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Design and wellbeing: Bridging the empathy gap between neurotypical designers and autistic adults

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Abstract:

This paper is focused on the wellbeing of people with autism spectrum disorders, who are often excluded from design research. Drawing upon on-going design research collaboration between The Helen Hamlyn Centre for Design and the autism charity The Kingwood Trust, this paper reflects upon a neurotypical (i.e. not on the autism spectrum) designer's experience of working with adults with autism who have limited verbal speech and additional learning disabilities. The hypothesis under investigation is that, by interacting with and observing a person in conjunction with his or her physical environment, the designer can unravel clues and insights to develop empathy and better understanding of a person with autism's everyday experiences, which can thereby inform empathic designs that enhance and sustain a state of wellbeing. The conclusion explores how the inclusion of autistic people within the design process creates a shared experience, which helps to develop trust and empathy between the designer and the person with autism, enabling the designer to understand and appreciate different ways of being in the world.

Keywords: *autism, wellbeing, design, empathy, sensory environment*

- * In compliance with research ethics, the real names of the participants have not been used within this paper.
- * The term 'autistic' person is the preferred language of many people with autism (see Sinclair, 1999). In this paper, I use this term as well as person-first language (such as 'children with autism') to respect the wishes of all individuals on the spectrum.
- * Throughout the paper, the term 'neurotypical' is used to describe people who are not autistic; it is a word that is widely used in the autism community. This research does not condone the use of this word (what is typical), nor does it attempt to provide a definition of any words that label or separate people from one another, but due to the subject of this paper, it was deemed necessary to use the word 'neurotypical'.

1 Introduction

Wellbeing is subjective and can mean different things to different people; its meaning is determined by a number of factors, including their culture, values, preferences, and relationship with the world in which they live. This paper is concerned with the wellbeing of people with autism. With an estimated prevalence rate of 1 in 100 people, autism is not rare (Baird et al., 2006; Brugha et al., 2009). These are not only people whose perceptions, experiences, and interactions with their surroundings are

unique, but are also people who may not be able to verbally communicate their experience to the remaining 99% of the population. Therefore, an autistic person's sense of wellbeing may neither be heard nor understood. Either way, their experiences remain largely unexplored.

The World Health Organization (WHO, 2013) defines mental health as 'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able

to make a contribution to her or his community.’ However, in the case of autistic people, how much of this definition relates to their way of being in the world? Living within a world that is largely designed by and for neurotypical people, even the stresses of life considered ‘normal’ can be a challenge for a person with autism, such as sitting on a bus or walking on wet, shiny floors. People with autism may also experience difficulties relating to other people, leading to social isolation. Further, with only 15% of people with autism in full-time employment (Howlin, Moss, Savage & Rutter, 2013), the concept of getting a job is not all that ‘fruitful’. As Milton and Bracher describe, ‘it is crucial that researchers explore the subjective significance of AS (autistic spectrum) related experiences in relation to wellbeing, as this may not be immediately apparent to non-AS observers’ (Milton & Bracher, 2013, 64).

This sentiment is precisely what this paper is about. The research investigates how the non-human material infrastructure of the environment and what it affords are critical to a person with autism’s understanding of themselves, other people, and the world around them. It may also be vital for designers to create better understanding of what happiness, comfort, and satisfaction might mean for autistic people, that can be translated into what design for the wellbeing of a person with autism (in this study) might mean. To explore this issue, the paper draws upon a four-year research collaboration between the Helen Hamlyn Centre for Design and the autism charity, the Kingwood Trust, which provides support and accommodation for adults with autism.

In this collaboration, participatory design approaches were selected and developed that were sensitive to the cognitive processing styles and perceptual experience of the people whom Kingwood supports. In addition, the development of empathy (a translation of the word *Einfühlung*, which means ‘in-feeling’ or ‘feeling into,’ coined in 1909 by Edward B Titchener) was simultaneously explored, to enable the designer to try and perceive the environment from the perspective of an autistic adult. This, however, presented many

challenges, as Milton hypothesised in his Double Empathy Theory:

The ‘double empathy problem’: a disjuncture in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld – perceived as a breach in the ‘natural attitude’ of what constitutes ‘social reality’ for ‘non-autistic spectrum’ people and yet an everyday and often traumatic experience for ‘autistic people’ (Milton, 2012, 2).

There is a body of autism research that proposes that people with autism experience delay in developing Theory of Mind (TOM) (Baron-Cohen, 1995; Baron-Cohen, Leslie & Frith, 1985), which is the ability to imagine another person’s thoughts and feelings, leading to empathic difficulties (Baron-Cohen, 2012). However, what if we flipped this around? How much empathy do neurotypical people have for people with autism? In support of Milton’s Double Empathy Theory, this study investigates how empathy can be learned and incorporated into the design process with the following underlying question: How can a neurotypical designer begin to understand and empathise with an autistic person whose lifeworld and lived experience are so different to their own, and who may not be able to verbally communicate this to them? For example, could the producers of the UK television program *Eastenders* have ever thought that changing the pitch of the theme tune would have made Sarah at the Kingwood Trust, a regular watcher of the show who has autism, feel so anxious? It would be surprising to learn that the designers of the Henry vacuum cleaner and the illustrators of *Thomas the Tank Engine* anticipated that their designs would cause so much enjoyment for Philip and David. Further, how could the designers at Dyson have anticipated that the sound of the new air hand-dryers would have been so frightening for Andrew?

This study explores how working with autistic people can inspire designers to be more aware of the sensory qualities of the environment and

experience things from different perspectives, opening up the design toolbox to include methods that move beyond written and spoken language to modes of non-verbal communication that can be extrapolated into general design practice. With reference to Dr Lorna Wing's description, 'once you've met one person with autism, you've met one person with autism', it is important to empathise that the descriptions in this paper are based solely on the people whom the Kingwood Trust supports and cannot be generalised. Nevertheless, this paper seeks to share design ideas and experiences with designers, autistic adults, family members, support staff, and service professionals, to encourage them to work together to make the environments and everyday experiences of autistic people more meaningful and enjoyable.

1.1 The beginning...

This paper begins with the designer's first experience at the Kingwood Trust. With little understanding of autism, the designer visited the home of a man called Tom. Tom was not present, but with notebook and camera in hand the designer documented the 'destruction' he had caused to his home environment: a ruined sofa where all the leather had been picked off and a damaged wall, where all the paint had been peeled and wood eroded. Leaving Tom's home, the designer's first question was, how could we prevent this from happening?

Several weeks later, the designer made a second visit to Tom's home, and this time met and interacted with him, by mirroring his favourite activities like ripping pages in magazines. In time, the designer could see that Tom looked content and relaxed sitting quietly picking at the leather on his sofa, resting his ear against a wall, rubbing it while listening and feeling the vibrations of the music above. Unable to ask Tom directly, 'What do you like about doing that?' the designer then mirrored Tom's actions and experienced it for herself, which enabled her to externalise her thoughts and begin to understand and empathise with Tom: picking the leather off the sofa was surprisingly satisfying and

could be equated to the satisfaction one gets from popping bubble wrap.

So instead of a ruined sofa, the researcher now perceived Tom's sofa as an object wrapped in fabric that is fun to pick. Pressing her ear against the wall and feeling the vibrations of the music above, the researcher felt a slight tickle in her ear while rubbing the smooth and beautiful indentation, which Tom had sculpted into the wall. So instead of a damaged wall, the researcher perceived it as a pleasant and relaxing audio-tactile experience. On reflection, this experience illustrates how upon the first visit to Tom's home, the designer instantaneously internalised and conceptualised her observations of the environment with negative connotations, 'destruction'. However, upon the second visit where the designer met and interacted with Tom, the designer began to empathise with Tom – the sofa, wall, and music revealed vital clues and helped the designer to form some understanding of the sorts of things Tom likes to do.

2 Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a lifelong complex neurodevelopmental disorder. It is a spectrum condition, so it affects people in different ways. Someone with autism might be very sociable or find social relations difficult; some have learning disabilities while others possess high levels of intellectual ability. In the latest revision of the diagnostic criteria (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-5, 2013, American psychiatric Association), sensory sensitivities are for the first time recognised as a core characteristic of autism. This can affect a person's ability to interpret, filter, and regulate sensory information from the environment, leading to person becoming hypersensitive (over-stimulated) and/or hyposensitive (under-stimulated) by what they sense, influencing how they perceive and experience the environment in which they live. Taking examples from the Kingwood Trust, Matt is hypersensitive to sound and feels anxious when he hears the lawn mower, Sarah feels relaxed by the sound of her

washing machine, and Steven feels calm when he flicks through the pages of a retail catalogue.

Currently, research on autism is largely focused upon the underlying biology and causes of autism (Pellicano, Dinsmore & Carman, 2013), including an emergence (since the 1970s) of cognitive theories to explain the core features of autism, such as problems in theory of mind (Baron-Cohen, 1995; Baron-Cohen et al., 1985), executive function (Pennington & Ozonoff, 1996; Ozonoff, Pennington & Rogers, 1991), and weak central coherence (Frith, 1989, 2003). These theories, however, largely focus on the internal characteristics of the autistic individual. Although the 'environment' does feature somewhat highly within autism research, in this context the environment equates to things that are considered by some as possible causes for autism, such as exposure to mercury and pesticides (Roberts et al., 2007).

Research has shown how sensory sensitivities may affect a person's experience with both everyday objects and the physical environment in which the activity is to be performed (Bagby, Dickie, & Baranek, 2012; Gaudion, 2013). Some studies have explored a person's interest within the unintended affordance of objects (Baron-Cohen, 1987; Charlop-Christy & Haymes, 1998; Gaudion, 2013; Loveland, 1991, 1994; Ungerer & Sigman, 1981; Williams, Costall, & Reddy, 1999; Williams, Kendell-Scott, & Costall, 2005; Williams & Kendell-Scott, 2006). Despite this research, the relationship between autistic people and the physical environment has been a relatively under-researched area. However, we do have accounts of the first cohort of people diagnosed with autism (Bemporad, 1979; Donvan & Zucker, 2010; Grandin, 1984; Williams, 1992, 1999) and the continuous flow of autobiographies and parent accounts subsequently (Blackman, 2001; Dickie, Baranek, Schultz, Watson, & McComish, 2009; Woodgate, Ateah, & Secco, 2008) that describe and reveal a person's unique way of perceiving and processing the sensory information of their surroundings. The composition of the 'physical' environment has begun to be considered causation,

not for autism per se, but for how a person with autism might feel and behave. As described by Donna Williams (1992, p. 11), 'I had always known that the world was fragmented. My mother was a smell and a texture, my father was a tone, and my older brother was something, which was moving about'.

The revised DSM-5 is an important milestone that puts the sensory environment back onto the roadmap within autism research, creating a natural avenue for designers to explore how their deep understanding of the sensory quality of materials, skills in making, and spatial/visual thinking can develop new modes of non-verbal communication, dialog, and understanding around the everyday experiences of people with autism.

2.1 Autism and the Environment

Dr Leo Kanner (1943) and Dr Hans Asperger (1944) formed the basis for our understanding of autism and the springboard from which research in autism has grown and evolved. This paper rewinds 70 years to Dr Kanner's seminal article, 'Autistic Disturbances of Affective Contact', which is a 33-page detailed account and discussion of observations on the patterns of behaviours and personalities of eleven children with limited verbal speech (eight boys and three girls) by both Kanner and the children's parents. Interestingly, Kanner's observations of the children are filtered through their preoccupation and direct engagement with the unintended affordance of the physical environment and things within it, rather than the persons present, for example, spinning objects, ripping paper, and placing books into the toilet. While the things in Kanner's office were a source of interest and entertainment for the children, parents also reported on how some things within the environment can also cause distress, for example, tricycles, dogs barking, and planes. In contrast to Heidegger's (1993), description that 'Man would not be man if it were denied him to speak,' meaning and understanding was harnessed not through knowledge and language, but via the children's tangible interactions of doing, sensing,

and interacting with the things in his office space. Kanner's article illustrates a different way of being-in-the-world, in which the children's reciprocal relationship with the office environment took precedence over the people present. As described by Kanner (1943, p. 246):

The children's relation to people is altogether different. Every one of the children, upon entering the office, immediately went after blocks, toys, or other objects, without paying the least attention to the persons present. It would be wrong to say that they were not aware of the presence of persons. But the people, so long as they left the child alone, figured in about the same manner as did the desk, the bookshelf, or the filing cabinet.

Kanner's observations of the children relates to James Gibson's concept of affordances, a term introduced in the article 'The Theory of Affordances' (1977) and further explored in 'The Ecological Approach to Visual Perception' (1979), which explains that, 'The affordances of the environment are what it offers the animal, what it provides or furnishes, either good or ill' (Gibson, 1979, p. 127). Gibson's key concept is 'Ask what's not inside your head but what your head's inside of' (Mace, 1977), meaning our 'head' is in the world (and receiving inputs for action and understanding via affordances), rather than that the world is in our heads (we have an inbuilt knowledge of how to interact with the outside world). According to Gibson, the physical environment generates action opportunities and an affordance is the 'fit' between a person and the environment, which then creates opportunities for actions, whether good or bad. It is therefore the 'fit' that determines these opportunities for actions and if the affordance is not compatible with a person's capabilities, they may find it hard to 'fit in' with their environment. This is a key concept for designers, where exploring the 'fit' between the capabilities of a person with the environment that they inhabit is an important part of design activity; for example, the OXO good grip can opener was developed through the designers' understanding of the capabilities of a person with limited hand strength.

In addition to physical acts, the affordances of our environment are also often designed to create social acts by and for neurotypical people; the quality and meaning of these affordances are not always compatible with the capabilities of people with autism, creating a confusing, uncomfortable, and frightening world for them to live in. For example, playing football, cooking, and reading are all things that we might do, that create shared dialogs, meanings, and understanding in which to exchange and connect with other people, but Jack at Kingwood avoids social interaction and perceives these things very differently: a football as an object to bite and a book as an object to flick and tear. Like Jack, if a person does not engage with the intended affordance of things, there's a danger people may perceive him as odd or strange, leading to further social isolation and a sense of not fitting in. As Loveland (1991, p. 104) describes:

It is the perception of a human environment with its layers of specifically human affordances that allows us to behave in human ways. It is also this complex set of transactions with the environment that looks to us like human behaviour. A person who fails to perceive the specifically human affordances of the environment will therefore exhibit behaviour that will seem strange, disturbing or even inhuman to us.

Whether autistic or not, individuals all share and live in the same multi-sensorial embodied world. The environment is furnished with designed objects whose sensory properties and affordances influence what we do and how we feel and behave. Design does not only result in form and function, it also results in feelings, affecting our state of wellbeing. Feelings are connected to our senses, which enable us to experience and respond to our environment, which can be very different from one person to the next. To create a better fit and enhance our levels of wellbeing we continually control, modify, and adjust ourselves to the environment, by designing, adapting, repurposing, and signifying new affordances. For example, to feel happy and energised we may turn the music up and dance and to feel more comfortable we may choose to sit in a no-mobile-phone 'quiet' carriage on a train.

But imagine if you had no or little control. Imagine if a sound became intolerably loud but you were unable to turn it down, or the light too bright but you were unable to switch it off. This situation can be the case for many people with autism, whose experiences and perceptions of the physical environment are individual and unique. For example, the majority of neurotypical people would recognise a paper clip as a tool to hold papers together, but for Zac at the Kingwood Trust, it offers comfort and support; fans are used to help us cool down when we are hot, but for Sarah the purpose of a fan is generating a pleasing sound: C minor pitch on speed dial 2. We might walk through shadows on the ground, but for Jack they are black rectangular holes that he could easily fall into and hence a source of much anxiety.

Affordances are the key mechanism that designers use to trigger understanding and action in others. As studies show that autistic people appear to have a different use/understanding for affordances, this means it is important to develop different design methods and empathic understandings. Like visiting another country whose culture, values, and language are very different to our own, the process of listening, observing, and adapting ourselves accordingly to connect, learn, and understand was of particular importance to this research. The paper briefly describes three perceptual theories the designer used to help understand or imagine the sensory perceptual differences between herself and the people whom the Kingwood Trust supports, to exercise a more flexible way of perceiving the affordances of the physical environment. The unique perceptual experiences of people with autism was first explored by Uta Frith's (1989) notion of weak central coherence, a theory that describes how a person tends to focus on the small details of the environment rather than perceive it as a whole. Therefore, in contrast to gestalt psychology, which describes how people first see an object as a whole before seeing it in parts (a whole is greater than the sum of its parts), an autistic person's strengths might be processing local or detailed information within their environment, in which the sum of its parts is

greater than the whole. The following description by an autistic person illustrates this perfectly:

When I step into a room for the first time I often feel a kind of dizziness with all the bits of information my brain perceives swimming inside my head. Details precede their objects; I see scratches on a table's surface before seeing the entire table, the reflection of light on a window before I perceive the whole window, the patterns on a carpet before the whole carpet comes into view. (Tammet, 2009)

Frith's weak central coherence theory was followed by Mottron & Burack's (2001) theory of enhanced perceptual functioning, whereby an autistic person may have not only excellent focus on details but also superior abilities in various aspects of perception – recognizing, remembering, and detecting objects and patterns. This relates to some of the people whom Kingwood supports, who have a heightened sense of details and aspects of the environment, which a neurotypical person may have overlooked. For example, Pete will not walk on shiny wet floors, Tim does not like it when the extractor fans in the staff room are turned off, and Sarah struggles with the sound of things that are not in C minor pitch.

Lastly, Pellicano & Burr (2012) describe how the perceptual experience of autistic people is one that is less influenced by prior knowledge about the sensory world. As a result, autistic people have a tendency to perceive the world more accurately rather than imbued by prior experiences. Therefore, in the context of an autistic person's interaction with the environment, could a person's difficulty with building up or using prior knowledge about the environment lead to an idiosyncratic set of affordances? For example, the idea of weakened prior knowledge might mean that a person does not have a robust template of what a washing machine is (within a neurotypical context), in terms of what it looks like (the perception of the washing machine) or what it is used for (the concept of the washing machine). This might explain why Tim at Kingwood is interested in the unintended affordance of his washing machine, so instead of perceiving it as an

object to wash clothes, he has it on all day (with or without clothes) as he enjoys the sound and spinning effect that it makes.

3 Design Studies

There is growing realisation of the influence our physical environments have on our sense of wellbeing within environmental psychology (Parr, 1966; Lang, 1987) architecture (Pallasmaa, 2005), and experimental psychology in which Dr Charles Spence expressed ‘...our need for a balanced sensory diet and the essential part that this has to play in our wellbeing’ (Spence, 2002). In response to this, a succession of methods of measuring and assessing the sensorial qualities of our environments is being explored. For example, Malner and Vodvarka (2004) developed the sensory slider as a method of comparing the sensorial qualities of buildings. Environmental adjustments are also being made to compensate for our sensorial intolerances; for example, quiet carriages on trains, no mobile phone zones in public spaces, and massage chairs in busy airports. However, the needs of people with autism, whose sensory tolerances are more extreme, have rarely been considered. While there are a growing number of design researchers who are considering the physical environment as an important point of intervention for people with autism, by improving the design of schools (Beaver, 2003, 2011; Gumtau, Newland, Creed & Kunath, 2005; McAllister, 2012; Mostafa, 2008; Scott, 2009; Tufvesson & Tufvesson, 2009; Vogel, 2008) and supported living accommodation (Ahrentzen & Steele, 2009; Brand, 2010; Burlison, Newman, & Brotsman, 2012; Linehan, 2008; Lopez & Gaines, 2012; Whitehurst, 2006, together with outdoor spaces (Gaudion & McGinley, 2012; Herbert, 2003; Hussein, 2010; Menear, Smith, & Lanier, 2006; Sachs & Vincenta, 2011; Yuill et al., 2007), it is doubtful as to how much of this research starts with the autistic person and involves them as active participants within the design process.

To create a holistic picture of how the Kingwood Trust’s residents engage within the environment, the

designer examined their different interactions and reactions to three environmental contexts of the home, namely the garden, the interior, and everyday objects. All three vary in scale, action opportunity, and sensory elements, presenting different levels of control, the garden being the least controllable environment due to the unpredictable nature of the outdoors. The design research started with the person and instead of focusing on a person’s often-cited triad of impairments (Wing & Gould, 1979) in which difficulties in social communication, social interaction, and social imagination are often used to describe autistic people, the research took on board a strengths-based approach by exploring a person’s triad of strengths, in which a person’s sensory preferences, special interests, and different action capabilities (not deficits) were an important part of the design process, which helped the designer to connect, communicate, and understand a person’s interaction with their home.

A person’s triad of strengths enabled the designer to adapt the affordances of each environment in three different ways, where positive behavioural responses could be anticipated and wellbeing extended. This involved (1) creating an entirely new affordance (garden), (2) adding affordances into the home (artworks), and (3) adapting the affordance of an existing object (a bubble blowing vacuum cleaner). Although each design project resulted in real-world applications of the findings, the most important part of the journey was the selection, adaptation, and development of appropriate participatory design methods that involved people with autism in the design process (see Fig. 1). These are people who are often excluded from traditional qualitative design methods, which are largely designed by and for neurotypical people and dependent on written and spoken feedback, such as questionnaires, interviews, and co-design workshops. In support of this, the research built upon existing design research that involved autistic people within the design process (Benton, Johnson, Brosnan, Ashwin & Grawemeyer, 2011; Benton & Johnson, 2014; Brand, 2010; Brand & Gaudion, 2012; Frauenberger, Good, & Keay-Bright, 2010, 2011; Frauenberger et

Table 1: Design methods used within the three stages of each design study.

	Study One GARDEN	Study Two OBJECTS	Study Three INTERIOR
Stage One	<p>ASD: <i>Connecting, communicating, building trust and empathy.</i></p> <p>Sensory activities Mirroring interests Making & doing activities Participatory observation Shadowing Garden activities</p>	<p>ASD: <i>Connecting, communicating, building trust and empathy</i></p> <p>Sensory activities Mirroring interests Making & doing activities Participatory observation Shadowing</p>	<p>ASD: <i>Connecting, communicating, building trust and empathy</i></p> <p>Sensory activities Mirroring interests Making & doing activities Participatory observation Shadowing</p>
Stage Two	<p>AS: <i>Gathering and documenting context specific insights</i></p> <p>Mapping interests Mapping sensory preference cards Garden diary evaluation</p>	<p>AS: <i>Gathering and documenting context specific insights</i></p> <p>Mapping interests Mapping sensory preferences Objects of Everyday Use Doing things with things Hubble Bubble vacuum cleaner trial</p>	<p>AS: <i>Gathering and documenting context specific insights</i></p> <p>Mapping interests Mapping sensory preferences Artworks I like booklets Online survey Artwork selection activity Artwork evaluation</p>
Stage Three	<p>SD: <i>Generating design ideas</i></p> <p>Storyboarding Co-creation workshops Ready Steady Make Interviews</p>	<p>SD: <i>Generating design ideas</i></p> <p>Storyboarding Co-creation workshops Ready Steady Make Interviews</p>	<p>SD: <i>Generating design ideas</i></p> <p>Storyboarding Co-creation workshops Ready Steady Make Interviews</p>

al., (2012); Gaudion & McGinley, 2012; Gaudion, 2013; Guha et al., 2004; Keay-Bright 2007, 2009; Millen, Cobb, & Patel, 2011; Van Rijn, 2012).

Although neurotypical people and autistic people perceive and experience the world differently, the common ground they share is the physical environment. In Stage One of the design process, the design methods were themed around a person's triad of strengths, but disseminated and mediated through the environment. For example, during the sensory activities, non-verbal conversations were mediated through the exchange of an assortment of props that were chosen for their visceral and sensory properties in terms of touch, sound, sight, smell, and movement. To create an equal platform for interaction between the designer and participant, the props were abstract in shape, stripped of social context, with no intended affordance. The purposeful purposelessness of the props helped the designer observe a person's interactions with them without being distracted by their own subjective

prior knowledge of the intended affordance of the prop. Equally, the design method of mirroring the interests and interactions of the people whom Kingwood supports enabled the designer to break away from how they conventionally interact with and perceive the environment, and instead, be flexible.

One of the most important environmental variables to consider during the research (particularly for people with autism who can be uncomfortable with social interaction) within the design process was the presence or absence of persons; and should there be persons present, what combination they were in: be it one-one, in a group situation, or online. Each study involved three separate configurations of people at different stages within the design process: people with autism (A), their support staff (S), and the designer (D). Each person brought with them their own unique lifeworld and lived experiences; yet, as the lifeworld of an autistic person can be very different from that of the neurotypical designer

and support worker, each configuration presented a different set of challenges, which influenced the selection, development, and facilitation of the design methods.

Figure 1 illustrates that the first stage (A-S-D) involved all parties: a person with autism, their support staff, and the designer. In this stage, in which the design brief unfolds, the design methods are primarily used to help connect, communicate, and build trust and empathy between each person. The second stage (A-S) involves people with autism and their support staff, where design methods are used to uncover and gather insights, knowledge, and understanding about their everyday experiences, to validate the designer’s initial observations and interpretations from Stage One. This stage is also largely involved in the evaluation process of the design prototypes. The third stage (S-D) involves the designer and the support staff, where slightly more directive design methods are used to generate design ideas. The diagram below illustrates that the support staff are consistently present throughout the research; this is because the majority of the participants in this study have limited verbal speech and learning difficulties. The support staff act as informants throughout the research, whose expertise in observing, interpreting, and communicating with the person they support helped to develop understanding between the autistic person and designer. Therefore, much of the

data gathered during the project did not derive first-hand from the people whom Kingwood supports, but was largely interpreted by the support staff through direct observation.

4 Developing Empathy

Figure 1 illustrates how the people whom the Kingwood Trust supports, their support staff, and family members were invited to participate in a range of design methods that included workshops, storyboarding, and sensory profiling, however overshadowed by the question of ‘How can a neurotypical designer subjectively form an understanding of a situation, when their observations are being processed neurotypically far removed from the cognitive processing style of the autistic participants within the research?’ In light of this, it was the designer’s empathic ability to listen, observe, and interpret the information derived from these design methods that proved to be the most important and challenging design method of all.

The design process revealed that through their thousands of hours of collective observances, family members and support staff hold the key to understanding the person they support and every day engage in empathic acts to help them feel happy and their environment comfortable and enjoyable to live in. For example, the designer

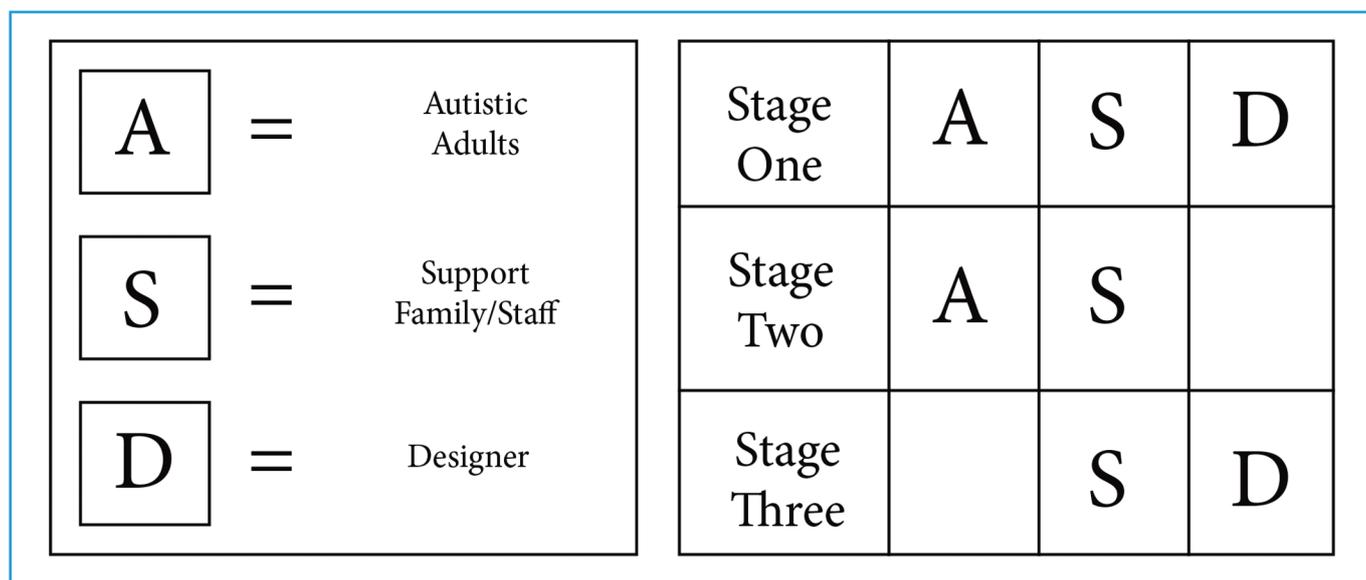


Figure 1. Persons present during the research

would not have asked the taxi driver to stop on the opposite street to where Sarah lives if the support worker had not informed her that Sarah does not like the sound of a car engine running. The support worker would not have connected Tim's anxiety one evening to the washing machine that had been switched off, if she had not first connected Tim's feeling of enjoyment to the sound of his washing machine. The support staff are now mindful not to arrange an outing with Pete on a rainy day, since they had connected his anxiety on previous outings to wet and shiny floors.

These empathetic acts are the result of developing deep and sustained relationships with the people they support and avoiding fundamental attribution errors, by which they objectively connect the person's behaviours to the surrounding environment. The designer's visit to Tom at the beginning of this paper is an example of how effective it can be. From the onset, the designer committed a fundamental attribution error, whereby on her first visit to Tom's home she internalised her thoughts and applied her subjective biases to the situation. However, on the second visit to Tom, the designer externalised her thoughts and objectively connected Tom's actions with the environment. It was this slight change of perspective that created a little understanding and empathy between the designer and the person with autism, where different ways of seeing, doing, and behaving are embraced, accepted, and celebrated.

It is difficult to know how reciprocal this empathic connection was with the people whom Kingwood supports, but what was genuine was the connection the designer felt while joining in with the things the participants enjoyed, for example, blowing bubbles with Tom, ripping magazines with Sam, and spinning objects and listening to the sound of the last spin of the washing machine with Sarah. These simple acts should not be underestimated, as they are the important things that describe what wellbeing might mean for some of the people Kingwood supports, which as described by Milton may not be immediately apparent to a neurotypical person.

5 Conclusion

This research paper set out to expand our understanding of what wellbeing might mean for a person with autism, as well as how a neurotypical designer might empathise with an autistic person, who has different perceptions and experiences of the world. By reflecting upon three design studies that involved people with autism, the paper concludes that while small adaptations had to be made to existing participatory design methods (e.g. swapping words for pictures), the majority of the methods were appropriate and complementary to the capabilities of the people whom Kingwood supports. Consequently, exploring new ways to develop autism-friendly design methods was of little concern to this research. Instead, priority was placed upon the designer and her skills of interacting, listening, observing, and accurately interpreting information derived from the design methods. The priority of this direction was triggered and exposed by the designer's first visit to Tom's home (described at the beginning of this paper), where the designer's poor observation and misinterpretation led to an incorrect interpretation of 'destruction' with regard to his door and sofa.

The paper concludes that it was not the design methods but the perceptual shift of the designer that needed to change; this helped to create understanding and empathy between her and the people whom Kingwood supports. The perceptual theories (described in this paper) in combination with the expertise of the support staff aided this shift that encouraged the designer to step outside herself and exercise more flexible ways of perceiving the affordances of the environment. This is illustrated in the second visit to Tom's home, where the designer externalised her thoughts and tried to engage with how Tom experienced and perceived the affordances of his home by experiencing it for herself. Consequently, it was only when the designer knew how she felt about things and what her emotional responses to things were, that she was able to start empathizing and understanding what another person's emotional response to those things might be.

The research proposes that Gibson's concept of affordance best supports a framework for designing with autistic people, as it describes how it is the relationship between the environment and a person's capabilities and not the infrastructure of our environment alone that creates action opportunities. 'Affordance is the mutual relationship between environment and animal. This relationship only exists relative to a particular animal, which can perceive it and use it' (Gibson, 1979, p. 29). Gibson's theory is therefore a useful framework to encourage more flexible design that invites different types of action opportunities and encompasses a subjective way of experiencing the world. It foresees making the environment compatible with all human actions rather than trying to direct and control human actions solely from a neurotypical perspective. By creating flexible environments that relate to the perceptual world of everyone, designers can help progress our conventional attitudes to the point where different ways of seeing, doing, and behaving are embraced, accepted, and celebrated and wellbeing extended.

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