

Designed with DeMentia: Building Long-lasting Collaborative Care

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Introduction

Dementia strips people of the unique attributes that form a person's identity, but it is suggested that how we relate to the world emotionally is one of the last things to escape us (Evans, 2001). Therefore, it is imperative to work within models of care that recognise and engage with how people living with dementia feel about things they are engaging with. In terms of emotional wellbeing a diagnosis of dementia is also often accompanied with a sense of loss, a loss of purpose, a loss of value and the loss of societal usefulness diminishing self-worth (Batsch and Mittelman, 2012). It is commonly recognised that people with a diagnosis of dementia are often written off by society long before their time (Katsuno, 2005). In addition to this, all too frequently people living with dementia underestimate themselves further contributing to a lack of self-belief, capacity and esteem (Kinnaird, 2012).

This research rejects those widely held assumptions and pre-conceived ideas surrounding people living with dementia. Instead, it focuses on the positive aspects people living with dementia possess such as the ability to learn new things, develop new knowledge and skills, and participate in new creative ventures. In particular, this work explores how design as an interventionist tool and method can empower people and support the reinforcement of their personhood (Kitwood, 1998). The work presented in this paper looks to develop an individual's capabilities above and beyond their existing personal experiences and does not dwell on incapability. As such the way design is used unlocks latent skills, explores personal knowledge and tastes, and promotes personal opinions within collaborative practices. Through developing projects, products and events the inclusive social activities in *Designed with DeMentia* unpick these themes. In this work multiple media, techniques and tools, all seen as part of the designer's toolkit are utilised and have been adopted by people living with dementia. Through the design-driven projects described in this paper, the act of conducting real world research leading to the formulation of ideas plays-out within groups of people who desire to make some sort of impact in their own lived experience. In their production of very real and impactful outcomes, which have been purchased by the general population, people living with dementia have taught themselves new ways of looking at the world. Stimulated by engaging with the influences that surround them, people living with dementia have explored their capabilities, and in so doing promote a genuine sense of value and self-empowerment. People living with dementia, through their participation in these projects and abilities to deliver new ideas or by driving new approaches, are recognised throughout this chapter as co-designers.

Design Research Intent

In this work the design researchers' (authors) journeys have formed long-standing relationships with people living with dementia. The intention of this work is not to see them as subjects but rather as true collaborators and co-conspirators in design adventures. Therefore, the idea of design as a creative process, a disruptive influence, a provocative force, and as a method of social interaction has become central to the research. By looking

at the design process as consisting of valued interactions each capable of revealing individual and collective influence, insight and efficacy, the process and projects had to be open and responsive, nimble and adaptive to emerging opportunities. Central to the ambitions for *Designed with DeMEntia* is a set of projects where ownership does not dominate the creative processes and outcomes and is often structured, directed and led by the people living with dementia as co-designers. For the co-designers this results in new experiences that supports exploration both collectively and individually which builds self-esteem, delivers a sense of value and delivers purposeful outcomes.

Project Methods

Designed with DeMEntia projects are grounded in active participation and a desire to work *with* people living with dementia. Therefore, the practical design methods used by the co-designers need to be accessible and adaptable by those engaged in the collaborative ventures. It was identified early on that specialist design skills which take years to become proficient with are unlikely to work well within these settings. Some of these methods might support inspired and direct creative disruption by the individual involved and as such nothing utilised was viewed as precious or un-hackable. Materials do not necessarily need to be of great value and any intended use of them have to be open to interpretation by the co-designers. The tools developed and used were selected to form kits of creative action and although some of these were to a degree prescriptive their application was not. It was important that the kits were of sufficient quality, and designed so that they communicated a sense of value in terms of user engagement and experience. Within our approaches, a variety of layering of materials, collaging of content, cutting, drawing or scribbling, templates, paints, lighting gels, printing techniques, cutting gluing, material explorations along with accessible technologies were used. This occurred with the knowledge that the toolkits and the products, materials or tools selected were collated and designed (fit) for purpose. Thus, tailoring methods to the variety of design opportunities being explored.

Photography has also played an important role in the Designed with DeMEntia methods. Giving cameras to the co-designers and getting them to document what they liked has been key, allowing them to make images from the outset. Since the first project where Steven¹ (one of the participants) stated that he really liked photography, that his niece was a professional photographer, but lamented that “... *nobody would give me a camera now ...*” it became clear that this could be one of the most accessible approaches. Interestingly, the use of photographs has also become central to the final project.

Open Sharing Practices

How the co-designers, carers and design researchers behave in regards to one another is essential in nurturing the creative community that supports doing long-term design collaborations. In the same manner as IDEO’s guiding principles for better brainstorming (Kelley and Littman, 2001) where they stipulate “... *encourage wild ideas*” and “... *do not critique or debate ideas*”, central to this approach is:

- Make no judgements;
- Refrain from bias in regards to creative or illustrative capabilities;
and
- Welcome ideas that are different and that may change the original intention or scope of a project.

Indeed, it was common within the projects to find interesting informed positions playing a role where personal histories and capabilities helped to progress the creative collaborations but were not restricted to formal creative modes of communication (*i.e.*, drawing).

¹ The names used in this chapter are not the individuals’ real names.

Revealing and Building Upon Skills and Knowledge

Throughout the practices involved in making investigating, shaping, designing and delivering the projects the co-designers were at least equal collaborators if not the project leaders. Within this empowered position regular revelations would occur and these would often be brought to the fore by tasks in hand. Personal narratives would be shared about historic practices and these would be shared not only with the design researchers but with the other co-designers. These revelations would often give personal empowerment where, at least for that day, they were the expert. This first came to the fore when one co-designer stated that she was not going to follow the plan of a project, rather she was going to do it her own way based upon her long history and experience of collaging. In another project, a former professional book binder Laura informed the construction of a piece of work and thanks to her knowledge changed the final design assemblage and output. Whereas in another project, one of the co-designers Mel supplied guidance and insight into how to wire a prototype lighting design where her past experiences as an electrician supported her in informing the design researcher (first author) on how to do things. Throughout the projects personal capabilities were reinforced by sharing such insights and by using this kind of knowledge to progress a project or to shape the future of the plan. Another participant, Gordon, used this position to start his own photographic scanning lab for other people living with dementia. Noting the values that these people had, their passions and their valued insights is at the core of the collaborative approach adopted here.

Collaborative Design Time

The methods used here have been developed across long periods of collaboration punctuated throughout by practical hands-on experimentation, designing, making and producing. Challenging how collaborative some co-design projects report to be, this work has been developed from the perspective of building enduring creative relationships with people living with dementia. Often, due to financial and time pressures, co-design is undertaken in a manner that is front-end loaded and more akin to public or stakeholder consultancy. In this type of co-design (Braenkhart and den Ouden, 2017; Jakob *et al.*, 2017), the actions might be creative and collaborative but the findings are then often taken on by the designer in order to shape them into a suitable outcome. In the work of *Designed with DeMEntia*, the creative relationship is loosely structured with the intention to develop conversations, to have changing dynamics and to last from project inception to project completion where the design responsibilities are shared throughout. Some of the collaborations have spanned years of creative partnership although most commonly last around 6 months.

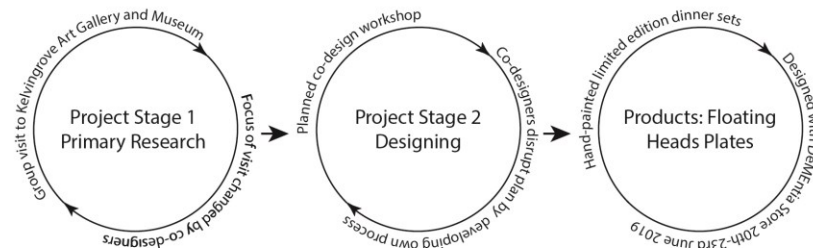
Through these methods of working, *Design with DeMEntia* has achieved a number of co-designed outcomes which have included:

- Guidelines and parameters for new inclusive social settings or activities.
- The production of four new textile designs.
- A range of *Designed with DeMEntia* products.
- Lighting designs.
- Methods for public engagement and public exhibitions.
- A series of pop-up shops.
- Lighting signage for a charity allotment.
- A person living with dementia-led photographic scanning network.

The range of projects undertaken here shares an interdisciplinary philosophy of design within which the full engagement and actions undertaken by people living with dementia have the capacity to shape their own world and that of others. How they have done this is discussed through explanations of two of these co-designed projects. The first project was a

more rapid design project and consisted of a couple of months of work. The second project was far larger where the participant group naturally morphed along the design process with some participants leaving and others joining the group. This project evolved over a two-year period which included periods of intense action and periods of less engagement. This occurred as a result of production time, holiday periods, the introduction of rapid design projects into the creative mix and returning to the project when opportunities arose (Figure 3.1).

Project One
Floating Heads



Project Two
75BC Textiles

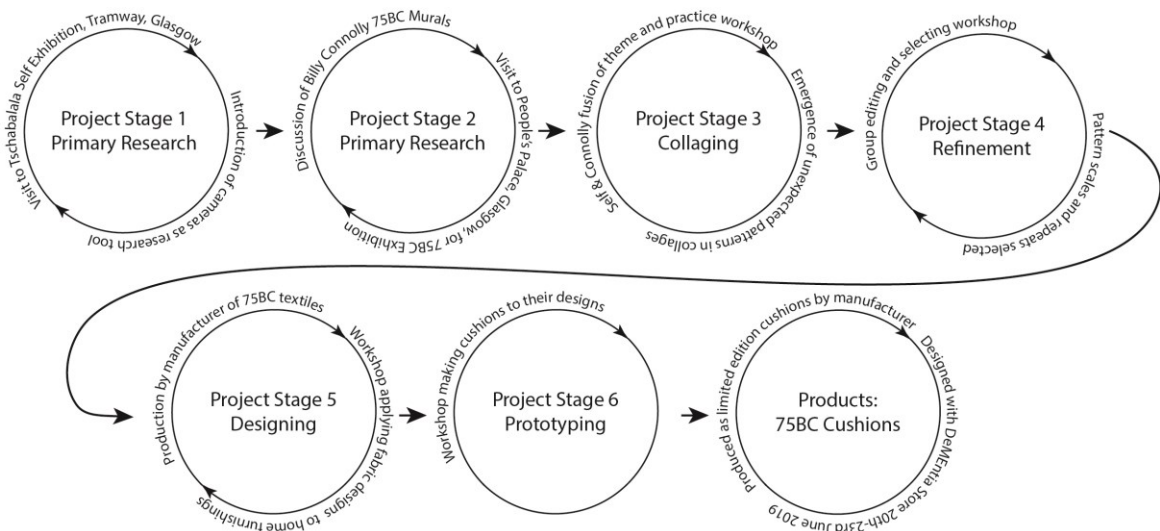


Figure 3.1: Projects' Process Diagrams Sharing Stages

Project 1: Floating Heads Plates

The Floating Heads Plates were one of the collections of products produced for the *Designed with DeMentia* pop-up shop in the St Enoch Centre in Glasgow 20th to 23rd June, 2019. The plates contributed to the existing portfolio of designs that the people living with dementia had previously undertaken. In the production of the plates a number of empowered discussions, actions and interventions took place. A core tenet of the processes included visits to a number of cultural institutions including galleries, museums and public parks and other stages.

Stage 1 consisted of a visit to the Kelvingrove Art Gallery and Museum in Glasgow. The purpose of the visit was to view a new art installation where pottery had been blown-up in historic war zones. The process had been filmed and photographed and replayed within the

gallery alongside the exploded artefacts. The fragility of the ceramic pieces and their fragmented forms were arranged to generate questions in regards to collateral damage. The group were unimpressed as expressed by one participant - "I get it, I just don't like it..." and by another who stated "... nah, it's not for me". There was a general sense that it was too serious and largely uninteresting. In juxtaposition to that exhibition, the group noted the large ceramic heads that hung in the adjacent stairwell. These were the 'Floating Heads' by Sophie Cave. They photographed these noting their joy in their appearance and playful nature.

Stage 2 included a workshop that responded to the commentaries and photographs that the group had taken during their visit in stage 1. A number of ideas based on the 'Floating Heads' installation were explored in this workshop. Different materials and processes were considered and explored in both 2-dimensional and 3-dimensional forms. These ideas were very quickly abandoned the moment one of the participants decided to start drawing her own versions of the faces of the floating heads on ceramic plates. This co-designer had taken the approach of diving in and acting on impulse. Sheila picked up one of the plates, a template and a set of porcelain marker pens as the materials were being unpacked. Instantly, she started to alter the template and to draw directly on a plate using the hacked template as a guide. Quickly the other participants got on board with doing their versions of the same thing. The hour-long session was transformed by the co-designers. By disrupting the planned workshop, the project became the groups' own where they experimented with hacking templates and using marker pens to create their own designs.

Four of these were selected by the group to become a set for the *Designed with DeMentia* pop-up shop (Figure 3.2). It was important that the workshop allowed this to happen, rather than redirecting the efforts of the group towards the original plan. In these workshops it is particularly important to embrace unexpected outcomes as this was singularly their design process. This gave a sense that the co-designers were both stimulated, knowledgeable and empowered. They appeared to be building on their confidence and their right to make decisions or to direct design practices - reinforcing the point that the control in all of the workshops rests with the co-designers. The empowerment is best explained here by the understanding or prowess displayed by participants to disrupt a planned workshop in order to develop a better design outcome.



Figure 3.2: 'Floating Heads' Plates - The Result of a Design Disruption Workshop

In the case of this project, the design process was short and sharp. Many of the projects were not necessarily as quick to resolve and delivered with such instant certainty. However, as stated above it was important to punctuate longer-term projects with more rapid design explorations. The final designs were created as hand painted limited-edition pieces, exhibited and sold through the *Designed with DeMentia* pop-up shops.

Project 2: 75BC Textiles

The first longer-term project resulted in the production of four printed textiles which were used to design a range of home furnishings and personal products that were also sold through the *Designed with DeMENTia* pop-up shops. These were inspired by the famous Glasgow comedian Billy Connolly-themed 75BC street murals, the 75BC exhibition at the People's Palace, Glasgow, and the American artist Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. During this project, five co-designers photographed the exhibitions and content they saw. The photographs became a reference point for the range of visual representations of Billy Connolly that they produced and documented the creative practices they would explore.

Stage 1 introduced the group to undertaking primary research, during the visit to Tschabalala Self's exhibition at the Tramway Gallery, Glasgow. The participants were given a digital camera and asked to photograph the artworks, focusing on their composition and their structure. Each participant was asked to photograph what appealed to them. The participants set about eagerly photographing the exhibition from different perspectives, selecting what to photograph and how. One participant was particularly adamant that only two of the artworks appealed to her and those were photographed because of the vibrant background colours. The task appeared to reinforce the visit, introducing a layer of discussion based upon what they were collecting through their photographs.

After visiting the three Billy Connolly 75BC murals in Glasgow, Stage 2 began with discussing what the group felt about them. The group were largely unimpressed and didn't recognise these representations of Billy Connolly as Steven stated "*I don't get it...*" and Tam revealed "*I don't like it*". This discussion led to a follow-up visit to the Peoples' Palace in Glasgow where again armed with digital cameras the group photographed artworks and artefacts of significance that were more closely related to their vision of Billy Connolly.

Following the Tramway and People's Palace visits, a suggestion was made to the group to combine what they had been exploring through a tailored and responsive creative workshop. The one-hour workshop considered the visits and the work of the artists that the group had seen. In this workshop the group made sense of what they had seen, organised what they had recorded and discussed, and most importantly how they felt about these things. By being the generators of the research materials through their own curated photography their thoughts and decisions shaped the content for Stage 3 (Figure 3.3).



Figure 3.3: Designing the Billy Connolly figures and New Bridgeton Textile Fabric Design Proposals

Stage 3 incorporated the results of the group discussion and reviews of the visits. Their primary investigations identified Tschabalala Self's use of layering of scraps of materials stuck and stitched onto canvas to create highly expressive portraits and figurative artworks. Their photographs and discussions pinpointed elements of layering, pattern and colour as being important. Their other visits and photographs reviewed the alternative ways in which Billy Connolly had been represented and identified the depictions that they felt more closely allied to.

A one-hour workshop was devised in response to the co-designers framing of their investigations. Here a project kit was developed to allow quick, accessible methods for creating visuals. The kit repurposed Tschabalala Self's artistic process where different scraps of fabric formed different body parts. Based upon more widely recognised images of Billy Connolly from highlights of his career such as those discussed within the group, four historically significant pictures of trademark outfits and poses were converted into outlined graphic forms. These forms were then printed on the reverse side of a collection of patterned laser prints. The laser print patterns were of textile designs inspired by Tschabalala Self's medium of choice. The choice of patterns reproduced in the laser prints were significant, as they originated from historical textiles produced in Glasgow. This anchored the designs locally supporting an embedded link to the local surroundings of the Bridgeton Resource Centre. With this in mind, it was pertinent to include patterns that had been manufactured in the area in the past. These patterns were situated alongside works by Charles Rennie Macintosh, Timorous Beasties and Laura Spring all of whom are, or have been, well known textile designers working in Glasgow.

In total fifteen different patterns were utilised. A range of patterned heads, legs, bodies, hands, feet and clothing were cut into small portions (or scraps) to be assembled (Figure 3.3). The component parts were offered to the group from which they selected the elements they wanted to use. As part of the co-design kit, a guide to how the parts should be rearranged was included. The designs were then systematically reproduced in a sequence, although freedom of choice in regards to pattern and arrangement were entirely that of the individual. The serendipitous nature of how the original source patterns aligned with the form of the Billy Connolly component cut shapes, supported diversity in decision making affording a range of colour opportunities and pattern glimpses to work with, although not every piece contained a highly decorative or colourful pattern. What was important in this process was individual choice and form giving.

The workshop invited the participants to collage their own designs for their vision of Billy Connolly from the component parts. During the workshop the five co-designers generated individual artworks. In the workshop, four of the participants created two completed artworks each. The fifth participant produced one artwork consisting of two representations of Connolly.

During the making of the individual collages, it was observed that each participant's image revealed personal tastes where component part selection was particularly important to them. In one example, Steven stressed that the right hand and right boot should match but that "...*the hands and the feet shouldn't match*". This was a clear personal choice of the participant and an articulately expressed creative decision relating to the organisation and arrangement of the constituent parts. Throughout the process very distinct and clearly considered decision making was evident. Continuing to make judgements and to explain what they were doing, Tom stated "*I've used too much blue, I need another colour in, it's too much the same*". Another co-designer was adamant that they were not interested in making the image in the form of a human figure. Instead, they explained "*I'm waiting until everybody has got their parts and then I'm going to use the parts I want*". After this, they proceeded to select multiples of figure parts to create their own more abstract patterns. Marge took great joy in collecting and arranging the vast array of surplus parts into her own creative outcomes.

The rest of the participants produced very close facsimiles to the original designs. These were, however, highly individualistic in terms of pattern choices and colour combinations. Throughout the process all the participants were assertive in directing what they wanted, what would work and what wouldn't. Rejecting in no uncertain manner what they did not

want in their designs. The result was similar representations of Billy Connolly that were nonetheless highly individual in colour arrangement and pattern.

At the outset of the workshop, it was expected that each representation would be produced on an individual sheet. The group by their actions took control of what would be generated and created arrangements that informed the next phase of the design process. Remaining fluid to participant actions the design intent or use for the collages changed. What became apparent was the potential that existed, within the unexpected visual arrangements, for patterns to be produced. This was discussed as a developmental stage with the group and acted upon by the design researcher. The visual representations were worked up into a selection of potential repeat patterns which shaped the workshop in Stage 4.

Stage 4 invited the group to look at, edit and select from a range of repeat patterns which were structured around the prior discussions and the group's artworks. The various patterns were produced at a variety of scales. The co-design group were then informed that three patterns should be selected for digital textile production. The group selected four. During the process they discussed each pattern before deciding whether or not it should make the final collection. Once the four patterns were selected, they collectively chose at what scale it should be produced. This process was a chance to debate tastes in regards to their own designs and encouraged them to get up and walk about, to be physically active in the process.

The first few stages of this project represented three visits and two practical workshops. What followed were a number of other explorations based upon the printed textiles. The chain of projects, which were developed through discussion and active workshops supported opportunities which included the design of home furnishings, lighting, exhibitions and products.

Stage 5 was a workshop where the use of templates in the shape of ubiquitous household furniture and textile-based products were produced so that the co-designers could select and apply their patterns (Figure 3.4). The workshop had developed from a prior discussion where a show-and-tell of the printed textiles asked how they might be used.



Figure 3.4: The Four Textile Fabrics (top) and the Textile Designs being Applied to Products (bottom)

During this stage a new member who had not created the original textile designs joined the group. Being new to the group and the project they did not have the same opportunity to have ownership of what had previously occurred, however, they eagerly got involved with the task at hand. Joe was particularly non-verbal, limited in his ability to hold a conversation or find the words that would aid participation. By the time of this workshop, he had been attending the group for more than a month and had taken part in another of the rapid design projects. The other members of his co-design group aided his participation when they informed him of what had been done and that there had been a tangible result in the form of the textiles. Joe paid particular interest in creating designs for the lampshades for pendant lights. Here, he layered up a variety of quite raw arrangements of the materials sometimes tearing them to get the desired proportions of pattern. During the process he was animated, fighting in order to find decision affirming words and displayed a sense of being thoroughly engaged which resulted in two unique designs. The lack of sophisticated verbal communication was no barrier in this process, though there was a clear desire to explain the design decisions made and approaches used. On completion, Joe appeared to display pride in what he had achieved and showed a sense of ownership of these new designs. This view was reinforced in a later workshop for another project, where he informed new co-design members through his limited vocabulary "*I did this...*".



Figure 3.5: Cushion Production by the Group at Bridgeton Resource Centre

A key outcome of the continuing workshops (Stage 6) within the 75BC project was the production of cushions which have become a feature of the Alzheimer Scotland Dementia Resource Centre in Bridgeton, Glasgow (Figure 3.5). Here each participant chose the fabric they wished to use along with backing fabric. Using card templates to chalk out the designs the group chalked their materials, cut them out and with support pinned them together. In this process the participants shared their own knowledge of how to construct the cushions and explained the method in which they were to be sewn. The cushions were then sewn by the first author on a sewing machine. The result was that each participant had their own cushion. The participants gladly left these within the resource centre where they worked, free for anybody to use. It was interesting however that each co-designer knew exactly the particular cushion they had designed and ensured that they had their own cushion when they were in the centre. This was a point remarked on by one of the centre's professional care support workers who helped to facilitate each session.

In these projects, the co-design decisions and actions, displayed the often-leading roles played by the people living with dementia. Throughout the process the participants displayed ownership and confidence to drive, act within or indeed disrupt planned processes whilst also bringing their personalities into the design of objects. The process adapted regularly to the choices, behaviours and actions of the co-designers meaning that positions and propositions were regularly re-evaluated. The applications of the visual outcomes as designs, were driven by the design conversations that occurred whilst shaping each stage that followed. Throughout the project there were various aspects of their thinking and desires which formed workshops of action. To support their long-term engagements with the design process the design of the participative and collaborative workshops had to respond to previous interactions between the co-designers, subjects, and the design researchers. These occurred because the process was an open collaborative discussion that naturally evolved through these situations of action and reaction.

Conclusions

As these projects highlight, creative decision-making occurred not only in the preparation of the activities but also during the live workshops. In the shaping and control of the workshop activities, the people living with dementia were individually empowered within their creative groups, collectively empowered as a group to develop ideas and externally empowered by designing for the world outside of the spaces in which they worked. Their exhibition and design of the participatory workshop in Lancaster city centre and their production of design artefacts for the Designed with DeMEntia pop-up shop in the St Enoch Centre in Glasgow provides substantial evidence of this farther-reaching empowerment.

During the pop-up shop event, public comments and thoughts were recorded as written responses to wall-based prompts which included questions about the work, perceptions of the capabilities of people living with dementia, and visitors' personal experiences of dementia. This along with the notable sale of designed goods provided valuable insight as to how the public reacted to and thought about the project and the people behind the designs. The public responses included:

"I'd never have thought people living with dementia would be capable of this"

"Fabulous concept everyone should see this amazing work. X"

"Insightful, educational, inspiring, very positive and we need to talk about key issues more"

"People should not purely be defined by their dementia they are more than that!"

"It's amazing how much things have progressed in 20 years since my dad. Good to know things other than medical care are being looked at. It's about the person"

However, on a visit to the *Designed with DeMEntia* pop-up shop one visitor summed it up best when they wrote *"Brilliant! I never thought dementia people could do this. I did and I've got dementia"*. This displayed the value and esteem that being involved in the project brought and the change in understanding within a person living with dementia had experienced through the design-supported relationships that had developed. Relationships to people, to creative processes, to shaping their own capabilities and to themselves.

Throughout the adaptable design approach and journey that these projects represent, time has been the most important part of the co-design process. Our approach is enduring often lasting many years and peppered with challenges that have had differing time requirements. These aspects created the space for trust, collaboration and friendship to develop.

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