

AS IT WAS HEARD REPORT
French & English Focus Groups
Held in Ottawa between May 30th and June 9th 2005

OTTAWA COMMUNITY RESPONSE TO HOARDING COALITION

***SUPPORT TO COMMUNITY PARTNERSHIP INITIATIVES
PROJECT***

SUMMARY OF FOCUS GROUPS HELD
To assist in developing
a coordinated, interagency Service Delivery Model
for Hoarding situations in Ottawa and environs

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PREPARED BY THE FOCUS GROUP PLANNING COMMITTEE

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ASSUMPTIONS

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

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 ie. 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**

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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**

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- **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**

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- **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**

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- 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 ie. 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

Accountability

- Ottawa Community Response to Hoarding Coalition membership

KEY THEME ISSUE # 3

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**

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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

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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

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

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- 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 need 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**

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- **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**

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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**

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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 “decluttering “ 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

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- 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,

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- **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.

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Participants attending Focus Groups

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Jane Blair	Centretown CHC		
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