

A Designer's Approach:  
Exploring how Autistic Adults with  
Additional Learning Disabilities  
Experience their Home Environment



KATIE GAUDION

April 2015

A thesis submitted in partial fulfilment of the requirements of the  
Royal College of Art for the degree of Doctor of Philosophy



# Copyright

This text represents the submission for the degree of Doctor of Philosophy at the Royal College of Art. This copy has been supplied for the purpose of research for private study, on the understanding that it is a copyright material, and that no quotation from the thesis may be published without proper acknowledgement.



# Abstract

Autistic adults with limited speech and additional learning disabilities are people whose perceptions and interactions with their environment are unique, but whose experiences are under-explored in design research. This PhD by Practice investigates how people with autism experience their home environment through a collaboration with the autism charity Kingwood Trust, which gave the designer extensive access to a community of autistic adults that it supports.

The PhD reflects upon a neurotypical designer's approach to working with autistic adults to investigate their relationship with the environment. It identifies and develops collaborative design tools for autistic adults, their support staff and family members to be involved. The PhD presents three design studies that explore a person's interaction with three environmental contexts of the home i.e. garden, everyday objects and interiors. A strengths-based rather than a deficit-based approach is adopted which draws upon an autistic person's sensory preferences, special interests and action capabilities, to unravel what discomfort and delight might mean for an autistic person; this approach is translated into three design solutions to enhance their experience at home.

By working beyond the boundaries of a neurotypical culture, the PhD bridges the autistic and neurotypical worlds of experience and draws upon what the mainstream design field can learn from designing with autistic people with additional learning disabilities. It also provides insights into the subjective experiences of people who have very different ways of seeing, doing and being in the environment

# Table of Contents

Abstract.....	3
Table of Contents.....	4-5
List of Appendices.....	6-7
List of Illustrations.....	8-11
List of Tables.....	12
Acknowledgements.....	13-14
Author’s Declaration.....	15
Chapter 1: Introduction.....	17-20
Chapter 2: Foundation Work.....	21-30
Chapter 3: Literature Review.....	31-88
3.1 Neurotypical.....	31
3.2 Autism Research.....	33
3.3 Affordances in the Environment.....	46
3.4 Design for Autism.....	61
3.5 Design Approaches.....	72
Chapter 4: Collaboration with Kingwood.....	89-92
4.1 The Kingwood Trust.....	89
4.2 Ethical Considerations.....	90

Chapter 5: Design Studies.....	93-190
5.1 Three Design Studies.....	94
5.2 Three Participants.....	95
5.3 Three Design Stages.....	99
5.4 Design Tools.....	101
5.5 Design Study One: Garden.....	102
5.6 Design Study Two: Everyday Objects.....	143
5.7 Design Study Three: Interior.....	174
Chapter 6: Discussion.....	191-202
6.1 Answering the research questions.....	191
6.2 Developing Empathy.....	196
6.3 Limitations.....	200
Chapter 7: Conclusions.....	203-212
7.1 Five original contributions to knowledge.....	203
Appendices.....	213-482
List of References.....	483-508
Viva Voce Examination.....	509

## List of Appendices

- Appendix 1: Five diary accounts by the author whilst facilitating sensory sessions in multi-sensory environments at the charities FACT and Kids Active between 2006 and 2007 p.212
- Appendix 2: DSN-IV: the diagnostic and statistical manual of 'normal' disorders (1998) p.220
- Appendix 3: DSM 5: the diagnostic and statistical manual of mental disorders fifth edition (2013) p.224
- Appendix 4: The Kingwood Trust's code of conduct p.226
- Appendix 5: The Kingwood Trust's core values and credo p.236
- Appendix 6: A list of rules for Kingwood Trust support staff (compiled by the autistic people Kingwood Trust support) p.244
- Appendix 7: Kingwood media consent form p.246
- Appendix 8: Diary account of a creative activity by the author p.248
- Appendix 9: A selection of sensory props used in the sensory activities p.252
- Appendix 10: Sensory activities: photographs and sketches p.254
- Appendix 11: Diary accounts: sensory activity, by the author p.256
- Appendix 12: A selection of personalised sensory props p.266
- Appendix 13: Diary account: mirroring interests, by the author p.268
- Appendix 14: Diary Account: garden picnic, by the author p.270
- Appendix 15: Adult/adolescent sensory profile® self questionnaire (Brown and Dunn, 2002) p.272
- Appendix 16: Sensory profile checklist (Bogdashina, 2003) p.278
- Appendix 17: Information compiled from the Adult/adolescent sensory profile® self questionnaires (Brown and Dunn, 2002) and sensory profile checklists (Bogdashina, 2003) of three autistic participants p.286
- Appendix 18: 'What Do You Like' sensory preference cards p.290
- Appendix 19: The sensory likes and dislikes of the autistic participants in studies one, two and three p.326
- Appendix 20: A completed interest checklist (Kielhofner and Neville, 1983) p.336
- Appendix 21: A selection of completed Interests and Hobbies booklets p.340



- Appendix 22: Information compiled from the completed Interests and Hobbies booklets p.344
- Appendix 23: Mapping special interests into a tree of opportunity p.350
- Appendix 24: Photographic documentation of the Ready Steady Make workshops 2012-2014 p.360
- Appendix 25: A selection of sensory props made by the support staff in the Ready Steady Make workshops p.364
- Appendix 26: A selection of completed garden dairies p.366
- Appendix 27: A selection of observations made by the designer and support staff of the autistic participants' interactions with their environment p.398
- Appendix 28: Three diary accounts of the designer's visits to three autistic adults p.406
- Appendix 29: The Lawton Instrumental Activities of Daily Living (IADL) Scale (Lawton and Brody, 1969) p.412
- Appendix 30: A selection of completed Objects of Everyday Use cards p.414
- Appendix 31: A compilation of feedback from the completed Objects of Everyday Use cards p.422
- Appendix 32: A selection of completed Doing Things with Things booklets p.434
- Appendix 33: Storyboards drawn by support staff in a Ready Steady Make workshop describing their different everyday experiences with the autistic adults they support p.446
- Appendix 34: Evaluation: trial one feedback p.450
- Appendix 35: Evaluation: trial two feedback p.456
- Appendix 36: Sketches drawn by author exploring support staff's anecdotal examples of empathy p.460
- Appendix 37: A selection of feedback from support staff about the Ready Steady Make workshops (2012-2014) p.464
- Appendix 38: Feedback from six members of the Expert Reference Group p.470
- Appendix 39: A description of the 'Celebrating Neurodiversity' workshop (October, 2014) p.476

## List of Illustrations

- Figure 1: A diagram to illustrate the structure of this PhD by practice p.20
- Figure 2: Ultraviolet woven textile sculptures, photograph by author p.22
- Figure 3: Multi-sensory van at FACT, 2006, photograph by author p.23
- Figure 4: Observational drawings of the childrens' interactions in the multi-sensory environment, illustrations by author, 2007-8 p.24
- Figure 5: Sensory prop for Ben, photograph by author p.25
- Figure 6: Sensory prop for Lucy, photograph by author p.25
- Figure 7: From sensory prop to adapting a chair, photograph and illustration by author p.26
- Figure 8: Before: a damaged wall, photograph by author p.28
- Figure 9: After: Ben enjoys rubbing the door, photograph by author p.28
- Figure 10: A collection of drawings showing the children interacting with the objects in Kanner's office, illustrations by author p.35
- Figure 11: A collection of quotes by autistic people describing their sensory experience with the environment, illustrated by author p.40
- Figure 12: Strengths based model (Winter-Messiers, 2007b p.71) p.44
- Figure 13: Joe interacting with a door handle, photograph by author p.51
- Figure 14: Storyboard: shadows (2004), illustration by Ian Wilson p.57
- Figure 15: Storyboard: puddles (2004), illustration by Ian Wilson p.57
- Figure 16: Framework for creative understanding through encounters with autistic children (Van Rijn, 2012, p.147) p.65
- Figure 17: Sanders' map of key design/research areas (2008) p.73
- Figure 18: Four phases of empathy (Kouprie and Sleeswijk Visser 2009, p.445) p.81
- Figure 19: The Triad of Strengths framework, illustration by author 2015 p.84
- Figure 20: Three Participants (from left): a designer, autistic adult and support staff member, photograph by Petr Krejci p.95
- Figure 21: The design tools used for design studies one, two and three p.102
- Figure 22: The garden at White Barn prior to redesign, photographs by author p.103
- Figure 23: Spending time with the autistic participants at White Barn, photographs by author p.105
- Figure 24: Participating in the creative activity, photograph by author p.106

- Figure 25: Sensory space (before and after), photograph by author p.107
- Figure 26: Curating the space around a person's sensory preferences and interests, illustration by author p.107
- Figure 27: Sensory props, photograph by author p.108
- Figure 28: Sensory activity, photograph by author p.108
- Figure 29: Sensory prop preferences, photograph by author p.109
- Figure 30: Tom's preference for stretching and pulling developed into the prop 'fiddlebrick', photograph by author p.110
- Figure 31: Matt's preference for tapping and stroking developed into the prop 'marbelous', photograph by author p.110
- Figure 32: The designer mirroring the actions of an autistic participant, photograph by author p. 112
- Figure 33: A photographic collage of the garden activity, photographs by author p.114
- Figure 34: Sensory Preference Cards, photograph by author p.116
- Figure 35: Examples of seven sensory preference cards (front and back), photograph by Author p.117-119
- Figure 36: Support staff member and autistic adult using the sensory preference cards, photograph by author p.120
- Figure 37: A participant's sensory preferences curated using the sensory preference cards, photographs by author p.121
- Figure 38: Taxonomy of interests featured in the Interests and Hobbies booklet, illustration by author p.122
- Figure 39: Examples of completed pages from a participant's Interest and Hobby booklet, photograph by author p.123
- Figure 40: A tree representing the interests of an autistic participant, illustration by author p.124
- Figure 41: Extending a person's interests of taxonomy and spinning into the garden, illustration by author p.125
- Figure 42: A photographic collage of the co-creation workshop, photographs by author p.127

- Figure 43: A photographic collage of the insights drawn from the Guess Who activity performed by the support staff during a Ready Steady Make workshop, photographs by author p.128
- Figure 44: A photographic collage of support staff's tree designs during a Ready Steady Make workshop, photographs by author p.129
- Figure 45: The designer facilitating a Ready Steady Make workshop, photograph by Staff member p.130
- Figure 46: Final garden design, illustration by Sasha Mihajlovic, p.133
- Figure 47: Photographic collage of the garden development, photographs by author p.135
- Figure 48: Completed garden diary (front), photograph by author p.136
- Figure 49: Completed garden diary (back), photograph by author p.137
- Figure 50: Garden evaluation results compiled, illustration by author p.138
- Figure 51: A photograph collage of the autistic participants in their new garden, photographs by support staff p.140
- Figure 52: Exterior of Beeching Way, photograph by author p.143
- Figure 53: A photographic collage of the designer's environmental observations, photographs by author p.144
- Figure 54: Three examples of an autistic persons' interaction with the unintended affordance of everyday objects, illustration by author p.145
- Figure 55: A photographic collage of the designer engaging with the autistic participants in their home, photographs by author p.146
- Figure 56: A participant interacting with a selection of sensory props, photographs by author p.147
- Figure 57: The designer, autistic adult and support staff member blowing bubbles together, photograph by Petr Krejci p.147
- Figure 58: Three photographic collages by support staff of autistic participants engaging in everyday activities, photographs by support staff p.148
- Figure 59: A selection of the Objects of Everyday Use cards, photograph by author p.150
- Figure 60: Two completed Objects of Everyday Use cards, photograph by author p.151

- Figure 61: A graph to illustrate the level of support required for an everyday activity p.152
- Figure 62: A graph to illustrate the most popular and least popular everyday activities p.152
- Figure 63: Responses to six everyday activities using the Objects of Everyday Use cards p.154
- Figure 64: A completed Doing Things with Things booklet, photograph by author p.155
- Figure 65: The three graphs illustrate how many of the steps involved in washing clothes, vacuum cleaning and toasting bread the autistic participants were able to complete p.156
- Figure 66: A photographic collage of the Ready Steady Make workshop, photographs by author p.158
- Figure 67: Two storyboards drawn by support staff during the Ready Steady Make Workshop p.159
- Figure 68: The bubble blowing vacuum cleaner used in Trial One, photograph by Pete Walter p.161
- Figure 69: The participants' sensory preferences p.162
- Figure 70: A photographic collage of Trial One, photographs by support staff p.164
- Figure 71: A revised bubble attachment prototype for Trial 2 p.167
- Figure 72: A photographic collage of Trial Two, photograph by support staff p.169
- Figure 73: Kingwood College and White Barn next door (left), photograph by author p.174
- Figure 74: 21 artwork categories, (Gaudion and McGinley 2014) p.175
- Figure 75: A photographic collage of the sensory and artwork activities, photographs by author p.179
- Figure 76: The sensory preferences of two autistic participants, photograph by author p.181
- Figure 77: A photographic collage of the Ready Steady Make Workshop, photographs by author p.182
- Figure 78: A photographic collage of the artwork selection activity, photographs by author p.184

- Figure 79: The participants' selected artworks, photographs by author p.185
- Figure 80: Support staff's feedback on postcards, photographs by author p.186
- Figure 81: The final selection of four artworks, photographs by author p.188
- Figure 82: Artworks framed and installed at Kingwood College, photograph by author p.189
- Figure 83: Storyboard: Shadows, illustration by Ian Wilson p.198
- Figure 84: Four stages of empathic understanding, illustration by author p.199
- Figures 85-87: Using the Triad of Strengths as a design framework p.207-208
- Figure 88: RCA students engaging in an empathic exercise in the 'Celebrating Neurodiversity' workshop p.211

## List of Tables

- Table 1: Describing three layers of affordance (Loveland, 1991, p101) p.55
- Table 2: Sensory Design Matrix, (Mostafa, 2008, p.208) p.63
- Table 3: Autistic characteristics and their implication for participatory design (Benton, 2013 p.66) p.68
- Table 4: Framework for organising the tools and techniques for participatory design, (Sanders, et al., 2010 pp. 196-197) p.77
- Table 5: Describing the context, aim and type of accommodation in which the three design studies are situated p.94
- Table 6: Example pages taken from a Kingwood communication passport p.96
- Table 7: The Expert Reference Group p.98
- Table 8: Three design studies: participant configuration p.99
- Table 9: A table describing what the participants like and/or dislike about the activities p.157
- Table 10: Support staff's observations during Stages One, Two and Three of Trial 1 p.164-165
- Table 11: Support staff's observations during Stages One, Two and Three of Trial 2 p.168
- Table 12: 17 artwork principles p.177
- Table 13: A modification of Sanders et al., (2010) participatory framework p.206

# Acknowledgments

This journey would not have been possible were it not for the help of a diverse range of people whom I would like to thank for their invaluable support.

I would like to express my extreme gratitude to my lead supervisors Professor Jeremy Myerson and Professor Ashley Hall, for their generosity of time, ongoing support, enthusiasm and their genuine involvement in my research, which ensured that I remained on the right path. Specifically I want to acknowledge Jeremy for his creative input and ongoing constructive advice, and Ashley for his immense help with regard to my theoretical investigation. It was always a delight to discuss my research with them both.

I am deeply grateful to my external supervisor Dr Liz Pellicano who has been incredibly generous, supportive and resourceful in guiding my research. Her knowledge in the field of autism enabled me to consider points I may have overlooked otherwise. Thank you to everyone at CRAE, our conversations, nights out and conference trips have been invaluable.

A special thank you to Professor Ranulph Glanville, his fountain of knowledge, creativity and magnificent honesty will always be remembered.

I want to thank profusely Sue Osborn at Kingwood Trust, for her ongoing support with the research and importantly for giving me the opportunity to make it all happen. A special thank you for everyone who participated in this research and for inviting me into their homes. Thank you to Professor Stephen Boyd Davis, Colum Lowe, Rama Gheerawo and all the members of the Expert Reference Group for their advice and support.

A huge thank you to all my peers and colleagues in IDE and the Helen Hamlyn Centre for Design for their support and encouragement during my PhD and for putting up with

my ever-expanding work space. In particular Andy Brand, Dr Chris McGinley, Elizabeth Roberts and Helen Fisher for their contributions to the research, Mark Byrne (Bernie) for responding to my never ending questions, Margaret Durkan for her help with formatting, Kay Sandford-Beal for all her work behind the scenes, Dr Jo-Anne Bichard, and Dr Dan Lockton for letting me tap into their reservoir of knowledge.

I would like to thank Cathy Johns for her generous advice and support with regards to formatting and referencing for the final thesis, and I am grateful to Qona Rankin for her advice with regards to dyslexia support.

I would like to thank Ian Wilson the Art Co-ordinator at the Hoffman Foundation, whose creativity and experience working with autistic adults has been truly inspirational.

Thank you to the Ted Powers and the Monument Trust who contributed towards the payment of my tuition fees and living expenses, thus enabling me to complete my PhD.

Last but not least I would like to thank all my friends and family - the Parkholmies, Dixons, Lindsay Hiscox and Humphrey my cat for keeping me company during the writing up. Thank you to all my family, especially Nan and Grandad (Betty and Ken) for always believing in me. In particular I would like to thank my wonderful partner Pete for his endless supply of love, faith and support.



# Author's Declaration

During the period of registered study in which this thesis was prepared the author has not been registered for any other academic award and qualification.

The material included in this thesis has not been submitted wholly or in part of any academic award or qualification other than that for which it is now submitted.

A handwritten signature in black ink, appearing to read 'Katie Gaudion', is centered on the page. The signature is fluid and cursive, with a large initial 'K' and 'G'.

Katie Gaudion

April 2015



# Chapter 1: Introduction

This PhD by Practice explores how autistic adults with limited speech and additional learning disabilities experience their home environment. It is estimated that 1 in every 100 people is diagnosed with autism (Baird et al., 2006; Brugha et al., 2009), these are people whose perceptions, experiences and interactions with their surroundings are unique, and but also are people who may not be able to communicate their differences verbally to the remaining 99% of the population. This, in combination with their distinctive cognitive profile, has resulted in a lack of autism and design studies involving autistic adults; consequently their life experiences may neither be fully heard nor understood and remain largely unexplored.

Work by Dr Leo Kanner and Dr Hans Asperger form both the current basis for our understanding of autism and a springboard from which research in autism has grown and evolved. A core feature of Kanner's seminal article (1943) was the preoccupation of the children he studied with their physical environment and the things within it, rather than any persons present. Since then, however, a person's relationship with their environment has rarely featured within autism research. Instead research focuses largely upon the underlying biology and causes of autism (Pellicano et al, 2014). But the revised DSM-5 (the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-5, 2013), which recognizes the unusual way autistic people respond to sensory input, has put the sensory environment back on the agenda within autism research, and it has also opened the door for design to play a role. A designer's deep understanding of the sensory quality of materials, skills in making and spatial/visual thinking has the potential to develop new modes of non-verbal communication, dialogue and understanding around an autistic person's everyday experiences in a way that is separate to, but equally as valid as, the medical approach.

This PhD research gives agency to the material world and explores how affordances are the key mechanism that designers use to understand others and to trigger action in

others. This project focuses not just on the autistic person but looks externally at the autistic person in combination with their environment. The perceptual psychologist James Gibson echoes the design approach of this PhD in his work, perhaps best summarized in his sentence “Ask not what’s inside your head, but what your head’s inside of” (Mace, 1977, p.43). This PhD uses Gibson’s concept of affordances and theory of direct perception as a framework to explore and autistic person’s relationship with their environment - one that challenges the affordance and conventional structures of the neurotypical world.

The PhD was carried out in collaboration with an autism charity called the Kingwood Trust, who provide support and accommodation for autistic adults. Kingwood Trust recognises that the physical environment can affect an autistic person’s everyday experience; it therefore looked beyond medical and scientific research to the field of design to explore an autistic person’s engagement with their home environment. To explore how autistic adults experience their home environment the PhD involves three design studies that explore an autistic person’s interaction with, and reaction, to three environmental contexts of their home.

To explore how autistic adults experience their home environment the PhD involves three design studies that explore an autistic person’s interaction with and reaction to three environmental contexts of their home. In response to Wing and Gould’s Triad of Impairment classification of autism (1979), this research adopts a strengths-based approach. It investigates how an autistic person’s sensory preferences, special interests and action capabilities combined with their reactions to the designed world can create tangible insights into what gives them delight, comfort and satisfaction. Furthermore this PhD looks at how those insights can be translated into design outputs that enrich the everyday lives of adults with autism.

To investigate an autistic person’s relationship with the environment, particular attention is paid towards the careful selection, adaptation and development of collaborative design tools for use in the design process by autistic adults, their support staff, family members and the designer. The designer looked at existing design

approaches and explored relevant design research, resulting in research gaps being identified that this PhD will address. The designer discovered that most of the existing research in the field is both child and deficit-focused, and excludes the physical environment as well as autistic adults with additional learning disabilities.

The project reflects upon a neurotypical or non-autistic designer's approach and experience of working with autistic adults. It examines how the inclusion of autistic people within the design process creates a shared experience that helps to develop mutual trust and empathy. Through a design, as opposed to a medical, approach this PhD aims to add to the understanding of autism. By informing the wider design, autism and care communities this research aims to enrich and improve autistic people's experience of their homes. Also, this PhD aims to contribute to the progression of neurotypical attitudes towards a point where different ways of seeing, doing and being are embraced.

To minimise the risk of overlooking significant areas of research and to reduce the possibility of misinterpretation and to challenge any assumptions made, an expert reference group was established to advise the designer on all aspects of the project. This consisted of 16 autism and design professionals, and parents of autistic adults, who provided important multiple perspectives and advice for each of the three design studies. In addition to the expert reference group, the designer sought guidance from her external supervisor Dr Liz Pellicano, who is the Director of the Centre for Research in Autism and Education (CRAE) at The Institute of Education in London.

### **Research Questions:**

1. Can a designer's approach generate insights about how autistic adults experience their home environment, and what design principles can be developed from this?
2. How can autistic adults who have limited speech and additional learning disabilities be involved in the design process?
3. What can the broader design field learn by designing with autistic people with additional learning disabilities?

# PhD by Practice Structure

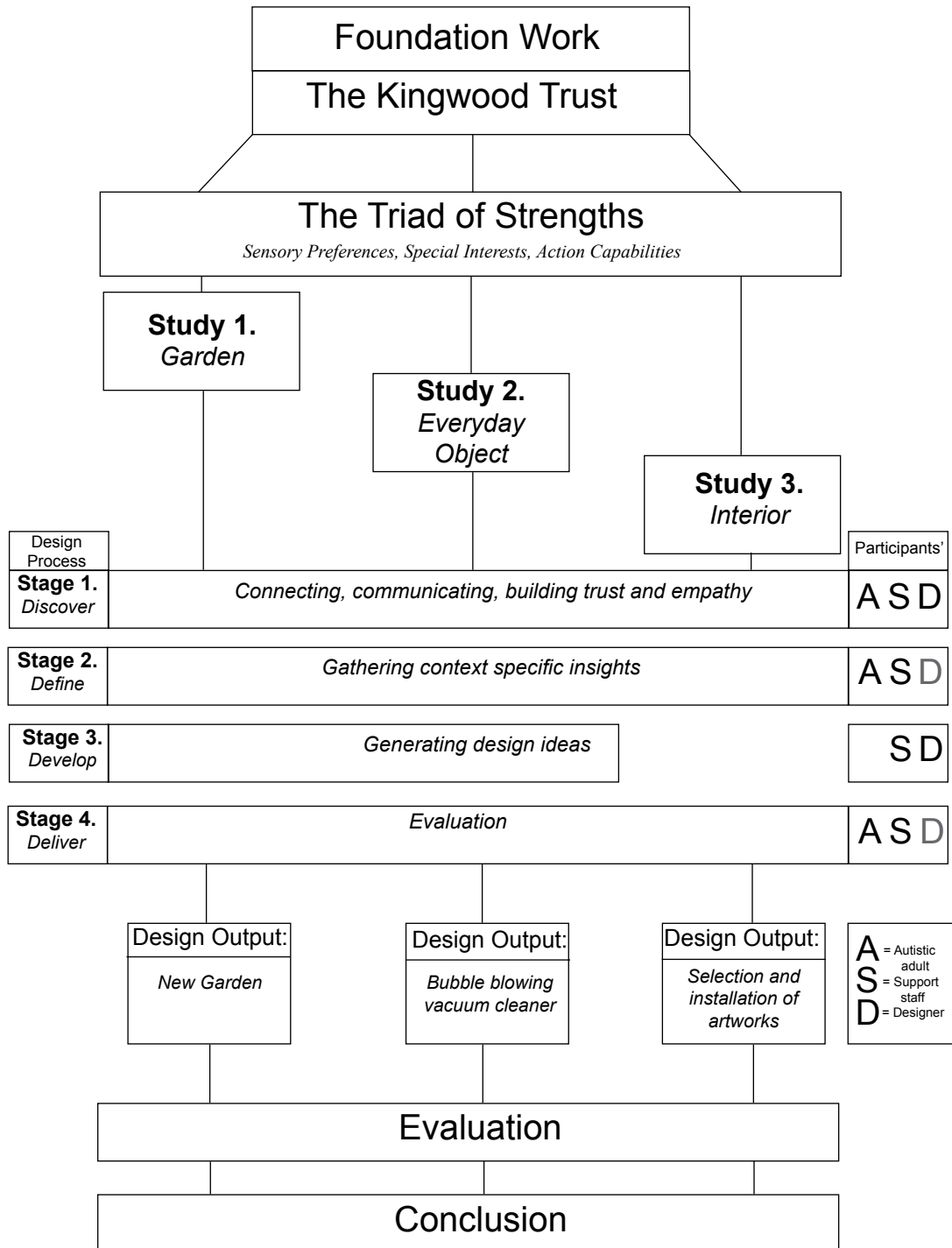


Figure 1. A diagram to show the structure of this PhD by Practice

# Chapter 2: Foundation Work

## **Jack and the Paperclip**

Jack was inconsolable. There was nothing I could do or say to help. If only I could understand. If only he could talk. I called his mum who said, “Has he got a paperclip in his hand?” Luckily I found one in a drawer and gave it to him. Jack’s fingers wrapped around the cold metal and instantly he relaxed. Who would have thought a length of wire bent into flat loops used to hold papers would offer so much comfort and support?

Jack was the first autistic person I had worked with and since my experience with Jack, I have worked with a number of autistic people of all ages and abilities. What I consistently observed was their unique emotional response and interaction with the physical environment that was very different to my own. Experiences not prescribed around the social construct of the intended functionality of things, but instead representing different ways of being in the world that continuously challenged my own perceptual experience (diary entry by author, June, 2006).

## 2.1 Design Background

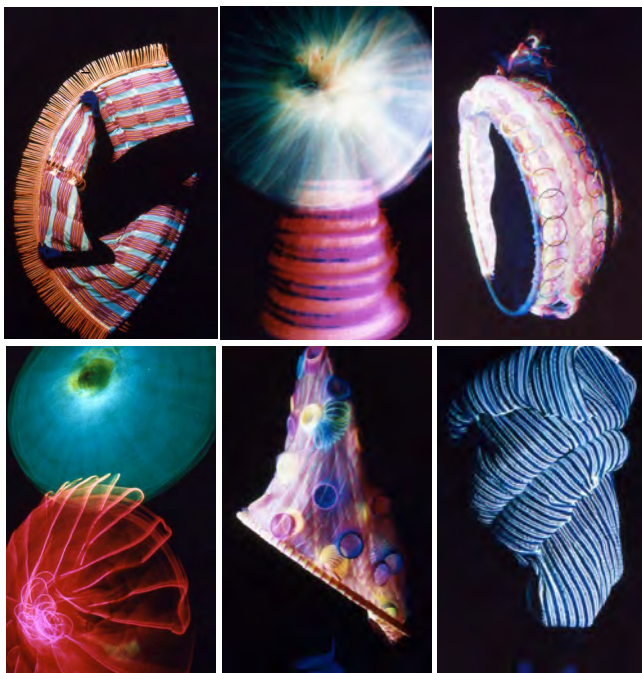
This chapter will describe four early experiences, which have led up to this PhD by practice. Each experience has seen a gradual but significant transition in my thinking around design and human experience, which has influenced the direction of my design practice in a way that may not have otherwise occurred. My curiosity and reflection upon each situation creates an accumulation of questions, one influencing the next.

### 2.1.1 Rondel House

One of my earliest experiences of being with people with neurological conditions took place in Rondel House, a school for children with special educational needs, in Guernsey where my mother worked. It was the only school of that kind on the island. I was five years old and would play with the children whilst waiting for my mother to finish work. I remember playing with Hannah - she always stuck her tongue out and wanted to hold my hand, but sometimes squeezed it so hard that my mother would have to gently open her fingers. I loved to jump in the ball pool where I would find Tim, and wondered why he could not walk and was so much smaller, yet older, than me. Matt would laugh and flap his hands as we pushed his wheelchair fast around the room. Most of the children could not speak, but that was okay, as we communicated through facial expressions and our interactions with the toys and equipment. This early experience invited me to question why the children were so different from me – a questioning not driven by negative thoughts but by curiosity and fascination.

### 2.1.2 Kids Active and FACT (Federation for Artistic and Creative Therapy)

My first degree was completed at the University of Brighton from 1998 -2001 in Textiles Design. It was during this time that I became interested in the sensory qualities of materials. My graduate show comprised a collection of ultraviolet textile sculptures that were designed to stimulate the sense of touch, sound, sight, vestibulation and proprioception (Figure 2).



22 Figure 2. Ultraviolet woven textile sculptures



After graduating as a textile designer and having worked at the Jim Henson's Creature Shop thereafter, I developed a deeper interest in learning about the diversity of human experience so I worked for two charities; the first was Kids Active (2006) where I worked as a play worker for autistic children and the second was The Federation for Artistic and Creative Therapy (FACT) (2006-2008), where I facilitated sensory sessions for both children and adults with different neurological conditions in a multi-sensory environment and van (Figure 3). The multi-sensory van is furnished from floor to ceiling with objects and materials designed to stimulate the primary senses, and the mobile nature of the van enabled us to facilitate sensory sessions in schools and care homes.



Figure 3. The multi-sensory van at FACT, 2006

Now a qualified textile designer I was particularly interested in observing a person's engagement with the sensory qualities of the environment, which I documented through drawing (Figure 4). I made three important observations. First, I observed the positive effect the environment had on the people I was working with, for example the fibre-optics on the ceiling encouraged Kevin to move his head and make happy sounds (see Appendix 1) and the soft brush helped to relax Tim's hands (see Appendix 1). Second, the environment and things within it helped to mediate non-verbal communication between the participants, for example a tweeting bird toy formed a connection between Dom and myself (see Appendix 1). Thirdly I consistently witnessed a person's unique interaction with everyday things, for example Jack's engagement with a paperclip and Ben's alternative use for a chair (described below).

### Ben's chair activity

Ben leads me to a chair, his second ritual of the day; he leans over and places the left side of his face onto the seat, pressing his ear, cheek and part of his helmet firmly against the hard plastic surface, whilst simultaneously trying to push the chair along. Ben takes my hands and places them onto the back of the chair and puts his face back into position. As the chair tilts I begin to pull, the legs glide along the surface of the textured carpeted floor creating a subtle vibro-tactile sensation, which vibrates through the side of his face, Ben doesn't want me to stop (Diary extract by author, 2006 (see Appendix 1)).

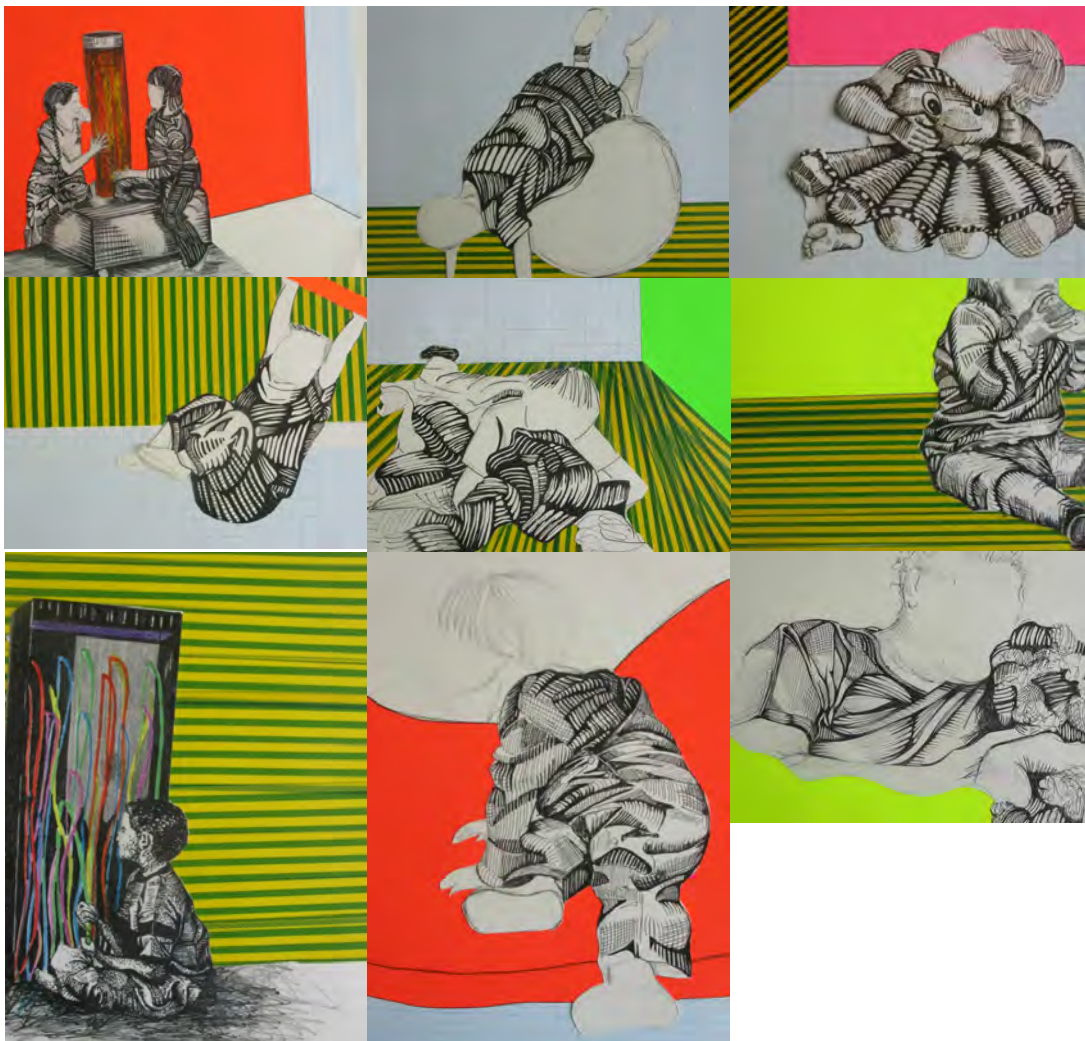


Figure 4. Observational drawings of the children's interactions in the multi-sensory environment, illustrations by author (2007-2008)

### **2.1.3 MPhil Textile Design, Royal College of Art**

My experience at Kids Active and FACT and the observations I had made helped to form my own research proposal for an MPhil by practice in Textiles Design at the Royal College of Art (2008-2010). The aim of the research was to critique the design of multi-sensory environments also known as Snoezelens® and develop a range of sensory props which adults could use as well as children. During the course of the research, I was also commissioned to design an interactive structure for a large multi-sensory complex called the Golden Horn (Guldhornet) in Denmark.

This research helped to bridge my textile practice into the world of neurodiversity – the project received a Helen Hamlyn Design Award for Creativity in 2010. Upon completing the MPhil I began to reflect upon my design practice; though I was initially excited by the final output – the sensory props – I became more interested in the process and methods for how the props evolved. For example, what was it that I was doing and how did I translate Ben’s interaction with a chair and Lucy’s love for slinkies, into sensory props? (Figures 5-6)



Figure 5. Sensory prop for Ben



Figure 6. Sensory prop for Lucy

### **2.1.4 Research Associate, the Helen Hamlyn Centre for Design**

To complement my research interests and making skills developed during my MPhil, I joined the Helen Hamlyn Centre for Design in autumn 2010 as a Research Associate, which is where I was introduced to the autism charity The Kingwood Trust. The

Research Associate project enabled me focus on the design process, and explore how the Centre’s people-centred design philosophy could be applied to the autistic adults I was designing with.

During the collaboration my design practice and approach changed from designing for people to designing with people. This is evidenced by critically reflecting back upon my experience with Ben at Kids Active and the sensory prop I made for him during my MPhil in response to his ‘chair activity’ (Figure 5). Instead of embracing the thing that Ben enjoyed doing, the sensory prop guided his actions away from the chair and into what I considered to be a more ‘appropriate’ activity? On reflection the sensory prop may have been a method to overcome my own feelings of discomfort and embarrassment whilst pulling the chair, representing my inability to interact with a chair beyond its intended use. To illustrate how my design approach has changed, if I could rewind the clock, I would design a sensory prop with Ben that enhanced his ‘chair activity’, possibly a chair on wheels, with a soft pad indented in the seat for Ben’s head to rest on with handles to help me pull the chair and maybe an umbrella holder in case it rains (Figure 7).



Figure 7. From sensory prop to adapting a chair

### **2.1.5 PhD by Practice**

The collaboration between The Helen Hamlyn Centre for Design and The Kingwood Trust was a learning curve that revealed to me how empathy plays a significant role within the design process. I thought empathy was innate, but now realise that it can grow and evolve. For this to happen (in the case of working with autistic people) it requires a perceptual shift in thinking that is open to different ways of being in the world. This perceptual shift is illustrated below in the description of my first two visits to Tom's home at Kingwood Trust.

#### **My visits to Tom's home**

I visited the home of a man called Tom for the first time. Tom was not present, but with notebook and camera in hand I 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 (Figure 8), where all the paint had been peeled and wood eroded. Leaving Tom's home, my first question was; how could we prevent this from happening?

Several weeks later I 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 I 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 whilst listening and feeling the vibrations of the music above (Figure 9). Unable to ask Tom directly 'what do you like about doing that?' I then mirrored Tom's actions and experienced it for myself, which enabled me to externalise my 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, I now perceived Tom's sofa as an object wrapped in fabric that is fun to pick. Pressing my ear against the wall and feeling the vibrations of the music above, I felt a slight tickle in my ear whilst rubbing the smooth and beautiful indentation, which Tom had sculpted into the wall. So instead of a damaged wall I perceived it as a pleasant and relaxing audio-tactile experience. On reflection this experience illustrates how upon my first visit to Tom's home, I instantaneously

internalised and conceptualised my observations of the environment with a negative connotation - ‘destruction’. However upon the second visit I met and interacted with Tom, I began to empathise with Tom - the sofa, wall and music revealed vital clues and helped me to form some understanding of the sorts of things Tom likes to do. (Diary extract by author, October, 2010)



Figure 8. Before: a damaged wall



Figure 9. After: Ben enjoys rubbing the door

Noticing this perceptual shift in myself was a revelation. This combined with my interest in the tools used to involve autistic adults in the design process, and my fascination with their unique experience with the environment, led to this PhD by Practice. The combination of my professional training as a textile designer, interest in multi-sensory environments, trajectory of experience from an early age of working with people with neurological differences, and finally a growing realisation that the role of design is not simply to design for but to design with, create the foundation for this study.

This PhD is structured to reflect upon my approach within three design studies and critically apply, analyse and evaluate a series of tools used to explore how autistic adults with learning disabilities experience their home environment. The research draws from three organizations, providing different perspectives and a diverse but complementary

range of expertise: the people-centred design ethos of The Helen Hamlyn Centre for Design, the making and experimental design nature at the Innovation Design Engineering programme at the Royal College of Art, and the autism expertise at The Centre for Research in Autism and Education, whose main goal is to enhance the lives of autistic people.

### **2.1.6 Designer and Researcher**

The designer's background is textiles design, which played a lead role in discovering new knowledge relating to experience. Textile designers are educated to be especially attuned to a range of tactile experiences and materials to enable senses of colour, texture, weight, mass, movement, temperature, sound and smell. This specialist knowledge and sensitivity to the sensorial qualities of the environment was valuable and poignant when working in the context of autism and people who experience sensory sensitivities.

As this PhD title suggests, a 'designer's approach' was used to explore how autistic adults experience their home environment, but it is important to note that the designer also took on the role of a researcher. This PhD therefore bridges design and research. Research is considered "a systematic enquiry whose goal is communicable knowledge" (Archer 1995 p.6), whilst "design knowledge is of and about the artificial world and how to contribute to the creation and maintenance of that world" (Cross, 2001, p5). Instead of fixed methods and predetermined goals, the design approach in this PhD was a flexible and evolving process, where the tools emerged through the practice, that intuitively responded to people and situations as they naturally unfolded. This contrast and tension between the research and design process was important as it supported and accelerated new ideas, and the fuzziness and the ambiguity that surrounds it stimulated thinking, which in turn necessitated creativity and new knowledge

Throughout the three studies, design and research worked in tandem, concurrently and in parallel, one supporting the other. The research generated insights about how the autistic participants currently experience their home environment, and these findings provided the source of information for ideation and concept development (design). For

example in stages one and two of the design process, it was important to understand what the autistic participants were experiencing now (research), but simultaneously attempt to understand what might be and what could be (design). The tools and prototypes developed by the designer facilitated the research process, which generated knowledge to feed the research goals.

Core to the design process was the designer's ability to follow her instinct, reflect and empathise, which created an archive of tacit knowledge (Polanyi, 1958) that cannot easily be codified and put neatly into a replicable framework, but instead is embedded within the designer, making it difficult to articulate and transfer to another person. Reflective practice (Schön, 1983) was critical for this PhD as it enabled the designer to form meaning from the plethora of design approaches, thoughts and experiences that culminated during the design process. Reflection helped the designer to refocus her thinking from her existing knowledge to generate new knowledge and ideas, which influenced the modification of the methods and her actions along the way.

Working with autistic people with limited speech required a continuous cycle of reflection and move from an expert mindset to a more participatory design mindset. In situations of confusion and uncertainty, reflection was even more crucial for the designer to step back, unpack and identify her emotions in relation to a situation in order for the project to move forward. "When we reject the traditional view of professional knowledge, recognising that practitioners may become reflective researchers in situations of uncertainty, instability, uniqueness, and conflict, we have recast the relationship between research and practice" (Schön, 1984, p308).

To help investigate the research questions, the following chapter presents a critical assessment of literature in the field covering relevant key areas that are essential to accurately locate and underpin this PhD.



# Chapter 3: Literature Review

This chapter presents a critical assessment of the relevant literature that locates and underpins the PhD. It outlines and critiques the most significant and pertinent historical, social, theoretical and applied research in relation to the following key areas:

## **3.1 Neurotypical**

## **3.2 Autism Research**

## **3.3 Affordances in the Environment**

## **3.4 Design for Autism**

## **3.5 Design Approaches**

Throughout the thesis, the term neurotypical is used to describe people who are not autistic – a term widely used by the autism community. The term autistic person is the preferred language of many people with autism (see Sinclair, 1999). The designer uses this term as well as person-first language (such as ‘adults with autism’) to respect the wishes of all individuals on the autistic spectrum.

## **3.1 Neurotypical**

Neurotypical (NT) is a term coined by the autism community to describe the 99% of the population who are not on the autism spectrum (Sinclair, 1998; Gray and Attwood, 1999). This PhD describes a neurotypical designer’s journey of working with autistic adults to unravel clues and insights around their experiences with the home environment. The designer will use the term neurotypical and reflect upon both the autistic and neurotypical experience, to help create empathic understanding.

The majority of research on autism is facilitated by neurotypical people, whose research habitually starts with the question, ‘what is autism spectrum disorder?’ followed by a generic description that is characterised by a triad of impairments: impairment in social

interaction, social communication and social understanding and imagination (Gould and Wing, 1979). In response to this, and the fact that the designer has rarely met an autistic person who neatly slots into this description, this chapter begins with a short description of the symptoms and behaviours associated with being neurotypical, from the perspective of an autistic person.

Neurotypical is short for neurologically typical and refers to a person who is within the typical range of human neurology that falls within the dominant societal standards of “normal.” Some autistic people think of being neurotypical as a disorder rather than autism being the disorder, for example the Institute for the Study of the Neurologically Typical features the DSN-1V (The Diagnostic and Statistical Manual of Normal Disorders): 666.00 Neurotypic Disorder (1998) (see Appendix 2). There is also a growing number of blogs, publications and websites that describe the neurotypical experience. ‘A field Guide to Earthlings’ (Ford, 2010) presents 62 behaviour patterns used by neurotypical people and states that ‘Neurotypical perception is restricted by their use of language and cultural symbols’ (p.16). Below is another description of neurotypicality by an autistic person:

Neurotypicality is a pervasive developmental condition, probably present since birth, in which the affected person sees the world in a very strange manner. It is a puzzle; an enigma that traps those so affected in a lifelong struggle for social status and recognition. Neurotypical individuals almost invariably show a triad of impairments, consisting of inability to think independently of the social group, marked impairment in the ability to think logically or critically, and inability to form special interests (other than in social activity) (Human 19, 2011).

The extract above and others like it provide a useful starting point for this PhD, as from the onset it helps to frame and adjust the neurotypical reader’s perspective to the point of view of an autistic person. The extract is an empathic exercise; whilst it may not relate to the reader’s understanding of who they are, this inadvertently highlights how an autistic person might feel when they are continuously being characterised through a

generalised description that does not necessarily relate to or create a holistic impression of who they are.

## 3.2 Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a lifelong complex neurodevelopmental condition, which affects the way that a person interacts with and experiences the world around them (American Psychiatric Association, 2013). It is a spectrum condition that affects people in vastly different ways. Someone with autism might be sociable, while others find it difficult to sustain and initiate social relations. Some have learning disabilities while others possess high levels of intellectual ability. It is no longer considered rare: it is estimated that 1 in every 100 people is diagnosed with autism (Baird et al., 2006; Brugha et al., 2009). According to the National Autistic Society 44% - 52% of autistic people may have a learning disability, which is defined by The Department of Health (2001, p. 14) as; “a person who has a significantly reduced ability to understand new or complex information, to learn new skills and reduced ability to cope independently which starts before adulthood with lasting effects on development.”

Although autism is most often associated with its effects on social communication and interaction, the latest revision of diagnostic criteria (the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; DSM-5, 2013) (see Appendix 3) recognises the unusual way that autistic people respond to sensory input. These so-called “sensory sensitivities” can affect a person’s ability to interpret, filter and regulate sensory information, leading to a person becoming hypersensitive (over-stimulated) and/or hyposensitive (under-stimulated) to incoming information, thereby influencing how they experience the environment around them. For example, while some autistic people find certain sounds (e.g. dogs barking) or visual input (e.g. fluorescent lights) disturbing, others seek out and take pleasure in such stimuli.

Currently, research on autism is largely focused upon the underlying biology and causes of autism (Pellicano et al., 2013), including an emergence (since the 1970s) of cognitive theories to explain the core features of autism. These theories include difficulties with theory of mind (TOM) which was developed in the 1980s by Baron-Cohen, Leslie, and

Frith, 1985. TOM is the ability to be able to reflect on ones own mind and have the ability to understand what other people are thinking. Secondly executive dysfunction (ED) theory (Pennington, and Ozonoff, 1996; Ozonoff et al., 1991), which is an umbrella term used to describe a persons' difficulty with planning, organising and sustaining attention. 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).

### **3.2.1 Autism: from the beginning**

Dr Leo Kanner (1894-1981) and Dr Hans Asperger (1906-1980) formed the basis for our understanding of autism and the springboard from which research in autism has grown and evolved. An important starting point for this PhD was to rewind around 70 years to Kanner's seminal article 'Autistic Disturbances of Affective Contact' (1943). The article is a 34-page clinical account and discussion of observations on the patterns of behaviours and personalities of eleven children (eight boys and three girls) by both Kanner and the children's parents.

Kanner provided Sequin boards for the children to play with, but the descriptions reveal how the children gravitated towards and became preoccupied with his office environment and the things within it, rather than the people present. It was the waste paper bin, light switch, books and furniture that held the children's attention (Figure 10). In Kanner's article 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 also describes how the people present may also have been perceived in the same way as the artefacts in his office environment:

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, 1943, p.246).

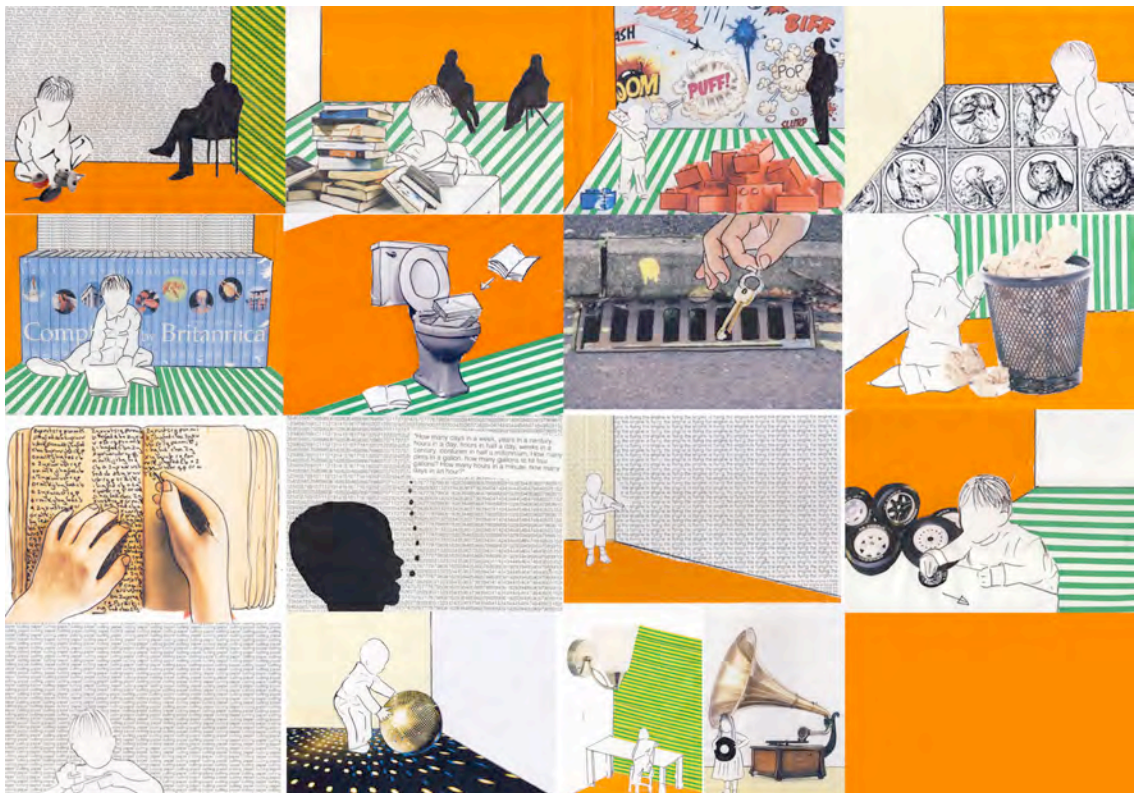


Figure 10. A collection of drawings showing the children interacting with the objects in Kanner's office, illustrations by the author

As described in the article, each child would create an activity from the physical elements of Kanner's office. Each interaction was different from the last e.g. spinning objects, turning the light switch on and off and throwing things onto the floor. Although these activities initially appear different from one another, on reflection they share commonalities. Every activity involves repetition and elicits a sensory response that is controlled and triggered by the child's physical engagement with the object. In other words their action creates a re-action. For example, spinning an object activates movement, pressing a light-switch activates light and throwing an object on the floor activates sound. These reactions elicit sensory responses, which are consistent and predictable. If the activity is repeated it will produce the same sensory output as before.

It is very rare that a flick of a light-switch results in anything other than a clicking sound and the lights coming on or going off. Consequently the child could always predict what is going to happen next and control the levels of sensory input. “Objects that do not change their appearance and position, that retain their sameness and never threaten to interfere with the child’s aloneness, are readily accepted by the autistic child” said Kanner (1943, p.246).

Although Kanner’s article describes how the children appeared to enjoy the sensations they sought from their surroundings, the parents’ accounts describe how the environment and things within it could also be frightening for their children, sometimes triggering extreme anxiety. Trains, cars, vacuum cleaners, tricycles and dogs barking were just some of the things that frightened the children:

Another intrusion comes from loud noises and moving objects, which are therefore reacted to with horror. Tricycles, swings, elevators, vacuum cleaners, running water, gas burners, mechanical toys, egg beaters, even the wind could on occasions bring about a major panic (Kanner, 1943, p.245).

Again, although these objects initially appear to be a random collection of things, correlations can be drawn. In contrast to the things the children gravitated towards, the objects they were frightened of elicit unpredictable sounds, lacking pattern and consistency; sounds that might be imposed on the children and most likely controlled by someone else for example a car. As a parent explains, “he became upset by any change of an accustomed pattern; if he notices changes, he is very fussy and cries. But he himself likes to pull the blinds up and down, to tear cardboard boxes into small pieces and play with them for hours, and to close and open the wings of a door” (Kanner, 1943, p.232). The objects also moved in addition to making sounds, therefore making it difficult for a child to understand what the sound was, where the source of the sound was coming from and how to escape from it, heightening their levels of anxiety: “The disturbance comes from the noise or motion that intrudes itself, or threatens to intrude” (Kanner, 1943, p.245).

Some of the insights drawn from the article also revealed the children's likes and dislikes and how the children perceived people: "When he had any dealings with persons at all, he treated them, or rather parts of them, as if they were objects" (Kanner, 1943, p. 218). The article goes on to shed light on how the children displayed good skills development when engaging with objects ("Objects absorbed him easily and he showed good attention and perseverance in playing with them" (Kanner, 1943, p.224), and finally the parents' concern regarding their children's over-attachment to objects that may inhibit social interaction.

Kanner concludes the article with an observation that, despite a clear lack of connection to other people, "children were able to establish and maintain excellent, purposeful and intelligent relations to objects" (Kanner, 1943, p.249). Interestingly one year later Dr Hans Asperger contradicted this statement in his seminal article 'Autistic Psychopathy In Childhood', stating that 'Autistic children's relation to objects, too, are abnormal' (Asperger, 1944, p.81).

Whilst both Kanner and Asperger identify the children's idiosyncratic engagement with the objects in the environment e.g. spinning saucepans, putting keys down the drain and dropping books into the toilet, it is unclear precisely what Kanner meant by excellent and purposeful relations to objects? But his thinking could relate to a recent theory by Pellicano (2013) that suggests the children's interactions could be excellent and purposeful as she describes "...such fascinations as well as repetitive behaviours (like spinning the wheels of a toy car) - behaviours over which the individual has full control- might be a means of reducing the uncertainty in the environment" (Pellicano, 2013, p.10).

Kanner's article illustrates that it was not people but the physical environment that influenced how the children engaged and behaved, which inadvertently generated clues and insights into how the children might perceive their surroundings. To investigate an autistic person's engagement with the environment, the following section draws upon three characteristics – sensory sensitivities, special interests and perception – to explore how an autistic person's experience with each can influence how they respond and

relate to the physical environment; 1) sensory sensitivities – how does a person receive and process information from the environment? 2) special interests - what is a person's point of focus and attention in the environment? 3) perception- how does a person organise and interpret the sensory information from the environment?

### **3.2.2 Sensory sensitivities**

Kanner's (1943) and Asperger's (1944) articles highlighted how the children's unique reactions to the sensory qualities of the physical environment can have an enormous – and often negative – impact on people's everyday lives (Pellicano, 2013). Surprisingly, however, a person's relationship with the environment is rarely featured within autism research, and it was not until the 1960s and 70s that a small succession of researchers started to identify sensory and perceptual difficulties within autism. Rimland (1964) emphasised the importance of exploring the perceptual abilities of autistic children. Wing (1969) showed how autistic children have more sensory difficulties than typically developing children and children with Down's syndrome. Eveloff (1960) described severe perceptual difficulties experienced by autistic children. Ornitz (1969,1989) extended the notion of a disorder of sensory processing to the notion of sensory and information processing and Delacato (1974) proposed that unusual sensory experiences were an important characteristic feature of autism.

In response to this body of research, practical interventions were developed to help a person cope better with their surroundings such as sensory integration therapy (Ayres, 1972) and Snoezelen environments (Glover and Mesibov, 1978). The pioneer of this may have been the British educator Sybil Elgar (1914-2007) who forged new thinking on education for adults and children with autism. Sybil Elgar set up a school in the 1960s in the basement of her own home. She was trained in Montessori, whereby teaching through the senses and adapting the environment to meet the needs and capabilities of the children is encouraged, and this philosophy may have formed the platform for her practice.

From the 1970s onwards, research on sensory sensitivities continued to be revived thanks to the accounts of the first cohort of people diagnosed with autism (Bemporad, 1979; Grandin,



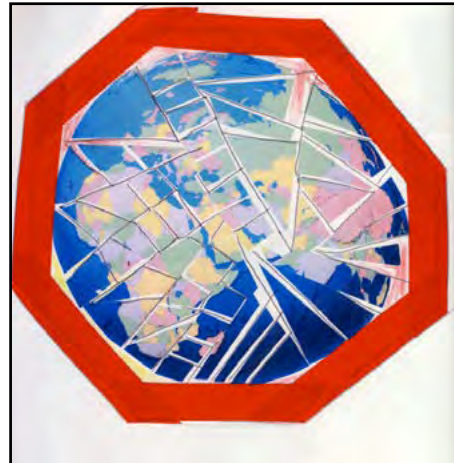
1984; Williams, 1992, 1999; Donovan and Zucker, 2010). Figure 11 contains quotes by autistic people that describe their sensory experience with the environment; the author has illustrated each quote to help conceptualise the experience. The advent of the Internet has made a strong contribution to this revival with global conversations on sensory sensitivities springing up across the web. Examples include autism specific blogs and forums (for example Wrong Planet and Aspies Central) and autobiographical accounts by people with autism as well as their parents (Blackman, 2001; Woodgate et al., 2008; Dickie et al., 2009).

The Internet has become a powerful platform to enable people with autism to share and talk about their experiences. For example, Amanda Baggs, a nonverbal autistic woman made a film for YouTube entitled 'In my language' (2007) which gives a personal account of her sensorial experiences and physical engagement with her environment. Baggs explains; "my language is not about designing words or even visual symbols for people to interpret, it is about being in a constant conversation with every aspect of my environment, reacting physically to all parts of my surroundings".

The film shows Baggs interacting with water, stroking computer keyboards, doorknobs and smelling books, which illustrates how pertinent every aspect of the physical environment is for her. These first-hand accounts have created a growing pool of knowledge and insights that help neurotypical people to try and imagine how autistic people perceive and experience their environment. Interestingly many of these insights are not so dissimilar to those described by Kanner and Asperger; spinning objects, looking at reflections and turning light switches on and off continue to be a popular source of interest and delight for some people with autism.



“I sometimes was seeing my hands and the things I was touching as if they were multiplied...[the] image was either multiplied or overlaid by similar reproductions of itself in duplicate” (Blackman, 2001, p.268).



“To some...individuals [with visual processing problems] the world looks like it is viewed through a kaleidoscope. Flat, without depth perception and broken into pieces. For others, it is like looking through a small tube, seeing only the small circle of vision directly in front of them, with no peripheral vision” (Grandin, 2008, p.78).



“The distant noise on the main road that ran about sixty metres from our house were always present. They sloshed against the day-to-day sounds of my own home in sort of wave-on-the-shore effect. I could feel the sensation of cars and a heavy laden truck pass, and also feel my own physical response to the noises that the vehicle made from its tyres, the engine and the wind of its passing” (Blackman, 2001, p.35).



“I think I knew I was different, but I didn't know why. My world was a rich one, full of colour and music that seemed to splash over and around me where ever I walked” (Lawson, 1998, p.40).

Figure 11. A collection of quotes by autistic people, describing their sensory experience with the environment, illustrated by the author

### **3.2.3 Perception**

How we interpret and perceive the environment is dependent upon what information we pick up through our senses. Consequently if an autistic person experiences sensory sensitivities, the information they pick up might not be attuned to that of a neurotypical person, resulting in more unconventional and idiosyncratic interactions with the environment. There have been a handful of autism researchers who have explored how autistic children perceive and interact with the physical environment, most notably Ungerer and Sigman (1981) assessed how 16 autistic children use objects in their daily environment. Out of a total of 62 objects, it was reported that 25 percent of the objects were not used properly even with verbal cues. Williams et al., (1999) urged for more research into an autistic child's idiosyncratic relation to objects and emphasised the corresponding difficulties in facilitating interpersonal interaction and social skills. Williams et al., (2005), Williams and Kendell-Scott (2006) conducted a comparison study involving 10 autistic children, 10 neurotypical children and 10 children with Down's syndrome, and conducted semi-structured interviews with their parents who were asked to report on their children's use of everyday objects at home during meal times and washing routines. The study concluded that the autistic children were interested in isolated, non-functional aspects of objects and the parents had problems in introducing the conventional object use.

To explore possible reasons for an autistic person's unique engagement with their home environment, this PhD draws upon three key theories related to autism and perception. Each theory suggests how an autistic person might organise and interpret the sensory information from their environment in order to understand it, which might invariably influence how and why a person acts and interacts with the environment the way that they do.

The unique perceptual experiences of people with autism was first explored by the developmental psychologist 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 with gestalt psychology, which describes how people firstly 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 are greater than the whole. The following description by an autistic person illustrates this idea.

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, p.177).

Frith's weak central coherence theory was followed by Mottron and 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 – recognising, remembering and detecting objects and patterns. This experience relates to some of the autistic participants within this research, who had a heightened attention to details and aspects of their environment. For example, Pete would not walk on shiny wet floors, Tim would know when the extractor fans in the staff room had been turned off, and Sarah had memorised all the times on her bus timetable.

Finally, in the third perceptual theory, Pellicano and 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 for 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 means effectively that the autistic person is unencumbered by their prior beliefs about

the world, which might explain why an autistic person might be interested in the unintended affordance of a washing machine e.g. the sound and visual effect of it spinning.

### **3.2.4 Special interests**

In 1971, 28 years after his seminal article, Kanner conducted a ‘Follow-up study of eleven autistic children originally reported in 1943 to see how the children in the original study had progressed. Four of the children had since spent most of their lives in institutional care with poor results. Kanner described “they all lost their lustre early after their admission” (Kanner, 1971, p.143). However two children, Donald T and Fredrick W, went on to work as a bank teller and duplicating machine operator respectively. Kanner believed their success was thanks to family members who nurtured their preoccupations and interests to create new positive experience: Fredrick through his interest in music and photography, and Donald “...because of the intuitive wisdom of a tenant farmer couple, who knew how to make him utilize his futile preoccupation for practical purposes” (Kanner, 1971, p.143). The follow-up study revealed that a person’s special interests and preoccupations with the things in their environment could be a point of contact and a way to help transition a person into learning and experiencing new things. This had already been emphasised in Asperger’s paper (Asperger, 1944, p.45) where he states; “We see here something that we have come across in almost all autistic individuals, a special interest, which enables them to achieve quite extraordinary levels of performance in certain areas”.

The progress of research on special interests within autism is similar to that of sensory sensitivities. Irrespective of Kanner and Asperger’s articles and a more recent article Donvan and Zuker (2010) which further describes Donald T’s special-interest-led progress, it is only recently that a person’s special interests have begun to be used as a way to help connect them with opportunities for social, emotional, academic and vocational growth. One of the earliest studies to examine special interests (Kerbeshian and Burd, 1986) looked at autistic childrens’ special interest in pinball machines. Since then, special interests have become a growing topic of conversation within blogs,

forums and autobiographical accounts (Welton, 2003; Grandin, 1984, 2008; Trehin, 2006) and parent accounts (Fling, 2000).

There is a growing body of research exploring special interests and how they may influence social interaction (Baron-Cohen, Leslie, and Frith, 1989; Charlop-Christy and Haymes, 1996, 1998; Baron-Cohen and Wheelwright, 1999; Baker, 2000; Attwood, 2003; Boyd et al., 2007; Dunst et al., 2010). Researchers have also begun looking at special interests as an important intervention for learning and skills development. (Vacca, 2007; Vismara and Lyons, 2007; Winter-Messiers et al., 2007a; Winter-Messiers, 2007b, 2007c; Gagnon, 2001; Kluth and Schwarz, 2009, 2010; Kavan and Kavan, 2011). Most notably a strength-based model was developed by Winter-Messiers et al., (2007a, p.71), which illustrates the strengths resulting from engagement of children and youths with autism in their special interest areas (Figure 12). Winter-Messiers (2007b) defined special interests as, “those passions that capture the mind, heart, time, and attention of individuals with AS, providing the lens through which they view the world” (Winter-Messiers, 2007b, p.124).

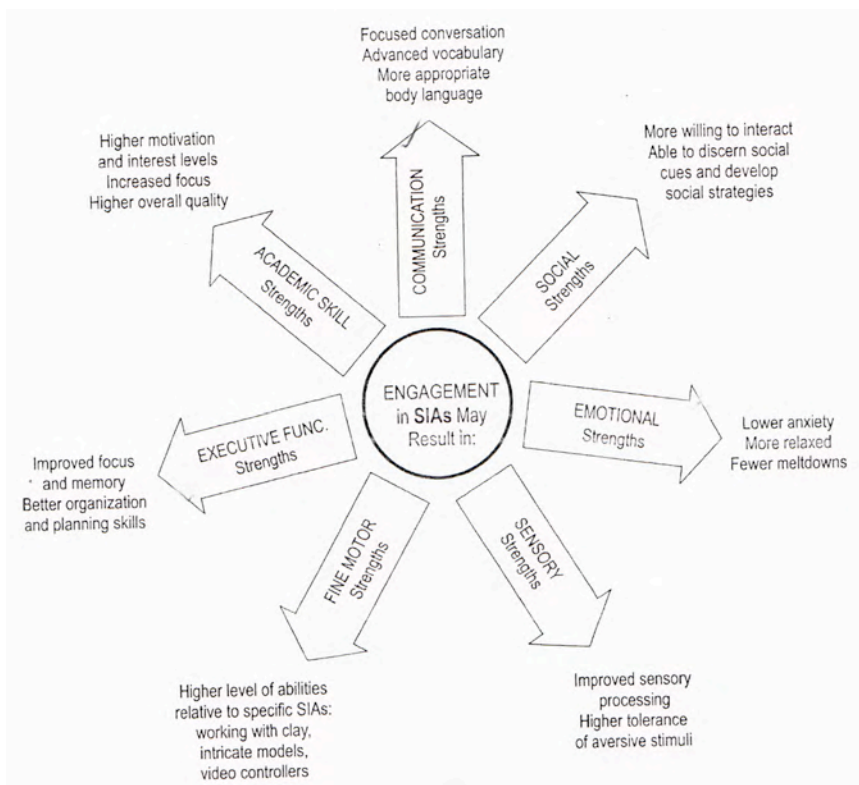


Figure 12. Strengths based model, (Winter-Messiers, 2007b, p.71)

Many autistic people have led successful careers that have been carved and shaped around their special interests. Temple Grandin, an American autism activist and best-selling author, has a successful career designing livestock equipment and gives credit to her Science teacher Mr. Carlock who helped Grandin to realise her abilities, her interest in automatic doors inspired her teacher to encourage her to investigate this further, which led her to becoming an engineer.

### **3.2.5 Autism Research - Summary of key points**

This chapter aimed to describe the key limitations identified within existing autism research. The limitations are supported by the views and perspectives of autistic people and family members who participated in the report 'A Future Made Together' (Pellicano et al., 2013), which mapped autism research in the UK.

The introduction to Kanner's seminal article (1943, p.217) features a pertinent quote from Rose Zelig:

To understand and measure emotional qualities is very difficult. Psychologists and educators have been struggling with that problem for years but we are still unable to measure emotional and personality traits with the exactness with which we can measure intelligence.

On reflection, the problems with measuring emotional and personality traits could have set the precedent for autism research thereafter, which has largely situated itself within a positivist approach, measuring and representing autistic people in quantitative terms - as numbers on a bar chart or percentages on a pie chart. This approach, however, misses the opportunities that the qualitative insights of design research can provide in bringing to the fore the personalities of autistic people and their subjective lived experiences in relation to the physical environment.

The majority of autism research studies and interventions are child-focused (Pellicano et al., 2013) and concerned with treating the person rather than looking externally at the environment, focused on understanding the biology, brain and cognition of an autistic

person with little research conducted on interventions, services and societal issues, relating to the day-to-day lives of autistic people (Pellicano et al., 2013). The Future Made Together report demonstrates autistic people are rarely actively engaged in the research process and particularly little is known about the lived experience of autistic adults with limited speech and additional learning disabilities.

Autism research largely explores a person in isolation or set within a clinical controlled setting that is far removed from their natural environment (Lord et al., 2005). This project proposes that the person cannot be explored in isolation from their environment and suggests that it is the non-human material infrastructure of the environment and what it affords that is critical to an autistic person's understanding of themselves, other people and the world around them. To further investigate and draw understanding about an autistic person's relationship with the environment the following section explores the concept of affordance, and how this can be used as a key mechanism to bridge understanding between the two.

### 3.3 Affordance in the Environment

The previous section described the condition of autism and illustrates how an autistic person's ability to filter, process and perceive the information from their surroundings can manifest into unique interactions and reactions to the environment. Kanner's article also demonstrated how the children's interactions were relative to the information available in the office space, which provided light switches for the children to flick, paper to rip and objects to spin. Consequently, without ignoring the many other crucial factors that have been the subject of much of the study of autism thus far, this research proposes that an autistic person's perception of, and action on, the affordance of the environment should be considered as an important explanation for their distinct behaviours.

This section brings together the person and the environment by exploring the concept of affordance, meaning a person's reciprocal relationship with the environment. As affordances signal a person's action for being-in the world, this research takes the premise (particularly when working with autistic people with limited speech) that



affordances are the key mechanism for exploring an autistic person's relationship with their home environment. Building upon Kanner's seminal article (1943) and autobiographies by autistic people thereafter, this PhD proposes that the affordances of the environment are inflexible and embedded within a socio-cultural context that is not always applicable to autistic people. Therefore, by exploring an autistic person's reciprocal relationship with their home environment in conjunction with what it affords and the different action opportunities reflected in this, the research aims to unravel insights into how autistic people perceive, value and make use of the affordances in an environment that is safe and familiar to them.

### **3.3.1 Gibson and affordance**

The concept of affordance was introduced by the psychologist James Gibson (1904-1979) in the article, 'The Theory of Affordances' (1977) and further explored in 'The Ecological Approach to Visual Perception' (1979, and later published in 1986), 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). Before Gibson's ecological approach to affordances had fully evolved, some of his earlier works include *Perception of the Visual World* (1950) *Senses Considered as Perceptual Systems* (1966), in which Gibson (1966) proposed a direct, bottom-up theory of perception. Synthesising this with Gibson's theory of affordance, his theory asserts that there is enough information in the environment for people to be able to directly perceive unaided by representations, memory inferences. Gibson's theory claims that all the information needed to make sense of the environment is directly present in the visual input which triggers action, as he states, "The theory of affordances implies that to see things is to see how to get about among them and what to do or not do with them. If this is true, visual perception serves behaviour, and behaviour is controlled by perception" (Gibson, 1979, p.223).

According to Gibson (1979), "an affordance points two ways, to the environment and the observer" (p.129) and explains that it 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). Therefore 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; if the affordance does not complement a person’s capabilities, they may find it hard to ‘fit in’ with their environment. In some situations, when an affordance is not compatible with a person’s capability, that person may adapt themselves and the environment to create a better fit. For example, the educator Maria Montessori (1870-1952) noted that her classrooms were designed and furnished for adults rather than the children’s capabilities; the furniture was too big and door handles too high. In reaction to this (providing the children did not mind heights) the door would only afford opening by the children if they stood on a box and reached for the door handle. Consequently Montessori lowered the door handles and designed the classrooms around the children’s capabilities.

According to Gibson, “The observer may or may not perceive or attend to the affordance according to his needs, but the affordance, being invariant, is always there to be perceived” (1979, p.139). This implies that depending on the needs of the person, people will attend to a different set of affordances in the environment. Gibson describes a set of affordances as a ‘niche’, which he suggests refers to ‘*how* an animal lives rather than *where* it lives’ (1986, p.128). As described in the literature review, an autistic person’s sensory perceptual engagement with the environment is unique, therefore it is proposed that an autistic person may occupy a different ‘niche’ or set of affordances to that of a neurotypical person. Channelling Gibson’s ‘niche’ construct, via the three design studies, this PhD seeks to examine how autistic adults live in their home environment.

### **3.3.2 Norman and affordance**

Since Gibson, the concept of affordance has travelled beyond the world of perceptual psychology. It was popularised within the field of human-computer interaction design by the cognitive scientist Donald Norman, who re-appropriated the term in his book, ‘The Psychology of Everyday Things’ (1988), (later to be retitled *The Design of Everyday Things*, 1998/2013). Norman claims “...the term affordance refers to the perceived and actual properties of the thing, primarily those fundamental properties that

determine just how the thing could possibly be used. A chair affords ('is for') support and, therefore, affords sitting" (Norman, 1988, p.9). In contrast to Gibson's 'bottom-up' theory of direct perception (perception directs cognition), Norman adopted a 'top-down' cognitive approach (perception is constructed by cognition) and describes how "affordances result from the mental interpretation of things, based on our past knowledge and experience applied to our perception of the things about us" (Norman, 1988, p. 219). Norman (2013) illustrates this top-down approach through describing three levels of processing applicable to cognition and emotion: 1) Visceral level: perceptually driven, 2) Behavioural Level: expectation driven and 3) Reflective Level: intellectually driven (2013, p. 50). Norman goes on to say that "to the designer, reflection is perhaps the most important of the levels of processing" (2013, p.53).

Norman's definition of affordance is more prescriptive and deviates from Gibson's theory of there being a reciprocal relationship between the person and environment, to a detached relationship whereby an affordance is implied within the object, with an emphasis on enhancing its usability. Norman applied this concept to a door handle to illustrate how different door handle designs specify different action opportunities for a person. Norman's concept of affordance has since expanded into different design domains, such as industrial design, interaction design and engineering design used predominantly to support and measure usability and ease-of-use in digital and physical artefacts. This includes technology and computer interface design (Gaver, 1991, Van Vugt et al, 2006) product design, (Galvao and Sato, 2005; Fuente et al., 2014; You and Chen, 2007; Hsiao, Hsu, and Lee, 2010), engineering (Maier and Fadel, 2009a, 2009b), interaction design (Hartson, 2003; Gaver, 1996), landscape design (Zeleeke and Junshan (2009), used in architecture as a framework to understand the relationship between people and the built environment (Maier and Fadel, 2009c), and used to evaluate how children interact with their environment (Heft, 1988; Chawla and Heft, 2002; Clark and Uzzell, 2006).

But if designers are using affordance as a tool to measure the usability of digital and physical artefacts, the question becomes 'usable to whom?' Can the evaluation of one person be applied to others when not all humans act in concert and when "a danger for

one might be an opportunity for others” (Zelevke and Junshan, 2009, p.12). The majority of design research that focuses on usability often introduces measures in relation to a person’s physical capabilities, and how well they fit in with the required operation of the artefact. For example Mark (1987) looked at eye height for sitting on chairs and climbing stairs and Warren (1984) investigated stair climbing in relation to height with respect to leg length.

If we take Norman’s example of a door handle, its usability is evaluated by height and grasp-ability based upon the door handle’s predetermined goal of opening a door. Norman’s description of the door handle is built upon the assumption that the motivation for making use of the affordance of a door handle is the same for everyone, but what about people who perceive things differently? For example, a door handle for an autistic boy called Joe is an object of entertainment which he enjoys moving up and down; whilst Joe uses the door handle in the same way as most people (grasping and moving it up and down), his motivation, emotional response and the meaning associated with the door handle is altogether different (Figure 13). This failure to understand how another person experiences the environment can lead to ‘poor design’, as described by Fulton Suri:

Poor design is often the result of an assumption that other people will like what we do, do things the same way we do; that they will know, as we do, that pulling the round switch will turn the machine on; that green will remind them of fresh leaves. Clearly this is not the case. People are very different in many ways (Fulton Suri, 2003, p.52).



Figure 13. Joe interacting with a door handle

In contrast to Norman, and in support of people who perceive things differently, Gibson does not support the categorisation of affordance and proposes that, “the theory of affordances rescues us from the philosophical muddle of assuming fixed classes of objects, each defined by its common features and then given a name” (Gibson, 1979, p.134). Gibson uses a stone to illustrate this point, “The fact that a stone is a missile does not imply that it cannot be other things as well. It can be a paperweight, a hammer, or a pendulum bob. It can be piled on another rock to make cairn or a stonewall.” For products whose measure of success is associated with usability based against specific criteria of use, then would a person’s atypical interaction with the artefact be considered a design error? This PhD research proposes that it is not necessarily the design of the product that is at fault but the designer’s lack of empathy and understanding of the capabilities and motivations of the person interacting with it.

Supporting this, Zaff (1995, p.259) states, “A significant number of design errors may be directly attributable to a failure on the part of the designer to accurately assess the affordances for another person”. There are some designers who have looked beyond a person’s physical capabilities and considered a person’s experience, culture and social settings (McGrenere and Ho, 2000; Gaver, 1991), and cognitive and sensory capabilities and how this may affect the way in which they perceive and make use of the

affordances of the environment. Hartson (2003) touched upon this in his research, which defined four complementary affordances in the context of design interaction and evaluation: cognitive affordance, physical affordance sensory affordance and functional affordance. In addition to creating a design framework for (in their case) human computer interaction, each affordance simultaneously guides the researchers to consider the physical, cognitive and sensory capabilities of a person. Hartson (2003, p. 48) states that, “while it is important for designers to help all users see and hear cognitive and physical affordances, special attention is required in design of sensory affordances for users with sensory disabilities”. The functional affordance category also guides the designer to question their own assumptions around the intended function of things: “The designer would do well to begin by asking if the intended functionality, the functional affordance, is appropriate and useful to the user” (Hartson, 2003, p. 25).

Norman’s definition has created debate within the design field over what affordance actually means and particularly the difference between Gibson and Norman’s definitions (McGrenere and Ho, 2000; Chemero, 2003; Oliver, 2005 Jenkins, 2008). In 2008 Norman changed the term ‘affordance’ to ‘signifier’: “Forget affordances: what people need, and what design must provide, are signifiers. Because most actions we do are social, the most important class of these are social signifiers” (Norman, 2008 p.18). Norman further describes a social signifier as “... one that is either created or interpreted by people or society, signifying social activity or appropriate social behaviour” (Norman, 2008 p.18). The question is what is ‘appropriate’ social behaviour? Norman’s concept of signifier assumes that everyone thinks and acts the same, dependent on a person’s ability to understand the given context of a situation and the social cues and clues that it encompasses. The concept of signifier therefore excludes autistic people who find it difficult to understand social context and cultural affordances as identified by Loveland (1991), see Table 1. p. 54.

### **3.3.3 Autism and affordance**

Whether autistic or not, individuals all live in the same multi-sensorial embodied world. Our environments are furnished with objects predominantly designed by people who share common values, perceptions and behaviours, creating ‘generic’ affordances with

specific purposes that shape and guide our actions. Chairs are designed to afford sitting, cars to afford driving and toothbrushes to clean teeth, “Our world has already been shaped by human activity, and is full of things designed by people to be used in specific human activities, by people who share common body shape, needs and cultural history” (Williams and Kendell-Scott, 2006, p.54).

In addition to physical acts, the affordances of the environment are also often designed to create social acts, predominantly by neurotypical people. Almost every action in life is impossible without some sort of past action or present reaction from our fellow humans. Take the simplest act of social interaction: making a phone call. It requires technology developed by someone else, the skill of speech (learned from someone else) and last but not least, someone else to talk to. But what if we found it difficult to relate and communicate with other people?

If an autistic person finds it difficult to communicate and relate to people, this project proposes that it might impact upon their understanding of the ‘appropriate’ and intended use of objects, and environments leading to corresponding difficulties in acquiring the social conventions relating to everyday object and environmental use. For example, playing football, cooking, and reading are all things people do that create a shared dialogue, meaning, and understanding in which to exchange and connect with others. But how inclusive are these action opportunities for an autistic boy called Sam, who avoids social interaction and perceives these things very differently. He sees a football as an object to bite and a book as an object to flick and tear. If Sam has little understanding of the shared values, norms and accepted behaviours of society, then he will have difficulty learning the socially constructed preferred affordances of the environment and therefore construct his own unique meaning and relationship with the things in the world around him. Like Sam, 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.

Research by Loveland (1991, 2001) explores autism in relation to affordances of the human environment, and explains:

...autism is not a static condition existing within a person, but a *developmental process* that can only be understood as taking place through the interaction of person and environment. Thus, autism is located not “within the head” of the person with autism, but in the disordered relationship between person and environment” (2001, p.23).

In the paper; *Social Affordances and Interaction 11; Autism and the Affordances of the Human Environment (Loveland, 1991)*, three ‘layers’ of affordance are outlined which define the human environment (Table 1), Loveland used this as a benchmark to assess how autistic people experience the affordances of the human environment. Layer one refers to physical interactions with the environment; layer two specifically relates to culturally selected affordances and layer three, to social and communicative affordances. Each layer of affordance presents different levels of meaning, which helps a person to navigate and manage the environment and people within it. But if a person fails to perceive the layers of affordance, it can have a negative effect. Loveland concludes that an autistic person’s perception of both the second and third layers of affordances are ‘impaired’, and goes onto describe how this will affect their engagement in the environment and another person’s perception of them - “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” (Loveland, 1991, p.100). Understanding social engagement, through how people perceive and share affordances was later explored by Hellendoorn (2014), which states “people with ASD are attuned to the same information as people without ASD. This leads to the specification of different affordances and may have cascading effects for the interaction with other people” (2014, p.3).



<b>3x Layers of Affordance</b>	<b>Value</b>	<b>Meaning</b>
1. Affordance for physical transactions with the environment (e.g. grasping, walking, eating).	The perception of affordances such as these allows us to manage getting around in the immediate environment, to determine which things may be picked up, manipulated, squashed, and so on.	Failure to recognize the first layer of affordance would lead to a catastrophic inability to get around in the environment, to explore, to survive. Virtually no recognizable behaviour would take place.
2. Specific, culturally selected affordances that reflect preferred but not necessary interactions (e.g. socks afford wearing on one's feet).	They reflect participation with other people in a shared cultural milieu that predisposes the individual to use objects, interpret events, and so on, in particular ways.	(a) A person who has an extremely limited or inflexible set of preferred affordances will seem rigid, ignorant or culture bound.  (b) A person who lacks awareness of the preferred selected by a the culture he or she happens to be in will alien, or at best, incongruoud an unacculturated.  (c) A person who perceives an idiosyncratic set of preferred affordances (not shared by others) will look bizarre inhuman.
3. Social and communicative affordances that reflect the meaning of human activity for other humans (e.g. human conversation, writing, facial expressions, gesture, bodily postures and movement).	Social and communicative affordances embrace not only the significance of events, objects, and so on for the perceiver himself or herself, but also the significance of the human environment for other persons or animals.	Failure to grasp the third layer of affordance would lead to an absence of communication and a complete disruption of interpersonal behaviour. Unable to determine the specifically human affordances of social interactions.

Table 1. Three layers of affordance, (Loveland, 1991, p.101)

So if an autistic person's understanding of the world is developed through their interactions with the physical environment rather than interactions with people, what does the environment and things within it afford that people do not? A clue comes in the comforting nature of predictability. The physical elements can offer comfort and support; they act as anchor points that give a sense of grip (Baumers and Heylighen, 2010b) to ground and focus attention away from the persons present. As described in the previous section, people have complete and pleasingly predictable control over objects; the behaviour of a washing machine, for example, is predictable and has very few surprises in store and our interactions with it are consequently straightforward and systematic. People on the other hand are unpredictable and inconsistent; they move, make sounds and change their appearance. As described by Gibson:

The richest and most elaborate affordances of the environment are provided by other animals and, for us, other people... They move from place to place, changing the postures of their bodies, ingesting and emitting certain

substances, and doing all of these spontaneously, initiating their own movements (Gibson, 1979. p135).

But the environment too can be unpredictable, furnished with a myriad items that generate an assortment of sensations, so for people who find it difficult to filter, adjust and process stimuli around them, such environments can trigger anxiety as well as enjoyment. An example of this is illustrated by a support worker who was supporting an autistic man unwilling to walk over shadows and puddles; this man interpreted the shadows as black holes to fall down (Figure 14) and the sky and tree tops reflected into the puddle as if they were really there (Figure 15). Shadows and puddles are examples of unpredictable elements in the natural environment that change, and the autistic man's response to them revealed a more direct and conscious way of experiencing the world; this approach aligns with Gibson's concept of direct perception. Research supporting this was conducted by Baumers and Heylighen (2010a, 2010b) through analysing autobiographies by autistic people, they discovered that "interpretation of the world is mostly based on immediate perceptions of the physical space" (2010a, p.7).

If an autistic person's understanding of the world is developed primarily through their interactions with the physical environment rather than people, whose behaviours are often triggered by the physical environment, this research suggests that the material infrastructure of the world and what it affords is critical to an autistic person's understanding of themselves, other people and the world around them. It is also vital for how others understand them.

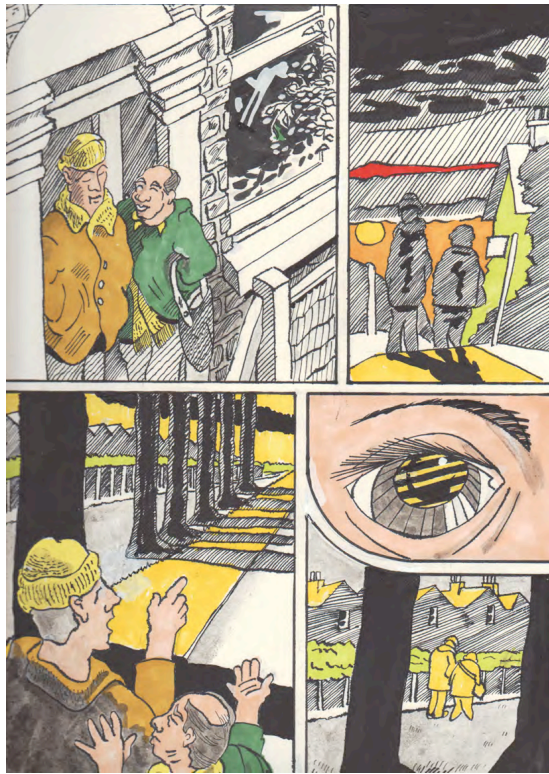


Figure 14. Storyboard: shadows (2004)



Figure 15. Storyboard: puddles (2004)

### 3.3.4 Comparison between Gibson and Norman

This PhD sides with Gibson's concept of affordance as best supporting different ways of understanding an autistic person's relationship with their environment. The reasons in support of Gibson are outlined below.

*Bottom-up approach:* Norman's cognitive approach to affordances is limited by the nature of autism. If a person with autism may not accrue an archive of prior knowledge (Pellicano and Burr, 2012), this may influence how they perceive affordances; that is, they might not be able to just look at something and know what it is and how it is meant to be used. In contrast to Norman, Gibson proposed a direct theory of perception in which a person perceives the environment without any cognitive processing.

*Human-centred:* Before Gibson, the designer and educator Victor Papanek (1923-1998) wrote the book *Design For The Real World: Human Ecology and Social Change* (1971), which remains influential in the world of design today. Although this book does

not reference Gibson's ecological approach, the title itself and Papanek's strong advocacy for human-centred design, and social and ecological responsibility in design, resonates with Gibson's concept of affordance, which best supports a framework for people-centred design. Krippendorff supports this line of thinking: "Although the term human-centeredness did not exist at Gibson's time, his theory of perception is a human-centred one" (2005, p.211). Gibson's definition emphasises that an affordance has to fit in with the 'capabilities of the animal' and places importance on bringing the best out of a person's ability to do something. It is the relationship between the environment and a person's capabilities and not the infrastructure of the environment alone that creates action opportunities.

*Flexible design:* Norman specifies that action opportunities are implicit within the object that guides and directs a person's actions towards the intended use of the object. In other words, the usability of a product is predetermined and based on how something should be used rather than how someone chooses to use it. In contrast to this, Gibson's approach encourages flexible design, which invites action opportunities that relate to a person's subjective way of experiencing the world. It discourages specific/intended action possibilities. It foresees making the environment compatible with all human actions rather than trying to direct and control human actions from a neurotypical perspective. Supporting this, Burlamaqui and Dong (2014) promote the idea of "Weak framing", which asserts "more flexible uses, where affordances are perceived in such a way that the operation/or the purpose of the artefact are intentionally open to the agent's interpretation, which can be viewed as a process of empowerment of the end- user" (Burlamaqui and Dong, 2014, p. 19).

### **3.3.5 Summary of key points**

This section identifies Gibson's concept of affordance as central to the study of autistic people and their environment. Identified below are some gaps in research, which this research aims to explore and address.

Whilst direct perception and the reciprocal relationship between the person and their environment are at the heart of Gibson's concept of affordances, he gives very few

concrete examples of this and how it can be applied to areas outside of psychology. Consequently Gibson's theory remains abstract and does not get to the level of detail that would help a designer. By investigating how autistic adults experience their home environment, this research aims to create a context and provide concrete examples that would illuminate Gibson's theory of affordance relating to design and the physical environment.

In Gibson's early work he explains, "The eyes, ears, nose mouth and skin can orient, explore and investigate. When thus active are neither passive senses nor channels of sensory quality, but ways of paying attention to whatever is constant in the changing stimulation" (Gibson, 1966, p.4). Yet his research has almost exclusively focused on visual perception as evidenced in his opening line, "How do we see the environment around us? How do we see its surface, their layout, and their colours and textures? How do we see where we are in the environment?" (Gibson, 1979, p.142). Whilst this research supports Gibson's bottom-up approach to perception, it aims to broaden his concept by exploring how people perceive and experience their environment through not just sight alone but also other senses.

Norman's concept of affordance has derived from the field of human computer interaction (HCI) which, in contrast to the physical environment, deals with isolated objects (rather than a whole scene) with a limited set of action opportunities such as tapping, pressing, clicking and swiping. This trend in research focuses on the capabilities of products and environments rather than people, where the products are for a generic market, which furnish the environment with affordances that exclude many. Norman himself (1999) explained the problem with how the definition of affordance has been changed and adapted within the design community, "To my great surprise, the concept of affordance was adopted by the design community, especially graphical and industrial design. Alas, yes, the concept has caught on, but not always with complete understanding." Norman goes on to explain how designers have become preoccupied with the actions the user perceives to be possible rather than what is true.

Norman's definition might be useful to computer interface designers, but one could argue it is not necessarily transferable to design practices situated within the physical environment and dealing with different contexts, variables and uncontrollable properties. The literature on the relevance of affordance in this area remains sparse; this research therefore aims to situate affordance into the physical environment, moving beyond usability, to investigate how a person directly perceives and experiences their home environment.

Whilst the negative associations attributed to an autistic person's relationship with the unintended affordances of the environment are a concern, there is consolation in Loveland's statement; "Part of what we call creativity seems to involve the ability to transcend the preferred set of affordances when considering the affordances of objects and events" (1991, p.101). Supporting this, Aurisicchio et al., (2011) investigated the function of the Alessi Juicy Salif Lemon Squeezer. They mapped the unintended affordance of the lemon squeezer, naming them 'Emergent Functions' (for example using the lemon squeezer as a paperweight) and conclude that, "Examining emergent functions teaches designers about human behaviours and provides novel signals for future innovative design direction" (p. 447). Autistic people have always existed in a neurotypical world. But an autistic mind works in ways that a neurotypical mind never could. Experiencing how autistic people afford their environment can open up an otherwise impenetrable avenue of thought and conceptual direction for not only autism related design, but design as a whole.

Whilst Gibson describes an affordance as being dependent on a person's capabilities, there is very little design research on affordances that goes into detail about how to assess another person's capabilities and to understand the affordance that another person experiences, particularly if another person's capabilities are different from one's own. Research by Zaff (1995) comments on this and describes how people are good at judging their own affordances, which they take for granted, but fail to recognise the difficulties with judging another person's affordances. This PhD aims to fill this gap in research by developing design tools for understanding the action capabilities of autistic adults within their home environment – capabilities that might be very different to that of the designer.

The previous two sections have looked at autism as a condition and explored the reciprocal relationship between a person and the environment that affords different action opportunities based on a person's capabilities. The next section will investigate existing design research in autism to examine what design approaches were used for generating insights for involving autistic people into the design process, to establish where the gaps and opportunities lie.

## 3.4 Design for Autism

This section identifies the most significant design research in the field of autism, primarily looking at design within the context of the physical environment and a secondary consideration is technology, as this is where a lot of participatory design has been developed and examples of design approaches that can be brought across into this research. Important gaps, challenges and opportunities are identified and analysed, creating a platform upon which this PhD aims to build.

### 3.4.1 Design for autism: Environment

The earliest design study relating to autism involved the design of a playroom for autistic children and guidelines for staff to illustrate how it could be used (Richer and Nicoll, 1971). Following on from this, in Holland in the early 1980's came the Snoezelen (Hulsegge and Verheul, 1987), also known as the multi-sensory environment, which is an environment designed to stimulate the primary senses for leisure and relaxation. The Snoezelen was one of the first 'environmental interventions' that considered the person in relation to their physical surroundings; this model has since expanded internationally, and can be found in schools and care homes.

Since the Snoezelen, the physical environment has continued to be an important point of intervention and the phrase 'autism friendly environment' has become a buzzword within the autism community that fetches 2,290,000 results on Google (March 2015). Through online blogs, forums and social networks, autistic people and family members are sharing tips and ideas on how to make the domestic environment more autism friendly. Autism friendly environments have also extended into the wider community,

several UK cinemas (Odeon, Cineworld) and theatres (such as The Lyceum) host autism friendly screenings and productions; this involves the lowering of lights and sound, freedom to move about and visitors can bring along their own food and drink. The airline JetBlue also offers autistic children a programme called Blue Horizons, which takes them through the process of taking a plane flight in preparation for a real flight, and the Royal Caribbean is the world's first autism friendly cruise line. For more everyday experiences, autistic charities such as The National Autistic Society provide support and advice for people on what to expect when visiting different environments, such as a dentist's surgery, hairdressers and the workplace.

With the increased awareness of the physical environment and its profound impact on an autistic person's everyday life, there are a growing number of designers working in this area within different environmental contexts, such as schools (Beaver, 2003, 2011; McAllistera and Maguire, 2012; Mostafa, 2008; Tufvesson and Tufvesson, 2009; Vogel, 2008; Khare and Mullick, 2008, 2009; Scott, 2009), multi-sensory environments (Gumtau et al., 2005) housing (Ahrentzen and Steele, 2009; Brand, 2010; Lopez and Gaines, 2012; Woodcock et al., 2013) and outdoor spaces (Linehan, 2008; Herbet, 2003; Hussein, 2010; Menear et al., 2006; Sachs and Vincenta, 2011; Yuill et al., 2007). Inspired by her autistic brother Marc, Decker's, urban design project (2014) used a theoretical urban systems toolkit to evaluate how inclusive the city of Nashville, Tennessee, was for autistic people. The evaluation looked at services such as health, education and work, and the findings informed the design of a visual proposal that described how to make the city more inclusive for autistic adults.

Several of the design projects mentioned above took a top-down approach, starting with a pre-determined goal of how to fix or make the environment more functional for autistic people. Whilst some researchers do assert that their design guidelines are not prescriptive and do not apply to everyone (Ahrentzen and Steele, 2009; Brand, 2010), the majority of the projects are framed around the generalised classification of autism, that focuses on a person's deficits such as poor social interaction and communication (Francis et al., 2009; Khare and Mullick, 2010), thereby producing generic guidelines that are derived from and restricted to functional need such as safety, robustness,



accessibility and durability (Humphreys, 2005; Vogel, 2008; Beaver, 2003, 2011; Ahrentzen and Steele, 2009; Khare and Mullick, 2008; Scott, 2009). There is little consideration for a person’s strengths, interests and aspirations (Humphreys, 2005; Beaver, 2003, 2011; Ahrentzen and Steele, 2009). A less generic and more person-centred architectural design guideline was developed by Mostafa (2008); the researcher recognised the unique sensory processing style of autistic children and created a sensory matrix (Table 2) for customizable educational spaces for both individual or group settings. The sensory matrix organises and matches the sensory characteristics of the built environment with an autistic person’s sensory profile. Equally the doctoral thesis; *Sensory experiences of individuals with autism spectrum disorder and autistic traits: a mixed methods approach* (Robertson, 2013) developed and piloted a sensory audit to help make environments safer for people with autism. Robertson concludes that, “consideration should be given to modifying the environment to counter at least the most severe sensory causes, for example strong smelling environments, high-pitched loud noises and flicker in lighting” (p. 97).

		Sensory Issues															
		Auditory			Visual			Tactile			Olfactory			Proprioceptive			
		a	b	c	a	b	c	a	b	c	a	b	c	a	b	c	
ARCHITECTURAL ATTRIBUTE	Structure	A	1	2		1	2	1	2	1		1	2		2	1	1
		B	3	4	3	3	4								4	3	
		C	5	6	5	5	6	5	6	5					6	5	5
	Balance	D					7									7	7
		E	8			8										8	8
		F	9	10		9	10	9							9	10	9
	Quality	G					11									11	11
		H				12	13	13	12							13	13
		I				14	15	14							14		14
	Dynamic	J				17	16			18							
		K	19			19	20										
		L	21	21	21												
	Dynamic	M		22					22	23							
		N										24	25	24			
		O				26	26	26		26						26	26
P					27		27								27	27	
Q		28			28		28								28	28	

Sensory Issues  
a. Hyper    b. Hypo    c. Interference

Architectural Attributes

A. Closure	J. Color
B. Proportion	K. Lighting
C. Scale	L. Acoustics
D. Orientation	M. Texture
E. Focus	N. Ventilation
F. Symmetry	O. Sequence
G. Rhythm	P. Proximity
H. Harmony	Q. Routine
I. Balance	

Table 2. Sensory Design Matrix (Mostafa, 2008, p. 208)

For the majority of the projects the designer took on a consultancy role and little is known about whether autistic people were involved in the design process. Despite the title ‘Towards co-design with users who have autism spectrum disorder’ (Francis, Balbo, and Firth, 2009), the research predominantly excluded autistic people from participating and instead psychologists were chosen and considered the experts. The research also discounted parents and carers because it was thought that their intimate knowledge of one individual might limit their ability to generalise. However, in their conclusions the researchers assert, “The preferred solution would be to empower parents and carers to work with the user (of whom they have the requisite intimate knowledge)” (p.134). When the architect Christopher Beaver (2003, 2011) designed a residential accommodation for autistic children, insights about the children were derived from listening to staff but it is unknown how or if the children were involved. Equally Ahrentzen and Steele (2009) developed guidelines to direct the design and development of different types of accommodation. Whilst the research does mention that some of the design goals were tested with autistic people, it is unclear as to how and to what extent the autistic people participated in the design process.

Research that did practice a more person-centred approach include Mostafa (2008), whose project involved two design phases: in the first phase, questionnaires were provided for caregivers and teachers to fill out about the school children’s sensory profile and response to the environment; it was only during the intervention phase that the autistic children were involved. Brand (2010) developed design principles for housing, which used people-centred design methods to involve autistic adults, family members and support staff in the design process. Unlike Mostafa’s research, autistic adults were invited by Brand to participate throughout the entire design process.

Most notably, design research by Van Rijn and Stappers, 2007, 2008a, 2008b; Van Rijn et al., 2009, 2011b; Van Rijn et al., 2011a; Van Rijn, 2012, successfully involved autistic children with limited speech, which simultaneously explored and reflected upon the designer’s journey and approach. The LINKX (Van Rijn and Stappers, 2007) involved the design and development of a language-learning toy for autistic children, which led to the development of eight guidelines on how to design for children with

autism. These guidelines were: 1) Give them a feeling of being in control; 2) Provide a structured situation; 3) Let them create structure themselves; 4) Make use of their special interest; 5) Facilitate their excellent memory; 6) Reward them with sensory experience; 7) Facilitate their eye for detail and 8) Let them use their whole body (pp. 3-7). The project also highlighted the key role that parents and pedagogues play in communicating insights about the autistic children’s lived experiences, but also warned about the need to balance their expectations. Later ‘Meaningful Encounters’ (Van Rijn, 2012) focused on what designers can learn from autistic children and their caregivers through direct contact. To help designers engage and develop creative understanding with autistic children and their caregivers, a framework was developed which consists of the activities: familiarize, observe, reflect, theorise, try-out (Figure 16) and the transition between activities are labelled as: discover, immerse, connect, detach and apply. The framework was explored through five design studies with design students and their encounters with autistic children; importance was placed on the development of empathic understanding and the designer’s ability to subjectively connect but also objectively detach themselves from the autistic child. This can be difficult, as Van Rijn (2012) explains, “designers and children with autism have little in common, and therefore the empathic understanding between them is low” (p.162).

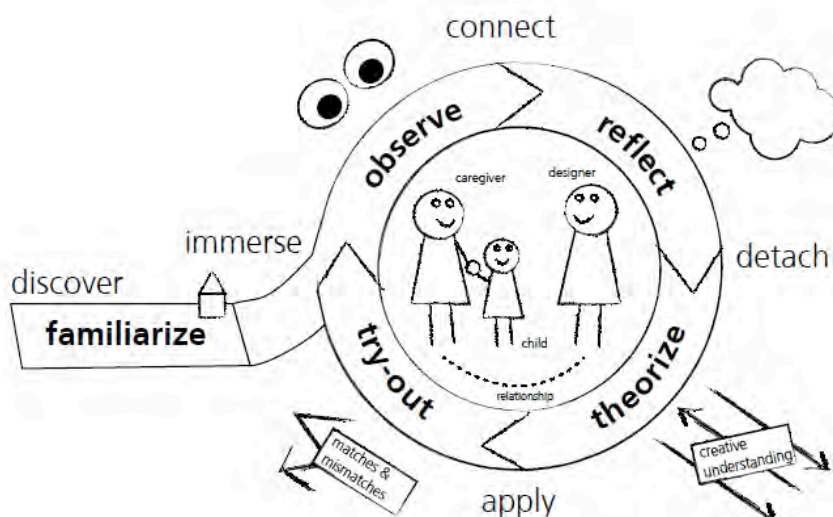


Figure 16. Framework for creative understanding through encounters with autistic children (Van Rijn, 2012, p.147)

The present investigation aligns itself with studies that take a person-environment approach, and whose main starting point and concern is with the autistic person's subjective perception and lived experience in the environment (Baumers and Heylighen, 2010a, 2010b). With the fitting title 'Beyond the Designer's View', Baumers and Heylighen (2010b) used a selection of autobiographies by autistic people to gain insights into the experience of the environment from the perspective of autistic people. The research contains rich autobiographical accounts of an autistic person's reaction to the predictable and unpredictable characteristics of the environment. The insights reveal the heightened sense of grip and security the environment can provide for an autistic person, and importantly, various strategies autistic people have independently developed to compensate for any challenges experienced with the environment. The researchers supplemented these written accounts with real interactions with autistic people, joining in with the everyday lives of autistic people in their home environment and conducting an audit of a university building in collaboration with an autistic student (Heylighen et al., 2010).

### **3.4.2 Design for autism: Technology**

The recognition of the beneficial impact that technology can have for autistic people has led researchers to consider the role and involvement of autistic people in the design of technology to promote communication and independent living. Research in this area is growing at a fast pace, covering virtual environments (Parsons and Mitchell, 2002; Parsons, Leonard, and Mitchell, 2006; Parsons and Cobb, 2011; Millen et al., 2011, 2012), robotics (Feil-seifer and Matarci, 2009; Goldsmith and LeBlanc, 2004; Welch et al., 2010) and technology-enhanced learning environments (Keay-Bright, 2007, 2009, 2012a, 2012b; Benton et al., 2011; Benton, 2013; Benton and Johnson, 2014; Frauenberger and Keay-Bright, 2010; Frauenberger et al., 2011; Frauenberger et al., 2012a, 2012b, 2013; Frauenberger et al., 2012c).

Technology-related design projects in autism differentiate from those related to the physical environment because in many of these studies priority is placed upon the design process and the involvement of autistic people rather than the design output alone with pre-determined goals. As described by Keay-Bright, (2007 p.28), "Whilst it

is often critical to have statistic analysis to satisfy scientific approaches, it is of equal importance, within this area of research to understand the idiosyncratic behaviour patterns of individuals on a spectrum of autism difference”.

Person-centred research in this design area has demonstrated the increased value this places on the final technological output (Frauenberger et al., 2011; Frauenberger et al., 2012b), plus the benefit this has for the autistic people involved (Benton, 2013, 2014; Benton et al., 2011; Druin, 1999).

Several studies have mapped the different levels of participation with autistic people. Most notably, Druin proposed a co-operative enquiry method (Heron, 1971) for designing ‘with’ rather than ‘on’ children for the development of technologies (Druin, 1999). Through reflection Druin (2002) categorised how the autistic children were involved in the design process and proposed four levels of participation – users, testers, informants or design partners. User involves the researcher observing the autistic child’s interaction with the technology, tester involves the researcher receiving feedback from the autistic child’s interaction with initial prototypes; with informant, the researcher involves the autistic person at different points throughout the design process; and lastly, with design partner the autistic child is involved throughout the entire design process and is considered an equal partner.

Druin’s cooperative enquiry informed the development of Guha et al., (2008) Inclusionary Model, which is composed of three layers: (1) levels of involvement, (2) the nature and severity of the disability and (3), the availability and intensity of the support. Frauenberger et al., (2012b) adapted the ladder of citizen participation by Arnstein (1969), which ranges from non-participation to tokenism and citizen power. Their levels of participation extended from technology designed for children to participation via proxy and, lastly, full participation, The participatory design methods practiced in the IDEAS (Interface design experience for the autism spectrum) project by Benton et al., (2011, 2013) was guided by the structured learning approach of the educational programme TEACCH (Treatment and Education of Autistic and related

Communication handicapped Children), developed by Dr. Eric Schopler and Robert Reichler in the 1960s.

In addition to exploring the autistic children’s level of participation, several studies reflected upon the designer’s journey and experience of working with autistic people, identifying key challenges and opportunities. Most notably Benton (2013) mapped the implications of involving autistic people as identified by other researchers (Table 3). But while it is important to be aware of the challenges, one should also note that the implications cannot be generalized as everyone with autism is different. Some of the implications described in Table 3 can be positive for participatory design, for example ‘focus on details’ can be a great strength for a person, enabling them to identify things which might otherwise get overlooked.

<b>ASD Characteristic</b>	<b>Implications for Participatory Design</b>
Impairments in social skills/mindblindness (Millen et al., 2010b, Frauenberger et al., 2012b)	May cause problems when interacting with other members of the design team. May be very direct and potentially insensitive in their criticism. Also may struggle to consider opinions of others when making design decisions.
Communication difficulties (Francis et al., 2009, Millen et al., 2010b, Frauenberger et al., 2012a)	May have problems participating in discussions, expressing ideas and opinions as well as understanding instructions and alerting adults to any difficulties they are experiencing.
Problems of thought and attachment to routines (Francis et al., 2009, Millen et al., 2010b, Frauenberger et al., 2012b)	May not recognize if other team members are upset, frustrated or bored and be unable to adapt their behaviour accordingly.
Rigidity of thought and attachment to routines (Francis et al., 2009, Millen et al., 2010b, Frauenberger et al., 2011, Frauenberger et al., 2012b)	May have trouble adapting to sessions that disrupt their normal routine and are unfamiliar environments potentially resulting in anxiety and distress.
impairments in motor skills (Francis et al., 2009)	May not be able to undertake certain design activities, such as low-tech prototyping, which require more advanced motor skills.
Motivation issues (Francis et al., 2009, Frauenberger et al., 2012b)	May not be full engaged in sessions that are unrelated to their own special interests.
Cognitive and learning difficulties (Francis et al., 2009, Millen et al., 2010b)	May have difficulty understanding more complex instructions and activities.
Inability to deal with failure (Francis et al., 2009, Frauenberger et al., 2012b)	May assume that there is a ‘correct answer’ to the activities. Concerns about failing to do the right thing may prevent them from sharing ideas and opinions.
Higher levels of anxiety and stress (Francis et al., Frauenberger et al., 2011)	May be easily stressed particularly when working with unfamiliar people within an unpredictable situation.
Lack of Imagination (Millen et al., 2010b)	May struggle with initiating design ideas, particularly when asked to imagine abstract concepts such as system that is not yet built.
Focus on details (Frauenberger et al., 2012b)	May become fixated on the minor details of the design and fail to consider the ‘bigger picture’ and how everything is linked together.

Table 3. Autistic characteristics and their implication for participatory design (Benton, 2013, p.66)

*Interpretation:* The contribution and level of participation between autistic people, family members, support staff, teachers and the designers varied from one project to the next. Some projects acknowledged that it is important to be mindful of the different contributions and interpretations the participants bring to the research. Frauenberger et al., (2012b) for example proposed that one of the key challenges is how to faithfully represent input from the participants, and Keay-Bright's research speaks of 'mindful interpretation' but with little description of what this actually means.

*Empowerment:* Several studies were concerned by what the autistic participants gained through being involved in the design process, for example Benton (2013, p.54) summarized the benefits the children gained from participating in the research, which included increased independence, creative skills and enjoyment. Frauenberger et al., (2011) developed a five-minute film for the autistic children who took part in the research to take home and show their family. The film summarised all the activities the children participated in and participants were also presented with a personalised certificate at the end, helping them to feel empowered and proud of their contributions. However Frauenberger et al., (2011, p.3) asserted that "the balance between empowering children and overburdening them with responsibility is a delicate one to manage". By drawing upon the LINKX project Van Rijn et al., (2008) explored what motivated and gave the users a sense of ownership during the co-design process, in which several things were identified. To help them feel proud of their contributions to the project, the parents and care professionals were given reports during and at the end of the research and were also invited to the final presentations. The research was facilitated in the participants' own environments, which gave them a sense of control and ownership; and to ensure they felt an equal partnership between themselves and the design, the parents and care professionals were considered and referred to as researchers, co-researchers and autism experts.

*Empathy:* Several studies acknowledged the important role of empathy within the design process. Francis, Balbo, and Firth, (2009) expressed that there needs to be an investment of time and empathy on the part of the designer; this, they say, outweighs all other needs. Frauenberger et al (2012c) describe the empathy they gained through being

immersed in the world of the autistic participants and conducting co-design activities; Van Rijn et al., (2009) advocate the use of toys with different sensory qualities to help to bridge direct contact and foster empathy between designers and autistic children with limited speech.

*Low tech:* Several design methods explored the autistic children's tangible interaction with the sensory qualities of the physical environment. This process of discovery helped Keay-Bright (2007) to identify the objects the children enjoyed playing with, such as slinkies, spinning tops, glow balls and kaleidoscopes, which became an important point of inspiration for the ReacTickles software project: "The way in which autistic children interact cannot be presented systematically; therefore gaining understanding through their actions, for example body activities, expression and language, was paramount to the research" (2007, p.8). Van Rijn and Stappers (2008) used a toolkit of expression. Consisting of different materials for the autistic children to interact with during interviews with their parents, this method helped the researchers to identify the different sensory qualities the children gravitated towards. Equally, in the ECHOES project (Frauenberger et al., 2011), sensory exploration was an important method to facilitate meaningful participation: the Desert Island activity involved a treasure chest containing ten objects chosen for their different sensory qualities to explore the children's interactions with the objects.

*What designers can learn:* Several studies discussed how designing *with* autistic people can enrich and expand design practice. As described by Frauenberger et al., (2012c, p.369) "Their life-worlds give rise to an application space for technology that is yet unknown to us, and key to exploring this space is developing methods that allow children to show us its possibilities." Baumers and Heylighen (2010b, p.3) complement this idea: "Considering these fragments of an autistic world of experience in the context of designing space may also inspire designers to burst the banks of their own world of experience."



### **3.4.3 Summary of key points**

This section illustrates that autistic people can be involved in the design process, but there is a lack of participatory design that involves autistic adults with learning disabilities in their natural environment.

This PhD involves autistic adults, yet the majority of design research in autism is concerned with autistic children - only a few projects focus on autistic adults (Madsen et al., 2009; Ahrentzen and Steele, 2009; Beaver, 2006; Brand, 2010; Decker, 2014). As most autistic people will spend the majority of their lifetime as an adult, this lack of design research is of concern. To rely entirely on methods designed for children is highly inappropriate as there are important differences between children and adults (whether autistic or not), which pose different challenges and opportunities that need to be addressed during the design process. The context of working with adults as opposed to children is different, they are at different stages in life and have different aspirations, knowledge, skills and life experience. A person's attitudes and expectations towards children and adults in the community can be different; people are generally a lot more forgiving and empathic towards children. Also, their living situations might be different: most children might live with their parents and go to school, whilst adults might live in supported accommodation, unemployed and have little access to services.

This PhD explores how autistic adults physically experience their home environment, yet the majority of design projects that involve autistic people within the design process are developing new technologies, whereby a person interacts and learns through virtual environments, simulated avatars, robots and digital representations of the world. It is important to be mindful of the differences between the physical and virtual environments and the different challenges they present to both the autistic person and the designer, and how this can influence the design process. For example, a person's interaction and reaction to a predictable programmable virtual world might be different to that of the unpredictable physical world populated by people. Research such as the LINKX project successfully bridges the virtual with the physical by integrating computers into toys, "The toy refers to real objects in their environment instead of symbolic representations in a generic drawing of an environment, and play takes place

in their own environment, involving their bodily actions. These aspects help children to learn in a way that makes sense to them. These aspects should be exploited more in interaction design for these children” (Van Rijn and Stappers, 2007, p.13).

This PhD involves autistic adults with learning disabilities, yet the majority of design research is concerned with autistic people who are ‘high-functioning’ or cognitively able, with only a few projects that focus on and involve autistic people with limited speech and additional learning disabilities (Keay-Bright et al., 2007; Van Rijn et al., 2007, 2008, 2009, 2011; Khare and Mullick, 2010; Brand, 2010; Hourcade et al., 2012; Van Rijn, 2012). The Reac-tickles project (Keay-Bright, 2009) involved autistic children with additional learning disabilities as ‘key-informants’ within the design process, using an inspire-listen-and- develop model. However there is little explanation on this and how it was used.

This section has identified key gaps in research relating to design and autism. In order to meet these gaps and explore in more detail about how autistic adults with learning disabilities experience their home environments and can be involved in the design process, the next section will outline the design approaches best suited to achieve the aims of this PhD.

### 3.5 Design Approaches

This section rounds off the literature review by looking at existing design approaches relevant to exploring how autistic adults experience their home environment. It goes on to develop an overarching framework termed ‘The Triad of Strengths’ by rethinking Wing and Gould (1979) triad of impairments from a strengths-based perspective. It concludes by pulling out the key findings from the whole literature review as a basis for this designer’s approach to working with the Kingwood community.

Sanders (2008) maps design research into five key areas – participatory design, user-centred design, design and emotion, critical design and generative design research – on the vertical axes of design-led and research-led and horizontal axes of an expert and participatory mindset (Figure 17).

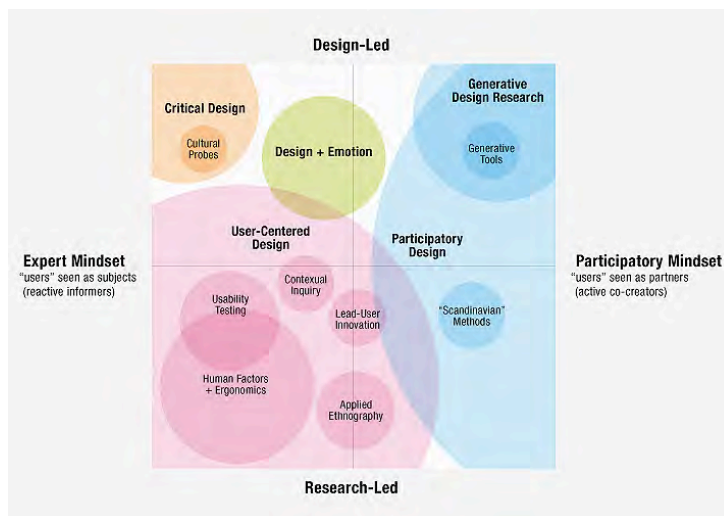


Figure 17. Sanders' map of key design/research areas (2008)

The first three of these are explored as offering insight into this designer's approach. In addition, action research and people-centred design (drawn from the designer's role within the Helen Hamlyn Centre for Design at the RCA) are addressed.

### 3.5.1 User-Centred design approach

User-centred design was founded in sociology, psychology and anthropology as an attempt to understand the person. Norman and Draper (1986) were some of the first designers who considered the user central to the design process. In the introduction of their publication *User Centered System Design: New Perspectives on Human-Computer Interaction*, they suggest: "The computer can be viewed from the experience of the user, a view that changes considerably with the task, the person, the design of the system" (Norman and Draper, 1986, p.1).

In the book *The Psychology of Everyday Things* Norman (1988, p.188) emphasizes that user-centred design is about making products usable and understandable, so that, 1) the user can figure out what to do, and 2) the user can tell what is going on. Priority for user-centred design is to ensure that the person is able to use a product as it is intended to be used, where user-experience is isolated solely to product interaction. User-centred design has become a pervasive methodology in commercial product, service and interaction design (Saffer, 2006), often somewhat conflated with usability. Many methods developed under the UCD banner, such as personas (Cooper, 1999) and mental

model analysis, have become seen as universal methods for design (Martin and Hanington, 2012) and are widely taught.

User-centred design often involves anthropometric data to meet ergonomic needs, and due to the advent of the computer, cognitive ergonomics became a recognised human factor in the 1970s, but the context for most of these projects resides in human computer interaction to enhance a person's performance on cognitive based tasks or designing easy-to-use software interfaces. Arising from essentially a cognitive science and HCI background with its notion of the "end-user", user-centred design takes on a designing 'for' approach and perhaps takes a particular view of people as relatively passive individuals divorced from the design process - there is still an inherent insider/outsider divide (Woolgar, 1990).

Later Norman changed the phrase 'user-centred design' to 'human-centred design', in the revised edition of *The Design of Everyday Things* (2013), which is described as a "process that ensures that the designs match the needs and capabilities of the people for whom that are intended" (p.9). Whilst the needs and capabilities of a person are given more consideration, a person's capability is still largely concerned with the usability of a given product, based upon a pre-determined goal. Methods commonly used involve observation and interviews, where information can be collected and interpreted into specifications and guidelines. As described by Dong and Vanns (2009, p.95) a "deep understanding of the target users" is claimed to be central to user-centred design, but in seeing people as 'targets', the approach still avoids treating people as anything approaching participants in the process. As illustrated in Sanders' (2008) diagram in user-centred design the designer takes the role of the expert and the people involved are referred to as the subject, consumer and user.

User-centred design will be used during this PhD because an important part of the investigation will be to explore how autistic adults afford their environment. As this project involves autistic people with limited speech, observation will be a key design tool and information will also be accessed via the support staff through interviews and informal conversations. This research will deviate from user-centred design in a

traditional sense in several ways. In this project people (not products) are central to the design process therefore instead of user-centred design the term person-centred design is preferred. Rather than investigating a person's interaction with a prescribed set of objects, measured against the intended use of the object, the design approach will be non-directive, led as much as possible by the autistic participant to explore how they choose to afford their environment. Lastly, as the designer's contact with the autistic participants will at times be indirect and mediated by the support staff, a designing 'for' approach will at times be exercised; but in contrast to Sanders (2008) diagram, the designer's mindset will be participatory, whereby the autistic adults and their support staff will be considered the experts and equal partners throughout the design process.

### **3.5.2 Participatory design approach**

Participatory design originated in Scandinavia in the 1970s and 1980s, emerging from the trade union movements which engaged workers into the development of the systems in their own workplace. Since then participatory design is widely used within the field of design, and has been applied in contexts ranging from the redesign of communities (e.g. Condon, 2008) to workplace IT systems (Bødker, Kensing, and Simonsen, 2004). Spinuzzi (2005, p. 163) argues that participatory design is always research, even if not explicitly framed as such, and describes participatory design as "a way to understand knowledge by doing: the traditional, tacit, and often invisible... ways that people perform their everyday activities and how those activities might be shaped productively." Participatory design is also referred to as co-creation, collective-creativity and co-design, Sanders and Stappers, (2008) broaden the concept of co-design in which they describe it as the collective "...creativity of designers and people not trained in design working together in the design development process" (p.6).

In contrast to user-centred design, in participatory design the participants are active agents, who are considered the experts; an equal partnership is exercised between the designer and the participants. The design process takes on a designing 'with' approach and one of the interesting challenges of participatory design is to explore appropriate ways of involving different people in the design process. Participatory design method's

which have been developed include cultural probes (Dunne et al., 1999) and co-creation workshops.

To organise and make sense of existing participatory tools and techniques, Sanders et al., (2010) developed a framework that provides an overview of tools and techniques to help designers engage non-designers within specific contexts (Table 4). The tools and techniques identified are based upon the premise that a person's experiences can be accessed via what people *Make*: making tangible things; *Say*: Talking telling and explaining, and what people *Do*: acting enacting and playing. In addition to tools and techniques Sanders (2002) also advocates that participatory design is a mind-set and explains:

Participatory experience is not simply a method or set of methodologies, it is a mindset and an attitude about people. It is the belief that all people have something to offer to the design process and that they can be both articulate and creative when given appropriate tools with which to express themselves (Sanders, 2002 p.1).

	PURPOSE				APPLICATION			
TOOLS AND TECHNIQUES	PROBE	PRIME	UNDERSTAND	GENERATE	INDIVIDUAL	GROUP	FACE-TO-FACE	ON-LINE
<b>MAKING TANGIBLE THINGS</b>								
<b>2-D collages</b> using visual and verbal triggers on backgrounds with timelines, circles, etc.								
<b>2-D mappings</b> using visual and verbal components on patterned backgrounds								
<b>3-D mock-ups</b> using e.g. foam, clay, Legos or Velcro-modeling								
<b>TALKING, TELLING AND EXPLAINING</b>								
<b>Stories</b> and <b>storyboarding</b> through writing, drawing, blogs, wikis, photos, video, etc.								
<b>Diaries</b> and daily logs through writing, drawing, blogs, photos, video, etc.								
<b>Cards</b> to organize, categorize and prioritize ideas. The cards may contain video snippets, incidents, signs, traces, moments, photos, domains, technologies, templates and what if provocations.								
<b>ACTING, ENACTING AND PLAYING</b>								
<b>Game boards</b> and <b>game pieces and rules</b> for playing								
<b>Props</b> and <b>black boxes</b>								
<b>Participatory envisioning and enactment</b> by setting users in future situations								
<b>Improvisation</b>								

Table 4. Framework for organising the tools and techniques for participatory design, (Sanders et al., 2010, pp. 196-197)

A participatory design approach and mindset will be practiced throughout the three studies within this PhD, as it is the involvement and combination of views and experiences of multiple informants - the autistic adult, designer and support staff, that guides the design process, and working with autistic adults with learning disabilities demands such triangulation. An interesting challenge of this project will be to develop ways in which autistic people can participate without the necessity of spoken language, and how participatory design can be facilitated remotely without the designer's presence. Using Sanders et al., (2010) participatory framework (Table 4), the designer

will use this as a bench mark to make a comparison between this framework, and the tools and techniques used during the three studies. This will help to decipher how and if the participatory framework needs to be refined when facilitating participatory design in the context of autism.

### **3.5.3 Action research approach**

Participatory design overlaps with action research as discussed in the paper ‘Participatory Design and Action Research: Identical Twins or Synergetic Pair?’ (Foth and Axup, 2006). *Action research* as a methodology (Crotty, 1998, p.5) has been widely adopted in practice-based design research, particularly in participatory contexts, and the approach has been used in this PhD by practice. The concept was introduced by Lewin (1946, p.35), originally in a social psychology context:

Research needed for social practice can best be characterised as research for social management or social engineering. It is a type of action-research, a comparative research on the conditions and effects of various forms of social action, and research leading to social action. Research that produces nothing but books will not succeed.

Applied to design, Lewin’s methodology involves design researchers being involved in action themselves, creating or promoting change rather than solely describing or attempting to be a detached observer. The designer takes an active, perhaps even *activist*, stance; she:

attempts to develop results or a solution that is of practical value to the people with whom the research is working, and at the same time developing theoretical knowledge. Through direct intervention in problems, the researcher aims to create practical, often emancipatory, outcomes while also aiming to reinform existing theory in the domain studied (Davison, 1998, p.36).

This is very much the approach the designer has taken in this project, furthering her knowledge of the experience of autistic adults through attempting to develop design



which is of practical value to the people with whom she was working, including both support staff and autistic adults themselves.

Lewin (1946, p.38) described action research as “proceed[ing] in a spiral of steps each of which is composed of a circle of planning, action, and fact-finding about the result of the action.” In this PhD the three design studies fit this kind of *plan—act—observe—reflect* cycle (Robson, 1993, p.438), particular in stage one whereby the designer plays an active role with both the autistic adults and the support staff. This is also similar to Van Rijn’s (2012) framework (Figure 16) used for her work with autistic children with limited speech.

Archer (1995, p.11) makes it clear that the findings of action research in a design context will “only reliably apply to the place, time, persons and circumstances in which that action took place”, so it is important to make clear the circumstances of the action taken, and to explain the reasoning and positions taken so that other researchers can understand what findings might be generalisable and which are very specific to the individual participants and situations involved. This has been done in Chapter 6 of this thesis, when discussing the limitations of the PhD’s findings.

#### **3.5.4 Design, emotion and empathy approach**

Sanders (2002) promotes a design mindset called Postdesign, which as she describes, “transcends the traditional domain of design by making user experience (as opposed to artefacts, interfaces, systems or spaces) the focus for design inspiration and ideation” (Sanders, 2002, p.7). Sanders outlines three levels of experience in which we can learn from people, from the surface of experience about what people say and think towards a deeper level of experience about accessing a person’s feelings and dreams.

Accessing a person’s deeper level of experience relates to the design and emotion section positioned within the design-led axis of Sanders map (Figure 19). To access this deeper level of experience Sanders explains that it is not dependent upon the designer’s ability to know but to also to empathise with the person. The term *empathic horizon* (McDonagh-Philp and Denton, 1999) is used to indicate the limits on a designer’s

individual ability to empathize beyond certain characteristics of his or her group, such as nationality, background, age, gender, culture, experience and education.

Empathic design is an emerging field in design research, where growing numbers of designers are recognizing that empathy plays an important role (Sanders and Dandavate, 1999) Empathy supports designers to go beyond usability and functionality in product use into the realm of pleasure (Jordan, 1997), empathy can unravel supra-functional needs; emotional, spiritual, social, aspirational and cultural aspects (Weightman and McDonagh (2003), and help designers to move to deeper levels of expression, by accessing people's feelings, dreams and imaginations (Sanders and Dandavante, 1999).

Empathic tools and exercises are developed and used by designers to help simulate what it might be like to experience arthritis, sight loss and mobility restrictions, however the majority of these tools are focused on physical abilities and very few look at different cognitive abilities. Several designers have explored ways to develop empathic skills; for example Fulton Suri (2003, p.54) identified three ways to develop empathic interpretation (see below), which ranges from an objective to a subjective process, and explains "given that experience is, by its nature, subjective it is not surprising to discover that a good way to understand the experiential qualities of an interaction is to experience them subjectively" (Fulton Suri, 2003, p.54).

1. Looking at what people really do, either in their current natural context or with prototypes we expose to them.
2. Asking people to participate, either by making records of their behaviour and context, or expressions of their thoughts and feelings.
3. Trying things ourselves to gain personal insights into the kinds of experience others may have.

Kouprie and Sleeswijk Visser (2009) developed a framework for applying empathy in design and identified four phases of empathy; 1) discovery, 2) immersion, 3) connection and 4) detachment (Figure 18), which illustrates how within each stage the relationship between the designer and the person changes.

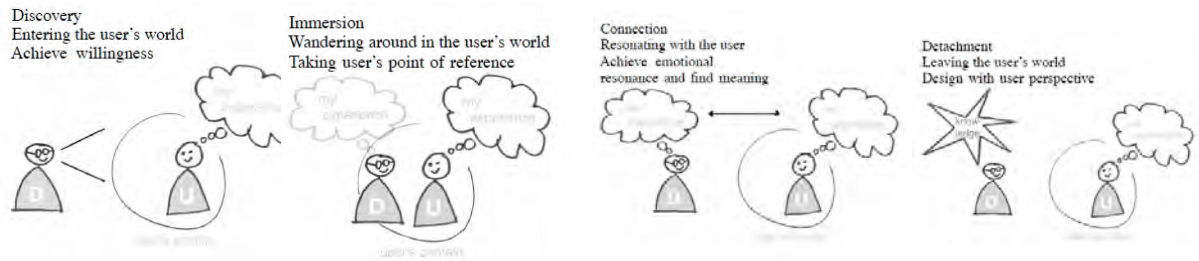


Figure 18. Four phases of empathy (Kouprie and Sleeswijk Visser 2009, p. 445)

This PhD involves a neurotypical designer working with autistic adults. Due to an autistic person's unique sensory and perceptual processing, they may not be adjusted to picking up the same information as a neurotypical person, and consequently experience and attend to the physical properties of the environment in a very different way. To enable the designer to perceive the environment from the perspective of an autistic adult, and create better understanding of what happiness, comfort, and satisfaction might mean, an empathic approach will play a crucial role throughout this project to enable the designer to appreciate different ways of being in the world.

### 3.5.5 People-centred design approach

This PhD is situated within The Helen Hamlyn Centre for Design, at the Royal College of Art (RCA), whose people-centred and inclusive design ethos has influenced the methodological approach for this PhD. Three key events that took place at the RCA are of particular relevance to this PhD.

The first design project relating to autism arose from the Royal College of Art in an exhibition called 'Playthings for the Handicapped Children' (1971), which showcased play equipment for 'handicapped' children. The exhibition was organised by the Industrial Design Research Unit at the Royal College of Art, one of the exhibits was a model of a play therapy room for autistic children, and the research resulted in the article, "The Physical environment of the mentally handicapped, a playroom for autistic children and its companion therapy project" (Nicoll and Richer, 1971).

In the same year as ‘Playthings for the Handicapped Children’, Victor Papanek, a seminal figure in the universal design movement published the first edition of the book, *Design for the Real World: Human Ecology and Social Change* (Papanek, 1971), which asserts the moral responsibility for designers and need for social change. Five years later the Royal College of Art held a symposium entitled ‘Design for Need’ (1976) which featured a keynote presentation by Papanek, entitled ‘Twelve methodologies for Design- Because People Count’.

The ‘Playthings for the Handicapped Children’ and ‘Design for Need’ are two significant events at the Royal College of Art, which set the precedent for an inclusive design approach at the RCA. However the path to people-centred design at the RCA did not formally begin until 1991 with the Design Age Action Research Programme, led by Roger Coleman and funded by the Helen Hamlyn Foundation. Design Age encouraged designers to explore issues around ageing and to support the dignity and independence of older people by demystifying the notion of an ‘average’ person. As Cassim et al., (2007, p.11) put it, “Great social and economic benefits ensued for the majority of people, but those who did not conform in terms of height, weight, cognitive or sensory capacity or physical strength became vulnerable to design exclusion”.

In 1994 Coleman delivered a paper at the 12th Triennial Congress of the International Ergonomics Association in Toronto, which set out the case for Inclusive Design as the most appropriate response to population ageing and, in effect, defined the term. Coleman then went on to co-found the Helen Hamlyn Centre for Design with Jeremy Myerson in 1999, with the objectives to improve the lives of all ages and abilities through people-centred design research. While the needs of older people and autistic people are not the same, design approaches and tools developed in the HHCD have informed the development of this PhD. However it is important to point out that inclusive design has largely focused on physical needs rather than cognitive ones.

### **3.5.6 Triad of strengths**

Having looked at different design approaches, we come back to the way autism research is dominated by the medical model of disability. This looks at what a person cannot do

rather than what they can do, it is concerned with the severity of the impairment, and looks for ways in which it can be cured or treated. This PhD supports the social model perspective (Oliver, 1981,1990), which was created by disabled people themselves between the 1960s and 1970s. The social model is not concerned with individual deficit but believes disability is caused by the way society is organised rather than the person's impairment. It tries to remove physical, organisational and attitudinal barriers that restrict people to give them more choice and control over their life.

As discussed in the preceding sections autism is often described and generalised by a Triad of Impairments (Wing & Gould, 1979) in which difficulties in social communication, social interaction and social imagination is commonly used to describe autistic people. Much existing research in autism and design is framed around the Triad of Impairments whose goal is to improve a person's deficits, for example developing technologies and environments to enhance communication and social interaction (Madsen et al., 2009; Parsons et al., 2006; Benton, 2013; Frauenberger et al., 2011).

In contrast to the Triad of Impairments and in support of the social model of disability, this PhD takes on board a strengths-based approach termed the 'Triad of Strengths', that views autism through a positive and enabling light. The Triad of Strengths is a framework that overarches the three design studies to support a less generalised and more individualised design approach. The approach builds upon Kanner's (1943) observations of the children's interactions with his office environment, and is framed around three diagnostic components of autism presented in the fifth Diagnostic and Statistical Manual (DSM-5); 1) sensory preferences, 2) special interests and 3) action capabilities (Figure 19).

It is proposed that a person's Triad of Strengths can influence their actions and reactions to the environment. To put this idea into context, if we take the example of music being played at the top of a flight of stairs, if a person is interested in the music, this might motivate them to walk up the stairs to the source of the sound. Conversely, if a person is hypersensitive to sound they might choose to walk away from the music altogether. If a person likes the music but has limited mobility, then the affordance of the environment

(the stairs) may not support their action capabilities, preventing them from going up the stairs. The example describes how an environment that complements a person's Triad of Strengths can create positive experiences, but highlights how the environment and what it affords (i.e. the music and stairs) in conjunction with how well it fits with a person's Triad of Strengths, is an important consideration to avoid negative experiences. The three diagnostic components of autism are outlined below and inverted through a positive lens to create the Triad of Strengths, with a description of how a person's sensory preferences, special interests and action capabilities could inform the design process.



Figure 19. The Triad of Strengths framework, by author (2015)

1) The DSM-5 states that autistic people may experience ‘hyper- or hypo-activity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).’ It could be proposed that by exploring and identifying a person’s sensory preferences, the quality of stimuli relating to the sensory elements of the environment can be modulated to suit a person’s preferences and reduce or even eliminate their sensory dislikes, making the environment more relaxing and enjoyable to be in.

2) The DSM-5 states that an autistic person may ‘experience highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).’ It could be proposed that exploring and identifying a person’s interests may help inform the design of personalised environments to greatly increase the likelihood of active engagement. The research also suggests design can potentially harness a person’s interests and connect that interest with opportunities for more meaningful social, emotional and vocational growth.

3) The DSM-5 states that autistic people may experience ‘stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).’ This PhD proposes that affordances are the key mechanism that designers can be used to trigger understanding and action in others. Through exploring a person’s action capabilities to a world predominantly designed for and by neurotypical people, tangible insights and clues can be unravelled, which enables designers to create flexible environments that also relate to the perceptual world and capabilities of autistic people.

### **3.5.7 Summary of literature review**

This chapter creates the foundation that supports the designer’s approach to exploring how autistic adults experience their home environment. The designer’s personal experience of facilitating sensory sessions in multi-sensory environments, Kanner’s seminal article (1943) that describes the children’s preoccupation with the things in his office space, and the growing number of autobiographies by autistic people themselves, which describe their positive and negative response to their surroundings, are concrete examples that suggest the composition of the ‘physical’ environment can be considered a causation not for autism per se, but for how a person with autism experiences the world around them.

To complement this the research also identifies three autistic characteristics sensory sensitivities, special interests and perception which can effect how a person perceives

and experiences the environment. This, in combination with the revised DSM-5 (2013), in which sensory sensitivities are now one of the diagnostic criteria for autism, is an important milestone that puts an autistic person's relationship with the physical environment onto the roadmap within autism research. This gives agency to the material world creating a natural avenue for this design project, which takes the view that the material infrastructure of the world and what it affords is critical for an autistic person's understanding of themselves, other people and the world around them, and for another person's understanding of them.

Building upon this, the section on 'affordances and the environment' places the person within the context of the physical environment and uses affordance to bridge understanding between the two. By comparing Gibson and Norman's concept of affordance, this study sides with Gibson, who describes an affordance as relative to the perceiver's capabilities, therefore best supporting a framework that is person-centred and open to different ways of experiencing the world. Gibson's theory of direct perception also resonates with Kanner's observations and autistic people's accounts of how they engage and interact with the sensory qualities of the environment. This is eloquently described by Amanda Baggs, a nonverbal autistic woman: "My language is not about designing words or even visual symbols for people to interpret, it is about being in a constant conversation with every aspect of my environment, reacting physically to all parts of my surroundings."

The first two sections of the literature review created key building blocks for this PhD: 1) explored the condition of autism and its influence on how a person perceives and experiences the physical environment and vice versa; 2) identified an avenue for design by using Gibson's concept of affordance to draw understanding of a person's relationship with the environment. The next important building block was to explore how autistic people can be involved in the design process. Therefore the following section 'Design for Autism' identified the most significant design research in the field of autism, to explore gaps, opportunities and design approaches that can be brought into this research. This section revealed that autistic people can be involved in the design process but demonstrated that there are different types and levels of involvement by



autistic people and their support network. Four important gaps are identified which also resonate with existing autism research: 1) the majority of research is child focused; 2) the majority of research focuses on autistic people who are cognitively able; 3) the majority of research is deficit-based and 4) the majority of projects are focused on the development of new technologies rather than material qualities of the environment.

The final section of the literature review explores the designer's approach and draws upon four design approaches to be used in the three design studies; user-centred design, participatory design, action research, and design, emotion and empathy. When combined, these four design approaches aim to create a holistic account of how autistic people use and experience their home environment. The designer's approach is also grounded in the inclusive and people-centred design ethos of the Helen Hamlyn Centre for Design and building upon previous sections the designer developed a overarching framework termed the Triad of Strengths, where it is proposed that a person's sensory preferences, special interests and action capabilities can create understanding about a person's action's and reaction to the environment and equally inform the design process.

This PhD therefore aims to fill important gaps in design and autism research by focusing on a person's strengths and involving autistic adults with limited speech and additional learning disabilities in the design process, within the context of their home environment. The next section will describe the collaborative partner, the Kingwood Trust, which provided the important platform for the practice element of this PhD and enabled the designer's approach to be carried out.



# Chapter 4: Collaboration with Kingwood

This chapter sets the scene for this PhD by Practice. The autism charity the Kingwood Trust is introduced and the ethical implications associated with the project are discussed.

## **4.1 The Kingwood Trust**

## **4.2 Ethical Considerations**

### 4.1 The Kingwood Trust

The PhD was carried out in collaboration with an autism charity called the Kingwood Trust, who provide support and accommodation for autistic adults. Kingwood was founded in 1994 when Dame Stephanie Shirley brought her autistic son and other men out of institutional care to live in ordinary houses in the community. Kingwood has since grown steadily and now supports 97 autistic adults across the spectrum.

The Kingwood Trust provides different types of accommodation from supported care homes to people living in their own house or flat under supported living arrangements. Although some people pay privately this is quite rare; Kingwood receives the majority of its funding from local authorities for individual support packages. At Kingwood college (a Kingwood residence) because they own the building they also receive rent for the student licenses but for almost all other people they support it is support funding only. Historically funding would be received per house but with personalisation the care managers now assess according to individual needs and funding is per person and should not be dependent on their co-tenants.

Person-centred support is practiced throughout Kingwood. This means that autistic individuals are at the centre of everything Kingwood does, and support is tailored around a person's interests, abilities and aspirations, to enable them to live full and active lives that are meaningful to them. The person-centred support programme at Kingwood Trust echoes the principles of people-centred design practiced at The Helen Hamlyn Centre for Design, which partnered with Kingwood to support this PhD. The partnership is unique as both parties entered new ground; the Kingwood Trust looked beyond medical and scientific research to the field of design to explore an autistic person's engagement with their home environment, and this was the first autism-related project facilitated at The Helen Hamlyn Centre for Design.

Collaborating with the Kingwood Trust provided a unique opportunity for the designer to gain privileged access to the autistic adults the charity supports and their network of support staff. There was also the luxury of time to allow strong relationships to grow and evolve. The fact that the Kingwood Trust recognises that the physical environment can affect an autistic person's everyday experience and that a design approach might enhance this area of investigation, was a huge advantage to the designer. This meant that the designer received encouragement from the management team and network of support staff at Kingwood, who provided suggestions for who might like to participate within the design process and which Kingwood residences to visit. The management team also enabled the designer to gain access to information that was already known about the autistic people Kingwood supports e.g. communication passports (Table 6), and provided advice and preliminary feedback with regards to the research.

## 4.2 Ethical Considerations

The PhD was conducted in compliance with the code of practice for research ethics at the Royal College of Art, and sought guidance from the ethical procedures compiled by The Helen Hamlyn Centre for Design for involving people in the design process, documented in its EPSRC-funded project *i~design* (2011, see [www.designingwithpeople.org](http://www.designingwithpeople.org)). The Centre's key principles and good practice extends the model of the three 'Cs' in user research developed by Higgins (1992) by adding contact and context.

- Contact – how do you recruit people for your project?
- Consent – how do you obtain their consent to participate?
- Confidentiality – how must you treat the information you are given?
- Conduct – how should you behave when engaging with people?
- Context – how should you conduct yourself in specific situations, for example when researching on the web, with children or with vulnerable adults?

In addition to the RCA's code of practice for research ethics, the designer also complied with The Kingwood Trust's code of conduct (see Appendix 4), Kingwood's Credo (2009) (see Appendix 5) and respected the list of rules compiled by the autistic people Kingwood Support (2011) (see Appendix 6). Consent has been granted through the Kingwood Media release forms (see Appendix 7) for all photographs used within this thesis. The real names of the participants have been replaced with pseudonyms to preserve anonymity.

Throughout the PhD the designer worked closely with the management team at Kingwood Trust, to ensure the design process within the three design studies were appropriate and ethical. Before the design tools and activities were facilitated they were firstly discussed and approved by the management team, and on occasions amendments were made to make them more accessible for the autistic people they support, such as making the language and imagery more literal. The designer also sought regular advice from the support staff during the facilitation of the design tools; this was important as it soon became evident that how the tools were facilitated was dependent on the individual. Two members of the expert reference group were also parents of autistic adults, which proved to be really useful when any ethical concerns arose throughout the project.

To ensure the autistic participants' best interests were central to the research, the project exercised a principle of 'beneficence' and the designer used the golden rule 'one should treat others as one would like others to treat oneself' as an important reference point,

that continually prompted the designer to reflect, question and unravel any assumptions that may have emerged during the design process.

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 emphasize that the descriptions in this PhD cannot be generalised. Nevertheless, this project 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.

# Chapter 5: Design Studies

The chapter introduces the three design studies which are at the heart of this PhD, outlining the context, aims, objectives and participant involvement for each. The three design studies are located within three different contexts of the home environment: study one (garden), study two (everyday objects) and study three (interior). The aim of each study was to explore a designer's approach to generating insights about how autistic adults experience their home environment, and investigate how this information combined with a person's Triad of Strengths can be used to inform the design of key aspects of the home environment. There are three design outputs: a new garden (study one), a bubble blowing vacuum cleaner (study two) and a selection and installation of artworks in an interior (study three).

In contrast to most conventional design studies the designer was unable to directly ask questions of the people who would ultimately benefit from the design outputs – the autistic adults. To ensure their needs, abilities and interests were considered, the designer used a mix of tools that invited the autistic adults and their support staff into the design process. Specifically, the three studies examine how to strike a balance between each person's triad of strengths and explore how this can be translated into design concepts. Reflecting upon the designer's journey and the sequential progression of each study is an important part of this PhD. The reflection helped to identify significant limitations and assumptions along the way, creating an accumulated body of knowledge on what worked and what did not work.

## **5.1 Three Design Studies**

## **5.2 Three Participants**

## **5.3 Three Design Stages**

## **5.4 The Design Tools**

## **5.5 Study One**

## **5.6 Study Two**

## **5.7 Study Three**

## 5.1 Three Design Studies

The aim of each study was agreed in collaboration with Kingwood Trust. However the charity gave the designer autonomy over the direction and facilitation of the work to create a holistic picture for how the autistic participants experience their home environment.

The three studies were situated within three types of supported living. They included a shared house, independent flats and a shared transitional home. The studies explored an autistic person's interaction with and reaction to three domestic environmental contexts: study one (the garden), study two (everyday objects) and study three (interior). All three vary in scale, action opportunity and the degree of control of sensory elements; the garden, for example, is the least controllable environment due to the less predictable nature of the outdoors. The design studies had three main objectives; 1) to involve autistic adults in the design process, 2) to investigate how autistic people experience their home environment, and 3) to explore how a person's subjective experience can be translated into the design of space, objects and activities that create more positive experiences (Table 5).

<b>Design Studies</b>	<b>Study One</b>	<b>Study Two</b>	<b>Study Three</b>
<b>Environmental Context</b>	Garden	Everyday Objects	Interior
<b>Kingwood Trust Aims</b>	Design an active garden space.	Adapt and redesign objects to encourage active engagement in everyday tasks.	Select and install artworks for the home interior.
<b>Accommodation</b>	Shared home	Independent flats	Transitional home

Table 5. The table describes the context, aim and type of accommodation in which the three design studies are situated



## 5.2 Three Participants

There are inherent difficulties in working with autistic people, particularly if a person is extremely uncomfortable in the presence of, or interacting with, others. Therefore, a key consideration was the presence or absence of participants in the design process, and their scope for agency. To explore a person's experience with their home environment this PhD combines the experience of multiple informants - the autistic adult (denoted by A), support staff/family members (S) and the designer (D) (Figure 20). Working with autistic participants demands such triangulation as it ensures that multiple perspectives and perceptions are gathered to form some understanding about an autistic person's experience, away from any assumptions and misinterpretations embedded within a neurotypical context.



Figure 20. Three Participants (from left): a designer, autistic adult and support staff member

### 5.2.1 The autistic adults

The majority of the autistic participants within this research have limited speech and additional learning disabilities, and are described as having high support needs (defined as receiving more than 15 hours per week). Depending on the individual, support ranges from a few hours a week, to help with managing finances, to 24 hour cover assisting with personal care and all house-related tasks such as meal preparation, grocery shopping and cleaning. The research invited all the people Kingwood support to participate in the research, but to gain a more in-depth understanding of how autistic people experience their home environment, each study placed priority on working with a small group of people.

Each autistic person at Kingwood has a communication passport, which is a small booklet compiled by family members and support staff that essentially documents all the things a support worker or visitor might need to know about that person, such as their likes, dislikes and communication skills. This was a valuable source of information for the designer, which helped her to be mindful of how to compose herself and communicate with the autistic person she was visiting. But, as the design studies unfolded, it became clear the communication passports were not necessarily a holistic representation of a person. The designer discovered things about a person’s sensory preferences, interests and action capabilities that were not recorded in the passports (Table 6).

<p><b>Things I can do for myself:</b></p> <ul style="list-style-type: none"> <li>• Use the internet (for my favourite sites)</li> <li>• Logging onto the computer using my letter Key rings</li> <li>• Use the T.V, C.D and D.V.D player</li> <li>• Drying/ Dressing after personal care</li> <li>• Brushing my hair and applying deodorant</li> <li>• Refilling my juice jug</li> <li>• Making my bed</li> <li>• Preparing my breakfast</li> </ul> <p><b>Things I can do with supervision or verbal prompts:</b></p> <ul style="list-style-type: none"> <li>• Brushing my teeth – independently first and then with staff support</li> <li>• Some cleaning tasks in my flat hoovering and emptying the bin</li> <li>• Loading / Unloading washing machine</li> <li>• Helping to prepare my dinner</li> <li>• Hanging out washing/bringing it in</li> <li>• Some of my food shopping</li> </ul> <p><b>Things I need someone else to do for me:</b></p> <ul style="list-style-type: none"> <li>• Cut my toe nails / finger nails</li> <li>• Washing my hair and shaving</li> <li>• Administering my medication</li> <li>• Counting money and managing my finances</li> </ul>	<p><b>Things I am good at and like:</b></p> <ul style="list-style-type: none"> <li>• Listening to my favourite CDs</li> <li>• Watching DVDs</li> <li>• Singing and dancing in my bedroom</li> <li>• Using the Computer</li> <li>• Spending time in the activity room</li> <li>• Keeping my flat organised</li> <li>• Shopping for books, DVDs and magazines</li> <li>• Interacting with staff when I'm in a happy mood!</li> </ul> <p><b>Things I dislike/that upset me:</b></p> <ul style="list-style-type: none"> <li>• Too much noise in the building</li> <li>• People talking too much around me</li> <li>• Being rushed</li> <li>• Crying babies</li> <li>• New situations, unfamiliar places</li> <li>• Being asked to do things when I don't feel happy about participating</li> <li>• I get upset when my belongings are moved</li> </ul>
---	--

96 Table 6. Example pages taken from a Kingwood communication passport

### **5.2.2 The support staff**

There are approximately 170 support staff at Kingwood Trust who play an important role in the lives of people with autism, providing assistance with meal preparation, shopping, managing money, leisure activities and personal care. This support helps each autistic individual to develop a greater degree of independence in order to help unlock their potential and live full and active lives. Through their collective observations, support staff and also family members are pivotal in understanding how autistic people perceive and experience everyday life and are best placed to notice what a person enjoys and responds to, as well as what might trigger stress and anxiety. As the majority of the autistic participants in this research have limited speech, the designer sought expertise and guidance from support staff who were essentially the mediators and interpreters between the autistic participants and herself. For example, the designer would not have known to ask a taxi driver to stop on the opposite street to where Nicky lives had her support worker not informed her that Nicky does not like the sound of a car engine running.

### **5.2.3 The designer**

The PhD involves one designer who utilised her background and skills in making, spatial and visual thinking and sensitivity towards colour texture and pattern to help observe a person's experience with their environment. Colleagues from the Helen Hamlyn Centre in particular Andrew Brand and Chris McGinley supported the designer intermittently. For each design study the designer used an existing design process formulated at The Helen Hamlyn Centre for Design, derived from the UK Design Council's 'double diamond' design process model (2005). The model maps the divergent and convergent aspects of the design process in four stages: discover, define, develop and deliver. Discover typically refers to the explore-and-understand stage of design; define to problem focus and definition; develop to the design-and-create stage; and deliver to final specification and production.

An expert reference group (Table 7) was established to advise the designer on the research. This consisted of sixteen design professionals, specialist external advisors and parents of autistic adults. The group was formed partly to minimise the risk of

overlooking significant areas of research relevant to this study and to reduce the possibility of misinterpretation. The designer visited several members of the expert reference group intermittently through out the studies, and a group meeting was held for each study between stages two and three of the design process, and due to geographical divide Skype meetings were also arranged. Each member was asked to review the three studies systematically against the project aims at critical development stages and to provide both verbal and written feedback. In addition to this, to gain further feedback and disseminate the research within both an autism and design context, the designer participated in various symposiums and conferences, and joined the weekly research meetings held at The Centre for Research in Autism and Education (CRAE), at the Institute of Education.

Sue Osborn	Chief Executive	The Kingwood Trust, UK
Andrew Brand	Teaching Fellow	Imperial College london, UK
Kevin Charras	Administrator	ARPEnv (Association for Reseach in Environment Psychology), France
Monica Cornforth	Media Relations Consultant Parent of adult with autism	Independent, UK
Valerie Fletcher	Executive Director	Institute for Human Centered Design, USA
Dr Matthew Goodwin	Assistant Professor	Bouve College of Heath Sciences, USA
Derek Hooper	Equality and Diversity Consultant and Trainer	Derek Hooper Ltd, UK
Colum Lowe	Design Advisor	BEING, UK
Richard Mazuch	Director of Design Research and Innovation	Nightingale Associates, UK
Marc Sansom	Director	International Academy of Design and Health
Richard Seymour	Director and parent of adult with autism	Seymour Powell, UK
Francis Sorrell	Chair	Sorrell Foundation, UK
Dr Teresa Tavassoli	Post Doctoral Fellow	Seaver Autism Center, Mount Sinai School of Medicine, USA
Dr Sandy Toogood	Senior Lecturer in Applied Behaviour Analysis	Bangor University, UK
Ad Verheul	Founder of Snoezelen	De Hartenberg Center, The Netherlands
Dr John Zeisel	President	Hearthstone Alzheimer Care, USA

Table 7. The Expert Reference Group

### 5.3 Four Design Stages

Two participant configurations (A-S-D/S-D) were identified within the four stages of the design process (Table 8). Each design stage lasted approximately three months and the participant configuration within each stage presented different objectives and challenges that influenced the selection and facilitation of the tools used. The designer was involved within stages one, two, three and four of the design process and it is important to note that her presence affected the situation. Consequently the designer’s contact with the autistic participants during stages two and four was minimised, and the support staff (not the designer) facilitated the design tools. The designer’s main responsibility during stages two and four was to collate and analyse the data generated from the design tools

	Design Stage	Design Process	Participants		
			A	S	D
<b>A</b> = Autistic Adults	Stage One	Discover	<b>A</b>	<b>S</b>	<b>D</b>
<b>S</b> = Support Staff/Family	Stage Two	Define	<b>A</b>	<b>S</b>	<b>D</b>
<b>D</b> = Designer	Stage Three	Develop		<b>S</b>	<b>D</b>
	Stage Four	Deliver	<b>A</b>	<b>S</b>	<b>D</b>

Table 8. Three design studies: participant configuration during the design process

*Stage One: Discover – connecting, communicating, and building trust and empathy*

The first stage of the design process involved all three participants (A-S-D): an autistic adult, their support staff and the designer. Forming positive relationships was key, so the design tools within this stage of the study, such as the sensory activities and mirroring interests facilitated non-verbal communication, to develop trust and empathy between each participant involved. The activities were led by the autistic participant and facilitated within their own homes and the designer’s skills in communicating, listening and observing were of particular importance. To explore different ways of

communicating, the designer spoke literally, avoiding metaphors and abstract scenarios so as not to be embedded within a neurotypical context. For this stage the designer participated in a Makaton and a Montessori for autism course and drew upon previous experience of working in multi-sensory environments. This stage helped the designer to move beyond her neurotypical way of experiencing and perceiving the environment towards the perspective of the autistic participants.

### *Stage Two: Define - generating context specific insights*

The second stage of the design process involved all three participants (A-S-D), autistic adults, their support staff and the designer, which built upon the empathic understanding developed in stage one to validate initial observations and interpretations. The design tools used within this stage were context specific, exploring a person's experience with the garden, everyday activities (such as cleaning) and artwork preferences, from which patterns and connections could be made. The designer developed a range of visual mapping tools, some of which were succinct visual redesigns of existing lengthy questionnaires, these tools used literal photographic imagery instead of words and tick-boxes to create a more engaging activity to be used remotely without the designers presence, and facilitated by the support staff to mediate communication and observations between the autistic adults and the designer. The tools encouraged the support staff to foster a design way of thinking, to observe and direct their observation towards the person they support and their experience with their home environment and Triad of Strengths. The designer's participation within this stage involved the collecting and analysis of information generated from the design tools.

### *Stage Three: Develop - generating design ideas*

The third design stage predominantly involved the support staff and the designer (S-D). The design tools in stages one and two generated rich insights about the autistic participants, which informed the structure and content for the co-creation workshops in stage three. In stage one and two, the support staff were essentially the mediators between the autistic adult and the designer, and an important challenge was to encourage the staff to foster a designer's perspective, to understand what insights might be interesting and relevant. This was an important ingredient for stage three, which

involved a series of co-creation workshops that encouraged the support staff and family members to generate their own design ideas for the people they support.

#### *Stage Four: Deliver - evaluation*

The final stage of the design process involved autistic adults, their support staff and the designer (A-S-D). This stage involved the introduction and evaluation of the design output including prototypes. The process of implementing and evaluating the design outputs needed to be met with empathy, caution and sensitivity, as introducing new things and making changes to an autistic person's home and routine might trigger stress and anxiety. Similar to stage two the designer developed a range of visual observational tools and questionnaires to be used remotely without her presence, to help direct the support staff's observations and assess the autistic participant's level of engagement and response to the new prototypes and design outputs.

## 5.4 Design Tools

A person-centred, participatory, action research and empathic design approach was practised throughout this PhD. The methods used are best seen as *design tools*, reflecting the active nature of the work, and this is the terminology that will be used. The diagram below (Figure 21) illustrates the different tools used throughout the three design studies, which are framed around the four stages of the design process—discover, define, develop and deliver - and include the participant configuration for each stage.

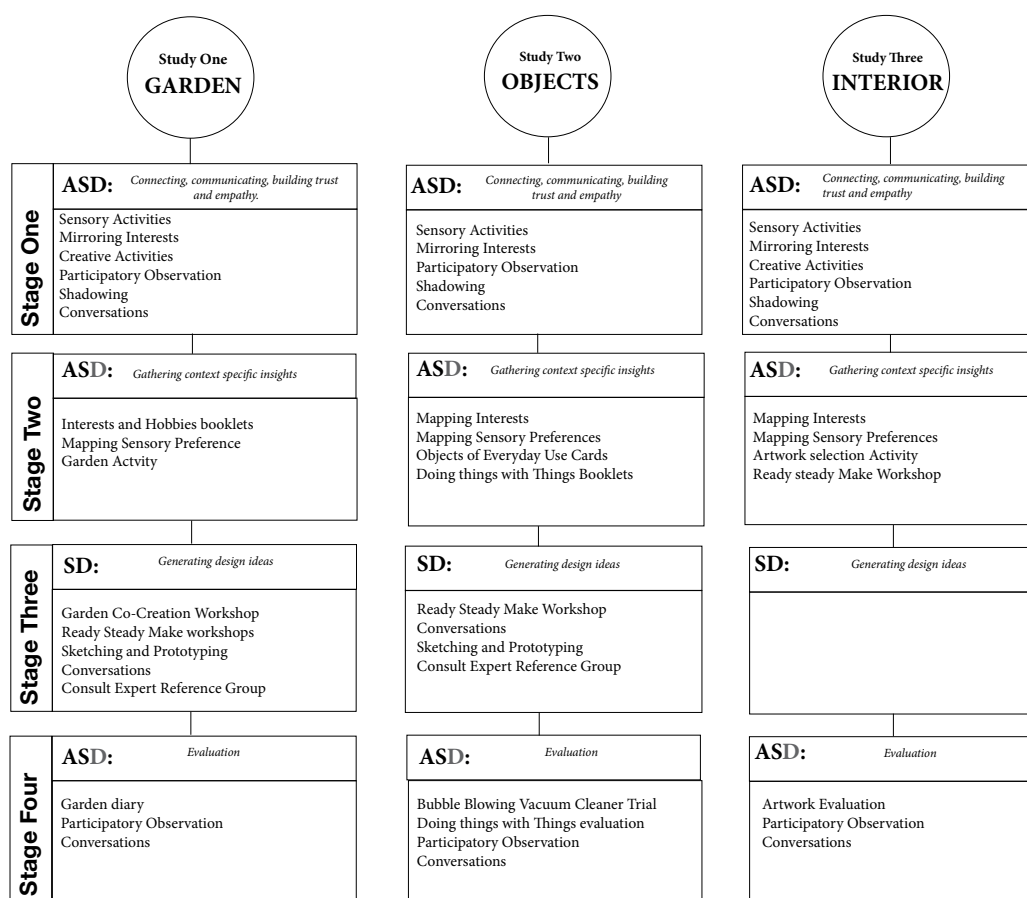


Figure 21. The design tools used for design studies one, two and three

## 5.5 Design Study One: Garden

This study took place at White Barn, which is a house based in Reading that provides support and shared accommodation for four autistic adults (three male and one female) aged 25 to 50 years old. White Barn has a large garden (Figure 22), which rarely gets used and the aim of this study was to redesign the garden at White Barn to encourage the autistic adults to be more actively engaged with the outdoor space.

The study examined how a proposed shared garden space might look and feel, on an individual and group basis, whilst anticipating and managing the inevitable challenges of the unpredictable sensory elements of the outdoors. During the study plans were in



place to extend White Barn and build a transitional residence next door called Kingwood College for five autistic adults leaving school. This was an important design consideration as the garden would be split and shared between the autistic adults living in both residences.



Figure 22. The garden at White Barn prior to redesign

### **6.5.1 Autistic participants**

Four autistic adults and their support staff participated in this study. Below is a description about each autistic participant, which is based on the information derived from his or her communication passport, with additional insights that unfolded during the research.

*Tom* is sociable and often engages in repetitive conversations about his watch and his dad. Tom enjoys horse riding, exercising at stepping-stones, the cinema, walks, going to the shops and visiting his dad. Tom does not like doors to be closed, but likes flicking the Argos catalogue, books on fish and lining objects up in rows. He enjoys talking about his watch (making it ‘disappear’ by covering it with his hand) and switching light switches on and off.

*Pete* enjoys pressing the buttons on his television controls and computer keyboard, looking through magazines, listening to music on his computer, going on walks, trips on trains and buses, rubbing the surface of a wooden door, white noise, maps, pushing door handles up and down, and looking through the edge of doorways. Pete dislikes it when his television is not working, and being amongst crowds.

*Emily* enjoys parties, discos, knitting, painting her nails, local shops, visiting her mum's house, chatting to people (often engaging in repetitive conversations about wanting a coffee or coca cola), Cliff Richard and the colours pink and purple. *Emily* dislikes household chores, too much noise, unfamiliar places and spending too long on one activity.

*Matt* enjoys visiting his mum and dad's house, going to an exercise class, parks and going into the same shops in town. *Matt* also enjoys ice skating, running water, flushing toilets and putting different things down the toilet and watching them disappear, throwing objects out of his window, milkshakes, walking outside, jumping on a trampoline and bubbles.

### **5.5.2 Stage One: Connecting, communicating and building trust and empathy**

*Shadowing*: An important first step in the design study was to meet the autistic adults and support staff at White Barn. For this the designer spent several days shadowing the support staff to build trust, rapport and make herself known to the autistic adults within the comfort of their own home. At this stage there were no goals or expectations set, and to minimize disruption to the autistic adults' daily life, the designer would only interact with the autistic adults if they initiated the contact. To begin with, the designer avoided taking photographs as it was too intrusive and disruptive and therefore recorded her thoughts and observations in a notebook. It was only when the autistic adults felt relaxed and familiar with the designer that she felt comfortable to ask whether she could take photographs. The aim of this method of discretion was for the designer to adapt herself into the environment of the autistic adults as far as possible in order that a totally natural pattern of behaviour could emerge and be observed - especially important given the lack of information that could be gleaned through detailed verbal communication.

From these initial encounters the personalities of the autistic adults unfolded and the designer observed the different things the autistic adults liked to do in their home. *Pete* spent the majority of his time in the activity room leaning against a wall, appearing to enjoy rubbing the wall and feeling the vibrations generated from the music above. *Matt* would greet the designer with a clap of the hands and *Tom* and *Emily* were very sociable. The designer would engage in repetitive conversations with *Tom* about his

watch and Emily enjoyed knitting whilst continuously asking for a cup of coffee (Figure 23).



Figure 23. A photographic collage: spending time with the autistic participants at White Barn

During this stage the designer realized that it was difficult to remain discreet as her presence added a new element to the environment which the participants were all too aware of. In a world where the slightest disruption of routine and regularity can cause anxiety and distress the designer began to question the appropriateness and efficacy of her visits. The designer was reminded of Kanner’s observation that autistic children viewed other people “as if they were objects” (Kanner, 1943, p.218).

Consequently the designer developed a heightened sense of self-awareness and responded to unpredictable situations that emerged along the way. Stepping into an environment afforded through a unique autistic perspective opened the possibility that every action could cause an infinite number of non-neurotypical reactions or consequences. The designer had to quickly adapt herself to an autistic person’s emotional response to different artifacts within the home environment, which the designer could not have anticipated; for example the distress caused by closed doors and flicking a light switch.

Experiences like this illustrated how the environment can trigger a different emotional response for an autistic adult to that of the designer, and with this the designer began to question how she (a neurotypical person) can begin to understand and empathise with an autistic person whose reaction to and interaction with the environment is different, and who may not be able to verbally communicate this. The designer explored this

question by observing the support staff, who everyday carried out empathic acts and were experts at connecting the autistic person's behaviour with the surrounding environment.

*Creative Activity:* A creative activity took place on the dining table at White Barn, which invited the autistic adults and their support staff to make gift cards, pasta decorations and hanging mobiles. Each activity was broken down into manageable steps and the materials chosen were based on the preferences of the autistic adults, already identified by the designer. For example purple and pink stickers were chosen for Emily and crystal effect stickers for Pete and Matt, to complement their enjoyment of sparkling lights (Figure 24, see Appendix 8). Two participants and their support staff joined in who appeared to enjoy exploring the different materials, the activity created an opportunity for the designer to interact with the autistic participants and support staff.

On reflection the designer questions the environment in which the activity was facilitated. The two participants who did not join in spend most of their time away from the dining room, and the designer hypothesized that those participants have a fixed association of the dining room table with eating food. Even though the activity was planned to be person-centred it was not sufficiently disseminated in a person-centric fashion. Would it have been better to create a more flexible mobile activity for an individual or group basis, that can be adapted to how and where each individual is attracted to take part in that activity? Was the rigidity of holding the activity at the table, rather than say the floor or another environment of a person's choosing, the aspect that undermined the activity's success?



Figure 24. Participating in the creative activity

*Sensory Activities:* To explore an autistic person’s action capabilities, the designer facilitated three sensory activities by way of exploring a person’s action capabilities through directly observing their reaction to and interaction with the environment. The activities were structured around the designer’s past experience of facilitating sensory sessions in multi-sensory environments and took inspiration from Maria Montessori’s sensorial approach to learning. The support staff advised on an appropriate space to facilitate the activity and a space was adapted and dressed with props based on the autistic participants’ interests and sensory preferences (Figures 25-26). The support staff had reported that two of the participants like to walk in bare feet, therefore the texture of the floor was an important consideration.

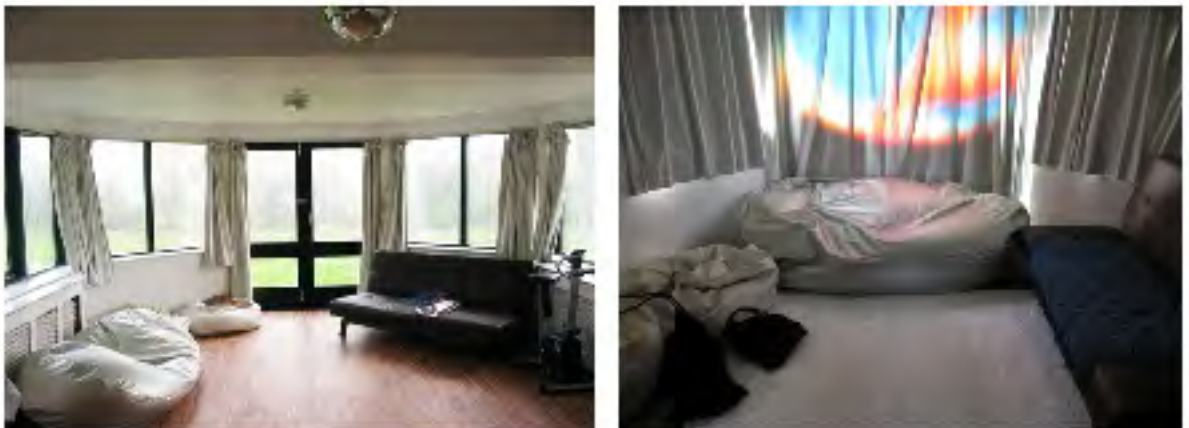
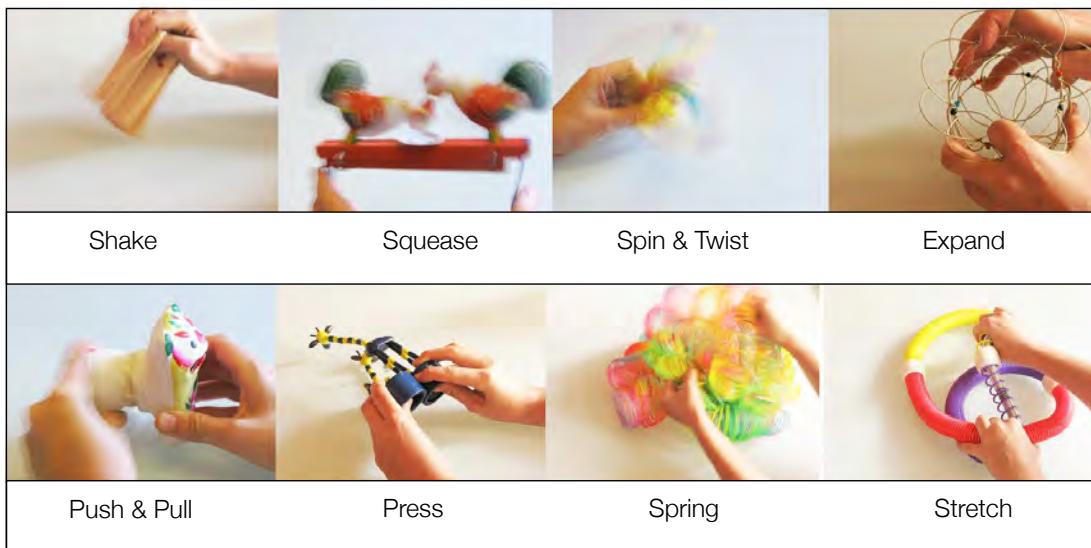


Figure 25. Sensory space (before and after)



Figure 26. Curating the space around a person’s sensory preferences and interests

The designer and support staff were present but the activities were led by the autistic participants who were invited to engage with various props (rather than engaging with people and having to achieve specific tasks) to help them explore and test the boundaries of their sensory preferences in a safe, fun and relaxed manner (Figure 28). The props were chosen for their visceral and sensory properties in terms of touch, sound, sight, smell and movement (Figure 27, see Appendix 9). They were abstract in shape, stripped of social context with no intended affordance. The function and archetype of the props was deliberately undefined, which helped the designer to observe a person's interactions with them without being distracted by subjective prior knowledge about the intended affordance of the prop.



The sensory activities became a group activity lasting between 45 minutes and two hours; each activity was filmed, photographed, sketched and informal conversations were conducted before and after each activity (see Appendix 10 and 11). The activity provided a rich palette of insights about a person’s sensory preferences and action capabilities, and the designer looked for patterns of use and connections between the sensory characteristics of the props that the participant discarded, appeared indifferent to, or gravitated towards. To help this process the designer took note of a person’s actions, contact and sensory engagement with each prop and afterwards created a compilation of the sensory props that each participant engaged with (Figure 29). The compilation of props helped the designer to make comparisons between each participant’s preferences, for example Matt enjoyed the props that made a sound or movement to his motion of tapping and Emily liked the props that changed shape in response to her interaction.

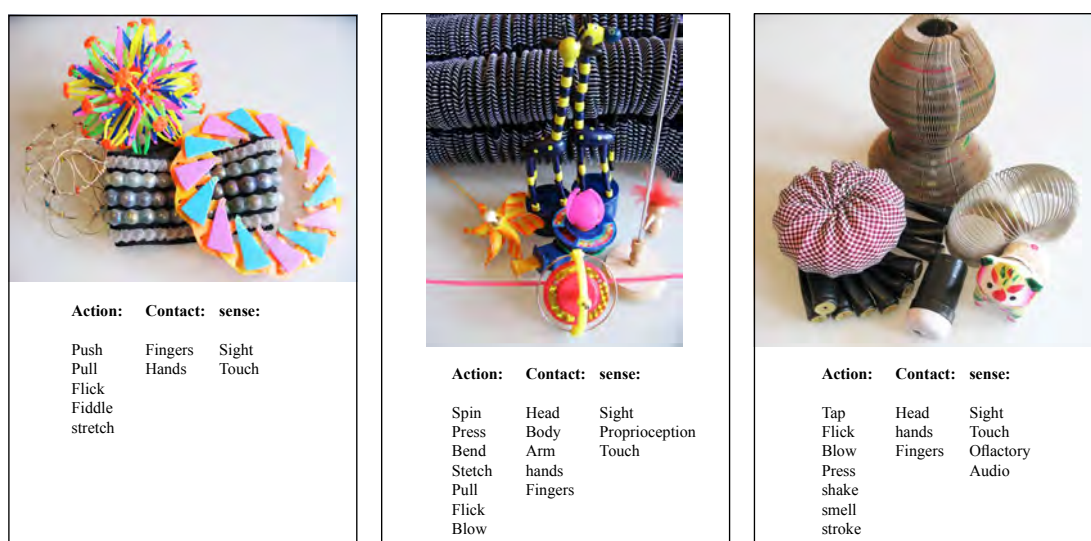


Figure 29. Three participants’ sensory prop preferences

This information from the prop compilations helped the designer to develop more individualised sensory props (see Appendix 12), for example Tom enjoyed the props that offered resistance which encouraged him to stretch and pull, therefore taking his enjoyment for stretching and pulling a sensory prop called fiddle brick was developed

(Figure 30). Equally a sensory prop called Marbelous was developed for Matt who enjoyed tapping and stroking different textures (Figure 31).



Figure 30. Tom’s preference for stretching and pulling, developed into the prop ‘Fiddlebrick’



Figure 31. Matt’s preference for tapping and stroking different textures, developed into the prop ‘Marbelous’

During the sensory activities it was the environment and exchange of props that triggered positive responses, and mediated non-verbal communication and shared experience between the autistic adult, designer and support staff – a noted change in responsiveness experienced by the designer’s initial visits. The deliberate abstract nature of the props meant they had no intended affordances, either neurotypical or otherwise. This was crucial. For the duration of the activity the autistic adults, designer,



and support staff simultaneously experienced a sensorial exploration of the unfamiliar. This brought out as yet unseen behaviours in the autistic adults and allowed the designer to capture some valuable insights about a person's sensory preferences and action capabilities. But it also allowed the support staff to experience the sensorial engagement of the people they support and its connection with their own. For a moment they were not 'supporting', but sharing an experience equally.

The fact that the activity was disconnected from their everyday life allowed insights into possible explanations of wider patterns of behaviour. For example Pete liked objects that created a cause and effect through his action of tapping. Having later been told by the support staff that Pete flushes the toilet repeatedly, the designer was able to hypothesize that this could be due to the cause and effect of pressing the toilet handle and immediately hearing and seeing the flushing water. This hypothesis was informed by the designer's conclusions from Kanner's paper about how consistency of action and effect reactions in objects was desirable for some of the children Kanner observed.

*Mirroring Interests:* It is common for non-autistic people to engage in 'small talk' when meeting another person to build up rapport. But for autistic people with limited verbal abilities the designer mirrored the interests and things the autistic person liked to do as a way to create dialogue and reciprocal interactions. For example the designer mirrored Tom's enjoyment in hiding his watch (Figure 32), flicking Argos catalogues and ripping paper with Sam (see Appendix 13). This activity enabled the designer to break away from how she perceived the environment and instead afford it in the way an autistic person chooses to. Mirroring the interests and interactions of the participants followed the principles and methods used in intensive interaction (Nind and Hewett, 1994; Caldwell, 2006) which is an exercise used by carers to let the autistic person lead and respond to things they do. This reciprocal relationship is also encouraged in Gernsbacher's (2006) paper 'Towards a behavior of reciprocity.' The research supports the notion that when professionals and parents act reciprocally, autistic children become more responsive. Gernsbacher (2006, p.139) defines reciprocity as "a relation of mutual dependence, action, influence or mode of exchange in which transaction take place between individuals who are symmetrically placed."



Figure 32. The designer mirroring the actions and interests of an autistic participant

*Informal Conversations:* There was limited opportunity for the designer to speak with the support staff alone. The long hours and often-stressful nature of their work, combined with a degree of scepticism of an outsider wanting to ask questions, made them reluctant to sacrifice their free time to conduct formal interviews. Therefore conversations were informal, spontaneous and conducted as the staff worked; taking place in a variety of locations such as the kitchen, dining room, activity room and lounge, and recorded on a dictaphone. The informal nature of the conversations did encourage the support staff to speak freely and the open-ended questions were changed and adapted depending on their response. During these conversations the support staff were able to inform the designer of some of the things the autistic adults liked to do in the garden, such as playing football, walking and blowing bubbles.

Speaking with the support staff whilst they were working with the autistic participants in their environment was genuinely beneficial as it triggered anecdotal evidence of behaviours directly relating to that environment. For example observing Pete's enjoyment for pressing the keys on his computer keyboard prompted his support worker to reflect on an occasion when Pete received a new computer keyboard for Christmas, but was not happy with it because it was modern and the keys were a lot more shallow in comparison to his old keyboard. Consequently the support staff looked for an older computer keyboard with thick keys. This is a clear example of how Pete directly perceived and engaged with visceral qualities of pressing the keys on the keyboard, and it did not represent the neuro-typical affordance of typing letters. Therefore the re-

design and apparent progress of the modern shallow keyboard had unintentionally attempted to consign to history Pete's very present enjoyment of the older design.

*Garden Activity:* As the garden at White Barn was rarely used, the designer organised a garden activity to encourage the autistic participants and their support staff to step outside into the garden (Figure 33). The garden was dressed with a selection of props and activities based upon the autistic participants' interests and action capabilities that were revealed from previous activities. Some furniture was carefully positioned near the door of the home for easy access whilst more furniture was positioned a little further out to encourage the participants to venture out into the garden. Food was also an important consideration and selected around what the autistic participants liked to eat and drink. The garden activity lasted two hours and demonstrated that, once the garden was dressed with props and furniture, three out of four of the autistic adults ventured outside and participated in a variety of group and individual activities. On occasion the props even encouraged the autistic participants to take the unusual step of spontaneously interacting with each other. As for the autistic adults who were less adventurous, Emily stayed seated next to the door and a staff member suggested a reason for this might be because she does not like standing on grass. The designer connected with Matt whilst blowing bubbles together and mirroring his action of flapping his hands. Pete enjoyed looking out at everyone from a window inside and staff members were surprised to see him come outside briefly (see Appendix 14). The garden activity enabled the designer to trial the sensory prop 'fiddle brick' with Tom, which he appeared to really enjoy.



Figure 33. A photographic collage of the garden activity

The unusual thing about the activity was that it was not undertaken by groups of autistic people alongside groups of neurotypical people, but became just one group of people. Whether it was the less predictable nature of the outdoors, or the larger unconfined green space as opposed to the limits of the indoor environment, the autistic adults seemed to relax and experience the activity in the present, rather than via the language of their usual environment and its well-established associated behaviours. This could also be said for the support staff, as their daily schedule had been disrupted. The garden – unfamiliar to us all - led to the divide between the autistic and neurotypical experience being significantly narrowed.

### 5.5.3 Stage Two: Gathering context specific insights

The garden is a space that makes us keenly aware of our senses. The simple experience of being in a garden teaches us about our sensory preferences – whether we love the smell of lavender or dislike the taste of mint, enjoy sitting in the sun or prefer pushing around a wheelbarrow. In appreciating and experiencing a garden fully, sight, smell, hearing, taste and touch are all engaged. The important distinction between designing for indoors and outside is that inside the home we have control over much of the sensory quality of our environment. We can turn down a loud TV set or pull down a

blind if the sun gets too bright. Outdoor spaces, however, feature many sensory experiences over which we have little control. The weather, wildlife and the changing of the seasons are difficult to adjust. An important starting point for the design process was to enable individual sensory preferences to be incorporated into the planning, layout and general flow of a garden space.

*Mapping Sensory Preferences:* To help identify and map a person's sensory preferences, two widely used questionnaires were examined: Adult/Adolescent sensory profile ® (Brown and Dunn, 2002) (see Appendix 15) and sensory profile checklist (Bogdashina, 2003) (see Appendix 16). The questionnaires have been used in research concerning sensory processing and autism (Rogers et al., 2003; Kern et al., 2006, 2008; Liss, 2006) and were largely developed for psychologists and/or therapists.

To investigate the usefulness of the questionnaires, three autistic adults and their support staff were invited to complete the questionnaires and comment on them in terms of format, accessibility and clarity (see Appendix 17). Although the questionnaires generated interesting insights about each participant, three shortcomings were identified: 1) The tick-box format provoked rushed responses and raised doubts about whether sufficient consideration was being given to answering questions. 2) The support staff thought it was unclear why they were being asked certain questions. 3) Due to the wordy tick-box format, the staff were concerned that the people they support were excluded from contributing to the process of expressing their own preferences and made the suggestion to “add pictures and things like that if the point was to get the individual more involved with their own actual opinions.”

The designer's *What do I Like? Sensory Preference Cards* are a physical and visual extension of the existing sensory profile questionnaires and a key design tool for the studies. The 72 cards are set within the context of the home, each card shows a different type of sensory experience, which is described in simple words and illustrated by photographed images (see Appendix 18). The cards act as visual prompts inviting the participant to express whether he or she likes, dislikes or is neutral about the subject of each card. The activity aims to involve autistic people in the sensory profiling as active participants rather than relying on family members or support workers to express

preferences on their behalf. For family members, service providers or design professionals who may be facilitating the asking of the preference cards, tips and guidance on how to ascertain, interpret or respond to an autistic person's sensory preferences are shown on the reverse side of each card. In some cases, the participant may not know or have revealed his or her preference to a particular experience. When this happens, the facilitator is charged with helping the participant to create the sensory experience and discover together whether he or she likes, dislikes, or is neutral about that form of stimuli (Figure 34).



Figure 34. *Sensory Preference Cards*

The reverse sides of the cards are colour-coded by the sensory systems – touch, sight, smell, auditory, vestibulation and proprioception – providing a quick-reference visual indication of the participant's preferred sensory system(s) (Figure 35). This feature negates the need for further processing of the sensory data and presents an individual's sensory profile in a way that is ready to use by autistic adults, family members, service providers and designers.



## Bright natural light

People who are drawn to bright natural light may benefit from using sunlight lamps, especially in winter months. People who avoid bright natural light may be over-sensitive to visual stimulation. Small changes to the home environment, such as the addition of dimmable lights, black-out curtains, shutters or self-adhesive window film, can make a difference to their comfort. Wearing sunglasses may also help.



## Wind and rain noise

People who like the sound of natural elements may enjoy the amplification of rain falling on a metal surface.



## Getting messy

People who dislike getting messy or having things on their hands or feet may be over-sensitive to tactile stimulation.

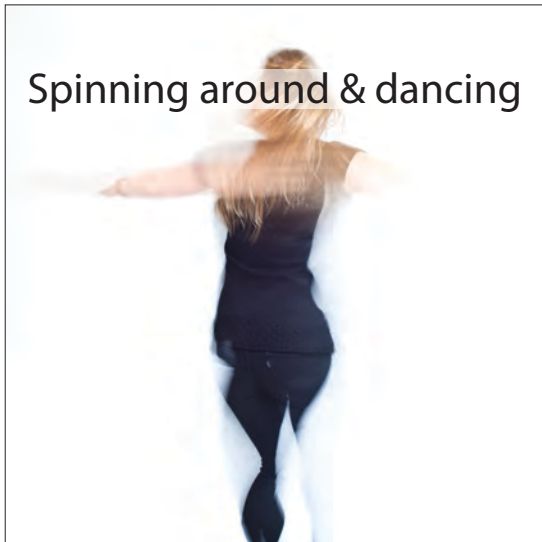
Gradual introduction of different material surfaces may help these people to gain confidence in anticipating the sensations they will get from touching different objects.





## Floral smells

People for whom the scent of flowers is too intense and overpowering can still enjoy the pleasures of a garden when it is planted with unscented flowers and shrubbery.



## Spinning around & dancing

People who like the sensation of spinning themselves around or dancing may enjoy activities that further develop their vestibular (balance) system such as trampolining, bouncing on Swiss balls or swinging.

Covered outdoor spaces and indoor spaces with high ceilings give people areas in which they carry-out vestibular activities; helping them to incorporate these movements in their daily routine.



## The colour orange

## Colours

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.







Figure 35. Examples of seven *Sensory Preference Cards* (front and back)

Once categorised into groups of likes, dislikes and neutral, the cards create visual mood boards about a person’s sensory profile and can be used to make decisions about the manner in which they are supported and the design of their home.

One Kingwood support (2012) worker commented:

The pictures seem to make what we should be asking more precise, which makes me feel more confident about providing an answer. I also like how the picture cards will help towards involving the people we support. It is about them after all, and it’s important to give them the tools to be heard and to contribute opinions and input.

The autistic participants at White Barn were invited - with the help of their support staff - to express their sensory likes and dislikes using the sensory preference cards (Figure 36, see Appendix 19). The participants communicated their preferences through eye contact and pointing, and when the activity was too difficult for the participant information was derived from the support staff’s understanding of that person.



Figure 36. Support staff member and autistic adult using the *Sensory Preference Cards*

The *Sensory Preference Cards* encouraged the support staff to reflect and think about the person they support in relation to their experience with the physical environment, which also inspired one staff member to make a sensory prop based on a person's sensory preferences:

I feel that it would be exciting to see how Matt would respond if I were to make a prop that incorporated hair and smell. Maybe something along the lines of a blanket with five or so pockets containing various hairy textures infused with different aromas. I think he would really like that because he loves hair and scent (Support worker, 2012).

Framing the autistic participant's sensory preferences within the context of the garden enabled design decisions to be made. For example one participant's sensory cards revealed that they like darkness, walking in bare feet, jumping and water (Figure 37). These preferences suggest that the person may benefit from a garden that has plenty of opportunities for shade, a den or enclosed space, and that a variety of safe and tactile materials are used on the garden pathways for the person to explore barefoot. Also incorporated into the garden could be a water feature, a trampoline and plenty of herbs

and flowers that emit a variety of scents. Equally, it is important to be mindful of a person’s sensory dislikes, for example two of the participants found balancing difficult, making it important that the garden surfaces are even, with few steps.



Figure 37. A participant’s sensory preferences created using the *Sensory Preference Cards*

*Mapping Special Interests:* The garden is an active space capable of hosting a variety of leisure, occupation and exercise activities. Clearly a person’s interests can help inform the choice of specific features and activities, which greatly increases the likelihood of active engagement with the garden. To help identify and map a person’s special interests, the revised interest checklist (Kielhofner and Neville, 1983) was used, which is a self rating-tool for a person to rate 68 different activities or area of interest according to a) level of interest in the past 10 years/past year, b) whether he/ she currently participates, and c) if he/she wants to pursue it in the future (see Appendix 20). Four autistic adults (with the help of their support staff) were invited to complete

the checklist and comment on it in terms of format, accessibility and clarity. Three shortcomings were identified; 1) the checklist was inflexible and contained a prescribed set of ‘conventional’ interests which prevented a person from recording more idiosyncratic interests, such as spinning objects; 2) the interest checklist was a word based tick-box format, which largely excluded the autistic participants from taking part in expressing their own interests and 3) the checklist did not consider how a person might perceive and experience activities in different ways, for example enjoying an untuned television because of the sound of white noise.

To help develop an interest mapping tool the designer drew upon research conducted by Baron-Cohen and Wheelwright (1999), which invited 92 parents to complete a questionnaire, designed to determine the subject of their autistic child’s special interests. This information was then used to develop a taxonomy of interests found within autism, and this became a framework for the designer to create a visual *Interests and Hobbies booklet*. Each page in the booklet is dedicated to one of the 19 interests described by Baron-Cohen with ample room for the participant to expand upon through writing or drawing (Figure 38).

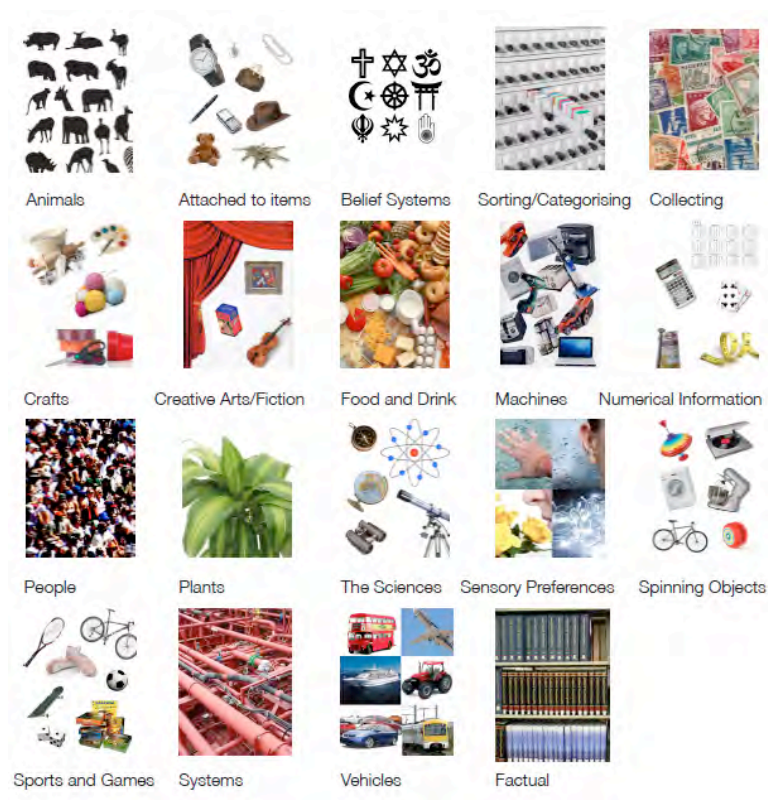


Figure 38. Taxonomy of interests featured in the *Interests and Hobbies booklet*

In addition to the autistic participants at White Barn, all of the autistic adults across Kingwood Trust were invited to write or draw their interests down in the *Interests and Hobbies booklets*, to generate insights about their different types of interests and what they like to do in their free time. Altogether twenty-four autistic adults participated with the help of the support staff, the booklets revealed all sorts of interests from kangaroos to washing machines (Figure 39, see Appendix 21). Patterns and correlations of special interests were also identified: spinning objects, bubbles and vehicles were popular topics of interest (see Appendix 22).



Figure 39. Examples of completed pages from participants' *Interest and Hobbies booklets*

To visualise the wealth of information, a tree was used as a metaphor to represent the interests of each autistic participant (Figure 40, see Appendix 23). The branches on the each tree are colour-coded and represent an area of interest drawn from Baron-Cohen’s taxonomy of interests. Leaves are then added to each branch to go into more detail about the particular interest of each person. Each branch therefore represents potential areas of growth. This lyrical way of representing the special interests of adults with autism, using a *Tree of Opportunity*, aimed to encourage the support staff to identify and create opportunities for growth based on a person’s interests.

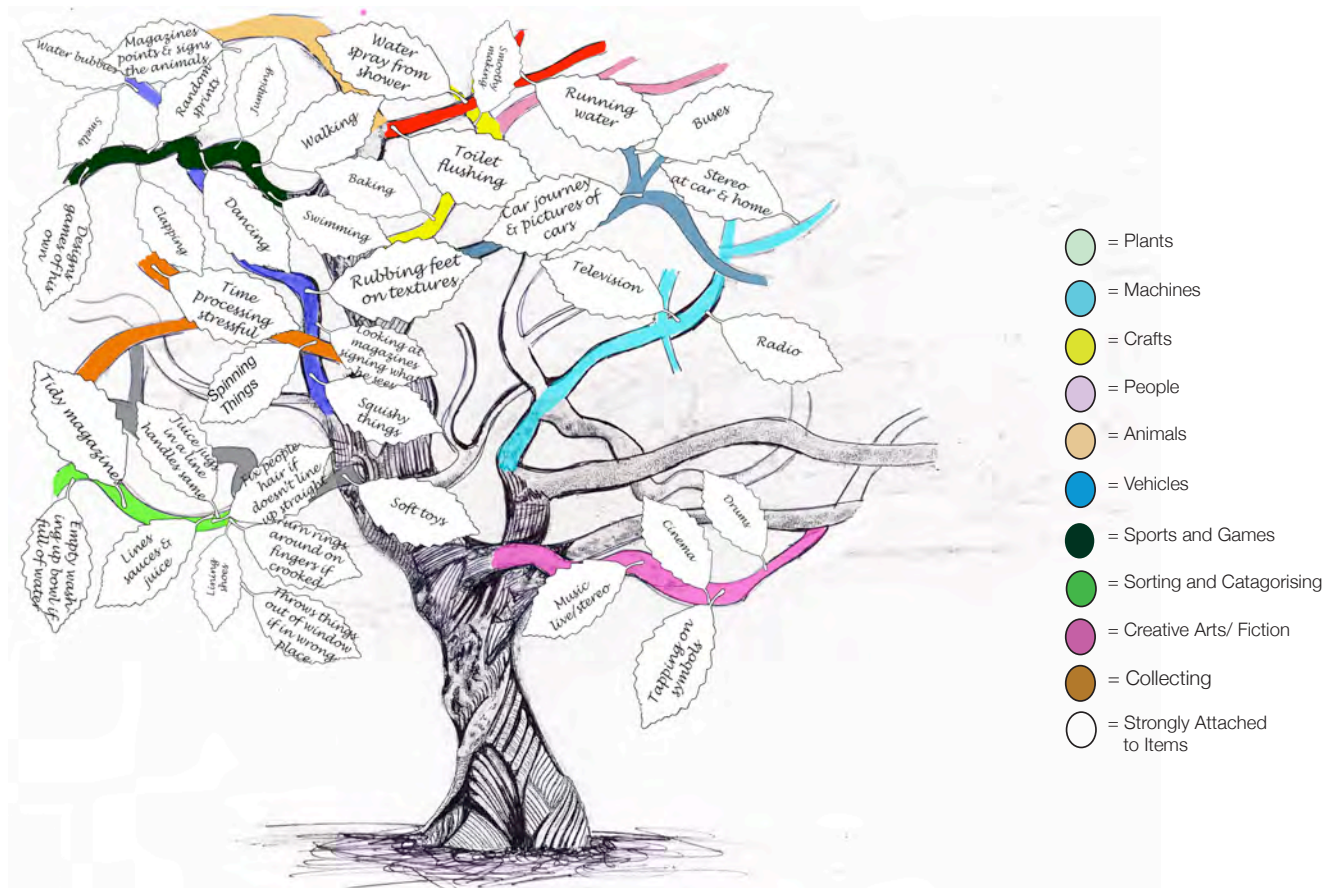


Figure 40. A tree representing the interests of an autistic participant, illustration by author

The *Interests and Hobbies* booklets helped the designer to learn more about the autistic participants’ special interests, enabling her to connect with a person based on the things they like to do. A person’s interests can play an important role in the design process, for

example the tree (Figure 40) illustrates the interests of an autistic participant at White Barn, who enjoys jumping, running water, drums and tapping on cymbals. These interests can trigger design ideas to help create a personalised garden space, for example finding part of a garden set aside for a trampoline, a water feature and audio garden props responding to the wind and rain. As autistic people may resist participating in new and different activities, small steps might be required when introducing them to something new. The designer proposed that using existing special interests as a central theme may help with this transition as it provides a familiar strand to which new activities and experiences can be added. For example (Figure 40) also reveals that the person likes spinning things and lining objects up such as sauces and juices. The two illustrations below (Figure 41) suggest how these particular preferences can be extended and translated into activities for the garden environment. The participant's interest in spinning (right) can be incorporated into activities that involve objects that spin i.e. rotary washing lines; equally the participant's interest in taxonomy (left) can be incorporated into gardening activities such as placing seeds in rows.

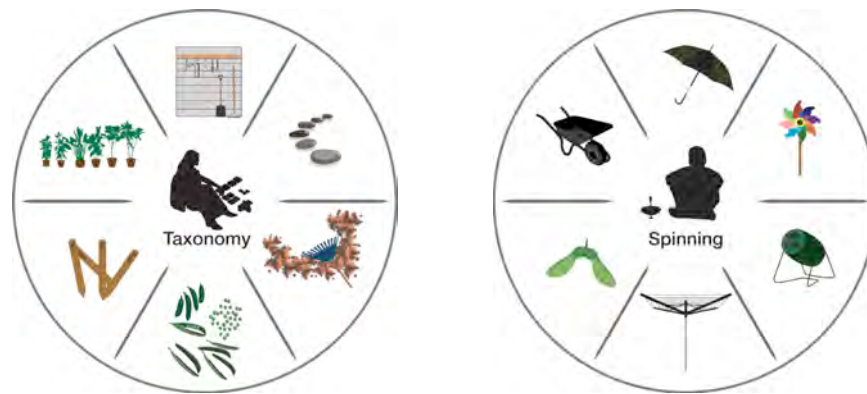


Figure 41. Extending a person's interests of taxonomy and spinning into the garden

Gaining the right information was difficult as it was often the things the support staff deemed irrelevant that were highly relevant to the designer. For example on occasions during the *Interests and Hobbies booklet* activity, the person's timetabled activities such as swimming and bowling were recorded, but their more idiosyncratic interests, such as spinning objects, were left out. This led the designer to challenge her own assumptions as to what was considered an 'interest'. Given the designer's philosophy of designing

around a person's interests, accurately diagnosing a genuine interest was vital. Was flushing a toilet or flicking a light-switch a true interest, or just a pattern of behavior masquerading as an interest?

#### **5.5.4 Stage Three: Generating design ideas**

To generate design concepts, co-creation workshops were held inviting support staff and family members to imagine how a proposed shared garden space might look and feel. The co-creation workshop involved 17 staff and family members which took place at Kingwood's head office. As a hypothetical garden was being discussed, a simple layout was presented in the form of a rectangular grass patch – essentially a blank canvas. A pack of cards illustrating possible garden features, spaces, furniture, flooring, partitions, utility, wildlife and activity ideas, was given to each participant, each of whom was asked to select those cards that they thought would be most appropriate. Additional blank cards could be written or drawn upon to represent new features or activities. The participants were also given stickers representing either himself or herself or the person they support to be placed on the areas or features they thought would be most appropriate, which quickly gave an indication of the popularity of each space (Figure 42).

*Outcomes:* The exercise proved very useful in identifying recurring themes and the needs of those being considered. It was also a good tool for engaging people and eliciting sometimes revealing anecdotes. As the participants had to negotiate shared spaces, there was discussion and consensus on what should or should not be included, what should be grouped and what should stand alone. From the workshop several desirable spaces naturally emerged: social space, private space, exercise space, horticulture space and utility space.

Overall the consensus was that several spaces should be provided, and that clear options should be in place. The need for both social and solitary spaces was highlighted several times. One of the interesting outcomes was that although the garden was being designed with adults with autism in mind, what was emerging was a desirable space for all, a space where people with autism, their family members and support staff would enjoy spending time with one another. Without any encouragement from the designer the



participants' ideas evolved from a person's sensory preferences and interests, for example seating placed out of direct sunlight, was thought desirable to avoid the sun's glare. One parent also described how her son would find walking on pebbles too unstable and unpredictable, yet would enjoy interacting with them by picking and sorting them. Some more unusual suggestions emerged too which related to a person's special interests, for example a mother described how her son had a special interest in cars and suggested a car chassis might be a fun idea for the garden.



Figure 42. A photographic collage of the co-creation workshop

*Ready Steady Make:* In addition to the design of the garden, another design consideration was how the activities being performed in the garden can be designed and personalised around the autistic adults' preferences. The designer facilitated four *Ready Steady Make* workshops, which took place at Kingwood's head office (see Appendix 24). *Ready Steady Make* is a creative workshop for staff and family members, to share ideas and experiences on the subject of sensory preferences and special interests through the medium of making sensory props as a gift for the autistic person they support. In total 24 support staff were invited to share ideas, experiences and explore ways to enrich the garden experience for the autistic person they support. The support

staff were invited to work collaboratively and asked to write down the sensory preferences and interests of the person they support and place them into a Guess Who game frame – an amusing way to extend the participant’s concentration and consideration of a particular autistic adult’s preferences (Figure 43). The insights were then translated into ideas for decorating trees (Figure 44), which enabled the staff to visually compare and describe the different interests and sensory preferences of the autistic people they support. The trees created a direct and visual impression of a person’s sensory profile, for example the trees that had minimal decoration related to a person who was hyper-sensitive (avoiding sensory input) and conversely the more decorative trees related to a person who is hypo-sensitive (seeking sensory input).



Figure 43. A photographic collage of the insights drawn from the Guess Who activity performed by the support staff during a *Ready Steady Make* workshop



“He likes soft touchy things, he likes to smell staff’s hair so I’ve put scents in the cotton wool. He likes colour and expressions and twiddling things. I’ve some soft textures in the tree and its quite visual and bouncy. I think the person I support would enjoy it!”



“He likes things that roll, things that are round, bright colours that he can look at. He likes spinning things so on the top of the tree there’s something that resembles that, its round and it spins so I thought that would be good to put at the top of the tree.”



“She likes crunching things, and she likes horses so there is a picture of a horse. She likes colour blue, red and squishy things, she likes music so there are bells and there are lots of scents at the top of the tree because she likes perfumes.”



“I’ve put little steering wheels and cars on his tree. The person I support likes to flick things, so I’ve made some flicky twirls and a cracker so when it bursts, cars come out. There is also thunder bolts coming out because he likes loud sounds.”



“He absolutely loves plastic and also likes to walk no matter what the weather, so I have put some snow on the tree and lots of plastic things. He is also into horror films and anything to do with zombies and space hence the plastic space ships.”



“This tree was created for someone who likes red, he likes red cars. He loves traffic lights so there are some red stars.”

Fig 44. A photographic collage of the support staff’s tree designs during a *Ready Steady Make* workshop

In other *Ready Steady Make* workshops the participants were presented with a variety of cheap and easy-to-find materials such as wooden spoons, bottle tops, marbles, CDs, flip flops, pencils, bamboo sticks and sink strainers (Figure 45). The materials were imaginatively transformed into personalized garden props (see Appendix 25). An important aim of the workshop was to explore how the process of making something can help to encourage communication and trigger different experiences and ideas between staff. For example, the support staff's discussions about sound (prompted by making wind chimes) triggered talk about drills and car engines, sources of sounds problematic for some of the people they support. The making of the CD spinners sparked conversation about an autistic man who loves spinning objects and has an impressive collection of windmill ornaments. This train of thought prompted his support worker to plan a trip to a field of wind turbines, which proved a great success. The main challenge of the workshops was to steer discussions away from negative experiences and to manage the participants' expectations of what a co-creation workshop actually means. As the staff were used to attending more 'passive' training sessions, an interactive workshop where they are considered the experts and learning is facilitated collaboratively and creatively through making things, was at first met with cynicism.



Figure 45. The designer facilitating a *Ready Steady Make* workshop

### **5.5.5 Design output**

The different design tools facilitated in stages one, two and three created insights that informed the design of the new garden. Inspired by the co-creation workshop, the final garden design is composed of seven different activity spaces; escape, exercise, occupation, sensory, social, transition and wilderness (Figures 46). White Barn and Kingwood College both have their own private garden and the seven activity spaces can be accessed from both residences. Careful consideration was given to the location, orientation and navigation to and from each activity space. The design and layout of the garden was influenced by Frith's (1989) perceptual theory of weak central coherence. It was proposed that to support an autistic person who finds it difficult to see things as a whole, the activity spaces in the garden would need to be separated and compartmentalised, to help that person differentiate and transition between activities and create order in what could be potentially a disordered environment. The signposting and flow of the garden was also important to enable a person to navigate the space independently.

The concept of a gradual transition through an increasingly experiential sensorial space was a way to make a space accessible to people who experience hyper and/or hypo sensitivities. Examining the sensory preferences, interests and action capabilities of the participant played a fundamental role in the eventual design. The participants' preferences for running, jumping, spinning and walking led to the installation of a trampoline and spinny disc and creating a long circular pathway that utilised the whole expanse of the garden. A participant's sensory preference for interacting with water, sand, different smells and sounds led to a water feature and a large sensory space towards the back of the garden. Two participants in particular like to spend time alone, so the designer ensured there were plenty of hideaway spaces including a den for the participants to relax away from other people. The designer noted that two of the participants disliked changes to their home and getting messy which, influenced how the garden was landscaped. The sections of the garden nearest the living accommodation were highly ordered. Plants that keep their leaves and maintain a consistent colour all year round were neatly planted so as to appeal to those participants who were particularly comforted by regularity. However the greater the distance from

the buildings, the more irregular and changeable the garden became, encouraging the more adventurous participants to explore a more diverse sensory environment.

As the garden was to be shared between nine autistic adults, precisely tailoring the garden to each individual's specific interests was extremely difficult as there would be inevitable clashes between rival sensitivities. The designer was also mindful of the fact that an autistic person's interests are not set in stone, and a garden for the long-term would be undermined by a design based on what could very well be short-term interests. By working with the support staff in the Ready Steady Make workshops it was hoped to get their input on the spectrum of activities that the garden may need to accommodate, but also that the designer could encourage the support staff to view the garden as an elemental space, whose elements could be tailored to create an experience suitable for each autistic adult they support – even as the garden naturally grew and evolved.



Figure 46. Final garden design

The garden development was completed in June 2013 and the last of the main plants went in summer 2013 (Figure 47). The finished garden is an exact replica of the sketch above and each of the seven green spaces are described below.

*1. Escape:* The garden included three 'escape' spaces, which were positioned in different areas of the garden. In two of these the designer took advantage of natural canopies provided by mature trees, simply adding seating underneath.

*2. Exercise:* This is a designated activity zone which includes age-appropriate equipment to take full advantage of the outdoor location. Activities such as jumping are encouraged by the provision of a sunken trampoline. The area is floored with rubber mulch and subtly fenced with curved sections that guide the person to the equipment. Foliage on the fence helps to filter sound from the rest of the garden.

*3. Occupation:* A vegetable garden offers a host of occupational possibilities. Garden maintenance and embellishment is multi-faceted, offering many opportunities to incorporate people's natural interests and abilities.

*4. Sensory:* Towards the back of the garden is a space divided into a series of sensory 'rooms' that cater to each sense, helping people to focus upon one sense at a time. Paths, signposts and other forms of orientation offer clear indication of the possibilities for exploration, allowing a person to select the sensory space that appeals to them and avoid those that do not.

*5. Social:* An open area connected to an outdoor classroom is provided in the centre of the garden. This space would not only be used for crafts and games but also for barbecues (dining and relaxing were established to be important garden activities).

*6. Transition:* A veranda within the private gardens allows the autistic adults to make the transition from indoors to outdoors. The immediate layout visible from the window and first experienced when entering the garden is that of an uncluttered space with low stimulation, minimal detail and limited palette. The design of the garden is deliberately graduated making the entrance serene before progressing to the more stimulating social



and activity spaces. The most arousing sensory and wildlife spaces are located at the back and around the perimeter of the garden.

7. *Wilderness*: The space surrounding two mature trees was made onto a feature. This area could not be built upon due to the potential risk of damaging the trees' roots. It was therefore a natural choice for a wilderness area. A bird's nest swing, big enough to accommodate more than one person, was also included to further reinforce the experience of being in an open space while encouraging vestibular activity.

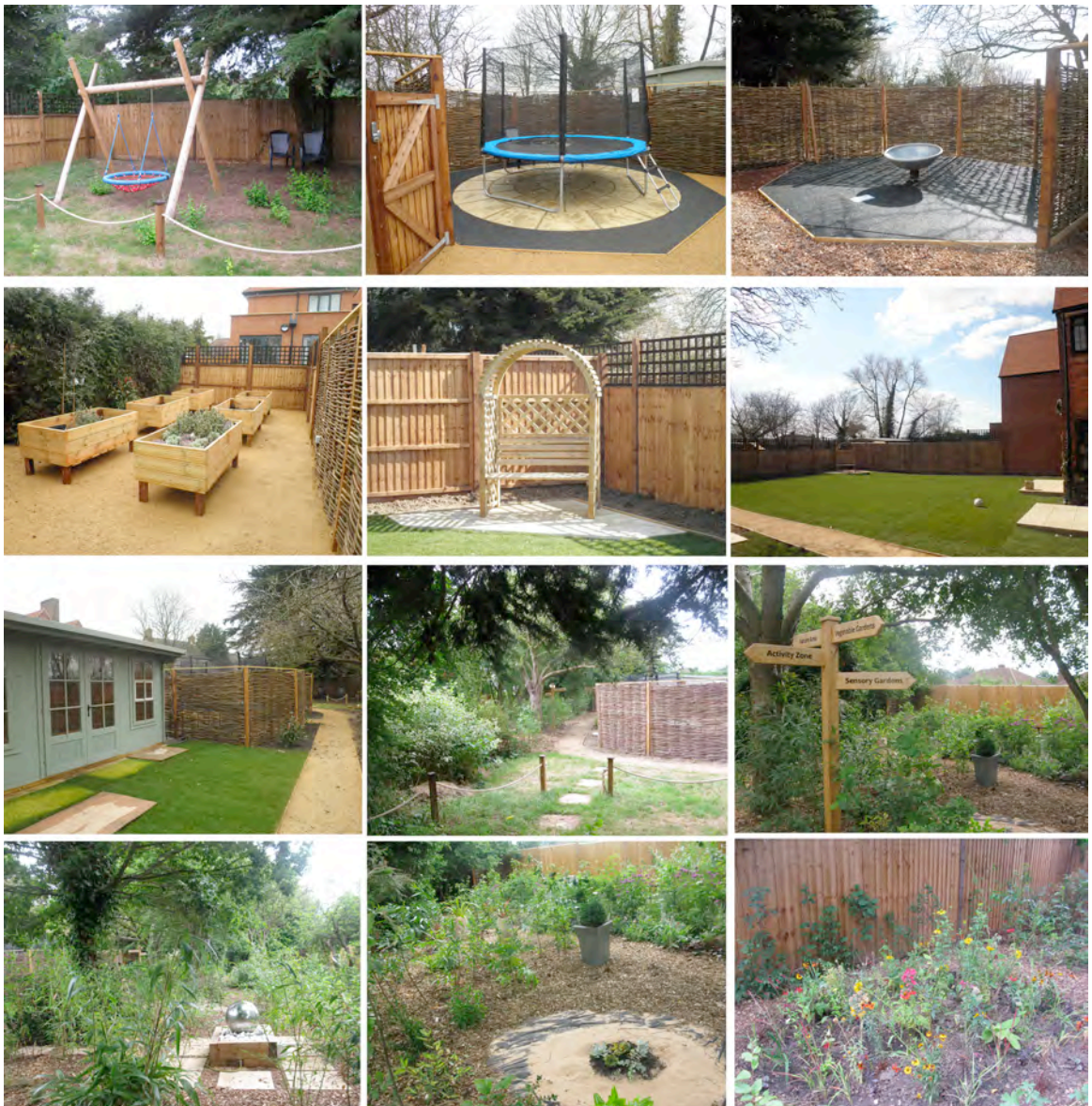


Figure 47. A photographic collage of the garden development

### 5.5.7 Stage Four - Evaluation

The garden was developed in 2013, at the same time as the adjoining house next door (Kingwood College) was being built. This meant the needs and interests of any prospective residents at Kingwood College could not be taken into account. The five subsequent residents were, however, invited to take part in the garden's evaluation.

To explore how the garden was being used, garden diaries were developed and given to each autistic participant at White Barn, including five adults at Kingwood College. The garden diary was an A4 sheet of paper, containing eight visual questions. The autistic participants with the help of their support staff were invited to complete a sheet every time they used the garden. On one side of the garden diary was the sketch of the garden. To gauge how the autistic participants felt about the garden they were asked to place happy-face and sad-face stickers onto the areas they liked or disliked (Figure 48). On the reverse side were seven simple questions, to explore how the garden was being used (Figure 49). The garden diaries were supported by photographs and follow-up informal conversations were facilitated with the staff (Figure 51).

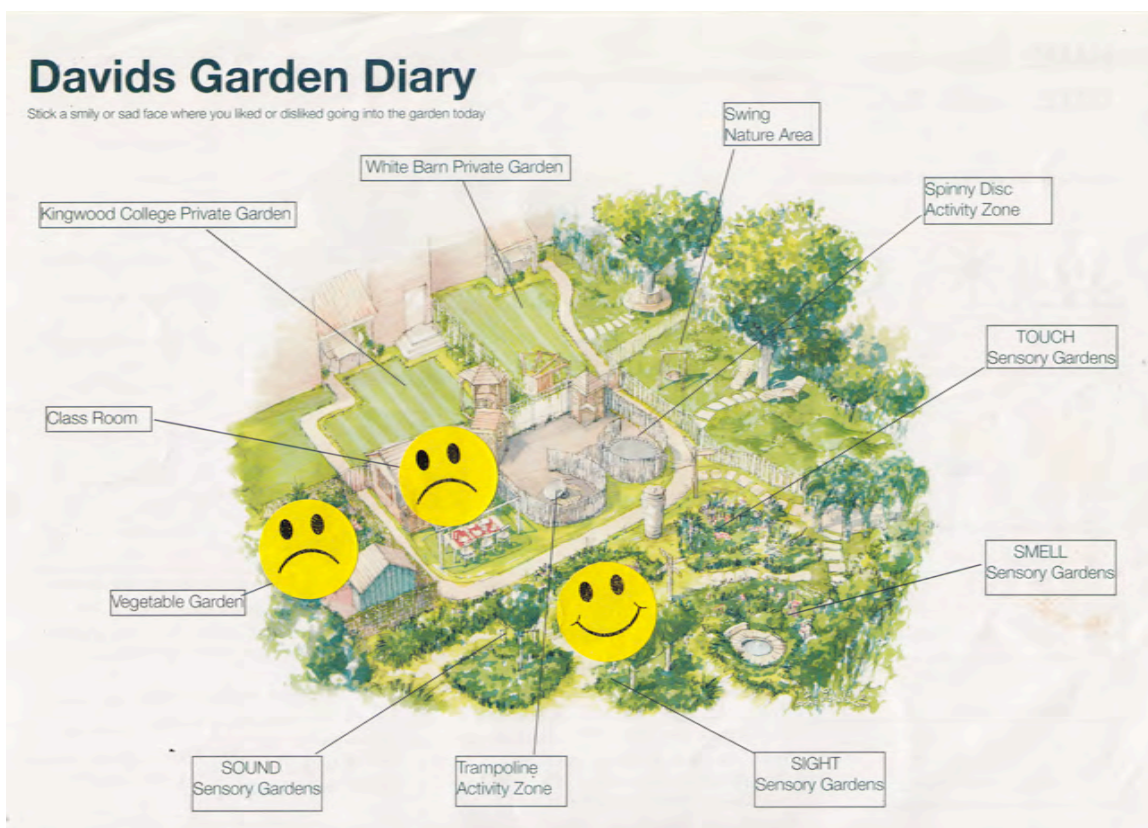







Figure 48. Completed garden diary (front)

**NAME:** David  
**DATE:** 04/09/13

1. Circle when you visited the Garden:






 Morning	 Afternoon	 Evening
---	---	---

2. Circle today's weather:






		
---	---	---

3. Circle how you feel?

\* Before entering the garden

				
--	--	--	--	--

\* After entering the garden

				
---	---	---	---	---

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnery Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

David enjoys using the rake in his personal garden.

David generally likes to wander around the sensory gardens pointing things out. Today he was excited about all the pears on the tree. Hundreds of pears he kept pointing and saying. The sprinkler was on in the herb area and David giggled gleefully as he thought about walking through it - he put one leg in.

7. Things I dislike about the garden today:

David was frustrated that we could not get into the veg patch to see what was growing.

David would really like to take part in activities in the outside classroom. He has shown great interest in the building from when it was first built (empty).

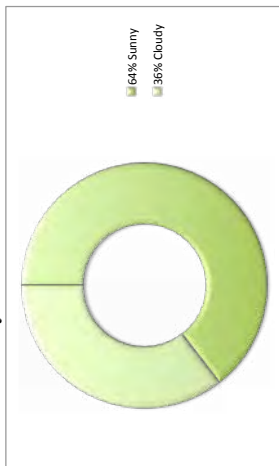
A. Clark

Figure 49. Completed garden diary (back)

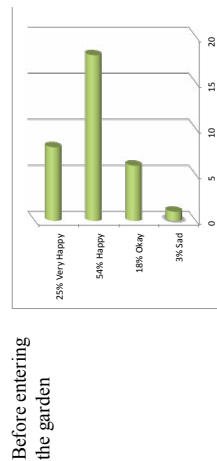
### 1. Circle when you visited the garden



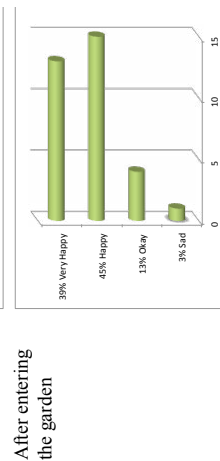
### 2. Circle today's weather



### 3. Circle how you feel?

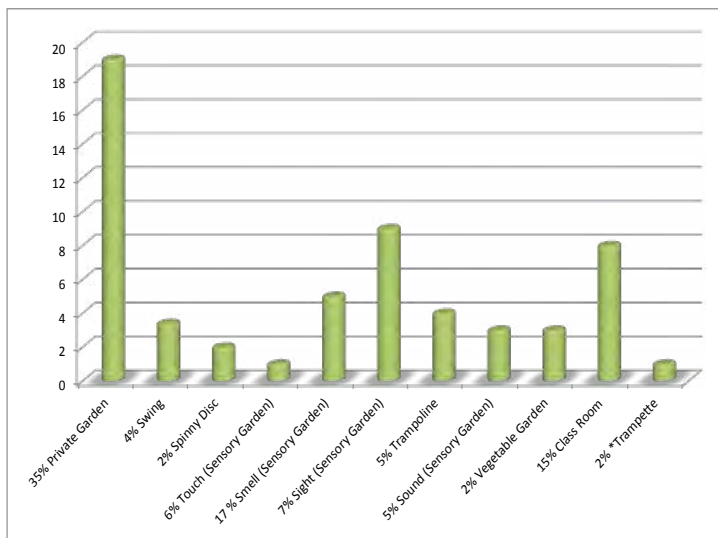


Before entering the garden



After entering the garden

### 5. Tick today's activities



### 6. Things I like about the garden today

Walking the dog around the garden  
 Just relaxing in the garden  
 Going into the art room to do some writing  
 Enjoy making her art work  
 Drawing Victorian furniture  
 Just relaxing out in the garden and being lazy  
 Enjoyed going on the trampoline  
 The lovely weather  
 Going to the garden several times for short periods and sitting on a garden chair  
 Sat in communal area at joint BBQ with Kingwood College. Enjoyed sitting with housemates and others  
 Lucy likes to just sit out in the garden for a few minutes with staff  
 Sitting on a pagoda bench for 10-15 minutes  
 Relaxing in a chair and chatting  
 Sitting on a bench for some time  
 The sun shine and the space  
 Walking around the garden for 10 minutes  
 The walk around to the classroom/paint shed. Quietness  
 BBQ at the back of garden- I ate a lot today  
 Fixing balloons on a fence for a birthday party  
 Played football and walked around  
 Playing football  
 Walking around and using the trampoline  
 Playing jenga blocks  
 Using the swing and trampoline also smelling sensory garden  
 Having a cup of coffee after lunch and relaxing  
 He enjoys using the rake in his personal garden  
 He generally likes to wonder around the sensory gardens pointing things out.  
 Today he was excited about all the pears on the tree, 'hundreds of pears' he kept pointing and saying.  
 The sprinkler was on in the herb area and he giggled gleefully as he thought about walking through it! He put one leg in.  
 He has shown great interest in the building from when it was first built (and empty).  
 We had a BBQ in the garden and she enjoyed using the garden space. She sat down to eat on the grass of the art studio.  
 Came down outside for a BBQ and enjoyed himself.  
 She enjoyed looking out at the garden and the weather outside.  
 I enjoyed being on a swing, spinnny disc and jumping on the trampoline and also touch (sensory garden).  
 He came down in the classroom to help with Fred the horse.  
 He made a visit to the classroom because dogs for the disabled came to see him.  
 She visited the art studio walked down the path.  
 He was sitting in the sensory room with a view of the garden with the sun shining in.

### 7. Things I dislike about the garden today

Being Loud  
 Can't handle it being loud  
 Trampoline  
 When to many people are outside  
 Frustrated that we could not get into the veg patch to see what was growing.  
 Would really like to take part in activities in the outside classroom.

Figure 50. Garden evaluation results compiled

The designer received thirty-three completed garden diaries over the space of six months, in which eight out of the nine autistic adults living at both White Barn and Kingwood College (and their support staff) participated (see Appendix 26). Compiling the information from all the completed garden diaries together (Figure 50), they reveal that the garden is largely used in the afternoon (68%) and the participants showed a 5% increase in level of happiness after entering the garden. All the activity spaces in the garden were used, the most popular space was the private garden areas, followed by the sensory garden (sight), classroom and sensory garden (smell). The participants used the garden in a variety of ways and the new space encouraged new activities such as dogs for the disabled, Henry the horse and BBQ gatherings that had not been organised before. The things the participants disliked about the garden was the sound level and when too many people were using the garden; from the feedback there appeared to be confusion as to how the communal space was to be shared between White Barn and Kingwood College.

Informal conversations with the support staff revealed that relevant insights were not always captured in the garden diaries. For example, one staff member at Kingwood College described how the person she supports does not like wearing shoes and socks so he will go out to the immediate garden in bare feet but does not venture beyond this into the activity zones. They suspected this was because the floor is composed of pieces of bark - something he does not like the feel of on his feet. The most disappointing comment about the garden from a support worker was that autistic adults “don’t go out because there is no real point” (2014). This revealed that although the garden design presents lots of opportunities for activity, what is equally important is the motivation and enthusiasm of the support staff to facilitate the garden activities.

The evaluation was discussed at length with managers and recorded on a dictaphone for later analysis. Informal conversations with the managers at White Barn and Kingwood College revealed the lack of communication between both residences. Despite the garden being a shared space between both residences, White Barn were unsure whether they were allowed to use certain parts of the garden. This confusion was also felt by the autistic adults as reported in the garden diaries, one participant felt ‘frustrated’ because he could not go into the vegetable garden and another participant wanted to join in with

the activities in the classroom. As it is a shared garden space it is important that the staff are informed and mindful of the sensory sensitivities of the autistic adults at both Kingwood College and White Barn, which might influence how things are kept and maintained. For example one manager is concerned with how the pots of paint are left out in the art classroom, as one of the people she supports would be inclined to mistake the paint for a drink. To avoid conflicts of interest, there might need to be an agreed structure and timetable in place illustrating clearly when different parts of the garden will be in use by certain people.



Figure 51. A photographic collage of the autistic participants in their new garden

The results of the garden study showed that the participants used the garden in the ways that the designer anticipated and intended. The difference in the participants' indoor behaviour and their behaviour outdoors was clear. The new, more flexible, environment of the garden had created a place free from the fixed affordance and routine of the interior environment.

### **5.5.8 Summary**

The designer established four stages of the design process. Stage One: Connecting, communicating, building trust and empathy; Stage Two: Gathering context specific insights; Stage Three: Generating design ideas; Stage Four: Evaluation.

*Stage One:* The lack of verbal communication set a challenge of acquiring information in different ways. The designer shadowed the participants until the point where she had gained their confidence and was able to play more of an active role and undertake different activities with the autistic adults. A creative workshop led by the designer was held which gave the opportunity to interact with the autistic adults and their support workers in a fun environment. This fostered a closer relationship without the need for verbal conversation, but put the autistic adults in a more passive mode, making the possibility of any useful observations limited. In contrast, introducing a rich palette of sensory props to each autistic adult and allowing them to explore as they chose provided more useful observations. With no expected outcome all results assumed significance. The practice of mirroring an autistic adult's interests allowed the designer to form a more meaningful and truly reciprocal relationship for the first time. A picnic in the garden was held with encouraging signs that given the right context, the garden could be a space that was used and enjoyed by all on a regular basis.

*Stage Two:* The designer collected the sensory preferences and special interests of all autistic adults using the *Sensory Preference Cards* and *Hobbies and Interest* booklets, with the help of the support staff. This triggered conversations and further thought about the autistic adults within the context of the garden.

*Stage Three:* A productive co-creation garden design workshop featuring family members and support workers was facilitated by the designer, encouraging collaboration in the design process. In particular the possibility of successfully adhering to so many individual needs by physically compartmentalising the garden into themed areas became clear. A ‘Ready-Steady-Make’ workshop was conducted with support staff, which encouraged a deeper exploration of each autistic adult’s preferences.

*Stage Four:* Thirty-three garden diaries were collected showing how the autistic adults experienced the garden. Informal conversations were held with support staff and management on the efficacy of the garden.

### **5.5.9 Reflection**

In study one the design tools emerged through the practice. For example in stage one the designer had identified her presence affected the situation, and that the information provided in the communication passports was limited. These insights in stage one led to stage two which involved the development of a range of design tools that could be used remotely without the designer’s presence, to provide more context-specific insights. Tools such as the *Sensory Preference Cards* encouraged the staff to stop and reflect upon their practice and generate ideas; however as there was not a platform for the staff to express and share their ideas with each other, the co-creation workshops in stage three enabled the support staff and family members to get together. The tools provided enabled the participants to express and share their ideas; experiences and generate more insights about the autistic people they support. Stages one, two and three generated insights, which helped to create a holistic impression of the autistic participants in the research, which supported the design and development of the garden in stage four.

On reflection there are three identifiable experiences that informed the design and development of study two.

1. The support staff’s feedback and involvement during the evaluation of the garden was limited. In study two more thought should be given to exploring ways to involve the support staff and integrate the design tools into their working day.



2. Guidance on how to facilitate the garden diaries was given to the managers but not the support staff. In study two it is important that the designer demonstrates the design tools with the support staff face-to-face, to ensure they understand the reason and importance of their involvement.
3. The time scale for the evaluation of the garden was very open ended. The design tools used in study two might benefit from shorter and clearer timeline.

## 5.6 Design Study Two: Everyday Objects

This study took place at Beeching Way based in Wallingford, which provides support and accommodation for 12 autistic adults (male and female) (Figure 52). Most people at Beeching Way require one-to-one support but live in their own apartments, housed in a building with a communal front door, activities room and garden. The aim of the study was to explore how the autistic adults at Kingwood perceive and experience everyday activities and the domestic objects associated with them, and to help inform the design and adaptation of everyday activities that are more enjoyable and meaningful for the autistic adult. The profiles of the autistic participants involved in study two are not presented here, because the designer interacted with a number of different people.



Figure 52. Exterior of Beeching Way

### 5.6.1 Stage One: Connecting, communicating and building trust and empathy

*Participatory Observation:* The designer visited three autistic adults in their own homes, and engaged with them in different activities. The aim of each visit was to build trust and rapport between the designer, autistic adult and support staff and explore in a relaxed manner how each autistic adult engages in everyday activities at home. The designer documented her observations of the home environment (Figure 53) and peoples' interactions with their home through note-taking and photography, and asked the support staff questions as and when interesting insights arose (see Appendix 27).

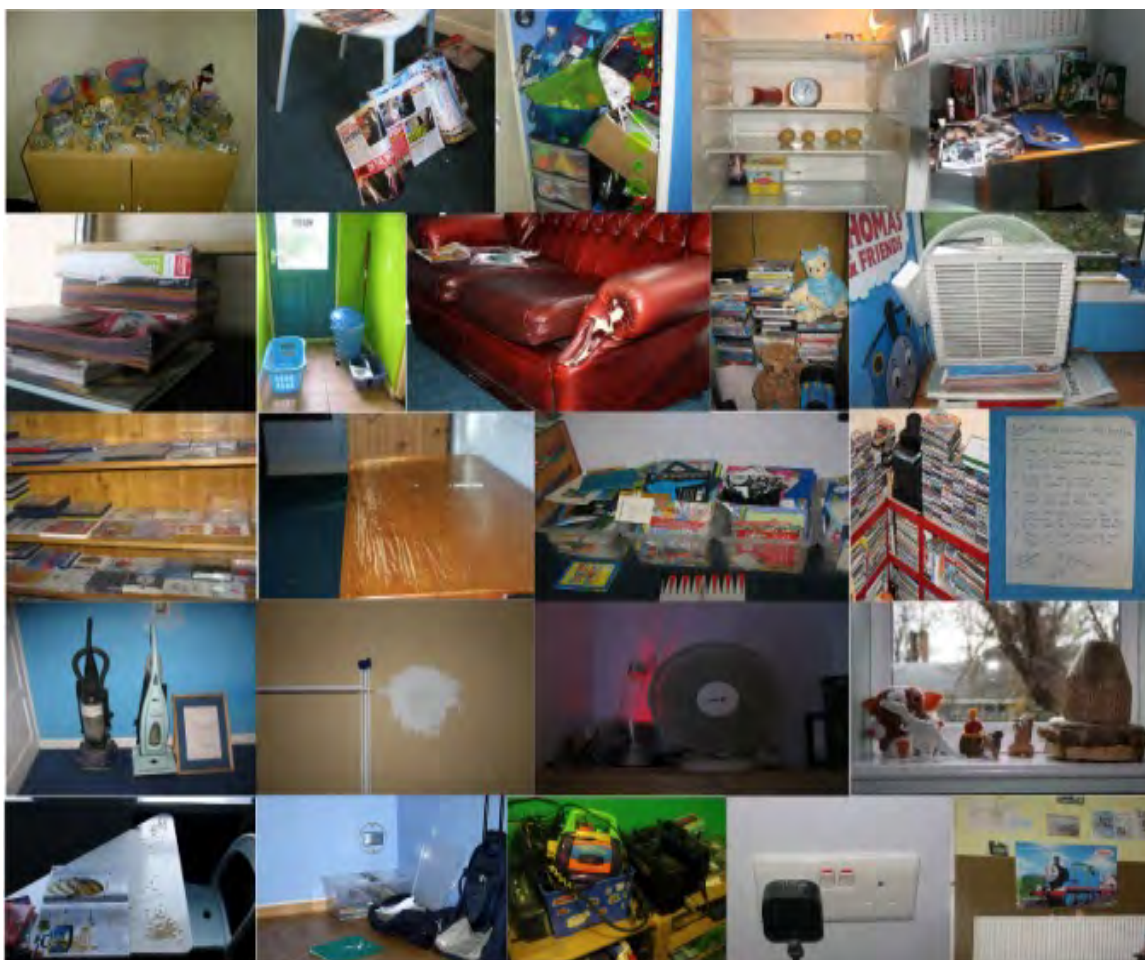


Figure 53. A photographic collage of the designer's environmental observations

Participatory observation revealed that the choice of activity was influenced by a person's interests and sensory preferences, for example Nicky loves Thomas the Tank Engine, hence most objects in Nicky's home are blue and Nicky likes using her blue Henry vacuum cleaner because she enjoys the sound. The designer observed that some

of the autistic participants were interested in the unintended affordance and visceral qualities of everyday objects, for example the sound of desk top fans, fish tanks, playing with the buttons on the radio and the visual effect of a spinning washing machine. These examples illustrate how the autistic participants directly engaged with the environment not through sight alone but through their other senses. Below are examples of different everyday objects with comments by support staff for how the autistic person perceived and interacted with them (Figure 54).

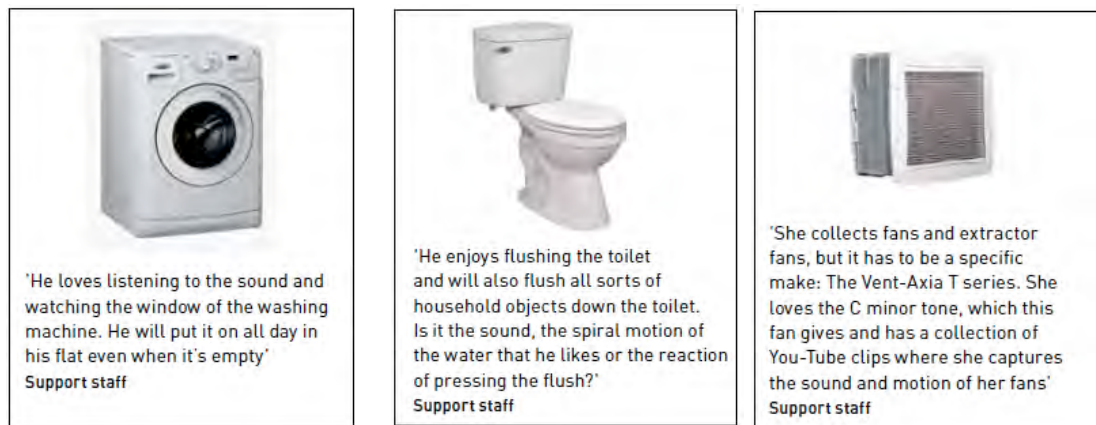


Figure 54. Three examples of an autistic person's interaction with the unintended affordance of everyday objects

Participatory observation was a useful tool which highlighted how the things the designer found interesting does not necessarily get documented in existing literature or noticed by the support staff, whose attention is focused on personal care, health and safety (Figure 55). For example, it was only by being with Nicky in her home that the designer discovered she likes the sound of her washing machine on the last spin cycle. An autistic person's idiosyncratic relationship with their environment might remain abstract had the designer not seen or experienced it for herself; for example, by observing Nicky's positive expression as she heard the last spin of the washing machine, the designer was able to empathise with Nicky and appreciate that this was an important and enjoyable experience for her (see Appendix 28). Experiences like this encouraged the designer to reflect upon her own visceral response to the environment, breaking down her own assumptions about how people afford the environment, for example the sound of extractor fans, washing machines and a running car engine are audio qualities which the designer had not stopped to consider before.



Figure 55. A photographic collage of the designer engaging with the autistic participants in their home

As in study one it was helpful to speak with the support staff within the context of the autistic person's home, as it was the environment that provoked different insights. For example whilst visiting Nicky in her home, a staff member warned the designer not to touch any light switches or park directly outside her home, because she does not like anyone to touch her switches and dislikes the sound of a running car engine to the point where staff try not to take Nicky out when schools close to avoid the sound of car engines running in traffic queues. These examples illustrate how the support staff have respected and adapted themselves to the way in which Lucy chooses to afford her environment.

It was difficult for the designer to observe and document the autistic participant's natural engagement with their home environment because her presence affected the situation. An extreme example of this happened in study two when the designer experienced an outburst of challenging behaviour whereby an autistic participant put the designer into a headlock. It was difficult to ascertain the reason for this behaviour. It might have been triggered by the colour of the designer's clothes, where she was standing or it could have been entirely unrelated to the designer.

*Sensory Activities:* The autistic participants in this study lived in their own flats, consequently unlike the group sensory activities in study one, the sensory activities in study two were facilitated individually. To prevent too much change and disruption to a person's home the activity was less of an event and simply involved bringing a selection of props along to a person's home (Figure 56). The sensory props essentially became a tool kit for the designer, for creating an interactive activity that mediated non-verbal

communication. During a sensory activity a support worker showed the designer a small toy car, which he takes to work to help connect with the person he supports.



Figure 56. A Participant interacting with a selection of sensory props

*Mirroring Interests:* As in study one the designer would also connect and engage with the participants through mirroring or taking part in their interests. One autistic participant really enjoys bubbles therefore when the designer visited this person she ensured that she always brought along a bubble wand so they could blow bubbles together (Figure 57).



Figure 57. The designer, autistic adult and support staff member blowing bubbles together

*Disposable Cameras:* As the designer's relationship with the autistic participants developed, she became extremely conscious of objectification and felt increasingly uncomfortable taking photographs, particularly as she was unable to receive direct verbal consent from the autistic participants themselves. Following initial visits where the designer's presence was inevitably a disruption to a daily routine, the designer chose to continue the photographic documentation process by removing herself from the environment and distributing eight disposable cameras to the support staff. This was with the aim of creating as relaxed and natural environment as possible in which to document how the autistic participants interacted with everyday objects and activities. The manager of Beeching Way organised the distribution of the cameras to each support worker with clear instructions of what they should be used for (Figure 58).



Figure 58. Three photographic collages by support staff of autistic participants engaging in everyday activities,

### **5.6.2 Stage Two: Gathering context specific insights**

*Objects of Everyday Use:* Lawton and Brody (1969) were the first authors to describe two levels of activities of daily living. The first 'Activities of Daily Living' (ADL) includes the basic tasks of dressing, bathing, grooming, using the toilet, eating, walking, or getting in and out of bed. The second (which this study focuses on) are 'Instrumental Activities of Daily Living' (IADL), referring to more complex tasks that require a range of adaptive skills, which are important for independent living and maintaining the home, such as cooking, cleaning and doing the laundry (see Appendix 29). IADL

questionnaires are used by healthcare practitioners to determine a person's functional ability and level of independence to help plan their future.

The designer identified that the majority of IADL questionnaires are word based, which immediately excludes a person who struggles with literacy to take part in expressing their own abilities. They also do not take into account the heterogeneous nature of people's homes, the objects in their homes, and the effect this may have on their ability to perform everyday activities. For example, a person may score low on their performance to use a telephone, but this might be because the design of the phone is inappropriate for that person. Maybe the buttons and screen are too small, so therefore it is not the person's ability but the design of the phone itself that is making it difficult for that person to participate in the activity.

In response, the designer developed a set of 43 visual cards called *Objects of Everyday Use*, which adapts the existing IADL questionnaire (the Lawton IADL scale) (Figure 59). Forty-three everyday activities are photographically represented on the cards to create explicit visual prompts to help the participant conceptualise and process what the activity is (Figure 59). It also includes simple tick box questions for those who find it difficult to read and write, or for those whose first language is not English to take part in the process. This approach makes it more inclusive for the autistic participants with the help of their support staff to take part in expressing the things they do or don't like to do around their home, with the opportunity to describe their reasons why and how much support (if any) they might need to perform certain activities.

The environment and everyday objects play an important role in a person's ability to perform an activity. To help set the scene and encourage the participants to start thinking about the environment and objects used to perform the activity (and how they could be improved), each card contains a fact about when the object was invented or patented (Figure 60). The *Objects of Everyday Use* cards are held together using a plastic book binding screw and swivel 360 degrees in a playful movement with the aim of creating a fun, interactive activity that encourages a meaningful interaction between the autistic participants and their support staff.

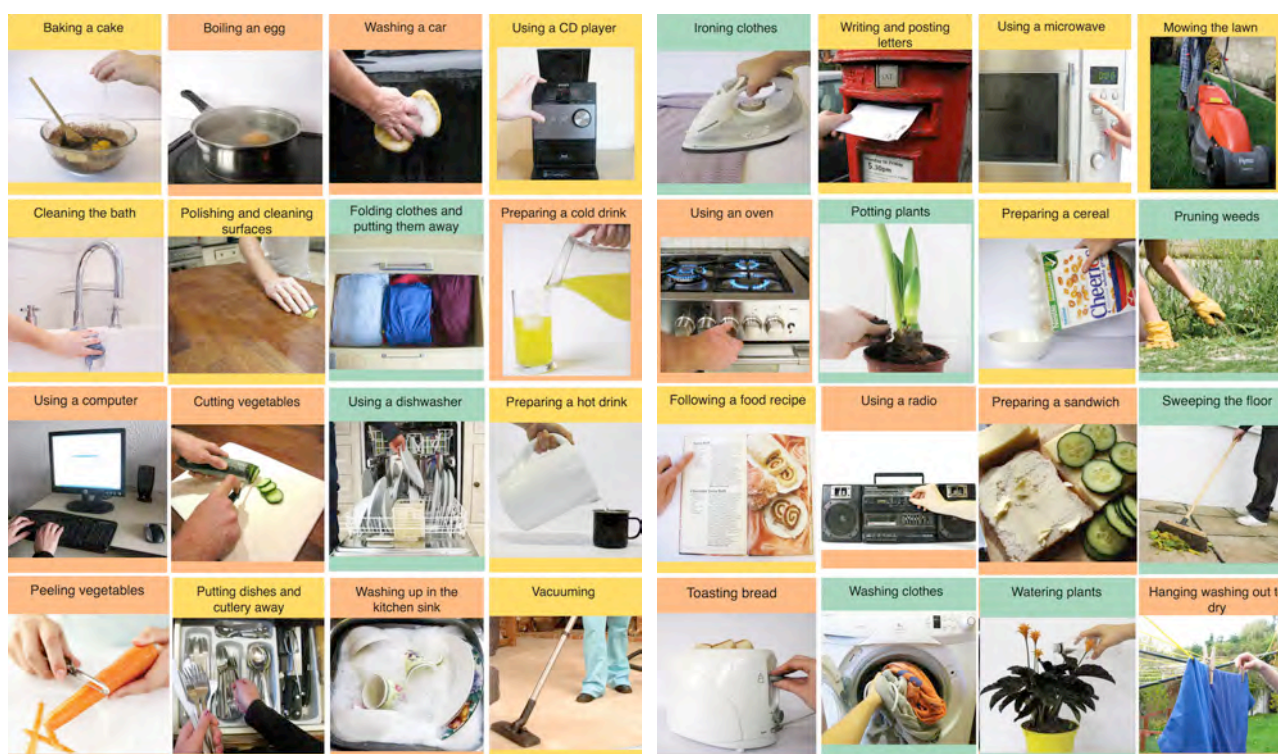


Figure 59. A selection of the *Objects of Everyday Use* cards

In addition to the autistic adults at Beeching Way. The *Objects of Everyday Use* cards were sent out to everyone that Kingwood supports with a self-addressed stamped envelope. Each participant received a raffle ticket, so on receipt of the completed cards each participant automatically entered into a draw to win a £20 gift voucher. There was no pressure of time and the cards could be filled out as and when was appropriate for the participants.



Seventeen autistic adults (with the help of their support staff) participated and completed the *Objects of Everyday Use* cards, generating rich insights (see Appendix 30 and 31). Although some of the autistic participants drew and wrote on the cards themselves, the majority of the cards were filled out by the support staff, therefore the level of detail varied, dependent on how well the support worker knew the autistic adult. The designer was not present during this stage so it is unclear how much the information came directly from the autistic participant or derived from the support staff's interpretations. The cards enabled the research team to explore patterns and correlations between the most popular and least popular activities, the amount of support required to perform an activity and the reasons, when possible, why the participants liked or disliked various activities.

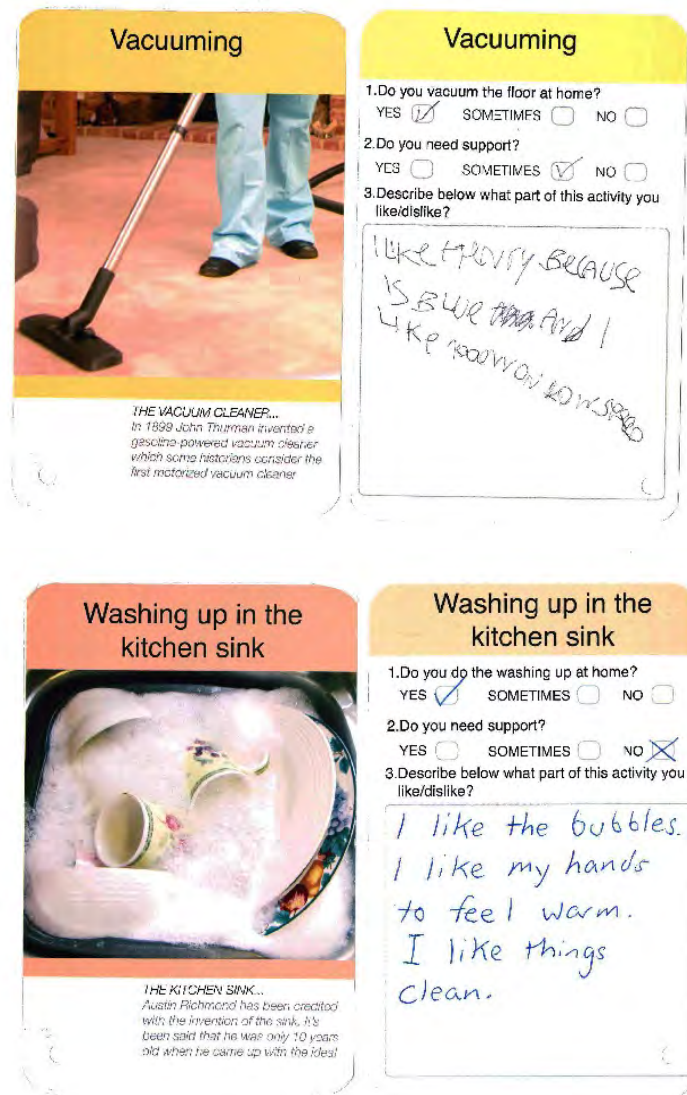


Figure 60. Two completed *Objects of Everyday Use* cards

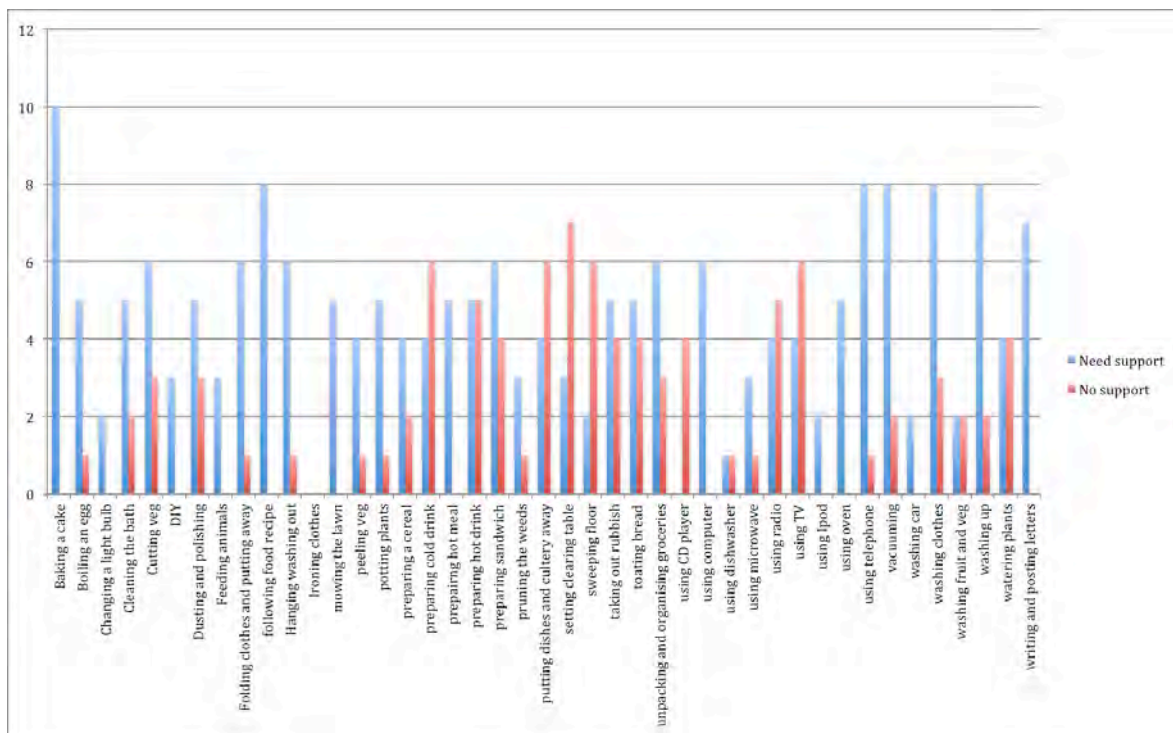


Figure 61. A graph to illustrate the level of support required for an everyday activity

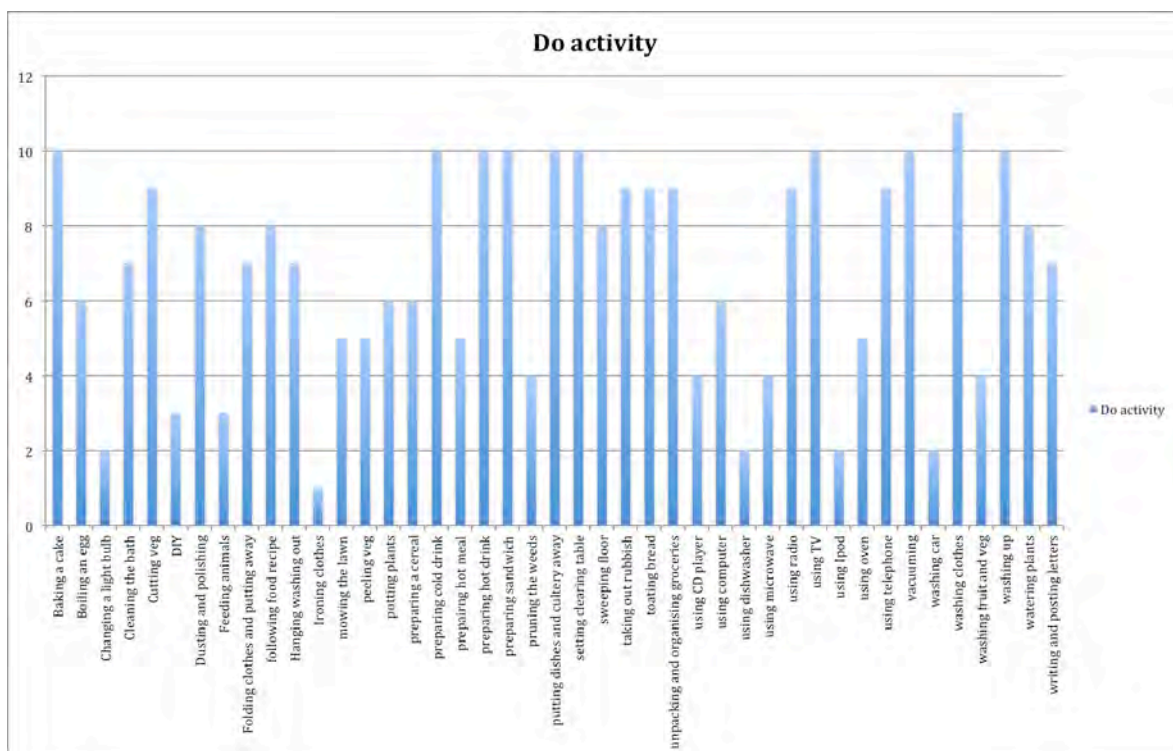


Figure 62. A graph to illustrate the most popular and least popular everyday activities

Figure 61 illustrates how baking a cake, following a food recipe, using a telephone, vacuuming, washing clothes, and washing-up required the most support. Activities such as setting and clearing a table, preparing a cold drink, putting dishes and cutlery away, sweeping the floor and using the television required the least support.

Figure 62 illustrates how washing clothes was the most popular activity followed by baking a cake, preparing a cold drink, preparing a hot drink, preparing a sandwich, putting dishes and cutlery away, clearing a table, using a television and washing up. The least popular activities were changing a light bulb, DIY, feeding pets, ironing clothes, using a dishwasher, using an iPod and washing a car.

The *Objects of Everyday Use* cards supported some of the designer's initial observations in stage one, for example the designer had observed that several participants like bubbles, and the *Objects of Everyday Use* cards revealed that a person's interests such as bubbles motivated them to do the activity of washing up. The feedback from the cards also echoed Kanner's observations of the children in his office, as they showed how the autistic participant's motivation for doing an activity was influenced by their sensory preferences and fuelled by the sensory feedback of the activities, rather than the intended affordance for doing the activity. For example some participants enjoyed boiling eggs to watch the egg move around the pan, putting cutlery away to hear it chime, and pegging clothes on a washing line to watch them move in the breeze. Equally some participants avoided certain activities due to their sensory sensitivities, for example avoiding vacuum cleaning and mowing the lawn because of the sound and washing up because of getting wet. Illustrated below is a selection of comments that describe how the sensory feedback of the everyday activities can influence a person's propensity for performing an activity (Figure 63).



Figure 63. Responses to six everyday activities using the *Objects of Everyday Use* cards

One of the most useful outputs of the *Objects of Everyday Use* cards was identifying the everyday tasks that the autistic participants found to be the most difficult. Vacuum cleaning, washing clothes and toasting bread in particular were reported as requiring the most support and therefore warranted further investigation as to why. Although each of those three activities can be summed up in two words, the designer began to appreciate all three are a sequence of many smaller tasks, each with their own respective challenges. Each of these sub-tasks could be the potential ‘roadblock’ that, if identified and removed, would make the overall task seem much more attractive to a person with autism.

In response to this and to help identify how each activity challenges or complements the participants' capabilities, the designer developed *Doing Things with Things* - a series of booklets that visually breaks down activities into manageable steps, to help guide the autistic participant through the actions required to perform the activity (Figure 64). By taking a holistic view of one activity, the aim of the booklet is to encourage self-evaluation, identify opportunities for support and to record how a person has progressed over time.

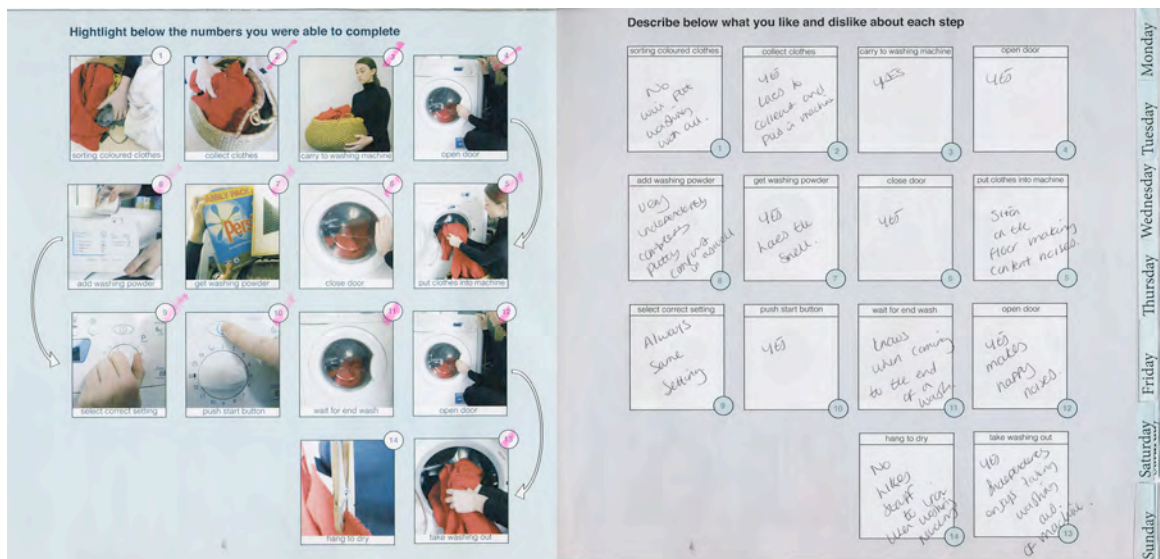


Figure 64. A completed *Doing Things with Things* booklet

The designer distributed *Doing Things with Things* booklets to three autistic adults and their support staff, which they filled in over a six-week period. The booklets helped to guide the support staff to observe and record the autistic person's performance in doing the activities, and documenting anything the person they support liked/disliked or found easy/hard during the activity and articulate reasons why (see Appendix 32). Altogether 35 sub-tasks were observed and recorded; 14 from washing clothes, 13 from vacuum cleaning, and 8 from toasting bread. The graphs below illustrate the participants' ability to perform each step of the activity (Figure 65). The numbers on the vertical axis correlate with the steps involved within each task and the numbers on the horizontal axis indicate the participant's ability to perform each step. The red bars therefore indicate the participants ability to perform the steps involved in washing clothes, vacuum cleaning and toasting bread, and simultaneously highlight which steps the participants found difficult; step one in washing clothes (sorting coloured clothes), step

one in vacuum cleaning (getting the vacuum cleaner), and step three in toasting bread (setting the dial).

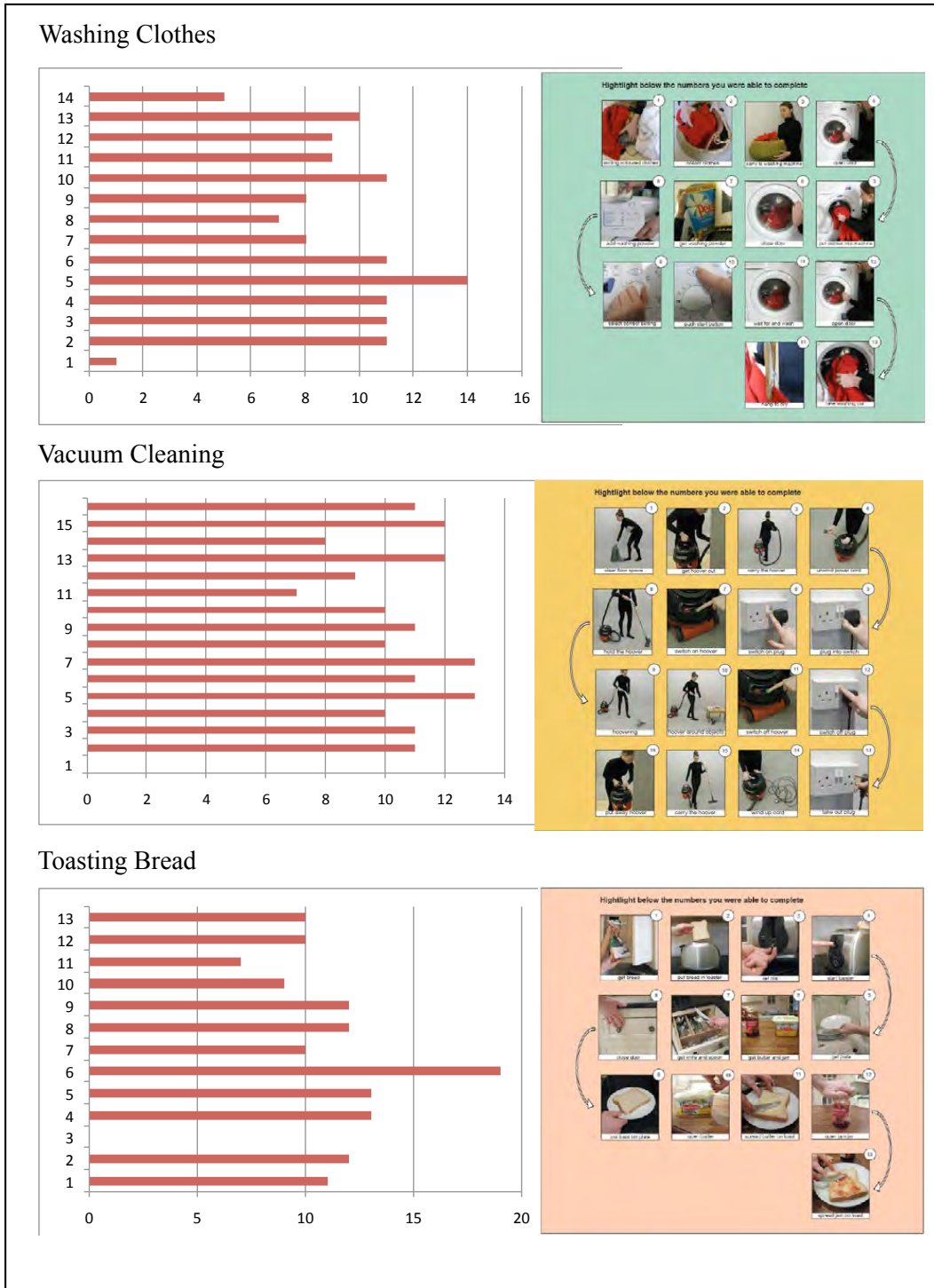


Figure 65. The red bars (above) illustrate how many of the steps involved in washing clothes, vacuum cleaning and toasting bread the autistic participants were able to complete

*Findings:* The booklets were filled with descriptive observations made by staff, which helped to pinpoint what the autistic participants liked/disliked about each activity, how they chose to afford each activity and where the affordance of each activity did not complement a person’s capabilities (Table 9). For example one participant enjoyed step eight in washing up (putting the soap power in the washing machine) because he likes the smell. The action of winding the vacuum cleaner lead proved to be difficult, and another participant wanted to have his washing machine on all day. Pinpointing which part of an activity the autistic person finds difficult, and detecting where in an activity a person may need extra prompts and support, helps identify what affordances need to be adapted or designed differently to complement a person’s capabilities. For example some participants disliked operating a toaster because of the unpredictability of the toast popping up, which might be prevented by adding an affordance (a visible timer) to enable a person to anticipate when this might happen to mitigate sensory discomfort.

Likes	Dislikes
<p>Likes to leave the hoover running  Loves to sit on the floor and winds the cord  Enjoys opening the washing machine doors  Enjoys hanging the washing out  Enjoys turning the washing machine dial  Loves putting washing powder in  Loves to take washing powder out and smell it  Loves to collect washing and put into the machine  Sits on the floor and makes content noises when doing the washing  Makes happy noises when he opens the washing machine door  I like hoovering my flat to make it tidy  He seems to like to get rid of the little bits on the carpet  Does not turn the washing machine off likes to keep it going  Loves to switch washing machine on as he enjoys it  Likes putting the vacuum cleaner away as he does not like to hoover  Likes the smell of the washing tablets  He likes the sound of the vacuum cleaner  Enjoys opening the washing machine door  He would have the washing machine running all the time  Likes putting his thumb through the bread</p>	<p>I find it difficult to wind the cord  I don't like having to move my things  Struggles with switch  Can sometimes finds coordination a little hard to use switch  Finds the wind up cord difficult  Becomes agitated sometimes when taking plug out  Will not move any objects  I don't understand sorting clothes into colours, and it makes me anxious  Select settings – I don't like it if I don't understand  I don't like hanging things out to dry as it's difficult to do  Finds the coordination of plugging hoover into a switch difficult  Finds it difficult to push over the carpet  The only thing he won't do is turn the dial  He does not like butter but will get out other spreads  Finds it difficult to hoover around furniture  Finds it difficult to put one slice of bread in each hole</p>

Table 9. A table describing what the participants liked and/or disliked about the activities

Generally, the *Doing Things with Things* booklets encouraged support staff to observe and record how someone they support chooses to engage with different activities. This data can inform future support techniques, and encourage a transfer of experiences amongst staff, with particular value to new members of staff who can benefit from a growing data bank of expertise. By breaking the activities down into steps, the booklets enabled the staff to identify specific details a person likes about an activity, to enhance ideas for future person-centred support. One staff member observed how an autistic participant likes to watch the vacuum cleaner lead swirl as it is wound. This observation gave the support worker the idea to take the thing the person liked (the swirly effect) and apply it to the action of using a duster when encouraging that person to dust their home.

### 5.6.3 Stage Three: Generating design ideas

To explore an autistic person's everyday experiences further a *Ready Steady Make* workshop was facilitated which invited a mix of 11 new and long-term Kingwood support staff to share their ideas and experiences through the act of making. The aim of the workshop was to encourage the participants to share and exchange their different everyday experiences with the autistic person they support, to gather further insights on how the autistic participants perceive and experience everyday activities. Working in pairs the participants exchanged their experiences through storyboarding (see Appendix 33), which were then brought to life through the making of three-dimensional mini-theatre sets and productions to share with the rest of the group (Figure 66 and 67).

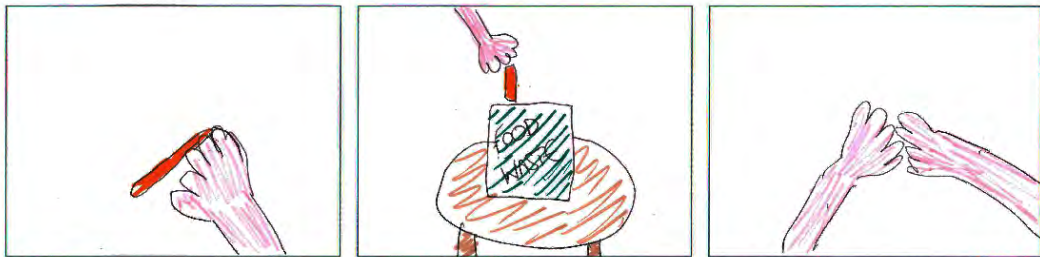


Figure 66. A photographic collage of the *Ready Steady Make* workshop





Millie likes cooking. She rips the lid off the bin + brings it to the table... To chop carrots!



She likes to feel the carrot skin between her fingers... Before putting them individually in the bin She gives me a high five and is pleased with herself



This is me and this is James, James has limited speech. One day I could tell James was trying to tell me something pointing at washing machine. So we got the washing to start a wash.



'washing machine' This made James very happy watching the washing spin.

Figure 67. Two storyboards drawn by support staff during the *Ready Steady Make* workshop

#### **5.6.4. Design Output: A bubble blowing vacuum cleaner**

The designer's observations and the *Objects of Everyday Use* cards clearly revealed that an autistic person afforded everyday activities quite differently to the designer. An autistic person notably responded to the visceral qualities of an activity. Furthermore they were motivated to perform an everyday activity due to the sensory feedback the activity gave them. One visceral and sensorial theme that kept repeating through the designer's observations was bubbles. The designer noted that activities that involved bubbles were particularly popular such as washing up, boiling an egg, cleaning the bath, and watching porridge bubble in the pan.

The *Doing Things with Things* booklets also had an equally recurrent theme. In this case vacuum cleaning was an activity that many participants had identified as needing more support with, in particular because their attention to carry out the activity was limited, usually to as little as a few seconds. Requests and prompts from the support staff to encourage more vacuuming were ineffectual. So having identified one clear theme of delight from her research and one clear theme of difficulty, there seemed to an opportunity developing, that could lead to a design solution.

Therefore the designer decided to explore ways in which vacuum cleaning can become a more meaningful and enjoyable experience. The designer used the completed *Objects of Everyday Use cards* to look for patterns and correlations around the everyday activities the participants liked to do and the reasons given. Washing up was found to be a particularly popular activity largely due to the bubbles. In response to this the designer began to explore ways of extending bubbles into other activities such as vacuum cleaning, so making the pleasurable element – the bubbles – intrinsic to more than one activity. To achieve this, the designer designed and developed a bubble blowing vacuum cleaner (Figure 68).



Figure 68. The bubble-blowing vacuum cleaner, used in Trial One

The bubble attachment for the vacuum cleaner was made by adapting an off-the-shelf bubble-blowing toy. The toy's fan was removed, original power source and gear train were left in order to actuate the bubble wands and it was attached to the vacuum cleaner in line with the exhaust vent to blow bubbles from the rotating wands. The designer wanted to ensure that the bubble blower could be robustly affixed to the vacuum cleaner in order to resist knocks, yet be taken off when required. To ensure the bubble blower could withstand impacts and be removable, a compliant boss and stud fixture was adhered to the outer body of the vacuum cleaner and with the bubble blower affixed with washers and nuts. A Henry style vacuum cleaner was chosen due to the simple design, wind-up cord, expressive face and range of colours available. The designer had also observed that this style of vacuum cleaner was the most popular choice for the autistic people Kingwood support.

### 5.6.5 Stage Four - Evaluation

Two trials were conducted to investigate whether incorporating a person's interest and sensory preference into everyday activities could intrinsically motivate the autistic adult to do the activity and enhance positive experiences. Each trial was formed of three stages; in stage one (weeks 1-2) the bubble blowing vacuum cleaner was introduced to the participant without the bubble attachment. In stage two (weeks 3-4) the bubble attachment was introduced with instructions to switch the attachment on mid vacuum cleaning. In stage three (weeks 5-6) the bubble attachment was removed. The support staff were given a new *Doing Things with Things* booklet for each stage of the trial to record their observations, and they were also encouraged to take photographs and film.

#### Autistic participants

The manager at Beeching Way suggested to the designer two autistic participants who might like to take part in the vacuum cleaner trial, based on the fact they both like bubbles but have little motivation for vacuum cleaning. This was confirmed by their mapped sensory preferences, which demonstrated the participants enjoy such things as interacting with water, the colour red, and household sounds (Figure 69, see Appendix 19). Both participants gave consent to take part in the trial via their support staff and were given a two-month notice period before the trial started. Two autistic adults at Kingwood (Nathan and Zac) participated in the evaluation stage with the help of their support staff. Below is a description of Nathan and Zac (with additional insights based upon their triad of strengths) drawn from information in their communication passports.

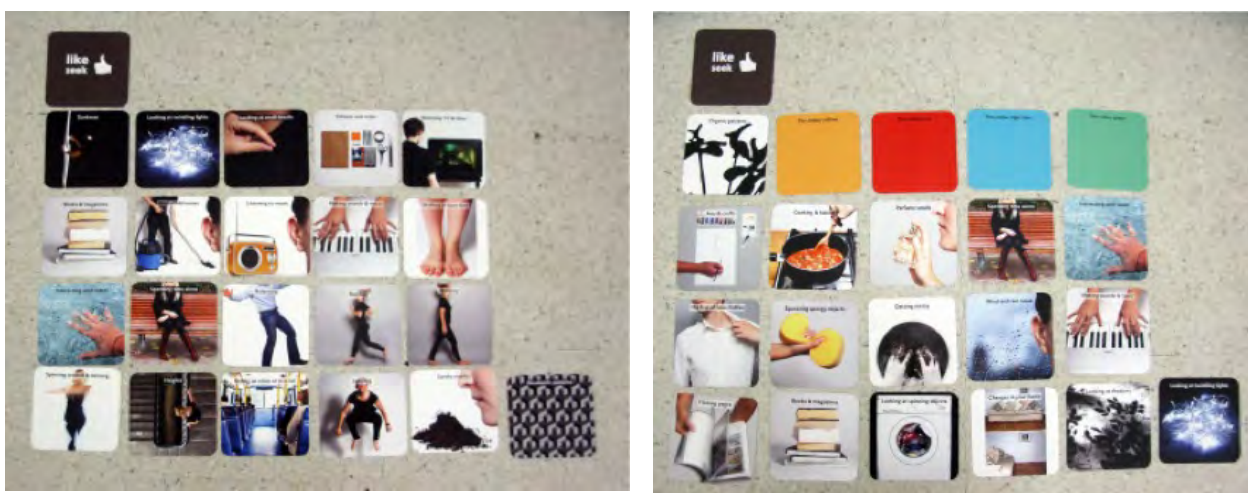


Figure 69. The participants' sensory preferences

*Nathan* enjoys listening to music, shopping for books, CDs, magazines and going out in the car, he trampolines, and swims and enjoys watching Disney cartoons on his computer. *Nathan* dislikes too much noise, people talking too much around him and the sound of crying babies; he always has his washing machine and tumble dryer on whether there are clothes in there or not, because he likes the sound they make.

*Zac* likes the films *Titanic* and *Mama Mia*, he especially likes the song ‘Honey – Honey’ and ‘Dancing Queen’ by Abba. *Zac* likes bowling, blowing bubbles, making cakes, washing his hair, wrapping presents for his family, drawing and using the computer. *Zac* dislikes it when people use his television, cauliflower, and when people click and point their fingers.

Pre-trial, a colour picture of the red Henry vacuum cleaner was also sent to the autistic participants, to help prepare them for the arrival of a new vacuum cleaner. The designer visited the participants and support staff at the start of stage one and then after each stage of the trial (equating to every two weeks). This enabled the designer to hand over the new recording booklets and reiterate the instructions for the next stage of the trial and ask/answer any questions.

#### **5.6.6 Trial One**

Is it a strange thing to encourage vacuuming at all? Do any of us enjoy it?

During her first visit the designer witnessed the difficulty of introducing the vacuum cleaner to *Nathan* - the autistic participant (Figure 70). Despite showing an initial interest in getting it out of the box and putting it together and even using it for one minute in his flat, the participant soon wanted it out of his flat as he was happy with his existing vacuum cleaner. The support worker suggested storing the vacuum cleaner in the cupboard beneath the communal stairs and reassured the participant that it is not for his flat but to be used in the activity room upstairs where he regularly plays on the computer (a favourite activity). The participant was happy with this and soon placed the vacuum cleaner at the back of the cupboard. The support worker was very pleased that the participant independently did this because it gave him a sense of ownership of the vacuum cleaner. Sixteen record sheets in total were completed by support staff for trial

one: two in stage one, seven in stage two and seven in stage three (Table 10, see Appendix 34).

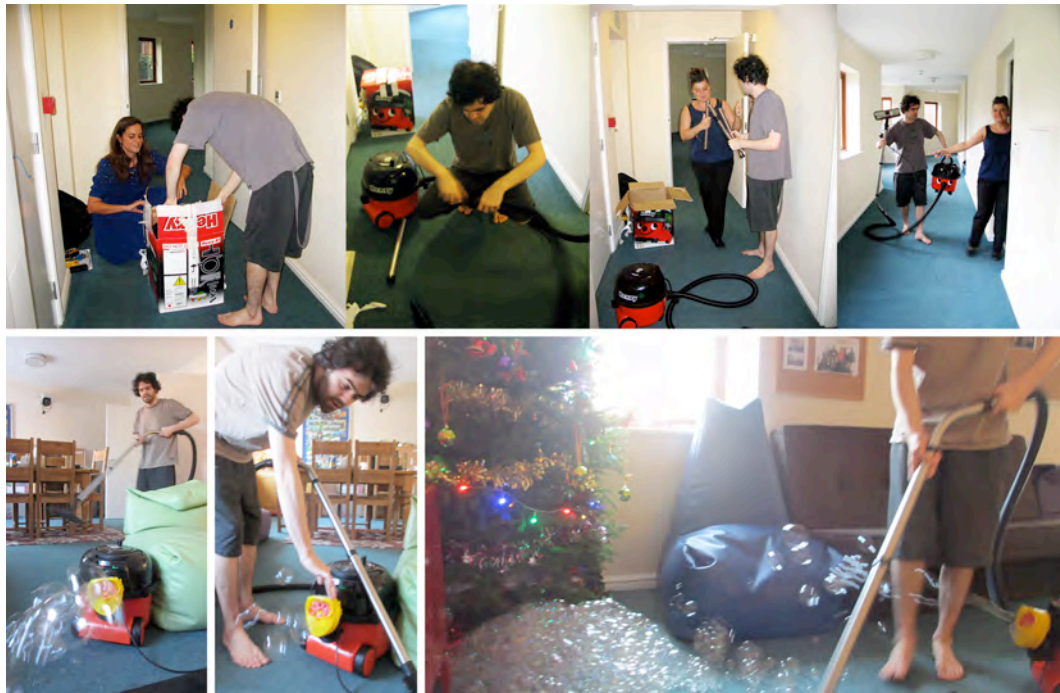


Figure 70. Introducing the vacuum cleaner during Trial One

Stage One															
Step.1 Clear floor space	Step.2 Get Hoover out	Step.3 Carry the Hoover	Step.4 Wind the cord	Step.5 Plug into switch	Step.6 Switch on plug	Step.7 Switch on Hoover	Step.8 Hold Hoover	Step.9 Hoovering	Step.10 Around objects	Step.11 Switch off Hoover	Step.12 Switch off plug	Step.13 Wind up cord	Step.14 Put away Hoover		
He doesn't do a lot of clearing before Hoovering as he likes his stuff to stay in certain places around which he will Hoover	He does it quickly and with confidence. He perhaps likes the fact that he always finds it in the same place.	He carries it vigorously, sometimes runs with it up the stairs He might like the ability to pace himself up, prepare for the activity whilst carrying.	He might not be very patient with doing that (unwind cord), sometimes one strong pull will be sufficient for him	He is focused when he does it and tries to get around that He might like plugging in as its short-time movement and apart from getting it right there may be a degree of noise – "clicking" present.	He appears to understand the need to switch on plug, he doesn't pay much attention to this step, yet might like it as its an easy movement on his part.	He doesn't hesitate to use the switch on button. He might like the fact that it will immediately initiate the Hoover.	He seems to be holding the Hoover, perhaps him a feeling of being in control of the activity.	He seems to like the noise coming out of the Hoover, he appears to enjoy picking things up from the carpet though not for long.	He appears to enjoy a little challenge of getting around various shapes. He becomes more focused but if it takes too long he discontinues.	He is happy to use the switch off button as it may be linked to the feeling of relief once the activity is finished.	As with plugging in	He doesn't do that (wind up cord) as it requires more patience, is more time consuming and his attention may already be on something else.	He leaves the Hoover out on occasions, but more often he'll put it back as he appears to enjoy certain order in the flat to be maintained.		
Stage Two															
Step.1 Clear floor space	Step.2 Get Hoover out	Step.3 Carry the Hoover	Step.4 Wind the cord	Step.5 Plug into switch	Step.6 Switch on plug	Step.7 Switch on Hoover	Step.8 Hold Hoover	Step.9 Hoovering	Step.10 Around objects	Step.11 Turn bubble machine on	Step.12 Hoover with bubbles	Step.13 Switch off Hoover	Step.14 Switch off plug	Step.15 Wind up cord	Step.16 Put away Hoover
He wouldn't clear the floor space as once he organised all things around the room the way he like them to be he doesn't move them and wouldn't like anyone to move them	He likes putting the Hoover out, he usually sings when doing it as he likes it when the Hoover is clean, so when taking the Hoover out of the cupboard he is probably imagining a picture of a clean carpet in his head and singing when he sees it.	He thinks more in pictures the process of Hoovering is very quick for him, he wants to put the Hoover onto the carpet as soon as possible to start the task immediately.	He can do it for a bit but then goes immediately to the process of Hoovering so I have to help him with unwinding the cord.	If the Hoover doesn't make any sound Eddie would always look to see if everything is on, he is very aware of what to press.	He knows very well when to do it.	He know very well that in order for Hoover to be working he needs to switch it on, so he does it himself.	He normally holds the Hoover with both his hands. This is because he wants to have a full control in the activity he is doing and also as a result of his full concentration on the task, usually only at the very beginning of the test.	He can concentrate very well on the test he is doing but his concentration is very short and he's got to be prompted to continue if the test requires also as a result more time and concentration.	He wouldn't normally move any objects so he would rather move the Hoover around them	He wouldn't normally move any objects so he would rather move the Hoover around them	He wouldn't normally move any objects so he would rather move the Hoover around them	He would always switch off the Hoover as he likes to have control over things making sounds and noises, so he always remembers to switch the Hoover off.	He doesn't have enough patience to wind up the cord as he can't concentrate for too long on this task. He needs some verbal and physical help to do it.	He doesn't have a clear picture in his mind what to do with the Hoover and where to put it, so his mind moves to another picture of him on the computer.	He has to be reminded to put the Hoover away, this is probably because he thinks more in pictures and the Hoover is new to him he doesn't have a clear picture in his mind what to do with the Hoover and where to put it, so his mind moves to another picture of him on the computer.















Stage Three													
Step.1	Step.2	Step.3	Step.4	Step.5	Step.6	Step.7	Step.8	Step.9	Step.10	Step.11	Step.12	Step.13	Step.14
Clear floor space	Get Hoover out	Carry the Hoover	Wind the cord	Plug into switch	Switch on plug	Switch on Hoover	Hold Hoover	Hoovering	Around objects	Switch off Hoover	Switch off plug	Wind up cord	Put away Hoover
													
He picked up some plates when prompted	When prompted he got out the Hoover from the cupboard	He pulled the Hoover from the cupboard into living room without being prompted	He pulled out the power cord without prompting		He switched Hoover plug on independently	Edward switched on the Hoover	He held Hoover independently with no prompting	He Hoovering independently	He Hoovered around his table	He switched off the Hoover after some prompting	Needed quite some prompting to turn off switch	He needed P/H to rewind cord	He did not want to put Hoover away needed P/H

Table 10. Support staff’s observations during stages one, two and three of Trial One

Although the sensory preference cards revealed the participant disliked change to his home environment, the designer underestimated quite how much the replacement of a seemingly interchangeable and relatively mundane object as a vacuum cleaner would affect him. He refused to allow the vacuum cleaner into his flat at all, and the trial had to be moved to a communal space with the vacuum cleaner kept out of sight in a cupboard.

The prototype had clear flaws in regards to compatibility with this participant. Firstly it blew out too many bubbles making the carpet wet. Having reflected on the sensory cards they reveal participant liked to walk in bare feet, and the feeling of the carpet on his skin may well have made him feel uncomfortable. This theory was backed up by later anecdotal evidence from the support staff explaining he dislikes wet surfaces. Secondly, the bubbles came out at such a rate that they landed on top of each other, creating mounds. Again, returning to the sensory preference cards shows the participant dislikes getting messy and being untidy. So it may well have been that the participant saw the vacuum cleaner as something that created, rather than removed, mess. Finally the vacuum cleaner’s bubble attachment made a distinct and noticeable (if not loud) sound, a report from one of the participant’s support staff revealed that the participant disliked this sound. Although his sensory preference cards had identified him as someone that liked household sounds, participatory observation revealed that he is very sensitive to sound. He enjoys listening to the vibrations in the fish tank and washing machine but dislikes the sound of a lawn mower and high-pitched voices. In light of this, one staff member commented on how the bubble attachment made a loud sound,

and because the bubble attachment was new to the participant, he may have not understood what the sound was, therefore no control over how to turn it off.

The record sheets covering the time until the designer's next visit clearly describe how the participant does not like change or things to be moved, hence he will vacuum around things. During stage two of the trial the participant only showed an interest in the bubbles on one occasion, the rest of the time he was not interested. One staff member suggested that it might be because of the unpredictable movement of the bubbles, which also created a wet residue on the carpet. During this stage the bubble attachment also broke and went missing, which was not reported to the designer until her next visit.

On her subsequent visit one staff member suggested to the designer that the participant may have thrown the bubble blowing attachment away as he often throws away things he dislikes. This might be a clear indication that it was something he disliked and did not want to see.

The participant was clearly motivated by computer time, which was his reward once he finished vacuum cleaning. As the vacuum cleaning took place in a communal space, near to the incentive of the computer, the trial conditions were altered in a way that made it harder to glean useful feedback. On one occasion he did not vacuum at all because there was no pc/laptop available for computer time. Although this behaviour wasn't what the designer had hoped for, it does illustrate that the participant was motivated by his special interest, in this case watching Disney cartoons on his computer.

During the evaluation trial the designer visited the participant's flat and observed that every piece of electrical equipment was switched on, such as the washing machine, tumble dryer, fans and lights. This interest in electrical equipment was undocumented and therefore the designer began to question how ethical it was to introduce yet another piece of equipment (the bubble blowing vacuum cleaner). Had the trial been successful the participant may well have wanted to keep the vacuum cleaner constantly switched on, causing a noisy and possibly dangerously wet environment. As the support staff



were obviously trying hard to lessen the participant's dependence on electrical appliances, it seemed at odds with their efforts to encourage the use of another one.

### 5.6.7 Trial Two

Based on the feedback and results from trial one plus the fact that the bubble attachment went missing, a new bubble attachment prototype was re-designed (Figure 71). The adjustments made were as follows:

- The design was simplified and, to save time and money, the prototype consisted of a shop bought bubble machine, simply attached to the vacuum cleaner using strong Velcro, which meant it was now easy to attach and detach.
- There were two prototypes so if an attachment went missing it could be easily replaced.
- The bubble attachment emitted less bubbles than the first, preventing the carpet from getting too wet.
- The bubble machines were also a lot quieter and more muted in colour compared with the initial prototype.



Figure 71. A revised bubble attachment prototype for Trial Two

This trial was unsuccessful. Despite delivering the *Doing Things With Things* booklets to the support worker and describing the process, the trial was not recorded in the booklets. Instead the support staff's general observations were typed up. An extract of her observations are below (Table 11).

<b>28th August</b>	I arrived in Zac's flat and asked him if he would Hoover with the red Hoover for Katie he saw 'Hoover women', sorry Katie you are known as the Hoover woman. Zac was keen to clean his flat, so I asked him to get the Hoover from the cupboard. Zac unlocked the cupboard and brought the Hoover to the lounge. Zac plugged it in with no prompting then started hoovering. He carried the Hoover to the bedroom, to Hoover and when he finished I asked him to put it away he went to the plug and unplugged it before winding the cord.
<b>1st September</b>	Refused to Hoover with red Hoover happy to Hoover with his yellow one.
<b>25th September</b>	Arrived at Zac's flat to ask him to Hoover with the red Hoover, he didn't want to Hoover. When talked into cleaning his flat he took the red Hoover out of the cupboard then the yellow one and hoovered with the yellow Hoover.
<b>16th October</b>	Went to Zac's flat to ask him to Hoover he was not going to Hoover with the bubbles we let him look at the attachment then asked again to Hoover he didn't want to Hoover with the red one so I got it out and left it in his lounge. We talked about the bubbles and the red Hoover I filled the bubbles and put it in the Hoover I plugged it in and the bubbles started. Zac watched for a while but still refused to Hoover we kept asking he eventually got up to Hoover and just hovered. He was completely oblivious to the bubbles. Holly was working with him that day and while he was hoovering the bedroom she kept saying oh Zac look at the bubbles but Zac was too busy hoovering. He finished the hoovering and stopped to watching the bubbles, Holly tried to encourage him to touch the bubbles as they blew out Zac reached out and told the Hoover 'no bubbles', he then walked away from the Hoover and went and sat down.
<b>23rd October</b>	I asked Zac do the hoovering with the bubbles. He went to the cupboard and brought out his yellow Hoover after a lot of prompting Zac changed it to the red Hoover and was quick to plug it in and get started we attached the bubbles Zac was not interested in the bubbles only focused on getting the hoovering done. He was very good and picked up clothes in the bedroom but paid no attention to the bubbles and was keen to finish we tried to draw his attention to the bubbles, he knew there were bubbles but he didn't appear to be very interested.

Table 11. The support staff's observations during stages one, two and three of the Trial Two

The staff member allocated to facilitate the trial was not Zac's support worker but an activity coordinator, therefore unfamiliar to the participant. The activity coordinator also fell ill during the trial, limiting her interaction with Zac (the participant) and communication with the designer. Only five written records were recorded, often with little detail and few photographs were taken. The vacuum cleaner trial was treated as a separate activity in addition to the regular vacuum cleaning Zac does in his flat. This meant the red Henry vacuum cleaner was placed next to Zac's yellow Henry in the same cupboard, which may have caused confusion as Zac insisted on most occasions that he

wanted to use his familiar yellow vacuum cleaner (Figure 72). Zac showed no interest in the bubbles in stage two despite lots of encouragement from the staff (see Appendix 35).



Figure 72. A photographic collage of Trial Two, showing Zac's preference for his yellow vacuum cleaner

Reflecting on the participant's sensory preference cards it was identified that he specifically liked the colours yellow and red. The participant already possessed a yellow vacuum cleaner. Replacing it even with a red coloured (but otherwise identical) vacuum cleaner was more problematic than the designer had hoped for. The designer hypothesised that this could have been to do with the affordance that the participant placed on the colour yellow. Perhaps the colour afforded cleanliness, or at least the act of vacuuming, and to change that colour, albeit to another favourite colour, may have jarringly altered the affordance in the mind of the participant. The participant's disinterest in the prototype may have arisen from a lack of familiarity, or the intrusion of a new object, as felt in trial one. The *Sensory Preference Cards* also reveal a dislike for pushing and pulling, two actions that need to be constantly repeated to vacuum even the smallest space. So the participant may not have been the ideal candidate for the trial. To compound this issue, the activity coordinator who ran the trial insisted on treating it as an extra activity on top of the participant's everyday activities, meaning the participant was asked to vacuum and then had to repeat the task with the prototype vacuum cleaner, lowering any chance for a natural enthusiasm to appear. The designer witnessed that the participant was fond of bubbles, and played with a bubble wand on

the first day of the trial to compensate for the fact that due to the terms of the trial he would have to wait for two weeks until the bubble attachment was added to the vacuum cleaner. But the evidence from the trial was that he showed no interest at all in the bubbles when they came out of the prototype. The designer hypothesised that the participant's enjoyment of bubbles comes down to context and an element of self-determinism. The participant is in control of the bubble wand and blowing his own bubbles, at his own pace. Yet the bubble vacuum cleaner set its own velocity and size of bubbles, perhaps contributing to his lack of interest in them.

### **5.6.8 Evaluation**

The success of the evaluation was dependant upon the dedication, interest and involvement of the support staff, which at times was compromised due to staff illness, varying shift patterns, time constraints and changes to management. This resulted in mislaid evaluation forms, time and workload constraints meant that the evaluation was not given priority.

As both the participants had identified a dislike of pushing and pulling via their sensory preference cards, another route that the designer could have taken was to make the physical action of vacuuming easier for the participants. A vacuum cleaner is a noisy appliance that makes brief and aurally jarring appearances in the home. By adding yet more visceral sensory levels on top of the sound, with the sight and feel of the bubbles, it may have been too much of a sensory overload for the participants to easily accommodate.

In study two the designer sought advice from the manager who suggested who to invite for the evaluation. However during the evaluation trial another staff member informed the designer that the autistic participant does not like change, wet surfaces or even bubbles in his bath (all things involved in the trial). This illustrates that important information about a person's likes and dislikes does not always get shared between staff. If the designer had been made aware of this information pre-evaluation, another person may have been invited to participate.

The designer also began to contemplate the attainability of the ultimate goal of the bubble blowing vacuum cleaner i.e. getting autistic people to “have active engagement in everyday tasks”; in this case vacuuming. The best, and perhaps only way to make anyone have a long-term active engagement in a task is to make it enjoyable. Yet using a vacuum cleaner is for the vast majority of people (neurotypical or otherwise) a chore. To make vacuuming more enjoyable for anyone would be a challenge, but to make it more enjoyable for someone who affords a vacuum cleaner in a totally different way and has no concept of the purpose of vacuuming, seemed a significant challenge

### **5.6.9 Summary**

The designer established four stages of the design process. Stage One: Connecting, communicating, building trust and empathy; Stage Two: Gathering context specific insights; Stage Three: Generating design ideas; Stage Four: Evaluation.

*Stage One:* Participatory observation was undertaken with three autistic adults. The designer was able to make observations beyond what was previously communicated to her regarding the participants by support workers, notably that the participants were interested in the unintended affordance of everyday objects.

*Stage Two:* The designer created a series of visual cards *Objects of Everyday Use* as an evolution from text-heavy healthcare information collection techniques such as the Katz ADL Scale and the Lawton IADL. Information on 17 autistic adults was collected and analysed, revealing likes and dislikes of various everyday activities around the home. Three of the more troublesome activities were broken down into sub-tasks and visually catalogued in a booklet *Doing Things With Things*. The booklets were distributed to three autistic adults and their support staff, asking them to make observations about each sub-task.

*Stage Three:* A *Ready Steady Make* workshops was conducted with 11 support staff that gathered further insights on how the autistic participants perceive and experience everyday activities.

*Stage Four:* Two autistic participants and their support staff took part in an evaluation trial formed of three stages; in stage one (weeks 1-2) the bubble blowing vacuum cleaner was introduced to the participant without the bubble attachment. In stage two (weeks 3-4) the bubble attachment was introduced with instructions to switch the attachment on mid vacuum cleaning. In stage three (weeks 5-6) the bubble attachment was removed.

### **5.6.10 Reflection**

In study two the design tools emerged through the practice. For example participatory observation in stage one, revealed how sensorial aspects of the environment triggered both joy and anxiety. An incidence of challenging behaviour occurred during this stage and whilst it is difficult to ascertain the reason for this, it suggests that the designer's presence can affect the situation. Consequently, as in study one, in stage two the designer developed a range of design tools that could be used remotely without her presence to generate context-specific insights on how the autistic adults at Kingwood engage in everyday activities. The support staff facilitated the tools with the people they support, and in doing so it encouraged them to reflect on their practice and inspire new person-centred support techniques. For example one staff member identified in the *Doing Things with Things* booklet activity that the person she supports enjoyed the flicking of the vacuum cleaner lead, which led her to think about how this action preference could be extended into other activities. As in study one, the co-creation workshops and tools in stage three enabled the support staff to express and share their ideas, thoughts and generate more insights about the autistic people they support. Stages one, two and three generated insights, which helped to create a holistic impression of the autistic participants in the research and to develop ideas around adapting everyday objects.

On reflection there are three identifiable experiences that informed the design and development of study three.

1. In stage four the participant threw away the bubble attachment, which presumably signified that he disliked it. In study three it is important that before the selected artworks are permanently fixed to the walls, there is an opportunity

for the participants to communicate their preference for the artworks, by destroying or throwing them down.

2. As the participants in study one appeared unaffected by the introduction of a completely new garden, in study two the designer had not anticipated the autistic participant's dislike for change within a familiar environment. During the first trial the autistic participant did not want the bubble-blowing vacuum cleaner in his home and as a compromise was happy to use it in a communal activity space. In study three it is important to create a smooth transition when making changes to a familiar environment.
3. It was clear in study two that the designer's presence affected the situation as she was essentially adding another dimension of change to the environment. In light of this, study three encourages the support staff to take more of a lead.

## 5.7 Design Study Three: Interior

Study three took place at Kingwood College based in Reading, which is a shared transitional home that provides educational training for autistic adults aged between 18-25 years (Figure 73). The aim of the project was to explore what artworks (if any at all) the five autistic residents would like to have in their home environment, and how to involve the residents in the selection and installation. In contrast to study one and two, the aim of this study was more straightforward and stage three was not applicable because it was not about generating design ideas but working with existing artworks.



Figure 73. Kingwood College with White Barn next door (left)

### 5.7.1 Background

The artworks were supplied by a charity called Paintings in Hospitals. This study built on a previous collaborative project between the designer and Paintings in Hospitals (Gaudion and McGinley, 2014), which explored an autistic person's responses to 21 different categories of artworks, to develop some understanding of how autistic people perceive and experience art. The 21 categories were animals; countryside; photograph/realism; fragmented; buildings; optical; tactile; shapes; polychrome; technical/ detailed; sculpture; everyday life; flowers and plants; people; sea and sky;



abstract; cartoons/comics; impressionist; minimal; pattern/ repetition and monochrome (Figure 74).

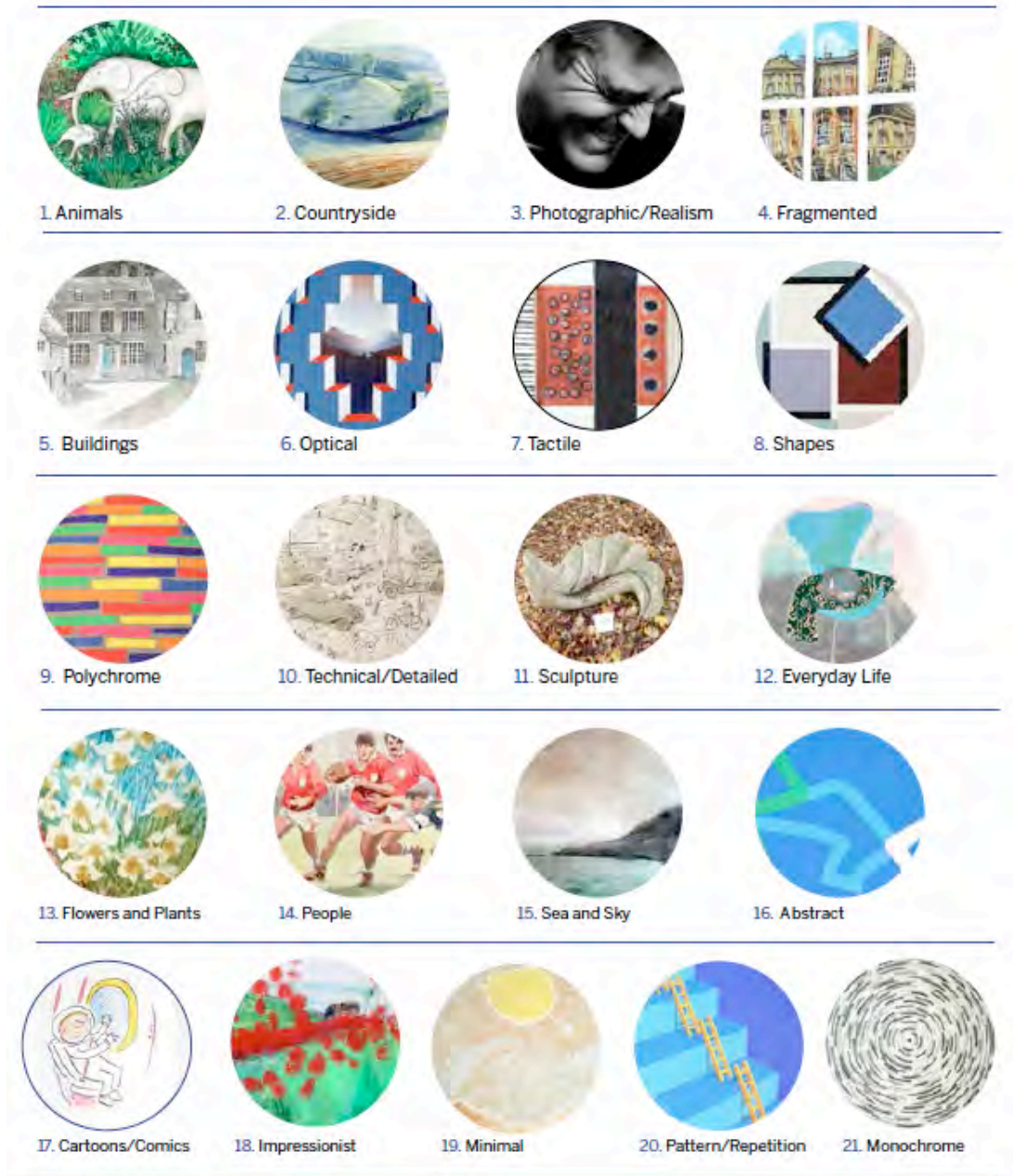


Figure 74. Twenty-one artwork categories

The project invited autistic people across the spectrum, together with caregivers and experts in the field, to express opinions on the 21 styles of art, with regards to what they liked and/or disliked and to qualify (where possible) the reasons for their response. An

online survey, a specially designed booklet and interviews created a rich collection of qualitative insights that helped to identify the types of artwork or qualities within artworks that provide the most interest and positive engagement for autistic people across the spectrum. The designer drew upon patterns and correlations of response, to develop themes that informed 17 artwork principles. These principles are not intended to be prescriptive but instead are suggested as a helpful starting point for consideration when selecting artworks for and with autistic people. The artwork principles helped to frame the designer's perspective on how to mindfully and sensitively approach the area of art for the home with the autistic adults and support staff at Kingwood College. The artwork principles are as follows (Table 12):

1. *Special interests*: Pairing the subject and/or style of an artwork to a person's special interests is a good way to engender positive engagement.
2. *Detailed*: Technically drawn artworks proved popular with some participants who became preoccupied with the level of detail.
3. *Balance/Symmetry*: Artworks that are balanced and symmetrical are important to many people with autism who find uneven or incomplete work frustrating.
4. *Pattern/Repetition/Order*: Artworks with repeating patterns, shapes and details proved to be popular - appealing to a need for predictability and order.
5. *Counting/Systemising*: Artworks with repeating elements that viewers could count and systemise (e.g. leaves or bricks) were seen as relaxing and calming.
6. *Colour*: While the study did not reveal any direct correlations between specific colours and reactions to artworks, it did reveal the general importance of choosing colours with special care for both hyper- and/or hypo-sensitive people.
7. *Narrative*: Artworks that communicate stories and events in a single image that is clear, simple and unambiguous can create a positive experience and trigger dialogue.
8. *Associations*: Artworks that encourage reflection on positive past experiences and associations (e.g. a scene of a seaside resort) are useful to people with autism.
9. *Realistic/Technical*: Artworks with a realistic, precise and accurate depiction of subjects were popular with participants, who were quick to point out any inaccurate details.
10. *Distorted/Fragmented*: Artworks that were neither realistic nor abstract but adopted a distorted or fragmented approach to subjects were widely criticised.
11. *Sound*: It is important to be mindful of responses to artworks that evoke different sounds through colour, texture or pattern (e.g. the buzzing of bees next to flowers).
12. *Tactile*: Satisfaction can be gained from touching tactile artworks that use thick paint and/or other materials such as lace, wood, ribbon or leather.
13. *Foreground and Background*: Some people with autism find it difficult to distinguish between foreground and background, so it is important for compositions to have a focal point and for background detail to be treated with equal importance.
14. *Context*: Vague, incomplete or ambiguous information in an artwork does not give the clear sense of context that many people with autism require to enjoy it.
15. *People*: Individuals with autism can find social interaction and eye contact a challenge, so caution should be exercised in the use of portraits that gaze out directly.
16. *Motion*: Care should be taken in selecting artworks that elicit different movements, rhythms and vibrations, especially three-dimensional objects that require people with poor depth perception to navigate and manoeuvre around them.
17. *Abstract*: Some autistic people are literal thinkers and find it difficult to understand abstract concepts and metaphors. Concrete representational artworks tend to create more positive engagement than abstract work.

Table 12. Seventeen artwork principles

### **5.7.2 Autistic participants**

Below is a description of the five autistic participants at Kingwood College who took part in the selection and installation of artworks.

*Molly* likes being outside, enjoys bubbles, the colour yellow, using the computer, looking at YouTube clips and interacting with staff. Molly is wary of boys who are noisy and bigger than her and will occasionally run away to avoid them.

*James* likes juggling, music, going on the trampoline, McDonalds, playing skittles and used to enjoy swimming. James dislikes wearing shoes and does not like it when people get into his personal space. He finds it difficult when not knowing who is supporting him, and what is happening next.

*Toby* enjoys walking in any weather, using the computer, YouTube, puzzles and colouring. Toby dislikes the sound of babies crying, and loud noises in general.

*Carla* likes to Google and search for a variety of topics, Halloween and Christmas events being particular favourites. Carla likes to watch cartoons, animated movies and singing along to musical movies. Carla likes to go shopping does not like not knowing what she is doing (now and next).

*Emma* enjoys cooking, painting, going on the computer, listening to music, spending time alone, the colour pink.

### **5.7.3 Stage One: Connecting, communicating and building trust and empathy**

*Participatory Observation:* It was important for the designer to familiarise herself and build trust with the autistic participants. Therefore time was spent within their own home. The designer actively engaged with the autistic adults through various activities such as cooking, sensory activities and artwork activities. It was soon evident that this was a creative household and the autistic adults enjoyed making their own artwork, both in their activities room and the art classroom in their garden, even collaborating together on a painting (Figure 71). Some of the autistic adults had independently put their own

artworks on display. Due to this, the manager of Kingwood College was very sceptical of the artwork trial. Initial conversations between the designer and the manager established the manager felt it would be best to encourage the participants to put their own art up in their home, to give them a sense of control and ownership.



Figure 75. A photographic collage of the sensory and artwork activities

The manager saw more value in decorating the home with artworks that the residents had created themselves and the designer wondered whether priority should be placed on supporting the participants to make their own artworks. The designer from the onset began to question the appropriateness of the study. For example, is having artworks on the wall a neurotypical person's preference for how a home should be decorated? Is it important for the walls to remain blank? The artworks were due to be installed in the communal spaces of a shared house whose residents had very different sensory preferences and strong reactions when those preferences weren't respected. A new and potentially emotionally stirring work of art might be a negative thing to some or

possibly all of the residents. As a plain wall was working as a compromise, was that in fact the best option?

#### **5.7.4 Stage Two: Gathering context specific insights**

Art is composed of a variety of textures, colours and shapes, all with different intensities and styles that can affect the ‘feel’ of the environment the artwork is placed in. Therefore, particularly with autistic people, it is in fact important that artworks complement a person’s sensory profile. For example if a person is hyposensitive they might choose and enjoy artworks that include bright colours, rich textures and detail. Conversely, a person who is hypersensitive might feel vulnerable and overwhelmed by too much visual information, and may prefer structured or perhaps visually muted art, where colour, texture and details are limited or compartmentalised.

*Mapping Sensory Preferences:* The autistic adults with the help of their support staff were invited to map their sensory preferences using the *Sensory Preference Cards* produced by the designer in study one (see Appendix 19). This was done to help interpret and inform the selection of artworks based on the designer’s 17 established principles. To give an example of the designer’s methodology, if we compare the sensory preferences of two autistic participants (Figure 76), the person on the right might like artworks with lots of colour, and maybe a collage or sculpture that is rich in texture that they are able to touch. The person likes being untidy and getting messy, therefore they might enjoy artworks that are chaotic and expressive with little sense of order. The person on the left however might prefer artworks that are minimal in colour or have red. The person likes to be tidy so they might appreciate artwork that are neat and concise - perhaps a realistic drawing or photograph. The person likes spending time alone so might prefer artworks without people.



Figure 76. The sensory preferences of two autistic participants

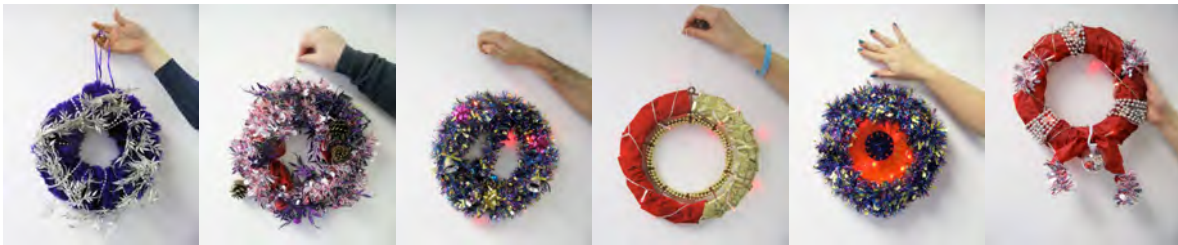
*Ready Steady Make Workshop:* To explore further how a person’s sensory preferences can help inform aesthetic decisions, a *Ready Steady Make* workshop was held with eight support staff. Developing on from the *Ready Steady Make* workshops in studies one and two, each participant was given a set of sensory preference cards, a wooden ring and lots of materials to choose from. The aim of the workshop was for each participant to map the sensory preferences of the autistic person they support, and to explore how this information helps them make informed choices on how to decorate a ring for that person i.e. colour, texture, sound (Figure 77).



Mapping Sensory Preferences



Making and designing



Sensory props

Figure 77. A photographic collage of the *Ready Steady Make* Workshop

Several ambiguities were raised by the support staff with reference to the sensory cards, for example the ‘bus and car’ card revealed how one autistic participant likes travelling in the car but not on a bus, and highlighted how a car and bus can mean two different things to an autistic person, as on a bus involves being with the public and a car is a safe place. The card ‘The sound of household noises’ raised the issue that one autistic participant likes the sound of household noises in in his flat, but not household noises outside of his flat where he has no control.

The *Sensory Preference Cards* encouraged the support staff to reflect and think about the autistic person they support’s sensory response to the environment in more depth, which created new insights. For example the sensory card entitled ‘touching sand’ prompted a support worker to realise that the person she supports does not like sand, which she had not identified before;



He loves the beach but stays in the water the whole time which means it could be something to do with the sand and that's why he stays in the sea. His dad says he loves the seaside. But no he doesn't. He feels safe in the sea because he can't be near the sand... I've never realised that and I would imagine that's what that was (Support worker, 2014).

*Artwork selection activity:* Despite the reservations that arose during participatory observation and speaking with the manager, it was agreed that it was important to give the autistic adults the opportunity to make their own decision on whether they want artworks (other than their own) up in their home, rather than make the assumption that they might prefer to have their own artworks up. The aim of the selection activity was to invite the autistic adults to select an artwork of their choice from the designer's shortlist of 21 artworks, one for each of the categories identified in the previous study, and influenced by the sensory profiling conducted earlier in this stage.

The designer sought guidance from the support staff, who suggested that the participants should have no more than three artworks to choose from, to avoid overloading them with too much choice. To help with this, the support staff went through the 21 artworks and selected three artworks for each person they supported. Their decision-making was based upon whether the subject related to a person's interests and colour preferences (where again the work done with sensory profiling cards came into play). For example, the staff chose an artwork with an elephant for a person who likes animals and a daffodil painting for a person who likes the colour yellow. The staff also identified quickly which artworks to avoid. Through the sensory preferences cards the staff knew to avoid the colour red for one person in particular. Consequently, as it is a shared living space, all artworks containing red were removed from the entire collection.

Five autistic adults participated in the selection activity, which took place in their lounge and lasted on average three minutes per person. The support staff informed each participant about the activity and, as each participant entered the room separately, the three artworks were either spread out on the floor or held in front of them whilst a staff member asked them to point to which picture they liked (Figure 78). Interestingly in

every case the autistic participants chose the artworks, that the staff member had initially thought they would like (Figure 79).

The process of the selection raised the issue of whether the participants were truly engaged in their choice. The participants clearly made a decision between the artworks, but it is doubtful whether they understood that their choice would have the consequence of that picture being displayed in their home. This raised the difficulty the designer also experienced in the first and second studies of not being convinced that the design process was fully participatory – in terms of whether the participants really understood the reasons for their involvement.



184 Figure 78. A photographic collage of the artwork selection activity

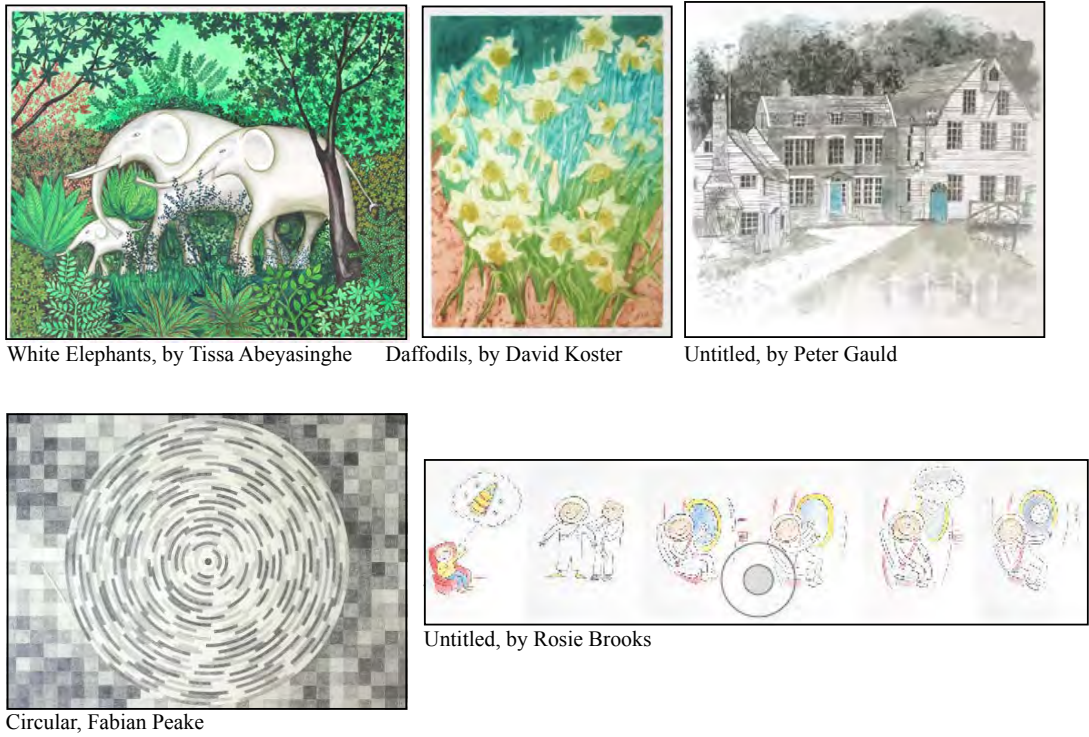


Figure 79. The participant’s selected artworks

**5.7.5 Stage Four: Evaluation**

**Trial One:**

Once the selection process was complete, as a way to offer an important transition before the final installation and to prepare a person for change in their environment, each participant was given a poster of their selected artwork. The autistic participants (with the help of their support staff) were invited to stick the posters on a wall of their choice using white tack; this allowed for the posters to be repositioned (or taken down) if a person dislikes the image, hence it gave the person a sense of control and ownership over the space and positioning of their artwork. During this process feedback postcards were also available for the support staff to note any important observations about a person’s response to the artwork (Figure 80).

After three weeks the designer visited Kingwood College to speak with the staff and find out where the posters had been positioned. During the trial the posters were stuck on the walls with minimal support from their support staff, three of the posters were positioned in shared spaces i.e. kitchen and the sensory room. One poster was

positioned on a wall at the bottom of the staircase as a resident often sits at the bottom of the stairs when he is feeling agitated to try and calm himself down. Another resident put his poster up in his bedroom. The participants' response to the artwork was mixed; a staff member explained that one person would sit on the floor and look up at his artwork and point at it to the staff members passing, whilst other residents were indifferent. The trial however came to an abrupt end when one participant got agitated and ran around the ground floor ripping down the posters. One poster was ripped in half leaving just one daffodil poster remaining on the wall, though it was reported that the same participant hit this poster when passing it.

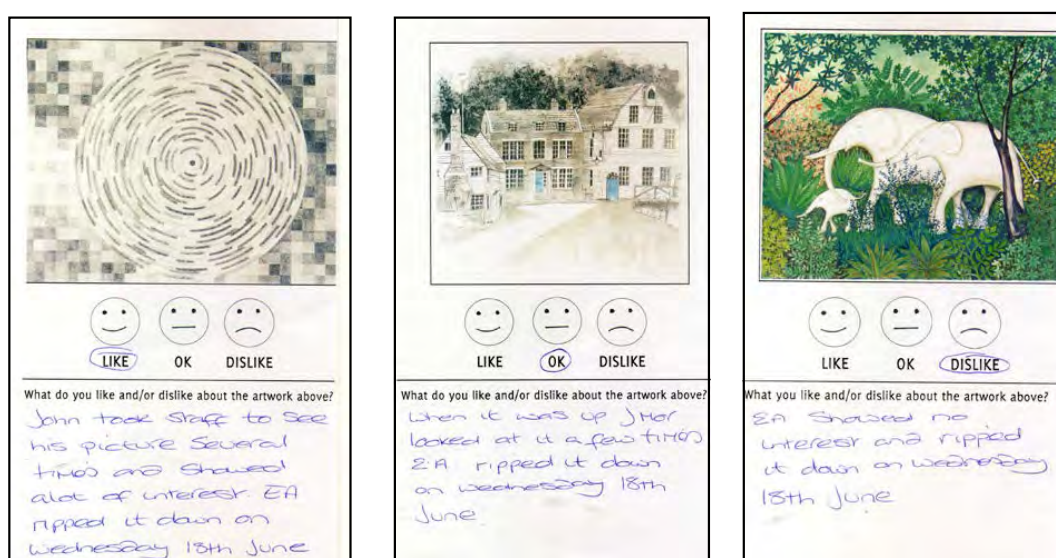


Figure 80. Support staff's feedback on postcards

The designer was able to make some observations from this first stage of the trial. Firstly the posters were not a true representation of the actual artworks in terms of scale, colour and texture. This was something to consider and communicate to the participants so they could expect the actual artworks to look different if and when they were installed. Secondly it is unclear what the motivation was for the participant to rip down the artworks. Was it the subject, colour or because they were not fixed to the wall properly and peeling away, making it tempting for the participant to pull them down? Thirdly one artwork was positioned at the bottom of the stairs next to a doorway. It was reported that one person struggles to move in between rooms if he is agitated, so the artwork may heighten this struggle. The staff suggested that if there were another trial

there would need to be a little more guidance for the positioning of the artwork, supporting the designer's hypothesis that in shared accommodation it is a challenge to balance and accommodate everyone's interests and preferences.

### **5.7.6 Trial Two**

In response to the artworks having been taken down by one participant, there was a lot of debate between the manager of Kingwood College and the management of the Kingwood Trust as to whether a second artwork trial should be facilitated. However the staff felt that it would be a shame to deprive everyone of having an artwork based on one person's negative response. Therefore, based on the feedback and suggestions by the support staff, a second trial was facilitated. This trial differed from the first because the autistic participants were encouraged by their support staff to position their artworks in their private bedrooms, rather than in shared space.

Three weeks into the trial the designer visited Kingwood College to see where the artworks had been positioned. The manager was unable to identify what had happened to the posters so a tour of the house commenced. Three residents had their posters up on their bedroom walls. The fourth participant had torn his poster down from his bedroom wall. The manager immediately presumed that this was because he did not like it, but his support worker suggested that it might be because he likes to rip paper. The final participant had taken their poster from their bedroom and hid it behind a sofa in the lounge. The manager suggested that this is because he does not like having things in his bedroom, not even curtains. As this particular resident appeared to be fascinated by his poster on the initial trial, the manager made the suggestion (see quote below) of re-positioning the poster from his bedroom to his private corridor space. "James...now has a corridor leading from his bedroom to the main hallway where he has put his chair so that he can sit there, the grey circles that he chose could go on that wall as he seemed fascinated with it" Support worker (2014).

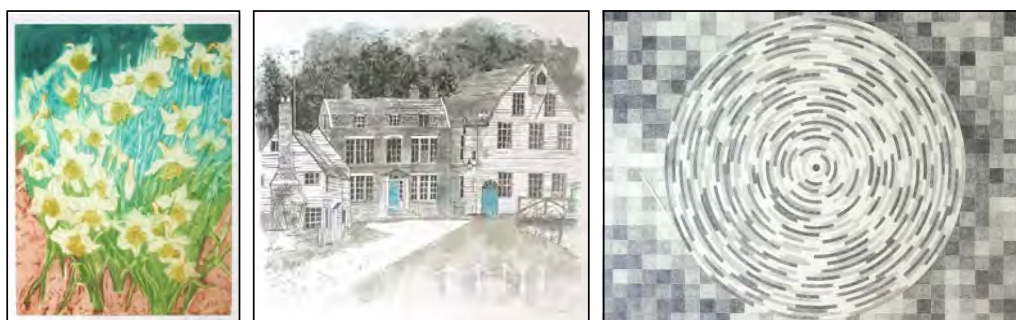
Two challenges emerged for the designer at this stage. The first involved the important consideration of managing expectations. The external organisation donating the artworks had to be flexible with any deadline that was set. The second trial was not initially planned but was necessary in response to what happened in the first trial. The

external partner was also keen to get feedback from the residents on how the artworks made them feel. The designer had to remind the partner that the participants are people who may not understand or be able to articulate how they feel, and the best response possible may well be an expression of sorts on which artworks they like.

The second challenge was the revelation in the evaluation stage that the support staff's interpretations can be different. For example, the autistic participants were invited to select an artwork and stick a poster of it onto their walls. Soon afterwards a participant ripped the artworks off the walls and tore them into pieces. It was the same participant who ripped down his own poster in trial two as ripped down all the posters in trial one. One staff member thought the ripping of his poster signified that the person disliked the artwork, but the designer's presence allowed for a further conversation with another staff member who felt it could have been because he likes to tear paper. Had the designer been made aware of this preference for ripping paper (and the hypothesis of the second support worker who suspected it was this), and not any negative reactions to the art per se that was responsible for the posters' destruction, the designer would have experimented with different formats for the trial artworks (e.g. wood or canvas).

### 5.7.7 Final selection and installation

Based on the feedback from the second trial, the support staff made the decision to have four of the five chosen artworks installed in the private spaces guided by the participants who chose the artworks (Figure 81). For the participant who continuously ripped the posters down, the staff felt that it would not be appropriate to install an artwork in his bedroom (Figure 82).



Daffodils, by David Koster

Untitled, by Peter Gauld

Circular, Fabian Peake



Untitled, by Rosie Brooks

Figure 81. The final selection of four artworks



Figure 82. Artworks framed and installed at Kingwood College

### 5.7.8 Summary

The designer established three stages of the design process. Stage One: Connecting, communicating, building trust and empathy; Stage Two: Gathering context specific insights; Stage Three: Evaluation.

*Stage One:* The designer actively engaged with the autistic participants through various activities, noting that they had an interest in creating their own art.

*Stage Two:* The support staff mapped the sensory preference of the participants. The designer produced a shortlist of 21 artworks, from which an artwork selection activity took place.

*Stage Three:* Initially one three-week trial took place, where posters of the chosen artworks were placed with input from the autistic participants. At some point during the trial most of the posters were ripped down by one of the participants. After a discussion a second trial was established as an attempt to complete the full three weeks. This time participants were encouraged to place the posters in their bedrooms. After three weeks three participants' posters remained in their rooms. A fourth participant had ripped his poster into pieces and a fifth had hidden their poster behind the sofa in a different room. Based on the feedback from the second trial, the support staff made the decision to have four of the five chosen artworks installed.

### **5.7.9 Reflection**

In comparison to studies one and two the aim of study three was not about generating ideas; but to explore ways to engage the autistic adults in choosing artworks for their home environment. The lessons learnt in studies one and two helped to inform the design process. Like study one the participants lived in a shared house so it was important to be mindful of the hyper and/or hypo sensitivities of each participant. As the artworks were essentially going to create change to a familiar space, the designer this time was prepared for this and, as advised in study two, this study involved two transitional steps between the selection and final installation of the artworks. Posters of the selected artworks were used before the permanent fixture and installation of the final artwork to enable the participants to rip them down if they disliked the position or artwork aesthetic. Access was difficult in study three and therefore the support staff played more of a lead role throughout the design process.



# Chapter 6: Discussion

This chapter discusses the designer's approach in the light of the results of the three design studies, reflecting on how the main research questions have been answered through the PhD by Practice. It goes on to identify and structure an important additional dimension to the research – the role of empathy in designing with autistic adults – and it concludes by setting out the limitations of the work.

## **6.1 Answering the research questions**

## **6.2 Developing empathy**

## **6.3 Limitations**

### **6.1 Answering the research questions**

1. Can a designer's approach generate insights about how autistic adults experience their home environment, and what design principles can be developed from this?
2. How can autistic adults who have limited speech and additional learning disabilities be involved in the design process?
3. What can the broader design field learn by designing with autistic people with additional learning disabilities?

Early in the research, the designer noted how Kanner (1943) described the preoccupation with the physical environment of the autistic children he was studying. However Kanner's observation proved a false dawn for the role of environmental design in autism research – the ensuing focus was primarily on the underlying biology and causes of autism (Pellicano et al, 2014). The triad of impairments identified by Wing and Gould (1979) – deficits in communication, social interaction and imagination – helped to frame a deficit-focused approach to autism research in which the relationship with the environment was not a priority.

However, in the three design studies in this PhD, aspects of the environment are ever-present, echoing back to Kanner's seminal work, and the triad of impairments have been reversed into the Triad of Strengths – a key component of the designer's approach. Gibson's theory of affordance (1977) with its focus on direct perception of the environment was instrumental both as a link back to Kanner and as a framework for looking at a person's relationship with the sensory and physical environment. Sanders' work in participatory design was influential in helping the designer to form her approach to exploring how the autistic adults at Kingwood experience their home environment and to giving Gibson's theoretical model some concrete practical applications. In tandem with these theoretical building blocks, privileged access to the Kingwood community of autistic adults, support workers and family members over the life of the research gave the designer a practice platform through which to address the main questions of the PhD.

### **6.1.2 Can a designer's approach generate insights about how autistic people experience their home environment, and what design principles can be developed from this?**

Whilst it is important to emphasise that the descriptions in this PhD are based solely on the autistic participants in the research and cannot be generalised, this study illustrates a design approach that generated a rich collection of insights about how autistic people experience their home environment. Three patterns of experience were identified which relate back to Kanner (1943) and his observations of the children interacting with his office space: 1) a person can be interested in the unintended affordance of everyday objects, for example enjoying the sound of desktop fans; 2) a person's choice of everyday activity might be influenced by their sensory preferences, for example enjoying putting the cutlery away to hear them chime; 3) a person's special interests can influence their choice of what to do and how their home is decorated, for example the home interior of one participant is blue because of her interest in Thomas the Tank engine.

The three key insights above helped the designer to extract three design principles: 1) adapting the environment to incorporate a person's special interest; 2) adapting the

environment to incorporate a person's sensory preferences and 3) exploring ways to extend and enhance a person's interest with the unintended affordance of things to inspire new design ideas. These design principles influenced the designer's line of thinking, for example in study two the designer explored ways of extending a person's preference for bubbles into other activities such as vacuum cleaning, so making the pleasurable element – the bubbles– intrinsic to more than one activity.

Through making a comparison between studies one, two and three there was a gradual withdrawal by the designer, and the support staff took more of a lead role in the design process. On reflection the design outputs for each design study created different degrees of change to a person's home and the evaluation process essentially shed light on how the autistic participants responded to these levels of change. In study one a new garden was developed and the participants made the choice whether to step outside into the garden or not; in study two the vacuum cleaner was stored in a cupboard, out of sight and used occasionally, but in study three the participants were confronted daily by the artwork posters. The evaluation stage that received a strong reaction was in studies two and three, for example ripping the posters off the wall and throwing the bubble attachment away. It is unclear whether these were reactions to the objects themselves or to an uncontrollable or misunderstood change.

### **6.1.3 How can autistic adults who have limited speech and additional learning disabilities be involved in the design process?**

Whilst a co-design and participatory design process in the traditional sense was not practiced with the autistic participants, the involvement of the autistic adults in the research significantly impacted on the process and design outputs. Central to every stage of the design process was the strengths and aspirations of the autistic adults, which were explored holistically through the triadic interactions of the autistic adults, support staff and designer. It is however important to question the validity and appropriateness of participatory design for a person who dislikes social interaction and does not understand the context and reason for their involvement.

The designer recognised that her presence affected the situation. Whilst she took on-

board a participatory mindset and considered the autistic adults and their support staff the experts throughout the design process, her contact with the autistic participants in stages two and four of the design process was indirect and mediated via the support staff. The tools developed were to enable information to be accessed remotely by the designer. Consequently based on this research, the PhD has made a theoretical contribution to participatory design by finding that actually co-creating with autistic people with limited speech and additional learning difficulties may be neither appropriate nor as possible as the 'inclusivity' imperative assumes, and that designing remotely and with people's families or support staff offers an effective way round this.

Benton (2013) mapped the implications of involving autistic people in participatory design as identified by other researchers (Table 3). The table illustrates 11 deficit-based characteristics of autism and their implication for participatory design, which could potentially discourage other designers from working in the field of autism. Whilst it is important to be mindful of the challenges, it is important that they do not override the positive opportunities working in this field can bring.

Many of the challenges identified could be a reflection on a neurotypical designer's lack of empathy and inflexibility to adapt themselves to how an autistic person is, or provide the right tools to enable a person to express themselves in the way that they choose. By approaching the 11 deficit-based characteristics through an empathic mindset, the notion of their challenging implications for participatory design is quickly dispelled. For example 'impairment in social skills' and 'communication difficulties' were described as having implications for participatory design, however throughout this PhD most of the autistic participants had social skills, especially through the mediation of artefacts. Equally whilst some of the autistic participants experienced difficulties with verbal communication, they were able to communicate explicitly through actions, sounds and gestures. 'Motivation issues' was also highlighted as having implications for participatory design. The motivation of the autistic participants in this PhD did not prove to be a problem providing the activities were interesting and enjoyable to them. This surely relates to everyone, whether autistic or not. Whilst some of the autistic participants did have 'an attachment to routines', this challenged the designer to be

more organised and explore ways in which the design process could integrate within the participant's daily life.

In models of participation (Arnstein, 1969), the project would fall between the consultation and placation stage of the ladder; the designer and support worker consults with autistic adults to share their preferences to influence the design process. Whether the research had moved up the ladder beyond this stage is a huge unknown as it is difficult to establish whether the autistic participants entirely understood the reason for their participation and whether they felt a sense of partnership and empowerment by taking part within the design process. But what was genuine (from the designer's perspective) was the connection the designer felt interacting with each participant through the mediation of the environment with the things they enjoyed doing. For example, blowing bubbles with Matt, ripping magazines with Sam, spinning objects and listening to the sound of the last spin of the washing machine with Nicky. These simple acts should not be underestimated, as they are the important things that describe what might be meaningful for an autistic person, which may not be immediately apparent to a neurotypical person.

#### **6.1.4. What can the broader design field learn by designing with autistic people with additional learning disabilities?**

How often do we stop and wonder how a fan, washing machine, or a paper clip makes us feel? Most of us, when we see everyday objects will immediately attend to the functionality of the thing and habitually interact with the object, the way it was intended. This research has highlighted the designer's own disengagement from the visceral qualities of the environment and loss of touch with the 'delightfulness' that this can engender. This project proposes that being with people whose engagement and visceral reaction to the physical environment is a priority, and can re-educate designers to directly experience and perceive the environment; an environment not mediated cognitively through rational thought but re-awaked via a physical engagement with the sensory qualities of the world around them. In other words, bringing to the fore the 'delight' factor within the Vitruvian synthesis *Commoditie, Firmness and Delight* (Wotton, 1624) and Gibson's ecological approach of 'direct perception.'

## 6.2 Developing Empathy

In addition to the three main questions of the PhD, as the research developed so the designer increasingly recognised an important additional dimension – the issue of empathy. The designer recognized the importance of approaching the research through an empathic mindset, however underestimated how empathy was difficult to achieve and repeatedly found herself asking the question - how can a neurotypical designer begin to understand and empathise with an autistic person whose lived experience is so different to their own, and who may not be able to verbally communicate this? In response to this and theories that suggest autistic people have difficulty with theory of mind (Baron-Cohen et al., 1985), which is the ability to imagine another person's thoughts and feelings, leading to empathic difficulties (Baron-Cohen, 2012). This research has reversed these theories by questioning how much empathy do neurotypical people have for people with autism, which supports Damian Milton's Double Empathy Theory, which he describes as:

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, p. 2).

The designer explored the question of empathy by observing the support staff who everyday carried out empathic acts for the autistic person they support. The designer noticed that the support staff were experts at avoiding fundamental attribution errors, as they were able to objectively connect an autistic person's behaviour to the surrounding environment, rather than internalising their thoughts and explaining another person's actions through their own. Avoiding fundamental attribution error identifies with Fulton Suri's (2003) three ways to develop empathic interpretation, which ranges from an objective to a subjective process, and the connection and detachment phases described in Kouprie and Sleeswijk Visser (2009) four phases of empathy and Van Rijn (2012) framework that similarly contains a connect and detach element, described in the literature review.

To explain this further the storyboard below (Figure 83) is drawn by a support worker (Ian), which describes his experience of walking in a park with an autistic man (John) with limited speech. John becomes anxious when they get to a path containing shadows cast by the trees, as he might perceive the shadows as black holes. This storyboard provides important clues for how a support worker was able to interpret a person's emotional response to a situation and empathise without the support of spoken language. By sketching and reflecting upon similar experiences made by the support staff (see Appendix 36) and analysing the storyboard, the designer identified four stages of empathic understanding; 1) redirecting, 2) connecting, 3) imagining and 4) empathising (Figure 84). The diagram reveals that what bridged empathy was the support worker's ability to objectively observe the situation to subjectively form an understanding of the situation. For example in 1) redirecting and 2) connecting, the support worker objectively redirected his own thoughts, externalised and connected John's behaviour to the shadows in the environment. Conversely in 3) imagining and 4) empathising, the support worker subjectively formed an understanding of the situation by imagining and adapting the situation accordingly. The designer's visit to Tom described in the Foundation chapter of this thesis (section 2.1.5), is a good example of how effective avoiding fundamental attribution errors 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 associated his damaged wall with an act of 'destruction'. However, on the second visit to Tom, the designer externalised her thoughts, recognised that Tom likes to rub the wall, therefore the indented wall exemplified an act of delight. It was this slight change of perspective that created a little understanding and empathy.

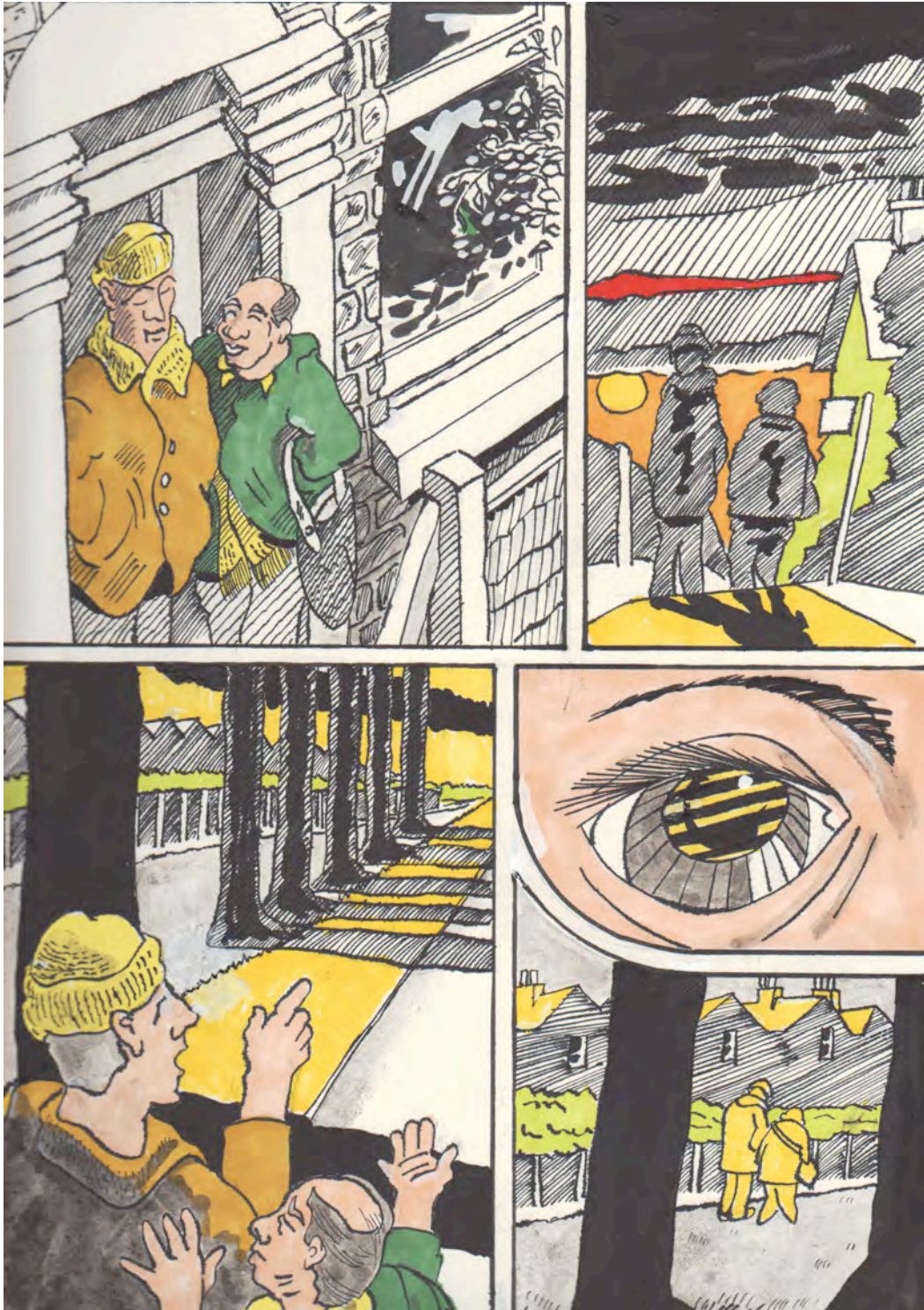


Figure 83. A storyboard that describes a support worker's experience with an autistic man, who perceived shadows as black holes.



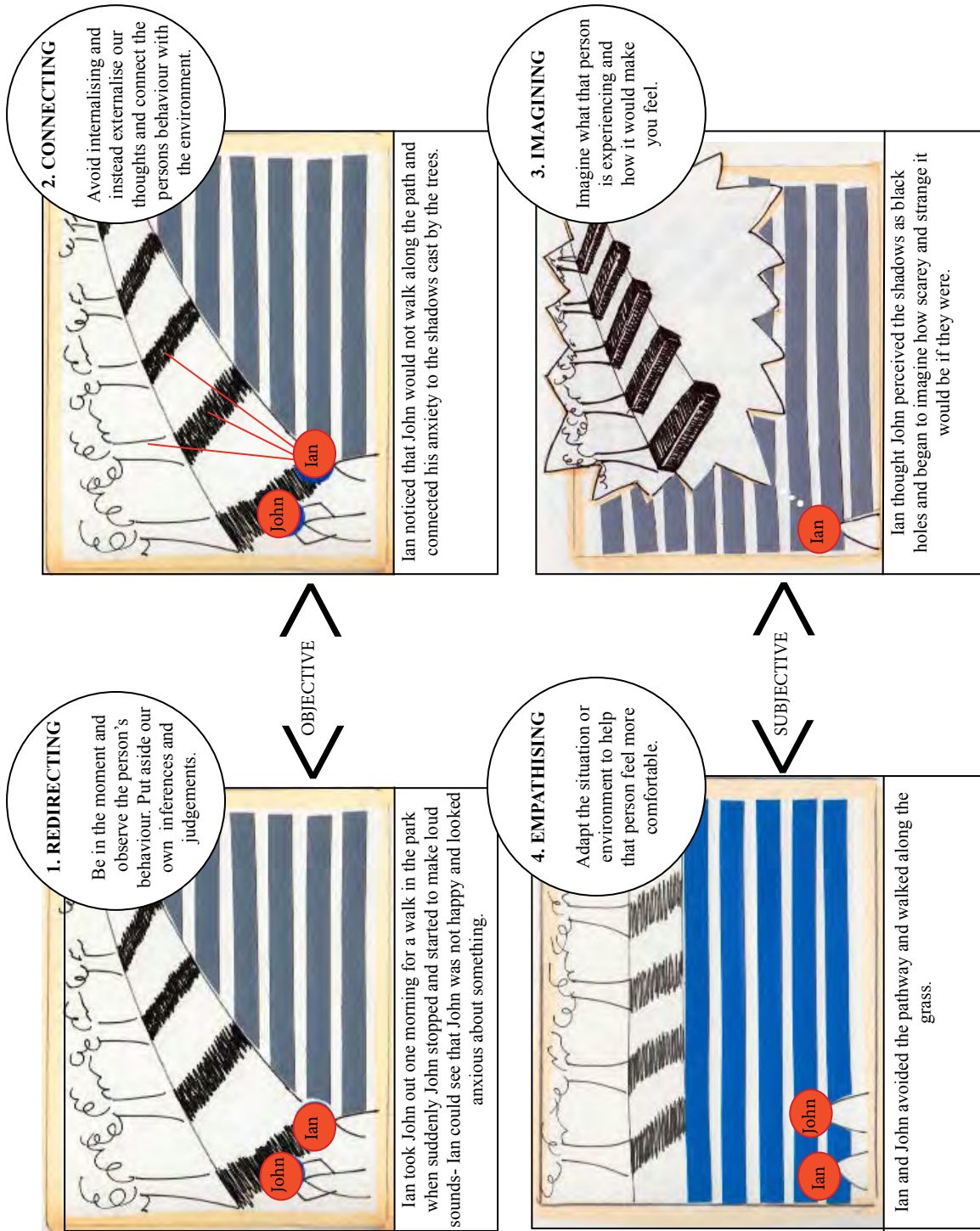


Figure 84. Four stages of empathic understanding

## 6.3 Limitations

The design studies as a whole revealed that the support staff's interpretations differ. Consequently to create a more holistic picture it would have been good to widen the support network and invite at least two support workers for each autistic person. This way a comparison study could have been facilitated to explore how, if and to what extent the support staff's interpretations differ. Equally the information derived from the design tools were dependent on the quality and accuracy of a designer's interpretations. To create a more holistic picture it would have been good to have invited other designers to participate. This way a comparison study could have been facilitated to explore how and if the interpretations and approaches differ between designers.

Stage three of the design process involved predominantly the support staff, family members and the designer and only on two occasions did autistic people participate in a co-creation workshop. In hindsight it would have been useful to have more autistic adults participate within stage three of the design process. Even if a group activity was not appropriate for an autistic person, some of the tools and activities used in the workshops could have been facilitated on a one-one basis.

The evaluation was the most challenging stage. This process was difficult on many levels as in comparison to stages one and two the evaluation process was less integrated within the autistic participants' daily lives. By its nature the evaluation stage brought change to the participants' environment, and the designer underestimated the impact this would have, particularly as it was unclear whether the autistic participants understood what was going on. In hindsight more time needed to be spent on the evaluation stage of the design process, working closely with the support staff to explore ways to communicate and prepare the autistic adults for what is about to happen and exploring ways to integrate the evaluation into their daily lives.

The support staff participated in all four stages of the design process. The success of the design tools was very dependent on the cooperation and participation of the support staff. Whilst the mapping tools in stage two were designed to create an activity between the support staff and the autistic person they support, they did create additional work for

the support staff within their busy schedule. Although the designer brought along sweets and cakes as a way to say thank you, other and better incentives should have been explored and to ensure the tools were integrated within the staff's daily practice at work.

Challenging behaviour was one of the operational difficulties, which affected the designer's confidence; therefore it is important that there is support and an ethical framework in place to protect the designer from incidents of this kind. On a practical level a training programme to help the designer understand the potential risks, detect early warning signs of behavioural outbursts and how to deal with them when they occur would be beneficial. Whilst the designer in this PhD only experienced challenging behaviour once, it had a big impact, as she immediately internalised it, blamed herself and was overcome with a sense of guilt. It was only by discussing what had happened with a supervisor afterwards, that she was able to externalise her thoughts and take herself out of the situation, and break down this feeling of guilt. If an incident does occur it is therefore important that there is a person the designer can turn to and meet to debrief and discuss what happened. In reaction to this it is important to question how appropriate participatory design is for an autistic person who avoids social interaction, and equally what constitutes participation or being involved for an autistic person, whose threshold to participate might be limited.



# Chapter 7: Conclusions

This final chapter identifies five original contributions to knowledge and discusses their practical relevance to the wider design, autism and care communities.

## 7.1 Five Original Contributions to Knowledge

1. Development of design tools
2. Adaptation of Sanders et al.'s (2010) participatory design framework
3. Development of a design framework termed the Triad of Strengths
4. Provide concrete examples that build on Gibson by illustrating people who engage with the environment in a direct and visceral level.
5. Development of design practice

The aim of this PhD is to extend our understanding of how autistic adults with additional learning disabilities experience their home environment and to explore the ways in which a designer can involve autistic adults into the design process. It represents a project that carried out empirical work that never before has been attempted, forging a synthesis between the neurotypical designer's experience with autistic adults and person-centred design research. In addition to answering the research questions set out in Chapter One, this PhD presents five original contributions to knowledge to methods, theory and practice.

### 7.1.2 Developing design tools

The literature review highlights how there is very little existing research in design and autism that involves autistic adults with limited speech and additional learning disabilities. This PhD directly addressed this issue by developing a range of design tools to help connect, communicate and involve the autistic participants into the design process and it was the principles behind these tools that are the contribution to new knowledge. Tools such as the *Sensory Preference Cards*, the *Objects of Everyday Use*

cards and *Interests and Hobbies* booklets were inspired by existing questionnaires used within other disciplines stemming from social science, but critically adapted to make them more accessible to autistic adults with limited speech and additional learning disabilities. These tools were also developed so they could be used remotely (i.e. without the presence of the designer) and facilitated by the support staff that knows the autistic participant best. The tools themselves were a success: they helped to frame and direct the support staff's attention and observations towards the autistic person's visceral engagement with the environment, which extended their understanding and generated rich insights that triggered design ideas.

External to this PhD, the design tools have bridged design practice into other contexts and disciplines and vice versa; for example, occupational therapists and psychologists are using the sensory preference cards within schools to help them involve autistic children with learning disabilities into their practice. The sensory preference cards are also being trialed at Hearthstone Dementia Care in the US, extending their application into the field of dementia.

*Ready Steady Make* workshops were facilitated across all three design studies which received much positive feedback by the support staff themed around three strands. First, the workshops encouraged team building and created an opportunity for the staff to meet, and share ideas and experiences. Second, they helped the support staff to be aware of sensory sensitivities in relation to autism and the environment. Finally, the participants enjoyed being creative, thinking positively about the people they support and making something for them that shows aspects of their personality (see Appendix 37). Due to the success of the workshops they have now become embedded within Kingwood's biannual training programme and expanded into a workshop entitled 'Making Sense', both at the Institute of Making and the UCL Institute of Education, University College London, to create awareness and discussion amongst teachers and students around the complex nature of autism and sensory sensitivities. *Ready Steady Make* was also extended into a sensory prop-making workshop for autistic people at the autistic-led conference, Autscope, which also received positive feedback.

### **7.1.2 Adaptation of Sanders et al.'s (2010) participatory design framework**

The designer used Sanders et al.'s (2010) participatory design framework to organise, reflect and communicate the design tools that amalgamated across the three design studies. This process helped to identify whether adjustments needed to be made to the framework, for involving autistic adults with learning disabilities into the design process.

To accommodate the design tools used within each design study, modifications were made to Sanders et al.'s (2010) framework. Table 13 illustrates how the framework was adapted to accommodate the design tools used in study two. Several additions were made to the framework which are highlighted in red, the generic tools to the left are replaced with the tools used in study two, and an 'x' indicates where each tool correlates with the application sections above. 'Communication' was added within the 'purpose' section, as exploring different ways of communicating without written and spoken language was central to the design process, equally, 'interacting', 'observing' and 'listening' were added alongside 'talking, telling and explaining'. Working 'one-to-one' was also added within the 'application' section, as in cases when an autistic person avoids social interaction, a group situation was inappropriate and one-to-one interaction preferred.

The study involved and combined the views and experiences of multiple informants - the autistic adult, designer and support staff, and working with autistic participants demanded such triangulation. The designer identified how different participant configurations within each design stage can strongly influence the selection and facilitation of design tools. The person's presence is therefore an important consideration during the design process, rendering it necessary to add a third dimension entitled 'person?' Finally, 'evaluate' was added to the 'purpose' section. This was an important consideration particularly when working with autistic people who may dislike changes to their environment and find it difficult to express how they feel.

In addition to modifying Sanders et al (2010) participatory design framework, the research highlighted several important questions for future research with regards to

involving autistic adults with limited speech and additional learning disabilities. If an autistic participant does not understand the context and reason for their participation can their involvement be defined as genuinely participatory? Equally, if the designer’s contact with the autistic participants is indirect and mediated via the support staff, has the designer exercised a ‘designing with’ co-creation approach? Whilst there are no hard and fast answers to these questions as yet, they aim to provoke further investigation into what ‘participatory’ actually means within the context of designing with hard-to-reach individuals.

Design Study 2.	PURPOSE						APPLICATION					PERSON		
TOOLS AND TECHNIQUES	PROBE	PRIME	COMMUNICATE	UNDERSTAND	GENERATE	EVALUATE	INDIVIDUAL	ONE TO ONE	GROUP	FACE-TO-FACE	ON-LINE	AUTISTIC ADULT	SUPPORT STAFF	DESIGNER
<b>MAKING AND INTERACTING WITH TANGIBLE THINGS</b>														
Co-Creation workshops	X		X	X	X			X	X	X			X	X
Sensory Activities	X		X	X	X			X	X	X		X	X	X
Mirroring Interests	X		X	X	X			X		X		X	X	X
Creative Activities	X		X	X	X			X	X	X		X	X	X
Vacuum cleaner trial	X			X	X	X				X		X	X	X
<b>OBSERVING, LISTENING, TALKING, TELLING AND EXPLAINING</b>														
Objects of everyday Use Cards	X	X	X	X	X			X		X		X	X	
Doing things with things booklets	X	X	X	X	X	X		X		X		X	X	
Sensory preference cards	X	X	X	X	X			X		X		X	X	
Participatory Observation		X	X	X	X	X		X	X	X		X	X	X
Mapping special interests	X	X	X	X	X			X		X		X	X	
Informal conversations	X	X	X	X	X	X		X	X	X			X	X
<b>ACTING, ENACTING AND PLAYING</b>														
Sensory Activities	X		X	X	X			X	X	X		X	X	X
Co-Creation workshops	X		X	X	X				X	X			X	X

Table 13. A modification of Sanders et al., (2010) participatory framework

### 7.1.3. Developing a new design framework termed the Triad of Strengths

Autism is often characterised by the triad of impairments (Wing and Gould, 1979), including impairments in social interaction, social communication, social understanding and imagination. As identified in the literature review, the majority of existing research in design and autism focuses on a person’s deficits, where the main goal is to overcome a person’s impairments. This PhD, however, has taken a novel approach that inverts a person’s deficits to strengths by creating a design framework termed the Triad of



Strengths, in which a person’s sensory preferences, special interests and action capabilities can help guide the design process. This research revealed that the Triad of Strengths supported the design process in a variety of ways. Information about a person’s interests helped the designer to connect and communicate with the autistic participants in stage one of the design process. A person’s sensory preferences and action capabilities helped the designer to anticipate and explain a person’s motivations, interacts and reactions to the physical environment in stage two. In stage three, a person’s strengths provided an important palette of ingredients that triggered design ideas. The three figures below illustrate how a person’s Triad of Strengths influenced the three stages of the design process that led to the design output, with each stage of the design process influencing the next (Figure 85-87). For example, during a creative activity in Figure 86, the designer observed that an autistic participant liked to watch windmills spin. In stage two, the sensory preference cards highlighted how some people liked to wash their clothes in order to watch the washing machine spin. To accentuate and celebrate this recurring preference for spinning, the designer developed ‘Spinny Disc’, which added an extra – and pleasurable- fun step in the process of washing clothes. Spinny Disc is attached to the inside of the washing machine door and creates different visual effects as it spins with the washing.

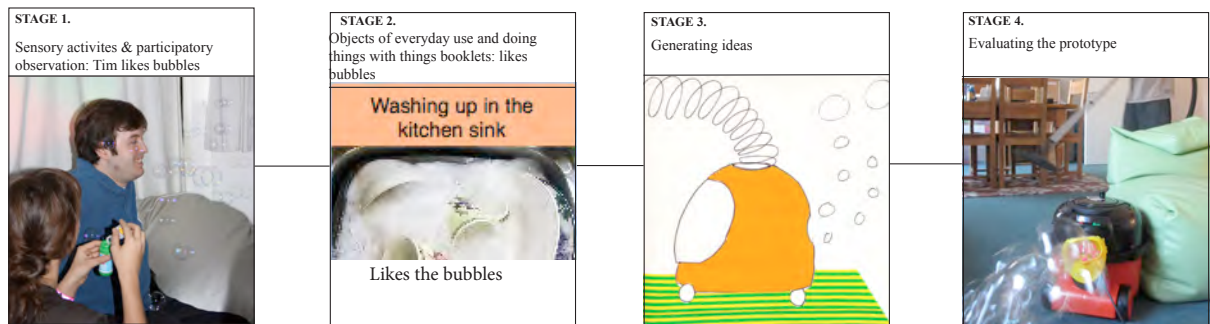


Figure 85. *Sensory Preferences*: bubbles – bubble blowing vacuum cleaner

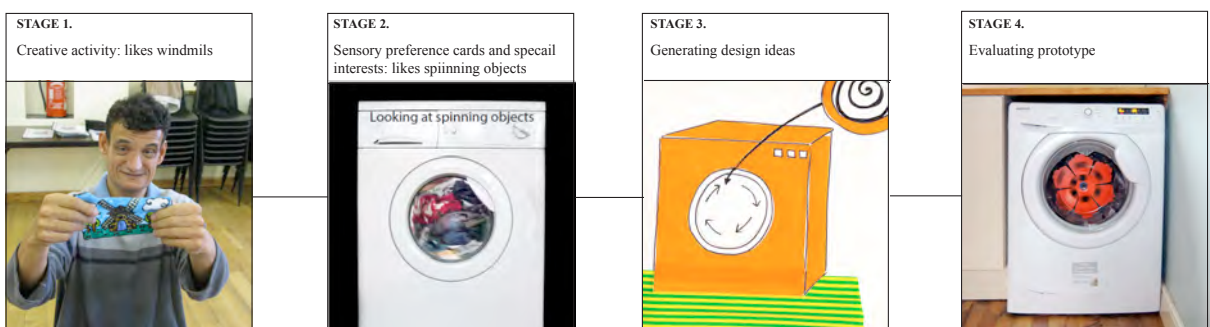


Figure 86. *Special Interests*: windmills- spinny disc

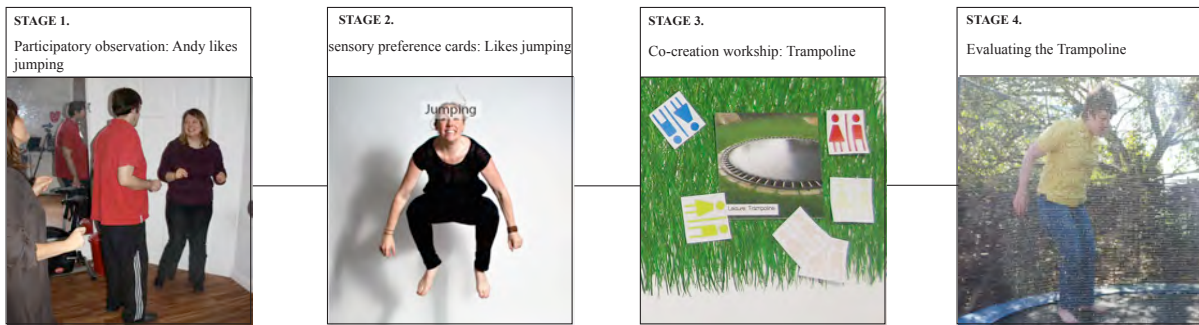


Figure 87. *Action Capabilities* – jumping - trampoline

The Triad of Strengths can alternatively be perceived as a person’s capabilities, which complements Gibson’s concept of affordances and resonates with the capability approach developed by economist Sen (1999) and philosopher Nussbaum (2000). But whilst Gibson describes how an affordance is dependent upon a person’s capabilities there is very little information about how to assess another person’s capabilities, particularly if another person’s capabilities are different from one’s own. The Triad of Strength’s therefore addresses this question by supporting an individualised rather than generalised design framework to help identify a person’s strengths and capabilities. The designer seeks to explore what the world of design would look like if the Triad of Strengths applied to everyone based on what people enjoy and are good at.

**7.1.4 Provide concrete examples that build on Gibson by illustrating people who engage with the environment in a direct and visceral level.**

This research has generated concrete examples and a context missing from Gibson’s theory of affordance, which supports, positions and applies Gibson’s concept of affordance into design and the physical environment. The research sheds light on a unique type of engagement where direct perception and a visceral level of experience with the environment took precedence, which contradicts Norman’s top-down cognitive approach in which he states, “to the designer, reflection is perhaps the most important of the levels of processing” (2013, p. 53). In contrast to this, for this PhD it was the visceral level that took priority as the designer needed to suspend her own reflective and behavioural levels of experience. The research revealed that, for the autistic participants, meaning and understanding about the world is harnessed not through

knowledge, language and visual perception alone but via their tangible interactions of doing, sensing and interacting, which expands Gibson's concept of direct perception to include other senses, not just sight.

This PhD revealed a unique niche (Gibson, 1979, p.128) inhabited by autistic people, who occupy a different set of affordances to a neurotypical person. Autism is a neurodevelopmental condition, meaning a person's brain and central nervous system functions differently which can effect emotion, perception, memory, learning, speech and language. This PhD made a special synthesis between a neurotypical designer and autistic person's experience of the world. Whilst the designer identified commonalities of experience, the autistic participants also occupied a *different* set of affordances to that of the designer, and the designer proposes that some of the autistic participants extreme variations in experience from the neurotypical, is characteristic of their neurological style. This is an important consideration that questions Gibson's claim that an affordance is independent of the observer and "points two ways, to the environment and the observer" (1979 p.129), and instead proposes that different brains can engage a different set of affordances. Consequently, therefore an affordance is largely influenced by the subjectivity of the perceiver.

#### **7.1.5 Development of design practice**

The designer gained a great deal by working with autistic adults with limited speech and additional learning disabilities. It was an incredible journey that expanded her skillset from textiles to garden design, and importantly at the beginning she thought she was an empathic designer, but this PhD challenged her to reassess this and in doing so widened her empathic horizon.

This investigation exposed the designer to a different way of being in the world, which helped her to break down her own assumptions and cognitive bias of how people *should* experience things. The designer exercised a way of perceiving the environment outside of socially constructed norms, which helped her to learn to experience things as they really are, which as described by Gibson can be a challenge, "we must, of course, learn to see what things really are... and this can be difficult" (1979, p.130).

An important lesson the designer learnt was that, in order to understand others, it was important for her to understand first her own experiences. For example, the Argos catalogue was a popular object of interest, and only when the designer flicked the pages and experienced the weight, colour and sound herself was she able to understand its delightful qualities. Equally, being with people who experience the world at a visceral level encouraged the designer to be more in tune with her own visceral response and engagement with the sensory qualities of the environment, instead of being distracted by their intended functionality.

Being with people who have limited verbal speech heightened the designer's sense of awareness of her own actions and encouraged her to develop a range of tools to help connect, communicate and create reciprocal interactions between the designer and autistic participants, without the requirement of speech. The designer also developed a range of tools to be facilitated remotely by the support staff to help interpret and mediate communication between the designer and autistic participants.

This research illustrates a designer's approach that provides an important platform and collection of tools for other designers to use who are interested in working in autism and neurodiversity. The designer hopes to expand the field of inclusive design to consider neurodiveristy and encourage more designers to collaborate with people who are neurologically diverse who can offer unique ideas for innovation that are excluded from mainstream ways of thinking.

The design tools developed during this project are not entirely dependent on spoken language or the presence of the designer, which can be extrapolated into general design practice for wider applications. Tools such as this can be used for design projects to help break down language barriers, access hard-to-reach areas and bridge geographical divides. To explore how this investigation can benefit the wider design field the designer sought feedback from some of the members of the Expert Reference Group (see Appendix 38) and the tools, insights and empathic exercises developed during this PhD amalgamated into a five-day workshop for artists and designers entitled

‘Celebrating Neurodiversity’, which was piloted at the Royal College of Art in November 2014 (see Appendix 39). The workshop invited autistic people across the spectrum to share their life experiences with a group of RCA students, to encourage them to reflect and challenge their own neurotypical assumptions and ways of experiencing and perceiving the world (Figure 88). The students worked in teams and were asked to make a gift for four autistic adults at Kingwood based on their sensory preferences and interests. The workshop resulted in a very thoughtful collection of works including: a pink tactile flipbook, a range of badges with different labels and a tactile communication toolkit.



Figure 88. RCA students engaging in an empathic exercise in the ‘Celebrating Neurodiversity’ workshop



# Appendix 1

**Appendix 1: Contains five diary accounts by the author, which reflect upon her experience facilitating sensory sessions in multi-sensory environment, at the charities FACT and Kids Active between 2006 and 2007**

## Half an hour with Kevin...

Kevin is non-verbal and paralyzed from the shoulders down. The bed is his most immediate environment, followed by the small residential home where he lives. There are ten residents altogether, the majority of which are elderly, with dementia. Kevin is the youngest: he is 32 years old, and came to the residential home due to a tragic car accident that left him in need of 24-hour care; his parents visit him every day.

Kevin is always to be found in the corner of the room, where he lies down amongst the olfactory delight of bleach and the background murmur of the television in the next room. The magnolia walls around him are blank; there is nothing to look at and the only stimulation he may experience is from his parents' visits and the daily routine of washing and eating.

Kevin seemed particularly down today: his head is tilted awkwardly to one side, his gaze fixed onto the lino floor and his mouth locked open. Neither my presence nor the stroke of the forehead makes him stir.

"It's your turn next, Kevin. Dorlies and I are going to help you into the sensory bus, is that ok?"

It's a lovely sunny day and we wheel Kevin's bed outside into the fresh air. The sun shines, reflecting onto the white sheets. Kevin's blank gaze starts to stir and his eyes slowly move in response to the elements outside.

“Kevin, we are just going to wheel you onto the lift and into the sensory bus, so once you are inside it might be dark for a few moments, before we turn the lights on.”

We close the van doors and Kevin’s head is still tilting uncomfortably to one side. To gently ease Kevin into the new environment we project colourful patterns in the direction of his gaze; his eyes immediately respond and begin to track the movements of the shapes.

“Kevin, I’m just going to put some music on, what do you fancy? How about the new Jack Johnson album?”

The music and projections of colour seem to work well together. I sit with Kevin listening and watching the shapes. His face already appears to be relaxed, his mouth slowly starting to unlock and move. To encourage Kevin to move his head I turn off the projector and switch on the fibre optic panels installed in the ceiling directly above his head. Kevin responds instantly to the optics. He begins to make positive loud noises and moving his head in what appears to be an attempt to stretch up and touch the fibre optics.

I glance towards my watch, the half an hour is over, and it is time to wheel him back to his corner. It was a shame that the session was so short, but still half an hour in the sensory bus was enough time to take Kevin out of his normal routine. The sensory bus activated Kevin: as Kevin could only move his head it was important that the sensory props could follow his gaze. This is why the projector worked well as the moving patterns covered all perspectives, and the movement encouraged him to move too. The fibre-optic panel in the ceiling was a great success as it was positioned directly above Kevin, I could see that he almost wanted to reach and touch the optics. I think next time I will adapt the panel with a ‘shower of textures’ that Kevin could touch if he was to slightly raise his head; also, if it’s a nice sunny day I might see if Kevin would respond well to part of the sensory session being outside.

(FACT: sensory bus, London, April 2007)



## An hour with Tim...

It is Tim's first visit to FACT. Tim is an adult wheelchair user and is non-verbal. He lives in a residential home and has developed self-stimulating behaviours of chewing his fingers and grinding his teeth. As the MSE is unfamiliar, I decide to make this an introductory exploratory session where I gently introduce him sensory props and observe Tim's reactions, in the hope of gauging his likes, dislikes and abilities.

Tim understandably looks very nervous and uncomfortable; the slightest unpredictable noise or movement causes him to jump and begin grinding his teeth and chewing his fingers.

Tim sits with a tense posture, no doubt somewhat due to the wheelchair that is far too small for him. There is also no footrest so his legs are left to dangle. To take the pressure off his legs, I immediately take a piece of foam and position it underneath his feet.

I talk to Tim throughout the session to familiarise him with my voice and to help me gauge just how much he can understand. As Tim is an adult I am anxious to communicate with him in an age-appropriate manner - unsure of his cognitive ability it takes time to get the right balance.

As Tim was nervous, I tried to create a relaxing environment to calm his nerves, switching off all the equipment and lights apart from the bubble tube, and with gentle soothing music humming in the background. I spend the majority of the session touching and stroking Tim's hands, which were tightly clenched, nestled either to the side of his chair or in his mouth. After approximately 45 minutes Tim opens one of his hands and lets me hold it. As I cup his hand in mine, I gently stroke his fingers using the bristles of a soft brush. Tim responds to the different texture and raises his head, only to notice the bubble tube. He becomes transfixed and his posture is a lot more relaxed.

Tim is a very nervous person, so for the next session I will play some relaxing music and make sure that all of the other equipment is turned off; he does not like sudden

movements or changes in his environment that he is unfamiliar with. Tim responded well to the tactile sensation of brushing on his hands: for the next session I will gently introduce vibration.

(FACT, London, March 2007)

### An hour with Tim...

The bubbles of the tube can change into four different colours at the flick of a switch. Tim responds immediately to the colour red. Stopping and starting the bubbles in ten second intervals. I watch as Tim tracks the ascension of the bubbles with his eyes, echoing the movement with his head. When I stop the bubbles altogether, he eventually looks at me as if to say in protest “where have they gone?!”

Over time, Tim has become more relaxed and comfortable in the multi-sensory environment (MSE) His hands are no longer so tightly clenched and he appears less nervous and reactive to spontaneous noise. While he still spends a lot of time chewing his hand, he grinds his teeth less frequently.

As Tim is prone to falling asleep, I feel it is important to create a more interactive, less passive session. I introduce a guitar to deter him from chewing his hands. I gently place it onto his lap and start to strum; the strumming of the strings sends a subtle vibration through his legs. Tim immediately reacts to the sound and vibration of the guitar. When I stop playing he looks towards me as if to say ‘play more.’

After approximately 20 minutes of strumming I place Tim’s fingers onto the strings so he could feel the continued vibrations of the strings as they peter out. Tim would not engage with this at first and would immediately pull his hand away, placing it directly back into his mouth. I repeatedly place his hand onto the strings and eventually, Tim independently moves a single finger against one string, flicking it back and forth, producing a sharp sound. Tim continued to strum on this one string, doing so for two to three minutes at a time, before pulling away.

As Tim played the guitar he began to smile, moving his body as he made slight noises ‘dancing and singing to his tunes.’ It was great to have identified a prop that he enjoyed

and could focus on. The guitar seemed to have energized him and distracted him from chewing his hands.

After approximately 30 minutes of playing the guitar I then place a plastic keyboard onto Tim's lap, running my fingers along the keys. Tim tracks the movement with his eyes and moves his head towards the sound. His interest begins to fade. Tim was more responsive to the guitar; maybe it was the combination of the vibration, sound and touch of the strings that he enjoyed.

Tim responds well to the combination of music and vibration, he has a good understanding of cause and effect. It did not take him long to realise that the strumming of the guitar strings created the music that generated the haptic experience of the vibrations. With this he would strum with more force so the sound would be louder and heighten the tactile sensation of the vibrations. The strings of the guitar encouraged Tim to unlock his clenched fingers and he appeared very comfortable with the simple action of 'flicking' the strings. I introduced Tim to a plastic keyboard as I felt he may also enjoy the instant cause and effect of touch and sound, but he was not as interested. This may have been because it did not vibrate, the keys required the action of pressing rather than flicking which appeared more difficult and the Tim may have enjoyed the texture of the strings rather than the plastic keys. Next time I will introduce Tim to the beaded drum that creates an intense sound and vibration with very subtle movements.

(FACT, London, April 2007)

### **An hour with Dom...**

One of the benefits of the MSE is that it houses an assortment of interesting sensory props, which interact and stimulate the service-users in ways in which words cannot. The 'tweeting bird' prop often creates interactive multi-sensory experiences, as users respond to the textures of the bird and the tweeting sounds it makes. Dom, a non-verbal six-year-old boy, reveals his unique personality through various sounds and facial expressions he makes when reacting to the bird. At the beginning of each session with Dom I always start with the tweeting bird, as I know it is something he really enjoys.

He relates the bird with his surroundings in the MSE, giving him an immediate understanding and awareness of where he is.

The tweeting bird was a great tool that encouraged Dom's personality to shine through. This simple prop informed me of Dom's way of communicating through his eyes and familiarized me to his unique sounds and facial expressions. I stop the tweeting of the bird, asking Dom if he would like to hear the bird tweet again. He would respond encouragingly through blinking. I move the bird as if soaring through the air, moving in different directions around his body - above his head, to the side of his face and by his arm. Dom instantly responds, following the bird with his eyes and head.

Conscious that the tweeting bird might get a little repetitive for Dom, I introduced other audio-tactile props: for example, shakers and the strumming of a guitar. After approximately 20 minutes of audio-tactile stimulation I turned on the projector, which created a colourful moving ocean scene on the wall opposite Dom, which he instantly started to track using his eyes.

For the rest of the session I decided to concentrate on Dom's feet. I was very conscious that I have not touched Dom's feet before - this can be a very sensitive area for many of us. I very slowly took his shoes and socks off waiting for any flinch or response. Dom's feet were initially very tense with his toes tightly clenched so I gently applied some massage cream to his feet, which I let Dom smell first. As I gently rubbed the cold cream through his feet Dom breathed softly whilst still transfixed onto the ocean scene opposite.

As I continued to massage his feet, Dom's toes begin to slightly open and gradually became less tense. As Dom's feet visibly loosened I then introduced two different vibrating props. I began by placing his feet onto a foam tube, which emits subtle vibrations. I then rolled the tube underneath his feet back and forth. Dom started to smile and began to move his head and eyes distracting him from the ocean scene. To ensure that he was enjoying the sensation I took the tube away from his feet and Dom

would then independently move his feet forward in search of the tube, which he would find and clip his feet onto.

I tried the same exercise again but with a spiky plastic ball, which emits a very strong, rapid vibration. I placed Dom's feet onto the ball, which provoked an instant reaction. It was quite unusual for me to witness Dom responding so instantly to something, so I repeated this a few times with caution observing Dom all the time. I then took the ball away from his feet and again, Dom independently searched for the ball stretching out his toes and resting one onto the ball, he would then let go of the ball and repeat again with his toe.

Today's session was really interesting; Dom really enjoyed his feet being massaged and particularly the sensation of vibration. It was fantastic to witness Dom for the first time independently making his own choices. Dom also showed great movement in his feet and legs. As he spends much of time in a wheelchair this is definitely something I would like to encourage for the next session. He also showed no signs of tiredness and falling asleep. (FACT, London, March 2007)

### Morning time with Ben...

As I push the swing higher the warm soft summer air blows onto Ben's face. He begins to smile and hum louder creating a duet between his voice and the whispering trail of breeze that sweeps past his ears.

Ben is 13 years old and has been diagnosed with Autism Spectrum Disorder, leaving him unable to communicate verbally. He will take my hand and lead me to the swing; it's his ritual, every morning, come rain or shine. We will spend an hour sometimes longer on the swings. In fact, he never wants me to stop. Ben interacts and responds to the rhythmic and repetitive motion of the swing, humming as he swoops back and forth.

'I'm sorry Ben but I think its time let the other children have a go on the swing'

Ben gets so transfixed with the sensation of the swing that it is always difficult to lure him away. I stop the swing and, protected by his soft helmet, Ben begins to bang his head against the rope of the swing. I was alarmed at first by this action, but I now understand that this is just one of Ben's unique ways of communicating. As I help him off the swing he squeezes my hand and continues to bang his head against my arm.

'Don't worry Ben, we can go back on the swing later, once everyone else has had a turn'

Ben then leads me to a chair, his second ritual of the day; he leans over and places the left side of his face onto the seat, pressing his ear, cheek and part of his helmet firmly against the hard plastic surface, whilst simultaneously trying to push the chair along.

'Ben, are you ok, do you want me to help you'

Ben takes my hands and places them onto the back of the chair and puts his face back into position. As the chair tilts I begin to pull, the legs glide along the surface of the textured carpeted floor creating a subtle vibro-tactile sensation, which vibrates through the side of his face. Outside, the chair legs now battle with the uneven, hard textured surface of the ground, consisting of coarse tarmac, pebbles, cracks, concrete and the occasional abandoned toy. I am concerned that this must be uncomfortable for Ben, his face however, remains fixed to the chair. With difficulty I continue to drag the chair, thinking: if only we had a more convenient vibro-tactile prop.

The awkward motion and friction between the chair legs and the hard surface below transmits loud sounds and heavy vibrations through Ben. He starts to hum loudly, creating his second duet of the morning in collaboration with the vibro-tactile sensation of the chair. I continue pulling the chair, as expected, Ben doesn't want me to stop. (Kids Active, London, July 2006)

# Appendix 2

## **Appendix 2: Describes the DSN-IV: The Diagnostic and Statistical Manual of 'Normal' Disorders' (1998), featured on the website of The Institute for the Study of the Neurologically Typical.**

Diagnostic Criteria for 666.00 Neurotypic Disorder

*A. Qualitative impairment in independent social interaction as manifested by the following:*

1. Marked delusional sense of awareness of the existence or feelings of others (e.g., treats a person as if he or she were an extension of himself; behaves as if clairvoyant of another person's distress; apparently projects own concepts and needs onto others).
2. Extreme or abnormal seeking of comfort at times of distress (e.g., constantly comes for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, e.g., cries, whines needs demands for attention whenever hurt).
3. Constant or mindless imitation (e.g., always wave bye-bye; copies mother's domestic activities; mechanical imitation of others' actions whenever perceived to be in context).
4. Constant or excessive social play (e.g., always actively participates in simple games; prefers group play activities; involves other children in play only as long as the other children are exactly like themselves with no differences "mirrored images").
5. Gross impairment in ability to make peer friendships (e.g., obsessive interest in making peer friendships with other Neurotypics; despite interest in making friends and afore mentioned delusion of clairvoyance, demonstrates lack of understanding for those who are different and an obsessive rigidity for social convention, for example, constantly seeks attention/positive reinforcement while staring mocking or laughing at others while they stim and rock and remain mute).

**B. Qualitative impairment in verbal and nonverbal communication, and in imaginative activity, as manifested by the following:**

1. Blatant overuse of all modes of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language.
2. Markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (e.g., anticipates and enjoys being held, does not stiffen when held, constantly looks at the other person or smiles when making a social approach, compulsively greets parents or visitors, insists on invasively stares into the eyes of others in social situations).
3. Excessive imaginative irrelevant activity, such as playacting of adult roles, fantasy characters, or animals, lack of interest in computers or other logical fulfilling pastimes.
4. Marked abnormalities in the production of speech, including volume, pitch, stress, rate, rhythm, and intonation (e.g., gregarious grandiose tone, overly emotional or syrupy melody, or over controlled pitch).
5. Marked abnormalities in the form or content of speech, including stereotyped and repetitive use of speech (e.g., immediate mindless or mechanical repetition of NT peers' latest 'in' or catch phrases) (e.g., "whatever" to mean "I am saying I disagree with you but I want you to be upset by my saying so in this way"); idiosyncratic use of words or phrases (e.g., "are you dissing me?" to mean "don't disrespect me"); or frequent irrelevant remarks (e.g., starts talking about the behaviour of autistics at a table nearby during a meal at a restaurant).
6. Marked impairment in the ability to refrain from initiating a conversation or once initiated to sustain a full thought during conversation with others, despite adequate speech (e.g., unable to stay on topic/on thought due to the interjections from other Neurotypics).

**C. Markedly restricted repertoire of activities and interests, as manifested by the following:**

1. Inability or lack of understanding for or interest in stereotyped body movements, e.g., hand-flicking or -twisting, spinning, head-banging (except for during certain types of rock concerts), complex whole-body movements.
2. Persistent lack of awareness or inability to perceive parts of objects (e.g., seeing 'a windmill' but failing to see the existence of the many beautiful finite parts which comprise the whole object, oblivion to feelings of texture of materials,



spinning wheels of toy cars) or has an attachment to unusual objects (e.g., insists on driving around in a BMW, wearing Rolex watches, carrying a cellular phone or briefcase).

3. Marked oblivion to changes in aspects of environment, e.g., when a vase is moved from usual position.
4. Unreasonable insistence in sameness in others in precise detail, e.g., insisting that exactly the same social behaviours always be followed when shopping.
5. Markedly restricted range of interest and a preoccupation with one narrow interest, e.g., interested only in status quo climbing, impressing friends, or in pretending to be smarter or better than they are.

**D.** *Onset during infancy or childhood. Specify if childhood onset (after 36 months of age).*



# Appendix 3

## **Appendix 3: Describes the DSM 5: The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (2013)**

*A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):*

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):*

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)

# Appendix 4

## **Appendix 4: The Kingwood Trust's code of conduct**

### **Introduction**

The provision of, and compliance with, policies and procedures are very important in any organisation. Kingwood has a comprehensive set of policies and procedures, which it believes provides a clear framework for the provision of support it expects will be delivered by its employees. Whilst section one of the employee handbook, the introduction section, is a policy in its own right, it must be read alongside Kingwood's other policies and procedures. All Kingwood policies are held within the Staff Handbook and Operational Policy Folder. Staff should ensure they are conversant and compliant with those policies and procedures at all times.

Kingwood's code of conduct should also be read in conjunction with The Skills for Care Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England. The two documents provide the overarching framework for the expected standards of conduct and working practice whilst delivering support to adults at Kingwood.

The code is here to help all employees fulfil their role and understand what is expected of them. Failure to adhere to the code of conduct may result in disciplinary action being taken.

The code is defined under three headings:

- Basic Matters of Conduct
- Personal Conduct
- Administrative Conduct

### **Basic Matters of Conduct**

#### **Accountability**

Whilst Kingwood provides policy, procedure and guidelines to help employees do their job correctly, each employee is accountable (responsible) for their own actions and omissions. This applies to every action and omission undertaken in the workplace. Likewise, it is incumbent upon every employee that they report any action or omission by others that does not conform to

this code of conduct. This ensures consistency of delivery, the safety and wellbeing of the people we support and Kingwood standards are upheld across all the services provided.

The safety and well-being of the people we support is dependent on how well employees do their job. It is important that if an employee has any doubt about their ability to perform a task or an action they should take, they should raise this with their line manager. This will enable the line manager to reassess any support and training required to enable the employee to achieve the correct standard and to feel confident in performing specific tasks independently.

Employees should not ascribe abilities or knowledge to themselves that they do not possess. It is important that all members of staff are competent in the tasks they undertake and only undertake those that they are competent and able to complete. It is an employee's responsibility to ensure they attend and actively participate in all mandatory training provided and to attend and participate in any optional relevant training offered to them. Further, it is an employee's responsibility to ensure they discuss any concerns about their competence or knowledge with their line manager. Kingwood view open and honest discussions about competence as key to the quality of service provided and crucial to the ongoing development and support of its staff team.

### **Confidentiality**

Information about people we work with should be shared between staff on a need to know basis only. In providing information, you should be guided by whether it is in the best interests of the person\ s being supported for the other party to know and refer to their personal file for a consent form. Information should be shared with the individual's consent, where this is possible to obtain, otherwise you should consider what is reasonable to exchange in the circumstances and seek guidance where necessary from your line manager.

If you are found to be sharing confidential information in a defamatory, self-serving or frivolous way, you may be liable to action under the Kingwood Disciplinary Procedure. Equally, it is expected that information regarding other Kingwood employees will be treated sensitively and shared with others only in that person's best interests or in the best interests of the people we support. Persistent gossip, deliberate or frivolous falsification or reporting of information/facts about the conduct or personal lives of colleagues, or the wilful failure to use the appropriate lines of communication, may render you liable to action under the Kingwood Disciplinary Procedure.

Kingwood has an open access to files policy - this means that people we support have a right to see everything that is written down about them and to have that information made accessible to them. Care should be exercised in recording information on personal files so as to make the information accessible, relevant and accurate. Personal information belonging to people we support should be kept in their home in a space accessible to them.

### **Health & Safety**

All employees must make themselves familiar with Kingwood's Health & Safety guidelines and policy, National Health & Safety legislation and attend mandatory Health and Safety training provided.

It is every individual's responsibility to make sure people we support and colleagues are protected from danger and are not placed at risk by unsafe or negligent actions. It is therefore imperative that all staff operate in compliance with guidance and policy. Breach of policy, deliberate or accidental, may render an employee liable to action under the Kingwood Disciplinary Procedure.

### **Clothing standards**

An important part of delivering a service to the people we support is to act as role models for our service users. With this in mind it is important that staff should wear clothing appropriate for the role of support worker, team leader, manager etc.

Clothing must be clean, tidy and appropriate for the activities planned. There may be occasions when carrying out dirty jobs (e.g. gardening) or taking part in sports with people we support, when rough clothes may be necessary. In these circumstances a change of clothing should be available.

The following clothing may be considered as unacceptable for work/duty occasions. This is not an exhaustive list and if in doubt about the suitability of an item of clothing staff should check with their line manager:

- Shorts (i.e. hot pants) and skirts more than 2" above the knee.
- See through revealing clothes.
- Low cut or crop tops.

- Ripped clothing
- Skimpy swimwear – bikinis etc.
- T-shirts with offensive logos.
- Staff should not walk about in bare feet\*

\*Some people we support do not allow staff to wear shoes in their homes. In this instance this will be recorded fully and made reference to in the workplace assessment. In this circumstance the person we support will be encouraged to accept alternative footwear i.e. slippers or shoes kept for indoor use only.

Staff should also consider the value of the clothes they wear to work when supporting individuals who may become challenging. Kingwood will reimburse the cost of clothing damaged by people we support up to set limits and subject to strict criteria. Kingwood asks all its employees to consider sensibly the value of clothes they wear when practically supporting individuals.

Staff should wear nightwear that is practical and decent as they may have to deal with an emergency situation or people during the night.

Careful consideration should be given to jewellery that can be grabbed or caught by people we support or machinery and cause injury. Consideration should also be given to jewellery that could scratch someone we support and may need to be removed during personal care.

Staff remain employees whilst supporting people on holidays. Appropriate clothing should still be worn and all the above considerations still need to be thought about.

### **Conflict of interest**

It is not acceptable for Kingwood employees to abuse their position for personal gain or to benefit their family and friends. Employees should declare any potential conflicts of interest to their manager. This includes all business interests which could potentially result in personal gain or gain for a family member or associate as a consequence of their position.

Any employee considering taking up a second job should inform their line manager or the HR department. It is rare that Kingwood would object to secondary employment except where it is believed that it may interfere with carrying out responsibilities required by an employee's contract of employment or will conflict with Kingwoods best interests.



### **Alerting others to concerns**

Kingwood has a Whistle Blowing Policy that provides full details around the process; but it is important that every employee raises issues that cause them concern to their line manager as soon as is practicably possible and in some cases immediately. Particularly where these relate to:

- how support is delivered
- the personal health, safety and security of people we support
- harm and abuse of any person we support

Employees should ensure they are fully conversant with the Whistleblowing Policy and consider it in conjunction with Kingwoods Safeguarding Adults Policy. Furthermore employees should ensure they are aware of the alternative routes to communicate their concerns if their immediate line manager is either not available or it is not appropriate to alert that individual.

### **Personal Conduct**

#### **Working with others**

It is vital that Kingwood employees act in a professional manner at all times and this will include working positively with colleagues, families and other health or social care professionals. It is important that staff communicate effectively and co-operate with colleagues to meet the needs of the people we support. Withholding of information that has the potential to impact working practice or operations is not acceptable.

It is not appropriate for staff to enter into a disagreement whereby voices are raised, offensive language is used or aggression apparent. Any action or comment that is considered to be offensive or distressing by a Kingwood employee will be investigated and may lead to disciplinary action. All employees should familiarise themselves with the Positive Working Environment Policy and ensure they operate in compliance with this policy at all times.

#### **Conduct outside of work**

Whilst a person is an employee of Kingwood it is important to recognise they are an ambassador for the organisation and that at all times whilst in and outside of working hours,

they act responsibly as representatives of Kingwood. An employee should not bring the reputation of the organisation into disrepute as a result of their actions.

### **Professional Boundaries**

It is recognised that employees working with people supported by Kingwood may develop a close working relationship; however, it is important to keep in mind that over familiarity and friendships are not appropriate. Despite good intentions a close familiar relationship may lead to an unhealthy dependency on certain staff and if/when that member of staff leaves the distress that this can cause the individual could have been avoided.

Where an employee is unclear about their boundaries or feels that the relationship they have with a person we support is becoming overly dependent, they must raise those concerns with their line manager immediately. Employees are expected to co-operate with Kingwood management where it is considered professional boundaries may be becoming blurred, in order to achieve an appropriate balance.

### **Respect differences**

Kingwood embraces cultural difference and recognises the strength and richness that different beliefs, opinions and customs can bring to an organisation, its staff team and the people it supports.

Kingwood employees should respect the beliefs and opinions of the people we support; enabling and assisting them as per their support plan. This includes supporting people with cultural or religious beliefs regardless of staff members own beliefs and where they may differ.

Should a member of staff have any objection to supporting an individual fulfil any aspect of their support plans, they must discuss this with their line manager immediately. If Kingwood believes the request to support an individual with a particular activity is reasonable, having considered any objections, they can require the activity be supported. Persistent failure to follow a reasonable request to support an individual may lead to disciplinary action.

Staff members are also required to be culturally sensitive to other staff and to be respectful of their beliefs and opinions even where they may differ from their own. Discriminatory behaviour is not tolerated within Kingwood and any employee found discriminating against, or

engaging in discriminatory behaviours towards another member of staff may face disciplinary action.

### **Personal & family relationships**

It is recognised that close personal relationships may develop between members of staff. In order to ensure that potential problems are avoided, employees are expected to advise their managers accordingly.

Kingwood reserves the right, where close relationships exist between staff, to ensure that the persons concerned are not employed in a situation where one would be responsible for managing, auditing or authorising the work of the other. Whilst Kingwood reserves the right to move an employee's base of work, this should not be undertaken without full consultation with the employee.

### **Use of alcohol, drugs (including medication)**

Employees have an individual responsibility to ensure they are fit for work. It is not permitted to drink alcohol whilst supporting people (including during meal breaks) under any circumstances. Social events, e.g. leaving parties at which alcohol will be consumed should be arranged after work. All employees are required to familiarise themselves with Kingwoods Drug and Alcohol Misuse at Work policy and to comply with the requirements of the policy at all times. This includes the disclosure and storage of prescribed medication within the workplace.

It is an employee's responsibility to present themselves in the workplace fully functional and free from the effects of any substance they may have consumed in their free time. Any employee found at work under the influence of alcohol or any other substance will be subject to an investigation and may face disciplinary action.

### **Home of people we support**

Employees must remember that they are entering the home of someone Kingwood supports and should pay respect to that persons home as they would expect it in their own. This includes knocking to enter at all times unless a documented agreement is in place.

It is not appropriate for staff to store personal belongings in the home of someone we support, nor use their home for personal use i.e. having post delivered. Staff should not borrow items

belonging to people we support nor use their food and drink unless a documented agreement is in place and the person is compensated accordingly.

Staff are required to familiarise themselves and comply with Kingwood's Support Worker Rules which have been developed by the people we support and fully endorsed by the organisation.

### **Contact with the Police**

Kingwood requires the disclosure of any criminal convictions, including any driving offences, as part of the recruitment process. Any individual that is offered employment or is employed and fails to disclose a criminal conviction that is subsequently discovered will have their employment terminated or their application withdrawn.

Employees must inform their line manager as soon as practicable if they are arrested or are the subject of a police investigation regardless of the nature of the alleged crime. Employees must also inform the organisation of any criminal convictions, including any driving offences (including speeding, but excluding parking offences).

An arrest or subsequent conviction may not necessarily result in any punitive action in relation to their work but will be considered within the overall context of employment with Kingwood.

### **Administrative Conduct**

#### **Record keeping**

Records are essential to safeguard the interests of both staff and people we support. Staff should keep records which are brief, purposeful, current and objective, in a form which can be understood by those that need to use them. Written entries should be clear, legible, signed and dated, with the name of the signatory clearly identified.

Employees are required to familiarise themselves with the documentation required for each particular service and complete accordingly. In addition employees should be sensitive to those records potentially being analysed as part of investigations and that they may be examined by external organisations.

**Finances**

Employees must familiarise themselves and comply with the Kingwood Finance Policy – Supporting People and the Kingwood Expense Policy. Under no circumstances should employees use money belonging to people we support or belonging to Kingwood for personal reasons.

It is not acceptable for staff to use purchases for Kingwood or people supported by Kingwood as contributions towards points collected on store cards or petrol cards.

In most circumstances an employee should not accept a gift from someone Kingwood provides support to. Any exception to this must be with Area Manager documented approval. An acceptable exception may be a bar of chocolate on an employee's birthday where the person being supported will become distressed or offended if they cannot give a gift.

**Telephones**

Telephones belonging to people we support should not be used unless in an emergency and in this instance, the call should be recorded and associated cost reimbursed. Kingwood mobile phones are issued for work related calls only. Other calls should be declared and paid for. Personal calls should not be made or taken when working directly with people we support.

**Internet and Social Media**

All employees should familiarise themselves and comply with Kingwood's IT and Communication Equipment Policy and Social Network Policy. Excessive use of the internet during working time will be investigated.

Limited personal use of the internet utilising work equipment is permitted however any employee found accessing non work related internet sites frequently or accessing inappropriate or forbidden internet sites on computers belonging to Kingwood or the person we support, may face disciplinary action.

If an employee chooses to name Kingwood as the organisation they work for on a social networking site, they must understand that they become representatives of the organisation online and should behave accordingly.

**Communication and the media**

When writing or speaking publicly on any matter which could be seen as representing Kingwood; speeches or articles should be cleared with the Area Manager.

Employees should not make direct contact with the media or respond to media enquiries unless it has been agreed in advance that they should do so. All media enquiries should be directed to the Chief Operating Officer.

# Appendix 5

## **Appendix 5: The Kingwood Trust's core values and credo.**

### **What are Kingwood's core values?**

Kingwood enables people with an autistic spectrum disorder to work towards the goals and outcomes they desire in life. We support people within their communities in natural settings such as home, neighbourhood and work. We help people to have choice about where and how they live.

### **Relationship with people we support**

We work sensitively and innovatively with people with Autistic Spectrum Disorder (asd) to learn what matters to them, to identify and capture their desires; and we make sure that current thinking and the expectations of others do not constrain individual choice. Kingwood's aim in working with people is to identify the most appropriate living environment for them and to support them within this. We are committed to ensuring that appropriate funding supports the lifestyle chosen and agreed by those we work with.

### **How we deliver services**

Kingwood is a specialist autism service. We aim to ensure that across the organisation we have skills and expertise in working with people who have asd: an understanding of the complexities and challenges these can create and the tools and knowledge to ensure such challenges are not insurmountable barriers to achieving realistic aspirations that everyone in society is entitled to hold for their lives.

Kingwood delivers person-centred services at all times. This means that there is a continual process in working alongside an individual person to use all forms of communication available to capture, record and implement choices and desires. We commit to making sure that this process is at the centre of an individual's service at all times.

We aim to create a professional culture where this will happen based on:

- Questioning each other, planning, explaining and recording decisions and practice appropriately
- Ensuring our structure and processes promote high levels of accountability throughout the organisation
- Training people when they start working for us and throughout their employment to make sure everyone understands our values and how to ensure these underpin their practice
- Providing appropriate staff supervision, appraisal and support
- Ensuring that we have a high level of expertise to support and enable the people we work with to communicate, stay healthy and safe, progress and develop choices in life.
- Recording, sharing and disseminating the knowledge and skills we develop as an organisation and as individuals
- Ensuring that the personal choices of people we support are always held as central to our work and to our professional decisions at individual and organisation wide level.
- Our actions and behaviours will always reflect our fundamental belief in these values

### **Valuing our staff**

Kingwood values our staff as the most important resource we have for delivering our services. The success of Kingwood, its employees and the people we support depends on us working together with people we support, their families and other local agencies in partnership.

Kingwood is an equal opportunities organisation with an equal opportunities employment policy. We see all people as full members of society with equal rights and responsibilities not determined by gender, ethnic origin, cultural background, benefits, lifestyle, age or disability. Our employment policy is founded on these principles.

Kingwood's commitment to staff is to ensure that they have the appropriate training, supervision, support, environment and benefits to enable them to work confidently and positively.

### **Kingwood's credo**

In September 2007 Kingwood's trustees adopted a credo which sets out the aspirations and ambition Kingwood has for the work and support we provide. These are based closely on the Reach standards for supported living, developed by Paradigm along with Skills for People, CSIP (Valuing People Support Team) and the Association for Supported Living. The specific aspirations and indicators were developed by a group of people with learning disabilities to



ensure that people with learning disabilities could check the quality of their own housing and support.

The credo will be used as a benchmarking and development tool to review and refine how a service is delivered to each individual. Application of the credo will always be tailored to the specific needs, capabilities and wishes of the individual.

The credo was extended in 2009 with a set of rules developed by a working party of People We Support that are regularly reviewed by the People We Support Forum and can be found in the Operational Policy & Procedure Manual.

The credo is outlined on the following page:

**Kingwood’s credo**

<b>Aspiration</b>	<b>Indicator</b>
I choose who I live with.	If I want to, I live on my own.
	If I want to live with someone, I get help to work out what kind of person I want to live with.
	If I want to live with someone, I choose my new housemates, along with any other people who live with me.
	If I’m unhappy about who I live with I get help to change things.
I live in a home that I want to be living in and that works for me.	Someone helps me work out what kind of place I want to live in and where I want to live and that my environment is appropriate to my needs.
	Someone helps me to understand what choices I have so that I can decide for myself where I live.
	If I’m not happy with where I live, I get help to change things.
I have my own tenancy or I own my own	I own or rent my house.

home.	
	If I rent I have a tenancy agreement.
	My landlord has no control over my support workers.
	My support staff have no control over my tenancy.
	It's up to me what happens in my house and what the rooms are used for.
	My house does not look like a workplace for staff. They do not hold meetings or get their post sent to my house unless I say it's ok.
	People do not take breaks and smoke in my garden unless I say it's ok and I have signed an agreement with the Area Manager.
	No one has the keys to my house unless I have given them a set. Even then, they should always knock and wait for me to let them in.
	Someone helps me to understand my rights and responsibilities as a tenant or home owner.
I can choose just the right type and amount of support for me.	I get help to understand how much support and what type of support I want (and need); and this matches the support I get.
<b>Aspiration</b>	<b>Indicator</b>
	Support workers are there to support me. They fit work around me and my choices and it is not the other way round.
	My support workers know what kind of help I want and don't want from them. I get just the right amount of help for me.
I choose who comes into my house to support me.	I get help to know about the kind of people I want to support me. I decide whether they are men or women, their age, the skills they need, the type of personality, interests and life experience.
	I take part in choosing my support staff, advocates and Circle of Support (if I have one) and I am happy with them.
	If I am not happy with my support staff or the job they do, I will get help to make changes within reason.
	If I do not like a member of staff, I do not have to have them working

	with me.
--	----------

The people who support me are good at their job.	I am happy with the way support staff talk to me and I like the way they treat me.
	I can get to know and trust all of my support staff really well because they have supported me for some time.
	Support staff can communicate well with me. They know how I show my feelings and “listen” to my words or actions, even if I am angry or upset. There is trust between us.
	I am happy with the way support staff give me personal care and other support.
I get the support I need to make and keep friends and relationships that I choose.	My support staff know who is important to me. They help me spend time with who I want.
	I get enough support and space to help me with my relationships, and I can get to know new people if I want to.
	I have the same rights as everyone else to choose my relationships. My support workers give me support and advice to help me make choice about my friendships and relationships.
<b>Aspiration</b>	<b>Indicator</b>
	I have the same rights as any adult to have a romantic or sexual relationship with people I choose. If I am vulnerable to people taking advantage of me, my support staff help me think about this and plan how to keep myself safe.
I get support to understand how to keep myself healthy and safe in	My support workers and I know about the risks I might take and we have agreed ways of dealing with them

the things I choose to do.	
	I have a say in what is safe for me. Support workers help me to take risks sensibly so that I can do what is important to me. I am not stopped from doing things just because other people worry.
	Staff know about my fears and worries and they help me to feel safe in and outside my home.
	I get friendly advice about my body and health but I don't have to take it. I can decide for myself.
	I get help to understand about treatments and medicines and about the choices I have.
I get the support I need to make choices about work, education, community activities, hobbies & interests.	I get help to understand what there is to enjoy near where I live and get to know my neighbourhood.
	I am supported to join groups that I am interested in and make links with other people.
	I have the support I need to get a job, learn new skills and travel independently if I want.
	I am supported to contribute to my local community in ways that I choose and I am not made to go to places that I don't want to.
	I understand that I can use the same local services as everyone else.

I have the same rights and responsibilities as other citizens.	I am supported to understand my responsibilities about money and how to use it. This helps me to use my money the way that I want to.
	I am supported to understand my rights and responsibilities as a tenant or home owner.
	I know how to complain in a way that is easy for me. I get support to

	do this. When I complain, people listen to me and take me seriously.
	I know what information other people keep on me. It is private and kept in a way that I can understand. I can see this information whenever I want.
	Support staff help me to understand the things that are going on around me or that might affect me. They help me to understand the news and politics so that I can vote if I want to.
People ask me often if I want to make changes in my life. If I do, I get help to make those changes.	People around me listen to what I want and how I feel. I get support and feel comfortable talking with them about my dreams and plans.
	I can plan how I want my future to be. I get help to plan with people who care about me, in a way that helps me to have more choice and be more independent.
	If I need meetings to make changes I decide when and where I have those meetings. I decide who comes and how to run those meetings. I am always the most important person at meetings about me.
	I am supported to get an advocate if I need one.



# Appendix 6

## **Appendix 6: A list of rules for Kingwood Trust's support staff, compiled by the autistic people Kingwood Trust support**

The people we support have created these rules on how they would like their support staff to be when they are at work:

- Be cheerful and happy.
- Don't be miserable or grumpy because you are having a bad day.
- Be polite and have manners.
- Have fun and make me laugh!
- Stick to the rota because I like to know who is coming and I don't like changes – particularly at short notice.
- Tell me how you are feeling because I can't always tell and I might think you are angry with me.
- Help me to be calm by being calm yourself.
- Understand when I am worried and reassure me if I see things or hear voices.
- Explain what you mean clearly.
- Think before you tell me something that is not relevant to me as I might prefer not to know.
- Be patient with me, sometimes I forget what you said
- Ask me how I am feeling today.
- Don't assume I will want to shake your hand.
- Be honest with me and tell me if I have done something wrong or when I do something right.
- Don't tell me things about other people you support or I will wonder if you tell them about me.
- Plan ahead and have the things you need to come to work.
- Check before you enter my house by knocking first, even if you have a key.

- Ask if you want to use my toilet.
- Suggest things I might like to do or places I might like to go.
- If I don't want to go out or there is no work to do, check that it is ok to watch my television.
- Find out about my interests and then we can talk about interesting things.
- If you don't understand me – ask again – I won't be offended.

With thanks to the following people who helped to prepare these rules;



S Alves



P Morley



S Green



# Appendix 7

## Appendix 7: Kingwood Trust's media consent form

This form operates alongside the Kingwood policy on photographing and videoing.

Kingwood would like to take your photograph and/or make a video recording of you and the support you receive for promotional purposes. These images may appear in our printed publications, on video, on our website and be used for commissioning purposes with the local authority or on all four.



There are laws that we need to follow and one is called the Data Protection Act 1998, we need your permission before we take any photographs or recordings of you. Please answer questions 1 to 4 below, then sign and date the form where shown.



If we are not sure that you understand how we might use your photo, we might ask a family member or your care manager and we will ask them to sign.

**Please answer the questions below;**



1. May we use your image in printed publications produced by Kingwood for promotional purposes?

**Yes / No**

2. May we use your image in press releases, which may subsequently appear in the local or national media?

**Yes / No**



**Yes / No**



3. May we use your image on our website?



4. May we record your image on our promotional videos?

**Yes / No**

I have read and understood the conditions of use on the bottom of this form.



Your signature: \_\_\_\_\_

Date: \_\_\_\_\_

Family\Carer Signature: \_\_\_\_\_ Date: \_\_\_\_\_

where appropriate)

Care Mgr Signature: \_\_\_\_\_ Date: \_\_\_\_\_

where appropriate)

### Conditions of use

1. This form is valid for two years from the date of signing. Your consent will automatically expire after this time.
2. We will not include details or full names (which means first name **and** surname) of any person in an image on our website, on video, or in printed publications, without good reason. For example, we may include the full name in a press release or of a competition prize winner if we have their consent. However, we will not include the full name of a person we support when used in promotional literature.
3. We will not include personal e-mail or postal addresses, or telephone or fax numbers on video, on our website or in printed publications.

# Appendix 8

## Appendix 8: Diary account of a creative activity, by the author

28th November 2012

The sensory preference cards and sensory activities provided immediate insights into individual interests and sensory preferences that helped to generate ideas for the design of a creative activity. The activities were broken down into manageable steps, which were short and attainable so that there was a clear goal that was not beyond the participant's capacity.

### Three Creative Activities:

Emily likes to draw, therefore in addition to drawing equipment, stickers were also available for those who prefer not to draw. The stickers were lilac and pink stickers and were chosen for Emily for her love of these colours. Crystal stickers were chosen for Pete and Matt who like twinkly light effects. This activity was unstructured and hoped to encourage creativity with the purpose of making a card for a friend or family member.



Inspired by Montessori's bead bars this activity involved threading pasta beads onto wire to then bend into different shapes. This activity can be broken down into two stages. For the first stage pasta was presented in separate containers that offered different shapes, textures and colours.

The aim of this activity was to explore the tactile qualities and sounds of the pasta shapes; Aromatic oils were also available for Matt who enjoys different aromatic smells.



For the second stage the activity encouraged the participant to choose their own pasta beads and make pasta garlands rings as they are threaded through wire. According to the size of the hole in the pasta bead, different levels of skill and effort were required. The goal of this activity was to make hanging decorations. The activity was structured and hoped to encourage concentration, hand-eye coordination and fine motor skills.

Tom likes objects that offer resistance, which he can stretch and pull, therefore to decorate the washing line small slinkys were chosen to pull along each spoke. For Matt who enjoys mirrors and reflections, readily available mirrored baubles were available to hang onto the end of each spoke alongside the pasta decorations. The physical outcome of the activity was a decorative mobile to hang in the activity room at White Barn, to catch the sunlight and create visual effects for all of the residents to enjoy.

### Creative Activity



Without any coaxing Emily immediately gravitated towards the stickers, she liked the colours and for a few seconds tried to peel one off, but would become quickly distracted and asked for a mince pie and coffee. Sarah (a support worker) came and joined us too who began to make some pasta garlands with the hope that Emily would want to join in. We began to talk about Christmas and Emily enthusiastically described her Christmas dinner. When I showed Emily a completed pasta decoration she seemed interested, and held one for a short time and then put it down again asking for coca cola and mince pies. On three occasions Emily picked up the cellotape and spent a few moments trying to peel it before putting it back onto table.





Tom and Mark then began to thread string through the mirrored baubles to hang onto the mobile. At first Tom would hold the bauble whilst Mark threaded the string through the hole. After a while David confidently threaded the baubles and independently decided to thread several baubles onto a piece of string, which looked great. At one point tried to create game out of this by sliding the ball balls along the string, which made him laugh!

During the activity Pete would walk past the dining room and peer in from the doorway. Matt had just returned from visiting his family and walked into the dining room a couple of times. I asked him if he would like to join in and showed him the container of pasta beads, which he immediately sunk his hand into for a few seconds. I also held the mobile up to show Matt what Tom had made where he instantly flicked one of the mirrored baubles.



Throughout activity Emily continually asked for coffee, coca cola and mince pies. Anne (a support worker) also joined in with making some pasta garlands. Emily was wearing a lovely beaded necklace and often wears jewellery so I suggested that instead of a decoration why not make a nice bracelet to match her necklace. This did prompt Emily to join in and she wore the bracelet for the rest of the day. Tom was doing really well and was now making his own pasta garlands and appeared to enjoy the repetition of threading the beads through the wire. On one occasion a pasta bead broke in Tom's hand, which he found really funny. Tom made two hanging pasta decorations and looked very proud as he went to show his support worker.

Towards the end of the activity we hung the mobile up in the activity room and Tom really enjoyed reaching up to hang the decorations from the spokes. Once the activity had ended Emily helped to pack away the materials and was finally able to enjoy her coca cola and mince pie.

### **Conclusions**

Tom fully participated in the activity and appeared to enjoy all the different challenges that were presented to him. Tom showed great amounts of concentration and the activities diverted his attention away from his watch, which is a subject he repeatedly talks about.

Emily did not fully participate yet spent most of the afternoon in the dining room talking and watching us make the decorations. Emily appeared intrigued by what was going on and there were several moments when she almost joined in. As the theme was Christmas, when Emily's attention turned to coca cola and mince pies we managed to divert her attention onto stories about Christmas so the activity provided a cue for narrative and conversation.

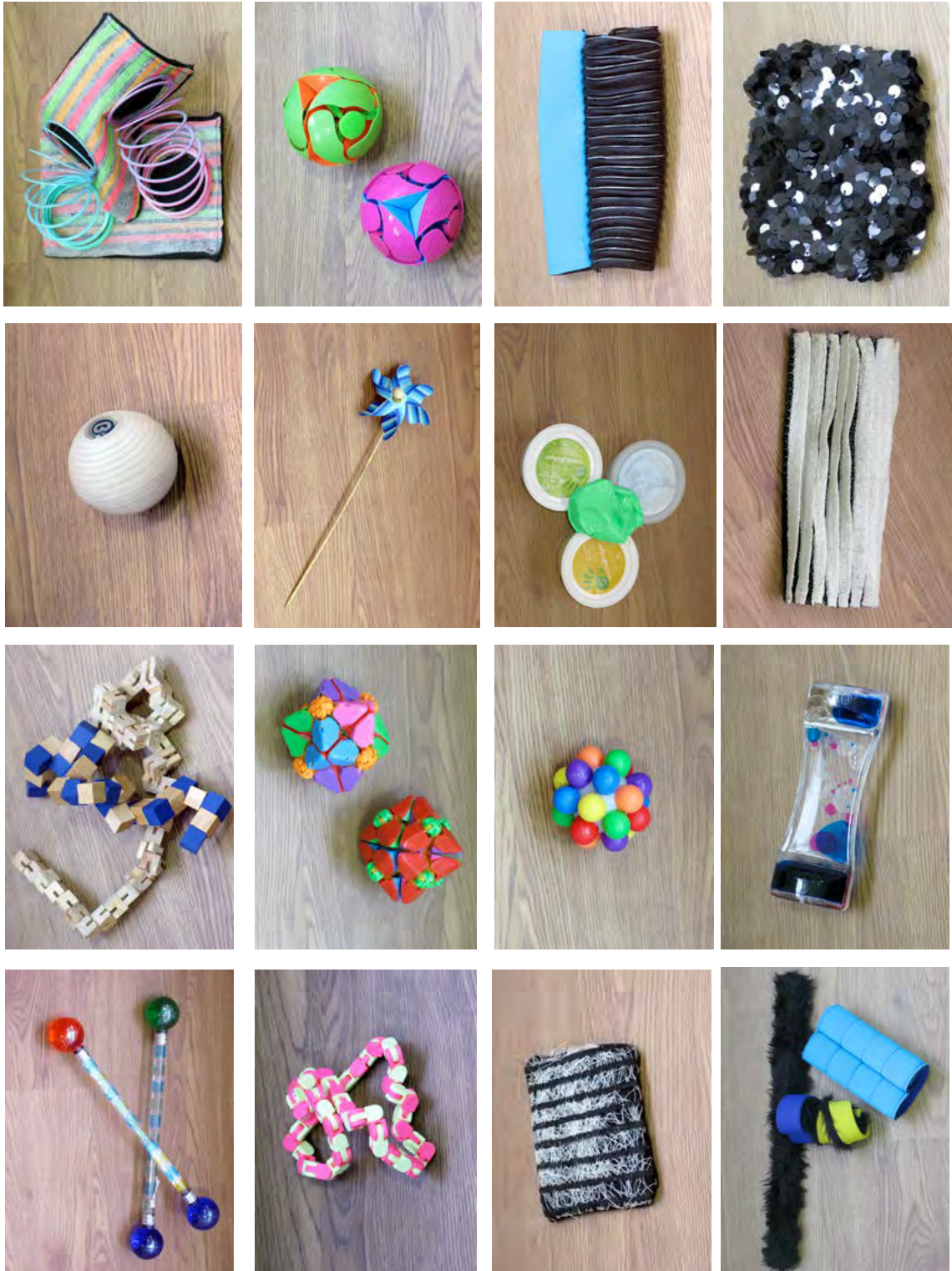
The creative activity added something new to the routine of the day and three support staff voluntarily participated. The activity helped to create an informal setting for us all to chat and exchange stories and experiences.

### **Key Challenges:**

- The materials were laid out on the dinner room table on top of a pattern tablecloth, which in hindsight looked chaotic and confusing. In future I would recommend a plain white tablecloth so that that it is clear what is on the table.
- A one-one session might have been more successful. Everyone had different skills, preferences and abilities and it can be difficult to share the time between the participants. A one-one activity with Emily may have helped Emily to concentrate and not get too distracted by all the people in the room.
- In future it is best to not mention coca cola until the activity has ended.
- Matt likes to listen to music so for any future activities I will play music to entice Matt to join in.

# Appendix 9

**Appendix 9:** A selection of sensory props used in the sensory activities

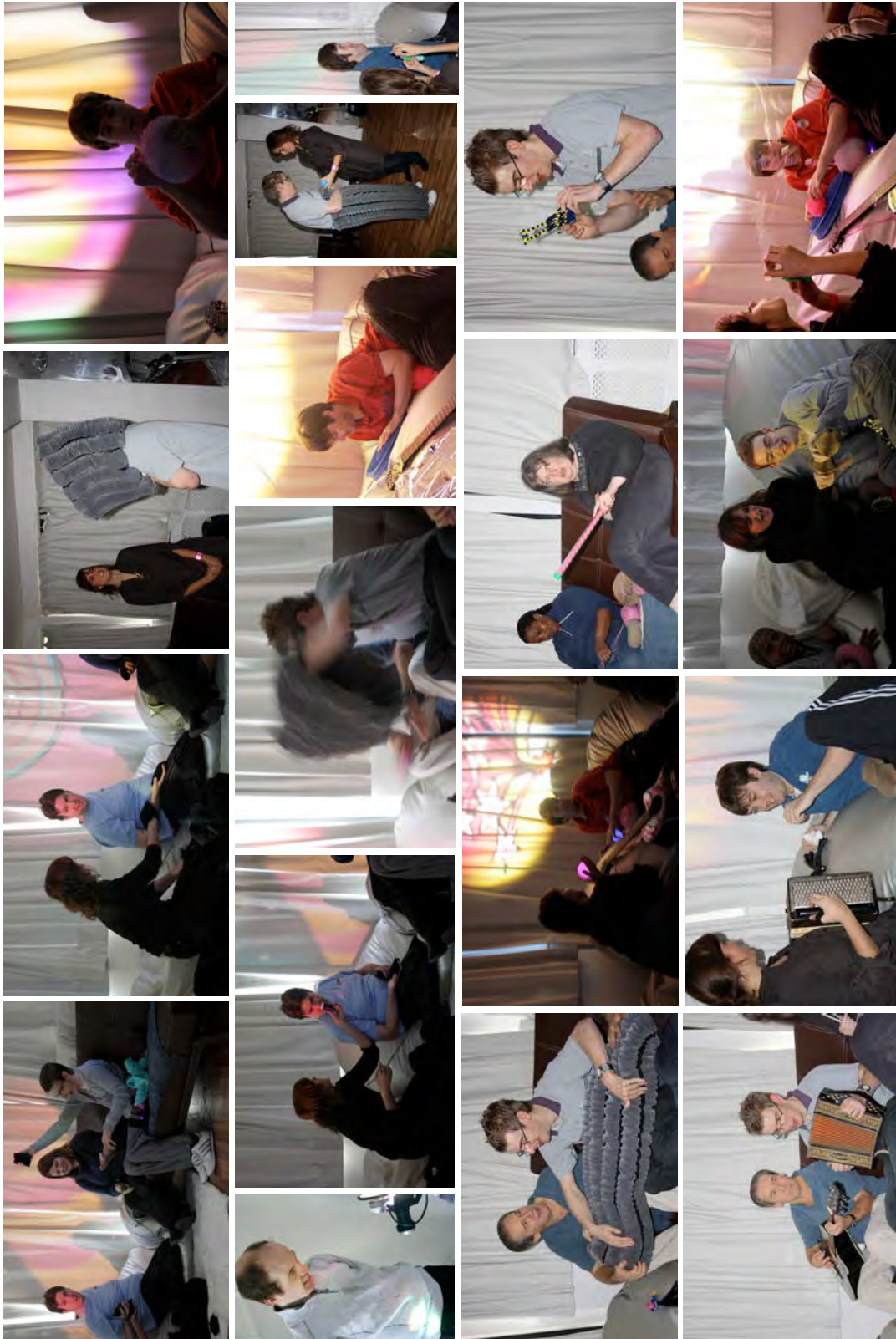


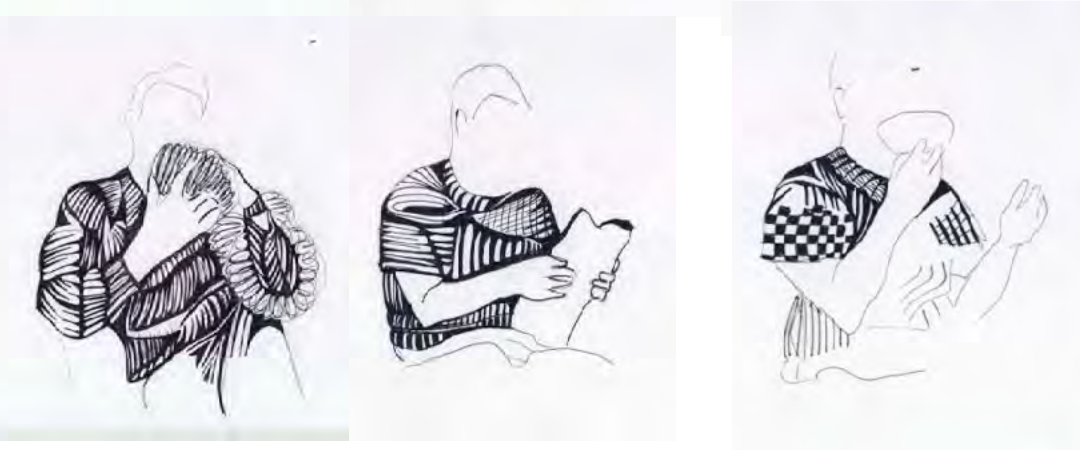




# Appendix 10

## Appendix 10: Sensory activities: photographs and sketches





# Appendix 11

## Appendix 11: Diary accounts: sensory activities, by the author

\* The designer was joined by Andy Brand (a designer) to help facilitate the sensory activities

### The Journey

It's 7.30am and everything just about fits into the car; cables, lights, ultra-violet (UV) light, sensory props, UV-reactive props, guitar, Springy-Thingy Pouf, rug, cable ties, gaffer tape, knitting needles, wool, snap cards, puzzles, bubbles, coca cola, cookies, chocolate milkshake for Matt and, a last minute thought, my squeezebox (Cajun accordion). During the drive I was feeling more and more anxious and nervous, with many thoughts and questions racing around my mind such as; what if none of the residents want to join in with the activity? What if they only join in for one minute during the entire day? What if they do not engage with any of the sensory props? What if Matt and Pete become agitated or anxious as a result of us rearranging their sensory room? What if the sensory activity does not meet the support workers' expectations? And what if we observe no correlation between the results of the sensory questionnaires and our sensory activities?

### Setting up

At 10am we arrive at White Barn. We are welcomed with a warm greeting from Brian (member of staff) who is working in the outdoor office. I can see Tom peering out of the window. From my previous visits, I know he is always interested in the comings and goings at White Barn and often points to different cars in the car park, naming who owns which car. As we enter, Tom greets us and presents his new watch, hiding it under his hand and asking 'where has it gone?' Tom will repeatedly do this throughout the entire day and has done so for a few months now. We walk into the sensory room where we find Pete and Matt. Pete is standing, rubbing and scratching the cupboard door and Matt is sitting on the sofa. The sensory room at White Barn is rarely used nowadays as a space for sensory integrative activities and is generally used by the residents for sitting and listening to music or relaxing.

As Andy and I fetch our equipment from the car, Pete left the sensory room to press buttons on the computer next door. Tom and Matt, however, appear to be very intrigued and interested in what is going on. Emily also comes into the sensory room to say hello and asked us if she may have a cup of coffee. The sensory room at White Barn is a large room that is sparsely furnished. To help create a smaller, relaxed, cosy, comfortable and inviting environment we lay down a big textured rug and rearranged furniture. (Maria Montessori often used rugs in her classrooms to help define different work spaces). A white rug was selected to contrast with the black sensory props and also enabled us to project light patterns onto it. We selected a rug with an interesting texture to add an additional tactile experience. Matt and Emily often like to take off their shoes so we think they may like the feel of the rug. We draw all of the curtains to avoid any visual distraction from the outside and dim the lights to enhance projected patterns on the walls and floor. The patterns look really effective on the curtain fabric too. Drawing the curtains certainly makes the space feel smaller and cosier. We rearrange the beanbags and sofa around the rug and angle them to reinforce the boundary and create an enclosed, secure space. From discussions with support workers and my earlier observations, I know that Matt likes to sit on the beanbag and watch people moving about the house. With this in mind, I positioned the beanbag opposite the door to the sensory room so that Matt can join the sensory activity and still see what's happening in the adjacent circulation space. All the props and equipment are stored out of sight behind the sofa to free the space from clutter. With all of the furniture and equipment in place,

we turn on the projector to lure the participants into the sensory space. In a previous visit, I learnt that Matt and Pete will only enter the sensory room when music is playing so I turned on the stereo to entice them in. We are ready to start.

### **The Morning Session**

Before we can even press play on the camcorder and without any verbal coaxing from Andy or myself, Matt comes and sits on the beanbag, followed by Tom and Emily who sat on the sofa. Support workers Brian and Mark also joined us. This was amazing, we had not prepared ourselves for a group session, as White Barn staff had explained that the residents rarely participate in group activities. I was keen to follow the philosophies of the multi-sensory environments and Montessori and allow participants to define what happens throughout the activity (a non-directive enabling approach). However, I was conscious that Emily, Tom or Matt could lose interest or concentration at any given moment. So I promptly started the sensory activity with a slightly more directive approach and, one by one, passed the audio, audio-tactile, tactile and olfactory props around in a circle. The participants spend only a few seconds with each prop and, as a result, we exhausted our selection of single-sensory props within minutes. As Emily interacts with the props she continually asked “is it coffee?” or “can I eat it?” She appeared to gravitate towards props that felt warm and soft such as the velvet-covered tactile prop. Emily also liked the glimmer and shine of sequins. Matt first inspects each prop by raising it to his nose and smelling it and gravitated towards the audio and olfactory props, particularly liked the smell of clove sticks. All of the participants spend more time engaged with the audio-tactile props, intrigued by what might be inside the prop. In particular, a cushion filled with ball bearings appears to please the participants. They seemed surprised by its unexpected heavy weight. Matt holds this prop in his hand for several minutes.

### **Matt**

Matt appears to like the audio-tactile props, in particular props where sounds are activated by his fine motor movements and interaction. He interacts with the prop first by smelling it and then by tapping it. Shaking and picking at the props, Matt inspects the props, delicately removing tiny specs of fluff or hair filaments. Matt chooses props that have a range of tactile qualities, including objects that are made from paper, ceramic, textiles, plastic, metal and rubber. Matt appears to understand everything I am saying. We have good eye contact and he is smiling all of the time. I demonstrate ways of interacting with the Springy-Thingy wrist shaker and paper and then Matt repeats the actions. He enjoys sliding the paper expanding hat onto his head. Matt occasionally stands up, circles the room and then returns to his seat, the bean bag. He is regularly signing “is the music still on?” I reassure him that the music is playing. During the morning activity, Matt had been drawn to the audio-tactile props and so it occurs to me that he might like the squeezebox. Matt responds positively and through his behaviour, we observe more and more of his ways of communicating. For example, Matt flaps his hands quickly and laughs out loud when the squeezebox is played. Brian explains afterwards that this action indicates Matt is happy and excited.

### **Tom**

Tom is a very sociable and chatty person and he clearly enjoys sitting with the group. Tom particularly enjoys the cause and effect props; the ones that move or react in a surprising way when a button is pressed or a cord is pulled. Tom holds the props carefully and demonstrates controlled fine motor skills. After several minutes interacting with one particular object, Tom is becoming over excitable. The props that spin and flash may be too stimulating for him and we try to calm the mood. We introduce Tom to one of the props, a hand-painted wooden giraffe that collapses when its button is depressed. He excitedly shows the giraffe prop to Matt, demonstrating how it works. The results of the sensory perceptual questionnaire had indicated

that Tom would enjoy deep pressure and being squeezed. With this in mind, we introduce the Springy-Thingy Pouffe. It is a great success. Tom steps inside the Pouffe and stretches it over his body and, appearing to enjoy its weight and flexibility, lifts the Pouffe aloft and threads it over his head. Tom also responds well to the squeezebox. He appears to like the action of compressing and pulling the bodies of the squeezebox and overcoming the resistance of its bellows. While playing the squeezebox, we invite Tom's support worker, Mark, to play guitar. There is great interaction between Tom and Mark, as they play their instruments together. Later in the day, Tom and Mark play snap and complete a puzzle.

### **Emily**

Emily appears to enjoy the props that expand or change shape as a result of her interactions. Perhaps her interest relates to her enjoyment of knitting and arts and crafts. Emily shows her concentration, hand-eye coordination and fine motor skills. The props she spends most time handling are wiry or have an intricate aesthetic. The sensory activity appears to have provided a positive distraction for Emily, with longer gaps between her requests for a coffee. At the end of the morning session, she selects two needles, a ball of purple wool and starts to knit. "It's a scarf" she tells us, "for mum"

### **The Afternoon Session**

It's the afternoon. Throughout the morning, Pete has regularly walked past the entrance to the sensory room, looking sideways into the space to see what is happening. Matt and Tom have gone to an exercise class so Andy and I take advantage of their absence to try to entice Pete into the sensory room. Pete's support workers have told us that he likes guitar sounds so I sit on one of the bean bags, strumming the open strings. Pete walks to the door, but cannot bring himself to cross the threshold. I am now sitting with Emily, who is quietly knitting, and two members of staff, Paula and Angela. They missed the morning session and are keen to learn about how it went and try some of the props themselves. It's getting dark outside and so we turn off the main lights and projector and switch on our UV light.

I take out my UV reactive props, which glow and shimmer with many colours under the UV light. Tom and Matt have rejoined us, but Emily does not like the dark and leaves the room. Matt holds onto two illuminated balls. He becomes ever more excited by the lights and jumps up and down. Since we are on our feet, I encourage everyone to dance, which they do! The sensory activity ends with an impromptu disco with Matt, Emily, Andy and me.

### **A gustatory thank you**

We end the day by thanking all participants and offering refreshments of coca-cola, cookies and a milkshake for Matt. The appeal of chocolate chip cookies finally entices Pete to join us. Very excitedly, he places a whole cookie in his mouth and laughs.



19th JANUARY

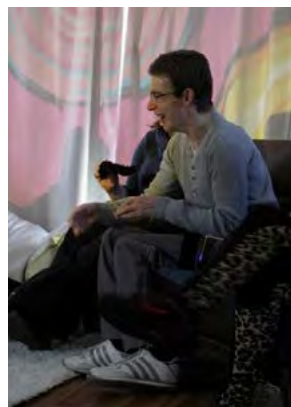
We arrived at 9.30am and were greeted with a warm welcome. Whilst setting up, in the sensory room, Matt entered, headed straight for the bag that contained our sensory props and selected a springy-thingly shaker. It was a delight to see Matt joining us voluntarily and making selections without being prompted.

We had planned to conduct individual sessions with each resident in order to give our full attention. However, within one minute of setting-up, Tom had sat down on the sofa, followed shortly by Emily, who sat next to him, and Matt had fallen into one of the beanbags. Emily picked up her knitting and continued to knit a scarf for her mum. Staff

Members informed us that Emily had been knitting more regularly since our visit in December.



I began this session by introducing the textured pouches. Matt responded most positively to props that created noise when they were handled. He particularly liked heavier objects that cupped in his hands such as the textile pouches filled with sand, ball bearings or marbles. As each pouch sunk into his hand, Matt looked at me, smiled and then moved his fingers in order to knock the marbles or ball bearings against one another, creating a clicking sound.



At first, Tom responded indifferently to the textured pouches (these props were all one colour to minimise visual stimulation). In the first activity, we had observed Tom interacting with brightly coloured and patterned objects so perhaps we needed to provide more visual stimulation to gain his interest.

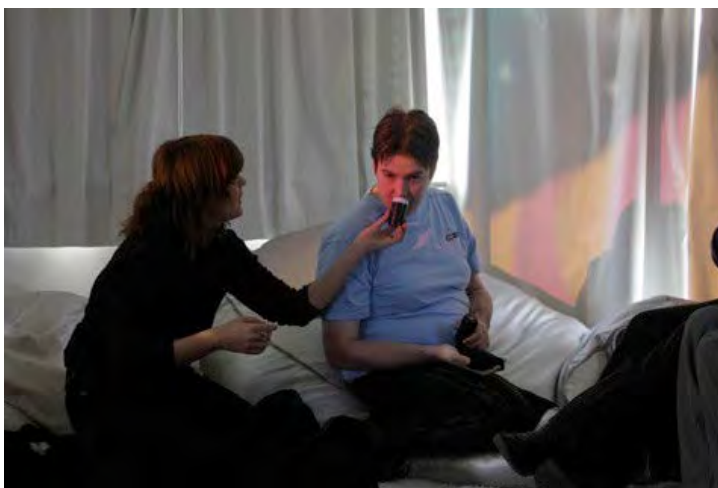
Five minutes into the session, Tom had created his own game with these props. Now throwing them back and forth to Angela and myself, he was wholly engaged. Because the props were all coloured black and of the same size,

Tom could not predict their weight or texture as they flew through the air. Some of the props contained dense materials such as sand, whilst others contained light materials such as feathers. Each throw presented an exciting and unexpected surprise for Tom. The motion of the props travelling through the air and being caught also caused the filling materials to move around, generating noise as they went.



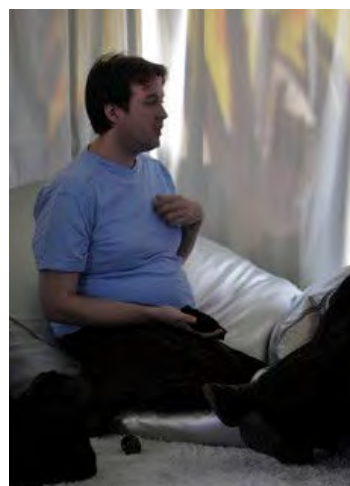
Emily spent most of her time knitting, listening and watching the activity around her.

As in the first sensory activity, Emily was drawn to the textured props and particularly enjoyed the ones with sparkly sequins. Andy spent some time with Emily, cutting paper and challenging her to cut around hand-drawn shapes. She also drew a picture of a house for us.



As we had observed in the first sensory activity, Matt was drawn to the olfactory props and the paper hat. When he saw the hat, he immediately reached for it and placed it on his head. Matt spent a lot of time during the activity watching Tom interact with props.

Approximately every 10 minutes Matt signed to Angela in Makaton to express that he wanted to go to the toilet.

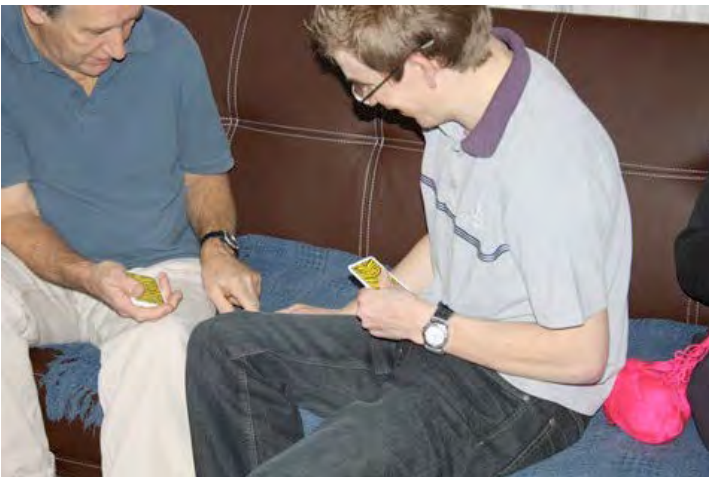


As we had observed previously, Matt often touched his ear and looked at me as if to ask if the background music was still playing. I turned up the volume, but he continued to ask. Could Matt's auditory sense have been cutting out whilst he was processing another sense? I placed an iPod and loudspeaker unit next to him so the music source was closer. However, Matt continued to signal to Angela or me; 'is there music playing?'



In the first activity, Matt and Tom enjoyed the interactive props, especially the ones that responded to their actions. With this in mind, I had brought a new prop with me; a wooden ladder and peg toy. Matt watched with interest as I showed him how the prop worked. The action demanded concentration, hand-eye coordination, delicate touch and fine motor skills but he picked up the technique straight away!

Tom found this activity very difficult, but he did not give up and appeared to enjoy the challenge.



From speaking with support staff I knew that Tom liked to turn everything into a game and that he liked to hide things. When I suggested we play cards, he hid his cards under his arm and said, "where have they gone?"

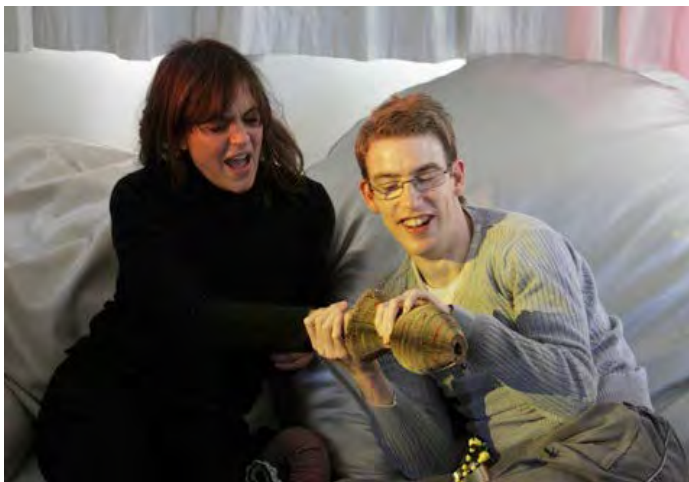


Tom often hid his watch, too, covering it with his hand. So to encourage him to interact with different props, I placed the props over his watch and said, "where has your watch gone?"





Tom was particularly taken with the springy-thingy shakers, which he rolled along his arm. At one point, he had three shakers on his arm.



Tom invented new ways of using props. He turned the paper hat upside-down to create a 'basket' and prompted me to throw the textured pouch props into its mouth. Tom caught many of the objects in the hat.

The hat has an opening in its lid so when Tom released his grip caught items fell to the floor. 'As if by magic', the caught items had disappeared from the hat. Tom thought this was hilarious!



Tom expanded the springy-thingy shaker prop and looked through the aperture that he had created. He encouraged me to do the same. And then he placed the prop on top of his head and said, "where has it gone?"

Matt and Tom interacted with one another throughout the session. On several occasions, Tom showed Matt how he was using a prop and interacted with the springy-thingy pouf together stretching it at both ends.

Pete spent most of the session pacing in the adjacent hallway. At one point, he entered the room and approached Emily, pointing to the props that she was holding. We recognised that entering the room had been a significant challenge for Pete. We hoped that next time, he would join us for longer.



Andy chatted with Tom and Emily. I sat with Matt. One by one, I passed the textured pouch props to him. He handled each prop delicately and then lifted them to his nose. Having smelled a prop, Matt passed it back to me and presented his hand to receive the next. I then placed the props in a line on the floor in front of Matt and asked him to touch the prop he liked the feel of. I repeated the question slowly several times, but Matt did not respond. I had laid out twelve props, which might have been too overwhelming for him. With this in mind, I started the exercise again, selecting just three props at a time, each one with a very different texture to the other two. When asked again to select a texture that he liked, Matt picked up the coarse, hairy prop. Matt had a good understanding of what I was saying and showed that he can express his preferences.

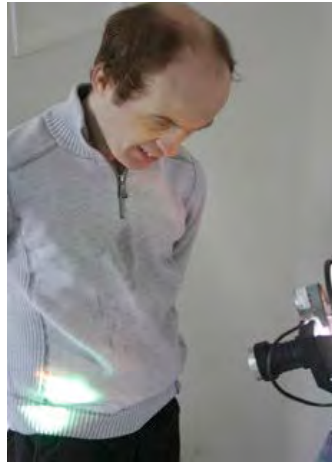
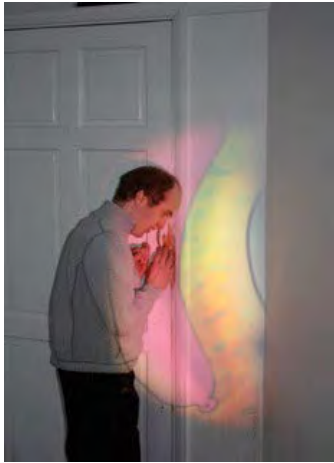


Taking a similar approach to the textile pouch exercise, described above, I presented Matt with three hand-drawn shapes on three separate pieces of paper and asked him to select his favourite. Matt appeared to be disinterested. At this point he signed to me to ask if the music was still playing and his attention turned to what Tom and Andy were doing.



On reflection, this activity may have worked better if we had represented colours and shapes with three-dimensional objects and explored these qualities through touch.

Andy repeated this activity with Tom and asked him to select a shape. After a long period, Tom identified the circle (“round”) and square. Our point and select method had limited success with shapes on this occasion. Tom was much quicker to identify ‘green’ when we asked him about colours. Towards the end of the activity, I showed Matt the fire blanket and brought his attention to the crackling noise that it made as I waved it up and down. Matt appeared to really enjoy the motion and sound of the blanket and flapped his hands and jumped up and down in excitement.



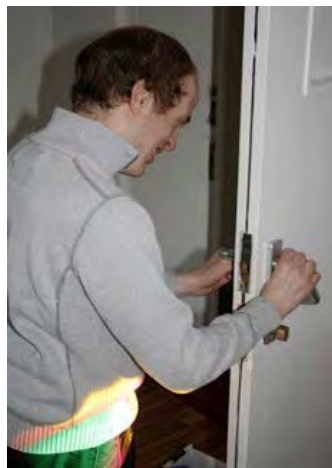
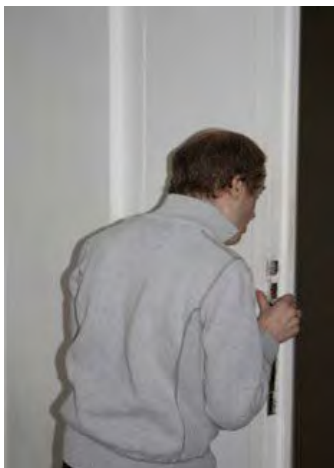
To our (contained) excitement, Pete joined us for most of the activity. He remained by the cupboard door throughout.

We angled the projector towards the cupboard door, which made Pete laugh. He tracked the moving shapes and patterns with his eyes. On several occasions, he walked over to the projector and seemed to enjoy watching the motion of the turning filter wheel. Pete was more visually-seeking than we had thought.



We introduced several material samples to Pete by placing them on a box to the right of him. Pete appeared to be uninterested in the samples, but did enjoy the interacting of repeatedly pushing Andy's hand away as he tried to pass them to him.

placed the fire blanket in front of the cupboard door to see if it would deter Pete from standing there. His response was intriguing.

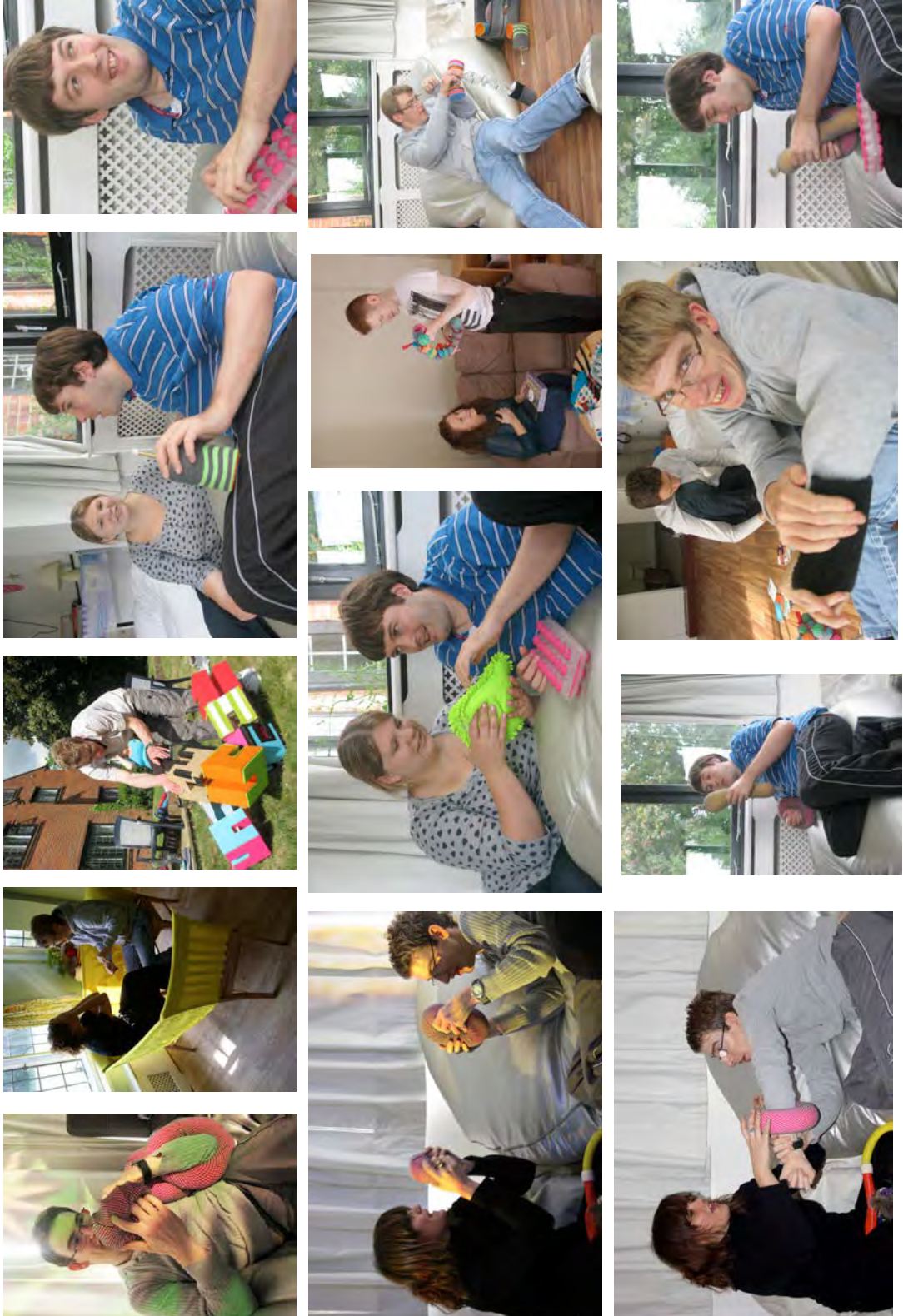


Pete migrated to the room entrance door and, holding onto the handles, placed his head against the edge of the side stile and appeared to be looking across the width of the door. When we removed the blanket, Pete returned to the cupboard door.



# Appendix 12

**Appendix 12: A selection of personalised sensory props**





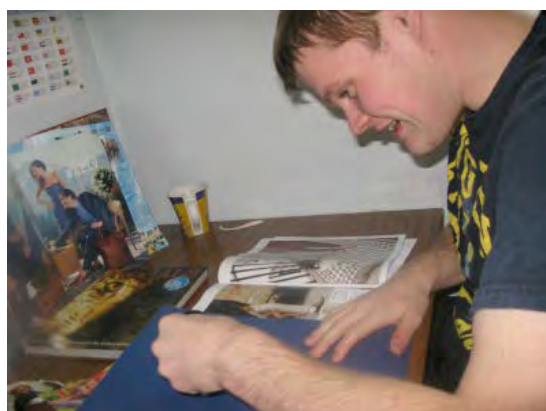
# Appendix 13

## Appendix 13: Diary account: mirroring interests, by the author



I met Sam last year and recall his love for spinning objects and tearing magazines. So on my visit I brought along some magazines. As I was not sure what type of magazines Sam likes I offered a selection ranging from cars to gardening. I also brought along some coloured paper and drawing equipment in case Sam wanted to make something with the torn pieces of magazine paper.

When I offered the magazines to Sam, he was immediately drawn to the GQ magazine where I soon began to realise that Sam is interested in faces, particularly male faces, and in fact that is the only thing he was interested in tearing. Sam would tear around the faces of people very carefully and meticulously. Once he had torn around the face he then put it to the side and repeated.

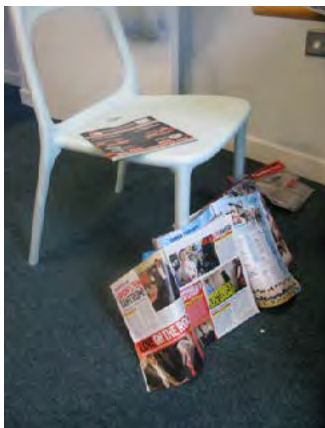


I sat with Sam and started to tear around faces with him, though he has limited verbal speech looked happy for me to sit and tear the magazines with him.



Sam positioned an open magazine opposite to where he was sitting, showing a group of people smiling. Every now and then Sam would look up at the page, smile and move the angle to make sure it was facing him. It was like he was having a conversation with the people in the photo which gave him a sense of comfort and reassurance.

After about an hour of tearing we soon had a large collection of different faces, at which point I thought it would be fun to make a collage. I took lots of coloured paper and asked Sam to point to his favourite colour (green) and then asked him to choose a face and point to where he would like me to stick it. Sam was very engaged and seemed to enjoy the activity. He was very meticulous about the positioning of the faces.



Sam would also look through different magazines and spot the same advert. He then lined each magazine along the floor with the advert.

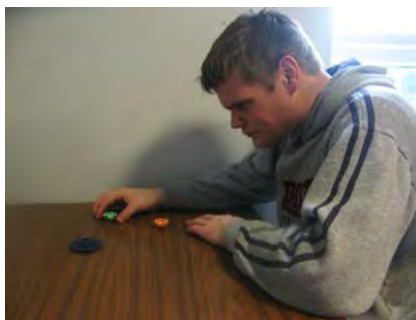


As well as magazines Sam loves to spin objects and has a collection of over 200 spinning objects, he enjoys spinning objects so much that he can get very over stimulated. Due to this Sam plays with his spinning objects for half an hour, three times a day, which he seems very happy with. The day I visited Sam he chose to play with rubber objects that bounce and pop up. Sam appeared to enjoy the suspense of waiting for them to flip up.

### Passions to Actions

Imagine if: Sam's love for spinning objects may tell us that he might be interested in visiting a wind farm or having a go at making a smoothie in a blender at home.

#### Interest



#### Action





# Appendix 14

## Appendix 14: Diary account: garden activity, by the author



Upon arrival, I wanted to entice everyone into the garden so brought out the beanbags, chairs, turned on a bubble machine and played some jolly music. Matt and Tom joined us in the garden without hesitation. Matt went straight to the bubble machine - smiling, he flapped his hands and watched the bubbles fly up into the air.



We had also brought a bubble wand, which Matt adeptly used to create huge bubbles. Above all the other objects, Matt enjoyed interacting a bowl of washing-up liquid, which Mary had brought out. He flapped his hands in and out of the water to create ever more bubbles in the surface foam. With foam clinging to his hands, Matt held them aloft and wiggled his fingers in delight – ‘Bubbles’, he said, ‘shampoo’. In all of our previous visits, we had not heard Matt speak. How exciting to hear him talk! I mirrored Matt’s actions; we looked at each other, said ‘bubbles’ together in unison and span around with our arms in the air like a windmill. I really felt like I was having a conversation with Matt.



Tom appeared to be in his element, playing football with Terry and bouncing balls on a parachute with a group. What fun!



It was great to see Matt and Tom handling the springy-thingy prop together.



Support worker, Paul also enjoyed interacting with Springy-Thingy.

Emily appeared a little reluctant to join us in the garden but appeared happy to watch the activities from the patio.




The Fiddle-Brick prop was a huge success with Tom, who spent a long time pulling, stacking and re-configuring the brick elements; independent of help from others. He thoroughly enjoyed showing his creations to Sandy.

Pete remained indoors for most of the afternoon, but I regularly saw him peering through the windows, watching the activities and events outside. After I had laid out the cakes and drinks, however, Pete joined us in the garden.

# Appendix 15

## Appendix 15: An example of a completed Adolescent/Adult Sensory Profile® self questionnaire (Brown and Dunne, 2002)



**ADOLESCENT/ADULT  
SENSORY PROFILE™**

Catana Brown, Ph.D., OTR, FAOTA  
Winnie Dunn, Ph.D., OTR, FAOTA

**Self Questionnaire**

Name: Emma Ann Age: \_\_\_\_\_ Date: \_\_\_\_\_

Birthdate: 12-11 Gender:  Male  Female

Are there aspects of daily life that are not satisfying to you? If yes, please explain.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**INSTRUCTIONS**


Please check the box that **best** describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

**Please answer all of the statements. Use the following key to mark your responses:**

<b>ALMOST NEVER</b>	When presented with the opportunity, you <b>almost never</b> respond in this manner (about 5% or less of the time).
<b>SELDOM</b>	When presented with the opportunity, you <b>seldom</b> respond in this manner (about 25% of the time).
<b>OCCASIONALLY</b>	When presented with the opportunity, you <b>occasionally</b> respond in this manner (about 50% of the time).
<b>FREQUENTLY</b>	When presented with the opportunity, you <b>frequently</b> respond in this manner (about 75% of the time).
<b>ALMOST ALWAYS</b>	When presented with the opportunity, you <b>almost always</b> respond in this manner (about 95% or more of the time).

**Therapy Skill Builders®**  
A Harcourt Assessment Company

Copyright © 2002 by The Psychological Corporation, a Harcourt Assessment Company. All rights reserved.  
Printed in the United States of America  
3 4 5 6 7 8 9 10 11 12 A B C D E



**THE PSYCHOLOGICAL CORPORATION®**  
A Harcourt Assessment Company  
0781649727

Item	A. Taste/Smell Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).	X				
2	I add spice to my food.	X				
3	I don't smell things that other people say they smell.	X				
4	I enjoy being close to people who wear perfume or cologne.	X				
5	I only eat familiar foods.	X				
6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).	X				
7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).	X				
8	I go over to smell fresh flowers when I see them.	X				

Comments

Item	B. Movement Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
9	I'm afraid of heights.	X				
10	I enjoy how it feels to move about (for example, dancing, running).					X
11	I avoid elevators and/or escalators because I dislike the movement.	X				
12	I trip or bump into things.					X
13	I dislike the movement of riding in a car.	X				
14	I choose to engage in physical activities.					X
15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					X
16	I become dizzy easily (for example, after bending over, getting up too fast).					X

Comments

Item	C. Visual Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
17	I like to go to places that have bright lights and that are colorful.					X
18	I keep the shades down during the day when I am at home.	X				
19	I like to wear colorful clothing.			X		
20	I become frustrated when trying to find something in a crowded drawer or messy room.		X			
21	I miss the street, building, or room signs when trying to go somewhere new.					X
22	I am bothered by unsteady or fast moving visual images in movies or TV.	X				
23	I don't notice when people come into the room.	X				
24	I choose to shop in smaller stores because I'm overwhelmed in large stores.	X				
25	I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).	X				
26	I limit distractions when I am working (for example, I close the door, or turn off the TV).	X				
Comments						

Item	D. Touch Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
27	I dislike having my back rubbed.	X				
28	I like how it feels to get my hair cut.				X	
29	I avoid or wear gloves during activities that will make my hands messy.		X			
30	I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					X
31	I am bothered by the feeling in my mouth when I wake up in the morning.		X			
32	I like to go barefoot.	X				
33	I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).	X				
34	I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).	X				
35	I move away when others get too close to me.	X				
36	I don't seem to notice when my face or hands are dirty.	X				
37	I get scrapes or bruises but don't remember how I got them.					X
38	I avoid standing in lines or standing close to other people because I don't like to get too close to others.	X				
39	I don't seem to notice when someone touches my arm or back.	X				
Comments						

Item	E. Activity Level	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
40	I work on two or more tasks at the same time.		X			
41	It takes me more time than other people to wake up in the morning.	X				
42	I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					X
43	I find time to get away from my busy life and spend time by myself.		X			
44	I seem slower than others when trying to follow an activity or task.					X
45	I don't get jokes as quickly as others.			X		
46	I stay away from crowds.	X				
47	I find activities to perform in front of others (for example, music, sports, acting, public speaking, and answering questions in class).	X				
48	I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					X
49	I avoid situations where unexpected things might happen (for example, going to unfamiliar places or being around people I don't know).	X				

Comments

Item	F. Auditory Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
50	I hum, whistle, sing, or make other noises.					X
51	I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					X
52	I have trouble following what people are saying when they talk fast or about unfamiliar topics.					X
53	I leave the room when others are watching TV, or I ask them to turn it down.	X				
54	I am distracted if there is a lot of noise around.			X		
55	I don't notice when my name is called.	X				
56	I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).	X				
57	I stay away from noisy settings.	X				
58	I like to attend events with a lot of music.					X
59	I have to ask people to repeat things.		X			
60	I find it difficult to work with background noise (for example, fan, radio).			X		

Comments



## Summary Score Sheet

### Quadrant Grid

Instructions: Transfer from the Self Questionnaire the item raw score that corresponds with each item listed (refer to the User's Manual for directions on how to obtain item raw scores). Add the Raw Score column to get the Quadrant Raw Score Total for each quadrant.

— QUADRANT 1		S QUADRANT 2		G QUADRANT 3		QUADRANT 4	
Low Registration		Sensation Seeking		Sensory Sensitivity		Sensation Avoiding	
Item	Raw Score	Item	Raw Score	Item	Raw Score	Item	Raw Score
3	1	2	1	7	1	1	1
6	1	4	1	9	1	5	1
12	5	8	1	13	1	11	1
15	5	10	5	16	5	18	1
21	6	14	5	20	3	24	1
23	1	17	5	22	1	28	1
36	1	19	4	25	1	29	2
37	5	28	4	27	1	35	1
39	1	30	5	31	2	38	1
41	1	32	1	33	1	43	2
44	5	40	2	34	1	46	1
45	3	42	5	48	5	49	1
52	5	47	1	51	5	53	1
55	1	50	5	54	4	56	1
59	2	58	5	60	3	57	1
Quadrant Raw Score Total	42	Quadrant Raw Score Total	50	Quadrant Raw Score Total	35	Quadrant Raw Score Total	17

SCORE KEY	
1	Almost Never
2	Seldom
3	Occasionally
4	Frequently
5	Almost Always

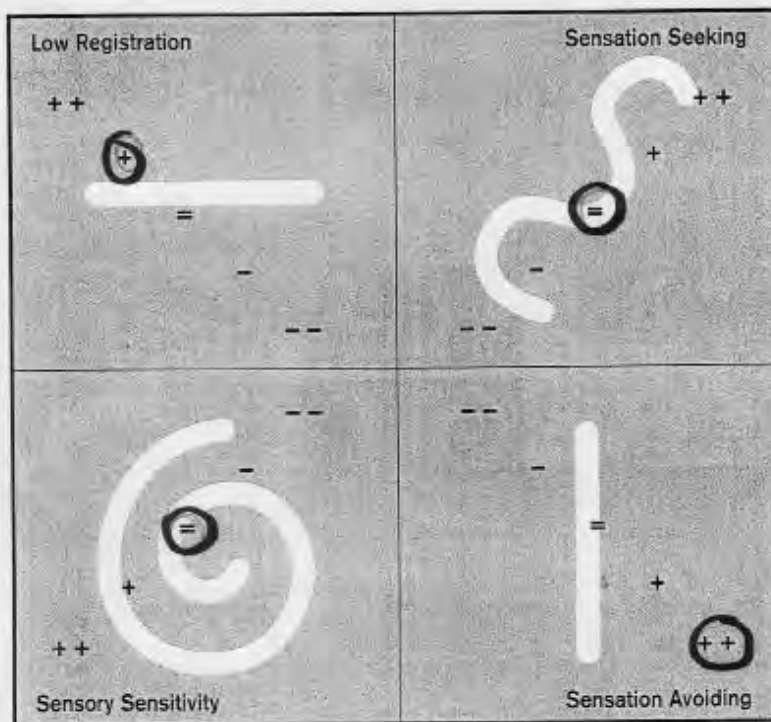
ICON KEY	
—	Low Registration
S	Sensation Seeking
G	Sensory Sensitivity
	Sensation Avoiding

## Quadrant Profile

**Instructions:** Transfer the information from the classification columns of the Quadrant Summary Chart (the areas marked with an X) to the Quadrant Profile. Circle the classification symbol in each quadrant below that corresponds with the classification information for that quadrant. Finally, check the appropriate age box.

The following symbols are used to represent the classifications on the Quadrant Profile:

- Much Less Than Most People
- Less Than Most People
- = Similar to Most People
- + More Than Most People
- ++ Much More Than Most People



See chapter 5 for more information regarding interpretations and intervention.

Check the correct age:

- 11–17 years
- 18–64 years
- 65 years and older



# Appendix 16

## Appendix 16: An example of a completed Sensory Profile Checklist Revised (Bogdashina, 2003, p.184-194)

**Sensory Profile Checklist Revised (SPCR)**

Name of Young Person: [Handwritten Name]

Name of parent/support worker: [Handwritten Name]

Date Completed: [Handwritten Date]

**WT** = True in any time in the past (Specify age when statement was true)  
**T** = True now (if was true and is true now tick both answers)  
**F** = False (if the statement is not true)  
**NSE** = not true or do not know

No	Behaviours	WT	T	F	NS
1	Resists any change		X		
2	Notices every tiny change in the environment		X		
3	Does not recognize a familiar environment if approaches it from a different direction.			X	
4	Does not recognize people in unfamiliar clothes.			X	
5	Is not fooled by optical illusions		X		
6	Constantly looks at minute particles, picks up smallest pieces of fluff			X	
7	Dislikes dark and bright lights			X	
8	Is frightened by sharp flashes of light, lightening etc.			X	
9	Looks down most of the time			X	
10	Covers, closes or squints eyes at bright lights			X	
11	Is attracted to lights		X		
12	Looks intently at objects and people			X	
13	Moves fingers or objects in front of eyes			X	
14	Is fascinated with reflections, bright coloured objects			X	
15	Runs a hand around the edge of the object			X	
16	Perimeter hugging			X	
17	Gets easily frustrated / tired under fluorescent lights			X	
18	Gets frustrated with certain colours (Specify:.....)			X	
19	Is frustrated with coloured and shining objects (Specify:.....)			X	
20	May respond differently (pleasure – indifference – distress) to the same visual stimuli (lights, colours, visual patterns)			X	
21	Selects for attention minor aspects of objects in the environment instead of the whole thing (e.g. a wheel rather than a whole toy car, etc.)			X	

1

	lost	WT	T	F	NS
22	Gets lost easily		X		
23	Fears heights, stairs, escalators			X	
24	Has difficulty catching balls		X		
25	Appears startled when being approached suddenly		X		
26	Makes compulsive repetitive hand, head or body movements that fluctuate between near and far			X	
27	Hits/rubs eyes when distressed			X	
28	Feels/acts blind			X	
29	Ritualistic behaviour		X		
30	Response to visual stimuli is delayed (e.g. fails to close eyes when the light is being switched on, etc.)			X	
31	Any experiences are perceived as new and unfamiliar, regardless of the number of times the child had experiences the same thing			X	
32	Sudden outbursts of self-abuse/ tantrums or withdrawal in response to visual stimuli			X	
33	Does not seem to see if listening to something			X	
34	Avoids direct eye contact			X	
35	Appears to be a mindless follower			X	
36	Surprises with knowing 'unknown' information		X		
37	Smells, licks, touches, or taps objects			X	
38	Seems to be absorbed (merged) with lights, colours, patterns			X	
39	Seems to know what other people (who are not present) are doing			X	
40	Covers/rubs/blinks, etc. eyes in response to a sound/touch/smell/taste movement			X	
41	Complains about (is frustrated with) the 'wrong' colours of letters/numbers, etc. on coloured blocks, etc.			X	
42	Displays a good visual memory		X		
43	Reactions are triggered by lights, colours, patterns			X	
44	Easily solves jigsaw puzzles		X		
45	Remembers routes and places		X		
46	Memorizes enormous amounts of information at a glance			X	
47	Poor mathematics		X		
48	Learns nouns first		X		
49	Has difficulties with adverbs and prepositions		X		
50	Idiosyncratic patterns in language development (e.g. names one thing to denote the other, etc.)			X	
51	Gets easily frustrated when trying to do something in a noisy, crowded room			X	
52	Does not seem to understand instructions if more than one person is talking		X		
53	Covers ears at many sounds			X	
54	Is a very light sleeper		X		
55	Is frightened by animals			X	
56	Dislikes thunderstorm, sea, crowds			X	

WT T F N5

57	Dislikes haircut			X	
58	Avoids sounds and noises			X	
59	Makes repetitive noises to block out other sounds			X	
60	Bangs objects, doors		X		
61	Likes vibration				X
62	Likes kitchen and bathroom				X
63	Likes traffic, crowds		X	#	
64	Is attracted by sounds, noises		X	#	
65	Tears paper, crumples paper in hand		#	X	
66	Makes loud rhythmic noises		X	#	
67	Gets frustrated with certain sounds (Specify: _____)			X	
68	Tries to destroy/break objects producing sounds (clock, telephone, musical toy, etc.)			X	
69	Is fascinated with certain sounds (Specify: _____)			X	
70	May respond differently (pleasure-indifference-distress) to the same auditory stimuli (sounds, noises)			X	
71	Hears a few words instead of the whole sentence		X		
72	Pronunciation problems		X		
73	Unable to distinguish between some sounds			X	
74	Hits ears when distressed			X	
75	Feels/acts deaf			X	
76	Response to sounds, questions, instructions is delayed		X		
77	Echolalia in monotonous, high-pitched, parrot-like voice			X	
78	Sudden outbursts of self-abuse/tantrums or withdrawal in response to auditory stimuli			X	
79	Does not seem to hear if looking at something			X	
80	Reacts to instructions better when they are 'addressed to the wall'			X	
81	Looks for the source of the sound		X		
82	Seems to be absorbed (merged) with sounds			X	
83	Seems to be able to 'read' thoughts, feelings, etc. Of others		X		
84	Complains about 'non-existent' conversations, sounds			X	
85	Covers/hits ears in response to lights, colours/touch, texture/smell/taste/movement			X	
86	Complains about (is frustrated with) a sound in response to colours/textures/touch/scent/flavour/movement			X	
87	Displays a good auditory memory (for nursery rhymes, songs, etc.)			X	
88	Reactions are triggered by sounds/words		X		
89	Uses idiosyncratic routinized responses		X		
90	Uses songs, commercials, etc. to respond			X	
91	Cannot keep track of conversation		X	X	
92	Composes musical pieces, songs			X	
93	Unable to distinguish between tactile stimuli of different			X	

		WT	T	F	VS
94	Resists being touched			X	
95	Cannot tolerate new clothes; avoids wearing shoes			X	
96	Overreacts to heat/cold/pain			X	
97	Avoids getting messy		X		
98	Dislikes food of certain texture (Specify: )			X	
99	Moves away from people			X	
100	Insists on wearing the same clothes		X		
101	Likes pressure, tight clothing		X		
102	Seeks pressure by crawling under heavy objects, etc.			X	
103	Hugs tightly		X		
104	Enjoys rough and tumble play		X		
105	Prone to self-injuries		X		
106	Low reaction to pain, temperature		X		
107	Cannot tolerate certain textures (Specify: )			X	
108	Is fascinated with certain textures (Specify: )			X	
109	May respond differently (pleasure – indifference – distress) to the same tactile stimuli (clothes, touch, heat, pain, etc.)			X	
110	Complains about parts of the clothes		X		
111	Hits/ bites themselves when distressed			X	
112	Feels/acts numb			X	
113	Sudden outbursts of self-abuse/tantrums or withdrawal in response to tactile stimuli			X	
114	Does not seem to feel being touched if looking at/listening to something			X	
115	Fails to define either texture or location of touch			X	
116	Can tolerate only 'instrumental' (not 'social') touch			X	
117	Sometimes does not react to any tactile stimuli			X	
118	Seems to be absorbed (merged) with certain textures			X	
119	Seems to feel pain of others			X	
120	Complains about being touched/hot/cold, etc. in the absence of the stimuli			X	
121	Complains about (is frustrated with) feeling colours, sound, etc. when being touched			X	
122	Complains about (is frustrated with) feeling being touched when being looked at			X	
123	Complains about (is frustrated with) backache, etc./heat/cold in colourful/noisy/crowded places			X	
124	Displays a good tactile memory			X	
125	Reactions are triggered by textures/touch/temperature			X	
126	Unable to distinguish between strong and weak odours				X
127	Toileting problems		X		
128	Runs from smell			X	
129	Smells self, people, objects etc.			X	
130	Smears/play with faeces			X	
131	Seeks strong odours			X	
132	Bedwetting		X		

		W	T	F	N
133	Cannot tolerate certain smells (Specify )			X	
134	Is fascinated with some smells (Specify )			X	
135	May respond differently (pleasure – indifference – distress) to the same smells			X	
136	Complains about smells of some pieces of food while ignoring the rest			X	
137	Hits nose when distressed			X	
138	Has difficulty in interpreting smells				X
139	Response to smells is delayed				X
140	Sudden outbursts of self-abuse/tantrums or withdrawal in response to smells			X	
141	Does not seem to feel smell when looking, Listening, etc.			X	
142	Avoids direct smells			X	
143	Sometimes does not react to any smell		X		
144	Inspects food before eating			X	
145	Seems to be absorbed (merged) with smells			X	
146	Complains/talks about 'non-existent' smells			X	
147	Covers/rubs/hits nose in response to a visual/auditory stimulus/touch/ taste/movement			X	
148	Complains about (is frustrated with) the smell in response to a visual/auditory stimulus/touch/taste/movement			X	
149	Displays a good memory for smells			X	
150	Reactions are triggered by smells			X	
151	Unable to distinguish between strong and weak tastes				X
152	Poor eater			X	
153	Uses the tip of the tongue for tasting			X	
154	Gags/vomits easily		X		
155	Craves certain (plain) foods			X	
156	Eats anything (pica)		X		
157	Mouths and licks objects			X	
158	Eats mixed food (e.g. sweet and sour)			X	
159	Regurgitates			X	
160	Cannot tolerate certain foods			X	
161	Is fascinated with certain food (Specify )			X	
162	May respond differently (pleasure – indifference- distress) to the same food			X	
163	Is confused with (complains about) the food he uses to like			X	
164	Has difficulty in interpreting tastes			X	
165	Response to tastes is delayed			X	
166	Sudden outbursts of self-abuse/tantrums or withdrawal in response to taste			X	
167	Does not feel any taste while eating something and looking at/listening to something			X	
168	A very careful eater			X	
169	Sometimes does not react to any taste		X		
170	Seems to be absorbed (merged) with certain food			X	

WT T F NS

171	Complains/talks about 'non-existent' taste in mouth			X	
172	Makes swallowing movements in response to a visual/ auditory stimulus/ touch/smell/movement			X	
173	Complains about (is frustrated with) some taste in response to a visual/auditory stimulus/touch/smell/movement			X	
174	Displays a good memory for tastes			X	
175	Reactions are triggered by certain food			X	
176	Clumsy, moves stiffly		X		
177	Odd body posturing (places the body in strange positions)		X		
178	Difficulty manipulating small objects (e.g. buttons)		X		
179	Turns the whole body to look at something		X		
180	Low muscle tone			X	
181	Has a weak grasp, drops things		X		
182	A lack of awareness of body position in space		X		
183	Unaware of their own body sensations (e.g. does not feel hunger)			X	
184	Bumps into objects, people		X		
185	Appears floppy; often leans against people, furniture, walls		X		
186	Stumbles frequently; has tendency to fall		X		
187	Rocks back and forth			X	
188	Cannot tolerate certain movements/body positions			X	
189	Is often engaged in complex body movements, esp. when frustrated or bored		X		
190	May have different muscle tone (low-high)		X		
191	Pencil lines, letters, words, etc. are uneven (e.g. Sometimes too tight, sometimes too faint)			X	
192	Complains about limbs, parts of the body			X	
193	Difficulty with hopping, jumping, skipping, riding a tricycle/bicycle		X		
194	Does not seem to know what their body is doing			X	
195	Very poor at sports			X	
196	Tires very easily, esp. When in noisy/ bright places, or when standing		X		
197	Does not seem to know the position of the body in space/what the body is doing, when looking at/ listening to/talking		X		
198	Has difficulty imitating/copying movements		X		
199	Does not seem to know how to move their body (unable to change body position to accommodate task)		X		
200	Watches their feet while walking		X		
201	Watches their hands while doing something		X		
202	Seems to be absorbed with body movements			X	
203	Complains about 'non-existent' physical experiences (e.g. 'I am flying etc.)			X	
204	Involuntary postures of the body in response to a			X	

	visual/auditory stimulus/smell/taste/touch	W	T	F	N
205	Displays a very good proprioceptive memory (e.g. understands directions better if produces exact movements they have to do in order to follow these directions)			X	
206	Reactions are triggered by body positions/movements			X	
207	Mimics the actions when instructions are being given			X	
208	Resists change to head position/movement			X	
209	Fearful reactions to ordinary movement activities (e.g. swings, slides, merry-go-round, etc.)			X	
210	Has difficulty with walking or crawling on uneven or unstable surfaces		X		
211	Dislikes head upside down			X	
212	Becomes anxious or distressed when feet leave the ground			X	
213	Enjoys swings, merry-go-round		X		
214	Spins, runs round and round		X		
215	Fears falling or height		X	X	
216	Spins, jumps, Rocks, etc. esp. When frustrated or bored			X	
217	May respond differently (pleasure-indifference-distress) to the same movement activities (swings, slides, spinning, etc.)			X	
218	Resists new motor activities			X	
219	Tiptoeing		X		
220	Becomes disoriented in noisy/bright places, or after physical activities			X	
221	Seems oblivious to risks of heights, etc.			X	
222	Holds head upright, even when leaning or bending over			X	
223	Gets nauseated or vomits from excessive movement (swings, merry-go-round, cars, etc.)			X	
224	Does not seem to mind any movements when looking at /listening to something/ talking			X	
225	Avoids balancing activities			X	
226	Becomes disorientated in noisy/bright places, or after physical activities			X	
227	Rocks unconsciously during other activities (e.g. watching a video)			X	
228	Inspects the surface before walking in it			X	
229	Appears to be in constant motion		X		
230	Involuntary movements of the body in response to a visual/auditory stimulus/smell/taste/ touch			X	
231	Experiences movement while being still (e.g. 'I am flying' while being in bed)			X	
232	Reactions are triggered by motor activities			X	





# Appendix 17

## **Appendix 17: Information derived from the Adult/Adolescent Sensory Profile® self questionnaire (Brown and Dunne, 2002) and the Sensory Profile Checklist Revised questionnaire (Bogdashina, 2003), about the three autistic participants**

### Participant 1

#### **VISION: Hyper**

Chris resists any change and notices any tiny change in his environment. He appears startled when being approached suddenly, is attracted to lights, patterns and colours and has a good visual memory. Chris easily solves jigsaw puzzles and remembers routes and places. He finds it difficult to filter visual stimuli and often shuts down other senses whilst seeing. Chris occasionally gets frustrated when trying to find something in a crowded drawer or messy room.

#### **AUDITORY: Hypo**

Chris displays ritualistic behaviour, bangs objects and doors as attracted by sounds and noises and often makes loud rhythmic noises and looks for the source of the sounds. Chris is unable to screen out background noise, experiences delayed auditory processing and frequently becomes distracted if there is a lot of noise around. Chris often checks auditory perception by other senses. His memory is triggered by auditory stimuli.

#### **TACTILITY: Hypo**

Chris avoids getting messy and insists on wearing the same clothes. He likes pressure, tight clothing, hugs tightly and enjoys rough and tumble play. Chris has a low reaction to pain and temperature. He has a weak grasp; drops things and complains about parts of his clothes. Chris always touches others when talking and likes how it feels to get a hair cut.

#### **OFLACTORY: Hyper/Hypo**

Sometimes Chris does not react to any smell and insists on wearing the same clothes.

#### **PROPRIOCEPTION: Hyper/Hypo**

Chris has difficulty catching balls, he is clumsy, moves stiffly and turns the whole body to look at something. He has a lack of awareness of body position in space and is often engaged in complex body movements, especially when frustrated or bored. Chris has difficulty with hopping, jumping, skipping and riding a tricycle/bicycle and does not seem to know how to move his body in space/what the body is doing, when looking at/listening to/talking to another person.

#### **VESTIBULAR: Hypo**

Enjoys swings, merry-go-round spins, he runs round and round, is often in constant motion and chooses to engage in physical activities. Chris always does things on the spur of the moment and seems slower than others when trying to follow an activity or task he always finds it hard to concentrate for a length of time. 287

**COMMUNICATION: verbal**

Chris does not seem to understand instructions if more than one person is talking and hears a few words instead of the sentence. Chris learns nouns first and has pronunciation difficulties. His response to sounds, questions and instructions is delayed and he cannot keep track of conversation. Chris's reactions are triggered by sounds/words and has difficulty imitating/copying movements. He has trouble following what people are saying when they talk fast. Chris needs to be looking at you before you start talking to him and use short sentences with simple words, speak slowly and in a relaxed manner. Chris expresses that he does not like something by pushing it away and he can be very repetitive.

## Participant 2

**VISION: Hyper**

Kevin notices every tiny change in the environment. Though he is attracted to lights, patterns and colours he gets frightened by sharp flashes of light, lightening etc.. and covers, closes or squints eyes at bright lights. He gets easily frustrated / tired under fluorescent lights and may respond differently (pleasure – indifference – distress) to the same visual stimuli (lights, colours, visual patterns). Kevin appears startled when being approached suddenly. He is prone to sudden outbursts of self-abuse/ tantrums or withdrawal in response to visual stimuli. Kevin smells, licks, touches, or taps objects. He covers/rubs/blinks, etc. eyes in response to a sound/touch/smell/taste movement and complains about (is frustrated with) the 'wrong' colours of letters/numbers, etc. on coloured blocks, etc. Kevin finds it difficult to filter visual stimuli and becomes frustrated when he can't find something in a messy drawer.

**AUDITORY: Hypo**

Kevin gets easily frustrated when trying to do something in a noisy, crowded room and bangs objects and doors. Kevin likes vibration and is fascinated with certain sounds and displays sudden outbursts of self-abuse/tantrums or withdrawal in response to auditory stimuli, he seems to be absorbed (merged) with sounds. He has delayed processing of auditory stimuli. Kevin often uses strategies to drown out sound but will attend events with a lot of music.

**TACTILITY: Hyper**

Kevin smells, licks, touches, or taps objects, resists being touched and moves away from people. He checks his tactile perception by other people. Kevin always dislikes his back being rubbed. Occasionally Kevin feels uncomfortable wearing certain fabrics and touches others when talking.

**OFLACTORY: Hyper**

Kevin occasionally enjoys being close to people who wear perfume and cologne.

**PROPRIOCEPTION: Hypo**

Kevin has low muscle tone and a lack of awareness of body position in space. He mimics the actions when instructions are being given. Kevin is frequently afraid of heights, and avoids escalators and elevators because he dislikes the movement. Kevin often enjoys how it feels to move about and engages in physical activities.

**VESTIBULAR:**

Kevin spins, jumps and rocks, etc. especially when frustrated or bored and rocks unconsciously during other activities (e.g. watching a video). Kevin may respond differently (pleasure-indifference-distress) to the same movement activities (swings, slides, spinning, etc.). He resists new motor activities and becomes disoriented in noisy/bright places, or after physical activities. He gets nauseated or vomits from excessive movement (swings, merry-go-round, cars, etc.) Kevin avoids balancing activities and becomes disorientated in noisy/bright places, or after physical activities.

**COMMUNICATION: Non-Verbal**

Kevin hits/rubs eyes when distressed and avoids direct eye contact. He has difficulties with adverbs, prepositions and pronunciation. He does not seem to understand instructions if more than one person is talking and hears a few words instead of the whole sentence. Kevin hits ears when distressed and his response to sounds, questions and instructions is delayed and he moves away from people. Kevin responds to objects of reference and may take your hand and lead you to what he wants. Kevin slaps himself when he is not happy. Kevin has trouble following what people are saying if they talk fast and will frequently spend time on his own and avoid situations where unexpected things may happen.

## Participant 3

**VISION: Hypo**

Jane engages in ritualistic behaviour and looks intensely at objects and people. She is fascinated by lights, patterns and colours. Jane sees in bits and often shuts down the other senses whilst seeing. Jane prefers small shops and becomes bothered when she sees a lot of movement around her and she frequently likes to wear colourful clothes, becomes frustrated when she tries to find something in a messy drawer or room and tries to limit distractions. Occasionally she will go into a place with bright colourful lights.

**AUDITORY: Hyper**

Jane gets easily frustrated when trying to do something in a noisy, crowded room, she is unable to screen out background noise and avoids sounds, noises and looks for the source of the sound. Jane displays a good auditory memory (for nursery rhymes, songs, etc.) Reactions are triggered by sounds/words. Jane composes musical pieces, songs and checks auditory perception by other senses, is distracted when there is a lot of noise around and stays away from noisy settings.

**TACTILITY: Hyper**

Jane cannot tolerate new clothes; avoids wearing shoes and moves away from people. Jane may respond differently (pleasure – indifference – distress) to the same tactile stimuli (clothes, touch, heat, pain, etc.) Jane may display sudden outbursts of self-abuse/tantrums or withdrawal in response to tactile stimuli She complains about (is frustrated with) feeling colours, sound, etc, when being touched. Jane gets frustrated with backache, etc./heat/cold in colourful/noisy/crowded places. Jane occasionally touches other people when she is talking, walks barefoot and dislikes particular textures.

**OFLACTORY: Hypo**

Jane does not seem to notice or pay attention to smell when looking or listening, etc. She sometimes does not react to any smell and shuts down her other senses whilst smelling.

**PROPRIOCEPTION:**

Jane has difficulty catching balls. Her pencil lines, letters, words, etc. are uneven (e.g. sometimes too tight, sometimes too faint). Jane is very poor at sports and has difficulty with hopping, jumping, skipping, riding a tricycle/bicycle. She tires very easily, especially when in noisy/ bright places, or when standing. Jane has difficulty imitating/ copying movements and mimics the actions when instructions are being given. Jane will always do things on the spur of the moment, stay away from crowds, finds it difficult to concentrate for a long time and avoid situations where unexpected things might happen. Frequently she will seem slower than others when trying to follow an activity and does not get jokes as quickly as others. Occasionally it will take her more time than others to wake up in the morning, spend time by herself and find activities to perform in front of others.

**VESTIBULAR: Hyper**

Jane complains about 'non-existent' physical experiences (e.g. 'I am flying etc.) She has fearful reactions to ordinary movement activities (e.g. swings, slides, merry-go-round, etc.) She becomes anxious or distressed when her feet leave the ground and fears falling or height. Jane may respond differently (pleasure-indifference- distress) to the same movement activities (swings, slides, spinning, etc.) and does not seem to mind any movements when looking at /listening to something/ talking. Jane avoids balancing activities and becomes disorientated in noisy/bright places, or after physical activities.

**COMMUNICATION: Verbal**

Idiosyncratic patterns in language development (e.g. names one thing to denote the other, etc.) She surprises us with knowing 'unknown' information and experiences pronunciation problems. Jane can read and write. Jane always has trouble following what people are saying when they talk too fast.

# Appendix 18

## Appendix 18: What do you like? Sensory Preference Cards

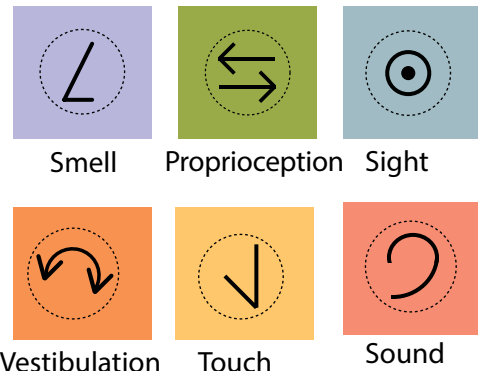
### What Do You Like?

#### Kingwood Sensory Preference Cards

What Do You Like? is a set of 75 cards, each showing a different type of sensory experience, which is described in simple words and illustrated by photographic images.

The cards act as visual prompts for autistic people who may be unable to verbally articulate their preferences.

Together with a family member, friend or support worker the cards may be used by a person to express whether he or she likes, dislikes or is neutral about the subject of the card.



### How to use the cards

#### Step 1

Place the cards with like, dislike and ok onto a flat surface. Take each card and decide whether you like/dislike or find the experience ok and place under the relevant card heading.

#### Step 2

The reverse sides of the cards are colour-coded by sensory system, providing a quick-reference, visual indication of the participants' preferred sensory system(s).

#### Step 3

Take all the cards in the 'Like' pile and spread them out. Now you have a visual mood board of your sensory preferences. This will help you to choose activities and modify your environment to make it more comfortable, relaxing and fun!

This activity aims to involve autistic people in their own sensory profiling as active participants rather than relying on others to express their preferences of their behalf.

Once categorised into groups of likes, dislikes and neutral, the cards create a visual sensory profile of an individual that may be used for making interior design decisions.

**like**  
**seek**



**ok**

**avoid**  
**dislike**





## Bright natural light

People who are drawn to bright natural light may benefit from using sunlight lamps, especially in winter months. People who avoid bright natural light may be over-sensitive to visual stimulation. Small changes to the home environment, such as the addition of dimmable lights, black-out curtains, shutters or self-adhesive window film, can make a difference to their comfort. Wearing sunglasses may also help.



## Darkness

People who prefer dark environments may be over-sensitive to visual stimulation. Small changes to the home environment, such as the addition of dimmable lights, black-out curtains, shutters or self-adhesive window film, can make a difference to their comfort. Wearing sunglasses may also help.



## Looking at twinkling lights

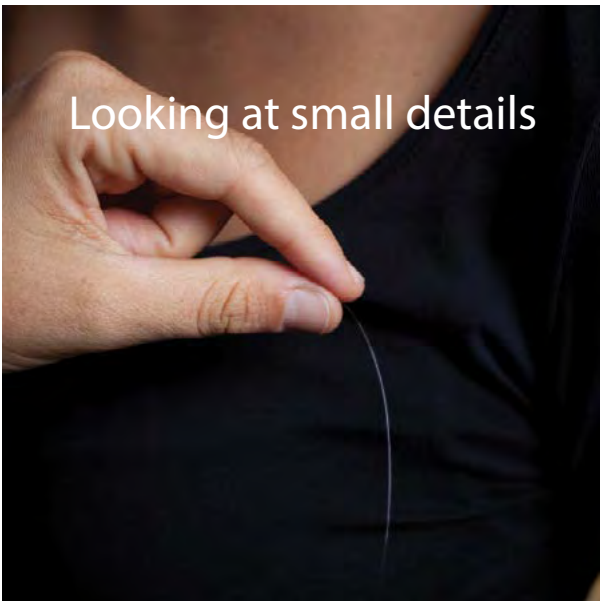


## Looking at twinkling lights

People who enjoy looking at twinkling lights may respond better to bright bold colours, moving objects, and shiny surfaces. Incorporating furnishings with these qualities, such as crystal chandeliers, mirrors and glossy surfaces, can make their home environments more appealing. People who avoid twinkling lights may find soft lighting schemes with multiple, directional light sources more comfortable.



## Looking at small details



## Looking at small details

People who notice small details, such as the tiny features of an object or lint on an item of clothing, may find it more relaxing to live a clutter-free home environment with minimal decorative detail.

People who tend not to notice small details may feel more satisfied with home environments that have unusual architectural features and decorative interiors with displays of objects.





## Looking at shiny surfaces



## Looking at shiny surfaces

People who enjoy looking at shiny surfaces may respond better to bright bold colours and moving objects. Incorporating furnishings with these qualities, such as crystal chandeliers, mirrors and glossy surfaces, can make their home environments more appealing.

Some people may find it less stressful to avoid reflective surfaces such as mirrors, glossy work-tops or even puddles.



## Changes in your home



## Changes in your home

People may be resistant to changes to the decoration, layout or furniture in their home. It is helpful and respectful to keep people informed and prepared for any changes.

People who like to regularly change their home environment may feel more satisfied with an open-plan design and moveable furniture. For example, free standing storage units and pieces of furniture can be rearranged to create new, different spaces within a larger room.





## Looking at shadows

### Looking at shadows

For people who enjoy interacting with shadows, the experience can be enhanced by placing things, especially plants and trees, in line with windows or direct sunlight so that they cast shadows on accessible surfaces.

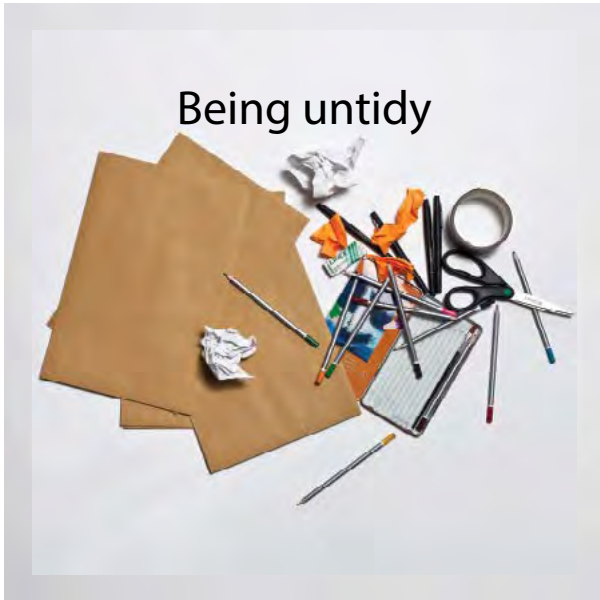


## Tidiness and order

### Tidiness and order

People who like order in their surroundings and everything in its right place may prefer home layouts that are more functionally organised with plenty of accessible, closed storage.





### Being untidy

People who have less need for tidiness may feel more satisfied with open living spaces and surfaces on which they can decorate as well as shelves and tables to display objects.

⦿ ◡ ∟ ∠ ↻ ↔



### Looking at spinning objects

Looking at spinning objects may appeal to people, who are under-sensitive to or seek visual stimulation. Be mindful that this form of stimulation can become the focus of obsessional behaviour.

⦿ ◡ ∟ ∠ ↻ ↔

## Books & magazines



## Books & magazines

If there are books and magazines that you particularly like to read, look at or listen to, list them here:



## Watching TV & films



## Watching TV & films

If there are TV programmes and films that you particularly like to watch, list them here:





## Flicking pages

Some people enjoy the visual stimulation of flicking pages. The experience can be enhanced by choosing books or magazines with vivid images.



## Listening to music

If there are types of music that you enjoy listening to, list them here:





## Household noises

## Household noises

Some people can be particularly sensitive to sound or be unable to filter out sounds; especially background noises which can be distracting or even distressing. Noise transmission can be reduced by separating floors and walls, adding sound absorption materials in cavities, installing sound resistant plasterboard or acoustic tiles. Soft furnishings, such as wall or ceiling fabrics and rugs, will also reduce noise.

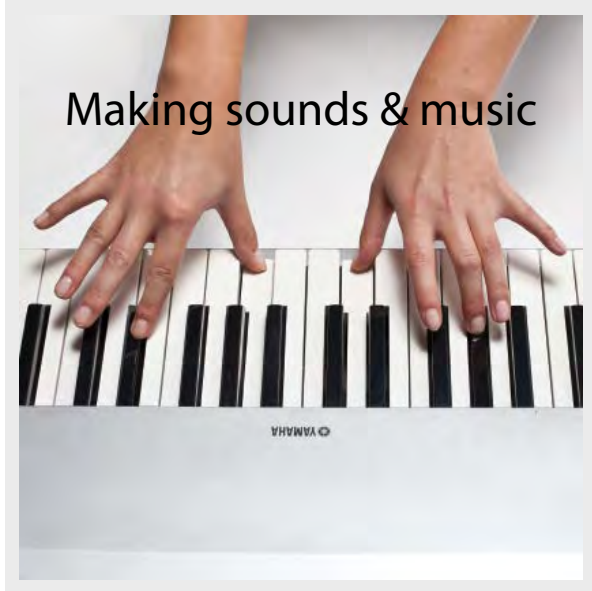


## Tapping surfaces

## Tapping surfaces

Sound works together with the other senses to help people navigate and construct an understanding of their environment. The auditory qualities of building materials are important in creating informative and interactive surroundings that invite people to explore with their ears and hands rather than just their eyes.





## Making sounds & music

Making sounds and music is not just about playing musical instruments. People also enjoy singing, humming, and whistling.

People may also make their own sounds to help block out background noises, which they find distracting or distressing.



## Wind and rain noise

People who like the sound of natural elements may enjoy the amplification of rain falling on a metal surface.



## Getting messy



## Getting messy

People who dislike getting messy or having things on their hands or feet may be over-sensitive to tactile stimulation.

Gradual introduction of different material surfaces may help these people to gain confidence in anticipating the sensations they will get from touching different objects.



## Touching warm surfaces



## Touching warm surfaces

Some people may not sense they are in contact with warm surfaces. Safety measures may need to be taken to mitigate the risk of these people injuring themselves.





## Touching cool surfaces



## Touching cool surfaces

Some people may not sense they are in contact with cool surfaces. Safety measures may need to be taken to mitigate the risk of these people injuring themselves.



## Walking in bare feet



## Walking in bare feet

Some people dislike the texture of socks or restrictiveness of shoes and so prefer walking around in bare feet. Whilst other people may enjoy the sensation of different textures underfoot and in between their toes. The experience of walking in bare feet indoors can be enhanced by adding carpets and rugs.



## The feel of new clothes



## The feel of new clothes

People may dislike wearing certain clothes - especially when they are new - because they cannot tolerate the feeling of labels, starchy newness or texture of the fabric. If you prefer to wear certain types of clothing because of the way they feel, list them here:



## Squeezing spongy objects



## Squeezing spongy objects

There may be several spongy materials in your home, such as playing-balls, washing sponges and foam mattresses.

Explore your home and discover what materials appeal to you.



## Touching feathery objects



## Touching feathery objects

There may be several things in and around your home that feel like feathers, such as feather dusters, pillowcase fillers and dandelion seed heads.

Explore your home and discover what materials appeal to you.



## Touching woolly surfaces



## Touching woolly surfaces

There may be several woolly surfaces in your home, such as clothes, blankets and carpets.

Explore your home and discover what materials appeal to you.



## Touching hair or fur



## Touching hair or fur

There may be several hairy or furry surfaces in and around your home, such as shag rugs, curtain tassels and your pets' coats.

Explore your home and discover what materials appeal to you.



## Touching stone surfaces



## Touching stone surfaces

There may be several stone surfaces in and around your home, such as a pestle and mortar, pavements and exterior walls.

Explore your home and discover what materials appeal to you.





## Touching silky fabrics

### Touching silky fabrics

There may be several silky fabrics in and around your home, such as bed sheets, some scarves, and neck-ties.

Explore your home and discover what materials appeal to you.



## Touching wooden surfaces

### Touching wooden surfaces

There may be several wooden surfaces in and around your home such as kitchen chairs, a rolling pin and floor boards.

Explore your home and discover what materials appeal to you.





## Touching grass

There may be several things in and around your home that have a similar feel to grass, such as tinsel, long-pile carpets or rugs and soft brushes.

Explore your home and discover what materials appeal to you.



## Touching sand

There may be several things in and around your home that have a similar feel to sand, such as sugar, rice and flour.

Explore your home and discover what materials appeal to you.



## Touching gooey surfaces



## Touching gooey surfaces

There are several things that you can make feel gooey, such as dough, jelly and modelling clay.

Explore your home and discover what materials appeal to you.



## Interacting with water



## Interacting with water

Interacting with water can be therapeutic. Be mindful that interacting with water can become the focus of obsessional behaviour.






### Active touch

People who like active touch may enjoy actively exploring objects and surfaces with different textures.



### Jumping

People who like the sensation of jumping may enjoy activities that develop their vestibular (balance) system such as trampolining, bouncing on Swiss balls or swinging. Jumping is also great exercise. Covered outdoor spaces and indoor spaces with high ceilings give people areas in which they carry-out vestibular activities; helping them to incorporate these movements in their daily routine.







Riding on a bus or in a car

## Riding on a bus or in a car

The motion of riding on a bus or in a car stimulates the vestibular (balance) system. People who find this motion relaxing may enjoy other vestibular activities such as rocking and swinging.



Heights

## Heights

When looking out from a height, visual cues recede and people rely more on their sense of balance. People who dislike heights may have an under-developed vestibular (balance) system and can benefit from vestibular activities such as catching a ball or walking along curbs.



## Spinning around & dancing



## Spinning around & dancing

People who like the sensation of spinning themselves around or dancing may enjoy activities that further develop their vestibular (balance) system such as trampolining, bouncing on Swiss balls or swinging. Covered outdoor spaces and indoor spaces with high ceilings give people areas in which they carry-out vestibular activities; helping them to incorporate these movements in their daily routine.



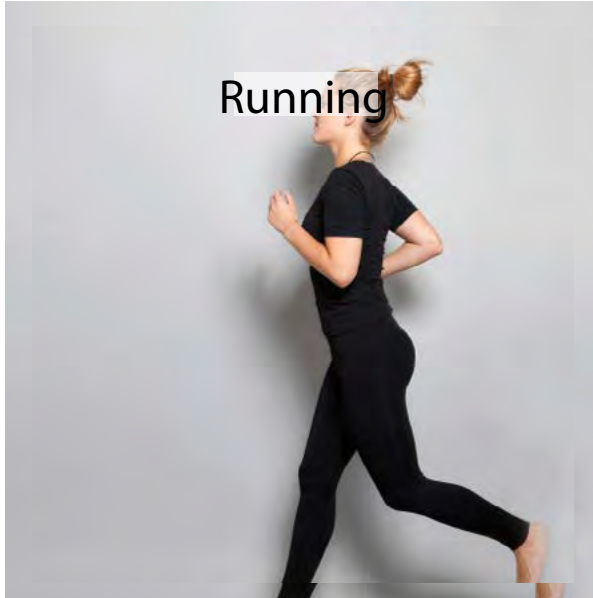
## Walking



## Walking

People who like walking may enjoy activities that further develop their vestibular (balance) system such as trampolining, bouncing on Swiss balls or swinging. Covered outdoor spaces and wide indoor circulation spaces give people areas in which they walk during inclement weather; helping them to incorporate walking in their daily routine.

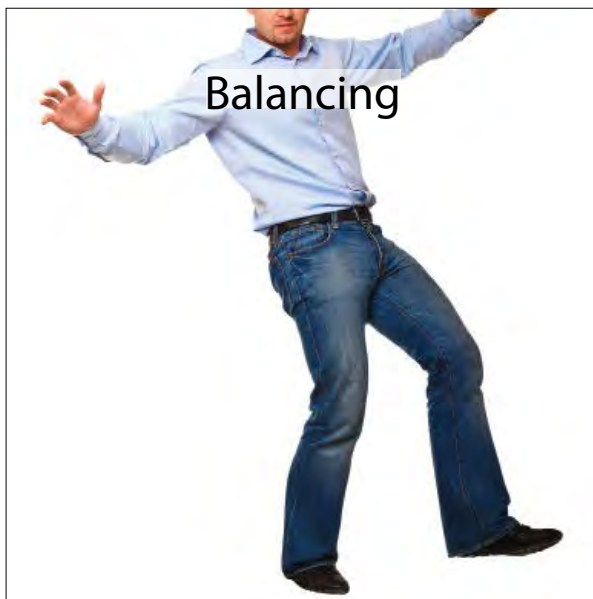




## Running

---

People who like running may enjoy activities that further develop their vestibular (balance) system such as trampolining, bouncing on Swiss balls or swinging. Covered outdoor spaces or an indoor treadmill give people space to run during inclement weather; helping them to incorporate running in their daily routine.



## Balancing

---

People who like balancing may enjoy activities that further develop their vestibular (balance) system such as such as catching a ball or walking along curbs.





## Spending time alone

Some people like spending time alone whilst others appear to dissociate themselves from groups of people but often remain in the same space as them. In the latter case, people may want to engage in group social activity, but require greater personal space and access to an exit route at all times. Floor plans and furniture can be arranged to help these people to participate in group situations from a distance.



## Spending time in groups

Locating communal spaces at the heart of a building, with main circulation routes passing through or tangential to them creates opportunities for constant, informal contact among residents. Such common spaces give people places to meet and engage in group activities.





### Lifting objects

People who like the sensation of lifting objects may enjoy activities that develop their proprioceptive (body awareness) system such as being massaged and using Deep Pressure products.

Having moveable furniture or a home gym helps people to incorporate proprioceptive activities into their daily routine.



### Being held firmly

People who like being held firmly may find it calming to apply pressure to parts of their body through massage, heavy blankets or Deep Pressure products, such as weighted vests.

People who avoid being held may be over-sensitive to tactile stimulation. For them, a hug may be painful rather than comforting.





## Being massaged

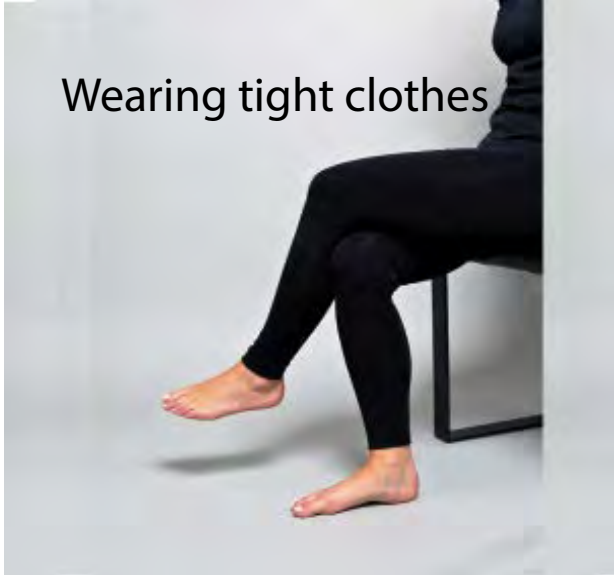
People who like being massaged may find it calming to be held firmly or apply pressure to parts of their body with heavy blankets or Deep Pressure products, such as weighted vests.



## Pushing & pulling

People who like the sensation of pushing and pulling objects may enjoy activities that develop their proprioceptive (body awareness) system such as being massaged and using Deep Pressure products. Having moveable furniture, home gym or a wheelbarrow in the garden helps people to incorporate proprioceptive activities into their daily routine.





### Wearing tight clothes

People who like the sensation of wearing tight clothes may enjoy activities that develop their proprioceptive (body awareness) system such as being massaged and using Deep Pressure products such as weighted vests.

⊙ ↻ ↓ ∟ ↺ ↔



### Confined spaces

People who like positioning themselves in confined spaces may be more satisfied with home environments that incorporate spaces under, behind and above things to which they can withdraw.

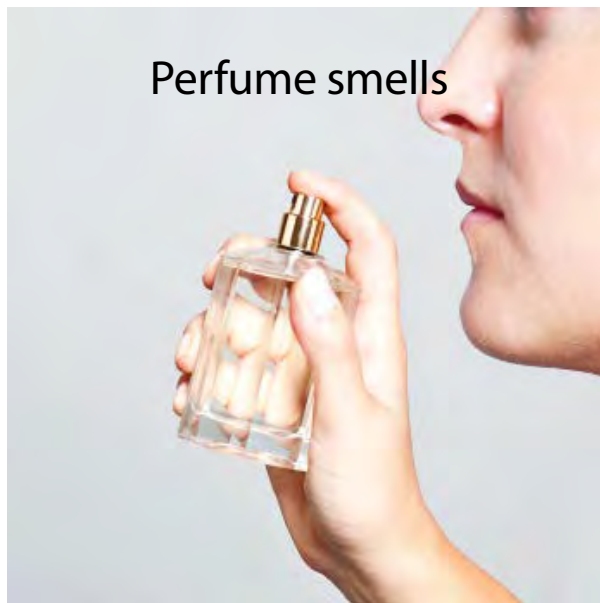
⊙ ↻ ↓ ∟ ↺ ↔



## Floral smells

---

People for whom the scent of flowers is too intense and overpowering can still enjoy the pleasures of a garden when it is planted with unscented flowers and shrubbery.



## Perfume smells

---

People for whom perfume smells are too intense and overpowering may benefit from using unscented detergents and shampoos and making their home as fragrance-free as possible. Natural fabrics such as cotton absorb odours better than synthetic materials.





## Spicy, aromatic smells



## Spicy, aromatic smells

People who like aromatic smells may enjoy cooking on an oven hob. Aromatic oils are also a great way to experiment with smells.



## Earthy smells



## Earthy smells

People for who like earthy smells may enjoy being outside and gardening.





## Discos

---

⦿ ◡ ∇ ∟ ↻ ⇄



## Cooking & baking

---

Cooking and baking activities can engage all of the primary senses.

People who like the feel of different textures may enjoy making dough whilst people who seek out strong smells may enjoy making recipes with aromatic spices.

⦿ ◡ ∇ ∟ ↻ ⇄



## Playing board games

If there are particular games that you enjoy playing, list and describe them here:



## Arts & crafts

If you like participating in certain creative activities, list them here: nging, humming, and whistling.



## The colour pink

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour orange

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour light blue

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour green

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour brown

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour dark blue

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour yellow

### Colours

---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## The colour red

### Colours

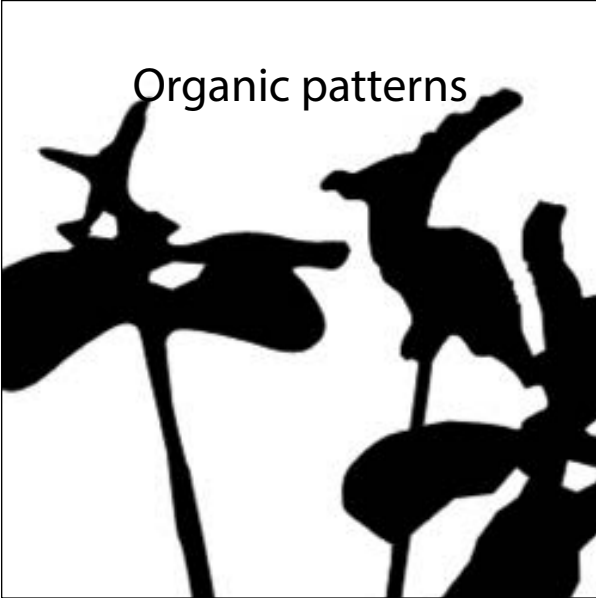
---

In shared spaces, different visual preferences and sensitivities can be satisfied by using muted, matt and harmonious colour schemes. Colour can be added as appropriate by using decorative objects, pictures and textiles.

In private spaces, people can experiment with their use of colours.



## Organic patterns

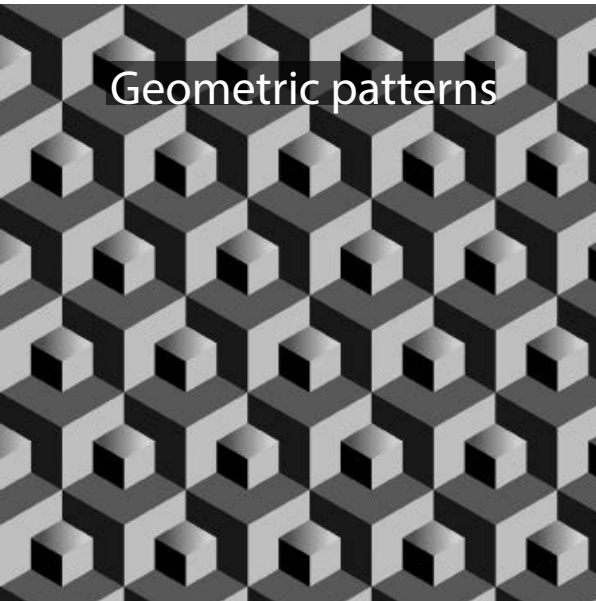


## Organic patterns

People who prefer wearing clothing with irregular prints or those who prefer the look of naturally-finished materials may be more satisfied with using organic patterns in the decorative schemes of their home.



## Geometric patterns



## Geometric patterns

People who prefer wearing clothing with regular patterns such as stripes may be more satisfied using geometric and repeating patterns in the decorative schemes of their home.

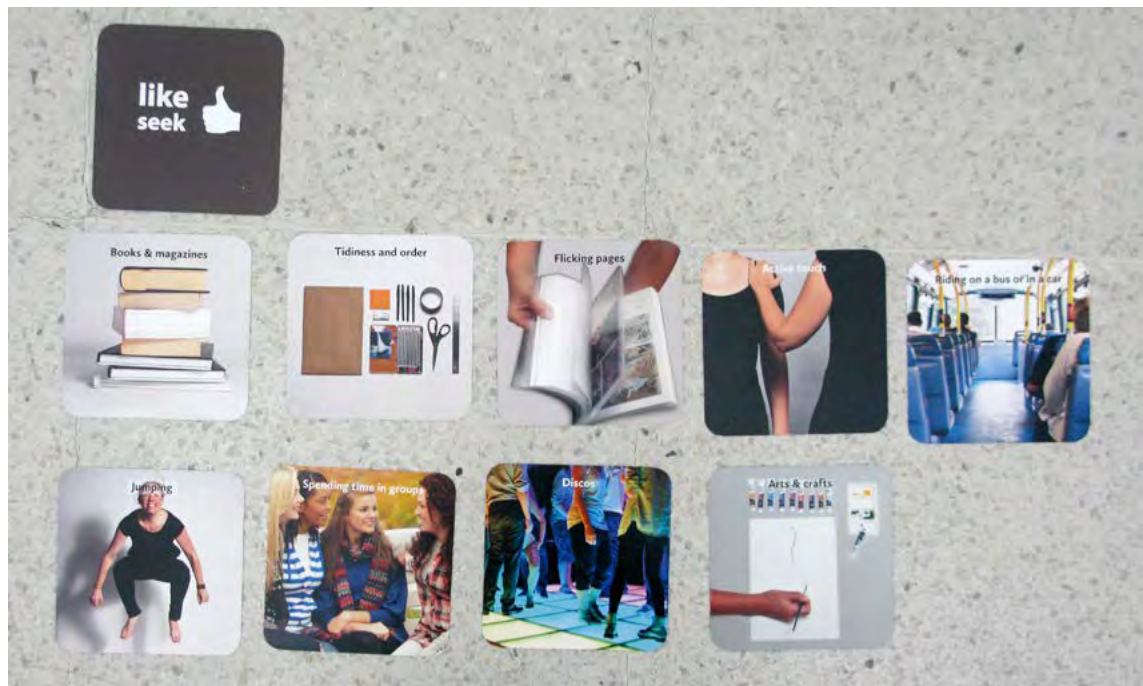




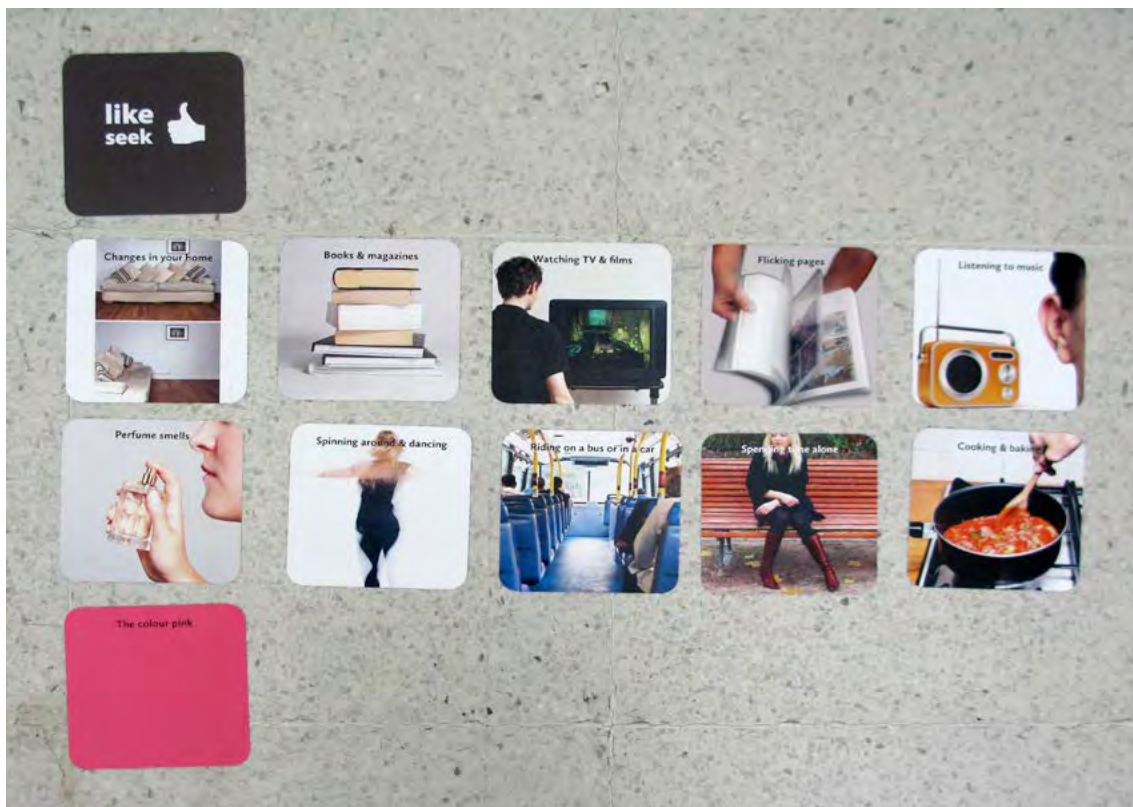
# Appendix 19

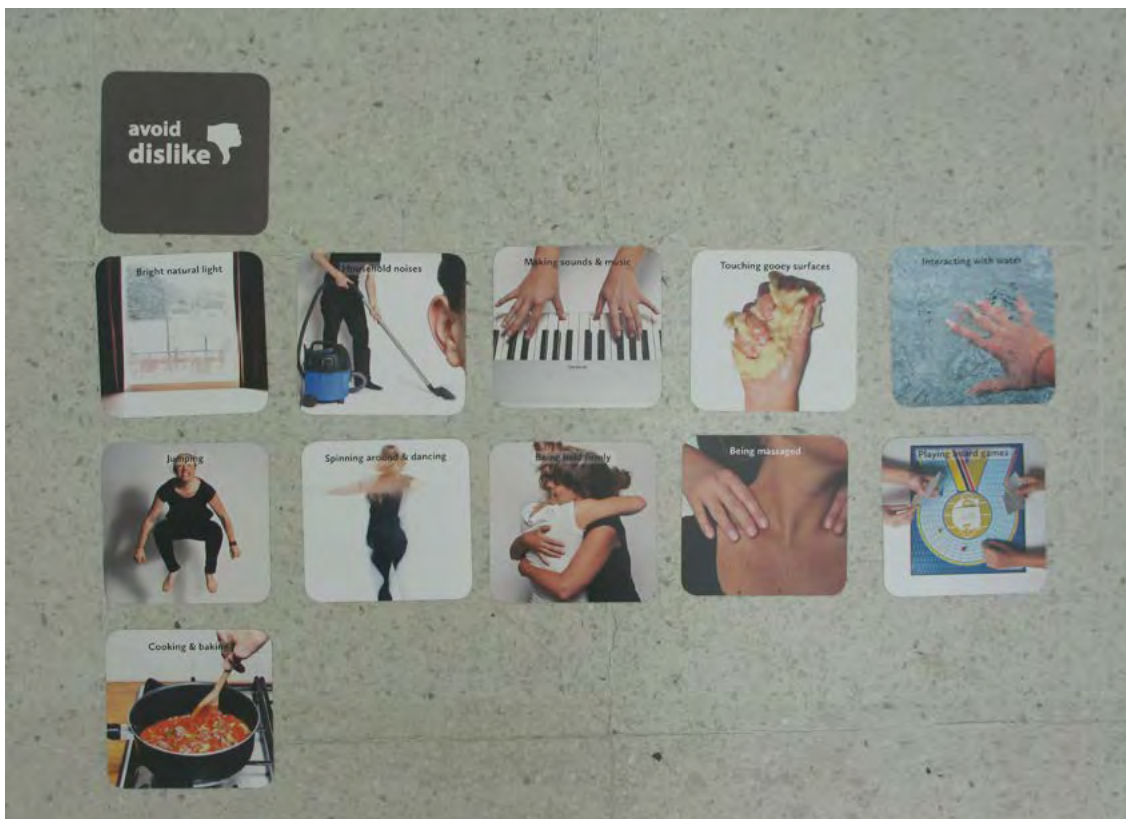
## Appendix 19: Mapping the sensory preferences of the autistic participants in studies one, two and three

### Mapping Sensory Preferences: Study One





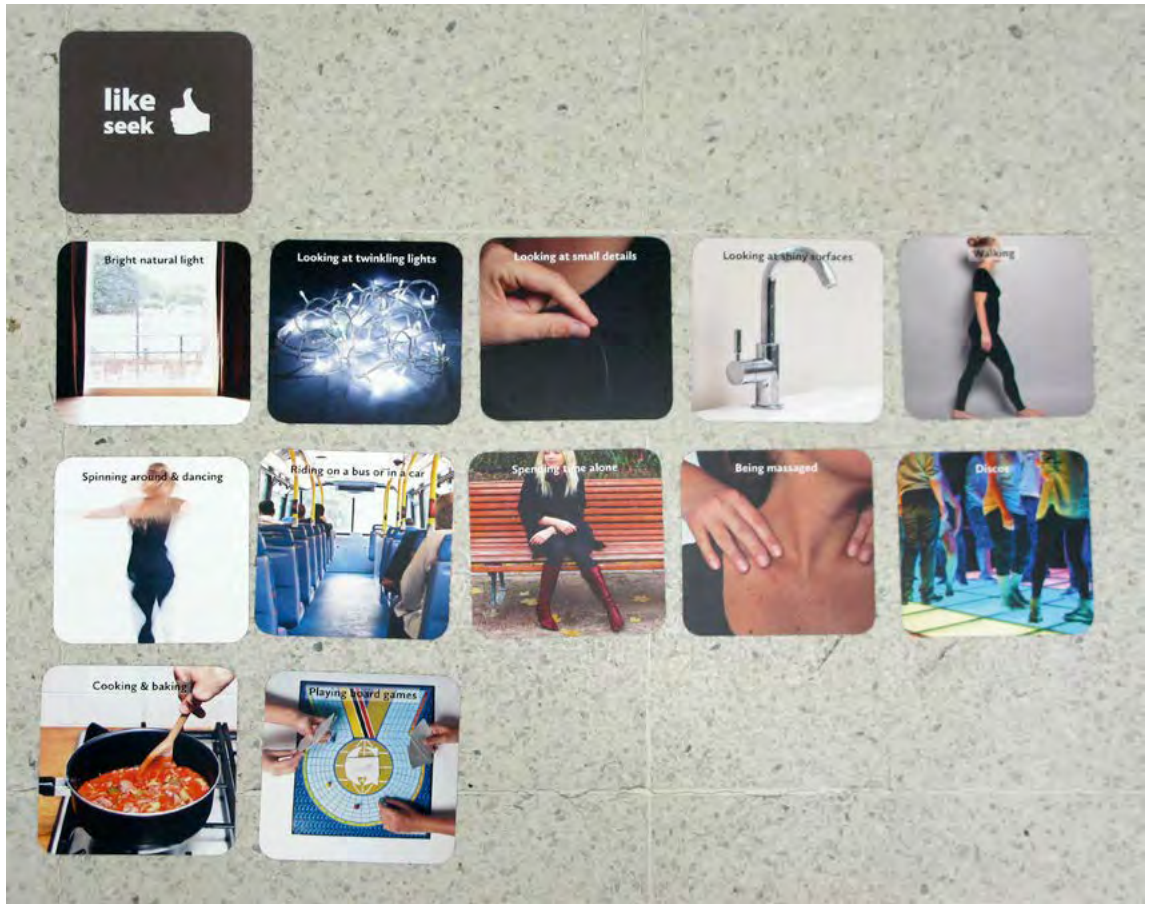


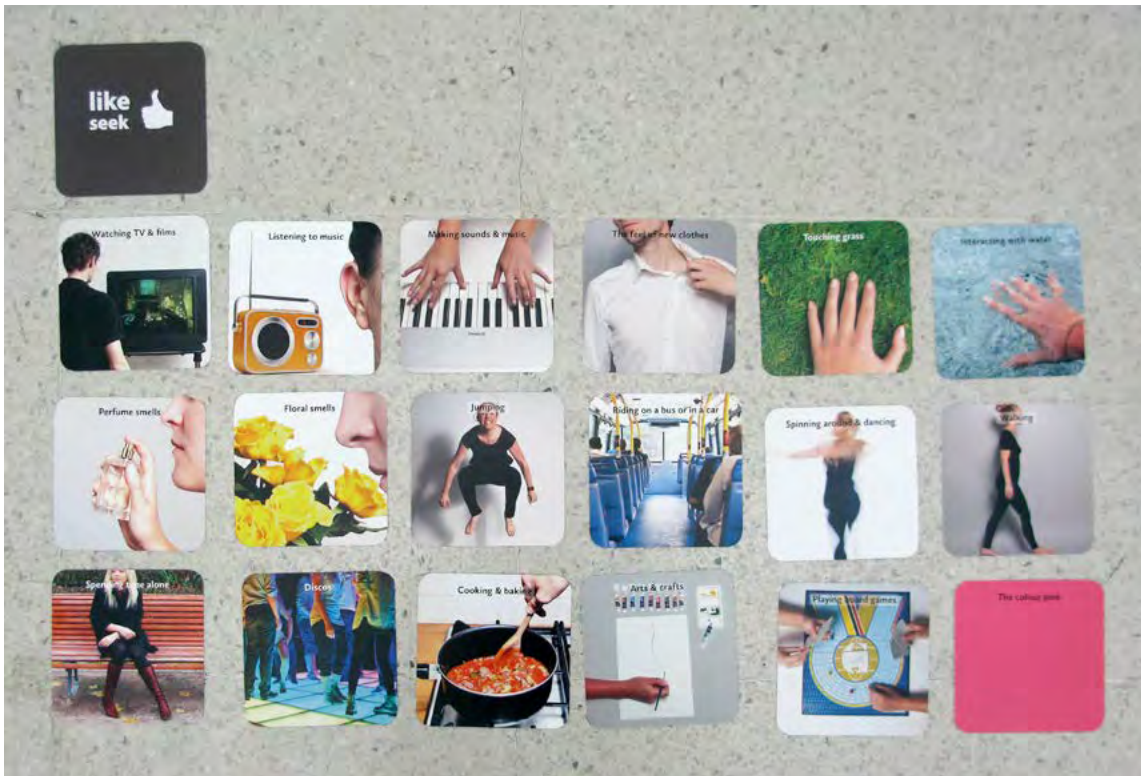




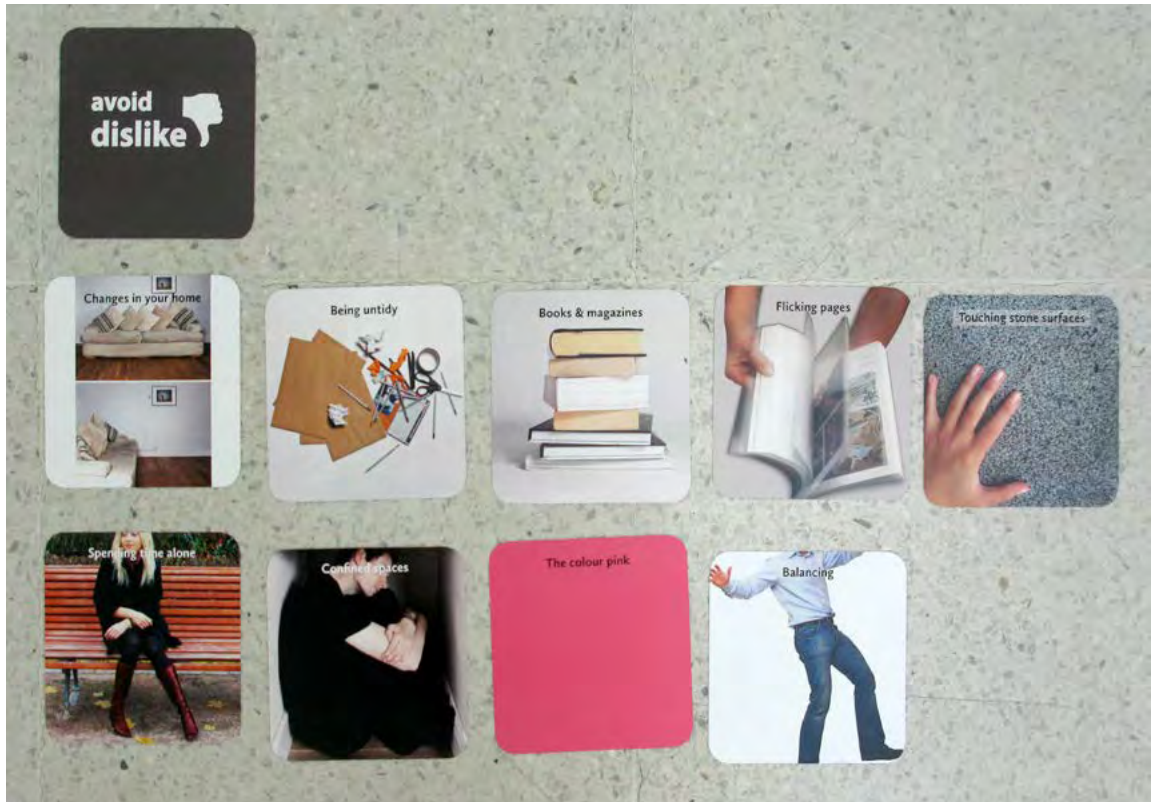


# Mapping Sensory Preferences: Study Three











# Appendix 20

**Appendix 20: An example of a completed interest checklist  
(Kielhofner and Neville, 1983)**

**INTERESTS & ACTIVITIES TOOLKIT  
FOR USE WITH PEOPLE WITH DEMENTIA** **A GUIDE FOR STAFF & CARERS**

## INTEREST CHECKLIST - 1

NAME: ..... DOB: .....

ACTIVITY	WHAT HAS BEEN YOUR LEVEL OF INTEREST						Do you currently participate in this activity?		Would you like to pursue this in the future?	
	IN THE PAST TEN YEARS			IN THE PAST YEAR			YES	NO	YES	NO
	STRONG	SOME	NO	STRONG	SOME	NO				
GARDENING			✓			✓		✓		✓
SEWING / knitting		✓			✓		✓		✓	
PLAYING CARDS			?			✓		✓		✓
CHURCH ACTIVITIES		✓				✓		✓		✓
RADIO		✓			✓		✓		✓	
WALKING		✓			✓		✓		✓	
DANCING		✓			✓		✓		✓	
GOLF			✓			✓		✓		✓
FOOTBALL			✓			✓		✓		✓
MUSIC		✓			✓		✓		✓	
PUZZLES		✓				✓	✓			✓
PETS			✓			✓		✓		✓
FILMS		✓			✓		✓		✓	
SWIMMING			✓			✓		✓		✓
BOWLING			✓			✓		✓		✓
VISITING		✓				✓	✓		✓	
CHESS/DRAUGHTS			✓			✓		✓		✓
READING		✓			✓		✓		✓	
TRAVELLING			✓			✓		✓		✓
HOUSEWORK		✓			✓		✓		✓	
MODEL BUILDING			✓			✓		✓		✓
TELEVISION	✓			✓			✓		✓	
CONCERTS		✓				✓		✓		✓
POTTERY			✓		✓			✓		✓
IRONING			✓			✓		✓		✓
POLITICS			✓			✓		✓		✓
TABLE GAMES		✓			✓				✓	

## INTEREST CHECKLIST – 1

NAME: ..... DOB: .....

ACTIVITY	WHAT HAS BEEN YOUR LEVEL OF INTEREST						Do you currently participate in this activity?		Would you like to pursue this in the future?	
	IN THE PAST TEN YEARS			IN THE PAST YEAR			YES	NO	YES	NO
	STRONG	SOME	NO	STRONG	SOME	NO				
GARDENING			✓			✓		✓		✓
SEWING / <i>knitting</i>		✓			✓		✓		✓	
PLAYING CARDS			?			✓		✓		✓
CHURCH ACTIVITIES		✓				✓		✓		✓
RADIO		✓			✓		✓		✓	
WALKING		✓			✓		✓		✓	
DANCING		✓			✓		✓		✓	
GOLF			✓			✓		✓		✓
FOOTBALL			✓			✓		✓		✓
MUSIC		✓			✓		✓		✓	
PUZZLES		✓				✓	✓			✓
PETS			✓			✓		✓		✓
FILMS		✓			✓		✓		✓	
SWIMMING			✓			✓		✓		✓
BOWLING			✓			✓		✓		✓
VISITING		✓				✓	✓		✓	
CHESS/DRAUGHTS			✓			✓		✓		✓
READING		✓			✓		✓		✓	
TRAVELLING			✓			✓		✓		✓
HOUSEWORK		✓			✓		✓			✓
MODEL BUILDING			✓			✓		✓		✓
TELEVISION	✓			✓			✓		✓	
CONCERTS		✓				✓		✓		✓
POTTERY			✓		✓			✓		✓
IRONING			✓			✓		✓		✓
POLITICS			✓			✓		✓		✓
TABLE GAMES		✓			✓				✓	

ACTIVITY	WHAT HAS BEEN YOUR LEVEL OF INTEREST						Do you currently participate in this activity?		Would you like to pursue this in the future?	
	IN THE PAST TEN YEARS			IN THE PAST YEAR			YES	NO	YES	NO
	STRONG	SOME	NO	STRONG	SOME	NO				
CLUBS			✓					✓		✓
SINGING		✓			✓		✓		✓	
CLOTHES		✓			✓		✓		✓	
CRAFTS		✓			✓		✓		✓	
CYCLING			✓			✓		✓		✓
THEATRE		✓				✓		✓		✓
BIRD WATCHING			✓			✓		✓		✓
EXERCISE			✓			✓		✓		✓
WOODWORK			✓			✓		✓		✓
POOL/SNOOKER			✓			✓		✓		✓
DRIVING			✓			✓		✓		✓
TENNIS			✓			✓		✓		✓
COOKING		✓			✓		✓		✓	
BAKING		✓			✓		✓		✓	
HISTORY			✓			✓		✓		✓
COLLECTING			✓			✓		✓		✓
FISHING			✓			✓		✓		✓
SCIENCE			✓			✓		✓		✓
SHOPPING		✓			✓		✓		✓	
PHOTOGRAPHY			✓			✓		✓		✓
PAINTING		✓			✓		✓		✓	
DRAWING		✓			✓		✓		✓	

DATE COMPLETED: 24.11.11



# Appendix 21

## Appendix 21: A selection of completed Interests and Hobbies booklets



### SYSTEMS

e.g. toilet flushing, drains, light switches, etc.,

YES [  ] NO [  ]

If YES, please specify.....

turning the light  
switch on and off.....



### SYSTEMS

e.g. toilet flushing, drains, light switches, etc.,

YES [  ] NO [  ]

If YES, please specify.....

toilet flushing.....  
- running water - especially mid air - like  
the spray from the  
shower.



## **SORTING/ CATAGORISING**

e.g. lining objects up, arranging objects in alphabetical order by size, shape, colour, etc.,

YES [  ]      NO [  ]

If YES, please specify.....

*lining model cars up  
doesn't like anyone  
rearranging the position  
of cars*



## **MACHINES**

e.g. computers, radios, TV's, washing machines, clocks, burglar alarms, etc.,

YES [  ]      NO [  ]

If YES, please specify.....

*washing Machines, the  
buttons on the TV*





## SENSORY PREFERENCES

e.g. touching things, hearing specific sounds, lights, smells, tearing paper, etc.,

YES [  ] NO [  ]

If YES, please specify.....

...Smells... rubbing his feet on various

Surfaces... music (on adverts on radio).

- Playing with water/bubbles.....

- Taste.....

-



## SENSORY PREFERENCES

e.g. touching things, hearing specific sounds, lights, smells, tearing paper, etc.,

YES [  ] NO [  ]

If YES, please specify...touching...

things...hearing specific sounds

(music), light, smells, even

tearing paper (from big...

algos book).



# Appendix 22

## Appendix 22: Information compiled from the completed Interests and Hobbies booklets



Blue photo album files, books. I like to arrange general objects around my flat i.e. bath mat, washing up liquid lid, my towel.

Toys, books and videos. Arranging books on shelf in an orderly manner, colours, size, lining objects up. Playing cards (sorting into numbers). Lining model cars up, doesn't like anyone rearranging the position of the cars. Lining objects in colour. At Superdrug store. Lines the sauces/ juices etc.. up on table. The juice jugs have to be in line with the handles in the same direction. Lines shoes up- tidies piles of magazines to be even. Turns rings around on people's fingers if they are crooked, fixes other people's hair if it doesn't line up right to him. Has to empty the washing up bowl if it is full of water. Arranging objects e.g. lining objects up in a row.



I like cakes, party food and drink fresh pasta, quiche, egg pancake. Fish & Chips, chocolate mousse, cheese sandwiches, coffee, spicy foods, sausages, crisps, diet coke, chocolate, crisps and sticky things. Sausages, chips, pies, scampi, fish, chicken, coke peas. I like diet coke, squash, lasagne, pizza, chicken korma, chocolate bars/ cookies, crumble, rhubarb and custard, also a mixture of foods. Food, drink, pizza, ice cream, Ginger beer, lemonade, Bear, cider, baileys, curry, chilli con carne, sausages, bacon mash, set meal for two, Coca cola, biscuits beer. Fish and chips, mix grill, tea, squash, hot chocolate. Likes putting tree branches in mouth and spitting them out. Red wine, pork, fruit. Pasta, cheese, chicken, vegetables, fruit, olives. Roast chicken, Yorkshire puddings. Cheese, milk. Will eat anything and particularly likes sauces and milkshakes. Squash, biscuits. She is 'obsessed with drink especially coke and coffee asking them even if she is not thirsty. Cup of tea, chocolates, most food.

## Machines



TV, washing machines, fans, windmills, drills, radio. TV-music channel, dvds, radio, listening to music in bed. Washing machines, pressing the buttons on the TV. Washing machines, mowing grass, listening to music on the radio, TV channels, on a stereo (at home and in car). computers, radios

## Plants



I like plants and flowers, I attend a gardening project and do like moving plants and watering it is a social activity. I like plants because of the smell. Flower, trees, gardening. Growing trees, flowers, smelly plants, lavender. With encouragement she can water plants at home.

## Systems



Toilets, boiler room, bath taps, shower sink basin, water pipes, water features, electricity (pylons & sub stations), toilet flushing, switching lights on and off. Doors opening with manual/electronic key. Light switches when anxious. Turning the light switch on and off. Flushing toilets. Flushing toilets after use. Toilet flushing, running water- especially in mid air like the spray from a shower. It is not a special interest but when she is agitated she will turn off lights to upset people. Light switches, switching lights on and off

## Collect-



Windmills, Dr Who magazines, toy cars (emergency vehicles), key rings, toy cars, memorabilia, toys, books, dvds, videos, magazines, polythene bags, cottage ornaments, maps. I love to collect music cds and old LPs, especially from the 60s. Money, animal pictures, animal books, soft toys, stamps for charity- used, playing cards, jigsaws and lots of beads and collecting up to date car magazines.

## Factual Information



Internet, emails, letters, writing, reading stories. I like to read my staff rota and things that interest me, I have a very good memory of past and present activities or days out. Reading, Memorising activities of the week, playing with words, writing, animal books. TV magazines. She likes writing letters but she needs a lot of encouragement, she can read but for a short time. Catalogues, documentaries, books on fish, Argos catalogue.

## Belief Systems



Church of England, goes to church. I go to church with family on special occasions i.e. Christmas. I am also a Christian and attend my local church, politics, Joy church, singing. Christian. From time to time she is talking about god but without deeper understanding

## Spinning Objects



Windmills, spinning tops, washing machines, disco balls, fans, wheels, washing machine to get my washing clean, spinning model car wheels, mixer.

## Vehicles



I like trains, cars. Turn the engine off, all vehicles! Boat trips and going for walks, cars and buses. I like to fly to go on holiday with dad, train trips, travelling by bus or car, like to look at what's around me. Disney, Pixar, trains, cars, looking at the view. My car, I have a bus pass and I like to take trips. Visiting car museums. Collecting model modern and vintage cars. Likes being in car, driving, looking at pictures of cars and buses, he will point and say bus when he sees one and enjoys being a passenger. trains, buses.

## Numerical Information



Lottery numbers, quiz show prizes, rotas for staff working with me, prime numbers, calculators, telephone numbers so I can call people on my phone. Calendar, television guide, playing cards (sorting into numbers).

Marks each calendar each day with an X and speaks the day and date around, timetable, cards. Finds time processing stressful. Only wants to know what is happening now. She has special preferences e.g. calendar with Cliff Richard pictures

## Strongly Attached to Items



Light switches, ventilation, fan controllers, spur switch windmills, letters from my girlfriend, photos, titanic DVD, rolling small objects with fingers, key rings, toy cars, toys, clothes, key, cottages, 'snoggies', photos, Harry Potter toys. My daily money I like to hold in my hand and count it, watch, lots of soft toys, bracelets, necklaces, watch, keys. He has lots of stuffed toys in his room and doesn't appear to ever touch or use them in any way. Though some people feel he must like them, as he hasn't thrown them out of windows. I have observed that he only throws things out of the window if they are in the wrong place (and for a laugh). Watch- talks about his watch all the time. Cant be without it

## Sensory Preferences



I like the sound of fans, kettle, fridge, freezer, music, MC Hammer, church bells, clocks striking, whistles, engine and machine sounds, things that hum, bells and chimes, disco lights, smells of vanilla, dinner, aftershave, Jacuzzi.

Sounds and smells, Sounds of cars, 80s pop music, mixing sounds, smells hair, water, lights, sounds i.e., bird music or pop songs, Argos catalogue, smelling hot chocolate, lavender, shower gels.

Touching and picking at things, smelling clothes, flicking through books and catalogues, music, tearing paper into strips from magazines, smell of favourite food. Touch, smells, rubbing his feet on various surfaces, music (not adverts on radio), water bubbles, taste, sounds, tearing paper, touching things, lights.

## The Creative Arts/ Fiction



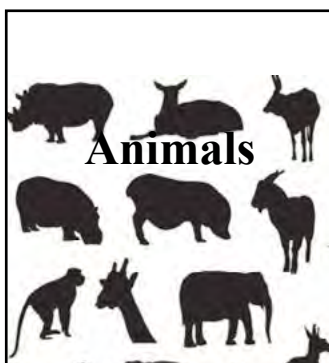
Hand chimes, orchestra music, EastEnders, filming, photography, playing guitar, listening to music, playing instruments, theatre, cinema, watching TV.

I enjoy going to the theatre with family and being supported to pantos, I like to laugh and joke. Cinema, descendants, musicals, cartoons, listening to music.

TV, cinema, films, listening to music, films such as High school musical and Harry Potter.

Listening to music and singing. Listening to favourite songs i.e. Stily Span party songs. Listening to music.

Music live and on stereo, cinema. Loves going up to drummer at stepping stones and crouching down right in front to watch and taps symbol as he is trying to play. She loves pantomime, but she is very impatient in the cinemas. She also loves music and dancing. Listening to music and cinema.



Dogs, cats, horses, birds (especially red kites), bats.

Goes horse riding but not sure if interested in horses?

Kangaroos. I like all animals and I like to call people I know animals i.e. James a hedgehog and Hazel a duck. Turtles, birds and dolphins, wild animals, tigers, elephants, cats, dogs (puppies), Looking at pictures of animals, birds, dogs, cats, all animals, Zoo, watches wildlife on TV, farm animals, fish. When we go through magazines together he always points and signs the animals he sees, though he doesn't usually show much interest in animals. She likes to watch animals on TV and she likes to talk about them, they had a cat when she was younger.

## Crafts



Drawing, colouring, painting, cooking and preparing meals. Being supported to bake cakes for shared meals or for family occasions. Colouring, painting.

Map drawing, photography of landscapes. Enjoy making cakes with my support staff. Cooking, painting, drawing. Making craft things, jewellery, flowers. Cooking class and jigsaws. Cooking cake. Baking, smoothy making. She enjoys to help in the kitchen (cooking) and knitting but not a long time. Glue, cutting out and sticking making pictures.



## Sports/Games

Swimming, athletics, motor racing ( as spectator) cricket, darts, ice skating. Bowling, swimming, walking, Bowling, walking. I like to watch a mixture of sports i.e. football.

Darts, motor racing, volley ball (sports day).

Bowling, swimming, walking, cycling, Pool, walking, football Walking, puzzles, football, catch. Swimming with friends, bowling with friends, games.

Swimming, walking, jumping, dancing, clapping, snapping, random sprints (not often). Doesn't often participate in games but does join us sometimes to play with something on his own. Likes looking at magazines with staff and signing what he sees. Likes calculated games of his own design i.e. sneaking around and doing something naughty and then laughing as we try to guess what. She enjoys walks especially the environment, she is used to e.g. local shop with good intentions to buying herself goodies.

Books, puzzles, swimming, horse riding, board games



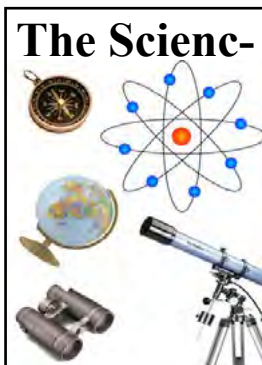
Friends, girl friend, chatty to all people, talks about family and friends. Talking to people, interested to know what staff are up to and looking at rotas.

I like to talk to family, friends and staff about things I have done or going to do. I also don't like crowded places or feeling lost and need full attention of staff and people around me.

Family, friends, staff, laid back people, talking to people (sign), mimicking songs . I am a very sociable fellow, I like to say hello to strangers I especially like to talk to my doctor who visits me. People (being friendly). Talking to staff about vintage cars.

Will interact with others when it suits him. It is felt that he has more respect for and will sit with male staff more than female- generally easy going and friendly to everyone.

Sometimes he can talk a lot to staff using the same sentence. He is always talking about his dad



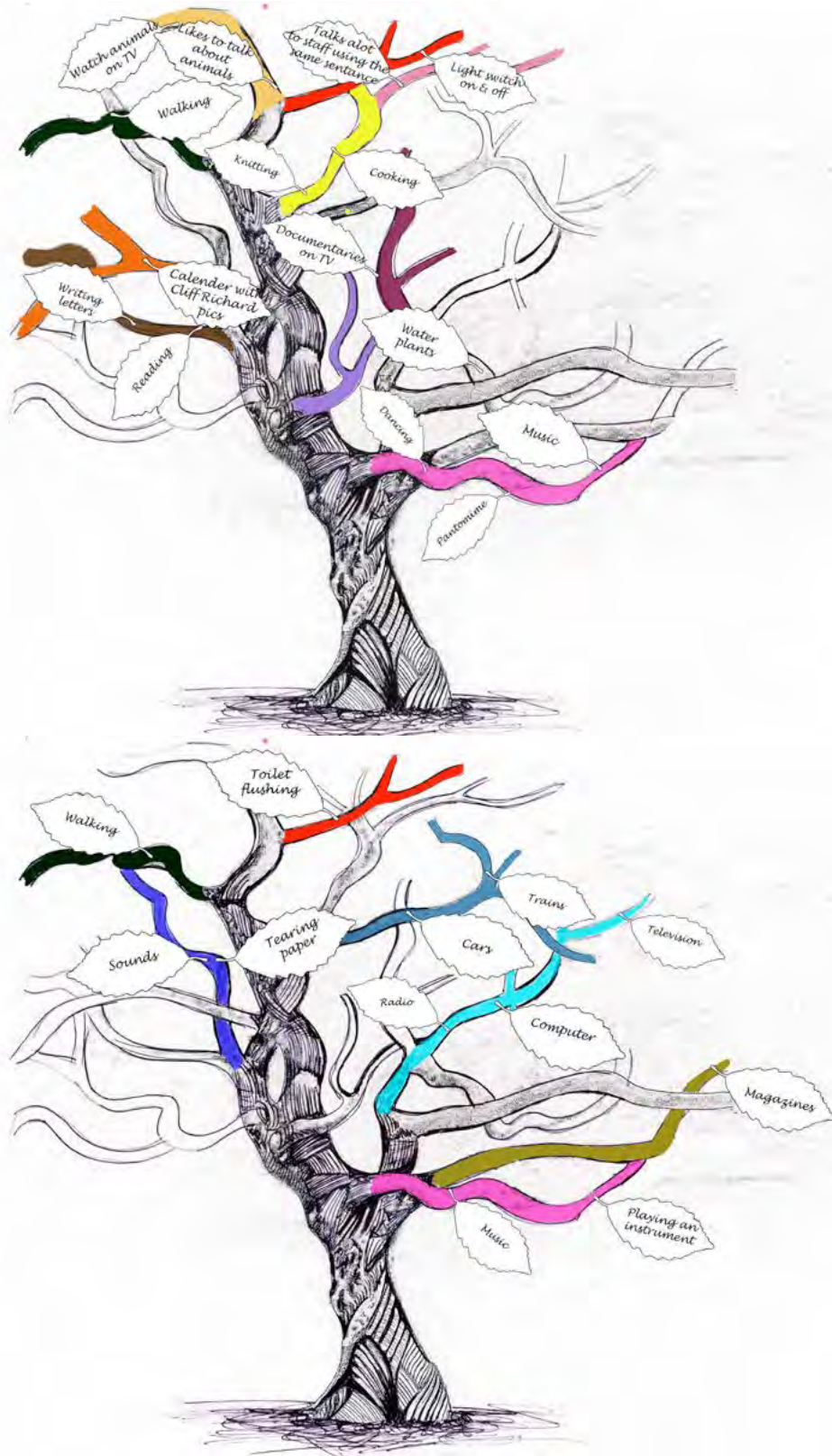
## The Scienc-

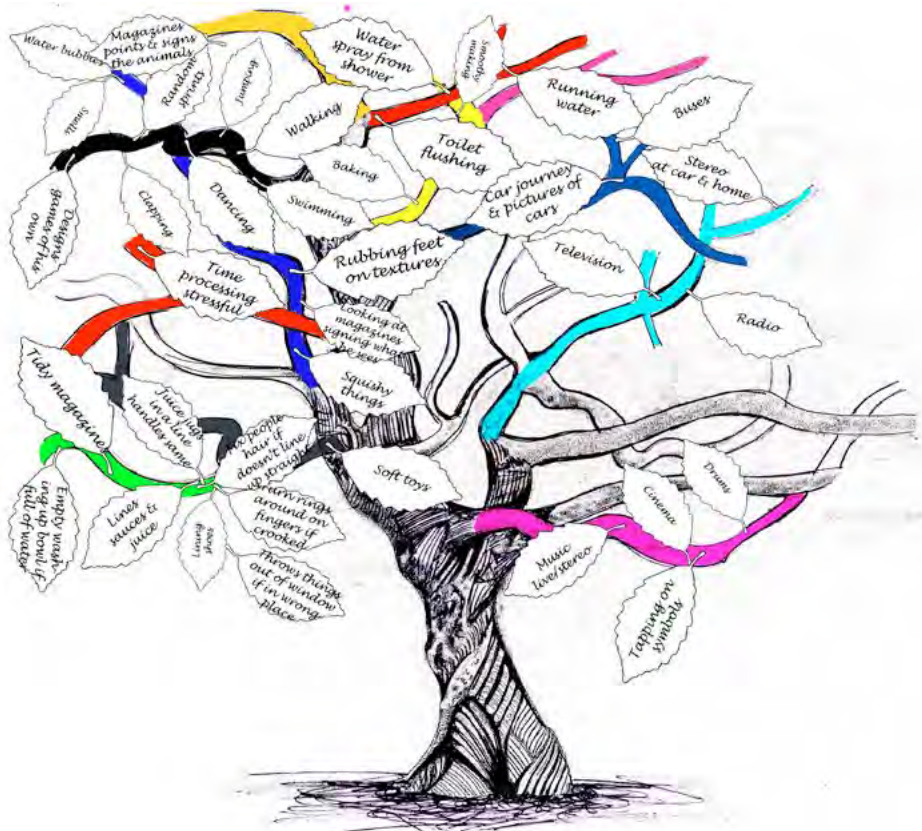
Geography, geology, topography, planets, google earth, Mars, moon. How a car works allowed to sit behind the wheel of friends BMW, loves examining. Globe, atlas. When she is watching documentaries on TV and she is relaxed she likes to interact with staff and discuss what is on TV. She listens to explanations and she remembers a lot of information.



# Appendix 23

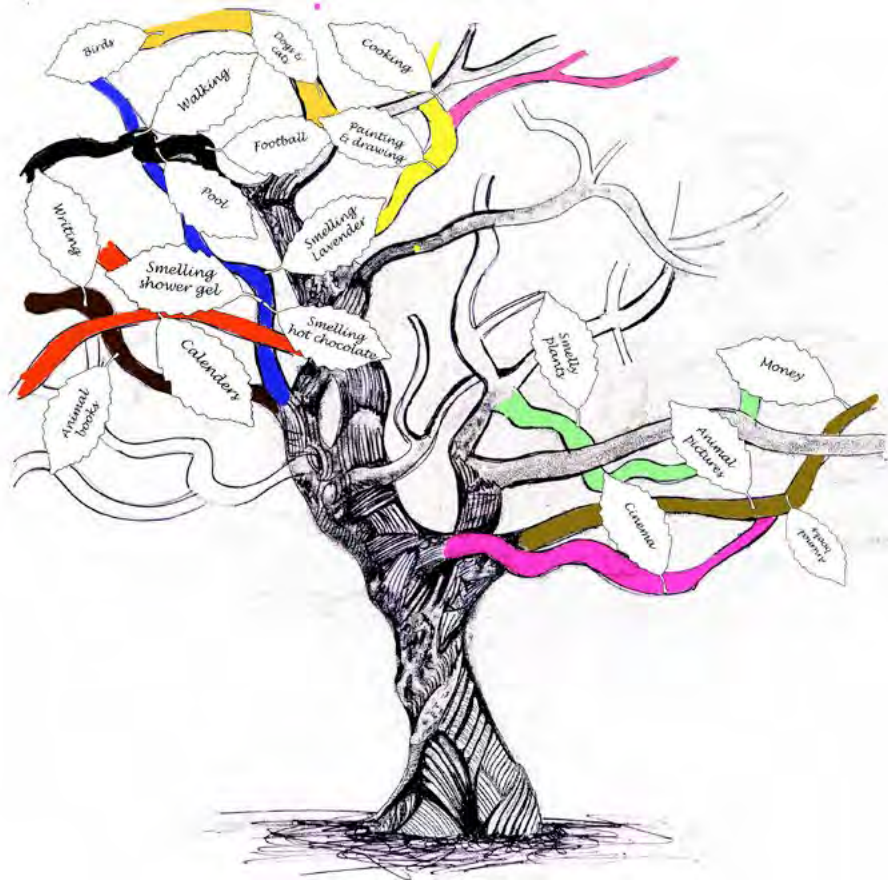
## Appendix 23: Mapping special interests into a 'tree of opportunity'



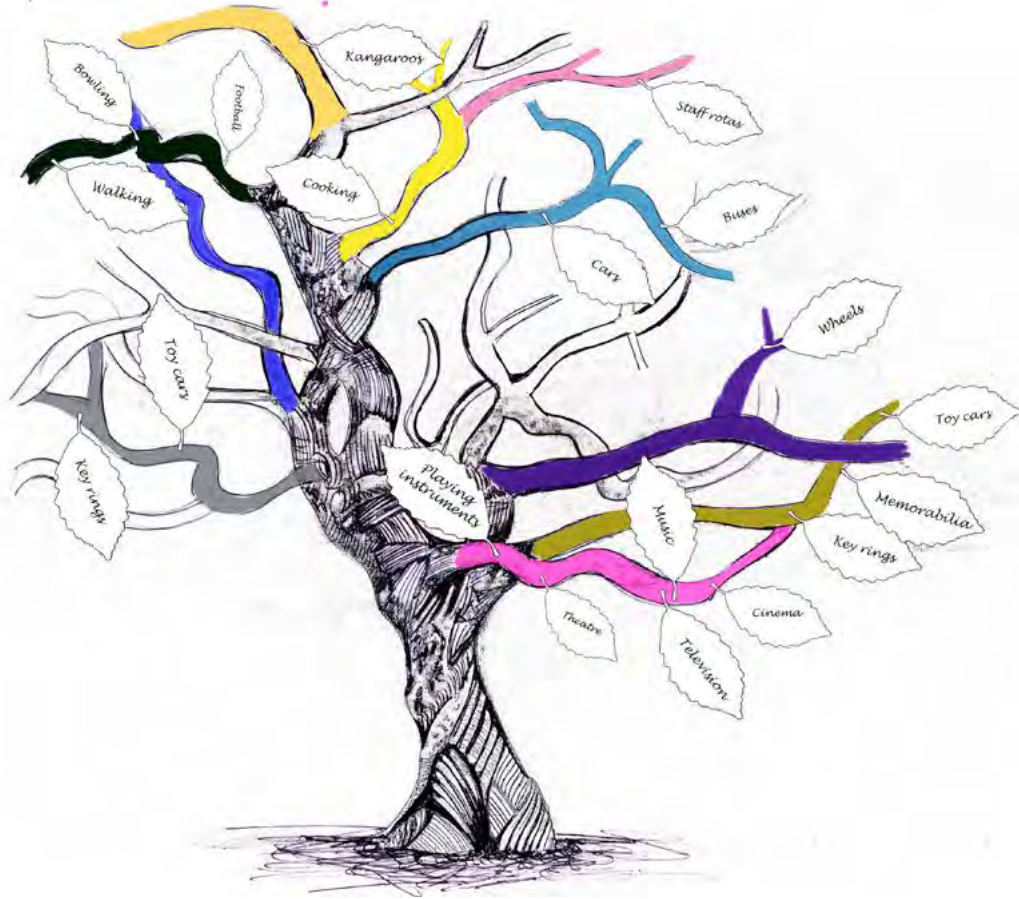


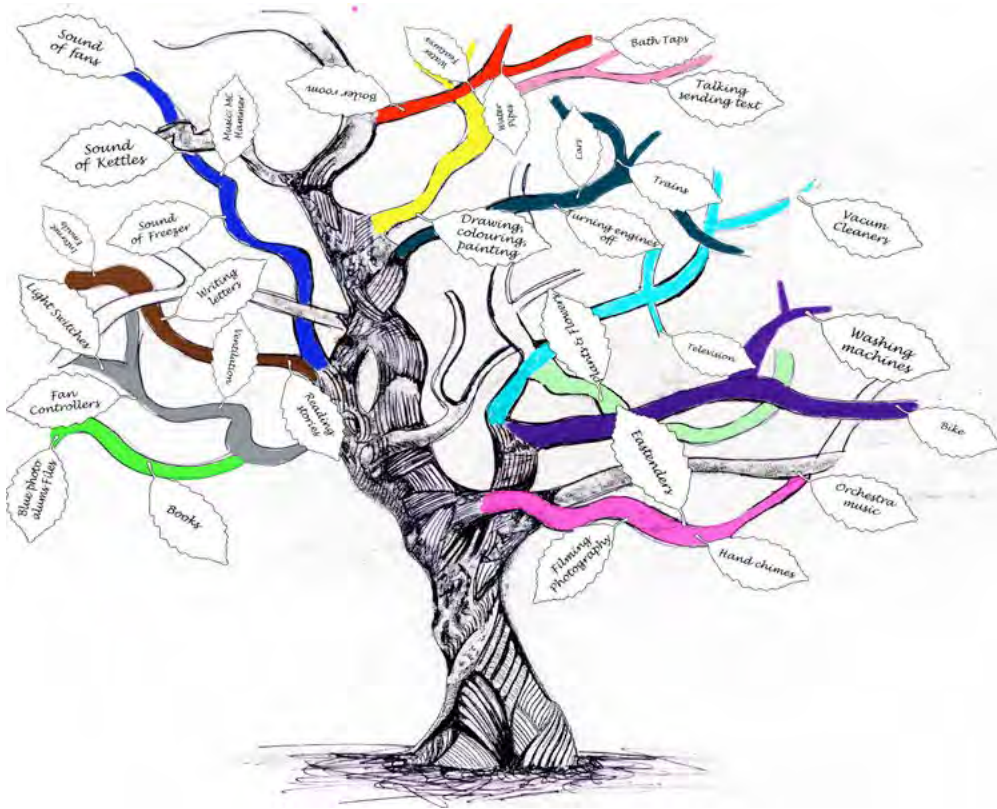


















# Appendix 24

**Appendix 24: Photographic documentation of the Ready Steady Make workshops, between 2012 - 2014**



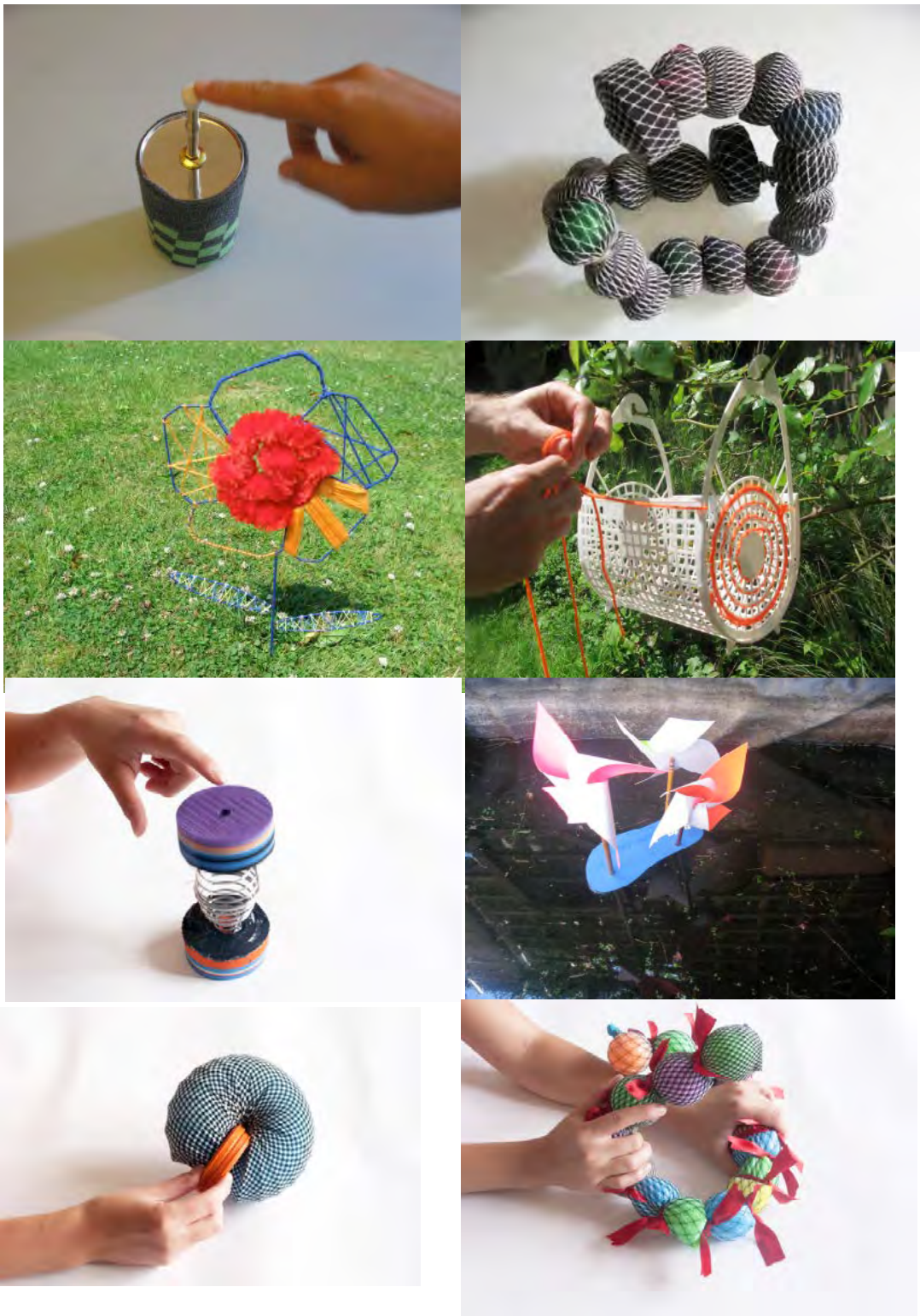






# Appendix 25

**Appendix 25:** A selection of sensory props made by the support staff at the Ready Steady Make workshops







# Appendix 26

Appendix 26: A selection of completed garden diaries

**NAME:** Ebrahim  
**DATE:** 2/9/13

**1. Circle when you visited the Garden:**

Morning:  Afternoon:  Evening:

**2. Circle today's weather:**

Sunny  Partly Sunny  Cloudy  Rainy

**3. Circle how you feel?**

*Before entering the garden*

Very Happy  Happy  Okay  Sad  Very Sad

*After entering the garden*

Very Happy  Happy  Okay  Sad  Very Sad

**4. Draw on the map below where you walked in the garden today**



**5. Tick today's activities**

Private Garden  Swing  Sprinkler  Touch (Sensory Garden)  Smell (Sensory Garden)  Sight (Sensory Garden)  Trampoline  Sound (Sensory Garden)  Vegetable Garden   Class Room

**6. Things I like about the garden today:**

ED came Down to the Chicks Room to help with making food the horse Rollie

**7. Things I dislike about the garden today:**

**NAME:** .....

**DATE:** .....

1. Circle when you visited the Garden:

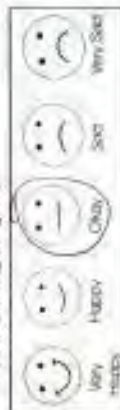


2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

7. Things I dislike about the garden today:

Things I like about the garden today:  
I always enjoyed looking out  
at the garden and the  
weather outside.

**NAME:** .....  
**DATE:** 7.10.13

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spiny Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

7. Things I dislike about the garden today:

6. Things I like about the garden today:  
 I enjoyed being on Swing, Spiny disc and jumping on Trampoline and also touch (Sensory Garden)

**NAME:** ..... 4

**DATE:** 30/8/17

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Earth (Sensory Garden)
- Sight (Sensory Garden)
- Telescopine
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

Came down outside for a BBQ And enjoyed himself

7. Things I dislike about the garden today:

**NAME:** T. A. ...  
**DATE:** 30/8/13

1. Circle when you visited the Garden:

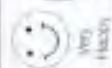
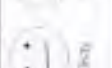

 Morning	 Afternoon	 Evening
---	---	---

2. Circle today's weather:

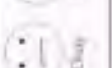
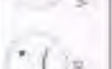
		
---	---	---

3. Circle how you feel?

*Before entering the garden*

				
Very Happy	Happy	Okay	Sad	Very Sad

*After entering the garden*

				
Very Happy	Happy	Okay	Sad	Very Sad

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Eppity Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Taste (Sensory Garden)
- Trainquino
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*we had a b.b.q. in the garden. I quite enjoyed having the garden space. She sat down to eat on the grass instead of the Art Studio.*

7. Things I dislike about the garden today:

NAME: m.....

DATE: 04/09/13

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

Before entering the garden



After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Bowling
- Spenny Disc
- Touch (Sensory Garden)
- Sneeze (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Ball (Sensory Garden)
- Water Table Garden
- Glass Room

7. Things I dislike about the garden today:

David was frustrated that we could not get into the veg patch to see what was growing.

David would really like to take part in activities in the outside classroom. He has shown great interest in the building from when it was first built - empty.

6. Things I like about the garden today:

David enjoys using the rose in his personal garden.

David generally likes to wander around the sensory gardens pointing things out. Today he was excited about all the pears on the tree. Hundreds of pears he kept pointing and saying. The spinner was on in the herb garden and David gazed joyfully as he thought about walking through it - like part one leg in...

**NAME:** *أحمد محمد*  
**DATE:** *14/11/2023*

1. Circle when you visited the Garden:

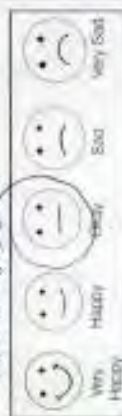


2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*Walking around and using the trampoline.*

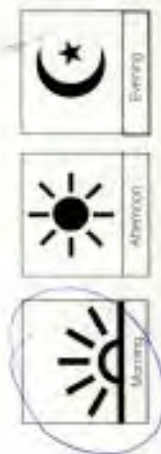
7. Things I dislike about the garden today:

*When too many people are outside*

NAME: .....

DATE: 2.6.14

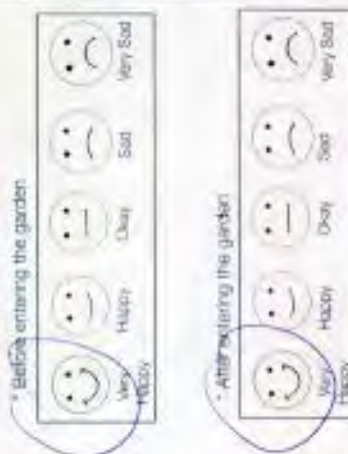
1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnery Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

going to come on a fence  
for a birthday  
party

7. Things I dislike about the garden today:



NAME: *27/4/14*

DATE: *27/4/14*

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnery Dazz
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Glass Room

7. Things I dislike about the garden today:

*Nothing*

8. Things I like about the garden today:

*Played football and walked around*

NAME: .....

DATE: 10/8/13

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

Edward made a visit to the  
Class Room breakfast stops for  
the disabled came to see  
Ed  
Return

7. Things I dislike about the garden today:

Blank box for writing dislikes.

NAME: .....  
 DATE: 28 JUNE '14

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinn/ Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*3BA at the back  
 garden - a lot of  
 food, I ate a lot today  
 )*

7. Things I dislike about the garden today:

**NAME:** .....  
**DATE:** 5 July 14

1. Circle when you visited the Garden:

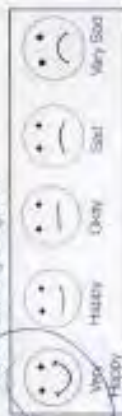


2. Circle today's weather:



3. Circle how you feel?

Before entering the garden



After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*Walking around the garden for about 10 minutes*

7. Things I dislike about the garden today:

**NAME:** ...  
**DATE:** 12-06-14

1. Circle when you visited the Garden:

 Morning	 Afternoon	 Evening
--	--	--

2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden

				
Very Happy	Happy	Okay	Sad	Very Sad

\* After entering the garden

				
Very Happy	Happy	Okay	Sad	Very Sad

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Taste
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

THE SUN SHINE AND THE SPACE

7. Things I dislike about the garden today:

**NAME:** .....  
**DATE:** 30.6.14

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

→ Before entering the garden



→ After enjoying the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Sperry Dec.
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

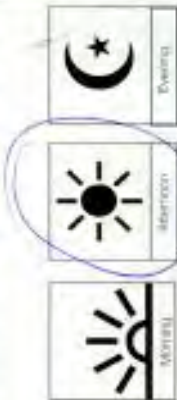
*Sitting on a bench  
for some time*

7. Things I dislike about the garden today:

(Empty box for writing dislikes)

NAME: .....  
 DATE: 6.8.14

1. Circle when you visited the Garden:

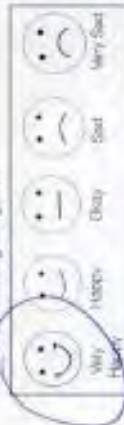


2. Circle today's weather:

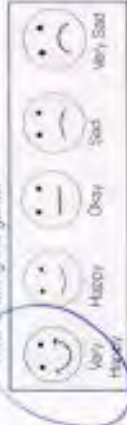


3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Physical Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Small (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

Relaxing in the chair  
 & walking

7. Things I dislike about the garden today:



**NAME:** .....  
**DATE:** 2.8.14

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today





5. Tick today's activities

- Private Garden
- Swing
- Spinning Disk
- Touch (Sensory Garden)
- Scent (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

7. Things I dislike about the garden today:

6. Things I like about the garden today:  
 sitting on a Papada  
 bench for 10-15  
 mins



NAME:   
 DATE: 

1. Circle when you visited the Garden:

		
Morning	Afternoon	Evening

2. Circle today's weather:


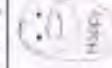
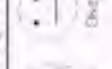
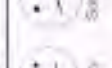
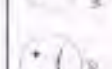


3. Circle how you feel?

\* Before entering the garden

				
Very Happy	Happy	Neutral	Sad	Very Sad

\* After entering the garden:

				
Very Happy	Happy	Neutral	Sad	Very Sad

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnny Disc
- Tower (Sensory Garden)
- Slide (Sensory Garden)
- Earth (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Glass Room

6. Things I like about the garden today:

*Jackie visited the cave slides, walked along the path -*

7. Things I dislike about the garden today:

*Things have been open -  
 Nothing  
 See Sensory garden*

NAME: .....

DATE: 19. Apr. 14

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Sperry Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

going to the garden  
several times - for  
short periods + sitting  
on a garden chair

7. Things I dislike about the garden today:

**NAME:** ...  
**DATE:** 24/3/14

1. Circle when you visited the Garden:

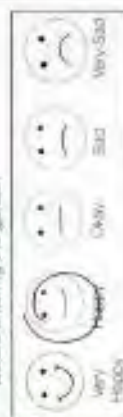


2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

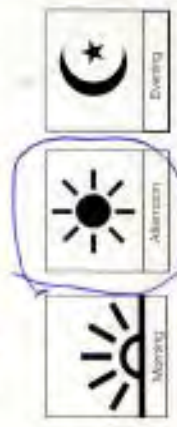
THE WALK ALONGS TO THE  
 CLASS ROOM/PART SHED.  
 QUIETNESS

7. Things I dislike about the garden today:

NOTHING

**NAME:** .....  
**DATE:** 4-8-14 .....

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnery Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline | Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Glass Room
- Other

6. Things I like about the garden today:

the lovely weather.

7. Things I dislike about the garden today:

Nothing.

NAME: .....

DATE: 3-2-14

1. Circle when you visited the Garden:

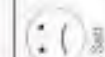


2. Circle today's weather:

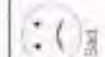
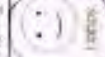


3. Circle how you feel?

Before entering the garden



After entering the garden



5. Tick today's activities

- Private Garden
- Swing
- Spooky Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room
- Other

4. Draw on the map below where you walked in the garden today



6. Things I like about the garden today:

Enjoyed going on the trampoline

7. Things I dislike about the garden today:

Nothing



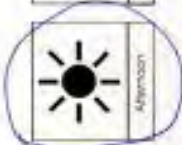
NAME: .....

DATE: 03.07.14

1. Circle when you visited the Garden:



Morning



Afternoon



Evening

2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



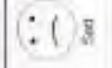
Very Happy



Happy



Okay



Sad



Very Sad

\* After entering the garden



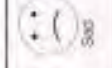
Very Happy



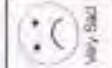
Happy



Okay



Sad



Very Sad

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinnery Disk
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Cases Room
- Other

6. Things I like about the garden today:

Just relaxing out in the garden and being cozy

7. Things I dislike about the garden today:

Nothing

NAME: *Miss P. ...*

DATE: *21.07.2014*

1. Circle when you visited the Garden:

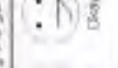
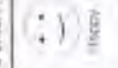


2. Circle today's weather:

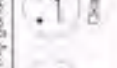
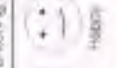


3. Circle how you feel?

*Before entering the garden*



*After entering the garden*



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spiny Class
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Frisbee
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room
- Other

6. Things I like about the garden today:

*drawing Victorian furniture*

7. Things I dislike about the garden today:

**NAME:** *Tea*  
**DATE:** *11.2.14*

1. Circle when you visited the Garden:




 Morning	 Afternoon	 Evening
---	---	---

2. Circle today's weather:








3. Circle how you feel?

*Before entering the garden*

 Very Happy	 Happy	 Okay	 Sad	 Very Sad
--	---	--	---	--

*After entering the garden*

 Very Happy	 Happy	 Okay	 Sad	 Very Sad
--	---	--	---	--

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Scrimmy Disc
- Touch (Sensory Garden)
- Small (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Canteen Room
- Other

6. Things I like about the garden today:

*Enjoyed making her art work.*

7. Things I dislike about the garden today:

*Can't handle it being so cold*



**NAME:** .....

**DATE:** 21.3.14

1. Circle when you visited the Garden:



 Morning	 Afternoon	 Evening
---	---	---

2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden

 Very Happy	 Happy	 Okay	 Sad	 Very Sad
--	---	--	---	--

\* After entering the garden

 Very Happy	 Happy	 Okay	 Sad	 Very Sad
--	---	--	---	--

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room
- Other

7. Things I dislike about the garden today:

going into the art room to do some writing



NAME: .....

DATE: 4-2-14

1. Circle when you visited the Garden:


<input checked="" type="radio"/>  Morning	<input checked="" type="radio"/>  Afternoon	<input type="radio"/>  Evening
--	--	---

2. Circle today's weather:

<input checked="" type="radio"/> 	<input type="radio"/> 	<input type="radio"/> 
--	---	---

3. Circle how you feel?

\* Before entering the garden

<input checked="" type="radio"/>  Very happy	<input type="radio"/>  Happy	<input type="radio"/>  Okay	<input type="radio"/>  Sad	<input type="radio"/>  Very Sad
---	---	--	---	--

\* After entering the garden

<input checked="" type="radio"/>  Very happy	<input type="radio"/>  Happy	<input type="radio"/>  Okay	<input type="radio"/>  Sad	<input type="radio"/>  Very Sad
---	---	--	---	--

4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spinning Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room
- Other

6. Things I like about the garden today:

walking the dog around the garden

7. Things I dislike about the garden today:

Nothing

NAME: *.....*

DATE: *31/10/2014*

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Slippy Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*Using the Swing and Trampoline. also Smelling Sensory Garden.*

7. Things I dislike about the garden today:

*Not applicable.*

**NAME:** .....  
**DATE:** 13/07/14

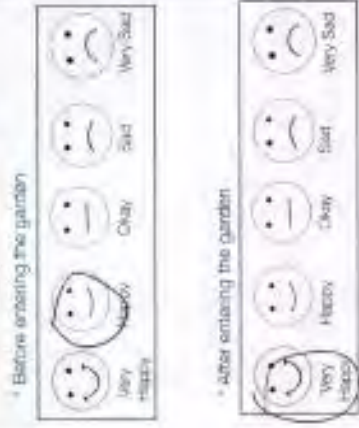
1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Spooky Daze
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

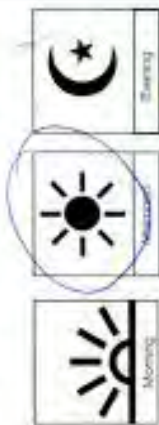
- playing football  
 - playing Jenga blocks.

7. Things I dislike about the garden today:

- no mp3

**NAME:** .....  
**DATE:** 4/5/14

1. Circle when you visited the Garden:

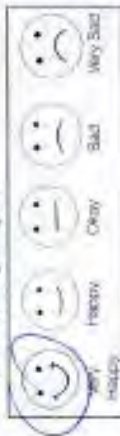


2. Circle today's weather:



3. Circle how you feel?

\* Before entering the garden



\* After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick todays activities

- Private Garden
- Swing
- Spinnly Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Class Room

6. Things I like about the garden today:

*Having a cup of coffee  
 after lunch and  
 a relax*

7. Things I dislike about the garden today:

NAME: 6  
 DATE: 13.11.13

1. Circle when you visited the Garden:



2. Circle today's weather:



3. Circle how you feel?

<sup>1</sup> Before entering the garden



<sup>2</sup> After entering the garden



4. Draw on the map below where you walked in the garden today



5. Tick today's activities

- Private Garden
- Swing
- Sensory Disc
- Touch (Sensory Garden)
- Smell (Sensory Garden)
- Sight (Sensory Garden)
- Trampoline
- Sound (Sensory Garden)
- Vegetable Garden
- Clean Room

7. Things I dislike about the garden today:

6. Things I like about the garden today:

Eel was sitting in the Sensory room with a view of the garden, with the sun shining in (sensory experience)  
 PA praise.





# Appendix 27

**Appendix 27:** A selection of observations made by the designer and the support staff of the autistic participant's interactions with their environment





Likes to ping the door stop with his foot



Likes to watch the eggs move around the pan. likes listening to the eggs bump against the pan.



Dislikes the sound of dogs barking



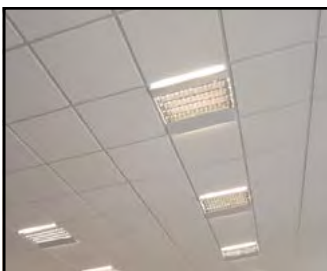
Likes hearing the ding noise. Likes watching the food go around.



Like the sound of a ticking clock



Likes the noise frosties make when they fall.



Likes to know how many lights there are in the ceiling. Gets dizzy with ceiling tiles



Likes the sound of the desk top fans



Dislikes the sound of hand-dryers in public toilets



Likes the sound of cutlery chiming together. Dislikes it when the cutlery gets mixed



Likes looking at the computer screen saver



Dislikes shiny and wet surfaces



Likes stirring porridge and watching it bubble



Likes to press the steam button on the iron



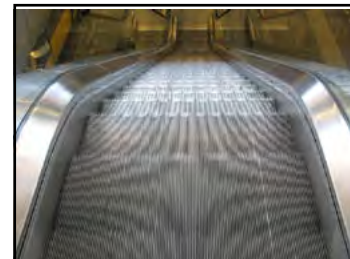
Likes turning light switches on and off  
Dislikes other people using light switches



Likes to flush objects down the toilet



Likes the sound of extractor fans



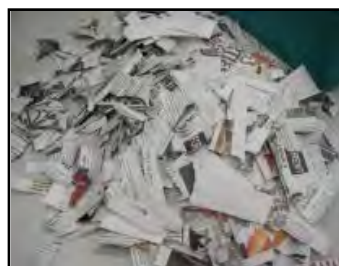
Difficult to differentiate between the steps on an escalator



Likes and dislikes the sound of the vacuum cleaner.  
 Likes watching the lead being wound  
 Likes turning it on and off



Rips down curtains



Rips paper  
 Rips paper and makes into balls



Liks fiddling with keys



Likes listening to it boil and the sound of the switch



The paper clip brings comfort and support



Likes bubbles



Likes flicking the pages in an Argos catalogue



Likes the sound of drills



Dislikes the sound of the lawnmower



Likes watching the washing machine spin  
Likes listening to the last spin  
Watching the water fill and clothes tumble



Likes the feel and smell of plastic bags



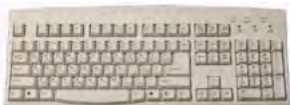
Dislikes wearing shoes



Likes twisting the knobs on a radio.  
likes switching through radio stations.  
dislikes interruptions of news and adverts



Dislikes the sound of rain



Likes to press the keys on a computer keyboard



Likes listening to the fish tank



Likes pressing the buttons on a remote control



Disliked it when the television programme Easteners changed the pitch of the theme tune



Likes ripping fabric including clothes



Dislikes wearing socks



Dislikes phone chargers and will break



Dislikes the sound of a projector



Likes moving the door handle up and down



Enjoys watching and listening to the white noise



likes to put things in the bin and watch it disappear



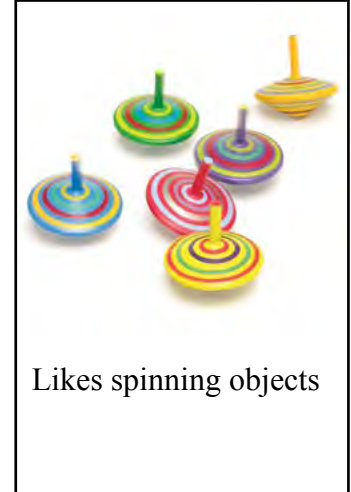
likes to throw objects out of the window



Likes sweeping the floor and the sound the broom makes



Likes to talk to the fridge and personalise inanimate objects



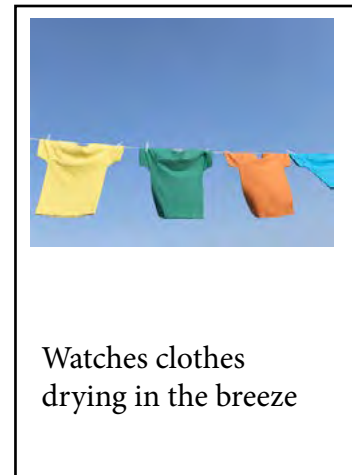
Likes spinning objects



Dislikes it when doors are closed



rubbing furniture



Watches clothes drying in the breeze





# Appendix 28

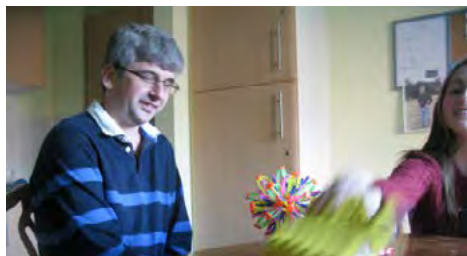
## Appendix 28: Three diary accounts of the designer's visits to three autistic adults

7th November 2013

I spent the day with Peter at Beeching Way. I had only met Peter once before so in preparation for the visit I looked at his Interests and Hobbies booklet, from last years project. The booklet revealed that Peter has lots of interests which includes; listening to the radio, going to church, bowling, swimming, walking, rolling small objects with his fingers, sounds, smells, playing the guitar, boat trips and chatting to people. Therefore prompted by the booklets I brought along a selection of objects, which included an eye spy book about boats, small objects to roll with his fingers and a game called 'win to spin' to encourage a group activity.

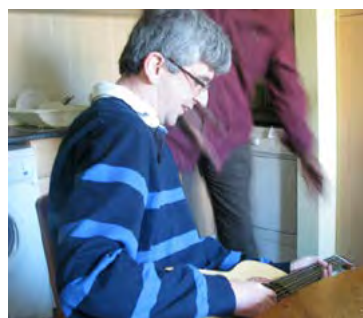
Peter was very welcoming. Throughout the course of the morning the aim was to get to know Peter and to make sure he felt relaxed and comfortable in our presence. The props and activities we brought along were a way of helping us to connect, communicate and create a shared interest with Peter. So one by one we introduced a new a prop/activity. We had been informed that Peter's concentration is very limited but he did really well to engage in the activities even if it were for a few moments. He seemed to particularly enjoy music and was very keen to show us his radio, which gives him a lot of enjoyment and something that he has great amounts of focus and attention for. He will spend up to half an hour at a time listening to his radio and tuning into different radio stations.

Whilst I was there, Peter found it difficult to sit down and would move around quite a lot. He enjoyed looking out of his window which is near the front entrance of the building, and watching the cars and people coming and going outside. Peter was particularly interested in asking where certain people were, referring to their names, some of which were support staff who had left years ago. He has a great memory for names and people.



Interacting with sensory props

Peter's support worker always carries a toy car in his pocket. Many of the people he supports likes spinning the wheels and this is his way to connect with them.



Peter enjoys playing the guitar



Peter looks briefly at the Eye Spy booklets

Along with listening to his radio, at home Peter also likes to watch Eastenders, Tom & Jerry and enjoys the feel of running water. It was also very apparent that Peter is very socialable and enjoys being out and about. For lunch we walked together to a local pub, where Peter ordered his own sausage and chips. It was nice to be outside with Peter as there were lots of things to point out and talk about.



Walking to the pub for lunch and enjoying sausage and chips

After lunch the aim was to gain some insights into what (if any) everyday activities Peter likes to do around his flat. To help us with this we used an Argos catalogue as a prompt to encourage Peter to point or gesture whether he likes certain activities i.e. on the Vacuum Cleaner page we talked about hoovering at home. We also laid out a table cloth with everyday objects printed onto it, to encourage Peter to point to the different things he might like to do. Lastly we showed him the Objects of Everyday Use booklet. Though Peter is very sociable it was very difficult for him to concentrate on the tasks above, so John who supports him filled out the booklet on his behalf.

## Insights

Whilst being with Peter it appeared that he had difficulty with tasks that require fine motor skills and dexterity such as unscrewing the cap of a juice bottle, peeling a banana, chopping his food and undoing a ketchup packet. Apart from pouring himself a glass of water he he relies on the person who is supporting him to complete the task for him.

John explained that Peter's participation in everyday activities around the home is very limited and he will always ask or gesture for the person who is supporting him to do the task for him. However, John mentioned that Peter will spend 3-4 minutes vacuum cleaning, pushing the trolley in the supermarket and will help to take a shopping bag from the car to his flat. John felt the reason why Peter takes a little bit of interest in hoovering is because it is not so hard for him as it does not require alot of thinking.

8th November 2013

I spent the morning with Zac, I had met Zac before so already knew the sorts of things he likes and brought along a bag of shiny colourful props for him to touch and interact with. Zac was very welcoming and made me a lovely cup of coffee. He also made Helen (his support worker) a cup of coffee and knew exactly how she liked it. Zac is very sensory, therefore it was not much of a surprise to see his flat decorated with lots of pictures, colours, textures, bubble pots and a revolving disco lamp, which projected colours onto the walls. I offered a selection of props and Zac gravitated towards ping-pong. He seemed to enjoy flicking the springs and held it firmly in his hand whilst he watched 80's music on the television.



Helen has been supporting Zac for a number of years and it was interesting to observe how they communicated. As I do not know Zac very well I found it difficult to understand what Zac was saying, but Helen knew what every word, sound and gesture meant. Helen has clearly learnt to understand Zac's way of communicating and to help other staff members understand, she has compiled Zac's vocabulary onto a sheet of paper, with the meanings and suggestions of how to respond to each word or sentence.

“There is a way of communicating you've got to repeat a lot you've got to have patience as you may have to repeat something 50 times a day, but you make it fun at the same time and every now and then he says something different.” Support worker

Helen explained that Zac's vocabulary may seem limited, but time and time again he surprises her with another word and understanding for something;

“His vocabulary is a lot wider than what we first thought. From him communicating to me about splinters with the wooden fence – he came out the back with me and said ‘wooden fence- splinter – I didn’t know that he knew what a splinter was or a wooden fence“ Support worker

The majority of the conversation between Helen and Zac was based around what is going to happen next in the day or even events happening in the future. For example what he is going to eat for lunch, the concert he is going to in the afternoon and when will he decorate his flat for Christmas. To help Zac understand what’s going to happen in the days and weeks ahead the support staff have created a visual weekly timetable and also a count down of important events leading up to Christmas.

Day	Morning	Afternoon	Evening
Monday	Bath Brush teeth/Mouth Wash Prepare Breakfast Laundry Mop Floor Bank Dawn Washing up	Shave/ Apply Deodorant ✓ Put away washing Prepare tea Set table Clear table Washing up Music or TV Milk	Fix & Brush teeth Put away washing Prepare tea Set table Clear table Washing up Phone family TV or Music Fix & Brush teeth
Tuesday	Bath Brush teeth/Mouth Wash Prepare Breakfast Laundry Mop Floor Washing up Spare parts	Shave/ Apply Deodorant ✓ \$1.00pm - 12.00pm Chum Section	Bowling Prepare tea Set table Clear table Washing up Music or TV Put away washing Fix & Brush teeth
Wednesday	Bath Brush teeth/Mouth Wash Prepare Breakfast Gardening (1.30 - 2.00) Laundry Mop Floor Phone Mop	Shave/ Apply Deodorant ✓	Bowling Prepare tea Set table Clear table Washing up Music or TV Put away washing Fix & Brush teeth
Thursday	Bath Brush teeth/Mouth Wash Prepare Breakfast Laundry Sole shopping	Shave/ Apply Deodorant ✓	Put away washing Prepare tea Set table Clear table Washing up Music or TV Fix & Brush teeth

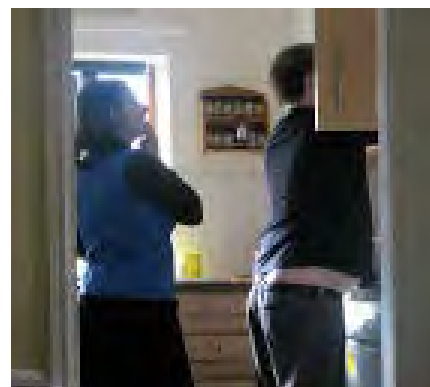
“Staff use charts so that we can monitor the progress of that person of whether they are taking the cup out of the cupboard or if you’re taking it out of the cupboard whether you are putting the weetabix into the box or the person your supporting puts the weetabix into the box, or do you put the milk on the side to instigate that person lifting the milk. You have little charts for independence.” Support worker

An active support chart to record weekly activities at home

Whilst I was there Zac made his own sausage sandwich. Interestingly Helen is trying to introduce Zac to porridge and realised that this will be a gradual process. For the first stage of the process Helen has placed the packet of porridge oats out on display in the Kitchen, for Zac to get used to how it looks and feels, in preparation for the next stage which will be the opening of the packet of oats.



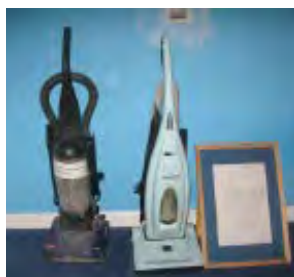
Zac seemed to enjoy chatting with Helen and there seemed to be a great connection and understanding between them. Helen mentioned that Zac has come along way since he moved to Beeching way, the skills he has learnt are amazing and he is now a lot more independent.



Zac preparing his lunch

15th November, 2013

Nicky Skuce kindly invited me into her home in Didcot Parkway. As Niky does not like the sound of a running car engine, upon our visit we made sure that the taxi driver did not stop directly outside her house. Nicky's dislike for the sound of car engines means that her support staff have to be mindful of when Nicky leaves her home, to avoid traffic jams and school closing. Nicky was very welcoming and when we arrived her support staff made us a lovely cup of tea.



Nicky has a huge interest in Thomas the Tank Engine and the reason she lives in Didcot is because that is where Thomas is from. As Thomas is blue, blue is Nicky's favourite colour. The external and internal walls in her house are painted blue and much of the furniture, lighting and objects, from her collection of hoovers to her washing equipment. Nicky's home is also decorated and accessorized with lots of images of Thomas the Tank Engine including DVD's, drawings, posters, cushions and fridge magnets.



Nicky also has an interest for technology/equipment. She has a collection of camcorders, hoovers, fans, enjoys working on her computer and also likes to draw the equipment. Nicky loves the pitch 'C minor' and has a collection of fans (The Vent-Axia T series) which produce this sound, so much so that she enjoys filming the fans in action and uploading them onto Youtube. During our visit Nicky was really keen to use my camera (and also purchase one on ebay!) and gave us a guided tour of her house whilst filming it through my camera.

Towards the end of the day we ate cake together and whilst we were enjoying the cake, Nicky rushed over to her washing machine to listen to the last cycle, as this is something she loves the sound of too.



# Appendix 29

## Appendix 29: The Lawton Instrumental Activities of Daily Living (IADL) Scale (Lawton and Brody, 1969)

The Lawton Instrumental Activities of Daily Living Scale	
<b>A. Ability to Use Telephone</b>	<b>E. Laundry</b>
1. Operates telephone on own initiative; looks up and dials numbers..... 1	1. Does personal laundry completely ..... 1
2. Dials a few well-known numbers..... 1	2. Launders small items, rinses socks, stockings, etc..... 1
3. Answers telephone, but does not dial..... 1	3. All laundry must be done by others ..... 0
4. Does not use telephone at all..... 0	
<b>B. Shopping</b>	<b>F. Mode of Transportation</b>
1. Takes care of all shopping needs independently ..... 1	1. Travels independently on public transportation or drives own car..... 1
2. Shops independently for small purchases..... 0	2. Arranges own travel via taxi, but does not otherwise use public transportation ..... 1
3. Needs to be accompanied on any shopping trip ..... 0	3. Travels on public transportation when assisted or accompanied by another ..... 1
4. Completely unable to shop ..... 0	4. Travel limited to taxi or automobile with assistance of another ..... 0
	5. Does not travel at all ..... 0
<b>C. Food Preparation</b>	<b>G. Responsibility for Own Medications</b>
1. Plans, prepares, and serves adequate meals independently ..... 1	1. Is responsible for taking medication in correct dosages at correct time..... 1
2. Prepares adequate meals if supplied with ingredients ..... 0	2. Takes responsibility if medication is prepared in advance in separate dosages ..... 0
3. Heats and serves prepared meals or prepares meals but does not maintain adequate diet..... 0	3. Is not capable of dispensing own medication ..... 0
4. Needs to have meals prepared and served..... 0	
<b>D. Housekeeping</b>	<b>H. Ability to Handle Finances</b>
1. Maintains house alone with occasion assistance (heavy work) ..... 1	1. Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income..... 1
2. Performs light daily tasks such as dishwashing, bed making..... 1	2. Manages day-to-day purchases, but needs help with banking, major purchases, etc ..... 1
3. Performs light daily tasks, but cannot maintain acceptable level of cleanliness ..... 1	3. Incapable of handling money ..... 0
4. Needs help with all home maintenance tasks ..... 1	
5. Does not participate in any housekeeping tasks ..... 0	
<hr/> <b>Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).</b> <hr/>	






# Appendix 30

## Appendix 30: A selection of completed Objects of Everyday Use cards

**Vacuuming**



1. Do you vacuum the floor at home?  
YES  SOMETIMES  NO


2. Do you need support?  
YES  SOMETIMES  NO

3. Describe below what part of this activity you like/dislike?

I like heavy because  
is blue and I  
like how it works

**THE VACUUM CLEANER...**  
In 1859 John Thurman invented a gasoline-powered vacuum cleaner which some historians consider the first motorized vacuum cleaner

**Mowing the lawn**



1. Do you mow the lawn in your garden?  
YES  SOMETIMES  NO

2. Do you need support?  
YES  SOMETIMES  NO

3. Describe below what part of this activity you like/dislike?

I don't like the mower  
engine left running

**THE LAWN MOWER...**  
The lawn mower was invented by Edwin Budding in 1827

## Preparing a cereal



**THE CEREAL BOX...**  
Henry Perky was a pioneer of the "cookless breakfast food" and it was he who first mass produced and rationally distributed ready-to-eat cereal.

## Preparing a cereal

1. What is your favourite cereal?

Sugar Frosties

2. Do you prepare your own bowl of cereal?

YES  SOMETIMES  NO

3. Do you need support?

YES  SOMETIMES  NO

4. Describe below what part of this activity you like/dislike?

\* I do need prompting but like to pour into the bowl because I like the noise the frosties make when they fall in.

## Washing up in the kitchen sink



**THE KITCHEN SINK...**  
Austin Richmond has been credited with the invention of the sink. It's been said that he was only 10 years old when he came up with the idea!

## Washing up in the kitchen sink

1. Do you do the washing up at home?

YES  SOMETIMES  NO

2. Do you need support?

YES  SOMETIMES  NO

3. Describe below what part of this activity you like/dislike?

Love the bubbles and blowing them in the air - !!  
Nothing to dislike  
favourite hobby every day.

## Ironing clothes



**THE IRON...**  
The electric iron was invented by Henry W. Seeley in 1882. His iron weighed almost 15 pounds and took a long time to warm up!

## Ironing clothes

1. Do you iron your clothes?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

\* Like putting on the board and pressing the steam button.

\* Dislike Straightening onto the board again fiddling to complete.

## Washing clothes



**THE WASHING MACHINE...**  
In 2001 Electrolux introduced Washy Talky, the washing machine that speaks to you! Including words such as "drop the detergent, close the lid and relax"

## Washing clothes

1. Do you use the washing machine at home?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

All of it love washing putting in the machine hearing the machine watching it going round - - -



Please list or draw below any other everyday activities, you like to do at home.

I like  
writing  
and  
doing  
craft  
a lot and



~~was~~ I a bit of an artist

23



Please list or draw below any other everyday activities, you like to do at home.



## Washing a car



**THE CAR...**  
A steam powered vehicle was  
invented by Nicolas-Joseph Cugnot  
in 1769

## Washing a car

1. What is your favourite car?

COROLLA 1.8 car

2. Do you wash your car?

YES  SOMETIMES  NO

3. Do you need support?

YES  SOMETIMES  NO

4. Describe below what part of this activity you like/dislike?

I don't like water  
running

## Potting plants



**THE WHEELBARROW...**  
The wheelbarrow was invented by Chuko Liang (181-234 A.D.). Liang was a general who used wheelbarrows to transport supplies and injured soldiers.

## Potting plants

1. Do you pot your own plants?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

I have potted plants in my garden but I am not keen on getting my hands dirty so would rather watch someone else do it.

## Toasting bread



**THE TOASTER...**  
The first electric toaster was invented in 1893 in Great Britain by Crompton and Co (UK).

## Toasting bread

1. Do you toast your own bread?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

Likes: Putting on the bread in the toaster. Switching it on. Smell & feel the heat during toasting. Putting on butter. Seeing it spreading on the toast.

Dislikes: Bread breaking on putting or taking out of toaster. Toaster playing up.

## Taking out the rubbish



**RECYCLING...**  
The universal symbol for recycling was designed by Gary Anderson in the late 1960s.

## Taking out the rubbish

1. Do you take out the rubbish in your home?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

**Like:** To take the rubbish out to the collecting bin - feel responsible. Also putting in the plastic bag in the bin - to feel and like the smell of the plastic.

**Dislike:** Messy bin, picking up or cleaning up if any rubbish falls on the floor

## Cleaning the bath



**THE BATHTUB...**  
In the late 1800s John Kohler developed an enameled iron watering trough for animals. He attached his trough to four cast-iron feet and began selling it as a bathtub for the house in 1883.

## Cleaning the bath

1. Do you clean your bathtub?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

**Like** to watch the soapy water bubbles draining away and to dry up the tub.

**Dislike** wet surfaces - so dry up using towel and putting away in the washing basket for laundry

## Vacuuming



**THE VACUUM CLEANER...**  
In 1899 John Thurman invented a gasoline-powered vacuum cleaner which some historians consider the first motorized vacuum cleaner

## Vacuuming

1. Do you vacuum the floor at home?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

I LIKE TO TURN THE VACUUM CLEANER ON AND OFF

## Boiling an egg



**THE EGG CARTON...**  
The egg carton was invented in 1911 by Joseph Coyle to solve a dispute between a local farmer and hotel owner in Telkwa, British Columbia over the farmer's eggs often being delivered broken

## Boiling an egg

1. Can you boil an egg?  
YES  SOMETIMES  NO
2. Do you need support?  
YES  SOMETIMES  NO
3. Describe below what part of this activity you like/dislike?

LISTENING TO THE EGGS BUMPING AGAINST THE PAN WHEN BOILING





# Appendix 31

## Appendix 31: A compilation of feedback from the completed Object of Everyday Use cards



Cup, tea, milk, sugar, teabag – I am thirsty  
Tea  
Hot chocolate – I like mixing it up  
Coffee – putting the milk in  
Cup of tea – Like boiling the kettle pouring the water adding lots of sugar and milk  
Dislike –tidying up  
Tea  
Tea- I like taking the tea bag out  
Coffee/cappuccino  
I like my hot drinks and can prepare them myself with a little reminder of how much coffee to use now and again  
Soup  
Like: putting on the kettle hear the boiling of the water and the cling off of the switch. On pouring enjoy the smell of the soup flavour  
Dislikes: Cleaning up when it over fills  
Pouring milk



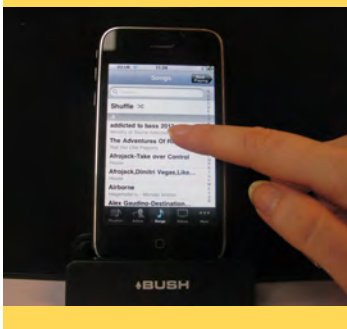
Smells burning  
Like hearing the toaster click  
Spreading butter  
Putting the toast in the toaster and hearing it pop up then putting my ham on it  
I like popping it up and down to see if it's cooked enough for me. I dislike this because it takes too long  
I like it when the toast pops up  
I like the smell of fresh toast  
I can make my own toast and sometimes need reminding not too much jam  
Likes: Putting on the bread in the toaster. Switching it on. Smell and feel the heat during toasting. Putting on the butter and seeing it spreading on the toast  
Dislikes: Bread breaking on ..... or taking out of toaster. Toaster playing up

### Using a computer



Play games and make video  
I like Argos, EBay, YouTube, Facebook – shopping  
Don't use one  
Finding a song I ask support staff to type in, I try sometimes but lose interest very quickly  
– I like writing letters and looking at old photos of myself  
I like the computer screen  
I look up cars on the computer  
I like to use my computer to look up cars. I used to do a computer course. I can copy and paste pic with little help  
I like the IPAD and listen to music or watching different colours and designs  
Like: Listening to my downloads and watching different colours and designs  
Dislikes: Not knowing how to access the artist or song I want

### Using an i-pod



Don't have one  
You tube – same as computer looking for songs  
don't like when it buffers  
I listen to an I-pod – I like this because I can listen to my own music

### Ironing clothes



Too hot  
Rather someone else did it  
Putting ironed clothes into cupboard  
Likes putting on the boards and pressing the steam button  
Dislikes – straightening onto the board again-fiddly to complete  
I do not iron clothes

### Using a dishwasher



I don't have one  
Don't use one  
Do not have a dishwasher

### Mowing the lawn



I don't like the lawn mower engine left running  
I like to talk about mowing the lawn with my dad, as it is something I have done and reminds me of my family  
Like the noise  
I like the noise the mower makes  
I like watching the lawn being mowed  
I can mow the lawn but can get bored after a couple of pushes  
Like: to smell the grass and the noise of the mower also pushing it forward on cutting  
Dislike: to be asked to follow rows on cutting just likes to push it

### Feeding animals



I don't like it  
I like feeding animals at the Zoo  
Measuring food for feeding fish  
Don't like animals especially dogs  
I like to go to my parent's house when they are on holiday and feed the wild birds for them

### Changing a light bulb



Likes: energy saving light bulb  
Dislikes: normal light bulb  
It's fun  
I do not change light bulbs; health and safety dos not allow me to do it

### Following a food recipe



Chocolate cake  
Enjoy measuring things out  
Mixing  
Likes bringing recipe book  
I like making different things  
I dislike it as I find it hard  
If I am told what to do step by step and I want to cook

### Using the telephone



I have my own mobile phone. I like to call everyone  
Does not have a mobile he likes speaking on the phone  
I talk about calling mum and dad or friends or family  
staff support me fully and when  
I talk to people on the phone, I tend to wonder off and  
talk away from the phone  
Like speaking to friends on the phone  
I do not have a mobile I like talking  
Picking up the phone and talking  
I like talking to my family but staff have to dial for me,  
as it is too fiddly  
I have my own mobile phone. I like this because I can  
ring dad and jean

### Using a microwave



Macaroni cheese  
I like hearing the ding noise  
Putting sausages in and watching them going round and  
the bell ping when finished  
I like opening & shutting to see if my food is cooked  
I like the ding at the end  
I heat up things on the microwave, I ask how many  
minutes  
I do not use a microwave because of my risk assessment

### Baking a cake



I like the fact that I am making something nice to eat  
Mixing, cooking, measuring, icing, butter  
My favourite cake is sticky things, and I like these as I  
have made them with staff for many years  
I like the mixing  
I like mixing the ingredients  
I like to do the crumble, Lick the bowl but dislike to eat  
the end product sometimes  
I like decorating  
Eating cake and watching it being prepared  
Listening to the eggs bumping against the pan when  
boiling  
I like the fact that I am making something nice to eat  
I did do a cooking course in 2008-9 I did bake a cake and  
enjoyed it with help  
Likes mixing up flour and making biscuit shapes and  
putting icing on top of cake. Watch the browning of cake  
or biscuits and likes the smell of baking

### Washing fruit and vegetables



I don't like tap running  
Washing vegetables – likes carrots with water in basin  
I like the end result of eating it  
I find it boring

### Preparing a cereal



Rice crispies– I like milk and sugar in my bowl  
I like all cereals. I like to talk about food all the time, I may say a cereal I like but when it comes to choosing I tend to grab the first one closest to me. I find it hard doing things by myself and get anxious when I feel I am being pushed.

Weetabix, I like putting the milk on

Muesli- likes setting up table/ putting bowl near the preparation area/pouring milk into the bowl

Frosties – I do need prompting but like to pour into the bowl because I like the noise the

Frosties make when they fall

Sugar puffs – I like choosing what I have for breakfast

Porridge – I like stirring the porridge and watching it bubble

Weetabix – I like choosing which cereal I want

Bran flakes like eating it

### Pruning weeds



Stings

Don't really enjoy this

I do not like it

Likes to put prunes into the bin

I used lawn mower with the help of my SW to mow and weed the back garden

### Setting and clearing a table



I like parties

I can take my dirty dishes to the sink, when I have finished eating. I need to be encouraged to get out cutlery or plates/bowels etc.... I may refuse to do this as I don't like being made to do things I find hard work.

Means that I am going to eat

I like all parts of it except cleaning

I need prompting and enjoy eating my food soon

I don't use my dining table for eating at but I'm quite happy to get my cutlery and drink sorted ready for dinner

Like: to set up my fork and knife and feel proud of doing it

Dislikes: food on the floor or on clothes cleaning up

Like to help

### Sweeping the floor



I am not sweeping my floor

Like making it clean

I like helping keep my flat tidy

I like the sound

I will sweep my floor when it looks messy

When sweeping the floor I like to direct what to do and where to sweep

### Boiling an egg



Saucepan  
Watching the bubbles  
Eating it  
I like the way the egg moves around  
I put the egg in water and watch it boil  
I am not keen on taking off the shell but will do

### Folding clothes and putting them away



Wet clothes  
Don't like doing it  
Putting clothes away  
I like folding my jeans  
I dislike it, as it takes too long  
I wash and hang my wet clothes on the clothes horse/tumble dryer. Once they are dry I put them away where they belong  
Likes: hanging the clothes in the wardrobe and putting other items e.g. socks in designated drawers  
Dislikes: Folding clothes- challenging to me

### Hanging washing out to dry



I don't like the cold weather I like the warm weather  
As long as not too much  
To use pegs  
Likes carrying laundry basket  
Likes to see clothes all washed and clean and smell nice  
Dislikes putting the pegs in as it's a fiddly task  
I like to see my clothes lining up nicely  
I like pegging the clothes up. I like how the wind blows the clothes  
I like to watch the clothes drying in the breeze  
I hang my washing out on the line in my garden  
Like: to put the pegs on, touch and smell the clothes when I pass by

### Potting plants



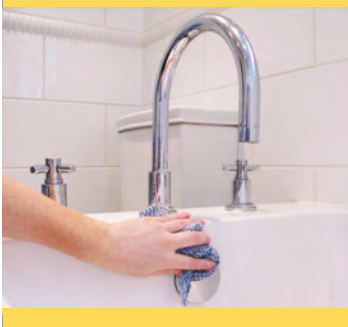
I don't like rainy day  
I attend the gardening project with other PWS my friends and I have been encouraged  
To pot plants with support staff and have enjoyed this. I find it hard to do things on my own and may withdraw from the activity  
Enjoy gardening  
I love the whole process  
Likes watering plants  
I like putting mud on top of seeds and watching them grow  
I have potted plants in my garden but I am not keen on getting my hands dirty so would rather watch someone else do it  
Have no pot plants

### Vacuuming



I like Henry because is blue and I like putting on low speed  
I find this task difficult to do and tend to let staff do it, if prompted, I will try but  
Only for a few seconds  
I like noise  
Connecting Hoover to the main/ actual hovering/putting away the Hoover  
Not really like but will do it encouraged and I can do a good job  
I dislike this because I don't like doing housework  
I like the noise  
I like to turn the vacuum cleaner on and off  
When very dirty or with prompting, I like to have a clean house

### Cleaning the bath



Hard work  
can rinse the bath with the showerhead with support  
Spraying the bath  
Cleaning the bath is a chore but I am pleased with myself when I have done it  
I like to watch the soapy water bubbles draining away and to dry up the tub. Dislike wet surfaces – so dry up using a towel and putting away in the washing basket to do laundry

### Washing clothes



Like to put my washing machine on  
Putting the clothes in the machine  
I can take my dirty cloths to the washing machine and load it and turn it on with staff  
and have done this task for many years  
I like watching it spin around  
Put clothes in  
Putting clothes into the washing machine/ taking clothes out, airing clothes outside/  
I need help with washing detergent and soap  
I like all of it – putting washing into the machine and hearing the machine and watching it  
Going round  
I like this because it cleans my jeans. I dislike this because it takes time  
I like watching clothes spin around and the noise it makes  
I know how to use my washing machine  
Like: Loading the clothes, switching machine and see the filling in of water and tumbling washing  
Dislikes: Finding a load is in the wash when I want to load mine or when the machine plays up

### Polishing and cleaning surfaces



I like vacuum cleaning, sometimes I do polishing  
Don't really enjoy cleaning  
Cleaning the table  
Likes spraying anti-bacteria on kitchen surfaces  
I like to keep my flat tidy  
I like the spraying  
I like to sit and watch the cleaning being done  
I will dust off my cars occasionally if prompted. I am pleased I done it in the end

### Preparing a cold drink



Diet coke and apple juice- I am thirsty  
I like orange squash or juice  
Squash, I help to get squash out and put in cup and fill with water. I tend to grab the first bottle closest can get anxious if being pushed or do not feel like doing the latter  
Coke- like seeing the bubbles  
Orange squash – mixing  
Ginger beer-Likes pouring ginger beer into a glass  
Coca Cola – I associate cola with fun times. Parties etc. fizziness makes me chuckle when it goes near my nose!  
Orange juice- I like being able to make my drink as strong/weak  
Peach Juice. I like putting the water into the cup  
I love coke and pouring my own drinks when I want to  
I only drink cold drinks and prefer beer  
Orange squash/juice  
Like: topping up with water i.e. diluting and filling up water from tap  
Dislike: To clean up and dry surface when it spills over

### Putting dishes and cutlery away



Dishes and cutlery  
Hard work  
Arranging the cutlery  
Likes putting plates away but dislikes putting cutlery away – too fiddly  
I like this because it makes me independent  
I like the noise  
I put all my dishes away after washing, I like my house to look clean  
Like: to put cutlery in the tray and hear the clinging sound of forks and knives. Also like to dry up the utensils

### Using a television



Police programme  
Eastenders, I like music  
He likes BBC1 Eastenders, he likes watching TV and doesn't like it if its been moved  
I like soaps. I sometimes watch soaps on my TV, but cannot operate it on my own  
and my attention is easily distracted and will wander around my flat  
Grand prix and boxing  
Casualty- music  
Deal or no Deal, one man show, eastenders – likes changing channels to the one that suits  
SKY + Watching my favourite channels and turning them over  
X factor – I like being able to watch the programmes I like  
Music channels  
Top gear, snooker, antiques road show  
Like – music football news  
Likes: It should always be on. Enjoy music, like the changing of different colours, people cars  
Dislikes: Crying or violent scenes  
Golf



### Preparing a hot meal



Fresh pasta. Mayonnaise – I am hungry  
He says curry but he calls all food with sauce curry  
Meat pie and mash – I like mashing potatoes  
Pie – mixing  
Chilli con carne- likes washing mushrooms, carrots and onions, dislikes touching hot plates  
Meat & pasta – Like chopping onion and peppers pouring mince in and tomato sauce  
Dislike and need support to take off stove  
Chilli & Rice – I like doing this because I can make it as spicy as I like. I dislike this because it takes a long time  
Chicken  
Roast dinner  
I like pasta, curry,  
I can help prepare my meals sometimes. I love food  
Hot meals are prepared for me

### Using a radio



BBC radio Oxford  
Likes listening to a tape of his own voice, he likes turning it on  
I listen to a mixture of radio stations. I like to switch through the radio stations and  
I get really happy and excited and express myself with talking to staff and dancing to show happiness  
Music I like finding the station  
Radio 1 – I like the different songs  
Heart FM  
I like RnB, pp, new release  
Like: I enjoy listening to music always, it is part of me.  
Switching it on

### Watering plants



I like watering the plants sometimes  
He said he likes the garden  
I have watered plants in the past at the gardening project and did get some enjoyment from that and have achieved something by showing happiness  
I like filling the watering can  
Summer  
I water the plants in the garden every Thursday/I can tap water into the watering can  
I can water plants independently with minimum supervision  
I like this because the flowers smell good  
I like pouring the water in  
I like to water plants for mum and dad when they are away  
Do not have plants at home  
Pouring water

### Cutting vegetables



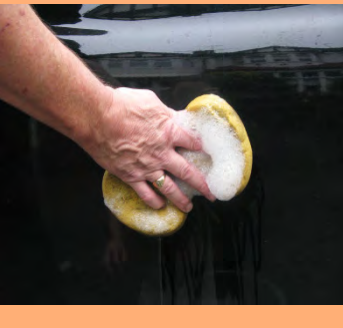
Prepare dinner  
Don't really enjoy it  
I like cutting potatoes  
Dislikes using knives  
Like – being independent and completing himself – dislikes tidying away at this end, except washing up  
I like his because I can choose what goes into my dinner  
Making the shapes  
I will help to cut vegetables but sometimes like to watch someone else do it  
My risk assessment does not allow me to do it  
Like chopping

### Writing and posting letters



I like to send the invitation for the party  
Staff helps support me with this as I find this something I can only do with staff, I can't write or read by myself  
I like posting them in the post box  
Putting stamps on post/ going to buy stamps  
putting the letter into the letter box/  
Staff has to write for me  
No but just started signing for money at the bank  
I like the writing when doing letters  
I like doing this because this is how I keep in contact with dad  
I like to give cards to family  
I post letters. I write my name and the persons name on a card. I need some help with spelling  
I sometimes post letters but do not write letters

### Washing a car



I don't like water running  
I like blue cars  
Blue cars- I like the water  
I have a Ford Fusion – I like being in the car when it goes through the car wash  
My favourite car is a Rover 3 Litre (Gaydon Motor museum)  
I wash dad's car on occasions but not recently

### Using an oven



It have got the fan  
Staff fully support me with this as it is a risk towards me and staff mainly cook my main meals for me  
Putting things in  
Only staff helps me use this, as it's too hot  
I like this because it cooks my dinner  
I dislike this because I don't like waiting  
I like taking things out  
I like watching the food cooking in the oven  
I need help with temperature  
Baking cake and biscuit

### DIY



Quite like painting  
Fixing the Christmas tree, decorating the Christmas tree  
I like building things and doing the screws  
Likes the sound of drills or machinery. Dislikes: Too loud noise or banging

### Preparing a sandwich



Egg mayonnaise – I am hungry  
Cheese and ham  
Ham and cheese – I like putting on the butter  
Cheese- nothing  
Tuna egg mayo- spreading butter/putting cutlery together for the process  
Ham sandwich – Like lots eating the ham and cutting the bread  
Dislikes and won't paste butter with it  
Cheese I like this because I can make it how I like it  
Cheese and ham and mayonnaise – I like cutting the bread  
Tuna Mayonnaise  
Coronation Chicken  
Like: Buttering of the bread and putting on the filler, likes the smell of the filler  
Dislikes: Washing up the utensils after use. To get wet or mess the floor  
Cheese and Marmite - spreading

### Taking out the rubbish



Dirty  
Quite like pushing the bin  
I have support to empty my rubbish bins and will help staff to take out to the bins with support and help from staff  
Moving bins  
Dislike tying rubbish  
I don't like I need prompting but enjoy the praise from staff after I have done it  
I like emptying the bin  
I know when to take out the rubbish and do my recycling. I just ask what colour bin goes out on bin day and take the bin to the street  
Like: to take rubbish out to the collecting bin- feel responsible. Also putting in the plastic bag in the bin- to feel and like the smell of the plastic  
Dislike: Messy bin, picking up or cleaning up if any rubbish falls on the floor

### Unpacking and organising groceries



I can put my shopping away  
Don't like hard work  
Putting them into cupboards and fridge  
I like unpacking shopping which includes my coca cola that's what I like to unpack first  
I like buying the shopping, but dislike having to put it away  
I like putting things away  
I like watching the shopping being put away  
I like to put the nice things to eat and drink away that I brought, I sometimes ask if it goes in freezer or fridge  
Likes: To unpack putting the groceries in their designated cupboards. Folding the empty bags and tearing to small pieces paper boxes, which had groceries and putting it into a bin  
Dislikes: Breakages to clean up or new products or food, which do not know where to store

Washing up in the kitchen sink



I don't like soap and water  
The bubbles  
I tend to refuse washing up as I find this a difficult task and can make me anxious  
I like the bubbles  
Putting dishes into the sink, washing them/my washing up may need to be checked  
Love the bubbles and blowing them in the air – nothing to dislike favourite hobby everyday  
I like this because of the smell of the washing up liquid. I dislike the drying up  
I like the bubbles  
I like bubbles, I like my hands to feel warm, I like things clean  
Like: Putting soap on the utensils- seeing bubbles and the smell of soap. Drying up of the utensils, I am obsessed with drying up things  
Dislikes Getting wet whilst doing the task or water getting on the floor

Peeling vegetables



Sharp  
Might cut myself  
Likes – chopping the vegetables and eat them raw  
Dislikes tidying away  
I dislike this because it takes a long time  
I like peeling the vegetables  
I like eating peeled raw veg such as carrots

Using a CD player



Christmas songs, only used for the party  
Beatles – Music is important to me. I like music and the Beatles is one of my favourites and I can control the CD player. I sometimes need staff as I tend to stop the CD and want it putting back on, could be due to feeling anxious  
ABBA – Like choosing some music on my own  
Abba – pressing play  
Good-bye black berry way - I like choosing my favourite CDS listening on my earphones  
Don't like when it jumps and scratched would want to buy a new one  
Leona Lewis and Shania Twain  
Looking at photos- I like to type things in on the computer  
I like rock music- I like listening to music on CD and listening to the radio  
Likes various music mostly likes RnB pop and any latest release  
Likes: Switching it on, put disc and choose, pressing the buttons, putting on my earphones ad listening  
Dislikes: When a disc plays up because of scratches or dirt  
Drawing  
Plays Lego and paper balls  
I like playing with my cars and windmills  
I would like a Hoover that makes bubbles  
Sit on my beanbag. Sit in the garden in nice weather, look through the Argos catalogue, looking at my photo albums, relax in the bath, and bounce on my sofa  
Pictures) doing the weekly rota, collecting dirty dishes, doing puzzles, playing with my cards, watching TV








Other?

# Appendix 32

## Appendix 32: A selection of completed Doing Things with Things booklets



Highlight below the numbers you were able to complete

 1 get bread	 2 put bread in toaster	 3 set dial	 4 start toaster
 5 close door	 6 get knife and spoon	 7 get butter and jam	 8 get plate
 9 put toast on plate	 10 open butter	 11 spread butter on toast	 12 open jam jar
			 13 spread jam on toast

Describe below what you like and dislike about each step

get bread yes	put bread in toaster Happy to do so	get dial no	start toaster -yes
close door -no	get knife and spoon yes	get butter and jam no also get the ketchup	get plate -yes
put toast on plate yes	open butter no	spread butter on toast no	open jam jar open ketchup
spread jam on toast Does not like butter ketchup on toast			

Describe below what you like and dislike about each step

get bread yes	put bread in toaster -yes	get dial only thing put would not do is turn the dial	start toaster -yes
close door yes door	get knife and spoon yes no spoon	get butter and jam yes ketchup	get plate -yes
put toast on plate -no	open butter ketchup	spread butter on toast Don't like butter	open jam jar open ketchup
spread jam on toast Spread the ketchup			

Describe below what you like and dislike about each step

get bread	put bread in toaster	set dial	start toaster
close door	get knife and spoon	get butter and jam	get plate
		Butter does not like Wither back will get out other people	
put toast on plate	open butter	spread butter on toast	open jam jar
	June 15 no. 6	June no. 6	
			spread jam on toast

Describe below what you like and dislike about each step

25/6 //

get bread	put bread in toaster	set dial	start toaster
Butter is thicker spread it is better to be spread than a thin layer	✓	2 in 1 + 1/2 cup butter + 1/2 cup jam + 1/2 cup sugar + 1/2 cup flour + 1/2 cup milk + 1/2 cup oil + 1/2 cup eggs	✓
close door	get knife and spoon	get butter and jam	get plate
✓	with butter butter	✓	✓
put toast on plate	open butter	spread butter on toast	open jam jar
With butter	✓	Hand over hand assistance Poa	OPEN JAM JAR TO LOOK AT FLOOR
			spread jam on toast
			Hand over hand hand movement

# Doing Things With Things



Hoovering...

Highlight below the numbers you were able to complete

 1 clear floor space	 2 get Hoover out	 3 carry the Hoover	 4 unroll power cord
 5 fold the leaves	 6 switch on Hoover	 7 switch on plug	 8 plug into switch
 9 hoovering	 10 hoover around objects	 11 switch off Hoover	 12 switch off plug
 13 put away Hoover	 14 carry the Hoover	 15 wind up cord	 16 take out plug



Describe below what you like and dislike about each step

clear floor space No needs prompts.	get Hoover out Papa has if prompts	carry the Hoover YES	unwind power cord like prompt
hold the Hoover YES	switch on Hoover YES	switch on plug YES	plug into switch YES
hoovering Paul will Hoover and can do it with little of encouragement	hoover around objects Paul will have to give + prompt directions to Paul	switch off Hoover Paul will leave Hoover running!	switch off plug No brings to search
put away Hoover YES with prompts	carry the Hoover YES	wind up cord finds it difficult	take out plug become disoriented sometimes

Monday  
Tuesday  
Wednesday  
Thursday  
Friday  
Saturday  
Sunday

Describe below what you like and dislike about each step

clear floor space no	get Hoover out YES no to happy to do it	carry the Hoover push Hoover along	unwind power cord YES slowly and rolling
hold the Hoover Paul's Hoover has needs prompts + support	switch on Hoover YES	switch on plug YES	plug into switch YES but some-times find it difficult to wind cord
hoovering only will do the hoover machine work	hoover around objects only will hoover round will not move items	switch off Hoover YES	switch off plug YES
put away Hoover Happy to do it	carry the Hoover no push it along	wind up cord sit on the floor and wind it	take out plug YES really does not like to hoover!!

Describe below what you like and dislike about each step

<p>clear floor space</p> <p>Took the office chair and moved it to the side with some papers</p> <p>1</p>	<p>get Hoover out</p> <p>Not keen that we use it ind. 😊</p> <p>2</p>	<p>carry the Hoover</p> <p>Carried it ind. also. Getting there</p> <p>3</p>	<p>unwind power cord</p> <p>4</p>
<p>hold the Hoover</p> <p>ind. 😊</p> <p>5</p>	<p>switch on Hoover</p> <p>ind. 😊</p> <p>6</p>	<p>switch on plug</p> <p>ind. 😊</p> <p>7</p>	<p>plug into switch</p> <p>ind. 😊</p> <p>8</p>
<p>hoovering</p> <p>Took the vacuum ind. But he was for hole up and he down it</p> <p>9</p>	<p>hoover around objects</p> <p>Took the vacuum around the table legs with foam</p> <p>10</p>	<p>switch off Hoover</p> <p>I finished. Took us some time - he finished the ind.</p> <p>11</p>	<p>switch off plug</p> <p>ind. 😊</p> <p>12</p>
<p>put away Hoover</p> <p>ind. 😊</p> <p>13</p>	<p>carry the Hoover</p> <p>ind. 😊</p> <p>14</p>	<p>wind up cord</p> <p>ind. 😊 Said I did it Hugs</p> <p>15</p>	<p>take out plug</p> <p>ind. 😊</p> <p>16</p>

7/2/13  
405

Describe below what you like and dislike about each step

<p>clear floor space</p> <p>1</p>	<p>get Hoover out</p> <p>2</p>	<p>carry the Hoover</p> <p>3</p>	<p>unwind power cord</p> <p>4</p>
<p>hold the Hoover</p> <p>5</p>	<p>switch on Hoover</p> <p>6</p>	<p>switch on plug</p> <p>7</p>	<p>plug into switch</p> <p>8</p>
<p>hoovering</p> <p>9</p>	<p>hoover around objects</p> <p>I don't like having to move my things</p> <p>10</p>	<p>switch off Hoover</p> <p>11</p>	<p>switch off plug</p> <p>12</p>
<p>put away Hoover</p> <p>13</p>	<p>carry the Hoover</p> <p>14</p>	<p>wind up cord</p> <p>I find it difficult to wind the cord up</p> <p>15</p>	<p>take out plug</p> <p>16</p>

Describe below what you like and dislike about each step

clear floor space have clear basket with power for longish time	get Hoover out 1st	carry the Hoover 1st	unwind power cord 1st
hold the Hoover 1st	switch on Hoover 1st	switch on plug Plug switch is always on as that's how Eddie has them.	plug into switch 1st
hoovering he does bits - not sure if he likes it or not to do it again to have to get out of the house but on the floor	hoover around objects like Hoover around table	switch off Hoover hard to turn it off Sometimes Eddie leaves it running then disappears	switch off plug no.
put away Hoover	carry the Hoover	wind up cord Flowers - no. - will do with power for computer now	take out plug no.

Describe below what you like and dislike about each step

clear floor space N/A	get Hoover out 1st in Turbo	carry the Hoover N/A	unwind power cord Promoted to unroll the cord
hold the Hoover 2	switch on Hoover 3	switch on plug 4	plug into switch 5
hoovering 7 I like hoovering my feet to make it dry.	hoover around objects 8 I find it difficult to hoover around furniture I like stuff a bit.	switch off Hoover 11	switch off plug 9
put away Hoover 13	carry the Hoover 12	wind up cord 10 I find it difficult to wind up the cord - I would like a plug for it.	take out plug 10

20/11/11  
Sun



# Doing Things With Things

## Washing Clothes...

Highlight below the numbers you were able to complete

 load clothes into machine	 collect clothes	 carry to washing machine	 open door
 read washing powder	 get washing powder	 close door	 put clothes into machine
 select correct setting	 push start button	 wait for end wash	 open door
	 hang to dry	 take washing out	

Describe below what you like and dislike about each step

<p>sorting colored clothes</p> <p>No want put clothes</p> <p>1</p>	<p>collect clothes</p> <p>Yes</p> <p>2</p>	<p>carry to washing machine</p> <p>Yes</p> <p>3</p>	<p>open door</p> <p>Yes</p> <p>4</p>
<p>add washing powder</p> <p>like putting washing powder in</p> <p>5</p>	<p>get washing powder</p> <p>Yes note for the key!</p> <p>6</p>	<p>close door</p> <p>Yes</p> <p>7</p>	<p>put clothes into machine</p> <p>Yes</p> <p>8</p>
<p>select correct setting</p> <p>Yes Always same setting</p> <p>9</p>	<p>push start button</p> <p>Yes</p> <p>10</p>	<p>wait for end wash</p> <p>Yes</p> <p>11</p>	<p>open door</p> <p>Yes</p> <p>12</p>
		<p>hang to dry</p> <p>put in tumble dryer</p> <p>13</p>	<p>take washing out</p> <p>Yes like to Smell them</p> <p>14</p>

Describe below what you like and dislike about each step

<p>sorting colored clothes</p> <p>No low put washing out out</p> <p>1</p>	<p>collect clothes</p> <p>Yes like to collect and put in machine</p> <p>2</p>	<p>carry to washing machine</p> <p>Yes</p> <p>3</p>	<p>open door</p> <p>Yes</p> <p>4</p>
<p>add washing powder</p> <p>Very inconveniently expensive please confirm of amount</p> <p>5</p>	<p>get washing powder</p> <p>Yes like the smell</p> <p>6</p>	<p>close door</p> <p>Yes</p> <p>7</p>	<p>put clothes into machine</p> <p>Smell of the floor making in the machine</p> <p>8</p>
<p>select correct setting</p> <p>Always same setting</p> <p>9</p>	<p>push start button</p> <p>Yes</p> <p>10</p>	<p>wait for end wash</p> <p>like when coming to the end of a wash</p> <p>11</p>	<p>open door</p> <p>Yes makes happy noise</p> <p>12</p>
		<p>hang to dry</p> <p>No like stuff to wear from the washing machine</p> <p>13</p>	<p>take washing out</p> <p>Yes like on top washing out of machine</p> <p>14</p>

**Describe below what you like and dislike about each step**

sorting coloured clothes No just all done	collect clothes Yes with prompting	carry to washing machine with prompts will pick bag myself	open door Yes with prompt	21/2 Sunday   Saturday   Friday   Thursday   Wednesday   Tuesday   Monday
add washing powder No very confused to fill up	get washing powder Yes	close door Yes	put clothes into machine with prompts	
select correct setting Enjoys turning the washing machine on	push start button Yes push forgot to push button the first time	wait for end wash No doesn't know	open door No	
		hang in dry No	take washing out No keeps machine going	

**Describe below what you like and dislike about each step**

sorting coloured clothes	collect clothes Enjoys putting things into machine	carry to washing machine yes	open door yes
add washing powder	get washing powder Enjoys all the things in the machine	close door yes	put clothes into machine yes
select correct setting Likes sets it to the correct setting	push start button yes	wait for end wash Enjoys just watching the machine as he likes the noise	open door looks at no. 4
		hang in dry Same as no. 4	take washing out Same as no. 4

Describe below what you like and dislike about each step

sorting coloured clothes NO wash clothes	collect clothes YES	carry to washing machine YES	open door YES
add washing powder Likes putting washing powder in	get washing powder YES note for the key!	close door YES	put clothes into machine YES
select correct setting YES Always same setting	push start button YES	wait for end wash YES	open door YES
		hang to dry puts in tumbler dryer	take washing out YES takes 10 minutes

Describe below what you like and dislike about each step

sorting coloured clothes Take sorted in clothes washer pump	collect clothes Take coloured clothes independently	carry to washing machine carried to the machine independently	open door He opened the door with power
add washing powder Like Sponner added the washing powder	get washing powder he got the powder from Sponner	close door closed door independently	put clothes into machine He put clothes independently
select correct setting Like Sponner he selected the correct setting	push start button then Sponner pushed the button independently	wait for end wash watched till the washing was done	open door he independently opened the door
		hang to dry Like Sponner he hung clothes to dry	take washing out He took the washing out independently

Michael

4/3/13





# Appendix 33

**Appendix 33:** Storyboards drawn by support staff in a Ready Steady Make workshop, describing their different everyday experiences with the autistic adults they support



Get up breakfast with  
Stay & explain the day positive  
Rassurama will come  
back DTS Hovering as he  
Wes



Head office gave count  
Back in car  
at Home  
down Sains



Left office



Car back Home



Get up breakfast with  
Stay & explain the day positive



Rassurama will come  
back DTS Hovering as he  
Wes



In car  
Head office  
Smurtes



Head office gave count  
Back in car  
at Home  
down Sains



Left office



Car back Home



H/N came over very sad as Teddys hat had been. Ripped off. H/N got very anxious and became very challenging



I asked h/n to bring teddy bear and we should make him a new one to keep her warm



I supported h/n to get scissors + a old sock and we all sat at table H/N myself + Teddys sock + scissors



I assisted h/n to cut heat off sock with scissor and we measured it against Teddys head



We put Teddys new hat on and I said he look lovely + he is a happy boy. I asked if h/n was happy



h/n Smiling and dancing with Teddys with his new hat on. 😊



This is me and this is Eddie, Eddie loves spending time in the garden.



Eddie loves the grass, small and touch of grass. Also loves watching clouds go by



But Eddie lives right near airport and doesn't like the sound of the airplanes flying over the garden



Eddie would run into the house



Now Eddie listens to music when in his garden.





Mr C reports to housing provider his tap is not working properly.



Mr C says the hot and cold water are not mixing properly. Maintenance job is reported for a faulty tap.



Maintenance team look at the tap and tighten the screw so it doesn't drip, but say it cannot mix any differently that is the way tap works.



Housing provider pay for maintenance call out & tell client tap is in good working order.



Mr C is not happy as the tap is not mixing the water as he wants it to do.



Housing provider say it works and there's nothing wrong with the tap so they will not replace or do anymore maintenance.



Lena enjoys going to the disco with her housemates.



She also likes going for a drive back home.



But on the way back it's dark and raining!



And there's lightning which Lena doesn't like.



Lena is anxious and just wants to get back home.



She is happy to be home, and she enjoyed the disco.



JO HADN'T BEEN TO THE DOORS FOR SOMEONE



JO APPROVED VERY HAPPY ALSO ENJOYED BEING AT THE OTHER



NEAR JO HAD A CAR IN THE CARE



JO ENJOYED LISTENING TO MUSIC ON THE WAY HERE



JO WAS FULL AND SMILES WHEN ARRIVED HOME



JO



This is me and this is Jane. One day it was a nice sunny day so we chose to go to the park.



But walking down the pathway to the park, big dark black shadows were cast down the pathway.



This made Jane anxious, to Jane these most of looked like big black blocks blocking pathway.



So we chose a different route.



# Appendix 34

## Appendix 34: Evaluation trial one feedback

Step.1 Clear floor space		Step.2 Get hoover out		Step.3 Carry the hoover		Step.4 Wind the cord		Step.5 Plug into switch		Step.6 Switch on plug		Step.7 Switch on hoover		Step.8 Hold hoover		Step.9 Hoovering		Step.10 Around objects		Step.11 Switch off hoover		Step.12 Switch off plug		Step.13 Wind up cord		Step.14 Put away hoover	
<b>20/11/12</b> He does not clear the floor space- he tends to hoover around things like the table	I got the hoover out of the cupboard and carried it up to the activity room for Eddie	He pulled out the cord	He plugged into the switch with gesture and prompt	He switched in the plug independently and the hoover switch too.	The hoover switch no	He held the hoover but it fell apart so he left it running until I fixed it together	He hoovered around the seats for about 5 minutes	Yes he hoovered around the floor cushions	Yes	Yes	Yes	As with pluggin in	He doesn't do that (wind up cord) as it requires more patience, is more time consuming and his attention may already be on something else.	He doesn't leave the hoover out on occasions, but more often he'll put it back as he appears to enjoy certain order in the flat to be maintained.													
<b>23/11/12</b> He doesn't do a lot of clearing before hoovering as he likes his stuff to stay in certain places around which he will hoover		He carries it vigorously, sometimes runs with it up the stairs. He might like the ability to pace himself up, prepare for the activity whilst carrying.	He is focused when he does it and tries to get around that. He might like plugging in as its short-time movement and apart from getting it right there may be a degree of noise - 'clicking' present.	He appears to understand the need to switch on plug, he doesn't pay much attention to this step, yet might like it as its an easy movement on his part.	he doesn't hesitate to use the switch on button. He might like the fact that it will immediately initiate the hoover.	He seems to be holding the hoover, perhaps it gives him a feeling of being in control of the activity.	He seems to like the noise coming out of the hoover, he appears to enjoy picking things up from the carpet though not for long.	He appears to enjoy a little challenge of getting around various shapes. He becomes more focused but if it takes too long he discontinues.	He is happy to use the switch off button as it may be linked to the feeling of relief once the activity is finished.	As with pluggin in	He doesn't do that (wind up cord) as it requires more patience, is more time consuming and his attention may already be on something else.	He doesn't leave the hoover out on occasions, but more often he'll put it back as he appears to enjoy certain order in the flat to be maintained.															

## Trial Two

	Step 1 Clear floor space		Step 2 Get Hoover out		Step 3 Carry the Hoover		Step 4 Wind the cord		Step 5 Plug into switch		Step 6 Switch on plug		Step 7 Switch on Hoover		Step 8 Hold Hoover		Step 9 Hoovering		Step 10 Around objects		Step 11 Turn bubble machine on		Step 12 Hoover with bubbles		Step 13 Switch off Hoover		Step 14 Switch off plug		Step 15 Wind up cord		Step 16 Put away Hoover
---	-----------------------------	---	--------------------------	---	----------------------------	---	-------------------------	---	----------------------------	---	--------------------------	---	----------------------------	---	-----------------------	---	---------------------	---	---------------------------	---	-----------------------------------	---	--------------------------------	---	------------------------------	---	----------------------------	---	-------------------------	---	----------------------------







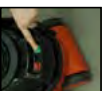




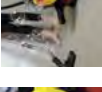


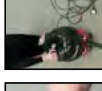

Reluctant to move things around	Done with help	Not interested done for him	Done with help	Done for him reluctant to use some concrete plugs	Plugs are always on as it's the way he likes it	Done it well	Done it well keen to do it	Done it easily in the activity	Done it well got tired very soon	Done for him	He got very surprised about the bubbles but then did not look too interested	Done it for him more focused on computer	Plug always on- Nathan likes it that way	Not interested done for him	Reluctant to do it
---------------------------------	----------------	-----------------------------	----------------	---	---	--------------	----------------------------	--------------------------------	----------------------------------	--------------	--	--	--	-----------------------------	--------------------

30/11/13

He didn't want to clear the floor before Hoovering as likes things to remain as they are	He was happy to do it however when the top of the Hoover got disconnected he looked a bit puzzled and stopped the activity	As the Hoover was close to the designated area for the activity Nathan wasn't required to carry it. However later on when moving around he needed me to support as not happy to carry he would rather pull it once only.	He did just one pull to unwind the cord and wouldn't be patient enough to continue with it, staff supported.	He makes sure he pushes the plug right into the switch and checks it twice with his hand if properly plugged in	He is aware of where the switch is and is comfortable with switching on properly as it doesn't require much time and get it uncomplicated when Hoovering	He seems comfortable with holding the Hoover, however it can get quite upset if the pipe twists around and he cannot twist it straight	He gets consumed by the hovering at times being oblivious of staff being present in the room. He is precise and not in a hurry.	He rather moves around objects instead of moving the objects themselves. He picked a small object from the floor and put it in his mouth uncomplified.	He seemed to acknowledge that the machine will be on, but staff supported him in turning it on uncomplified.	He continues to hover when bubbles were being produced, but didn't seem to be pleased about them. Maybe as he doesn't like wet surfaces and where he steps on the floor with bare feet he gets the feeling of discomfort. Could be the movement of the bubbles that gets him anxious or "spoil" the clear floor space.	He didn't like the noise from the bubble machine to continue and needed staff support to put it off	He seemed fine with switching off the plug to wind the cord up and puts it on top of the computer	He doesn't like or have the patience to wind the cord up and puts it on top of the computer	He once finished the activity he didn't seem interested in tidying up the Hoover
--	--	--	--	---	--	--	---	--	--	--	---	---	---	--

01/12/13

## Trial Two

Step.1 Clear floor space	Step.2 Get Hoover out	Step.3 Carry the Hoover	Step.4 Wind the cord	Step.5 Plug into switch	Step.6 Switch on plug	Step.7 Switch on Hoover	Step.8 Hold Hoover	Step.9 Hoovering	Step.10 Around objects	Step.11 Turn bubble machine on	Step.12 Hoover with bubbles	Step.13 Switch off Hoover	Step.14 Switch off plug	Step.15 Wind up cord	Step.16 Put away Hoover
															
02/03/13	With support	No found the lid coming off and he attached the bubble thing more awkwardly	No but does like to plug the wire in a certain socket	Yes	Yes	Yes- after prompting and support	Yes- will Hoover but not realising when the Hoover has come apart	Yes- does not like to move things from their place	No	No	Not really interested in the bubbles	No left them and became agitated – chin flicking	No	No	No became agitated

## 03/12/13

Eddies does not complete the task this day as no pc/laptop available for computer time – so not motivated to complete daily tasks

## 04/12/13

Not keen to move things around	with help as it needs to be assembled	done well	done for him	done well	done well with no help or prompt	done well with no help	done well	done well, short time	done well	Done for him	Not very interesting	Done for him	Done well rush to finish	Done for him	Done independently
--------------------------------	---------------------------------------	-----------	--------------	-----------	----------------------------------	------------------------	-----------	-----------------------	-----------	--------------	----------------------	--------------	--------------------------	--------------	--------------------

## 12/12/13

No I moved the chairs so he would Hoover beneath the table	Yes he got out the Hoover help	Yes, he carried it to the middle of the room	I did this	Yes with prompt	Yes	Yes no prompt needed	Yes fixed Hoover tube together	Carried this out independently around furniture for a short time	Yes he did this	he tried to turn the bubble machine on but we could not get it to work	He seemed interested but probably not that bothered, it didn't work- just continued with hovering task	Yes with prompt	Yes	I did this first showing he, Hoover he did a little back in the hand over cupboard with help
--	--------------------------------	--	------------	-----------------	-----	----------------------	--------------------------------	--	-----------------	--	--	-----------------	-----	--

## Trial Two

	Step 1 Clear floor space		Step 2 Get Hoover out		Step 3 Carry the Hoover		Step 4 Wind the cord		Step 5 Plug into switch		Step 6 Switch on plug		Step 7 Switch on Hoover		Step 8 Hold Hoover		Step 9 Hoovering		Step 10 Around objects		Step 11 Turn bubble machine on		Step 12 Hoover with bubbles		Step 13 Switch off Hoover		Step 14 Switch off plug		Step 15 Wind up cord		Step 16 Put away Hoover
---	-----------------------------	---	--------------------------	---	----------------------------	---	-------------------------	---	----------------------------	---	--------------------------	--	----------------------------	---	-----------------------	---	---------------------	---	---------------------------	---	-----------------------------------	---	--------------------------------	---	------------------------------	---	----------------------------	---	-------------------------	---	----------------------------

13/12/13

He wouldn't clear the floor space as once he organised all things around the room the way he like them to be he doesn't move them and wouldn't like anyone to move them

He likes putting the Hoover out, he usually sings when doing it as he likes it when the carpet is clean, so when taking the Hoover out of the cupboard he is probably imagining a clean carpet in his head and singing when he sees it.

He thinks more in pictures of the process of hovering is very quick for him, he wants to put the Hoover put on the carpet as soon as possible to start the task immediately.

He can do it for a bit but then goes immediately to the Hoovering process of winding the cord. If the Hoover doesn't make any sound he would always look to see if everything is on, he is very aware of what to press.

He knows very well that in order for Hoover to be working he needs to switch it on, so he does it himself.

He normally holds the Hoover with both his hands. This is because he wants to have a full control in the activity he is doing and also as a result of his full concentration on the task, usually only at the very beginning of the test.

He can concentrate very well on the test he is doing but his concentration rather is very short and he's prompted to continue if the test requires more time and concentration.

He wouldn't normally move any objects so he would move around them

He would always switch off the Hoover as he likes to have control over things making sounds and noises, so he always remembers to switch the Hoover off.

He doesn't have enough patience to wind up the cord as he can't concentrate on this task for too long in pictures and the Hoover is new to him he doesn't have a clear picture in his mind what to do with the Hoover and where to put it, so his mind moves to another picture of him on the computer.



## Trial Three

Step.1 Clear floor space	Step.2 Get Hoover out	Step.3 Carry the Hoover	Step.4 Wind the cord	Step.5 Plug into switch	Step.6 Switch on plug	Step.7 Switch on Hoover	Step.8 Hold Hoover	Step.9 Hoovering	Step.10 Around objects	Step.11 Switch off Hoover	Step.12 Switch off plug	Step.13 Wind up cord	Step.14 Put away Hoover
-----------------------------	--------------------------	----------------------------	-------------------------	----------------------------	--------------------------	----------------------------	-----------------------	---------------------	---------------------------	------------------------------	----------------------------	-------------------------	----------------------------

20/01/14

Staff cleared the floor

Staff prompted him to get the Hoover out of the cupboard

He carried the Hoover

He did this also without prompting

He pulled the Hoover from the cupboard into living room without being prompted

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

21/01/14

When prompted He got out the Hoover from the cupboard

He pulled the Hoover from the cupboard into living room without being prompted

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

22/01/14

He would not really do this himself so today I helped him move his chairs

He did this well with a little PH

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

He did this with a little gesture prompt

### Trial Three

													
---	---	---	---	---	---	---	---	---	---	---	---	---	---

23/01/14	He doesn't like changing the position of chairs in air, so wouldn't do it himself	With help of staff	He did it well	Did it with a bit of help	Yes with no problem	Did it with no help from staff	Yes with no problem	No help needed	He is quite good at hovering but cannot concentrate for a long time	Yes did it quite well	Yes he knows when to switch off Hoover	Yes no help needed	Yes did it with a bit of help from staff	Did it with help of staff
----------	---	--------------------	----------------	---------------------------	---------------------	--------------------------------	---------------------	----------------	---	-----------------------	--	--------------------	--	---------------------------

24/01/14	He did not clean space before hoovering	Did with a little help from staff	Pulled the Hoover to the plug	Pulled the cord out fine	Did this fine with no help	Fine with no help	Switches on Hoover fine. I switched it to full power	Has no problem holding the Hoover	He hoovered fine. Had to prompt in order to Hoover in some spots	Did this fine with a few prompts	Did this fine	Did this fine	Did this well but did have a little help when cord getting twisted	Did this with staff well
----------	---	-----------------------------------	-------------------------------	--------------------------	----------------------------	-------------------	--	-----------------------------------	--	----------------------------------	---------------	---------------	--	--------------------------

25/01/14	No Hoover around objects	Independently went to cupboard and got Hoover	Yes carries the Hoover	Yes unravels the cord	Co-ordination is very good improves all the time	Yes can switch off	Knows how to switch on and the colour of the button	Can hold the Hoover	Hoovers around all objects	That's how he hoovers	Yes knows when to switch and finish hoovering	Independently	Tries his best to wind cord up	Independently
----------	--------------------------	---	------------------------	-----------------------	--	--------------------	---	---------------------	----------------------------	-----------------------	---	---------------	--------------------------------	---------------

26/01/14	He did clear the floor before hoovering	Did it with help	No help	No help	No help	No help	No help	No help from staff	Hoovered all the carpet with no help	Didn't want to move any objects	No help	No help	No help	Staff helped to open the cupboard
----------	---	------------------	---------	---------	---------	---------	---------	--------------------	--------------------------------------	---------------------------------	---------	---------	---------	-----------------------------------

# Appendix 35

## Appendix 35: Evaluation: trial two feedback

Hoover trial 21/08/14

### PS is taking part in a hoover trial with Katie Gaudion

Before Katie arrived I showed Paul the picture of the red henry hoover, and explained that Katie would be coming to watch Paul clean his flat with a new red hoover. The hoover will make bubbles; Paul was keen to get started, so he waited in his flat for Katie to arrive.

When Katie arrived we talked in the office for a while then I realised the bubble attachment would be added at a later date, with this in mind we decided to take bubbles from Tuesday club to Pauls flat with the hoover. Paul was happy to welcome us and Henry to his flat. Paul was keen to use the bubble wand and watched as the bubbles full to the floor. We watched till each one popped before Paul did another wand full of bubbles, we watched again all the while Paul was smiling and happy watching the bubbles.

I then asked Paul if he would show Katie how he hoovers his flat, without question Paul took the plug off the red hoover and plugged it in. He started to hoover his lounge Paul made his wooh wooh noise to express happiness. Paul was focus on hovering and hovered up to the door then round the sofa I was sat on I lifted my legs so he could hoover under them, and Paul laughed Paul then hovered round the table and paused as if he was finished. I asked Paul to hoover his bed room. Paul said no hoover; I explained that hovering kept the flat clean. Paul happily hovered the hall way then his bedroom. The hoover lead was a bit short to get to the bed room, so I assisted Paul will bring out more cable as he was so focus on hovering. He hadn't noticed the hoover got stuck on the door way Paul returned to the hoover and took it into his bedroom to finish hovering. When it was completed Paul returned to the lounge without the hoover, I asked Paul to put the hoover away. Paul said no hoover away, I asked Paul if the hoover should stay in the hallway, Paul then went to the hoover to wind up the cord when the cord was wound up we made room in the cupboard next to the yellow hoover. Paul locked the cupboard, I asked Paul if he will hoover with the red hoover another day he said yes.

### PS Hoover trial 28<sup>th</sup> August

I arrived in Pauls flat and asked him if he would hoover with the red Hoover for Katie he saw 'Hoover Woman' sorry Katie you are known now as Hoover woman. Paul was keen to clean his flat, so I asked him to get the hoover from the cupboard Paul unlocked the cupboard and brought the hoover to the lounge He plugged it in with no prompting then started hovering

he carried the hoover to the bed room to hoover when he was finished I asked him to put it away he went to the plug and unplugged it before winding up the cord I asked Paul to put the hoover away Paul put the hoover in the cupboard and locked the door Paul was keen to do the hovering I did not take the bubble wands today it was just hovering . Paul just got on with it he never made and woo woo noises of happiness as he had last time with the bubble wand before hand.

September 1<sup>st</sup>

Refused to hoover with red hoover happy to hoover with his yellow one

4<sup>th</sup> September

Paul had day out hovered with other staff

8th September

Paul took some persuading to use the red hoover today he pugged it and hovered for a few seconds before going back to bed

11<sup>th</sup> September

No trial done today Paul out all day

15<sup>th</sup> September

I was off sick

18<sup>th</sup> September

I was off sick

23<sup>rd</sup> September

Not done

25<sup>th</sup> September

Arrived in Paul's flat to ask him to Hoover with the red Hoover Paul didn't want to Hoover when talked into cleaning his flat he took the red Hoover out of the cupboard then the yellow one and Hoovered with the yellow Hoover

Not done

29<sup>th</sup> September

Hoovered with yellow Hoover

2<sup>nd</sup> October

6<sup>th</sup> October

9<sup>th</sup> October

14<sup>th</sup> October

Hoovered with Yellow Hoover

16<sup>th</sup> October

Went to Paul's flat to ask him to Hoover he was not going to Hoover with the bubbles we let him look at the attachment then asked again to Hoover he didn't want to Hoover with the red one I got it out and left it in his lounge we talked about the bubbles and the red Hoover I filled the bubbles and put it in the Hoover I plugged it in and the bubbles started Paul

watched for a while but still refused to Hoover we kept asking he eventually got up to Hoover but just hovered he was completely oblivious to the bubbles Holly was working with him to day and while he was Hoover the bedroom she kept say oh Paul look at the bubbles but Paul was too busy Hoovering he finished Hoovering and stopped to watch the bubbles Holly tried to encourage him to touch the bubbles as she blew out Paul reached forward told the Hoover no bubbles he then walked away from the Hoover and went and sat down.

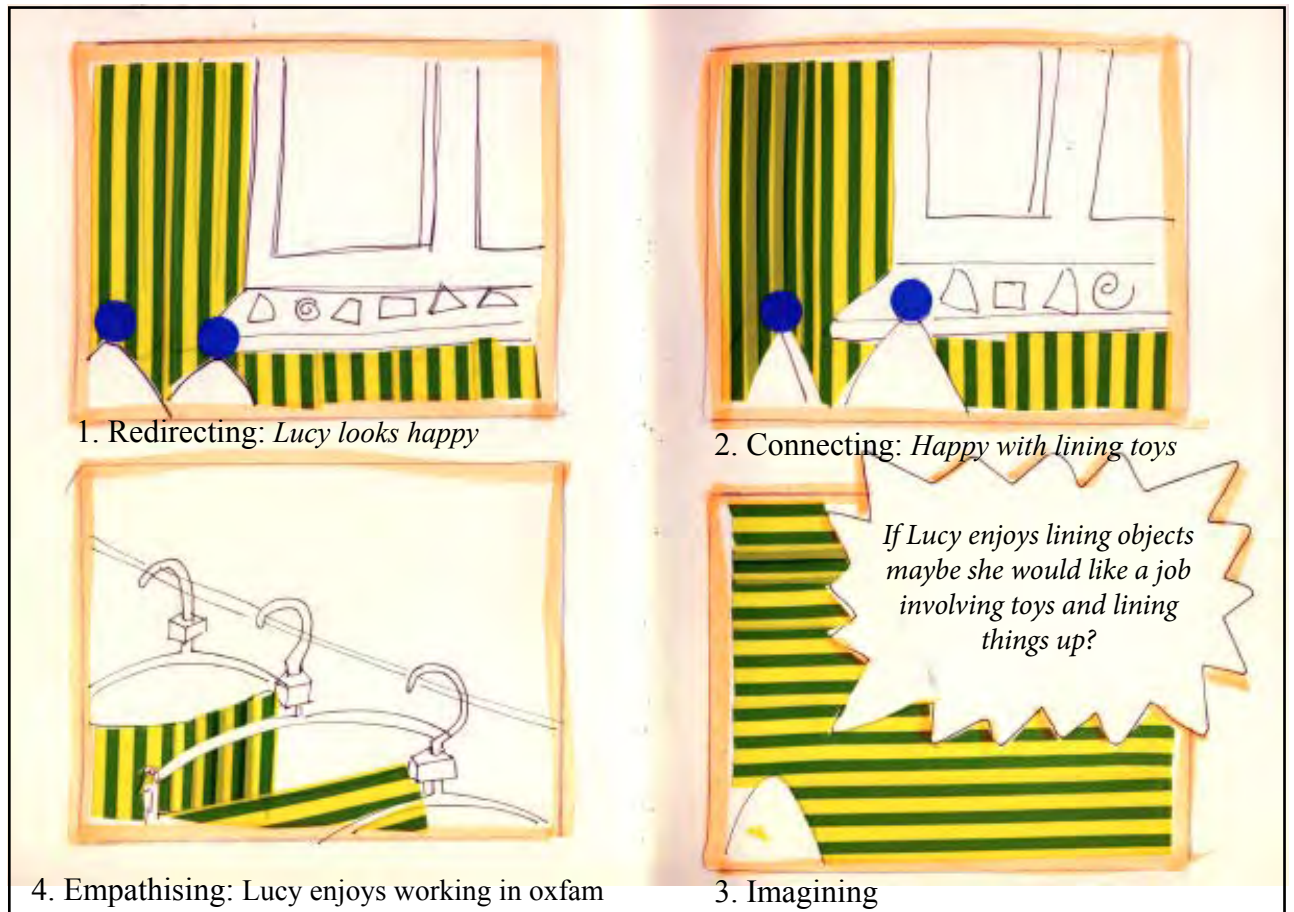
20<sup>th</sup> October

23<sup>rd</sup> October

I asked Paul to do the Hoovering with the bubbles He went to the cupboard and brought out his yellow Hoover after a lot of prompting Paul changed it to the red Hoover and was quick to plug it in and get started we attached the bubbles Paul was not interested in the bubbles only focused on getting the Hoovering done he was very good and picked up clothes in the bed room but played no attention to the bubbles and was keen to finish we tried to draw his attention to the bubbles he knew they were bubbles but he didn't appear to be very interested

# Appendix 36

**Appendix 36:** A selection of sketches drawn by the author, exploring the support staffs anecdotal examples of empathy





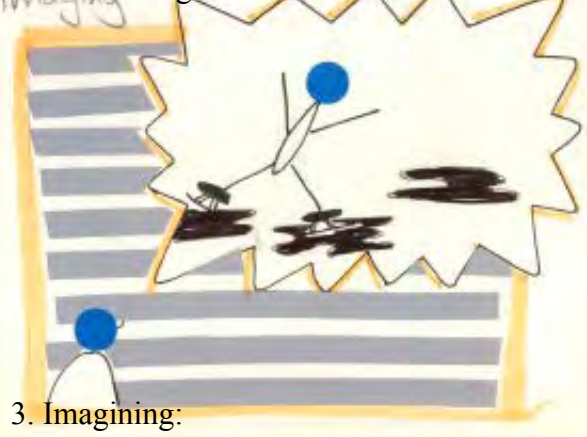
2. Connecting: *The wet floor*



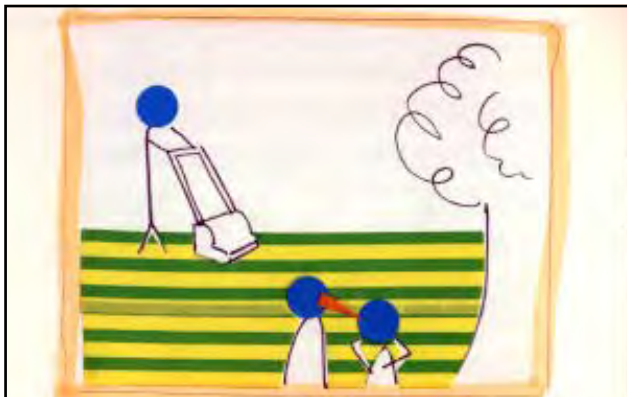
4. Empathising: *We avoid the rain*



1. Redirecting: *Jane looks worried*



3. Imagining:



1. Redirecting: *Steve looks scared*



2. Connecting: *The sound of the lawn mower*

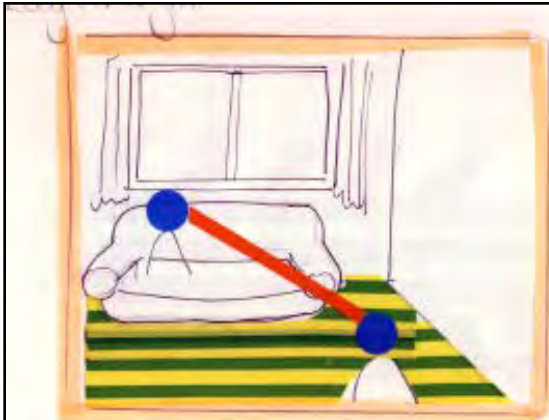


4. Empathising: *move away from the sound*

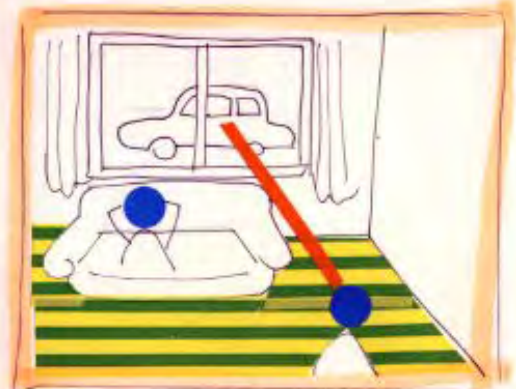


3. Imagining:

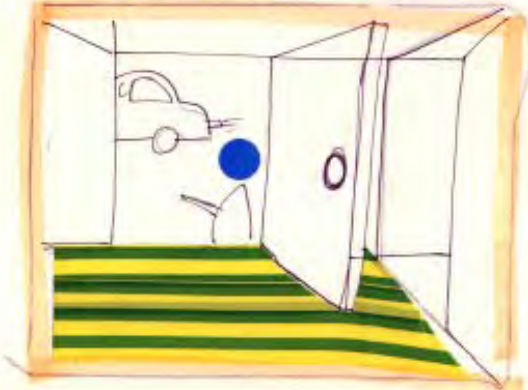




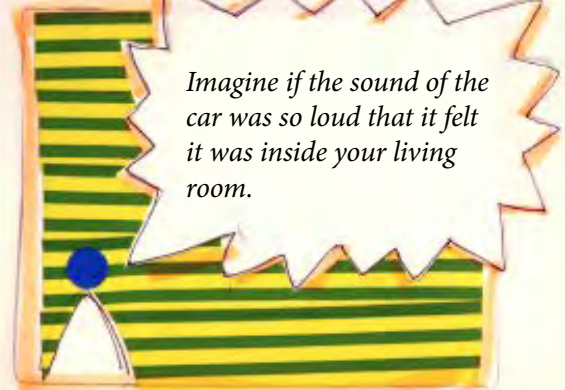
2. Connecting: *Tim looks anxious*



1. Redirecting: *Sound of the car engine outside*

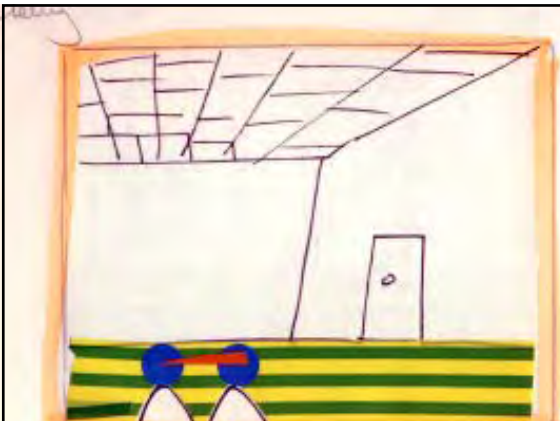


4. Empathising: *Ask the car to drive forward*

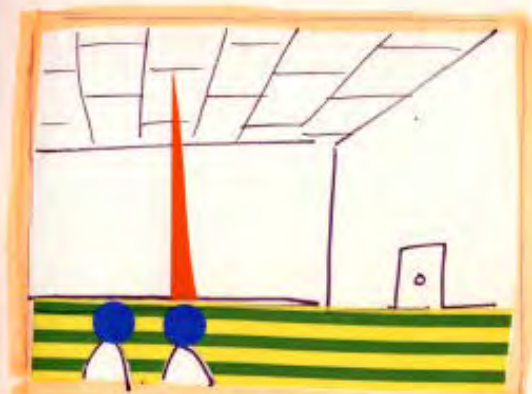


*Imagine if the sound of the car was so loud that it felt it was inside your living room.*

3. Imagining:



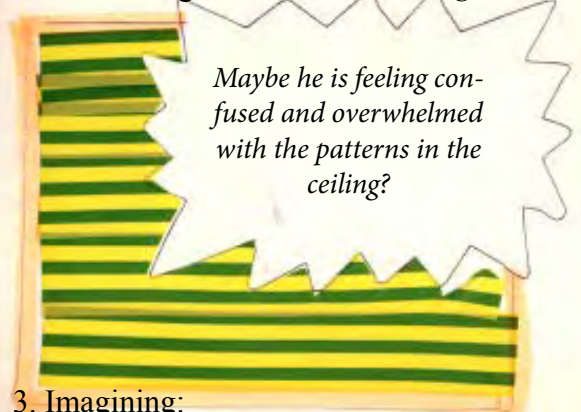
2. Connecting: *Fred looks confused*



1. Redirecting: *The tiles in the ceiling*



4. Empathising:



*Maybe he is feeling confused and overwhelmed with the patterns in the ceiling?*

3. Imagining:



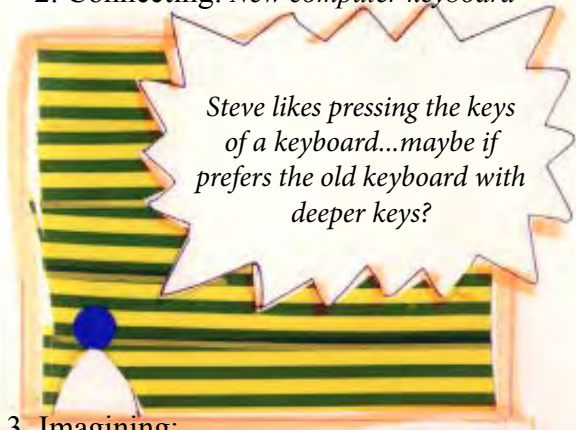
1. Redirecting: *Steve looks bemused*



2. Connecting: *New computer keyboard*



4. Empathising: *I put his old keyboard back*

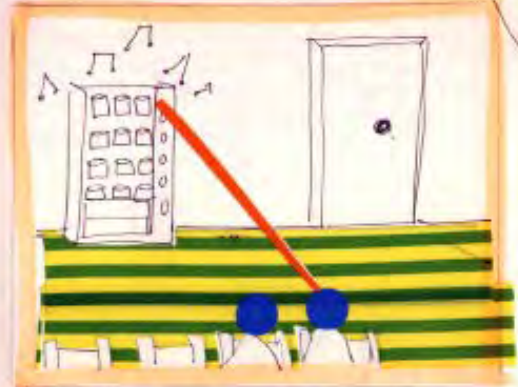


3. Imagining:

*Steve likes pressing the keys of a keyboard...maybe if prefers the old keyboard with deeper keys?*



1. Redirecting: *Tom looks anxious*



2. Connecting: *The sound of the drinks machine*



4. Empathising: *Sound dampening headphones*



3. Imagining:

*It must be loud for him, teh sound is unpredicat-able which he ha snot control of.*

# Appendix 37

## **Appendix 37: A selection of feedback from the support staff about the Ready Steady Make workshops between 2012 - 2014**

“I thoroughly enjoyed the workshop you, covered a lot. What was good about it was that it was formal but not too formal because it was quite hands on. It wasn't just a lecture. It was good to have all the different senses explained as it is such a major part of this job and autism.”

“The sensory profile handouts you gave us would have been fun to have done in advance. You could then include a component in your workshop where people pick random materials off the table and create a prop to reflect the profile.”

Very much enjoyed today, great to get creative together! I think it was a great way to get to think positively about the men and women we support and make something for them, which shows aspects of their personality. I thought it was a really positive time!

“Really good fun and interesting, makes you think a lot about sensory things. Looking forward to giving it to Kayleigh.”

I found today's workshop quite fun, artistic and creative for the people we support.”

“Really enjoyed being able to be creative on behalf of someone else. Maybe we could have another workshop where the PWS are included in purchasing materials with a view to making something together based on a theme.”

Perhaps I could get Lee to make a collage about things he likes. Really enjoyed the workshop, gives you a lot to think about.”

“ I really enjoyed making the tree for the PWS. Also the slide shows on the research of sensory for people with autism. I will put what I have learnt into practice and read up more on sensory.”

“There were very good ideas and I personally have enjoyed it throughout the session and I will look forward to future workshops.”

“It was fun very relaxed and inclusive. Good chance to team build.”

“This was a good chance to use team building and help fellow support workers. It was fun and really made you think of what the person you support likes.”

“Katie had a wide knowledge and experience on the sensory subjects. It was a fun day with creative ideas. Made you think and motivated the room.”

“An enjoyable afternoon with Katie, you have opened my eyes to the importance of sensory activities with the people we support.”

“It has been good training to be more aware of sensory issues, and how we can take that knowledge to best serve out service users. It will help interaction and reduce anxiety.”

“Truly fantastic workshop, really inspiring way to support the people we support in their daily lives.”

“It was a brilliant course and I think some of the people we support would benefit from attending. Other staff who have not attended could be included if other sessions are planned.”

“Loved this! I don't class myself as creative person but after this workshop Katie has shown me how simple and cheap some fantastic props are to make. It will be great to take these ideas back to my work place.”

“Really great training. It’s great to get some good practical ideas that are affordable as sometimes it is hard to get money together to get products.”

“I really found the sensory workshop very interesting and fun. The information will help us how to find more sensory props. Really good training, the trainer was really knowledgeable.”

“The content of the course was really good and made you think of individuals we support and how the resources and information and how to make sensory objects, I feel this will benefit most individuals we support. Was very enjoyable course and will take all I learnt on board and pass this information onto others.”

“ I enjoyed the sensory workshop, I learnt that we can make sensory props without spending much money, and as well as them being fun to touch, they are fun to make.”

“Thanks for a very informative workshop. I made me more aware of how we can use things in the environment to create varying sensory experiences for the people we support. I look forward to trying out the ideas with the clients and expanding them.”

“I have found this morning a good experience to use my imagination for finding uses of everyday materials- often recycled rubbish to turn into sensory items which will provide enjoyment for people with sensory needs. I feel the people we support will benefit from being supported to make some items to which they can get enjoyment from.”

“The sensory garden workshop is fun, entertaining and informative. It’s nice to learn how we can use simple everyday items into useful and creative stuff. It’s definitely something we can apply and teach our service users to make. I wish there’s more time to do all these creative fun stuff, other than that, it’s very interesting.”

“It was a very interesting and fun morning. The things you can buy are so cheap and affordable. It highlighted that anyone can do it and make such simple and fun sensory

stimulating items. I think a lot of the people we support would benefit in making many of the items made. My favorite was the Hoopla-Hoop!”

“Thoroughly enjoyable. We were kept engaged throughout and it was great fun. Learnt a lot and it was good re-capping what I learnt on the other sensory workshop. Please do another one, really enjoyed it.”

“Really got inspiration going and some brilliant ideas to introduce to people and the garden. Nice to spend time having fun with other staff.”

“Thank you for a very inspiring workshop. I look forward to trying out some of these ideas in the garden. It would be really good to work with you and devise a workshop that involved plants and working outside in the garden setting using natural materials.”

“Another fun and interesting workshop, thank you Katie. I really like the idea you mentioned about bringing random materials and having a free for all session. Sounds good!

The workshop was interesting and the participants were hands on creating designs as per guidance of the tutor who actually know the topic quite well. I for my part learnt a few skills about the workshop of simple creation that are actually not expensive but quite colourful, bright and nice to look at.”

I really enjoyed this sensory workshop, Katie and Marie were very experienced in the area. I can’t wait for the next one. I enjoyed making and creating the items.”

“Very good workshop. Interesting to learn how to make things for little money. I liked how relaxed it was made me feel comfortable. Katie was very welcoming and happy which made the training fun.”

“Many thanks for the workshop –enjoyed meeting all and the opportunity to get ‘hands-on’. I’m sure J will love his Christmas wreath!”

“Really opened my eyes to the sensory possibilities. Very inspirational, would really like Katie’s input at Horpath. Please, please, please!”

“I really enjoyed the workshop I think what you are doing is really good and on the right lines to what us support workers are doing with the service users homes and is good to give each other ideas.”

“The workshop was FAB! I learn’t a lot and will take lots back and apply it to my work /my service every shift.”

“I’ve never been on a workshop like this before. Although I am not very good a drawing, I enjoyed the creative approach. It’s very different from other workshops. It made me think what activities service users could do to communicate how they feel about events that’s happened.”

“Good fun. Something I wouldn’t have thought about doing myself, and would be interesting to try the storyboards, or play with the service users.”

“ I really enjoyed the storyboard thing about the steps it takes to go on an activity made me realize more about the visual expectations the people we support imagine daily.”

“ I think it was a good way to share experiences. Also making the boards was fun; thinking of way to make a table sink etc.... I think a story will stick in my head more too. I think I will think more of steps when I do an activity to break down.”

“Would be a nice idea to use storyboards with service users to show the activities or achievements done during the day.”

“Really enjoyed the course, very useful insight to breaking down activities into frameworks and acting out the day’s activities.”





# Appendix 38

## **Appendix 38: Feedback from six members of the Expert Reference Group**

### **Sue Osborn, Chief Executive, The Kingwood Trust, UK**

**April 2015:** The importance of design in improving the lives of people with autism has been long overlooked and unrecognised. Katie Gaudion's work has demonstrated unequivocally that an appropriately designed environment can have a profound impact on the health and well-being of autistic people. Kingwood has implemented many of the design recommendations with a demonstrable positive outcome for each individual.

### **Monica Cornforth, Media Relations Consultant and parent of adult with autism.**

**February 2015:** As a parent of son with ASD, subconsciously I have been 'designing' his life from day one. Always aware of what upsets Joe, I've tried to make his life run as smoothly as possible and it's the smallest - almost imperceptible - changes and situations that can upset him. I suppose I always have viewed his difficulties with situations as really negative, difficult and annoying. I've found it really helpful that you are using these challenges as less negative and more of a set of criteria to address in your designs.

I also liked the non-prescriptive way of working. Everything seemed to work across a wide range of abilities and specific needs and I think that's an important message to give. Despite creating systems and ideas for a wide group of individuals, there seemed to be a way that each individual could have their needs met. As soon as you began the project, I've been so impressed by the way you have pulled the information together and assimilated it into creating environments and activities that encourage a positive interaction with the outside world.

Something I have really liked about the way the work has been carried out is that it is all incredibly positive. Focusing on the positives rather than the negatives. It's probably

helped me view autism as less of a disability and more of a set of specific needs. Subtle I know but it makes for more achievable goals. Everything in the project always seemed to make sense and I could see how the projects could actually work really effectively in practice.

I think that giving people with autism the opportunity to be involved in the design process has been great. I think everyone likes to feel that they have control over their environment and activities so I'm sure that has been an empowering activity for them. Also giving parents and carers a key role in the design process has been very positive.

**Richard Seymour, Director of Seymourpowell and parent of adult with autism.**

**April 2015:** Why is design important in the area of autism and what is it about autism that can assist and inform design? Well I am one of them. I sit at pretty much the soft end of the spectrum, I don't have communication issues but what I have is the blessing of one of the savant abilities and when I look back on my life as an undiagnosed person on the spectrum it all makes perfect sense. I could not read until I was nine or ten but could draw a perfect proportion of a fire engine when I was three. It has given me a personal insight into the way in which the brain operates in a design area so my answer sits between both those questions. Many designers I know who are really good at what they do are people who have had a focus and a capability of extreme linearity, and I am always suspicious when I see them; is it just that you really like what you do or is there something else going on.

It is a critical issue to bring design into the autistic spectrum because of the sympathetic nature of design. The original meaning of the word is the ability to determine how people are that are different to you and what their needs are. To be able to extend that thinking into the minds of people who are not as yourself I think is a super critical issue for autism, yes, but how about all the other issues that compromise a person's ability to operate independently in society? My son's autism has give me huge insight into design. It's given me huge insights into the emotional aspects of design and how environmental factors can trigger an event. So to patrol that area and understand these elements helps you to understand design full stop.

The great power in what you have done is it has set up a different framework for evaluation and you are determining the whole issue in a different way. Most people that know as much as you about autism are medical professionals or psychologists and you come in from a design perspective, which is virtually unique.

**Colum Lowe, Design Advisor, BEING UK.**

**February 2015:** Before Katie undertook her PhD there was very little structured and researched thinking on Design for Adult Autism. The relationship between the Kingwood Trust, Monument and Helen Hamlyn Centre for Design has resulted in a far greater understanding how the physical world within which adults with autism live shapes the quality of their lives, and how this environment in turn must be shaped. Working in the field of design and adult autism has resulted in a new way of thinking about design research. Katie was forced to develop new techniques to create insights that did not always involve talking with users, observing them in their daily lives or communicating ideas through visuals and images of potential solutions. This has wide reaching implications for working with many other groups who may be neurologically non typical.

**Valerie Fletcher, Executive Director, The Institute for Human Centred Design, USA.**

**February 2015:** The WHO International Classification of Function, Disability and Health from 2001 was a huge turning point in thinking about the role of design in human experience. It established parity between physical and mental reasons for functional limitation and stated that the experience of functional limitation in the 21st century is a universal experience because of longer lifespans and dramatic increases in survival of illness, injury and congenital and genetic conditions. But, most importantly, they redefined disability as a contextual variable. Functional limitation is a fact but it is at the intersection of the person with a functional limitation and their environment that disability happens or is avoided. They were smart about environments and included not only the physical but also the information, communication, social and policy environments. And they called for the identification of "facilitators" that would

minimize disabling experiences and enhance both performance and experience. WHO identified universal design/inclusive design as the most promising framework for identifying facilitators. Barrier removal is an inadequate goal but more a starting point. I think that the work you have done so well has been a tour-de-force in identifying facilitators.

**Dr Sandy Toogood, Senior Lecturer in applied behaviour analysis, Bangor University, UK**

**March 2013:** Many people perform many activities for pleasure and to avoid unpleasant consequences. This is quite normal. Problems arise, however, when aversive control (or excessive appetitive control) becomes a barrier to living an ordinary life. Researchers have found that good staff support, for example in active support environments, has the dual effect of increasing appetitive control and of reducing aversive control. Researchers have paid scant attention to the effect equipment, such as washing machines and vacuum cleaners, may have upon people when performing activities. This is surprising since it seems obvious that the design of equipment may enhance or diminish a person's motivation to use the equipment, and that this may especially be the case where a person has a diagnosis of autism and his or her sensory perception is thought to have been altered in some way. Affordances may, of course, enhance or diminish a person's motivation to engage in activity.

Thoughtful, sensitive and personalised attention to the design of equipment balances a person's motivation to engage in activity. An activity may become intrinsically more fun or less arduous as a consequence of attending to the critical features of equipment design. In this regard design may become a natural bedfellow of active support, working hand-in-hand with arrangement of the physical and social environment to create conditions that correspond optimally with what it is that a person wants or needs.

**Dr Teresa Tavassoli, Post Doctoral Fellow, Seaver Autism Center, New York**

**April 2015:** Your research is important, because it helps individuals with autism to live in a more sensory-friendly environment. Rather than changing an individual we can change his/her environment to make it more sensory-friendly. Your work comes from a

designer perspective, which is highly needed. A lot of the existing research comes from psychologists or OT's, which work on how to change the individuals perception, e.g. to tolerate certain stimuli. Your project comes from another important angle, which makes it possible to adapt the environment rather than the person. Your work is particularly important since sensory issues in ASD are now part of the new DSM-5, as part of Symptom B category

Increase of awareness: Your work is important, since it increased the awareness of sensory preferences or design ideas, for everyone working and living with people who have autism. You have made support staff aware and mindful of how an individual with autism might experience their environment, which might lead to a perception shift.



# Appendix 39

## **Appendix 39: A description of the ‘Celebrating Neurodiversity’ Workshop**

Part of AcrossRCA interdisciplinary collaboration week at the Royal College of Art  
27- 31 October 2014

There is a great deal of 'differences' among human brains and human minds, this is called neurodiversity. Autistic adults, who are often excluded from design research, were central to this workshop. Autistic adults are people whose sensory perceptual experience of their surroundings is unique, but also they are people who may not be able to communicate those differences verbally.

The workshop invited autistic people across the spectrum to share their life experiences with a group of RCA students. The students were encouraged to reflect and challenge their own neurotypical assumptions and ways of experiencing and perceiving the world and to explore how different ways of seeing, doing, and behaving can inspire their creative practice. The students, working in teams explored how, by being creative: using making, spatial and visual thinking skills, new modes of non-verbal communication and dialogue and understanding about themselves could be developed.

The students took part in a range of games and empathic exercises to help them explore their own sensory perceptual experiences and cognitive profiles.



Speakers were invited to explore and discuss the topic of sensation and perception in relation to autism and create a holistic picture for the students of the lived experience of autistic adults:

**Katie Gaudion** presented her design work and empathic design approaches using sensory props and Sensory Preference cards.

**Lizzie Raby** took the students on a gustatory journey involving ice cream to explore an autistic person's hyper and/or hypo sensitivities.

Works by **Rebecca Lyddon** were presented to create better awareness and understanding of the autistic sensory world.

**Jon Adams**: an artist and geologist by training who has Asperger's Syndrome, talked about his synesthetic experiences through the medium of his art, which combines installations, illustration, film and sculpture.

**Andrew Brand** talked about 'Squease', an inflatable pressure vest designed for people who have difficulties processing sensory information, such as people with autism, ADHD, sleeping or anxiety disorders.

**Robyn Steward** who has a diagnosis of Asperger's Syndrome and is an artist and author of *The Independent Woman's Handbook to Super-safe Living on the Autistic Spectrum*, gave a lively and informative presentation through the act of singing, music and painting. The presentation exemplified some of the challenges she has experienced being female and autistic.



**Ben Connors** an artist/illustrator and campaigner gave a very thought-provoking presentation about his PA work with a young autistic man, which he documented through drawing.

**Monica Cornforth** spoke about her experiences raising her autistic son and some of the challenges and joys she had experienced along the way.

**Lucy Skuce** who is autistic and a talented filmmaker, presented to the group. She gave a presentation about her interests, films and everyday experiences, and played her film: *People and Power*.

Outings during the week included a visit to The Hub Day Centre where the group met Ian Wilson, Art Co-coordinator at the Hoffman Foundation. He has over 23 years experience working with autistic adults on arts and crafts activities, such as drawing, textiles and furniture making. Ian showed the students some of the artworks his clients had created, which illustrated different visual perceptual styles. Ian also facilitated some perceptual exercises for the students.

The students also visited The Centre for Research in Autism and Education (CRAE) at the Institute of Education, where they had the opportunity to meet researchers working in the field of autism from a social science background.

Towards the end of the week the students, split into three groups, were asked to explore and prototype ideas and work through an accelerated creative process to arrive at three ideas to share and present to the expert panel. The brief encouraged the students to explore and reflect what they had experienced during the week. Each team was given the sensory profiles of four autistic adults (using the Sensory Preference Cards) and were asked to make a gift for a person based on their sensory likes and dislikes.

The students presented their projects to the panel and an audience from the RCA. The results were a very thoughtful collection of works including: a pink tactile flipbook for Lucy; a range of badges with different labels and a tactile communication toolkit.



**Group One:**

*Laura Venables, RCA Textiles; SooJin Hong, RCA Painting; Carrie Dickens, RCA Jewellery*

Group One's individual creative responses to the workshop included a range of interactive, sensory cubes aimed at a designer's personal sensory experience and responses. Inspired by keywords and the sensitivity towards language, a member of this group created a collection of laser cut badges. Together, the group made an interactive library of tactile, audible and scented cards with textured with encapsulated items, that designers can keep around as for reference and inspiration, or, they could be used by an autistic individual to explore their sensory preferences with others.

*"Thanks for organising such an amazing week. It was thoughtful, challenging, honest, a bit raw, and very human." RCA student*

**Group Two:**

*Monika Bansal, RCA Visual Communication; Ayesha Saeed, RCA Photography;*

*Hannah Robson, RCA Textiles*

Individual responses from this group included: a range of badges based on conversations with Jon Adams; an enquiry into the theme of repetition and an artwork (embroidery) based on the phrase: 'When you've met one person with autism you've met one person with autism' omitting the words 'with autism' in the embroidery. Based on the sensory preferences of 'Lucy' the group created a sculptural pink tactile flipbook.

*"The week was really inspirational and I am loving exploring the new ideas and sensory concepts." RCA student*

**Group Three:**

*Seth Pimlott, RCA Sculpture; Jude Crilly, RCA Sculpture; Jessica Lyons, RCA*

*Architecture*

A member from this group showed a music video and discussed his concept for a music video with an autistic individual with which he has some contact. This generated a discussion around ethical and Intellectual Property implications when working with autistic people. Based on the sensory preferences of 'Tony' the group created a textured dance mat that interacted with a musical device.

*"It was a fascinating week and so much has stayed in my mind since. Great job bringing together so many interesting people and ideas." RCA student*



# List of References

Ahrentzen, S. and Steele, K. 2009. *Advancing full spectrum housing: designing for adults with autism spectrum disorders: a technical report*. Tempe, Arizona: The Herberger Institute School of Architecture and Landscape Architecture and the Stardust Center for Affordable Homes and the Family.

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders: DSM 5 development*. [Online]. [Accessed 5 February 2014]  
Available from: <http://www.dsm5.org/Pages/Default.aspx>

Archer, B. 1995. The nature of research. *CoDesign Journal*, **2**, pp. 6-13.

Arnstein, S. R. 1969. A ladder of citizen participation. *Journal of the American Planning Association*. **35** (4), pp. 216-224.

Asperger, H. 1944. Autistic psychopathy in childhood. In: Frith, U. ed. 1991. *Autism and Asperger syndrome*. Cambridge: Cambridge University Press, pp. 37-92.

Attwood, T. 2003. Understanding and managing circumscribed interests. In: M. Prior. ed. *Learning and behavior problems in Asperger's syndrome*. New York: Guilford Press. pp. 126-147.

Auricchio M., Eng, NL., Nicholas, JCO. 2011. On the functions of products. In: *Proceedings of the 18th International Conference on Engineering Design (ICED), August 15-18 2011, Copenhagen, Denmark*. Castle Cary: Design Society, pp. 443-455.

Ayres, A. J. 1972. Types of sensory integrative dysfunction among disabled learners. *American Journal of Occupational Therapy*. **26**, pp. 13-18.

- Baggs, A, 2001. *In my language*. [Online]. [Accessed 10 December 2010]. Available from: <https://www.youtube.com/watch?v=JnylM1hI2jc>
- Bagby, M. S., Dickie, V, A., Baranek, G,T. 2012. How sensory experiences of children with and without autism affect family occupations. *American Journal of Occupational Therapy*. 66, pp. 78-86.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., Charman, T. 2006. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism project (SNAP). *The Lancet*. **368** (9531), pp. 210-215.
- Baker, M. J. 2000. Incorporating the thematic ritualistic behaviours of children with autism into games. *Journal of Positive Behaviour Interventions*. 2, pp. 66-84.
- Baron-Cohen, S. 2012. *Zero degrees of empathy*. Penguin UK.
- Baron-Cohen, S., Leslie, A, M., Frith, U. 1985. Does the autistic child have a ‘theory of mind’? *Cognition*. 21, pp. 37-46.
- Baron-Cohen, S. and Wheelwright, S. 1999. ‘Obsessions’ in children with autism or Asperger syndrome: a content analysis in terms of core domains of cognition. *British Journal of Psychiatry*. 175, pp. 484-409.
- Baumers, S. and Heylighen, A. 2010a. Harnessing different dimensions of space: the built environment in anti-biographies. In: Langdon, P., Clarkson, P, J., Robinson, P. eds. *Designing inclusive interactions*. London: Springer, pp. 13-23.
- Baumers, S. and Heylighen, A. 2010b. Beyond the designer’s view: how people with autism experience space. In: *Design Research Society, 7-9 July 2010, Montréal*. [Online]. [Accessed 4 March 2013]. Available from: <https://lirias.kuleuven.be/bitstream/123456789/270650/3/008.pdf>
- Beaver, C. 2003. Breaking the mold. *Communication*. **37**(3), p. 40.

Beaver, C. 2011. Designing environments for children and adults on the autism spectrum. *Good Autism Practice*. **12**(1), pp. 7-11.

Bemporad, J. 1979. Adult recollections of a formerly autistic child. *Journal of Autism and Developmental Disorders*. **9**(2), pp.179-197.

Benton, L. 2013. *Participatory design and autism: supporting the participation, contribution and collaboration of children with ASD during the technology design process*. PhD thesis, University of Bath.

Benton, L., Johnson, H., Brosnan, M., Ashwin, E., Grawemeyer, B. 2011. IDEAS: An interface design experience for the autistic spectrum. In: *Extended Abstracts on Human Factors in Computing Systems. CHI'09: CHI Conference on Human Factors in Computing Systems, 4-9 April, Boston, MA*. New York: ACM Press., pp. 1759-1764.

Benton, L. and Johnson. 2014. Structuring participatory design for children: can typically developing children benefit from additional support during the design process? *Instructional Science*. **42**(1), pp. 47-65.

Blackman, L. 2001. *Lucy's story: autism and other adventures*. London: Jessica Kingsley.

Bødker, K., Kensing, F., Simonsen, J. 2004. *Participatory IT design; Designing for business and workplace realities*. Cambridge, MA: MIT Press.

Bogdashina, O. 2003. *Sensory perceptual issues in autism and Asperger's syndrome: different sensory experiences - different perceptual worlds*. London: Jessica Kingsley.

Boyd, B. A., Conroy, M, A., Mancil, G, R., Nakao, T., Alter, P, J. 2007. Effects of circumscribed interests on the social behaviours of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. **27**, pp. 1550-1561.

- Brand, A. 2010. *Living in the community: housing design for adults with autism*. London: Helen Hamlyn Centre for Design, Royal College of Art.
- Brown, C. and Dunn, W. 2002. *Adult/adolescent sensory profile: user's manual*. San Antonio, Texas: Psychological Corporation.
- Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F, J., Purdon, S., Harris, J., Bankart, J. 2009. *Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey 2007*. Leeds: The NHS Information Centre for Health and Social Care.
- Burlamaqui, L. and Dong, A. 2014. The use and misuse of the concept of affordance. In: *Sixth International Conference in Design Computing and Cognition, 23-25 June 2014, University College London*.
- Caldwell, P. 2006. Speaking the Other's Language: Imitation as a Gateway to Relationship. *Infant and Child Development*, **15**, pp. 275-376.
- Cassim, J., Coleman, R., Clarkson, J., Dong, H. 2007. Why inclusive design? In: Coleman, R., Clarkson, H., Cassim, J. eds. *Design for Inclusivity*. Hampshire UK: Gower Publishing Ltd.
- Charlop-Christy, M. H. and Haymes, L. K. 1996. Using obsessions as reinforcers with and without mild reductive procedures to decrease inappropriate behaviours of children with autism. *Journal of Autism and Developmental Disorders*. **26**(5), pp. 527-546.
- Charlop-Christy, M. and Haymes, L. 1998. Using objects of obsession as token reinforcers for children with autism. *Journal of Autism and Developmental Disorders*. **28**(3), pp. 189-198.



- Chawla, L. and Heft, H. 2002. Children's competence and the ecology of communities. *Journal of Environmental Psychology*. 22, pp. 201-216.
- Chemero, A. 2003. An outline of a theory of affordances. *Ecological Psychology*. 15 (2), pp. 181-195.
- Clark, C. and Uzzell, D. 2006. The socio-environmental affordances of adolescents' environments. In: Spencer, C., Blades, M. eds. *Children and their environments: learning, using and designing spaces*. Cambridge: Cambridge University Press, pp. 176-196.
- Coleman, R. 1994. The case for Inclusive Design – an overview. In: *Proceedings of the 12th Triennial Congress*. International Ergonomics Association and the Human Factors Association of Canada.
- Condon, P M. 2008. *Design Charrettes for Sustainable Communities*. Washington, DC: Island Press.
- Cooper, A. 1999. *The Inmates are Running the Asylum: Why High-tech Products Drive Us Crazy and How to Restore the Sanity*. Indianapolis: MacMillan
- Crotty, M. 1998. *The Foundations of Social Research: Meaning and Perspective in the Research Process*. London: Thousand Oaks, New Delhi: Sage publications.
- Cross, N. 2001. Designerly ways of knowing: design discipline versus design science. *Design Issues*. 17 (3), pp. 49-55.
- Davison, R. M. 1998. *An Action Research Perspective of Group Support Systems: How to Improve Meetings in Hong Kong*. PhD thesis, City University of Hong Kong.
- Decker, E. 2014. *A city for Marc: an inclusive design approach to planning for adults with autism*. Master's thesis, Kansas State University.

Delacato, C. 1974. *The ultimate stranger*. Novato, CA: Academic Therapy.

The Department of Health. 2001. *Valuing People: A New Strategy for Learning Disability for the 21st Century; a white paper*.

Dickie, V. A., Baranek, G.T., Schultz, B., Watson, L.R., McCornish, C.S. 2009. Parent reports of sensory experiences of preschool children with and without autism: a qualitative study. *American Journal of Occupational Therapy*. 63, pp. 172-181.

Dong, H. and Vanns, N. 2009. Meeting the challenge of introducing inclusive design to degree level teaching: a case study. *The Design Journal*, **12** (1), p 95-116

Donvan, J. and Zucker, C. 2010. Autism's first child. *The Atlantic*, article no. 308227 [Online]. [Accessed November 2012]. Available from: <http://www.theatlantic.com/magazine/archive/2010/10/autisms-first-child/308227/>

Druin, A. 1999. Cooperative inquiry: developing new technologies for children with children. In: *Proceedings of the ACM CHI 99 Human Factors in Computing Systems Conference, 15-20 May 1999, Pittsburgh, PA*. New York: ACM Press, pp. 592-599.

Druin, A. 2002. The role of children in the design of new technology. *Behaviour and IT*. 21, pp.1-25.

Dunne, A., Gaver, W. W., Pacenti, E. 1999. Cultural Probes. *Interactions*, **6** (1), pp. 21-29.

Dunst, C.J., Trivette, C.M., Masiello, T. 2010. Influence of the interests of children with autism on everyday learning opportunities. *Psychological Reports*. **107**(1), pp. 281-288.

Eveloff, H. H . 1960. The autistic child. *Archives of General Psychiatry*. **3** (1), pp. 66-81.

Feil-Seifer, D. and Matarić, M. J. 2009. Toward socially assistive robotics for augmenting interventions for children with autism spectrum disorders. *Experimental Robotics*. 54, pp. 201-210.

Fling, F.R. 2000. *Eating an artichoke: a mother's perspective on Asperger syndrome*. London: Jessica Kingsley.

Ford, I. 2010. *A field guide to earthlings*. Albuquerque, NM: Ian Ford Software Corporation.

Foth, M and Axup, J. 2006. Participatory Design and Action Research: Identical Twins or Synergetic Pair? In: *Proceedings of the Participatory Design Conference*. pp. 93-96

Francis, P., Balbo, S., Frith, L. 2009. Towards co-design with users who have autism spectrum disorders. *Universal Access in the Information Society*. 8 (3), pp. 123-135.

Frauenberger, C., Good, J., Keay-Bright, W. 2010. Phenomenology: a framework for participatory design. In: *Proceedings of the 11th Biennial Participatory Design Conference, 29 November – 3 December 2010, Sydney*. New York: ACM Press, pp. 187-190.

Frauenberger, C., Good, J., Keay-Bright, W. 2011. Designing technology for children with special needs: bridging perspectives through participatory design. *CoDesign: International Journal of CoCreation in Design and the Arts*. 7(1), pp. 1-28.

Frauenberger, C., Good, J., Keay-Bright, W., Pain, H. 2012a. Interpreting input from children: A designerly approach. In: *CHI '12: ACM SIGCHI Conference on Human Factors in Computing Systems, 5-10 May 2012, Austin, TX*. New York: ACM Press, pp. 2377-2386.

Frauenberger, C., Good, J., Alcorn, A., Pain, H. 2012b. Supporting the design contributions of children with autism spectrum conditions. In: *IDC '12: Proceedings of*

*the 11th International Conference on Interaction Design and Children, 12-15 June 2012, Bremen, Germany.* New York: ACM Press. pp. 134-143.

Frauenberger, C., Good, J., Alcorn, A. 2012c. Challenges, opportunities and future perspectives in including children with disabilities in the design of interactive technology. In: *IDC '12: Proceedings of the 11th International Conference on Interaction Design and Children, 12-15 June 2012, Bremen, Germany.* New York: ACM Press, pp. 367-370.

Frauenberger, C. Good, J., Alcorn, A., Pain, H. 2013. Conversing through and about technologies: design critique as an opportunity to engage children with autism and broaden research(er) perspectives. *International Journal of Child-Computer Interaction*, **1**(2), pp. 38-49.

Frith, U. 1989. *Autism: explaining the enigma.* Oxford: Blackwell.

Frith, U. 2003. *Autism: explaining the enigma.* 2nd ed. Oxford: Blackwell.

Fuente, J. Gustafson, S., Twomey, C., Bix, L. 2014. An affordance-based methodology for package design. *Packaging Technology and Science*. **28**(2), pp. 157-171.

Fulton Suri, J. 2003. Empathic Design: informed and inspired by other people's experience. In: Koskinen I, Battarbee K and Mattelmäki T eds. *Empathic Design: User Experience in Product Design.* Finland: IT Press, pp. 51 -57

Gagnon, E. 2001. *Power cards: using special interests to motivate children and youth with Asperger syndrome and autism.* Shawnee Mission, KS: Autism Asperger Publishing Company.

Galvao, A.B. and Sato, K. 2005. Affordances in product architecture: linking technical functions and users' tasks. In: *Proceedings of IDET/CIE ASME 2005 International Design Engineering Conferences & Computers and Information in Engineering*

Conference, September 24-28 2005, Long Beach, CA. New York: ASME Press, pp. 1-11.

Gaudion, K and McGinley, C. 2014. *Artworks I Like, Exploring Artwork Preferences for Autistic People. Report. Paintings in Hospitals. [Online]. Available from: <http://www.paintingsinhospitals.org.uk/evidence/our-research>*

Gaver, W. W. 1991. Technology affordances. In: *CHI '91: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems: Reaching Through Technology*. New York: ACM Press, pp. 79-84.

Gaver, W. 1996. Situating action II: affordances for interaction: the social is material for design. *Ecological Psychology*. **8**(2), pp. 111-129.

Gibson, J.J. 1950. *The Perception of the Visual World*. Boston: Houghton Mifflin.

Gibson, J. J. 1966. *The senses considered as perceptual systems*. Boston, MA: Houghton Mifflin.

Gibson, J. J. 1977. The theory of affordances. In: Shaw, R. and Bransford, J. eds. *Perceiving, acting and knowing: toward an ecological psychology*. Hillsdale, NJ: L. Erlbaum Press, pp. 67-82.

Gibson, J. J. 1979. *The ecological approach to visual perception*. Boston: Houghton Mifflin.

Gernsbacher, M.A. 2006. Toward a behavior of reciprocity. *Journal of Developmental Processes*. **1**, pp. 139-152.

Glover, E. and Mesibov, G. 1978. An interest centre sensory stimulation programme for severely and profoundly retarded children. *Education and Training of the Mentally Retarded*. **13**, pp. 172-176.

Goldsmith, T. R. and LeBlanc, L. A. 2004. Use of technology in interventions for children with autism. *Journal of Early and Intensive Behavior Intervention*. **1**(2), pp.166-174.

Grandin, T. 1984. My experiences as an autistic child. *Journal of Orthomolecular Psychiatry* **13**, pp. 144-174.

Grandin, T. 2008. *The way I see it: a personal look at autism and Asperger's*. Texas: Future Horizons.

Gray, C. and Attwood, T. 1999. The discovery of aspice criteria. *The Morning News*. **11**(3), pp. 18-28.

Guha, M. Druin, A., Fails, J. 2008. Designing with and for children with special needs: an inclusionary model. In: *IDC '08: Proceedings of the 7th International Conference on Interaction Design and Children, 11-13 June, Chicago, IL*. New York: ACM Press, pp. 61-64.

Gumtau, S., Newland, P., Creed, C., Kunath, S. 2005. MEDIATE: a responsive environment designed for children with autism. In: *Accessible Design in the Digital World Conference, 23-25 August 2005, Dundee*. [Online]. [Accessed 21 September 2013]. Available from: <http://ewic.bcs.org/content/ConWebDoc/3805>

Hartson, R. 2003. Cognitive, physical, sensory, and functional affordances in interaction design. *Behaviour and Information Technology*. **22**(5), pp. 315-338.

Heft, H. 1988. Affordances of children's environments: a functional approach to children's environments. *Children's Environment Quarterly*. **5**(3), pp. 29-37.

Hellendoorn, A. 2014. Understanding social engagement in autism: being different in perceiving and sharing affordances. *Front Psychology*. **5** pp. 850.

- Herbert, B. 2003. *Design guidelines of a therapeutic garden for autistic children*. PhD thesis, Louisiana State University.
- Heron, J. 1971. *Experience and method*. Guildford: University of Surrey.
- Heylighen A., Neyl, E., Baumers, S., Herssens, J., Vermeersch, P,W. 2010. Conservation meets inclusion: model meets reality. In: *Proceedings of the 5th Cambridge Workshop on Universal Access (UA) and Assistive Technology, 22-25 March 2010, Fitzwilliam College, University of Cambridge*. Cambridge: University of Cambridge, pp. 209-218.
- Higgins, R. 1992. Conducting user research: the three 'Cs', *Social Research Association Newsletter*. August, pp. 5-6.
- Hourcade, J. P., Bullock-Rest, N, E., Hansen, T.E. 2012. Multitouch tablet applications and activities to enhance the social skills of children with autism spectrum disorder. *Personal and Ubiquitous Computing*. **16**(2), pp.157–168.
- Hulsegge, J. and Verheul, A. 1987. *Snoezelen: another world*. Chesterfield: Rompa.
- Hussein, H. 2010. Using the sensory garden as a tool to enhance the educational development and social interaction of children with special needs. *Support for Learning*. **25**(1), pp. 25-31.
- Hsiao, S.W., Hsu, C.F., Lee, Y.T. 2012. An online affordance evaluation model for product design. *Design Studies*. **33**(2), pp. 126-159.
- Human 19. 2012. Understanding neurotypicality. *Politics.ie*. [Online]. [Accessed 12 January 2013]. Available from: <http://www.politics.ie/forum/culture-community/201954-would-you-laugh-3.html>
- Humphreys, S. 2005. Autism and architecture. *Autism London Bulletin*, Feb-Mar, pp. 7-8.

Jenkins, H.S. 2008. Gibson's 'affordances': evolution of a pivotal concept. *Journal of Scientific Psychology*. December, pp. 34-45.

Jordan, P. 1997. Human factors for pleasure in product use. *Applied Ergonomics*. **29** (1), pp. 25-33.

Kanner, L. 1943. Autistic disturbances of affective contact. *Nervous Child*. **2**, pp. 217-50.

Kanner, L. 1971. Follow-up study of eleven autistic children. *Journal of Autism and Childhood Schizophrenia*. **1**(2), pp. 119-142.

Kavan, S. and Kavan, B. 2011. *Trainman: gaining acceptance and friends through special interests*. Kansas: AAPC Publishing.

Keay-Bright, W. 2007. The reactive colours project: demonstrating participatory and collaborative design methods for the creation of software for autistic children. *Design Principles and Practices: An International Journal*. **1**(2), pp. 28-35.

Keay-Bright, W. 2009. ReacTickles: playful interaction with information communication technologies. *International Journal of Art and Technology*. **2**(1/2), pp. 133-151.

Keay-Bright, W. 2012a. Designing interaction through sound and movement with children on the autistic spectrum. In: *Arts and Technology: Lecture Notes of the Institute for Computer Science, Social Informatics and Telecommunications Engineering*, 101. Berlin: Springer, pp. 1-9.

Keay-Bright, W. 2012b. Is simplicity the key to engagement for children on the autism spectrum? *Journal of Personal and Ubiquitous Computing*. **16**, pp. 129-141.



Kereshian, J. and Burd, L. 1986. Asperger's syndrome and Tourette syndrome: the case of the pinball wizard. *The British Journal of Psychiatry*. 148, pp. 731-736.

Kern, J. K., Trivedi, M.H., Garver, C.R., Grannemann, B.D., Andrews, A.A., Savla, J.S., et al. 2006. The pattern of sensory processing abnormalities in autism. *Autism: the International Journal of Research and Practice*. **10**(5) pp. 480-494.

Kern, J. K., Garver, C. R., Carmody, T., Andrews, A.A., Mehta, J.A., Trivedi, M.H. 2008. Examining sensory modulation in individuals with autism as compared to community controls. *Research in Autism Spectrum Disorders*. **2**(1), pp. 85-94.

Khare, R. and Mullick, A. 2008. Educational spaces for children with autism: design development process. In: *Proceedings of CIB W 084: Building Comfortable and Liveable Environments for All, 15-16 May 2008, Atlanta, GA*, pp. 66-75. [Online]. [Accessed March 31 2015]. Available at: <http://www.irbnet.de/daten/iconda/CIB8861.pdf>,

Khare, R. and Mullick, A. 2009. Incorporating the behavioural dimension in designing inclusive learning environment for autism. *International Journal of Architectural Research*. **3**(3), pp. 45-64.

Khare, R. and Mullick, A. 2010. Universally Beneficial Educational Space Design for Children with Autism. In: *Designing for Children, 2-6 February 2010, IDC, IIT, Mumbai, India*. [Online].[Accessed 2 April 2015]. Available at: <http://www.designingforchildren.net/papers/r-khare-designingforchildren.pdf>

Kielhofner, G. and Neville, A. 1983. The modified interest checklist. Unpublished manuscript, University of Illinois at Chicago, Chicago, IL.

Kluth, P. and Schwarz, P. 2009. *Just give him the whale: 20 ways to use fascinations, areas of expertise, and strengths to support students with autism*. London: Jessica Kingsley.

- Kluth, P. and Schwarz, P. 2010. *Pedro's whale*. London: Jessica Kingsley.
- Kouprie, M. and Sleeswijk Visser, F. 2009. A framework for empathy in design: stepping into and out of the user's life. *Journal of Engineering Design*. **20** (5), pp. 437-448.
- Krippendorff, K. 2005. *The semantic turn: a new foundation for design*. Boca Raton, FL; London: CRC Press/Taylor and Francis.
- Lawson, W. 1998. *Life behind glass: a personal account of autism spectrum disorder*. Lismore, NSW: Southern Cross University Press.
- Lawton, M.P. and Brody, E.M. 1969. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. **9**, pp. 179-186
- Lewin, K. 1946. Action Research and Minority Problems. *Journal of Social Issues*, **2** (4) pp. 34-46.
- Linehan, J. 2008. *Landscapes for autism: guidelines and design of outdoor spaces for children with autism spectrum disorder*. PhD thesis, University of California.
- Liss M., Saulnier, C., Fein, D., Kinsbourne, M. 2006. Sensory and attention abnormalities in autistic spectrum disorders. *Autism*. **10**(2), pp. 155-172.
- Lopez, K. and Gaines, K. 2012. Environment and Behavior: Residential designs for autism. In: *Proceedings of the 43rd Annual Conference of the Environmental Design Research Association, 30 May- 2 June 2012, Seattle, OR*, pp. 265-266. [Online]. [Accessed October 11 2013]. Available from: <http://www.edra.org/content/impact-acoustical-environmental-design-children-autism>

Lord, C., Wagner, A., Rogers, S., Szatmari, P., et al. 2005. Challenges in evaluating psychosocial interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, **35** (6), pp.696-708.

Loveland, K. 1991. Social affordances and interaction II: autism and the affordances of the human environment. *Ecological Psychology*, **3**(2), pp. 99-119.

Loveland, K. 2001. Towards an ecological theory of autism. In: Burack, J., Charman, T., Yirmiya, N., Zelazo, P,R. eds. *The Development of Autism: Perspectives From Theory and Research*. NJ: Earlbaum Press, pp.17-37.

Mace, W. M. 1977. James J. Gibson's strategy for perceiving: ask not what's inside your head, but what your head's inside of. In: Shaw, R. and Bransford, J. eds. *Perceiving, acting, and knowing: toward an ecological psychology*. Hillsdale, NJ: L. Erlbaum Press, pp. 43-67.

McAllister, K. and Maguire, B. 2012. A design model: the autism spectrum disorder classroom design kit. *British Journal of Special Education*. **39**(4), pp. 201-208.

McGrenere, J. and Ho, W. 2000. Affordances: clarifying and evolving a concept. In: *Proceedings of Graphics Interface 2000, 15-17 May 2000, Montreal, Canada*. Hillsdale, NJ: L. Erlbaum Press, pp. 179-186.

Madsen, M., Kaliouby, R., Eckhardt, M., Hoque, ME., Goodwin, MS., Picard, R. 2009. Lessons from participatory design with adolescents on the autism spectrum. In: *Extended Abstracts on Human Factors in Computing Systems. CHI'09: CHI Conference on Human Factors in Computing Systems, 4-9 April, Boston, MA*. New York: ACM Press, pp. 3835-3840.

Maier, J.R.A. and Fadel, G.M. 2009a. Affordance-based design methods for innovative design, redesign and reverse engineering. *Research in Engineering Design*. **20**(4): pp. 225-239.

Maier, J.R.A. and Fadel, G.M. 2009b. Affordance based design: a relational theory for design. *Research in Engineering Design*. **20**(1), pp. 13-27.

Maier, J.R.A. and Fadel, G.M. 2009c. An affordance-based approach to architectural theory, design and practice. *Design Studies*. **30**(4), pp. 393-414.

Mark, L. S. 1987. Eyeheight-scaled information about affordances: a study of sitting and stair climbing. *Journal of Experimental Psychology: Human Perception and Performance*. **13**, pp. 683-703.

Martin, B. and Hanington, B. 2012. *Universal Methods of Design*. Gloucester, MA: Rockport.

McDonagh-Philp, D. and Denton, H. 1999. Using focus groups to support the designer in the evaluation of existing products: a case study. *The Design Journal*, **2** (2), pp. 20–31.

Menear, K. S., Smith, S. C., Lanier, S. 2006. A multipurpose fitness playground for individuals with autism: ideas for design and use. *Journal of Physical Education, Recreation and Dance*. **77**(9), pp. 20-25.

Millen, L., Hawkins, T., Cobb, S., Zancanaro, M., Glover, T., Weiss, P. L., Gal, E. 2011. Collaborative technologies for children with autism. In: *Proceedings of the 10th International Conference on Interaction Design and Children, 20-23 June, Ann Arbor, MI*. New York: ACM Press, pp. 246-249.

Millen, L., Cobb, S., Patel, H., Glover, T. 2012. A collaborative virtual environment for conducting design sessions with students with autism spectrum conditions. In: *Proceedings of the 9th International Conference on Disability, Virtual Reality & Associated Technologies (ICDVRAT '12), 10-12 September 2012, Laval, France*. ICDVRAT. Reading: University of Reading, pp 269-278.

Milton, E. M. D. 2012. The ontological status of autism: The 'double empathy problem'. *Disability and Society*, **1** (5), p. 2.

Mostafa, M. 2008. An architecture for autism: concepts of design intervention for the autistic user. *International Journal of Architectural Research*. **2** (1), pp. 189-211.

Mottron, L. and Burack, J. 2001. Enhanced perceptual functioning in the development of autism. In: Burack, J. A., Charman, T., Yirmiya, N., Zelazo, P, R. eds. *The development of autism: perspectives from theory and research*. Mahwah, NJ; London: L. Erlbaum Press, pp. 131-48.

Nind, M. and Hewett, D. 1994. *Access to Communication: Developing the basics of communication with people with severe learning difficulties through Intensive Interaction*. London: David Fulton.

Norman, D. 2008. The way I see it: signifiers not affordances. *Interactions*. **15** (6), pp. 18-19.

Norman, D. A. 1988. *The psychology of everyday things*. New York: Basic Books.

Norman, D.A. 1990. *The Design of Everyday Things*. New York: Doubleday.

Norman, D.A. 1999. Affordance, Conventions and Design. *Interactions*, pp.38-43

Norman, D.A. 2013. *The Design of Everyday Things*. Revised and expanded ed.. New York: Basic books.

Norman, D.A. and Draper, S.W. 1986. *User-Centered System Design: New Perspectives on Human-Computer Interaction*. NJ: Earlbaum Press

Nussbaum, M. C. 2000. *Women and Human Development: The Capability Approach*. New York: Cambridge University Press.

Oliver, M. 1981. A New Model of the Social Work Role in Relation to Disability. In: J. Campling ed., *The Handicapped Person: a New Perspective for Social Workers?* London: RADAR.

Oliver, M. 1990. *The Politics of Disablement*. Basingstoke: Macmillan.

Oliver, M. 2005. The problem with affordance. *E-Learning and Digital Media*. **2**(4), pp. 402-413.

Ornitz, E. M. 1969. Disorders of perception common to early infantile autism and schizophrenia. *Comprehensive Psychiatry*. **10**(4), pp. 259-74.

Ornitz, E. M . 1989. Autism at the interface between sensory and information processing. In: Dawson, G. ed. *Autism: nature, diagnosis and treatment*. New York: Guilford Press, pp.174-207.

Ozonoff, S., Bruce, F., Pennington, F., Rogers, S, J. 1991. Executive function deficits in high-functioning autistic individuals: relationship to theory of mind. *Journal of Childhood Psychology and Psychiatry*. **32**, pp. 1081-110.

Papanek, V. 1971. *Design for the Real World*. New York: Pantheon Books.

Parsons, S. and Mitchell, P. 2002. The potential of virtual reality in social skills training for people with autistic spectrum disorders. *Journal of Intellectual Disability Research*. **46**, pp. 430-443.

Parsons, S. and Cobb, S. 2011. State-of-the art of virtual reality technologies for children on the autism spectrum. *European Journal of Special Needs Education*. **26**(3), pp. 355-36.

Parsons, S., Leonard, A., Mitchell, P. 2006. Virtual environments for social skills training: Comments from two adolescents with autistic spectrum disorder. *Computers and Education*. **47**, pp. 186-206.

Pellicano, E. 2013. Sensory symptoms in autism: a blooming, buzzing confusion? *Child Development Perspectives*. 7 (3), pp. 143-148.

Pellicano, E., Dinsmore, A., Charman, T. 2013. *A future made together: shaping autism research in the UK*. London: Institute of Education.

Pellicano, E. and Burr, D. 2012. When the world becomes too real: a Bayesian explanation of autistic perception. *Trends in Cognitive Sciences*. 16, pp. 504-510.

Pennington, B. F. and Ozonoff, S. 1996. Executive functions and developmental psychopathology. *Journal of Childhood Psychology and Psychiatry*. 37, pp. 51-87.

Polanyi, M. 1958. *Personal Knowledge: Towards a Post-Critical Philosophy*. University of Chicago Press, Chicago.

Richer, J. M. and Nicoll, L. 1971. A playroom for autistic children, and its companion therapy project. *British Journal of Mental Subnormality*. 17, pp. 132-143.

Rimland, B. 1964. *Infantile autism*. New York: Appleton Century Croft.

Roberts, E. M., English, P, B., Grether, J,k., Windham, G, C., Somberg, L., Wolff, C. 2007. Maternal residence near agricultural pesticide applications and autism spectrum disorders among children in the California central valley. *Environmental Health Perspectives*. 115(10), pp. 1482-9.

Robertson, A. E. 2013. *Sensory experiences of individuals with Autism Spectrum Disorder and autistic traits: a mixed methods approach*. PhD thesis. University of Glasgow.

Robson, C.1993. *Real World Research: A resource for social scientists and practitioner-researchers*. Oxford: Blackwell.

Rogers, S. J., Hepburn, S., Wehner, E. 2003. Parent reports of sensory symptoms in toddlers with autism and those with other developmental disorders. *Journal of Autism and Developmental Disorders*. 33, pp. 631-642.

Sachs, N. and Vincenta, T. 2011. Outdoor environments for children with autism and special needs. *Implications*. 9(10), pp.1-7.

Saffer, D. 2006. *Designing for Interaction*. New York: New Riders.

Sanders, E. 2002. From user-centred to participatory design approaches. In: Frascara, J. ed. *Design and the Social Sciences*. London: Taylor and Francis. pp. 1-8

Sanders, E. and Dandavate, U, 1999. Design for experiencing: new tools. In: C.J. Overbeeke and P. Hekkert, eds. *Proceedings of the first international conference on design and emotion*, 3–5 November, The Netherlands: Delft University of Technology, Delft, pp. 87–92.

Sanders, E. and Stappers, P.J. 2008. Co-creation and the new landscapes of design. *CoDesign*, 4 (1), pp. 5-18.

Sanders, L., Brandt, E., Binder, T. 2010. A framework for organising the tools and techniques for participatory design. *Proceedings of the 11th biennial participatory design conference*. ACM.

Sanders, L. 2008. An evolving map of design practice and design research. *Interactions*. November- December, pp. 13-17.

Schön, D, A. 1983. *The reflective practitioner: how professionals think in action*. Boston: Arena Publishing.

Scott, I. 2009. Designing learning spaces for children on the autism spectrum. *Good Autism Practice*. 10(1), pp. 36-51.



Sen, A. 1999. *Development as Freedom*. New York: Anchor Books.

'Shelley from Kalamazoo'. 1998. DSN-IV (The Diagnostic and Statistical Manual of 'Normal' Disorders). *Institute For the Study of the Neurologically Typical*. [Online]. Available from: <http://isnt.autistics.org/dsn.html>

Sinclair, J. 1998. A note about language and abbreviations used on this site. *Jim Sinclair's website* [Online]. [Accessed June 2012]. Available from: <http://web.archive.org/web/20080606024118/http://web.syr.edu/~jisincla/language.htm>

Sinclair, J. 1999. *Why I dislike 'person first' language*. [Online]. [Accessed September 24th 2012] Available from: <http://www.autcom.org/articles/defeated.html>.

Spinuzzi, C. 2005. The Methodology of Participatory Design' Technical Communication, **52** (2), pp. 163-174.

Tammet, D. 2009. *Embracing the wide sky*. New York: Hodder and Stoughton.

Trehin, G. 2006. *Urville*. London: Jessica Kingsley.

Tufvesson, C. and Tufvesson, J. 2009. The building process as a tool towards an all-inclusive school: a Swedish example focusing on children with defined concentration difficulties such as ADHD, autism and Down's syndrome. *Journal of Housing and the Built Environment*. **24** (1), pp. 47-66.

Ungerer, J.A. and Sigman, M. 1981. Symbolic play and language comprehension in autistic children. *Journal of the American Academy of Child Psychiatry*. **20**, pp. 318-337.

Vacca, J. J. 2007. Incorporating interests and structure to improve participation of a child with autism in a standardized assessment: a case study analysis. *Focus on Autism and Other Developmental Disabilities*. **22**, pp. 51-59.

Van Rijn, H. 2012. *Meaningful encounters: explorative studies about designers learning from children with autism*. PhD thesis, Delft University of Technology.

Van Rijn, H., Sleeswijk Visser, F., Stappers, P, J. 2009. Connecting through interacting: toys that help designers learn from children with autism by playing with them. In: *Proceedings of the International Association of Societies of Design Research: Rigor and Relevance in Design, 18-22 October 2009, Seoul, South Korea*.

Van Rijn, H., Sleeswijk Visser, F., Stappers, P, J. 2011b. Stories at the spot: designers learning from caregivers of children with autism. In: *Proceedings of the International Association of Societies of Design Research: Diversity and Unity, 31 October - 4 November 2011, Delft, The Netherlands*.

Van Rijn, H. and Stappers, P. J. 2007. Codesigning LINKX': A case of gaining insight in a 'difficult to-reach user group'. In: *The International Association of Societies of Design Research: Emerging Trends in Design Research, 12-15 November 2008, Hong Kong*.

Van Rijn, H. and Stappers, P, J. 2008a. The puzzling life of autistic toddlers: design guidelines from the LINKX project. *Advances in Human-Computer Interaction*. [Online] pp. 1-8. [Accessed 12 November 2012]. Available from: <http://dx.doi.org/10.1155/2008/639435>

Van Rijn, H. and Stappers, P. J. 2008b. Expressions of ownership: motivating users in a co-design process. In: *Proceedings of the Tenth Anniversary Conference on Participatory Design. 30 September – 4 October 2008, Indiana University, Bloomington, IN*, pp. 178-181. [online]. [Accessed 30 March 2015]. Available at: <http://dl.acm.org/event.cfm?id=RE368&CFID=653200479&CFTOKEN=51272129>

Van Vugt, H., Hoorn, J, F., Konijn, E, A., Bie Dimitriadou, A. 2006. Affective affordances: improving interface character engagement through interaction. *International Journal of Human-Computer Studies*. **64** (6), pp. 874-888.

Vismara, L. A. and Lyons, G. L. 2007. Using preservative interests to elicit joint attention behaviours in young children with autism. *Journal of Positive Behaviour Interventions*. 9, pp. 214-228.

Vogel, C. L. 2008. Classroom design for living and learning with autism. *Autism Asperger's Digest*. 7.

Warren, W. H. 1984. Perceiving affordances: visual guidance of stair climbing. *Journal of Experimental Psychology: Human Perception and Performance*. 10, pp. 683-703.

Weightman, D. and McDonagh, D. 2003. People are doing it for themselves. In: Forlizzi, J, Hanington, B and Ayoob, E eds., *The 67 Proceedings of the International Conference on Designing Pleasurable Products and Interfaces*. Pittsburgh: ACM Press, pp. 34-39.

Welch, K. C., Lahiri, U., Warren, Z., Sarkar, N. 2010. An approach to the design of socially acceptable robots for children with autism spectrum disorders. *International Journal of Social Robotics*. 2(4), pp. 391-403.

Welton, J. 2003. *Can I tell you about Asperger's syndrome? A guide for friends and family*. London: Jessica Kingsley.

Williams, D. 1992. *Nobody nowhere*. London: Doubleday.

Williams, D. 1999. *Like colour to the blind: soul searching and soul finding*. London: Jessica Kingsley.

Williams, E., Costall, A., Reddy, V. 1999. Children with autism experience problems with both objects and people. *Journal of Autism and Developmental Disorders*. 29(5), pp. 367-78.

Williams, E., Kendell-Scott, L., Costall, A. 2005. Parents' experiences of introducing everyday object use to their children with autism. *Autism*. 9(5), pp. 495-514.

Williams, E. and Kendell-Scott, L. 2006. Autism and object use: The mutuality of the social and material in children's developing understanding and use of everyday objects. In: Costall, A., Dreier, O. eds. *Doing things with things: the design and use of everyday objects*. Aldershot; Burlington, VT: Ashgate, pp. 51-47.

Wing, L. 1969. The handicaps of autistic children: a comparative study. *Journal of Child Psychology and Psychiatry*. 10, pp.1-40.

Wing, L. and Gould, J. 1979. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*. 9(1), pp. 11-29.

Winter-Messiers, M. A., Herr, C, M., Wood, C,E., Brooks, A,P., Gates, MA,M., Houston, T,L., Tingstad, K,I. 2007a. How far can Brian ride the daylight 4449 express? a strength-based model of Asperger syndrome based on special interest areas. *Focus on Autism and Other Developmental Disabilities*. 22(2), pp. 67-79.

Winter-Messiers, M. A. 2007b. From tarantulas to toilet brushes: understanding the special interest areas of children and youth with Asperger syndrome. *Remedial and Special Education*. 28(3), pp. 140-152.

Winter-Messiers, M. A. 2007c. *Dinosaurs 24/7: understanding the special interests of children with Asperger's*. 2 April. [Online]. [Accessed 10 April 2012]. Available from: [http://iancommunity.org/cs/about\\_asds/the\\_special\\_interests\\_of\\_children\\_with\\_aspergers](http://iancommunity.org/cs/about_asds/the_special_interests_of_children_with_aspergers)

Woodcock, A., Georgiou, D., Jackson, J., Woolner, A. 2013. Designing a tailorable environment for children with autism spectrum disorders. In: *Proceedings of the Tri-annual Conference of the International Ergonomics Association, 'TEC', July 10-14 2006, Maastricht*. [Online]. [Accessed October 11, 2013]. The Design Institute, Coventry. Available from: <http://www.iea.cc/ECEE/pdfs/art0228.pdf>

Woodgate, R., Atech, C., Secco, L. 2008. Living in a world of our own: the experiences of parents who have a child with autism. *Qualitative Health Research*. **18**(8), pp. 1075-83.

Woolgar, S. 1990. Configuring the user: the case of usability trials. *The Sociological Review*, **38**, pp. 58–99.

Wotton, H. 1624. *The Elements of Architecture*. London.

You, H.C. and Chen, K.S. 2007. Applications of affordance and semantics in product design. *Design Studies*. **28**(1), pp. 23-38.

Yuill, N., Strieth, S., Roake, C., Aspden, R., Todd, B. 2007. Brief report: designing a playground for children autistic spectrum disorder: effects on playful peer interactions. *Journal of Autism Developmental Disorders*. **37**(6), pp. 1192-96.

Zaff, B. 1995. Designing with affordances in mind. In: Flach, J.M., Hancock, P.A., Caird, J., Vicente, K, J. eds. *Global perspectives on the ecology of human-machine systems*. Hillsdale, NJ: L. Erlbaum Press, pp. 238-272.

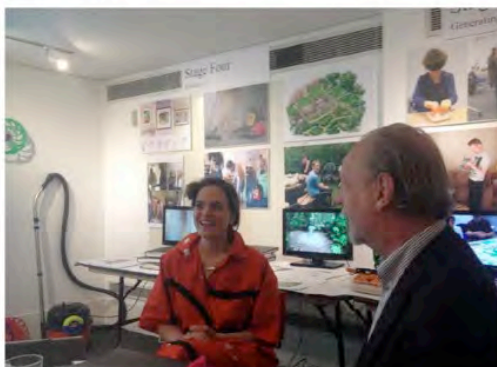
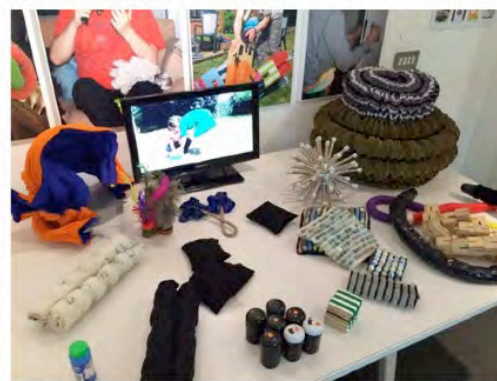
Zelege, S. E. and Junshan, M. 2009. *The theory of affordance as a conceptual tool for landscape design and evaluation*. [Online]. [Accessed 10 April 2013]. Available from: [http://www.paper.edu.cn/en\\_releasepaper/content/36951](http://www.paper.edu.cn/en_releasepaper/content/36951)



# Viva Voce Examination

14.00, 21<sup>st</sup> May 2015

With thanks to my PhD examiners; Prof Pieter Jan Stappers and Prof Paul Chamberlain, Chair; Prof Stephen Boyd Davis and lead supervisors; Prof Jeremy Myerson and Prof Ashley Hall.



16.30 Dr Katie Gaudion!