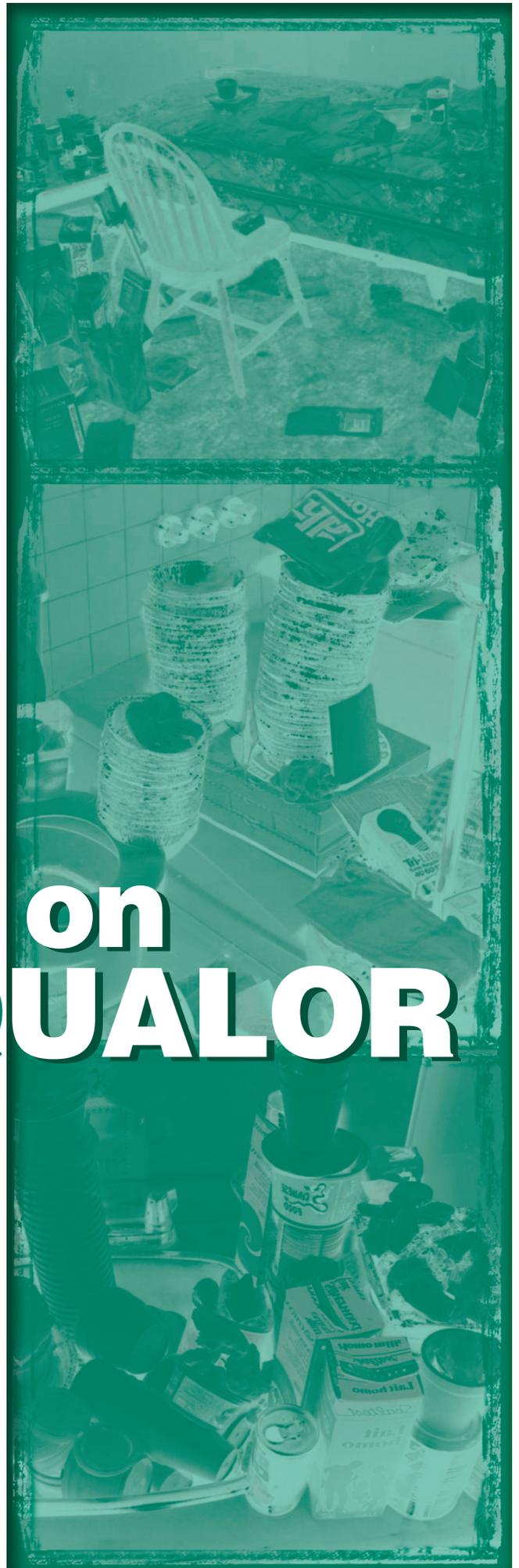




Task Force on **SENILE SQUALOR**

FINAL REPORT • APRIL 2000



**Task Force
on
Senile Squalor**

Final Report



April 2000

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Executive Summary

Over the years the Middlesex-London Health Unit has been concerned with the frail elderly. This concern led to the establishment of the *Special Risk Recluse Program* (also known as the *At-Risk Registry*) in the early 1980's and, more recently, to the *Special Risk Assistance Fund*, supported by a grant from the City of London and the Mayor's Anti-Poverty Action Group.

Frequently public health inspectors and public health nurses are called upon to assist in addressing public health issues associated with the frail elderly.

During the summer of 1999, Mary Huffman, a public health nurse with the Middlesex-London Health Unit (MLHU), organized a meeting with a number of local service providers to consider a condition known as **senile squalor**. Dr. David Harris of the Geriatric Mental Health Program at London Health Sciences Centre made a presentation on this condition in which individuals exhibit a range of behaviours that may include social isolation or withdrawal, extreme self-neglect, domestic squalor, a tendency to hoard rubbish, lack of shame, and a stubborn refusal of help.

It was felt by those in attendance that individuals exhibiting these symptoms often fall through the cracks. Their needs are not effectively addressed and they present a health and safety risk to themselves or to others. Those in attendance agreed that the issue needed to be considered in more detail and that a task force should be established. Dr. Graham Pollett, the Medical Officer of Health agreed to support the efforts of the Task Force through the provision of funding to engage a project manager. The Rev. Susan Eagle, a member of the Middlesex-London Board of Health and a London city councillor agreed to chair the Task Force. Richard Pelletier, a local consultant, was engaged to undertake this assignment.

The Task Force began its activities in September 1999 and met on eight occasions reviewing pertinent legislation, service delivery, and planning issues. The Task Force sponsored a forum in December 1999 to generate further community input into the issue and to assist in formulating a realistic set of recommendations for action. While **senile squalor** was the condition that prompted formation of the Task Force, it became clear during its deliberations that symptoms attributed to **senile squalor** are not limited to the elderly.

Among the findings of the Task Force are the following:

- The legislation that bears on the issue of senile squalor is not always well understood. Elements of the legislation are complex and there are sometimes inconsistencies in interpretation.
- The gaps through which at-risk individuals fall are between agencies/services as well as within legislation. There is a lack of coordinated and integrated service delivery and as a result, an individual or family with ongoing needs and challenges leaves the caseload of one agency or service without being picked up by another.
- There is currently limited interagency service coordination and planning for organizations that service at-risk populations.
- Assessment of at-risk individuals is not easily arranged and there are often waiting lists. The requirement that referrals for psycho-geriatric assessments be made through a physician sometimes creates delays, especially for agencies without medical backup.
- Capacity assessment was a frequent concern of the Task Force because it is not broadly understood by health care providers or by the public, can be costly, and usually requires the consent of the person being assessed. As a last resort, capacity assessment does not lead to the early and timely addressing of problems.
- At the present time, there is no means to clearly identify the incidence of senile squalor within Middlesex-London. While it is known that instances of senile squalor are time consuming, extremely challenging, and sometimes result in or contribute to death, the extent of the problem remains unknown. While the Middlesex-London Health Unit does have a database of at-risk individuals, there is no central community-wide database of at-risk individuals.
- Confidentiality and protection of personal privacy with non-compliant or non-receptive individuals impair the ability of agencies to effectively coordinate case management services.
- There is currently a service gap for non-compliant or non-receptive at-risk individuals and families. Generally these individuals are not

receiving services as no one agency has clear responsibility.

- Early identification of at-risk individuals is key to timely intervention and resolution of risk factors. Early intervention may also result in less costly measures being necessary. Currently there is no early identification and tracking system in place.
- Younger individuals may also demonstrate similar symptoms or behaviours and present some similar challenges.
- Once squalid living conditions have been identified and addressed, there is the need for ongoing monitoring and support to prevent or minimize recurrence of the problem.

The Task Force has now completed its mandate and has formulated a local action plan. A central focus and key element in the action plan is the establishment of a **consortium** of agencies that are concerned with at-risk individuals and families. The consortium would serve as a central case management service and work closely with a network of **community gatekeepers** who will contribute to the early identification of at-risk individuals. The consortium will review referrals received from gatekeepers and from health and social service agencies, facilitate a complete assessment, and arrange case assignment to the most appropriate service provider.

The Task Force recommendations pertaining to service coordination are as follows:

1. That the Middlesex-London Health Unit (MLHU) facilitate development of a consortium of service providers and other stakeholders to coordinate services for at-risk individuals, and to provide ongoing strategic advice to community partners and funders regarding the needs of **at-risk** individuals as well as any related service coordination issues.
2. That the **consortium** assume a lead role in encouraging health and social service agencies to actively identify and address service gaps and issues.

The Task Force recommendations pertaining to early identification and case management are as follows:

3. That the **consortium** seek funding to undertake a **gatekeeper program** and foster the early identification of at-risk individuals including the frail elderly.

4. That the existence of the **gatekeeper program** be widely publicized in order to encourage referrals from community organizations as well as from the general community.
5. That the **consortium** establish a mechanism for effective and timely assessment, case management, and service delivery to at-risk individuals.
6. That the **Special Risk Recluse Program (At-Risk Registry)** currently residing at the MLHU be enhanced to serve as a central database of at-risk individuals within Middlesex and London.
7. That the **consortium** forge a close working relationship with **Special Services for the Frail Elderly - Centralized Intake and Triage**, a centralized intake point for geriatric services currently being established at Parkwood Hospital.

The Task Force recommendations pertaining to education are as follows:

8. That the **consortium** develop specific education strategies pertaining to at-risk populations with an initial focus on service providers including those with various levels of involvement in interventions, services, and treatment programs.
9. That the **consortium**, as part of the **gatekeeper strategy**, include a public education component to encourage early identification of at-risk individuals and publicize the range of available services.

The Task Force recommendations pertaining to research and evaluation are as follows:

10. That the Thames Valley District Health Council be encouraged to assess system capacity to respond to the increased number of at-risk individuals identified as a result of increased publicity.
11. That the **consortium** encourage as well as, monitor, and seek funding for ongoing medical and/or social research efforts into the condition known as **senile squalor**.

The Task Force recommendations pertaining to legislative and social policy are as follows:

12. That the MLHU obtain legal advice on confidentiality and due diligence issues associated with case management and service coordination.
13. That the **consortium** sponsor a seminar on **capacity assessment** for community agencies with a view to developing a better understanding of this function provided for by the **Substitute Decisions Act**.
14. That the **consortium** identify issues associated with legislation and policy, and advocate for appropriate change.

In developing these recommendations, the Task Force was of the opinion that there should be a sense of shared leadership and partnership amongst the individuals and organizations involved. At the same time, there was a strong concern that the momentum developed during the life of the Task Force not be lost. For that reason, the Task Force suggested that the MLHU take the initiative to facilitate the establishment of the consortium. Without a designated responsibility, the recommendations would not likely be implemented.

Introduction

In the summer of 1999 representatives of several local agencies were invited to a meeting at the Middlesex-London Health Unit to learn about a condition known as **senile squalor syndrome**. Dr. David Harris of the Geriatric Mental Health Program at London Health Sciences Centre (LHSC) reviewed the research and clinical management issues associated with this syndrome. In approximately 50% of cases there is a psychiatric disorder and in other cases there is an underlying personality disorder.

Those in attendance discussed a number of case scenarios, as well as related issues and challenges. Typically, individuals with this syndrome exhibit a range of behaviours that may include social isolation/withdrawal, extreme self-neglect, domestic squalor, a tendency to hoard rubbish, lack of shame, and a stubborn refusal of help. A distinct challenge in working with this population is the refusal of help, accompanied by strong denial of any problem, which makes assessment and other interventions extremely difficult. Among the issues raised by participants in the meeting were questions of an appropriate community response: what organization might best respond and in what manner? In some cases there are clearly psychiatric disorders or a lack of decisional capacity, while in other cases, the behaviour may be merely eccentric but with health and safety concerns. Community strategies to deal with these individuals are required, including the establishment of clear processes and coordinated service delivery.

It was clear to attendees at the initial meeting that **senile squalor** presents many challenges to service providers, to landlords, and to residents of London and Middlesex. The initial sense was that there are gaps in services and in the legislation that touches on the issue: that people appear to “*fall through the cracks*” was a common sentiment. The specifics of the condition, an analysis of the problem and possible solutions were seen as needed and that a Task Force should be established. The Middlesex-London Health Unit committed funding to engage a project manager and the Task Force looked to complete its task within a relatively short time frame and have in place an action plan for early in 2000.

Several members agreed to establish terms of reference for the project. The time frame was set at four months and the following terms of reference were adopted:

Task Force on Senile Squalor Terms of Reference

Senile Squalor represents a frequently overlooked yet important social problem within London and Middlesex County. Residents so affected usually fall outside the mandate of health and social service agencies resulting in lack of care for those involved and frustration for those trying to help. The purpose of this project is to review the current situation and to develop an action plan to deal effectively with Senile Squalor in this community.

1. To review existing legislation and identify its strengths and limitations (i.e. what is covered and what isn't).
2. To review existing services in Middlesex County and the City of London and identify gaps/limitations in service.
3. To conduct a workshop to present the findings from Steps 1 and 2 and to seek input in addressing same.
4. To prepare a final report with recommendations.

The Process

Task Force Meetings

At the end of August 1999, Richard Pelletier began duties as project manager. The Rev. Susan Eagle, a London city councillor and a member of the Middlesex-London Board of Health assumed the role of Task Force Chair. The Task force began regular meetings in mid-September and met on eight occasions.

From its inception, the Task Force adopted the position that it should be inclusive in its approach and, during its life, several new members joined. Meetings were scheduled over the lunch hour, as that was most convenient to the members who were all heavily engaged in other activities. Each meeting focused on the review of specific pieces of legislation and the related challenges faced by service providers.

Media Coverage and Public Awareness

Once the Task Force was established a media release was issued and this led to some positive media coverage. The London Free Press ran a story and followed up with an editorial in support of the Task Force. The CBC contacted Dr. Pollett, the Medical Officer of Health and he was interviewed on Radio Noon. As well, local radio broadcasters reported on the Task Force. This coverage generated a number of calls to the health unit from individuals interested in the issue and willing to assist. In addition, a writer for the Journal of the Canadian Medical Association contacted Dr. Pollett and wrote an article that appeared in the November 16, 1999 issue of the CMA Journal. In turn, this article led to the Task Force being contacted by the City of Toronto Health Department where a study of non-receptive frail elderly was completed in 1998.

Project Activities

In undertaking the assignment the project manager completed a literature review and utilized the Internet to seek references to senile squalor. He interviewed Task Force members as well as other local service providers and made home visits with a public health inspector and a public health nurse to see first hand the living conditions of at-risk elderly individuals.

In addition, he met with a group of staff from the London & Middlesex Housing Authority as well as with a large private sector landlord in order to increase understanding of the issues from a landlord's perspective.

The Task Force spent a significant amount of time reviewing the legislation that bears on the issue of senile squalor. A review of the legislative framework is included on page 11 while a summary of the pertinent legislation appears as Appendix D.

The Task Force also spent time considering some of the research into the syndrome and explored some of the sensitive legal and ethical issues:

- To what extent does an individual have the right to live a different lifestyle without interference from the community?
- At what point does the different lifestyle impact upon the health and safety of others and necessitate a community response?
- Once an agency's role with an individual living in squalor is ended, what organization, if any, has responsibility for continuity of service?

The Award Winning 1987 National Film Board movie **Mr. Nobody** was identified as providing an excellent illustration of these issues. The NFB web site contains the following abstract of the video:

Abstract

Jack Huggins is sixty-five years old. He doesn't take very good care of himself, but he lavishes attention on his menagerie of cats. He repairs and hoards electronic equipment he has picked from the garbage. When Jack did not comply with a Health Department order to clean up, he was forcefully removed from his home, certified incompetent, and the Public Trustee took charge of his affairs. Jack felt that he was being treated "like Mr. Nobody. Just Mr. Nobody out on the street." This film will provoke the discussion of legal and ethical dilemmas concerning the self-neglecting elderly. Do mentally competent elders have the right to neglect themselves? Does the state have an obligation to intervene? Support material available.

The video was viewed by the Task Force and used by staff of the Geriatric Mental Health Program to explore the issue of **senile squalor** at one of their professional development sessions.

Terminology

The Task Force identified a number of issues that need to be taken into account in the development of a local plan. Initially, the Task Force expressed a significant degree of discomfort with the name applied to this syndrome. **Senile squalor** was seen as being a negative label and members hoped to find a term that is more reflective of the fact that younger adults also exhibit similar signs and symptoms. As well, some of the calls the Health Unit received in response to the media coverage expressed concern with the term. In addition, not all individuals who present the symptoms associated with the syndrome are senile, nor are they all elderly. As well, the syndrome has been known in the literature as **senile squalor** and to use another name could generate confusion. Ultimately, the Task Force continued with its use of the term.

Community Input

Once the Task Force had completed its initial review of the issues, a half-day community forum was arranged for mid-December. The forum had three purposes:

- To provide an overview of the issue;
- To review the current legislative framework; and
- To generate input and recommendations for inclusion in a local action plan.

Forty-eight individuals participated in the day and a summary of their comments appears in the appendices, as does a list of participants and a set of case studies used to trigger discussion at the forum. In summary, the forum reinforced the preliminary findings of the Task Force. There was a confirmation that **senile squalor syndrome** exists in this community and that it presents significant challenges to service providers as well as to the residents of London and Middlesex. It was clear that most participants had come across individuals who appeared to fit the profile but this was often too late for effective intervention. It was also apparent that health and social service agencies do not always work in a coordinated manner.

One suggestion that arose at the community forum was new to the deliberations of the Task Force. Specifically, the suggestion was to consider implementing a **gatekeeper program** (See Appendix F). A social worker in Washington State named Raymond Raschko developed the gatekeeper model in 1978 as a means of early identification of at-risk elderly. The model proposes that community members who come into contact with at-risk elderly be recruited and oriented to risk factors. This group may include mail carriers, meter readers, bank tellers, firefighters, police officers, neighbours, phone and cable installers, property managers, etc.

A simple and confidential referral process is established to ensure timely follow-up with the at-risk individual. The model has been in place in many communities and has been responsible for early interventions and timely service provision. The model was developed with a focus on the at-risk elderly but can be implemented in a manner that serves a much wider population.

About Senile Squalor

A Selective Review of the Literature

In 1966 the British Medical Journal reported on the results of a study by Dr. Duncan MacMillan and Dr. Patricia Shaw. The study involved a group of 72 individuals between 60 and 92 years of age (one was 48) who ceased to maintain standards of cleanliness and hygiene normally accepted in their community. The investigators suggested that there was sufficient evidence that the condition should be considered as a syndrome and they called it **senile breakdown**. Their findings indicated that by the time these individuals became known, their condition was such that service providers were required to spend a disproportionate amount of time and energy trying to address their situation, often without a positive outcome. Their study found that in about half the cases, there was a psychosis involved. As well, social isolation and a marked resistance to any interventions were features. In cases where "home helps" were accepted, the study found that "their transformation of filthy premises is nothing short of miraculous" even though the individuals were reluctant to throw anything away. Additionally, the study identified two other significant factors:

1. Assuming the individual is prepared to accept help, early identification is important in avoiding the final deterioration and,
2. "There is usually no organization to which cases can be referred and from which efficient action can be obtained."

A.N.G. Clarke et al published an article in the Lancet, February 15, 1975 that described a similar condition and suggested it be called **Diogenes Syndrome**. The 30 individuals in this study exhibited similar characteristics to those identified in the MacMillan study. Half showed no evidence of a psychiatric disorder but all lived in squalor with a lack of self-care. As in the earlier study, Clarke referred to the lack of study attracted by this population.

Ungvari and Hantz wrote in 1991 about the syndrome sometimes referred to as **Social Breakdown in the Elderly** (SBE). Once again, they described a condition that is common but that has attracted "surprisingly little attention in geropsychiatry. Profound social isolation, extreme lack of self-care, and stubborn refusal of help are the main characteristics of SBE." Once again, the article suggested that the literature indicated a major

psychiatric illness was responsible for only about half of the cases. A second article by the same authors referred to the shortage of information available on the aged recluse.

In 1996, B.V. Refler, in the Journal of the American Geriatrics Society proposed to use the term **syndrome of extreme self-neglect** to refer to the condition and to drop the reference to **senile**. A subsequent letter to the editor that appeared in the December 1997 issue endorses Refler's removal of the "senile" reference as many who live in squalor are not old.

In summary, the literature indicates the following:

- The Name:**
- Senile squalor
 - Diogenes Syndrome
 - Social Breakdown of the Elderly (SBE)
 - Senile recluse
 - Social breakdown syndrome
 - Syndrome of Extreme self-Neglect
- Indicators:**
- Social isolation/withdrawal
 - Extreme self-neglect
 - Domestic squalor
 - Tendency to hoard rubbish
 - Lack of shame
 - Refusal of help

It also describes some important legal and ethical issues:

- Legal & Ethical Issues:**
- Rights of the individual to live in a socially unacceptable manner which may place their health and safety at risk.
 - Rights of the individual to live in a socially unacceptable manner which may jeopardize the health and safety of others.
 - Should society have the capacity to enforce treatment on individuals who do not comply.

Clearly, the debate about an appropriate name for the syndrome that the Task force has been calling **senile squalor** continues. Seeing that the literature has

used various names for the syndrome, it is not surprising that the Task Force was unable to find a term that all members supported.

The literature does not provide a clear set of strategies for addressing the issue nor does it provide answers to the legal and ethical challenges posed by non-compliant and non-receptive individuals who live in social breakdown conditions.

The literature usually refers to older adults, but it should be noted that individuals with these symptoms are not always elderly, nor is senility always involved. In some cases individuals are living in poverty but that is not always the case. In a surprising number of instances money is not a factor.

Senile Squalor in Our Community

In the early 1980's, staff of the Middlesex-London Health Unit identified instances of vulnerable, at-risk, or frail elderly and proceeded to establish a registry of these "special risk" adults. Often these individuals demonstrated several of the above-noted symptoms, but the terms **senile squalor** and Diogenes Syndrome were unfamiliar.

The incidence of this condition has not been quantified, as there has been no systematic process to identify individuals who exhibit these generalized symptoms. When asked, health and social service practitioners frequently indicate that they have come across individuals who demonstrate some or all of these symptoms, but standardized data has not been collected. There has, consequently, been no central data collection point and it has been impossible to identify the extent of the condition. This difficulty has been compounded by the reality that sometimes more than one agency or organization has been involved with the same individual(s) at the same time. An important and unanswered question is whether there is only a small number of individuals who exhibit these symptoms but consume a large amount of health and social service agency time, or is there really a large number of individuals whose existence is learned by exception?

Case Finding

Cases are often identified as the result of complaints received by the Health Unit or by a community agency. A neighbour might notice an offensive odour coming from an adjoining apartment, and that results in an investigation by a public health

inspector. Additional sources of identification include landlords, the Community Care Access Centre, police, hospital emergency departments, or other health and social service agencies. Once identified there is a whole range of issues which surface.

Assessment

An important initial challenge is to arrange a thorough psycho-geriatric, mental health, or capacity assessment, and typically, there is a refusal to willingly undergo an assessment. Even if the individual were willing, there is often a three-month waiting list for a **psycho-geriatric assessment** through the Geriatric Mental Health Program based at the London Health sciences Centre. Once an initial visit is made by a nurse or by a social worker, a psycho-geriatrician will make a home visit to complete the assessment, usually within two weeks. Because this service usually requires a medical referral, health and social service agencies may be handicapped in arranging a referral. In addition, the service is only able to make infrequent exceptions to the requirement that individuals being assessed are 65 years of age or older. Recently, there have been a number of requests for assessment of younger individuals referred by nursing homes. The Regional Geriatric Program located at Parkwood Hospital is also in a position to complete assessments, and can usually become involved within two weeks of receiving a referral. In either case, the individual being assessed must agree to an assessment being completed.

At the present time, a common intake point is being established for all geriatric services and this will likely result in more closely coordinated services. The focus will, however, continue to be on individuals who are 65 years and older.

Psychiatric assessment of those who are unwilling can be arranged under the Mental Health Act and the mechanism is described under the **Legal Framework** section of this report. Essentially, there are three means of effecting a psychiatric assessment of an unwilling individual: by order of a physician, by order of a justice of the peace, or by action of a peace officer. Members of the Task Force described their experiences in trying to arrange for such an assessment. In a number of instances it appeared that those in a position to act are often unwilling. One member identified that in 60 cases taken before a justice of the peace, only a few orders were issued. As a result of this, the Task Force believes that there is the need for education of specific groups.

Capacity assessment is provided for under the Substitute Decisions Act. Again, if the individual is unwilling, an assessment requires a court order. There are limited numbers of qualified capacity assessors in the area and, as private practitioners, there is a cost for assessment. The person requesting the assessment is normally expected to cover costs, and the individual being assessed may be unwilling to pay even if they have the financial resources. While the Capacity Assessment Office of the Public Guardian & Trustee has a small fund to cover the costs of assessments in some circumstances, cost is often seen as a barrier.

The issue of capacity assessment came up many times during Task Force deliberations as well as at the community forum. It became clear that there is the need for a better understanding of capacity assessment. Task Force members had been under the impression that capacity assessment is almost solely cognitive in nature, whereas, a more complete understanding includes the need to assess functional elements.

The basis of capacity assessment in Ontario is an enquiry into mental competency commissioned by the Ministry of Health in 1991. General recommendation number six of the final report of the **Enquiry on Mental Competency** reads:

“6) **Functional Basis of Assessment** - The assessment of an individual’s decisional capacity must reflect the specific functional requirements of that particular decision. It is not therefore to be based solely on the individual’s abilities in the abstract, the status of the individual or the probable outcome of the individual’s choice.”

The Task Force has recognized several issues associated with capacity assessment including a generalized need for service providers to develop a better-informed understanding of the process. To that end, the Task Force has recommended that a seminar be arranged to increase community understanding of capacity assessment.

Addressing the Issue

Assessment is only the second stage of the process, and to be clear, not all cases of social breakdown receive a thorough clinical assessment. Whether they do or not, the next challenge is to put in place appropriate service to address the situation. Members of the Task Force have all identified cases that fit the profile of this syndrome and just as willingness to undergo an assessment is not often

present, neither is willingness to accept the support or involvement of community agencies typically present.

In cases that involve a private landlord, the outcome may be a move to evict the individual who presents as a health and safety hazard or who exhibits other unacceptable behaviours. These individuals may not be known to health or social service agencies or, if known, their living conditions may not have been recognized for what they were.

In the case of social housing, staff frequently make repeated attempts to address the issue before proceeding to an eviction. These efforts are often met with little success. Under the lease currently in use by the local housing authority there is a provision for inspections of dwelling units that can be used when squalor is suspected. Unfortunately, it is extremely difficult to have individuals living in squalid conditions change their behaviour and keep their apartments and person clean. Sometimes short-lived improvement is made but, over time, the improvement is not maintained.

On several occasions, the housing authority has had to proceed to an eviction. In some cases, this is because the housing authority has had to clean units or fumigate a building as the result of a squalid situation and charges back the costs to the occupant. The eviction in these cases would be for non-payment of maintenance charges rather than for unacceptable living conditions.

Recently the Middlesex-London Health Unit has received special funding from the City of London to assist with cleanup of squalid conditions in dwellings. This fund has not been used extensively as the funding protocol requires that there be an ongoing plan to prevent recurrence. In cases of this syndrome, even if the individual cooperated with an initial cleanup, there would need to be the possibility of an ongoing monitoring and support system which might include the periodic services of a visiting homemaker. There is currently a shortage of appropriately qualified homemakers and no funding mechanism or agency to ensure continuity of service for these individuals who are non-receptive or non-compliant.

Once evicted from social housing the role of that agency is ended and it is not clear that any agency has an ongoing mandate to work with the individual in question. The evicted person has not changed their behaviour and continues the same pattern in other accommodations. There is no continuity of service and as a result, the problem continues.

Some instances of social breakdown involve individuals in owner-occupied homes. In these cases, it may be neighbours who complain as the result of exterior rubbish or ill-kept homes that detract from neighbourhood appearance. In other cases, large numbers of animals may be kept as poorly cared-for pets. A recent visit to such a home in London identified an outbuilding full of hoarded belongings, such that it represented a fire hazard to nearby homes.

Local cases of squalor that have come to light in recent years have been extremely problematic. The accommodations have been amazingly filthy with animal feces on the floor in some cases. Conditions sometimes include narrow passageways in the midst of hoardings with no apparent value, stacked television sets with a maze of hazardous wiring plugged into inadequate circuits, filthy washroom and kitchen facilities, stacked garbage, piles of old newspapers, a strong odour of urine or other health hazards. Recently there have been falls or fires resulting in serious injury and, in at least one case, death.

Aside from the difficulty in gaining access to the individual and their accommodations, addressing the squalor presents several challenges:

- Establishing a trust relationship with the individual sufficient to gain agreement for an initial cleanup.
- Arranging an initial cleanup of the home. This is not a routine homemaking function and has even been known to require body suits worn by contractors.
- Funding the initial cleanup.
- Ongoing monitoring of the situation with the possible provision of more routine periodic homemaking services. Maintaining a trust relationship with the individual to facilitate their acceptance of needed services.

The Task Force has identified the need for early identification of at-risk individuals. As well, there is recognition of the need for a shared case management approach that includes an assessment team in a position to respond in a timely manner to instances of senile squalor.

The Legal Framework

The Task Force *terms of reference* called for a review of legislation that bears on the issue of senile squalor as well as identification of strengths and limitations of specific acts. The initial sense was that the legislation presents some significant challenges to service providers as they try and work with senile squalor syndrome individuals. This was seen as being the case particularly with those who are non-compliant and non-responsive. The Task Force anticipated that some recommendations for legislative change might emerge from the review.

During its deliberations, the Task Force reviewed several pieces of legislation which in one way or another touch on issues associated with *senile squalor*:

- Mental Health Act
- Substitute Decisions Act
- Health Protection & Promotion Act
- Tenant Protection Act
- Long Term Care Act
- Fire Protection and Prevention Act
- City of London, Property Standards By-Law.

A general description of each of these appears as Appendix D.

Once a case of senile squalor is identified it is most important to know how to respond most appropriately. Is it an emergency situation or is it more chronic in nature? Is it a case of mental illness, a lack of capacity, or merely an eccentric self-determined life style? Is the individual living in a detached single-family dwelling or in a multi-unit building? An assessment is called for and that is usually difficult to arrange, as the individual tends to be unwilling to participate.

The Mental Health Act

This is an act that was reviewed as the literature suggests that mental illness is involved in about half of senile squalor cases. In those instances, the living conditions of the person, or their degree of self-care may present a risk to themselves or to others. This act provides three tools for arranging a psychiatric assessment in cases where the individual may be unwilling: *by order of a physician, by order of a justice of the peace, or by action of a peace officer*. In each case there are specific requirements for the order or action leading to a psychiatric assessment. There must be either evidence or cause to believe that the person "has shown or is showing a lack of competence to care for self". The physician or peace officer must form an opinion that the individual is apparently suffering from "mental disorder that will likely result in serious bodily harm to self or others, or "imminent and serious physical impairment of self". The justice of the peace must have reasonable cause to form such an opinion.

Arranging for an assessment under the Mental Health Act has some limitations. For example, past or chronic behaviours are difficult to assess and may not be known by the assessor. Family and friends cannot easily make input into the overall assessment and home visits are not required. The psychiatric assessment usually takes place in a hospital and the person's living environment is not seen firsthand.

In attempting to have an assessment order issued by a justice of the peace (JP), Task Force members recounted instances of inconsistency or difficulty making a case that would give the JP reasonable cause sufficient to issue an order. Even if a person is taken for an assessment, they may be discharged after only a few hours and there is a sense that that might be insufficient time for a complete assessment.

In instances where admission to a mental health facility does take place, upon release, the individual may be non-compliant with treatment decisions, cease taking medications, and revert to prior behaviours. The Mental Health Act is not seen as effectively dealing with the non-compliant, non-responsive individual. It is, however, understood that Ontario is currently considering revisions to the Act that might make it easier to enforce treatment once an individual is released from hospital. Attendees at the community forum voiced some support for the introduction of community treatment orders in Ontario but noted the controversial nature

of such orders. There are certainly divergent opinions on the appropriateness of such orders and the degree that they interfere with individual rights and freedoms.

The Substitute Decisions Act

This act has been of great interest to the Task Force, in particular the act's provision for assessing an individual's decisional capacity regarding personal property or for personal care. Specially qualified assessors who usually operate as private practitioners complete capacity assessments on a fee-for-service basis. They are sometimes engaged by a court but may provide their service on the request of an individual or by a lawyer on behalf of a client. In any case, capacity assessors charge a fee that currently ranges between \$80.00 and \$160.00 per hour. The Capacity Assessment Office of the Ministry of the Attorney General has a fund available in cases where the full cost cannot be covered by the requestor. The task Force was fortunate to have as a member Ike Lindenburger, one of the original professionals qualified as a capacity assessor in Ontario.

A finding of incapacity means that the person is unable to understand information that is relevant to making a decision or is unable to appreciate the reasonably foreseeable consequences of a decision or lack of a decision with respect to the management of the person's property or personal care. The Task Force was, for a period, under the impression that capacity assessment is a purely cognitive exercise and that the individual's functioning was not taken into consideration. We now know that to be assessed as having or not having capacity requires a review of both cognitive and functional elements. What is clear, however, is that in Ontario an individual must have cognition to be considered as having decisional capacity. If an individual demonstrates functional skills without cognition they will be deemed to lack capacity and will require a substitute decision-maker.

Task Force members have expressed concern with the process to arrange a capacity assessment as well as with the costs involved. The requirement that an individual agree to the assessment unless it is court ordered was seen as a limiting factor.

Health Protection & Promotion Act

This act took effect in 1984 and replaced the Public Health Act. Its purpose is to provide for "the organization and delivery of public health programs and services, the prevention of the spread of disease

and the promotion and protection of the health of the people of Ontario."

The act defines programs and services all provincial boards of health must provide. Further, under the act, the Minister of Health publishes **Mandatory Health Programs and Service Guidelines**, the most recent set being dated December 1997. General guidelines provide for the investigation of health hazards and that includes hazards resulting from senile squalor. At the same time, this current set of guidelines makes very limited reference to the elderly. The specific references that do exist, deal with vaccination programs and with the reduction of fall-related injuries. In the past, Health Units were also charged with the delivery of the healthy elderly initiative and, prior to the establishment of community care access centres, with homemaking services.

Since at least the early 1980's the MLHU has had in place a registry of at-risk individuals. Known as the Special Risk Registry or the Special Risk Recluse Program, it exists to facilitate the ongoing monitoring of special risk individuals, and is maintained by the Environmental Health Division with input from the Public Health Nursing, and the former Home Care divisions of the Health Unit. This registry defined special risk individuals as:

- Persons who are suffering from grave chronic illness, and
- Persons being aged, infirm or physically incapacitated, and
- Persons living in unsanitary, unsafe conditions, and/or
- Persons who are unable to devote to themselves, proper care and attention and are not being taken care of by any specific organization or will not accept active care.

Senile squalor certainly appears to fall within this definition.

Current policy calls for Environmental Health and Public Health Nursing to meet on a regular basis for case management purposes and, for individuals on the registry to be monitored at least two times per year.

In exercising its responsibility for health hazard investigation, the Health Unit is called upon to investigate instances of senile squalor that appear to offer a threat of adverse health outcomes. As with other pieces of legislation, the Health Protection & Promotion Act provides a right of access to inspectors. At the same time, individuals commonly refuse access and this may result in an application to the courts for a warrant. This step is rarely taken. Rather, a persistent approach is made to gain access and an attempt is made to persuade the person living in squalor to comply with a cleanup.

The Long Term Care Act

This act was originally passed in 1994 with subsequent amendments in 1996, 1997, and 1998. It was not until July 1999 that regulations were enacted. Under this Act, Community Care Access Centres (CCACs) provide home care (nursing and other professional services, personal support services, and homemaking services) based on the assessment of client need completed by CCAC staff. **Homemaking Services** include housecleaning; doing laundry, ironing, mending, shopping, banking, paying bills, planning menus, and preparing meals. **Personal Support Services** include personal hygiene activities, and routine personal activities of living.

The CCAC of London and Middlesex, under direction from the Ministry of Health and Long Term Care, has faced a limitation on its capacity to provide home care services to individuals with psychiatric disorders. Because approximately 50% of individuals living in senile squalor suffer from a psychiatric disorder, home care may not be readily available, even if the individual in need were prepared to accept service. As well, the extensive nature of the service required for an initial cleanup in squalid conditions is not typically seen as homemaking.

The senile squalor population is clearly difficult to serve and it appears that for individuals with a psychiatric disorder who are living in squalor and for individuals who are non-receptive or non-responsive, there is a current service gap.

The Tenant Protection Act

In 1997 this act replaced the Landlord Tenant Act and is in place to govern residential tenancies in Ontario. It is relevant to senile squalor as some individuals with the syndrome live in rental accommodation. The act requires the tenant to keep the rental unit clean but landlords are not usually in a position to ensure that that happens unless there

is a specific provision in the lease. Landlords may move to evict if the tenant's behaviour interferes with the reasonable enjoyment of the residential complex by other tenants. This reasonable enjoyment might be affected by odours or health hazards that originate in the tenants unit. The Ontario Rental Housing Tribunal (which is the legal body that makes eviction decisions) does not maintain statistics on the grounds for eviction so it is unclear how often squalor situations result in eviction.

Landlords are not usually concerned with the cause of the senile squalor. What does matter is a timely resolution of problems, an end to complaints from neighbours, and removal of any dangerous conditions. Whether the underlying cause is mental illness or merely eccentric behaviour is not a concern for landlords. If the problem is not resolved relatively quickly, the landlord will likely seek an eviction.

The London & Middlesex Housing Authority has a clause in its lease that allows unit inspections to monitor sanitary conditions. As noted elsewhere in this report, the Housing Authority sometimes incurs expenses in cleaning units or in fumigating a building due to squalor in a particular unit. Associated costs are charged back to the tenant and, in the event that they do not pay, an action to evict may be initiated.

The Fire Protection and Prevention Act and Municipal Bylaws

These sometimes come into play in cases of senile squalor. A recent eviction took place, in part due to the individual presenting a fire hazard within their rental unit. Hoarding and collection of "junk" associated with senile squalor may contravene the current City of London By-Law prescribing "Standards for the Maintenance and Occupancy of Property" if it occurs outside a building.

A Common Theme

A common issue with all of the above legislation is that of *access*. Individuals with the syndrome tend to be non-compliant and are generally neither willing to allow service providers into their homes, nor to accept services. Some of the laws provide a *right of access* but in cases of non-compliance, court action is usually required. This affects the timeliness of resolution and certainly involves additional costs to whoever is initiating the action.

Findings and Recommendations - A Local Plan for Action

Principal Findings

As a result of deliberations and the input received from the community forum, the Task Force confirmed its principal findings as follows:

- The legislation that bears on the issue of senile squalor is not always well understood. Elements of the legislation are complex and there are sometimes inconsistencies in interpretation.
- The gaps through which at-risk individuals fall are between agencies/services as well as within the legislation. There is a lack of coordinated and integrated service delivery and, as a result, an individual or family with ongoing needs and challenges leaves the caseload of one agency or service without being picked up by another.
- There is currently limited interagency service coordination and planning for organizations that service at-risk populations.
- Assessment of at-risk individuals is not easily arranged and there are often waiting lists. The requirement that referrals for psycho-geriatric assessments be made through a physician sometimes creates delays, especially for agencies without medical backup.
- Capacity assessment was a frequent concern of the Task Force because it is not broadly understood by health care providers or by the public, can be costly, and usually requires the consent of the person being assessed. As a last resort, capacity assessment does not lead to the early and timely addressing of problems.
- At the present time, there is no means to clearly identify the incidence of senile squalor within Middlesex-London. While it is known that instances of senile squalor are time consuming, extremely challenging, and sometimes result in or contribute to death, the extent of the problem remains unknown. While the Middlesex-London Health Unit does have a database of at-risk individuals, there is no central community-wide database of at-risk individuals.
- Confidentiality and protection of personal privacy with non-compliant or non-receptive individuals impair the ability of agencies to effectively coordinate case management services.
- There is currently a service gap for non-compliant or non-receptive at-risk individuals and families. Generally these individuals are not receiving services as no one agency has clear responsibility.
- Early identification of at-risk individuals is key to timely intervention and resolution of risk factors. Early intervention may also result in less costly measures being necessary. Currently there is no early identification and tracking system in place.
- Younger individuals may also demonstrate similar symptoms or behaviours and present some similar challenges.
- Once squalid living conditions have been identified and addressed, there is the need for ongoing monitoring and support to prevent or minimize recurrence of the problem.

Based upon these findings the Task Force developed fourteen recommendations. These recommendations provide the framework for a local action plan that addresses the issue of senile squalor.

A Plan for Action

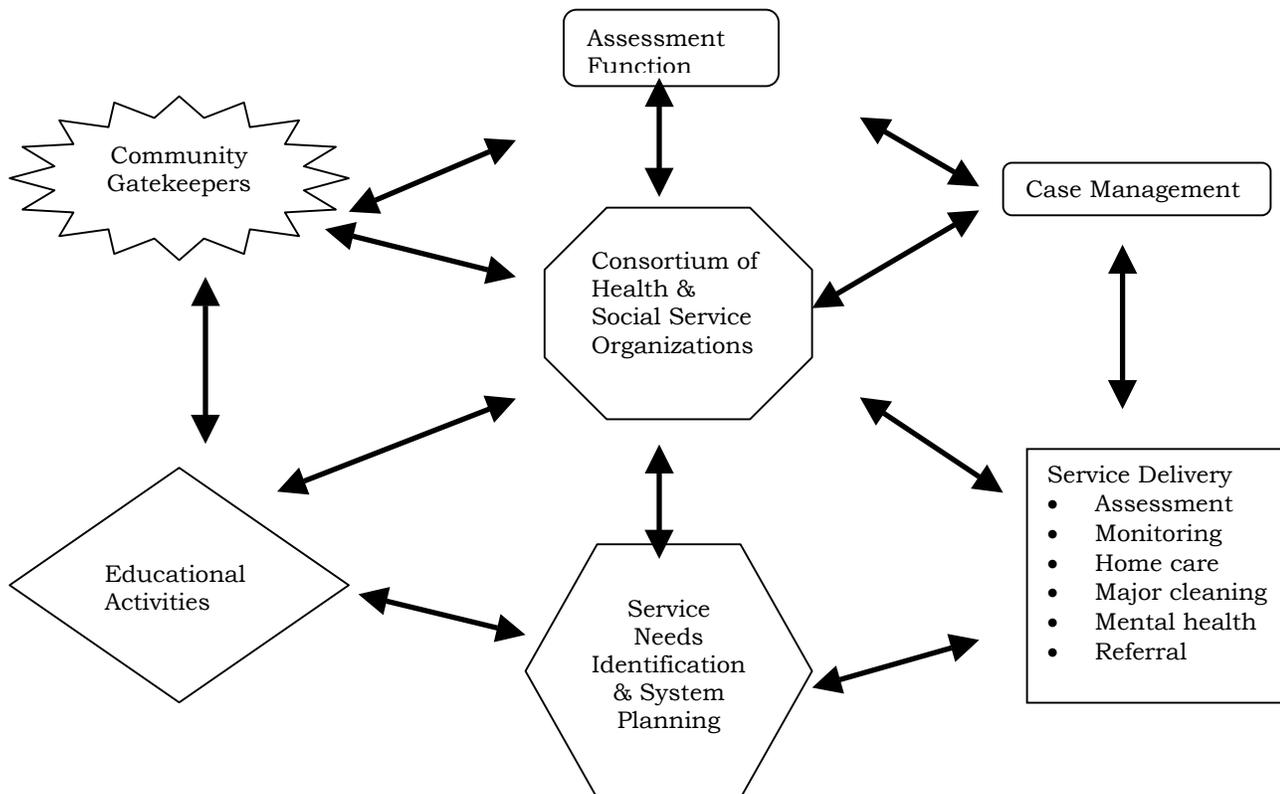
In shaping its local action plan the Task Force adopted two key strategies: **early identification** (case finding) and a **coordinated and shared service response**. Interestingly, these two features of the action plan address two of the factors that were identified in the earliest reference to this syndrome that the Task Force located. Among other things, the 1966 MacMillan and Shaw study identified these two factors that were relevant at that time and are to this day:

1. Assuming the individual is prepared to accept help, early identification is important in avoiding the final deterioration and,
2. "There is usually no organization to which cases can be referred and from which efficient action can be obtained."

A central focus and key element in the action plan is the establishment of a **consortium** of agencies that are concerned with at-risk individuals and families.

The Task Force did not wish to rigidly define the shape and membership or the roles, functions and protocols of the consortium. Rather it saw those features as the province of the consortium and its membership and instead chose to provide a brief snapshot of what might emerge. Among other things, the consortium might serve as a central case management service and work closely with a network of **community gatekeepers** who will contribute to the early identification of at-risk individuals. The consortium would then review referrals received from gatekeepers and from health and social service agencies, facilitate a complete assessment, and arrange case assignment to the most appropriate service provider.

Without precisely defining the contents of each component, the set of roles and functions necessary to implement the action plan might look something like the following (Once an actual consortium is formalized, precise roles, relationships, and protocols can be established):



Task Force Recommendations

The Task Force recommendations pertaining to service coordination are as follows:

1. That the Middlesex-London Health Unit (MLHU) facilitate development of a consortium of service providers and other stakeholders to coordinate services for at-risk individuals, and to provide ongoing strategic advice to community partners and funders regarding the needs of **at-risk** individuals as well as any related service coordination issues.
2. That the **consortium** assume a lead role in encouraging health and social service agencies to actively identify and address service gaps and issues.

The Task Force recommendations pertaining to early identification and case management are as follows:

3. That the **consortium** seek funding to undertake a **gatekeeper program** and foster the early identification of at-risk individuals including the frail elderly.
4. That the existence of the **gatekeeper program** be widely publicized in order to encourage referrals from community organizations as well as from the general community.
5. That the **consortium** establish a mechanism for effective and timely assessment, case management, and service delivery to at-risk individuals.
6. That the **Special Risk Recluse Program (At-Risk Registry)** currently residing at the MLHU be enhanced to serve as a central database of at-risk individuals within Middlesex and London.
7. That the **consortium** forge a close working relationship with **Special Services for the Frail Elderly - Centralized Intake and Triage**, a centralized intake point for geriatric services currently being established at Parkwood Hospital.

The Task Force recommendations pertaining to education are as follows:

8. That the **consortium** develop specific education strategies pertaining to at-risk populations with an initial focus on service providers including those with various levels of involvement in interventions, services, and treatment programs.

9. That the **consortium**, as part of the **gatekeeper strategy**, include a public education component to encourage early identification of at-risk individuals and publicize the range of available services.

The Task Force recommendations pertaining to research and evaluation are as follows:

10. That the Thames Valley District Health Council be encouraged to assess system capacity to respond to the increased number of at-risk individuals identified as a result of increased publicity.
11. That the **consortium** encourage, as well as monitor, and seek funding for ongoing medical and/or social research efforts into the condition known as **senile squalor**.

The Task Force recommendations pertaining to legislative and social policy are as follows:

12. That the MLHU obtain legal advice on confidentiality and due diligence issues associated with case management and service coordination.
13. That the **consortium** sponsor a seminar on **capacity assessment** for community agencies with a view to developing a better understanding of this function provided for by the **Substitute Decisions Act**.
14. That the **consortium** identify issues associated with legislation and policy, and advocate for appropriate change.

In developing its recommendations, the Task Force was of the opinion that there should be a sense of shared leadership and partnership amongst the individuals and organizations involved. At the same time, there was the concern that the momentum developed during the life of the Task Force not be lost, and for that reason, the Task Force suggested that the MLHU take the initiative to facilitate the establishment of the consortium. Without a designated responsibility, the recommendations would not likely be implemented.

Appendix A - Media Articles

- **London Free Press**, Monday September 20, 1999.
London Seniors Living in Filth
- **London Free Press**, Tuesday September 21, 1999.
Editorial - Saying 'stop' to squalor
- **Canadian Medical Association Journal**, November 16, 1999; 161 (10)
Task force seeks solutions for "senior squalor"

London Free Press, Monday September 20, 1999.
London Seniors Living in Filth

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MONDAY, SEPTEMBER 20, 1999 • PAGE A3

Task Force on Senile Squalor set up to tackle problem a first in Ontario

London seniors living in filth

By **Mary-Jane Egan**
Free Press Health Reporter

An alarming number of seniors are living in squalor in homes that have become junk yards. And London stands poised to develop the first provincial model to measure the extent of the problem.

Dr. Graham Pollett, medical officer of health for the Middlesex-London Health Unit, said the Task Force on Senile Squalor — established last week — marks what's believed a provincial first in tracking a serious health risk that's been ignored far too long.

He said the health unit has discovered seniors living in filth with homes over-run by mice and cockroaches.

He's hopeful the task force's findings will form the first benchmark in battling a poorly understood syndrome that's all the more worrisome as the population's life expectancy increases.

"The most frustrating aspect of this particular condition is the refusal for help," Pollett said, looking over photographs taken in the homes of local seniors living in filth.

In one photo, pots, bottles, mops and other articles overflow from the bath tub and sink of a senior's washroom. In another, the kitchen counters are a clutter of newspapers stacked to the ceilings while the stove and microwave oven are littered with bottles, papers and oil cans.

Pollett said no one agency has ever been mandated to focus on the problem like the local task force will. It's hoped local experts — from agencies that include the psychogeriatric clinic, hospitals, the health unit and London Housing Authority — will shed light on the problem, which is marked by three key characteristics.

Pollett said social isolation, neglect of personal care and the refusal of help

are common threads in the condition in which sufferers "otherwise don't appear to have any overt psychiatric illness."

"The most frustrating aspect of this particular condition is the refusal for help."

Dr. Graham Pollett, London-Middlesex medical officer of health

In the cases photographed by the health unit, Pollett said concerned neighbours called, often only after noticing a stench from an elderly person's home or seeing a mountain of litter through a window.

He said most of the seniors included in the task force's new "at-risk registry" are single.

The task force was granted \$25,000

over two years by London city council to help in the cleanup of homes that come to the task force's attention. The health unit has budgeted about \$20,000 to hire a project co-ordinator.

Seniors on the at-risk registry — about 15 to date — receive regular visits to ensure they are managing their own care. In some instances, a senior may be determined unfit to care for themselves and a nursing home may be the answer.

"Until now, people with this condition literally fell through the cracks and it's usually some kind of crisis that brings them to our attention. What we want to do is better co-ordinate our services to ensure people get the help they need," Pollett said.

Coun. Susan Eagle, a minister and expert on housing and poverty issues, will chair the task force.

"... It's a critical issue for us to be addressing," she said.

London Free Press, Tuesday September 21, 1999.
Editorial - *Saying 'stop' to squalor*

A12 • TUESDAY, SEPTEMBER 21, 1999

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Saying 'stop' to squalor

Life should be more about quality than quantity.

It's a consideration seldom made today, when the average life expectancy approaches 80 and modern medicine is redefining what "old age" means.

This quest for longer life shouldn't blind us to how many seniors are living — amidst filth and litter. Were it not for concerned neighbours, the deplorable conditions that many of the elderly live in would go entirely unnoticed.

That's why the Middlesex-London Health Unit has established the Task Force on Senile Squalor, what it believes is the first provincial group charged with measuring the extent of the deterioration in elderly lifestyles.

Already, seniors have been discovered living in homes infested with mice and cockroaches. A photograph shows a collection of pots, bottles, mops and other items spilling out of a bath tub and sink.

Count on more information and images that will arrest consciences as this task force continues its work. Many people don't realize the problems at-home seniors face and, if they do, are ignorant of the extent of those difficulties. Seniors, too often dismissed on the basis of senility, are often just scared people uncertain of what to do. If the task force is able to penetrate this ignorance, it will have already achieved significant success.

Its other duty is more tangible. Seniors who come to the task force's attention will be placed on a registry that entitles them to regular check-up visits, sparing them the indignity of a filth-strewn existence.

Council has granted this task force \$25,000 to help in the cleanup of seniors' homes.

It's an excellent investment.

Canadian Medical Association Journal, November 16, 1999; 161 (10)

Task force seeks solutions for “senior squalor”

Task force seeks solutions for “senior squalor”

Lynne Swanson

Although London, Ont., is known as a wealthy university town, local public health staff and other service providers were so disturbed to find some seniors living in filth that the municipality allocated \$25 000 for a 2-year Task Force on Senior Squalor.

Public health staff have found reclusive seniors living in homes overflowing with garbage amid huge stacks of debris and papers, surrounded by human and animal feces, urine on the floor, soiled bedding and decomposing waste.

Although their condition represents a health risk to themselves or others, these seniors are usually unwilling to accept help. “If ever there was a frustrating condition to deal with, it’s senior squalor,” says Dr. Graham Pollett, medical officer of health for the Middlesex-London Health Unit. A major issue is that “no one community agency has a legislated mandate to deal with the problem.”

Pollett says social breakdown of the elderly has 3 chronic characteristics: profound social isolation, extreme neglect of self-care and refusal of help.

Senior squalor is not always a condition of poverty. Pollett says people have been discovered living in squalor who have significant financial resources or own their home. In fact, when a person lives in an apartment or a multiunit building, it is frequently brought to the health unit’s attention by neighbours complaining of odour or pests. The health unit has a better chance to intervene in these cases than in an owner-occupied house.

Although senior squalor is not well documented in North America, Pollett says British studies indicate that about 50% of people living this way have an underlying psychiatric illness, such as schizophrenia, chronic depression or dementia. In those situations, legislation is available to assist.

Pollett says the other half come through a capacity assessment “with flying colours. That’s an especially difficult group to deal with. What do you do as a physician, as a public health unit, as a housing authority, as a public trustee?”

“This is where you realize in many instances you are powerless to help. People fall through the cracks and you come smack up against individual rights versus societal rights or responsibilities to care for people who can’t care for themselves.”

When attempts are made to help, people are often bounced between agencies. If people are evicted from housing because they are placing others at risk, the problem moves elsewhere — sometimes to shelters or the street — with them.

Since 1988, London has had an At Risk Registry of people identified as being unable to care for themselves, living in deplorable conditions and who are not being cared for by any organization or will not accept care. There are usually 15 to 25 people on the registry at one time, but others may be living in squalor without social welfare agencies knowing it.

Although numbers are small, Pollett expects them to grow because of Canada’s aging population. He also points to a study that indicated seniors living in squalor face a 50% mortality rate within a year. “Knowing the high mortality rate, it just adds to the concern and frustration. Are people

making an informed decision to live in this state? To me, the answer is not clear cut.”

Mary Huffman, a public health nurse, says seniors living in squalor usually live alone and have no family support or reject such efforts. Many don’t have health coverage. “But it’s not just a medical issue,” says Huffman.

She says the role of the task force will be to look at “how the community is going to address this so these people get the help they need in the most efficient and unobtrusive manner. We really need to look at some type of community system so needs are addressed in the least intrusive but most beneficial way for the community, but also for that individual to maintain their rights and dignity.”

Pollett expects the task force to look at ways to improve the coordination of services, identify gaps and recommend strategies for addressing needs. The group will also examine various legislation. Pollett is unaware of similar Canadian initiatives and hopes other communities learn from London’s experience. He is particularly pleased the group is chaired by Rev. Susan Eagle, an ordained minister who also serves on city council and is a social activist.

Lynne Swanson is a journalist in London, Ont.



Many isolated seniors refuse to seek or accept help

Appendix B - Case Studies

These case studies reflect recent actual cases in Middlesex-London. They have been written in a manner to disguise identities and were used to trigger discussion at the Community Forum held in December 1999.

CASE STUDY #1

Mrs. S. is an 84-year-old woman. She was widowed more than 20 years ago. She lives alone in a detached, 2-storey home, which she owns. Her income is approximately \$1200 a month from pensions. She has no siblings. She has one son who is estranged and who lives in California. She has no contact with him.

Recently, a concerned neighbour contacted the public health unit because of the conditions of the home. Mrs. S. does not allow anyone inside her home. When the inspector investigated, she found the following:

- Weed growth and tanglements in the front yard
- Accumulation of old furniture and decomposing waste on rear porch which was causing an obnoxious odour
- Rear yard full of various debris (old shopping cart, clothes, empty cans, boxes, etc.)
- Pile of decomposing garbage in broken garbage bags piled at rear of house
- 2 sheds in the rear yard that appeared dilapidated. Upon further inspection, it was found that the sheds were full to the ceiling with cardboard boxes, clothing, books and other household items
- There was no answer at the door. However, the inspector could see through the mail slot that the house was also full from floor to ceiling and wall-to-wall with cardboard boxes, clothes, books, etc. Heavy mice droppings could be seen on the windowsills.

As a result of her findings, the inspector is concerned that the conditions at the house are a possible fire hazard, to both Mrs. S.'s home and adjacent houses. Also, the accumulation of items can potentially provide harborage to rodents and pests.

Mrs. S. called the inspector the next day. She was upset that someone had contacted the health unit about her house. She assured the inspector that she has been attempting to clean up and would continue to do so. She agreed to have a public health nurse visit.

The public health nurse visited Mrs. S. and saw her in her backyard but was not admitted into the house. She found that Mrs. S. ate well, regularly sees a family doctor and although frail, seemed in general good health. She noted that her personal appearance is unkempt but Mrs. S. is coherent and aware. In consultation with Mrs. S.'s family doctor it is agreed that Mrs. S. does not warrant a capacity assessment.

Although Mrs. S. has been offered financial and manpower assistance to clean the premises and its accessory buildings, she refuses all help.

After several weeks, and after the inspector has contacted other provincial and municipal agencies, there has been no change in the conditions of the home and they seem to be getting worse.

CASE STUDY #2

Harry was found in a small bachelor apartment. He collected lots of items of interest to himself. It was impossible to enter the apartment without moving items out from behind the apartment door. The short hallway was filled with floor fans and clothes. The living area had a pathway from the hallway to the single bed between stacks of boxes and clothes piled to the ceiling. It would have been impossible to get more than 3 people into the apartment, as it was standing room only. Access to the balcony door was blocked. The kitchen counter and floor were covered with appliances, food cans, used coffee filters, dirty dishes and pipe smoking paraphernalia. The refrigerator was stuffed with small white plastic bags. There was a pile of crushed food cans behind the stove piled from the floor to the top of the stove. The bathroom had an assortment of gallon bottles of chemicals. The fixtures and floor were coated with filth. The apartment had that distinctive odour of filth that was noticeable in the apartment building hallway.

Harry liked electrical appliances and electronics. There were 6 TV sets piled in a neat arrangement, all plugged in and working. He had sets of Christmas lights and wiring across his living room window. There were several radios, 4 coffee makers, 5 toasters all connected to electricity. Harry liked his coffee. He always had a pot of hot coffee and one of hot water on the burners on his electric stove but there was also a pile of used rinsed coffee filters stacked on top of the stove.

Harry always paid his rent on time. Every time he was asked to clean out his apartment, he threatened everyone with legal action. He knew his rights. He had serious leg ulcers and his personal hygiene was poor to non-existent. He liked the way he lived and saw no reason to change anything.

CASE STUDY #3

Mrs. S. is a 79-year-old female who has lived alone since being widowed 9 years ago. She has had some difficulty with her heart and has had CCAC nursing going in for several years to monitor her medications and her cardiac status. Nursing has identified her home environment to be of great concern. She has 15 cats. Upon entering the home, one is overwhelmed with the stench of urine and feces. She has hoarded garbage and newspapers over the years and it is very difficult to move around the home because of the clutter. Mrs. S. is incontinent of bladder and has been recycling her incontinence products that are hanging to dry all over the house.

She has had some paranoid delusions for the past 9 years of people living in her basement that are quite distressing to her. For this reason, she has cleared her basement and keeps everything on the upper level of her home. She refuses medications and medical intervention for these delusions.

On assessment, she was found to be capable of making her own decisions regarding personal care and where to live. Risks include: hygiene, fire (garbage all over the house including on the stove), personal health of Mrs. S., health of cats, pests.

CASE STUDY #4

Mr. J. is an 89-year-old gentleman who lives with his wife in the country. His wife has a diagnosis of Alzheimer's dementia and relies on him for all care giving. They have lived for the past 50 years in quite a marginal way. Their farmhouse has never had running water or an indoor bathroom. They have never had central heating, but have relied on a wood stove for heat. Their home has been described as squalor by family and friends with garbage, newspapers and food all over the place. Concerns were raised regarding risk of fire, poor storage of food, home hygiene and risk of pests and vermin. Family do not feel that it is a healthy environment.

Mr. J. recently had a significant decline in his physical health. He was taken to a local hospital for medical management. On his admission to hospital, his wife was temporarily placed in Long Term Care (LTC) as she was not able to care for herself. Upon his discharge from hospital, he wanted to return home, but hospital staff were reluctant to send him home given the state of his living environment and he was therefore sent to the same LTC Centre as his wife.

Mr. J. underwent a capacity assessment to determine whether he was able to decide where he wanted to live. He was found capable and elected to return to his previous living environment. He refused CCAC intervention. In addition, he is the legal substitute decision-maker for his wife and wanted to take her home. Family and care providers feel that it is not within Mr. or Mrs. J.'s best interests to return home.

CASE STUDY # 5

Ms. T. is a 70-year-old woman well known to residents of the Dundas and Adelaide Street neighbourhood. She was often seen picking through garbage cans for food and other items. Her hygiene was very poor; she rarely dressed appropriately during extreme weather conditions, and demonstrated some obvious delusional behaviours - such as loud verbal arguments with no one in particular. Ms. T. appeared to have no known home (residence) or family contacts.

A worker from a homelessness outreach program initially had no success in his attempts to engage Ms. T. in conversation. She became verbally abusive when approached, and on more than one occasion struck out at the worker with her hands and feet.

A landlord contacted the worker's office requesting assistance in securing new accommodation for a tenant he wanted to evict from a building he'd recently sold. The landlord reported that though the tenant always paid rent on time and there was no real "cause" for an eviction notice, the apartment unit required extensive renovation and the new owner apparently wanted the tenant removed as soon as possible. The landlord expressed concern for the "welfare" of this tenant. This tenant turned out to be Ms. T.

The landlord invited the worker over to view the ground floor apartment. Upon arrival, the worker discovered:

- The only running water was in the kitchen, the toilet no longer worked, the broken stove had been pulled out to the middle of the kitchen, and the empty fridge contained no shelves;
- The majority of bedroom floor boards were rotted through to the basement due to a large hole (leak) in the bedroom ceiling;
- The only furniture in the apartment was one piece of a sectional couch in the living room that had become Ms. T.'s bed, chair and toilet;
- The walls of every room were covered with a damp, slimy filth and the apartment reeked of urine and feces;

- The only food in the house was a half loaf of bread covered with bugs;
- Ms. T. had no personal items or clothing in the apartment other than a blanket nailed across the bedroom door.

The landlord reported he'd known Ms. T had been living in this condition for quite some time, as he had "... cleaned her out" the previous year by carting a truck load of garbage she'd collected in the apartment off to the dump.

The worker's concern for Ms. T. had greatly increased. He contacted several agencies and services over the following 10 days, only to be told by many that assisting Ms. T. did not meet their mandate. He was also told by someone that living this way was obviously Ms. T.'s choice. The Public Health Inspector did come to see the apartment at his request, and the Parkwood Hospital Geriatric Outreach Team agreed to assess Ms. T. Ms. T. was eventually sent to a psychiatric ward for further monitoring, where the worker visited and took her on shopping outings. Although her mental health improved somewhat, it was agreed her declining physical health and mental incapacity precluded her ability to continue living independently. Ms. T. now resides in a geriatric unit at a provincial psychiatric hospital.

Appendix C - Community Forum

Participants

| | |
|--------------------|--------------------------------------------------|
| Tom Appleyard | London Intercommunity Health Centre |
| Alison Arsenaault | Regional Geriatric Program – Parkwood Hospital |
| Catherine Beaton | Regional Geriatric Program – Parkwood Hospital |
| Reta Bere | London & Middlesex Housing Authority |
| Clarke Boddy | ESAM Group |
| Richard Bunt | Geriatric Mental Health, LHSC |
| Vanessa Clarke | Middlesex-London Health Unit |
| Audrey Coulthard | Private Citizen |
| Wendy Cowdry | London Fire Department |
| Brad Davey | Ministry of Health & Long Term Care |
| Kathy Desai | Community Care Access Centre London-Middlesex |
| Anne Evans | South-western Regional Psychogeriatric Program |
| Pearl Fernandez | ESAM Group |
| Patrick Flemming | Geriatric Mental Health, LHSC |
| Hugh Goodfellow | Middlesex-London Health Unit |
| Donna Heffron | Chateau Gardens Queens |
| Bruce Henry | By-Law Enforcement, City of London |
| Dorothy Hickey | Cherryhill Health Promotion & Information Centre |
| Mary Huffman | Middlesex-London Health Unit |
| Yvonne Irvine | Geriatric Mental Health, LHSC |
| Van Johncox | Community Services, City of London |
| Ann Kirby | London Psychiatric Hospital |
| Dianne Lesperance | Office of the Public Guardian & Trustee |
| Susan Lloyd | Regional Geriatric Program – Parkwood Hospital |
| Susan McLellan | London Psychiatric Hospital |
| David Norton | London & Middlesex Housing Authority |
| Helen Padega | London Health Sciences Centre |
| Richard Pelletier | FUTURE <i>trends</i> Consulting Services |
| Pam Pelletier | London & Middlesex Housing Authority |
| Graham Pollett | Middlesex-London Health Unit |
| Mary Poore | London & Middlesex Housing Authority |
| Elaine Reddick | Middlesex-London Health Unit |
| Jim Reffle | Middlesex-London Health Unit |
| Linda Richards | London Psychiatric Hospital |
| Patricia Robertson | Private Citizen |
| Barry Sanders | London Psychiatric Hospital |
| Judy Seaman | London Psychiatric Hospital |
| Joan Shewfelt | Victorian Order of Nurses |
| Doris Smith | Western Ontario Therapeutic Community Hostel |
| Cathy Staltari | London Fire Department |
| Georgia Sweeny | Cherryhill Health Promotion & Information Centre |
| Sylvia Vanderkooy | London Psychiatric Hospital |
| Gill Villanueva | London Police Service |
| Sally Waddell | Community Care Access Centre London-Middlesex |
| Donna Waterman | Middlesex-London Health Unit |
| Judy Watson | Streetscape |
| Bonnie Williams | Canadian Mental Health Association |
| Slavomir Wojtowicz | Streetscape |

Comments on the Issue

These comments are from participants at the Community Forum.

Senile Squalor

1. **Have you ever come across situations that seem to fit the profile of senile squalor?**

- Yes.
- Definitely not limited to seniors.
- Not to the extent seen or reported in examples or video.
- Yes.
- Residents admitted to the nursing home from squalor situation within the community. Also, residents wishing to vacate the nursing home to a “squalor situation”.
- Yes, I’m a Public Health Inspector.
- Frequently.
- Yes.
- Yes. Several.
- Yes, 3 cases.
- Yes, but never with seniors. The examples I can think of are in their 30’s or 40’s.
- Yes but in younger clients. Likely they will be consistent in when in old age.
- Yes, several. One member is part of my extended family. As in the video, I believe a pattern has been established by a previous generation so this can be learned behaviour.

2. **Does the legislative framework contribute to effectively addressing the needs of individuals at-risk? Are there any legal changes you would suggest?**

- Make information well-known and accessible.
- Gaps are there – we all need to be more aware of using what is available.
- Addition of functional capacity absolutely necessary.
- Not at best – too many frameworks with limited capabilities & many gaps & grey areas – central core agency to coordinate the legal framework.
- Issue of rights vs legislation; competence vs. choice, etc.
- No. Doctors and other health care people who are either 1) making a decision to ask for a capacity assessment, or 2) doing the assessment should be required to see these individuals in their own environment when requested in order to take into account the living conditions.
- No. Capacity assessment issues – legislation looks at specific details & not at whole picture.
- Define a specific piece of legislation at this situation rather than trying to apply together bits and pieces.
- Sharing of personal information & issues of confidentiality may restrict help.
- I would recommend legislation similar to Kendra’s Law in NY State (Mandatory community treatment).
- Most legislation is OK but there is no single Act that can cover every situation. Don’t spend too much energy on legislation at the local level. Leave it to the lawyers, bureaucrats, and grassroots lobbyists.
- Capacity is an issue. Included is cognitive vs. functional, expense & availability of assessors is a major source of breakdown. The inability of psychiatrists or other duly qualified practitioner to assess capacity in the community is another setback.
- The capacity assessment as cognitive rather than functional clearly needs to be reconsidered.
- The legislation was new material to me. No comments.
- Issues around capacity assessment – cognitive vs functional; the ability of many of the clients to manage on their own is compromised. Needs are overwhelming.

3. Please identify any current service gaps that need to be addressed.

- Coordination/case management.
- Case identification inventory at PHU, CCAC, & hospital ERs.
- Lack of coordinated system.
- Agency specific to this problem with legislative strength and flexibility and an action plan.
- Lack of community treatment orders.
- Central agency to coordinate the service giving-agencies of London to which workers could apply for their clients.
- Identification of services available for easy access by all care providers.
- Centralized agency that could coordinate all other agencies' involvement with at-risk individuals.
- Housing for people who need some assistance but do not have a mental diagnosis – functional capacity challenges – one central agency to collectively address issues.
- Need for greater coordination from all services present – within a case management approach.
- Agencies that provide heavy-duty cleaning with regular follow-up. (Dream on!)
- Public/professional education.
- Community awareness.
- Information sharing and common law.
- Consent/confidentiality.
- Communication between service providers.
- Needs analysis/demographics for funding.
- Access to central registry by all recognized service providers.
- Advocacy services need enrichment.
- Development of a Case Management model.
- More basic needs provision and outreach. e.g. Meals on wheels, clean-up etc.
- Assessments are far from complete, I believe since home care under the CCAC has contracted out services to private companies.

Today's Session

1. What subject matter was most useful to you?

- All – the flow, tangible useful info, excellent setting, planning, facilitator.
- Legislation that is present.
- Case study planning and discussion.
- Conversation during problem solving session.
- Discussion around case studies.
- Dialogues with other community members including private sector.
- All of it. Group case studies with a mixture of agency representatives allowed diverse perspectives.
- Review of legislative framework.
- Opportunity to meet and share ideas with all the service providers and start to see the development of a cohesive group of professionals with shared service interests and motivation to find solutions. The real challenge, of course, is to get people out of “protect my own turf” and be prepared to objectively look at the best, most stream-lined, linear service delivery model.
- Great overview of the issue.
- All topics were useful.

2. What areas were not covered?

- Re: #1 – not limited to seniors.
- Situation needs to be seen as more than geriatric problem.
- I have asked about and wondered about —▶ who is responsible for finding out if squalor conditions are actually part of a ‘disease’ process and not merely a social breakdown? The ‘symptoms’ seem overwhelmingly similar in terms of how this syndrome is played out —▶ higher than average intelligence, hoarding of garbage, lack of caring what others think. I guess it is not an attractive area for researchers but I think there are a lot of questions to be asked. For example, what is the connection between anosmia (lack of a sense of smell) and this syndrome?
- Recommendations/suggestions.
- The reality of agency liability issues in the event that something adverse happens to the individual senile squalor person. Did the agency follow due diligence? Given the case management/holistic approach that was popular, is this a problem?
- Basic needs assessment..
- Funding format & guidelines.
- A number on incidence /prevalence is a real requirement before “Actual” need can be determined. Some needs assessment & risk assessment should be done.

General Comments

- Well done & thank you. You all need to be commended.
- Excellent program – informative – excellent cross-section attending.
- Great forum – could have used more time – however, this should be repeated when the draft action plan is developed.
- Big subject, too little time. Video too long, poor sound quality.
- As always, not enough time. I think a little more time doing the case studies and brainstorming would have been productive.
- Next step is to target what in a very realistic way can and should be done.
- The seminar was most useful bringing a number of support services together.

Recommendations or Suggestions for the Future

- Future opportunities for agencies to come together to problem-solve.
- List of contact persons available to all providers.
- Follow-up session to review action plan.
- Develop implementation phase.
- Develop evaluation phase.
- Develop funding proposal.
- Develop process to include informal community supports.
- Seek out special pilot funding from MOH<C.
- Seek legal opinion on the due diligence question.
- Extend participation to other groups that were not present (e.g. JPs & family physicians).
- How do/would special risk citizens want to be handled?
- Have there been any evaluations done of similar programs (e.g. “Gatekeeper” projects in Iowa, North Carolina, Vancouver)?
- Any intervention research studies, esp. in UK?
- Bring together all agencies/providers once or twice a year to update everyone on changes.
- Things are moving in the right direction.
- Identify 3 priorities. Don’t tackle it all.

- Could (you obtain) some tips on what the climate is in LTC; trends in terms of funding; what is politically most attractive; also proposal guidelines. That would help set the right priorities.
- Would a dual/tri-ministry proposal have more clout?
- Target the current problems with the goal of getting a better safety net in place through teamwork and shared ownership & responsibility.
- I believe a community response should be able to come up with very individualized interventions. I think that there may be a lot of room for paradoxical interventions that legitimize certain behaviours. I think informal support such as family members should be used as much as possible. Indeed, if there is a community response group born of the task force, family members of people diagnosed with “Diogenes Syndrome” should be sought to participate.
- We still need to change the name “senile squalor”. It’s a dreadful term.
- Design & implement a needs assessment.
- A community forum to develop an awareness of the problem and a focus on educational opportunities for interested community people.
- Meeting with MPPs to develop an awareness of how easily people fall through the cracks.

Appendix D - Summaries of Pertinent Legislation

During its deliberations the Task Force reviewed several pieces of current law in Ontario. This appendix is a summary of the legislation. It does not fully detail each act but does provide a short overview.

Mental Health Act

ENACTED

Major amendments were enacted in 1978. The Act was subsequently amended in 1986, and again in 1987. In recent years, the Ontario government has indicated its intention to revise or replace this Act.

PURPOSE

The Mental Health Act was established to govern issues associated with the assessment, admission to hospital, detention, status, rights, and release of persons who may be suffering from a mental disorder.

DEFINITIONS

"mental disorder" means any disease or disability of the mind.

"informal patient" means a person who is a patient in a psychiatric facility, having been admitted with the consent of another person under section 24 of the *Health Care Consent Act, 1996*;

"involuntary patient" means a person who is detained in a psychiatric facility under a certificate of involuntary admission or a certificate of renewal;

"mentally competent" means having the ability to understand the subject-matter in respect of which consent is requested and able to appreciate the consequences of giving or withholding consent;

RELEVANT PROVISIONS

The Act sets out three means whereby an individual may be assessed as to their mental status: 1) by order of a physician under Section 15; 2) by order of a justice of the peace under Section 16; or 3) by action of a peace officer under Section 17. These are summarized in the following table (Provided by Michael Bay, Chair of the Consent & Capacity Board).

| Section 15: By order of a physician | Section 16: By order of a justice of the peace | Section 17: Action by a peace officer |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| If the following 3 requirements are met, any physician in Ontario may order a person to be taken into custody and brought to a psychiatric facility for an assessment of up to 72 hours. | If the following 2 requirements are met, a justice of the peace may order a person to be taken into custody and brought before a physician for a section 15 examination. | If the following 4 requirements are met, a peace officer may take a person and bring the person before a physician for a section 15 examination. |
| The physician has examined the individual within the last seven days. | | The officer has observed the person acting in a manner that in a normal person would be disorderly.* |
| <p>Past/Present Test:</p> <p>The physician must have reasonable cause to believe that the person:</p> <ul style="list-style-type: none"> • Has threatened or is threatening to cause bodily harm to self; or • Has attempted or is attempting to cause bodily harm to self; or | <p>Past/Present Test:</p> <p>The justice of the peace must receive evidence under oath that the person:</p> <ul style="list-style-type: none"> • Has threatened or is threatening to cause bodily harm to self; or • Has attempted or is attempting to cause bodily | <p>Past/Present Test:</p> <p>The officer must have reasonable cause to believe that the person:</p> <ul style="list-style-type: none"> • Has threatened or is threatening to cause bodily harm to self; or • Has attempted or is attempting to cause bodily harm to self; or |

| Section 15: By order of a physician | Section 16: By order of a justice of the peace | Section 17: Action by a peace officer |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> • Has behaved or is behaving violently towards another person; or • Has caused or is causing another person to fear bodily harm from self; or • Has shown or is showing a lack of competence to care for self. | harm to self; or <ul style="list-style-type: none"> • Has behaved or is behaving violently towards another person; or • Has caused or is causing another person to fear bodily harm from self; or • Has shown or is showing a lack of competence to care for self. | <ul style="list-style-type: none"> • Has behaved or is behaving violently towards another person; or • Has caused or is causing another person to fear bodily harm from self; or • Has shown or is showing a lack of competence to care for self. |
| <p style="text-align: center;">The Future Test:</p> <p>The physician must form an <i>opinion</i> as to whether the person is <i>apparently suffering from mental disorder</i> that will <i>likely</i> result in:</p> <ul style="list-style-type: none"> • Serious bodily harm to self; or • Serious bodily harm to others; or • Imminent and serious physical impairment of self. <p>The decision may be based on the physician's own information/examination and/or information from others.</p> | <p style="text-align: center;">The Future Test:</p> <p>The justice of the peace must have reasonable cause to form an <i>opinion</i> as to whether the person is <i>apparently suffering from mental disorder</i> that will <i>likely</i> result in:</p> <ul style="list-style-type: none"> • Serious bodily harm to self; or • Serious bodily harm to others; or • Imminent and serious physical impairment of self. | <p style="text-align: center;">The Future Test:</p> <p>The officer is of the <i>opinion</i> that the person is <i>apparently suffering from mental disorder</i> that will <i>likely</i> result in:</p> <ul style="list-style-type: none"> • Serious bodily harm to self; or • Serious bodily harm to others; or • Imminent and serious physical impairment of self. |
| | | The officer has reasonable cause to believe that it would be dangerous to proceed by way of an application to a justice of the peace. |
| The form is valid for 7 days. | The form is valid for 7 days. | |

* Case law indicates that the term "disorderly" can be interpreted broadly to include behaviour that appears to the police to be "to some extent irrational although not unruly." R. v. O'Brien (1983), 9W.C.B. 270. (Ontario County Court).

In summary, the conditions which may lead to a psychiatric assessment include evidence that the person:

- has threatened or is threatening to cause bodily harm to self; or
- has attempted or is attempting to cause bodily harm to self; or
- has behaved or is behaving violently towards another person; or
- has caused or is causing another person to fear bodily harm from self; or
- has shown or is showing a lack of competence to care for self, and the physician, the justice of the peace, or the peace officer is of the opinion that the person is apparently suffering from a mental disorder that will likely result in:
 - serious bodily harm to the person; or
 - serious bodily harm to another person; or
 - imminent and serious physical impairment of self.

On admission to a psychiatric facility, aside from a psychiatric assessment, an examination of the patient's capacity to *manage personal property* is to be completed. If the person is found not to be capable of managing personal property, the attending physician shall issue a certificate of incapacity and send it to the Public Guardian & Trustee.

An assessment of the person's capacity to make self-care decisions cannot be made under the Mental Health Act.

RIGHT of ACCESS

The Act provides a right of access by way of an order issued by a justice of the peace that the person be taken into custody and brought before a physician for an assessment. If a peace officer has reasonable cause to believe that it would be dangerous to proceed by way of an application to a justice of the peace, the peace officer has the authority to apprehend the person and take them before a physician for a section 15 examination.

ISSUES

- Past or chronic behaviours are difficult to assess.
- Family and friends cannot easily make input into the overall assessment.
- Home visits are not required.
- Even if the person is “formed”, they might be released in only a few hours.
- JP’s are not consistent; some JP’s may be unfamiliar with the Mental Health Act.

Substitute Decisions Act

ENACTED Passed in 1992

PURPOSE

Addresses the issue of mental capacity or incapacity to make decisions regarding *personal property* or *personal care*. It provides a process for assessing capacity. It also provides for the appointment of substitute decision-makers by individuals if they have capacity, or by others if they lack capacity.

DEFINITIONS

Mental Incapacity means that the person is unable to understand information that is relevant to making a decision or is unable to appreciate the reasonably foreseeable consequences of a decision or lack of a decision with respect to management of the person's property or personal care.

RELEVANT PROVISIONS

- A person who has the capacity to make property or personal care decisions can give a *power of attorney* to an individual making them a *substitute decision maker* able to act if the grantor is not.
- The Public Guardian and Trustee is required to investigate any allegation that a person is incapable of **managing property** and that serious adverse effects are occurring or may occur as a result. If, as a result of the investigation, the Public Guardian and Trustee believes that a person is incapable of managing property and that a temporary guardian of property is required immediately to prevent serious adverse effects, PGT shall seek a court order appointing him or her as **temporary guardian of property**.
- A person may request a capacity assessment to determine if the PGT should be appointed another person's statutory guardian of property, if they have reason to believe that another person may be incapable of managing property, does not know of any previously appointed attorney, and does not know of any spouse, partner, or relative who might apply to be appointed the person's guardian of property.
- An assessor may issue a certificate of incapacity if indicated by their assessment.
- "A person is incapable of personal care if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, nutrition, shelter, clothing, hygiene or safety, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of decision."

- The Public Guardian and Trustee is required to investigate any allegation that a person is incapable of **personal care** and that serious adverse effects are occurring or may occur as a result. If, as a result of the investigation, the Public Guardian and Trustee believes that a person is incapable of personal care and that a temporary guardian is required immediately to prevent serious adverse effects, PGT shall seek a court order appointing him or her as **temporary guardian of the person**.
- The court may only make an order for full guardianship of the person if it finds that the person is incapable in all of the following domains: nutrition, health care, shelter, clothing, hygiene, and safety.
- If the guardian of the person has custodial power over the person, the court may authorize the guardian to apprehend the person with police assistance.

CAPACITY ASSESSMENT

Capacity Assessors complete their assessment based upon the following domains:

- Property
- Personal Care
 - Nutrition
 - Health Care
 - Shelter
 - Clothing
 - Hygiene
 - Safety

RIGHT OF ACCESS

An assessment requires a person's consent unless it is court ordered.

- ISSUES
Cost is typically between \$80.00 and \$160.00 per hour. If an individual requires financial assistance, application can be made to the Capacity Assessment Office at the Office of the Public Guardian and Trustee.
- Who pays?
- Streamlining the process

Health Protection & Promotion Act

ENACTED Took effect July 1, 1984 replacing the Public Health Act

PURPOSE

"The purpose of this Act is to provide for the organization and delivery of public health programs and services, the prevention of the spread of disease and the promotion and protection of the health of the people of Ontario."

DEFINITIONS

Under the Act:

"*health hazard* means,

- (a) a condition of a premises
- (b) a substance, thing, plant or animal other than man, or
- (c) a solid, liquid, gas or combination of them, that has or that is likely to have an adverse effect on the health of any person."

"*health unit* means an area that, by or under any Act, is the area of jurisdiction of a board of health."

RELEVANT PROVISIONS

This act provides for the delivery of a wide range of health services by local boards of health including community

sanitation, control of communicable diseases, and family health (includes programs directed to high-risk health categories and the elderly).

Section 10. (1) requires the medical officer of health to "inspect or cause the inspection of the health unit served by him or her for the purpose of preventing, eliminating and decreasing the effects of health hazards in the health unit." Furthermore, the Act allows that the MOH/PHI "by a written order may require a person to take or to refrain from taking any action that is specified in the order in respect of a health hazard." This would be the case where the MOH/PHI "is of the opinion, upon reasonable and probable grounds,

- (a) that a health hazard exists in the health unit served by him or her; and
- (b) that the requirements specified in the order are necessary in order to decrease the effect of or to eliminate the health hazard."

These provisions give the Medical Officer of Health/Public Health Inspector extensive powers to address health hazards. Orders may require whatever is necessary in the circumstances up to and including vacating of the premises. It may include requiring specific work to be completed including removal, cleaning, disinfecting, or destruction of anything found to be a health hazard.

In the case of non-compliance with an order, the MOH may issue directions to staff to undertake the activities contained in the order. Cost for removal of the health hazard may be recovered through court action or by collection through property taxes.

RIGHT OF ACCESS

Part V of the Act deals with *Rights of Entry*. It provides for the MOH or a Public Health Inspector to enter any premises for purposes of the Act or its enforcement, duties, or directions. At the same time, it does not provide authority to enter a private residence *without the consent of the occupier*. If entry is refused by the occupier, the MOH/PHI may apply to a Justice of the Peace for a warrant. Such warrant may be executed with police assistance.

Tenant Protection Act

ENACTED November 1997

PURPOSE

Governs residential tenancies in Ontario. Defines rights and obligations of landlords and tenants, and specifies the means of resolution of issues.

RELEVANT PROVISIONS

Right of Access

A landlord may enter a rental unit at any time in case of an emergency or with the tenant's consent. As well, the landlord may enter a rental unit under the following circumstances:

- Without notice to clean if the tenancy agreement requires the landlord to clean the rental unit at regular intervals;
- Without notice between 8:00 a.m. and 8:00 p.m. to show the unit to prospective tenants if the landlord and tenant have agreed that the tenancy will be terminated;
- With 24 hours written notice to effect repairs;
- Written notice must specify the reason for entry as well as the date and time between the hours of 8:00 a.m. and 8:00 p.m.

Additional Responsibilities of Tenant

Under Section 29, 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.

Early Termination of Lease

Sections 61 to 67 deal with early termination of the lease by the landlord. Reasons include termination for cause as the result of *behaviour which substantially interferes with the reasonable enjoyment* of the residential complex by other tenants, or if the tenant *seriously impairs* the safety of others.

London & Middlesex Housing Authority (LMHA) Lease (Tenancy Agreement)

Tenancy agreements may contain additional provisions. In the case of the London & Middlesex Housing Authority, the additional clauses are as follows:

Tenants Obligations:

(8) The Tenant is responsible for ordinary cleanliness of the Leased Premises and shall notify the Landlord immediately of the presence of pests in the Leased Premises or the Residential Complex.

SCHEDULE "B"

3. The Tenant's personal property shall be in a clean and sanitary condition and shall be free from household pests. The Landlord may inspect the Tenant's personal property before it is moved into the Leased Premises, and may require the Tenant to have it treated at the Tenant's own expense and to the satisfaction of the Landlord, to ensure that household pests have been eliminated. The Landlord, between the hours of 8 am and 8 pm, shall have the right to enter the Leased Premises, upon giving twenty-four (24) hours prior written notice to the Tenant, to inspect the sanitary conditions of the Leased Premises and the Tenant's personal property, and to perform, when necessary, in its opinion, and at the Tenant's expense, all appropriate pest control treatments required to eliminate household pests from the Leased Premises and the Residential Complex.

Enforcement

Ontario Rental Housing Tribunal

ISSUES

- Once evicted, the individual may well carry on with the same behaviours that led to the eviction.
- The Sheriff may call the Public Guardian & Trustee to assist an individual at the time of eviction.
- The problem likely began prior to being housed and there is no current mechanism to allow for an initial assessment.
- Where does responsibility reside after an eviction?
- What is the situation with private landlords vs. LMHA? To what extent are there evictions for property or self-care reasons in the private sector?
- The usual means of identifying a problem is some physical manifestation (e.g. smell)

Long Term Care Act

ENACTED

Passed in 1994; Amended in 1996, 1997, and 1998

Regulations under the Act were announced in July 1999

PURPOSE

The purposes of this Act are:

- To ensure that a wide range of community services is available to people in their own homes and in other community settings so that alternatives to institutional care exist;
- To provide support and relief to relatives, friends, neighbours and others who provide care for the person at home;
- To improve the quality of community services and to promote the health and well-being of persons requiring such services;
- To recognize, in all aspects of the management and delivery of community services, the importance of a person's needs and preferences, including preferences based on ethnic, spiritual, linguistic, familial and cultural factors;
- To integrate community services that are health services with community services that are social services in order to facilitate the provision of a continuum of care and support;
- To simplify and improve access to a continuum of community services by providing a framework for the development of multi-service agencies;
- To promote equitable access to community services through the application of consistent eligibility criteria and uniform rules and procedures;
- To promote the effective and efficient management of human, financial and other resources involved in the delivery of community services;
- To encourage local community involvement, including the involvement of volunteers, in planning, coordinating, integrating, and delivering community services and in governing the agencies that deliver community services;
- To promote co-operation and co-ordination between providers of community services and providers of other health and social services;
- To ensure the co-ordination of community services provided by multi-service agencies with those services offered by hospitals, long-term care facilities, mental health services, health care professionals, and social service agencies, and to promote a continuum of health and social services.

HOME CARE SERVICES

Under this Act, Community Care Access Centres provide home care (nursing and other professional services, personal support services, and homemaking services) based on the assessment of client need completed by CCAC staff. *Homemaking Services* include housecleaning, doing laundry, ironing, mending, shopping, banking, paying bills, planning menus, and preparing meals. *Personal Support Services* include personal hygiene activities, and routine personal activities of living.

The CCAC of London-Middlesex is not expected to provide these home care services if the primary reason for the services being required is due to a mental illness.

ISSUES

- In cases of senile squalor, it is not always clear whether there is a mental illness.
- Homemaking support is not always available to individuals who require it.
- The types of homemaking services currently available may not be appropriate to cope with the extent of squalor in which an individual may be living.
- There appears to be a shortage of trained homemakers.

Fire Protection and Prevention Act, 1997

This Act governs the operation and responsibilities for the protection and prevention of fire in Ontario. It specifies the powers and authority of fire department personnel in fighting a fire or in undertaking inspections.

RIGHT OF ACCESS

The Act provides firefighters authorized by the fire chief or the Fire Marshall to enter lands or premises without a warrant for the purpose of fighting a fire or to provide emergency or rescue services or to remove or reduce serious threat to the health and safety of any person,

“The Fire Marshal or a fire chief may, without a warrant, enter on land or premises if a fire has occurred on the land or premises; or he or she has reason to believe that a substance or device that is likely to cause a fire may be situated on the land or premises.”

14.(6)Warrant authorizing entry

14.(6) A justice of the peace may issue a warrant authorizing the Fire Marshal or a fire chief named in the warrant to enter on land or premises and exercise any of the powers referred to in subsection (2) or (3) if the justice of the peace is satisfied on evidence under oath that there are reasonable grounds to believe that entry on the lands or premises is necessary for the purposes of conducting an investigation into the cause of a fire or of determining whether a substance or device that is likely to cause fire is situated on the land or premises and,

An inspector may, without a warrant, enter and inspect land and premises for the purposes of assessing fire safety. An inspector who enters land or premises under this section may take with him or her a police officer or such other person as he or she considers advisable to assist. A warrant may be issued by a justice of the peace if the inspector is denied access.

Municipal By-laws

The City of London has enacted By-Law CP-16 which prescribes:

Standards for the Maintenance and Occupancy of Property

This by-law, also known as *the Property Standards Bylaw*, among other things deals with exterior property areas. It requires exterior property areas to be “maintained in a neat and tidy condition” including the removal of “rubbish, garbage, brush, waste, litter, and debris”. It also specifies specific requirements for dwelling units and provides that all buildings “shall be kept free of rodents, vermin, and insects”.

The Property Standards Bylaw may be relevant to senile squalor in the case of owner occupied dwellings.

Appendix E- Special Risk Recluse Activities

The Middlesex-London Health Unit policy on **Special Risk Recluse Activities** and the protocol for the **Special Risk Assistance Funding** are included for information.

**MIDDLESEX-LONDON HEALTH UNIT
ENVIRONMENTAL HEALTH DIVISION**

ADMINISTRATION MANUAL

SUBJECT: Special Risk Recluse Activities
SECTION: Health Hazard Investigation

POLICY NUMBER: 3-101
PAGE: 1 of 2

IMPLEMENTATION DATE: October 8, 1991
REVISION DATE: April 16, 1997
March 13, 2000

APPROVED BY: Division Director
SIGNATURE

PURPOSE

To ensure that reports about Special Risk Citizens are promptly investigated as to the validity and resolved through actions by the Environmental Health Division, by referral to another agency, or monitored in conjunction with the CCAC and Public Health Nursing.

POLICY

Reports registered with the Environmental Health Division about suspected Special Risk Citizens will be investigated and monitored by the assigned Public Health Inspector in accordance with the procedures noted below.

DEFINITION

“Special Risk Citizens” are defined as:

- persons who are suffering from grave chronic illness, and,
- persons being aged, infirm or physically incapacitated, and
- persons living in unsanitary, unsafe conditions, and/or
- persons who are unable to devote to themselves, proper care and attention and are not being
- taken care of by any specific organization or will not accept active care.

PROCEDURE

1. Complaint/Referrals are generally registered with the Duty PHI and/or district PHI from various sources. (eg. neighbours, relative, other social agencies)
2. Complaint documentation is to follow same protocol as any other complaint.
3. The District PHI conducts the initial investigation. After the initial investigation, the District PHI must decide if the person involved in the complaint fits the definition of the “Special Risk Citizen” (SRC).

4. If the case is not consistent with the SRC definition, the PHI will continue to deal with the situation.
5. If the case is consistent with the SRC definition, the case will be assigned to the PHI assigned to deal with the SRC Program.
6. The assigned PHI will continue to investigate the situation in order to determine:
 - the nature of the SRC's problem. (ie. medical, social, housing, sanitation, etc.)
 - persons or agencies who may have contact with the SRC. (eg. relatives, friends, neighbours, physician, social, housing, sanitation, etc).
 - prospects for resolving or enhancing SRC's situation.
7. Cases of SRC's will be entered into the Special Risk Register in the computer in the Environmental Health Division. (Confidentiality to be protected through access restrictions)
8. Individual files will be created for each SRC in order to manage documentary information. All time spent on monitoring SRC's would be recorded under their file number.

NOTE: Preliminary investigations of suspected SRC's will be recorded under Activity Number 009-056.

9. Referrals will be made to appropriate personnel within the Health Unit when necessary. For example, concerns for medical assessment and ongoing medical monitoring, may be referred to Public Health Nursing.

Case management will involve discussion between Environmental Health and Public Health Nursing representative in regular meetings of the Special Risk Action Team. This team allows for the structured sharing of information in order to facilitate effective and efficient case management decisions.

10. Routine monitoring of SRC's by the assigned PHI will be scheduled according to need. The minimum frequency will be two times per year.
11. When it is evident that our assistance is no longer required, the file would be closed and the contents placed in a street file. These inactive files would be retained for 6 months, then destroyed, if no further intervention required.

NOTE: Files may be closed due to death of SRC, placement in long-term care facility, sanitation/care concerns have been resolved.

A General Administrative File is maintained for the Special Risk program under File #31911.

SPECIAL RISK ASSISTANCE FUNDING

TO RECEIVE FUNDING, THE FOLLOWING PROTOCOL WILL APPLY:

1. Request for funding must be through a government or social agency.
2. Person or persons to receive assistance must meet the definition for "Special Risk Citizen" which is defined as:
 - Persons who are suffering from grave chronic illness
 - Persons being aged, infirm or physically incapacitated
 - Persons living in unsanitary, unsafe conditions, and/or
 - Persons who are unable to devote to themselves, proper care and attention and are not being taken care of by any specific organization or will not accept active care.
3. When a location for assistance has been identified, a call is to be placed to Hugh Goodfellow, Environmental Health Division, Middlesex-London Health Unit (663-5317, ext. 2467; Fax: 663-9581).
4. An inspection of the premises will be carried out by Hugh Goodfellow in the company of the caller, their representative and an estimated time period for clean-up will be established.
5. This funding is available on a one time only basis and prior to a clean-up program beginning, there will be a plan to prevent a reoccurrence of the problem.
6. The proposal for funding will be presented to the Director of Environmental Health Division, Middlesex-London Health Unit for approval.

SAMPLE

**SPECIAL RISK ASSISTANCE FUND
REFERRAL FORM**

Forwarded to Hugh Goodfellow
Phone: 663-5317, ext. 2467; Fax 663-9581

NAME OF CLIENT: Ima Messe **DATE OF REF:** June 24, 1999

ADDRESS: Do Drop Inn **POSTAL CODE:** HOH OH0

PHONE: No phone

CONTACT PERSON & AGENCY: Lotta Hope **PHONE:** 668-2395
London Support Services

REASON FOR REFERRAL:

Due to physical ailment (recovering from pneumonia) and present mental state Ima is overwhelmed and lacks motivation to bring unit up to satisfactory living conditions. Limited finances/lives alone/no friends or family supports. Unit has safety/fire/environmental/health issues. Tenure in jeopardy.

DATE OF JOINT INSPECTION: June 28, 1999
(HEALTH UNIT & REFERRAL AGENCY)

PERSON COMPLETING INSPECTION: Hugh Goodfellow

PICTURES TAKEN: YES NO

PROPOSED DATE OF CLEAN-UP: June 30, 1999

ESTIMATED COST OF CLEAN-UP: Cleaning of appliances
Kitchen area cleaning
Removal of debris from unit
Bathroom cleaning
Laundry
Bedroom cleaning
Living room cleaning
Cleaning supplies

TOTAL COMBINED COST: \$206.79

PROPOSED PLAN TO PREVENT REOCCURANCE AND FOLLOW-UP: Scheduled weekly visit from London Support Services to support client with maintaining unit. Additional support initially to assist client with present physical and emotional care.

Appendix F - The Gatekeeper Model

At-risk individuals are frequently unwilling to seek assistance and it is difficult to determine the number of individuals who might be characterized as being at-risk. Often the means of identification is after the situation reaches a crisis: complaints from neighbours, hospitalization, fire, or an eviction. Earlier identification can lead to earlier appropriate interventions and hopefully timely resolution of the situation.

Raymond Raschko, Elder Services Director at the Spokane Community Mental Health Centre, developed “the Gatekeeper Model” in 1978. The model is an interesting and promising proactive approach to case finding that has now been widely implemented in the United States.

What is the Model?

The Gatekeeper Model was developed as part of research efforts that focused on the needs of isolated and at-risk older adults. The model is intended to facilitate early identification of at-risk older adults by enlisting the active involvement of a broad cross-section of the community. Individuals who have routine contact with persons who might be at-risk serve as non-traditional referral sources. These individuals are known as Gatekeepers. Included are mail carriers, meter readers, bank tellers, firefighters, police officers, neighbours, phone and cable installers, property managers, etc.

Gatekeepers receive an orientation to risk factors that they might observe during their routine contact with older adults and are provided with an easily accessed and confidential means to make a referral. The signs of risk might include:

- Personal appearance
- Mental/emotional state
- Personality changes
- Financial problems
- Suicide clues
- Condition of the home
- Physical losses
- Social problems
- Caregiver stress

Once identified, Gatekeepers make a referral to a case-management team that responds with a face-to-face contact and completes an assessment and evaluation.

A consortium of agencies in Niagara Region currently has a Gatekeeper Program in place with financial support from the Ontario Trillium Foundation. Referrals may be made by phone or using the Internet. Referrals are assessed by an intake committee and passed on to the most appropriate service for follow-up.

An evaluation of the effectiveness of the model in Niagara is currently under way.

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