



# HOARDING IN THE REGION OF PEEL: A COLLABORATIVE RESPONSE TO A COMPLEX ISSUE

Prepared for the Coalition on Hoarding in Peel

Prepared by Carter Sehn, Jenny Lam, John Ecker, and Anika Mifsud, Hub Solutions, Canadian Observatory on Homelessness

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# 1. Background

Hoarding disorder is recognized as a distinct mental health diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition (DSM-5). It is commonly defined as feeling compelled to collect and save items, and a persistent difficulty to discard items (Kress et al, 2016; Dozier & Ayers, 2017). The compulsion to collect leads to an over-crowding of living spaces which can spread outside of living areas, and significantly hinders an individual's ability to perform daily living tasks such as preparing food and performing self-care (Kress et al, 2016; Ayers et al 2013). Although *hoarding disorder* is the clinically correct term, other ways to describe the behaviour include *collecting behaviours* or *accumulating clutter*. In this report, the term *collecting behaviours* is used as appropriate.

## 2. Description of the Issue

Responses to collecting behaviours are largely focused on appropriate mental health interventions; however, individuals with collecting behaviours may interact with other service providers, such as Fire Services, Police Services, and Municipal Bylaw Officers, due to the impact of their behaviours on their place of residence (e.g., fire hazard, neighbour complaints). As a result, a comprehensive response when working with individuals with collecting behaviours is needed.

## 3. Purpose of Project and Scope of Work

To create a comprehensive response to support individuals with collecting behaviours in Peel Region, Service and Housing in the Province (SHIP), in partnership with the Coalition on Hoarding in Peel (CHIP), worked with Hub Solutions to understand the impact of collecting behaviours in the Region, survey the scope of collecting behaviours in the Region, and analyze best practices to develop a coordinated approach to care and interventions.

The project focused on six main data sources:

1. A literature review of emerging and/or best practices and service delivery models;
2. A review of key policies and legislations which relate to hoarding;
3. An environmental scan of current services available in Peel Region;
4. Interviews with key stakeholders who have experience working with individuals with collecting behaviours;
5. Interviews with individuals with lived experience of collecting behaviours;
6. A jurisdictional scan of existing hoarding networks and coalitions.

This report presents results from these six data sources. A companion report was also created based upon the results from this report to develop a strategic framework for CHIP.

## 4. Methodology

**Literature Review.** A review of the empirical and grey literature was conducted using the following keywords: “hoarding”; “hoarding disorder”; “hoarding intervention”; “collecting behaviour”. Several databases were used, including PsycInfo and Google Scholar.

**Policy Review.** A review of municipal and provincial legislation related to collecting behaviours was conducted. Municipal legislation included municipal licensing and standards, and relevant bylaws. Provincial legislation included the Fire Code, the Fire Protection and Prevention Act, the Residential Tenancies Act, and the Human Rights Code.

**Environmental Scan.** A review of current service offerings in Peel Region, as well as an estimation of the number of individuals with a diagnosis of hoarding disorder was conducted. Service offerings were compiled through conversations with CHIP members, as well as a web-based search. The prevalence of hoarding disorder was calculated based upon the estimations of hoarding disorder rates and the population of Peel Region, as well as localized service use numbers.

**Interviews with Key Stakeholders.** CHIP members identified 21 key stakeholders to be interviewed. This included representatives from the mental health sector, including Hoarding Specialists, Fire Services, Police Services, Animal Welfare Services, and Regional Governments. A total of 16 interviews were conducted. All interviews followed a semi-structured interview format, meaning that a set of questions was developed with the opportunity to expand on themes as they arose during the interview. All interviews were audio recorded and later transcribed. Data was analyzed using a thematic approach.

**Interviews with Individuals with Lived Experience of Collecting Behaviours.** CHIP members identified individuals with lived experience to whom they have provided services. A total of 10 individuals were identified and 10 agreed to participate. All interviews followed a semi-structured format, described above. All interviews were audio recorded and later transcribed. Data was analyzed using a thematic approach. Participants received either \$20 in cash or a \$20 gift card of their choice.

It should be noted that many participants stated that they chose to participate in the interviews because they wanted to help others who were in similar situations. Having lived experience of collecting behaviours and understanding the difficulties that come with that, participants hoped to make a difference for others in their community who are also experiencing these issues. One participant shared:

*I thought I could help other people. It was the hardest thing in my life. I like the fact that I can help give information in Peel Region to help people that deal with hoarding.*

**Jurisdictional Scan.** A review of similar coalitions and task forces related to community-based responses to collecting behaviours was conducted. Jurisdictions were identified by CHIP members and through a web-based search. A total of 15 jurisdictions were identified. Of these jurisdictions, 5 participated in an interview. All interviews followed a semi-structured format, describe above. All interviews were audio recorded and later transcribed. Data was analyzed using a thematic approach.

Canada	United States	United Kingdom
1. The Toronto Hoarding Support Services Network	6. Hoarding Task Force of Washtenaw (Michigan)	15. Hoarding UK
2. The Durham Region Hoarding Coalition	7. Philadelphia Hoarding Task Force (Pennsylvania)	
3. The Wellington-Guelph Hoarding Response	8. Montgomery County Task Force on Hoarding Behaviour (Maryland)	
4. The Prairie Mountain Inter-Agency Hoarding Coalition (Manitoba)	9. Orange County Task Force on Hoarding (California)	
5. Hoarding Response Action Team (Vancouver)	10. County of Los Angeles Department of Mental Health GENESIS – Older Adults Hoarding Task Force (California)	
	11. Milwaukee Hoarding Task Force (Wisconsin)	
	12. Colorado Hoarding Task Force	
	13. Chicagoland Hoarding Task Force (Illinois)	
	14. Brookline Massachusetts Hoarding Task Force	

**Ethics.** This study received ethical approval from York University’s Office of Research Ethics.

## 5. Limitations

The COVID-19 pandemic impacted the data collection for this project. It was originally planned to speak with family members and natural supports of individuals with hoarding disorder in a focus group setting. Due to the pandemic, we were unable to conduct this

in-person focus group. The pandemic also limited opportunities to engage with the CHIP membership, as it disrupted the number of team meetings we were able to be conducted.

Although the insights shared by individuals with lived experience are vital to this project, the relatively small sample size means that the opinions of our participants may not be reflective of all individuals with collecting behaviours in Peel Region.

Despite these limitations, we were able to complete the major components of the research.

## 6. Results

### LITERATURE REVIEW

#### Causes of Hoarding Disorder

***What May Cause Collecting Behaviours and Hoarding Disorder?*** There is no singular cause of collecting behaviours and hoarding disorder. It has been linked to the experience of a traumatic event and/or loss, having a family member who also has a problem with hoarding, and individuals with brain injuries (American Psychiatric Association, 2013).

Focusing on families, studies have shown that adults with a hoarding disorder diagnosis have an average of two biological relatives with hoarding symptoms, and one study reported that 50 percent of elderly hoarders had a mother with hoarding behaviours (Dozier & Ayers, 2017).

Genetics research has also demonstrated that there may be a familial inheritance to hoarding disorder or collecting behaviour (Hirschtritt & Mathews, 2014), and that identical twins were more likely to both experience hoarding disorder in comparison to fraternal twins (Iervolino et al., 2009).

#### Traits of Individuals with Hoarding Disorder

***What is the Age of Onset for Hoarding Disorder?*** Onset of symptoms tends to start in the teenage years leading to negative effects on daily activities by the mid-twenties and significant daily impairment to wellbeing and daily functioning after age 30 (Nakao & Kanba, 2019; Dozier & Ayers, 2017). Some recognized childhood collecting behaviours include an excessive level of attachment to possessions and personification (e.g. stuffed animals) of the objects (Frost, Ruby & Shuer, 2012).

Though symptoms are present for much of the lifecycle, hoarding disorder is more prevalent with populations aged 55 and older (Kress et al, 2016), which can create a greater impact on the health of a demographic where chronic disorders are more common. Age 50 is the average age of seeking treatment for hoarding disorder; this is believed to be because of increased clinical significance and with age, the possibility of, and time, to amass possessions increases (Kress et al, 2016).



***Does Gender Have an Impact on Hoarding Disorder?*** Some research shows that hoarding disorder is more prevalent among males than females (American Psychiatric Association, 2017); however, women with hoarding behaviours have been shown to seek help more frequently than men (Kress et al, 2016).

## **Assessing Hoarding Disorder**

***How is Hoarding Disorder Assessed?*** When individuals with collecting behaviours seek treatment, it is difficult to assess hoarding disorder since it often co-occurs with other disorders, such as mood or anxiety disorders, obsessive-compulsive disorder (OCD), and attention deficit hyperactivity disorder (ADHD) (Brakoulias & Milicevic, 2015).

Kress and colleagues (2016) state that a multifaceted and holistic approach should be taken to assess hoarding disorder. A holistic approach uses numerous sources of information, such as self-reports from close friends or family members and other health professionals to accurately diagnose and treat the disorder (Kress et al., 2016). This information is valuable as it provides the counsellor information on the clients' level of symptoms, as well as their level of insight (Kress et al., 2016).

There are several hoarding measures that have been developed to specifically assess hoarding behaviour, each with their own strengths and limitations.

- The most widely used self-report measure of hoarding is the **Saving Inventory-Revised (SI-R)** (Frost & Hristova, 2011). This measure is a 23-item questionnaire with three subscales designed to measure the main features of hoarding disorder. These main features are clutter, difficulty discarding, and excessive acquisition (Frost & Hristova, 2011; Muroff, Bratitotis & Steketee, 2011; Kress et al., 2016). Extensive data is available to support the measure's reliability and validity (Frost & Hristova, 2011; Kress et al., 2016).
- The **Clutter Image Rating (CIR)** is another commonly used tool. It is designed to help provide an objective measure of clutter regardless of the individual's beliefs about what constitutes clutter (Frost & Hristova, 2011; Muroff et al., 2011; Brown & Pain, 2014). The CIR contains nine photos for three rooms (the kitchen, living room, and bedroom); these photos are then used and compared with the actual room being assessed. The strengths of this measure are that it has high test-retest correlations and high inter-observer correlations (Frost & Hristova,

2011; Muroff et al., 2011); meaning, the tool will generate the same conclusion even when different individuals are conducting the assessment at different times. It is important to note, however, that the CIR only captures one aspect of hoarding: clutter (Frost & Hristova, 2011). Therefore, other measures should be used in tandem with the CIR to gain a fuller assessment of the hoarding behaviour.

- The **Hoarding Rating Scale-Interview** is another hoarding assessment tool. It is a five-question, semi-structured interview that assesses hoarding and its critical features (Frost & Hristova, 2011). One of the tool's strength is that it demonstrates high test-retest correlations, which means the tool can clearly distinguish hoarding clients from patients without hoarding behaviours (Frost & Hristova, 2011; Muroff et al., 2011).
- Other measures available to assess hoarding include: (1) UCLA Hoarding Severity Scale; (2) Hoarding Assessment Scale; (3) Activities of Daily Living Scale; (4) Saving Cognitions Inventory; (5) Children's Saving Inventory; (6) Compulsive Acquisition Scale; and (7) Florida Obsessive-Compulsive inventory (Schneider et al., 2008; Frost & Hristova, 2011; Muroff et al., 2011; Kress et al., 2016).

### **Impacts of Hoarding Disorder**

***What are the Consequences of Hoarding Disorder for Individuals?*** Hoarding disorder has been shown to affect individuals' daily lives. For example, middle aged individuals with hoarding disorder report an increased number of missed workdays per month (Tolin et al, 2008). Older individuals with hoarding disorder are more likely to have difficulty performing daily activities and self-care due to the level of clutter in their living space (Kim et al, 2001; Ayers et al, 2013). There is also an increased risk for falls, house fires, health code violations, and difficulty to perform basic self-care activities (Diefenbach et al, 2013). In emergency situations, first responders are finding themselves struggling to access people safely either due to concerns about the homes' structure or the mere ability to maneuver through the home (Ayers, Lyt, Howard et el., 2014; Burki, 2018; International OCD Foundation, 2009).

***What are the Consequences of Hoarding for Family Members?*** Those with difficulties with collecting behaviours are more likely to have impaired relationships with family and friends (Grisham, Steketee & Frost, 2008). Hoarding has been associated

with lower rates of marriage and higher rates of divorce (Steketee & Frost, 2003). Five key areas of family discord were identified (Wilbram, Kellett & Beail, 2008). These were: (1) a loss of normal family life, reduced living space and social life; (2) a need for understanding; (3) coping with the situation through decluttering; (4) impact on relationships; and (5) physical, emotional, and social marginalization.

Family members have cited that the negative impact on family relationships occurred because of their need to try and make sense of the hoarding, their efforts to remove the clutter themselves, and the impacts it had on their social life (Wilbran et al., 2008). Family members may have negative feelings toward the person who hoards because they lack an understanding of hoarding behaviour and experience feelings of loss (such as loss of family relationships) (Sampson, 2013). Arguments about clutter were also found to be common, which was exacerbated by the denial that there was anything wrong (Tolinet et al., 2010).

### **Interventions to Address Hoarding Disorder**

***What are the Interventions Used to Work with Individuals with Hoarding Disorder?*** There are few established protocols to guide the intervention of hoarding disorder (McGuire et al., 2013; Brown & Pain, 2014), but several promising treatment options are available. These treatment options range from family-based approaches and coordinated responses, to group interventions and cognitive therapy.

Forceful interventions to hoarding have been identified as a highly ***ineffective*** intervention (Frost, Steketee & Williams, 2000; Steketee, Frost & Kim, 2011; Brown & Pain, 2014). Forceful interventions include instances where clutter is removed from the home of a hoarding individual who is reluctant or not fully involved (Steketee, Frost & Kim, 2011). Such interventions may even further exacerbate the individual's hoarding behaviour (Brown & Pain, 2014).

**Coordinated and Integrated Responses.** A coordinated response to hoarding, such as the creation of task forces, is a promising intervention. Since hoarding is a complex issue, professionals from across different fields and agencies are needed to collaborate to bridge gaps in service (Muroff et al., 2011; Bratiotis, 2013; Koenig et al., 2013; Kress et al., 2016). A multidisciplinary approach to hoarding requires involvement from both public and private agencies, ranging from health providers and animal control agencies, to law enforcement officers (Koenig et al., 2013). Mental health professionals are emphasized as important members of this approach given available evidence

suggesting the benefits of mental health services to individuals who hoard (Koenig et al., 2013). In this response, using strength-based and person-centered approaches are key (Brown & Pain, 2014).

A coordinated approach to hoarding can yield several benefits. Firstly, it addresses the limited resources available when there is a division of labour across different groups (Bratiotis, 2013). Coordination also leads to a cross-pollination of information and ideas, and consequently a deeper understanding of an individual's hoarding problem when multiple perspectives are involved (Bratiotis, 2013).

Koenig and colleagues (2013) identify the four key components to successful teamwork within a hoarding taskforce. These components are: (1) team members working together; (2) agency policies; (3) external support; and (4) trust. When working together, team members should have knowledge of each other's roles in order to avoid duplicating services. It also helps to know who to call when extra help or support is needed. Agency policies define the scope or extent that a team member can be involved in a hoarding case. External support, such as funding, is another factor that can either enhance or act as a barrier to successful teamwork. Lastly, trust between team members, as well as between the team member and hoarding individual, is vital (Koenig et al., 2013; Brown & Pain, 2014). Without trust, team members will have difficulty openly interacting with the individual with hoarding behaviours (Koenig et al., 2013).

**Cognitive-Behavioural Therapy.** Cognitive-behavioural treatment (CBT) is considered the gold-standard treatment for hoarding disorder (Kress et al., 2106). CBT techniques have shown somewhat more promise than exposure and response prevention (ERP) strategies (Muroff et al., 2011), which involve exposing individuals to stimuli that evoke fear and letting those obsessive thoughts occur without responding to them (MentalHelp.net, n.d.). It is important to note, however, that CBT is only effective when it is specific to hoarding disorder rather than for individuals with OCD (Kress et al., 2016).

**Group Interventions.** The group-cognitive behavioural therapy (G-CBT) approach was adapted from the individual cognitive-behavioural therapy (I-CBT) approach (Bodryzlova et al., 2018). There is strong evidence supporting the efficacy of G-CBT (Kress et al., 2016; Bodryzlova et al., 2018). Some of the benefits of G-CBT over I-CBT are: (1) group settings can help reduce the hoarding individual's feelings of shame and guilt; (2) it can enhance social interaction with other individuals sharing the same

experience; (3) it can enrich participation, involvement, and motivation; (4) it is expected to achieve higher cost-efficacy. (Bodryzlova et al., 2018); (5) reduced feelings of isolation and additional opportunities to be more comfortable around other people; and (6) added motivation to complete practice assignments at home, such as sorting and discarding exercises (Frost, Steketee, & Greene, 2003).

**Peer-Led Group Interventions.** The inclusion of individuals with lived experience of hoarding in group interventions has been found to be beneficial. Comparing group peer-facilitated therapy to a mental health professional-led CBT group, Mathews et al. (2018) found that the peer-led intervention was as effective as the mental health-led intervention in reducing hoarding symptom severity. These treatment gains were maintained for at least three months.

**Family-Based Interventions.** Family-based approaches have been identified as a useful form of hoarding intervention, especially in cases where children and adolescents are involved (Kress et al., 2016). Under this approach, parents are offered psychoeducation on, which involves training them to modify their behaviours when reacting to their children's hoarding behaviours, such as by training and encouraging them to use positive reinforcement and reward systems. This is important since, as cited in Kress and colleagues' study (2016), the children's hoarding behaviours were often reinforced by their parents' reactions. It is important to note, however, that the effectiveness of family-based approaches has not yet been assessed (Kress et al., 2016).

### **Stigma of Hoarding Disorder**

***What is the Public Perception of Hoarding Disorder?*** Although more attention was brought to hoarding disorder when it was recognized within the DSM-5, it became a part of mainstream conversation after popular television shows brought the complex disorder into people's living rooms and filled people's minds with images of what a hoarder's home looks like. Social awareness is often beneficial with mental health disorders, but this popularity appears to have elicited stigma and brought judgement upon people who live with hoarding disorder (Hoarding Toolkit, 2016).

## POLICY REVIEW

Relevant provincial and municipal policies were reviewed.

**Provincial Legislation.** Relevant provincial legislation was reviewed, including the *Ontario Fire Code*, the *Fire Protection and Prevention Act*, the *Residential Tenancies Act*, and the *Human Rights Code*. Acts and Codes are grouped into three categories: (1) Rights and responsibilities of tenants; (2) Building safety and right to enter; and (3) Rights of workers encountering hoarding situations.

### Rights and Responsibilities of Tenants

- **Residential Tenancies Act.** Part IV. 2006. c. 17. s. 33. Responsibilities of Tenants. Tenant's responsibility for cleanliness. The tenant is responsible for ordinary cleanliness of the rental unit, except to the extent that the tenancy agreement requires the landlord to clean it.
- **Residential Tenancies Act.** Part IV. 2006. c. 17. s. 34. Responsibilities of Tenants. Tenant's responsibility for repair or damage. The tenant is responsible for the repair of undue damage to the rental unit or residential complex caused by the wilful or negligent conduct of the tenant, another occupant of the rental unit or a person permitted in the residential complex by the tenant.
- **Human Rights Code.** Part I. Freedom from Discrimination. 2017. c.7, s.2 (1). Every person has a right to equal treatment with respect to the occupancy of accommodation, without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status, disability or the receipt of public assistance. (Disability can include a "mental disorder").

### Building Safety and Right to Enter

- **Ontario Fire Code.** Section 2.4 Fire Hazards. Combustible materials shall not be accumulated in any part of an elevator shaft, ventilation shaft, means of egress, service room or service space, unless the location, room or space is designed for those materials.

- **Fire Protection and Prevention Act.** Part V. Rights of Entry in Emergencies and Fire Investigations. 15(1) (c). If the Fire Marshal, an assistant to the Fire Marshal, or a fire chief has reasonable ground to believe that a risk of fire poses an immediate threat to life, he or she may, without a warrant, enter on any land or premises and, for the purpose of removing or reducing the threat, may remove combustible or explosive material or anything that may constitute a fire menace.
- **Fire Protection and Prevention Act.** Part V. Rights of Entry in Emergencies and Fire Investigations. 21(1) (c). An inspector who has carried out an inspection of land on premises under section 19 or 20 may order the owner or occupant of the land or premises to take any measures necessary to ensure fire safety on the land and premises and may for that purpose order the owner or occupant to remove combustible or explosive material or anything that may constitute a fire hazard.

### Rights of Workers Encountering Hoarding Situations

- **Occupational Health and Safety Act.** c. O.1, s. 25 (2)(a). An employer shall provide information, instruction and supervision to a worker to protect the health or safety of the worker.
- **Occupational Health and Safety Act.** c. O.1, s. 25 (2)(d). An employer shall acquaint a worker or a person in authority over a worker with any hazard in the work and in the handling, storage, use, disposal and transport of any article, device, equipment or a biological, chemical or physical agent.
- **Occupational Health and Safety Act.** c. O.1, s. 25 (2)(h). An employer shall take every precaution reasonable in the circumstances for the protection of a worker.
- **Ministry of Labour, Training, and Skills Development.** Firefighter guidance notes. Section 6-44. Hoarding conditions. Employers must:
  - make fire personnel aware of the potential hazards of hoarding.
  - provide information, instruction and supervision to firefighters to protect their health and safety when working in hoarding conditions.

Employers should:

- develop a system to report hoarding locations and situations through pre-planning exercises
- develop procedures for the safety of firefighters when responding to fires in hoarding locations and train fire personnel on procedures
- consult with their joint health and safety committee or health and safety representative in the development of procedures and training

**Municipal Legislation.** Municipal legislation included municipal licensing and standards, and relevant bylaws. These are largely focused on property standards and animal control.

### Property Standards

- **City of Brampton. Minimum Maintenance By-law 104-96 (Property Standards).** Part II. 7. (1) (c). A yard shall be kept clean and free from rubbish or other debris.
- **City of Brampton. Minimum Maintenance By-law 104-96 (Property Standards).** Part II. 7. (1) (e). A yard shall be kept clean and free from anything that may attract or harbour rodents or insects.
- **City of Brampton. Minimum Maintenance By-law 104-96 (Property Standards).** Part III. 10. Steps, walks, driveways and parking areas of a yard shall be maintained so as to afford safe passage under normal use and weather conditions.
- **City of Brampton. Minimum Maintenance By-law 104-96 (Property Standards).** Part IV. 32. (2). All means of egress shall be maintained in good repair and free of objects or conditions which constitute an accident or fire hazard.
- **City of Brampton. Minimum Maintenance By-law 104-96 (Property Standards).** Part IV. 35. (2). Every building shall be kept free from rubbish, debris, or any condition which constitutes an actual or potential fire, health or safety hazard.



- **City of Mississauga. Property Standards By-law 654-98. 42. Human Habitation. (10).** Every occupant of a dwelling unit shall maintain the dwelling unit and all supplied facilities and equipment therein in a clean and sanitary condition and shall co-operate with the landlord in complying with the requirements of this by-law.
- **City of Mississauga. Property Standards By-law 654-98. 44. Egress.** Every means of egress from a dwelling unit, building or structure shall be safe and unobstructed and comply with the Ontario Building Code and Fire Code.

## **Animals**

- **City of Brampton. Animal by-laws. By-law 250-2005 and 261-93.** Pertaining to dogs and animals other than dogs. Number of animals. You can keep as many as three dogs and six cats in a residence in Brampton.
- **City of Mississauga. Animal care and control by-law 98-04. 16. (1).** No person shall keep, or cause to be kept, more than four (4) animals on any premises.

## **Analysis**

In each Act and Code, hoarding is not explicitly mentioned, but there are relevant policies related to cleanliness and access to fire exits. With the inclusion of hoarding disorder within the DSM-5, individuals with a diagnosis of hoarding are protected under the Ontario Human Rights Code and cannot be refused accommodation. This is important, since it protects individuals with hoarding disorder from a possible eviction. The limitation is that many individuals with collecting behaviours may not have an official diagnosis of hoarding disorder, leaving them unprotected by the Human Rights Code.

The vague language in many of the Acts and Codes related to cleanliness and access to fire exits may impact the ability to support individuals with hoarding disorder, particularly with regards to prevention. The distinction of what may pose a public health or safety hazard risk as it relates to hoarding can be questioned, particularly without any defined criteria in the Acts and Codes. The clearest regulation in place is limitations to the number of pets a household can have.

## ENVIRONMENTAL SCAN

***Prevalence of Hoarding Disorder in Peel Region.*** It is estimated that 2 to 6 percent of adults live with hoarding disorder (American Psychiatric Association, 2017); however, it is difficult to truly estimate the prevalence of hoarding disorder since individuals who have hoarding disorder are unlikely to self-present for assessment and/or treatment (Brakoulias & Milicevic, 2015). Rather, individuals with hoarding disorder are often coerced to seek help by others, such as concerned relatives or the police.

Applying this 2 to 6 percent estimate to the population of Peel Region (1.38 million people), approximately 27,600 to 82,800 of individuals in Peel Region may have hoarding disorder. Since this number is only an estimate, it may underestimate or overestimate the number of individuals with hoarding disorder in the region and should not be used as an accurate assessment.

Figures provided by CHIP offers a more localized account of community-based responses. In 2017, fire departments in the Region of Peel reported responding to 58 known cases of hoarding, and the Region of Peel's housing providers identified 58 cases of hoarding. From 2016 to 2018, SHIP received 53 referrals to their Hoarding Support program. These numbers likely represent a large underestimation of the degree of individuals experiencing hoarding disorder in Peel Region. The numbers also reinforce how hoarding disorder can be a hidden phenomenon since individuals may be reluctant to access supports and/or lack awareness around their own challenges with collecting items.

***Current Services Available for Individuals With Collecting Behaviours in Peel Region.*** The web-based search identified the following organizations that provide supports to individuals with collecting behaviours:

- Community response
  - CHIP
  - Peel Public Health
- Specialized Hoarding Services
  - SHIP
    - Hoarding Specialist Program
  - Next Steps Solutions
    - Moving management, specialized hoarding services training and workshops)
- Extreme Clean Out Services

- VHA Home HealthCare
- o Private Practice Professionals focused on Mental Health Supports
- o Private Moving Services
- o Private Organizational Services

As can be seen, there are few services specific to hoarding disorder available in Peel Region. SHIP is one of the only agencies with dedicated Hoarding Specialists in the Region. Mental health professionals in private practice may also offer services, but they are not specific to hoarding. This demonstrates a very large need for more specialized services to be made available in Peel Region.

**Previous work of CHIP.** In 2018, the then co-chair of CHIP along with division fire chiefs from Brampton and Mississauga, presented to the Region of Peel Council on the need to address hoarding as it relates to fire prevention and community safety. During the presentation, CHIP representatives called for a collaborative multi-agency approach to hoarding disorder, similar to that developed by the City of Toronto. They also highlighted the need for public awareness, education, resources, and prevention programs for landlords.

Membership of CHIP include:

- Brampton Animal Services
- Brampton Fire and Emergency Services
- Caledon Fire and Emergency Services
- Central West and Mississauga/Halton Local Health Integration Network
- City of Brampton
- City of Mississauga
- CMHA Peel/Dufferin, Crisis 24/7
- Mississauga Fire and Emergency Services
- Next Steps Solutions (Private Consultant)
- Ontario Provincial Police
- Peel Children's Aid Society
- Peel Regional Police
- Region of Peel
- Services and Housing in the Province (SHIP)
- Town of Caledon

***Cost of Collecting Behaviours in Peel Region.*** Determining the financial impact of collecting behaviours in Peel Region is challenging. When excessive cluttering behaviours are left unaddressed, the costs can be substantial. For example, in the City of Toronto, a fire in a 30 storey Toronto Community Housing apartment tower in 2010 caused more than \$1 million in damage and resulted in over \$4.85 million in compensation being paid out to victims. The cause of the fire was a discarded cigarette landing on a balcony with excessive amounts of combustible materials. The financial costs of this fire were large, but it also resulted in societal costs, such as the loss of housing for tenants, and put the lives of firefighters and tenants at risk.

There are also significant costs associated with the extreme cleanouts that are sometimes required in cases of excessive collecting. This is particularly true for cases of animal hoarding or hoarding that results in health hazards (e.g., biohazards such as feces, urine, etc.). In these type of cases, the number of cleaners required, and the amount of personal protective equipment is increased.

Due to these potential high financial costs, a preventative approach to hoarding disorder and collecting behaviours is warranted.

## KEY STAKEHOLDER INTERVIEWS

The results from key stakeholders are presented below. Where appropriate, participants are identified based upon the type of work that they do: 1) Hoarding Specialists and 2) Other Support Service workers (e.g., Fire services, Police services, Mental Health services, and other Regional supports).

### Hoarding Diagnosis

**Nearly all individuals who have symptoms of hoarding do not have a formal diagnosis.** Participants from both groups identified the difficulty in diagnosing hoarding disorder. Some participants stated that “100 percent” of their individuals they work with, or “nearly all of [their] clients” were undiagnosed.”

**Hoarding disorder is difficult to diagnose due to lack of insight, stigma, lack of awareness within the community, and its hidden nature.** Participants shared that this was because of the nature of the disorder, personal characteristics (such as living in isolation), feelings of stigma and shame, and a lack of insight of individuals with hoarding disorder.

Related to a lack of insight, a participant stated:

*I think it's just really hard to diagnosis because insight is really low. It would be really hard for a physician, counselor, or family doctor to recognize that someone has a hoarding disorder if they are not forthcoming about the state of their home.*

Stigma also plays an influential role, particularly how hoarding is portrayed in the media. This can make seeking out supports challenging for individuals who may be considering doing so and can make their experience of receiving support traumatic.

Participants also stated that there is a lack of knowledge within social service and health fields and, because hoarding disorder is hidden within the home, it is difficult to diagnose without seeing the home. As one participant stated, “*When we talk about diagnosis that is compounded. When people are at home, they are isolated, and there are many services that are not aware that hoarding is a diagnosis, and because other services don't go to people's homes so they can't diagnose.*”

Other participants stated that this it is difficult to diagnose hoarding disorder because it is hidden in the home and few medical professionals have in-depth knowledge of the disorder.

## Comorbidity

**There is a very high percentage of co-morbid mental and physical health conditions present in individuals with collecting behaviours.** Most of the participants reported that the clients they work with have co-morbid mental health issues like anxiety, depression, OCD, post-traumatic stress disorder (PTSD), ADHD, bipolar disorder, and schizophrenia, and physical health issues such as diabetes, mobility issues, and arthritis. In almost all cases, the Hoarding Specialists stated that their clients have several of these issues: *"I can't think of any of my clients who do not have other health issues"* and *"I would say they always have two to three other diagnoses."*

The presence of multiple health issues makes supporting clients with issues of excessive clutter a more complex process because Hoarding Specialists are not only addressing the issues of clutter, but also the multiple interacting issues as well. Often, it is necessary to address the most pressing issue at that time:

*We try to take a holistic approach [to treatment] where if we are working with someone with those other mental health issues, we are working with the one [issue] that is in the most need at the moment and then trying to work with the other issues over time.*

## Profile of Individuals with Collecting Behaviours

**Clients with collecting behaviours are typically older individuals but collecting behaviours may begin in adolescence.** Hoarding Specialists all agreed that a typical person who experiences hoarding disorder tends to be an older adult usually from mid-life or older.

*What I generally get from them is those who are older, generally 38 plus, and when you see people who are 50 or 60 you see more volume of items. Because someone who is 50 may actually own their own home. And those are generally not those who have been homeless. They have been living in the community, and now their acquiring behaviours are affecting their neighbors. So, I would say that's part of the profile.*

However, participants also made clear that excessive collecting behaviours begin to appear in adolescence. If left unaddressed, it becomes problematic in middle and older ages as individuals would have had more time to acquire items and would have a home where they can store the items. As one participant stated, “*so hoarding actually starts at about 15, because of the executive function, but it actually comes out at about 55 and up.*”

A person’s childhood and upbringing play a major role in affecting their collecting behaviours, particularly related to a history of trauma and forbiddance of collecting possessions as a child. In this way, collecting items was thought to be a coping mechanism for the trauma experienced in the past and a response to childhood desires of collecting items that were never fulfilled. Participants also believed that collecting items is a learned behaviour in families where items were seldom removed from the home as they were perceived to have a potential future use:

*I think there is a huge trauma background for people. Maybe a life of poverty perhaps, or maybe a life of growing up of not having so then you become a collector of things, or you buy multiples of things and you are stocking up and you can't just let things go because there might be a use for it in the future.*

**Excessive collecting behaviours do not appear to be more prevalent among individuals of any culture and is about equal between genders.** No discernible trends were identified related to culture and gender, though it was pointed out that women are more likely than men to seek out help for collecting issues.

**It may be more common for individuals with collecting behaviours to be living on their own or living in subsidized housing.** Some participants stated that they believe excessive collecting behaviours are becoming more common in homes that individuals own themselves, while others pointed out that it is more common in affordable housing because such homes are more likely to have unit checks and to be involved with social services which enter the home.

## **Trends Related to Collecting Behaviours in the Region**

**Increase in the number of young people.** One Hoarding Specialist stated that they are starting to see an increase in young people who have issues with collecting behaviours. For some young people, this may be caused by a personal desire to hold on to items that can be used to build or modify technological items.

*Tech addicts will not throw away the iPhone that they continue to purchase, or they pull apart old computer towers to make a new one. So, I would say that technology has changed what is hoarded.*

**Increased pest infestations.** Other Support Service participants stated that there is a trend of increased pest infestations in homes that have large amounts of acquired items. A participant shared, “*we are noticing a pest control issue, where we go into the units many of the ones that are really really infested also have issues of hoarding.*” This creates increased risk to the individual’s health and can also pose a potential risk to neighboring units.

**Over-representation of community members who have personally experienced the effects of war or conflict, or children of whose parents experienced this conflict.** A small number of participants from the Hoarding Specialist and Other Support Service groups stated that individuals who have experienced war or conflict feel like they need to hold onto items because of their family’s experience.

*At one point, we were having discussions on what their tendencies could be. Some individuals are post-war kids and will want to hang on to every resource. We are seeing with these younger generations who won’t let stuff go.*

**Potential differences between urban and rural cases of excessive collecting.** The participants agreed that rural hoarding may be occurring more commonly than they are aware of because it is more difficult to discover in rural communities. Having less interaction with other people in less populous areas and because there is much more space outside the home to store items, excessive hoarding cases may only be discovered when social service agencies get involved for other reasons. A participant stated, “*Rural, you have a lot of space between your houses, and it’s not really identified as a problem until some community service comes along.*” Interestingly, though excessive collecting behaviours can be hidden more easily in rural communities, one respondent stated that in smaller communities, word-of-mouth may spread more quickly because of stronger social connections. This potentially means easier access to services but also potentially greater feelings of shame: “*People behind the scenes are talking to each other... People hear about it more quickly.*”

**The presence of intergenerational hoarding.** Several of the Hoarding Specialists stated that excessive collecting behaviours seem to be more common if other family members have had issues with acquiring items. These behaviours can be



learned behaviours that are shared within the family, and there may be a genetic component as well: *“There’s usually someone in their past that had an unhealthy attachment. It’s genetic. It’s also learned behaviour.”*

Some of the Hoarding Specialists also stated that several of their clients had strict parents who never allowed the clients to have a messy home or to acquire desirable items. A Hoarding Specialist stated that their client’s current collecting behaviours may give the client a reason to attempt to ‘gain control’ over their lives by hoarding: *“They’re trying to control their negative emotions by hoarding and it makes them feel good.”*

## **Consequences of Collecting Behaviours on the Individual, Family, and Other Supports**

**Health impacts and fire hazards.** A home with excessive clutter can be harmful to the health of the individual living in the space, can lead to unclean living areas, and can cause potential fire hazards. The clutter in the living space can exacerbate other mental and physical ailments that may be present, as one participant reported: *“If you are the hoarder you tend to be solitary, you don’t go out, there is shame, it gets exhausting, so their health suffers. Hoarders are nocturnal so they are up all night moving stuff around.”*

**Housing security.** Participants also stated that acquiring items can create risks to individuals’ housing security. Landlords may try to evict tenants who they feel pose a risk to their properties. In this case, issues related to acquiring items are not addressed:

*The consequences are twofold, if they start losing their subsidies or housing then the family may have to move them somewhere, with them or help them afford somewhere else. Or they may not be able to live independently so they will have to go to a long-term care facility, and they will bring all their stuff to the facility.*

**Stress on relationships.** Excessive collecting behaviours can also put stress on a person’s relationships with family and friends:

*It’s very difficult. You can be quite ostracized. Break down of familial relationships, either directly or indirectly related to hoarding. Children leaving home earlier, not letting children see grandparents, breakdown of relationships.*

As there is a lack of knowledge pertaining to hoarding disorder, family members and friends often do not understand the circumstances a person with excessive collecting behaviours is living in, or reasons why they may acquire items. This lack of understanding creates stress on relationships and can in turn negatively affect the health of the person who is hoarding:

*With hoarding nobody seems to understand that it's not as easy as just removing the stuff. And nobody understands that. [People think] I was raised in the same house as my brother, but my brother won't throw anything away and I can, so siblings just walk in and throw stuff away... so the tension grows and grows.*

Increased tension with family and friends can further isolate individuals who are living in a home with excessive clutter and can make it more difficult to seek out help.

## Effective Strategies and Interventions

**Client-centered, strengths-based, and keeping pace.** The Hoarding Specialists all made clear that when working with individuals with excessive collecting behaviours, the work needs to be client-centered, strengths-based, and move at a pace that is acceptable to the client. Frontline workers must address the underlying issues of excessive collecting because hoarding is not simply the act of someone collecting items; there are many interacting issues that are related to, and potentially causing, as well as exacerbating, the situation.

**Being empathetic, understanding, and trying to put one's self in their shoes are all vital processes.** Working to foster trust with clients is a key aspect and frontline workers need to understand that this process will take time and cannot be rushed. Harm reduction is also very important; recognizing that responding to issues of excessive collecting is not always about removing items, it may consist of cleaning one area, or a small number of items at a time, and understanding that there are different perceptions of what is clean.

*Exploring someone's values. What they value. Often talk about safety and goal setting. What are their goals for what our work can do for them? They often want a cleanout. Evidence has shown that cleanouts do not always work, so need to do an intervention prior to clean out. One of the strategies is they don't start with a clean out for that reason. They are looking for a buy in from the clients. Clients*

*are not always willing to work with the team off the bat. So, a big goal is assessing readiness. Are they ready for the hard work of doing this process?*

**Relationship building.** Participants in the Other Support Services group stressed the importance of relationship building when working with individuals with collecting behaviours, and an understanding that “*the first approach is being non-judgmental. Having somebody allow you to go into their home and having you actually see it, so just taking all of that in and not being judgmental.*” Moreover, building trust so that community members are willing to receive the supports available to them was identified as a key element of service. By developing trust, support workers can begin to address the most pressing issues at a pace that is acceptable to the community member.

**Clean-outs do not work on their own.** The Hoarding Specialists were all in agreement that clean-outs do not work on their own. A participant shared, “*Every professional knows it doesn’t work. It has a 100 percent relapse rate*”. A response to personal and mental health issues are far more important and successful. For this reason, trained mental health counselors were thought to be extremely valuable to effectively meeting the needs of individuals with excessive collecting behaviours:

*At the end of the day, it’s a mental health issue. It’s very complex. It’s about cognitive issues, and developmental, and physical. I don’t expect someone with no experience or any background in hoarding to be able to do the work. But I have an expectation, or a wish, for a general mental health counsellor who has a basic understanding of hoarding.*

**Peer support interventions.** One Hoarding Specialist shared that having peer supports has proven to be helpful for individuals with excessive collecting behaviours as it “*allows them to make connections, helps to let them know that they are not alone in this, and even though they feel alone and isolated that there are other people who have similar struggles.*”

**System navigation and advocacy.** Participants in the Other Support Services group often work as intermediaries for the different systems that individuals with acquiring behaviours need to navigate, helping to communicate the needs of the community member to other professionals. This included advocating for the rights of the community member, as well as ensuring everyone is on the same page and to give the client reassurance and more time to meet the demands of bylaw officers and landlords.

*A main thing I find is that people are scared so they need some advocacy and some support in just dealing with the people they have to deal with. Often it is property management and bylaw, so it is getting consent to talk with property management and bylaw so that you can help guide a conversation and calm everything down.*

**Working with individuals with acquiring behaviours is a long process.** Fostering a relationship where service providers can begin to respond to issues of collecting items can be a very time-consuming process and is different for every relationship. A participant shared: *“It’s really a case-by-case basis. Sometimes somebody won’t let you in the door and you have to walk away, other times you tell them that if they have any problems anytime to give us a call.”* Service providers need to understand that working with community members with collecting behaviours is a long process that can last years before a dramatic change occurs in the individual’s home and in their behaviour. Even after those changes are achieved, it may still be an on-going process:

*It’s a long process. I think it takes two forms, one where it’s getting the hoarder to a safety standard for fire or where fire or bylaw will come in and say this is no longer a safety risk... and the other portion we have to deal with is we have to help them with the behaviour going forward, so we can work on the hoarding so they can stay in a safe environment.*

## **Relationships and Partnerships in the Community**

**Enhanced relationships and coordination are required.** All Hoarding Specialists agreed that more relationships and coordination between services in Peel Region is needed to effectively meet the needs of individuals with excessive collecting behaviours. Participants expressed that the relationships that they already have are very useful though they are largely informal; they also stated their desires for furthering these efforts.

**The work can happen in a silo.** Participants from the Other Support Services group voiced that they often feel like they work in silos with little interaction with other organizations: *“There are no resources really who I can call on to help me with my client. There’s nobody who does that, or who does that for someone on a fixed income.”* Some participants also felt that they did not know who could be contacted for support:

*One of our staff who works on community initiatives is looking into all the different communities to see who can be involved, as well as police and fire, and we are looking at CAMH, for example, could be a player in this. Local agencies in the area who can help with these issues.*

When compared to the Hoarding Specialist group the Other Support Services group expressed that they are less connected to other community supports and less knowledgeable of what supports are available. To address this, one participant commented: *“Some kind of community support program or community support plan would be very beneficial to us.”*

**Existing relationships with some agencies, such as cleaning agencies and peer support groups, exist.** Participants spoke of several informal relationships that currently exist, including cleaning agencies, religious organizations, peer social support groups, and organizations that support seniors. A commonly suggested relationship that would be useful was with landlords and landlord associations. Working with landlords was difficult at times because it *“requires a lot of negotiating to extend timelines that suit the clients, and having landlords understand their responsibilities as landlords and that this is a mental health issue.”* Improving landlord knowledge related to issues of excessive collecting and developing working relationships would be useful in creating a person-centred response that matches the circumstances of each client without fear of eviction for the client.

**Importance of relationships with non-clinical organizations and agencies (e.g., EMS, Fire, Police) when working with someone with hoarding disorder.** All participants felt that the relationship between Hoarding Specialists and non-clinical organizations is key. Working cooperatively and having other specialists to coordinate with was the most effective way to respond to hoarding:

*I always say it takes a village approach, so if fire called to say there is somebody who could benefit from our work. Everybody is then very aware that we stay in communication.*

Fire Services were thought of as being particularly important in responding to cases because of their ability to respond quickly and because they are often the first point of contact in excessive collecting cases: *“In terms of rights and power, Fire can enter. Fire is the best bet to getting into someone’s home if there’s a major concern.”*

Participants in the Other Support Services group also stated that relationships with Police Services are important. This is because police officers, along with firefighters, are one of the few institutional workers that enter the homes of individuals with collecting behaviours.

## **System-Level Changes Necessary to Respond to Hoarding Disorder in Peel Region**

**Enhanced coordination across services.** Hoarding Specialists thought that it was difficult to coordinate different agencies and sectors in Peel Region. Though the participants greatly valued the working relationships they have with other agencies and organizations, all participants agreed that increased coordination and communication is needed:

*Everybody works in silos. Nobody is actually connected in my experience... everyone is just trying to pass the baton, and that is hard because you want to make connections with other service providers... how can one worker address all these complex issues on their own?*

Participants voiced their concern that agencies may fear being held liable once they begin working with a client, and this may discourage agencies from taking on a hoarding case:

*The challenge is everyone is looking for solutions, but nobody wants it to be their responsibility. There's a high liability factor. The second they get involved in something, they're liable for so much more.*

**Changes to Acts and Codes.** Several participants thought that there needs to be amendments to the Fire Prevention Act and the Ontario Fire Code to recognize hoarding as a fire hazard. In doing so, fire departments will have a greater opportunity to respond. Currently the Ontario Fire Code does not explicitly recognize hoarding as a fire hazard, which means Fire Safety Officers cannot give remediation to community members who may need funding to access services. Participants in the Other Support Services group thought that the Ontario Fire Code needed to provide better directives on how to enforce fire safety codes in units with excessive clutter, and to hold municipalities accountable in enforcing the Fire Code. Amendments would allow for Fire Safety Officers to allocate more resources to identifying cases of excessive acquisition of items much earlier by doing more preventative work.

*Currently the Fire Code does not explicitly address hoarding as being a fire hazard that I can identify and then I can then ask for remediation to occur. So, I am very limited in how I can affect hoarding.*

**The Region of Peel needs more funding set aside for individuals with collecting behaviours.** Several of the participants in the Other Support Services group stated that more funding needs to be allocated by the province and municipalities to properly respond to hoarding disorder and collecting behaviours in the community: *“Funding and resources aren’t nearly at the demand level right now.”* Funding could be used to provide more supports for community members with acquiring behaviours, which could include social services, health services, and housing supports such as assisting with cleaning.

**Funding should be set aside to support clients with clean outs.** In some cases, personal finance plays a large role in a person’s ability to address their collecting issues, and often individuals will have to pay for supports themselves, which may not be possible: *“Sometimes people are given a deadline, they have to clean the place up by the deadline or they are evicted, so it all depends on the motivation and the conditions around it.”* Further, because individuals experiencing excessive collecting behaviours tend to have several comorbid disorders present, community members may be physically unable to clean their homes on their own. Even though clean-outs have been shown to be an ineffective response to hoarding disorder, in some cases it may be needed to avoid having individuals be evicted. For this reason, some participants advocated for more funding to respond in emergency situations when a community member’s housing is at risk.

**Housing workers who specialize in responding to cases of hoarding disorder would be beneficial.** Several of the participants in the Other Support Services group stated that it would be very helpful to have assistance from Hoarding Specialists on how to respond appropriately to hoarding cases:

*I think that is a piece that is missing [for hoarding disorder], like we have housing support workers who do housing and support, we are in the community, we are in people's homes, so it would be very easy to add an extension of a hoarding specialist onto the programs.*

Such positions should be present in multiple organizations and agencies throughout the Region, rather than having a small number of experts being overwhelmed with a large

caseload of all hoarding disorder cases. Having more of these experts was thought to help improve interaction between agencies and to better coordinate a response to hoarding disorder. However, participants also stated that all support workers need to improve their knowledge related to hoarding disorder:

*It would be good to have someone who is the go-to person who has knowledge, but this day in age absolutely all housing and support workers need to have a knowledge base. Instead of training one or two people in region who know how to do it, that's not sustainable. Everybody should be able to have access.*

## Role of CHIP

**A variety of stakeholders should be at the table.** Most importantly, the participants stated that all the relevant frontline workers should be involved, especially Fire Services, EMS, Police Services, Children's Aid Society, and mental health workers. Participants also agreed that having specialists such as a psychiatrist, and someone who can tackle the legal aspects would be useful. Because hoarding disorder is hidden within the home, participants believe it would be useful to have as many different sectors as possible to better identify different cases. A participant shared:

*Doctors or nurses. Nurses even before doctors. Just to ask what they are seeing. A family GP can get more insight. Even if we can reach out to family social workers, or even someone like a chiropractor. You never know. I know teachers for me is a big one. Our early partnership with waste management, that's a big one. They may be seeing more garbage in some areas over others. Are they seeing less garbage out for pick up for weeks? Because it's such an isolating behaviour they aren't really getting out, so not a lot of people may know.*

The participants also advocated for a team of specialists from various sectors who could form a group of case workers working together on the same case, responding to the various complex issues that are experienced for individuals who have issues with collecting items.

**Connect all relevant social services and supports for a better coordinated response.** All the participants made clear that their agencies and community members with lived experience of collecting behaviours would benefit from a greater coordination of services. Some of the participants felt that they are working independently and are unaware of the other supports that are available. One participant



stated that improved communication and awareness would help all support services to improve the supports that they provide:

*If a provider needs our support, like financial support, then they can have the person make an application sent to us, and we would do an assessment of what kind of supports they have and if we can give them financial supports. And then vice versa if we have a client who needs services like mental health services, we can contact them (other support services] to support them (the client] so it would be like a two-way street thing.*

**Facilitating a coordinated response to hoarding in Peel Region.** The Hoarding Specialists stressed the importance of improving communication between sectors so that each agency and worker knows who to contact in every situation. Participants also stated that a team would make responding to cases more efficient and would eliminate confusion relating to responsibilities of each agency:

*I think we would really benefit from having a program that just works to identify all of the needs that we come across with people who have hoarding disorder. And all of the different disciplines and having one program where we are all working together without having to reach out and wait for response and coordinate schedules and figuring out if that is my responsibility or not. I think if there was a way that we could all just work under the same roof maybe. Like work on the same caseload and work with the same people from start to finish. That would probably create the best turnaround so that we aren't working with the same clients for years on end. Maybe we need like an ACT (Assertive Community Treatment) approach.*

Participants envisioned a coordinated response where there was a team of professionals working together on every hoarding case to provide multiple important services that community members need access to:

*In housing and Housing First, there's this whole idea of about having a collaboration there, a collaboration of agency supports when a client makes an application for housing. I'd like to see something like that from all of our agencies when we have a client with hoarding.*

## INTERVIEWS WITH INDIVIDUALS WITH LIVED EXPERIENCE

The results from the interviews with lived experience of collecting behaviours are presented below.

### Services Participants Have Accessed

**Peer support groups.** Several of the participants stated that they have accessed peer support groups in the past and that they were very helpful in providing social support. According to one client, SHIP's peer support pilot group meeting was a 6-week program where individuals had the opportunity to work with people in groups to understand their stories. One client shared that she really enjoyed the group meetings and "*found it so very helpful that [she] didn't want it to end.*" Other participants shared that they have attended social groups that were not specifically for individuals with collecting behaviours, but stated that the groups were still helpful:

*It is like a social program. It's like you have group and you get coffee. You talk to people. Sometimes you watch TV. You have free coffee. It's nice. It's just down the street from me.*

Social groups like these were described as being helpful in encouraging participants to be more social, which at times could be difficult to do. One participant commented, "*I can talk to people. Sometimes I have to force myself to go to these things. I am pretty sociable sometimes. But I was isolated. I was a lot more sociable before. I don't want to be that. I want to get out and talk to people.*"

**Supports for other mental health issues.** Several of the participants stated that they have accessed mental health supports in the past, not only for issues directly related to their collecting behaviours, but for other mental health issues as well. As one participant commented:

*I attended the mood disorder clinic. They were treating me for depression and anxiety but not OCD or hoarding. It was a therapist who was doing a little bit of work with me. It was minimal. There was something to offer there, there was a little bit there.*

Participants shared that they originally accessed mental health counselling to attend to issues not related to their collecting behaviours. This included receiving support for anxiety, depression, and experiences of past trauma, which often co-occur with

hoarding disorder. One participant described the following therapy that is commonly used to address experiences of past traumas, which has also been shown to be commonly present in the past of individuals with collecting behaviours:

*I did have an EMDR (Eye Movement Desensitization and Reprocessing) therapy at Salvation Army at the women center. I was referred to a doctor through the women's shelter family transition place. I went to see a trauma doctor and he does EMDR therapy that is covered by OHIP because he is a retired surgeon.*

Comments such as these represent years of efforts made by participants to address their mental health issues that interact with, and complicate, their experiences of collecting behaviours.

## Strengths of Services Accessed

**Gaining different perspectives and hearing other people's stories.** Participants who were engaged with SHIP's services were grateful for the opportunity to hear from others in their community who also had issues with collecting behaviours. This was especially important to them because they felt comfort in knowing that other individuals diagnosed with hoarding disorder were able to overcome their diagnosis. For example, one participant explained:

*There was actually one woman in our group who had lived in a big house and was a hoarder and she had to sell her house and move and get rid of large quantities of stuff. So, it was great for me to meet her and hear her say she had done this, and she was glad that she did and she was okay. That was a good experience for me to meet her. Also, it would be important to hear how long it was taking so the other participants could see we weren't unusual in the painstakingly slow process.*

Listening to these stories gave participants hope that change and management of their hoarding disorder was possible. It also gave them a marker for how long the process of clearing out items could take. For that one participant, it allowed them to feel less self-conscious that the process of clearing things was taking a long time.

One participant described the usefulness of being able to gain different perspectives from other individuals with similar experiences while attending group therapy and peer support sessions. They said, *"It's just easier having a group of people to hear how they*

*are doing and to get more motivation to do stuff in your own home.” The same participant shared that it has been helpful to gain “other viewpoints from the therapy situation and other ways of thinking and how to fix it.”*

**Group therapy was thought of very positively.** Group therapy was something that many participants looked forward to. The participants discussed how important group therapy was to them, as it provided participants with a space to talk about their collecting behaviours in a safe and nonjudgmental space:

*In fall or winter, we also met with a group that they assembled. A group of seven.... People dealing that same issue. That was tremendous. It was very helpful. I think everyone really liked it.*

Group therapy was helpful as it allowed participants to receive moral support and recognize that they were not alone in dealing with the issues they are experiencing in their lives. It also allowed participants to see that it was possible to live with dignity and high self-worth. One participant explained:

*The first thing I think of is a kind of moral support. A kind of recognition. Like what happened in our hoarding group is feeling like we weren't alone and although we have a problem that are in some cases needs pretty urgent addressing that also we are good people who are ... Like a kind of a self-worth. To have feelings of self-worth and to deal with feelings of shame and inadequacy and feeling crazy. So that's the first thing I think of is the self-image of being able to view yourself.*

Another important aspect of group therapy was the educational component. One participant discussed how their support group allowed them to understand more about hoarding disorder. Support groups provided information in a safe, accessible way. They said:

*Support groups are really important. So, having the educational ones where you are learning about what it is like and also ongoing ones where you are just supporting each other. You're always adding education. So, I know you need to have groups that are safe, warm, accessible, available, provide information, support and to have some fun and make connections...especially the connection.*

**Acceptance of diagnosis through group therapy.** Another positive aspect of group therapy was that it allowed participants to be more accepting of their own collecting behaviours. Many participants spoke of how they had low self-esteem and a low self-image due to their collecting behaviours and how it has affected their lives; however, by participating in group therapy, they were able to overcome these feelings while interacting with others who were undergoing similar issues. One participant explained:

*One big thing...first time I was there, it really had an impact on my self-image and sort of sorting out for myself...I definitely had feelings like I didn't belong to the group. But as we talked, and I learned about them I really...It had an impact and I am glad to be here, and it changed my mind to some extent. It's kind of accepting the diagnosis, you know what I mean?*

**Support from knowledgeable and caring staff.** Several clients noted that they really appreciated the support they received from hoarding specialist they worked with. These support workers were described as being knowledgeable of characteristics and experiences associated with collecting behaviours and helped to connect participants to other supports. One participant commented:

*What has helped me the most was my previous worker from [name of organization]. She was very familiar with hoarding, the traits and what went with it. She had quite a few clients who were hoarders including me and she had a great understanding. She was the one that knew how to get in contact with people to help you with hoarding.*

Participants also stated that receiving non-judgmental support from Hoarding Specialists has been very helpful and supportive of their efforts to address their collecting behaviours. One participant shared, *"I like that I'm getting help and I don't feel alone. I'm not judged. I'm supported. It's absolutely amazing."* Receiving weekly check-ins, either in person or over the phone, was stated as being crucial to normalizing participants' feelings, as well as increasing their motivation to begin to address emotional issues and to declutter their homes.

## **Weaknesses of the Services Accessed**

**There is a lot of paperwork.** Some of the participants stated that they had difficulty filling out some of the required paperwork needed to receive supports. In

some cases, support workers would assist participants in this process, but completing paperwork was still thought to be time-consuming.

**Need more time with one-on-one support with Hoarding Specialists.** Participants made clear that they would like to have more one-on-one supports with Hoarding Specialists, either in the home or over the phone. Participants remarked:

*Yeah and she comes for an hour every week. It's kind of hard you know. I need more time with her. Sometimes it is okay but it could be more than an hour. She has a lot of clients. An hour is not so bad but sometimes depending on the person's situation it may take longer.*

*There is nothing about the services that I don't like. I guess I just wished I had a longer appointment. The appointment is an hour on the phone, but I sometimes wish I could keep having the appointment longer. I enjoy the appointment, the supports and the help. It seems like the hour goes by too fast. I would like a bit more time, but I know that's not possible because they have so many people to see. If I could get a longer appointment, I would love it.*

**Hoarding Specialists are very important in addressing issues, but it is challenging to continue that work when support ends.** Some of the participants described how it can be difficult to continue to maintain and progress in their decluttering efforts after they stopped receiving support from Hoarding Specialists. Participants felt that they were more motivated to continuously make progress in reducing the number of items in their homes when they were receiving support in their homes, but when the support ended it became challenging to continue to do so. One participant stated:

*When she (Hoarding Specialist) left, she wants me to do stuff myself. Once she left me in the program, she didn't want me to go back the way I was before. Everything would start piling up again. I felt like I was almost reliant on her to help me get rid of stuff. When she was gone, I didn't have the motivation to get rid of anything. She would tell me just go through this pile. I made progress. She would ask how much you got done by the next week. I had a whole bag full of stuff I was getting rid of. If I get rid of a whole bag of stuff, I felt like I accomplished something. I get excited sometimes. I want to get rid of stuff. I don't want to lose my house.*

**Long waitlists to access services.** The long waitlist to accessing SHIP services was identified as a source of inconvenience by one client. They said, *“It took a year. In between our first meeting with them and the time they were actually able to assign us a worker.”* The client commented that this waitlist initially had a negative impact on their ability to address their collecting behaviours since they were unable to do anything immediately to address their situation. As a recommendation, they proposed that the therapy component of the service should occur immediately, while the in-house visits can occur later on when the worker is available:

*I think it might be helpful if there was a way to get the therapy part, addressing it at the right time you could get the therapy as soon as possible. Wait until they were available to do the home visits. That way it’s a start. You’re not left out in the cold for a year, if that’s something you are trying to build upon.*

**Cleaning services are an unexpected expense.** Some participants discussed unexpected expenses that occurred due to their collecting behaviours. For instance, several participants discussed how expensive cleaning services were. For many participants, who were on social assistance [e.g., Ontario Works (OW), Ontario Disability Support Plan (ODSP)], the extra expenses associated with cleaning was inaccessible. One participant explained:

*One thing that we run into is that our garbage collection is restricted to one bag a week. Fortunately, a lot of what we are disposing of is paper, recycling cardboard and metal. Recycles are things that don’t go in the garbage. But we try to get as much garbage as they will take but it just feels like it slows us down in some case.*

Participants shared that the Region of Peel restricts the amount of garbage per household. For participants who were actively engaging in reducing their items, this posed as a challenge for them. One participant discussed how there were options to reduce their garbage through other methods but that these were expensive and more time consuming:

*Some weeks we don’t have very much to throw out but when we do, it could be helpful if we could dispose of it right away rather than keeping it and letting it go little by little. There are other possibilities of going to a transfer station and getting a bin. The transfer station I feel is pretty expensive to take garbage there and the trouble with the bin is it takes us so long to sort through stuff.*

Participants explained that it can be both expensive and time-consuming to take their collected items to the dump, as well as emotionally traumatic to do so. Several participants suggested that it would be beneficial to have a method to more easily dispose of large amounts of items when they feel they are able to do so:

*We accumulate a lot of garbage and items that need to get thrown away. It's expensive to do it to take it to the dump. To have some way of actually being able to get rid of the garbage would be very helpful.*

## Accessing Services Outside of Peel Region

**Services outside Peel were accessed because of a lack of resources in the Region.** While the majority of participants were residing in Peel Region, many were also accessing services outside of the municipality. The most common supports focused on mental health. This was mainly due to the lack of services available in the municipality or long wait-times. For instance, two participants gave a list of services that they were accessing outside of Peel Region. They said:

*Yes, [name redacted] has done work at Sunnybrook Hospital. I should tell you about that. We have taken couples counseling in Toronto and once we saw a couple of counselors for a short time in Guelph.*

Other participants discussed how they were able to find services outside of Peel Region through their own search. These services were typically therapy sessions or support groups that they wanted to attend. One participant explained:

*We had connections and that's how we came to them. Also, I went to a men's group which changed into a mixed group with [name redacted]. He is a psychologist. He was in Orangeville. So, we have used services when we found them, and we found them in various places.*

Another participant spoke about services located in Guelph that were similar to SHIP. This coalition also had several key stakeholders and front-line workers who came together to provide services for individuals with hoarding disorder. These individuals were adept at dealing with issues such as evictions by landlords or with passing fire-safety codes. This participant said:



*I attended one in Arthur-Wellington and one in Guelph which is much bigger. They are doing amazing things. They have everybody at the table, and they share the information. If someone is in trouble with the landlord, you got the firefighters and legal aid. They are not coming down on the people, but they work together to see, as group of service providers, how they can help the person to do what's needed to make the place safe, satisfy their landlord or to look after their animals. There are animal control people and social workers, too.*

**Financial and geographical limitations to leaving the region.** Several clients stated that they had learned of different resources outside of Peel Region, but they could not access them due to financial constraints. Leaving the Region was seen as being too financially taxing for participants, which was further complicated with a lack of personal transportation. One participant remarked: *“Yeah, like I know there was a program in Toronto I wanted to do for a long time but I couldn't because I didn't have the transportation.”*

## Service Suggestions in Peel Region

**Services that address stigma related to collecting behaviours.** Participants commented that it would be helpful to have more resources to combat the stigma related to collective behaviours. This was emphasized as particularly important for family and friends of individuals with collecting behaviours. As one participant stated:

*Like how do you explain this to somebody even if you have a helpful family? My mom was supportive of me. I tried to get mom to help me. My brothers are tired of helping. My dad doesn't want to come to my place. I am still left to do everything myself. I just have to rely on myself. I don't have anybody else to help me. I wanted my family to help me, but they weren't really helpful.*

**More Hoarding Specialists.** Several of the participants stated that they would like to see more Hoarding Specialists who can provide one-on-one support in the home. One participant commented that they learned of other regions with more support workers providing support in the home, and that was something he would like to see more of:

*When I was at Sunnybrook they talked about VHA. These nurses went in homes and helped people with hoarding. It was only in the Toronto area. With SHIP, what I understand they are going to come in and do some work. That's*

*great. I think that's important to have that type of support available. If there was more like that sort of specific hoarding program that would be good too.*

Having more Hoarding Specialist was also thought to be helpful in decreasing wait times for new clients to receive support. Moreover, having more Hoarding Specialists was thought to make it possible to receive more individual support each week, as one participant stated:

*I guess because she said how busy they are and how long the waitlists would be, I'd like to see if maybe they would hire somebody else so people wouldn't have to wait as long. I think a lot people are suffering in silence. By the time...It takes years to get there. It would be nice to have another worker because they have such a huge area to help with wait times – could also allow for more than one hour per week of one-on-one support.*

#### **More supports for family members of individuals with lived experience.**

Participants believed that there should be more supports available to their family members. These supports could take the form of one-on-one counseling, support groups, and the development of educational materials. One participant shared:

*Just kind of similar support that the individual gets. There can be some sort of therapy that they can get. It could be a group support. They can have a therapist for them. The family can help support each other.*

Providing family members with access to resources could help them cope with issues that they may be experiencing and may help them to better understand what individuals with collecting behaviours are going through. One participant stated:

*Yeah there should be support for the family as well. So how the family can cope with it and how the family can help the individual. There can be more education and support for the family.*

**Peer support groups.** The provision of peer support groups was suggested by many participants to be a useful resource in the Region. Having a space to talk to other community members who are experiencing similar issues in their lives was thought to be useful in generalizing their emotions, reducing feelings of shame or guilt, and reducing isolation.

Participants understood that the on-going threat of COVID-19 has made in-person group meetings unsafe, so some participants suggested that virtual meetings would also be useful, as one participant commented:

*They wanted to do it again but then the pandemic happened. I told her whenever they did it again, I would be interested. I think it would be beneficial especially with everybody going through this difficult time, to meet other people and know they're not alone. I know they can't do it in-person. If they could do a support group on Zoom I would be interested in that. I think that would be great. I would be willing to do a zoom call with other hoarders.*

One participant recommended that support groups are provided to clients past the standard 52 weeks, as it allowed them to continue their therapy on a long-term basis. They also suggested that when their time with their support group ends, that SHIP should provide an ad-hoc service that allows them to check-in on past participants. They suggested:

*Having support that goes past the 52 weeks is helpful, so you don't lose all the work that you've put into getting better. Having someone reach out to check in on you or a hotline that you can contact would be helpful.*

**Additional mental health programs.** One participant simply urged for more mental health supports. The client shared that they would like to “*hav[e] more mental health programs.*” They further shared that, “*I know I already have [Name of staff] helping me with hoarding issues but we need to have more programs that support people.*” Another client observed that there is a lack of mental health programs available for young people under 18, and urged for more mental health supports for this age group:

*They should have more [social] programs like [Friends & Advocates] in the Region especially for youths as well. Like my cousin she got mental health issues. All the programs are for persons aged eighteen and up. She is only sixteen. So, there is nothing really out there for her.*

**Early intervention supports.** One participant believed that early intervention supports can help to prevent their hoarding or collecting behaviours from getting out of hand, which might result in an eviction notice. The participant said: “*The only thing I can say if I had known in prior years to that if there was somebody I could contact to help me with hoarding situation it probably wouldn't have reached to that extent.*” The participant

went on to share their personal experience of how their situation spiraled out of control:

*I can say being a hoarder and back in 2005 when I was going to be evicted it starts off so innocently with the hoarding and then it just progresses and progresses. Looking back on the whole scenario it is just mind blowing. In a one-bedroom you had to climb over stuff. It was really bad. Looking back on it I wonder how it ever got to that extent. It was just one of those things. As I said, at the beginning it was very innocent and it compiles.*

## Participants' Interactions with Police

**Interactions with police officers and accompanying crisis workers.** One participant spoke of two different instances where they interacted with a police officer. This participant said that these kinds of interactions were much more pleasant when the police officer was accompanied by a crisis worker. However, when recalling an incident where the police officer was alone, the client talked about police officers' lack of mental health awareness:

*I know long before they started with the crisis worker, I had a horrible experience with the police people. Yeah, they would just talk down to me or say I was just faking or having a bad day you know. That wasn't the case and I find a lot of the police don't understand mental health issues.*

## How Can CHIP's Network Better Support Participants?

**Ongoing access to supports for more than one year.** Two participants believed that a coordinated response could help them by providing ongoing access to supports. Participants stated that when supports from one service provider ends, for instance in-home support from hoarding specialists, having access to other community supports would assist participants in their efforts to continue to address their collecting behaviours. One of the participants noted that it is unrealistic to expect clients to complete the program within the 52-week mark because they may "*fall behind or things slip up or something comes up that's really difficult for them.*" The participant believed that it would be helpful to know that supports are available down the line, especially since unanticipated events happen in life (e.g., job loss). Therefore, having a safety net in place that is comprised of multiple community supports could ensure that the clients' progress is not lost.

## Who Should Be at the CHIP Table?

**Importance of lived voice.** Participants articulated the importance of having the voice of lived experience when creating services and supports for those with hoarding disorder. One participant believed that showcasing those with lived experience was necessary as it promoted a more positive and less stigmatized view of hoarding disorder. They explained:

*We are not lazy, crazy or stupid. People misunderstand me. It's not just that we are somewhat crazy or lazy. These are real issues. I wouldn't mind being public about it. I think that is important to have a real face to it.*

Participants also thought that it would be helpful to have other members involved in CHIP who have lived with collecting behaviours or who are still working to address their issues, as it would provide an example of someone who has been in the same place as participants are now. Having more representation of individuals with lived experience could help others in similar situations better understand how to respond to their issues and could be a source of insight on what steps could be taken. One participant shared:

*You know seeing other people who have conquered it and what they do on a daily basis, what they are doing and how they are doing it. If they fall off the path and how they get back on. I think it is very helpful to have someone who is actually a hoarder to be able to provide some kind of the help. Maybe they were part of the groups to have them come to a couple sessions or all of them to give their point of view from the other side. That would be very helpful.*

**All professionals and individuals who interact with community members with collecting behaviours should be a part of CHIP.** Participants suggested many different service providers, sectors, and organizations that should be involved with CHIP going forward. Some of the more common suggestions were service providers, specifically health professionals, ODSP, first responders, mental health agencies, and housing agencies. Each of these sectors and service providers were included because they often interact with community members with collecting behaviours. One participant shared:

*I guess just get the word out to counsellors and to healthcare workers, I guess even physicians because a lot of physicians don't know a lot about mental*

*health. They can get the information out to them so they can refer clients to services.*

Participants also suggested that family members of those with lived experience should also be involved in CHIP. Family members were described as being important sources of support and also experiencing their own stresses from their relatives' collecting behaviours. One participant shared:

*I think the family is important because it affects the family. The family can give more information about the individual such they are suffering from than the individual themselves. So, I think family is definitely important.*

## COMMON THEMES AMONG KEY STAKEHOLDERS AND INDIVIDUALS WITH LIVED EXPERIENCE

The themes discussed below emerged from interviews with key stakeholders and with individuals with lived experience of collecting behaviours.

### Education

Education is a major theme that emerged during conversations with both key stakeholders and individuals with lived experience. In particular, education in four main areas were recommended: (1) educating frontline workers on hoarding disorder and collecting behaviours to improve the provision of services; (2) educating the general public on hoarding disorder and collecting behaviours to reduce stigma; (3) educating the general public about hoarding resources and services available to them and their family; and (4) educating frontline workers about other hoarding services to facilitate a coordinated response.

#### *1. Educating frontline workers on hoarding disorder*

**Educating frontline workers can support early intervention.** A key stakeholder stated, *“in order for prevention to be successful is for it to be identified early on and the only way for it to be identified early on is through education.”*

Training front-line service providers can improve the experience of individuals with lived experience. Individuals with lived experience believed it was important to educate social services within Peel Region since they felt that not many front-line providers understand the nature of hoarding disorder. Consequently, education would allow these workers to develop more empathy, as well as gain a better understanding, for those with a hoarding disorder diagnosis.

The importance of training and education extended beyond front-line service providers. One individual with lived experience discussed how difficult it was for them to receive a diagnosis of hoarding disorder. They explained how distressing it was accessing services from professionals who did not support their self-diagnosis of hoarding disorder. Another individual believed that this denial was not helpful and was detrimental to their mental health.

Another individual with lived experience spoke about their experience with occupational therapists who had less knowledge and experience in hoarding disorder than their client. This serves as an example highlighting the importance of education. They said:

*I had someone from Occupational Therapists from [name of organization] who didn't have any experience. I had to teach her because I had more knowledge and experience about hoarding in hoarding support than she did. She was trying to be helpful but she just didn't know and she was the best they had.*

## **2. Educating the general public on hoarding disorder and collecting behaviours**

**Educating the general public on hoarding disorder and collecting behaviours can support early intervention.** Similar to educating frontline workers, increased public awareness of hoarding disorder and collecting behaviours can also play a major role in early prevention, as it can help the public recognize the signs of excessive collecting and understand how to help someone who may have issues collecting items:

*Improve awareness of what hoarding is, and what early warning signs are. So, if we have or are working with someone who is around the age of 16, because they start living on their own around then, then it's a great indicator. Another great indicator are folks who are accessing shelters, because they work with staff. So, in those programs we have direct interactions with folks over a year's timeframe. I like to think we do see indicators there, so we can have built-in unit checks or room checks at least once a week or once a month.*

**Educating the general public can help to reduce stigma.** Key stakeholders stated that more efforts should be made in educating the public to help reduce stigma and shame. Reducing stigma may influence more individuals to seek help and can provide the education for family members and other social connections to try and connect the individual with hoarding behaviours with support. The education system and professionals outside the mental health sector were thought to be important sectors to reach out to. In particular, a common suggestion was to educate schoolteachers:

*So even teachers knowing the warning signs. Talking with parents. Because a lot of acquiring behaviours can start in schools, and impact learning. So, teachers are great for getting that word out and identifying signs. Maybe like a 2- or 3-day conference and educating people on the front lines. I think that is really*



*where we need to get started, and to come up with the messaging for a campaign that can really get the word out there.*

**Educating individuals with lived experience can generate better understanding of their own situation.** Individuals with lived experience discussed how useful it was when SHIP provided resources and educational materials on hoarding disorder. These guides allowed them to better understand their collecting behaviours and to identify coping mechanisms. One individual explained that education on hoarding disorder allowed them to understand how treatment could be more effective. They shared:

*They have given us guides and outlines of what other people experiences have been with hoarding. Some of it applies and some of it doesn't. So, we were able to identify like our style of hoarding and then identify what we need to do to change it. We could have probably done some of that without them, but they really focused on very effectively providing helpful information. I really value that part of what they did to kind of describe what the hoarding disorder is and help us to see how we fit into it.*

Having a better understanding of hoarding disorder allowed individuals with lived experience to know that hoarding disorder was not caused by internal negative traits and that it is something that can be managed. Education was seen as a powerful tool that these individuals could use to navigate their behaviours in addition to the support of group therapy. One individual explained:

*I think understanding the issue is important. Understanding what hoarding is for each of us who is dealing with it really helps. If we understand how big of a population it is and how it's not just laziness, OCD or procrastination or whatever. It is its own thing and understanding different kinds and the different issues. Some people in our group were big in acquiring. They couldn't stop shopping all the time and other people like me just had certain things they kept. I am more of a "keep all kinds of stuff." The reasons we hoard are different and it helps to understand that. So that piece is important. It really helps to have somebody help me deal with the emotions I was facing and stuff. To help make choices of what I can let go of.*

### **3. Educating the general public on available services**

**Ensuring information about available services is easily accessible.** Hoarding Specialists and Other Support Service participants requested CHIP to provide information to all professionals and members of the public freely so that information can be easily accessed. It was suggested that part of this effort could include an educational campaign to improve awareness, but more importantly was that anyone who needed to learn more about hoarding disorder in Peel Region would be able to do so: “Ideally we get to the point that we recognize that this is a concern for a lot of people in the community and we give them access to the information freely.” Key stakeholders suggested that every service provider should have the resources and knowledge to assess a case where a person is acquiring items to their own detriment, and to know who to refer community members to, to best meet their needs:

*Like swim lanes, if you are in this lane then you can go this way and if you are in this lane then you go this way. The more information that we can provide to people so that they can deal with situations without even going through formal social institutions, the better. And then when you are in those situations, giving them access to the workers, and not having to wait for your name to come up on the waitlist.*

Moreover, raising awareness of these services can help reduce the stigma related to collecting behaviours and would make services more accessible. A key stakeholder shared, “Somebody has to lead the way and provide the information and put the information together, so I think that the coalition really has to step up.” It was believed that CHIP should help facilitate this process.”

#### **4. Educating frontline workers on available services**

**Lack of awareness of available services.** Several individuals with lived experience thought the services and supports that are provided by the agencies involved with CHIP are very helpful but stated that it is not well known within the Region. These individuals thought that not many community members or service providers or health professionals know of the services that CHIP provides. One participant stated:

*I think more information.... Letting the public know.... My mom randomly met somebody who was involved in this and got their card, but I have never heard of it. I never heard of it at the doctor’s office or mood disorder clinic. It wasn’t known to us.*

**Educating frontline workers on where to refer clients can facilitate a better coordinated response in the region.** Several individuals with lived experience suggested that more awareness is needed among workers of current programs and agencies to properly refer clients to other programs. It was thought that educating and spreading awareness to other service providers would be helpful in developing a more coordinated response:

*Yes, probably more social support. Not especially if you are having a bad day but if you need something like a referral. That would be very helpful. I know for a fact at Recovery West my worker doesn't know anything about different programs, and I think workers should be informed of different agencies and programs.*

An individual with lived experience suggested that formal relationships are not necessarily needed; however, CHIP could provide educational materials to other service providers and inform them of the services that CHIP can offer. The individual commented:

*I guess how they would normally educate doctors...They can have the pamphlets at counselling offices and doctor's offices. They can have pamphlets for hoarding to get the word out.*

## **Landlords**

Another common discussion point was the potential influence that landlords can have in addressing and supporting the needs of individuals with lived experience.

**Importance of working with landlords.** Collecting behaviours have a large impact on one's housing stability. Two individuals with lived experience talked about unpleasant interactions they had with their landlords, which ultimately led to an eviction. One individual shared that it was difficult communicating with landlords because they were not very understanding of mental health issues. This individual believed that it would have been helpful having a mediator while interacting with the landlord. They said: "*What would really help me is having a lawyer as mediator between the landlord and myself and my Relink worker.*"

The other individual revealed that their landlord was not understanding of their mental health issues as soon as they saw the cluttered state of the apartment things changed.

They said, *“They were a little helpful and understanding at the beginning but as soon as they saw the apartment all that went out the window.”* Moreover, they talked about the negative reactions their landlords had: *“They were very negative about it and very disgusted. Having those negative emotions being blasted at you during this time doesn’t help anything.”*

As a recommendation, several individuals with lived experience believed that it would be helpful if landlords had more knowledge of and compassion towards individuals with hoarding and collecting behaviours. One individual discussed how landlords in the County of Wellington work with front-line service workers and have a more compassionate approach to their collecting behaviours: *“Again, in Wellington they work with landlords to try to get the legal aids and firefighters. They try to help the situation instead of policing it or coming down hard on people.”*

Another individual believed that it was possible for landlords to be more compassionate towards those with collecting behaviours by forming partnerships. They believed that relying on alternative pathways, other than eviction and calling emergency services, was more compassionate and helpful for those with hoarding disorder. They explained:

*If other landlords could learn there was other ways to deal with them other than calling fire department, it might help if there were good landlords out there. It can be done and there can be a partnership.*

**Engaging and supporting landlords can help them better support tenants with collecting behaviours.** Often, service providers and community members experiencing issues related to collecting items feel like they are at odds with landlords, which can be very detrimental to the wellbeing of community members and can make responding to cases much more difficult. Hoarding Specialists and Other Support Service participants stated that landlords often feel like they have no options other than to evict tenants who are collecting many items in their units. Participants believe that CHIP can play a role in educating landlords on how to assist tenants who may have hoarding disorder, and connecting landlords with resources to help support their tenants:

*So, landlords right now don’t have an avenue, all they can do is put out the N5 to start the eviction process and for some of them... they have a tenant who is elderly and wheelchair-bound and if they aren’t staying here then where are they going to go? So, their process is they can’t follow through with an eviction. So, they are at their wits end because human rights will be involved, but*

*the units around that unit (hoarding unit] are not happy and they are going to sue the landlord. So, if the landlord knew who she (the client] can go to for mental health support it may be a way to move through the process much faster.*

## JURISDICTIONAL SCAN

The following section reports on insights gained through interviews with five different Hoarding Coalitions in North America as well as from the web-based scan of 15 Hoarding Coalitions. The themes presented in this section represent common experiences, suggestions, and learnings described by members of various Hoarding Coalitions that were interviewed, as well as common resources and materials found on each Hoarding Coalitions websites examined for the environmental scan.

### Organizing Coalitions

**In forming Hoarding Coalitions, it is most often frontline organizations who take the lead.** Participants commonly stated that their Coalitions and Task Forces were originally formed when service providers came across cases of collecting behaviours in the community. These service providers were commonly fire departments, mental health agencies, senior care organizations, and housing organizations. In identifying a support need in the community, these organizations worked to establish a Hoarding Coalition or Task Force.

To provide greater access to services, the Coalitions grew in membership. New partner organizations wanted to learn more about collecting behaviours and to better provide support to community members. One participant commented:

*At the start they brought together Fire, Police, and Bylaw. But then they realized that it spread out much farther than that. And you got [name of community] mental health, animal services, so everybody sort of sat together at a table and figured out where they fit into this.*

What began as a handful of front-line organizations grew to form a Coalition of service providers to enhance service coordination and provide a greater breadth of supports. Although, as Coalitions grew in membership, there often remained a smaller group of key organizations who were more involved with the Coalitions. A key feature of the Coalitions and Task Forces was having dedicated staff and a network of volunteers who provided support to community members, counseling, and connections to other member organizations and services. One participant stated:

*The [name of community] Hoarding Support Network has now developed into a full-fledged program that we specifically work with network partners that we have about 15 of them, I think. But we also have a facilitator that specifically works*

*with referrals that come to the network, as well as we have staff that provide counselling and coaching to those clients.*

In reviewing the community organizations and service providers commonly involved in the formation of Hoarding Coalitions, it was found that front-line service providers such as Fire and Emergency Medical Services were involved, as well as mental health agencies, organizations working with seniors, and housing organizations. Other common partner organizations included youth and family services, local animal welfare organizations, human rights organizations, and community legal services. In Toronto, cases of hoarding were sometimes address through a Specialized Program for Inter-Divisional Enhanced Response (SPIDER) to Vulnerability team. A SPIDER program supports City Divisions to develop a coordinated, interdivisional response to complex and unresolved health and safety risks.

### **Coalition Composition**

**Having landlords and property managers involved is crucial.** Several participants across the different jurisdictions stated that having landlords and property managers involved with the Coalitions can be very impactful. Landlords often have tenants who may be experiencing issues related to collecting behaviours and can therefore notify Coalitions as an early response process. Having an early response is vital to responding to cases where a community member is at risk of losing their home because of their collecting behaviours, as one participant commented:

*Having more property managers at the table especially those larger property managers who primarily offer subsidized housing at the table would be really helpful because often times in places like subsidized housing where they're having inspections. They identify hoarding more quickly and if somebody loses their subsidized housing, they're not going to get it again.*

Having a good relationship with landlords is useful to better educate them about why their tenants are collecting items, and how to better reach a resolution where both the tenant and landlord are satisfied. One participant shared:

*We want them to be at the table so we can educate them and provide training and support them in any way that we can to help those living in their residences maintain safe and sanitary spaces to the extent that they maintain their housing which all has this secondary impact.*

However, in some cases it can be difficult to work with landlords, especially when a tenant's home is at risk due to the severity of items acquired within the home. In such cases participants stated that Hoarding Specialists will often accompany tenants, occasionally along with a mediator, to meetings with landlords and Landlord Tenant Boards. The purpose would be to ensure that tenants' rights are being respected, and to help find a solution where all involved can feel heard, as one participant shared:

*We would go to Landlord Tenant trials and ask for a mediator and then sit there with the Landlord and Mediator and talk about both sides so that the landlord understood better the challenges with the tenant. And the tenant understood why too.*

In these situations, the Hoarding Specialists work to find common ground and make clear to the landlord that the tenant is an individual in need of support, and that they can address the landlord's concerns. Hoarding Specialists also communicate that the landlord may also stand to lose compensation in terms of lost rent and having to pay for cleaning services.

Ultimately, the goal of the Hoarding Coalitions in these difficult situations with landlords is to educate them about how they can work together to keep the tenants housed and supported, so they can make progress in their efforts to address their collecting behaviours. Moving forward, participants stated that they hope to build further relationships with landlords so that if issues arise again, the landlord contacts the Coalition for support. One participant illustrated this dynamic:

*They're there to really offer education and support to all of the people at the table and property managers to talk about what rights do people who are dealing with hoarding have at a property and then what rights do the landlord have. And how can they work together so that everybody comes out of it with a better outcome, you know because landlords could potentially end up with...if they evict somebody who's hoarding, it could cause them a lot of money to have to clean out the spaces or repair all the damages and things like that versus putting in services to help that person reduce the clutter and get their home into safe and sanitary conditions.*

**Core members should have the most training and education.** Participants felt that it is important to have all organizations and service providers who come across cases of collecting behaviours in the community to be involved with the Coalition. The



participants suggested that it is important to have all the member organizations educated on how to support community members with collecting behaviours but stated that it is particularly important to have key member organizations to have more education. The key organizations were understood to be all organizations that commonly encounter cases of collecting behaviours.

Therefore, a fundamental element of a Coalition is ensuring that all organizations involved have a basic understanding of the best practices of supporting community members with collecting behaviours. This was thought to be important to reducing caseloads for key Coalition members and to develop greater self-sufficiency and capacity of all member organizations, as one participant stated:

*But the other part is really getting community organizations staff trained on how to work with someone with hoarding issues. Because the training is the key because otherwise, if you only have one person who is trained on this, then all the work gets passed off to them.*

Common methods of training included holding quarterly workshops with front-line service providers, virtual workshops, posting educational materials to Coalition websites, hosting annual conferences, and monthly newsletters informing member organizations of available resources.

**Agreeing on member organization responsibilities.** Some Coalitions developed agreements with core member organizations regarding roles and responsibilities. For example, in Montgomery County in Maryland, the Coalition developed some key goals they hoped to achieve (creating a practice framework and developing tools, public education, and advocating for collecting behaviours to be included as a mental diagnosis) and divided these goals between the member organizations. The Coalition decided as a group which organizations would be best suited to achieve these goals and developed agreements to ensure that each organization understood their responsibilities. This was one method that was particularly interesting as an approach for a Coalition to best use their resources to accomplish shared goals.

A second example of the operations of Hoarding Coalitions was in Durham County where they developed the Safeguarding Durham Adults Hoarding Toolkit. Part of the toolkit outlines how each service provider should support individuals with collecting behaviours based on an initial assessment and level support needed. The toolkit provides a table that service providers can follow as they support community members,

and it provides descriptions of how to provide strength-based care, how to do an assessment, what other agencies should be contacted and when, and what steps to take as the support process proceeds. This outline is divided by profession of service providers and serves as another example of how hoarding agencies can work to inform member organizations of their responsibilities within the Coalition.

### **Coalition Services That Have Been Effective**

**Support groups and support network for individuals with collecting behaviours are important.** Several of the participants shared that establishing support groups for individuals with collecting behaviours have been quite successful. Support may consist of regular meetings of individuals with lived experience with collecting behaviours, which are often led by trained counselors. One participant stated that their Coalition has developed a network of volunteers with lived experience to help community members in the home and through social support: *“One of the things we developed was a volunteer hoarding support network and it has been quite effective.”*

Participants stated that support groups have been useful in providing support to community members by creating a space where community members can learn about their own issues and of the resources and strategies they can apply in their efforts to manage their collecting behaviours. Participants shared that they have recently been working to establish more virtual support groups to increase access to services. This process has been found to be more important now due to the COVID-19 pandemic, which has caused support groups to cancel their scheduled meetings. One participant shared:

*Some of the support groups are really useful and we are trying to do more with that. And we will be doing more virtual support groups. And we will be opening up regionally in the next couple months.*

Support group information was also commonly found on hoarding Coalition websites. Common support groups included *Buried in Treasure* support groups [which follow best practices developed by Toli, Frost, & Steketee (2013)], support groups for family members, peer- and counselor-led support groups for individuals with lived experience, and virtual support groups.

**Having full-time Hoarding Specialists is important.** Most of the Coalitions we examined in the environmental scan had full-time Hoarding Specialists and several

participants stated that their full-time staff have been critical to the success of their Coalitions. Important responsibilities of the Hoarding Specialists are to provide support to community members with collecting behaviours, to connect community members with other supports, and to have the items in homes reduced to a manageable level. One participant shared:

*We have a Hoarding Facilitator who goes out and does the assessment, develops a support plan of how they are going to address the specific person's situation. And then helps coordinate and puts the supports in place. And part of the supports can be clutter coaches, who help them develop a plan to sort, discard, and organize. If it's at that lower end of the continuum, we may refer that to our volunteers. But that middle group of the continuum, we have clutter coaches, and that facilitator who will do the counseling work about acquisition and how they attain their goals and what other resources do they need to be linked to in the community.*

Educating front-line workers and other Coalition members was also a common responsibility of Hoarding Specialists. This was stated to be an important aspect of the position as it can help to build capacity within the Coalition and works to provide better supports to community members overall:

*Another thing that that facilitator does is train our network staff. First of all, we provide a training for our network staff just so they know best practices, but we are also trying to develop those staff knowledge experts within those community partners so that they can do that work and handle it in house. Rather than always referring to the network.*

Not all communities were able to have full-time Hoarding Specialists and there was variation in the responsibilities that Hoarding Specialists have. This may be due to differences in the amount of funding between communities, and differences in approaches. However, nearly all of the communities examined in the jurisdictional scan had full-time staff working with individuals with collecting behaviours on behalf of the Hoarding Coalition. The communities that did not have staff were volunteer-based and focused on providing educational materials online and improving coordination between service providers.

**Success in increasing awareness of collecting behaviours in the community and by professionals.** A common success stated by participants was that because of their

efforts to reduce stigma and to better educate the public, they reported an increase in referrals received. One participant commented:

*The organizations who do provide direct service are getting more referrals than they can manage because people are coming to the table to talk about it and you know I think that just shows that there's more awareness. And that's what we want. We want more awareness around there. Throughout the years we have more organizations come to the table.*

Having a more informed public was thought to be helpful in supporting community members before their collecting behaviours become more severe, in ensuring access to supports is more efficient, and in bringing more service providers and organizations into the Coalition.

All organizations examined in the jurisdictional scan provided various educational materials on their websites and many provided seminars, workshops, and conferences to better educate service providers and the public. Commonly, the website of Hoarding Coalitions would include misconceptions about collective behaviours and “Do’s and Don’ts” of communicating and supporting individuals with collecting behaviours. In some cases, Hoarding Coalitions would detail what information is most useful to service providers, friends and family members, and individuals with lived experience.

However, despite most Hoarding Coalitions having an ample amount of information presented on their websites, one participant commented that having a website can be difficult when financial resources are hard to come by:

*First of all, it costs money. Second of all, you have got to keep it updated. Whereas if you got somebody who is willing to do it, if you have a hoarding specialist, it's much easier to make an update to a YouTube channel or something. You know, there is 211 in towns and 311 that if they got the information that is needed that should be where you go to.*

This participant described that it can be difficult to afford and maintain platforms such as a website, and that in some cases it may be more beneficial and financially appropriate to find other means of sharing information. Context, therefore, is important to consider when developing a Coalition’s approach to providing educational materials and sharing information about resources.

## **Policy and Advocacy Efforts**

**Advocating for collecting behaviours to be made a priority in community health responses.** Several of the participants stated that it is important for municipalities and cities to prioritize issues related to collecting behaviours. Having Hoarding Disorder identified as a mental health issue has helped to identify it as an issue that requires responding to. A participant said, *“Firstly, to identify it as a priority because it often is not. One of the biggest helps was when hoarding was identified as a legitimate mental health issue, in the DSM.”*

**Framing collecting behaviours as a community health issue, not an individual health issue.** Participants made clear that collecting behaviours should be framed as a community health issue that requires buy-in from cities and municipalities. When advocating for more resources, participants stated that it is important to identify how one individual experiencing issues related to their collecting behaviours can affect others. This includes family and friends who may experience stress, as well as neighbors whose housing may be at risk because of fire code violations, structural risks due to weight of collected items, and the presence of pests. All these shared risk factors carry with them an increased financial burden in terms of a need for resources to be allocated to a larger group of individuals and the coordination of many different services. Therefore, participants advocated to municipalities and cities to consider collecting behaviours as a serious issue with consequences experienced by the community at large. For this reason, participants argued that more preventative efforts should be made by municipalities and cities. One participant commented:

*In [name of city] the homes are a lot older; we’re talking about homes that are 90 or 100 years old and it’s a city of rowhomes. If one home is structurally unsound it could have negative impacts on the house next to it, same with fires. You know hoarding in [name of city] is something we want to really highlight that this is an issue that doesn’t impact the individual, it impacts the community and we have been really pushing the education and trying to gather more data so we understand what is the level of hoarding in [name of city] and show people that this is something that would need to fund the resources to be able to address this as a mental health disorder because it does have such an impact on the individuals’ safety, neighbors, the community and people from every angle.*

**Inspections should be more respectful and consistent.** A common policy suggestion was to make changes in how inspections are completed in low-income housing. It was

thought that the process should be laid out more clearly, including an inspection list to be provided to tenants so that they know what is expected. Participants stated that often when inspections occur, tenants were not given the chance to make changes to their homes or were given unrealistic timelines. Moreover, inspectors often use language that is stigmatizing and confusing because of jargon. One participant highlighted this:

*A big thing is language. We worked a lot with Fire Departments to go over what language they use in their inspection orders. Because just to say to somebody you have too many combustibles, they may not understand what a combustible is, they think it's a can of gasoline. Whereas you say to them you can only have things up to two feet high and you have too many things on your counter. Because if you just give them a piece of paper, they don't know what it means.*

Participants commented that Hoarding Coalitions should advocate for a more respectful inspection process that is understanding of the time commitments needed by tenants who have collecting behaviours to meet the demands of inspectors. It was suggested by participants that Hoarding Coalitions should work to educate policy makers on how these changes can support community members and bring living spaces to a level of safety that is acceptable.

## 7. Recommendations

Recommendations were developed based upon the findings from the literature review, environmental scan, policy review, key informant interviews, interviews with individuals with lived experience of hoarding, and the jurisdictional scan. The recommendations are grouped under three main target areas: 1) Provincial and municipal systems; 2) Service provision; and 3) CHIP.

The recommendations will inform the development of the strategic framework, the model outlining the coordinated approach to address hoarding in Peel Region, and the implementation plan.

### System-Level Recommendations

#### Provincial

1. ***Increase access to psychiatrists in Peel Region so that individuals may receive an appropriate diagnosis of hoarding disorder.*** The ability to attain a hoarding disorder diagnosis is impacted by the limited access to psychiatrists. By increasing access to psychiatrists in Peel Region, individuals with collecting behaviours may be more likely to receive a clinical diagnosis and increase the number of supports available to them.
  
2. ***Advocate for changes to the Ontario Fire Code and the Fire Prevention Act that explicitly address hoarding.*** Based upon the policy review and feedback from key informants, it was clear that hoarding disorder and collecting behaviours were not adequately addressed in the *Ontario Fire Code* and the *Fire Prevention Act*. Without explicitly naming hoarding disorder, it is difficult for Fire Services to effectively address households with excessive clutter, including referrals to appropriate mental health services. Therefore, CHIP members should advocate for changes to the *Ontario Fire Code* and the *Fire Prevention Act* that explicitly address hoarding disorder and excessive clutter. These policy changes should be made in consultation with individuals with lived experience of hoarding disorder.

Regional

- 3. Increase public education and awareness on hoarding disorder in Peel Region in order to increase insight, reduce stigma, and enhance early intervention strategies through a public health campaign.** It was clear from the key informant interviews, interviews with individuals with lived experience, and the jurisdictional scan that education is critical to enhancing self-awareness of collecting behaviours and reducing societal stigma. In enhancing education, individuals with collecting behaviours may be more apt to engage in preventative interventions and acknowledge their own behaviours. Therefore, a public health campaign focused on collecting behaviours should be developed in collaboration with CHIP and Peel Public Health. To ensure that the public health campaign is client-centered, individuals with lived experience should be consulted.
- 4. Specific public health promotion strategies should be developed that target specific populations (e.g., older adults, children and adolescents, social housing residents, refugees, rural residents) and specific types of collecting behaviours (e.g., collecting of technological items, animal hoarding).** Public health messaging may need to be tailored to specific populations and specific types of collecting behaviours. For example, children and adolescents can be targeted in school-based promotion strategies and the collection of technological items may be important to highlight. Teenagers may need specific messaging, since onset of symptoms tends to start in the teenage years (Naka & Kanba, 2019). Messages for older adults could focus on treatment options, since age 50 is the average age individuals with collecting behaviours seek treatment (Kress et al., 2016). Landlords and social housing providers may require messaging specific to tenant rights as they relate to hoarding disorder. Therefore, targeted messaging may best address the complex nature of hoarding disorder. These strategies should be made in consultation with individuals with lived experience.
- 5. Ensure that all relevant sectors (e.g., Fire Services, Police Services, Municipal Bylaw Officers, Peel Public Health, landlords) have received training on collecting behaviours, relevant legislation, appropriate approaches, including respectful language, to address collecting behaviours. The training should be offered through CHIP representatives.** Results from the key informant interviews, interviews with individuals with lived experience, and the jurisdictional scan all highlighted the importance of having informed and well-trained front-line personnel from all relevant sectors. Without



specific training on collecting behaviours, front-line personnel may inadvertently cause a great deal of trauma to an individual with collecting behaviours. This training should be mandated and be regularly offered. CHIP members should be involved in the development and implementation of this training.

6. ***Ensure that all relevant sectors (e.g., Fire Services, Police Services, Municipal Bylaw Officers, Peel Public Health, landlords) are aware of the services available to individuals with collecting behaviours via Peel Public Health's website and 211/311.*** Along with training, it is important for all relevant sectors to have an understanding of the available services in Peel Region for individuals with collecting behaviours and their families and natural supports. This list of services should be available on Peel Public Health's website and 211/311 and regularly updated. CHIP should inform Peel Public Health and 211/311 of any changes or additions. CHIP should not host the website, as Peel Public Health will have greater capacity to keep the website updated.

#### Recommendations for Service Provision

1. ***Ensure that services for individuals with collecting behaviours take a holistic approach that address potential comorbidities.*** Key informants and individuals with lived experience shared that individuals with collecting behaviours often have other comorbid health conditions. Therefore, in delivering services to individuals with collecting behaviours, a holistic approach should be taken that addresses an individual's mental and physical health.
2. ***Provide services for family members and natural supports of individuals with collecting behaviours, with a focus on peer support initiatives.*** Individuals with lived experience shared that it would be beneficial to have services for families and natural supports of individuals with collecting behaviours. From the literature, it is known that individuals with problematic collecting behaviours are more likely to have impaired relationships with family and friends (Grisham et al., 2008). A monthly support group, led by families and natural supports with lived experience, should therefore be created in Peel Region.
3. ***When providing services to individuals with collecting behaviours, take a strengths-based approach focused on rapport building.*** Key informants shared that it is important to deliver services to individuals with collecting

behaviours from a strengths-based approach that is focused on building relationships with clients. This follows best practices as it relates to mental health service delivery.

4. ***Enhance opportunities for peer support and group therapy.*** Peer support was highlighted as a promising intervention by key informants, individuals with lived experience, and within the jurisdictional scan. Group settings can help reduce the hoarding individual's feelings of shame and guilt, can enhance social interaction with other individuals sharing the same experience, can enrich participation, involvement, and motivation (Bodryzlova et al., 2018), reduce feelings of isolation and additional opportunities to be more comfortable around other people, and add motivation to complete practice assignments at home, such as sorting and discarding exercises (Frost, Steketee, & Greene, 2003). Further, one study found that peer-led therapies are as effective as mental health-led hoarding disorder interventions (Mathews et al., 2018). Therefore, it is important to continue to offer and enhance peer support and group therapy sessions in Peel Region.
  
5. ***Enhance system navigation and advocacy support, particularly with landlords.*** Key informants, individuals with lived experience, and the jurisdictional scan highlighted the importance of engaging with landlords. For individuals with lived experience, some participants recounted unpleasant experiences with landlords. Therefore, Hoarding Specialists should be prepared to act as a mediator between their clients and landlords, highlighting tenant rights under the *Residential Tenancies Act* and the *Ontario Human Rights Code*.
  
6. ***Develop longer-term supports for individuals with collecting behaviours.*** Individuals with lived experience shared that longer-term supports would be helpful. They thought that supports would still be beneficial once their collecting behaviours have been addressed and stabilized. Therefore, follow-up supports, including peer supports, should be developed within Peel Region.

### CHIP Recommendations

1. ***Advocate for dedicated funds to address collecting behaviours in the Region of Peel, including funds to increase the number of Hoarding Specialists, and funds specific to clean outs when necessary.*** In order to continue the work of CHIP, it will be important for members to advocate for

dedicated funds to address collecting behaviours in Peel Region. As was previously completed, CHIP members should present to the Region of Peel Council and highlight findings from this report. Funding should be earmarked to support the administration of CHIP, increase the number of Hoarding Specialists, and cleanouts, when necessary.

**2. *Ensure that a system to address collecting behaviours is client-centered.***

Individuals with lived experience shared that it is important to have their experiences shape the response to collecting behaviours in Peel Region. This includes making decisions that are focused on the needs of clients, rather than the needs of organizations. To facilitate this process, individuals with lived experience should be consulted on any initiative developed by CHIP.

**3. *Consider identifying a backbone organization to sustain the operations of CHIP.***

In order to sustain operations, members should consider identifying a backbone organization that can administratively house CHIP. By having dedicated time and resources for CHIP, the coordination of activities will be more easily formalized. Suggestions for the backbone organization include Peel Public Health and/or SHIP.

**4. *Support the development of a website that includes information on collecting behaviours, effective strategies to address collecting behaviours, and advocacy opportunities.***

An enhanced understanding of collecting behaviours in Peel Region was identified as a key activity for CHIP by key informants, individuals with lived experience, and the jurisdictional scan. To facilitate knowledge on collecting behaviours, CHIP should consider developing a website that includes information on collecting behaviours, effective strategies to address collecting behaviours, and advocacy opportunities. This website should link to the proposed website on available services in Peel Region (see System-Level Recommendation 6).

**5. *Enhance the relationships that currently exist within CHIP and increase the number of partners at the table, specifically individuals with lived experience, landlords and landlord associations, legal representatives, municipal bylaw officers, school officials, and waste management officials.***

Although the membership of CHIP is expansive, membership could be enhanced. Since collecting behaviours are a complex issue, professionals from across different fields and agencies are needed to collaborate to bridge gaps in

service (Muroff et al., 2011; Bratiotis, 2013; Koenig et al., 2013; Kress et al., 2016). A multidisciplinary approach to hoarding requires involvement from both public and private agencies, ranging from health providers and animal control agencies, to law enforcement officers (Koenig et al., 2013). Membership should be expanded to individuals with lived experience of collecting behaviours, landlords and landlord associations, legal representatives, municipal bylaw officers, school officials, and waste management officials. These stakeholders were identified by key informants, individuals with lived experience, and the jurisdictional scan. Individuals with lived experience should be compensated for their time.

6. ***Enhance the coordination of services for individuals with collecting behaviours, including intake, assessment, service provision, and aftercare support.*** A coordinated response to collecting behaviours was identified as a key need in Peel Region. This includes intake, assessment, service provision, and aftercare support. Currently, there are some ad hoc coordinated processes, but coordinated services would enhance service provision. A coordinated approach to hoarding can yield several benefits as it addresses the limited resources available when there is a division of labour across different groups (Bratiotis, 2013). Coordination also leads to a cross-pollination of information and ideas, and consequently a deeper understanding of an individual's hoarding problem when multiple perspectives are involved (Bratiotis, 2013). A coordinated model is presented in the accompanying document.
7. ***Continue to liaise with other Coalitions and Task Forces focused on collecting behaviours.*** There are a number of existing Coalitions and Task Forces focused on collecting behaviours in Canada. Two of these coalitions exist in the GTA (City of Toronto, Region of Durham). CHIP should coordinate a meeting with these existing Coalitions and Task Forces to develop an information sharing pathway and to learn from each organization.
8. ***Include an evaluative component in future work of CHIP.*** To ensure that CHIP is meeting its objectives and goals, an evaluative component should be developed. A performance measurement framework is presented in accompanying documents.

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## Contact Information

Canadian Observatory on Homelessness

[thehub@edu.yorku.ca](mailto:thehub@edu.yorku.ca)

[www.homelesshub.ca](http://www.homelesshub.ca)