
ServDes2018 - Service Design Proof of Concept
Politecnico di Milano
18th-19th-20th, June 2018

Adapting the design process for different learning styles and abilities

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Abstract

We begin by exploring what is meant by cognitive impairment, and some of the difficulties and challenges faced by people with varying levels of cognitive impairment, including specific issues related to adaptation and abstraction. We consider how designers (who can also be viewed as ‘outsiders’) can act as enablers, supporting people with cognitive impairments to contribute their insights and ideas to design services that work for them. We emphasise the importance of mindset and methodological framework, and, in the spirit of sharing and collaborating, use examples from practice to illustrate the iterative development of a range of methods and tools to create a safe and supportive co-design environment.

KEYWORDS: co-design, service design, inclusive design

Introduction

In beginning this paper, we must make it clear that Snook do not take a ‘deficit’ based approach to our work with people with cognitive impairments. We believe there is no such thing as ‘normal’ and we all need different levels of support at different phases of our lives, and each face our own challenges related to information processing, social interaction and communication. We take an asset-based approach, recognising that, as Paul Hunt, the noted disability rights campaigner, stated in 1966,

‘The value of a human person transcends his social status, attributes, or possessions, or his lack of them.’

This is not to negate the support needs of those with multiple and profound learning disabilities, but to concur with the UN Convention on the rights of persons with disabilities, which stated in 2006 that it recognised,

‘that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.’

Learning disabilities and cognitive impairment – what are the common definitions?

The term cognitive impairment covers a wide spectrum of learning disabilities and difficulties, from people with profound and multiple learning disabilities to those with Mild Cognitive Impairment (MCI) and specific learning difficulties such as dyslexia. The Scottish Government strategy for learning disabilities (2013), *The Keys to Life* (developed with learning disability advocacy groups) defines those with learning disabilities in the following way,

‘People with learning disabilities have a significant, lifelong, condition that started before adulthood, which affected their development and which means they need help to:

- Understand information;
- Learn skills; and
- Cope independently’

The Scottish Government strategy excludes specific learning difficulties, such as Dyslexia as it has alternative strategies for dealing with this. It also states that, “We recognise that some people with learning disabilities are also on the autism spectrum. However, people on the autism spectrum do not necessarily have learning disabilities.” (Scottish Government 2013)

Specific Challenges of working with people with a range of cognitive impairments

As a lot of our work as Service Designers at We are Snook involves working with communities to innovate new models of public or community services, we have worked with a wide range of people with different abilities and challenges. We have encountered a range of specific cognitive impairments, from foetal alcohol syndrome to dementia, in our co-design work with communities. We recognise that there is a range of support needs for people with general, non-condition specific, learning disabilities, and that every condition is on a spectrum, from those requiring intensive support and care, to those living independently.

We have found the following list of signs and symptoms, while specifically related to Foetal Alcohol Spectrum Disorder, to be indicative of the some of challenges we have faced in co-design projects with people with a range of cognitive impairments:

- Problems with language
- Lack of appropriate social boundaries (such as over friendliness with strangers)
- Poor short-term memory
- Inability to grasp instructions
- Failure to learn from the consequences of their actions
- Egocentricity
- Mixing reality and fiction
- Difficulty with group social interaction
- Poor problem solving and planning
- Hyperactivity and poor attention
- Poor coordination.

(Drink Aware 2013)

Through our own learned experience and through reviews of the literature related to cognitive impairments, we have grouped cognitive difficulties into four main categories:

Information Processing

Working memory, reading difficulties, ability to remember or recall instructions, problems understanding meaning and intent (literal interpretation), difficulty in understanding abstract concepts or being able to abstract from personal experiences to general principles.

Focus and Transition

Intense focus and repetitive behaviours related to specific areas of interest - and inability to recognise when this is not appropriate; difficulties in making transitions between activities; lack of tolerance of, or ability to cope with, change.

Social Interaction

Lack of self-control and social awareness; inability to moderate or control emotional responses; lack of inhibition, demonstrating impulsivity; problems recognising or responding appropriately to social cues.

Communication

Very poor literacy skills- limited ability to write by hand; language difficulties – inability to express needs and opinions verbally; occasionally accompanied by poor hearing and eyesight.

Designing in a social context – designers as ‘outsiders’

Obviously all of these symptoms are on a scale from moderate, requiring minimum support, to extreme. However, at Snook, we have recognised that often we are sending our designers into situations that are the domain of qualified social and community development workers, and they need to be equipped to deal with the issues that arise. We put all of our staff through Mental Health First Aid training and Sexual Health training (kindly provided by NHS Greater Glasgow and Clyde), and Protection of Vulnerable Groups (PVG) screening. We recognised that our staff needed to be able to recognise signs of mental distress (in themselves as well as others) and also indicators of physical and sexual abuse. Our concern is twofold – firstly that all groups are run with appropriate concern and attention to the wellbeing of group participants; secondly that staff themselves can recognise when they are being emotionally affected by the personal stories and circumstances of those involved in projects.

Designers themselves have been identified as ‘outsiders’ by Gamman and Raein, (2010) who suggest that creative people often set themselves outside of social norms and adopt a ‘critical inquiry’ approach to society. They also highlight the link between creativity and dyslexia and the fact that up to 60% of Art and Design students exhibit some degree of difficulty with reading, spelling, written language and processing instructions, often making them ‘outsiders’ in educational processes. Quoting West (1997) who states “adaptability in complex situations evidently allows dyslexics to solve problems in unusual ways that employ unconventional methods”, they suggest that this makes them particularly suited to more creative disciplines where they can work in very practical and visual ways (Gamman and Raein 2010). Csikszentmihaly (1997) and Runco (2007) have both suggested that overcoming disability, whether intellectual, mental or physical, is often a defining feature of creative people.

It is worth noting here that while dyslexia is linked to enhanced capacity for creativity, it is recognised that other developmental disorders, such as Autism Spectrum Disorders (ASD)

and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) seem to limit an individual’s capacity for imaginative creativity. It appears that they cope better with reality-based creativity and a limited variety of options or choices (Craig and Baron-Cohen 1999; Happé 1999). Having taught Design Thinking to IT students (a high percentage of whom were ASD) I can concur that they were much more comfortable in analytical tasks compared to those that involved inductive reasoning and abstraction.

Understanding Learning Styles

Experiential Learning Theory (ELT) is not just a theory of education but a model of personal development, outlining how we all learn and grow. Kolb states that ‘learning is *the* major process of human adaptation’ (1984). Piaget proposes that resolving states of ‘disequilibrium’, where existing knowledges or ‘schema’ are challenged by new encounters results in ‘intelligent adaption’ and ‘formal operational’ maturity (1958). It is recognised that this is a particular challenge for people with learning disabilities, who Scottish Government have defined as having specific ‘problems in adaptive functioning’ (2013). From experience, we recognise that some people with cognitive impairments face challenges in assimilating new knowledge and may be able to critically evaluate their own experiences, but are less able to abstract from that to general principles for service delivery. Figure 2 illustrates the design process We are Snook use, which is built on the Design Council Double Diamond (Design Council 2005) and ties this in with the different learning styles proposed in Kolb’s ELT (Kolb 1984; Kolb and Kolb 2005). We have identified that the phases of the design process that involve more divergent thought and abstraction (indicated by the dotted ellipse) are those in which people with cognitive impairments require additional support.

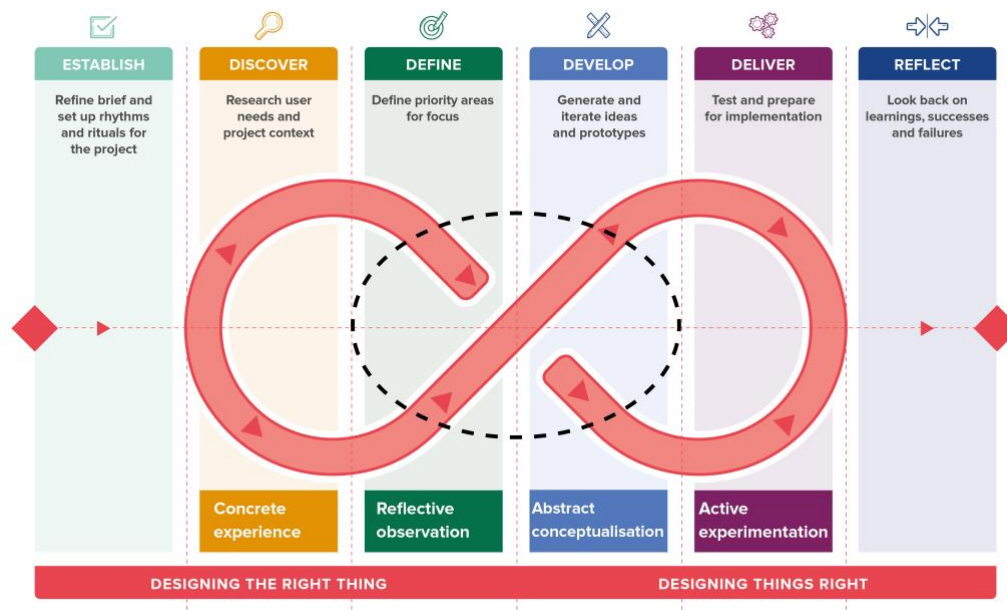


Figure 1

Current challenges in service co-design with people with cognitive impairments

Initiatives to allow people with learning disabilities to exercise choice and control over how they receive support have grown in recent years, building on programmes such as ‘In Control’ (Leadbeater, Bartlett and Gallagher, 2008).

Scottish Government has a programme for direct payments called Self-directed support (SDS) which,

‘empowers individuals to have greater choice and control over the support they receive, either through receiving a direct payment in lieu of services, or by having greater control over decisions about what types of services or supports are provided. Rather than being a passive recipient of services, citizens can become actively involved in selecting and shaping the support they receive.’ (Scottish Government 2013)

The Scottish Government has confirmed that this involves including people with learning disabilities, “to deliver the changes necessary they need to involve the third sector and most importantly people with learning disabilities and their carers to ensure that developments are fit for purpose.” (Scottish Government 2013)

A recent Scottish Government report (2016) has reiterated the commitment to ensure that:

- ‘Disabled people can participate as active citizens in all aspects of daily and public life.
- Support for independent living for disabled people of all ages, with increased say over how that support will be managed and provided.
- Delivery of high quality health, social care and third sector services, with services working together to remove the barriers faced by disabled people of all ages
- Increased opportunities for disabled people to be fully involved in the design and delivery of services.’

Robertson and Wager (2012) explain that this is the core value of Participatory Design, ‘It expresses the ethical stance that different voices need to be heard, understood and heeded if a design process is to be genuinely participatory.’

Traditionally people with cognitive impairments have suffered from having things done ‘to’ them and ‘for’ them, with little involvement on deciding what services are appropriate or desirable. Older people with learning disabilities have suffered the most from this and sometime struggle to think independently about what they really want, as opposed to what they have been offered and always accepted.

One older man (60s) with learning disabilities told us how, in the institution he was previously in, they were actively discouraged from forming romantic relationships and even too close friendships. This man also had a work placement for many years in a factory, doing very repetitive assembly work. He can’t remember if he was paid, but said that, if he was, he was given no choice about what to do with the money or how it was spent. We can see from these stories that being suddenly offered the opportunity to decide what to do themselves can be very unsettling and often leaves people feeling more vulnerable and exposed to possible failure: “But what if I think it might be the right thing to do, then it doesn’t work out. What happens then?” People have even expressed incredulity, “No, there’s no way they’d let you do that!”

How can we, as designers, support people to consider their needs and wishes in this new (and for some, completely revolutionary and unsettling) landscape? How can we create a safe and supportive environment that facilitates co-design of new service models?

Creating a safe and supportive space for co-design

One of the most important things in engaging people with cognitive impairments in any project is providing clear explanations, in easy to read language, well in advance of any engagement. People should be given the opportunity to address any questions or concerns they may have after reading at the Establish kick-off meeting (see Figure 2 for illustration of co-design process). Written communication should cover, at a minimum, these three main headings:

1. Project purpose, process and participant’s roles

2. Activities and tools
3. Expectations of outcomes

It is very helpful to work with a learning disabilities Advocacy Group, such as My Life, My Choice, Change, Grapevine, Mencap, Enable or People First; or with a condition specific group such as Alzheimer's Scotland. People with cognitive impairments who receive support from, and are members of, such advocacy groups have been empowered to recognise that their opinions are important and people should listen to them. Others, with FASD and particularly alcohol or drug related cognitive impairments, are often less able to articulate their preferences, as groups they may be members of focus more on support than advocacy. As this latter group can be quite unpredictable, it is vitally important that support and/or social workers are involved in any group work.

Actually the involvement of formal or informal carers and support workers is often key to success of any co-design project with vulnerable groups or people with cognitive impairments. At Snook, this is a clear requirement in our Vulnerable Adult and Child Protection policy. Support workers bring an understanding of the background and specific challenges of participants in a group; can also alert designers to any potential conflicts between participants; and can provide continuing support to participants, talking through, and providing support, on any particular issues that may have been uncovered during the co-design project. Ethically, this is very important. Asking people to reflect on their lived experience, especially in a group situation, can mean that one person's story prompts a different person to recall something that happened to them that may be distressing, and may potentially involve a traumatic memory, or disclosure of ill-treatment or abuse. Any project working with the public should have Ethical Approval that provides guidelines for dealing with such situations.

Explaining the purpose, the process and roles

Part of any ethics application focuses on clearly explaining the purpose of a project so that participants can decide whether or not to be involved. We must be clear about who is sponsoring the project, who will ultimately benefit from the outputs, what will happen to any information they provide and who will have access to this.

Explaining clearly how the co-design process will work can alleviate nervousness and anxiety. We should explain here how important their role is in bringing insight into the everyday lived experience of the service (or product) we are co-designing. We always say that any non-designers joining our co-design projects (whether part of the senior management team, or service users) are experts in their own lives. Czyzewski, Johnson and Roberts (1990) perspective on the expertise of workers can also be applied to service users,

‘It assumes that the workers themselves are in the best position to determine how to improve their work and their work life. In doing so, it turns the traditional designer-user relationship on its head, viewing the users as the experts – the ones with the most knowledge about what they do and what they need – and the designers as technical consultants.’

Robertson and Wagner (2102) explain the additional care required when engaging ‘vulnerable’ groups:

‘A related concern is vulnerable and frail participants, such as children, people with disabilities including dementia, refugees, immigrants and in general people in marginalised situations. We use ‘vulnerability’ here as a term indicating that some groups of users may require special sensibility and care.’

It is very helpful for people with cognitive impairments to have clear and detailed outlines of exactly what will happen in any workshops. As designers we often seek to be dynamic and

responsive in our workshops, ‘going with the flow of energy’ as we say. This can be very disconcerting for participants if they have taken the time to study the programme and familiarise themselves with the schedule. We must either make it clear that the programme is indicative only, and may change, or make every effort to keep to the programme. This, again, avoids unnecessary anxiety and distress.

Explaining activities and tools

This is a very important issue that we must address sensitively. Often, in co-design workshops we use playful, primary coloured tools such as lego, playdoh, and other toys such as dolls and building blocks, alongside stickers and simple graphic images. If we are not careful our co-design participants can think that we have provided these tools specifically for them and interpret this as patronising and indicative of our judgement of their abilities. When I asked one group why a previous participant had a negative reaction to such tools, when we used them with senior professionals all the time, they said, “Yes, but they have not been told all their lives they are just children in an adult’s body.” It is helpful, therefore in any material sent out before the project, to provide illustrations of these tools in use by ‘professional looking’ people and explain our reasons for use of naïve tools. We should create our own stickers that have clear, simple icons without being childish in any way.

If we indicate that workshops will involve writing or drawing we must emphasise that people will be available to support them with this, and that they can talk while other people scribe or draw for them if required. However we must also respect project participant’s desire to do this independently if preferred: “Please don’t try to finish my sentences for me. That just shows your impatience and is disrespectful. I know what I want to say but just take longer than other people to say it.”

Understanding learning styles and preferences should prompt provision of a range of different activities. For example there might be a video diary space, supported drawing of journey maps, and labelling or voting with stickers on a prepared grid. It is helpful to try to move people around, but there are activities that some people feel more comfortable with than others.

Managing expectations of outcomes

At the project outset we must be clear about what will happen as a result of the project and what the timetable for any service changes might be. Sometimes people are delighted just to have been asked to contribute their views and ideas, but, understandably, there is an expectation that something will change as a result of their feedback and involvement. Complex procurement processes, particularly in the public sector, can extend the time period between producing a service proposal and actually implementing a new service. This can cause frustration and disappointment if not managed appropriately. Because co-design projects often involve close working over an extended period we must agree together some boundaries around friendship and continuing contact. As Stalker (1999) has made clear, it is sometimes difficult for people with learning disabilities to realise that this may be a professional relationship that will not continue beyond the project’s end.

Because designers can produce mock-ups and prototypes that look professional, sometimes project participants can interpret these as indicating that something, (such as a web-based service) they have helped to co-design, is almost ready to launch, and want to direct others to it. It is helpful to give project participants a takeaway, in the form of an illustrated, easy read version, of a project report that they can show others to demonstrate their involvement in the project.

Tools to support self-expression in people with cognitive impairments

Having discussed all of the challenges and ethical considerations of creating a safe and supportive space for co-design with people with cognitive impairments, what methods and tools best support project participants in actively contributing to the co-design process?

As mentioned previously most people with cognitive impairments are more comfortable working with ‘concrete’ experiences, rather than abstract or conceptual ideas. In any team or group work situation the best results are achieved by allowing each member to work to their strengths, and this also applies to participants with cognitive impairments.

Establish – the pre-project or project preparation phase

At the establish phase of a project it is important to clearly articulate desired outcomes and how these will be measured. These are not only outcomes required by the client, but also outcomes expected by the service users involved in the project. Working together to set a range of Key Performance Indicators at this stage of the project allows effective evaluation at the end of the project. If some of the Key Performance Indicators relate to attitudes, behaviour and capacity (skills development) of those involved in the project, it is important to establish a baseline for these measures before the project commences.

The ideal way for the designer to understand the lived experience of the service (or product) users is to spend time with them, mostly just observing daily life, but asking questions where appropriate. This is the design ethnography phase, which is often squeezed when project budgets are tight. However it is incredibly valuable in forming our understanding of the capacity and skills of the service user, the challenges they face, and their adaptability in overcoming these.

As an introduction to the project and a prompt to begin to think about the issues to be considered in the project some preparatory work can help people get into the right frame of mind. If we want to start with some insights into their daily experiences of using a service (or place or product), cultural probes, particularly cameras with GPS, work very well. Rather than being asked to suddenly describe their lives in detail in a workshop with people they don’t know, they can take time to take photographs, or make videos of their daily routine. It is best if the project introduction is quite instructive about what is required and perhaps asks specific questions, as sometimes the amount of material produced can be overwhelming. If the cultural probe material is available in advance of the first workshop, the project team can take the time to analyse and synthesise the information and identify some specific issues or themes to be considered in the workshops.

First activity – the discover phase

In our first workshops with project participants we are usually looking to obtain some further insight into their lived experience of a service if they have completed some cultural probe activities beforehand, or to support them in describing their experience if this is the first activity they have been involved in. As Liz Sanders says, ‘Asking even highly creative people to write in a blank book was just over the border, they didn’t know where to start.’ (Sanders 2012) So it is important to have prepared materials to support people in telling their stories.

We usually try to obtain two specific insights at this stage

1. What does your world look like? Who are the people supporting you in your daily life?

Using pre-prepared stickers and maps makes this activity accessible for everyone. A support person can help scribe any comments the person makes to identify the different

people and places they engage with. We usually put the person at the centre of the map and ask them to place the other places and players in order of importance, from the centre outwards. (Figure 3)

We must be aware of two specific issues in mapping lives like this.

- a) Some people we have worked with become very distressed when they see the paucity of their social network in visual form
- b) Routine and support structures are often very important to people, providing a sense of comfort and security. They may become stressed if they feel we are questioning these or suggesting change.

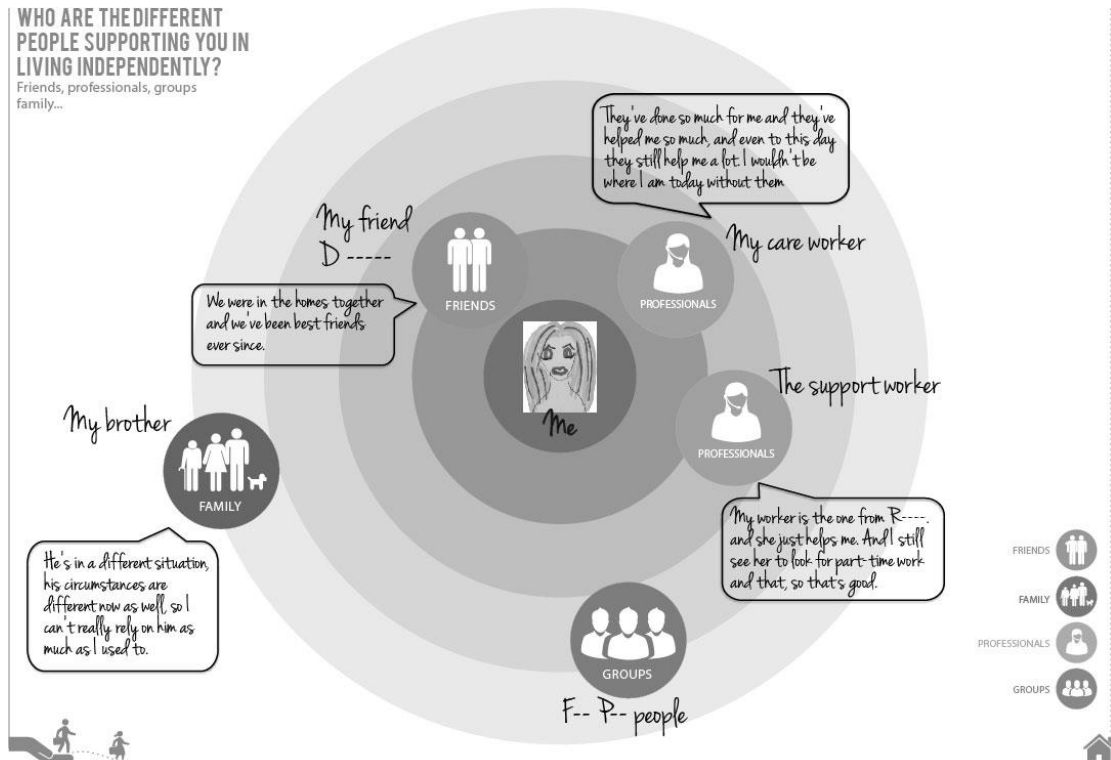


Figure 2

2. What does your experience of using this service (place or product) look like?

In a small group, where there is one to one support, it is possible to use reasonably standard journey maps, where the participant is supported to draw or write in step-by-step captions to describe their experiences. The journey map below illustrates the experience of a young person who was supported to move into independent accommodation, only to have a party where someone was stabbed, which resulted in her being evicted from the flat. This confirms the need to have support for the designers who are asked to illustrate such experiences and who may be emotionally traumatised by the stories they become involved in.



(Figure 3)

If the participants have previously taken photos of their day-to-day experiences these can be mapped along a timeline and emotions can be mapped to specific points. Some people find the interpretation and expression of emotion difficult due to their specific learning disability. Others because they have been admonished to control their emotions, and suppress emotional expression so often, they find it uncomfortable and stressful when asked to do this. We have used emoticon and coloured stickers to make this easier. Use of colour and symbol can be problematic, however, and we must be aware of cultural and sectarian associations (Riley 1995, Gage 1999).

Second activity – the define phase

Defining the key aspects where a co-design intervention might have the most impact involves a degree of analysis, synthesis, and evaluation. There is a level of abstraction here that is sometimes challenging for people with cognitive impairments. Some people find it hard to abstract from their specific experiences to general principles that apply to everyone and can be addressed collaboratively.

It is easiest to do this in a series of simple steps,

1. grouping similar experiences and phases together to create a series of themes (such as going out, contacting professionals, getting help in an emergency) This can be done by creating on-the-spot visual headings that participants can add their existing images, notes, stickers or comments to.
2. Interrogating these themes to identify some keys insights, such as,
 - a) What things can you see that are working really well? (we like to retain an asset- rather than a deficit-based approach)
 - b) What do you think could make them even better?
 - c) How might we make improvements?

This can, again, be done with emoticons or with clearly labelled colour stickers.

Usually it requires a scribe to write out people's comments and add them to the board or table.

3. Identifying the areas with the most potential for impact. It is useful to have a simple grid or chart (derived from the previous two exercises) where each individual can indicate what they feel are the most important issues to take forward. It is best if each individual has colour coded stickers so that the project team can trace the individual contributions and identify if anyone has significantly different views from the rest of the group. If we allow the group to vote on what to take forward to the develop phase, it is important to manage the disappointment of those who feel the most important issue for them is not being addressed.

Third activity – the develop phase

Overcoming the challenges of developing ideas and concepts into something more tangible, often involves an interim phase where the designer takes the nascent ideas away and works them up into something more tangible which is then re-presented to the group. However, simple cardboard or paper prototypes can also be quickly produced in a workshop to allow participants to act out how they would use a product or service very effectively. These can also be adapted quickly to address comments or refinements suggested.



Figure 4

Asking participants to think about web page layouts is a particular challenge. People can quickly tell you what they don't want and what doesn't work for them but are absolutely frozen if given an image of a blank screen and asked to draw what they want. Pre-prepared components with standard elements, such as search bars, play buttons as illustrated in Figure 6, work well.



Figure 5

As this phase moves from developing concepts to more tangible outputs, people with cognitive impairments often become more confident about giving feedback on products and web layouts specifically. Giving tangible examples of specific service interfaces, or touchpoints, such as forms or leaflets helps, as does enacting each phase of the service interaction.

Fourth activity – the deliver phase

If presenting a project back to a client or commissioning organisation, involvement of the service users in the presentation is very effective. The service provider cannot dispute the experience of those who engage with the service and their involvement adds to the validity of the project proposals.

If the deliver phase also becomes part of a further co-production phase, then the fact that the service users have been involved in developing the proposals, achieves a degree of buy-in to the new service and motivation to make it work.

Reflect – the project evaluation phase

Whole project team (including participants)

It is very important to return to the Key Performance Indicators established at the start of the project to ascertain whether the desired outcomes have been achieved, re-administering any measurements taken to determine impact.

Project Design team

The project design team should also take the opportunity to reflect on what worked well and what could be improved in the methods and tools used. This is also a good opportunity to identify if any further training is required to make the design team more effective in supporting people with cognitive impairments through the co-design process.

Project support team

The project lead from the design team should meet with the carers and/or support workers to ensure that any negative issues that surfaced through the project will be dealt with to ensure no adverse effect on project participants.

Conclusion

We have considered the real drivers for involving people with cognitive impairments in co-design of services and the specific challenges associated with this. Through experience of facilitating a wide range of projects involving people with varying degrees of learning disabilities and specific learning difficulties, we have come to recognise that the tools and methods used are of fundamental importance. However it is the attitudes, values and operational framework of the design team that are most important in creating a safe and supportive co-design space for people with cognitive impairments. Recognising the particular strengths and contributions of the different member of the co-design team, and matching tasks to particular areas of expertise and experience will produce the best outcomes, as in any group project. Where those with cognitive impairments feel most comfortable contributing and where they need more support depends very much on individual ability. We have presented above some general guidelines about where people might feel most at ease, and most challenged. However we must work together with advocacy organisations and individuals to ensure we create the most supportive environment possible to allow people with cognitive impairments to feel comfortable and able to contribute. As one participant said when asked to help us create a persona description for a person with learning difficulties,

‘I don’t know what you mean by a typical person with learning disabilities. There is no such thing, in the same way there is no such thing as a ‘typical’ Scottish person.’

This statement highlights the need for education of staff involved in co-design, to enable them to empathise with participants and explain clearly the purpose of design activities and designed outputs. From this we recognise that working with people with cognitive impairments is a mutual learning process, as Robertson and Simonsen (2012) explain, ‘Mutual learning and the setting of mutual learning processes are defining commitments of participatory design.’

Acknowledgements

We gratefully acknowledge the contributions of People First Scotland, Grapevine Coventry and Think Forward to our learning and understanding of working with people with cognitive impairments.

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