



THE BREAKTHROUGH HOARDING PROJECT

A NEW APPROACH

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BACKGROUND

What is Hoarding? Clinical Definition

Until relatively recently, Hoarding was thought to be a category of Obsessive Compulsive Disorder (OCD). Nowadays, Hoarding Disorder is a DSM-5 (Diagnostic and Statistical Manual of Mental Disorders 5th ed.) diagnosis assigned to people who have a persistent difficulty discarding or parting with possessions, regardless of their actual value. This difficulty is due to a perceived need to save the items and to distress associated with discarding them. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, or the authorities). The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining an environment safe for oneself or others).

People with this diagnosis experience feelings of anxiety or mental anguish whenever those possessions get thrown away. While some people affected by the disorder accumulate valuable items, most people accumulate things with limited or no real-world value, such as books, old magazines or newspapers, self-made notes, outdated clothing, or old mail.

According to Anxiety UK, *“Hoarding is characterised by two major behaviours: Acquiring too many possessions and experiencing difficulties in discarding them when they are no longer of use. When these behaviours lead to clutter becoming a threat to a person’s health or safety, or they cause significant distress, then hoarding becomes a ‘disorder”* (Anxiety UK, 2017).

Research has found that people who hoard do so for a variety of reasons including previous traumatic life events. One of the many reasons people hoard is to avoid waste as they believe an object may still be usable or of interest to someone. Thinking about discarding the object makes them feel guilty about wasting it. Hoarding can ultimately lead to people becoming isolated in their own homes as they struggle with feelings of shame and embarrassment over their predicament.

Hoarding as a Safeguarding Issue

In April 2015 the Care Act of 2014 was enacted. The Chapter Fourteen guidance on Adult Safeguarding included three additional categories of abuse to those that had been used from the “Pan London” document of 2011. One of these was self-neglect and included Hoarding as a sub-set of this category. This meant that Local Authorities were obliged by Section 42 of the Act to enquire into reports of concern around self-neglect. The change in eligibility criteria for social services and the focus on wellbeing, create a clear basis for social work intervention with people who hoard.

Development of the Croydon Project

In November 2014, Croydon's Service Manager for Safeguarding hosted an internal conference for London Borough of Croydon (LBC) staff on the topic of Self-Neglect and Hoarding. The conference was largely attended by housing staff and the focus of the discussion was largely rooted in the difficulties that housing staff had with tenants who hoard. Housing officers accepted that they had powers to take steps to evict tenants who hoard, but were reluctant to use these as it would result in street homelessness in many cases. The feedback from the conference was that housing legislation and policy was being used to deal with what the officers felt was clearly a clinical issue. Subsequently, Croydon Safeguarding managers agreed that a clinical group to help provide psycho-social counselling for identified hoarders would be a better approach than punitive eviction processes.

In 2016 two potential provider agencies were approached to provide the counselling sessions. The scope initially included only group work. A decision was made to commission Mind in Croydon to deliver the service on the basis that they ran a British Association of Counselling and Psychotherapy (BACP) accredited counselling service and were already providing highly valued and effective group work in other areas. Discussions with them highlighted their innovative thinking in the area of Hoarding which would provide an intervention that went above and beyond the service delivery model initially conceived by the Council. It was also recognised that Mind in Croydon was a very well established and trusted local organisation with significant existing links to local mental health services, service users and carers, and health and social care services generally. Funding was agreed for the project and was secured from Community Safety, Public Health, Adult Social Care (ASC) and Housing (all agreeing to pay 25% of the cost).

Recruitment of Participants

Initially a scoping exercise was led on by the Council's Professional Standards Team. Teams put forward names of clients who they felt were hoarders. The London Fire Brigade (LFB) also provided a list of addresses where they believed there to be significant hoards that response crews would need to have intelligence on in the event of responding to a fire. In total over 120 names were put forward.

In December 2016 information promoting the new service was sent out to Adult Social Care teams. Of the original 120 names only a handful were formally put forward by social workers. The recruitment took 3 months longer than initially expected and a ratio of 4:1 (for every 4 referrals received only 1 person would agree to join the group and be group eligible). As a result, information went out several more times and was also circulated to South London and Maudsley NHS Foundation Trust (SLAM) and GPs. This generated more referrals. Unsurprisingly (given the genesis of the idea) housing officers made the most referrals by far.

Prospective group members were asked for permission to be referred to the group and the Council's Safeguarding co-ordinator wrote a letter to each client willing to be assessed. Those who agreed were then referred to Mind in Croydon for their assessment interview.

Initially, some clients were reluctant to engage with the service if they had to be referred via the Local Authority. They were fearful that the involvement of a statutory agency might increase the risk of being evicted, detained under the Mental Health Act, or having their children taken from

them. It was agreed that Mind in Croydon would take a fuller role in the recruitment of participants and this resulted in much better uptake.

Prospective group members had to be willing to receive the counselling in a group setting. They also had to be the correct type of character for the group (not be too dominant for example) and also had to have approval from their care coordinators if they were an existing patient of SLAM.

Information about participants

Eight participants took part in the project, consisting of two men and six women. Participant's ethnicity ranged from White British, Asian, and Black British. There were two male and six female participants who all signed release forms for a risk assessment to be undertaken at their homes and for photographs to be taken and used as part of providing evidence of the group's effectiveness.

The majority of the participants were living in their own homes, although two were in either Housing Association homes or Council homes. All of the participants were known to secondary mental health services.

Developing the Intervention – A New Approach

Prior to the project beginning, Mind in Croydon undertook significant research and planning in order to develop their approach. It was difficult to find any existing models of successful hoarding projects. There was some evidence of clinical groups being run or projects where people provided practical help and support to help people de-clutter. Mind in Croydon developed a new way of working that combined these approaches.

Psycho-educational Workshops

The groups took the shape of 6 fortnightly psycho-educational sessions which ran from August to November 2017. The groups took place at Mind in Croydon premises in East Croydon on Thursday evenings. The East Croydon site was selected in order to provide a central venue with the most transport links.

Materials for use within the groups were sourced following a literature search and consultation with a Clinical Psychologist from the local mental health trust. The Clinical Psychologist offered direction and some useful insights into experiences to date with regard to group work for hoarders and potential blocks/difficulties experienced.

The group sessions lasted one and a half hours and were educational as well as experiential. The sessions were facilitated by two therapists from Mind in Croydon. Each session had a plan but was flexible depending on what issue the clients brought. Declutter buddies also attended the groups. The buddy role was mainly to observe, but they were also there as a facilitator to encourage and support participants to engage with other group members. By observing, the buddies developed a better understanding of their clients and gained a better insight into the decluttering work.

Post workshop discussions were attended by buddies and facilitators after each meeting to answer any queries raised in the workshop.

All participants expressed how much they enjoyed the workshops and how much support they got from each other as well as their buddies. At the end of the project the participants, of their own volition, swapped telephone numbers and agreed to stay in touch to continue to give each other support.

One participant expressed their learning from the workshops by saying:

“I now understand why I hoard and what makes it difficult for me to sort and de-clutter”

De-clutter Buddies

A team of de-clutter buddies was recruited to attend the group sessions and then work with the clients to undertake the de-cluttering work that had been agreed at each group.

Buddies were recruited by advertising within the Mind in Croydon counselling team with the express purpose of getting the buddies to establish a good therapeutic working alliance with the participants. As part of the recruitment process, each buddy completed a questionnaire devised to assess their suitability and were then interviewed to ensure they understood the nature of the work they were undertaking. Those buddies chosen were then asked to undertake fortnightly supervision one hour prior to the group workshop.

The aim of using the buddies was to empower participants to make changes to their living environment as well as giving them one to one weekly therapeutic support to enable this to happen. The buddies offered the participants emotional and practical support on a weekly basis throughout the programme. This sometimes involved going with the clients to the recycling centre or to take goods to be donated to charity shops.

Mind in Croydon enhanced its existing Lone Workers Policy to ensure that de-clutter buddies were safe at all times. A risk assessment was undertaken with every participant before a buddy entered the premises. Each buddy was given a personal phone with enough credit minutes to ensure they could text or phone the office as appropriate at the completion of each session. Safety measures were put in place to give buddies back-up in cases where risk might have escalated. In practice there were no such situations.

The buddies first weekly session with their clients were at a mutually agreed neutral place for coffee in order to establish a rapport with them before meeting at the client's home.

Buddies were encouraged to gain as much data as they could whilst working with their clients to provide evidence of de-cluttering and to monitor results as part of the pilot project. Statistical evidence was gained from photographs before and after sorting objects. The hoarding rating scale was completed weekly with the number of boxes/bins of rubbish cleared being recorded.

Clients clearly valued this support and four further weekly support groups were added after the formal groups finished ensuring that the behaviour change was maintained. A formal follow up group, facilitated by Mind in Croydon therapists, was run at the end of January 2018.

OUTCOME MEASURES

- **Clutter Image Rating Scale** – This is a scale of images that rate how cluttered the rooms in the house are. Participants chose which image they thought was applicable to the room in their home, (*Steketee et al 2014*).
- **Saving inventory** - A measure to determine whether or not participants had a problem with hoarding and to what degree it affected their lives, (*Steketee et al 2014*).
- **The CORE Outcome Measure (CORE-OM)** - This is a client self-report questionnaire designed to be administered before and after therapy. The client is asked to respond to 34 questions about how they have been feeling over the last week, using a 5-point scale ranging from 'not at all' to 'most or all of the time'. The 34 items of the measure cover four dimensions: Subjective well-being, Problems/symptoms, Life functioning, Risk/harm. All Core forms indicated improved overall wellbeing for participants.
- **Photographs** - Before and after pictures were taken.
- **Bin bags** - The amount that was de-cluttered was measured by the number of bin bags filled, either to be donated to charity or to be disposed of.

Governance Meetings

Meetings were held regularly between the Council's Safeguarding Coordinator, Mind in Croydon CEO and the Clinical leads for Mind in Croydon. These were recorded with notes being circulated with agreed actions.

DIFFICULTIES AND UNFORESEEN MATTERS

Delays: The programme was due to commence in March 2017, but was delayed until August 2017. The delay was mainly due to difficulties in recruiting suitable candidates for the project. Over two hundred hoarders had been identified through the Council, however it was found that many of the hoarders were not amenable to joining the project with some denying they had any problem with clutter. Of the number willing to participate in the project, two were deemed to be unsuitable and one withdrew consent prior to the group starting.

Interface with SLaM: Several clients were active patients of SLaM. As such all had to have their care coordinators contacted for their views on their patient being a part of the process. As such there were delays at times until the relevant care coordinator could be contacted and effectively "sign off" on their patient's participation.

Risk Assessments: It was not considered at the start of the project that each house would need to be visited. However, in order to assess the risks to the de-clutter buddies entering the properties, what work was required, and the nature of the hoarded material, a risk assessment was required. Housing colleagues provided a tool which we were able to adapt and visits were done by the Safeguarding Coordinator to each house in order to complete a room by room clutter image rating, make LFB home fire safety check referrals and discuss the project with clients as well as agree information sharing. Some participant's homes proved problematic to arrange a risk assessment. Therefore, one buddy did not enter the client's home until the fourth workshop session (three quarters of the way through the project).

Recruitment of Buddies: This was less problematic than originally anticipated because Mind in Croydon already had volunteer counsellors who wished to take on the buddy role.

LEARNING FROM THE PROJECT

Learning from the project was continuous.

Client engagement, participation and commitment was greater than anticipated. There was 100% attendance apart from planned absences.

Sorting and discarding by participants was quicker than anticipated. There was some concern that clients might not agree to undertake the “homework” set at the groups. However, all clients completed their homework promptly.

Visits by buddies were received very well by the clients. Initially it was anticipated there would be resistance from clients to allow buddies into their homes. However, this was not the case and three quarters of the buddies had visited their clients in their homes within the first fortnight. Participants were very grateful to have the support of the buddies in their homes with one participant saying:

“This is the third time I’m experiencing a de-clutter project and it’s the first time I’ve felt empowered”

Another participant expressed their gratitude to the buddy by saying:

“You don’t know how much it has helped me to have the emotional support of my buddy and I can’t thank you enough.”

Further praise for the project from another participant as related by her buddy;

“She has now been able to half her depression tablets. She thinks because of her therapy but mainly due to the de cluttering. She is so grateful for this help. She feels like she is getting her life back. This experience has been life changing for her. She now feels as though she will be making friends for the first time in 20 years. She said she is now finding a space in her head to do things she was not able to before. She said “The negative voices in her head have been thrown out with the rubbish”, She cannot thank everyone involved enough.”

Participants were concerned that input from the buddies would finish at the last workshop session. However, it was possible to negotiate extra resources to allow for 4 more weeks of support from buddies after the last group session. We were also able to refer the participants to another Mind in Croydon service, The Hub, where they could meet up twice weekly if they so desired.

The Buddy communication after home visits worked well. Buddies phoned in after each session and sessions were written in the diary and left in the administration area to be checked every day to ensure all buddies were accounted for after each one to one session with the client.

Buddy to client ratio was identified ideally to be 1:4 buddy to clients.

PROJECT OUTCOMES

- 100% of the participants discarded at least two bags of clutter. The largest item decluttered was a car. The largest overall bags of clutter discarded were 25.
- The Savings Inventory completed weekly showed that participant's levels of anxiety whilst sorting and discarding clutter decreased over the twelve week programme.
- Clutter Image Rating Scale showed improvement in the areas targeted in 100% of the participants.
- Core rating scale showed overall improved wellbeing for all participants
- During the time of the group no clients were evicted, served with an ASBO or ABC. Several clients made statements to indicate that they felt better and that their anxiety had decreased.
- There was an increase within the borough to meet obligations surrounding mental health and Safeguarding/Care Act issues.

FUTURE DEVELOPMENTS

The Clients themselves have named the group and would like future projects to be named

“BREAKTHROUGH HOARDING”

Recruitment: This can be done via Mind in Croydon next time. It was felt that the notion of a social worker calling from the Council was off putting for many clients who were potentially facing punitive action from the same Council. Prospective clients may have been suspicious. Given that Mind in Croydon had a better success rate than statutory colleagues in recruiting to the project the evidence seems to be that it is easier for a non-statutory service to complete the recruitment task.

Risk Assessing: This time needs to be built into the project plan and budget for future groups. It is important that participants fully understand that a risk assessment is only to ascertain how safe the premises are. It was felt that this needs to be explained to clients at the beginning of the programme before assessment takes place.

Extra buddy support sessions post group: It was found that momentum and motivation remained high immediately after the group and that a lot of progress was made as the group was terminating. 4 extra buddy support sessions were added after the last group. This should be included as part of future projects.

Follow up meeting: A follow up group in January 2018 took place (two to three months after that last psycho-educational group). The purpose being to allow clients a chance to evaluate how they are coping post group and take stock of achievements to date. This should be included as part of future groups.

Publicity: This needs to be more comprehensive as many hoarders identified do not consider they are hoarders.

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