

Literature Review To Support the Development of A Community Response to Hoarding

Prepared for:

The Ottawa Community Response to Hoarding Coalition

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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:

1. Incidence - is there statistically valid or credible anecdotal evidence that the rates of hoarding is changing;
2. demographics – does the type and/or nature of hoarding behaviour differ by area;
3. community response – what are other areas doing about their community's hoarding situations;
4. 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 centred 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, care giver 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:

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

These features distinguish hoarding from the collecting of objects generally considered interesting and valuable 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, HARC¹ 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)

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

¹ Hoarding of Animals Research Consortium (U.S.)

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 31st: 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 zoonotic² 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, 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)

² Pertains to diseases transmittable from vertebrate animals to humans

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 framework³ 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 based upon a vision of the ideal continuum of care and desired outcomes⁴. 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.

³ 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>

⁴ intended (desired) or unintended results (short- or long-term) of activities/strategies/processes

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.
- 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:

1. 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.
2. Develop an action and evaluation plan to make a picture of the ideal a reality, defining the what and how (i.e. relevant activities, tasks and processes), the who, and the when, all with respect to specific objectives.
3. Document what happens when the action and evaluation plan is implemented with respect to activities, processes, and outcomes/impacts.
4. 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:

- Where are we now and where do we want to go?
- How do we get to where we want to go?
- What did we do, how did we do it, and what were the results?
- What do we need to change in order to move forward?
- 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 people 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.

(Patronek, 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:

- 1) Intake
- 2) Assessment
- 3) Case Management
- 4) Voluntary Interventions
- 5) Involuntary interventions
- 6) 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 is 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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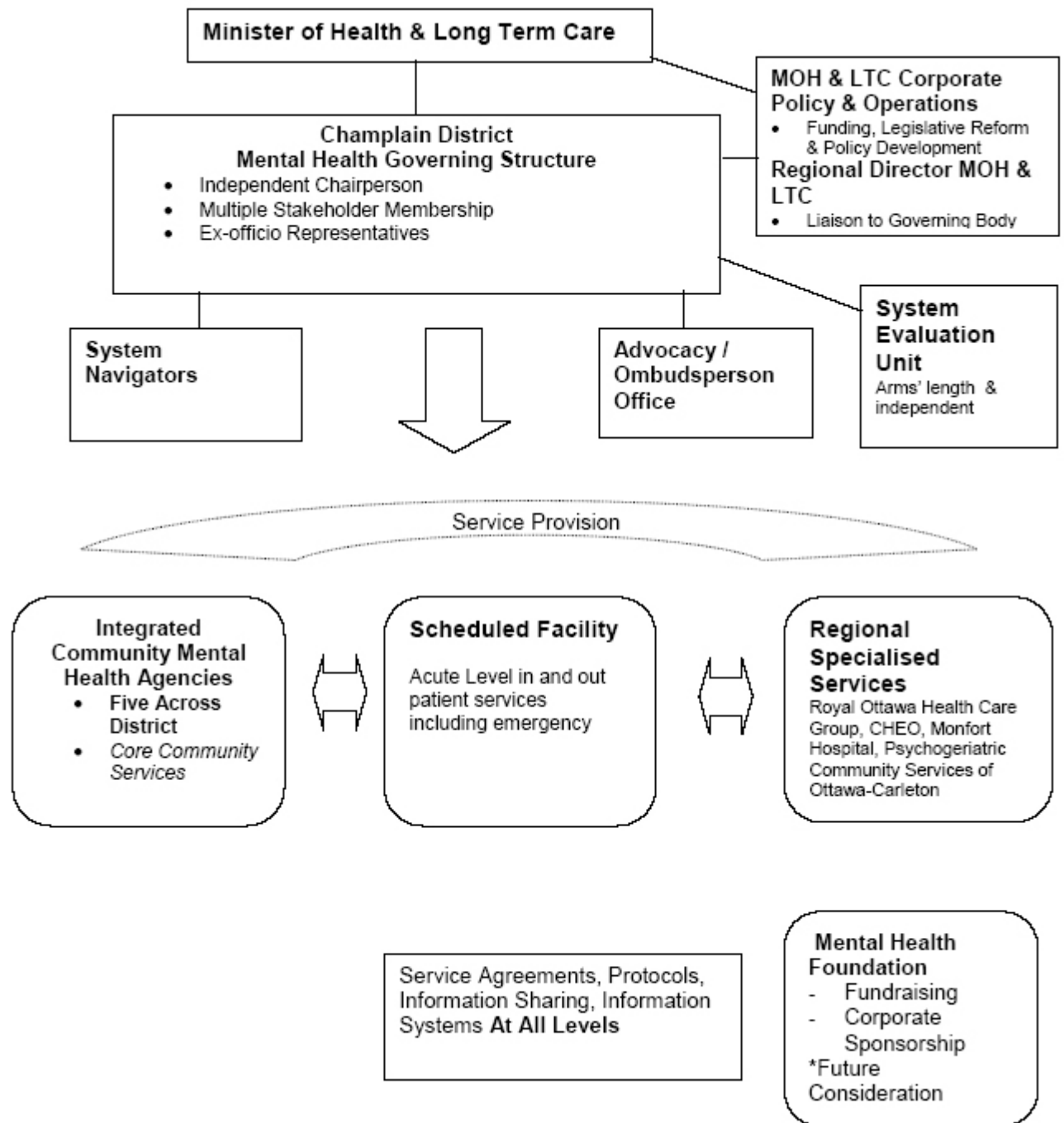
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Appendix 1



(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 are 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:

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

(Dane County website)

Appendix 3

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)
