



We need to change the way we think about hoarding

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About the author

Ian Porter has worked at local, regional and national levels during his career in the NHS, social care and higher education. Since October 2021 he has:

- Developed and coordinates a Northwest 'Hoarders Helping Hoarders' network of 12 (soon to be 14) psychosocial intervention and peer support groups for people who exhibit hoarding behaviours
- Initiated and leads the Greater Manchester Hoarding Improvement Partnership
- Designed and leads the recently launched Wirral Hoarding Improvement Project which will include the development of a multi-agency pathway to support people who exhibit hoarding behaviours across the local authority area.

Ian also works as consulting psychologist to the team of hoarding specialists at Onward Homes, and to the national hoarding project 'Inside Out' at Places For People and provides supervision to the caseworkers and volunteers within the 'Making Space Project' (hosted by We Care Home Improvements) in Bristol and Bath. During 2023 alone, he has designed and delivered training to over 800 housing, health, fire and rescue service, and social care and community service colleagues.

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Introduction

In the beginning, was the word and the word was... *'hord'*. This is an Old English/Anglo-Saxon word (pre-1150) that was literally defined as 'treasures'. The word was then combined with others in 'compounds' – for example, in the case of *'bōchord'* (bōc = book), literally 'book-hoard', meaning 'library'.

In more recent times the word has gained another vowel and is used (and misused) in several damaging and, ultimately, stigmatising ways. The ensuing impact of the social stigma attached to 'hoarding' on people I work alongside and support is further compounded by the range of media programmes which often reduce our folks to little more than eccentric novelties who can be 'fixed' by a couple of skips and some tough love.

We really do need to change the way we think about 'hoarding'.

Decluttering our thinking about hoarding



Hoarding is an overwhelming psychological condition defined, in part, when someone cannot discard or part with their items (for several differing reasons) without feeling extremely distressed. In addition, the person may continue to acquire items despite the subsequent negative impact on functionality and safety within their immediate environment.

It is a recognised mental health disorder, but unlike other mental health issues it is continually defined by what people have in their HOMES, instead of what people have in their HEADS.

The 'official' definition of Hoarding Disorder can be found in a number of different tomes, but when working alongside people I like to help them to create a personalised model of their hoarding behaviours, which includes a personal definition. Here is an example that was developed over time by a member of the Pan-Merseyside Hoarders Helping Hoarders Peer Support Group:

*"It's a love-hate relationship: hoarding provides comfort as it's familiar – like a security blanket – yet the chaos creates stress in all areas of my life, thus it's something I hate. Hoarding is the visible manifestation of experiences, memories (both good and bad), hopes, dreams and delayed decision-making, being unable to decide what to keep (and why) coupled with the inability to consider the consequences of 'saving' acquiring and not putting an item away in its designated place. **Hoarding is an old friend that is a bad influence!** And the quest to try and remove them from my life is a continuous effort."*

Because of the complexity of the disorder there is no quick fix (and no skip big enough to provide one).

So, if you want to provide anything that resembles effective support, in the first instance you need to see the person and NOT the 'hoard'. In other words, start off by personalising, not pathologising or stigmatising – it will pay dividends.

People who exhibit hoarding behaviours are tired of being othered and often self-stigmatise (experience debilitating shame, embarrassment and/or self-loathing) because of the unhelpful initial responses of other people – and this can include services, agencies and people who ‘purport to support’, but who end up inflicting collateral damage which further compounds the situation.

Bad vibes and good omens: Some dos and don'ts

People who exhibit hoarding behaviours FEAR people will:

- Judge them
- Punish them
- Ridicule them
- Threaten them
- See them as ‘just a hoarder’
- Make them throw away their ‘treasures’ against their will.

On the other hand, they HOPE people will:

- Listen
- Show respect
- Be consistent
- Show sensitivity and understanding
- See them as a person
- Recognise that it takes time to make ‘improvements’ at all levels.

So, here are some practical tips about what to do and what not to do when you encounter a person who you believe to be impacted by their hoarding behaviours:

- Start with compassionate curiosity – understanding and kindness are a good start and powerful levers
- Relationship building is crucial and will happen quickly if you are patient and work at the person's pace
- Ask about the person's wants, worries, expectations
- Work on shared goals and aspirations, not on aims dictated by how YOU think people should live
- Persistence is vital – not all steps will be forward steps
- Do not ask ‘what's wrong with you?’ – ask ‘what happened to you?’ Try to understand a person's world view

- Aim for some small/quick wins for the person when they are ready to address issues within their home
- Avoid further stigmatising people by using terms such as ‘self-neglect’
- Remember proportionality is important – ie, do not use a ‘sledgehammer to crack a nut’
- Please bear in mind people’s practical abilities – do not negotiate unrealistic goals/targets, because you are effectively setting people up to fail.

Finally, please try to remember that:

*The thing about hoarding...
The most important thing about hoarding...
Is that it is about more than just hoarding.*



Hoarders Helping Hoarders (HHH): Psychosocial intervention and peer support groups



In October 2021, I started to work with and develop a support group for a small group of people who exhibited hoarding behaviours, and who had been known to me as a result of work I had undertaken within a role on Merseyside Safeguarding Adults board (one of only two combined boards/authorities in the country at that time).

The purpose of the HHH peer support group is to provide structured, psychosocial intervention, including 'in vivo'/exposure activities within people's home environments and, just as importantly, to coordinate a range of activities/discussions aimed at challenging/changing unhelpful cognitions, beliefs and behaviours.

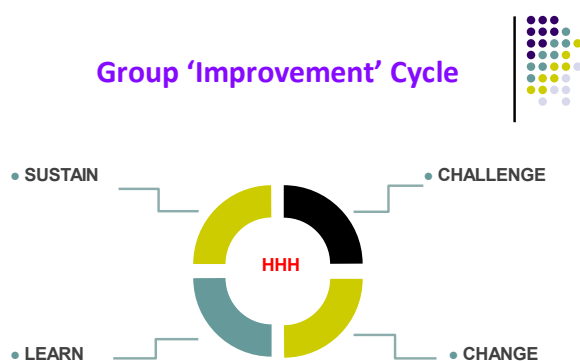
The group also uses and promotes the help and support that people with lived experience of hoarding and associated mental health issues can give to one another. The group meets every two weeks and members discuss personal developments, acquiring and hoarding behaviours, co-morbidity (mental health) issues which impact on their current situation, participate in structured psychosocial intervention sessions (eg, psychoeducation about hoarding; organising and planning to discard sessions) and make suggestions when issues are raised by other peers.

Between October 2021 and May 2022, the membership of the group grew from eight or so to over 25-30 'peers' attending on a regular basis. The model we developed was presented to the North West Regional Hoarding Conference, 'Behind Closed Doors', which we organised and which sold out within a few weeks.

The first thing to impact group development are the normal group processes and dynamics which need to be nurtured by group facilitators:

- **Universality:** This relates to the experience of 'being in the same (non-judgmental) boat' or, as Phoebe once told me, *"Being in different boats but the same storm!"*
- **Social contact:** The development of co-operative relationships (and having a laugh/enjoying the company)
- **Group cohesion:** Which results in positive peer pressure to motivate change
- **Mutual aid:** This relates to the reciprocal peer support which results in people supporting each other within their home environments (when ready to do so). In other words, we take the concept of 'peer support' way beyond the boundaries of tea, sympathy and 'symptom-swapping'.

Our group improvement cycle has four components:



- **Challenge:** This can come from the group facilitator and/or from within the peers
- **Change:** The challenge leads to people 'testing' something out or making a planned change
- **Learn:** Then we look at the impact of that (positive or negative) and what we can take from the 'change experience' (which often entails supporting people to cope with progress. Change can be frightening and messy)
- **Sustain:** This is the most difficult of all – how to sustain/maintain progress (which often entails supporting people to address issues relating to 'self-sabotage').

Because of the success of the Merseyside initiative, and the subsequent 'bounce' following the enormous success of that first regional hoarding conference, we now have a Northwest network of similar groups across Merseyside, Lancashire, Greater Manchester and Cheshire. There are currently 12 groups in the network – all at differing stages of development and maturity, and we are currently at the planning stages for the development of two more.

Here are some examples of the impacts and outcomes of our approach to group-based intervention from the peers' perspectives:

“After each meeting I attend, I go home fired up with increased enthusiasm and nearly always get stuck in, doing some active decluttering. That gives me such a feeling of satisfaction because what I most want to do in my life now is ‘walk the walk and not just talk the talk’.

Attending the group gives me the opportunity to ‘speak my truth’ about how this taboo, traumatic and painful condition has affected my whole life. I also speak regularly by phone to another member, and we support and encourage each other. Sometimes I have thought that by attending this support group I am ‘in danger of coming alive again’! A rather daunting prospect.”

“Another outcome that I didn't mention is the fact that the laughter is one of the things about the group that energises me to enable me to do decluttering when I get home.”

Or, as a member of one of the newer groups said recently: “A huge thing we didn't realise was missing just turned up!”

In addition to fortnightly group sessions, we have also made a film addressing the stigma associated with hoarding and are working with a theatre company which is writing a musical about the subject. We also ensure a multi-agency connection by giving open invitations to colleagues within the housing, health, social care, fire and rescue, and community service sectors to attend and participate in group sessions. Not only is this one way of reducing stigma, it is also a way of increasing colleagues' hoarding literacy. Here are some of the things our guests from social housing have had to say following their attendances:

“I feel it’s an absolute lifeline for people suffering with hoarding issues and I think every employee in our entire organisation should go to gain a better understanding of it. The people who were the regulars were extremely brave and open about their experiences, and the whole meeting felt relaxed, well run and organised. I’m looking forward to being able to attend again.”

“No negatives from me. I had no expectations, but the session far exceeded any expectations I could have had. I can see why your members come back week after week as the support is amazing and very generous, both from you as well as from each other.”

“I thought the session was fantastic! Really informative, well-constructed and focused, and I loved that everyone gave such a positive update on working together. I also like the way group members are challenged about behaviour and the idea of the group improvement being driven by the ‘Challenge – Change – Learn – Sustain’ cycles that you have developed.”

Despite the success of the group-based intervention, I was aware of the systemic issues plaguing a range of multi-agency colleagues and the lack of available expertise in supporting people who exhibit hoarding behaviours.

Following an initial exploratory meeting in Manchester (July 2022) with a dozen or so colleagues across the relevant sectors, I organised and initiated the Greater Manchester Hoarding Improvement Partnership (HIP), in the hope of bringing representatives from the 10 local authorities together in order to identify and address common, problematic experiences when attempting to provide meaningful support to people with ‘hoarding issues’.

The Greater Manchester Hoarding Improvement Partnership



Since its inception in September 2022, we have held a series of six HIP symposia (roughly one every two months), with attendances that range between 40-60 people.

The structure of each three-hour symposium is a constant and will contain segments focusing on some or all of the following:

- A psychoeducational segment
- Updates from peer group facilitators
- Improvement/development initiatives across the region
- Good practice examples/latest research findings
- General NW HHH Network updates and developments.

Most importantly of all, we ensure that we have at least one person with lived expertise on each of the multi-professional tables. The lived experience voice is essential to the development of any initiative of this kind. For example, at one of the symposia we organised a Q&A session with a panel of HHH group peers and the multi-professional attendees asked a range of questions of those who exhibited hoarding behaviours. At our next symposium, the roles will be reversed.

The first symposium took place in September 2022, with the first HHH peer group established in Salford in October 2022. Since then, we have developed groups in North Manchester, Tameside and Wigan, will shortly launch a group in Oldham and are considering the development of a group in Trafford.

In addition, there have been a variety of improvement and development initiatives, ranging from the design and conduct of anti-stigma campaigns, the revision of hoarding policy documents and related literature, and a series of training workshops, to the development of assessment processes and best practice guidelines.

The next stage in the development of the HIP is to localise the initiative and attempt to encourage each of the 10 local authority areas to create their own – particularly those areas where we have an established peer support group. An HIP is simple to organise and facilitate but so impactful – all you need to do is give people a reason to turn up and then keep turning up.

As the result of the huge momentum and traction the HHH ‘movement’ has gained across the North West (and beyond), we organised a series of three regional conferences in May 2023 during National Hoarding Awareness Week – w/c 15 May: Merseyside (Monday), Lancashire (Wednesday) and Greater Manchester (Friday). Over 350 people from across the NW/UK attended and 20% of all delegate groups were people with lived expertise – the impact of all three was substantial and we have since had a huge number of referrals to our groups from across the NW regions.

We need to change the way we think about hoarding and that shift needs to lead to a change in multi-agency practices across the whole system. It is not easy and, as I have indicated, there are no ‘quick fixes’, but if you keep doing what you have always done and expect a different outcome...well, just be aware that somebody (Albert Einstein, allegedly) once described that as the definition of insanity. Make some noise!

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