

Focus on...

# Hoarding Behaviour

April 2016

People with hoarding behaviours have difficulty parting with possessions that may seem to have little value to others. When this is significant the expanding clutter disrupts their ability to appropriately use some or all of the areas of their home. When extreme, hoarding behaviours can result in fire risk, squalor, infestation and/or structural collapse. Concerns impact not only the individual but family, neighbours, and professionals, including fire fighters.

Many of us collect. Some may live chaotically. The images below illustrates the spectrum in which this can occur.



Average saving

Collecting

Cluttering

Hoarding

## KEY FACTS & FIGURES

**5% of hoarders come to the attention of professionals**  
2008

**Between 4,000 and 11,000 people in Islington may be experiencing measurable hoarding behaviours**  
based on a 2008 national estimate

**272 hoarding related fires in Islington**  
between 2010 and 2015

**10 fatalities and 41 hoarding related injuries in Islington**  
between 2010 and 2015

**£10,000+ tenancy intervention costs**  
London Borough of Islington estimate

## KEY POPULATION GROUPS

While 50% of people with hoarding behaviours will have someone with hoarding or Obsessive Compulsive Disorder in their family, there is no distinction between age, gender, ethnic group, socio-economic status, educational, and/or occupational tenure who experience hoarding behaviours.

## WHAT IS HOARDING DISORDER?

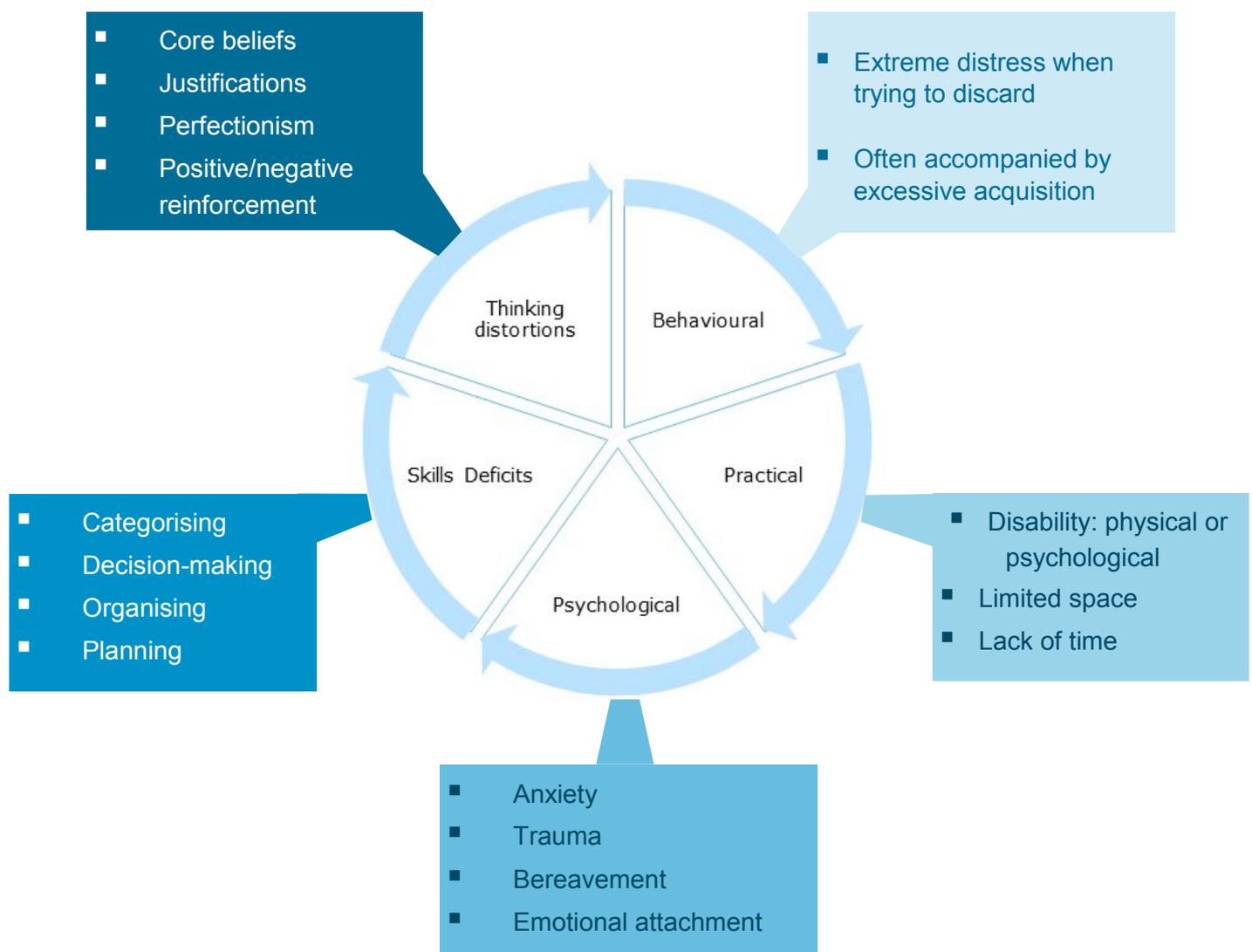
Hoarding is defined as difficulty in discarding items which may seem to have little or no value to others. The resulting clutter can mean that living spaces are unable to be used as intended. People may not be able to sleep in their bed, cook and/or carry out other basic functions. This can also create a significant risk to self and/or others.

Hoarding Disorder was recognised in the United States with the publication of the Diagnostic Statistical Manual (DSM-V) in 2013. It is expected that it will also be included in International Classification of Diseases (ICD) in 2016/17. However not all professionals in the United Kingdom currently recognise hoarding as a clinical disorder.

Many people with hoarding disorder also face other psychological challenges, including depression, anxiety, attention deficit/hyperactivity, psychosis and dementia. Traumatic and stressful life events such as bereavement can often trigger increased hoarding behaviours. Hoarding behaviour is also associated with distinct abnormalities of brain function and neuropsychological performance, distinct from those seen in people with Obsessive Compulsive Disorder or other disorders.

## What influences hoarding behaviour?

The diagram below illustrates some of the recognised causes and effects of hoarding behaviour.



Reproduced from Hoarding UK (2012) based on Steketee & Frost (2007)

# WHY ARE WE CONCERNED ABOUT HOARDING BEHAVIOURS?

## High risk of fire and harm

The accumulation of combustible materials, such as newspapers, clothing, aerosols and rubbish creates fire safety concerns.

People with significant levels of hoarded materials are more likely to die in fires when they occur due to difficulties presented during escape and access by firefighters. There is also a significant level of fire loading caused by the amount of combustible material and sources of ignition and increased risk of fatalities from asphyxiation.

## Increased risk of structural damage

Structural damage may occur through concealed damage, such as leaks which can cause damp and structural decay. Structural damage threatens the occupants, neighbours, emergency services personnel and adjacent buildings.

## Health and wellbeing

The storage of hoarded items makes maintaining a hygienic environment challenging, which can lead to unsanitary living conditions, infestation including harbourage of rats and mice and increased risk of disease. As well as impacting on people experiencing hoarding behaviours, this can also affect carers, families and neighbours.

People experiencing hoarding behaviours may also be at increased risk of eviction.

## ASSESSING RISK: THE CLUTTER IMAGE RATINGS SCALE

Reports to statutory services of how hoarding behaviours manifest are assessed against the risk posed to the individual with hoarding behaviours and the impact caused to others.

The Clutter Image Ratings scale is a recognised tool which works to standardise risk assessments, and is currently used by the London Fire Brigade. This can be used across all services in commonly describing the degree of the problem.



Reproduced from Steketee, G. and Frost, R (2007) Compulsive Hoarding and Acquiring: Therapist Guide (Treatments That Work). Oxford University Press

## TREATMENT

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Hoarding behaviours can be difficult to address due to varying degrees of both client and professional understanding of the disorder and the multi-agency nature of the issues associated with dealing with hoarding. A focus purely on housing, health and safety issues, for example blitz cleans and/or evictions have limited degrees of success because they fail to address the underlying psychological issues for the individual.

There are no easy treatment pathways and resolution of hoarding situations normally require intensive and long-term intervention to resolve.

Psychological interventions have limited success, although Cognitive Behavioural Therapy (CBT) is currently the recommended treatment. A special form of CBT has been developed to treat hoarding mainly in the USA and this has been tried at the South London and Maudsley NHS Foundation Trust.

The shortage of effective treatment options and early intervention/assistance strategies and a lack of awareness or knowledge within social care, clinical and public services can exacerbate hoarding behaviour. Evidence suggest that the most effective interventions to support those experiencing hoarding behaviour is through coordinated multi disciplinary training and client-led therapy.

## Safeguarding Care model

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The Care Act (2014) Care and Support Statutory Guidance recommends safeguarding self-neglect and hoarding. This entitles individuals who experience substantial difficulty in engaging, and who have no-one who is willing or able to represent them, to be referred to statutory Care Act advocacy provision.

It is now a statutory requirement to establish adult safeguarding boards.

Anyone who is facing eviction should be provided with appropriate representation via a legal aid funded solicitor.

## NATIONAL & LOCAL STRATEGIES

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Other than some local authority protocols and NICE guidelines on Obsessive Compulsive Disorder and the Clutter Index Rating Scale, there are limited national and local resources or strategies.

NATIONAL STRATEGIES	LOCAL STRATEGIES
<p><b>National Institute of Care Excellence guidelines on Obsessive Compulsive Disorder 2005</b></p> <p>Covers what treatments may be offered including psychological therapies and medication.</p>	<p><b>Islington Hoarding Protocol 2015</b></p> <p>A joint working protocol that health, social care, public health and voluntary and community sector organisations have developed to help support individuals with hoarding related behaviours.</p>
<p><b>British Psychological Association Guidance 2016</b></p> <p>Sets out recommendations of how mental health and social care services should provide support for people with hoarding difficulties.</p>	<p><b>Islington Integrated Care Pioneer Program</b></p> <p>This strategy sets out the need and benefits of integrated care through health, social care, public health practitioners and voluntary and community sector organisations working collectively and collaboratively.</p>
<p><b>Care Act 2014</b></p> <p>Act which regulates the provision of care and support and introduces a shift from service-led provision to person-centred outcomes.</p>	

# THE ISLINGTON PICTURE

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## Key issues for Islington:

- No commissioned treatments/clinical pathways or clinical options available for hoarding
- Agencies working disjointedly or in isolation with no clear pathway to integrated support
- Improving advocacy for clients, particularly those considered to have capacity and in good mental health
- Improving referral pathways to services for clients seeking support with hoarding behaviours

## Existing programmes and services:

- Islington Adult Safeguarding Board: The Islington Hoarding Protocol recommends invoking safeguarding at level five on the Clutter Index Rating Scale and/or in instances where there is accumulation of combustible, hazardous materials or in dwellings impacted by squalor, vermin or infestation.
- Single Homeless Project: provides floating mental health support and specialist hoarding workshops
- Adult Social Care Rehabilitation and Recovery Team: enables people with complex needs to live safely in the community
- Tenancy Support Teams within Islington housing services
- Islington Hoarding Support Group
- Third sector support via Hoarding UK and Mind Re-ablement

## What is being done locally to address the issue?

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The Islington Hoarding Protocol has been developed by a cross-sector partnership including health, social care and public health practitioners and manager, and provides a platform for the following activities:

### Joint-working mechanisms

Islington Hoarding Protocol sets out joint-working mechanisms for services including social landlords, mental health services, adult social care and statutory services.

### Forum to identify solutions to complex cases

Islington Hoarding Panel provides a forum for organisations to present difficult cases and identify solutions in partnership with other services.

### Islington Hoarding Support Group - Single Homeless Project

Professional led, free to attend group which can help reduce acquisition and support self-led de-cluttering. The group provides advocacy support and referral.

### Sharing information

Facilitating information sharing where legal to protect individuals and property, such as notifying the fire and rescue services so that the premises with high fire loading can be flagged so that sufficient number of fire appliances can be dispatched to reports of fire incidents.

### Cross-disciplinary training

Islington Hoarding protocol sets out the need for cross disciplinary training to raise awareness of the joint working protocol and share good practice in supporting those with hoarding behaviour.

## WHAT WORKS?

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- Effective intervention requires appropriately skilled and early psychotherapy in conjunction with housing support and engagement of a number of other services and agencies
- Training for clinicians, mental health professionals and social workers
- Training for other agencies, such as health visitors and other public health professionals
- Commissioned clinical treatments for hoarding
- Joint-working protocol and panel mechanism to encourage early identification, intervention and a clear multi-disciplinary approach.
- Enhanced training for individuals, carers and families

## FUTURE DEVELOPMENT

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- Improving clinical diagnosis of hoarding behaviours
- Training of all consultant psychiatrists, health and social care professionals and other stakeholders to raise awareness and embed technical knowledge
- Better data collection on the prevalence of hoarding behaviour locally
- Dedicated clinical treatment services
- Increased awareness and understanding of the Islington Hoarding Protocol and self-care aspect of the Care Act 2014
- Ensuring recommended pathways are understood and actioned by all agencies and services

## TARGETS & OUTCOMES

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There is a lack of data on data and evidence on diagnosed hoarding disorder, locally and nationally and no formal targets or outcomes for supporting individuals.

Target	Document or strategy that target is taken from
<b>Appropriately skilled professionals across health, social care, public health and the Voluntary and Community Sector in responding to hoarding behaviour</b>	<b>Islington Hoarding Protocol</b>
<b>Treatment pathways available to residents with hoarding related behaviours</b>	<b>Islington Hoarding Protocol</b>
<b>Preventing delay in accessing treatment among complex cases of hoarding behaviour, and reducing the associated costs.</b>	<b>Islington Hoarding Protocol</b>

## FURTHER INFORMATION

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Further information on this topic can be found at the following locations:

- **British Psychological Society (2015): A Psychological Perspective on Hoarding**

Available at: [http://www.bps.org.uk/system/files/Public%20files\\_a\\_psychological\\_perspective\\_on\\_hoarding.pdf](http://www.bps.org.uk/system/files/Public%20files_a_psychological_perspective_on_hoarding.pdf)

- **Islington Hoarding Protocol (2015)**

Available at: [http://www.islington.gov.uk/publicrecords/library/Public-health/Team-management/Collaborate-to-publish/2015-2016/\(2016-03-12\)-Islington-Hoarding-Protocol.pdf](http://www.islington.gov.uk/publicrecords/library/Public-health/Team-management/Collaborate-to-publish/2015-2016/(2016-03-12)-Islington-Hoarding-Protocol.pdf)

- **Chartered Institute of Environmental Health: Professional Practice Note (2015).**

Available at: [http://www.cieh.org/policy/hoarding\\_and\\_how\\_to\\_approach\\_it.html](http://www.cieh.org/policy/hoarding_and_how_to_approach_it.html)

- **Karnes, M, Within the Context of the Social Model of Disability: Finding a Way Forward**

Anticipated publication date May 2016

- **NHS Choices: Hoarding Disorder**

Available at: <http://www.nhs.uk/Conditions/hoarding/Pages/Introduction.aspx>

## About the Evidence Hub

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The Evidence Hub is a partnership between the local NHS and Islington Council that brings together information held across different organisations into one accessible place. It provides access to evidence, intelligence and data on the current and anticipated needs of the Islington population and is designed to be used by a broad range of audiences including practitioners, researchers, commissioners, policy makers, Councillors, students and the general public.

This profile has been produced by Ellis Turner, Environmental Health Manager and Megan Karnes, Director Hoarding UK. It has been signed off by Denise Brend, Head of Service Housing Operations.

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