EXECUTIVE SUMMARY

Hoarding in the Region of Peel:

Strategic Framework, Coordinated Model, Implementation Plan, & Performance Measurement Framework

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Project Context

Hoarding disorder is recognized as a distinct mental health diagnosis in the Diagnostic and Statistical Manual of Mental Disorders, 5th 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). To combat the stigma associated with hoarding disorder, it is sometimes referred to as collecting behaviours.

It is estimated that two to six percent of the population may have hoarding disorder (American Psychiatric Association, 2017). Applying this 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.

Given the potential prevalence of individuals with hoarding disorder in Peel Region and to better support community members who experience social and health issues related to hoarding disorder, the Coalition on Hoarding in Peel (CHIP) is mobilizing a coordinated approach to improve access to supports and wrap-around services. Key goals of CHIP are to improve coordination between service providers, educate the public and professionals, ensure that service providers understand best practices when working with individuals who have collecting behaviours, and to advocate for relevant policy changes.

CHIP worked with Hub Solutions, a social enterprise of the Canadian Observatory on Homelessness, to develop a comprehensive response to support individuals with collecting behaviours and hoarding disorder in Peel Region.

Background of the Project

The purpose of the current project was to provide insights on aspects for service provision that should be implemented and to suggest key steps CHIP can take to ensure that community members are well supported. To frame how collecting behaviours are experienced and what is needed to effectively support individuals, this project incorporated a number of different sources of evidence:

1. A literature review to understand causes, traits, and impacts related to collecting behaviours, and what are the most effective methods of assessment and treatment;

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2. A policy review to identify relevant policies that affect service provision in the region;

3. Interviews with individuals with lived experience of having collecting behaviours and key stakeholders in the Region;

4. An environmental scan evaluating how other regions developed community level responses to collecting behaviours as well as interviews with stakeholders from these regions.

Main Findings

1. Key Elements of Service Provision

When supporting individuals with collecting behaviours it is important to apply a strength-based approach, work at a pace dictated by the individual, and develop a sense of mutual respect and trust. One key stakeholder shared:

> **"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."**

It was also thought that access to psychiatric care should be enhanced since it can be difficult for individuals to receive a diagnosis of hoarding disorder.

A breadth of services is required to support individuals with hoarding disorder and collecting behaviours, including those for family members and other natural supports. Individuals with collecting behaviours appreciated the support they were provided by Hoarding Specialists in Peel Region. They found these supports to be convenient and easily accessible. Having access to mental health services, Hoarding Specialists, and peer support groups were understood to be particularly important. Providing peer support groups for family members and other supports were also identified as important services that should be made available in Peel Region.

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2. Educating Policy Makers, Frontline Workers, First Responders, and the General Public

The importance of education emerged during conversations with both key stakeholders and individuals with lived experience. In particular, several education needs were identified:

1. Educating frontline workers and first responders on hoarding disorder and collecting behaviours in order to better support their clients who may exhibit collecting behaviours;

2. Educating frontline workers, frontline workers, and policy makers about hoarding services to facilitate a coordinated response among service providers;

3. Educating the general public on hoarding disorder and collecting behaviours to reduce stigma;

4. Educating the general public about hoarding resources and services available to them and their family.

Participants agreed that educational information must be accessible, so that best practices can be shared. Accessible information will also improve the coordination of services as more community members and organizations learn of available resources. By educating the public and policy makers, it was thought that this could result in broader policy changes, such as recognition of hoarding disorder in relevant legislation (e.g., Ontario Fire Code)

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 think workers should be informed of different agencies and programs."**

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3. Enhancing Coalition Membership

Participants identified several groups that should be involved with CHIP. These included Fire Services Officers, Bylaw Officers, Paramedics, Polices Officers, Emergency Medical Services, mental health agencies, organizations working with older adults, and waste management.

Landlords were also identified as an important group that CHIP should engage.

Participants from the jurisdictional scan agreed that it is important to have relationships with landlords and to explain the benefits of supporting their tenants with collecting behaviours, such as improved maintenance in the home and eviction prevention. 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."**

Some participants with lived experience talked about unpleasant interactions they had with their landlords. Others shared that it was difficult communicating with landlords because they were not very understanding of mental health issues. A suggestion to improve this relationship was having a mediator while interacting with landlords. A participant with lived experience said: "What would really help me is having a lawyer as mediator between the landlord and myself and my worker."

4. Enhancing the Coordination of Services

A major goal of CHIP is to improve coordination of services within the Region. Important methods suggested to help achieve this goal were to advertise what resources are available, to train service providers by holding workshops, and to create a protocol of how and when each service provider can provide support and who they can refer clients to.

Some hoarding coalitions examined in the jurisdictional scan have developed network care paths which outline how each member can support community members and the work of other coalition members. Defining member organizations roles and responsibilities and outlining how each member can provide support are important steps to improving coordination of services and ensuring that community members are receiving the supports they require.

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Strategic Framework

Based upon the results, a strategic framework for CHIP was developed. The strategic framework functions as a guiding framework to be used to enhance coordination of services in Peel region. The framework is based off the Objectives, Goals, Strategies, Measurements model, as well as the insights gained from the literature review, the policy review, the environmental scan, the key informant interviews, interviews with individuals with lived experience of collecting behaviours, and the jurisdictional scan. There are four guiding objectives outlined, with corresponding goals, strategies, and measurements, all of which are align with CHIPs mandate to improve coordination of services to better support community members with collecting behaviours in Peel Region.

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Objectives

● **Awareness** ● **Coordination & Service Provision** ● **Training** ● **Advocacy**

Goals

Reduce stigma and enhance understanding of collecting behaviours	Collaborative approach to care	Services for family members and natural supports	Develop "Care Path" plan	Identify and empower backbone agency	Train & educate service providers across sectors	Advocate for dedicated funding for training	Advocate for policy change

Strategies

Health promotion strategies and campaigns for general and at-risk populations	Development of website	Engage individuals with lived experience and service providers for coalition growth	Enhance support groups for individuals and families and natural supports	Develop coordinated service delivery model	Designate backbone agency	Hold training and work-shops in the community	Hire more Hoarding Specialists, a CHIP coordinator, and other positions	Advocate for changes to Fire Code

Measurements

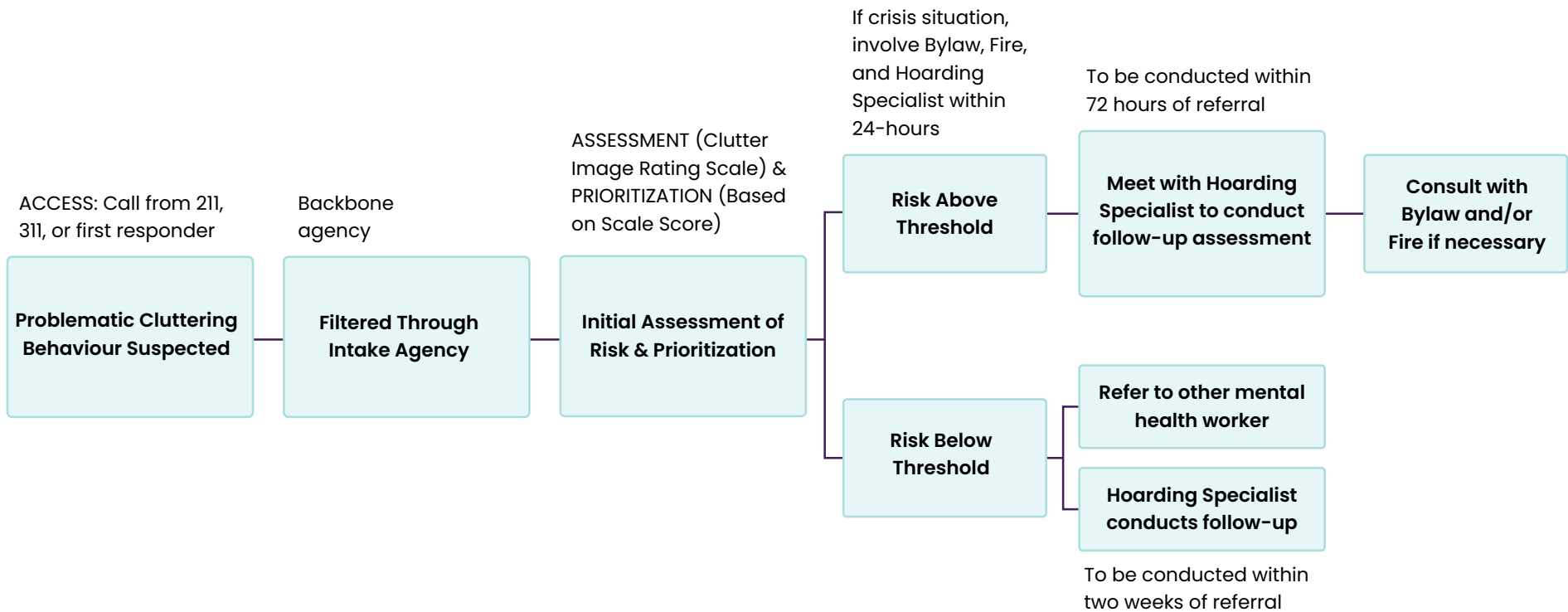| Record # of campaigns	Monitor website traffic	Monitor website traffic	Record # of support groups and attendance	Evaluate service model	Develop post-training survey for service providers	Evaluate service model

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Coordinated Access to Services

The results produced from this evaluation demonstrate the need for a greater coordinated effort in Peel region to provide supports for community members with collecting behaviours. Below, a diagram of a potential coordinated access system is presented.

Coordinated Response to Collecting Behaviours Example

ACCESS: Call from 211, 311, or first responder

Problematic Cluttering Behaviour Suspected

Backbone agency

Filtered Through Intake Agency

ASSESSMENT (Clutter Image Rating Scale) & PRIORITIZATION (Based on Scale Score)

Initial Assessment of Risk & Prioritization

If crisis situation, involve Bylaw, Fire, and Hoarding Specialist within 24-hours

Risk Above Threshold

To be conducted within 72 hours of referral

Meet with Hoarding Specialist to conduct follow-up assessment

Consult with Bylaw and/or Fire if necessary

Risk Below Threshold

Refer to other mental health worker

Hoarding Specialist conducts follow-up

To be conducted within two weeks of referral

Data Management - Performance Measurement

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Key Recommendations

Based upon the results of this evaluation, and to actualize the components outlined in the strategic framework and coordinated access model, the following recommendations were developed:

→ **Provincial**

1. **Increase access to psychiatrists in the Region of Peel 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 the Region of Peel, 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.** 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.

→ **Regional**

1. **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.

2. **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.** CHIP should lead these training initiatives to ensure that all service providers who regularly interact with individuals with collecting behaviours understand best practices and how to support community members.

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→ **Recommendations for Service Provision**

1. **Provide services for family members and natural supports of individuals with collecting behaviours, with a focus on peer support initiatives.** CHIP should lead the development of programming and support services for family members and chosen supports.

2. **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.

→ **Recommendations for CHIP**

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

2. **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 the Region of Peel. CHIP should work to bring in more member organizations and to increase communication between organizations to have a well-defined and understood distribution of responsibilities.

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