

SUMMARY

Programme: *The Paristamen CIO £20,000 grant to HoardingUK for an intensive one-year capacity building programme for charitable works supporting a specialist medical condition that currently receives little funding*

OUR WORK

HUK is the only UK-wide charity solely dedicated to supporting people impacted by hoarding behaviour. Our aim is to empower individuals experiencing overwhelming distress who are at risk of self-harm/neglect due to living in unsafe uninhabitable environments to achieve spatial and personal change, improve health, wellbeing, reduce homelessness, isolation and re-engage with life and work. We offer sustainable, holistic, educational, empowering and person-centred programmes such as:

- National free and confidential helpline
- In-Home specialist support (IHS) and Access and Safety Improvement (ASIP) services
- Individual remote advocacy
- Peer and professionally led groups
- Training, community talks, media and other awareness raising activities
- Student placement scheme
- National Hoarding Conference and Roadshow

Hoarding disorder (DSM-V, 2013 and ICD-11, 2018) is a complex and comorbid mental health condition impacting between 2-5% of the population. Help for Hoarders, a website set up by our Patron Jasmine Harman, estimates that up to three million people in the UK are impacted. Hoarding behaviour is characterised by people experiencing overwhelming distress when trying to throw items away (regardless of their monetary value) which is caused by a range of issues including trauma, anxiety, dysfunctional coping mechanisms, resulting in self-neglect/self-harm (both intentional/unintentional) due to the person living in unsafe environments and – in extreme cases – completely uninhabitable homes. Nearly 90% have another physical and/or psychological disability.



National Hoarding Conference-2018

Compulsive hoarding can have a detrimental effect on the physical and mental health of the person, their family, friends, neighbours and professionals. HoardingUK's data shows that over 70% of participants have expressed suicidal ideation. Research has shown that people with hoarding behaviour (HB) are more likely to: live alone, be unmarried, have had a deprived childhood with a lack of material objects or experience a poor relationship with other members of their family. Many are the targets of bullying behaviour from others and those closest to them.

Practically, structural damage; eviction by landlords/compulsory purchase; infestation; disease/infection; legal conflict and bullying are common. **One in four people who die in all fires live in hoarded conditions.** Many have no gas, heat or water because workpeople are unable to access the wiring/plumbing or are unable to carry out statutory inspections.

People who hoard fall through the gaps, currently only 6% of local authorities record people with hoarding behaviour. This means that resources and budgets are not appropriately allocated resulting in an increased economic burden to society due to haphazard and costly management. Councils spend money clearing the house only for the person with hoarding behaviour to fill it up again. **A recent London HoardingUK case cost the local authority £36K on legal actions without a single pound being provided to actually support the person.**

Despite provisions within the Care Act (2014), Anti-Social Behaviour, Crime and Policing Act (2014) and Homelessness Reduction Act (2017), local services and interventions are still too frequently focused on punitively and short-sightedly.

HoardingUK exists to fill the gap in expert provision, we are a first point of call for people impacted, friends, family, neighbours and professionals. **The support and information we provide is predominantly free, of the highest quality and accessible.**

THE PROJECT

The £20,000 large grant was distributed as a £15,000 (*restricted*) grant for the expansion of HoardingUK's core services: telephone helpline and advocacy and £5,000 (*unrestricted*) grant for an organisational capacity building programme – both of which ran between Apr 2019-Mar 2020.

HoardingUK's core service is its telephone helpline where we hear things every day such as "I wouldn't have been able to get this far without you." "It's like the weight has dropped off my shoulders talking to someone that understands." "Your input really was key and made a difference." "You're the only one that reminds me to look after myself."

In 2018/19 we helped 9,315 people face to face and via our phone line virtual support. 87% of our beneficiaries tell us HoardingUK is the only place they feel safe, unjudged and supported to discover what they need, how they might move forward and find the support through the process. HoardingUK can be among the only relationships many people with hoarding behaviour have. **We managed over 7,000 calls** from people impacted by hoarding, including family friends and professionals. Over 30% of people who contacted us do so while being threatened with eviction.

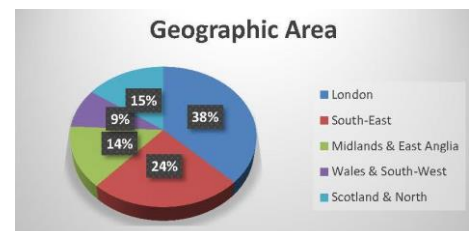
Promoting choice and control' our advocacy service has been at the heart of our work since our inception. After twelve years we can proudly say that no one has been evicted or lost their children into care with the help of this vital support.

The Paristamen CIO grant was used to fund/recruit a Helpline Manager and an Advocacy Services Manager, working one day per week responsible for recruiting and managing up to five volunteers each.

Overview of Telephone Helpline/Advocacy Services (Restricted Funds)

Helpline outcomes

- Recruited Shamiso Mazaiwana to Manager's post. Shami has a psychology degree, a counselling degree and is currently studying for her Masters. She had volunteered with us for over a year, providing support to our most complex cases. She also works part-time in the community with Mental Health services which gives her the rounded experience we needed.
 - We recruited 5 helpline volunteers and expanded the programme to facilitate both creating a work experience programme for both undergraduate and Masters levels psychology students (achieved May 2020 impacted by Covid19 lockdown) as well volunteers from the general public and people with lived experience.
 - We have strengthened our long-term support service by standardising assessment, motivational interviewing and CBT tools.
 - We have empowered all managers to deliver volunteer recruitment, induction, training and supervision.
 - We are averaging 30 hours of calls and emails per week.
- Increased phone coverage 25%
- Expanded current capacity from 25 hours to a minimum of 30
- Added over 100 participants into short-term and long-term helpline support
- Improved understanding of hoarding within educational settings including continuing positive word of mouth recommendations of previous volunteers working to ensure participation by students is ongoing.



National Reach

Advocacy outcomes

At the end of the grant period we were working with sixty-five live cases with a waiting list of 28 people. **100% of evictions have been prevented.** A recent piece of support in Norfolk led to HoardingUK being mentioned in the judgement as a key factor in the positive outcome. This vital, integrated service is currently operational two days per week.

"HoardingUK has made this whole process much safer for me." Female Participant, aged 47

Advocacy differs slightly from the helpline in that cases can be more complex, involve more offline time and be longer term. While there is typically one case in each week which would require more intensive support, most are project managed over time. Work such as writing, researching and liaising with professionals takes place between calls. As an example, a recent case was supported over two years and successfully provided with multi-disciplinary package.

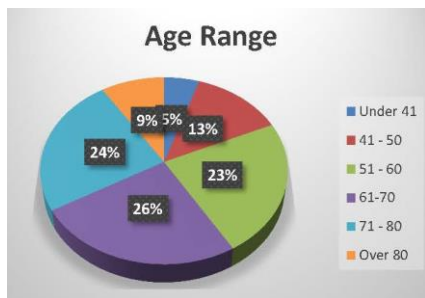
Referred to Hoarding Support Group
Arranged local advocate
Arranged advocate from Spinal Injury Association
Liaised regarding access inspection
Arranged legal aid
Referred for Mental Capacity assessment
Assisted regarding landlord

Crown Court case adjourned
Repossession halted
HUK Helpline
Accessed psychological support
Section 42 Safeguarding
Info pack
Appeal to Land Tribunal
PIP restored on appeal
Contacted MH Crisis Team
Assessment under Autism Act
Referred Learning Difficulty ASD assessment
Appeared in Court seizure overturned
Concluded Ombudsman case
Equalities Act test case

The outcomes pictured represent some of the complex and successful work over the period of the grant.

Ron Aitken was appointed as the Advocacy Services Manager. He is a qualified advocate, a person with lived experience of Mental Health, a former Lib Dem Councillor. He also has worked supporting people who hoard in his work by taking on cases when he was an advocate that no one would touch...and succeeding.

- We recruited 2 advocacy volunteers.
- We initiated quarterly advocacy focused support via the Islington Support Group



- Increased phone coverage 25%
- Expanded advocacy capacity from 15 hours a week to 20
- Added over 60 participants into both short-term and long-term support
- Empowered volunteers (some of whom have lived experience and/or disability) to develop confidence, skills and experience. Two volunteers obtained employment

Every Age Group

Overview of the Intensive Capacity Building Project (Unrestricted Funds)

Despite being a small charity, our work has been instrumental in changing the perception of hoarding disorder, which was considered a 'lifestyle choice' in 2008, until HoardingUK (alongside others) began pushing for systemic change. The service has successful outcomes across a range of situations. We work with people and provide effective solutions in what is often a complex power imbalance.

Hoarding behaviour crosses into many areas of need including but not exclusive to housing, mental health, social care, legal, advocacy, environmental health, fire and other emergency/front line services. We built up strong partnerships with organisations across the country - far too many to list here - but it includes local authorities such as Hackney, Kent, Waltham Forest, Essex, Wrexham and Isle of Wight.

HoardingUK has established positive relationships within the hoarding community and we are a valuable resource.

Our service is designed to not only directly support isolated, hard to reach, individuals but raise awareness and develop sustainable systems which outlast our engagement. We set up support groups in this model with the Westminster Society for People with Learning Difficulties Support Group and the award nominated BPHA Support Group.

We do this by co-production in partnership with people who may have withdrawn from interaction as a result of shame and stigma as well as working alongside local/national media, local services, individuals and professionals. Consultation, co-production and collaboration are central to every aspect of our work. Every aspect includes these values.

We measure success in the change/improvement that our work makes to our beneficiaries. As stated, before we aim for our beneficiaries to consistently stop/reduce hoarding, feel less isolated, feel their mental wellbeing and their quality of life has improved.

With the unrestricted funding from The Paristamen CIO, HoardingUK updated its Microsoft Dynamics CRM. We relaunched our website and membership area. We undertook a thorough review and updating of our policies which will be presented to our members at our upcoming AGM. We have begun, but not completed, the process of recruiting new Trustees to the board.

PROJECT FINANCIALS

GRANT		Budget	Actual	Difference
HelplineAdvocacy Intensive one-year capacity building programme				
Helpline Manager	Salary	5,400	4,725	(675)
Advocacy Manager	Salary	5,400	4,080	(1,320)
	Supervision (Vols/Mgr)	1,880	1,860	(20)
	Volunteer Expenses	-	1,260	1,260
Project Costs	Phones/IT/Software	480	320	(160)
	Travel	1,100	726	(374)
	Recruitment	740	781	41
	External Helpline Training		1,094	1,094
Total		15,000	14,846	(154)
HUK INTENSIVE ORGANISATIONAL CAPACITY BUILDING PROJECT				
Total		5,000	4,450	(550)
Total		20,000	19,296	(704)

THANKS

The Paristamen CIO grant transformed our services at a vital stage of our development.

The Trustees, team and participants at HoardingUK are extremely grateful for The Paristamen CIO Trustees support which has been more than financial. We are a passionate group of people working tirelessly to improve the systemic management of a problem which so many see as a 'lifestyle' choice...still.

Despite what we have accomplished, we were a reactive organisation struggling to keep up. This grant provided a base from which we could review, assess, change and improve. The accepting and empowering support of The Paristamen CIO has been such a valuable part of the process.

HoardingUK has learned so much, grown so much and improved so much.

The Paristamen CIO has been an empowering, encouraging, enthusiastic partner in what has been a transformational process.

Our heartfelt thanks.

HoardingUK is Proud of its Award Nominations and is proud to be a Pilotlight Partner Charity

