Providing support groups for individuals who hoard
- Developing and distributing information about hoarding to the general public and special interest groups
- Undertaking research to establish the prevalence of Hoarding in Ottawa

By implementing these activities the Ottawa Coalition expects to:

- Clarify agency, individual service provider, and stakeholder roles and obligations in implementing the plan. This includes the establishment of leadership – considered critical to implementation of the plan;
- Increase community agency participation in coalition activities, especially by those who represent the francophone community;
- Improve the knowledge base of service providers and establish consistent protocols for hoarding situations;
- Maximize multi-media communication opportunities to inform, stimulate, problem solve and advocate for those with hoarding behaviour;
- Implement quality assurance activities to ensure effective services and programs.

# “No Room to Spare” Ottawa’s Community Response to Hoarding

## 1. Introduction

Today’s reality and talk TV shows are abuzz with quick fixes for individuals whose cluttered homes are offered up to the voyeuristic TV watching public. Sadly such sensationalistic shows usually portray little understanding of the possibility that the individual under scrutiny is a compulsive hoarder.

21<sup>st</sup> century consumerism allows the accumulation of items for enjoyment or pleasure beyond those needed for daily living. When an inability to make decisions about what should be kept, recycled, replaced or discarded impacts one’s living space; health and safety issues arise for the individual, his/her family members, and the community.

Why all the concern? - *The Bottom Line*. 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. Financial disaster, eviction and homelessness for that individual are also frequent outcomes.

Historically, shelters for the homeless become the default care provider when a local plan is not in place. A few municipalities across North America, however, are slowly realizing the need for a coordinated community preventative response involving zoning, public health, fire safety, police, mental health animal control, and so on. Ottawa is one of those communities – **and** – the first in Canada<sup>3</sup>.

### 1.1 What is Hoarding?

In a presentation to 310 community service providers in Ottawa in December 2004, Dr. Randy Frost, PHD, Professor in the Department of Psychology at Smith College in Northampton, MA. in defining hoarding, described it as involving three distinct behaviours:

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.

“People who hoard can’t stop buying things”, said Frost, “Or keeping free items such as promotional flyers and give aways. Some comb through trash and a few have even been found to have kleptomania, an impulse to steal.”

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“Once acquired discarding becomes difficult and is avoided – items are believed to be sentimental, useful or too pretty to discard. Random piles emerge due to a fear of putting things out of sight and indecisiveness about importance or need. As items accumulate, ‘churning’ occurs in an effort to keep track of things. Each viewing of an item during this process can increase its value in the eyes of a hoarder”, according to Frost.

He continued by describing the cyclic process of hoarding. “Anxiety emerges when discarding is considered because of distorted hoarding beliefs. Continuing to save without considering discarding relieves anxiety thus reinforcing the process.”

The body of knowledge about hoarding is limited. A clear understanding of how it should be categorized and approached is still outstanding.

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

Attachment A contains more detailed information about what the literature says about hoarding.

## **2. Background**

Public Health staff with the City of Ottawa, concerned about their inability to adequately assist those with a hoarding crisis, organized 2 community workshops in June 2003 and December 2004 on the topic. As a result, organizations expressing similar concerns formed The Ottawa Community Response to Hoarding Coalition in July 2003. Today 35 organizations meet regularly to develop local solutions and advocate for policy changes regarding hoarding (Attachment B).

The Ottawa Community Response to Hoarding Coalition accomplished many things in its first few years:

- Presentation on the Ottawa Community Response to Hoarding Coalition’s work at the Obsessive Compulsive Foundation of America Conference in Nashville, July 2003.
- 2 Hoarding Workshops which informed a broad cross section of community professionals on the issue of Hoarding; as well as “best practices” in dealing with it.
- United Way grant approved to St. Joe’s Women Centre, to host the 2<sup>nd</sup> Hoarding Workshop on assessment and intervention strategies to deal with hoarding behaviours.
- Presentation on hoarding to 100 Fire Inspectors from municipalities across Ontario at the Ontario Fire College, October 2004
- TVO “Studio 2” segment on Hoarding and the work the Ottawa Community Response to Hoarding Coalition was first aired January 2004.
- November 5<sup>th</sup> 2005 presentation on Hoarding to 165 key stakeholders at the Ontario Non Profit Housing Association Annual Conference in Niagara Falls Ont.
- Feature article on hoarding and the work being done by the Ottawa Community Response to Hoarding Coalition was published June 15<sup>th</sup> 2005 in SUN newspapers across Canada.

- Feature article on hoarding in the Toronto Star, January 29<sup>th</sup> 2006, increased public awareness through quotes based on the experience acquired by the Ottawa Community Response to Hoarding Coalition.
- Hoarding brochure developed and ready for use when SCPI Service Delivery Model is implemented and roles for Community Partners have been decided
- Recommended resources reference guide developed and available upon request
- Current projects include: developing and delivering Hoarding Workshops at the Ontario Property Standards Officers Association conference in Hamilton Ont., to Canadian Mental Health Association Staff in Peterborough Ont., and in partnership with a local psychiatrist to Ottawa Physicians at continuing education sessions through the Canadian Medical Association in Ottawa Ont.
- Partnering with Community Partners to develop and conduct facilitator led support groups for people with hoarding behaviours.
- Development of a Collaborative Intervention Method with coalition partner (GEM Healthcare Services) which will provide in situ support for people in hoarding situations pre, during and after the clean up process.
- Work with Community Care Assess Centre – Ottawa and Geriatric Psychiatry of Ottawa to develop and test Best Practices for the Collaborative Intervention Model.
- Receipt of federal Supporting Communities Partnership Initiative (SCPI) funding to hire a consultant to work with the Coalition to develop a coordinated, interagency Service Delivery Model for Ottawa. This report is the result of that project.

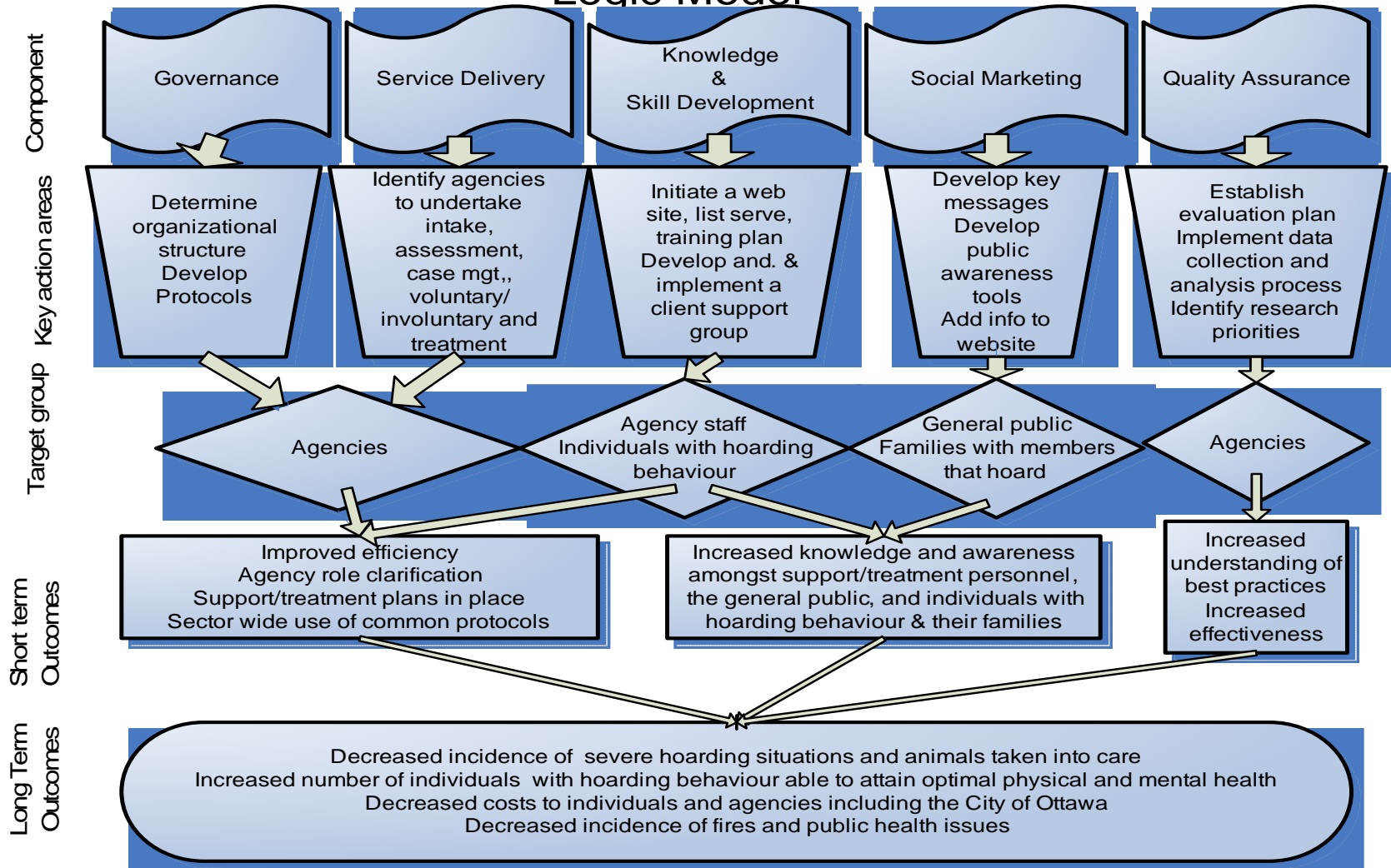
## 2.1 Project Parameters

The coalition directed the consultant to develop a community response to hoarding for Ottawa. Key activities included a literature review, focus groups with front line workers, and interviews with individuals with hoarding behaviour and designated agency management staff. Meetings with coalition representatives were also held to discuss recommendations and to develop mission, vision, values and operating principles for future coalition activities. Although the original focus was to develop a coordinated, interagency service delivery model, it became evident from the literature review (Attachment A), the interviews and focus groups (Attachment C) and discussions with coalition members that a much broader plan was needed. A strategic plan evolved requiring attention to the following areas:

- Governance
- Service Delivery
- Knowledge and Skill Development
- Social Marketing
- Quality Assurance

A logic model of the proposed plan follows:

# Ottawa Community Response to Hoarding Logic Model



### 3. The Ottawa Community Response to Hoarding Coalition Strategic Plan

The following sections provide more detail about the coalition’s plan to address hoarding in Ottawa. Specific activities to be undertaken over the next two years are contained in the operational plan in Attachment D. Readers of this report should also reference the appended Literature Review (Attachment A) and the Findings from Interviews and Focus Groups (Attachment C) for the background information to suggested recommendations.

#### 3.1 Governance

Information gathered from interviews and focus groups supported a coalition of community agencies and organizations to address hoarding. A review of forms of community organization outlined in section 5.1 of the literature review (Attachment A) identifies the Ottawa coalition as functioning closer to a Cooperation or Alliance at this stage of its development. However, it is well on tract to becoming a strong coalition/collaboration as demonstrated by the key action areas it has chosen to address.

It has also accomplished many of success factors for collaboration described below.

<b>Factors Influencing the Success of Collaboration<sup>4</sup></b>	
<p><b>Factors Related to the Environment</b></p> <ul style="list-style-type: none"> <li>History of collaboration exists in the community</li> <li>Collaborative group is seen as a leader in the community</li> <li>Favourable political and social climate exists for support of the collaborative</li> </ul> <p><b>Factors related to Membership Characteristics</b></p> <ul style="list-style-type: none"> <li>Mutual respect, understanding and trust exists among members</li> <li>There is an appropriate and representative cross-section of members</li> <li>Members see collaboration in their self-interest - benefits exceeds costs</li> <li>Members are able to compromise</li> </ul>	<p><b>Factors related to communication</b></p> <ul style="list-style-type: none"> <li>• Open and frequent communication between members and the outside</li> <li>• Established formal and informal communication links</li> </ul> <p><b>Factors related to purpose</b></p> <ul style="list-style-type: none"> <li>• Goals and objectives are both clear to members and obtainable</li> <li>• A shared vision and mission exists for the collaborative</li> <li>• A unique purpose exists for the collaborative different from each organization</li> </ul>

<sup>4</sup> The University of Wisconsin–Cooperative Extension outlines the factors influencing the success of collaboration based on work by Mattessich & Monsey (1992) in Evaluating Collaboratives (1998).

Factors related to Process/Structure	Factors related to Resource
<p>Members share a stake in the process and outcome of the collaborative</p> <p>Layers of decision-making - all levels of each organization participate</p> <p>Flexibility – varied forms and functions are allowed</p> <p>Clear roles and policy guidelines exist</p> <p>Adaptability to major changes in the environment</p>	<ul style="list-style-type: none"> <li>• Sufficient funds exist or are expected for functioning of the collaborative</li> <li>• A skilled convener in the collaborative has respect and legitimacy</li> </ul>

### 3.1.1 The Ottawa Community Response to Hoarding Coalition

The coalition has established the following goals within its strategic plan:

- Clarify agency, individual service provider, and stakeholder roles and obligations in implementing the plan. This includes the establishment of leadership – considered critical to implementation of the plan;
- Increase community agency participation in coalition activities, especially by those who represent the francophone community;
- Improve the knowledge base of service providers and establish consistent protocols for hoarding situations;
- Maximize multi-media communication opportunities to inform, stimulate, problem solve and advocate for those with hoarding behaviour;
- Implement quality assurance activities to ensure effective services and programs.

The Coalition abides by the following Terms of Reference. Presently, nothing within its current mandate restricts the freedom of any member organization from conducting its own programs and services on hoarding. However, this will require review given the coalition’s desire for the development and implementation of common policies, procedures and tools.

**Mandate:**

The Ottawa Community Response to Hoarding is to act as an advocate for solutions to hoarding in Ottawa and to develop programs and support services to deal with the issue of hoarding.

To accomplish this mandate the Community Response may:

- Consult and liaise with governmental and non- governmental sources in application for funding as needed;
- Gather information from members for the purpose of developing submissions  
Disseminate information to members;
- Consult with members on major policy directions and opportunities;
- Contribute to education and awareness raising regarding hoarding issues;
- Contribute to other educational initiatives as needs are identified;
- Act as an information/program clearinghouse on hoarding issues within the bounds of its resources;
- Communicate positions and news about hoarding issues to the media;
- Conduct research on hoarding issues as resources permit and disseminate the results of its research to members.

The current Terms of Reference will be amended in time to include the following recently agreed upon mission, vision, values and operating principles. These statements will help guide future actions undertaken by the coalition.

**Mission:**

The Ottawa Community Response to Hoarding Coalition exists to ensure that individuals in the City of Ottawa who engage in hoarding behaviour have access to the integrated services they need to maintain housing stability and a quality of life that optimizes their health and safety, and that of the community.

**Vision:**

The Ottawa Community Response to Hoarding Coalition leads the development and implementation of a coordinated plan to address hoarding where affected individuals receive relevant services that support optimal quality of life and safe environments

**Values and Operating Principles:**

The following template describes how the coalition expects its values to be implemented.

Values	Operating Principles
Collaboration	Collaborative development and implementation of a shared community plan are accomplished through inclusive and transparent processes.
Person Centered	Clients are respected for themselves and their diversity. Support personnel assist with decision-making and provide emotional support.
Equality	<p>Equality is achieved when the chosen approach recognizes both the rights of the individual as well as those of the community</p> <p>There is equitable access to treatment and knowledge of what treatment exists.</p>
Excellence	<p>A full range of appropriate bilingual services, supports and treatment is available.</p> <p>The continuum of services helps individuals to achieve maximum independence by investing in prevention, early intervention and long-term solutions.</p> <p>Knowledge and training promotes the development of best practices based on current research and evaluation</p>
Teamwork	Multi-disciplinary partnerships are based on a common understanding

	<p>of the issue, as well as the mission, vision, values and principles guiding implementation of the plan</p> <p>Multidisciplinary partnerships are developed to share and leverage knowledge for the benefit of the client and the community in which they live.</p>
Stewardship	<p>The shaping, influencing and developing of policies creates alignment with mission, vision, and values and principles statements.</p> <p>The Coalition assumes a leadership role in Canada by freely sharing its learnings with other communities.</p>
Credibility	<p>Programs and services operate as an entity, ensuring seamlessness for consumers, their families, practitioners, organizations and levels of care over service overtime</p>
Innovativeness	<p>Innovative ideas are piloted to fill system gaps and attempt to improve outcomes.</p>
Competency	<p>Services continuously improve, based on ongoing evaluation results and increasing knowledge of best practices and relevant research.</p> <p>Public funds are used responsibly, in that funding is allocated to prioritized needs using fair and transparent processes; and funded programs and projects are monitored for efficiency and effectiveness.</p> <p>Service providers identify training needs and are provided with learning opportunities</p> <p>A public awareness plan is developed and implemented</p>

### 3.1.2 A Centralized Hoarding Unit

Implementation of a centralized hoarding unit with bilingual capacity has been identified as a priority. The City of Ottawa is seen as the logical organization to undertake such a role. A specialized and multi disciplinary front line service delivery team with additional and specialized supports provided by community partners would undertake service delivery. Key activities of the unit would include:

- Provision of leadership in undertaking implementation of a community response to hoarding
- Coordination of all activities addressing hoarding in City of Ottawa departments
- Further development of an inventory of community agencies in order to provide clarity around roles, mandates and who does what in a hoarding situation.
- Case Conferencing with invested agencies (and the client as appropriate) to develop and implement a coordinated treatment and case management plan.
- Development and implementation of an ongoing bilingual training plan

- Development of coordinated policies and protocols for service delivery, i.e. a decision tree
- Development of common tools for agencies to use, such as an assessment form that gathers information about health and safety issues
- Development of culturally appropriate information tools such as brochures, fact sheets, a web site, videos etc, for use with existing clients and the public at large.
- Advocacy regarding service and funding requirements to address hoarding in both official languages
- Research and evaluation. This will require data base development & maintenance, and data collection and analysis
- Communication with the media

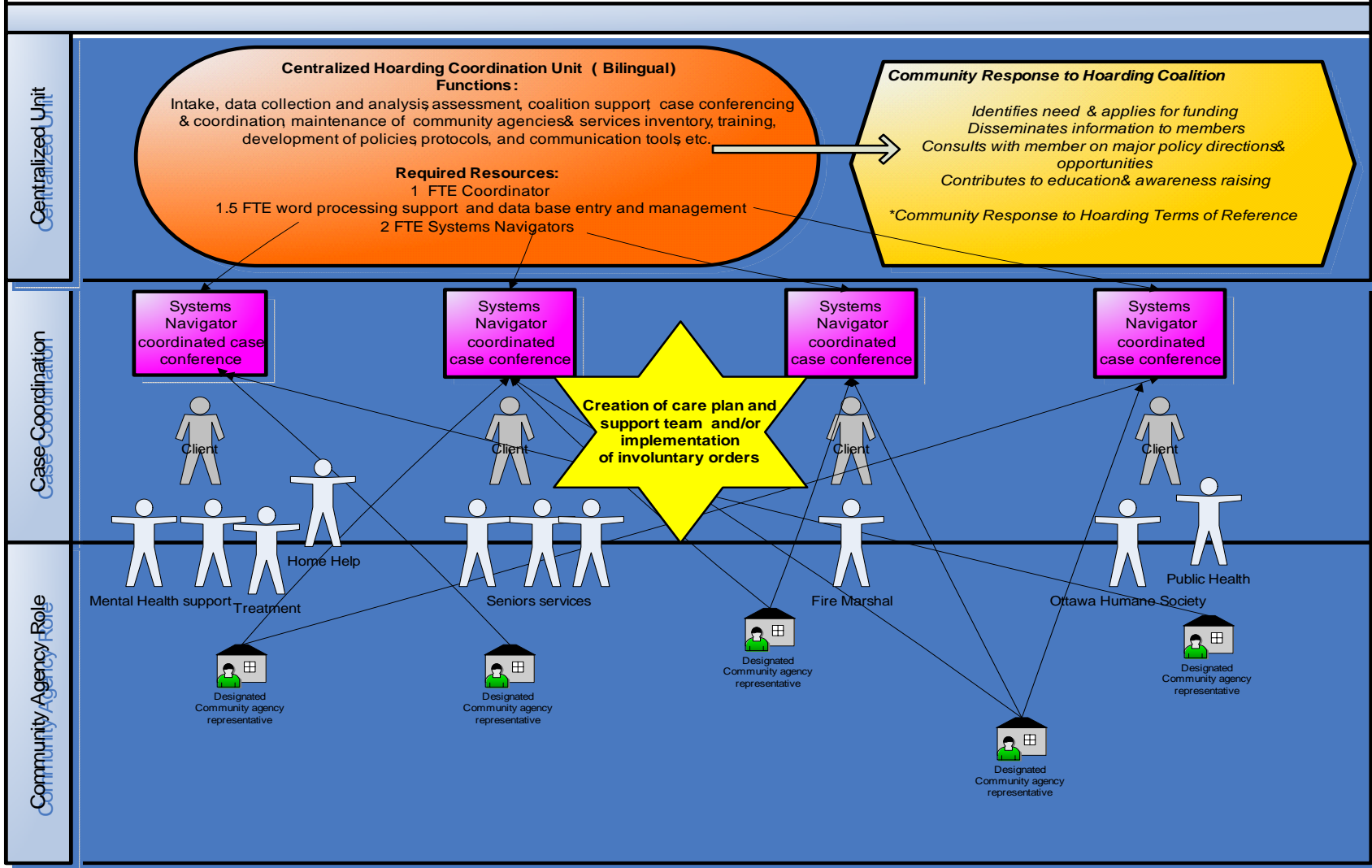
Implementation of a centralized unit will require a clear understanding of the decision-making relationship between the lead agency (anticipated as the City of Ottawa) and the coalition.

The City's consideration of establishing a centralized unit is expected to take longer than the time limitations of this project. A de-centralized approach, whereby the activities requiring coordination are undertaken by different agencies, is a compromise first step with numerous problematic barriers to its success. Implementing this approach will also depend on the willingness and capacity of several community agencies to commit themselves and staff to undertake aspects of the strategic plan.

An alternate, and more likely successful transition step, would be a hybrid approach in which some activities are centralized and undertaken by the "lead partner" considering responsibility for the centralized unit; while other activities are undertaken by community agencies.

The following schematic of a hybrid approach involves community agency representatives in case conferences led by Systems Navigators provided by the lead partner. The developed plan is then implemented by teams of workers assembled from various community agencies, according to the needs of the individual client. Such teams would follow the policies and protocols developed by the lead partner in consultation with the coalition.

HYBRID (CENTRALIZED/DECENTRALIZED) IMPLEMENTATION OF OTTAWA'S COMMUNITY PLAN TO ADDRESS HOARDING

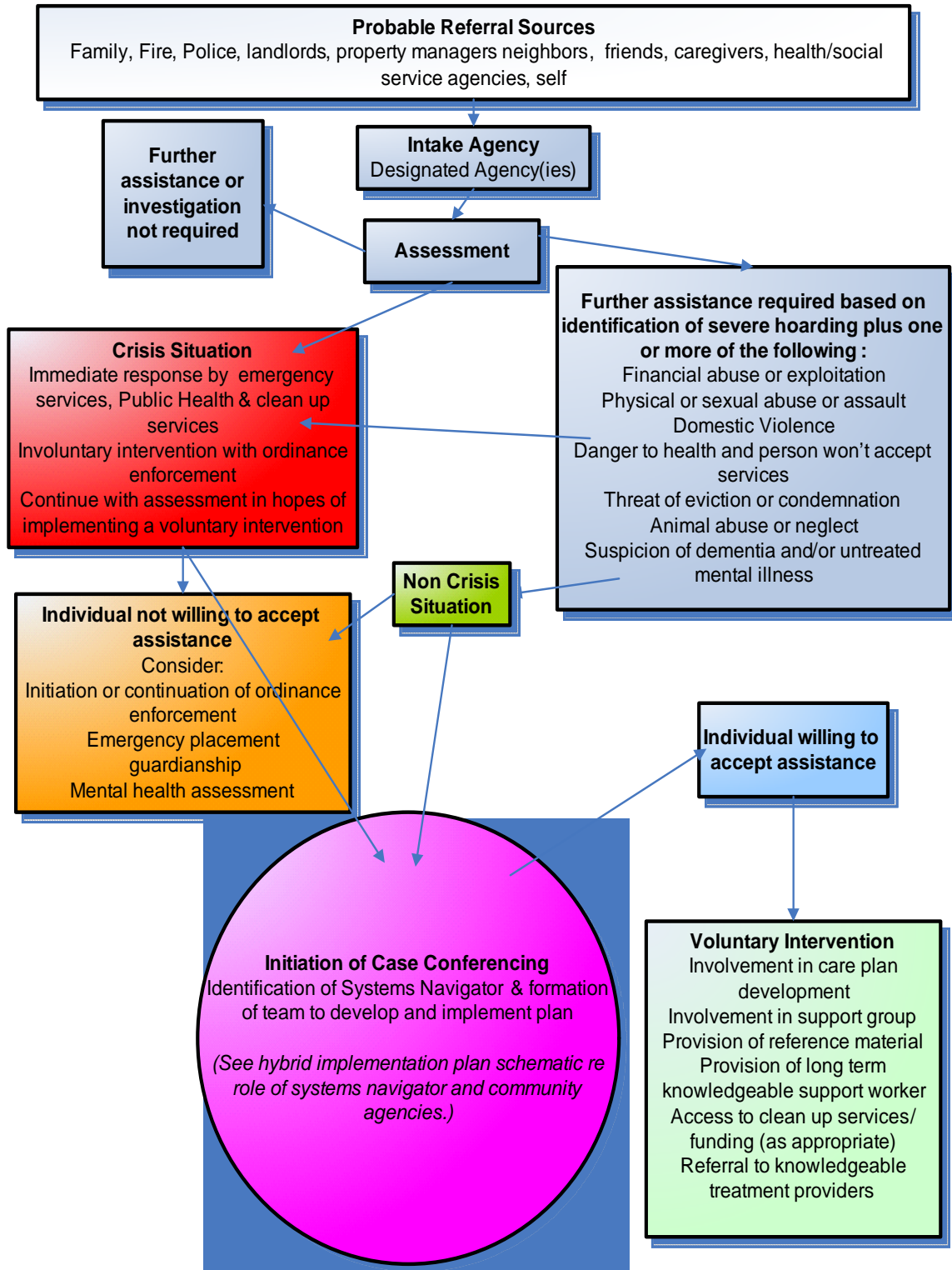


### **3.2 Service Delivery**

The literature and findings from interviews and focus groups support the development and implementation of an integrated service delivery model inclusive of intake, assessment, case management, voluntary & involuntary intervention and treatment processes. The coalition's guiding statements will need to play a key role in further development of this model. Who undertakes the identified activities and how they are implemented will be determined by the centralized, hybridized or de-centralized approach implemented in Ottawa. A rudimentary referral tree follows for completion once the organizational structure to implement the service delivery component of the plan is determined.

# Sample Referral Tree\*

\*Based on Dane County Hoarding Referral Guidelines



### 3.2.1 Intake

Intake provides the mechanism to activate assessment and an opportunity to gather data about hoarding in Ottawa. Ideally, only one or two agencies will undertake this activity on behalf of all agencies until a hybridized or centralized approach is determined and implemented. A separate intake seems reasonable for animal hoarding situations. Close collaboration, on both inanimate hoarding and animal hoarding situations, is vital as one often coexists with the other making response needs more complicated. The ability to provide 24-hour intake is required.

Use of common components within existing intake forms should be implemented as a first step even within a decentralized approach. Appendix 3 of Attachment A contains a sample telephone intake form.

### 3.2.2 Assessment

A comprehensive screening tool is key to determining whether the reported situation is in fact a hoarding situation. The following screening tool, developed by Gail Steketee, PhD., Boston University School of Social Work, is an example of the kind of tool needed to assist with assessment.

<b>CLUTTER SCREENING QUESTIONNAIRE</b>
<b>A. Do you have a problem with excessive clutter in your home?</b> YES NO
<b>B. Have family, friends, or visitors ever suggested that you need to reduce the clutter in your home?</b> YES NO
<b>C. To what extent does the clutter interfere with using rooms in your home in a normal way?</b> 0 = <b>No interference.</b> 1 = <b>Mild interference.</b> Up to ¼ of the home cluttered and not easily usable for normal activities (sitting, eating, sleeping, socializing, cooking, etc.). 2 = <b>Moderate interference.</b> Approximately half of the home cluttered and not easily usable for normal activities. 3 = <b>Severe interference.</b> Approximately ¾ of the home cluttered and not easily usable for normal activities. 4 = <b>Extreme interference.</b> Nearly all of the home cluttered and not easily usable for normal activities.
<b>D. When you try to clear out the clutter, how much distress or emotional upset do you experience?</b> 0 = <b>None.</b> 1 = <b>Mild.</b> Not too disturbing. 2 = <b>Moderate.</b> Disturbing but still manageable. 3 = <b>Severe.</b> Very disturbing. 4 = <b>Extreme.</b> Near constant and disabling distress.
<b>E. To what extent do you have a problem with collecting or buying more things than you need or can use?</b> 0- <b>No problem.</b> 1- <b>Mild problem.</b> Occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items. 2- <b>Moderate.</b> Regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items. 3- <b>Severe.</b> Frequently (several times per week) acquires items not needed, or acquires many unneeded items. 4- <b>Extreme.</b> Very often (daily) acquires items not needed, or acquires large numbers of unneeded items.

As appropriate, an on-site psychological, physical and social assessment will then need to be undertaken by a worker skilled in motivational interviewing and with in depth knowledge about hoarding. The immediate requirement is a preliminary assessment of the site regarding fire, public/personal health issues and safety. Where necessary in a decentralized or hybridized approach, notification and referral should be made for a more in depth assessment by public health, fire, SPCA, health care providers, and family; especially if these organizations were not involved in the initial investigation. Each responding organization will conduct their own in depth assessment according to their mandated service requirements.

Follow up assessment should gather additional information to support the development of an effective care plan for the individual at risk. The assessment should also be designed to gather data to assist in understanding hoarding in Ottawa. The Cognitive Behavioural Treatment Manual for Compulsive Hoarding (Steketee & Frost, 2004) contains several tools to assist with the assessment process. A tool specific to animal hoarding (source unknown) can be found in Appendix H.

The literature review as part of this project revealed the following guidelines in determining the next steps following assessment. These have been respected in developing the preceding referral tree.

- ✓ *When capacity is high, the client's right to self-determination should be respected.*
- ✓ *When capacity is low and risk is high, intervention is required, even to the extent of involuntary guardianship.*
- ✓ *When the individual's capacity is moderate and the risk is moderate, psychosocial interventions should be pursued that are geared toward encouraging the client to accept services such as the use of a clutter coach and participation in peer support groups*

(National Center on Elder Abuse 1999, Cermele et al 2001, Frost & Steketee 1998, Frost 2004, Dane County website)

The Coalition will need to determine which agency (such at the City of Ottawa), or agencies, can provide the initial and/or follow up assessment of individuals identified through intake.

### **3.2.3. Case Management**

Research has demonstrated that coordination of care, particularly for consumers accessing multiple sectors of the care system, facilitates the access and utilization of services across settings, resulting in improved outcomes. Those interviewed (Attachment C) expressed their desire for such a function in Ottawa and envisioned it involving a specialized frontline multi disciplinary hoarding team working out of a centralized office.

Case management is key regardless of what approach (centralized, decentralized or hybridized) is determined for Ottawa in the future. Given the extreme need, initiating this function immediately through agencies with the ability to undertake such a function should be a priority. The role of their designated staff would be to call a case conference and facilitate the development of a plan to be implemented by appropriate agencies. As needed, involved service providers would continue to meet under the facilitation of the identified Systems Navigator<sup>5</sup> to update the plan. Clients would participate as appropriate. Attachment E provides a listing of recommended resources for Ottawa

Much work is still outstanding to develop the policies and protocols regarding voluntary and involuntary interventions. Implementation of a centralized unit to undertake leadership in this area will certainly expedite this task. The immediate initiation of case conferences, however, can help identify needed policies and try out possible procedures. The appended Literature Review and Findings from Interviews and Focus Groups should be referenced for guidance (Attachments A & C).

The identification of treatment and counseling professionals knowledgeable about hoarding is an outstanding need in the Ottawa area. A list of such individuals should be compiled and distributed to all organizations involved in hoarding responses.

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<sup>5</sup> Coalition members expressed interest in using the term "Systems Navigator" rather than Case Manager or Coordinator.

### 3.3 Knowledge and Skill Development

The Ottawa coalition has already taken giant steps in addressing the knowledge and skill requirements of health and social personnel on the topic of “hoarding” Two well-attended conferences on the topic were provided in the past few years. A reference document (Attachment F) listing hoarding resources has also been produced.

Specific areas of information and training are now needed and identified in section 2.3 of Findings from Interviews and Focus Groups (Attachment C). Workshops and the development of resource materials on priority topics such as confidentiality and ordinances should be considered.

A patchwork of legislation, by-laws and policies (creatively used at times) was identified and documented in section 2.2.5 of Findings from Interviews and Focus Groups (Attachment C). An immediate activity of the coalition should be to update this list; while a long-term goal should be to identify what new ordinances are needed and then advocate for their implementation.

The coalition should consider establishing a working group to explore information sharing mechanisms such as list serves and web sites. The Alliance to End Homelessness list serve and web site are good examples of such tools.

Those who hoard also need their information needs addressed. An agency or agencies to develop and offer self-help groups for hoarders and their networks should be identified. Section 2.3 of Findings from Interviews and Focus Groups (Attachment C) includes self-help techniques provided by an individual who hoards.

Gail Steketee, PhD., Boston University School of Social Work, has developed the following list to assist those concerned about their cluttering.

#### THE TOP TEN CLUTTER LIST

1. Am I afraid I will get in trouble with my landlord because of clutter or have I already gotten in trouble?
2. Do I have too much stuff? Have I fallen over my clutter?
3. Do I have to move stuff off the furniture in order to use it?
4. Do people tell me that my place is dirty, a mess, or that it smells bad?
5. Am I reluctant to have people come over because of clutter?
6. Do I have to move stuff off the bed to go to bed at night?
7. Do I lose things all the time in the clutter?
8. Am I unable to get to my windows, fire escape, and doors?
9. Do I bring things home even though my place is already cluttered?
10. Do I get anxious when I think someone might take, rearrange, or throw away my clutter?

If you answered yes to two or more of these questions, you may have a hoarding/cluttering problem. This problem can be caused by depression, obsessive-compulsive disorder, or other disorders, and there is help. You might want to show this checklist to your therapist. Please be advised that optimal treatment for obsessive compulsive hoarding should take place in your home. If you feel your therapist is not helping with your hoarding/cluttering problem, you can call your county's mental health patient's rights office. This number should be available from your County Mental Health Department.

### 3.4 Social Marketing

Hoarding is a relatively unknown issue to the general public. As demonstrated by current TV programming aimed at organizing techniques, most think of clutter as a result of our busy lifestyles - not the symptom of a more complex situation with the potential to create both personal disaster and public health and safety hazards.

Respondents to key informant interviews and focus group discussion identified the need to promote prevention strategies and public awareness by using a variety of communication tools. Media personnel, pet storeowners and Veterinarians were specifically identified as groups, who with appropriate information can play a vital role in addressing hoarding. Section 2.4 of Findings from Interviews and Focus Groups (Attachment C), and section 5.3 of the Literature Review (Attachment A) should be referenced for further information.

Attachment G contains sample brochures from American hoarding initiatives.

### 3.5 Quality Assurance

A key barrier to justifying a centralized hoarding unit is the lack of data to justify its creation.

A determination of the costs associated with current hoarding responses should be undertaken and compared to the cost of creating a Central Hoarding Unit. It is anticipated that a Central Hoarding Unit 's impact will be to reduce the response demands and service costs currently made to Fire, Public Health, Bylaw & Property Standards, Police and Paramedics and Home Help/Essential health & Social Support Programs.

An attempt to capture the public health staffing costs associated with 94 hoarding cases in 2005 for the City of Ottawa produced the staggering total of \$133,328.00.

The majority of key informants and focus group participants expressed comments such as, "It is bigger than most people think." Guesstimates and statistics from individual organizations included:

- Fire personnel get involved about 6 times a week or approximately 300 times a year
- Approximately 7 incidents of animal hoarding are dealt with on a yearly basis
- Statistics reported by Public Health – Health & Social Crisis Program staff at the City of Ottawa
  - 2003: approximately 10% of caseload identified as hoarding (25 cases)
  - 2004: approximately 33% of caseload identified as hoarding (70 cases)
  - 2005: approximately 30% of caseload identified as hoarding (94 cases)

Frost et al. (2000) Reported a 5-year prevalence of hoarding-related complaints to 88 American public health departments in Massachusetts of 26 per 100,000. They note that this figure undoubtedly seriously underestimates the number of people with compulsive hoarding problems, as many have not had a public complaint filed against them. Using figures from studies of OCD, a rough estimate of lifetime hoarding frequency would be 4 per 1,000. This, most likely, is also an underestimate since this figure includes only those with an OCD diagnosis. Approximately a third are estimated to involve animal hoarding. Another study (Patronek, 1999) estimates 0.80 (median 0.25) new animal hoarding cases per 100,000 human population are investigated each year.

The collection of representative data becomes a challenging affair within a decentralized process as the only option may be for individual agencies to collect data. Such an approach can result in the accrual of inaccurate information due to different intake and assessment approaches, and double counting when more than one agency is involved. If Systems Navigators are put into position as described in section 3.2.3 of this report, they may be in a position to collect data, minimize duplication and maintain confidentiality.

Longer-term goals should include:

- Ongoing research to establish the incidence and nature of hoarding; and,
- Evaluation to further the understanding and prioritizing of client needs and service gaps.

## Attachment A –

# Literature Review to Support the Development of a Community Response to Hoarding

## 1. Introduction

This report presents the findings of the literature review conducted as part of Phase One of the study commissioned by **The Ottawa Community Response to Hoarding Coalition**.

The coalition directed the consultant to review the body of knowledge produced in the last 5 years to determine trends in:

- Incidence - is there statistically valid or credible anecdotal evidence that the rates of hoarding is changing;
- Demographics – does the type and/or nature of hoarding behaviour differ by area;
- Community response – what are other areas doing about their community’s hoarding situations;
- Benefiting from lessons learned by others – are there lessons to be learned from the work which has been done in others areas which would aid Ottawa in the development of a coordinated interagency service delivery model.

### 1.1 Parameters of the Review

The bulk of existing literature on hoarding provides descriptors of the phenomena linked to hoarding and the treatment approaches emerging from current research. This review, however, is not only about determining the best treatment approach. It also seeks to identify other needed aspects a community plan including how to unify its structure. Specifically, the review sought information about recommended strategies, frameworks, collective activities and best practices for consideration during the development of comprehensive plan for Ottawa.

Articles, books, and websites used in this literature review were identified through key word searches about “hoarding”. Particular emphasis was placed on seeking recent North American references containing information on community plans/responses and related success factors. Due to a lack of information about community plans addressing hoarding, additional searches centered on reviewing community plans about issues related to hoarding such as homelessness substance abuse, and mental health.

The findings from this literature review will guide the development of key informant, client and focus group interview tools that will be used during the primary data collection phase of this project. The combined results will inform the development a community response to hoarding for Ottawa.

## 2. An Overview of Hoarding

The body of knowledge about hoarding is limited. A clear understanding of how it should be categorized and approached is still outstanding.

Hoarding is usually considered a manifestation of obsessive-compulsive disorder (OCD). It may occur alone or in the context of other disorders such as dementia, schizophrenia, eating disorders, mental retardation, and obsessive-compulsive personality disorder. Relatively little research has been done on this problem despite its close association with OCD. 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 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. (Steketee & Frost, 2003 & 2004)

## **2.1 Identifying a Hoarding Situation**

Outside the home environment hoarders are almost always undetectable. However, sooner or later the compulsion will create a problem at the home that brings local government agents to their door. Neighbours may complain about odours or debris piling up outside, utilities may report that water, heat or electricity has been cut off, or a concerned relative, caregiver or friend may ask for help. A time always comes when an official determines that the hoarder has become a danger to the health and welfare of themselves and their community. In short, the “bubble” that the hoarder has spent years creating has burst! At this point governmental agencies are obliged to act. By then the individual may have lost their capacity for independent living and cost effective interventions are not longer possible. Success stories occur when the person is returned to a clean situation, receives medication as appropriate, obtains support to address the situation, and is able to live without sliding back into the situation that engulfed them. (Dane County 2001)

## **2.2 Features and Types of Hoarding**

There are 3 defining features of compulsive hoarding:

4. The acquisition of, and failure to discard a large number of possessions that appear to be useless or of limited value;
5. Living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and,
6. 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 and are 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. (Steketee & Frost 2003 & 2004)

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 health. (Reyes-Ortiz, 2001)

The Dane County Task Force Report divides hoarders into two groups: Generalists and 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 have all their excrement, their shed hair, used bandages, and so on. (Dane County, 2001)

In a presentation on hoarding to participants at a conference in Ottawa, Frost (2004) provided a more specific sub typing of hoarding:

- 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. (Frost 2004, Patronek 2001)

## 2.2.1 What Causes Compulsive Hoarding?

Although the ultimate cause of compulsive hoarding is unknown, Steketee & Frost (2004) 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 disorder (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 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.

## 2.2.2 Common Hoarding and Diogenes Syndrome

The following points have been gathered from a variety of research initiatives and case studies involving common hoarding and DS. Given the current status of research in this area it is unknown whether the following aggregation of personal and environmental findings constitutes features specific to hoarding, or merely a collection of incidental features of a variety of co-occurring conditions for those individuals studied. Such demographics, symptoms, risk factors and other features associated with hoarding for the most part should not be generalized. However, they are provided here in a collective format to assist community workers in detecting the potential for hoarding as opportunities for earlier intervention can forestall more serious outcomes for the hoarder, household members, and communities.

- Onset can occur in childhood or early adolescence. Trauma is associated with a later age of onset;
- 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;
- Many individuals who hoard have a lifelong history of criticism from others and have become sensitive to any kind of implied criticism. They may jump to conclusions about the views of those seeking to assist them;
  - Future need of an item is the most frequently given reason for hoarding followed by object worth and sentimental value;
  - Those that hoard frequently complain about memory problems and that they need visual cues to remember. Yet their memory about possessions appears very detailed;
  - Many have led successful professional and business lives, with good family backgrounds and upbringing;
  - Many people who have serious hoarding problems also experience significant depression and the problems associated with it – poor appetite, sleeping problems, low energy and possibly suicidal ideation;
  - Those that hoard are frequently described as independent, unfriendly, stubborn, obstinate, aloof, aggressive, suspicious, secretive and quarrelsome. They see themselves as having sole control over their things and may not allow anyone to touch them;
  - 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;
  - There is a low rate of marriage and high rate of divorce among people with compulsive hoarding. Most elderly hoarders are female, unmarried, and live alone. This is consistent with a description of those with a “hoarding orientation” as withdrawn and remote from others and may relate to findings of greater social anxiety and schizotypy. Never married status is associated with more severe hoarding, greater impairment and possibly worse intervention outcomes;
  - Self neglect (Diogenes Syndrome) can involve a lack of clothing and poor nutrition, medical; and/or dental care;
  - Those that hoard do not consider their behaviour unreasonable and may be oblivious to the distress it causes to other family members, friends and neighbours;
  - People with hoarding problems exhibit more perfectionism than those who do not hoard. One individual could not discard newspapers as she had not read them thoroughly enough nor committed their contents to memory;
  - Hoarding is associated with higher levels of personality disorders, but the specific disorders involved have been inconsistent across studies. This may make group intervention more challenging.

(Cermele et al 2001, Johnson & Adams 1996, Rosenthal et al 1999, Stein et al 1999, Steketee & Frost 2004, Steketee et al 2001)

### **2.2.3 Animal Hoarding**

Animal hoarding, considered the most difficult type of hoarding to treat, is procedurally cumbersome, time consuming, and costly to resolve. Resolution is further confounded by issues of personal freedom, lifestyle choice, mental competency, private property rights and jurisdiction. Expenses for veterinary care, housing of animals, litigation, and clean up or demolition of premises can run into the tens of thousands of dollars.

A hoarder may claim to be a pet rescuer, an effective ploy for the media or as a defense in court. Some individuals may actually enable the acquisition of animals, either by bringing them to the hoarder or encouraging others to do so: usually under the belief that they have found someone to legitimately care for needy animals. (Arluke et al 2002, Patronek 2001)

### 2.2.3.1 Profile of an Animal Hoarder

Although the stereotypical profile of an animal hoarder is an older, single female, living alone and known as the neighborhood "cat lady," in reality this behavior seems to cross all demographic and socioeconomic boundaries. One study found that the majority (76%) of animal hoarders were female and 46% were 60 years of age or older. (Patronek 1999 & 2001)

Animal hoarders tend to be very secretive, often leading a double life with a successful professional career. Inanimate objects are also frequently hoarded. Research suggests that hoarders grew up in chaotic households with inconsistent parenting, in which animals may have been the only stable feature. (Patronek 2001, Myers 2001)

The attitudes and beliefs of the animal hoarder are very distinct. The hoarder actually believes that they are doing a great service for their animals and may make statements such as:

- No one can love their animals like they do;
- Only they can cure these animals with their secret or special remedies (usually herbal);
- The animals are being saved from certain death;
- The animals are like their children;
- No one else would take care of them;
- Animals are their only friends or companions

(Myers, 2001)

In a recent monograph, HARC<sup>6</sup> outlined possible psychological models for animal hoarding:

- A focal delusional disorder could explain why an individual claims that animals are well-cared for in the face of clear evidence to the contrary;
- Delusional levels of paranoia about officials are consistent with a belief system that is out of touch with reality;
- Similarities have been noted between hoarders, substance abusers, gamblers, and others with impulse control problems;
- An attachment disorder could be present, such that relationships with animals are preferred because they are safer and less threatening than relationships with people;
- Obsessive-compulsive disorder (OCD) is likelihood.

(Patronek, 2001)

#### 2.2.3.1.1 Health and Social Implications

U.S. and Canadian public health officials involved in a study about animal hoarding reported significantly worse sanitary conditions and threats to health than common hoarding situations. The majority of cases satisfied criteria for adult self-neglect. Dependent elderly people, children, or disabled individuals were also present in many of the residences. When dependent family members were present they were often neglected to the point of abuse - most likely tolerating conditions in return for human care and companionship. (Arluke et al 2002)

Recent documents clearly establish the link between animal abuse and child abuse, as well as domestic violence. Consequently an increasing number of animal welfare agencies and child protection groups in the U.S. are recognizing the value of cross-reporting abuse and cross training their personnel. (Patronek, 2001)

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<sup>6</sup> Hoarding of Animals Research Consortium (U.S.)

### 2.2.3.1.2 Community Implications

From a community health perspective, such situations can pose a fire hazard as fireplaces and kerosene heaters are sometimes used for heat. Rodent and insect infestations, as well as odours, can create a neighborhood nuisance. Animal hoarding when compared to other hoarding situations usually involves the greatest number of agencies.

Some communities attempt to either prevent or remedy hoarding situations by passing ordinances that limit the number of pets a person can own. There is no data to indicate whether these measures are effective, but what is known is that they are wildly unpopular, difficult to enforce, and likely to be opposed by pet fanciers, breeders, rescue groups, and animal protection organizations.

The worst situations may be avoided through regulations that stipulate housing densities, sanitation requirements, veterinary care, and which provide for regular inspections of licensed facilities. For example, Colorado has developed licensing requirements and comprehensive standards for the operation of an animal shelter or pet rescue organization. Such criteria could also help the media and the public, as well as the courts, to distinguish between legitimate sheltering efforts and hoarding. (Patronek, 2001)

## 2.3 Prevalence

Neither formal prevalence statistics nor differences in the type and/or nature of hoarding behaviour by geographical area were discovered during the literature search. The following provides some understanding of prevalence as a result of estimates generated by specific but limited studies in the United States. Earlier documentation of estimates is more conservative but researchers conclude that there is no evidence to indicate that the incidence of hoarding is increasing.

Frost et al. (2000) reported a 5-year prevalence of hoarding-related complaints to 88 American public health departments in Massachusetts of 26 per 100,000. They note that this figure undoubtedly seriously underestimates the number of people with compulsive hoarding problems, as many have not had a public complaint filed against them. Using figures from studies of OCD, a rough estimate of lifetime hoarding frequency would be 4 per 1,000. This, most likely, is also an underestimate since this figure includes only those with an OCD diagnosis. Approximately a third are estimated to involve animal hoarding. Another study (Patronek, 1999) estimates 0.80 (median 0.25) new animal hoarding cases per 100,000 human population are investigated each year.

Resolution for 58 of the reported cases in one study (Frost et al., 2000) varied considerably:

- 32% willingly cooperated sometimes only in a limited manner, and improvements were not always maintained;
- 25% reluctantly agreed to improve conditions, but made few attempts to reduce the number of possession;
- 40% refused to cooperate at all and had some or all of their possessions removed by the city, and were monitored thereafter. For nearly half of these, the buildings were condemned, or the tenants evicted, and nearly a third were moved to assisted care facilities;
- 5 house fires were caused or exacerbated by the clutter, resulting in 3 fatalities;
- In several cases family members took responsibility for the person after the complaint was filed.

### 2.3.1 Prevalence Estimates and Statistics for Ottawa

Based on the conservative estimates provided in section 2.2, the following scenario is possible for Ottawa.

- More than 3200 of the 800,000 residents of Ottawa may be hoarders of which approximately 40 will be identified annually.
- Within those numbers, 1,000 most likely hoard animals and 3 to 8 new cases will be reported annually.

Statistics reported by Public Health – Health & Social Crisis Program staff at the City of Ottawa (without input from other agencies involved in hoarding situations) documents an even higher actual incidence in 2004 and predicted incidence for 2005 than estimates based on U.S. studies. This may be due to increased community awareness of the issue as a result of publicity about hoarding generated by 2 conferences on the topic in Ottawa.

2003: approximately 10% of caseload identified as hoarding (25 out of 256 cases)  
2004: approximately 33% of caseload identified as hoarding (70 out of 215 cases)  
2005 to March 31<sup>st</sup>: approximately 30% (14 out of 47 cases) for an estimate of 56 hoarding cases for the year

## 3. Barriers to Addressing Hoarding Situations

Several U.S. studies document the difficulties and resulting frustration arising when incompatible approaches or beliefs about hoarding exist in the same community. An inability or unwillingness of mental health, social service, and public health authorities, including departments of aging, to intervene is often described. The rationale frequently offered is that hoarding is a lifestyle choice and not a public health or mental health issue. In some cases, human health agencies discontinued involvement after criteria to establish mental incompetence were not met, despite clear risks from self-neglect, falls and injury, poor nutrition and extreme lack of sanitation including potential for infection and zoonotic<sup>7</sup> disease. In other instances a lack of knowledge about the role of other community agencies in hoarding situations or prevailing ordinances is documented. One study notes that while interventions to help people in these situations seem to be inadequate, there are comparatively effective and easily implemented laws in place to allow the rescue of animal victims.

In many 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 in 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,

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<sup>7</sup> Pertains to diseases transmittable from vertebrate animals to humans

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.

More timely assessment and coordinated intervention would result in less trauma for the hoarder, would be less expensive for municipalities, could prevent substantial animal suffering, and could provide needed services for the humans and animals involved.

(Burt et al 1992, Arluke et al 2002, Patronek 1999 & 2001, Smith 2001)

## **4. Benefits of a Community Response to Hoarding**

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.

Establishment of a coordinating body should be considered 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. (Arluke et al 2002, Patronek 2001)

### **4.1 Community Responses to Hoarding in Other Cities**

Information about the following community task forces/coalitions was reviewed to identify elements of community plans addressing hoarding. Ottawa is the only known initiative in Canada.

Arlington Virginia Hoarding Task Force  
New York City Hoarding Task Force  
Seattle, WA Special Emphasis Housing Group  
Fairfax County, VA Residential Hoarding Task Force  
Dane County, Madison, WI Hoarding Task Force

Collectively these organizations engage in the following activities:

Awareness raising including production of information flyers, media interaction and use of websites  
Peer support groups for those who hoard  
Specific case problem solving and case management  
Establishment of working groups/ sub committees on specific topics such as governance, evaluation, interventions, resource and protocol development, etc.  
Resource sharing  
Production of intake, screening, assessment and intervention tools  
Protocols for identifying priority cases, cleaning houses  
De-cluttering guidelines  
Use of a pre-guardianship panel to advise support workers

- Campaign to educate decision makers about hoarding
- Development of referral guidelines and decision trees
- Establishment, identification and/or coordination of multi-disciplinary front line intervention teams
- Development of interdisciplinary training curriculum

(Dane County, New York City, Los Angeles & Fairfax websites)

## 4.2 Community Planning Models and Frameworks Relevant to Hoarding

Existing plans addressing hoarding describe a variety of activities undertaken in each community. What guides these planning processes is not apparent.

To fill this gap, key strategic planning resources utilized by communities to address homelessness, addictions and health were reviewed to identify model or framework<sup>8</sup> components applicable to hoarding. These fields were chosen based on their relationship to hoarding established in the literature. Findings are profiled in the following sections.

### 4.2.1 The Four Pillar Approach

The Four Pillar approach to problematic drug use is a model that has been used around the world for some time. The approach balances prevention, treatment, enforcement and harm reduction initiatives, within a single coordinated community drug strategy. Briefly, the components of the four pillars are:

*Prevention* involves educating people (non-users, non-addicted drug users, addicted and problematic drug users, and their friends and family) about the dangers of drug use. It builds awareness about why people misuse drugs and tells what can be done to avoid drug use, addiction or worsened addiction.

*Treatment* consists of a continuum of interventions and support programs designed to help problematic drug users make healthier life decisions.

*Enforcement* is primarily concerned with the maintenance and enhancement of public order and safety, and targets the activities of those drug-involved individuals who are a threat to either.

*Harm reduction* focuses on decreasing the negative consequences of drug use for individuals and communities alike. Not all drug users are ready or able to stop using drugs right now; until they are, it is the goal of harm reduction to make sure that they do as little damage to themselves and others as possible.

(MacPherson, 2001)

### 4.2.2 Community Continuum of Care (CoC) Planning

A CoC plan is a community plan to organize and deliver housing and services to meet the specific needs of people who are homeless as they move to stable housing and maximize self-sufficiency. It includes action steps to end homelessness and prevent a return to homelessness

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<sup>8</sup> A framework or model for change can be thought of as an outline, skeleton or blueprint. It maps out how an initiative will achieve a predefined vision by guiding planning, implementation, and evaluation. As a result, its different components are aligned and focused towards agreed upon outputs and outcomes. Diagrams and logic models are frequently used to illustrate frameworks and models. <http://ctb.ku.edu/tools/developframework/index.jsp>

based upon a vision of the ideal continuum of care and desired outcomes<sup>9</sup>. Four components of a model focusing on service delivery have been established to guide development of a local plan:

1. Outreach, intake, assessment and referral;
2. Emergency shelters with appropriate supportive services;
3. Transitional housing with appropriate supportive;
4. Permanent housing and permanent supportive housing.

While challenges of implementing such a model involve working with siloed health and social services that may be resistant to integration and formalizing agreements necessary for linking services into a continuum, identified strengths include:

- Increased ability to secure funding;
- Increased coordination and collaboration among agencies services to enable homeless persons to move along the service spectrum;
- Increased awareness of the needs and available resources in a community;
- Encourages proactive solutions involving prevention of homelessness;
- Formal recognition and sharing of best practices;
- Outcome evaluations that could inform decision-making.

(HUD website)

### **4.2.3 Health Strategies, Models and Planning Frameworks**

Several documents in the field of health promotion, public health and population health were reviewed to identify content relevant to the development of a community response to hoarding. (Health Canada website, Canadian Public Health Association 1986, Kahan & Goodstadt 2002, Howard-Grabman & Snetro 2003) Collectively they provide the following information about developing community plans and how such plans can be strengthened through a link to health effects and outcomes:

- Place health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the consequences of their decisions.
- Concrete and effective community action requires setting priorities, making decisions, planning strategies and implementing them.
- Draw on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.
- Personal and social development can be enhanced through providing information, education for health and enhancing life skills. By so doing, it increases the options available to individuals to exercise more control over their own health and over their environments, and to make choices conducive to health.
- Communication plans/social marketing campaigns can assist with raising awareness in the general public. This can take the form of a wide array of activities from back of the bus posters and commercials to guidelines for media reporting on hoarding situations.

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<sup>9</sup> intended (desired) or unintended results (short- or long-term) of activities/strategies/processes

- The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services. Health services need to embrace an expanded mandate. This mandate should support the needs of individuals and communities for a healthier life, and open channels between the health sector and broader social, political, economic and physical environmental components.
- Pay attention to professional education and training
- Community collaboration can increase understanding of the issue at hand, build capacities and supports, increase communication and "team build"

The Interactive Domain Model (IDM) provides a framework to guide a systematic, comprehensive and critically reflective approach to health promotion practice. It considers not only evidence, but also values, goals, ethics, theories, beliefs, and understanding of our environment. The IDM Manual (Kahan & Goodstadt 2002) outlines the following steps to developing a Framework:

- Develop a solid foundation by: (a) identifying standards or recommended ways for taking action that can be used to assess or guide action (b) examining the current situation, and (c) developing a picture of the ideal situation.
- Develop an action and evaluation plan to make a picture of the ideal a reality, defining the and how (i.e. relevant activities, tasks and processes), the who, and the when, all with respect to specific objectives.
- Document what happens when the action and evaluation plan is implemented with respect to activities, processes, and outcomes/impacts.
- Based on evaluation and documentation processes, revise the ideal picture and/or the action and evaluation plan.

In other words, a Framework leads us through a process of answering the following questions:

1. Where are we now and where do we want to go?
2. How do we get to where we want to go?
3. What did we do, how did we do it, and what were the results?
4. What do we need to change in order to move forward?
5. What criteria and guiding principles will help us in our journey?

#### **4.2.3.1 Champlain District Mental Health Implementation Task Force**

The provincial policy framework "Making it Happen" (1999) was used as a planning resource by Ontario communities in 2002 to guide local restructuring plans. The Champlain District Mental Health Implementation Task Force (2002) was responsible for developing a plan for Ottawa. Core elements of the provincial policy include accessibility, accountability, based on best/emerging practices; consumer is at the centre of the system, and integration. Expectations set out regarding integration and the resulting plan for Ottawa are relevant to the development of a collaborative approach to hoarding. In brief, they are:

- The full spectrum of services is provided in a seamless manner, with necessary linkages to other service systems;
- Individuals are able to receive the level and intensity of services they require without experiencing a disruption in their services;

- Streamlined access to services and supports exist ensuring clients have access to clear information on what services are available, as well as clear information/assistance in accessing that service/support;
- Duplicated administrative functions, services and supports are eliminated;
- Timely and appropriate sharing of, and access to client information, with consent and confidentiality requirements is reflected in service protocols between providers;
- There exists a clear understanding of the roles and responsibilities of all care providers and their respective agencies within the system;
- Shared service models of care and protocols exist to ensure that individuals with multiple problems that cross a variety of services jurisdictions continue to receive integrated and comprehensive services.

A local governing structure or lead agency/entity is proposed for Ottawa to act as the administrative, funding, monitoring, and advocacy structure responsible for ensuring implementation of the above expectations. Other agencies will then be able to focus on service provision.

The Champlain District Implementation Task Force also proposed a new function called system navigation. Staff involved will provide a centralized intake function and undertake service planning, monitoring and advocacy on behalf of each client of the system. A referral process will engage community agencies to provide the required services identified during the planning process. A diagram depicting the Champlain District model can be found in Appendix 1

## **5. Components of a Community Response to Hoarding Framework**

Using a framework or model of change to guide planning, action, and evaluation can help a group:

- Create commitment to a common and organized understanding of an initiative's approach for change;
- Set the stage for strategic action based on research, community experience and available resources. Social change models often focus on multiple levels (i.e., personal, organizational, community, policy);
- Provide a clear rationale for program activities that can facilitate funding of certain program components, provide guidance to technical assistance and support staff, and guide identification of indicators and evaluation.

(Community Toolbox website)

Information gathered from the literature, community plans addressing hoarding, and related community planning models, provides clues of possible components of a community response to hoarding model that is in line with the goals of the Ottawa Coalition. Those components are:

- 1) Governance
- 2) Service Delivery
- 3) Skill Development

- 4) Social Marketing
- 5) Quality Assurance

## 5.1 Governance

Effective governance ensures objectives are realized, resources are well managed, important relationships are nurtured, and the interests of stakeholders are reflected in decisions. Different forms of community organizations produce different outcomes. The Ottawa coalition will need to identify the organizational format it requires to meet its goals and implement its desired service delivery model. The following table describes common types of community organizations.

**Table 1: Forms of Community Organization**

<i>Type</i>	<i>Purpose</i>	<i>Structure</i>	<i>Process</i>
NETWORKING	Dialogue & common understanding Clearinghouse for information Create base of support	Non-hierarchical Loose/flexible links Roles loosely defined Communication is primary link among members	Low-key leadership Minimal decision making Little conflict Informal communication
COOPERATION OR ALLIANCE	Match needs & provide coordination Limit duplication of services	Central body of people as communication hub Semi-formal links Roles somewhat defined Little or no new financial resources	Facilitative leaders Complex decision making Some conflict Formal communication within the central group
COORDINATION OR PARTNERSHIP	Share resources to address common issues Merge resource base to create something new	Central body of people consists of decision makers Roles defined Links formalized Group leverages/raises money	Autonomous leadership but focus is on issue Group decision making in central and subgroups Communication is frequent & clear
COALITION	Share ideas & be willing to pull resources from existing systems Develop commitment for a minimum of three years	All members involved in decision making Roles and time defined Links formal with written agreement Group develops new resources and joint budget	Shared leadership Decision making formal with all members Communication is common & prioritized
COLLABORATION	Accomplish shared vision and impact benchmarks Build interdependent system to address issues & opportunities	Consensus used in shared decision making Roles, time & evaluation formalized Formal links and written in work assignments Resources & joint budgets are developed	Leadership high, trust level high, productivity high Ideas & decisions equally shared Highly developed communication systems

Source: *Community Based Collaborations: Wellness Multiplied*, 1994, Teresa Hogue.

## 5.1.1 Protocol Development

Communities addressing hoarding have used time limited working groups as part of their governance structure to develop information resources, assessment/screening tools, decision trees, training opportunities and service delivery protocols/guidelines, etc. for collective use by local agencies. Samples are contained in Appendix 2, and 3, (New York, Los Angeles County, Dane County websites)

Randy Frost in a 2004 presentation to service providers in Ottawa recommended community wide risk management protocols that support:

- Developing guidelines for assessing risk
- Developing trust - especially after a forced clean-up
- Use of a clutter coach
- Getting workers visiting the home environment
- Obtaining commitment to keep certain areas clear of clutter
- Obtaining commitment for home visits to maintain safe living environment
- Arranging for food delivery or other services
- Arranging for repairs

(Frost, 2004)

## 5.1.2 Guidelines for De-Hoarding Protocol Development

Steketee & Frost (2004) underscore the importance of someone familiar with motivational interviewing strategies making a personal connection with the hoarding client. This does not necessarily need to be a therapist, but should be someone that can build a strong and trusting long-term relationship with the hoarding client. They suggest the following guidelines for developing that relationship:

- Help the person to remain focused on the task in front of them. People with hoarding problems often find themselves easily distracted, especially when they are trying to reduce clutter, make decisions about possessions, or resist the urge to acquire things. Often, the coach can be very helpful by simply reminding the person what they are supposed to be doing right now. Sometimes all that is required is casual conversation about the task itself.
- Provide emotional support. Don't argue with the person who has the hoarding problem and don't tell the person with the hoarding problem how they should feel. Such approaches cause the person with the hoarding problem to feel even more isolated and misunderstood, and to retreat. Use a "gentle touch", expressing empathy with statements such as, "I can see how hard this is for you," or "I know you have mixed feelings about whether to tackle this clutter." The person with the hoarding problem is under major stress, and often needs a sympathetic ear or a shoulder to cry on.
- Help the person with decision-making. This is different from making the decision for the client. It is important for the client to learn how to make decisions about possessions. Asking them questions about the usefulness or meaning of possessions will be most helpful. For example, "Is it useful?" "Do you need it?" "Can you do without it?" "In the long run, are you better off keeping it or letting it go?" Be sure to let the client make the decision, even though it may not be the best choice.
- Be a cheerleader. Staying in touch with clients during difficult times, telling them they can do it, and telling them what a great job they're doing are all good cheerleading strategies.

- Help with hauling. Clients get discouraged, when progress is slow. Coaches are very helpful when they roll up their sleeves and help remove items from the home, provided that the person with the hoarding problem remains fully in charge of the process. Don't touch or move anything in the client's home without his or her specific permission.
- Accompany the person on non-acquiring trips. People who accumulate too many things must learn how to resist the urge to acquire. It is helpful to have someone accompany them on a non-acquisition trip, to help them resist temptation.

Don't work beyond your own tolerance level. To be effective, coaches have to take care of themselves first and then help the client. Helpers must set limits on how long and how much work they do on any given occasion. Steketee & Frost (2004)

### **5.1.2.1 Guidelines for De-Hoarding Protocol Development Regarding Animal Hoarding**

HARC has developed the following tips for the management of animal hoarding cases:

- Hoarders often view the world as a very hostile place for both animals and people. Carefully consider your approach. Avoid badges or other official paraphernalia if possible. It may be helpful to identify a friend, neighbor, family member, or possibly a veterinarian, to intercede or act as an intermediary.
- Many people have difficulty feeling sympathy or even respect toward hoarders. By maintaining an awareness of their own emotional responses, the individuals attempting to intervene are likely to find it easier to retain perspective.
- Instead of arguing about the household conditions, assist the individual to problem solve. For example, are they having trouble cooking, or affording pet food, or sleeping? Working on these issues could be a conduit to trust and better communication that will let you indirectly work on the animal-hoarding problem.
- Do not assume a mental health problem is present. Since the problem of animal hoarding is a very new area of study, it is unlikely that mental health services that specialize in intervention with animal hoarders will be available. It may be useful to refer the hoarder to a clinician with extensive experience in assessing and diagnosing people with a wide range of mental health problems.
- Hoarders may have problems concentrating and staying on track with any management plan. Be prepared for a long-term process and frequent monitoring of the situation.
- Encouraging the hoarder to seek medical attention might be appropriate. In view of hoarders' financial problems, the hoarder might need social service help to obtain adequate medical services.
- Treat each hoarding case as unique. Avoid a "one-size-fits-all" protocol, which can jeopardize the sensitivity to the individual needs of each case.
- Much of the hoarder's identity may be tied to his or her possessions; therefore, giving up anything can be associated with tremendous fear, apprehension, and even a grief-like reaction. If possible, avoid any discussion of reduction in number initially, as this will likely evoke strong resistance from the hoarder and be a barrier to future communication. Slow reductions in the number of animals may be much more palatable and lead to greater cooperation.

- Hoarders often firmly believe they are providing quality care and have special empathy with the animals. It may be helpful to acknowledge their attempts to provide care, however unsuccessful, and their special connection with the animals, so as to gain their confidence and trust. Their care giving may be a conduit to communication.
- Expect denial of the problem on the part of the hoarder. There is probably little point in arguing about what may appear to be a serious lapse in care, or insensitivity to obvious suffering. Hoarders are often not lying; they lack the insight to appreciate the true conditions present.

(Patron, 2001)

## 5.2 Service Delivery

Some communities addressing hoarding have established specialized front line service delivery teams to intervene in hoarding situations. In one instance, an existing team with an adult protection mandate provides this role. In another, agencies coordinate efforts by creating a new team from their collective staffs for each hoarding situation. (Fairfax, New York City, Los Angeles County websites)

Members of the Ottawa coalition will need to agree on a service delivery model to meet their goals. A variety of terms are used in the literature to describe community service delivery models: a system wide approach, seamless services, comprehensive service system, total service delivery, integrated, coordinated, continuum, etc. Descriptors of a model based on integration and comprehensiveness, and inclusive of prevention, intervention, and treatment activities seem most compatible with actions taken by other communities addressing hoarding, Ottawa Coalition goals, recommended protocols, and frameworks described earlier in this report.

### 5.2.1 Comprehensive Service Integration Model

This model expects a combining of best practices from different sectors, systems and types of service into a structural whole based on common goals and objectives around a shared vision. Agencies participating at the governing level are accountable for protocol development and supporting integration at the practitioner level. With this approach, practitioners, working in a multi-disciplinary way, can achieve a seamless continuum of service from the client perspective even though these practitioners may work in different organizations and undertake different activities.

Specific service delivery activities described in the literature about hoarding include:

- Intake
- Assessment
- Case Management
- Voluntary Interventions
- Involuntary interventions
- Treatment

(Chandler Center for Community Leadership website, MacPherson 2001, HUD website, Champlain District Implementation Task Force 2002, AOHC position paper 1997, Burt et al 1992, Hierlihy et al 2003)

### **5.2.1.1 Intake**

Law enforcement, family members, housing units, landlords, neighbors, health clinics, and caregivers are often the people who begin seeking help for people with hoarding problems. In Dane County, the Elder Abuse Office has been designated as the agency to receive complaints about seniors involved in hoarding. The office strongly recommends reporting when there is severe hoarding or hoarding plus one or more of the following:

- a. Financial abuse or exploitation
- b. Physical or sexual abuse or assault
- c. Domestic violence
- d. Danger to health and person won't accept services
- e. Threat of eviction or condemnation
- f. Animal abuse or neglect
- g. Suspicion of dementia and/or untreated mental illness

Appendix 3 contains a sample telephone intake form.

A coordinated or centralized intake function ensures an effective data collection system, which in turn assists with future planning. Social Marketing campaigns will need to include information about where to report concerns about hoarding situations.

### **5.2.1.2. Assessment**

A comprehensive psychological, physical and social assessment is important for quantifying the severity of a hoarding problem. An initial interview should gather information on the current living situation, hoarding symptoms, family history and need for trash removal and/or temporary storage. During a more formal assessment, pictures and observational ratings of the home environment are appropriate for those lacking recognition of their problem while self-report instruments can be used with those willing to cooperate. The Cognitive Behavioral Treatment Manual for Compulsive Hoarding (Steketee & Frost, 2004) contains several tools to assist with the assessment process.

A motivational interviewing approach during assessment allows the client to disclose the extent of hoarding and cognitions that maintain and reinforce the behaviour. The results provide direction to care plan development. When capacity is high, the client's right to self-determination should be respected. When capacity is low and risk is high, intervention is required, even to the extent of involuntary guardianship. When the individual's capacity is moderate and the risk is moderate, psychosocial interventions should be pursued that are geared toward encouraging the client to accept services such as the use of a clutter coach and participation in peer support groups (National Center on Elder Abuse 1999, Cermele et al 2001, Frost & Steketee 1998, Frost 2004, Dane County website)

### **5.2.1.3 Case Management**

Case management is used in some communities to ensure effective planning and referral to meet the specific needs of the hoarding client. Planning may be done by an individual case manager or as part of a case conferencing process. Dane County uses the latter. It suggests using a facilitator to ensure the meeting is supportive and constructive and that a summary is provided. The solving of ethical dilemmas is emphasized.

In some instances specialized teams are developed that both plan and provide service – as is the future goal of Dane County. In Arlington County a central planning process involves a variety of

agencies in planning then implementing service provision. They also use a pre-guardianship panel that includes seven citizen and agency representatives to provide consultation to workers thinking of seeking guardianship for a client

When developing plans about animal hoarding, one key to success is the inclusion of an experienced and skilled animal welfare agency. They will be able to recognize cases where prosecution is optimal, as opposed to those in which a strategy of negotiation and building trust can lead to the gradual reduction of animal populations and an improvement in household conditions.

The development of resources listing cognitive behaviour therapists, professional house organizers/cleaners, self – help options, etc. providing services in a manner consistent with the service delivery philosophy of the coalition, can help with the referral process.  
(National Center on Elder Abuse 1999, Dane County website, Patronek 2001, Frost 2004)

#### **5.2.1.4 Voluntary Interventions**

Success of a de-hoarding intervention depends on several factors. First, level of trust in the therapeutic relationship is critical as a gateway for the intervention to take place. Second, the client is able and motivated to engage in cognitive restructuring. Third, acknowledgment of and respect of the client's emotional attachment to possessions are maintained. And finally, supporting the client's right to control the removal of possessions ensures empowerment to complete the process.

The literature provides describes several strategies to assist with a voluntary de-hoarding process:

- Support workers need to be listeners, explorers, collaborators and cheerleaders;
- Pay attention to stories of the importance of things. Take their pictures and assist with the creation of memory albums. This acknowledges the importance of possessions and provides a way to preserve emotional attachments while simultaneously disposing of a significant amount of clutter;
- Encourage clients to use skills learned in cognitive restructuring and problem solving to manage anxiety during and after the process;
- Take before and after pictures to document progress;
- Decision trees are useful tools to help workers determine next steps during the de-hoarding process;
- Challenge logic and use humour about keeping some items such as winter clothing when living in a warm climate;
- Well trained and screened volunteers can assist with the process;
- Donating and recycling different items, supports the belief that possessions have value while challenging the belief that all possessions must be kept.

(Cermele et al 2001)

A similar approach applies to animal hoarding where an additional goal is to lesson the suffering of the animals involved. In some cases, a worthwhile strategy may be to negotiate a situation in which the hoarder is allowed to keep a small number of special pets if living conditions are brought up to par and consent is given for regular monitoring. Animal control or sheltering groups and veterinarians are local allies in such a plan. Given the high potential for recidivism where all the animals are abruptly removed, this strategy may represent the best option for circumventing the denial and reluctance to cooperate and for providing long-term control of the situation.  
(Arluke, 2002, Myers 2001)

### **5.2.1.5 Involuntary Interventions**

Emergency measures are often necessary because of immediate health and safety risks. The typical pattern of intervention begins with a clean up order together and a deadline for this work to be completed. In severe hoarding cases this seldom works despite promises on the part of the client. Clear outs will resolve an immediate health and safety crisis, but won't stop the condition from recurring. In most cases, the homes of people with serious hoarding problems fill up again quickly. To resolve the problem, community agencies must work together to minimize risk for the individual and the community in which they live.

An involuntary intervention should be preceded by a formal assessment involving motivational interviewing techniques. This strategy will have several benefits, including shifting the focus from discarding possessions to identifying problems with the client's ability to function. This approach can be modeled after similar procedures used in the area of drug and alcohol abuse.

Cleanouts should be organized to meet minimal standards of health and safety with the understanding that the client is responsible for maintenance and further improvement. Structuring cleaning procedures so that clients have to make some decisions will more likely bring about long-term personal change and prevent further danger to the community. There are many forms this can take including doing the cleaning over a longer period of time with the client's help. This is often very difficult, but some structure may be useful here. For instance, the client can be allowed to make decisions about where each item will go (e.g., dumpster, storage unit, back in the house). If the item goes back into the house, rules can be established about where and what to do if that area is full. The assistance of a trusted helper/coach is critical during this process. (Steketee & Frost 2004)

A review of existing ordinances can improve local understanding of what control mechanisms are applicable and most appropriate for a given situation. It can also help identify the need for new or updated ordinances and policies at the community and agency level.

California now mandates that animal control personnel report child abuse; Connecticut and the District of Columbia encourage it. Ohio law provides for humane officers to take possession of children at risk, and a new bill will mandate it in Virginia. In Illinois, veterinarians are among the mandated reporters of elder abuse. Shelters for battered women are beginning to change agency policies to allow a safe haven for pets as an incentive to facilitate a woman's escape from an abusive partner. However, there is less awareness that neglected animals may also serve as a sentinel for adult self-neglect or elder abuse. (Patronek2001)

### **5.2.1.6 Treatment**

The best methods of treatment for hoarding remain illusive. Existing treatments effective for OCD have shown little benefit for compulsive hoarding. Medication and combination treatments have fared poorly. Modest success has been achieved with the use of specialized interventions based directly on a model of the psychopathology of compulsive hoarding. These have included comprehensive assessment, education, practice in decision-making and organizing, exposure to non acquisition and discarding, and cognitive restructuring directed at the major manifestations of hoarding: disorganization, compulsive acquisition and difficulty discarding. A comprehensive approach of this nature requires an integrated care team that includes appropriate front line community workers and the attending therapist. Unfortunately, while such approaches are available in some communities for clients who recognize their hoarding problem and want to do something about it, little is available for people who do not recognize or will not admit to having a problem with hoarding.

The obvious ambivalence of individuals about changing their hoarding behaviour is spurring research into the use of motivational interviewing. Motivational treatment and relapse prevention

methods involve assisting the individual to see change as important, and developing confidence in the individual to change and maintain that change. Such an approach may take up to 18 months. The goals of treatment are:

- Increase understanding of compulsive hoarding
- Create living space
- Increase appropriate use of space
- Improve decision-making skills for possessions
- Organize possessions to make them more accessible
- Reduce compulsive buying or acquisition
- Remove (discard, recycle, sell, give away) unneeded possessions
- Evaluate beliefs about organizing, acquiring, and discarding
- Learn problem-solving skills
- Prevent future hoarding

When co-morbid conditions such as isolation and limited social networks are identified they must be taken into consideration when planning treatment and preventing relapse. For example, clients who are socially phobic may be reluctant to alter behavior patterns that allow them to avoid social contact, while depressed individuals may have difficulty mustering the energy to sort, organize and remove clutter. In these instances, planning must consider the following:

- How much social support is there?
- Are there any home visitors?
- Can anyone monitor homework, schedules for organizing and discarding and other skills learned in treatment?
- Can the client tolerate discomfort and anticipate stressors in their life?

(Frost 2004, Steketee & Frost 2004, Cermele & Pandina 2001, Steketee & Frost, 2003)

### **5.3 Knowledge and Skill Development**

The hoarding client and agency front line and management personnel all require access to information and opportunities that increase their skills and knowledge about hoarding.

Managerial and supervisory staff require information to help them formulate appropriate decisions and policies about program design and front line supervision. Front line workers need information about what protocols have been approved and how to implement them, while clients and their families need access to information about recognizing and coping with hoarding.

In-house training, community workshops, conferences, orientation/information packages, internet newsletters and websites are all vehicles to assist agency personnel in providing integrated services while peer/self help and family support groups, and information sessions on cluttering/hoarding provide information to individuals at risk and their families and friends. This may lead to recognition of a problem and entry into the beginning stages of change. Communities sponsoring such information sessions have used them as a starting point for continued work with hoarding clients. Follow-up workshops can focus on the practical aspects of controlling acquisition, getting organized and learning how to discard. Workshops such as this require the time and energy of someone who is interested and committed to this topic. They can take a number of formats and can use a variety of materials.

Support groups are a specific form of group in which people with similar problems get together to share information and emotional support. When setting up support groups, it is important that they have a structure that makes them productive and not just opportunities to complain. Important social contacts may evolve from such groups. (Steketee & Frost 2004, Community Tool Box website)

## 5.4 Social Marketing

Social Marketing is a planned process for influencing change. It uses marketing approaches to promote social causes. In doing so it:

- Creates awareness and interest
- Changes attitudes and conditions
- Motivates people to want to change their behavior
- Empowers people to act
- Prevents backsliding

It can include the production of information flyers, media interaction, guidelines for media when reporting horrific situations, use of websites, publication of articles, campaigns to educate policy makers and so on. A key step in the development of a social marketing plan is the identification of the target group. Existing community task forces have developed products such as flyers and web site information aimed at the general public. (Community Toolbox, Dane County, Health Canada Social Marketing websites)

Excerpts from the following article in a magazine for Veterinarians illustrate a social marketing approach.

*Veterinarians may have animal hoarders or people who are on the way to becoming hoarders among their clients or even among their own staff. These situations are complex, but veterinarian can be a positive influence or they can unwittingly help these people to continue in a pattern that is detrimental to animals and to themselves. Veterinarians may unwittingly enable people with the tendency to become animal hoarders if they continually call the same person or refer clients to the same person who might be willing to give a home to one more old dog, or one more cat. Animal hoarders have a hard time saying no to another animal even if they are already stretched beyond their limits. The temptation to find room for more animals at home, either as permanent residents or in foster care, is an occupational hazard for people who work in veterinary offices and in animal shelters. It is important in orientation for these jobs and in continual messages of support to remind staff that they cannot save every animal by taking it into their own homes. Sending home too many free samples or donated supplies without knowing the situation may also make it easier for people to take on more animals than they should.*

*The following are considered warning signs of animal hoarding:*

- *constantly changing parade of pets, most seen once and not again*
- *visits for problems not usually seen in good preventive health care like trauma or infectious disease*
- *rarely see the same animal for diseases of old age like cancer or heart disease*
- *may travel great distances to the practice, come at odd hours and use multiple vets*
- *so as not to tip them off about the number of animals*
- *may seek heroic and futile care for animals they have recently found*
- *perfuming or bathing animals prior to a visit to conceal odor*
- *bringing in a relatively presentable animal in an attempt to get medication for more seriously ill animals at home, and trying to persuade the vet to provide medication or refills without seeing the animals*
- *being unwilling or unable to say how many animals they have*
- *claiming to have just found or rescued an animal in obviously deplorable condition, although condition of the animal including strong odor of urine, overgrown nails and muscle atrophy may be more indicative of confinement in filthy conditions than of wandering the streets*
- *an interest in rescuing even more animals, including checking the office bulletin board and questioning other clients in the waiting room*

*(Irwin, 2001)*

## 5.5 Quality Assurance

A quality assurance plan ensures both the effectiveness and the efficiency of service delivery. It requires that the management of priorities, planning, personal and professional development, monitoring and evaluation are carried out both systematically and transparently to create a positive approach to improving services. Frost (2004) in a presentation on hoarding suggested incorporating a research component into each strategy to evaluate their effectiveness and to determine which programs work/don't work, and for whom.

A quality assurance plan can assist with:

- Political and staff education and awareness raising.
- Priority setting and budgeting processes.
- Program and policy review and revision.
- The identification and implementation of capital and operational cost savings.
- Developing operations, planning guidelines, and bylaws.
- General public education.
- Key stakeholder education and awareness building.
- Partnership identification and development around commonly shared interests.
- Staff evaluation and performance incentive development

(Peck & Tomalty 2004)

### 5.5.1 Monitoring

A quality assurance plan requires the establishment, monitoring and reporting on agreed upon outcomes based on a coordinated data collection process. Monitoring a community initiative can help weigh actions against results in order to determine if goals are being met.

Additionally, a monitoring system can help:

- Understand how well an initiative is functioning and where actions are not producing the desired effects;
- Make decisions concerning the programming of the initiative;
- Promote awareness of accomplishments;
- Recruit support;
- Secure funding.

(Tool Box website)

### 5.5.2 Evaluation

Evaluation and monitoring go hand in hand. Monitoring provides the raw data to answer questions. But in and of itself, it is a useless and expensive exercise. Evaluation is putting those data to use and thus giving them value. Evaluation is where the learning occurs, questions answered, recommendations made, and improvements suggested. A monitoring program should not be designed without clearly knowing how the data and information will be evaluated and put to use.

There are four main steps to developing an evaluation plan:

1. Clarify objectives and goals
2. Develop evaluation questions

3. Develop evaluation methods
4. Set up a timeline for evaluation activities (Tool Box website)

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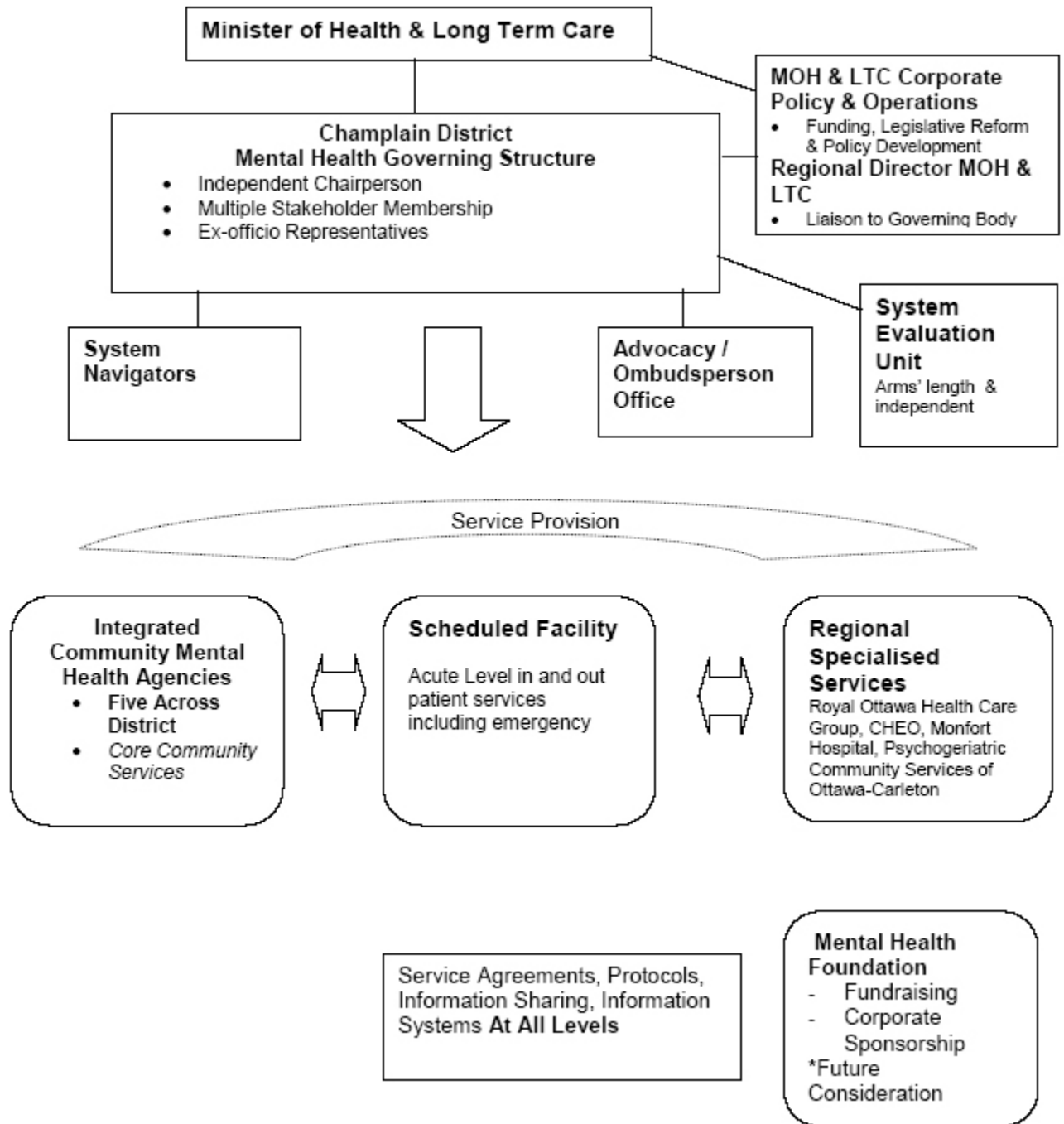
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Appendix 1 –Sample Framework



(Champlain District Implementation Task Force, 2002)

### Best Practices Top 20 Decluttering Tips

1. Let go of ideal notions of cleanliness. Your client may value items that appear to you as worthless or be rubbish. Parting with their belongings (even used paper cups) can cause severe emotional distress.
2. Listen to your client's ideas and plans for their belongings. Explore their hopes, both realistic and unrealistic, and accommodate them if possible. Clients have been helped to donate or sell their belongings. One woman even sent her "stuff" to relatives in her home country.
3. Work at the client's pace if you can. Start with short periods of time. Some clients cannot tolerate even a half hour in the beginning. Keep in mind, though, that a client's decluttering pace is usually slower than the eviction process.
4. Partner with a legal group, home care or nursing agency to find out what level of cleanliness your client needs to achieve in order to attain their goal, whether it be eviction prevention or home care services. You have to meet certain standards, but you don't have to exceed them.
5. Focus on fall prevention. Create pathways free of debris, loose cords or slippery rugs. Some frail clients hold onto furniture or other items while moving through the home; ask how your client gets around and preserve their "props" until other assistive devices (canes, walkers) can be introduced.
6. Focus on fire prevention. Make sure your client has a smoke alarm and test it monthly. Red flags include newspapers stored on top of or inside a gas stove or near working radiators. Help relocate their belongings from a hazardous area to a safe place.
7. Be creative and negotiate. Perhaps the client can keep the previous year's copy of a particular magazine, but throw away the prior twenty years' collection. Consider photographing belongings, as this may help the client part with them and preserve memories.
8. Begin by reorganizing, if time allows. Start with a small corner of a room, a single table, or just a section of the table.
9. Ask your client what they would like to do that currently they cannot do because of the clutter. For example, "Would you like us to help you to figure out how you can cook again?" or "How could you do this differently so you can use the stove?"
10. Motivate your client by helping them be realistic. Some clients will declutter only if told they face eviction or cannot be discharged home after a hospitalization. Gentle but firm pressure is appropriate if a client's home or health is at stake.
11. Create a limited number of categories for belongings. Large plastic crates or wicker baskets can help separate items into these categories.
12. Be resourceful in finding workers. Volunteers and other informal supports have been used with success, such as hired high school students who pack up agreed upon donations.
13. Have a social worker present during a major cleanout, preferably one who already has a supportive relationship with the client. Clean-outs can be overwhelming to people with severe hoarding behavior. Have a back-up plan in case emergency psychiatric services are needed.
14. Discuss how to safeguard valuables in the cleaning process. Have a written contract. Agree

on what to do with valuables that turn up, such as money, jewelry, checks, bonds, stock certificates, and collectibles.

15. Call the ASPCA if you need help finding a temporary or permanent home for pets while the cleanout is being conducted.

16. Consider relocating an individual to a new apartment if the clutter is the result of physical or mental frailty. A new environment can provide a fresh start and enable the client to receive needed services sooner.

17. Encourage the client to participate even during a major cleanout. Get them involved so they can be part of the process and have some level of control. Ask them if you can help find something they might be looking for, or give them a box to help sort through.

18. Plan for a carefully orchestrated clean up which can result in decreased client anxiety. Make sure you make arrangements with the building for entrance and egress when removing possessions and trash, for use of the elevators, for cost, rental and removal of dumpsters (Do not leave a dumpster or trash bags on the property after a cleanout, even overnight), for storage if needed, including cost of transportation to storage facility

19. Communication is Vital. It is important for the client to communicate with the cleaning crew - making their concerns known. If the crew doesn't speak the same language as the client, there should be a supervisor/translator/advocate present so that the client can make his/her needs known and can feel as if he/she has some control over the situation.

20. Plan for on-going maintenance and supervision to maintain a decluttered environment.

(New York City website)

## Cleaning Up a Trash House

The following are suggestions to those who need to find a cleanup organization or to clean up trash houses:

- Make sure all insurance policies are current and provide adequate coverage.
- Find out who the decision-maker is.
- Bring appropriate inspection equipment
- Gather information to help define the scope of work and prepare an estimate of costs.
- Obtain a general verbal description of how this property looks.
- Ask the decision-maker to answer the following questions:
  - Will the pack rat be participating in this cleanup work?
  - Who besides the cleanup crew will have access to the property
  - Will all things of value be removed prior to entry by clean up crew?
  - Will the clean up crew be asked to search for any particular item(s)?
  - Who will see that the water and electrical services are restored to the house?
  - Are there any known biohazards present on this job?
  - What code violations must be addressed?
  - Are there any known pest problems such as fleas, rodent mites, or rats?
  - Are there any hazardous materials on this property?
  - What items in the house are to be discarded?
  - How should the trash be removed from the property – truck, debris box?
  - Where is the nearest public dump? Can non-residents use the dumpsite? What are their surcharge fees for appliances, tires, mattresses, etc.?
  - What items in the house are to be saved? Floor covering, window coverings, appliances, etc?
  - Will anything be put into public storage?
  - What is to be cleaned? What is to be left as is?
  - Will the house have electricity, running water, phone service?
  - What tools must be rented to do the job, e.g. generator pressure washer, rug shampooer?
  - Does the house require animal proofing?
  - How much will this all cost and who will pay for it?

(Dane County website)

## REFERRAL TO CITY OF MADISON PUBLIC HEALTH DEPARTMENT HOUSING INSPECTOR

Completed by Phone

Date of contact

Referred to Date

Name

Phone

Address

Are there any infants or children living in the house?

YES NO

Is the owner/occupant possibly not competent to maintain the property in a sanitary condition?

YES NO

Are there any items of public health concern visible in the yard outside the house? [Example: garbage, tires, stacks of wood debris.]

YES NO

Are there any signs of rodent infestations visible in the yard or around the house?

[Example: actually see rats, see rat holes by dog pen, see paths worn by rats in grass.]

YES NO

Is there any evidence of serious insect (cockroach) infestation?

YES NO

Does the owner-occupant currently receive any services from the Human Services Department?

YES NO

Has anyone contacted the local building inspector about this problem?

Who: When:

YES NO

Does the complainant know of any relatives of the owner that live in Dane County?

Name: Phone:

YES NO

Comments:

(Dane County Website)

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**Attachment B –  
Membership of the Ottawa Community Response to Hoarding  
Coalition**

<p>Canadian Mental Health Association,</p> <p>Community Care Access Centre,</p> <p>Royal Ottawa Hospital, Humane Society,</p> <p>Children's Aid Society,</p> <p>Ottawa Hospital,</p> <p>Good Companions,</p> <p>Geriatric Psychiatry Community Services,</p> <p>Ottawa Community Housing,</p> <p>Options Bytown,</p> <p>Nepean Housing,</p> <p>Housing Help,</p> <p>Visiting Homemakers Association,</p> <p>Gem Healthcare Services,</p> <p>St. Joe's Women's Centre,</p> <p>7 of 14 Community Health / Resource Centres,</p> <p>Human Resources Social Development Canada,</p>	<p>Ottawa Fire,</p> <p>Ottawa Public Health- Health and Social Crisis Pgm ,</p> <p>the Coordinator,</p> <p>Health Inspection,</p> <p>Ottawa Property Standards and Bylaw Services,</p> <p>Employment and Financial Assistance - Ontario Works,</p> <p>Essential Health &amp; Social Support Pgm, ,</p> <p>Ottawa Police Services, ,</p> <p>Consumer,</p> <p>Project Upstream,</p> <p>Yearwood Efficient Solutions,</p> <p>Shepherd's of Good Hope,</p> <p>LESA Program</p>
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Others connected through an electronic distribution list include:

Minto Management, Queensway Carleton Hospital, Service d' Entraide, Action Logement, Senior's R Us	Causeway Clubhouse, Ontario Ministry of Agriculture, Family Services of Ottawa, Home Management Services, Faith Groups
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## **Attachment C –**

# **Findings from Interviews and Focus Groups to Support the Development of a Community Response to Hoarding**

## **1. INTRODUCTION**

The first phase of the development of a community response to hoarding for the Ottawa Coalition involved a literature search and review of relevant published and unpublished literature. Information obtained from that review guided the development of interview guides used in the second phase of the project.

The second phase of the project sought information from agency representatives and individuals engaged in hoarding in order to identify Ottawa's unique requirements in a community response to hoarding. The findings are contained in this report.

### **1.1 Methodology**

Eight key informant interviews, four focus groups - including one in French, and four client interviews were conducted. One relative of a hoarder sought out the consultant to provide her perspective on a sibling who hoards. Information obtained from that informal conversation was consistent with that obtained directly from individuals engaged in hoarding.

#### **1.1.1 Interviews with Individuals Who Hoard**

Those interviewed were clients of agencies participating in the coalition. All agreed they had a hoarding situation. Three were voluntarily addressing the situation with support. One was receiving assistance to comply with orders made under the Fire Protection and Prevention Act, 1997.

The profile of those interviewed, and of the sibling described by her sister, was consistent with that outlined in the literature review:

- All were single or divorced, living alone, well educated and middle aged or older. Two of the five were employed in professional positions requiring a tremendous amount of attention to detail. One worked from home and another rented out part of her home for income. Three of the individuals were women. One was a specialist in what he "collected". None were considered animal hoarders, although one had several pets in her home.
- Two spoke of traumatic events in their lives, which they identified as triggering excessive collecting.
- All were maintaining relationships with limited family and friends but outside of the home environment. All had family members frustrated and embarrassed by their hoarding behaviour. One claimed she hoarded items as a way to relive former family times together.

- Some family histories revealed other hoarders and alcoholism. Individuals interviewed or described had hoarding and perfection tendencies early in their lives. Two women talked about perfect homes in the past and an inability to enjoy their homes now. One described her home as a jewel in a garbage can. The other liked to clean the houses of others but couldn't work on her own. The sibling offering information described her sister's behaviour as similar to that of an alcoholic: she starts to talk about collecting before she actively starts again.
- 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.
- All had experienced difficulty in using some parts of their home due to clutter and two mentioned the fire department being involved.
- Those interviewed did not see their acquiring behaviour as a problem. Family, friends or a landlord were identified as bringing the situation to their attention. One commented that it opened her eyes but that she rationalized it as a problem others also had. Another sought information on the web and in books and felt this helped her keep the situation somewhat controlled. The individual who collected specific items felt he would no longer acquire those items, as they were no longer available in stores.
- It was important to all that items leaving their home had another use
- Most were worried about how to control their hoarding in the future. One only worried about the opinion of the municipal fire department and provincial Fire Marshal.
- One difference to the literature was noted. Although the literature describes hoarders as unfriendly and aloof, the interviewer found those she interviewed to be friendly to the point of seemingly desperate for conversation.

### 1.1.2 Service Provider Interviews

Key informant interviews were undertaken with management or supervisory personnel, while focus group discussions sought information from front line workers.

Agencies represented in the key informant and focus groups included:

Canadian Mental Health Association (CMHA)	CRC basse-ville
Community Care Access Centre (CCAC)	Gem Healthcare Services
Centre Espoir Sophie	Gloucester Housing
Centretown CHC	Ottawa Humane Society (OHA)
City of Ottawa:	Nepean CRC
• Public Health	Orleans-Cumberland CRC
- Health and Social Crisis Team	Ottawa Community Housing Corporation
- Public Health Inspection	Ottawa Hospital Mobile Crisis Team
• Fire	Pinecrest- Queensway CHC
• Home Help Program	Psycho Geriatric Community Services of Ottawa
• Property Standards	Sandyhill CHC
• Residential and Support Services	Service d'Entraide communautaire Vanier Community SC

## 2. INTEGRATED RESULTS

The focus group planning committee of the coalition produced an “As It Was Heard Report” (Appendix i) which consolidated information obtained through the 4 focus groups with front line workers.

This report combines the findings of that report with those obtained from individual interviews with agency management personnel and individuals engaged in hoarding. The findings were then synthesized to test out the validity of the possible components of a community response to hoarding, as documented in the literature review. The results of that synthesis appear under the following headings:

- Governance
- Service Delivery
- Skill Development
- Social Marketing
- Quality Assurance

### 2.1 Governance

The need of an ongoing role for the coalition was consistently identified by key informants and those involved in focus group discussions. The establishment of workgroups on topics such as education and terms of reference was suggested.

Future leadership of the coalition was of utmost concern, as its effective functioning was determined paramount to the implementation of the community plan. Specific comments included:

- “Leadership is needed that can cause political action.”
- “Leadership cannot rest on one person”
- “Leadership needs to be addressed at a senior level in the City”

Several barriers were identified that limit the effectiveness of existing attempts to address hoarding and underline the need for a coordinated plan:

- Use of ordinances when a voluntary approach would be more appropriate
- Confidentiality issues and hoarders rights
- Hoarding not seen as a priority by some agencies
- Lack of consistent assessment and referral mechanisms
- Lack of a centralized or coordinated case management or case conferencing mechanism
- Lack of services and personnel to undertake interventions
- Lack of knowledge about the issue amongst non-profit service providers, fee for service professionals, the media and the general public.

Four immediate tasks were identified for the coalition’s attention:

*Increase francophone representation on the coalition.*

*Continue to advocate with community agencies about their needed involvement in the coalition and service delivery.* Capacity building in treatment and referral options remains outstanding according to service and client respondents. City of Ottawa Public Health Nurses, Inspectors, Fire, and By-Law Officers, OHA, housing providers, Children’s Aid Society (CAS), Community Health & Resource Centres, CMHA, CCAC, Assertive Community Treatment Team (ACTT), and Inner City Health Inc. were identified by key informants as already responding to partnering/referral requests regarding hoarding situations.

Some agencies expressed concern through their interviewed representatives about pressure to participate when they do not have the resource capacity or a current mandate to do so. The coalition will need to remain sensitive to those in this situation and should begin to collect and analyze data in order to identify the magnitude of the issue and to justify its expectations of community organizations.

*Advocate at a political and corporate level within the City of Ottawa to create a centralized hoarding unit.* Such a unit is needed to coordinate all of the City departments called upon to resource hoarding situations, as well as community partners.

Key activities of the unit were identified as:

- Coordination of all activities addressing hoarding in City of Ottawa departments;
- Further development of an inventory of community agencies in order to provide clarity around roles, mandates and who does what in a hoarding situation;
- Case Conferencing with invested agencies (and the client as appropriate) to develop and implement a coordinated treatment and case management plan;
- Development and implementation of an ongoing bilingual training plan;
- Development of coordinated policies and protocols for service delivery, i.e. a decision tree;
- Development of common tools for agencies to use, such as an assessment form that gathers information about health and safety issues;
- Development of culturally appropriate information tools such as brochures, fact sheets, a web site, videos etc, for use with existing clients and the public at large;
- Advocacy regarding service and funding requirements to address hoarding in both official languages;
- Research and evaluation. This will require data base development & maintenance, and data collection and analysis;
- Communication with the media.

*Take steps to ensure ongoing and consistent leadership for the coalition.* Many envisioned such leadership as part of a centralized hoarding department with bilingual capacity that can provide expertise, resources, and coordination of invested services. Most respondents and discussions identified the City of Ottawa as best positioned to house such a unit, due to the broad range of activities it already undertakes in hoarding situations. Most respondents recognized the funding requirements for such an undertaking but felt that a coordinated response would be less expensive for the City and partnering agencies in the long run.

Some key informants, although acknowledging the need for a central coordinating function, expressed concern about the ability of any agency, including the City to fund and undertake such an initiative. A de-centralized approach was suggested by some whereby the various activities requiring coordination are undertaken by different agencies. The role of the City could be facilitation of case conferencing/case management meetings. Such an approach was also described as a possible first step to developing a business plan justifying the need for a centralized unit.

## **2.1.1 Guiding Values and Principles**

Key informants were asked to identify guiding values and principles. Other statements applicable to value and principle development emerged from focus group discussions and client interviews. The following list documents comments as stated:

- Prevention and early intervention would be guiding principles;
- Respect for individuals. Preserve their dignity;
- Community based;
- Appropriate and reasonable service and equitable access to that service. There is access to treatment and knowledge of what treatment exists;
- Educated care providers. There is a plan for education and training;
- Recognize the impact of hoarding on others in the community. An ethical approach recognizes the rights of “the individual” and “the many”;
- Formal and informal supports;
- People live independently in the community;
- What my house looks like is not yours – there is an acceptable level but where is an intervention required;
- Work with the person with a contract and in partnership before issuing orders;
- Service providers have a plan in place;
- Responsive to the uniqueness of clients;
- Self determination;
- Integrity;
- Communication;
- Programs and services should operate as an entity, ensuring seamlessness for consumers, their families, practitioners, organizations and levels of care or service overtime;
- Respect hoarder and each other as providers. Use a caring approach, not blaming;
- Share information amongst partners, e.g. articles;
- Don’t work in isolation, be transparent and engage in ongoing networking;
- Realize limits;
- Use a small step approach with hoarders. Give them the tools to prevent re-occurrences;
- Focus on best practices. There should be an ongoing review of evidence and research about what will lead to improved client outcomes;
- Consumer should be the centre of the system.

## 2.2 Service Delivery

Those engaged in hoarding, or dealing with a family member, who hoards, spoke about what had been helpful, not helpful, and what could be helpful to them regarding what and how services and supports were provided:

- Provide more homemaker services. Not enough is provided to help;
- Cleaning companies are helpful for maintenance;
- Provide long-term assistance. One individual could only get that through an on line chat room support group;
- Provide non judgmental support to family members in recognizing this is too difficult an issue for families to deal with on their own;
- Only involve support workers and professionals who are well informed about hoarding. Most were frustrated by experiences with therapists who knew little about hoarding. Professional help is very important. One spoke of it as being her salvation;
- Develop a list of treatment providers knowledgeable about hoarding,

- Consider bartering with a student for assistance with housekeeping in exchange for tutoring or room & board,
- Suggest sorting items into three piles: keep, toss away, and give away. Allow the person to be in control of what is kept and discarded. Use a storage locker. One individual developed the following list of questions to ask herself during the de-cluttering process:
  - Does it lift my energy when I look at it or think about it?
  - Do I absolutely love it?
  - Is it genuinely useful?
  - How much space am I willing to give up for it?
  - What is enough? Defining what is enough = just the right amount
  - Does this object enhance my life?
  - What's the worst thing that could happen if I got rid of it?
  - Are there legal implications for holding onto it?
  - If I got rid of it and discovered that I needed or wanted it later, could I replace it?
  - When was the last time I used it or wore it?
  - Does it work? If not, do I intend to fix it? If so, when?
  - Do I like it? For clothes: Does it fit? Do you have occasion to wear it? Do I have something matching to go with it (for a shirt, pants, skirt, etc.)?
- Instead of a professional cleaner provide a clutter buddy – someone dealing with the same issues. Create a Clutterers Anonymous similar to the 12-step approach for alcoholism. This is the best way to help, according to one individual;
- Taking pictures before clean up and after clean up didn't help one individual;
- Concentrate on solutions not how the individual got there. Don't tell them how bad it is. Suggest a plan of attack;
- Encourage people to use a shopping list. One individual developed the following list of questions to ask herself when shopping:
  - Am I going to use this object? Is it truly useful?
  - Do I genuinely need this object or do I just want it? Do I already own a similar object?
  - Do I already have enough of this kind of objects?
  - Do I absolutely adore it?
  - What will this object add to my life?
  - Will this object bring me joy and increase my energy?
  - Do I have space to store this object? If not, am I willing to make space for it?
  - Am I willing to look after this object, maintain it, dust it?
  - Can I afford to buy this object?
  - If I were to move, would I bring this object with me?

Service provider respondents favoured the creation of a specialized front line service delivery team with additional and specialized services and supports provided by community partners. Such a team would function out of the proposed centralized coordinating unit. One key informant noted that no organization currently has a mandate to address hoarding.

The need to deal with conflicting confidentiality requirements was a major focus of discussion in focus groups. Many felt interagency agreements would be useful. Avoiding duplication of services was also mentioned.

Intake, assessment, referral coordination, partnerships, voluntary & involuntary interventions, monitoring, follow-up and quality assurance of caseload management were identified by agency

respondents as required components of a service delivery model in Ottawa. Their specific comments are detailed in the following sections.

### **2.2.1 Intake**

The need for a 24-hour central hotline for referrals, intake and crises was identified. However, it was recognized that advertising such a line would bring expectations of assistance with it, which agencies already struggle to provide.

The Environmental Health Protection Line at the City of Ottawa presently takes such calls and would be a logical central intake point in the future. An additional Public Health Nurse and Inspector are required to meet current demands for follow up, according to one respondent. The City's current budget restraints and hiring freeze will most likely impact negatively on any additional staffing requests.

The Ottawa Humane Society (OHA) has a clear role in follow up regarding animal hoarding but only regarding the welfare of affected animals. A centralized intake could ensure that both animals and their owners are looked after.

### **2.2.2 Assessment**

Coordination in the use of a consistent assessment protocol/instrument is necessary. Assessment of pets in the case of animal hoarding is the responsibility of the Ottawa Humane Society (OHA).

### **2.2.3 Case Management**

Respondents spoke with a common voice about the need for a coordinated, interagency service delivery model and provided details about its form and function.

Establishment of a specialized multidisciplinary, mobile "Hoarding Team" with the capacity to respond to crisis situations and arrange for additional assistance including long term follow up was identified as a priority.

Key to its effective functioning would be the development of a collaborative case management approach. This would include the use of common tools, consistent strategies, and funding to undertake activities such as clean up.

Team members should be hoarding specialists capable of "mentoring" other agency staff. The team would also draw upon the discipline knowledge of its members. Physicians, nurses, social workers, support workers, psychologists, and group facilitators who use collaborative approaches reflecting common approaches and consistent strategies were identified as potential members. They in turn would link with other service providers such as Psychiatrists, General Practitioners, Psychologists, Social Workers, Health Professionals, CCAC, Community Health and Resource Centres, independent practitioners, ACT Team – French & English, hospital based outreach services, organization specialists, shelters, food banks, dieticians, etc.

The need to build relationships with housing providers, landlords and property managers was also identified. One informant pointed out the importance of keeping individuals housed while addressing the hoarding.

## 2.2.4 Voluntary Interventions

Early intervention and a focus on prevention were described as being key to an effective voluntary intervention. Respondents envisioned a continuum of services that allows for:

- The development of trusting relationships between client and service providers;
- Long term and flexible intensities of involvement - depending upon the need and stage of the hoarding situation. This was identified as the most challenging for resource strapped Ottawa organizations to provide;
- Quick response to requests for clean ups when severe threat to health or safety are present;
- Clear referral options for long term consistent support and monitoring for relapse. This may include referrals to self help groups and supportive housing providers when independent living is no longer considered an option;
- Trained volunteers to help with ongoing support needs. This could be friends and neighbours sensitized to the issue;
- Specific follow up dates with reminders to help with moving the treatment/service plan forward;
- The involvement of private landlord organizations;
- The ability to arrange special service agreements with key businesses/services so that that hoarding requests can be prioritized to prevent relapse. The Salvation Army was identified as a possible partner that may be able to immediately pick up reusable items.

## 2.2.5 Involuntary Interventions

Respondents described the use of ordinances as being both good and bad. Timing was described as being very important. For example, if their use is initiated through complaints by a neighbour, it may result in pressure applied at the wrong time. On the other hand, their application may assist in getting much needed services from community organizations for that individual.

One informant noted that landlords may be in the best position to know when such pressure is needed i.e. when all else has failed. Although most agreed that involuntary interventions should be a last resort, their application too late in the process may be disastrous, especially when animals are involved.

Many identified that an involuntary approach does not work well. Although some bylaws and agency policies, especially those related to property management could assist: according to some, they are not always in place. An added issue is when liens, must be coordinated for the clean up of private homes and funds are not available to cover costs. Services cannot depend upon the client being billed for service, as they may be unable or unwilling to pay.

Many respondents identified the need for more information about existing ordinances and when their application comes into play. Ordinances specific to hoarding could not be identified by key informants or focus group participants. What became apparent was a patchwork of legislation, by-laws and policies (creatively used at times) to address this issue.

Identified through this process were:

- Ontario Society for the Prevention of Cruelty to Animals Act (OOHA)  
[http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/90o36\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/90o36_e.htm)

- City of Ottawa Animal Care and Control by-law  
[http://ottawa.ca/city\\_services/bylaws/municipal\\_bylaws/animal/index\\_en.shtml](http://ottawa.ca/city_services/bylaws/municipal_bylaws/animal/index_en.shtml)
- Health Promotion and Protection Act – Section 13  
[http://192.75.156.68/DBLaws/Statutes/English/90h07\\_e.htm](http://192.75.156.68/DBLaws/Statutes/English/90h07_e.htm)
- Housing regulations
- City of Ottawa Property standards  
[http://ottawa.ca/city\\_services/bylaws/municipal\\_bylaws/public\\_nuisance/property/index\\_e\\_n.shtml](http://ottawa.ca/city_services/bylaws/municipal_bylaws/public_nuisance/property/index_e_n.shtml)
- Fire Code, Ontario Regulation 388/97, as amended  
[http://www.e-laws.gov.on.ca/DBLaws/Regs/English/970388\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/Regs/English/970388_e.htm)
- Fire Marshal's Directive: 02-001 & Guideline for Dealing with Combustibles in Units  
<http://www.ofm.gov.on.ca/english/FireService/announcements/Directives/02-001.asp>
- Fire Protection and Prevention Act, 1997 -  
[http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/97f04\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/97f04_e.htm)
- Privacy Act <http://laws.justice.gc.ca/en/P-21/> Respondents noted difficulty making referrals, undertaking case conferences and identifying family members when support is not wanted. Contravening privacy requirements could result in a court case being thrown out according to one informant.
- Personal Health Information Protection Act November 2004.  
[http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/04p03\\_e.htm](http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/04p03_e.htm). Some felt this was this act had the most power regarding entry in hoarding situations.
- Tenant's/homeowner's rights re belongings and access to owned homes. Key informants identified private ownership as creating the most difficult situations.
- Directive 31.0 - Ontario Works Directives.  
<http://ontarioearlyyears.ca/CFCS/en/programs/IES/OntarioWorks/Publications/ow-policydirectives.htm> Re health, community start up and maintenance benefits (CSUMB) for those on OW. Some aspects are also applicable to those on ODSP.
- City of Ottawa Employment & Financial Assistance (EFA) policy -
  - Financial support can be provided if it will prevent homelessness in the foreseeable future;
  - Provision can be made to include the cost of necessary house repairs in the shelter allowance for OW clients, if not already at maximum (Subsidized housing is the exception);
  - Approval of home repairs to homeowners on assistance can be paid as a one-time benefit after the work is completed and the client has signed a declaration of satisfaction.
- Mental Health Act - Form 1 and Form 2, under section 17.  
[http://192.75.156.68/DBLaws/Statutes/English/90m07\\_e.htm](http://192.75.156.68/DBLaws/Statutes/English/90m07_e.htm)  
Police may take a person against their will to a hospital emergency room for a psychiatric assessment if there are reasonable grounds to believe that the person is at risk of serious self harm or of causing serious bodily harm to others.

## 2.2.6 Treatment

A key identified gap is access to psychiatric treatment options and follow through with treatment or discharge plans when leaving hospital. A list of qualified professionals that provide counseling and other support, and who understand hoarding was suggested.

## 2.3 Skill Development

Further education & training for service providers, politicians and the general public about hoarding was identified as a priority by key informants, focus group participants and individuals engaged in hoarding. A hoped for outcome was “Champions” who understand the issue and its implications for their areas of responsibility.

Independent health & social service professionals and medical emergency & police personnel were singled out as requiring better knowledge about this issue.

Various suggestions on this topic included:

- *Workshops and training* on topics such as:
  - Confidentiality and the “Privacy Act”, (Identified as an immediate priority and one that should be done by legal experts)
  - Health & safety issues,
  - Available community resources and how to best use and access them
  - Multi cultural approaches,
  - Requirements of I.T. support i.e. Data base development
  - Coordinating case management, policies, procedures, and standards
  - Better ways to engage ambivalent, non-compliant clients
  - “Best practices”
  - Indicators of animal abuse, prevention strategies and links to human abuse.
- *Self help groups for hoarders and their networks.* Although suggested by service providers, the majority of those who hoard did not think it would be helpful. One who had attended group counseling felt participants were treated like children by the therapist. Information sessions for the families and friends of those who hoard, however, were supported by those who hoard.
- *Self help techniques.* One individual engaged in hoarding found on line support through a chat group extremely helpful. She also recommended the following web sites as particularly informative and helpful to her in controlling her cluttering behaviour.

<http://flylady.net/>

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

<http://clutterless.org/>

<http://spaceclearing.com/>

<http://nsgcd.org/>

The same individual found the following books helpful:

1. Making Peace with the Things in Your Life – Cindy Glovinsky
2. Overcoming Compulsive Hoarding – Fugen Neziroglu

3. Organizing from the Inside Out – Julie Morgenstern
4. Stop Clutter from Stealing Your Life – Mike Nelson

- *Hoarding training and information available in French.*
- *Training/coordination with the Public Trustees Office and capacity assessors. Inclusion of The Public Trustees Office in any negotiations about confidentiality should be required.*
- *Training of legal personnel regarding hoarding and training of service personnel by legal experts around a variety of legal issues.*
- *Use of newsletters.*

## **2.4 Social Marketing**

Respondents identified the need to promote prevention strategies and public awareness by using communication tools such as a web site, brochures, newsletters, pamphlets, etc. Such tools should include information on clues to who is hoarding and where to call. Use of the media to raise awareness about this hidden topic was described as good and bad by key informants. Without some form of sensitivity training their focus will remain sensationalism.

It was suggested that the coalition develop articles for placement in community newspapers and provide information to church groups, Veterinarians and pet supply outlets. For example, pet stores should be alerted to individuals purchasing large quantities of pet food

Although not required to report possible cases of animal hoarding, Veterinarians are positioned to identify such situations if well informed. Confidentiality issues and “who is the client – owner or animal?” however, can complicate decisions to report, according to one key informant.

## **2.5 Quality Assurance**

Data about hoarding is not formally or centrally collected in Ottawa. Key informants were asked to estimate the number of hoarding situations requiring staff involvement on an annual basis. Responses ranged from “not enough to validate a dedicated hoarding unit” to: “it is bigger than most people think – we get involved about 6 times a week or approximately 300 times a year. Approximately seven incidents of animal hoarding are dealt with on a yearly basis.

Informants indicated a need for anonymous data about:

- Number of complaints
- Number of cases
- Type of hoarding
- High or low risk assessment
- Agencies involved
- Family Practitioner
- Power of Attorney – family or Public Guardian if in place
- Monetary and social cost (suffering & lives lost) of clean up or cost savings
- Profile of the individual hoarding –gender, age, income, employment
- Outcomes i.e. housing loss due to eviction, health hazard identified, cluttering controlled, etc.

They also identified a need to coordinate the gathering of such data and suggested that it be a function of a centralized Hoarding Department. Whether this would include animal hoarding would need to be determined.

This will require the development and maintenance of a central database to support evaluation and research activities. It will be important that this function be secure in order to protect the privacy rights of the individual engaged in hoarding, family members, neighbours and others who may have reported the hoarding situation. Getting a legal opinion on how to undertake such a task was suggested.

Informants felt that a cost benefit analysis of hoarding situations and the current cost to agencies and the City of Ottawa would justify a centralized area of expertise in a City housed Hoarding Department.

### **3. CONCLUSIONS**

The findings from key informant interviews, focus groups and interviews with individuals engaged in hoarding validate the need for a strategic plan to address hoarding in Ottawa.

Aspects of that plan will need to address how leadership is provided, resources organized, services coordinated, service providers trained, the general public informed, and effectiveness & efficiencies achieved. These findings are consistent with the literature review, which suggested: governance, service delivery, skill development, social marketing, and quality assurance as the necessary components of a strategic plan to address hoarding.

Respondents have identified four immediate tasks for the coalition's attention:

- I. Increase francophone representation on the coalition;
- II. Continue to advocate with community agencies about their needed involvement in the coalition and service delivery;
- III. Advocate at a political and corporate level within the City of Ottawa to create a centralized hoarding unit, and;
- IV. Take steps to ensure ongoing and consistent leadership for the coalition.

Items i & ii can be undertaken within the current organizational structure of the coalition. Items iii & iv are more problematic.

The City of Ottawa has been identified through the interview and focus group process as the most logical entity to provide leadership and a central point of intake and expertise.

Two key actions are required to pursue the establishment of such a unit:

1. Community agencies, individuals and families affected by hoarding need to work together to place this issue on the political agenda.
2. In light of current City budget restraints, City management staff will need to prioritize the need for a hoarding unit over and above existing city services.

The ability to influence change through these two venues may be hampered by the lack of reliable statistics about hoarding in Ottawa. An alternate but less desirable step would see the strategic plan initiated using a decentralized approach. If such an approach becomes a reality, the collection of data to build a business case for a centralized unit should be a priority activity.

**OTTAWA COMMUNITY RESPONSE TO HOARDING COALITION**  
**“AS IT WAS HEARD REPORT”**

**A Summary of Focus Groups Held To Assist In Developing a Coordinated, Interagency  
Service Delivery Model for Hoarding Situations in Ottawa and Environs**

Prepared By The Focus Group Planning Committee:

Elaine Birchall Social Worker, Ottawa Public Health / Coordinator Ottawa Community Response  
to Hoarding Coalition

Clement Bamuamba Housing Loss Prevention Worker, Pinecrest Queensway Health and  
Community Services

Gaye Moffett Owner, Gem Healthcare Services and Gem Software Solutions

**CONTENTS:**

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- **Assumptions:**
- **Theme Issues**
- **Participants Attending Focus Group**
- **Next Steps:**

**ASSUMPTIONS**

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**The following assumptions were brought forward by the participants of the Focus Groups held to assist  
in developing a coordinated, interagency Service Delivery Model**

- 1. Focus Group participants have some experience if not with Hoarding situations  
then with issues associated with Hoarding Behaviours**
- 2. Participants in the French focus group are knowledgeable about the needs of  
the francophone community of Ottawa**
- 3. Participants in the English focus groups are knowledgeable about the needs of  
the population at large drawing upon Multicultural expertise as needed.**

## **THEME ISSUES**

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The following themes were identified by the Focus Group participants. These are also considered to be “key themes” to develop at this time.

**Theme 1: Need for a centralized, specialized Hoarding team with leadership and coordination functions**

**Theme 2: Need for further education & 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.**

### **KEY THEME ISSUE #1:**

**The need for a centralized, specialized Hoarding team with leadership and coordination functions**

#### **Part 1: Focus the Theme**

This theme will focus on the need for a centralized, specialized Hoarding team with leadership and coordination functions.

- To carry out intake, assessment, crisis intervention, referral coordination, monitoring, follow-up, quality assurance of caseload management, data base maintenance and evaluation.
- To coordinate the gathering of statistics by documenting cost savings in monetary and social costs (suffering and lives lost) of a centralized Hoarding Department. This department would use the (SCPI) coordinated, interagency service delivery model and would function as a centralized service of the City of Ottawa housed within an existing division which has responsibility/authority for coordinating City services across the full spectrum of services offered within the City.
- To coordinate all Hoarding training.
- To lead and coordinate the Ottawa Community Response to Hoarding Coalition
- To advocate for capacity building re. supports and services
- To promote prevention strategies and public awareness through communication strategies i.e. Web site, brochures, pamphlets.

Potential Problems/Concerns that Could Impede Action:

- To ensure that City of Ottawa councilors, managers understand the issue of Hoarding well enough to understand the need for the City of Ottawa to take responsibility for long term leadership and coordination of Hoarding activities through a centralized Hoarding department?
- To advocate for all City of Ottawa departments willing to adapt their record keeping practices to incorporate statistically valid Hoarding statistics?

#### **Part 2: Visioning the Future**

Key Components desired for the future:

- Full spectrum, multidisciplinary Hoarding team
- Hotline for referrals, intake and crises
- Adequate funding to pay for a crisis team and then long term follow up either centralized or decentralized services
- Central database maintenance with an evaluation component
- Clarity of roles and mandates for individual agencies/organizations i.e. Who does what
- Coordinator housed with centralized team
- Crisis team to do clean up with allocated funding to undertake it
- Effective management of waiting lists
- Case conference coordination between agencies involved in hoarding response as well as hoarding client.

Actions needed:

- Advocacy at a political and corporate level of the City of Ottawa for support of a centralized Hoarding department
- Development of a coordinated, interagency service delivery model to use as the foundation for development of a centralized Hoarding department
- Identify other organizations that can be useful partners to a centralized Hoarding department
- Organize a “Town Hall “ meeting among interested organizations and senior management of the City of Ottawa to explore the feasibility of developing a centralized Hoarding department
- Conduct a “Cost Benefit Analysis” of coordinating all involved City of Ottawa departments currently heavily invested in responding to Hoarding situations

Partnerships Necessary;

- City Manager's Office, /Deputy City Manager's Office, I
- Invested City departments,
- Other helpful community organizations,
- Membership of the Ottawa Community Response to Hoarding Coalition

Suggested Timelines:

- ASAP

Accountability:

- Ottawa Community Response to Hoarding Coalition membership

**KEY THEME ISSUE # 2:**

**Need for further education & training both for “responders, politicians and the general public about both animal and inanimate hoarding.**

**Part 1: Focus the Theme**

This theme will focus on the need for further education & training both for responders, politicians and the general public.

- Training for the centralized, specialized, multidisciplinary team to complete functions specified earlier.
- Training on coordination of Case management policies, procedures and standards

- More training for those who perform treatment functions i.e. Physicians, nurses, social workers (hospital and community based), support workers, psychologists, and group facilitators.
- Training/coordination with the Public Trustees Office and capacity assessors
- Training on requirements of I.T. support i.e. Data base development
- Training of and by legal experts around a variety of legal issues
- Training on health & safety issues
- Multicultural training as it interfaces with Hoarding
- Training on available community resources and how to best use and access them
- Training of a Crisis response Team
- Training on the “Privacy Act”
- Training on better ways to engage ambivalent, non-compliant clients
- More training of responders on “best practices”
- Training/orientation of all political levels and government levels to build “Champions” who understand the issue and its implications for their areas of responsibility

Potential Problems/Concerns that Could Impede Action:

- Possible lack of understanding of City of Ottawa councilors, managers and other Government leaders on the issue of Hoarding
- Possible lack of understanding of the implications for their areas of responsibility
- Willingness / readiness of City of Ottawa departments to make the necessary staff available/ freed up to develop, give and attend necessary training?
- Willingness of City of Ottawa councilors, managers and other Government leaders to make themselves available for the necessary training

**Part 2: Visioning the Future**

Key Components desired for the future:

- Full, multidisciplinary Hoarding team trained to be hoarding specialists able to respond and “mentor” other agency staff.
- Central database maintenance with an evaluation component
- Clarity around roles and mandates of individual agencies/organizations i.e. Who does what
- Need for a centralized coordinator
- Crisis team to do clean up with allocated funding to undertake it
- Effective management of waiting lists
- Case conference coordination of involved hoarding agencies including client.
- Lack of informational materials in French i.e. Pamphlets, videos, workshops, support groups for Hoarders, their families & close supporters.
- Lack of training or resources in French or other languages

**Part 3: Actions to Realize the Future**

Actions needed:

- Advocacy at a political and corporate level of the City of Ottawa for support of the need for training
- Development of a coordinated, interagency service delivery model to use as the foundation for training
- Identify other organizations that can be useful partners and recruit for training
- Training on “Forming” clients when necessary
- Form a training team to develop training modules from the best information available

#### Partnerships Necessary;

- City Manager's Office, /Deputy City Manager's Office,
- Invested City departments,
- Other helpful community organizations,
- Membership of the Ottawa Community Response to Hoarding Coalition

#### Suggested Timelines:

- ASAP
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#### Accountability:

- Ottawa Community Response to Hoarding Coalition membership

### **KEY THEME ISSUE # 3**

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#### **Clarification and coordination of the issue of Confidentiality and associated Acts**

##### **Part 1: Focus the Theme**

This theme will focus on the need for clarification and coordination of the issue of Confidentiality and associated "Acts".

- Training for all City staff and Community Partners invested in hoarding services on accurate requirements for rights to Confidentiality.
- Strategies to deal with conflicting Confidentiality requirements must be incorporated into any successful Service Delivery Model
- The Public Trustees Office must be included in any negotiations about Confidentiality
- Training on Confidentiality should be done by legal experts
- Training around the "Privacy Act"

#### Potential Problems/Concerns that Could Impede Action:

- Factoring in very different interpretations of Confidentiality requirements into a final strategy
- Getting individual organizations to adapt their interpretations of their requirements around Confidentiality.
- Conflicting Legal opinions

##### **Part 2: Visioning the Future**

#### Key Components desired for the future

- Full, multidisciplinary Hoarding team trained to be Hoarding specialists must work as a cohesive unit
- Central database maintenance with an evaluation component must protect privacy rights and be secure
- A consolidated Legal Opinion must be available

### **Part 3: Actions to Realize the Future**

Actions needed:

- Advocacy at a political and corporate level of the City of Ottawa for support of the need for the City of Ottawa's Legal Department to develop an interpretation of confidentiality which can be inclusive of that of other Partners'.
- Incorporate a way to work out differences as they occur within the coordinated, interagency service delivery model identify other organizations that can be useful partners and recruit for training
- Form a training team to develop a training piece on the coordinated Confidentiality policy
- Conduct a Workshop specifically on the coordinated Confidentiality policy

Partnerships Necessary;

- City Manager's Office, /Deputy City Manager's Office make available the City of Ottawa's Legal Department as a resource
- Invested City departments
- Other helpful community organizations,
- Membership of the Ottawa Community Response to Hoarding Coalition

Suggested Timelines:

- ASAP following the development of the coordinated, interagency Service Delivery model

Accountability:

- Ottawa Community Response to Hoarding Coalition membership
- The City Of Ottawa

### **KEY THEME ISSUE # 4**

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#### **Need for treatment and referral capacity building**

##### **Part 1: Focus the Theme**

This theme will focus on the need for capacity building in treatment and referral for service options:

- Psychiatrists
- General Practitioners
- Psychologists
- Social Workers
- Health Professionals (Public Health, CCAC, Community Health Centres, Private providers- for profit & not for profit, ACT Team –French & English, hospital based outreach services, others.
- Private in home support workers
- Self help groups for hoarders and their networks
- Workshops on helpful topics
- Shelters
- Food banks /dieticians

Potential Problems/Concerns that Could Impede Action:

- Lack of available new funding to cover these service needs

- Coordinating very different interpretations of mandate requirements into a final strategy
- Getting individual organizations to adapt their interpretations of their requirements on a variety of issues, which currently are barriers to an integrated strategy.
- Reaching support workers who need information on identification, (what to do, who to call, how to engage reluctant individuals who hoard, dealing with Landlords etc.)
- Staff responding to hoarding situations needs to be compassionate but firm. Being too nice or flexible can derail the forward movement being worked on by other workers.
- Some “Social Housing” bachelor units may be too small and require people to get rid of unreasonable amounts of the things from their pre social housing lives
- Lack of cooperation of family physicians due to a lack of awareness of the issue and potential for harm.
- Establishing the intake point of access and processes
- Overtaxed existing non- mental health supports and services necessary to complete work required and prevent relapse and long waiting lists.
- Lack of francophone services restrict access even to available training and resources which are only produced in English
- Lack of funding being made available to build French service capacity and resources for Hoarding situations

## **Part 2: Visioning the Future**

Key Components desired for the future:

- Opportunity to “Case Conference” with other invested agencies with the client present to negotiate a treatment and case management plan with as much consensus as possible. (i.e. community rounds format)
- Common Assessment tool being used by all, which accomplishes a global assessment of the individual re. Health and safety issues.
- Coordinated policies and protocols i.e. a decision tree.
- A centralized Hoarding office where expertise, resources and coordination of invested services can be accessed by everyone
- The multidisciplinary Hoarding team trained to be Hoarding specialists must work as a cohesive unit
- Sources of long term support as well as quick response to requests for clean ups when severe threat to health or safety are present
- Early intervention and prevention need to become a priority
- More training on a variety of topics as identified by these focus groups.
- Central database maintenance with an evaluation component must protect privacy rights and be secure
- A consolidated Legal Opinion must be available on a variety of issues associated with Hoarding
- Include the protection and concerns of “others” i.e. neighbours especially in multi –unit dwellings in protocols.
- A mobile team to respond to emergencies who can then call upon a follow-up team to arrange supports and service and then hand case over to a long term worker who will provide consistent support as needed and monitor for relapse
- Information available in mother tongue is especially important for those living with mental health issues
- Funding to pay for translation of available information into languages other than French & English
- New funding is necessary to enable:
  - Translation of existing documentation on hoarding
  - Training of specialized staff to do hoarding work
  - Expansion of hoarding services in French
  - Documents must be written in plain language

- Pamphlets and a video in French are needed to promote public awareness among the francophone community because existing ones are only in English
- Increase in funding to Mental Health Services

### **Part 3: Actions to Realize the Future**

#### Actions needed:

- Multidisciplinary team needs to include physicians, nurses, social workers, support workers, psychologists, and group facilitators who use collaborative approaches reflecting common approaches and consistent strategies
- Central coordination department must know and clarify for others individual organization's roles in hoarding work
- Services in place must allow for the unique requirements of Hoarding work i.e. trusting relationship development, long term involvement, flexible intensities of involvement depending upon the need and stage
- Capacity must be built for follow through with the "treatment plan" or "discharge plan" when leaving hospital
- Coordination of use of a consistent assessment protocol/instrument is necessary
- Special Service Agreements must be arranged with Key businesses/services that they will prioritize Hoarding requests which must occur quickly in order to prevent relapse i.e. Salvation Army pick up immediately of reusable items.
- Strategies and services must be developed for involuntary "problem" cases
- Strategies i.e. Liens, must be coordinated for clean ups in private homes where funds are not available to cover costs. Services cannot depend upon client being billed for service they can't or won't agree to pay.
- Consistent monitoring is key to successful outcomes, funding and authority to do this must be made available for this key element.
- Advocacy at a political and corporate level of the City of Ottawa for support of the need for the City of Ottawa to create a centralized Hoarding department which will be able to coordinate all of the City departments called upon to resource Hoarding situations as well as Community Partners.
- A list of qualified private professionals who understand hoarding and can provide counseling and other support as needed.
- Trained staff to aid with "de-cluttering" using "best practices" strategies and who are able to remain with the case as long as needed for relapse monitoring
- Quick access to Mental Health Services
- Central Data base development and maintenance
- Cost benefit analysis of hoarding situations and the current cost to agencies and the City of Ottawa to prove the efficiency of a centralized area of expertise in a City housed Hoarding department.
- Trained volunteers to help with ongoing support needs.
- Specific follow up dates with reminders to help with the moving forward of the treatment/service plan
- Getting private landlord organizations involved
- Consistent Leadership of the Coalition and centralized hoarding department
- Incorporate processes which resolve differences as they occur within the coordinated, interagency service delivery model
- Identify other organizations that can be useful partners and recruit for training
- Form a training team to develop a training piece on the coordinated Confidentiality policy
- Conduct a Workshop specifically on the coordinated Confidentiality policy
- Hoarding training being offered in French
- All documentation translated and available in French
- An organization with the capacity must take responsibility for translation required
- Funding for francophone hoarding services must be increased to pay for the expansion of existing services which are already stretched to the maximum

- Representation for francophone services on the Ottawa Community Response to Hoarding Coalition must increase from the present 2 representatives to aid in the work necessary.

#### Partnerships Necessary:

- City Manager's Office, /Deputy City Manager's Office make available the City of Ottawa's Legal Department as a resource
- Invested City departments
- Other helpful community organizations,
- Membership of the Ottawa Community Response to Hoarding Coalition
- Bereavement groups to help with the feelings of loss caused by getting rid of the items they part with.
- Private landlord groups
- City of Ottawa's Legal Department
- Other helpful community organizations
- Ottawa Public Health
- Other non emergency response City of Ottawa Departments
- Fire
- Police
- Mental Health Workers
  - Canadian Mental Health Association,
  - Royal Ottawa Hospital,
  - Montfort Hospital,
  - Queensway Carleton Mental health Services
  - The Ottawa Hospital Mental Health Services
  - ACCT Teams,
  - Outreach Pgm, Elizabeth Fry,
  - Community Resource and Health Centres,
  - Shelters
- Ottawa Community Housing
- Community health and Resource Centres providing services to the francophone community
- The City of Ottawa Translation Services Dep't
- Other funders who might pay for translation services if the City of Ottawa won't or can't provide translation services

#### Suggested Timelines:

- ASAP following the development of the coordinated, interagency Service Delivery model
- ASAP so that the francophone community can have the same information, supports and services as are being developed in English

#### Accountability:

- Ottawa Community Response to Hoarding Coalition membership
- The City Of Ottawa

#### **NEXT STEPS**

Make information gathered in all 4 Focus Groups available to the consultant and the Steering Committee of the Ottawa community response to Hoarding Coalition for use in the development of the coordinated, interagency Service Delivery Model to deal with hoarding situations in Ottawa.

**PARTICIPANTS ATTENDING FOCUS GROUPS**

<b>NAME</b>	<b>AGENCY</b>
Jeanne Francoise Moue	Centre Espoir Sophie
Helena Arruda	Vanier Community SC
Viviane Oger	Orleans-Cumberland CRC
Sonia Pouliot	CRC basse-ville
Nancy Darisse	CRCBV- intake
Clement Bamuamba	Pinecrest- Queensway CRC
Bonnie Dinning	Health & Social Services Consultant
Mireille Tourangeau	Geriatric Psychiatry Comm. Services of Ottawa
Norm Labillois	Ottawa Community Housing Corporation
Gaye Moffett	Gem Healthcare Services
Johanne Duhaime	Ottawa Community Housing
Lise Barrette	Ottawa Public Health's, Health & Social Crisis
Rusty McKague	Ottawa Fire
Elaine Birchall	Ottawa Community Response to Hoarding Coalition
Lynette Scobie	Canadian Mental Health Assoc
Lynn Robar	Nepean CRC
Norm Labillois	Ottawa Community Housing
Doris Conoley	City Of Ottawa Home Help Pgm
Derek Petch	Property Standards
Wayne Desormeaux	Public Health Inspection
Nancy Ellwood	Ottawa Community housing
Jane Blair	Centretown CHC
David Laut	Rooming House Services Coordinator, Housing Branch, City of Ottawa
Pam Antoine	CCAC
Sherry McKinnon	CCAC
Wendy Hyndman	Sandyhill CHC
Miriam Smith	Humane Society
Aysha Forouk	Gloucester Housing
Donna Grimard	Ottawa Hospital Mobile Crisis Team

## Attachment D - Ottawa Community Response to Hoarding Operational Plan 2006-2008

STRATEGIC PRIORITY: Governance					
Objective	Sub-activity	Responsibility	Input/data sources	Performance Indicators outputs/deliverables & Deadlines	Comments/progress
<i>Seek appropriate host with the capacity to establish and maintain a centralized hoarding unit</i>	Per recommendation of the SCPI project Focus Groups explore possibilities within the City of Ottawa	E. Birchall	City of Ottawa Management  No Room to Spare: Ottawa's Community Response to Hoarding Plan	Deadline: ASAP	
	continue to expand the number of agencies participating in the coalition to close existing gaps, especially among francophone agencies	Coalition partners	current participating francophone coalition members	Deadline: ongoing	
	Advocate for the establishment of a central hoarding office with City representatives	Coalition partners		Deadline: ASAP	
<i>Provide leadership to the development &amp; implementation of common guidelines and protocols</i>	determine approach to case management – centralized, decentralized, hybrid approach	Steering committee	No Room to Spare: Ottawa's Community Response to Hoarding Plan  Coalition	Deadline: December 2006	

	undertake role clarification re implementation of decision tree	Steering committee		Deadline: December 2006	
<b>STRATEGIC PRIORITY: Comprehensive Integrated Service Delivery Model</b>					
Objective	Sub-activity	Responsibility	Input/data sources	Performance Indicators outputs/deliverables & Deadlines	Comments/progress
establish intake process	Identify who will undertake intake including intake regarding animal hoarding on behalf of the coalition	Coordinator with support of the Steering Committee	Coalition	Deadline: November 2006	
	develop intake tool(s) and protocols	Steering Committee AND coalition partners OR working group	Coalition "No Room to Spare"	Deadline: ongoing through 2006-07	
establish assessment process	Identify who will undertake assessment, including assessment regarding animal hoarding on behalf of the coalition	Steering Committee	Coalition	Deadline: Dec. 2006	
	develop assessment and screening tool(s) and protocols	Steering Committee AND coalition partners OR working group	"No Room to Spare"	Deadline : ongoing through 2006-07	

Establish Case Management/systems navigator process	Identify which agency/agencies will undertake Systems Navigation on behalf of the coalition	Coalition partners		Deadline June. 2007	
	develop case management tools and protocols	Steering Committee OR working group	Coalition "No Room to Spare"	Deadline Dec. 2007	
Establish voluntary intervention process	identify who does what and when within decision tree	Steering Committee OR working group	Coalition "No Room to Spare"	Deadline: June 2007	
Outline involuntary intervention process	identify who does what and when within decision tree	Steering Committee OR working group AND coalition partners	Coalition "No Room to Spare"	Deadline : June 2007	
	ensure link to existing ordinances	Coalition partners	Coalition "No Room to Spare"	Deadline: Dec2008	
Identify treatment options consistent with the values and principles of the Ottawa Community response to Hoarding	Develop, maintain and distribute list	coordinator	Coalition "No Room to Spare"	Deadline: ongoing through 2006 -07.	

**STRATEGIC PRIORITY: Knowledge and Skill Development**

Objective	Sub-activity	Responsibility	Input/data sources	Performance Indicators outputs/deliverables & Deadlines	Comments/progress
<i>Identify yearly training plan</i>	Develop workshop/ resource on ordinances applicable to hoarding	Steering Committee OR working group	Coalition "No Room to Spare"	Deadline: ASAP after linkage ensured	
	Develop workshop/resource on privacy/confidentiality	Steering Committee OR working group		Deadline: June 2007	
<i>Establish a website and list serve</i>	Identify resources to undertake website development and implementation	Working group	Alliance to End Homelessness website	Deadline: Dec. 2007	
	Identify a resource to undertake and maintain a list serve	Steering Committee OR working group	Alliance to End Homelessness List Serve	Deadline: ASAP	
Implement a support group for individuals who hoard	Identify an agency to undertake development and provision of a support group	coordinator	Coalition "No Room to Spare"	Fall 2006	

	Undertake advertisement of the support group	Coordinator and community project partners		Fall 2006	
	collect data about participants and evaluate support groups	Support group facilitators		Deadline June 2007	
Explore opportunities with identified consumers re the establishment of alternative group support options	Contact self- identified individuals with Hoarding Behaviour to explore the feasibility of peer support groups AND/OR 12 step groups i.e. Messies Anonymous being established to supplement professional supports	coordinator		Deadline: ASAP 2006	
Explore feasibility of collaborating with Canadian Medical Assoc through their continuing education series to increase the capacity of professional treatment options with self-selected mental health professionals & MD's.	Conduct presentations as part of the CMA continuing education series to promote collaboration using compatible models of intervention between MD's and Coalition partners.	coordinator		Deadline: ASAP 2006	

<b>STRATEGIC PRIORITY: Social Marketing</b>					
Objective	Sub-activity	Responsibility	Input/data sources	Performance Indicators outputs/deliverables & Deadlines	Comments/progress
Inform the general public	Identify and Initiate activities such as the development of articles for local newspapers, seek speaking engagements/interviews with the media, service clubs, etc.	coordinator	"No Room to Spare"	Deadline ongoing	
Develop key messages for community crisis situations		Steering Committee		Deadline Dec. 2006	
Inform specific groups	Explore opportunities to educate and involve groups such as Veterinarians, pet storeowners, etc.	Coordinator AND Steering Committee	"No Room to Spare Local Veterinarian Associations?"	Deadline ASAP	

**STRATEGIC PRIORITY: Quality Assurance**

Objective	Sub-activity	Responsibility	Input/data sources	Performance Indicators outputs/deliverables & Deadlines	Comments/progress
Explore Research opportunities to establish prevalence of Hoarding in Ottawa	Identify interested/available funding partners	Coordinator and Working group	Centre for Research on Community Services, University of Ottawa	Deadline ASAP (priority set for 2006)	Explore Research opportunities to establish prevalence of Hoarding in Ottawa
Develop a data collection process	As necessary seek additional funding to develop a data collection process through several agencies.	Steering Committee AND working group		Deadline: begin fall 2006	

## Attachment E - Recommended Ottawa Resources in Hoarding Situations

Addiction Services		Competency Assessments	
AA	237-6000	Assessment Units	<i>Regional Geriatric Assessment Program</i> 798-5555
Addictions and Problem Gambling Services of Ottawa	789-8941	Geriatric Psychiatry Community Services of Ottawa	562-9777
ALANON	860-3431	<b>Crisis Intervention</b>	
Amethyst Women's Addiction Centre	563-0363	Police – Officer response	911
Gamblers Anonymous	567-3271	Ambulance	911
NA		Fire (Hoarding Complaints)	580-2860
Rideauwood	724-4881	Victim Crisis Unit	236-1222
Serenity House	733-3574	Ottawa Distress Centre	238-3311
Serenity and Renewal for Families	523-5143	Children's Hospital	737-7600
Smoking Help Line	1-877-513-5333	Montfort Hospital	746-4621
<b>Animal Control</b>		Ottawa Hospitals Emergency numbers:	
Humane Society	725-3166	Civic Campus	761-4621
Municipal Bylaw	580-2424	General Campus	737-8000
Exterminators	<i>refer to local directory</i>	Mobile Crisis Team	241-0422
<b>Children's Services</b>		Queensway Carleton Hospital	721-2000
CAS	747-7800	<b>Financial Resources</b>	
Children's Hospital Main Number	737-7600	Assistive Devices Program	1-800-268-6021
Ontario Early Years Centres	834-9620	Credit Counseling	728-2041
Success by Six (United Way)	228-6700	Employment and Financial Assistance	560-6000
Youth Services Bureau	729-1000	Essential Health and Social Support Program	560-0618
		Funeral Assistance	560-0618

Financial Resources (continued)		Home Support (continued)	
Office of the Public Guardian and Trustee	1-800-366-0335	Para-Med - Ottawa	728-7080
Ontario Disability Support Program	236-1188	- Orleans	830-3333
<b>Food Services</b>		- Kanata	728-7080
<b>Food Banks</b>		- Pembroke	267-1743
2040 Arrowsmith Drive	749-4728	Professional Organizers	<i>refer to local directory</i>
507 Bank Street	232-3059	Retire-At-Home	798-5111
1820 Carling Avenue	729-3172	Visiting Homemakers Association	238-8420
955 Debra Avenue	224-3824	VON Homemaking	749-7557
1480 Heron Road	737-5115	<b>Housecleaning (Heavy Cleaning)</b>	
161 Marier	747-2839	Emerald Homecare Services	526-1052
233 Murray Street	789-8210	Hodgins Interior	623-6422
424 Parkdale Avenue	722-8019	Maverick Maid Heavy Cleaning	744-6243
Jewish Family Services of Ottawa-Carleton (Kosher Meals on Wheels)	722-2225	Task Master	720-3852
King's Daughters' Dinner Wagon	233-2424	<b>Housing</b>	
<b>Home Support/Help</b>		Action Lodgement	562-8219
Community Care Access Centre	745-5525	CCOC	234-4065
City of Ottawa - Home Help Program	560-0618	City of Ottawa Housing Branch	580-2424
Community Health and Resource Centres	<i>refer to Medical Services</i>	Community Care Access Centre	745-5525
Home Management Services	230-2978	Community Legal Services	241-7008
<b>Private Associations:</b>		Emergency Housing	560-0622
Bradson - Ottawa	782-2244	Housing Help	563-4532
- Orleans	748-5308	Nepean	853-8452
- Kanata	592-1182	Ontario Rental Housing Tribunal	1-888-332-3234
- Kemptville	258-6100	Ontario Works	1-888-644-3444
ComCare	237-8460	Ontario Works for shelter approval Weekdays 8:00 a.m. - 4:30 p.m.	580-2424
GEM Healthcare Services	761-7474		

<b>Housing (continued)</b>		<b>Community Health Resource Centres</b>	
Ontario Works for shelter approval	1-888-644-3444	Carlington Community and Health Services	722-4000
<b>After hours</b> – explain the need for approval of emergency housing and speak with an Ontario Works Worker.		Centretown Community Health Centre	233-4443
Ottawa Community Housing Corporation:	731-7223	Cumberland Township Community Resource Centre	830-4357
- East Ottawa (Murray St)	789-4305	Gloucester Centre for Community Resources (North)	741-6025
- Central Ottawa (Chapel St)	564-1235	Gloucester Centre for Community Resources (South)	822-1886
- Central Ottawa (Rochester St)	569-2884	Lowertown Community Resource Centre	789-3930
- South Ottawa (Bank St)	249-0458	Nepean Community Resource Centre	596-5626
- West Ottawa (Caldwell)	729-3136	Overbrook Community Resource Centre	745-0073
- West Ottawa (Ramsey)	829-9354	Pinecrest-Queensway Health and Community Services	820-4922
Ottawa Salus Corporation	729-0123	Sandy Hill Community Health Centre	789-1500
Property Standards Client Service Centre	580-2400	Somerset West Community Health Centre	238-8210
Social Housing Registry	526-2088	Vanier Community Service Centre	744-2892
<b>Legal Aid</b>		Western Ottawa Community Resource Centre and West Carleton	591-3686
Community Legal Services	238-7931		

<b>Medical Services</b>		CCAC	745-5525
Client's own General Practitioner	Ask client	Elisabeth Bruyère Helpline	562-6368
Specialist Caring for Client	Ask client	Find a Doctor Service	1-800-268-7906 (ext. 626)
Ambulatory Care Riverside Campus	738-8534		
City of Ottawa Public Health Info Line	724-4179		
<b>Geriatric Assessment Outreach Units:</b>		<b>Geriatric Assessment Units</b>	
Geriatric Assessment Outreach Team (Civic Hospital – Outpatient)	798-5555 ext 16485	Geriatric Assessment Outreach Team (West Ottawa)	721-0041
Geriatric Assessment Outreach Team (Queensway Carleton Hospital – Outpatient)	721-3808	Geriatric Assessment Outreach Team (East Ottawa)	562-6362
Geriatric Psychiatry Community Services of Ottawa	562-9777	<b>Newcomer Services</b>	
Health & Social Crisis Program	580-6744 (ext. 23474)	Cultural Interpretation	237-0502
National Defense Medical Centre	733-6600	Immigrant Women's Services	729-3145
Ottawa Assertive Community Treatment Teams	722-9731	Ottawa Community Immigrant Services Organization	741-1368
Ottawa Dental Society	523-3876	<b>Others</b>	
Ottawa Hospital – Civic Campus	722-7000	Citizen Advocacy of Ottawa-Carleton	761-9522
Ottawa Hospital – General Campus	737-8006	Directory of Ottawa Community Services (Blue Book)	241-4636
Ottawa Regional Palliative Care	562-6301	<b>Senior Services</b>	
Telehealth Ontario	1-866-797-0000	<b>Seniors Guide 1-888-910-1999</b>	
VON	749-7557	Council on Aging	789-3577
<b>Mental Health Services</b>		Good Companions	237-6879
No family doctor? - Physicians Availability	1-800-268-7096	Help the Aged Canada	232-0727
Physicians Availability for Ottawa only?	1-800-268-7096 (626)	Lifestyle Enrichment for Senior Adults (LESA)	233-5430

<b>Mental Health Services continued</b>		Reaching out to Isolated Seniors	562-6381
Private Psychiatrists	<i>refer to local directory</i>	Senior Citizens Council of Ottawa Directory of Resources	234-8044
Memory Disorder Clinic	562-6322		
Mental Health Crisis Services	241-0400		
Jewish Family Services	722-2225		
Alzheimer's Society	523-4004	<b>Special Needs</b>	
Assertive Community Treatment Teams	722-6521	<b><i>Refer to websites listed on Hoarding Biography</i></b>	
Canadian Mental Health Association	737-7791	Bereaved Families of Ontario	567-4278
Catholic Family Services	233-8478	Clutterers Anonymous	<a href="http://www.clutterersanonymous.net">www.clutterersanonymous.net</a>
Causeway Work Centre	725-3494	Messies Anonymous	<a href="http://www.messies.com">www.messies.com</a>
Family Services Ottawa	725-3601	Sexual Assault Support Centre	234-2266
Community Health and Resource Centres	<b><i>refer to medical services</i></b>	Victims Assistance Services	238-2762
Geriatric Psychiatry Community Services of Ottawa	562-9777		

## Attachment F - Hoarding Resources<sup>10</sup>

### BOOKS

- **"Overcoming Compulsive Hoarding** , Why You Save & How You Can Stop - ISBN#1-57224-349-X authored by Fugen Neziroglu, Jerome Bubrick, Jose A. Yaryura-Tobias.
- **"Loving Someone With OCD: Help for Your and Your Family"**, ISBN # 152243295, authored by Karen J. Landsman, New Harbinger Publications, 2005.

For Information by Sandra Felton / Messies Anonymous contact: Nest Builders, P.O. Box 343566, Homestead Fl. 33034-0566

- **THE MESSIES MANUAL**: a complete guide to bringing order and beauty to your home. By Sandra Felton founder of Messies Anonymous cost \$14.99 US
- **MESSIE NO MORE**: the revelation of the "Messie Mindset", the deep rooted "why" of Messiehood, the "how" of breaking away from the behavior patterns that caused it. By Sandra Felton founder of Messies Anonymous cost \$12.99 US
- **WHY CAN'T I GET ORGANIZED & WHIZ BANG GUIDE**- you know you want to organize-but how? By Sandra Felton founder of Messies Anonymous cost \$24.95 US
- **MESSIE MEN** – Clean Up Their Act By Sandra Felton founder of Messies Anonymous cost \$7.00 US
- **HOPE FOR THE HOPELESS MESSIE** – Steps to restoring sanity to your Cluttered Life by Sandra Felton cost \$18.95 US
- **WHEN YOU LIVE WITH A MESSIE**- So you want to change but those around you won't cooperate. By Sandra Felton cost \$6.99 US
- **LIVING ORGANIZED** – Proven steps for a clutter-free and beautiful home. By Sandra Felton cost \$12.99 US
- **SMART ORGANIZING**: Simple strategies for bringing order to your home. By Sandra Felton cost \$13.99 US
- **I'VE GOT TO GET RID OF THIS STUFF**: If I want to get rid of it but I just can't. Sounds like you and if you are ready to change. By Sandra Felton \$7.00 US

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<sup>10</sup> Elaine Birchall, Coordinator: Ottawa Community Response to Hoarding Coalition, March 2006

- **MEDITATION FOR MESSIES:** By Sandra Felton cost \$\$10.00 US

**AUDIO TAPES:**

- CREATE YOUR OWN DREAM AND LIVE IT- \$9.95 US
- THE MESSIE MANUAL ON AUDIO - \$16.95 US
- ORGANIZING SECRETS OF TOP PROFESSIONAL ORGANIZERS - \$10.95
- GET ORGANIZED WITH MARSHA SIMS - \$14.00 US

**HOARDING WORKSHOP 2.** Bibliography especially Hoarding Websites & Self Help Websites (available upon request by contacting elaine birchall @Ottawa.ca

**ONLINE SUPPORT & GROUPS** now include:

- [www.flylady.com](http://www.flylady.com) (helpful for those who procrastinate and those who are so overwhelmed they don't know where to start
- [www.ocfoundation.org](http://www.ocfoundation.org), under the sub heading "Educate & Connect" select Hoarding Website and you will have expert information provided by 2 of the top internationally recognized clinical researchers (Dr. Randy Frost Ph.D and Dr. Gail Steketee Ph.D.

**PEER SUPPORT ONLINE:**

- Clutterers Anonymous @[www.clutterersanonymous.net](http://www.clutterersanonymous.net)
- (In Ontario) FLYingInOntario chatter group @<http://groups.yahoo.com/group/FIOChatter/>
- (In Toronto) [http://groups.yahoo.com/group/FLYingIn Toronto/](http://groups.yahoo.com/group/FLYingInToronto/)
- (In Ottawa) <http://groups.yahoo.com/group/FLYingInOttawaCarleton/>
- Beth Johnson's CLUTTER WORKSHOP online
- [beth@ClutterWorkshop.com](mailto:beth@ClutterWorkshop.com) OR by phone 1-(860) 232-3838

***SELF HELP QUESTIONS TO ASK YOURSELF (to get you started or keep you going)***

***Questions About Acquiring***

- Do I have an immediate use for it?
- Do I need it? How many do I already have?
- Can I get by without it?
- Do I feel compelled to have it?
- Can I afford it comfortably?
- Do I have time to deal with it appropriately i.e.?  
Maintain it?

***Questions About Discarding***

- Do I need it?
- Do I have a plan to use this?
- Have I used this in the last year?
- Can I get it elsewhere i.e. the library?
- Do I have enough space for it already clear and available?
- Do I love it?

***Questions About How to Organize & Let Go***

- Start with one area; spend as many future work periods as needed to complete your goal for this area.
- If entrances, exits or areas near heat and ignition sources for example, (furnaces, stoves, portable heaters, baseboard heaters, water heaters or uncovered light bulbs, are cluttered, start with them first for safety reasons and continue working in that area until clear. **The 1st fire safety priority is clear routes into and out of the residence. The 2nd priority is entrance and exits from each room.**
- **Caution:** Extension cords should not be used for permanent wiring purposes i.e. instead of adequate electrical outlets connected to the electrical panel. **Make sure smoke detectors are functioning.**
- Create categories for possessions
- Sort into discard, recycle/giveaway & keep piles
- Use questions provided in "Acquiring & Discarding" Sections to decide.
- Continue until chosen area is clear
- Imagine and plan a more pleasing use for the cleared area
- Plan for preventing new clutter build up for that area by following the ideas in "Relapse Prevention"

### ***Relapse Prevention***

- Evaluate current reasons for cluttering
- Get yourself support: 1.trusted family & friends
- 2.knowledgeable counselor
- 3. Knowledgeable professional organizer
- 4. Online support as provided above
- Schedule regular times to organize & let go
- Invite visitors home
- Anticipate known stressors and your reactions
- Apply skills developed so far and search out others to build on
- Identify resources for the future
- Be gentle with yourself and keep working at it.
- It's what you do every day, no matter how much, that will get you where you want to be.

**Remember: "The person who removes a mountain begins by carrying away small stones." (Dane County Elder Abuse Office - "This Full House"), Dane County, USA - 2000**

## Attachment G – Sample Brochures

### **This Full House**



**Information for  
older adults whose “stuff”  
fills their houses  
and  
limits their lives...**

### **When Saving Becomes a Problem ...**

Saving meant survival in earlier times. In later life, saving may threaten survival.

Houses full of saved items often result in falls and injury, loss of friends, isolation, and emotional distress. Sometimes there is a risk of fire or eviction.

Some older people become overwhelmed and don't know where to begin with all this stuff.

Hope and help is available through a variety of approaches and understanding resources.

*This material was developed  
by the*

**DANE COUNTY  
HOARDING TASK FORCE**

*Area Agency on Aging of Dane County  
1955 W. Broadway*

### **Change Takes A Team**

You can seek medical and emotional evaluation and treatment for this problem.

It is possible to get medications and other treatments that can help to reduce the collection and retention of things.

Even if you just want to find out more information before you ask for help, you can seek the assistance of understanding professionals.

Some of those professionals can be found in the agencies listed in this web page.

## Changes CAN Be Made!

Excessive saving may be immobilizing. Change is challenging but it is possible with time and understanding assistance from others.

### Here are some ideas and approaches:

1. Seek assistance. The problem won't go away by itself.
2. Develop an organizational plan to make the space more functional and safe.
3. Be patient – take small steps.
4. Work in one area sorting items into three boxes that hold

### Hoarders experience two or more of the following:

- Saving or collecting continues beyond what is needed or usable – even though the house and additional storage space are full.
- Value, uniqueness and sentiment is found in “stuff” that others do not find valuable, such as old papers, containers, and food items.
- Strong emotional attachments are formed with many items for comfort or safety.
- Efforts to stop collecting or to discard things are unsuccessful, leading to a sense of anxiety, emptiness, vulnerability, and more collecting.
- The fear of losing things prevents discarding them or gives rise to putting them away, out of sight.
- “Stuff” interferes with safe and

## You Are Not Alone!

Call:

Senior Hotline to Help: 266-9007

Elder Abuse and Neglect Helpline:

224-3666

Mobile Outreach for Seniors Team:

280-2480

### Local Senior Service Agencies:

Belleville Senior Center	424-6007
Colonial Club-Sun Prairie	837-4611
DeForest Area Senior Cntr.	846-9469
E. Madison/Monona Coal.	223-3100
Fitchburg Senior Center	270-4290
McFarland Outreach	838-7117
Middleton Senior Center	831-2373
N/Eastside Mad. Coalition	243-5252
NW Dane Senior Outreach	767-3757
Oregon Senior Center	835-5801
South Madison Coalition	251-8405
SW Dane Senior Services	437-6902
Stoughton Senior Center	873-8585

### Signs that Help for Hoarding is Needed

- There's no room to sleep in bed
- Interference with cooking, bathing, and socializing
- Homecare services will not provide services
- Appliances not working
- No water
- No working toilet
- Furnace not working
- Fire code violations
- Someone is threatened with eviction
- Safety and health risks are evident
- Strong odors
- Restricted or blocked exits, heating ducts or electrical outlets
- Clutter spilling out around the house, yard, garage
- Spoiled food
- Animal waste/bugs/rodents are present



Pamela M. Krawczyk,  
Commissioner

Erie County Department of Senior Services

95 Franklin St--13th Floor  
Buffalo NY 14202

Phone: 716 858 8526

Fax: 716 858 7259

Email: SeniorInfo@erie.gov

Web site: www.erie.gov

Revised 12/29/04



**When does it become  
"too much" stuff?**

*Has keeping  
things become  
a problem?*

*What would  
you like to do  
in your home  
that you  
cannot do  
right now?*

Erie County Department  
of Senior Services  
(716) 858 8526

**Causes of Hoarding**  
Collecting useless objects that  
interfere with living space and  
safety

"Things make me feel comfortable & safe."

"I'm overwhelmed."

"I have physical limits."

"I have money problems."

"It was on sale so I bought 20."

"I might need it later, and  
won't be able to afford it."

"I suffer from mental illness."

(depression, obsessive-  
compulsive disorders)

Some have problems with thinking  
(cognitive problems),

Some don't know where to turn for  
help.

**Reach Out**

For information.

For understanding.

Medications and other treatments.

### Hope & Help to Reorganize

Yellow Pages listings for "organizers" to help with sorting and "letting go"

Cleaning Agencies

Clutterers Anonymous  
(<http://www.clutterersanonymous.net/index.html>)

### Local Agencies

Erie County  
Department of Senior Services  
Information & Assistance  
(716) 858-8526

Erie County  
Department of Health  
Environmental Field Offices  
Buffalo 961-6800  
Hamburg 649-4225  
Lancaster 683-6487  
Tonawanda 874-1070

SPCA of Erie County  
Emergency Hotline  
559-1780

Building Inspectors  
Contact municipal offices

Erie County  
Adult Protective Services (when a person  
who hoards is at risk of harm) (716) 858-  
6877

Our gratitude to the leaders who have established  
Hoarding Task Forces in their communities (Dane  
County, WI and New York City, NY and Fairfax, VA)  
and those who are involved in research to provide  
assistance that is effective and respectful.

## Why worry?

### Saving things

- Can mean problems if they interfere with living space and safety
- In full houses can cause falls and injury
- Can lead to the loss of friends/entertainment opportunities, loneliness, unhappiness and feeling overwhelmed and ashamed

## What can I do with my stuff?

- ✓ Use it up
- ✓ Give it away to family & friends
- ✓ Sell it
- ✓ Donate it to charity
- ✓ Discard it

## Hoarding\*

- Saving or collecting continues beyond what is needed or usable—even when the house and additional storage space are full
- Value, uniqueness and sentiment is found in “stuff” that others do not find valuable, such as old papers, containers, and food items
- Strong emotional attachments are formed with many items for comfort or safety
- Efforts to stop collecting or to discard things are unsuccessful, leading to a sense of anxiety, emptiness, vulnerability, and more collecting
- The fear of losing things prevents discarding them or gives rise to putting them away, out of sight
- “Stuff” interferes with safe and functional use of the home for sleeping, cooking, bathing and socializing
- Savers may see the “stuff” as acceptable or may be too overwhelmed to respond
- Others see the “stuff” as both-ersome and dangerous

\* From the Dane County Hoarding Task Force, Madison, WI

### More helpful information:

[http://www.comellaging.org/gem/hoarding\\_index.html](http://www.comellaging.org/gem/hoarding_index.html)

<http://www.disposophobia.com/>

<http://www.newsroom.ucla.edu/page.asp?RelNum=5218>

## Take Action

Seek help

Make a plan for a functional and safe home

Take small steps and be patient

When sorting through “stuff”, ask

- Have I used this in the past year?
- What is broken or useless?
- What am I keeping for others?
- What do I really treasure?
- What is the cost of keeping things? (insurance, fees, storage space, relationships, emotional pain)

Avoid getting more possessions

Erie County Department of Senior Services

95 Franklin St-13th Floor  
Buffalo NY 14202

Phone: 716 858 8526  
Fax: 716 858 7259  
Email: SeniorInfo@erie.gov

## Attachment H – Sample Assessment Form

### Animal Hoarding Case Report Form

For purposes of this project, only submit cases consistent with the following definition of an animal hoarder:

*Someone who has accumulated a large number of animals and who fails to provide minimal standards of nutrition, sanitation, and veterinary care; and fails to act on the deteriorating condition of the animals (including disease, starvation, or death) and the environment (severe overcrowding, extremely unsanitary conditions) or the negative effect of the collection on their own health and well being and on that of other family members.*

1. What was the origin of the complaint? Circle all that apply:

1. Stranger	2. Friend or acquaintance	3. Relative not living there
4. Family member or roommate	5. Social service agency	6. Service person visiting home
7. Landlord / tenant / neighbor	8. Fire or Police Dept.	9. Veterinarian
10. Anonymous	11. Other:	

2. Please list the people living in the house, their age, sex and relationship to the person in question:

Person	Age (yrs)	Sex	Relationship to hoarder (circle correct choice)
1. Hoarder		M F	N/a
2. Person 2		M F	parent, child, sibling, grandparent, other relative, partner, roommate
3. Person 3		M F	parent, child, sibling, grandparent, other relative, partner, roommate
4. Person 4		M F	parent, child, sibling, grandparent, other relative, partner, roommate
5. Person 5		M F	parent, child, sibling, grandparent, other relative, partner, roommate

3. Please circle the marital status of the hoarder:

Single	<b>Married</b>	<b>Divorced</b>	<b>Widowed</b>	Partner/sig.other	Unknown
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4. Please circle the type of residence:

Single family home	Apartment/ Condo	<b>Trailer</b>	Other (describe):
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5. Please indicate the occupation of the hoarder: \_\_\_\_\_

6. Please indicate what other agencies are involved in the case:

Mental Health	Yes	No	Unknown
Fire Department	Yes	No	Unknown
Police Department	Yes	No	Unknown
Department of Aging	Yes	No	Unknown
Child Welfare	Yes	No	Unknown
Court	Yes	No	Unknown

7. Please indicate what areas of the house were cluttered and the degree of clutter present:

Cluttered Areas	Extent of Clutter (circle best choice)			
	None Unknown	Moderate	Substantial	Severe
Bedroom	None Unknown	Moderate	Substantial	Severe
Bathroom	None Unknown	Moderate	Substantial	Severe
Living room	None Unknown	Moderate	Substantial	Severe
Kitchen	None Unknown	Moderate	Substantial	Severe
Dining room	None Unknown	Moderate	Substantial	Severe
Stairwell	None Unknown	Moderate	Substantial	Severe
Hallway	None Unknown	Moderate	Substantial	Severe
Basement	None Unknown	Moderate	Substantial	Severe
Attic	None Unknown	Moderate	Substantial	Severe
Outside	None Unknown	Moderate	Substantial	Severe

8. Please indicate whether the following appliances /utilities were in working order:

Stove/Oven	Yes    No Unknown
Kitchen sink	Yes    No Unknown
Washer/Dryer	Yes    No Unknown
Electricity	Yes    No Unknown
Furnace/Heat	Yes    No Unknown

Fridge/Freezer	Yes    No Unknown
Bathroom sink	Yes    No Unknown
Toilet	Yes    No Unknown
Water heater	Yes    No Unknown
Shower/Tub	Yes    No Unknown



10. Was there any danger in addition to that noted above for the hoarder or other family members from the clutter or hoarding? If so, please describe:

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11. Please indicate the extent to which each of the following types of items were hoarded:

<b>Hoarded Objects</b>	<b>Extent of Hoarding</b> (circle best answer)
Newspapers or magazines	None   Moderate   Substantial   Severe Unknown
Books	None   Moderate   Substantial   Severe Unknown
Other paper	None   Moderate   Substantial   Severe Unknown
Clothing	None   Moderate   Substantial   Severe Unknown
Containers (plastic, paper, bottles, glasses)	None   Moderate   Substantial   Severe Unknown
Food or food garbage	None   Moderate   Substantial   Severe Unknown
Animals	None   Moderate   Substantial   Severe Unknown
Clutter outdoors	None   Moderate   Substantial   Severe Unknown
Other (describe):	None   Moderate   Substantial   Severe Unknown

12. List number, type, and vital status of all animals in the collection (note: if estimated rather than an actual count of the animals, please note using “≈“symbol):

Type of animal	Number in good or adequate health	Number alive but in poor condition; not in immediate risk of death	Number alive but severely injured, diseased or extremely malnourished	Number dead	Total
Dogs					
Puppies (< 1 yr old)					
Cats					
Kittens (< 1 yr old)					
Birds					
Reptiles					
Small mammals					
Horses					
Cattle / sheep / goats					
Other: _____					

13. How long has this individual been monitored or investigated for animal hoarding related problems?

< 1 year	1 – 3 years	4 – 5 years	> 5 years
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14. Please describe how the majority of animals were acquired. Rate the most common method as 1, the next as 2, etc. Use each ranking only once.

	Animals bred deliberately in hoarders home
	Animals bred accidentally in hoarders home
	People brought animals to the hoarder
	Hoarder purchased or adopted new animals
	Hoarder actively solicited new animals by advertisement, picking up strays
	Other (describe) _____

15. What were the reason(s) stated by the hoarder for having the animals? Check all that apply:

	Saving them
	Love animals
	Animals are like children
	No one else would care for them
	Animals are their only friends or companions
	Other (describe):

16. Circle how many of the individual animals the hoarder was able to identify by name:

ALL	MOST	SOME	FEW	NONE	UNKNOWN
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17. Did the hoarder attempt to conceal the presence of the animals in any of the following ways?

YES	NO	Unknown	Covered windows (shades drawn, blackened, etc)
YES	NO	Unknown	Solid fences or other similar external barriers
YES	NO	Unknown	Overgrown vegetation – bushes, trees, hedges, etc.
YES	NO	Unknown	External debris sufficient to block view or access
YES	NO	Unknown	Deny investigator or other persons access to residence

18. What was the resolution of the case investigation? Circle all that apply:

- 1) All animals were removed from hoarder
- 2) Some animals were removed from the hoarder
- 3) Hoarder prohibited from owning animals for a period
- 4) Hoarder agreed to ongoing monitoring
- 5) Hoarder ordered to undergo psychiatric evaluation
- 6) Hoarder was institutionalized or placed under protective care
- 7) Hoarder penalized by fine or jail term- describe: \_\_\_\_\_