WELLINGTON GUELPH HOARDING RESPONSE REPORT

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Contributors

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- Emily Gibson, Wellington Guelph Hoarding Response Coordinator
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SUMMARY

- Research goals: To provide recommendations to the Wellington Guelph Hoarding Response (WGHR) as to how individuals who struggle with hoarding can be better supported by local services and organizations within the Wellington-Guelph area.
- Methods: Focus groups and online surveys were conducted with members of the Wellington Guelph Hoarding Response Multidisciplinary Team and the Wellington Guelph Hoarding Response Steering Committee so as to understand their perspectives of how individuals who struggle with hoarding may be better supported. An interview with a key informant from a similar program in the Hamilton-Halton area was also conducted in order to better understand how other communities address and support individuals struggling with hoarding.
- Main findings: Participants identified several barriers for individuals who struggle with hoarding in accessing support services and resources within the Wellington-Guelph area. These barriers include the following: coordination of care; developing trust to engage clients in services; securing resources; and preventing the recurrence of unsafe hoarding behaviours and clients from becoming high risk cases.
- Conclusions: In addressing these issues, we provide several recommendations that include, but are not limited to, the following: build in additional time during committee meetings to network with members and overcome worker stress and burnout; develop contact lists and other resources to facilitate referrals and funding applications and incorporate a systematic procedure (i.e., a process plan) to addressing and supporting hoarding within the community.

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INTRODUCTION

This project was conducted in partnership with the Wellington Guelph Hoarding Response (WGHR). The WGHR is part of a wider network that includes the Hoarding Multidisciplinary Team and the Steering Committee. These committees consist of various community stakeholders who meet in an effort to better understand and respond to situations of hoarding[1]. The WGHR focuses on sharing information about hoarding, providing education, and building collaboration between community resources that individuals may encounter once diagnosed.

Research Goals

The main goal of this project was to better understand the accessibility of support services and resources for individuals who struggle with hoarding and are living in the Wellington-Guelph area. More specifically, this project aimed to provide recommendations to the WGHR that could improve access, as well as the level of support being provided to these individuals. This project was guided by the following goals:

1. To understand the "average" experience of an individual who is struggling with hoarding in the Wellington-Guelph area, as well as the difficulties they may encounter when accessing recommended services;

2. To compare the services offered in Wellington-Guelph to another response program (i.e., the Hamilton/Halton Gatekeepers Program[2]) to understand how their services operate and compare;

[1] The Wellington Guelph Hoarding Response describes hoarding as, "the build-up of items and failure to throw away items to the point that the house can no longer handle the number of possessions." For instance, an individual may be struggling with hoarding if they are: (1) accumulating a large number of items; (2) having difficulty discarding items; (3) unable to function within the home, or a space within the home (e.g., does not have access to bath; limited, or no, ability to navigate throughout the home).

[2] Catholic Family Services' Gatekeepers Program in Hamilton-Halton works with local health and social service community partners to identify and assist seniors living with Diogenes Syndrome, of which hoarding is a symptom. The program works to increase access to support services for at-risk seniors in the Hamilton-Halton areas.

3. To provide recommendations to the WGHR that may improve the level of support individuals who struggle with hoarding receive within the Wellington-Guelph area.

Background

The WGHR is a network of community organizations that exist within the Wellington-Guelph area, and include service providers from the following fields: emergency response; law enforcement; education; and community, health, and social services. These organizations work together in an effort to better understand and respond to hoarding in the Wellington-Guelph area.

Hoarding is defined as a mental health condition where an individual acquires various objects but has an unwillingness or inability to get rid of them (Frost and Gross, 1993; Thobaben, 2006). The accumulation of these objects can result in the disruption of an individual's home by cluttering open spaces and at times resulting in potential risk of injury to the individual. The accumulation of objects can potentially cause fire hazards or possible health issues to the individual as well as other occupants due to the home's state (Frost, Steketee and Williams, 2000; Thobaben, 2006). As such, those who hoard may be mandated by property standards, by-law and/or fire prevention officers to remove excess objects from the home in order to reduce the risk or level of harm to the individual.

The WGHR has implemented a harm reduction approach to assist those living in Guelph and Wellington who struggle with hoarding, and may have been mandated to remove belongings from their home. This approach focuses on the safety, health, and comfort of the individual when addressing high risk situations (Wellington Guelph Hoarding Response, 2018). Ultimately, the WGHR aims to establish and maintain individual as well as public (e.g., neighbours, service providers that enter the home, pets, etc.) safety, while attempting to help increase functionality and, ideally, prevent further accumulation of objects within the home (Wellington Guelph Hoarding Response, 2018).

While there are local services and organizations within Wellington Guelph to support individuals who struggle with hoarding, the WGHR note there may be barriers in accessing these services. For example, individuals who hoard may also be living with other mental health conditions such as obsessive-compulsive disorder, dementia, depression and anxiety (Thobaben, 2006; Vorstenbosch et al., 2015). This may further contribute to additional barriers in accessing support services and resources.

METHODS

To provide recommendations to the WGHR for future programming, two focus groups and an online survey were conducted with members of the WGHR. Individuals who participated in the focus groups and the online survey represented various health and social service sectors who provide support to individuals struggling with hoarding in the Wellington-Guelph area. This included individuals from the following health and social service sectors: emergency response workers (i.e., firefighters, paramedics, and police officers), community, health, and social service workers (i.e., day program recreational and support workers, housing support workers, occupational therapists, nurses, social workers) as well as those working in the areas of enforcement and education (e.g., property standards officers, by-law officers, fire prevention officers, legal experts and property managers).

In addition to the focus groups and online survey, an individual interview was also conducted with a key informant from a similar program in the Hamilton-Halton region. This interview was conducted for the purpose of understanding of how this program operates and compares to that of WGHR. Additional information about these procedures is provided below.

Focus Groups

A total of 17 members from the WGRH participated in the focus groups. Participants were divided into two focus groups to discuss different scenarios. The scenarios were fictional, and were created with help from both Dione Winter, the interim WGHR Coordinator, and Emily Gibson, the WGHR Coordinator. The first focus group, which included 9 participants, discussed the experiences of a middle-aged woman living in subsidized housing in Guelph. The second focus group, which included 8 participants, discussed the experiences of an older man who owned his own home in a rural area outside of Guelph. Both focus groups lasted two hours and took place in a private space provided by the WGHR in Guelph, Ontario. The focus groups consisted of questions that asked WGHR members to describe the average experience of an individual who is struggling with hoarding. In particular, WGHR members were asked to share their perceptions of the barriers and facilitators to receiving support that an individual who is struggling with hoarding may have. Participants discussed the following topics (See Appendix A for the Focus Group Guide):

- The average experience of an individual (who struggles with hoarding) when accessing local services;
- The barriers and facilitators an individual (who struggles with hoarding) may encounter when accessing local services;
- Members' recommendations and suggestions for improvement.

Online Survey

A total of 19 members from the Multidisciplinary Team participated in the online survey that was circulated a week after the focus groups were conducted. The online surveys were created and shared using Qualtrics, an online survey tool, and took approximately 10-20 minutes to complete. The online surveys were designed to fill in any gaps from the focus group data and offer members who were unable to participate in the focus groups the opportunity to share their perceptions of the limitations and strengths of the WGHR. Participants responded to the following topics (See Appendix B for the Survey Questions):

- The amount of time a service provider may spend on one case;
- The follow up process for an individual (who struggles with hoarding);
- The process of eviction and/or a house becoming condemned;
- The accessibility and organization of the local services being provided to an individual (who struggles with hoarding);
- Members' recommendations and suggestions for improvement.

Interview

One key informant from the Gatekeeper's Program of Catholic Family Services of Hamilton-Halton participated in a phone interview during a time that accommodated both the participant's and the facilitators schedules. The phone interview lasted approximately 45 minutes and consisted of questions that asked the informant to describe the average experience of an individual who hoards, as well as this participant's perception of the limitations and strengths of their own program. The phone interview questions were designed to develop a better understanding of the program and to compare and share its successes and pitfalls with the WGHR. During the

interview, the participant discussed the following topics (See Appendix C for Interview Guide):

- The average process of an individual (who struggles with hoarding) when accessing the program;
- The funding and number of staff and volunteers allocated to the program;
- The process of assessing the client and evaluating the program and services;
- The limitations, gaps and strengths of the program.

With permission from this individual, notes were taken during the interview by the facilitators and used to inform this report.

RESULTS/FINDINGS

The "Average" Client

One of the goals of this project was to better understand the average experience of an individual who struggles with hoarding when accessing services and programs within the Guelph-Wellington area. However, most WGHR members shared that *"[t]here is no average"* experience for an individual who struggles with hoarding. In part, this is due to different backgrounds and demographics of each client. For example, age, family type, type of housing, location, and financial status were all mentioned as shaping a client's experience. In addition, various factors including the service provider's role and caseload, the complexity of the client's health and the amount of support that is required were also brought up by members as contributing to different experiences.

As such, the amount of time, funding and the number of services allocated to a client were mentioned by members as being difficult to identify and often varied. For instance, members described scheduling daily, weekly, monthly, bi-monthly, quarterly, or yearly meetings with clients that could last anywhere from several minutes to a couple hours. The length and occurrence of meetings were also mentioned by some members as being dependent upon their employer and/or funder. For example, this resulted in a limited amount of time and/or number of visits some members could arrange with a client. On the other hand, some members suggested that visits could last *"[...] for as many years as someone is a [client] and they continue to struggle with excess items in their unit."* Furthermore, WGHR members were unsure as to the length of time that

clients are in the program, with only some members suggesting that it could take a year, or even longer.

Given that there was no average experience for an individual who struggles with hoarding, the recommendations we provide below were developed with the intention of being inclusive of different hoarding experiences. In presenting these recommendations, we first identify issues that were raised by members in the focus groups in the survey in addressing hoarding situations. These issues include:

1. The Coordination of Care;
2. The Development of Trust to Engage Client in Services;
3. The Limited Resources to Support Clients;
4. The Prevention of Recurrence and/or Becoming High-Risk.

Following each of the issues presented, we then provide a recommendation to the WGHR around ways to improve programming so that the WGHR may further support individuals who struggle with hoarding.

The Coordination of Care

WGHR members identified the coordination of service providers as both a facilitator and barrier to supporting those with hoarding issues in the community. In particular, themes of communication, leadership, and collaborating relationships among service providers were commonly discussed. Many members considered the WGHR to be a beneficial resource that provided them with the opportunity to address the diverse needs of clients and to ensure that agencies were not duplicating their work efforts by expending limited resources (e.g., time, funds, staff). For example, certain members viewed hoarding to be a complex issue that no single agency could address, and as such, considered the multiple agency approach of the WGHR to provide *"various resources at any given time" and "a lead or project coordinator of sorts."* Members also felt that the WGHR offered a platform to build relationships with other service providers, to discuss complex cases and to brainstorm unique solutions to overcome resource limitations. For instance, one member shared the following sentiment:

> *As a reactive role, the ability to have a multidisciplinary team is essential [...] having other agencies from which I can pull from to aide in getting compliance is an asset not only for the [community] but the property owner and their family.*

However, other members described a need for the WGHR to develop a greater sense of leadership in terms of coordinating care and sharing client information among members. For instance, some members mentioned that there are still gaps in terms of understanding the role of the WGHR within the community since *"there is no one contact that takes a project manager lead on any case."* Additionally, members commented on a lack of organization in terms of having a running list of WGHR members, an understanding of members' roles, as well as at which point during the process certain members should be contacted.

Recommendations:

Some WGHR members requested that more time be built into committee meetings as a way to enhance relationships between members. By allowing more time, some members felt this could contribute to a better understanding of other members' roles. This in turn would help in addressing complex hoarding cases by incorporating each members' strengths. In addition to this, having a hierarchical list of members, their roles and their contact information was mentioned as being beneficial. For instance, the WGHR could implement a system in which the consultant may be the main point of contact, who would then contact the lead designated to a group of members (e.g., first response members, mental health members, etc.), who would then contact one or multiple members from a group. In doing so, members would have a better understanding of who to contact, when, and under which circumstances.

Members also suggested that the WGHR could designate a project manager to take the lead on managing all client cases and smaller task forces, or teams from each field (e.g., emergency response workers; community, health, and social care workers and; enforcement and education). This project manager would be responsible for updating and sharing client cases to only one member of a designated task force. If necessary, the designated member from each task force would only then share the client case with the entire team, or only one particular member.

Because members of the WGHR had difficulty in describing the process in which a client may be supported, the WGHR may also find it beneficial to create a "process plan," that is shared with all team members. For instance, the WGHR may wish to adopt

similar protocols to that of the Gatekeepers Program of Catholic Family Services of Hamilton-Halton in order to improve organization and the coordination of care, such as:

- Receiving recorded referrals from service providers, WGHR members, and/or others involved in the process (e.g., landlords, neighbours, family, the client themself) to a centralized intake centre and/or project manager;
- Having one individual acting as a case manager[3] to conduct a full assessment of the home and create a client care plan. In order to share information and the care plan with all necessary service providers, WGHR members and/or others (e.g., landlord, neighbours, family, etc.), consent should be gained from the client;
- Conducting weekly team meetings that prioritize clients by urgency and need (e.g., upcoming evictions and those who are homeless are attended to first) and;
- Contacting all necessary service providers, WGHR members, and/or others (e.g., landlords, neighbours, family, etc.) in order to share and discuss the care plan.

The WGHR may also wish to organize all referrals as one of three options: (1) open-case (i.e., a case which is currently being investigated or mitigated), (2) closed-case (i.e., a case in which a client is not in agreement, or a case in which the client is no longer regarded as being in urgent need), (3) wait-list (i.e., a list of clients organized by need or priority). More complex referrals and cases may then be discussed during team meetings.

The Development of Trust to Engage Client in Services

Many WGHR members described the process of building trust with new clients as important in attaining compliance, that is, the client's consent to formal support in order to reduce the risks for harm within the home. However, some WGHR members identified barriers in their ability to build trust with clients. For example, one WGHR member shared the following perspective:

> *I am really only available to service users (i.e., those with hoarding concerns) directly by phone and email. I think that sometimes that can pose a barrier in that many of these folks struggle with organization, and don't return phone messages or emails. I think that there is something to be said for the face-to-face contact, too. There is more opportunity to build*

[3] In this report, we use the term "case manager" to explain an individual who oversees a client's process, while recognizing this term is not universal, and can differ from organization to organization.

> *rapport and develop a relationship that the client would be comfortable with. The only time I see clients face to face are at the peer support group (which I co-facilitate) for 1.5 hours per week, and if another service provider brings me to consult on an in-home visit.*

Some members also explained, that due to limited resources within their own agencies, they will often refer clients to other community support services. Under such circumstances, clients may be reluctant to follow up with such contacts because they are unknown to the individual. Due to this lack of follow-up, long-term solutions, such as prevention of recurrence, may be neglected.

Recommendations:

In interviewing the key informant of the Gatekeepers Program of Catholic Family Services in Hamilton-Halton region, they noted that building a level of trust with a client is one of the most foundational steps to engaging the client in the program. In order to do so, this program hired 14 full-time case managers, or main points of contact, to act as client liaisons to community resources. As such, it may be beneficial for the WGHR to consider electing case worker(s) who can then work with a client, face-to-face, and introduce them to each process, as well as the service providers associated with that process (e.g., *"[t]he cleaners keep touch with the case manager, [who then] introduces the cleaner to the client and says what needs to be done"*). For instance, the key stakeholder of the Gatekeepers Program of Catholic Family Services, described that a case manager will create a care plan with the client. This care plan is an agreement between the case manager and the client that states which areas need to be addressed in order to reduce the level of harm within the home. Care plans are client driven and include SMART goals (i.e., goals that are specific, measurable, attainable, relevant and time-based) and outline who is responsible, what will be done, and when it will be done by. For example, the key informant suggested:

> *[...] to pick the smallest goals and proceed with baby steps [so that it is] not emotionally stressful. Don't pick out an area of the house that would be the most emotionally charged to get rid of stuff. Approach with something that is easy.*

By discussing this plan in advance and involving the client as a key decision maker, clients may become more trusting of service providers and may be better prepared for changes within the home.

Additionally, in recognizing that clients may struggle with organizing phone calls and emails, it may not be enough to only provide the contact information of a service

provider (e.g., a cleaning company) to a client who are then expected to follow-up. Instead, an alternative option is for a case worker or consultant to reach out on behalf of the client to support services and resources. For instance, care managers from the Hamilton-Halton program are often assigned to speak on behalf of the client during team meetings and help make decisions in terms of whether the client's case should be closed.

The Limited Resources to Support Clients

Only a few WGHR members considered their services to be fully accessible to individuals that are struggling with hoarding. This is due to what some members described as a lack of agency, programming and/or committee resources. For example, one of the main concerns brought up by members was around funding and the costs of cleaning up a client's home. WGHR members explained that property clean-ups could range from $500.00 to $25,000.00 depending on the size of the home, the extent of the cleaning, the resources required (e.g., additional labour, time involved, appliance replacements, disposal costs, biohazardous waste versus 'clean' waste, etc.). Fines of up to $50,000.00 may also be issued (e.g., property standards and by-law). Clean-up costs were described as being the responsibility of the homeowner, property tenant and/or landlord. However, members mentioned there is some available funding available from community services to cover such costs, including exmaples such as: the Canadian Mental Health Association, County of Wellington Housing and/or Social Services, Local Health Integration Network (LHIN), Ontario Disability Support Program, Salvation Army, etc.[4] While these funds were described as contributing to some of the costs incurred, members often stated that they are not enough. This results in service providers needing to prioritize the most expensive cleaning projects because they are often considered higher risk.

WGHR members considered these funding barriers to overlap with other limited resources, such as staff time. For example, one member described how applying for funding and arranging a goal-setting meeting with a client prior to the clean-out requires additional time. WGHR members also mentioned time as a constraint to being able to support individuals who are struggling with hoarding. Factors such as funding, the number of clients and caseloads, and agency and/or programming restrictions were

[4] For a complete list of available funding, please contact WGHR by email (info@wghoardingresponse.ca) or by telephone (519-836-2332, ext. 108).

brought up in the focus groups and surveys as affecting the amount time of members could devote to supporting each client. For example, one member noted, *"[m]y ability to visit is limited by our funder the LHIN. There tends to be a restrictions on the number of visits we can complete."*

While members considered the clean-out to be an event which typically evokes a stressful, or emotional, response from clients they also noted that they were unable to provide ongoing supports throughout this process. Even when WGHR members considered referring clients to community resources, they questioned how the client's financial status may impact their ability to access such supports. For instance, some members noted that clients may not be able to take time away from work and/or be able to afford the associated costs (e.g., transportation, mental health services, etc.). Additionally, some members stated during the focus groups that their time was often spent raising public awareness, providing education to the community and soliciting understanding from neighbours. For instance, one member who works as a fire prevention officer described that he was often answering phone calls from concerned neighbours, rather than managing the clean-out process, or risks, associated with the client.

Recommendations:

Members suggested that the WGHR could organize a list of contacts that provides information, and applications, for different community organizations that provide funding. Members also stated that by coordinating, or standardizing the care process, the WGHR may be able to allocate supports more efficiently and effectively (i.e., see *The Coordination of Care*). Although hiring a full time team to address funding concerns was considered to be an unlikely, or lofty, goal, one member suggested at least one lead person could supervise funding applications and other budgetary concerns.

> *A full time hoarding team with a dedicated budget would be ideal but I feel that is not realistic or likely to happen so the system that we have put together with shared resources/staff is the best we can do at this time. Continuing to make sure that we access each pot of funds from the various agencies is great way to pull funds, however it is time consuming and requires a lead person to take on that responsibility.*

Considering that there may be financial concerns around hiring a new staff member to take on a lead budgetary position, the WGHR may consider soliciting additional volunteers, or appointing practicum students from local Universities and/or Colleges to

assist with non-confidential client matters. To reduce cleaning costs, members also suggested reaching out and building partnerships with various community businesses (e.g., bin removal, cleaning companies, storage units, staging areas, etc.). Our key stakeholder from the Hamilton-Halton also suggested that the WGHR may wish to consider contracting to select cleaning who have training and/or experience in working with such clientele:

> *You can go with cleaners who charge $50.00 to $60.00 or you can hire your own cleaning staff and you can have control over hourly wages. In the past we had other contractors, with different companies and they kept changing the rate [...] Since we hired [our own staff], we have [the] control.*

In order to receive additional financial resources that could be used toward hiring staff, or funding client clean-outs, we also recommend that the WGHR consider conducting yearly program evaluations in order to measure the success, impact and access of the program. As such, the WGHR may consider implementing the following strategies:

- Collect demographic information on the clients and the number of clients being served per week, in order to have a better understanding of this populations' needs;
- Collect statistics on the type and number of resources allocated to clients (e.g., time, funding, staff, disposal bins, storage units, cleaning services, etc.) and;
- Conduct pre and post-tests to demonstrate the effectiveness of the program.

For instance, Hamilton-Halton has a centralized intake procedure that allows for them to assess and evaluate their program. They also conduct full assessments of their clients at the time the case is opened, and again once the case has been closed. This assessment includes using a hoarding scale to initially assess a client's home for functionality and severity, as well as additional client intake information that is gathered at the time of referral. Such procedures allow the program to collect the statistical and demographic data of each client and measure the impacts of the program; which has demonstrated a positive influence on compliance and harm reduction at 5-6 months.

The Prevention of Recurrence and/or Becoming High-Risk

Mental health was described by members as a significant factor to the recurrence of hoarding by clients and cases becoming high-risk. As such, many members expressed concerns around the need to address underlying mental health issues related to

hoarding. While there are mental health services offered to clients who struggle with hoarding, members' expressed concerns related to waitlists, especially in terms of clients' being able to access affordable mental health services and resources. Based on WGHR members' experiences, the lengths of waitlists have deterred clients from accessing support services and resources. For instance, clients have declined community support services and resources because they either refused to wait or they lost motivation to address their concerns. For instance, one member shared the following:

> *Wait times for mental health services are very lengthy and usually not available when the client decides they are ready. Often that window of opportunity has long passed by the time their name make[s] it to the top of the waitlist.*

Other challenges around supporting individuals with mental health issues were also raised. For example some members stated services (such as support services) may not follow-up with a client after they refuse a referral for additional support.

Due to the number of cases, WGHR members also described having to prioritize clients by urgency (e.g., eviction) and/or risk (e.g., unsafe environment for the individual and/or public). However, by following a hierarchy of client need, members found that individuals in the earliest stages of hoarding are overlooked and are unable to access support services that could prevent urgent response. For instance, one member shared the following:

> *Only those in crisis--at risk of eviction-- might be seen. Those in earlier stages of hoarding would not be able to access services or supports. We need to [be] more proactive in our services and supports to avoid just being reactive [...] there are very limited financial supports to fund a clean and no after[-]clean supports[,] which generally means the client will return to previous behaviours.*

As such, many members expressed the need to reach clients and connect them with services early on when hoarding first becomes a problem.

Recommendations:

WGHR members requested that more long-term solutions be established in order to prevent the recurrence of high risk, urgent responses to clients. As such, members suggested that the WGHR consider conducting:

- Outreach initiatives so that the public, (neighbours, more specifically), may better understand the underlying issues related to hoarding and;
- Ongoing communication with members of what resources are available.

Regarding client follow-up, one WGHR member shared that, *"[p]eople's readiness to change fluctuates all of the time, so even though they might be ready one day, that can change quickly."* As such, members of the WGHR may consider following similar procedures to the case managers of the Hamilton-Halton program by following up three times with clients. For example, the key stakeholder from the Hamilton-Halton program shared that, *"we don't give up easily because we realize they are challenging."* By ensuring that clients have been provided with several opportunities to receive additional services and resources, individuals who struggle with hoarding may have a chance to change their mind and accept community supports. In recognizing that following-up with clients requires additional staff time, an already limited resource, the WGHR may wish to consider hiring volunteers and/or practicum students from Universities and/or Colleges in the community. For instance, the Hamilton-Halton program has solicited support from 6 volunteers to run a telephone program that keeps in contact with previous clients. If the WGHR were to adopt a similar program, volunteers and/or practicum students could be trained to follow up with clients.

Furthermore, in addressing and supporting clients who struggle with mental health, the WGHR may wish to consider developing a clinical treatment program. A need for such a program was raised by some members:

> *We lack a clinical treatment group for hoarding. The weekly peer support group is helpful for clients to connect and share experiences, but moves too slowly to foster change for most people. It would work better as a maintenance group for clients after they have completed 12-16 week CBT [cognitive behaviour therapy] treatment group.*

The Hamilton-Halton program, in partnership with a local psychiatric hospital, currently offers such a program which runs bi-weekly. The program is facilitated by a psychologist acting as an expert on hoarding and anxiety disorders in addition to a case manager. As such, the WGHR may wish to consider developing a similar program in partnership with a local community health and social service in the Wellington-Guelph area in order to further support clients who struggle with mental health. By offering a service like this, it may also help reduce the number of 'high risk' caseloads by addressing hoarding issues and underlying mental health issues early on.

CONCLUSIONS

In conclusion, participants identified a number of challenges that create barriers for individuals who struggle with hoarding in accessing support services and resources within the Wellington-Guelph area. These barriers include the following: coordinating of care (i.e., demonstrating leadership and ensuring effective communication and collaboration between members); building trust with clients in order to engage them in services (i.e., establishing a rapport and uptake of support throughout the entire process); securing resources (i.e., finances and staff-time) and; preventing the recurrence of unsafe hoarding behaviours and clients from becoming high risk cases (i.e., few long-term solutions available, follow-up, waitlists, public education and outreach). In supporting the WGHR to meet its goal to become more effective in their efforts to understand and respond to hoarding, we recommend the following suggestions:

- To build in additional time during committee meetings to network with members and overcome worker stress and burnout;
- To develop contact lists and other resources to facilitate referrals and funding applications;
- To incorporate a systematic procedure (i.e., a process plan) to addressing and supporting hoarding within the community;
- To elect case workers (i.e., volunteer or paid staff) that may build a rapport, set SMART goals, and check-in with clients, as well as provide information and outreach to the public;
- To designate a project manager to organize and apply for funding;
- To develop additional partnerships with businesses in the community;
- To conduct yearly program evaluations on the effectiveness of the program;
- To organize clinical treatment groups in partnership with a local organization and expert.

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APPENDIX A: FOCUS GROUP GUIDE

Focus Group Format

Working towards an Example Scenario of an "average" client

[Group 1: Older adult, owns their home]

[Group 2: Young adult, housing support]

Question 1: Creating a Persona

Give the "Example of the "Average" Client" a Name

What is [Name's] story?

How old are they?

What is their gender/sex?

What language do they speak?

Where were they born?

What type of neighbourhood do they live in?

When did they buy their house?/ When did they move into their housing unit?

Who do they consider to be their community/social network/social supports?

What is their family life like? / Who do they consider to be family (origin/chosen)? Do they have kids, siblings, parents, cousins, partner, etc.

Who lives with them (e.g., people, pets, etc.)?/ Who visits them?

When did they begin "hoarding"?

When did it become a problem?

Why is it a problem?

What transportation does [Name] use?

What are their motivators (e.g., goals, the positive aspects of their life, hobbies)? *This question should also discuss aspects outside of the hoarding/needing supports situation.*

What are their frustrations (e.g., mental/physical health, going to the doctor, paying the bills/mortgage, etc.)

Question 2: Creating the Narrative

Tell us about [Name's] average experience of the WGHR. Take us through the entire process, step by step, from the beginning to the end. What happens in order for [name] to be connected with the WGHR (referred vs. self-referral)?

What is the very first step?

How long does [that step] usually take to be processed?

How much does [that step] cost (financially)?

Is [that step] accessible to [Name] (e.g., transportation, the building itself, physical/mental barriers, scheduling/time]?

Can you say a bit more about…?

What happens then/before/after?

What is the final outcome for [Name]?

Summarize:

The process (in steps)

The local services [Name] accessed

Do you think this is the average amount of services a client might have to navigate? If not, what might be and which services are the most commonly accessed/referred/required?

If we put the number of services being accessed on a sliding scale, what would be the fewest and what would be the greatest number being accessed?

Add up the time this entire process would take

Do you think this is the average amount of time this process would take? If not, what might be and why?

The total “average” number of home visits.

The WGHR Multidisciplinary Team who visited, is there anybody else missing (e.g., volunteers)?

Question 3: Acknowledging WGHR’s Mission Statement (to support individuals & family)

[To be answers if the “client” has a family/friends/community]

What supports are [Name’s family/friends/community] receiving throughout this process?

Question 4: Worst Case Scenario

What if [Name] were to drop out of the program [or deny the service at the time of referral], at what point would that happen?

Would anybody follow up with [Name]?

Question 5: Gaps/Limitations and Strengths of the Program

How can we summarize the barriers that [Name] encountered throughout this process? What were the challenges?

Similarly, how can we summarize the facilitators [Name] encountered throughout this process? What was supporting them?

Question 6: The Miracle Question

If we could re-make this entire scenario, so that instead it depicted the ultimate goal for [Name], that is [Name] would get to continue to live a healthy and safe life in the comfort of their own home, how would their story change? What would be different?

Question 7: Further Thoughts

Is there anything else you might like to add, clarify, or change?

Is there anything else the Research Shop might like to add, clarify or change?

Question 8: Conclusion

Thanks for participation

If you have any questions, concerns, or think of something that you're like, "Oh I wish I had said that during the focus group"—feel free to contact Emily Gibson at egibson@dunara.com or 519-836-2332 ext. 108

APPENDIX B: SURVEY QUESTIONS

Question 1: Please indicate the focus group that you participated in.

- Focus Group 1: A profile of a 43-year-old woman living on housing support.
- Focus Group 2: A profile of a 71-year-old man who owns his own home.
- I did not participate in either focus group.

["SUBMIT AND NEXT" Button]

Question 2: Please use the following space to describe your field of work (e.g., nurse, building inspector, paramedic, legal services, etc.).

["SUBMIT AND NEXT" Button]

Note: If you attended a focus group, please consider the profile discussed during the focus group you attended.

Question 3: On average, how many appointments, or scheduled meetings, might you have with a client who is struggling with hoarding? Please include the length of each appointment or scheduled meeting, as well as any additional appointments or scheduled meetings you might have with families, friends, neighbours, etc.

["SUBMIT AND NEXT" Button]

Note: If you attended a focus group, please consider the profile discussed during the focus group you attended.

Question 4: What are the financial costs of cleaning out a home? Who is responsible for paying these costs and how might funding be accessed?

["SUBMIT AND NEXT" Button]

Question 5: If a client were to deny services and in-home cleaning/organizing, would you or somebody else at your organization, or the WGHR Multidisciplinary Team follow up with them? Please explain why or why not.

["SUBMIT AND NEXT" Button]

Question 6: If a client were to complete a clean-up in their home, would you or somebody else at your organization, or the WGHR Multidisciplinary Team follow up with them? Please explain why or why not.

["SUBMIT AND NEXT" Button]

Note: If you attended a focus group, please consider the profile discussed during the focus group you attended.

Question 7: If the client's home were to be condemned, what might happen to this person and/or their family?

["SUBMIT AND NEXT" Button]

Note: If you attended a focus group, please consider the profile discussed during the focus group you attended.

Question 8: How might you describe the accessibility of the services you provide to a client who is struggling with hoarding? Please consider the client and/or their families: transportation and/or parking needs, physical and mental health abilities or needs, the financial costs, the wait times, etc.

["SUBMIT AND NEXT" Button]

Question 9: How critical is the multidisciplinary team, or the steering committee, to ensuring agencies and services are in communication with one another? Please explain.

["SUBMIT AND NEXT" Button]

Question 10: Resources, such as time, finances and communication were recognized during the focus groups as barriers to clients, families, and/or the community receiving the supports they may need. Do you have any recommendations or know of any solutions to these barriers? Please explain.

["SUBMIT AND NEXT" Button]

Question 11: Is there anything else that you might like to share, in terms of improving the supports a client receives and/or their access to services?

["SUBMIT AND NEXT" Button]

Thank you for completing the survey!

If you would like to submit your responses, please click “Submit.”

If you would like to change a response, please click “Edit.”

If you would like to delete your responses and wish to no longer participate in this portion of the research study, please click “Delete.”

APPENDIX C: INTERVIEW GUIDE

Interview Questions

Question 1

What is your role in the program?

Question 2

How/why is this program related to Catholic Family Services (e.g., is CFS part of the referrals, do they allocate funds to this program, etc.)?

Question 3

How many staff are allocated to the program and what are their roles? Do you have volunteers?

Question 4

Can you provide an example scenario of an “average” client? Are there any common or consistent trends?

Demographics of a client (e.g., age, sex/gender, family type, etc.)

Geographic location (e.g., urban, rural, etc.)

Type of Housing (e.g., owns home, subsidized, renting, homeless, etc.)

Number of in-home visits you may have per day/week

Question 5

What is the average process through your program like (i.e., somebody calls the program, then what)? [Include average timing]

Can individuals be referred to your program or is it through self-referral? Who typically makes the referral? (i.e. family member, friends, professionals etc.)

How many services might a client interact with? If it were a sliding scale, what is the fewest to the greatest number of services a client may interact with?

What services might clients be referred to, and which are the most common referrals?

Does your program only serve older adults (aged 49+ or 60+), and if so how was that decision made? If there were a referral for a younger adult, what might happen?

What happens if a service receiver denies the support being offered by a case manager/worker, or drops out of the program? Does the program follow-up with clients if they drop out of the program?

How might this process differ for those who are home owners vs. renters vs. living in subsidized housing, etc.

Is there an average length of time that clients are in the program?

Question 6

How do you promote community and reduce isolation for the client (e.g., group meetings)?

Are there any support groups for family members or friends of a client struggling with hoarding?

Do you use a Harm Reduction Agreement with clients and what it includes?

Question 7

Who are your funders?

How do you apply for funding (i.e., what are the “buzz words” you use in your applications)?

How do you allocate your funds?

Question 8

How do you evaluate your program (i.e., collect data in order to measure the success/impact/access)?

Question 9

How has the program evolved since 2005? Have there been any changes?

Question 10

Can you identify any gaps/limitations to the program?

Can you identify the strengths/successes of the program?

Question 11

Is there anything else you might like to share with us, that we perhaps didn't touch on?

Do you have any questions for us?