What Is Compulsive Hoarding?

- The acquiring of and failure to discard a large number of possessions that appear to be useless or of limited value.
- Living spaces sufficiently cluttered so that the clutter precludes activities for which those spaces were designed.
- Significant impairment in functioning or distress caused by the hoarding.
Why Is Hoarding A problem?

**The Individual Problems**

- A high % of people suffer physical injuries in hoarded households, due to slips, trips & falls.
- People have been incorrectly diagnosed (OCD) in the past
- There is not a recognised support structure in place – where do you go for help?
- Stigma
In 2013, Hoarding Disorder was recognised as a Mental Health Disorder – it had previously been thought of as a personality disorder or a ‘lifestyle’ choice.

It is thought to affect between 2% - 5% of the population – that’s anywhere between 1.26 million and 3.78 million people in the UK.
Other than dementia, hoarding may be the only psychiatric disorder that actually increases in severity and prevalence throughout life course – growing ageing population!

Only 5% of people with Hoarding Disorder come to the attention of Mental Health Service….the other 95% remain untreated or misdiagnosed.
Why is Hoarding a problem?

**Individual**

**Housing**
The Housing Problems...

- It causes significant damage to the physical make up of our properties
- Some of the enforcement routes that were available to Housing are now harder to implement. Hoarding Disorder is now a recognised Mental Health Disorder
- It can lead to death – 1 in 4 Fire Fatalities involve hoarded households
- Safeguarding Guidance under Care Act 2014
- It costs a lot of money – it causes a significant drain on Housing budgets
Cost to Housing

- Missed Gas Appointments (£1,500)
- Disruption to planned replacement programmes (£4,000)
- Potentially costs due to eviction & court action (£6,500)
- Clearance Costs (£3,500)
- Repairs required to the property after the clearance (£6,500)
- Long Voids (£1,800)
- Relet Costs (£800)
- Staff Time (£10,000)

£35,000 - £50,000 per hoarder
How Housing Deals with Hoarding
Case Study – How Housing Deals With Hoarding

- A single male who became an LHT tenant in 1988
- He would acquire items from local bins and skips
- He found it extremely difficult and distressing to discard items
- He couldn’t use his property and the rooms within them for their intended purpose
- Sufferer of Hoarding Disorder but never treated for this
- LHT provided skips and contractors to clear the hoard after many attempts to make the tenant do it themselves
Case Study – How Housing Deals With Hoarding

AFTER

BEFORE

DURING
The hoard didn’t just return – it got worse

He began ‘Animal Hoarding’ and had in excess of 15 stray cats in his property

Between 1988 and 2011 LHT moved him twice due to hoarding as his flats became unliveable and dangerous

His Hoarding Disorder was never dealt with and ultimately he was evicted from his third tenancy in 2011

The cost to LHT over this period of time was in excess of £75,000 approx.
It has been found that people with Hoarding Disorder react differently to people who don’t suffer from the disorder when threatened:

- They would build back up their ‘comfort blanket’
  - replace what is missing
  - acquire more
  - Attempt to feel more at ease with the anxiety that they have been facing
Why is it Difficult for People to Discard Possessions?

We all like to keep control of our possessions – nobody likes having the control taken away from them.
Why Can’t Hoarders Keep Things Neatly Stored Away?

- Failure to retain information – they are visually stimulated.
- They create and build up a pile of ‘information’
  - “I’ll need to keep that because….”
- They need to be kept in view
  - “Out of sight, out of mind!”
- Then they just keep adding to the pile
Why Do Hoarders Bring Rubbish Home?

“That can’t go to waste – someone will need that – I’ll take that home…”

“I’ve got a hose pipe – but if that one gets damaged – I’ll need another – I’ll take it home just in case…”

“Fantastic, Joe’s got a new car – he’ll need a few spares at some point – I’ll take it home for when he needs them…”
Case Study - Reflection

- The problem was made worse – the hoarding behaviour was further embedded in this individual

- Threats of Eviction didn’t help – and often don’t when dealing with a Mental Health Problem – they often make it worse

- Tenancy Enforcement proved to be a waste of time and a waste of money – but we didn’t know that at the time – we know now – that’s why we need a different way to work.
Our approach to dealing with hoarders

Our approach to supporting hoarders
We had a number of complex Tenancy Support cases who were struggling with the number of possessions they had in their homes.

We didn’t have anywhere to go to get help/support – no specialists in Hoarding Disorder, GP’s saying it was a ‘lifestyle’ choice.

We had a huge task – we wanted to help people, but when we spoke to them we noticed that they were feeling a range of emotions:

- Scared
- Embarrassed
- Overwhelmed
And **Overwhelmed** was the thing that we latched onto and could empathise with – it was a huge task ahead of them – they wanted to make changes to the way they were living and feeling – but where do you start!!!

- The task seemed too big, too overwhelming
- We felt that the hoard needed to be broken down into smaller, more manageable tasks
- We sectioned the room or area that they wanted to work on
- We focused them by using pledges

We ended up producing our **Outside The Box** approach
Outside The Box Toolkit
The LHT Outside the Box Toolkit includes everything that is required to support a tenant suffering from Hoarding Disorder.

The Toolkit separates the property into 4 general areas (Kitchen, Bathroom, Bedrooms & Living Areas) to break the hoard down into smaller, more manageable and less intimidating areas.
Outside The Box Toolkit

LHT Outside The Box splits the process of managing a hoard within each room into 3 stages:

**STAGE 1 - BOXED IN**

**STAGE 2 - SORTING**

**STAGE 3 - BOXED OFF**
The first stage of the process is called ‘Boxed In’. This is generally the point in time when the hoard is causing distress to the tenant and having a significant impact on their health and wellbeing and they have lost the ability to utilise their property and the rooms within it for their intended purpose.
Outside The Box Toolkit
Stage 1 – Boxed In

We use a series of tools and assessments to gauge how much insight people have and whether they are truly ready to make changes.

We ask people to score an area of their house – using the **Room Rating Scale**

We measure people’s feelings, using the **Feelings Tower** – helping us to pace our work correctly to minimise the trauma.

We’ve developed with **Liverpool John Moores University** a **Hoarding Disorder Self Assessment** tool to find out how much the person’s **Thoughts**, **Feelings** and **Behaviours** are *Impacted* by their possessions and how much **Insight** they have into their Hoarding.
Fire is a risk which we can’t avoid.

We want to reduce risk as much as possible, whilst still being able to work at a pace that is suitable for the person.

To enable us to do this – we complete a **Hoarding Disorder Impact Assessment** working with the **Fire and Rescue Service** to identify the risks.

Some of the strategies we employ include:

- Portable Fire Suppression Units - Misting System
- Work alongside the Fire and Rescue Service to identify other Fire Safety Measures
- Possession Churning
Stage 2 – Sorting

The ‘Sorting’ stage is about working with the tenant to work through their hoard and decide how to best manage it.

At this stage of the process we will begin working with Merseycare/Talk Liverpool to start the process of CBT Therapy.
Stage 2 – Sorting

The ‘Sorting’ stage begins with identifying a starting point.

To enable this a photograph is taken of the room/area.

An Acetate sheet is then placed over the photograph to split the room into 4 areas. The tenant will then decide which section of the room they wish to start with.
Stage 3 – Boxed Off

The final stage of the LHT Outside The Box process is ‘Boxed Off’.

This represents the completion of sorting the hoard for a particular room/area.

‘Boxed Off’ attempts to embed the learning of the process and to provide the support requirement to enable long term management of the Hoarding Disorder.
During the ‘Boxed Off’ stage the tenant is encouraged to complete the Room Rating again to show the progression they have made, and to firmly establish their belief that change is possible for them.

The Feeling Tower is also revisited to discuss the range of feelings they have had during the LHT Outside The Box process.

The Boxed Off Pledge – is a final action plan to manage their possession and acquiring for the long term – it’s a person centred relapse prevention plan.
Outside The Box Approach

- Recognising **Hoardiing Disorder** as a **Mental Health** issue

  and

- Delivering **practical support** and **therapeutic intervention together** to provide long term treatment to sufferers
Therapeutic Intervention
What does a Hoarder look like?

Believe that all they acquire has a beautiful or useful purpose.

Believe that their possessions connect them to the outside world.

Visually stimulated and a belief that they can’t retain information.

They form attachments to possessions instead of people.

They have trouble paying attention, organising and making decisions.
Housing and Health Partnership

Clinicians experience of working with clients with Hoarding Disorder in the past had been difficult. Their clients did not have the practical help and support needed to actually get rid of items, so therapeutic gain was always limited.

We were able to provide the practical support and were acting as ‘co-therapists’ encouraging motivation to engage with tasks at home during graduated clear outs.
Outside The Box - Co-Therapy

Specialist Support Staff

When we first meet a hoarder, this is a key stage of working with them. It’s about working without judgement, and getting to know them as a person and how they think and feel about possessions.

We actually take time and build a relationship with them in order for them to trust us, and us to get to know them.

We use CBT techniques subtly to work with people through the different stage of change – from pre-contemplation through to action. We provide the bridge to prepare them to begin therapy – something they may not have considered alone.
Outside The Box Group Workshop

- Developed a partnership with our local Improving Access to Psychological Therapies (IAPT) service – Merseycare/Talk Liverpool
- Launched the only Hoarding Group Therapy Programme in the UK that links in with Housing
- Merseycare/Talk Liverpool and LHT jointly run the programme
- Merseycare/Talk Liverpool have funded CBT Therapists to deliver the course
- 10 sessions across 12 weeks
- Cognitive Behavioural Therapy (CBT) Model specifically designed for people who hoard
- People will be identified through the process for Individual Therapeutic Solutions (ITS)
The Outside The Box toolkit is used in the sessions and the therapy links back to the toolkit when used at home.
Hoarding Disorder/Outside The Box Treatment Process

- Assess
- Set Goals
- Stop Acquiring
- Develop Home Plan
- Decide on starting point
- Prepare
- Implement Organising Plan
- Sorting Rules
- Implement / Maintain Home Plan
Outside The Box Therapy Manual

Acting as ‘Co-Therapist’ in tenants homes we help them with a series of tests, experiments, assessments and exercises that they have learned in the group therapy sessions.
Establishing ‘My Rules’

**MY ACQUIRING RULES—I WILL ONLY GET THIS IF:**

1. I don’t already have another item which does the same thing
2. I have a definite use for the item within a definite timeframe
3. It is of good quality and reliable
4. It is something that I need, not just want
5. It’s not going to be detrimental to helping the clutter problem in my home

**MY DISCARDING RULES—I WILL GET RID OF THIS IF:**

1. I already have another item which does the same thing
2. I don’t have a definite use for the item within a definite timeframe
3. It is not of good quality and reliable
4. It is something that I want but don’t need
5. It’s going to help the clutter problem in my home

- The aim is to create new ways of thinking, new rules that the individuals will start to live by to manage their Hoarding Disorder.

- It about changing **thoughts, feelings** and **behaviours** to acquiring and discarding….
Case Study – Bill’s Story
He is a 55 year old male living alone – tenant since 1979

He hoards household waste and electrical items

He had a history of not engaging with LHT for a number of years

Serious signs of self-neglect – it was impacting on his health and wellbeing

We started working with him, using the Outside The Box approach in March 2013

Our starting point – don’t mention the hoard!!!
Within the first 3 months we completed Stage.1 – ‘Boxed In’

In October 2013 we progressed onto Stage.2 – ‘Sorting’

We set out what room to start on and what area to begin

He then created his first pledge

He started clearing his kitchen in November 2013

And this is his progress………
Outside The Box – Pilot Case

FEELINGS SCORES

- Anxious before clearances/sorting
- Less anxious during the clearances/sorting process
- Positive feelings after clearances/sorting

Average Discomfort Level Before: 3.6
Average Discomfort Level During: 2.8
Average Discomfort Level After: 2.6
### Hoarding Self Assessment

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He attended all of the Hoarding Therapy Group sessions

He now has self recognition & understands why he hoards

He knows how to improve his life and wants to change

He’s done all the work himself and learnt new skills
Outside The Box – Pilot Case
Outside The Box – Self Help Group

- Promotes relapse prevention
- STIGMA – they’ve found that are not alone and want to help others
- Provides advice/support to wider community to include
- Computer access/life-skills classes/days out/theatre trips/health & wellbeing activities

- Brings people together and reduces isolation

Hoarders Helping Hoarders
Outside The Box won the Partnership Award which recognises a team who has demonstrated how working in partnership can improve the lives of others.

Finalist in the Meeting Specialist Housing Needs category
Outside The Box - Recognition

LHT Tenant of the Year 2015

Healthy Living Award 2015
The social value created by the service averaged £83,227.38 per person. Major social gains included:

- Relief from anxiety/depression (£36,766)
- Improvement from poor to good overall health/wellbeing (£20,141)
- Feeling of control in their lives (£12,470)

Based on figures produced by HACT
Outside The Box Outcomes

There are the financial benefits associated with halting negative hoarding behaviours and the anticipated average costs of managing a hoarder have now stopped escalating for Outside The Box tenants.

It is estimated that this proactive work has saved LHT between £490,000 and £700,000 based on 14 participants.
Outside The Box Outcomes

Based on our **Hoarding Disorder Impact Assessments**, fire risks have reduced from **84.47% to 13.08%**

Based on our **Hoarding Disorder Self Assessments** the average impact score has reduced from **87% to 16%**

Based on our **Room Rating Scale** the average scores have reduced from **8 to 2**

We have recycled and given to charity over **4,300 kg** in weight.....rather than letting it go to landfill
Next Steps
Outside The Box – Top Tips

- **Decide** – if you want to *deal with* or *support* hoarders

- **Don’t get disheartened by non-engagement** – it’s all part of the change process – keep trying be *pleasently persistent*

- **Be Non-Judgemental** - *don’t mention the hoard!*

- **Be careful about threats** – it’ll often make the problem worse

- **They’re lonely** – hoarding is linked to loneliness so spend a bit of time with them

- **Quick Wins** – non-hoarding related help/support that you can offer helps to build up a relationship of trust

- **Remove the Stigma** – normalisation is key – *they’re not the only ones who struggle*

- **Use the Room Rating Scale** – it’s a good starting point and helps to detach from their own home
Outside The Box – Top Tips

- **Possession Churning** – reduce the immediate risks – ‘*don’t throw, churn*’
- **Imagine a different future** – help them to visual a different future, with a different way of living, help them to find goals that will be motivational
- **Stay the same or change?** – work through the pros and cons of staying the same or making changes – accepting that there will be hard challenges ahead for them if they change
- **Break it down** – focus on one room, one space at a time – don’t overwhelm
- **Hierarchical Ordering** – start with the easiest and gradually move on to more challenging items – ‘*not in at the deep end, its small steps from the shallow end of the pool*’ (Gradual Exposure)
- **Be SMART** – agree a goal/target – we use Pledges – but its really important that its achievable and realistic ‘*don’t set the bar too high*’
- **Celebrate Successes** – no matter how small – positive reinforcement is important throughout the process and helps to validate and embed behaviour change
Outside The Box – Top Tips

- **Measure Feelings** – adjust the pace if needed – its not consistent

- **Challenge Avoidance** – avoiding sorting possessions is part of the condition. It’s normal – but if you notice avoidance try and find out the reasons why – try and refocus on the goals that they are heading towards

- **Understand their Thoughts/Feelings/Behaviours** – they have had many years of unhelpful thinking patterns affecting how they feel and influencing how they behave. Changing these is ultimately the key to long term management – but it will take time and lots of practise.

- **Develop Rules** – for acquiring and sorting – the route to change is knowing when they are having an urge to acquire or to not let go of an un-needed item and stopping and thinking out the alternatives. **Self Developed Rules** will help to guide them to making a more informed choice.

- **Peer Support** – no cure, just management but peer support is really helpful and there is nothing more effective than ‘hoarders helping hoarders’
Share Your Thoughts

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