10 Years on - A retrospective on our unique research journey

It is 10 years since Step Change Design was formed to share the findings of our research into what it takes to create actively used dementia care setting gardens.

Our self-funded study, crowd funded books and tools and our unexpected journey deep into the care sector revealed much to us about how care gardens are used and, importantly, it also showed us what is needed to undertake a successful research project. Here we reflect on our particular journey versus more traditional routes and what we learnt along the way. We hope it inspires and guides those with a burning question needing an answer.

Traditional Route

Approval and proposal application stage

- area of research refined into a proposal question
- development stage, risk assessments, GDPR, ethics

Identify & seek funding

- agree methodology and create data capture materials
- set up a data management plan with key milestones
- peer review and amend proposal, if required
- cost proposal
- ensure proposal meets funder's terms and conditions
- review and make amends to application, if required

Project Management

- recruit researchers, if required
- undertake research and data capture
- carry out reviews at agreed milestones
- report to funders as required

Analysis

- undertake analysis on completion of data capture
- report outcomes, and any outstanding questions, to funders and academic setting
- produce final report and publish paper

Dissemination stage – applying learning

[often requires further funding]

- academic paper logged onto research data-bases
- findings shared within the academic setting
- findings shared at other events, usually supported by Academic setting or Funders
- produce materials for direct application of findings in real world

"I was bowled over when I got the Map and Book….I took it with me to a [activity group event] this week and had 8 of them poring over the Map as an exercise to see where they thought their care setting was on the journey. It will be a real asset to me as a training tool – Bet you never thought that would happen!" CEO NAPA, 2016

[re: research methodology] *"Your creativity and professionalism make a brilliant example of what I wrote about long ago now – a great piece of illuminative evaluation!"* Malcolm Parlett, Developer of Illuminative evaluation/ author 'Future Sense' 2022

"….I'm delighted to have been introduced to you both and your amazing map! It has made me rethink how we use gardens and I'm using it almost daily." Dementia Lead, Care Group UK 2018

[Re Research /Designer handbook] *"You dared to lift and peer under the skirt of care culture which needed desperately to be exposed as the underlying driver of all possible and actual outdoor experiences for residents, families and indeed staff themselves…… You called this out…. It is no exaggeration to say you have birthed a movement. Suffice it to say that this self-funded research endeavour of yours stands superior to any government funded university research project I've ever witnessed over the 15 years I spent within ….. academia."* Garuth Chalfont, Garden Designer, Researcher, Lecturer, Author 'Design for nature in dementia care'2020

Our Journey

We had a question:

'Why aren't Care Home Gardens more Actively Used?'

- Wanted our gardens to be well used, *Garuth Chalfont's book 'Design for Nature in Dementia Care'* referred to research method, **Environmental Behavioural Study** (EBS), observational approach
- Decided to **self-fund** a *small* project to share findings with Garden Design sector (2013)

Set Up

- **NAPA** sent out request to join our study, had ***50 enquiries*****!**
- Selected 24 Care Homes based on:
  - 90% residents living with dementia
  - geographically accessible, across England & Wales
  - private/ not-for-profit, large-small, urban-rural
- Ensured study met ethical/ privacy/ DBS requirements, pack issued to each home, permissions in place

Project Management

- captured nearly **1500 data** points, from diary records (17 homes) & observational visits (20 visits, 7 homes)
- **1st observation visit indicated more at play than just design, overnight revised approach** to include observations from inside as well as in the garden

Analysis, initial…..

- undertook detailed **thematic analysis**, which revealed a spectrum of care:
- ***Finding #1 - care settings practising truly person-centred care engage more with their gardens**
- ***Finding #2 – risk averse practices around Health & Safety will cap engagement outside**
- We still hadn't answered the question from a Designer perspective

Dissemination & analysis continued...

(Dissemination to real world was planned from the outset)

- Decided to create a visual tool, **'Care Culture Map'**(2014) for direct application of our findings. Shows the spectrum of care in relation to active engagement and organisational culture required. Enables the whole home to be part of the change.
- Tool reviewed by peers in the Care, design & research Sectors.
- Creating this tool revealed further insights:
  - the garden designer's role: ***Finding #3 – where design support is required this must match the care settings current cultural position and enable progress towards more person centred care practises.**
  - risks to residents & the Care home not obvious from earlier data. The **'Care Culture Handbook'** (2016) was written to share these insights. Funded via **Crowd funding**.
- Findings shared freely at events, via journals, social media, our website and workshops plus via our paid publications.
- In 2019 **Qualitative information** collated by a PHd student, this validated some of wider observations. Used for an '**A3 Infographic**' (2019) of quick wins for care homes
- In 2020 self-published the '**Designer Handbook**'(2020), sharing the findings & 'how to' apply **'Relationship-Centred Design'** so design support works more effectively with Care homes.

[Re Books & Map] *"Wow!!! I am reading the book WHY DON'T WE GO INTO THE GARDEN by Debbie Carroll and Mark Rendell and am blown away! It is a GAME CHANGER in how we view care communities! It is an excellent fit with the Montessori Approach to care"* CEO Montessori Care, Norway 2024

[Designer Handbook] *"It's ground breaking insightful work. You have really understood the complexity and realities of the sector and broken this down into a digestible and useful format for best practice and a ladder for implementing change. Truly amazing!"* Landscape Architect 2024

Pros

- **Freedom**—Over our question, methods, criteria for home selection & wider input
- **Flexibility** - to shift methodologies to suit evolving insights and later stage continuing analysis. Able to respond rapidly to shift focus from only design to wherever the evidence led without reference to other parties
- **Not being Care Experts**—We brought fresh eyes that helped us see aspects that can go unseen as 'just part of the norm'. This **Novice thinking** also helped us see our own sector from a new stand point and question our own designer thinking.
- **Real world change**—Our aim was always to share the findings back to the real world. Creating the finding driven visual books & tools to share and apply these within both care and design sector revealed further information that the raw data alone would never have done and we may never have found the role of designers.
- **Critical friends**—these came from within care, design and wider research circles and were key to checking and encouraging us in our chosen route.
- **Financial limits**—this drove us to be very concise in our writing to share our work and in how to apply this. Small is mighty.
- **Personal satisfaction**—we answered our question and have done our best to share it in ways that can be used by anyone with the will to do so.

Cons

- **Learning curve**— gaining the knowledge and skills needed to run the research project and to ensure our work stood up to scrutiny. This included: identifying and learning research methods, documentation control, objective analysis and becoming authors
- **Sacrifices**—Self-funding our study had a double impact, financial in running the study and time away from other work
- **Split focus**—Our findings affected two sectors. This needed differing approaches around the language and methods of diagnostic support which each sector provided
- **Misunderstood**—Early on, our final finding, was misinterpreted as literally 'its not about design'. This has resulted in a slower acceptance of our work by our designer peers
- **Low visibility**—Without the traditional paper we had no formally recognised peer review which slowed dissemination of our work as we built credibility. Consequently, as the research was not visible on academic databases it has been overlooked by related studies that only looked at other academic research.
- **Missed opportunities**- We were approached by some academic settings to publish a paper on our behalf. We discounted these as the conditions attached overstated their role in the original study. We identified many obstacles in getting independent studies verified and visible from experts in the field without formal academic training or connections.

Summary:

- Self-funding provided the flexibility to chose what we did, how we did it and the way we shared the findings
- Non-academics can do research and our wider life and business experiences help bring unique insights
- There is a financial and personal cost to balancing a study alongside earning a living
- Sharing the findings has been frustrating within academic routes, though our books and tools have been well received and have been used to make positive changes
- Finally, we had a question, which having answered we now hope that our insights will help turn that question into an invite heard across care settings, so….

'Why don't we go into the garden?'

Poster published at UK Dementia Congress 2024.

*Research publication references:

"Carroll D & Rendell M (2016), The Care Culture Map and Handbook, Step Change Design Ltd. " and

"Carroll D & Rendell M (2015), 'Why don't we go into the garden?' The Journal of Dementia Care 2015 Vol 23 No. 2"

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