

Communication and Non-Speaking Children with Physical Disabilities: Opportunities and Reflections from Design-Oriented Research

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Thesis submitted for the degree of

Doctor of Philosophy

2020

'I, Seray B Ibrahim confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.'

87,434 words

Signed:

Seray B Ibrahim, January 2020

Abstract

This thesis presents a series of design-oriented studies for investigating and describing communication involving children with severe speech and physical impairments (SSPIs). The overarching goal is to inform how designers conceptualise communication that involves children with SSPIs beyond a widely cited view that communication centres around speech and happens at the level of the individual through the transmission of information. Instead, by positioning communication as co-constructed, situated and multimodal, the goal is to stimulate how one designs for digitally mediated communication by applying multiple, alternative frames that acknowledge these features.

In order to achieve this goal, qualitative empirical fieldwork is undertaken that examines the everyday communication experiences of five children who have SSPIs. Drawing on theoretical influences from multimodal social semiotics and participatory design, study one and two investigate child centred accounts of communication involving children with SSPIs and their peers. The focus is on investigating communication, first in formal learning contexts involving existing augmentative and alternative communication (AAC) technologies, then in broader contexts beyond AAC use. Multi-layered perspectives are generated that consider: 1. a child's view, by attending to children's values and choices of modes; 2. an interactional view that attends to how communication is co-constructed in situ with other people and material objects, and; 3. a structural view, that examines the orderings of people, material objects and activities within an environment. These layered understandings produce research frames that are then utilised in study three. A design documentary is created and used to motivate design work for supporting face to face communication involving children with SSPIs and their peers with a team of designers who do not hold fixed orientations to designing assistive technologies.

The findings of the three studies make three new contributions to the fields of HCI and AAC. First, the findings produce a theoretical perspective on communication, acknowledging multiple modes and displacing the taken for granted centrality of language. Second, the findings reveal design opportunities for new and existing technologies. Third, the studies contribute methodological insights for design work by considering ways of involving both children and designers when designing with and for children with SSPIs.

Impact statement

The findings of this thesis provide insights that are of benefit both within and outside of academia.

First, the findings contribute to existing work by introducing a new theoretical perspective for studying communication that involves children with severe speech and physical impairments and their social groups. By displacing the value that is typically placed on linguistic modes and recognising child-centred accounts of communication as multimodal and co-constructed, this work contributed to theoretical perspectives on communication in academia and is beneficial for informing clinical assessment and intervention within speech and language therapy practice.

Second, the findings propose design implications for existing and future technologies. These implications are beneficial to the fields of AAC and human computer interaction, by introducing alternative points of foci. Crucially, in light of the high abandonment rate of existing AAC technologies, the design implications also contribute new directions for the assistive technology industry.

Third, by problematising ways of involving children with severe speech and physical impairments in design research, this work is beneficial for researchers and practitioners who work with hard to reach populations. By considering how to involve children with severe speech and physical impairments in informing and shaping outcomes, the insights of this work are beneficial for informing public engagement in both the public sector and in academia.

Acknowledgements

I wish to thank the ESRC for funding this PhD studentship between 2016-2018. It has provided many wonderful opportunities for conversations and learning both near and far.

I am deeply grateful to my supervisors, Dr Asimina Vasalou and Dr Michael Clarke. I could not have asked for a better team. I wish to sincerely thank both Mina and Mike for their unwavering support, compassion and guidance over the past four years. Mina's commitment to her role as supervisor and expertise has made my PhD journey an absolute pleasure. I am grateful to her beyond words for the many opportunities she has created in supporting me to develop as a researcher. Thank you to Mike for his encouragement, his gentle, yet challenging questions, and for planting the seed for bridging AAC and HCI research in a conversation many years ago, prior to Mike supervising my master's dissertation. I will genuinely miss our group discussions.

There are many people at the UCL Knowledge Lab who I am grateful to in what has become the lab's unofficial wellbeing programme. I especially wish to thank my research mentor and friend Dr Laura Benton for her encouragement and generous support, including practical help during my third empirical study. Thanks to Professor Carey Jewitt who has quietly offered her support in so many ways, including helping me with crafting my research proposal in the early stages. Thanks also to Professor Jeff Bezemer, for the opportunity to share this work with others. I owe special thanks to Dr Nikoleta Yiannoutsou and Dr Kerstin Leder Mackley for their practical and emotion support in achieving my writing goals. I am very grateful to Professor Gunther Kress who sadly departed too soon. Through the brief but wonderful conversations, Gunther has inspired me to extend this work in new and exciting directions. I wish to thank Professor Sara Price and Dr Rachel Rosen for their helpful advice at the upgrade examination. I also wish to thank Dr Dylan Yamada Rice from the RCA and to her students for the opportunity to work together during the third study.

Many thanks to my parents who supported me when I decided to quit my longstanding job in the NHS to embark on being a full-time student again, and to my close family members and friends for their patience and care.

Finally, I owe enormous thanks to the children, staff and families who so generously agreed to take part in this study. Their expertise, enthusiasm and time is hugely appreciated.

Table of Contents

ABSTRACT	2
IMPACT STATEMENT	3
ACKNOWLEDGEMENTS.....	4
CHAPTER ONE: INTRODUCTION	13
THESIS OVERVIEW	13
<i>Motivation for overall goal.....</i>	<i>13</i>
THESIS SCOPE.....	15
THESIS STRUCTURE AND CONTRIBUTIONS	16
<i>Chapter two - Theoretical and methodological approaches for investigating communication in children with SSPIs.....</i>	<i>17</i>
<i>Chapter three - Theoretical and methodological approaches to design.....</i>	<i>17</i>
<i>Chapter four - Study one: An observational study to investigate communication involving children with SSPIs and AAC technologies.....</i>	<i>18</i>
<i>Chapter five – Study two: A mixed methods study investigating multimodal communication in school-based environments.....</i>	<i>19</i>
<i>Chapter six - Study three: Designing for multimodal, digitally mediated communication</i>	<i>20</i>
<i>Chapter seven - A theoretical and methodological reflection on investigating children’s voices.....</i>	<i>20</i>
<i>Chapter eight – Conclusions and implications of future work</i>	<i>20</i>
RESEARCH QUESTIONS (RQs) AND RESEARCH GOALS (RGs)	21
CHAPTER TWO: INVESTIGATING COMMUNICATION INVOLVING CHILDREN WITH SEVERE SPEECH AND PHYSICAL IMPAIRMENTS	22
1.1 CONTEXT	22
1.2 THEORETICAL AND EMPIRICAL PERSPECTIVES ON AIDED COMMUNICATION	24
<i>1.2.1 Communication - at an individual level</i>	<i>25</i>
<i>1.2.2. Communication – distributed & co-constructed.....</i>	<i>29</i>
1.3 SUMMARY.....	35
1.4 RESEARCH QUESTIONS.....	37
CHAPTER THREE: THEORETICAL AND METHODOLOGICAL APPROACHES TO DESIGN.....	38
DESIGN APPROACHES.....	38
<i>Design thinking.....</i>	<i>38</i>
<i>Participatory design.....</i>	<i>46</i>
<i>Empathy and design.....</i>	<i>59</i>
APPLICATIONS OF DESIGNING FOR COMMUNICATION AND NON-SPEAKING CHILDREN	64

<i>Design frames in designing for communication and children with disabilities.....</i>	<i>65</i>
<i>Involving children with disabilities in the design process</i>	<i>71</i>
CHAPTER FOUR: STUDY ONE - INVESTIGATING COMMUNICATION INVOLVING CHILDREN WITH SSPIS AND AAC	79
INTRODUCTION TO STUDY ONE.....	79
<i>Research questions.....</i>	<i>80</i>
METHODOLOGY	80
<i>Epistemological foundations</i>	<i>80</i>
<i>Context</i>	<i>82</i>
<i>Clinician-Researcher role</i>	<i>82</i>
<i>Participants</i>	<i>84</i>
<i>Ethics</i>	<i>85</i>
<i>Data Collection Methods.....</i>	<i>87</i>
<i>Analytic Approach</i>	<i>93</i>
FINDINGS	94
<i>Competence and Agency in Child-Adult Interactions.....</i>	<i>94</i>
<i>AAC as a Material Object.....</i>	<i>102</i>
<i>Misalignments and Breakdowns</i>	<i>105</i>
DISCUSSION.....	110
<i>Communication is embodied</i>	<i>111</i>
<i>Respecting child competence and agency.....</i>	<i>111</i>
<i>Regulating the status of AAC in communication</i>	<i>113</i>
<i>Supporting child-initiated communication</i>	<i>114</i>
CONCLUSION TO STUDY ONE	115
<i>Limitations and future directions</i>	<i>115</i>
CHAPTER FIVE: STUDY TWO - A MIXED METHODS STUDY INVESTIGATING MULTIMODAL COMMUNICATION IN SCHOOL-BASED ENVIRONMENTS	117
INTRODUCTION TO STUDY TWO	117
<i>Research questions.....</i>	<i>118</i>
METHODOLOGY	118
<i>Epistemological foundations</i>	<i>118</i>
<i>Data Collection Methods.....</i>	<i>119</i>
<i>Analytic approach.....</i>	<i>122</i>
FINDINGS	124
<i>RQ2a – What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; how do children use resources available to them for meaning making?.....</i>	<i>124</i>
<i>RQ2b – What do children appear to value based on the ways that they communicate?.....</i>	<i>151</i>

DISCUSSION	167
1. <i>Regulating the orderings of modes and social structures</i>	167
2. <i>Interconnectedness and belonging</i>	169
3. <i>Advancing involvement through play</i>	171
CONCLUSION TO STUDY TWO.....	172
CHAPTER SIX: STUDY THREE - DESIGNING FOR COMMUNICATION	174
INTRODUCTION	174
<i>A review of existing research frames on communication involving children with SSPIs: From individual to co-constructed; deficit-oriented to distributed, and linguistic to multimodal</i>	175
<i>Studying language focused technologies in structured teaching contexts</i>	177
<i>Studying multimodal communication: Beyond technology use, beyond formal teaching contexts</i>	178
<i>Engaging with children’s values surrounding communication</i>	179
<i>Moving from researcher frames to designer frames</i>	179
RESEARCH GOAL:	180
METHODOLOGY	180
<i>Context</i>	180
<i>Participants</i>	181
<i>Materials</i>	183
<i>Design brief & scenario</i>	186
<i>Presentation</i>	187
<i>The participant-researcher as a resource</i>	188
<i>Methods</i>	188
<i>Data collection</i>	192
<i>Analysis</i>	192
FINDINGS	193
<i>Proposed design idea</i>	193
<i>Designer frames</i>	201
<i>Using design documentaries in early stages of the design process</i>	205
DISCUSSION	211
1. <i>Reflecting on the choice of a design documentary</i>	211
2. <i>How generative were design documentaries in inviting alternative frames?</i>	213
3. <i>The role of design documentaries in design work</i>	216
CONCLUSION TO STUDY THREE.....	219
CHAPTER SEVEN: A THEORETICAL AND METHODOLOGICAL REFLECTION ON INVESTIGATING CHILDREN’S VOICES	222
INTRODUCTION: WHY VOICE?	222
<i>Research goal</i>	224
THE APPROACH FOR INVESTIGATING VOICE	224

1. <i>Voices that are shaped by theory, epistemology and context</i>	225
2. <i>Incorporating multi-layered, polyvocal accounts</i>	230
3. <i>Studying Strong and Prominent ideas</i>	232
4. <i>Hearing non-normative voices</i>	234
5. <i>Promoting child centred accounts through choice of methods</i>	238
CONCLUSION	241
CHAPTER 8: CONCLUSION	243
CONTRIBUTION 1 – A THEORETICAL PERSPECTIVE ON COMMUNICATION	245
CONTRIBUTION 2 - DESIGN OPPORTUNITIES FOR NEW AND EXISTING TECHNOLOGIES	247
<i>Communication is embodied</i>	247
<i>Respecting child competence and agency</i>	248
<i>Supporting child-initiated communication</i>	248
<i>Regulating the orderings of modes and social structures</i>	248
<i>Interconnectedness and belonging</i>	249
<i>Advancing involvement through play</i>	249
CONTRIBUTION 3 - A METHODOLOGICAL CONTRIBUTION FOR DESIGN WORK.....	250
<i>Involving children who have SSPIs in design</i>	250
<i>Involving designers in new ways</i>	252
LIMITATIONS AND FUTURE DIRECTIONS.....	253
<i>Contexts of study</i>	253
<i>Participants: sampling and representation</i>	254
<i>Participatory work and participant gains</i>	255
FINAL COMMENTS.....	256
BIBLIOGRAPHY	257
APPENDICES	276
APPENDIX 1: PARENT / CARER INFORMATION SHEET	276
APPENDIX 2: STUDY 1, LIST OF 3 THEME CATEGORIES WITH 13 CATEGORIES	283
APPENDIX 3: WORKSHOP FLYER, RESEARCHER BIO, INFORMATION SHEET AND CONSENT FORM FOR DESIGN STUDENTS..	284
APPENDIX 4: DESIGN DOCUMENTARY SCRIPT.....	293
APPENDIX 5: PERSONA DRAFTS.....	295
APPENDIX 6: 'A CARD FOR OSCAR' STORY. BASED ON 'WHISPER' IN STUDY THREE.	296

List of tables

Table 4.01. Participant profiles	85
Table 4.02. Methods used in study one & two	88
Table 6.01. Participant profiles	183

List of transcripts

Transcript 4.01. Short excerpt from longer extract involving Maya (child) and Sally (S)	94
Transcript 4.02. Maya (child) and Sally (Adult) talk about the salty omelette.....	100
Transcript 4.03. The researcher asks Maya a question concerning consent	103
Transcript 4.04. Teacher uses Maya's AAC device as archival object	106
Transcript 4.05. Grace refuses to feedback with AAC	107
Transcript 4.06. Maya initiates word 'play' and Grace responds without AAC.....	109
Transcript 4.07. Maya (right) uses AAC to initiate communication.....	111
Transcript 5.01. Researcher acknowledges and encourages shared communication book use in morning class session	129
Transcript 5.02. SNA inhibits shared communication book use in morning class session	131
Transcript 5.03. Teacher and Grace talk about eating omelette. Their interests are not aligned.	134
Transcript 5.04. Clara (middle) uses whole body to reject physical hold from the SNA (left)	136
Transcript 5.05. Folding symbol communication board creates a barrier between Grace and Maya.....	139
Transcript 5.06. Maya's subtle actions signalling her attention are missed by the adult.....	142

Transcript 5.07. Grace (central) directs the researcher (left) to sit next to her	144
Transcript 5.08. Clara (seated on the floor, centrally) gazes towards SNA (seated on chair, on right side) before standing to move towards the whiteboard	149
Transcript 5.09. Oscar uses speech to respond to the teacher's 'Good morning' greeting.....	153
Transcript 5.10. Grace (left) calls out to researcher (standing, centrally) to be included in the conversation	155
Transcript 5.11. Clara is interested in her peers' collage, signalling she cares about and shares common interests	161
Transcript 5.12. Oscar uses gesture to stop the adult asking repeated questions	165

List of figures

Figure 3.01. Example of waterfall model of design, cited in Hughey (2009)	41
Figure 3.02. Illustration of the kinds of intermediate level knowledge that are situated between theories and instances	43
Figure 3.03. Design thinking process - Plattner, Meinel, & Weinberg, (2009).....	45
Figure 3.04. Double Diamond Design Thinking Model - Design Council (2015).....	45
Figure 3.05. Hart (1992) – The ladder of participation	52
Figure 3.06. Druin (2002) - Four roles that children may have in the design of new technologies	55
Figure 4.01. 'Ideas box' for explaining information sharing.....	86
Figure 4.02. Consent board using 'Talking Mats' approach, documenting discussion with child and adult on recording information	87
Figure 4.03. Video still of Maya (right) and researcher interacting whilst Grace (left) is distanced from the conversation.....	102
Figure 4.04. Video still of Grace (left) peering over top of her AAC device towards Maya (right)	103
Figure 5.01. Grace expresses she wants to eat by opening her mouth, leaning forwards and gazing to the teacher	147
Figure 5.02. Grace's collage conveying her motivation to do activities with others	155
Figure 5.03. Maya, Grace and Clara express their friendships through craft methods	157
Figure 5.04. Field note entry of interaction involving Clara and researcher (above), and image of torn and crumpled collage sheet (below).....	164
Figure 6.01. Double Diamond Design Thinking Model - Design Council (2015).....	189
Figure 6.02. Design team's proposed idea (page 1 of 6).....	195
Figure 7.01. Noah's collage	233

Figure 7.02. Line drawing from video still of Grace (right) resisting physical help from the researcher (left), Grace vocalizes “I do it!”	235
Figure 7.03. Line drawing from video still of Grace, intently focused on turning pages in a catalogue during collage making activity.....	236
Figure 7.04. Clara’s consent board using Talking Mats approach and collage materials.....	238
Figure 7.05. During story making workshop, Grace sits in semi-circle facing the researcher...	239
Figure 7.06. Life logging image captured of Grace at home	240

Chapter one: Introduction

Thesis overview

This thesis presents a series of design-oriented studies for considering child-centred ways of investigating and describing communication involving children with severe speech and physical impairments (SSPIs)¹. The overarching goal of the research is **to inform how designers conceptualise everyday communication situations involving children with SSPIs in the early stages of the design process so that this can impact on how they might design new technologies that frame communication in multiple ways.**

Motivation for overall goal

Children with severe speech and physical impairments (SSPIs) experience the world differently compared with children who are neuro-typical and use natural verbal speech. Connected to their bodily impairments, children with SSPIs can have limited opportunities for social interaction, learning and play. Through less participation in everyday life situations from an early age, they commonly form fewer intimate friendships compared with naturally speaking children (Webster & Carter, 2007) as well as increased risk factors for later life (Jones et al., 2012; Saito & Turnbull, 2007). Communication is fundamental in providing opportunities for participation in a wide range of everyday activities as well as being a passage for learning and building relationships with others.

Responding to how technologies might reduce some of the social risk factors such as reduced access to play, interaction and learning opportunities, the human computer interaction (HCI) community has increasingly focused on the middle and later stages of the design process by identifying and addressing targeted and bounded communication challenges, for example by designing for portability and affordability (Sampath et al., 2012), ease of AAC use (Hayes et al., 2010) and speed of speech generation through contextual data (Black et al., 2012; Shamdani & Peña, 2015). By responding to isolated instances that are intended to improve existing

¹ Throughout this thesis, a decision was made to describe the population of interest using person-first language, i.e. children with severe speech and physical impairments, in line with the broadly accepted descriptors in the UK at the time of writing this thesis. However, it is recognised that this widely varies both within the UK and worldwide.

augmentative and alternative communication (AAC) technologies, existing work has largely continued to reinforce the role of technology as supporting the transmission of information in the absence of speech. Moreover, as these design solutions have predominantly addressed communication barriers at the individual level, i.e. at the level of bodily speech impairment (Mankoff, Hayes, & Kasnitz, 2010), design oriented work is yet to show how technology can support communication involving children with SSPIs at an ecological level when communication is socially constructed with multiple parties in context (Smith & Murray, 2016). These kinds of explorations, that focus on children's communication contexts, offer opportunities for new interventions that can support communication by acknowledging the complex and situated nature of communication.

Another major concern in understanding about children's contextualised communication experiences for design purposes, is that the focus has predominantly been on involving proxies in place of children with SSPIs (Benton & Johnson, 2015; Börjesson et al., 2015). The importance of "understanding users" through their direct involvement is paramount in designing digital technology. Interaction design research has moved away from studying human beings as subjects to understanding the contextualized nature of interactions with people as human actors (Bødker, 2006), however, these contextualised studies have to date, involved parents and professionals who contribute a filtered version of children's input (Holone & Herstad, 2013). Therefore opportunities exist for exploring how to design new technologies that connect with children's interests and priorities. By engaging with children's values (Iversen et al., 2010) it is possible to investigate what children might prioritise for communication.

In order to build on existing design-oriented work for supporting communication that involves children with SSPIs, the field of AAC has investigated communication from a situated, social constructivist perspective. This offers complementary perspectives for design and communication by acknowledging the richness and complexity of co-constructed communication. One key focus of the AAC research community has been to investigate everyday communication by attending to how meaning is co-created by participants in conversations involving people and existing AAC and how actions are organised around talk. Linguistically-focused interactional perspectives have been useful in dispelling the view that communication is unidirectional, instead exposing that participants in a conversation jointly create meaning and work together to achieve common ground (Bloch & Wilkinson, 2004; Clarke & Wilkinson, 2007; Goodwin, 1981; Higginbotham, 2009). In studying the ways that social action is organised around talk, interactional perspectives like conversational analysis

have shown ways in which multimodality operates in these conversations and how interaction is affected by many other factors in the environment. However, this research has been linguistically focused and has had limited reach in examining how communication manifests in children when there is no linguistic benchmark in place. For children with SSPIs who have never used natural verbal speech, linguistically oriented perspectives that continue to overly credit the mode of speech have not examined children's meaning making practices without a speech reference point. Consequently, empirical work is yet to explore how children with SSPIs are able to skilfully and capably communicate in multimodal ways by organising communication independently of these linguistic reference points. There is therefore a broader need to understand situated, co-constructed multimodal communication by investigating in detail how children use and bring together a range of resources for the purposes of meaning making.

In order to understand and design for communication from a multimodal, non-linguistic perspective, further research is needed that identifies apt ways of examining and describing what child-centred communication looks like when it involves children with SSPIs and their social groups.

Further, to study communication in a more holistic way, in addition to observing and describing situated, co-constructed communication, there is a need for hearing and responding to what children express about their communication experiences by engaging with their values. Owing to the challenges of involving children with SSPIs in the design process, these voices are often mitigated in place of carers and specialists who act as proxies, speaking on children's behalves (Benton & Johnson, 2015; Börjesson et al., 2015). By first investigating the everyday communication experiences of children with SSPIs at the early stages of the design process, and using methods that allow for expressing their view on their own terms, we can focus on the child-centred ways that communication happens. This can be achieved by focusing closely on what children do and how their actions signify their interests. This in turn can offer new opportunities for framing communication situations in multiple ways that extend beyond a focus on linguistic requirements at the individual level.

Thesis scope

This work focuses on the early stages of the design process, often termed the 'fuzzy front end'. In design, fuzzy front end work seeks to inform and inspire what is being designed for through open exploration (Sanders & Stappers, 2008). This thesis seeks to investigate multimodal

communication in the context of children's everyday communication experiences and find apt ways of describing it so that these insights can be communicated to designers in an accessible design language. The focus is on generating new research frames for communication based on empirical work with children who have SSPIs so that these frames can be used to inform design frames on communication in the early design stages.

This research is motivated by participatory design (PD) that aims to positively impact on the lives of people lives who will be directed impacted by new technologies (Simonsen & Robertson, 2013). By researching with and for children with SSPIs, the aim is to understand what children express as important about their communication experiences, and to consider legitimate ways of involving children with SSPIs in the early stages of the design process.

Thesis structure and contributions

In order to address the overall goal of the research, to inform how designers conceptualise everyday communication situations involving children with SSPIs in the early stages of the design process, this thesis is structured into eight chapters that address two main research questions and two research goals connected to the overarching goal.

The research questions are separately pursued through two empirical studies involving children. The research questions broadly ask:

Study one, chapter four:

RQ. 1. What are the salient characteristics of communication involving children with SSPIs and AAC technologies?

Study two, chapter five:

RQ.2. What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; and what do children appear to value based on the ways that they communicate?

Following these empirical studies with children, the third empirical study uses the findings of study one and two to motivate the first research goal:

Study three, chapter six:

RG.1. To apply the findings of empirical work and prior literature to motivate new ways of framing the communication of non-speaking children with physical disabilities in their interpersonal communication with peers through design documentaries.

The second research goal considers how children's voices were studied by reflecting on methodological and theoretical decisions that influenced researcher decisions:

Methodological reflection, chapter seven:

RG.2. To critically examine how methodological decisions of the researcher impacted on engaging with children's voices.

The chapters are structured as follows:

Chapter two - Theoretical and methodological approaches for investigating communication in children with SSPIs

Chapter two establishes the background of who children with communication impairments are and how theoretical perspectives and methodological approaches from the field of AAC have informed what is understood about the nature of face to face communication involving children with communication impairments and their social groups. The chapter contributes to what is known about studying communication involving children with SSPIs by discussing two main perspectives. These are: 1. studying communication at the level of the individual, and 2. studying communication as socially constructed and situated. Thus, chapter two identifies the boundaries of how existing work has studied communication and suggests an alternative perspective for investigating communication involving children with SSPIs. This alternative perspective acknowledges that children's communication is situated, co-constructed and multimodal. Extending existing, a multimodal social semiotic approach is introduced as being important for disrupting the view that communication is organised around talk. Moreover, in addition to attending to the ways that children communicate on their own terms, the chapter identifies that very few studies have investigated the beliefs and attitudes that children with SSPIs themselves express. The empirical studies that follow are informed by a need for studying and describing communication from a multimodal, situated perspective, and engaging with children's values surrounding communication.

Chapter three - Theoretical and methodological approaches to design

Whereas chapter two presented a review of theoretical and methodological approaches for studying communication, chapter three examines theoretical and methodological approaches

to design. The first half of the chapter describes three prominent design approaches that are drawn from design and HCI literature, examining some of the widely adopted motivations and practices that are said to account for what designers and design researchers do when designing for other people. The three approaches that are discussed are: *design thinking*, *participatory design* and *empathy and design*. A discussion of design thinking exposes some of the common discourses that are said to account for what designers actually do. A discussion on participatory design shows how design knowledge can be distributed amongst all stakeholders who are involved in the design process, with practical applications for designing with children. Empathy and design, as the third approach, considers how designers have tackled designing for people whose lives are seen to be very different to their own. After introducing these three approaches, the second half of the chapter discusses applications of designing for communication and non-speaking children. The focus is on illustrating existing design frames based on empirical work, and examining how children with disabilities (as a wider group with greater applications) have been involved in the technology design process. The chapter synthesises what is understood about how designers have approached designing for communication in non-speaking children in terms of design frames and methodological approaches for involving children with disabilities. Through this synthesis, the chapter contributes to existing work by identifying opportunities for generating design frames on communication that serve a wider range of functions beyond speech generation. It also highlights a need for problematising how to involve children with SSPIs in the design process that has largely focused on involving proxies in place of children or involving children as testers in the later stages of the design process.

Chapter four - Study one: An observational study to investigate communication involving children with SSPIs and AAC technologies

Based on the need for understanding and describing how children with SSPIs and their social groups communicate on their own terms, and motivated by a need to talk back to interaction designers tasked with designing AAC and new technologies for children with SSPIs, the first empirical study takes an exploratory and inductive approach for studying situated, multimodal communication. The focus is on studying communication involving children with SSPIs, their social groups and AAC technologies, within structured learning contexts in the classroom. The classroom is chosen as the site of fieldwork as a typical environment for children using AAC technologies (Murphy et al., 1996). A video observation study involving five children with SSPIs and their social groups reveals the kinds of communication achieved through and around AAC use. These insights contribute to understanding how the design of existing AAC technologies

impacts on communication. The findings also contribute to the field of interaction design through design opportunities for existing AAC technologies. These design opportunities underscore the importance of attending to children's embodied communication that extends beyond spoken modes; respecting children's expertise in organising conversations by acknowledging their competence in their chosen ways of communicating; regulating the status of AAC, and supporting child-initiated communication. The findings reveal that AAC use is problematic and children rarely used AAC technologies during the study, which motivates a need for investigating communication by studying wider contexts beyond AAC use.

Chapter five – Study two: A mixed methods study investigating multimodal communication in school-based environments

Whereas study one was concerned with investigating one type of communication from an observational, interpretive stance, study two re-asserts the humanist agenda in design work (Wright & McCarthy, 2010) by expanding on a different aspect of communication that is experience centred. It examines: (i) communication beyond formal teaching contexts and where AAC technologies are not used, and (ii) children's values.

Informed by the theoretical insights and findings of the first empirical chapter (chapter 4), that highlighted the importance of attending to multimodal communication in children's everyday contexts, the first element of study two investigates situated communication involving children with SSPIs and their social groups in school environments beyond formal teaching contexts and beyond AAC use. This part of the study investigates what communication beyond technology use looks like by examining how children with SSPIs and their social groups use the resources available to them for meaning making.

The second part of this chapter investigates what children appear to value based on how they engage with mixed methods. This section of the chapter uses participatory methods to dialogically involve children in expressing their priorities and attitudes about their communication experiences.

Both studies form part of a participatory design approach that aims to understand child-centred perspectives about communication. The findings contribute to existing work on designing for communication that involves children with SSPIs in three ways: 1. building on a new theoretical perspective for describing multimodal communication based on study one; 2. building on a systematic and reflexive methodological approach for studying communication in children with SSPIs, and 3. generating design implications for new technologies that can mediate communication involving children with SSPIs.

Chapter six - Study three: Designing for multimodal, digitally mediated communication

The empirical findings of chapter four and five are used to generate research frames on communication. These research insights are then used to create a design documentary that functions as a design tool for designers in generating design frames for supporting face to face communication involving children with SSPIs and their peers. The chapter discusses how the empirical findings of the fieldwork studies with children informed the creation of the design documentary and how designers responded to the documentary by examining their design frames in the early stages. The findings of the study make two new contributions to the fields of HCI and design. First, the findings reveal a number of design frames that can guide the development of new technologies for communication. Second, the chapter makes a methodological contribution by illustrating how design documentaries can capture child-centred perspectives on communication for supporting designers in their interpretive work.

Chapter seven - A theoretical and methodological reflection on investigating children's voices

Following the empirical work involving children in chapters four and five, chapter seven reflects on theoretical methodological decisions that impacted on hearing and promoting children's voices. The aim of the chapter is to interrogate decisions made by the researcher in a bid to generate child-centred accounts from children with SSPIs that are often mitigated in early stages of the design process. The reflective discussion generates five themes that pose considerations for hearing and promoting children's voices in design work. Chapter seven also offers methodological considerations for future participatory design work involving children with SSPIs.

Chapter eight – Conclusions and implications of future work

Finally, chapter 8 concludes the thesis by summarising the three main contributions of the doctoral thesis. These are: 1. A theoretical perspective on communication; 2. Design opportunities for new and existing technology, and; 3. A methodological contribution for design work. It also discusses the broader limitations concerning the scope of the thesis with suggestions for future work. Moreover, the chapter considers the value of participatory design work involving children with SSPIs, by identifying the types of knowledge that can be generated with children. In doing so, it identifies how this co-constructed knowledge can inform the fields of AAC, speech and language therapy practice and HCI.

Research questions (RQs) and research goals (RGs)

Chapter four – Study one

RQ. 1. What are the salient characteristics of communication involving children with SSPIs and AAC technologies?

- a. What kind of communication is achieved in interactions involving children and AAC technologies?
- b. How do AAC technologies and their design shape communication?
- c. How does technology fit with other resources that children have when advancing their communication?

Chapter five – Study two

RQ.2a. What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; how do children use resources available to them for meaning making?

RQ.2b. What do children appear to value based on the ways that they communicate?

Chapter six – Study three

RG.1. To apply the findings of empirical work and prior literature to motivate new ways of framing the communication of non-speaking children with physical disabilities in their interpersonal communication with peers through design documentaries.

Chapter seven – methodological reflection

RG.2. To critically examine how researcher decisions impacted on engaging with children's voices.

Chapter Two: Investigating Communication Involving Children with Severe Speech and Physical Impairments

“One day I was positioned next to my best friend Will; as he was wheeled alongside me, he squealed in pure delight. His stiff limbs rose towards me like a swan spreading its wings preparing for flight. Looking into his piercing blue eyes we connected at a level beyond words.”

(Bryan, 2018, p.62)

1.1 Context

Through communication, children are able to express the things that are important in their lives. Communication is a vehicle for connection; building and sustaining relationships, learning, rejecting and enabling others to attend to and respond to our actions.

Communication impairments in children can have lasting consequences for quality of life and social interaction. Connected to interventions that aim to address this, digital technologies offer opportunities for supporting communication in different ways.

This section establishes the background of who children with severe speech and physical impairments are and how theoretical perspectives and methodological approaches have informed what is understood about the nature of communication for children with communication impairments.

In the UK, it is estimated that there are 2.5 million people with a communication disability (Royal College of Speech and Language Therapists, RCSLT, 2018). To give a sense of the problem, more than 10% of all children and young people, 1.4 million in the UK, have long term communication disabilities affecting their everyday life. Of this number, 2.3% of all children, which equates to approximately 32,000 children in the UK, have severe communication disabilities that are associated with neurodevelopmental conditions that include severe speech and physical impairment (SSPI) and learning disability (RCSLT, 2018).

On a societal level, children with SSPIs often participate less in everyday life situations (Fauconnier et al., 2009). Webster & Carter (2007) described children with SSPI as having severe and impoverished access to a range of play and language resources in early life, with

fewer and less intimate friendships compared with children without SSPIs. Children with SSPIs have also been identified as adopting a more passive role during interactions (Light, Collier, & Parnes, 1985a) and communicating for a limited range of functions through language (Clarke & Kirton, 2003). At a social level, children and adults with SSPIs are likely to have affected access to employment, participation in the community, as well as anxiety and stress factors associated with the use of assistive technologies for communication (Jones et al., 2012; Angelo, 2000; Huer & Lloyd, 1990; Saito & Turnbull, 2007; McNaughton & Bryen, 2002, 2007). Equally so, communication impairments greatly affect friendships. In a recent systematic review on friendship between children using assistive communication technology methods and their peers, Østvik, Ytterhus, & Balandin (2017) suggested that children using 'other ways of talking' had restrictions in presence, participation, interaction and communication, all impacting on the ways that peer friendships were established and maintained.

Children with SSPIs experience the world differently and connected to their bodily impairments, have different experiences and opportunities for social interaction, learning and play.

Children with SSPIs hold a unique place in being a very extreme case of a population for whom communication can be very different. This has motivated researchers and practitioners to investigate how communication manifests and what this means for the interventions that are proposed. However, the nature of investigations that inform interventions can vary drastically which demonstrates huge variation in kinds of perspectives that inform communication research. As it is not always explicitly clear which models or theories underpin communication research involving children with SSPIs, ontological and epistemological orientations can instead only indirectly be gleaned through methodological choices that underpin empirical work. With this in mind, the remainder of this chapter discusses how researchers from the field of Augmentative and Alternative Communication (AAC) have engaged in empirical work that predominantly studies communication involving children with SSPIs. The aim is to highlight the theoretical constructs underpinning the investigations that are presented.

The field of AAC is made up of an interdisciplinary community of researchers, practitioners, users, manufacturers and designers whose common goal has been to investigate communication for the purposes of understanding and supporting communication that involves people with little or no verbal speech through unaided or aided methods (Higginbotham & Engelke, 2013). Unaided methods are actions and strategies that occur through the body and include gestures, sign language, looking behaviours, vocalisation and

facial expression. Aided methods are strategies that involve an external component that can that support or replace natural speech such as speech generating devices.

Whilst still considered a fairly new community, the AAC field offers the widest breadth of research in terms of its scope across the human life cycle with studies that relate to learning and education, health and wider social contexts. It also integrates research from different research traditions, including computer science, arts and humanities, education and healthcare. For these reasons, literature from the AAC field provides a rich starting point for this thesis that begins by examining how communication has been studied.

1.2 Theoretical and empirical perspectives on aided communication

More than a decade ago, Blackstone et al (2007) proposed a need for clearly defined approaches to empirical work in the AAC field, grounded in widely accepted theoretical constructs (Blackstone et al, 2007). In the UK especially, the widely-skilled, yet intimate AAC community means that research directions can quickly inform practice owing to close ties between the community of users and family members, researchers, health and education practitioners, manufacturers and designers. For example, Communication Matters, the UK branch of the International Society of Augmentative and Alternative Communication (ISAAC) holds an annual conference with a strong presence from all of the groups mentioned above. Over the years, as a clinician and regular attendee of the conference, I have observed how theoretical insights based on user experiences, empirical research and practitioner insights can very quickly be translated into AAC solutions. To illustrate one example of this, as constructs of communication have moved towards seeing communication as an activity-based phenomenon, practical applications within existing AAC devices have also reflected this focus. For example, some AAC developers have introduced visual scene displays that embed hotspots of language within a picture scene of an event that is meaningful for the user. Connected with the notion of seeing communication as activity based, these displays acknowledge that language use is contextualised. Given such examples, as the outcomes of published work are likely to have a high personal impact on end users, it is essential that studies of communication for informing intervention are explicit in articulating the kinds of perspectives that inform the insights that are presented. By identifying the kinds of theoretical questions that research studies have asked, the review that follows discusses the kinds of assumptions that underpin

AAC studies based on the epistemological and methodological decisions that are taken in each study.

The review of the literature produced two overarching foci; 1.) communication at an individual level, and 2.) communication as a distributed and co-constructed phenomenon.

1.2.1 Communication - at an individual level

Cognitive perspectives

Cognitive perspectives that seek to explain behaviour through the brain's structure and processes have addressed the study of communication by focusing on the inner mental activities of individuals. In early work, Lloyd, Quist and Windsor (1990) described communication, in the context of aided AAC, in terms of reflecting hypothesised features of a 'natural speech' system. For example, by focusing on parameters such as *sender*, *message* and *transmission* of a message. Separately, Rudzicz (2016) focused on the biomechanics and neural aspects of speech production and perception to propose a framework for speech generation through technology. By attending to neural origins of speech production, Rudzicz proposed that by focusing on the physical and cognitive foundation of speech at the individual level, communication can be supported (Rudzicz, 2016). Further, in an empirical study that investigated parental responsive style in aided conversations with children, Broberg and colleagues focused on coding adult behaviours by attending to how parents responded to children's 'signals' and 'communicative contributions' (Broberg et al., 2012). The study framed aided communication as being made up of communicative patterns for sending and receiving information. In doing so, the study assumed that communication exchanges could be objectively measured and consequently adapted to improve parent-child communication exchanges. Broberg et al's perspective that children produced 'signals' which were received and responded to by adults, suggested that communication happened at the level of the individual.

The perspectives presented by Lloyd et al, Rudzicz and Broberg et al are in line with cognitive theoretical perspectives, framing communication as a series of systems that followed a path of stimulus to response. In one of the most notable, early origins of this, Shannon and Weaver (1949) proposed communication as a transmission process whereby the start and end points of 'sender' and 'receiver', were affected by various sub-stages including 'encoding', 'noise' and 'decoding' (Shannon and Weaver, 1949).

Whilst such information transmission models have not been prominent in more recent AAC studies on describing communication processes, these perspectives are still partly prevalent in therapeutically-oriented AAC intervention studies. For example, AAC studies are often grouped into separate categories of work focusing on 'learning' or 'communication', which separate 'language learning' from 'language use'. With this division, the idea that there are separate 'input' and 'output' mechanisms become more pronounced. These divisions align closer with other cognitively oriented models, that focus on the processing of communication through speech, for example, Stackhouse's & Wells' psycholinguistic speech processing models (Stackhouse & Wells, 1997).

Moreover, whilst not directly connected with studying aided communication in situ, the notion of communication as 'information transmission' has informed the design of AAC technologies by positioning AAC devices as tools for transmitting information through a digital mechanism in the absence of natural, spoken speech. Therefore, the design of AAC technology itself and how it functions in situ is to some extent, suggestive of this view. From a cognitive perspective, a person who is seen to be a *receiver* of information is supported to *retrieve meaning* through AAC that *transmits* information (Smith & Murray, 2016). This perspective continues to be a prominent feature underpinning design decisions in AAC technologies, however the information transmission model of communication has not continued to dominantly inform contemporary communication theories that have instead construed communication as a constant, active and dynamic process (Sperber & Wilson, 1988). Moreover, Higginbotham (2009) prompts AAC researchers to rethink how people perform using language in aided communication, suggesting that the sender-receiver model is insufficient for characterising augmented interactions.

Impairment-focused perspectives

By focusing on specific child capabilities, a portion of AAC research has adopted an individual impairment perspective by examining how the language of children with SSPIs resembles or deviates from normative language structures. For example, Light, Collier and Parnes (1985b), studied communicative interaction patterns in children with SSPIs and their primary caregivers (Light, Collier, & Parnes, 1985b). Interaction patterns were conceptualised as the distribution of turns such as attending to how children initiated or responded (for instance, by requesting or providing information). The authors found a marked asymmetry in the contributions of children using aided AAC methods and their partners, with children taking significantly fewer turns, and using far fewer functions than their partners. By this approach, the authors

addressed questions about the linguistic capabilities that children possess and how these linguistic capabilities impact on linguistic patterns in an interaction.

Todman, Alm, Higginbotham and File (2008) focused on measuring discrete aspects of aided communication performance by investigating ways of supporting improved speech rate in people who used AAC. Todman et al chose to focus on speech rate, arguing that a more rapid rate of speech through whole word utterances on AAC devices could support communication and social interaction that resembled 'normal' spoken interaction. Again, the theoretical constructs underlying the study arguably dealt with the notion of enhancing impaired linguistic capability at the individual level. Additionally, by focusing on speech rate and precision, through single word and whole sentence utterances, theoretically, the study was grounded in language theory constructing speech as formulaic and stored (Wray, 2002).

Developmental perspectives

In early work that examined how a developmental model of language acquisition might be applicable to children using AAC systems, Gerber and Kraat (1992) proposed a number of reasons why clinicians had been encouraged to use a body of work from typical language acquisition as a framework for developing intervention programs. Namely, by highlighting that the language development of children with a language impairment is more similar to, rather than different from, typical language development, children with SSPIs would represent a variation on this typical process (Gerber & Kraat, 1992). In a review of the literature on the cognitive and language acquisition processes in typical and aided language learning, Murray and Goldbart (2009) considered how research on typical child development has provided insights into what is known about communication and language use in young AAC users. Drawing on literature that had a focus on cognition and language, the review revealed some of the tensions in applying developmental models of language acquisition and communication use to explain communication in child AAC users (Murray & Goldbart, 2009). For instance, the lack of empirical studies involving child AAC users in areas that examine cognitive processes (e.g. attention, memory, initiation and sequencing), has made it difficult to draw conclusions about how developmental models might explain communication in a heterogeneous population of AAC users. This lack of conceptual models for communication in children who have SSPIs continues to be highlighted to date (Clarke, Price, & Griffiths, 2016).

In one of the most prominent frameworks that has continued to inform AAC research and practice for supporting communication development, Light (1989) introduced a model of communication competencies providing opportunities for young AAC users to address skill

development in their linguistic, operational, social and strategic competencies. For AAC users, linguistic competence is concerned with understanding the native language of a community and mastering the 'linguistic code' required by the AAC system. Operational competence is having the technical skills to proficiently use a system. Social competence is having knowledge, skill and judgement in the social rules of communication, e.g. discourse strategies and different communicative functions. Lastly, strategic competence refers to how AAC users drawing on compensatory strategies for communicating effectively within restrictions (Light, 1989). Whilst this framework conceptualises communication competence as a dynamic, interpersonal construct, much work has utilised Light's framework (1989) to support children in learning to become independent aided communicators by compartmentalising opportunities and challenges into Light's four areas of communication competence (Murray and Goldbart, 2009). For example, focusing on addressing linguistic competencies, McNaughton (1993) reviewed the use of scaffolding techniques for helping to develop semantic development of language in AAC users learning to use graphic symbols. Separately, focusing on the grammatical aspects of language use, Raghavendra and Fristoe highlighting the dominance of nouns in early AAC use (Raghavendra & Fristoe, 1990). To date, the area of linguistic competence has received most attention in AAC studies (Waller, 2018). It is therefore less clear how young AAC users are negotiating their competencies in other areas. For example, within the concept of strategic competence, even less is known about young AAC users' cognitive processes.

In an attempt to address the gap for understanding about some of the broader ways that children become aided communicators, at the time of writing this thesis, a multi-site, cross-cultural, international study is underway that is investigating the idea of aided communication use as language development. The study, titled 'Becoming an aided communicator' (BAC) is a collaboration involving 16 countries and is investigating aided language development and use in children and adolescents with little or no speech. The BAC group propose that the development of children using natural speech may not be an appropriate reference for understanding aided language development. One of the ambitions of the study is to understand what kinds of models of language and development best capture aided language development and use (Tetzchner, 2018). Examining the kinds of qualitative and quantitative experiments undertaken, the language perspectives posed extend beyond a focus on linguistic skills that lie with the child alone, by acknowledging that language acquisition is socially situated and affected by different conversation partner roles. It also seeks to understand how graphic and orthographic representations, language vocabularies and how these representations are structured all affect language development and use. From this

perspective, theoretically, this acknowledges that language development is not independent of the socially situated context, the project moves closer towards understanding how a developmental model of aided communication might explain how children learn to become aided communicators.

1.2.2. Communication – distributed & co-constructed

Whereas the previous sections have illustrated examples of AAC research that considers communication at the level of the individual or isolated into areas of foci that may have a cognitive, linguistic or developmental focus, a large body of AAC research has positioned communication as a situated and flexible practice. In these instances, researchers have been interested in studying the interactive, social processes of communication that position communication as co-constructed with a goal to establishing joint meaning (Blackstone et al., 2007). This dominant perspective draws on parallels with constructions of communication beyond the AAC field (for example, Goodwin, 2003).

Social constructivist perspectives – investigating talk

Informed by the view that communication is social constructed, Bloch & Wilkinson (2011) investigated how conversation partners achieved shared understanding in conversations involving adults with acquired progressive dysarthria, their conversation partners and AAC technologies. The authors used conversational analysis (CA) which is a qualitative, inductive method that focuses on how sequences of action and turns of both participants are inter-related (i.e. an interactional perspective) and examines 'talk-in-interaction' in situations of everyday life. Bloch and Wilkinson studied how 'repairs' were achieved in conversations where there was a problem with achieving shared understanding. Repair in its broadest sense concerns how participants organise interaction when some form of mistake has been made and is corrected, but it also incorporates a wider range of issues beyond the realisation of errors. In Block and Wilkinson's data, AAC technologies were often used when a spoken utterance or word was not clear to the communication partner as a consequence of dysarthria. In analysing the sequences of participant turns and actions, Bloch & Wilkinson found that whilst the use of AAC devices at key moments made previously unintelligible speech now *intelligible*, i.e. through speaking a letter or word more clearly, it did not always make it *understandable* for the communication partner as s/he was unable to always understand the relationship between the AAC turn and prior talk. From an interpretive, interactional perspective, this suggested that the accomplishment of understandability was nestled within

the communication context. Namely, understanding for the communication partner was contingent on being able to follow prior turns that were coherent with AAC mediated talk.

Clarke & Wilkinson (2007) also used CA to examine how turn taking involving AAC was organised focusing on children's peer interactions. Focusing on the ways that communication was constructed in situ, the authors found that asymmetrical patterns of contribution (see Light et al., 1985, above), rather than highlighting AAC user impairments may have provided important opportunities for achieving understandability. For example, naturally speaking children would organise points in the conversation in which minimal AAC mediated contributions (e.g. single words) could be understood. In connected work by the same authors, when the conversation exchanges were initiated by children using AAC devices, these could be difficult for the naturally speaking peer to understand when it was unclear how they were connected to the previous sequence of talk (Clarke & Wilkinson, 2008). In focusing on how conversations were structured and how these structures advanced understanding, these studies illustrated a shift in how AAC devices are seen to support *connectivity* (Blackstone et al., 2007). Whereas the focus at the level of the individual considered how AAC systems can provide users with connections to an environment, here the focus was on what a wider distribution of connections could provide for people with SSPIs and their communication partners. Clarke and Wilkinson's work proposed that rather than seeing AAC technology as solely the responsibility of the non-speaking partner, it is more appropriate to consider these as interactions involving *aided* communication. In doing so, this work acknowledged that the participants involved had greater flexibility to use a range of modes and strategies with AAC technologies being just one of these (Murray & Goldbart, 2009).

Extending interactional studies that investigate communication by studying how conversations are organised around talk (Mazeland, 2006), Solomon-Rice and Soto (2011) examined co-construction strategies in creating narratives in interactions involving a child AAC user and a Speech and Language Therapist. As well as analysing interactions at a micro level through transcribing speech and non-speech behaviours (in line with the authors' description), the study analysed co-constructed narratives at a macro level. This macro level analysis involved investigating the level of participation of both interlocutors and the extent to which narratives conveyed unexpected and out-of-the-ordinary events, amongst other factors. They showed that co-construction strategies are useful for advancing communication and supporting personal narrative development in conversations involving AAC users (Solomon-Rice & Soto, 2011). From a theoretical perspective, the study reinforced this distributed view of communication involving aided systems. Also, interestingly, the study also suggests the value

of supporting child-centred narratives, rather than situation centred interactions, encouraging children to tell stories from their own perspectives.

Social constructivist perspectives – investigating multiple modes

More than three decades ago, the seminal work of Arlene Kraat (1987) emphasised the *distributed* nature of communication, describing interactions that were made up of the participants, the communication setting and the codes and rules for language use amongst other factors. The AAC studies discussed above have responded to this by illustrating the practical ways that meaning is accomplished in naturally occurring interactions. Whereas these studies investigated aided communication by studying interactional phenomena organised around talk, multimodal perspectives have taken a different view, that distributes communication further by rejecting that communication is anchored around speech or words.

In work that examined communication, without aided methods, Goodwin (1981) proposed that participants were able to perform utterances through the simultaneous use of multiple resources with different properties beyond speech. Goodwin (2010) presented the case of a man with severe aphasia who was able to construct action with his restricted lexicon of three words; 'yes', 'no' and 'and', combining these words with other meaning making resources. In one example, Goodwin described the case of his father 'Chil' who, despite his speech impairment, was able to competently converse in multimodal ways. In examining contextualised conversations using a CA approach, Goodwin described that in the absence of verbal speech, Chil would use nonsense syllables alongside prosody, intonation and word placement in a sophisticated way for indicating what he was meaning. Goodwin's work showed that through interactional analysis, participants who might otherwise be perceived as having reduced capability in communication were able to draw on a range of actions to create meaning. Similarly, Korkiakangas (2018) illustrated the ways that autistic conversation partners were able to use eye gaze alongside speech, underscoring their eye gaze related competence when initiating and responding to another person. Whereas a traditional focus on looking behaviours in autistic people has taken a deficit-oriented focus, through a multimodal, co-constructed focus, these findings suggested that autistic children used looking behaviours in more nuanced ways. Considering both of these studies, such interactional multimodal perspectives assumed that language use was embedded within interactions and should be treated as one action of communication, not separate from it. Rather than placing the emphasis on 'talk' and words, their work underscores that language use is inextricable from broader communication that is made up of multimodal factors (Goodwin, 2004).

Connected to this concept, Higginbotham (2009) highlighted tensions in the prominence given to the mode of speech in aided conversations. He suggested that rather than examining ‘talk-in-interaction’, the focus should instead be on the multimodal resources of people with complex communication needs (Higginbotham, 2009). Higginbotham proposed investigating ‘in-person interactions’ that credit the multimodal ways that people engage in activities with a main goal of achieving common ground. Through his empirical work, he showed that people attended to a range of temporal-contextual requirements *in the moment* through actions that extend beyond the AAC device or even language alone. For example, in one case, Higginbotham describes how spatial positions and people’s orientations to each other and to a nearby clock impacted on decisions to use different modes. In the example, one of the study participants starts by using her electronic AAC device, shortly after opts to use a simple alphabet board when her communication partner moves next to her, then gazes to orientate to a clock to signal something about time. Besides evidencing the dynamic adjustment of communication modes employed by both partners, this example suggests that AAC technologies are sometimes perceived as inhibiting communication interactions or delaying communication further, leading to the selection of a more appropriate mode.

A multimodal theory of communication

The empirical perspectives discussed in the previous section illustrated that in aided conversations, both communication partners would draw on a range of modes and strategies to advance common ground or *understandability* (Bloch & Wilkinson, 2011) and that these decisions are flexible and jointly negotiated within context. Within the AAC literature, studies that have investigated communication involving non-speaking people, conversation partners and AAC systems have predominantly focused on describing communication that is organised around talk, with the exception of one noted perspective (Higginbotham, 2009). For studies investigating communication involving children, this has been even more pronounced, with an additional focus on the ways that children’s linguistic capabilities relate to their speaking peers or developmental norms, as discussed by Geerber & Kraat (1992), despite a lack of a conceptual model for communication in children who have SSPIs (Clarke et al., 2016). **Existing lenses for talking about communication involving children with SSPIs do not illustrate how children create meaning on their own terms.** Instead, they attempt to align how children construct meaning based on culturally appropriated references, like the use of verbal language and developmental norms. For this reason, existing work is yet to describe communication by acknowledging the skilful ways that children with SSPIs construct meaning in multimodal ways.

Multimodality as a term has been used across research traditions and disciplines. In the context of studying communication, a key principle of multimodality is the acknowledgment that all forms of communication and representation must be attended to as they each offer distinct potentials for meaning making (Jewitt et al., 2016). By attending to multiple means of meaning making, multimodality challenges communication theories that propose one form of meaning making has more value than others (Cowan, 2017), rejecting the view that 'verbal communication' is primary and 'non-verbal communication' make up a secondary category of means of communication (Jewitt et al., 2016).

One direction of multimodal research is that of multimodal social semiotics (Hodge & Kress, 1988; Kress, 2010; Van Leeuwen, 2005). Informed by the view that people act out social structures that signify their roles in relation to others (Halliday, 1979), multimodal social semiotics seeks to understand the social dimensions of meaning. By attending to the ways that meanings are produced, interpreted and circulated, multimodal social semiotics examines the implications of these meanings on individuals and societies (Jewitt et al., 2016). The 'social' refers to the power discourses surrounding meaning making. The 'semiotic' is the manifestation of how meanings are made in a cultural context.

Social semiotics emphasizes the agency of the sign-maker, being the person who creates meaning by selecting and organising a set of resources. The concept of the motivated sign implies that meanings are constructed by human action, which is informed by the cultural, social and historical experiences of the sign-maker (Jewitt et al., 2016). Social semiotics is interested in meaning making through multiple modes for example, through image, movement, sound and many others. In a social semiotic sense, resources are representational practices that people undertake for meaning making that are socially and wilfully made and in response to some prompt (Kress, 2010).

As a multimodal theory of communication, social semiotics focuses on the ways in which people use the resources that are available to them to create meaning for signifying their interests. Sign-makers who produce meanings construct representations of 'signs', which are elements through which meaning and form are brought together (Bezemer & Kress, 2016). The *documentation* that is said to occur through these combinations, i.e. the motivated *sign*, is inextricably linked to the features that the sign maker interprets as salient to the meanings that are being constructed. In the context of describing communication involving children with SSPs, this perspective is appropriate as it acknowledges the individualised ways that children create meaning, without crediting a common reference point (e.g. speech) in such a heterogenous population.

Through empirical applications, Mavers (2004) highlighted that children's drawings offered different potentials for meaning making through the ways in which different modes of presentation, layout and punctuation were brought together. Flewitt (2005), showed that rather than 'pathologizing' children's silences and lack of speech in early years settings, a multimodal approach illustrated that children used gaze and action to negotiate entry into other children's play. In other applications, researchers have studied a range of other artefacts such as children's model making (Stein, cited in Jewitt & Kress, 2003; Pahl, 1998), school textbooks (Kress et al., 2005), online video tutorials (Bezemer & Kress, 2016) and children's playground interactions (Cowan, 2017). Through these studies, the idea of what constitutes a 'text' is challenged, suggesting texts are multimodal and extend beyond linguistic modes. By focusing on 'multimodal texts' and seeing these as *assemblages of meaning* (Kress, 2010), for communication involving children with SSPIs, it is possible to investigate communication by attending to a much broader array of resources, strategies and arrangements that children bring together for expressing their interests. Instead of investigating communication through a focus on one dominant mode (for example 'verbal', then classifying all other actions as 'non-verbal'), social semiotics is an apt way of studying communication in this context, as it can illustrate how children create meaning using many different modes, and on their own terms.

Social constructivist & anthropological perspectives

Whereas social constructivist perspectives investigating talk or multimodal communication have studied communication inductively by attending to people's actions in situ, anthropological perspectives have sought to understand people's cultures from within a community. Acknowledging that theoretical constructs in AAC are not solely formed by researcher driven empirical research studies, but grounded in hearing what AAC users express (Blackstone et al., 2007), ethnographic and anthropological perspectives have been important in exposing rich accounts concerning the values and motivations of children and young people with SSPIs.

Motivated by a move away from analysing and categorising communication in a pathologizing way, Wickenden (2011a) investigated identity and lifeworlds of disabled teenagers who use AAC. The aim was to explore teenagers' views of their lives, whilst contextualized within the perspectives of those around them. Wickenden showed that participants largely viewed themselves as 'normal' teenagers, who aspire to live similar lives as their non-disabled peers. Whilst acknowledging disability as part of their identity, they expressed positive images of themselves as sociable and competent. By taking an ethnographic approach focusing on identity, Wickenden's work enabled participants lives to be studied 'in the round' (Dowling,

2006), exposing richness and variety in roles, identities and relationships across different places and times (Wickenden, 2010). Theoretically, this approach, which remains rare, raises a different set of questions than the perspectives described above, it asks: how is identity renegotiated across contexts; how do teenagers views of themselves (i.e. selfhood) differ to how others see them (i.e. personhood), and; how do these views inform each other?

Whereas other prominent works within the social sciences have investigated people's motivations and attitudes from a given frame point, such as investigating universal value types (for example, Rokeach, 1973; Schwartz, 2012), Wickenden's work acknowledged teenagers' inner beliefs and motivations as a contextualised, constantly renegotiated process. For this reason, an inductively driven process that acknowledged many factors, including the role of the researcher, was used.

In a separate study investigating self-reported experiences of using the internet and online social media in young people who use AAC, Hynan, Murray, & Goldbart (2014) showed that participants had a clear desire to be part of social practices like using social media, but faced challenges, especially regarding accessibility. In terms of self-representation, participants in the study described that being online offered unique opportunities for showing other people aspects about themselves which may otherwise be difficult to express in face-to-face situations, due to their complex communication needs.

Very few other studies have investigated the beliefs and attitudes of children and young people who are AAC users (Morris, 2003; Rabiee et al., 2005). For this reason, ongoing opportunities exist in exploring what AAC users express about their deeper values and attitudes connected with their communication, so that these insights can inform constructions of communication.

1.3 Summary

The goal of this chapter has been to present a number of conceptual or practical perspectives that have informed how AAC researchers have studied communication involving children and young people with SSPs by attending to the theoretical and methodological decisions that have underpinned their empirical work. Two overarching perspectives were highlighted. These consisted of: 1. studying communication at the level of the individual, i.e. examining the actions of the person with SSPs and how they use AAC, and 2. studying communication as distributed practice, i.e. attending to the co-constructed ways that meaning is created by people and the tools that they draw upon. Within the field of AAC, where research insights can

quickly have impact on the lives of end users, both perspectives have separately impacted on how interventions have informed practice at an educational, therapeutic and AAC design and manufacturing level. Cognitive perspectives that focuses on how children's mental processes allow them to encode and decode communication through a transmission model of communication has been less prevalent in recent AAC literature, yet this view continues to inform how AAC devices themselves are construed. Developmental and impairment-based perspectives continue to inform AAC interventions at the level of the individual, by targeting specific challenges that children are seen to face. Importantly, these kinds of AAC research engagements have been vital for informing work at the individual level, for example, by extending ways of thinking about the role of AAC technologies by utilizing knowledge from other fields, such as computational linguistics and human computer interaction, in a move towards more efficient communication (Waller, 2018). In contrast, social constructivist perspectives have attended to the distributed nature of communication, positioning AAC devices as a shared resource within *aided conversations* (Clarke & Wilkinson, 2007). In construing communication as a co-constructed process, these perspectives have examined the contextualised structures and arrangements that affect jointly establishing meaning (Tetzchner & Grove, 2003; Tetzchner & Martinsen, 1992) and the establishment of common ground (Higginbotham, 2009). To date, AAC research that has studied socially constructed communication has focused on how actions are organised around talk. Whilst studies that have used CA acknowledge how AAC users draw on different strategies and means for establishing common ground, as children with SSPs often have a different basis for meaning making in the absence of natural verbal speech, these perspectives have not explained how children create meaning on their own terms. Importantly, existing work is yet to describe distributed communication that attends to the semiotic properties of communicative acts, rather than linguistic characteristics (Barnes & Bloch, 2019). In order to do so, a social semiotic approach provides a theoretical apparatus for advancing this multimodal view by removing speech as a reference point, focusing instead on the broadest possible view of how children bring together meaning and form to create 'signs'. Further, in addition to establishing apt ways of describing multimodal communication by attending to how it manifests in contexts, little work has investigated children's voices by attending to what they themselves express as important concerning their communication experiences. Therefore, in addition to taking a situated view for describing distributed and multimodal communication, opportunities exist for engaging with children's values to understand about some of the motivations and attitudes that inform how children express themselves.

1.4 Research Questions

After reviewing relevant literature on theoretical and methodological perspectives, the first research question seeks to understand and describe how communication involving children with SSPIs manifests. In order to begin an exploratory and inductive investigation of communication, study one and research question one (RQ.1) first focuses on one type of interaction that children with SSPIs are typically involved in, namely, conversations that involve AAC technologies in formal learning contexts. A social constructivist perspective frames the investigation of communication that asks:

RQ. 1. What are the salient characteristics of communication involving children with SSPIs and AAC technologies?

This research question is addressed through a focus on three sub-questions:

a. What kind of communication is achieved in interactions involving children and AAC technologies?

b. How do AAC technologies and their design shape communication?

c. How does technology fit with other resources that children have when advancing their communication?

Following this exploratory investigation of one type of interaction that children with SSPIs are involved in, the second study then extends outward to investigate communication in a broader sense. RQ2 focuses on how multimodal communication manifests in wider contexts by attending to children's meaning making through a multimodal, and values-led approach.

The second research question asks:

RQ2a. What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; how do children use resources available to them for meaning making?

RQ2b. What do children appear to value based on the ways that they communicate?

Research questions 1 and 2 are addressed through two separate empirical studies, presented in chapters four and five.

Chapter three: Theoretical and methodological approaches to design

This chapter examines theoretical and methodological approaches to designing for communication. It first introduces three prominent approaches that have informed design work in the HCI community. Informed by these approaches, the chapter then considers how the HCI community have approached designing for communication and people with SSPIs through a discussion of the types of design frames that have been generated by existing work. Following this, and motivated by a need for distributing how knowledge is generated by multiple stakeholders, the chapter considers how children with disabilities, including children with SSPIs, have been involved in design work in the context of HCI. By considering the existing literature landscape on designing for communication in these contexts and involving children with SSPIs; and further, informed by the methodological approaches for studying communication introduced in chapter two, this chapter motivates two directions for the empirical studies that follow. These are investigating communication for design purposes, and examining ways of involving children with SSPIs in the design process.

Design approaches

Design thinking

The process of what designers do is often seen to be ambiguous. This is a challenge as it can be difficult to understand how designers come to accountable and rigorous decisions and outcomes within an adopted design approach (Frauenberger et al., 2015). In an attempt to demystify design research as a 'black art' (ibid) researchers have looked at the types of activities that reveal some of the abstract and intuitive practices that designers have been said to engage in.

Cross (2011) highlighted a number of key practices that underlie design thinking, with a focus on considerations that apply across different design contexts. Through a series of case studies involving experienced designers, Cross exposed the types of exploratory processes that designers are said to engage in towards reaching proposed solutions. Whilst the stages of information gathering, framing and generating possible solutions are not a strictly linear process, Cross outlined a number of characteristics for design work that include defining

problems, sense making and reflection within a 'to-and-fro' process. Cross suggested that designing is closer to what is described as an 'abductive' process, whereby the focus is on finding solutions by envisaging what *may* be happening, suggesting that ambiguity and openness can support a generative design process. Unlike an inductive process that examines what is *actually* happening, or a deductive process that examines what *must* be happening, an abductive design process leads to a number of possible solutions based on how the problem is framed. Similarly, Dorst (2010) has likened the abductive process of design thinking, to that of a logic-based formula whereby the thing being designed for (i.e. the 'what') and the working principle (i.e. the 'how') are both unknown. The idea that the act of what designers do is 'solution focused' rather than 'problem focused' has also been acknowledged in other literature (Brown & Katz, 2009; K Dorst, 2010; Stewart, 2011). As design research offers a very distinct and often, effective way of working through ill-defined problems, design thinking as an approach has been used in other disciplines, including Information Technology and Business.

Design thinking discourses

In a review of design literature, Johansson-Sköldberg et al (2013) identified five underlying discourses that position design thinking practices (Johansson-Sköldberg et al., 2013). These are:

1. Design as the creation of artefacts
2. Design as reflexive practice
3. Design as a problem-solving activity
4. Design as a way of reasoning and making sense of things
5. Design as the creation of meaning.

Design as the creation of artefacts – privileges creation as a central concept. Drawing on this idea, Chamberlain and Craig (2017) examined the ways healthcare is delivered at hospital and at home. By creating objects that would draw on the value of 'thinking with things', through a critical design approach, they highlighted the richness and complexity of people's lives in the context of cultural practices and environments surrounding care (Chamberlain & Craig, 2017). In this instance, tangible artefacts supported the development of knowledge through the ways they were able to mediate learning and thinking. Similarly, in a move away from evaluating final outcomes but instead focusing on the processes that inform them, Cassie Hester's graphic design practice focused on the process of making and discovering 'serendipitous moments' (Hester, 2017). Guided by Csikszentmihalyi's framework on flow and play (Csikszentmihalyi & Kanopy, 2014), Hester recounts on a project on words and letters by experimenting through

printing with gelatine, casting resin, drawing and scribbling without lifting the pen, and ice mould that melt in different ways, to name a few examples. Through this experimental process of making, knowledge is said to mediate learning, by playfully exploring ways of advancing the possibility of chance in the creative process.

Design as a reflexive practice - has been a dominant practice in design, acknowledging the need for seeing a design problem in different ways. Schön (1983) understood design as 'seeing-moving-seeing' whereby an evaluative stance would enable designers to engage with creating frames then testing these out. In a general sense, frames are ways of seeing and thinking about a specific situation that is being designed for, based on designer interpretation. Schön's seminal work on reflective practice has been widely adopted. Central to this, is the idea of on the spot experimentation that is initiated by observing what is happening, proposing an interpretation ('frame'), testing this through a new move, then re-evaluating based on the new move (Schön, 1983). Rather than retrospectively reflecting afterwards, *reflection-in-action* enables frames and possible solutions to be broken and re-formed by constantly changing how things *may* turn out, promoting rigour through on the spot testing. In this case, knowledge is constructed through evaluative moves and is concerned with how the situation is framed.

Design as a problem-solving activity – is connected with the idea that design is a way of dealing with 'wicked problems'. In early work by Rittel & Webber (1973) wicked problems were defined as "a class of social system problems which are ill-formulated, where the information is confusing, where there are many clients and decisions makers with conflicting values, and where the ramifications in the whole system are thoroughly confusing". Rather than moving sequentially through a linear design process, like the waterfall model illustrated in figure 1, Buchanan (1992) suggested instead that design is centred on two distinct phases: problem definition and problem solution.

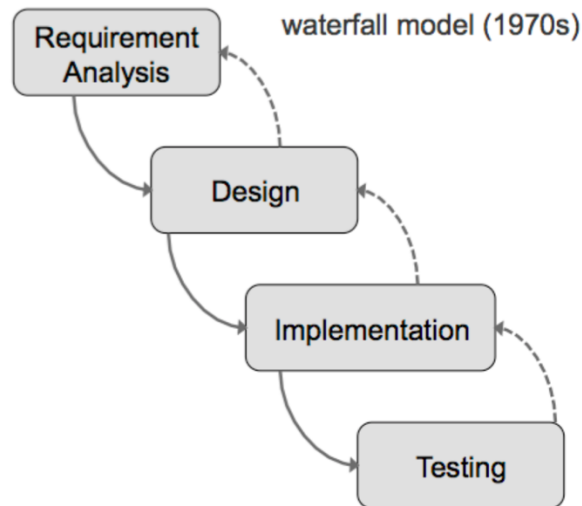


Figure 3.01. Example of waterfall model of design, cited in Hughey (2009)

Problem definition is associated with information gathering to understand the situation and problem solution concerns ways of framing and addressing this. Whilst Johansson-Sköldberg et al., (2013) describe this as a separate discourse, there are overlaps with how problem framing develops in design as reflexive practice. Unlike earlier linear models, design that is guided by these two distinct phases (problem definition and problem solution) is characterised by the recursive movement between the two, resulting in new problem definitions. Similar to the case of design as reflective practice, knowledge generation is concerned with understanding the nature of the problem by seeing it in different ways.

Design as a way of reasoning and making sense of things – is connected with the idea that the practice of working through the design process can itself advance the designer’s ‘ways of knowing’ instead of, for example, being guided by philosophical perspectives (Bratteteig & Wagner, 2016). Connected with the idea of the abductive reasoning approach described earlier, the high level of ambiguity concerning what to design and how to go about, acts as a vehicle for generating many possibilities for ways to approach design. In one example of this, Boucher and Gaver (2006) discussed how they explored designing domestic technologies in the home that were intended to motivate curiosity, exploration and reflection. Through an open design-led approach that aimed to design for pleasure rather than designing for utility, the authors used cultural probes as sources of inspiration for empathy and engagement (Gaver, Boucher, Pennington, & Walker, 2004). Cultural probes are described as “collections of evocative tasks meant to elicit inspirational responses from people—not comprehensive information about them, but fragmentary clues about their lives and thoughts” (p.53, Gaver et al, 2004). Rather than appropriating probes as a scientific process for identifying requirements,

the authors place value on uncertainty, play, exploration and subjective interpretations. In the case of interpreting design thinking as a way of reasoning and making sense of things, this then suggests that knowledge is advanced through staying open to endless possibilities and embracing ambiguity as a way of sense making. The notion that design problems do not have single conventional outcomes has also been promoted by others. Dorst, for example, suggested that as there is no dominant design solution, the situation to be designed for is constantly framed and reframed. In this case, Dorst uses the term 'frames' to describe a novel standpoint from which to tackle a problematic situation, based on perceiving the situation in a certain way (Dorst, 2010). In this case, reasoning comes from acknowledging that there are many ways of seeing what is being designed for, and that the designer is adopting one interpretation.

Design as the creation of meaning - the final discourse that Johansson-Sköldberg et al describe is concerned with design as a practice for creating meaning that can inform philosophical, semantic and other perspectives. Instead of taking a practice-based focus, Krippendorff (2006) for example, sees the core activity of design work being about creating meaning, where the artefact becomes the medium for communicating these meanings (Johansson-Sköldberg et al, 2013). For Krippendorff, through design, texts are created that become part of the discourse of the design community. Through systematically collecting accounts of successful design practices, methods and their lessons, design enables self-reflection and evaluation in the design community, informing the design profession more broadly. In one example of this, Verganti (2009) focused on the notion of innovation in meaning giving radical new ways of thinking about kitchenware through design. Giving the example of a corkscrew and lemon squeezer in Alessi's kitchenware range by Philippe Starck, Verganti describes the approach as informed by collaborations with a psychologist and people's connections with the ways people were attached to boundary objects. Boundary objects are broadly interpreted as artefacts that support communication and meaning in two or more intersecting worlds through the ways they satisfy knowledge requirement in each of those worlds (Liinasuo & Aikala, 2007). For Verganti, innovation in meaning prioritized the ways that the objects looked; as stylized products, rather than mundane kitchen tools. Arguably, this was connected with the belief system that the designer implicitly or explicitly brought with them.

Separately, in examining what design outcomes have to offer to wider design communities, Höök and Löwgren introduce the concept of intermediate level knowledge. The authors describe intermediate level knowledge as knowledge that is constructed from design-oriented research practices that are more abstracted than specific instances of design outcomes, yet

not as broad reaching as theories (Höök & Löwgren, 2012). Strong concepts are a type of intermediate level knowledge that have generative qualities in that they can be appropriated by design teams in new instantiations (Höök & Löwgren, 2012). A visualisation for intermediate level knowledge is presented in figure two.



Figure 3.02. Illustration of the kinds of intermediate level knowledge that are situated between theories and instances from Höök & Löwgren (2012)

Using Johansson-Sköldberg et al.'s (2013) interpretation of design thinking that is focused on the creation of meaning, Höök and Löwgren's proposal of intermediate level knowledge provides an example of a type of meaning that transcends specific design instances and can be applied by others.

Summary - Whilst it is evident that each of these five discourses and design processes propose different perspectives through which design practices are positioned, they are not mutually exclusive. For example, 'design as a reflexive practice' and 'design as a way of reasoning and making sense of things' both heavily connect with reframing ways of seeing things. Equally so, 'design as the creation of artefacts' can be seen as closely associated with 'design as a way of reasoning and making sense of things' in its focus on process. These discourses privilege different (and connected) kinds of knowledge, for example, mediating learning in the design process, generating multiple frames that lead to more rigor, acknowledging the benefit of ambiguity and uncertainty, and informing broader theoretical perspectives.

Design process

The discourses described above are very separate from instructional models of the design process. Whereas the discourses above have been concerned with what designers do by examining how they approach design situations, there are different stages that characterise the design process within interaction design. Interaction design is the point of focus in this thesis, as it is concerned with designing interactive products to support the ways people communicate and interact in their everyday and working lives' (Sharp et al., 2019). Whilst construed as a non-linear process, Sharp et al. (2019) describe the interaction design lifecycle as characterised by the following four basic activities:

- **Establishing requirements** for the user experience
- **Designing alternatives** that satisfies those requirements
- **Prototyping** the alternative designs so they can be communicated and assessed
- **Evaluating** the design and the user experience it offers.

Establishing requirements is concerned with knowing who the user is and what kind of support a new product could provide. Understanding requirements is achieved through data gathering and analysis and can include drawing on technical knowledge and experience, so that this can inform how the situation to be designed for is interpreted. *Designing alternatives* is concerned with framing the situation to be designed for in new ways so that this can generate new ways of conceptualising the problem at an abstract level, as well as at a physical level. *Prototyping* allows for designed physical artefacts to be evaluated with the intended user group so that the design can be developed further, and *evaluating* is the process of assessing the usability and acceptability of what has been designed against a number of identified criteria (Sharp et al., 2019).

An alternative representation of the design process that emphasizes the iterative movements back and forth between design phases has been illustrated by Plattner, Meinel and Weiberg (2009). This is conveyed in figure 3. It offers an expanded view of the earlier stages in the design process that seek to engage deeply with defining the problem through iterative loops of understanding, observing and developing points of view.

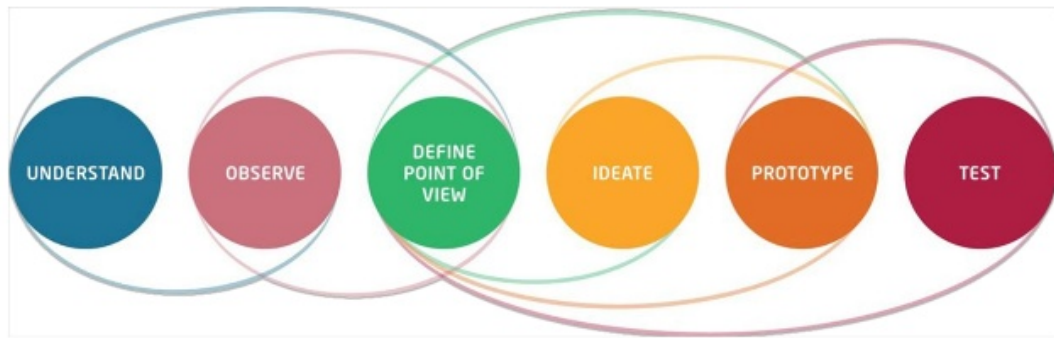


Figure 3.03. Design thinking process - Plattner, Meinel, & Weinberg, (2009)

Alternatively, the double diamond design thinking model (Design Council, 2015) captures the divergent and convergent nature of the design process in two discrete phases; problem definition and producing solutions (figure 4).

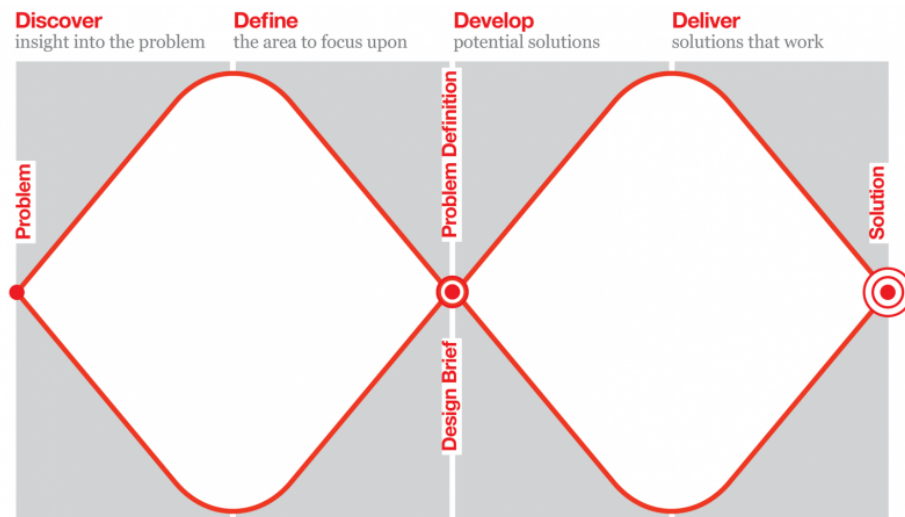


Figure 3.04. Double Diamond Design Thinking Model - Design Council (2015)

Like the earlier model, the double diamond model advocates for an iterative process for repeating many cycles of the stages. The main differences, compared with the earlier design thinking model is the idea of addressing *problems* through problem definition and solutions, as opposed to a broader view on defining the situation. Also, the double diamond model has a directive way of suggesting where ideas diverge and converge, which can be useful in design processes that benefit from a structured way of organising activities.

Within the context of this thesis, the focus is on deeply engaging with the early stages of this lifecycle; focusing on establishing requirements by gathering and analysing data so that new design frames can be identified. Work at these early stages is often referred to as the fuzzy

front end, as it can be messy, divergent, and open to exploring a number of possibilities for understanding the problem space (Sanders & Stappers, 2008). Connected with abductive reasoning (Cross, 2011; Dorst, 2010), this phase is motivated by the value of ambiguity (Gaver, Beaver, & Benford, 2003) and open-ended possibilities for thinking about designing for things in new ways.

Positioned at the fuzzy front end, this thesis draws inspiration from all of the different design thinking discourses, to different degrees. Namely, at the heart of this work, a design-orientation is taken for critically considering how communication has been interpreted in the context of designing existing AAC technologies as well as thinking through how technologies might support communication in new ways. The focus is on applying new interpretations that can lead to new perspectives for thinking about communication involving children with SSPIs. Each of the empirical studies within this PhD thesis considers researching and describing communication from a design orientation. The chosen methods and analysis reflexively focus on what the data reveals about designing for communication. The aim is to propose new frames on designing for communication involving children with SSPIs that acknowledge broader, situated interpretations of communication in line with the perspective that communication is co-construction and multimodal.

Participatory design

The previous section focused on describing some of the activities and motivations that have been said to guide design work and what designers do. The aim was to expose interpretations of what guides design work by focusing on the kinds of knowledge that is generated through design activities. As the focus so far has been on what designers do, the examples that have been discussed so far are yet to conceptualise the role of users. Namely, opportunities exist for understanding how intended end users and multi-stakeholders inform the design process. To this end, building on these discourses, participatory design (PD) offers a complimentary lens in its explicit focus on conceptualising the role of users within the design process. Further, it advocates for knowledge generation that is instead distributed, rather than purely lying with the designer.

As the field of HCI has increasingly widened its borders (Rogers, 2012), PD practices and research have become more prominent in technology design projects. Whereas PD initially emerged as a distinct set of practices connected with the workplace context, the underlying core values of PD, that critically problematize the nature of participation, have largely informed HCI work.

Three main politically motivated ideals that drive PD advocate for: *having a say*, *addressing power* and *mutual learning* (Bratteteig et al., 2012). These ideals are discussed in turn by drawing on HCI and PD work that has considered how knowledge is constructed with users, based on these underlying ideals.

Having a say

In its most basic and fundamental form, having a say means having something to say as well as affecting outcomes and decisions with what you say (Bratteteig et al., 2012). Whilst a great deal of technology-oriented PD work has problematized ways of enabling participants to have a voice through a focus on methods, on a deeper level, and arguably more importantly, this involves deciding on what problems to solve in the first place. Connected to the political conviction of PD which acknowledges the rights of intended technology users, this implies that those affected by technologies should have a say in their design (Ehn, 1993). This acknowledges the varied voices of different stakeholders. Therefore, the starting point for generating new knowledge encapsulates these varied opinions, rather than relying solely on the opinions and interpretations of the designer. As a fundamental principle in PD involves sharing decision making between all participants who are involved in the design process, having a say therefore directly addresses power and participation (Bratteteig et al., 2012).

Unlike other design approaches that might involve users for the purposes of information gathering for requirements, PD is committed to generating knowledge by *democratising voices* that consider the different perspectives of stakeholders, advocating for the active participation and decision making between groups of people, who are treated as design partners.

For Bødker and Kyng (2018), this involved not just ‘tapping into the expertise of users’ to develop better systems, but designing things that matter and impact on the lives of users themselves. Extending the remit of having a say, Bødker and Kyng suggest that PD work should not reduce the political element of participation to how ethically the researcher should have behaved when involving users, but instead consider the broader context of how to engage partners for accomplishing empowerment, for example, addressing issues of scalability and societal issues that matter.

Addressing power

Connected to the previous section, another core pillar of PD acknowledges that models of power exist across the design of a project and there is therefore a need to address how to share power among all participants. The emancipatory motivation behind this suggests that as

a basic human right, those who are affected by the introduction of technologies, should have the opportunity to influence the design of these technologies and practices that involve their use.

In arguing for a re-focus on the political dimension of PD, Beck (2002) suggested that PD researchers should actively reflect on questioning how their work understands and challenges dominance. In an emancipatory push that engaged with addressing quality of life, quality of work, dominance and envisaging different possible futures, Bossen (2006) considered the scope of PD as encompassing participation, power, methodology and knowledge (Bossen, 2006). In an example application of this, Bossen examined the case of designing a patient electronic record system. By identifying challenges connected with a newly designed patient electronic record system on the workload of healthcare staff, Bossen exposed power issues in an organisation who, despite its negative impact on people, decided to adopt the system. This work highlighted a need for PD work that explicitly considers who has the right and authority to act upon certain contributions and ignore others within a design process. Returning to Beck's call to address such issues, one of the central concerns of PD invites researchers to question power related issues, asking: what are the agendas guiding PD projects; who gets to influence them; and, who's problems are being addressed? (Beck, 2002).

In recent HCI work that has focused on addressing power issues in PD projects involving children, Bossen, Dindler, & Iversen (2010) examined the user gains and long-term effects of a PD projects in primary schools. By focusing on the personal and collective gains that child and adult design partners experienced, the authors showed that whilst it was difficult to sustain initiatives after the project ended, participant actions suggested that user gains were part of a network of local and organisational channels. For example, adult partners (teachers) who had an interest in educational technologies expressed that participation in the project had brought new competence to how they carried out their jobs, as well as connecting them to a network of new people for support. Equally, child partners expressed that on a personal level, they had gained new skills in information technology. By focusing on user gains, the study exemplified one way of addressing challenges of who and what to design for, by focusing on outcomes for participants, rather than the organisation's goal for design projects.

Mutual learning

Connected with the idea that different design partners hold different perspectives, a central concern for PD is to ensure mutual respect for different groups. This involves learning about each other and understanding about their ways of reasoning. For the user, this can include sharing their domain specific expertise. For the designer, this includes sharing their knowledge on technical issues and the design process (Bratteteig et al., 2012). By understanding about each other's roles, different members of the team can begin to envisage the possibilities of how to do things in other ways, by understanding the kinds of knowledge and opportunities available to them.

Simonsen and Robertson described PD as “a process of investigating, understanding, reflecting upon, establishing, developing, and supporting mutual learning between multiple participants in collective ‘reflection-in-action’.” (Simonsen & Robertson, 2013, p.2). Whereas a design thinking approach positions reflection-in-action as being within the designer's remit, within a PD approach, reflection is a core activity for the whole team, advancing learning across the whole team as the design process progresses.

Epistemological underpinnings and historical roots

Understanding what forms of knowledge is constructed and how this is achieved is a central concern of PD. With its social constructivist underpinnings, the epistemology of PD has been described as co-constructed, situated and embodied (Frauenberger et al., 2015). Connected with the underpinning ideals of PD described in the sections above, PD practitioners have advocated for a critical stance against cognitive accounts of human practice. Instead, PD in HCI contexts seeks to generate knowledge that includes understanding about people's social and embodied practices, theorising about the consequences of future technologies, engaging with stakeholder values and engaging with what should be designed for to name a few directions. Within PD, the ways of generating knowledge can be constructed differently, for example, seen as an emergent and situated process that is negotiated, as well as being informed by learning-by-doing perspectives, that have informed design enquiry strategies of prototyping (Bannon & Ehn, 2013, cited in Simonsen & Robertson, 2013).

As voiced previously, historic PD practises that have shaped the pillars and ethos of current PD work stemmed in work-based contexts. The aim of early PD work was to give people better tools for doing their jobs which enabled them to develop their skills, rather than replace or de-skill through the introduction of computers in the workplace. Acknowledging a need for

involving workers in legitimately engaging in design that has an impact on their workplaces, the UTOPIA project was a key example that took people out of their workplace into a shared design space for experimenting and imagining future solutions for digital tools they might need for their work (Bødker et al., 1987).

In another example that would go on to influence the development of PD, Lucy Suchman showed how through ethnographic methods, practitioners were able to attend to the detailed ways that work gets done (Suchman, 1987). Rather than following top-down organisational agendas, studying the situated relations between people, technology and work at the Xerox Palo Alto Research Centre, Suchman's work also rejected cognitive perspectives that suggested universal courses of action in the human mind. Instead, she argued that plans are driven by antecedent conditions and consequential actions (Suchman, 1987). This important contribution would go on to influence ethnographic methods in PD and underscore the importance of examining situated actions when understanding and designing artefacts. The underlying commitment of PD was to ensure that those who use information systems play a crucial role in their design (Simonsen & Robertson, 2013).

Whereas the first wave of HCI was concerned with studying humans as subjects and attending to human factors through a cognitive science lens, the second wave of HCI was characterised by a move from 'human subjects to human actors' (Bannon, 1995). The focus in the second wave was on studying distributed cognition and situated action in work settings. In the most recent third wave, the contexts and use cases for studying technology use have grown. By studying people's uses of technology beyond the workplace, the HCI community has moved beyond considering work related values of efficiency towards broader values that resonate with people's every day uses of technology, for example, acknowledging experiences and meaning making (Bødker, 2015). Like in the earlier chapter that examined the changing focus of studying communication, here, the foci have also moved toward understanding the distributed, situated and value-related ways that people act.

Connected with this third wave, PD has been embraced in many different traditions and disciplines, now reaching far beyond its original tenets of designing for the workplace (Iversen et al., 2010). For example, Halskov & Brodersen Hansen (2015) presented the varied research contributions of PD over the past decade, of identifying applications of PD in new domains, offering theoretical contributions and developing an understanding of the general nature of basic concepts in PD, amongst other contributions. Owing to the rich diversity of PD practices, it is not surprising then that definitions of participation have been varied (Halskov & Brodersen Hansen, 2015) as well as informed by different epistemological and value commitments

(Frauenberger et al., 2015). With its diverse applications, researchers are now questioning how far PD approaches have moved away from the politically motivated principles at its core (Iversen et al., 2010) suggesting a misplaced focus on methods, tools and techniques that overlook its underlying politically motivated ideals. Further, Kyng (2010) proposes that beyond revisiting the political discourses of PD, there is a need for focusing on bridging the gap between politics and techniques so that we can engage with the next stage of practices of PD that address issues that matter.

PD and child computer interaction

Connected with the increasing application of PD in new domains (Halskov & Brodersen Hansen, 2015), the child computer interaction (CCI) community has over the past two decades embraced PD for developing ways of designing technologies with and for children. The CCI community itself stemmed from a growing body of work in the 1990s of interdisciplinary researchers who were increasingly involved in sharing their experiences in designing interactive technologies for and with children. Bringing with them different perspectives on the ways of involving children, these researchers would begin to assemble in what would eventually lead to the establishment of the Interaction Design and Children (IDC) conference in 2002. Within the IDC community, a growing number of interdisciplinary practitioners continue to embrace a richly diverse wealth of approaches, methods, techniques and tools for involving children in the design process. With its richly diverse applications, Hourcade (2015) identified that collectively, the CCI community is supported by ten pillars that guide this type of work:

1. Working in interdisciplinary teams
2. Deeply engaging with stakeholders
3. Evaluating impact over time
4. Designing the ecology, not just the technology
5. Making it practical for children's reality
6. Personalising
7. Being mindful of skill hierarchies
8. Supporting creativity
9. Augmenting human connections
10. Enabling open-ended, physical play

(Hourcade, 2015)

Connected with the historical roots of PD, many of these statements acknowledge an appreciation of designing for users through relating to how they act in the context of their

everyday experiences, and in this case, treating children as experts in their own right and human beings, rather than ‘human becomings’ who are yet to develop (Qvortrup, 1994). Taking Hourcade’s second key pillar as one focal point for designing with children, *deeply engaging with stakeholders* is of key importance for involving children in ways that are not tokenistic. Connected with a central concern of PD for examining the notion of participation, deeply engaging with children as a key stakeholder has involved focusing on what participation looks like when set against a backdrop of the nine other pillars.

One key model that has influenced a number of frameworks and guidance on ways of involving children in the design process was proposed by Hart (1992). Appreciating that ‘involvement’ is not always synonymous with ‘participation’, Hart (1992) argued participation is a fundamental right of citizenship and involves the act of “sharing decisions which affect one’s life and the life of communities in which one lives” (Hart, 1992, p.5). In the case of being able to deeply engage with understanding and designing with children, legislative priorities, such as the UN Convention on the Rights of the Child (UNCRC, 1989), informed the development of Hart’s model for conceptualising participation. Hart proposed an eight-rung ladder model that depicted the different levels of participation that children are said to take. This model (figure 5) was influenced by earlier work by Arnstein who described a ladder of citizenship participation (Arnstein, 1969).

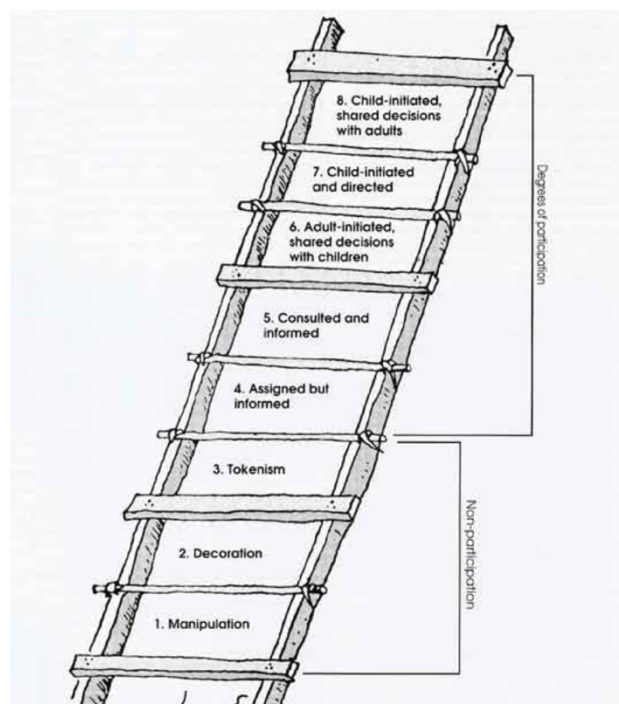


Figure 3.05. Hart (1992) – The ladder of participation

According to Hart, at the lower rungs of the ladder, children can be involved in non-participatory ways, like for example through manipulation to voice adult opinions by somehow 'carrying' adult views without understanding the issues that they have been asked to express. Other non-participatory ways can involve asking children to comment their views, but with little choice in or impact on the subject matter, hence tokenistic involvement. At the higher rungs of the ladder, the degrees of children's participation become more involved in affecting decision making and directing the agenda. Hart argued that it is not always necessary to aim for the highest rung (i.e. 'child-initiated, shared decisions with adults') as children might prefer to participate in different ways at different points.

Within both Hart's recommendations and those of the UNCRC, there is a suggestion that children who are capable to do so can and should freely be given the opportunity to actively express themselves (UNCRC, 1989). For some children, this can raise tensions in knowing how to interpret the notion of 'capability'. The Department of Education's Children Act argued that children with disabilities should not be assumed as incapable of making shared decisions (Department of Health, DOH 1991) advocating for arrangements that allowed children to establish their views. More recently the Special Educational Needs and Disability (SEND) reforms of the Children's and Families Act (DOH, 2014) proposed that professionals should seek the views of children in decisions that influence their lives. Collectively, these legal mandates underscored the importance of ongoing efforts to involve all children, including children with SEND in decision making processes. Despite this effort, these recommendations have challenged professions, particularly in cases where the challenges of supporting children to participate extend far beyond adapting generic methods. For example, Franklin and Soper highlighted the practical barriers preventing participation for children with disabilities (Franklin & Soper, 2009). Some of their identified factors included the pressure of time commitments, lacking resources and importantly, a need for a shift in attitudes for addressing power imbalances. With these priorities and challenges in mind, CCI researchers and practitioners have contributed to problematising some of these challenges.

Children's roles and levels of involvement

Informed by a need to address power imbalances towards involving children in legitimate ways, early interaction design work involving children investigated the meaningful ways that children could contribute to the design process. Scaife and colleagues proposed the concept of 'informant design' as a framework for addressing ways of involving children and teachers at different stages of a design process (Scaife et al., 1997). For Scaife et al, children were able to contribute to early design stages of defining domains and problems, then at a later stage,

designing and testing prototypes. The informant design framework recognised that children are very good at letting researchers know what keeps them engaged, yet children do not have the time, knowledge or expertise to collaborate as equal partners, as suggested by traditional, politically motivated PD practices. Instead, adult collaborators (e.g. HCI analysts, psychologists and software designers) are invited to interpret problems that have been identified by children and suggest possibilities based on children's contributions. At a later design stage, children are said to again contribute by providing insights for building low tech prototypes and evaluating and verifying whether these prototypes are an improvement on existing methods.

Whereas Scaife et al identified that different informants would shape the design of systems at different points through specialised inputs, others have positioned children as legitimate partners within an intergenerational team. Informed by Hart's conceptualisation of the kinds of roles children take, Druin introduced 'cooperative inquiry' as a design approach (Druin, 1999). Influenced by a participatory design and other design approaches, cooperative inquiry is guided by the principles of multidisciplinary partnerships with children, fieldwork that enables understanding of contexts, and a need for iterative prototyping. Cooperative inquiry advocates for building ongoing partnerships with children over longer periods of time, suggesting that intergenerational teams can work together, with children sharing responsibilities as researchers. Through cooperative inquiry, children and adult partners are said to engage in shared learning about the design process, learning how to communicate and collaborate in teams and developing new technology skills and content knowledge. These learning outcomes are referred to as 'design-centred learning'. Building on this, Druin (2002) examined children's levels of involvement, proposing four hierarchical roles that children can occupy in the design process (Druin, 2002). These are presented in figure 6 and summarised below.

the child as...

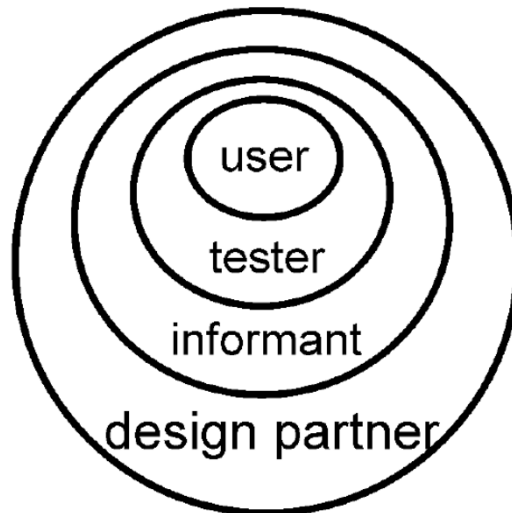


Figure 3.06. Druin (2002) - Four roles that children may have in the design of new technologies

User: As users, children are observed by researchers whilst interacting with existing technologies. The researcher is informed about the types of things that children are motivated by as well as learning about the challenges of existing tasks and situations.

Tester: As testers, children evaluate technology prototypes before they are released to the wider public. This provides formative feedback for designers who are then able to carry out further iterations on the prototype based on children's reactions. Ultimately however, the ideas still come from adults and children do not have a chance to give their ideas to the design team.

Informant: As informants, children share their ideas and opinions at key moments in the design process, acting as consultants. This can for example be at the early stages, providing insights based on domains that the researcher has defined. Similar to that described by Scaife, Rogers, Aldrich, & Davies, (1997), children's participation is situated between user-centred design and participatory design.

Design Partner: As design partners, children share responsibility in all stages of the design process and collaborate as members of the design team. They have a significant role in shaping the outcome of technologies. This kind of involvement is typical of participatory design. Also, Druin and colleagues describe how cooperative inquiry enables children to participate as design partners (Druin, 1999; Guha et al., 2013).

Building on the cooperative inquiry approach and informed by developmental considerations for involving younger children, the same authors also introduced a method for enabling

children to understand how their ideas were used (Guha et al., 2004). Through the 'mixing ideas' method, Guha et al describe a process whereby young children learn to collaborate with other children by first generating ideas individually then gradually mixing these in small groups until they generate a 'big idea'. The authors described a need for introducing this method as a response to children becoming upset when their ideas were not chosen. In other work that has taken a similar approach for being explicit in communicating to children how their ideas are used, Read and colleagues proposed the 'TRAck' method of: tracking, representing and acknowledging ideas (Read et al., 2014). Like in the work of Guha et al, Read et al propose an approach that provides workable design ideas through taking a descriptive perspective when analysing children's contributions. Considering the ethically driven ideal of participatory design that promotes democratising 'having a say', both the 'mixing ideas' and 'TRAck' methods provide systematic ways ensuring that children understand how their ideas inform the design process.

In revisiting the original ambitions of cooperative inquiry 15 years on, Guha and colleagues (2013) suggested that whilst the cooperative inquiry approach and a focus on children's roles remains relevant, with the expansion of social and technological practices, there is a need to expand on the dimensions that each of these roles addresses (Guha et al., 2013). For example, addressing how children can partner with international and diverse groups and expanding design methods that can support the design of mobile and social technologies. Further, in reflecting on the validity of the approach, the team argued that these roles are not intended to suggest that 'one role is better than the other', but rather present the different kinds of roles that children can take (Guha et al., 2013).

Others have criticised this approach however, arguing that the design partner role is hard to live up to as many researchers are unable to link up with children for several years of shared ownership (Barendregt et al., 2016; Mazzone, 2007). Also, others have proposed new roles, such as the child as protagonist (Iversen et al., 2017) and also a need for examining how children's roles might differ and sit in between the spaces between the initially conceptualised four roles. Large et al, for example, describe a stage between the 'design informant' role and 'design partner', questioning whether children can collaboratively work as partners. Using a 'bonded design' approach (Large et al., 2006), Large et al advocate for the active involvement of children in the design process, by acknowledging that it can be difficult for children to be design partners in intergenerational design projects. Instead, they suggest children can collaborate as 'child experts' across all stages of the design process, offering a different level of involvement compared with the design partner role.

Although there have been criticisms raised by depicting children as taking discrete roles, Benton and Johnson (2015) highlight that there are also benefits in representing children's level of involvement in this way. Namely, clear definitions on the responsibilities associated with each role can enable designers to plan activities that align with expected behaviour patterns. Further, children's roles can give a clearer indication about how much they were involved in the design process and consequently, how far children's involvement has impacted on the designed product (Benton & Johnson, 2015).

In an alternative approach that seeks to extend an understanding of the roles that children can take, Barendregt et al (2016) propose a need to understand how exactly children are involved in the design of new technologies. Rather than focusing on hierarchically arranged roles, they focus on three phases of design within which children are involved (i.e. identifying requirements, design and evaluation) and children's activity in relation to the designer. They propose that children's involvement can be appraised in terms of the credibility of design decisions based on a new role definition matrix (Barendregt et al., 2016). Further, they argue that children might change roles during a project, inviting others from the IDC community to use, evaluate and improve the role definition matrix for examining the ways that children are actively involved.

Designing the ecology, not just the technology

Connected with another pillar that Hourcade has proposed as guiding CCI work, other have taken an 'ecological turn' that has focused on designing for spaces and practices within which new technologies will be used, rather than focusing on technological artefacts themselves. Through an interpretive stance that aimed to appraise the kinds of knowledge that is generated through children's contributions, [Smith, Iversen, Hjermitsev, & Lynggaard \(2013\)](#) proposed that designing with children should be a dialogic process that seeks to engage with their values and understanding the ever-changing socially and spatially arranged environments that are being designed for. Extending the boundaries of cooperative inquiry, ecological inquiry sought to involve participants in negotiating the locations of shared design spaces, extending possibilities for sustainable use practices with new technologies (Smith et al, 2013). Drawing on the example of designing for school-based learning environments with 6th grade pupils and school staff, the authors uncovered that learning spaces extended beyond classroom environments. This in turn led to the creation of a social technology platform that afforded untraditional ways of teaching, for example, in 'on- and off- school locations' and through peer-to-peer learning. By focusing on cultivating values that emerged in thinking about the contexts of new technologies, the authors argued that ecological inquiry emphasises

empowering users through a focus on the ways that new technologies lead to changing practices within people's socio-cultural contexts.

Building on this ecological turn, Van Mechelen et al. (2017) focused on designing within children's peer group contexts and focusing on values. Taking an interpretive stance, they suggested a need for understanding children's contributions beyond their verbatim, descriptive accounts. The authors proposed a method for attending to the multimodal ways that children communicate their values about their lives and the design process. Van Mechelen et al proposed the GLID method, comprised of four distinct stages in analysing outcomes of co-design work with children. The first stage involved tracing outcomes back to origins within which initial ideas are targeted, for example, by the influences of researcher priorities. The second stage focused on separating out how communicative modes map onto specific design ideas. The third stage is concerned with interpreting and scrutinising how co-designed outcomes are presented as a coherent whole, and the fourth and final stage focuses on exposing which values are communicated through the co-designed outcome. By investigating how to trace ideas back to how they connect with children's values, the authors propose a systematic way for investigating the children's involvement through a focus on their values and how these are related to children's contributions.

In summary, as interaction design work with children continues to evolve, two significant points of focus include scrutinising the process of how children participate through an examination of roles and methods, but also designing for the ecology of children's everyday lives, in line with the third wave of participatory design in HCI. As this community of work matures, Barendregt, Torgersson, Eriksson, & Börjesson, (2017) propose a timely reminder for considering the importance of designing beyond technological artefacts themselves, voicing a call to focus on the transferable knowledge that is gained from interaction design work with children. Connected with the concerns of PD that have moved away from the politically dimension towards a misplaced focus on methods, tools and techniques (Iversen et al., 2010), the authors suggested that through a focus on 'strong concepts' and other intermediate level knowledge (Höök & Löwgren, 2012), there is promising scope for investigating how children's involvement can impact on the type of knowledge that is generated. Rather than descriptively documenting the methods and roles that children take part in, a shift towards attending to intermediate level knowledge might instead enable design teams to understand the strength of children's contributions by instead attending to how knowledge is generated that directly informs design decisions. Whilst Barendregt and colleagues describe intermediate level knowledge through examining how existing 'artefact-centred' papers present possibilities for

this kind of knowledge, there is potential for future work to engage with exploring how children's contributions align with strong concepts that transcend stand-alone design projects, and can be mobilised in PD work that focuses on matters of scale (Frauenberger et al., 2018). As this body of work continues to develop, the IDC community are acknowledging that different kinds of knowledge can have impact in different ways. It is recognised that transferable intermediate level knowledge is no panacea for legitimising children's contributions and the rigour of such design work as it arguably privileges knowledge abstraction over transfer, therefore ignoring situated dependencies (Torgersson et al., 2019). However, it offers a starting point for raising questions about internal rigour of interaction design work with children by critically examining insights and the contexts that they can inform. The authors suggest that this engagement can help the HCI subfield mature by considering the many different ways that insights connect with holistic bodies of knowledge.

Empathy and design

How empathy serves design

Envisaging and designing for people can be difficult when designers' lives are seen to be very different to the lives of people for whom they are designing for. In these cases, empathy has served as a key sensibility in HCI for enabling designers to engage with understanding more about the people and situations that they are designing for. Empathy has been described as *"our capacity to gain a grasp of the content of other people's minds, and to predict and explain what they think, feel, and do [enabling us] to respond in an ethically appropriate way"* (Coplan & Goldie, 2011). In the context of designing technologies that are intended to support people and their everyday lives, empathy has been seen as necessary for moving beyond system functionality to more humanistic perspective that acknowledges the subjective experiences, feelings and values of the user (Battarbee et al., 2015; Thieme et al., 2014).

Ways of working with empathy have varied widely, particularly within the third wave of HCI that has scrutinized the processes and outcomes of technology design projects that are intended to impact on people's lives (Hendriks & Wilkinson, 2017). PD and empathy have been closely connected, as PD practices have sought to foster empathic relations between people, fostering respectful relationships that drive PD (Lindsay et al., 2012). In order to reveal how HCI researchers have worked with empathy the following section examines how empathy has been used in different ways across design literature that extends beyond PD.

In work that focused developing empathy within the designer, Kouprie & Visser, (2009) proposed investigating the affective and cognitive components surrounding users. Their approach aimed to create a dedicated space to explore users by being immersed cognitively and emotionally being able to detach so that they could helpfully respond. Others have also focused on what the designer does. For example, in a popular and widely cited design school approach, the Stanford d.school has advocated for engaging with empathy through designers immersing themselves in understanding what it is like to be in another person's shoes. Similarly, in design and management industry contexts, the empathy maps are used in related ways, supporting designers in engaging with areas of user's behaviours, feelings and thoughts (Gray, 2018).

In the examples described above, the focus has been on examining methods and how empathy can be a source of inspiration through methods. This has sometimes been approached through direct or indirect contact with users, and/or through methods that are designed to prompt imagination, for example, understanding experience through probes. In these cases, empathy has been conceptualised as something that the designer does in order to gain a greater understanding of the intended user group. In these instances, empathy serves as a way of gathering insights through acquiring new information through empathic methods.

Whereas these engagements have looked at ways of rousing empathy within the designer, others have worked with empathy as a source for generating inspiration. Mattelmäki & Battarbee (2002) used empathy probes for supporting designer interpretation (Mattelmäki & Battarbee, 2002). Building on the idea of cultural probes (Gaver, Dunne, & Pacenti, 1999) which aim to support new readings of a situation, material packages which are created for users to document their private lives and experiences, are then shared with designers. They are intended to offer sources of inspiration for designers by attending to the personal contexts and experiences of users, beyond practical issues surrounding the uses of technologies. Through empathy probes, the designer has access to design tools that are intended to be new sources of inspiration.

In a turn for understanding users' lives and experiences in a holistic way, the work of McCarthy and Wright has been highly cited in the HCI community, advocating for a moral stance and commitment towards working with empathy and experience. Taking empathy as a construct for how to plan and use design methodologies, Wright & McCarthy (2010) attended to meaningful encounters between designers and people by attending to both the holistic and relational experiences that users encounter. Wright & McCarthy (2010) draw on the work of Mikail Bakhtin to apply the Bakhtinian term 'aesthetic seeing'. This involves engaging with the

felt responses of another whilst seeing it from a unique and separate stand point. Unlike with the design thinking view which focuses on applying multiple points of view and multiple frames for working through ways of interpreting the design problem, here, empathy serves as the core activity that informs how designers make sense of the situation, for example, through visceral engagement. For McCarthy and Wright (2007), working with empathy and experience involves understanding people's experiences in terms of the multiple centres of values connected with people, artefacts and settings. Through appreciating another's perspective from this separate position, the authors argue that designers can respond creatively from their own perspective.

Connected with the idea of deeply engaging with understanding people, others have prioritised ways of generating holistic narratives concerning people's lives. Focusing on the value of storytelling for offering compelling sources of inspiration, Nielsen (2002) advocated for well-rounded character development. Contrasting other narrative techniques such as personas and film script writing, Nielsen argues that for design purposes, user descriptions should be built on believable character stories, rather than focusing on a plot. For Nielsen, taking into consideration the physiology, sociology and psychology of the character, enables the designer to engage with a *cacophony of voices* that surround the person's lives. For example, as people interact in varied social discourses at different times, character development should be viewed as a process which is closely linked with the cultural signs and groupings around them. Like McCarthy and Wright (2007), Nielsen's view of rounded characters offers opportunities for designers to deeply engage with understanding real people's lived experiences, which for design purposes, is crucial for engaging in empathy by remembering that design is for real people.

Taking inspiration from documentary filmmaking, Raijmakers, Gaver, & Bishay (2006) further developed empathic techniques for deeply engaging with people's lives and rich situated experiences. The goal for Raijmakers et al was to develop sources of information and inspiration that appreciate the complexity of everyday life and avoid simplification. Unlike other narrative methods that seek to provide multi-layered sources of inspiration through creating fictional or extreme characters (for example, Djajadiningrat, Gaver, & Fres, 2000 and Gaver, 2007), design documentaries portray the real and everyday lives of users, incorporating and preserving ambiguities and paradoxes rather than reducing these to univocal accounts. Design documentaries are said to support designers in engaging creatively with situations that are multi-layered and which require multiple framings. How design documentaries are created can vary, for example, they can be made with or without users, and

can present characters that are wholly or loosely based on real people. The authors describe that it is the 'hunger for everyday details' concerning people's everyday lives, tastes and ways of expression that enable designers to understand who the people are beyond a list of needs and requirements. In addition to the detailed accounts of people's lives and how these sources are interpreted by those who are responding to these tools, this also acknowledges that design documentaries incorporate the perspectives of the person creating the tool, who interprets the situation in a certain way.

Tensions and challenges in working with empathy

In PD work that has positioned empathy as helping to bring the designer's and user's worlds closer to each other, the focus has been on using empathy to drive the development of knowledge that is co-constructed with users. Motivated by a humanistic perspective for developing rich understandings about people's values within the contexts of their everyday lives, empathy in PD has been driven by core ideals of mutual learning, addressing power relations and allowing of democratising having a say. However, with the move towards applying PD in new domains, new challenges have been posed when designing for and with users whose lives and perspectives are perceived to be very different to that of the designer, as might be the case when designing with children who have disabilities.

Spiel and colleagues for example, suggested that in the case of designing for and with children whose lives are very different to designers, empathy is not enough (Spiel, Frauenberger, Hornecker, et al., 2017). They proposed a systematic framework for drawing on a network of aspects that can support designers in getting closer to designing with people. Their approach suggested a need for attending to a number of different focal points that are networked around the children's everyday lives. This perspective poses one example of shifting the focus of understanding users away from a focus on empathy, to structuring and accounting for a network of factors that exist around the child.

However, others have been more interested in defining the terms and uses of empathy as a way of problematising how to engage with it. Brownlee (2015) and separately Kouprie and Visser (2009) for example, have proposed that designers need to move outside of their own experiences to see what it is like for someone else, for example, by putting oneself in a user's shoes (Brownlee, 2015; Kouprie & Visser, 2009). Often this 'moving into another person's shoes' has been approached by simulation activities that attempt to allow people who presumably do not have physical or sensory impairments to experience having a temporary impairment. However, Bennett and Rosner (2019) highlight some of the challenges this raises,

including prioritising the view that ‘the problem’ situation is located within the individual rather than connected society, and further diminishing the voice of end users whose lived experiences become reduced to a temporarily experienced disability, from the designer’s perspective. Similarly, broader work that has looked at the use of certain methods for rousing designer empathy, for example personas, has questioned whether these methods enable designers to deeply engage with users by understanding their experiences (Bødker et al., 2012), suggesting that it is problematic to treat empathy as a commodity to be acquired (Bennett & Rosner, 2019). Instead, suggesting a move towards working with empathy that is attuned to foregrounding shared experience and engage with the multiplicity of politics surrounding designer interpretation (Bennett & Rosner, 2019).

In summary, empathy has received a great deal of interest and serves an important role in design through a number of goals. These have included acquiring new understandings about people; providing inspiration for design; or, for helping to foster respectful relationships in the design process. Different design techniques have been used to provoke empathy, including directly and indirectly engaging with users, as well as methods that inspire imagination, for example, understanding experience through design tools, for example, cultural probes (Battarbee et al., 2015; Gaver et al., 1999), narrative tools such as design documentaries (Raijmakers et al., 2006), scripts that present well-rounded character descriptions (Djajaningrat et al., 2000; Nielsen, 2002) and ethnographic methods for understanding about the rich experiences surrounding people’s lives (Wright & McCarthy, 2010). While they each attempt to inspire design by engaging with people’s every day, situated lives in rich ways, they are also diverse in how they position the relationship between the designer and user. Some have positioned the designer’s experiences as very different to that of the user and reliant on information that needs to be acquired (for example, Brownlee, 2015; Kouprie & Visser, 2009), compared with sharing commonalities and experiences that can be bridged through empathically becoming attuned to each other (Bennett & Rosner, 2019).

For the purposes of this thesis, these insights suggest that to engage in design work that intends to understand and design for situated experiences, needs careful planning for considering ways of enabling designers to appreciate the complexities of how their perspectives relate to that of users. In the case of designing for communication and children with SSPs, carefully developed methods that incorporate rich and multi-layered accounts can enable designers to appreciate the complexities of children’s lives, when children themselves cannot directly be involved in the design process. In these instances, design work should consider how children’s voices are prioritised, for example, by scrutinising how to take child-

centred perspectives that do not overly credit the interpretations of the designer, but instead incorporate polyphonic accounts of the kinds of values and manifestations that children have expressed as important either directly or indirectly.

Applications of designing for communication and non-speaking children

The previous sections considered three separated yet related design approaches. Each discussed the kinds of practices that designers do and how design work is shaped by different goals. One useful way of thinking about what designers actually do has been to consider design thinking in terms of five discourses that inform knowledge generation through different practices. These were: 1. Design as the creation of artefacts; 2. Design as reflexive practice; 3. Design as a problem-solving activity; 4. Design as a way of reasoning and making sense of things; and 5. Design as the creation of meaning. PD has complemented these discourses by situating the role of the user in this knowledge generation that is seen as distributed and contextualised within people's everyday lives, also critically examining how children are involved. Empathy added an additional lens; considering what it means to understand users and how this serves design. Informed by these insights, this section considers applications of designing for communication involving children with SSPIs.

During the AAC-RERC 2006 conference, which is considered a prominent state of the science conference in the field of AAC, delegates made a call for the redesign of AAC technologies, particularly initiated by individuals with complex communication needs (CCNs) (Blackstone et al., 2007). Blackstone et al (2007) described two common requests concerning this redesign: (a) making speech generating devices easier for individuals with CCNs and their primary communication partners to learn and use, and equally importantly, (b) enabling them to connect more seamlessly with mainstream technologies and reflect contemporary design in a broader sense. This call reflected some of the challenges posed by the usability of existing technologies, but on a deeper level, also highlighted a need to rethink the role of these technologies and their connections with other technologies within people's lives. Considering the involvement of end users for understanding these issues, Blackstone et al highlighted that AAC users hold an intensely personal stake in AAC research and practice, yet they have found it difficult to influence AAC research and technology development. Consequently, AAC users have been disenfranchised from decision-making, design, and development processes that, in the end, primarily affects their wellbeing (Rackensperger et al., 2005). Whilst some

participatory research within the field of AAC has provided example cases of researching with AAC users (Blackstone et al., 2002; Krogh & Lindsay, 1999; O’Keefe et al., 2007), these have focused on therapeutic and educational interventions, rather than technology design. These insights suggest that opportunities exist for engaging with new perspectives on what to design for as well as understanding how to involve AAC users by considering the expertise, preferences and priorities of intended users (Blackstone et al., 2007). The remainder of this section discusses the kinds of perspectives that have impacted on what has been designed for, then discusses the approaches that characterise existing work. The focus is on identifying design frames, how they are theoretically informed, and describing moments of child involvement.

Design frames in designing for communication and children with disabilities

Whereas the AAC community has largely been concerned with understanding communication for the purposes of supporting a range of educational, therapeutic and social interventions, the HCI community has focused on technology design. Within the field of HCI there has been a growing concern to contribute to the wellbeing and inclusion of people with disabilities. As part of the third wave of HCI that has focused on understanding and supporting technology use in people’s everyday lives, disability has received huge attention. As part of this interest, the ACM Conference on Human Factors in Computing Systems (CHI), which is the premier international conference of Human Computer Interaction, has two separate subcommittees that have received interest from HCI researchers who are designing for the health and wellbeing of people who are disabled in some way; the accessibility and aging subcommittee, and separately, the health subcommittee. Also, there are special interest groups, ACM-sponsored conferences and journals all dedicated to contributing to this body of work, reflecting this ever-growing global interest. In order to discuss how this wide spread attention has contributed to understanding ways of designing for communication, this section discusses how HCI work has engaged with designing technologies that mediate interpersonal or face-to-face communication involving people with SSPIs. In reviewing key examples from existing work, this section identifies design frames and maps the theoretical assumptions that underpin existing design work.

Design can alleviate bodily impairment

The medical model of disability that focuses on the physical and functional limitations a person may present with has been a prevalent focus of HCI work as it often generates actionable frames and clear ways of measuring results (Mankoff et al., 2010). Connected with the view

that impairments at the individual level can pose significant effects on people and should be acknowledged and supported, some work has focused on designing by addressing individual level impairments that are commonly associated with specific groups.

Madsen, el Kaliouby, Goodwin, & Picard (2008) designed a piece of technology to help autistic individuals interact with people 'in the moment' by capturing and analysing facial affect. The design solution acknowledged that individuals in these situations often struggle with social interactions, due to difficulties picking up on interpersonal cues conveyed through facial expression. Using a mini computer that was connected to a video for live recording, individuals would hold up and make a video recording of the person with whom they were interacting with. This was said to enable them to identify their conversation partner's expression by comparing it with six predefined emotive states. Their work identified the importance of designing for everyday situations that people are personally situated within, through technologies that could be drawn on within natural, 'live' environments.

Hayes (2010) focused on the idea that visual representations of words make it easier for non-speaking children with autism or cognitive impairments to understand language through having a visual resource for mapping language onto the world around them. They designed a digital version of the Picture Exchange Communication System (Pyramid Education), which teaches people to exchange iconic pictures as a way of communicating phrases including: 'I want, I see, I feel' and some other fixed sentence structures. Hayes et al's digitalised speech generation system allowed users to take photos to capture and store images that represented vocabulary, which they could then select and speak using electronic voice, through a hand-held digital device with camera and speech generation functions. By focusing on ways of replacing natural speech through electronic speech, the design solution was framed as addressing function at the level of the individual. Theoretically, it aligned with a cognitive perspective on communication, prioritising the sending and receiving of information through the transmission model (Lloyd et al., 1990).

Similarly, the work of Sampath, Indurkha, & Sivaswamy (2012) and Lampe, Blumenstein, Turova, & Alves-Pinto (2018) also took similar perspectives, in supporting message transmission by focusing on ways of generating digitalised speech to address bodily impairment. In the case of Sampath et al, making digitalised AAC cheaper and easier to edit and use on mainstream devices, and in the case of Lampe et al, designing a more portable text to speech solution that users could wear as a jacket. Both solutions recognised the importance of designing for situated communication that needs to be accessible in different contexts and less conspicuous beyond a large mounted computer system. They also both focus on the

accomplishment of communication as a practical, speech transmission task that is performed by the person with a speech impairment.

In all of these described cases, technology becomes a central concern for the person whose impaired speech need augmenting or replacing. In these cases, the technology is part of the social configuration that implies the person with a speech impairment will demonstrate their capability to replace a lack of natural speech through an alternative digital speech mode. As the assumption is that the present technology will be used, their agency to use other means of their own choosing can be limited.

Design can support learning

Connected with a developmental perspective for supporting individuals to learn certain skills, the HCI community has been interested in design solutions that are intended to alleviate impairments through training. In one example of this, de Faria Borges, Filgueiras, Maciel, & Pereira (2012) took a therapeutic and learning perspective on designing AAC for a child who has cerebral palsy. The focus was on working with the school and therapy team to create a system that would support the child's language development based on the words and symbols that they were learning in school.

Separately, Zhao, Swanson, Weitlauf, Warren, & Sarkar (2018) designed a virtual environment game for supporting autistic children in developing their social interaction skills. Through collaboratively moving virtual objects with their virtually located peer, players were encouraged to work together to address puzzle games, with the goal to develop both collaboration and motor skills. In these cases, technology was intended to support communication through the development of skills that individuals are said to acquire in typical developmental trajectories. Owing to overlapping framings, other examples of design that can support learning as well as other functions are also included in the section below (e.g. Barendregt, Börjesson, Eriksson, & Torgersson, 2017; Brederode, Markopoulos, Gielen, Vermeeren, & de Ridder, 2005).

Design can enable co-constructed, situated communication

Extending this view that communication is co-constructed, Black, Waller, Turner, & Reiter, (2012) focused on the distributed sources of data that children can choose to use in communicating. Adapting existing text to speech AAC technologies, Black et al used environmental sensors to collect data that would be converted into text and made available on children's AAC devices through natural language generation. The aim was to enable children to

engage in extended conversations with narratives about their day. Through text options that were generated through data collected by radio frequency identification sensors, children had the option to use additional data sources when formulating speech through their AAC. This solution offered children agency in choosing to uptake data or not, attending to situated sources of data for communicating within those contexts.

Overlapping with the previous section, some work has been informed by both developmental and co-constructed perspectives on communication. Brederode et al. (2005) and separately, Barendregt, Börjesson, et al. (2017) designed collaborative games that were intended to encourage social interaction and play through collaborative activities. Brederode et al (2005) designed a collaborative tabletop game for bringing together children with mixed abilities for encouraging social interactions surrounding play. Through 'pOwerball' players are required to cooperatively 'liberate imprisoned creatures' by moving tangible objects that acted as handles for virtual obstacles. Separately, Barendregt, Börjesson, Eriksson, & Torgersson, (2017) designed a forced collaborative interaction game to support the training of collaboration skills of children in special education settings. Through a series of collocated and connected tablets, players were together required to solve puzzle games. In both of these examples, the design frames acknowledged that communication was distributed and co-constructed. Through a focus on play, both also prioritised learning goals for social interaction skills.

In all of these cases, technology use was distributed and part of the wider social configuration that all participants were part of. Considering the communication perspectives that were discussed in the previous chapter, this frame theoretically connects with the view of assistive technologies being a shared resource (Clarke & Wilkinson, 2007).

Design can facilitate experience

In what has been described as a post-modern approach, some HCI work has privileged an individual's lived experiences and the complexities and nuances that make up everyday life (Mankoff, Hayes, & Kasnitz, 2010). By considering multiple dimensions, including bodily impairment, social and cultural factors, designing for experience, has attempted to acknowledge and design for this complexity. Whilst there is still little work to date in this area, some studies have focused on designing for communication and experience.

Durrant et al (2013) focused on the early fuzzy front end of design, exploring how photographic practices might enhance the interpersonal communication experiences of children with mixed abilities and their teachers. They were interested in understanding

children's 'real world' needs, desires and experiences so investigated students' lived classroom experiences. By designing a photo sorting tool, they explored photo capturing and sharing practices with a focus on supporting and enhancing interpersonal communication and expression between students and staff. Through a series of design workshops with students and staff, the authors examined social complexities and the views of multiple stakeholders in thinking about designing for interpersonal communication in classes with diverse students.

Also taking user experiences as a focal point, motivated by a need to design technologies that are driven by the desires and ideas beyond a disability, Frauenberger, Makhaeva, & Spiel (2017) explored alternative roles of technologies beyond the traditional view that assistive technologies that are designed to mitigate functional limitations. Through a participatory design approach with autistic children, the focus of their work was on creating artefacts that afford meaningful and positive experiences for children, allowing for these experiences to be shared with others. Related work by the same authors has also taken an experiential perspective for focusing on the relational and interactional aspects of constructing experience with children. Through engaging with multiple viewpoints of human and non-human actors, (Spiel, Frauenberger, & Fitzpatrick (2017) describe a design case that prioritises child-led experiences by considering multiple data sources. These multiple data sources from varied channels (such as the child, the broader research project and created artefacts) are said to extend researcher assumptions that are generated through designer empathy. In both of these cases, design serves as a reflective practice for understanding about children's experiences.

Design can critically challenge norms and expectations

Earlier, in the section on design that can alleviate bodily impairment, the examples illustrated ways of designing artefacts for proposing solutions. In contrast to this, the examples presented in the section above on design that can facilitate experience, artefacts served a different purpose; reflecting the lives and priorities of the individual by engaging with their situated experiences. In a separate perspective, the creation of artefacts can also serve as challenging understandings of what to design for, by introducing critical or speculative perspectives. For example, Pullin & Cook (2013) used artefacts to prompt new discussions about what it means to design for communication. Through two separate projects, 'Six Speaking Chairs' and 'Speech Hedge' (Pullin & Cook, 2013; Pullin, 2013; McLeod, 2010) the authors offer two cases of provocations that are intended to spark discussion rather than provide design solutions. In creating artefacts at the early stages of design, the authors invite others to consider how one conceives tone of voice, generating a discussion on understanding and framing the notion of voice, long before providing solutions.

Similarly, the work of Sellwood (2017) invites designers and the broader public to reflect on understanding some of the underlying discourses surrounding how wheelchair users communicate through their bodies. Through creating an artefact called 'the Bummunicator', Sellwood exposes insights about broader communicative functions through body language, namely, highlighting that given wheelchair users' seated position, there is an opportunity for technology to expose a person's (clothed) behind through a screen that is mounted on back of a wheelchair. In what might, at a surface level, be considered funny and light-hearted, through humour, Sellwood's provocation prompts others to reflect on issues of disability, sexuality and communication. In these cases, design serves as a way of reasoning and making sense of things by drawing on critical design and speculative design perspectives.

Summary of existing design frames

In summary, the design frames presented all recognise the situatedness and contextual nature of communication in different ways, by attending to ways of supporting bodily function in situ (de Faria Borges et al., 2012; Lampe et al., 2018; Sampath et al., 2012), acknowledging co-construction (Barendregt, Börjesson, et al., 2017; Black et al., 2012; Brederode et al., 2005), attending to personal experiences (Durrant et al., 2013; Frauenberger et al., 2017) and unravelling social and contextual aspects of communication (McLeod, 2010; Pullin, 2013; Pullin & Cook, 2013; Sellwood, 2017). Some of these examples have been school-based technologies used with adults (e.g. Black et al., 2012; de Faria Borges et al., 2012; Hayes et al., 2010; Madsen, el Kaliouby, Goodwin, & Picard, 2008), and others have designed for peer collaboration in predefined, specific tasks (Barendregt, Börjesson, et al., 2017; Brederode et al., 2005; Zhao et al., 2018). Considering these examples, opportunities remain for exploring how designing for communication can serve a wider range of purposes, that are defined by the individualised ways that children with SSPIs communicate, motivated by their values and individual profiles. Whilst the examples above have touched on ways of designing for non-speaking people, many of these examples focus on identified groups (e.g. a large focus on autistic children and social interaction), therefore opportunities exist for considering new ways of framing and designing for communication involving children with SSPIs, who are a heterogeneous group in their own right. Informed by the literature review on acknowledging the situated, co-constructed and multi-modal nature of communication, this thesis therefore presents ways of designing for communication through inductively driven empirical work.

Involving children with disabilities in the design process

This section discusses how children, including children with SSPIs, have been involved in technology design work. Owing to the physical and social complexity of involving children with SSPIs in the design process, very little design-oriented work has specifically examined how children with SSPIs have been involved in the design process. For this reason, it is useful to consider how a wider population of children with varied disabilities have been involved and what this has meant for how their contributions have informed design decisions.

Two recent systematic reviews of the literature on involving children with special educational needs and/or disabilities revealed a number of methods and techniques that have guided the technology design process. Three main focal points that both systematic reviews highlighted include:

1. Adapting approaches for previously defined roles and forms of involvement.
2. Developing methods and techniques with specific user groups and children's profiles in mind.
3. Examining the role of adults, ways of addressing power struggles and democratizing 'having a say'.

Each of these focal points is discussed in turn below, followed by a critical discussion of what these insights suggest for involving children with SSPIs in design work.

Adapting approaches for interaction design and children with SEND

Many researchers have used Druin's levels of involvement and the cooperative inquiry approach as inspiration for adapting frameworks for involving children with SEND (Benton & Johnson, 2015). Interaction design approaches that focus on children's roles (for example, Guha, Druin, & Fails, 2010; Malinverni et al., 2014) have provided key examples of adapting established PD approaches to create frameworks for designing with children who have SEND.

In one example of this, Guha and colleagues extended Druin's cooperative inquiry approach to create an inclusionary model (Guha et al., 2008). Motivated by principles of inclusive education, aligning children's characteristics with provisions that are available. The inclusionary model incorporated three layers: 1. Druin's levels of involvement; 2. the nature and severity of the disability, and 3. the availability and intensity of support. The inclusionary model illustrated that the nature and severity of children's disabilities are a major factor in design work involving children with SEND, suggesting that children with 'more severe

disabilities' can take more constrained roles. To address this, the model takes an *enabling* form of design that focuses on providing scaffolds and supports to allow for child involvement. Informed by developmentally driven theoretical perspectives, the focus here is on scaffolding the ways that children can take part in design work by attending to the difficulties they can present with at an individual level, for example supporting with memory, reading or writing (Guha et al., 2008). In related work by the same research team at University of Maryland, Foss et al. (2013) make recommendations for employing cooperative inquiry in special education classrooms. They suggest ways of providing child-specific support strategies that include adding more 'informal time' for children and adults to get to know each other, having a high adult-to-child ratio, giving instructions in many modalities to support comprehension and planning for high engagement (Foss et al., 2013). Other approaches have also taken a similar approach for providing scaffolds for helping children to participate in activities. For example, de Faria Borges and colleagues used mixed methods to design a customised communication device. de Faria Borges et al (2012) worked with the school and therapy team to create a system that would support the child's language development based on the words and symbols that they were learning in school. The authors proposed the 'PD4CAT' method ('Participatory Design for Customised Assistive Technology') that was comprised of a number of phases. These phases included defining the design team; understanding the context being designed for; involving experts in proposing the design agenda; involving the child in expanding on details based on the proposed solutions, then; evaluation with the design team. In PD4CAT, adult experts (therapists and teachers) were largely actively involved in proposing solutions with child involvement at particular stages (de Faria Borges et al., 2012).

These examples provide methodological contributions for understanding how to adapt existing design approaches to enable inclusion for children with SEND. They also highlight that in considering children's forms of involvement, children's specific profiles have consequences for how they will be involved.

Developing methods and techniques with specific user groups and children's profiles in mind

A body of CCI work has considered how targeted user groups and children's individualised profiles have informed design approaches. Focusing on each child's individual profile, Kärnä, Nuutinen, Pihlainen-Bednarik, & Vellonen (2010) introduced the 'Child in the Centre' (CiC) framework for designing technologies with children with SEND. The CiC framework is described as a 'bottom up' framework that emphasises children's interests, strengths and needs as a core starting point and focus throughout the design process (Kärnä et al., 2010). It is arranged in levels that extend out from a focus on 'children's interests, strengths and needs',

to considering partnerships between children and multidisciplinary teams, child-centred technologies, flexible everyday environments and participation and inclusion to a society. Like Guha et al (2008), this framework acknowledges a need for providing supports for children's individual needs, but also incorporates designing for their strengths. In the CiC framework, children's parents and teachers play a key role in contributing knowledge about the child.

Another approach that has taken a similar design perspective for working outwards from the child, adapting the environment in line with children's repertoire of skills, has been proposed by [Frauenberger, Makhaeva, & Spiel \(2017\)](#). Building on prior work by Benton et al (2014) and Kärna et al (2010), the authors developed a tool for enabling designers to engage with autistic children that extends existing work by providing transparency by systematically incorporating designer expertise and experiences, building a repertoire of method elements for designers to tap into. Unlike the majority of other design engagements involving children with SEND, through their proposal of 'OutsideTheBox' the authors argue for creating technologies with children that are driven by the desires and ideas that extend beyond traditional assistive technologies that are designed to mitigate functional limitations. The authors propose a visual tool for illustrating how methodological choices in participatory design can be more transparent through critical reflection and blending methods that are related to the perspectives of the child, designers, context, previous work and available methodological repertoires. Related work by the same authors has taken an experiential perspective for focusing on the relational and interactional aspects of constructing experience with children. Through engaging with multiple viewpoint of human and non-human actors, Spiel, Frauenberger, & Fitzpatrick (2017) suggest a new methodology for engaging with child-led experiences that consider multiple data sources. In doing so, they argue that beyond researcher assumptions and interpretations, multiple data sources from varied channels (for example, the child, the broader research project and created artefacts) can extend what is gathered through designer empathy alone. What is less clear however, is understanding how non-human data sources can promote children's voices when these are contradictory to what children are saying in more direct ways. For example, data logs from digital artefacts that show technologies not being used might suggest a rejection of technology on a superficial level, without examining the nuanced reasons underlying this, e.g. motivation, access issues, learning challenges etc. With this in mind, there remains further opportunities for engaging with empathy and experience by establishing transparent and detailed ways of interpreting dialogic practices with children. Further, as the design cases described above have largely focused on working with autistic children who use natural speech, opportunities exist for

examining how different design methods might apply to working with children with different physical and cognitive profiles.

Examining the role of adults, addressing power struggles and democratizing 'having a say'

Reflecting on the roles of adults in the design process, Borjesson et al (2015) and separately, Benton and Johnson (2015) identified that adults often take mixed roles in the design process. Whereas the divisions of children's roles can be more discrete, the roles that adults take can be multifaceted and wide ranging (Benton & Johnson, 2015). Both systematic reviews highlighted that adults can act as proxies for speaking on children's behalf as well as facilitators to children's involvement. Borgesson et al (2015) also suggested that adults can be involved as users and experts (for example, Hirano et al., 2010; Hornof, 2009), whilst Benton and Johnson (2015) added that adults can also take the role of caregiver, motivator and co-designer. Unlike frameworks for designing with children without disabilities, with the uptake of these roles, there is a risk that the contributions of children with SEND become closely linked to the presence and type of adult involvement. This raises a risk of promoting adult-led agendas and consequently missing children's possible contributions about the kinds of things that are important to them.

Unlike the CCI approaches described earlier in the chapter in the context of designing with the broader population of children, design work involving diverse groups of children, beyond autistic children, are yet to critically engage with addressing power imbalances that occur as adults take more significant roles in scaffolding children's involvement. The one exception to this to date, that that of Hornof (2009) who's work specifically sought to attend to power struggles involving adults and children. Hornof (2009), investigated how to work with children who have severe motor impairments, focusing on how to 'unlearn the established power struggles'. Through a field-based observation study, Hornof identified a need to first build rapport with two girls with severe motor impairments by learning about how to communicate with them, then prior to design work, supporting them to gain some knowledge and experience about the process of design itself. Design activities were planned and delivered with the support of a speech and language therapist, who was reported to provide active support 'in the moment', recording verbal messages on children's single message switches (a type of AAC), based on the choices that were available to them. The design activities centred around designing a dress which was a topic that was chosen by the girls, from a list of choices suggested by adults (Hornof, 2009).

Considering how to address power imbalances involving adults and children, design researchers have begun to examine ways of involving children without focusing on their impairments. One prominent direction of design and disability has focused on designing for neurodiversity. Neurodiversity acknowledges that individuals have neurologically different profiles and that these differences should not be treated as deficits. The concept of 'neurodiversity' has grown from a movement of people who sought to remove negative or disabling connotations associated with the diagnostic label of autism. Attributed to Singer, (1999), the term neurodiversity was a call for mutual understandings and an appreciation of neurological differences that embraced a *relaxed view* about the different styles of being. In one example, Dalton (2013) responds to this call by suggesting new HCI engagements under the banner of neurodiversity HCI. Since its inception, the term neurodiversity has been adopted by wider groups of people who wish to promote the idea that varied neurological profiles are part of normal variations within a population. With this in mind, CCI researchers have investigated ways of involving children with neurodiverse profiles, implementing design work that moves away from focusing on their impairments.

Frauenberger, Good, & Keay-Bright (2011) identified that although the empowerment of children is hugely advantageous, "the balance between empowering children and overburdening them with responsibility is a delicate one to manage" (Frauenberger et al., 2011, p.3). With this in mind, some work, particularly involving children with autism, has looked at involving children in ways that focus on their strengths and skills and understanding the culture surrounding the communities who are involved.

Through the Diversity for Design (D4D) framework, Benton and colleagues (2014) introduced a way of facilitating the development of PD methods by directing designer attention to the strengths of children with autistic spectrum disorder and children with dyslexia (Benton et al. 2014). The D4D framework was informed by principles from the internationally recognised evidence-based educational program 'TEACCH' (Treatment and Education of Autistic and related Communication handicapped Children). The D4D framework is comprised of methods that allowed children to function as comfortably and effectively as possible, through understanding the culture surrounding a condition, tailoring activities to the individual, structuring the environment and providing supports. By providing scaffolds and supports that acknowledged and seek to understand the autistic culture, the framework offers a different way of thinking about how children can contribute and what adult designers can do to support this process.

Considering the issue of democratising voices, the various examples described in the sections above have illustrated the different ways that targeted groups of children have been involved in the design process. Both systematic reviews mapped out the stages that certain groups of children have been involved in design work, identifying that whilst autistic groups were often involved at different stages (for example in identifying requirements, designing and evaluation), children with physical impairments are involved much less frequently and often not in the early stages of identifying requirements. These insights allude to the complexity of legitimately involving children with SSPs in design work, and highlight an ongoing need for problematizing how children with SSPs can inform the direction of design work from these early stages.

Tensions in participatory design for inclusion

The CCI community have in recent years increasingly contributed methodological developments in involving children with SEND in the design process. Whilst design researchers are more confidently identifying the types of roles that children with SEND can take, it remains apparent that many participatory design projects continue to involve children as testers whose involvement is limited to providing feedback on prototypes that have largely been designed without their early stage involvement (Frauenberger et al., 2011) It is often challenging for children to take more involved roles, such as design partners, also raising tensions as to whether it is appropriate or relevant for children to be so involved. This has prompted researchers to consider the impact that participation has on the children involved (Guha et al., 2010).

Holone & Herstad (2013) highlighted that children with disabilities may not be accustomed to taking on roles as active participants, requiring extra time in supporting children to be comfortable in their roles as co-designers, as well as a need for time in becoming familiar and finding common vocabularies to talk about the things that are being designed. The same authors also highlighted tensions in involving other adults, whereby mediated communication by role of proxy inevitably introduces some level of filtering, influencing how the opinions of children are presented (Holone & Herstad, 2013).

Keay-Bright (2007) highlighted that the relations between design decisions and children's participation were not always clear. In line with wider discourses in participatory design that highlight a misplaced focus on methods ([Iversen, Halskov, & Leong, 2010](#)) there is a need for CCI researchers to explicitly engage with considering what participation means in terms of actual power to inform decisions, as well as improving how participation is managed and

supported, in line with new applications of participatory design in new domains (Halskov & Brodersen Hansen, 2015).

Some approaches have taken children's skills as a starting point (Benton et al., 2014; Frauenberger et al., 2017; Spiel, Frauenberger, Hornecker, et al., 2017). However, opportunities exist for understanding how these approaches affect the outcomes of design work and how children's contributions can be identifiable in design decisions, raising a need for scrutinizing the interpretive process (Barendregt et al., 2016). This is especially the case with contributions that are generated dialogically with 'hardest to reach' children who for example, do not use natural speech and have largely not been involved in design work. Participatory design researchers have increasingly been concerned with trying to understand how knowledge is generated with children who have SEND, largely involving certain groups of children, for example, autistic children. Further, a small proportion of the published literature have demonstrated how children's ideas are integrated into technological outputs (Benton & Johnson, 2015). There are a number of constraints to this, including knowing how to integrate individualised and distinct ideas into broader design outputs or how to faithfully represent input when adults were involved. These tensions raise issues of interpretation, prompting new considerations for how interpretative perspectives might inform ways of studying participation in children with disabilities. Existing work is yet to establish systematic and explicit ways of interpreting data that is generated with children, with very little design cases that have focused on involving children with SSPIs. Therefore, opportunities remain for building on existing work that can demonstrate how data that is generated with children with SSPIs informs knowledge construction and outcomes throughout the design process.

Chapter summary

This chapter has considered the value of varied design approaches as well as applications of these in HCI work on designing with and for children, including variations of design work involving children with disabilities. At the start of the chapter, design thinking, participatory design and empathy, each offered three separate lenses for supporting design. Design thinking offers the potential for generating multiple frames which can be generative for considering new ways of designing for communication that transcend existing viewpoints. Participatory design distributes knowledge generation by acknowledging and problematizing the importance of involving end users in the design process. Empathy serves as supporting participatory design and design thinking by considering how designers can get closer to understanding users' worlds. In considering applications of designing technologies for children, the CCI community has embraced the need for deeply engaging with stakeholders to

understand their situated lives as well as designing for the ecology surrounding children's everyday lives. Applications of design work involving children with disabilities have been more varied. Whilst many examples from the literature illustrate ways of designing to mitigate the challenges faced by bodily impairment, often guided by the perceptions of the designer and adult/expert proxies, a number of other frames have considered a need for designing for children's situated communication experiences. Namely, designing for situated communication, supporting experiences and design provocations each add different frames for thinking about design solutions. Considering applications for involving children in this design process, it was identified that the CCI community have focused on adapting existing methods and strategies for involving children in design work, as well as considering how to involve targeted groups of children by considering their strengths and individual profiles. Whilst a large portion of work has focused on involving targeted groups (e.g. verbal autistic children), opportunities remain for exploring ways of involving children who are arguably *harder to reach* owing to SSPIs that can make it difficult for designers to interpret their communicative actions and consider ways of involving them from the early design stages that inform design agendas.

Considering the insights that have been generated by existing work, opportunities therefore remain for considering both *what* to design for, and *how* to go about involving children in legitimate ways. Namely, building on the previous literature review on theoretical perspectives on communication, opportunities exist for considering new framing on communication that acknowledges how it is situated, co-constructed and multimodal. Further in addition to these theoretical insights, opportunities have been raised for advancing children's voices in the design process by focusing on how children's contributions inform knowledge at the fuzzy front end of design. Considering these opportunities, the three empirical chapters that follow engage with studying child-centred accounts that that expose the types of communication situations that are important for children, rather than those that are suggested by adult accounts.

Chapter Four: Study One - Investigating Communication Involving Children with SSPIs and AAC

Introduction to Study One

The first study takes an exploratory and inductive design-oriented approach to investigate salient features of interaction when it involves children with SSPIs and their social groups and what this means for the role of technology. In order to be able to study and describe in detail examples of the specific ways in which communication manifests, study one focuses on one type of interaction that children with SSPIs and their social groups are often involved in, that of face-to-face interactions that involve AAC technologies. Based on these observations, the goal of the study is to define the range of design opportunities and challenges that characterise these interactions.

The research field of AAC has evolved over the past two decades bringing together practitioners, researchers and industry stakeholders with the common goal to develop new theoretical and empirical understandings surrounding communication involving people who have little or no functional speech. However, to date there is little evidence that this research has ‘talked back’ to interaction designers tasked with designing AAC and new technologies for children with SSPI. At the same time, child computer interaction researchers have focused on methodological questions regarding the involvement of children with SSPI in the design process, for example, challenges involving them in legitimate ways so that their contributions can inform design decisions, rather than contributing a critical view on technology design. There is thus a need to further understand the relationship between child communication and AAC design toward maximising the opportunities for supporting communication for young children with SSPIs (Light & Drager, 2007).

This study seeks to address this area through an empirical qualitative, 14-week field study that examined how young children with SSPI’s communicated with their peers and adults when AAC technologies were present. Following AAC research that recognises situated communication, yet taking a design orientation, study one seeks to understand how communication manifests within typical everyday interactions involving children and their AAC. This study makes three contributions. *First*, it adds to the empirical research concerned

with how communication manifests for children with SSPIs, by emphasising how communication is shaped by design and people. *Second*, it demonstrates a systematic and reflexive methodological approach for investigating communication in children who use a range of modes to communicate. *Third*, it reveals four new areas for future design of technology and AAC: incorporating an embodied view of communication; designing to emphasise children's competence and agency, regulating the presence, prominence and value of AAC, and; supporting children in maintaining self-initiated communication.

Study one addresses the first research question that seeks to understand what communication looks like and what this means for design by taking a critical view on how existing AAC technologies are used in communication. RQ1 asks:

Research questions

RQ. 1. What are the salient characteristics of communication involving children with SSPIs and AAC technologies?

This research question is addressed through a focus on three sub-questions:

- d. What kind of communication is achieved in interactions involving children and AAC technologies?**
- e. How do AAC technologies and their design shape communication?**
- f. How does technology fit with other resources that children have when advancing their communication?**

Methodology

The data for study one and study two were generated simultaneously within the same fieldwork context. To avoid repetition, the methodology for both fieldwork studies involving children is predominantly described within this chapter. Chapter five also includes a summary of additional methods and approaches that were used to address the second study's research questions.

Epistemological foundations

A social constructivist perspective framed the investigation of communication. The study sought to understand how communication is socially constructed by adopting an interpretive

epistemological stance. In line with a qualitative research tradition, the study addressed research question one by attending to the ways that children and their social partners construct meaning in the context of everyday communication situations, rather than seeking to identify absolute truths that would be seen as quantifiable within a positivist tradition. Qualitative research methods that adopted an exploratory stance were chosen as they enabled the study of open ended possibilities for communication involving AAC technologies that are not part of a confirmatory procedure (Stebbins, 2001). This exploratory stance is in line with the higher-level goal of the thesis, that inductively investigated understanding how designers might conceptualise communication from child-centred perspectives.

To date, the AAC field has taken a situated view on communication by attending to the socially constructed nature of communicating that is made up of participants, tools, the environment and other social factors. Yet existing perspectives have investigated communication by focusing how actions are organised around talk. For example, in the case of AAC studies that use conversation analysis to study how actions are organised around talk (Bloch & Wilkinson, 2004; Clarke & Wilkinson, 2007; Higginbotham & Engelke, 2013), or observational studies that have examined disordered language in child with SSPIs by examining interaction patterns between participants (Light, Collier, & Parnes, 1985). Whilst these perspectives have undoubtedly spearheaded therapeutic and educational interventions for how one might augment or replace natural speech, the limitations of such speech-dominant analysis tools have not taken seriously the 'resourcefulness' (Mavers, 2004) of people with SSPIs whose broader signs are often missed. There is therefore a need for further investigation, utilising multimodal perspectives that recognise all means of meaning making instead of dismissing signs as errors and sign-makers as incompetent (Bezemer & Kress, 2016). This perspective treats all communicative acts and their arrangements as differently meaningful, rejecting linguistically-driven approaches or those that rely on the perspectives of others (proxies), which have been dominant trends in related previous work. As prior HCI studies on designing for communication and children with SSPIs has investigated designing from a given frame (Ibrahim et al., 2018), a qualitative, exploratory approach was taken. From the researcher's interpretive perspective, an inductively driven, multimodal social semiotic approach framed the research design for the current investigation (Bezemer & Kress, 2016; Kress, 2010). In order to investigate communication, in line with a social semiotic multimodal approach, both studies accepted the following assumptions:

- Meaning making is shaped by social factors. Communication is subject to social, cultural, economic and political givens,

- Practices, resources and technologies of communication respond to social, economic and technological developments which are mediated by the interests of the sign maker,
- All 'signs', that children produce through a combination of form and meaning, are *motivated* (Kress, 2010). These enable us to understand the sign-maker's interests.

At the early, exploratory stage there was a need to study the situated and context dependent ways that communication happened, without researcher intervention. As with the overarching stance of the thesis, this study was motivated by an emancipatory push for exposing what children express as important and what this means for design. Therefore, here and in the empirical studies that follow, child-centred methods were reflexively used to guide the investigation of communication. In this study, rather than opting for participatory methods that might inadvertently prioritise adult views (Parsons & Cobb, 2014) the observation method was used. This offered opportunities for focusing on child communication agency without adult intervention, in what Gallacher & Gallagher (2008) describe as an "attitude of methodological immaturity" (p.511) that exposes and reflexively considers notions of the powerful researcher and vulnerable participants.

Context

To reach the population of interest, both study one and study two took place in a primary special educational needs school in a major city in the UK where children deemed to have receptive language skills in advance of their expressive language abilities are often assessed for and provided with AAC devices. This is the primary context where children learn how to use AAC and are supported to become competent communicators. The research took place over the course of 14 weeks between November 2016 and February 2017 and consisted of 23 visits in total.

Clinician-Researcher role

Having previously worked in the school as a speech and language therapist with a clinical specialism in AAC, the researcher was previously involved in planning and delivering the communication curriculum jointly with the teaching team as well holding a detailed understanding of the children's day to day experiences of school life, their interests and some knowledge of their home lives. This prior knowledge was helpful for minimising obstacles, anxieties and nervousness in not knowing how to interact with children who have complex communication needs (Hornof, 2009). In similar circumstances, Cowan (2017) discussed the affordances of undertaking teacher-research through familiarity with the setting and practical

experience concerning the classroom layout, the curriculum and day-to-day practices. Having worked in the school setting as a therapist for eight years prior to undertaking the research, the role as familiar adult made communication with the school team and families more straightforward, as school staff and families had some prior awareness about the goals and values that typically guided the researcher's way of working in a clinical role within the school. More importantly, this familiarity offered opportunities for easier interactions with child participants who were interested and on the whole, comfortable by the researcher's presence. As a clinician researcher, a detailed understanding and experience of understanding conversational 'norms' and strategies used in 'aided conversations' was also highly useful (Du et al., 2018). For example, accepting prolonged silences whilst an AAC user constructed an utterance with their AAC device, or having the flexibility as a communication partner to move between different methods for children to access vocabulary (e.g. listing options, establishing means of expressing 'yes' and 'no' from the outset and other strategies).

Alongside the benefits of an 'insider perspective' there were also challenges. Negotiating this dual role as clinician and researcher was problematic at times, which required explicit communication of what the researcher role did and importantly, did not entail. For example, working to address power dynamics in situations where the researcher might be seen to have a role in surveillance or teaching. Given the researcher's previous clinical training and personal experiences, the researcher also brought along their own values which impacted on the process of investigation. Namely, having worked with children and existing AAC technologies for more than a decade and experienced the underuse and abandonment of existing technologies, the researcher's PhD studies were primarily motivated by feeling dissatisfied by the opportunities that existing technologies offer children with SSPIs, particularly for those children who do not read or write. These challenges and others are further reflected on in chapter seven that examined how methodological choices impacted on engaging with children's voices.

Further, given the role as a participant-researcher, it was important to maintain neutrality during both data collection and analysis (Patton, 1990). To manage this, the researcher and PhD supervisors met regularly to reflexively discuss and evaluate the researcher's actions; for example, managing expectations of being a familiar adult to people in the school to addressing power shifts from an authoritative adult within the setting to being a researcher, to acknowledging the affordances of existing AAC technologies when analysing the results.

Participants

There are no 'representative' or 'average' profiles for children with severe disabilities. It was therefore decided to recognise the different profiles of children who use AAC. Applying a critical case sampling strategy, information-rich participants were invited to participate (Patton, 1990) who would offer insights through their varied profiles. The sampling criteria were primary age students identified as having severe speech and physical impairments and using some form of AAC. It was difficult to measure how long each child had been using their AAC device prior to the study. Typically, as devices are introduced, there is an extended period where these are used with certain adults, and can take many years to learn to be used (Murray & Goldbart, 2009). In addition to technology, children typically used an assortment of communication methods including 'no-tech' paper-based communication books and other multimodal ways of communicating (e.g. body movement, vocalization, eye pointing). As the researcher held detailed knowledge about the students, she met with the school leadership team to select whom to invite. Five children aged 6-9 years were recruited. To avoid emphasising children's deficits, their clinical profiles were not considered. Instead, descriptive accounts of their communication styles and assistive equipment used were presented to provide additional context for the findings (Table 4.01). These accounts were created based on the knowledge the clinician-researcher held about participants and supplemented through discussions with their class teachers.

Name	Age	Gender	Description of communication and other assistive equipment used
Noah	6	M	Uses 5-10 intelligible words and a symbol communication system on a touch screen tablet, accessed through hand swiping and support to finger point. Uses partner assisted manual w/c with head support.
Maya	7	F	No intelligible oral speech, eye points to show interest and looks away to indicate negation, e.g. 'I don't like it'/'no'. Uses symbol communication system on an eye gaze device, mounted to her w/c. Uses partner assisted manual w/c with full head, torso, trunk and foot support. Partly enterally fed via g-tube and j-tube. Sometimes uses neck brace and oxygen to support her breathing. Has uncontrollable repetitive movements
Clara	7	F	Uses 5-10 intelligible words and can join 2 signs or gestures but signing is unclear owing to coordination difficulties. Becomes very anxious with unexpected events and opts out by self-harming and moving away. Uses symbol communication system on a touch screen tablet with a key guard. Walks unaided but unsteadily. Sometimes uses a walking frame outdoors and helmet.
Oscar	8	M	Uses 3-5 intelligible words and some hand gesturing/signing with right hand. Uses a symbol communication system on a touch screen tablet. Walks a few steps unaided and uses a walking frame and helmet, weaker on his right side.
Grace	9	F	Eye pointing, facial expression and tone of voice are most clear. Symbol communication system on an eye gaze device that is mounted to her w/c. Uses partner assisted manual w/c with head, torso, trunk and foot support. Likes to use her arms and fist to point to things and also has strong, uncontrollable movements.

Table 4.01. Participant profiles

In addition to the researcher (who was present for all recordings), children's parents and teachers of the five children were also involved. In total, five parents actively took part in interviews, four were female. Two teachers, both female, were also involved in interviews and class-based fieldwork. Whilst the study focused specifically on five child participants, as fieldwork was carried out in a school environment, it was recognized that a wider group of children were also present and would inform the data that was generated. This extended data about the wider group of students was not specifically reported on although in the following section, the informed consent procedure for this wider group is described.

Ethics

Ethical approval was initially obtained through the university ethics board. As gatekeepers to the school site, the headteacher and senior leadership team were contacted and invited to participate in the study which was described through the information sheet (appendix 1). Once the headteacher and school team had given consent, a face-to-face meeting was arranged to plan recruitment. As gatekeepers, the school team then contacted and invited participants to

take part on the researcher's behalf in the first instance through sharing the information sheet and consent form (appendix 1). Once parental consent was obtained, consent was sought with child participants and renewed regularly. On-going discussions were held with PhD supervisors, school staff and research participants to reflect on emergent ethical risks throughout the course of the research. For example, given the children's learning difficulties, it was deemed important to renew consent on each visit so that they understood what their participation involved and how their contributions would be used. One of the ways that consent was discussed was by explaining information sharing. Using a physical posting box to represent the process of collecting and sharing data (figure 4.01), alongside pictorial support, at the start of every session I described that child contributions would be collected and shared with designers with an interest in creating technologies for children's communication. The posting box acted as a concrete way of representing the abstract concept of sharing information with others outside of the school context.



Figure 4.01. 'Ideas box' for explaining information sharing

In addition to this, across the course of the 14 week period, regular discussions were held with child participants to gauge their responses to how the researcher collected data. One of the ways of initiating and capturing these discussions was through the use of 'Talking Mats', which is a conversation-based technique for eliciting a person's views about a given topic that is presented through picture images alongside speech (Murphy, 1998). In this method, typically, the person initiating the discussion will introduce a concept that is represented through a picture card (e.g. 'video recording') and the respondent is asked to place the card on a 'mat' under one of three headings to indicate whether they 'agree', 'don't know' or 'disagree'. An example of this, taken from a discussion with one of the child participants, is illustrated in figure 4.02.

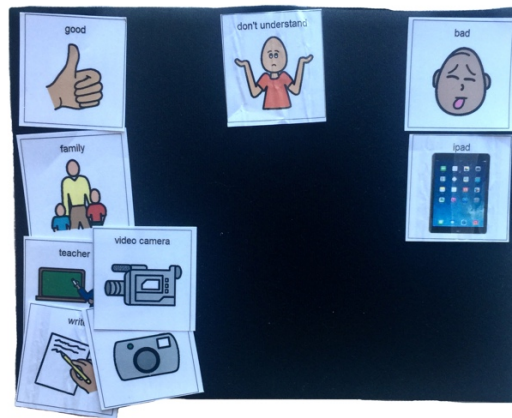


Figure 4.02. Consent board using 'Talking Mats' approach, documenting discussion with child and adult on recording information

Child participants were unfamiliar with this particular system but were used to communicating with similar graphical symbols, and were also provided with support to learn to use it. People, tools and methods involved in the research were represented on individual cards in writing and with a picture. Children were asked to move each card to one of three positions on a mat (good, don't understand, bad), as an indicator of their attitude about the topic discussed, and their understanding.

For the wider group of children present in class-based activities, an opt-out consent process was used. Information about the research was published in a school newsletter sent to all parents. Parents were asked to contact the school if they had questions, or reservations about their child being present during sessions involving data collection.

In addition to attending to the direct ways that participants chose to express their consent to participate in the study, the researcher paid attention to the indirect ways that participants expressed discomfort, anxiety and disengagement. By observing how children and adults in the school setting reacted to the researcher's presence and through ongoing discussion during planned visits, the researcher adapted activities accordingly to allow for children and adults in the setting to regulate the level that they participated and how their data would be captured. This meant that not all sessions that were observed were videoed.

Data Collection Methods

Previous research involving children with SSPIs has tended to include proxies in place of primarily engaging children in the research (Benton & Johnson, 2015). Given that we wanted to develop a child-centred account of communication, we used a combination of methods

across both study one and study two. Data collection methods and the critical points that were focused on in both studies are summarised in table 4.02.

method	study one	study two ²
observation & transcription	<p>* RQ1a, b & c</p> <p>20 class-based video recordings: 10 ½ hrs</p> <p>11 events involving AAC devices</p>	<p>* RQ2a</p> <p>20 class-based video recordings: 10 ½ hrs</p> <p>215 events comprised of a wider range of interactions</p>
Fieldnotes		<p>* RQ2a & b</p> <p>33 field note entries relating to varied setting and activities (e.g. classroom, playground, lunchtime, assembly etc)</p>
Photo capturing & retelling		<p>* RQ2b</p> <p>594 lifelogging images captured by 'Maya' documenting children's everyday lives.</p> <p>921 lifelogging images captured by 'Grace' documenting children's everyday lives.</p> <p>197 class-based photos captured by researcher</p>
Design workshops		<p>* RQ2b</p> <p>3 workshop sessions for each participant:</p> <p>2 collage making sessions on children's likes/dislikes,</p> <p>1 storyboard making session on children's interests,</p> <p>1 persona editing session to verify researcher's interpretations of children's profiles.</p>
Stakeholder involvement		<p>* RQ2b</p> <p>9 face-to-face or telephone interviews with 5 parents and 2 teachers to inform planning of other materials.</p>

Table 4.02. Methods used in study one & two

Video observation method - Video based research was chosen as it offered a powerful way of collecting, studying, sharing and archiving detailed cases of what communication looked like in

² Data collection methods for study two are described in detail in chapter five

practice (Derry et al., 2010). Whilst some social scientists have argued that qualitative video observation has received less methodological reflection compared with textual interpretive methods (Luckmann, in Knoblauch, Schnettler, Raab, & Soeffner, 2013), it offered particular opportunities for studying and representing the multimodal ways of meaning making in children's communication environments. Acknowledging that the researcher's interpretive perspective closely determined choices about what and how to study video data, the epistemological foundations and methodological choices presented above informed the interpretive work.

In study one, participatory research methods were considered as a possible methodological avenue. However, as this was the first exploratory, inductively driven study we recognised the challenges involved in managing adult driven agendas in these forms of engagement (Gallacher & Gallagher, 2008), particularly with children who have little or no functional speech. Thus, the observation method was chosen to record the multimodal, moment-to-moment ways in which children broadly communicated with their peers and adults in everyday contexts. I collected these observations through videos.

In study two, observations across the school day enabled me to closely follow how the data were generated in context. In line with the social constructivist orientation of the research, as a participant researcher (Guest et al., 2013; Patton, 1990), I was closely involved in 'co-construction' of data. Observations were intertwined with the researcher's interaction and dialogue with children and adults. This insider knowledge, provided context around events of interest and formed part of the analysis. The data collected were video footage of class activities and field notes of class and outdoor activities.

Video recording was generally arranged to minimise disruption to the class activity, positioning a small digital video camera at the edge of the classroom. Whilst it was intended that two cameras would be used to capture children's faces and their AAC screens, this was not possible in practice as the participants became very aware and uncertain when this was trialled. The broadest possible view of children's whole bodies and the people around them were therefore the focus of recordings through one camera. In total, 20 video recordings were made. One participant ('Clara') strongly disagreed with me videoing during the session and whilst she wanted to be part of the study, did not want to be recorded. In this case, detailed retrospective notes of the session were taken and the video camera was switched off in her presence. As a result, Clara's data is drawn on descriptively within the findings, rather than visually.

Transcription method - The transcription method was used which informed both data collection and analysis. In line with the social semiotic multimodal approach (Bezemer & Kress, 2016; Hodge & Kress, 1988; Kress, 2010), transcriptions were treated as artefacts in their own right, providing new data through the ways that they were constructed to convey the interests of the researcher (Bezemer & Mavers, 2011). The construction and analysis of transcriptions is detailed further in the analysis section below.


A multimodal transcription method that attended to the multiplicity of how participants communicated was used (Bezemer & Mavers, 2011). Although multimodal transcription has been identified in prior work as important for disrupting the view that verbal communication is primary compared with non verbal communication modes (Jewitt et al., 2016), this was especially pertinent for studying communication in children with SSPIs who used little or no verbal speech. Within the social constructivist view that treated representation choices as closely linked theoretical and political discourses, a social semiotic multimodal transcription method was used (Bezemer & Mavers, 2011) that illustrated the agentive ways that children communicated.

Videos were first broadly transcribed and time-marked using InqScribe® transcription software³ in order to capture sequences of utterances of talk, gesture and movement. In order to investigate the child-led ways that communication was constructed, shorter identified segments were then transcribed multimodally in Microsoft Word and Adobe Photoshop and organised in Microsoft Word. Whilst time consuming, this enabled flexibility to adapt the transcription layout and capture in detail the full repertoire of children's communicative behaviours.

As others have done so, the act of transcription was treated as 'semiotic work' (Kress, 2010) that produced new meanings through artefacts created through the act of transcription. Salient features of the video data that illustrated the findings were therefore carefully re-presented, paying close attention to what sections of the video data to select and how to re-present them through layout and mode (Bezemer & Mavers, 2011). In line with Kress (2010), transcription was considered a process of *translation* whereby, guided by the positions of the researcher, apt elements were re-presented from one mode (video-based) into another (paper-based). The video segment selections and chosen modes for representing these were informed by what was seen to be of interest to the researcher. Transcriptions credited the

³ InqScribe® transcription software by Inquirium, LLC, 2005

multiple modes that participants used, captured through line drawings of video stills, verbal descriptions of bodily action and speech (electronically-generated and naturally spoken speech). In addition to protecting the privacy of participants through distorting personal identifiable features, line drawings used alongside written descriptions allowed for salient features of the findings to be highlighted. Whereas text-based transcription enabled the description of utterances of talk, gaze behaviours, gesture and the uptake of other modes, the line drawings emphasised the consideration of important spatial elements, episodes of movement and stillness, and environmental factors from the videos. An example of the different contributions of each transcription mode is presented in Transcript 4.01 below.

Video still	Maya (child)			Sally (adult)		
	Speech (electronic speech in CAPS)	Eye gaze	Hand movements	Speech	Eye gaze	Hand movements
Sally: middle Maya: right side. Dark yellow highlight. time direction ↓ 00:43 	SPICY	To Sally	Hand wriggling continues	Not spicy, no. Yummy or yucky?	To AAC screen	Rested arm begins to lower then: Points between 2 points on screen

Transcript 4.06. Short excerpt from longer extract involving Maya (child) and Sally (S)

Transcriptions attended to the temporal unfolding of action, and equal attention was given to different modes of representation that were selected (Bezemer & Mavers, 2011) such as looking behaviours, speech and body movement. Within line drawings of video stills, colour was sometimes used to highlight key information about how participants used looking behaviours and gesture alongside other modes.

Two levels of transcription were used to represent the findings across study one and two. The decision to use two separate transcription styles was guided by the level of granularity that was needed for capturing critical moments. The first transcription style presented a broader summary of longer periods of time. Time is captured vertically, so events gradually unfold in a downwards direction with a summary of modes used by different people presented horizontally. This transcription style is used in the first study as in these cases, the gradual unfolding of critical moments involving AAC occurs over a longer period of time. In these cases, the reader is invited to first read along horizontally to the end of each row, then downwards to the next time-marked row.

In study 2, a finer-grain transcription style is used that captures more detail over shorter periods of time. The study 2 transcripts present time on a horizontal plane. Overlapping modes used by different people are presented vertically in rows. In these transcripts, the reader is invited to read downwards then across to the top of the next column. This ordering of events is indicated through line numbering.

Analytic Approach

RQ1a, b & c - Video analysis was used to investigate class-based communication. As participants had little or no verbal speech, video analysis enabled me to identify and interpret interactional phenomena associated with a range of modes including looking behaviours, gesture, proximity, tone of voice, as well as in-person processes including joint attention and common ground (Kawulich, 2005). A whole-to-part inductive approach to video analysis was taken (Derry et al., 2010; Erickson, 2006) whereby videos were viewed multiple times and indexed to identify shorter segments involving the use of AAC technology. Of the total 20 video recordings, 11 events involving AAC were identified and included in the analysis. The small volume of AAC mediated events reflects how little these were used by children. This will be discussed further within the findings.

A multimodal social semiotic analytic approach was also used (Bezemer & Kress, 2016; Kress, 2010). This offered a person-centred perspective, emphasising the agency of people and more specifically children, in using and organising multiple modes which contributed to meaning (MODE, 2012). In a social semiotic sense, the 'sign-maker', being the child participant who produced and/or interpreted signs was the focus of analysis. The sign maker's actions were analysed by identifying how children combined modes to signify meaning. The term *meaning making* is used throughout this thesis to refer to how children bring together resources for the production of the new (Kress, 2010). These resources are informed by social influences and manifest in a semiotic form (ibid).

In order to segment and analyse the interactional flow of communication, the chosen unit of analysis were *discourse units*. These were defined as "*any behavior initiated within the context of conversation, [...] that (a) developed or sustained the topic of conversation, (b) assisted with conversation repair, or (c) otherwise facilitated maintenance of the conversational flow (e.g., establishing eye contact to claim or relinquish a turn, contributing to the maintenance of social closeness by leaning forward and laughing)*" (p.80, Müller & Soto, 2002). Whilst the term 'discourse' has also been used in related analytic approaches to signal a focus on spoken units (e.g. Alm, Arnott, & Newell, 1989), in the case of this work, *discourse units* signaled a diverse range of socially and culturally produced modes (Kress, 2010), incorporating as broad a range of communicative dimensions as possible (Müller & Soto, 2002). Discourse units also allowed for identifying subtler units, such as indicating the maintenance of conversational flow, rather than prioritizing certain communicative functions, such as actions that explicitly propose new topics or content.

Using this data, an inductive thematic analysis was performed within a constructivist view that credited socially produced meaning, as described by Braun & Clarke (Braun & Clarke, 2006). In doing so, I identified and described patterns in the data set, illustrating salient dimensions that would be organised into themes. In order to apply a systematic and rigorous analysis, videos were watched multiple times so that the different possible interpretations of events would be exhausted. Group viewings involving the researcher and PhD supervisors enabled me to determine whether different researchers noticed similar phenomena or alternatives, testing out the different explanations of data as the team began to build on the themes. This process generated 13 descriptive categories which are found in appendix 2. These descriptive categories were then organized into three themes:

Competence and agency in adult-child interactions describes how adults made assumptions about children's capabilities to communicate via AAC, consequently impacting on child agency.

AAC as a material object describes the shift from the child's communication via technology to the AAC acting as an external object that obscured or fostered meaning.

Misalignments and breakdowns capture how AAC and their design faculties lead to child-to-child and child-to-adult breakdowns in communication.


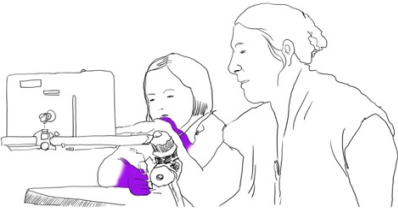

Findings

Competence and Agency in Child-Adult Interactions

The majority of technology-mediated interactions between adults and children consisted of adults initiating communication then scaffolding the child's language by using the option of technology. During these interactions, the adult had control over the conversation and provided a structured way of addressing competence by teaching children how to use their devices operationally and also by modelling language use in specific ways. This practice inadvertently limited children's agency in employing alternative ways of expression with AAC, e.g. to respond in more open and detailed ways, or to initiate communication for themselves. For example, in the excerpt in Transcript 4.02⁴, Maya and Sally (special needs assistant, SNA)

⁴ Transcript 4.02 presents vertically-organised data, capturing a broad account of multiple modes over an extended period of time.


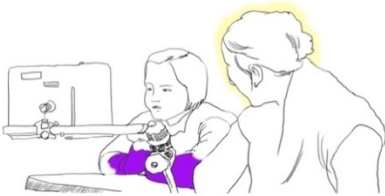
talked about tasting an omelette they had just made. After introducing the conversation context, the SNA directed Maya to the 'descriptions' page on her device prior to asking her 'Was it yummy or yucky?'. Here, the adult taught Maya one very specific way of responding to a closed question. Maya chose to provide alternative answers that could re-direct the conversation to different qualities of the food and prompt the adult to adopt an open-ended line of questioning. She also often moved her arms and direction of eye gaze upon responding with electronic speech. Yet, the adult rejected the relevance of Maya's responses and reoriented her to the original options, implicitly expressing her perception of Maya's limited communicative competence in that context.

Video still	Maya (child)			Sally (adult)		
	Speech (electronic speech in CAPS)	Eye gaze	Hand movements	Speech	Eye gaze	Hand movements
00:24 (in sec) 		To AAC screen	Hand wriggling movement near her mouth	Maya. Descriptions. Tastes. Was it yummy or yucky?	To AAC screen	Points to make an onscreen selection Points between 2 points on AAC screen
00:28 	SPICY	To AAC screen	One hand lowers before speaking word		To AAC screen	Points to AAC screen
00:30 	(appears to select a word on screen but unheard)	To AAC screen	Hand wriggling movement near her mouth	It wasn't spicy, Maya. Go back, Maya. Tastes. Not crunchy, Maya	To Maya To AAC screen	Her elbow rests on Maya's wheelchair tray and she leans on her wrist

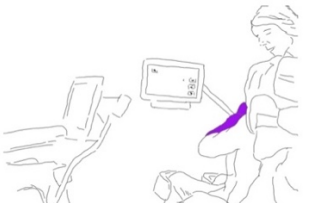
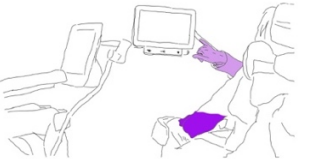


Transcript 4.07. Maya (child) and Sally (Adult) talk about the salty omelette. Yellow highlight indicates gaze direction. Dark purple indicates Maya's hand movement. Light purple indicates adult's hand movement (p.1 of 3)

Video still	Maya (child)			Sally (adult)		
	Speech (electronic speech in CAPS)	Eye gaze	Hand movements	Speech	Eye gaze	Hand movements
<p>Sally (right) pale yellow/purple: Maya (left) dark purple/yellow hands/face</p> <p>transcript 2 continues on next page 00:43</p> 	SPICY	To Sally	Hand wriggling continues	Not spicy, no. Yummy or yucky?	To AAC screen To AAC screen	Rested arm begins to lower then: Points between 2 points on screen
<p>00:52</p> 	SOUR	To AAC screen	Hand wriggling continues	Sour? Was it sour? Right, go to tastes.	To Maya To AAC screen	Moves hand away from screen towards her shoulder Points to a location on screen

Transcript 4.08. Maya (child) and Sally (Adult) talk about the salty omelette. Yellow highlight indicates gaze direction. Dark purple indicates Maya's hand movement. Light purple indicates adult's hand movement (p.2 of 3)

Video still	Maya (child)			Sally (adult)		
	Speech (electronic speech in CAPS)	Eye gaze	Hand movements	Speech	Eye gaze	Hand movements
00:58 	HOT	To Sally	Hand wriggling continues	Was it yummy or yucky?	To AAC screen	Points to 2 points on AAC screen
01:02 	SALTY	AAC screen	Hands lower to her tray	Salty! Was it salty? I didn't put <u>that</u> much salt in it, Maya.	To Maya	Arms lower to rest on Maya's tray

Transcript 4.09. Maya (child) and Sally (Adult) talk about the salty omelette. Yellow highlight indicates gaze direction. Dark purple indicates Maya's hand movement. Light purple indicates adult's hand movement (p.3 of 3)





Video still	Maya (child)		Researcher (adult)	
	Speech	Hand movements	Speech	Body movements
00:03 		Hand wriggling movement near her mouth	I had a quick question I wanted to ask you	Moves to sit next to Maya
00:09 		Hands lower to her lap	And I thought maybe I'm just gonna, go back to the categories	Points to AAC screen with little finger
00:20 		Raises hands to her mouth	And I'm gonna go to your feelings. Describing words. Aaaand,	Points to AAC screen and selects another button Hovers finger near AAC screen
00:28 		Hand wriggling movement near her mouth	Can you tell me where your feelings page is?	Hovers finger near screen, searching for button.

Transcript 4.10. The researcher asks Maya a question concerning consent

In a similar example illustrating how adults can limit children's communication agency, in transcript 4.03, the researcher asked Maya a series of closed questions concerning her consent for being video recorded in the research. Instead of letting Maya choose her own vocabulary, she prompted her to the 'feelings' opinions page on her AAC device.

Like in the example in transcript 4.02, here the researcher asked Maya to respond to closed questions that were structured around a series of bounded choices that the adult was trying to search for on screen. In the example, Maya is facing and gazing towards the screen as the researcher speaks and gestures. At one point, Maya stops moving her arms in a wriggling motion near her mouth and lowers her arms to her lap with stillness. Whilst this indicates that Maya is attending to the researcher's question, it may also have served other purposes, for example preparing to initiate communication. However, the researcher continues to prompt Maya by heavily structuring how she is expected to respond.

On rarer occasions, such as the one illustrated in transcript 4.04, children explicitly challenged adult assumptions of their competence to use AAC devices. During this interaction involving Maya and two adults, the teacher told the researcher that there was a problem with how Maya made onscreen selections using her eyes with her eye-control AAC device. The teacher suggested that Maya was only looking towards symbols in the middle area of her screen evidencing her limited operational competence in using the device. Yet, as the researcher moved closer to observe this, Maya began to move the cursor to different locations, selecting key words and phrases, e.g. *play*, that changed the topic of her previous discussion with the class teacher. Through her actions, Maya exercised agency and was able to show that the assumed operational issue concerning onscreen selections was not linked with her capability to eye point.

Video still	Maya			Researcher			Class teacher		
	Speech (electronic speech in CAPS)	Eye gaze	Gesture	Speech	Eye gaze	Gesture	Speech	Eye gaze	Gesture / movement
00:25 		AAC screen	Hands moving in wriggling motion near her mouth	Maybe delete all of that Cuz I think that might be –	to Maya’s AAC screen to Maya, then to teacher	Finger points towards ‘rubbish bin’ symbol on AAC screen	I think that umm	To Maya’s AAC screen To Maya’s AAC screen	Leaning over other child’s AAC device Walks to other side of Maya
00:33 			Hands lower to her lap	Mmm?	To AAC screen		What I’ve noticed, that, she’s umm, e-e I dunno, she’s just-	To Maya’s AAC screen	Points to middle area of AAC screen in a circular motion
00:34 	PLAY	AAC screen	Hands rest on her lap	Middle. You going to the middle?	To AAC screen To Maya then AAC screen		Using this area	To AAC screen then to Maya	Lowers hands to her side, her other hand rests on Maya’s AAC mount
00:39 	(selects a word but unheard)			Oh no, you’re on the top row. Maybe it’s just easier. You like it?	To Maya then AAC screen To Maya		Okay		

Transcript 4.04. Researcher and teacher talking about Maya's use of AAC

Despite showing communicative agency through their use of technology, children more commonly chose to use other modes of communication to interact. Other participants, Grace, Clara, Oscar and Noah for example, regularly turned to their communication books instead of AAC technologies when responding to adult questions, despite AAC technologies often being more readily available to them. In support of this, throughout the 20 video recordings made over the course of 14 weeks, the five participants who all had access to AAC technologies used these infrequently in conversation. Only two of the five participants are predominantly the focus of our examples illustrating that in naturally occurring communication the participants used other modes to communicate in ways that were more appropriate to them in the moment. By rejecting technology in this way, children ascertained agency over how they communicated in ways of their own choosing.

AAC as a Material Object

AAC technologies provide people who do not have natural speech with a new mode of expression. Paradoxically, in the majority of videos analysed, the AAC technology itself was often explicitly talked *about*. Instead of *mediating* communication it became a visible object that was attended to. One reason for this was related to apparent technical faults with the device. In figure 4.03, the researcher moved next to Maya's AAC screen, commenting that Maya navigated to a blank page. The initial topic of discussion was disrupted as the researcher began to talk about the device having inadequate language content. Attending only to the screen, the researcher missed Maya's subtle communicative modes e.g. looking behaviours and facial expression that may have offered information concerning her affect or intentions.



Figure 4.03. Video still of Maya (right) and researcher interacting whilst Grace (left) is distanced from the conversation




The focus of AAC as an object also resulted from the ordering of AAC and people, which placed the focus of the interaction overwhelmingly on the device. In a separate occurrence within the same video, Grace and Maya were orientated towards each other at an angle but partially hidden behind their screens (figure 4.04).



Figure 4.04. Video still of Grace (left) peering over top of her AAC device towards Maya (right)

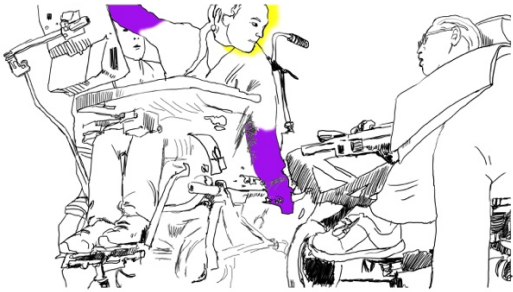
This was mainly due to Grace's eye gaze access requirement which was to position the device in front of her at eye level. However, the structural arrangement of both girls and technology credited value to technology. For Grace who was positioned on the left, this blocked her from being directly involved in interaction and forced her to adopt a passive role. As time passed, Grace stretched upwards to attempt to look at Maya and her screen but owing to the children's positioning and technology barriers, she was unable to do so. Given these structural arrangements children were not able to 'create' context through accessing what the other was doing.

While the examples so far emphasise how the design of AAC technology carved its role and presence as an object, this was also socially shaped. Specifically, AAC devices were used by adults as *archival* objects that were re-shared with others without the child's consent despite his/her presence. On three occasions in our data, an adult recounted a child's prior communicative act by accessing and reading out a previously constructed utterance with the device. This is illustrated in transcript 4.05 where the class teacher and Maya have finished talking about activities that Maya liked. As Clara, another participant of the study, wandered towards them, the teacher seized this opportunity to repeat to Clara what Maya had just said via her technology.

Video still	Clara (child)			Class teacher			Maya (child)		
	Body movement	Eye gaze	Speech	Gesture	Eye gaze	Speech	Speech	Eye gaze	Body movement
Clara: in background, person most left, yellow highlight. Class teacher: middle with lilac hands, Maya: bottom right 00:14 	walks towards teacher and Maya, stands on teacher's right side	to AAC screen		hands by her side	to AAC screen	(unclear speech)		to AAC screen	arms raise towards her mouth
00:20 	stands facing AAC screen	to card that teacher is holding		points to card with left index finger	to card in her right hand	so she said she loves... (following speech is unclear)		to teacher and Clara for 2.5 seconds	arms rest on her lap
00:26 		follows teacher's finger towards screen		points to AAC screen	to AAC screen	(unclear speech)		looks away from AAC screen then back towards it	arms rest on lap

Transcript 4.05. Teacher uses Maya's AAC device as archival object



The potential infringement of child agency in the adult sharing archived speech was brought to the foreground in transcript 4.06 presented below. When asked by the adult, Grace refused to feed back to the group about her weekend by rejecting the AAC, turning away and raising her arm between herself and the adult. Despite her assertion not to communicate in this context, the adult used her earlier AAC speech to recount Grace’s weekend to the group, apparently violating her stated desire not to share.

Video still	teacher	Grace (child)		
	Speech	Speech	Eye gaze	Body movement
Grace: middle, dark purple/yellow hands & face highlight teacher: left (partly hidden behind Grace), other child & adult: bottom right				
	Grace, can you tell everyone what you told me?	Nooo!	To her left	Turns head away from teacher. Right arm stiffens, raising as she pushes upwards in chair



Transcript 4.06. Grace refuses to feedback with AAC

Misalignments and Breakdowns


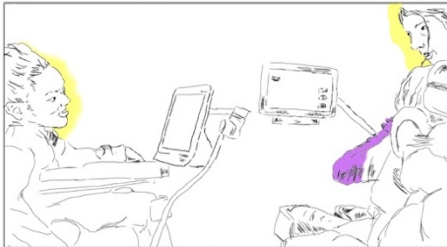
Earlier I considered the prevalence of adult conversation starters and subsequent child language scaffolding. There were times, however, when children used their AAC and other modes to initiate *themselves*, e.g. through phrases and sentence starters, engaging in ‘emergent’ (not adult-planned) communication with others. During these occasions, adult-child interactions in particular were characterised by difficulties, both in how the adult interpreted the child’s utterance and the child’s ability to engage in self-clarification. For example, Maya had been sitting opposite Grace and the researcher but was not involved in their conversation (transcript 4.07). Suddenly Maya used her AAC device to say ‘I’m sorry’. The researcher interpreted this first to mean Maya was apologising, asking ‘what are you sorry about Maya?’ and then as a request to join in asking ‘do you want to join in?’. Maya next generates ‘please’ on her device and the researcher treats ‘please’ as a confirmation that Maya wants to join in saying ‘please, ok alright’. However, Maya then says ‘I’m sorry’ again but this is not attended to by the researcher. The intended meaning of Maya’s second ‘I’m sorry’ remains unknown. It suggests the researcher is progressing on the basis of an unsubstantiated hypothesis that Maya wants to join in.

Video still	Researcher			Maya (child)			Grace (child)		
	Body movement	Eye gaze	Speech	Gesture	Eye gaze	Speech (electronic speech in CAPS)	Body movement	Eye gaze	Speech
<p>Grace: left, purple hands Researcher: middle, Maya: right, purple hands. yellow highlight on all people shows face and gaze direction</p>									
<p>00:09</p> 	<p>turns body toward M, smiling. Holding a picture symbol up in left hand</p>	<p>facing Grace to Maya</p>	<p>so let's say- what you sorry about, Maya? did you want to join in? Please. Ok, alright.</p>	<p>hands at mouth</p>	<p>to AAC screen</p>	<p>I'M SORRY PLEASE I –</p>	<p>facing AAC screen, left arm raised towards the communication symbols the researcher is holding up</p>	<p>to picture board in researcher's hands to Maya</p>	
<p>00:20</p> 	<p>turns to Grace briefly whilst pointing to Maya</p>	<p>to Grace</p>	<p>Yeah? Your buddy's saying something</p>	<p>Hands lower to her lap</p>	<p>to AAC screen</p>			<p>to Researcher then to Maya</p>	


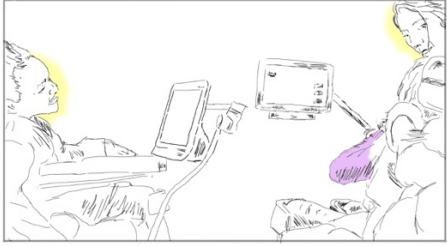
Transcript 4.07. Maya (right) uses AAC to initiate communication (p.1 of 2)

Video still	Researcher			Maya (child)			Grace (child)		
	Body movement	Eye gaze	Speech	Gesture	Eye gaze	Speech (electronic speech in CAPS)	Body movement	Eye gaze	Speech
<p>Grace: left, purple hands Researcher: middle, Maya: right, purple hands. yellow highlight on all people shows face and gaze direction</p>									
<p>00:22</p> 	<p>turns upper body to Maya</p>	<p>to Maya</p>	<p>Yeah?</p>	<p>hands to mouth</p>	<p>to AAC screen</p>			<p>to Maya</p>	
<p>00:27</p> 	<p>Reaches below Grace's wheelchair tray to re-attach it</p> <p>turns to speak to G</p>	<p>Uh huh?</p> <p>Oh your tray's falling down, my lovely.</p>				<p>I'M SORRY</p>	<p>smiling and reaching upwards to look over her own device to Maya</p> <p>(a crack is heard as Grace's movement dislodges her wheelchair tray)</p>	<p>to Maya</p>	

Transcript 4.07. Maya (right) uses AAC to initiate communication (p2 of 2)

Video still	Maya (child)			Researcher			Grace (child)		
	Body movement	Eye gaze	Speech (electronic speech in CAPS)	Body movement	Eye gaze	Speech	Body movement	Eye gaze	Speech
00:44 	hands at mouth	to AAC screen	PLAY		to Maya	you wanna play?		downwards, briefly to Maya then to researcher	
00:47 		to AAC screen			to Grace	shall we?	nods head and smiles	briefly gazes to own AAC screen then gazes to researcher	yeah
00:48	turns head to the left, towards G	to Grace			to Grace	with Grace?	raising her head from her chest to face M and R, smiling	to Maya	ya

Transcript 4.08. Maya initiates word 'play' and Grace responds without AAC (p.1 of 2)

	hands lower to her lap								
<p>00:50</p> 	turns her head back towards midline, hands to mouth	to AAC screen			to Maya then Grace	shall we? what now, now?	nods head and smiles	to Maya	ya

Transcript 4.08. Maya initiates word 'play' and Grace responds without AAC (p.2 of 2)

By contrast as transcript 4.02 earlier illustrated, adult reactions to misalignments were different. Sometimes adults only credited legitimate and intelligible child responses, whereas in other cases, adults made assumptions about what the child might be intending. In both cases (transcript 4.02 and transcript 4.07), adults treated the child's response as ambiguous whereas in transcript 4.07, the adult expanded on what they saw as an ambiguous response (*I'm sorry*) adding interpretations for what the child may have intended to say. In this example, the adult signals 'understandability' through first interpreting that Maya's utterance (*I'm sorry*) is signalling that she is apologising about something, then reinterprets this as Maya signalling a request to join the conversation. In table 4.07, Maya stops adding more detail about what she is communicating as the researcher becomes distracted by the clanking noise of Grace's tray becoming dislodged from her wheelchair at which point the topic changes.

Misalignments also occurred during AAC-initiated child talk between pairs of mixed ability children. AAC technologies that belonged to children were largely personalised to their individual characteristics through their access methods, representation of language and vocabulary content. Thus, each child had a separate language set up creating a rigid structure for flexibly managing to and fro communication within the temporal requirements of a conversation. In transcript 4.08, Maya who was in the presence of Grace initiated the word "play" using her AAC device. Grace did not have access to play-related language on her device at the time, and Maya did not have the words to respond to Grace's excited reaction to her initial comment to 'play'. Consequently, AAC was abandoned fully by Grace, who chose instead to use looking behaviours, orientation and vocalisation, and partly by Maya, who used her device for key words but also eye points to express her interest in playing with Grace. In the example (transcript 4.08, time: '00:47') Grace briefly gazes to her AAC screen before gazing to the researcher and communicating 'yes' through speech and nodding. Arguably, Grace's brief gaze towards her device references that she acknowledges it is there, yet chooses another mode that is apt at that moment. Maya in contrast, signals her interest in Grace's prior turn (*Yeah*) by turning her head to gaze towards Grace and lowering her arms to her lap momentarily. In summary, both girls' technologies alone were insufficient for building on Maya's utterance when the moment called for it.

Discussion

The goal of this empirical study was to 'talk back' to interaction designers by elucidating the everyday technology experiences of children with SSPI. A secondary goal was to reframe the way interaction design has sometimes understood communication through technology, i.e.

through a transmission model, by introducing a situated, multimodal view of communication present in theoretical and empirical research in the AAC field. The discussion presents a critical analysis of the findings and identifies new design opportunities for AAC technology and beyond.

Communication is embodied

The children of the study used technology much less frequently than their other modes of communication. This was despite all five children having access to their technologies, and being encouraged to use them by their teachers. Communicating through other modes provided a faster and more efficient way of expression than AAC. It also enabled them to ascertain control over self-initiated communication and their responses to others, given that the former was otherwise heavily controlled by adults during AAC use. In using modes other than technology, children expressed themselves persuasively through embodied means. For example, resisting to share what she did at the weekend, Grace tensed her body and pushed herself upwards in her chair, turning away and lifting her arm to create a barrier from the adult asking her a question. Other times, however, these communicative signs were expressed more subtly, and in turn missed by communication partners.

This reinforces one of the most robust findings in AAC research, i.e. that children rely on multiple modes to communicate and these choices are closely related to context, partners, task and intent (Baxter et al., 2012). It also shows the prevalence of embodied communication over spoken language use, highlighting an important gap in technology design for children with SSPI, which has been primarily driven by a cognitive approach to language and literacy skills. Therefore, an opportunity exists for further design research that seeks to *design for the embodied experiences* that motivate children with SSPIs to communicate with others. For example, following the observation that children's embodied expressions can be subtle and go unnoticed, technology could record and draw attention to these expressions during interactions, making the role of alternative modes visible and central to communication.

Respecting child competence and agency

According to Light, communicative competence is achieved through four inter-related domains of linguistic, operational, social and strategic competence (Light, 1989; Light & McNaughton, 2014). For AAC users, *linguistic* competence is concerned with understanding the native language of a community and mastering the 'linguistic code' required by the AAC system. *Operational* competence is having the technical skills to proficiently use a system. *Social*

competence is having knowledge, skill and judgement in the social rules of communication, e.g. discourse strategies and different communicative functions. Lastly, *strategic* competence refers to how AAC users drawing on compensatory strategies for communicating effectively within restrictions.

The three adults of this study primarily focused on children's *operational* and *linguistic* competence, showing their low expectations of children's competence by highly scaffolding their questions and children's replies. Children's lack of self-management during emergent communication could be interpreted as evidence that this scaffolding was required. These findings together indicate the high entry level requirements for accessing AAC, and as a consequence the requirement to use AAC as an instructional tool long before children can exercise agency in their communication using this technology. Even though adult scaffolding may have been beneficial for some of the children, it was also applied in a rigid rather than a dynamic way that was particularly problematic with one participant, Maya whose competence seemed to go unnoticed. Maya demonstrated *operational* competence in using her device to orchestrate a new topic by looking at different places, and in a different occasion she evidenced *strategic* competence when expressing her own opinions about a cooking activity. Drawing on the well-established principle of gradually and dynamically scaffolding learning (Vygotsky, 1978), this study underscores the importance for *AAC technologies to develop and 'grow' in pace with a child's competence while placing child agency in communication at the forefront of design*. It also recognises that children might have an uneven profile of competences that relate to their social, strategic, operational and linguistic skills suggesting the need for nuanced approach to how AAC is personalized.

Children's agency was not only constrained by the high entry barriers to using AAC, but also by how little control they had in regulating who had access to their disclosure and how it was interpreted. Adults approached a child's AAC as an archival object that could be used to retell a child's utterances to others. This practice brought to question children's agency in the moment of retelling, and their role in consenting to share their disclosure beyond its original context. This demonstrates the importance of problematizing privacy management in the context of AAC (Reddington & Coles-Kemp, 2011). The findings suggest the importance of creating new, nuanced ways of *regulating the temporal and spatial dimension of disclosure through AAC devices* – for example by allowing a child to control the ephemerality of their utterances or the spatial arrangement of their display to signal their desire not to disclose beyond the original context in which an utterance occurred.

Regulating the status of AAC in communication

Disability can be socially produced through the ordering of the social and material (Moser, 2006). This perspective was prevalent within the findings: AAC created physical barriers between children and communication partners, stopping them from seeing what others were doing and limiting their involvement in conversations. In another instance, technical or operational problems re-directed the adult's attention from the child to AAC. By gaining prominence and thus value through its form and function, technology took precedence over communication becoming the central object of attention. This echoes previous AAC literature claiming that the function and form of these systems should be critically considered within the complex and dynamic communication environments in which they are used (M. M. Smith, 2015). Considering communication from a structural perspective, the findings underscore the importance of thinking about AAC technology as one mode that is used alongside other methods. In line with Moser's considerations on the ordering of people, social and technological factors (Moser, 2006) the study underscores the importance of *designing to support children to agentively regulate how these orderings impact on how disability is created in communication situations.*

The obstruction created by the physical and technical presence of AAC, alongside the earlier insight that AAC is not always the right mode in the moment, prompts consideration for the importance of dynamically regulating its status within interaction through its form or spatial arrangement. Previous research has explored how hardware devices can shift in shape and in function to support a diversified set of interactions. Recognising the technology-driven nature of this work, these researchers have begun to consider the kind of scenarios that may benefit from these innovations (Sturdee et al., 2017). I posit that shape-shifting AAC may provide a child with options to mould the status of technology during communication. AAC displays that expand and reduce in size for example, might allow children to bring attention to AAC as needed. Alternatively, AAC may be designed to offer flexibility and child control in its spatial arrangement, for example through new ways of mounting the device for the child to fluidly move it in and out of focus. In a separate direction, at the time of writing this thesis, EyeFree Assisting Communication Ltd © (2018) is pursuing new possibilities for designing AAC that mitigates the physical barrier posed by screen-based devices. The company have started a UK crowdfunding campaign for manufacturing a new AAC technology that is designed to operate through audio feedback and eye gesture, without the need for a screen.

Supporting child-initiated communication

This study showed that the communicative functions for which AAC devices were used were largely limited in use, with many instances of adults teaching children how to respond to specific questions with specific response options. This meant children had few opportunities to learn how to participate in more diverse communication situations with adults and other children with SSPI, perpetuating unbalanced conversation dynamics that are typically structured by naturally speaking conversation partners (Clarke & Wilkinson, 2007; 2008). As David Crystal also identifies, opportunities for using language, in this case mediated through AAC, were bound by the academic goals of the adult, consequently limiting children's opportunities for manipulating the forms and functions of language through more playful opportunities (Crystal, 1996).

This study exposed a number of misalignments occurring during child-initiated communication informing new design scenarios for future improvements of AAC, or new technology design.

Establishing common ground in AAC communication

Much of the AAC research focuses on communication between children with SSPI and competent communication partners. Even though children with SSPI typically attend special schools and socialise with children of similar profiles, it is unclear if AAC can support their communication. This research provides some evidence to show how AAC design may inhibit these opportunities. One of the participants initiated a playful interaction with her peer using AAC. But given that children's screens and language content were different at this critical moment, these children were unable to build on the initial AAC utterance. This finding reaffirms the need to look beyond the sender-receiver model for AAC and highlights the importance of *supporting the establishment of common ground*. In practical terms technology could detect and share language pages between AAC users, allowing them to synchronise their content, and thus gaining access to high frequency vocabulary relating to the topic of discussion.

Self-clarifying communication misalignments

Conversations involving naturally speaking partners can result in misalignments due to ambiguities in how utterances are constructed, or interpreted. However, given their available resources, naturally speaking partners build on prior turns in different ways to engage in forms of repair (Schegloff et al., 1977), for example, through word replacement. When children with SSPI initiated their own topics with AAC utterances, adults often misinterpreted the meaning

of these, evidenced either through unsubstantiated guesses about what the child meant or by treating these utterances as illegitimate given the conversational context. In contrast to the ability of naturally speaking partners to self-clarify (Schegloff et al., 1977), in those situations children with SSPI did not have the resources through expressive modes to signal that problems had occurred in understanding, or to repair such issues. AAC could offer a child lightweight ways to explicitly *signal that a problem in understanding is occurring*, toward developing new skills for negotiating these instances.

Conclusion to Study One

This chapter reported a qualitative 14-week field study at a special school. The research aim was to examine how communication manifests in five children with SSPI who use AAC in school, and the mediating role of AAC design. Videos of communication incidents involving children and technology were collected. Inductive video analysis was then carried out applying a multimodal social semiotic approach. The analysis approached communication from three lenses: children's choice of modes (a child view), their interactions with each other and technology (an interactional view), and the ordering of people and technology (a structural view). This enabled identification of the kinds of communication achieved through and around AAC as well as unpacking how the design of AAC impacts on this communication.

Study one contributes to the field of interaction design and AAC research with four design opportunities: incorporating an embodied view of communication; designing to emphasise children's competence and agency, regulating the presence, prominence and value of AAC, and; supporting children in maintaining self-initiated communication. In doing so, the study contributes to understanding the kinds of communication that are achieved in aided conversations as well as understanding how to extend opportunities for existing AAC technologies.

Limitations and future directions

This study should not be interpreted as providing clear solutions to this complex problem space, but rather identifying new avenues for a future design agenda that brings interaction designers closer to the concerns of young children with SSPI who use technology. In particular, it is hoped that future design work will move beyond the transmission of information framing of technology to design for situated, embodied and co-constructed communication.

Whilst contributing to understanding future directions for existing AAC, the study exposed the infrequent use of AAC in children's everyday class-based interactions. Therefore, one limitation that was faced was understanding how multimodal communication was achieved in more nuanced, multimodal ways when initiated by children. Class based interactions involving AAC highlighted limited AAC usage and exposed power struggles between children and adults in these kinds of interactions but did not expose how communication was enacted in broader ways with children's interests, goals and values in mind. Building on study one, there was therefore a need to understand about the broader contexts for communication, specifically focusing on the multimodal ways that communication was enacted that reflected children's interests. Whereas study one exposed how AAC mediated communication was enacted and often structured by adults, further study was needed to understand how and what children communicated in situated contexts through the application of flexible, mixed methods extending beyond researcher observation.

Chapter Five: Study Two - A mixed methods study investigating multimodal communication in school-based environments

Introduction to Study Two

Whereas study one was concerned with investigating one type of communication from an observational, interpretive stance, study two investigated communication in a broader sense, focusing on communication beyond AAC use and in wider contexts. Informed by the findings of the first study that children express themselves in embodied ways that are often missed by adult conversation partners, study two investigated children's multimodal communication through further exploratory, inductive work. Unlike study one, which positioned children's participation in research as passive through researcher observation and interpretation, study two used mixed methods to promote children's active involvement in the generation of knowledge. Building on the theoretical insights posed by the first study, study two supported the gradual development of theory through extending the exploratory approach towards what Stebbin's has called *concatenation* (Stebbins, 2001).

The second study took a child centred approach for investigating how children constructed meaning in multimodal ways. The study also engaged with children's values by focusing on what children expressed as being important in their lives, based on the ways that they communicated. The goals of the second study were to: 1. present salient characteristics of multimodal communication involving children with SSPIs and 2. engage with children's values, so that these insights would define new design opportunities for interactions that are on children's terms, without the need for comparing children's meaning making against established developmental or language-based norms.

Through an empirical, qualitative study in the same field work setting of study one, study two examined how young children with SSPI's communicated with their peers and adults in multimodal ways, beyond AAC use. Like the first study, study two recognised the socially constructed nature of communication, investigating how communication manifests within typical everyday interactions involving children. Similar to the first study, taking a design orientation, study two sought to understand how children used the resources available to

them in conversations and how this might support digitally mediated communication in new ways.

Study two made three contributions. *First*, it introduced a new perspective for describing communication involving children with SSPIs without overly crediting a dominant mode (i.e. speech). *Second*, connected with the first study, it built on a systematic and reflexive methodological approach for investigating communication in children who use a range of modes to communicate. *Third*, it revealed a number of design implications for digitally mediated multimodal communication.

This study addressed the following research questions that sought to understand how to investigate and describe multimodal communication in child-centred ways:

Research questions

RQ.2a. What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; how do children use resources available to them for meaning making?

RQ.2b. What do children appear to value based on the ways that they communicate?

Methodology

Epistemological foundations

In addition to the epistemological perspectives described in the previous chapter, study two also took an inductive values-led approach. Whereas study one, inductively investigated situated communication through observation of classroom conversations that involved AAC technologies and people, study two extended the ways of investigating communication by attending to communication in a wider range of contexts. As well as taking a social semiotic multimodal approach for investigating interpersonal communication, study two also introduced a second dimension, studying what children appeared to value based on how and what they communicated.

Values were defined as referring to what people or groups considered important in life, and connected with motivating modes of conduct and desired end-states (Iversen et al., 2010). The following assumptions were accepted:

- Values are not universal nor are they measured against pre-existing moral or ethical human value categories such as ‘trust’ or ‘privacy’ (Friedman et al., 2008). Instead, they emerge through an *a priori* commitment to cultivating the emergence and discovery of local expressions of values (Iversen et al., 2010).
- Values are flexible and emerge in collaboration with other stakeholders, whereby values interact recursively with the context within which they emerge as well as the values that the researcher themselves brings to the investigative process (Iversen et al., 2010).

Data Collection Methods

RQ2a methods: Observation and transcription was the primary data collection method for RQ1a, as described in the earlier methodology section of the previous chapter (chapter four, pages 90-93). The criteria for selecting critical incidents that addressed RQ2a was different to that in study one. Whereas study one focused on face to face communication events involving AAC devices, study two focused on observing face to face communication involving children and their social groups where any form of communication resource was used, for example, the use of material and environmental resources as well as through the body.

RQ2b methods: Whereas RQ2a used the observational method to study the situated and context dependent ways that communication happened without researcher intervention, here child participants and their social groups were additionally involved in the generation of knowledge through their active involvement. In order to overcome issues in prioritising adult views, the reflexive application of mixed methods was used. Mixed methods also maximized opportunities for engaging with the meanings underlying children’s contributions as opposed to relying on one method (Spiel, Frauenberger, Hornecker, et al., 2017). Each method was chosen to reveal a different dimension about what children expressed as important in their lives about and through their communication. The focus was on dialogically engaging with values, and as others have done, adopting an *a priori* commitment for cultivating the emergence of local expressions of values (Iversen et al., 2010).

The primary data collection methods used were observation, photo capturing and retelling and design workshops. In order to help develop these primary methods and ensure that materials used would be relevant for the participants, other stakeholders including parents and guardians, teachers, school support staff and therapists were also involved through ongoing informal discussion over the course of the 14 week fieldwork period. Data collection using the different methods occurred in parallel, unless otherwise stated. Further, mixed methods

enabled the researcher to triangulate how and what children expressed about what they appeared to value in the context of the other methods. One of the ways of promoting reflection (Schön, 1983) was to build in dedicated time to revisit children's contributions to check that the insights had not been misrepresented. Through plenary activities that immediately followed craft-based activities, the researcher would recap on what children appeared to express through collages and storyboards, offering opportunities for children to confirm, reject and develop emerging insights. Further, during data collection, two follow up workshop sessions were organized, dedicated to editing and building on persona drafts that the researcher had created based on the outputs of earlier methods.

Observation and transcription: As before, for RQ2a of this study, the observation and transcription methods were used. This consisted of the 20 video recordings of 10 ½ hours of data, as well as 33 field note entries. The videos recordings were made in classroom settings owing to the challenges of seeking consent from the wider population of students through both the mainstream and special needs parts of the school. The videos aimed to capture everyday interactions involving the child participants and their social groups across the school day, so it was decided that on every school visit whenever possible, the researcher would see if the children and their social groups were happy to be recorded. This was negotiated at the moment the researcher entered the classroom which was typically at the start of a new activity. In situations involving more than one child, when one child did not consent to being videoed, filming did not take place. A range of activities were recorded, including wet playtimes indoors, transition periods between formal teaching activities, teaching sessions, lunchtime breaks, snack time and free play sessions. These recordings were supplemented with field note entries of situations that could not be videoed owing to them taking place in a more public space or in cases where children refused to be video recorded. Also, fieldnotes provided a useful perspective for reflecting on how children engaged with the methods in the moment.

Photo Capturing and Retelling: Photo capturing was used to document critical moments in children's everyday lives, extending the research into the home context. Out of the five participants, two provided consent for this element of the data collection. Acknowledging the physical challenges of asking these child participants to take photos, we invited them to wear a small clip-on 'lifelogging' camera on their shirt for 24 hours. The camera automatically captured images at the child's torso level, every 30 seconds. Over a 24-hour period, the camera recorded 594 images for one participant, and 921 images for the second participant. Following a photo capturing stage, participants, their parents and teachers were advised that

we would jointly view all of the photos so that children could choose whether to delete any photos they did not want to share. This was in line with Durrant and colleagues who found that children with special education needs wanted the agency to select photos reflected upon in the research (Durrant et al., 2013). We initially planned to discuss the photos directly with the children through semi-structured interviews. However, there were practical barriers that led to us dropping this element. Namely, children were not in control of what was being captured and owing to the ambiguous nature of the images without verbal commentary, they required high levels of (over) interpretation by the researcher.

In addition to the automatically captured images, 197 photos of class-based events were captured by the researcher. These consisted of class-based images of free play, workshop activities and teacher led sessions. Photo capturing was not used in other parts of the school owing to issues in seeking consent for recording the wider population of children and adults within the school.

Design Workshops: Each participant took part in four design workshops. These were organized in groups within the classroom, involving child participants, their class peers and teaching staff. As all workshops took place in school, children were supported by teaching staff to participate. In keeping with the child-centred perspective of PD, the researcher asked staff members to help children to physically accessing activities, whilst also paying close attention to, and being guided by, children's initiations and interests. The researcher was also present to facilitate.

Workshops built upon typical classroom activities. As such they were familiar to the children and involved tasks in which the children had previously demonstrated some competence in terms of their engagement. Two craft-based activities were chosen that centred on expressing information about what children liked and disliked generally. This informed an understanding of the type of activities they participated in and were motivated by. The craft-based activities involved (i) making collages about themselves, (ii) constructing story boards about themselves and fictional characters in order to reveal another perspective on children's interests.

Following these two workshops, the researcher constructed draft personas that incorporated personalised information about children's interests based on the previous two workshops. The purpose of this was to seek feedback from children on whether their interests and values were being accurately captured. A third workshop was planned at the end of the research to gain children's input on persona drafts constructed by the researcher. This was intended to ensure that the children could verify the researcher's interpretations. Across all three workshops, besides the visual artefacts generated (collages, storyboards, persona drafts), children's interactions during the workshops were also video recorded.

Stakeholder Involvement: Whilst the involvement of parents and teachers was not the primary focus of data collection, it offered a starting point for preparing workshop materials based on activities that adults associated with children's interests. Nine face-to-face and phone interviews were held with five parents and two teachers, in addition to email correspondence with some of the parents maintained by the researcher. Furthermore, I regularly shared children's progress and insights from the fieldwork with parents and school staff. On those occasions, parents and school staff were invited to share other activities that children had been involved in when I was not present. This involvement followed Boyle & Arnedillo-Sánchez (2016) who conceived of adults as providing an additional 'interpretation' to the data, in this case, informing the planning stages of the types of resources that would be needed (Boyle & Arnedillo-Sánchez, 2016).

Analytic approach

RQ2a - Following Stebbins' treatment of qualitative data within an exploratory process, the analysis was geared towards gradually building on theoretical insights from study one. In line with what Stebbins terms 'concatenation of theory development', the study sought to develop the themes that were generated from study one, yet took an inductive approach to analysing the data. Taking a thematic analysis approach (Braun & Clarke, 2006) that inductively attended to children's multimodal meaning making practices (Bezemer & Kress, 2016; Kress, 2010) the data was analysed within a social constructivist orientation. Further details of the coding process are described below.

The coding process entailed the following stages:

- Familiarising self with the overall data sources by systematically logging data to get an overview of chronologically organised episodes that were captured for each of the 5 participants. In terms of video data, this meant recording key details about each video clip, e.g. where and when it occurred, who was involved, type of activity and how the data was archived (file name, format and location).
- Watching each video and methodically cataloguing of communication episodes involving the five child participants and members of their social groups to form a database of all videoed interactions. These were broken down into discourse units, as described and also used in the first study in chapter four. In total, 215 discourse units were identified that illustrated examples of how communication was achieved.
- Grouping and organising the episodes in terms of how they related to theoretical insights from study one (i.e. competence and agency, misalignments and breakdowns

and technology as a material object) and identifying new subheadings of topics (e.g. being included, doing things for themselves etc).

- Selecting key video clips that formed specific examples of each separate dimension (i.e. an example of each individual sub-heading).
- Multimodally transcribing these selected video examples that were connected to each sub heading (e.g. study one theme and new identified dimension). In total, 18 episodes were multimodally transcribed. Importantly, the transcription process itself informed the analysis process by helping to extend the interpretation of what was happening and how this gradually informed the groupings of subheadings into broader themes.
- Building on existing themes from study one, as well as generating early drafts of new themes. Working through iterations to refine existing and new themes.
- Coding meetings with supervisors to watch selected clips and discuss the development of themes related to the data.
- Iteratively reworking themes in discussion with supervisors.

RQ2. – Values led approach

Following other values-led participatory design approaches (Iversen et al., 2010), the analysis focused on cultivating and presenting examples of the kinds of things that children appeared to value based on how they interacted with the methods.

To faithfully capture what children appeared to value based on what and how they communicated, as with the first part of the study, an inductive reflective approach was taken. Whereas other design led approaches have investigated values by drawing on pre-existing categories as a starting point (e.g. Friedman et al., 2008), the starting point was purposely left undefined. However, in line with other values-led approaches (Van Mechelen et al., 2017), the goal here was to use a social semiotic analytic approach for generating examples of the types of things that children expressed as important, as a way of prompting design. Values were treated as flexible and emergent, depending on who, when and where children were communicating. Whilst it was acknowledged that the flexible nature of values would suggest that they would manifest differently based on who, where and how they were being investigated, the static values that are presented below are intended to demonstrate a snapshot of value beliefs that were generated in the study. The goal is to present a case for the kind of insights that can come from taking this perspective, which ultimately would prompt design in the third phase of the study.

Findings

The findings of research questions 2a and 2b are discussed separately. First, the findings of the qualitative video study investigating children's communication (RQ2a) are presented through a discussion of four generated themes. In answering research question 2a, and building on the theoretical contribution of the first study, a case is presented for studying and describing multimodal communication in children with SSPIs that extends beyond interpersonal communication in structured teaching contexts. Whilst the examples that follow arguably illustrate multiple, interesting dimensions, the focus is on illustrating salient characteristics of multimodal communication involving children with SSPIs. The second part of the findings that addresses research question 2b adds an interactional view to this perspective through examples of the kinds of values that were connected with how children communicated. Collectively, the findings present a holistic portrayal of communication involving children with SSPIs by focusing on the salient features of communication from an observational stance, children's values, and; how both parts extend the insights of the previous study.

RQ2a – What are the salient characteristics of multimodal communication involving children with SSPIs and their social groups; how do children use resources available to them for meaning making?

Building on the existing themes of the first study, the analysis generated four themes:

- [Competence & agency in adult-child interactions](#)
- [Material & structural arrangements](#)
- [Multimodal communication that is on children's terms](#)
- [A sense of belonging & adopting roles](#)

Theme one: Competence & agency in adult-child interactions

In study one, the majority of adult-child interactions involving AAC illustrated that adults made assumptions about children's capabilities to communicate, consequently impacting on child agency. The theme 'competence and agency' was generated to reflect this ongoing assessment of children's capabilities for communicating. In study one, adults predominantly used AAC technologies as a teaching resource for heavily scaffolding children's learning. Here, children and adults used a wider range of strategies that shaped how each negotiated agency in advancing their own goals within the moment. For instance, in conversations involving children, their peers, teaching staff and paper-based communication books, unlike in study one, here adults were not instructionally trying to teach children with the help of children's

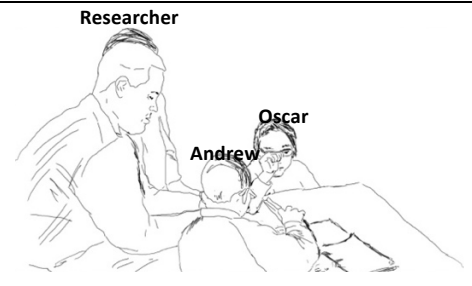


AAC systems (paper books, gestures, signs). Instead, communication books were used as a resource for communication largely used by the child. In these situations, adults acknowledged how and what children were communicating, then orchestrated the structure of the interaction to scaffold teaching goals or peer interactions, depending on the situation. Whereas in study one, adults prioritised the accurate use of AAC for speech generation, here, adults acknowledged children's multimodal communicative acts as meaningful in their own right. This meant that children were able to advance their own goals to some extent. However, adults then directed the structure of communication based on the situational demands. For example, for advancing teacher-led learning goals, promoting peer interaction or preventing/minimising peer conflict. In such instances, adults considered the meanings that children had signalled through their gestures, facial expressions, vocalisations and other modes before making judgements about how they should respond.

Transcripts 5.01 and 5.02: Adults encouraging and inhibiting children's shared use of communication books

In evidencing how adults first acknowledged children's multimodal actions before directing the structure of peer interaction, the following examples indicate how adults moved between encouraging and inhibiting shared communication book usage (transcripts 5.01 and 5.02⁵). In this extract, one of the child participants, Oscar, aged 8 years, is sitting at a table in class with another student, Andrew, and two adults; the researcher (who is next to Oscar) and a Special Needs Assistant (SNA) (who is next to Andrew). The adults are sitting between the children. Both boys have access to their own communication books that contain graphic symbols paired with written words for vocabulary that the teacher is asking them about. Their books are organised in semantic categories (e.g. people, places, weather), and adopt a navigational system that requires them to point to a graphic symbol so that their conversation partner can turn the pages to topic vocabulary that is specified by the child. During a morning registration session, the teacher, who is not visible in the video, is asking children questions about who is in school and what day of the week it is. This is a familiar activity for the class group. In transcript 5.01, the teacher has asked the students: "What day is today?" and the researcher is supporting the children in jointly using Oscar's book to find the answer to the teacher's question. In the first screen shot at line 1, Andrew is turning pages in Oscar's book and Oscar is

⁵ Transcripts 5.01 and 5.02 presents horizontally-organised data, capturing a more detailed account of the modes used over a shorter time period, compared with the vertically presented transcription layout presented in study one that presented broader events over a longer time period.




watching. In the second screen shot at line 13, Oscar slaps his hand onto the book page then points to a graphic symbol on the page. Following this, in the third screen shot at line 19, Andrew briefly pulls his hands away from Oscar's communication book and at line 25 the researcher reinforces what Oscar has expressed by pointing to the same graphic symbol and at line 27, verbalising the label of the symbol that Oscar has pointed to (i.e. "Something to say -"). Following this, the researcher verbally labels and points to the next picture icon that Oscar has pointed to (i.e. "turn to page two"-), indicating that she is encouraging the shared use of the book, inviting Oscar to continue to pursue this action.

Image shows Oscar (child participant) on the right side, behind the table. Andrew (class peer) is sitting centrally in the foreground.			Researcher 				
	line no.	time (in min)→	04:52	line no.	04:54	line no.	04:56
Andrew	1	bodily action	turning pages in Oscar's book	10		19	pulls hands away from Oscar's book briefly
	2	<i>gaze</i>	<i>Oscar's communication book on table</i>	11	<i>Oscar's communication book</i>	20	<i>book page, briefly to Oscar, then graphic symbol that Oscar has pointed towards</i>
	3	vocal		12		21	
Oscar	4	bodily action	leaning on table towards his book, right hand hovering in air above book, fist loosely clenched	13	slaps hand onto page	22	continues pointing to graphic symbol
	5	<i>gaze</i>	<i>communication book</i>	14	points to graphic symbol	23	<i>book page</i>
	6	vocal		15	Uh! Uh!	24	
Researcher (partly behind other adult on left)	7	bodily action	hands on lap	16		25	leans forward and reaches to point to graphic symbol that Oscar has indicated
	8	<i>gaze</i>	<i>Andrew's hands and book</i>	17	<i>Andrew's hands and book</i>	26	<i>Graphic symbol that Oscar has pointed towards, then briefly to Andrew</i>
	9	vocal		18		27	More to say – turn to page two -

Transcript 5 01. Researcher acknowledges and encourages shared communication book use in morning class session

Later in the interaction, in transcript 5.02, the adult inhibits shared use of the communication book, when the adult anticipates that the boys are starting an argument. In the example, at lines 1 and 4 Andrew and Oscar both reach to pull Oscar's book towards themselves which continues for a period of 3 seconds, into the next segment. At the start of the second segment, at line 16 the SNA stops Andrew from grabbing onto Oscar's book by lifting Andrew's wrist from the book. The SNA also then physically moves Oscar's book towards Oscar with his other hand, and repositions Andrew's own book in front of him. In the third and final segment, at line 19 Andrew pulls his hand away from Oscar's book as Oscar gazes to Andrew then towards his own book (line 23). At this moment, the SNA then verbally reinforces what he expects from the boys, commenting at line 27: "Okay, leave him – with his".

In the interaction illustrated across transcripts 5.01 and 5.02, adults set boundaries for how children should communicate; sometimes encouraging co-constructing meaning through a shared paper-based resource (transcript 5.01), and sometimes inhibiting it (transcript 5.02). In the first part, all parties collaboratively worked towards responding to the teacher's question through shared book use. At this moment, shared book use enabled them to competently advance a shared goal. In this instance, both boys have shared agency in the ways that they choose to communicate; through collaborative use of the book. Also, the adults take a softer approach for setting boundaries for communication, which supports the boys in advancing their goals. However, this is only partially successful as when the boys begin to argue over the possession of the book, the adult takes a different role; intervening to prevent further disruption. In this second part, adults limit child agency in allowing for children to communicate in their chosen ways. The adult makes a judgement that the boys are no longer able to competently co-construct a response, intervening to restructure communication on the adult's terms. At this point, it is unclear whether the boys would have been able to work together collaboratively with the book had they been left alone without adult intervention. In this instance, the adult has made a judgement to prevent a possible conflict from escalating, arguably judging that by pulling the book towards himself, Andrew has halted shared book use. The adult's actions consequently affirm an end point for shared book use through creating an explicit boundary between the boys. In this case, adults choose to minimise conflict and advance the immediate teaching goals that the teacher has set. In this case, adults acknowledge children's multimodal actions, yet structure communication based on the goals that the adult has prioritised.

							
	line no.	time (in min)→	05:44	line no.	05:47	line no.	05:49
Andrew	1	bodily action	reaching to pull Oscar's book towards himself	10	reaching to Oscar's book	19	Pulls reaching hand away. Leans his right elbow on the table, scratching his head and ear
	2	<i>gaze</i>	<i>Oscar</i>	11	<i>Oscar's book</i>	20	
	3	vocal	Uhhh!	12		21	
Oscar	4	bodily action	reaching to pull own book towards himself	13	reaching to book	22	turns book page
	5	<i>gaze</i>	<i>communication book</i>	14	<i>Andrew</i>	23	<i>Andrew then back to his book page</i>
	6	vocal		15		24	
Special needs assistant	7	bodily action	arms folded, leaning forwards	16	takes Andrew's wrist, lifting his hand off Oscar's book page. With other hand, pushes Oscar's book along the table towards Oscar	25	touching both boys' books
	8	<i>gaze</i>	<i>Oscar's book</i>	17	<i>Oscar's book</i>	26	<i>Oscar, then Oscar's book</i>
	9	vocal		18		27	Okay, leave him – with his.

Transcript 5.02. SNA inhibits shared communication book use in morning class session




Transcript 5.03: Adults resolve ambiguity in line with adult expectations

On other occasions, children had limited resources to meet their own goals so adults had authority in shaping the conversational direction. Whereas in study one, adults made assessments about children's capabilities to use their AAC devices (for example, transcript 4.02; salty omelette), in study two, adults acknowledged that children had different interests, yet chose to prioritise adult-led goals. In cases like these, children had limited opportunities to pursue their interests through the available modes, consequently limiting their agency in directing the topic of conversation.

One example of adults having authority over resolving ambiguity in conversations is presented in transcript 5.03. The episode involves one of the child participants, Grace, aged 9 years, and her teacher during a class-based cooking session. Grace has been eating an omelette that they have both previously made together. The interaction occurs at a point in the session where the activity is ending and the teacher is preparing to move the class on to the next activity, attempting to tidy up. There is a sense of time pressure on the teacher. The other adults and children are beginning to pack up in preparation for the next activity. At this moment in their interaction, Grace has just indicated that she wants to eat more omelette. The teacher has decided that Grace has eaten enough, possibly because Grace has already finished what is in her bowl, but also because of the time pressures to move on to the next activity. At this moment in the transcript, the teacher has acknowledged Grace's initiation, yet has treated this as relevant to what the teacher has previously said, advancing the adult-led goal.

The interaction in transcript 5.03 starts at lines 1-3 with the teacher asking Grace if she has enjoyed the omelette. They are using Grace's communication book alongside speech, looking behaviours, gesture and body movements. In the interaction immediately preceding the transcript, Grace has made eye contact with the teacher and eye pointed to the bowl, possibly to indicate 'more omelette'. The teacher has treated this as a possible request for more, asking: "More?" With a surprised expression, the teacher asks Grace if she has eaten her dinner. Grace briefly glances towards another adult then indicates 'No' by shaking her head which leads to the teacher asking the other adult if Grace has eaten. Following confirmation from the second adult that Grace has previously eaten her lunch, the teacher comments "You had your snack, you had your dinner, and you're still hungry." She then asks Grace: "Or did you enjoy it was hot?", which is the beginning of transcript 5.03. At the start of this episode, it can be assumed that Grace is annoyed by the teacher's previous rejection to offer her more to eat. At line 3, the teacher has asked: "Or did you enjoy it was hot?", to which Grace responds 'no'

by shaking her head, through speech and through a falling intonation tone (↘). It is unclear whether Grace's utterance "No" is in response to the teacher's question immediately preceding this, or to an earlier question or comment. At line 15, the teacher attempts to understand what Grace's "No" has signified. Four possible explanations for this are that 1. Grace is responding to the teacher's earlier question: "Did you have your dinner?", 2. Grace is responding to the teacher's current question: "Was it hot?", 3. Grace is objecting to stopping and wants to eat more (she has indicated this in the conversation prior to where the transcript starts), or 3. Grace is indicating 'no more' omelette, and wants to stop eating. At line 39, ambiguity is resolved by the adult by who treats Grace's initiations as being relevant to what the adult has said, i.e. 'no' signifying 'no more'. Throughout the interaction, the teacher's and Grace's actions and goals are not aligned. By line 54 there is a suggestion that Grace's communicative actions have been misinterpreted as she calls out: "No". Grace's "No" at line 54 sequentially can be treated as rejection of the question "finish, yes?". Alternatively, Grace's "No" might also be treated as an affirmation of the teacher's earlier "No more" comment. Regardless of either possibility, the teacher doesn't treat this as communicatively relevant and unequivocally shuts down this part of the conversation by moving away and even taking her book away. As Grace has limited resources to extend her "No", the teacher chooses to resolve this highly ambiguous event by interpreting Grace's actions as meaning she does not want any more to eat. In this example of competence and agency, both parties' actions are not aligned and they are unable to competently achieve common ground. Grace's agency in advancing her possible goal to eat more, is limited by the ways that the teacher chooses to resolve ambiguity. Whilst Grace's multimodal communicative actions are initially acknowledged by the teacher, the resources available to Grace do not enable her to extend her initiation of "No" for directing the course of the interaction. Consequently, the teacher resolves ambiguity in line with her own goals, moving away from Grace to change the activity and topic of conversation.

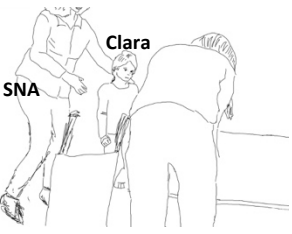



		 <p style="text-align: center;">teacher Grace</p>																			
	line no. ↓	time (min) →	17:56	line no. ↓	18:00	line no. ↓	18:02	line no. ↓	18:04	line no. ↓	18:07	line no. ↓	18:08	line no. ↓	18:09	line no. ↓	18:13	line no. ↓	18:15	line no. ↓	18:17
teacher	1	bodily action	points to icon in book	7		13	leans head closer to Grace	19	signs 'no' by swiping outward facing palm across front of book	25		31		37	leans head closer to Grace	43	leans away from Grace, pointing to graphic symbol on page	49		55	Moves away from Grace, taking book away to place on another table
	2	<i>gaze</i>	<i>Grace then book</i>	8		14	<i>book</i>	20	<i>book</i>	26	<i>book</i>	32	<i>book</i>	38	<i>book</i>	44	<i>Grace, then book</i>	50		56	
	3	<i>vocal</i>	<i>...or did you enjoy it was hot?</i>	9	<i>yeah?</i>	15	<i>No, what?</i>	21	<i>No more.</i>	27		33	<i>sorry?</i>	39	<i>no more.</i>	45	<i>Finish, yes? Finish.</i>	51		57	<i>Finish</i>
Grace	4	bodily action	chin tucked to chest, oriented towards book	10	raises head then shakes head 'no'	16		22		28	leans head closer to teacher	34	leaning head close to teacher	40	leaning head close to teacher	46	moves head back to midline as teacher moves away	52	begins to tense and move her arms that are by her side	58	
	5	<i>gaze</i>	<i>book page</i>	11	<i>book, then ahead</i>	17	<i>book</i>	23	<i>teacher then book</i>	29	<i>symbol in book</i>	35	<i>book page</i>	41	<i>ahead</i>	47	<i>downwards to book</i>	53	<i>ahead, to teacher then ahead</i>	59	<i>towards teacher who is moving away</i>
	6	<i>vocal</i>		12	<i>∩ No</i>	18		24		30	<i>[unclear speech]</i>	36		42	<i>[unclear speech]</i>	48		54	<i>∩No</i>	60	

Transcript 5.03. Teacher and Grace talk about eating omelette. Their interests are not aligned.

Transcript 5.04: Children asserted agency in advancing their own goals through bodily movement

In a separate example of competence and agency, at times, children asserted agency in advancing their own goals through bodily movement. In evidencing that she disliked adults physically moving her around the classroom, Clara used multiple modes through her whole body to quickly and efficiently reject adult support and express frustration. The example that follows in transcript 5.04 depicts Clara using her whole body, to explicitly reject the adult's request to move to the group semi-circle following a period of 'free play'.

At the start of transcript 5.04, the SNA who has been working with Clara is attempting to move her towards the class group who are sitting in a semi-circle. Clara has recently stood up from the floor and has already rejected the adult's prior physical attempt to take her wrist. At the start of the transcript, in the first picture segment at line 1, the adult is standing behind Clara and reaches to take Clara's hands which Clara is holding up in the air. In the second picture segment, at line 8, Clara begins to reject the adult's support by tensing her arms, pushing back her elbows and re-directing her gaze downwards. In the third picture segment, at line 16 Clara expresses her frustration vocally with an angry moan, whilst reaching her arms into the air to push the adult away (line 14). In the final segment at line 29, Clara drops to her knees, pulling further away as the adult loosens her hold of Clara's arms.

												
	line no.	time (in min)→	05:46	line no.	05:47	line no.	05:50	line no.	05:53			
Clara	1	bodily action	arms by her side, facing the table where researcher is working	8	pulls elbows back and tucks her chin to her chest as adult holds onto her	14	pulls arms up in the air, pushing away SNA's hands	26	drops to her knees, swaying from side to side, loosening SNA's hold			
	2	<i>gaze</i>	<i>table</i>	9	<i>downwards</i>	15	<i>ahead-downwards</i>	27	<i>ahead</i>			
	3	vocal		10		16	Urghhhh! (angrily moan, frowning)	28	Urghhhh! (angrily moans again)			
SNA	4	bodily action	turns to move towards Clara, reaching out both arms towards Clara's shoulders	11	grasps Clara's upper arms with both hands, standing behind Clara	17	continues holding Clara's arms	29	loosens her hold on Clara's arms and continues to loosely hold her hands, still behind her			
	5	<i>gaze</i>		12		18		30				
	6	vocal		13		19		31				

Transcript 5.04. Clara (middle) uses whole body to reject physical hold from the SNA (left)

In a typical mainstream classroom environment, this level of physical intervention may be seen as overly intrusive. In situations where children's physical impairments affect their balance and mobility, a higher level of physical guidance can be seen as normal. In the case of Clara, whose classroom environment means that she has to negotiate many obstacles, it is possible that some physical support is warranted. However, Clara rejects this, and also rejects joining the group, by calling out with a loud moan, pushing her body against the adult, dropping to her knees and pulling her arms away from the adult. Through her actions, Clara asserts her capability to move around the classroom independently. She also lets the adult know that through her body movement, like the adult, she has a repertoire of ways to act that can help her to express her goal in that moment. By combining vocalisation, muscle tone pressure (pushing against the adult), direction of body movement (downwards, away from adult) and other modes, Clara clearly expresses her discontent in adult physical support.

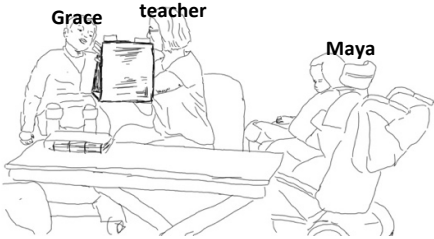


Theme two: Material & structural arrangements

Classroom arrangements and assistive devices offered children and adults ways of accessing activities together through positioning and postural support, yet building on the findings of study one, the orderings of people, material objects and processes often created disability.

Transcript 5.05: Material objects creating communication barriers

Like in study one, AAC systems, including paper-based communication books, were at times seen as an external material object that created physical barriers and inhibited communication opportunities. One example of this is illustrated in transcript 5.05 involving Grace, the teacher and Maya. The event occurs during a class-based design workshop whereby the teacher is individually asking each girl about their interests so that they can co-construct a collage of images and text. At the start of the transcript, the teacher is working with Grace and Maya is sitting close by at the other side of the table. At line 1, the teacher is holding up a folding board containing graphic symbol choices for Grace on the left, whilst Maya on the right is blocked from seeing Grace's actions. At line 6, the teacher directs her question towards Grace, holding up the symbol board. Maya is looking downwards towards their collage on the table (line 8). At line 17, Maya gazes towards the teacher and Grace however they are both engaged in their conversation that is happening behind the communication board which is causing a blockage for Maya. During the interaction, Grace and the teacher choose to use a physical artefact to augment ways of representing words. As one of Grace's primary modes of communication is via looking actions, the teacher is holding up the graphic symbol board at eye level. She is asking Grace questions about the symbol choices and focusing on where Grace

is looking towards on the symbol board. As both Grace and the teacher are intently focused on using the board, they do not attend to Maya who has signalled her interest in the interaction, by gazing towards them (lines 17 – 26.) The example demonstrates that material objects can be both supportive and inhibitory for communication. Whilst for Grace, the communication board is supporting her access to vocabulary through symbols that are positioned at eye level, for Maya, the board inhibits communication by blocking her from seeing both Grace and the teacher and vice versa. As with the case in study one, material objects blocked children from being directly involved in interaction, in this case, forcing Maya to adopt a passive role. Like in the first study and echoing the work of Moser (2006), constructions of ability and disability were created by the sociomaterial arrangement of relations and orderings of people and technologies. As adults prioritised adult-led learning goals, they structured the environment to advance these goals. Consequently, this disabled children's opportunities for leading the topic of conversation or engaging in group or peer interaction.

											
	line no.	time (in min)→	35:55	line no.	35:57	line no.	35:59				
Grace	1	bodily action	one arm on lap, other by her side	10		19					
	2	gaze	<i>communication board</i>	11	<i>briefly looks ahead, then back to board</i>	20	<i>specific place on board that the teacher has indicated</i>				
	3	vocal		12		21					
teacher	4	bodily action	holds up graphic symbol board facing Grace at eye level	13	holds up graphic symbol board facing Grace at eye level	22	holds up graphic symbol board facing Grace at eye level				
	5	gaze	<i>Grace</i>	14	<i>specific place on communication board, half way down</i>	23	<i>Grace</i>				
	6	vocal	<i>anything else from this row?</i>	15		24	<i>You like Gruffalo?</i>				
Maya	7	bodily action	hands rest on lap	16	raises hands towards her mouth, wriggling movement	25					
	8	gaze	<i>collage on table</i>	17	<i>Grace and teacher</i>	26	<i>Grace and teacher</i>				
	9	vocal		18		27					

Transcript 5.05. Folding symbol communication board creates a barrier between Grace and Maya

Transcript 5.06 – Adults organising the structure of interactions

Structural arrangements extended beyond the organisation of material objects to include the organisation of interactional turns. On some occasions, adult conversation partners enforced rigid conversation structures that placed expectations on children to respond in specific ways. For example, in transcript 5.06, the adult (Sally) is asking the child (Maya) a closed question that demands a 'yes' or 'no' answer. There is an expectation that Maya will respond with either a brief 'yes' or 'no'. The example shows that as the adult has organised the interaction in this way, any of Maya's actions are treated as a response to this question.






The interaction is taken from class-based cookery session that was also discussed in study 1, chapter 4. The transcript that is presented here in 5.06 precedes an interaction that was presented earlier, in chapter 4 (transcript 4.02). Here, the SNA and Maya are whisking an egg mixture and the SNA asks Maya if she would like to add salt into the mixture. Maya's reaction, or a lack of a recognisable action, is interpreted as an affirmation in response to the SNA's question. In the context of the wider conversation, and knowing that Maya later comments that it is 'salty' (in transcript 4.02), it is believed that the adult may have misinterpreted her response.

In the first picture segment of the current transcript (lines 4-6), Maya is gazing to the bowl that the adult is holding and she moves her hands close to her face in a wriggling motion. This is a typical movement for Maya which she frequently enacts throughout the day and it is generally not interpreted by others as communicative. At line 7, the SNA pauses from whisking the egg mix, leans and looks towards Maya. At line 9 she verbally asks her "You want some salt in there?". At the same moment, as the adult has turned her focus to Maya, Maya stops moving her hands and lowers them slightly towards her tray. Maya's sudden stillness and continued gaze towards the bowl gives some indication that she is likely to be attending to what the adult is doing and to the adult's question. Maya has been gazing towards the bowl up until now and following the adult's question, turns to look towards her AAC screen. At lines 16 and 17, one second after the adult has asked the initial question, Maya has resumed her hand wriggling and shifts her gaze towards the AAC screen in front of her. At this same moment, the adult asks a follow up clarification question: "Yes?". At this point, Maya is not given adequate time to formulate a response, and the adult begins asking a series of follow up questions: "Yes?... No?". At line 23, as the adult asks "No?" Maya closes her eyes as she turns back to look at the bowl then back to the AAC screen. She chooses not to use the AAC device to speak a response. In the third picture segment, at line 25, the adult continues to be still, gazing towards Maya in anticipation of a response. During this time, at line 28, Maya lowers her arms again and looks

towards the bowl. At line 33, the adult's verbal comment suggests that she has interpreted Maya's action of looking towards the bowl to indicate "Yes". As the adult says "You do", Maya resumes her hand movements and redirects her gaze to the AAC screen. In the last segment, the adult continues whisking the mixture and moves to fetch the salt.

During the interaction, Maya acknowledges the adult's question 'Do you want salt in there?' in a number of ways; the sudden stillness in her arm movements and lowering her hands, paired with her fixed gaze towards the bowl is indicative that she is attending to what the adult is doing and to what she has just asked. Maya then shifts her gaze towards her AAC screen, looks towards the screen for an extended period of 4 seconds which suggests that she might be formulating a response using the device. Maya then closes her eyes before turning to look at the egg mix again. Judging from the SNA's unbroken gaze towards Maya, it is assumed that she is waiting for Maya to respond either using the AAC device that she has just gazed towards, or by signalling 'yes' or 'no' with an understandable expressive means. During this time whilst the adult is still and watching Maya, at line 23, Maya has closed her eyes, reopened them, looked away from the AAC screen towards the bowl then looks back towards the screen. The adult is gazing towards Maya, yet does not explicitly respond to any of these actions, suggesting that she has not treated them as meaningful responses to the initial question ("do you want salt in there?"). At lines 28 and 29, Maya lowers her arms to her tray and gazes to the bowl. Immediately following this at line 33, the adult says "You do" which indicates that she has treated Maya's action, of gazing towards the bowl, as affirming "yes".

In this situation, the adult has asked a 'yes' or 'no' question that allows her to attribute any of Maya's 'answers' as a 'yes' or 'no' response. The adult is having trouble interpreting Maya's actions, yet owing to the structure of the conversation and the expectations that come with asking a closed question, Maya's actions are treated as 'yes'. However, Maya carries out a number of actions that can be interpreted as purposefully expressing something else. For instance, closing her eyes, turning away from the bowl, pausing from moving her arms or equally, choosing not respond through electronic speech could all be indications of negation. However, by using questioning as a resource in an ambiguous situation, the adult seeks to avoid a breakdown by interpreting Maya's actions within the conversational structure that she has created.

															
	line no. ↓	time (in min) →	07:16	line no. ↓	07:19	line no. ↓	07:20	line no. ↓	07:24	line no. ↓	07:25	line no. ↓	07:26	line no. ↓	07:27
Sally (SNA)	1	bodily action	Whisking egg mix	7	pausing from whisking egg mix, leans towards Maya	13	leaning on Maya's tray	19	leaning on Maya's tray	25	leaning on Maya's tray	31	leaning on Maya's tray	37	resumes whisking as she stands up and moves to collect salt
	2	gaze	<i>bowl</i>	8	<i>Maya</i>	14	<i>Maya</i>	20	<i>Maya</i>	26	<i>Maya</i>	32	<i>Maya</i>	38	<i>bowl then gazes ahead</i>
	3	vocal		9	You want some salt in there?	15	Yes?	21	No?	27		33	you do.	39	
Maya (child)	4	bodily action	hands wriggling	10	stops moving hands near her mouth and lowers hands slightly towards her tray	16	hands wriggling	22	hands wriggling	28	lowers arms towards her tray	34	hands wriggling	40	hands wriggling
	5	gaze	 <i>bowl</i>	11	<i>bowl</i>	17	<i>AAC screen</i>	23	<i>closes her eyes as she turns back towards the egg mixture, then gazes back to AAC screen</i>	29	<i>bowl</i>	35	<i>AAC screen</i>	41	
	6	vocal		12		18		24		30		36		42	

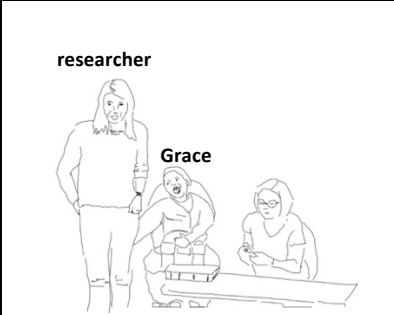



Transcript 5.06. Maya's subtle actions signalling her attention are missed by the adult

Transcript 5.07 – Children structuring arrangements for communication

In contrast, and unlike the findings presented in study one, study two showed that children had ways of structuring their environments to support communication on their own terms. Children drew on a broad range of resources in ways that enabled them to communicate. In two separate events, both Grace and Oscar directed the researcher to sit in a position that enabled each child to converse in a manner that was appropriate for them.

The transcript that follows occurs during a collage making workshop session led by the researcher. The researcher is walking around the classroom taking photos of the children's collages. Prior to the start of transcript 5.07, the researcher has moved next to Grace, and is pushing over a chair on wheels. The researcher is about to sit next to Grace but hovers a while looking towards some other people at another table. At the start of transcript 5.07, Grace calls out with a sudden burst, gaining the researcher's attention. Grace combines many modes to redirect the researcher's attention in a busy classroom. Once she gains the researcher's attention, Grace directs the researcher to sit next to her at eye level. In doing so, Grace commands the adult to be fully present in the activity, rather than watching from a standing position. From this sitting position, both Grace and the researcher have shared access to the materials on the table in front of them, which they begin talking about.

At the start of transcript 5.07, at line 1, the researcher is standing near to Grace but facing the opposite direction, looking towards a different group of people who are at a table. At the same moment, at lines 4 – 6, Grace gains the researcher's attention through a sudden burst of modes: simultaneously, she pushes her feet against the foot plate on her wheelchair, pushes her upper body upwards and backwards, turns her body to orientate towards the researcher, tenses her arms and calls out "Sit down!" whilst gazing to the researcher. Her speech is unclear but her other vocal properties; intonation, syllable stress, prosody and volume, help the researcher to understand what she has said. In the second picture segment at lines 7 – 9, the researcher redirects her attention to Grace and acknowledges Grace's initiation. The researcher asks Grace a question to clarify what Grace has said: "Sit down?". In the third segment, at lines 16 - 18, Grace affirms this by saying "Sit down" for a second time. This time, Grace is smiling and gazing to the researcher. Her arms are extended outwards, which is also part of her attention- grabbing action. In the final picture segment at lines 19 – 24, as the researcher sits to face Grace, the tension in Grace's arms begins to lessen and she lowers one arm, but is still holding up her right arm, which is closest to the researcher.

									
									
									
									
	line no. ↓	time (in min) →	37:00	line no. ↓	37:02	line no. ↓	37:04	line no. ↓	37:05
Researcher	1	bodily action	body turned away from Grace	7	turns body to face Grace	13	moves to sit whilst reaching to take something out from back pocket	19	sits facing Grace
	2	<i>gaze</i>	<i>other children at a table area out of view</i>	8	<i>Grace</i>	14	<i>ahead, towards table</i>	20	<i>Grace</i>
	3	vocal		9	sit down?	15		21	
Grace	4	bodily action	pushes her feet against her wheelchair foot plate as she pushes back in her chair and turns body towards researcher. Tension in arms as they raise slightly	10	facing researcher still, arms remain raised	16	arms are now extended outwards as she vocalizes again. Her upper body is orientated to the researcher	22	arms furthest away from researcher lowers whilst her body is still orientated to researcher
	5	<i>gaze</i>	<i>researcher</i>	11	<i>researcher</i>	17	<i>researcher</i>	23	<i>researcher</i>
	6	vocal	Sit down! [loudly, unclear speech but partly intelligible]	12		18	Sit down! (smiling)	24	

Transcript 5.07. Grace (central) directs the researcher (left) to sit next to her

The intensity of Grace's sign making is successful in gaining the researcher's attention and directing her to sit next to Grace in a position that enables Grace to interact more comfortably with the researcher. The example illustrates that when Grace has control of directing others to a preferred location, she can organise her communication setup so that it complements the other arrangements in the room. For example, once the researcher is sitting down, Grace and the researcher then have shared access to an array of picture cards, catalogues, stickers, sticking and cutting tools which are used in the collage making workshop. From this position, Grace is then more freely able to use looking actions to direct the researcher towards the things she is interested in.

Theme three: Multimodal communication on children's terms



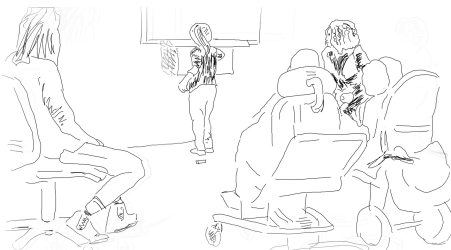
Study one showed that children used technology much less frequently than their other modes of communication. Despite all five children having access to their AAC technologies, communication through other modes provided a more efficient and faster way of expression. Building on this finding, as well as being more readily available, children's multimodal, full body communication allowed them to demonstrate their expertise in communicating by drawing on richer and more nuanced ways of communicating. Often, by combining multiple modes, children had access to a broader range of functions, could regulate the shades of intensity, and express themselves more persuasively compared with when communicating with their AAC devices alone.

Transcript 5.08 - Children provoking adult reactions through disruptions

On some occasions, children challenged adult authority to structure interactions through disruptions. These types of disruptions were not observed in conversations involving AAC devices, in the first study. In study two, disruptions served to advance children's interests by disturbing the flow of adult-directed activities. Children purposefully disrupted the flow of adult structured-interactions by making sure they were being observed. By drawing on multiple modes with escalating intensity, disruptions enabled children to agentively seek attention and provoke a reactive response from adults.

In one example of disruptions, one of the child participants (Clara) challenges adults to redirect their attention towards what she is doing rather than focusing on a teacher-led group activity. During the sequence, Clara draws on a range of resources that increasingly pose more 'risk' to disrupting the whole class group activity. Whilst the teacher is moving around a semi-circle of children, asking each child questions in turn, Clara moves to the centre of the semi-circle and

carries out a series of actions with increasing intensity and risk for damaging or breaking teaching equipment. Prior to each new action, Clara is aware that the SNA is attending to her; sometimes Clara gazes to the SNA as she initiates her next action, at other times she is watching the SNA through her peripheral vision. Over the course of the event, Clara throws whiteboard marker pens onto the floor; taps on the interactive whiteboard to change the screen display; pulls the whiteboard downwards on its moving mechanism so that it is within her reach, and; attempts to sit on the ledge of the whiteboard. Each of these actions disrupts the status quo of the session, demanding a reaction from the SNA. Reacting to Clara's initiations, the SNA responds by picking up the dropped pens, turning off the whiteboard screen and standing next to Clara. It is not until Clara's final action of attempting to sit on the ledge of the whiteboard, that the SNA physically stops Clara from doing so by taking her arm and guiding her to sit down. Taking one small part of this larger event, the example in transcript 5.08 illustrates how Clara's gaze and actions are synchronised with the SNA's reactions towards Clara. In the first segment at line 2, Clara, who is sitting in the middle of the semicircle, turns to her left to gaze towards the SNA who is sitting on the edge of the semicircle to the far right of the video still image. At line 7, Clara continues turning in a semi-circle to her left side, until she is facing the whiteboard that was previously behind her. As she does this, at line 10, the SNA slightly orientates towards Clara, indicating that she is aware of her moving. In the third picture segment, at lines 13 – 17, Clara stands up, facing the whiteboard. At the same moment, the SNA begins to spin her chair to orientate herself to face Clara. At lines 19 – 23, Clara reaches to take the marker pens from the ledge of the whiteboard. She is about to throw these onto the floor one by one. As she reaches to the pens, the SNA quietly pushes to stand up from her chair and moves in Clara's direction.

									
	line no. ↓	time (in min) →	12:25	line no. ↓	12:28	line no. ↓	12:32	line no. ↓	12:38
Clara	1	bodily action	hands held behind her back, kneeling forward	7	shuffles whole body in a semicircle to face whiteboard	13	stands up facing whiteboard	19	reaches to whiteboard pens and begins throwing them individually on the floor
	2	<i>gaze</i>	<i>turns to SNA</i>	8	<i>whiteboard</i>	14	<i>whiteboard</i>	20	<i>whiteboard</i>
	3	vocal		9		15		21	
Special needs assistant (SNA)	4	bodily action	Sitting, leaning back in her chair	10	Slightly orientates towards Clara	16	spins chair slightly to face Clara	22	pushes to stand up from chair, towards Clara
	5	<i>gaze</i>	<i>ahead towards child on other side of circle</i>	11	<i>Clara</i>	17	<i>Clara</i>	23	<i>Clara</i>
	6	vocal		12		18		24	

Transcript 5.08. Clara (seated on the floor, centrally) gazes towards SNA (seated on chair, on right side) before standing to move towards the whiteboard

During this sequence of events, Clara's actions are not arbitrary. She waits until the SNA is attending to her before carrying out her next 'disruptive' action. Over the course of the wider sequence, she draws on a range of material objects (for example, whiteboard pens, whiteboard screen, mounting mechanism, whiteboard ledge) as tools that allow her to gain the adult's attention and direct her attention to respond to the objects. Clara's actions are dependent on the SNA's previous move and she gradually steps up the intensity of what she is doing based on the SNA's reaction to her prior turn. For example, in the transcript she slowly and smoothly moves from sitting on the floor to spinning around to face the whiteboard, then methodically dropping pens onto the floor one-by-one. These escalating actions are coordinated with the adult's acknowledgement of her. Clara gains the adult's attention prior to introducing her next action which gradually builds in intensity.

Whilst it is unclear why Clara carries out the series of actions, the example illustrates she is aware that she can redirect the adult's attention and provoke a response to her actions that have escalating intensity and effects. Clara's actions illustrate some of the ways that she successfully redirects the adult's attention from the group activity. Conversely, the SNA is reacting to Clara's initiations by dealing with the objects rather than the child directly. For example, tidying the pens, switching off the whiteboard screen or moving Clara away from the whiteboard ledge. In the context of the session where the rest of the class group continue to focus on the teacher, the SNA chooses to respond to Clara's actions quietly, through action rather than speech, which arguably inhibits further disturbances to the teacher-led session. The example shows that Clara agentively draws on a range of semiotic resources to advance her goal for seeking attention and prompting a response from the SNA.

Figure 5.01 – Communicating by doing

A second way in which children communicated on their own terms, was by directly engaging in activities, rather than first introducing or 'talking' about them. 'Communicating by doing' was a key practice for communicating in a timely way, compared with first establishing the rules of how participants will communicate, which is a common practice in aided conversations (for example, see transcript 4.03 in chapter 4, where the adult explicitly sets up the scenario for asking the child a question).

Communicating by doing was often connected with constructing meaning by drawing on resources that were quickest, most effective and least effortful in the moment. Grace, for example, requested more omelette from the teacher who had been supporting her to eat, by opening her mouth widely, gazing to the spoon then at the teacher and calling out for the

teacher's attention whilst leaning forwards towards where the teacher was holding the spoon (figure 5.01). Her sign making expressed that she was ready for another mouthful.



Figure 5.01. Grace expresses she wants to eat by opening her mouth, leaning forwards and gazing to the teacher

Transcript 5.09 – Choosing apt modes for the moment

A third way in which children demonstrated ways of communicating on their own terms, was through their choices and assemblages of modes, chosen accordingly for the situation. Despite natural speech being difficult, there were times when accuracy of speech was not always needed and context encouraged children to use speech in supported spaces.

Oscar, for example, chose to use natural speech instead of other available resources such as his communication book or Makaton signing, during a morning registration routine where most other children also used natural speech. In morning registration routines such as these, that often follow an anticipated routine for greeting initiations and responses, Oscar's unintelligible speech ("da dada da dada") is treated as understandable in response to the teacher's initiation: "Good morning Oscar". The context of the activity, as a ritualised communicative interaction, provides a resource for others to understand Oscar's speech. At the same time, the ritual allows for Oscar to produce speech that can be understood. In the example presented in transcript 5.09, Oscar sits at the table with his class peers and teacher as they each take turns to say good morning. In the first picture segment at line 3, the teacher directs her greeting towards Oscar, saying: "Good morning Oscar". In the second picture segment at lines 11 – 13, Oscar responds by tapping his mouth with his finger and vocalising a series of word approximations for "Good morning everybody". Whilst the word approximations that Oscar uses are highly unintelligible, he regulates the pattern of intonation, syllable stress and uses expected pauses between probable words which helps to

guide others in their interpretation of what he is saying. He taps on his lips as he is speaking aloud, which directs others to attend to the way that he is responding verbally. Oscar skilfully makes use of different ways for maximising his verbal output, expressing that he too is responding in the dominant spoken mode.

	line no. ↓	time (in min) →	14:35	line no. ↓	14:37	line no. ↓	14:39		
teacher	1	gesture	upper body oriented towards Oscar, seated. Holding name cards	8	leans to put name cards on floor and picks up communication book	14	facing Oscar, turns book page as she begins to ask him another question		
	2	<i>gaze</i>	<i>Oscar</i>	9	<i>floor then Oscar</i>	15	<i>Oscar</i>		
	3	vocal	Good morning Oscar	10		16	((quietly)) good morning. And Oscar, look-		
Oscar	4	gesture	upper body oriented towards another child sitting opposite Oscar	11	Sways his body side to side briefly then stops as he reaches his finger to his mouth. Taps on his mouth at the start of each new speech segment	17	lowers arms to his lap		
	5	<i>gaze</i>	<i>peer</i>	12	<i>downwards to table</i>	18	<i>communication book</i>		
	6	vocal		13	da-dada-da-dada	19			

Transcript 5.09. Oscar uses speech to respond to the teacher's 'Good morning' greeting

Whilst this strategy would be less suited for situations where Oscar would be required to offer unrehearsed contributions that the communication partner is not expecting, here, Oscar's sign making is apt within the moment, allowing him to select modes that he is confident in using.

Theme four: A sense of belonging & adopting roles

Institutional environments including schools typically assert their membership in explicit ways, for example, through uniformed clothing, co-location and agreed cultural practices. In addition to these institutionally evoked practices, children themselves constructed meaning about the groups that they aligned with through their communicative actions. By constructing roles for themselves and acknowledging the roles of others, children illustrated the ways that they affiliated with a group.

Over the 14-week period of fieldwork, children's roles within their class and social groups became more apparent. By capturing a number of interactions across different activities, the findings illustrated that children pervasively embodied similar roles at different times when placed in similar situations. For example, one of the participants, Noah, frequently spent extended periods of time watching and being amused by his class peers who were doing or saying something that appeared to go against what the adults were expecting. On one occasion during a whole class activity, Noah reinforced his role as 'ally' to his peers by quietly listening to how his peer responded to an adult's questions then laughing in response to what she had said, when she unexpectedly told the group that she had cut her own hair at the weekend. By laughing, Noah arguably aligned with his peer as separate from the adult authority figure who has responded to this comment with shock and surprise.

Children's sense of belonging and group affiliation was also connected with their communicative agency. Children used multiple modes to take on specific roles that demonstrated they were key members of the class group and through their specific and highly individualised communication styles, carved out specific roles for themselves which underscored their value and importance in the group. Oscar for example, often knocked on the table to seek adult attention when he had something to say in the context of a whole group activity, such as morning registration. Over the course of the study, it was identified that his knocking action would act as a reminder for the teacher to do something, like remembering to move children's names and photos into a different column on the smartboard as the register was called. Oscar's role was therefore shaped to become the person who reminds the others about the technical aspects of the activity. This complemented what others in the group already perceived about him; being 'a techie boy'.

In the first study in chapter 4, adults made assumptions about children's capabilities which defined the types of roles that they saw children taking, for example, learner/receiver of support. However, here in study two, children carved out their own roles that aligned with personality traits and peer relations. For example, as illustrated in the cases of Noah as an 'ally' to his friends, and Oscar as a 'techie boy'. These insights indicated that when studying children's communication across broader contexts, children's agency to define their own roles, on their own terms, became more apparent.

RQ2b – What do children appear to value based on the ways that they communicate?

The second part of research question two investigated what children appeared to value based on how and what they communicated, in response to the methods. Children's values were grouped into five areas:

- [involvement](#)
- [care](#)
- [doing things the same as everyone else](#)
- [regulating privacy](#)
- [play and playfulness](#)





Involvement

In line with the definition of values as that which one considers important in life, involvement was identified as a key value for children. Involvement was seen as motivating children's modes of conduct and manifested in different ways. On a societal level, it encompassed the ways in which children broadly oriented themselves as being actively part of social activities. On a behavioural level, it included the strategic techniques and methods that children used to seek and maintain involvement. Lastly, on an affective level, it signalled the ways that children conveyed their motivation to contribute to different topics and situations around them.

In evidencing children's desires for being agentively involved on a societal level, across the data sets, children were keen to actively contribute to all of the communication situations that they experienced. Beyond being present as passive bystanders, it was important for the children in the study to actively contribute and to be acknowledged by others in both adult-to-child and child-to-child interactions. The scope of involvement on this broader, macro level ranged from being part of routine, mundane discussions like the weather or talking about who

was present and absent from school, to deeper forms of involvement that acknowledged their agentive role and belonging within a group, as identified in the first part of the study.

On a behavioural level, children were involved in conversations and activities that were happening inside and outside of the classroom through initiating new interactions, requesting to join existing interactions and expressing their interest in social activities happening around them. For example, during a workshop session where the researcher and teacher were communicating with another child who was sat nearby, Grace initiated and signalled wanting to be involved in the existing conversation by raising her head from looking downwards to gazing towards the others, and vocalising her discontent. During the event, Grace has used gaze, stillness and body orientation to signal her interest in being involved in a conversation that is already happening. It is not until she vocalised that the researcher acknowledged this, and responded to Grace's more direct request that was treated as a signal that she wanted to be part of the interaction. This is captured in transcript 5.10.

	researcher			teacher			Maya					
												
	line no. ↓	time (in min) →	49:51	line no. ↓	49:52	line no. ↓	49:53	line no. ↓	49:56			
Grace	1	bodily action	upper body and head tilted to her left, sitting with arms at her side, grimaces face with vocalization	13	upper body and head leaning to her left side	25	leaning to her left	37	now facing teacher and Maya, continues leaning to her left side but her right ear is now close to researcher (who is talking)			
	2	<i>gaze</i>	<i>in general direction of researcher, teacher and Maya but looking downwards, beyond them</i>	14	<i>shifts gaze towards table</i>	26	<i>table</i>	38	<i>teacher and Maya</i>			
	3	<i>vocal</i>	<i>Uuh!</i>	15		27		39				
Researcher	4	bodily action	standing, leaning forwards towards Maya and teacher, holding her hands still on her thighs as she interacts with them	16	turns upper body towards Grace	28	moves towards Grace, reaching to hold wheelchair handles	40	Pushes Grace's chair towards Maya and teacher, whilst leaning body forwards so that her head is close to Grace's.			
	5	<i>gaze</i>	<i>Maya</i>	17	<i>Grace</i>	29		41	<i>Maya</i>			
	6	<i>vocal</i>	<i>Uh huh. Thanks Maya!</i>	18	<i>Did you hear that?</i>	30	<i>Maya was telling [the teacher]</i>	42	<i>all the things that she likes</i>			
Teacher	7	bodily action	holding up a piece of card and points to words on card	19	holding up card still with one hand	31	nods and smiles briefly	43	holding the card, turns it over to see what's on the back			
	8	<i>gaze</i>	<i>card in her hands</i>	20	<i>researcher</i>	32	<i>Grace</i>	44	<i>card in her hand</i>			
	9	<i>vocal</i>	She likes animals, (...) books,	21	<i>and she likes play</i>	33		45				
Maya	10	bodily action	arms resting on lap, smiling	22	moves hands to mouth	34		46				
	11	<i>gaze</i>	<i>card</i>	23	<i>ahead (possible AAC screen or beyond it to Grace)</i>	35	<i>ahead</i>	47	<i>ahead</i>			
	12	<i>vocal</i>	(giggling)	24		36		48				

Transcript 5.10. Grace (left) calls out to researcher (standing, centrally) to be included in the conversation

At the start of the event in transcript 5.10, the first segment represents the researcher standing near to and interacting with Maya and the teacher. The teacher is telling the researcher about all of the things that Maya has indicated that she enjoys. Prior to the start of the event, Grace has been gazing towards them for an extended period of 26 seconds before she vocally calls out to the researcher at line 3. By this point, she has lowered her gaze slightly but is still looking in the general direction of the researcher, teacher and Maya. In the second segment, one second after Grace has vocally called out, lines 16 – 18 show the researcher redirecting her attention towards Grace by twisting her upper body towards her whilst still leaning over in Maya's direction. At this point, the researcher directs a verbal question to Grace: "did you hear that?". Here, the researcher is calling out to Grace to draw her into the conversation involving Maya, the teacher and the researcher. Grace's initiation to redirect the researcher's attention towards her and include her in the conversation is successful, as in the third segment, two seconds after her initial calling out, the researcher moves towards Grace and begins moving her wheelchair closer to the teacher and Maya. The researcher addresses Grace and begins to recap what Maya had said, bringing Grace closer to being involved in the conversation. During this third segment, as the researcher is interacting with Grace, the teacher and Maya also shift their attention to Grace, acknowledging her previous initiation. In the interaction that follows the transcript, Grace signals that she is interested in what the researcher is saying about Maya's interests. Grace is smiling, laughing, vocalising and gazing between Maya and the card that they are reading from. Retrospectively, Grace's "Uuh!" at line 3 is treated as a bid for involvement because she is positive about it once she is involved. Consequently, following her bid, the physical layout of the interaction is altered so that Grace is now more part of it and can access the shared resources that the others have been using.

Children signalled their motivation to be involved on an affective level by indicating that it was the social aspect of taking part in activities that they desired. During a workshop where children were invited to make collages of the things that were important to them, Grace conveyed that whilst she liked being part of a range of activities such as cookery, watching films and reading stories, it was the social aspect of such activities and undertaking them with others that was important for her. Her collage in figure 5.02 documents that for every activity she has listed, she has indicated whom she would typically undertake the activity with, for example, 'reading with x', 'films in school with y' (names have been removed for confidentiality).



Figure 5.02. Grace's collage conveying her motivation to do activities with others

Further, children conveyed their frustration when they were not involved in conversations and activities. For example, another of the child participants, Oscar, signalled his dissent at being excluded from a classroom interaction one lunchtime when only the researcher, a lunchtime supervisor and Oscar were present. Through his forms of engagement, Oscar became increasingly annoyed at being ignored to the point where he interrupted the conversation between the adults, redirecting the researcher's attention to himself. Whilst it did not support him in being included in the conversation (possibly also due to the topic of conversation being less accessible), it signalled his dissatisfaction at being present but not involved. The extract that follows is taken from the researcher's fieldnotes. It illustrates the ways that Oscar uses a number of strategies to draw the adult's attention with increasing intensity.

"The adult-to-adult conversation was evidently becoming frustrating to Oscar as he continued to point to more symbols in his book more vigorously, as if rushing to tell me lots of things. Eventually, he leaned close towards my face, eye-to-eye, raising his finger to his lips let out a loud 'Shhhh'. I replied 'okay, okay, sorry' and stopping the discussion with Leanne [mealtime supervisor], turning my full attention towards him."

Whereas in the first part of the study (RQ2a) children's multimodal communication served to show how they used a range of shades to signify intensity, here on an affective level, children's forms of engagement highlighted the importance of being involved and acknowledged, and children's dissatisfaction when they were excluded.

Previous findings have highlighted a common misconception that 'fewer words means fewer ideas' or that people with limited or no verbal speech will also have cognitive impairments that

impact on their understanding and involvement in conversations (Wickenden, 2011b). Echoing these findings, in the current study, children challenged these misconceptions. As identified in the cases of Oscar and Grace above, children's initiations to redirect adult attention illustrated their capability to follow and be part of interactions around them, highlighting that they understood what was happening around them and had strategic ways of conveying meaning and sharing their ideas.

Care

In line with an evolving body of HCI work that has studied various manifestations of care (Toombs et al., 2018) care was treated as a key value for children, evidenced both through their forms of engagement and subject matter of what they communicated. Whilst a large body of HCI work has explored isolated instances of care, for example, within residential care homes, or the specifics of healthcare or selfcare (Toombs et al., 2018), within the current study, care was treated as a social and relational, everyday practice that reinforced the ways that children and their social groups were interlinked. It was signalled through a compassionate stance towards others. Care as an underlying value manifested in three main forms. First, on a broad, societal level, care was enacted as a collaborative and ongoing practice. Second, on a material level, children signalled care through the creation of artefacts that had a broader reach and longevity. Finally, third, on a behavioural level, care was enacted through closeness and touch. Each of these dimensions is discussed in turn.

Collaborative and ongoing care practices - Participants in the study were frequently out of class due to health appointments. These included therapy sessions in school, out of school doctor appointments and in the case of one participant, an extended hospital admission for planned surgery. When this happened, the other children adopted the role of 'a caring friend' through the ways that they expressed concern for the wellbeing of others over protracted periods of time. Children's actions emphasised care that was enacted as a collaborative and continued practice, demonstrating interdependency and child relations (similar to Brown & Choi, 2018 and Light & Akama, 2014). For example, during the course of the 14-week fieldwork period, children regularly asked about their class peers when they were out of school and were often interested to find out why they were off and when they would be back. Children called upon adults to support them in making cards for their friends, decorating their possessions and asking about them in their absence. These initiations were multi-directional, indicated children's intertwined relations of care. In one instance of this, during the fieldwork period, one of the participants, Maya, had spent 3 weeks in hospital for a planned procedure. During this time, she herself initiated wanting to make a card for her class friends Grace and Clara

(two of the other participants) and was practically supported to do so by her mother during her hospital stay.

At the same time, Clara frequently asked the researcher why Maya was in hospital whenever Maya's name was mentioned. Equally so, Grace chose to decorate the collage image of Maya's photograph using sparkly purple spots. Both girls had previously been working on this together during one of the research workshop sessions in class. These examples are represented in figure 5.03 below.






Figure 5.03. Maya, Grace and Clara express their friendships through craft methods

Care expressed through the material – Taking the example presented above as a starting point, children's meaning making through material artefacts allowed them to express care to a broader audience reach, capturing and sharing meaning for longer periods than if communicated without visual representations. For example, the card that Maya and her mother had created for Clara and Grace (figure 5.03, left) was consequently talked about in class as Maya's teacher presented this to the children on Maya's behalf. It was also talked about in email correspondences involving Maya's mother and the researcher, reinforcing the prominence of care relations between children, carried through support structures that are facilitated by adults.

Material artefacts also supported other children to pursue interests about their friends' lives. For example, as the created collages were accessible for children to explore on their own terms, some children were interested in examining what their class peers had created. In one instance of this, Clara for example, who had opted out from creating her own collage, closely examined Maya's and Grace's collaborative collage during the final plenary of a workshop session. In transcript 5.11 that follows, Clara is intently interested in what the researcher is saying about what Grace's and Maya's collage conveys. Clara uses this as a hook for signalling that she cares about having common interests with her peers. In this instance, care practices involve establishing common ground and trading stories.

At the start of transcript 5.11, Clara has moved from another part of the classroom to closely stand facing the researcher and collage. As the start of the event, at lines 1 – 9, Clara is standing very still, sucking on her fingers, and listening to the researcher's explanation about the collage. At line 6, the researcher has described that the other girls (Grace and Maya) have chosen an image that depicts that they like to go on holiday. In the second segment, following this verbal comment, Clara takes her hands out of her mouth and loudly calls out "Yeah?" in a mid-rising intonation that suggests both questioning and agreement. She is visibly excited by this comment as she sways on her feet from side to side and raises her hands up to her head. In the third segment, the researcher gazes towards Clara briefly to acknowledge this then continues talking about the collage.

	<p style="text-align: center;">Researcher</p> 								
	line no. ↓	time (in min)→	01:11:07	line no. ↓	01:11:11	line no. ↓	01:11:12		
Clara	1	gesture	standing facing researcher and collage, between Grace and Maya, head tilted to her left, sucking on her fingers	7	takes hands out of her mouth, raises head to look straight towards collage	13	briefly moves left to right, shifting her weight side to side as she reaches her arms up to her head		
	2	<i>gaze</i>	<i>collage</i>	8	<i>collage</i>	14	<i>collage</i>		
	3	vocal		9	(?) Yeah?	15			
Researcher	4	gesture	standing facing Clara and other children, holding up and pointing to bottom right side of collage	10	pointing to another image on the collage she is holding up	16	pointing to another image on the collage		
	5	<i>gaze</i>	<i>Grace</i>	11	<i>collage</i>	17	<i>Clara</i>		
	6	vocal	and we said, we like it when we go on holiday-	12		18	- and we like talking on the telephone		

Transcript 5.11. Clara is interested in her peers' collage, signalling she cares about and shares common interests

Clara's "Yeah?" at line 9 is heard as demonstrating a form of receipt and alignment with Maya's and Grace's contribution that they like to go on holiday. With this alignment, Clara expresses affiliation with the things that the children like to do as a group, suggesting that such being interested in her friends' interests, trading of stories and affiliation are practices of care.

Enacting care through closeness and touch - These instances captured some of the subtler ways that children formed close and caring attachments with their peers in ways beyond speech. Care and interdependence were also enacted through touch and proximity. For example, for Oscar and his peers, care was expressed through physical contact; hugging, tickling and tapping each other in various contexts. During classroom activities, whilst partly attending to the teacher who was leading a whole group session, Oscar and his peers would often turn towards each other and seek attention from their peer in touch-related ways. Beyond purely occupying their time in moments of boredom, their forms of touch (for example, hugging or leaning on each other) and acknowledgement of their friends conveyed compassion and closeness.

Doing things the same as everyone else

In her anthropological study on the life worlds of teenage AAC users, Wickenden found that disabled teenagers with little or no verbal speech saw themselves as 'normal teenagers' who had many of the same interests as their non-disabled peers (Wickenden, 2011a). Connected with these findings, the participants in this study made it clear that it was important for them to do the same type of activities as other children of their age. This was expressed both by describing the wide-ranging activities that children liked to take part in, as well as rejecting situations that highlighted their differences.

When invited to describe some of the things that were important to him, though his collage, Oscar's collage conveyed many everyday activities that were not out-of-the-ordinary for a child of his age, such as going to the supermarket, to the park, cinema and friends' birthday parties. Similar insights were noted in Maya's and Grace's collages.

Despite the fact that participants had different opportunities and resources available to them, they valued finding ways of engaging in everyday activities such as playground games. This was captured in a fieldnote entry with Grace and Oscar during a game of tag in the playground:

"We were about to move towards the far side of the playground as Oscar joined us outside. He walked over in his walking frame, greeted us and gestured that we follow him by pointing towards an open space in the playground, grabbing hold of the side bars on his walker as if about to run off. I verbally clarified this: "You

want us to chase you?”, “Yuh!” he replied as he started to move. From behind, I leaned in towards Grace asking her “Shall we chase him?”, she smiled and vocalised so we were off. As I pushed Grace’s chair, picking up speed and calling out to Oscar that we would catch him both children smiled and giggled. We had covered a fair distance across the playground when Oscar moved under the climbing frame. At that point I wasn’t entirely sure if Grace’s chair would fit under the wooden bridge that Oscar had ducked under but to both of our pleasure, it did, at which point Grace burst into giggles again. The bumpy journey and jerking chair added to the excitement as we negotiated the steep upwards curve of the padded tarmac area that lined the climbing frame. This time, we were able to fit into one of those tiny and secure spaces of the school were only children go.”

This and similar episodes stressed that it was important for the children in the study to physically participate in these kinds of activity, rather than purely talking about them. Whilst their collages depicted examples of the kinds of activities they liked to take part in, observations of children across the school day added another dimension, illustrating how they participated in certain activities in the playground, classroom, dining hall etc.

Participants in the study strongly expressed their frustration at being seen as different to other children, particularly when the rationale for adaptations was not explicitly clear. When planning how to undertake the workshop activities, two teachers expressed that it would be best to organise the workshop within the classroom setting with all of the students taking part rather than taking out a selected few. As students frequently left the classroom for therapy sessions, dentist, doctor, eye appointments, wheelchair adaptations and other medical and therapeutic interventions associated with their SSPIs, children expressed their dissent in leaving the class group for interventions *on them*.

This view was highlighted through Oscar’s actions when he was reluctant to wear a protective helmet or to use a walking frame outdoors in the playground, until it was enforced by an adult. Whereas Oscar didn’t currently use either piece of equipment in the classroom (he had recently started walking with minimal assistance), in the playground there were heightened risks and barriers which meant that he was recommended specialised equipment.

Similarly, despite having highly unintelligible speech, Grace often refused to use her AAC device, which was visibly different to the tablet computers that other children used in her class. In one example of this, during a class group activity involving the teacher, researcher and class group, Grace was asked to respond to the teacher’s question using her AAC device. Eventually, she refused to use this and instead opted to use the communication book that the teacher had been using with all of the other students. In another interaction, Grace stopped the researcher from overly physically supporting her to stir an egg mix, shouting out ‘I do it!’ whilst pushing her upper body backwards in her standing frame. These examples evidenced





her desire for independence by rejecting unwarranted help that might signal different ways of doing things.

Regulating privacy

In study one, adults overwhelmingly organised conversations involving children with SSPIs and AAC devices, often by making judgements about children's capabilities. In some instances, adults used children's AAC devices as archival resources, posing infringements on children's privacy. Building on the breadth of infringements, the earlier part of study two showed that whilst acknowledging children's multimodal capabilities, adults often structured interactions to the point of organising what was shared and how meaning was co-created. Responding to such cases, children were aware of the privacy infringement and were active in regulating their interactions.

In interactions involving adults, naturally speaking peers and children who have little or no verbal speech, there is a tendency for naturally speaking adults and children to structure conversations by asking children many questions with closed 'yes' or 'no' answers (Clarke & Kirton, 2003; Light et al., 1985a). In the case of the current study, conversational asymmetry through frequent adult questioning meant that children were directed towards offering information that was directly sought from adults. To counteract this, the children in the study regulated privacy infringements through their actions. This was this case in one episode involving Oscar and the researcher when Oscar responded to the researcher's incessant questioning by holding up his hand to express 'stop'. During this interaction, the researcher asks Oscar a series of questions that require a personal response. His responses suggest that he is unsure how to answer. He hesitates and partially indicates a response but then stops the line of questioning until he is ready to offer information once he knows what activity he wants to do, and what to say. In this instance, privacy is enacted as holding back from offering information until he is sure about what he wants to express.

The example in transcript 5.12 is drawn from a breaktime event in the classroom. The children are choosing what they want to play. The researcher has recently sat next to Oscar in the picture segment, at lines 1-6, the researcher asks Oscar: "With who or what do you want to play?". Oscar attends to the researcher by gazing towards her. In the second picture segment, Oscar shrugs his shoulders to signal 'I don't know'. At line 15 the researcher then asks Oscar: "Would you like me to get you some crayons?" to which Oscar partially and, without enthusiasm, nods 'Yes'. This is quickly followed up with Oscar's 'stop' gesturing at line 22, which halts the researcher's questioning.

	researcher														
	lin e no. ↓	time (in min)→	00:20	lin e no. ↓	00:24	lin e no. ↓	00:26	lin e no. ↓	00:31						
Researcher	1	bodily action	Uses Makaton signs to indicate “who?”, “what?” then “play” with right hand	7	holding hands together on her lap	13	points to a graphic symbol on the open page of the communication book	19	points index finger towards her own chest to indicate ‘me/I’.						
	2	<i>gaze</i>	<i>Oscar</i>	8	<i>communication book on table</i>	14	<i>Oscar</i>	20	<i>Oscar</i>						
	3	vocal	who or what do you want to play?	9		15	would you like me to get you some crayons?	21							
Oscar	4	bodily action	arms resting at his side, sitting close to the table	10	shrugs his shoulders, drawing arms upwards and pouts bottom lip outwards indicating ‘don’t know’	16	biting his bottom lip, arms at his side, nods briefly to signal ‘yes’	22	immediately after nodding, holds up his hand, palm facing researcher to sign ‘stop’						
	5	<i>gaze</i>	<i>researcher</i>	11	<i>communication book</i>	17	<i>communication book</i>	23	<i>researcher’s direction, but at his eye level, gazing past his held out hand</i>						
	6	vocal		12		18		24							

Transcript 5.12. Oscar uses gesture to stop the adult asking repeated questions

Like Oscar, other participants use different strategies to stop adults from prompting responses, especially in cases of topics that they did not feel comfortable in discussing.

Over the course of the fieldwork period, whilst inviting children to take part in various participatory activities, it was acknowledged that certain values would be constructed as a direct result of the researcher's presence, thus induced by the situation (Halloran et al., 2009). This was the case with some instances of regulating privacy in response to infringements. Particularly for Clara, who was fearful of new people and unfamiliar activities, every new situation was a potential threat. Over the course of the 14-week fieldwork period, Clara expressed her fear of hospitals and doctors and knowing that the researcher worked as a speech and language therapist within the school prior to undertaking PhD studies, was anxious that her data would be shared with hospital staff. As a result, Clara used a number of strategies to regulate the opportunities that the researcher had for collecting data. Often Clara refused to have sessions video recorded when she was present, chose to opt out of craft-based workshops where there was an expectation that she would produce an artefact and asked the researcher to leave the classroom on some occasions. This is conveyed in both the field notes extract below, as well as the image in figure 5.04 depicting how Clara tore and crumpled a blank sheet of paper with her photograph attached that had been prepared by the researcher as a starting point for her collage:

“Clara was adamant that I leave. I suggested that I could sit with another child but I didn't push this. Clara commented (through signing) that I could come back after lunchtime, so respecting her wishes I left the room to return in the afternoon session. Incidentally, when I did return later in the day, she was happy for me to be in the room and interacting with other children.”



Figure 5.04. Field note entry of interaction involving Clara and researcher (above), and image of torn and crumpled collage sheet (below)

Through drawing on a range of strategies, Clara regulated situations that were perceived as privacy infringements.

Playing and playfulness

The concept of play has been defined differently across disciplines (Sutton-Smith, 2001). In line with Froebel's educational approach, in this study, play was treated as children engaging in self-directed encounters of the material world (Henricks, 2014). This applied to many different locations and situations, both inside and outside of the classroom. The concept of playfulness was seen to be connected and equally important, as it offered opportunities for creative and light-hearted interjections within an interaction. Play and playfulness were connected as they both invited creative, child-centred ways of meaning making, both largely motivated by children's intrinsic goals.

Play and playfulness were treated as serving a number of purposes. Three key dimensions that were identified included: 1. advancing children's communicative agency through wit and humour; 2. engaging others to stop and listen whilst children 'held the floor', and; 3. acting as a vehicle for expressing likes and interests. These dimensions emphasised the ways that outside of direct acts of teaching, play was key in advancing children's learning and expertise in everyday encounters (Cowan, 2018).

Oscar for example, would use humour to build in playful exchanges during everyday conversations that were instigated by adults. Whilst his teacher asked the students familiar instructional questions during registration time that required a practical answer, Oscar would create witty interjections that signalled his expertise in performing both what was required of him and more. For example, when asked to find his photo and written name using his communication book, Oscar pointed to his class peer's photo and written name instead of his own, then swiftly pointed to the graphic symbol for 'just joking' in his book as he laughed. By using his book to first select an unexpected answer then to correct himself using further symbol icons, Oscar illustrated his skill at using his paper based AAC system in a novel and unprompted way.

Through play, children were also able to *hold the floor* and draw other people in to stop and listen. Through their activity choices and ways of immersing themselves in play, children created vivid and interesting stories that were appealing to others. During a craft-based workshop session that was led by the researcher, Clara for example, instead chose to play in home corner with an adult, whilst the other children and adults made collages. During the group feedback session where the adults and children talked about what they had done, Clara retold the story that she had constructed in home corner. Whereas everyone else's feedback was brief and summarised by an adult, Clara retold her story independently, which allowed her

to focus on her interests and add the required level of excitement. Using her whole body, she acted out an elaborate storyline which is summarised through the following researcher fieldnote entry:

During the plenary, Clara also wanted to feedback on what she had been doing (as the other children had done), becoming very animated to tell all of the adults and children that she and [the SNA] had found out that a thief had broken into their house and broken the door to their fridge so they needed to call the police. When the police arrived, there was another dramatic accident so they needed to call the ambulance to take the thief who was apparently seriously injured on the floor. Through her signing and gesture Clara's story came to life, conveying drama and shock. She clearly enjoyed seeing everyone's heightened reactions to her dramatization.

In this instance, everyone involved was fixed on listening to Clara's story; reacting with laughter and surprise as she demonstrated the events, elaborating on her story as it was retold. Clara drew in the SNA to help in narrating at moments that she treated as appropriate. Through storytelling, Clara agentively captured everyone's attention and illustrated how she was able to narrate a compelling story through facial expression, signing, the using of home corner objects and mime.

Whereas Clara was able to independently navigate the direction of her story telling, drawing on the role of the adult for supplementing details, Grace, whose SSPIs impacted on her movements more greatly, used adult intermediaries for scaffolding play with other children. For Grace, play acted as a vehicle for expressing her likes and interests in friendship, doll play and birthdays. During a class-based observation involving Grace and the researcher, Grace used her communication book to initiate a request to play with her friend Amira. This is captured through the field note entry below:

After snack time, all of the children in wheelchairs were positioned around the whiteboard to watch part of the 'snowman' story. I asked Grace if she wanted to watch this, she replied 'no' and eye pointed to indicate she wanted me to get her communication book. Using her book, she commented:

"I'm telling you something --> activities --> dolls" then when asked: Do you like playing with the dollies? replied 'yes'. She then indicated 'Amira' (a little girl from another class who was with them today) - I asked Grace if she liked playing dolls with Amira, Grace replied 'yes'. Amira looked over and also said 'yes'.

In this instance, Grace had chosen to draw the researcher's attention to listen to her new initiation, and respond to her request. As Grace's communication system required the conversation partner to have an active role in co-constructing meaning (by turning pages when Grace looked towards a symbol and reading aloud the symbols that she eye-pointed towards), there was an obligation for the researcher to respond to Grace's suggestion to and interest in play. The fieldnote suggests the researcher's attention has been drawn to another girl, Amira,

who is sitting nearby. In this instance, Grace skilfully draws on the adult to help bring another child into the interaction, with the intention to play with her friend and the dolls. Examples such as these underscored the skilful ways that children used adults to setup and mediate interactions with their peers. Further, by drawing adults in to scaffold play episodes involving other children, the child participants in the study were able to direct other people's attention to the kinds of interests that were motivating for them.

Discussion

The goal of this empirical study was to build on the development of a theoretical basis for studying communication involving children with SSPs and their social groups. The first research question investigated and built on a multimodal perspective for studying and describing face to face communication involving children with SSPs, building on the theoretical insights of the first study. The second research question asserted a humanist agenda in design work by investigating a different slice of communication that engaged with what children appeared to value based on how they responded to varied methods. Collectively, these two separate approaches formed a holistic way of studying and describing communication for the purposes of informing design. Based on the insights that were generated in both parts of the study, the discussion that follows critically analyses these findings and identifies new design opportunities for digitally mediated communication involving children with SSPs.

1. Regulating the orderings of modes and social structures

Building on prior work, the idea that orderings of the material and social structures created disabling barriers was strengthened in the study (Goggin & Newell, 2003; Moser, 2006). Whereas in the first study, AAC devices themselves sometimes inhibited communication by explicitly being talked about rather than with, here, sometimes the broader structural dynamics of the classroom also inhibited communication and consequently created disability. In line with prior literature of an interactional view that treats disability as created through an interplay of bodily impairment alongside disabling social barriers (Shakespeare, 2014), in these instances, social structures paired with children's limited available resources created disability. This was particularly the case for peer interactions and/or spontaneous initiations by children. Structural arrangements that prioritised adult learning goals meant that children in the study were often positioned around a table in wheelchairs and standing frames. Whilst this supported learning by enabling all of the children to see the teacher or engage with their

individual formal learning task, it also created communication barriers between children, other people and hindered shared access to resources that others were using. This was evident in the case of Maya who was positioned behind the physical barrier of a symbol board (transcript 5.05), and also Grace, who's physical positioning in the room did not allow for her to see what Maya and the adults were talking about (transcript 5.10).

To counter this, the children in the study actively sought to organise some of these arrangements by directing adults towards where to sit and where to physically move their wheelchairs to so that they were in a better position for interacting, for example, as seen for Grace who directed the researcher to 'sit down' in transcript 5.07, or Oscar, who regulated the researcher's frequent questions by gesturing for her to 'stop' (transcript 5.12). Based on these findings, **opportunities exist for allowing children to signal to others when structural arrangements inhibit their desired participation, thus allowing children to regulate these orderings.**

Moreover, structural barriers also manifested through a dominant focus on linguistic modes of communication. Misalignments were created as adults missed some of the highly subtle ways that children created meaning, such as in the case of Maya where stillness in her arm movements and looking actions signalled she was attending and interested in a topic (transcript 5.06). This reinforced one of the most robust findings in AAC research, i.e. that children rely on multiple modes to communicate and these choices are specific to context, partners, task and intent (Baxter et al., 2012). Further, as discussed in study one, the prevalence of embodied, or 'full-body', communication over language highlights an important gap in technology design for children with SSPI, which has been primarily driven by spoken and written language. Building on the first study, a focus on misalignments revealed that communication partners overwhelmingly focused on talk during interactions. In the case of sign makers like Maya, whose multimodal communication can be difficult to interpret, **opportunities exist for developing strategies that promote waiting and wondering, rather than trying to predict what she might be saying.** One way of approaching this would be to make her expressive capabilities more noticeable by highlighting these in some way. This could be in the form of creating an archive of children's individualised and communicative meaning making actions. For example, through technology, new tools might enable us to learn about her ways of communicating so that we are tuned into her multimodal repertoire which is inevitably highly individualised. This kind of information might for example, be collected through an algorithm for identifying and archiving her subtle actions. As well as being helpful for mediating communication on an interpersonal level, this kind of information would also be

useful for informing both the study of communication involving children with SSPs, as well as informing speech therapy in practice by expanding that ways that clinicians attend to children's expressive communication which would inform the design of interventions.

Related to the structural issues encountered in adult – child interactions, building on study one, the findings from the section on competence and agency in study two showed that adults chose to resolve situations of ambiguity in line with adult expectations. For instance, during a class-based cooking session, when Grace's teacher was unsure about what Grace was expressing about eating, she 'resolved' the conversation by interpreting that Grace indicated she had eaten enough (transcript 5.03). Contrary to this, as seen in the case of Clara, children asserted agency in advancing their own goals through bodily movement and by drawing on other resources that were available to them. For example, in transcript 5.08 Clara used the pens, whiteboard and movement to redirect the SNA's attention away from the group activity. Informed by these findings, of a need for regulating misinterpretations as well as disrupting the flow of existing interactions, **opportunities exist for allowing children to signal a need for change in timely ways through light weight methods**. This could be helpful for indicating a need to stop, reflect, go faster, slow down, or other functions. On a practical level, such actions that require minimum effort yet acknowledge children's communicative practices can enable people to agentively change the course of an interaction by controlling the outcome through a basic action.

2. Interconnectedness and belonging

Investigating children's values exposed that children formed and strengthened friendships with other children by creating connections in different ways. Some of these ways were characterised by affiliating with their friends' interests, participation in everyday, mundane activities, and not being singled out. These instances were particularly evident for Clara; who aligned with Grace's and Maya's hobbies (transcript 5.11), Grace and Oscar; whose collages depicted the importance of doing activities the same as everyone else, as well as *with key* people (figure 5.02), and Oscar, who rejected his protective helmet and walking frame that signalled difference. The importance of belonging and being connected with friends was particularly evident in the ways that children expressed wanting to be seen as enjoying the same experiences as their friends. However, alignment through participation was not always straightforward, as it relied on adults providing a structure or 'language' for children to respond to, for example, via the researcher's collage making materials and also adult verbal commentaries of what different children appeared to be signalling. These insights highlighted that **opportunities exist for technology to allow for children to understand about the**

interests and activities that other children are interested in, even when there is not a word for it, so that these common interests can strengthen ties between children and their social groups.

Interconnectedness also manifested through a focus on care. Children themselves were sensitive to their friends' absences and expressed their care by asking about their friends when they were not present; talking about their friends' wellbeing, and; creating cards for each other with adult support (for example, as seen in Maya's card to Clara and Grace, figure 5.03). In the context of designing for care, the findings suggested that care was a dynamic process that changed over time, depending on the situation, and care practices were carried out differently by different people. It also alluded to the importance of interconnected relations between children, their peers, school staff and family members, who all worked together to enable care practices to be enacted. Maya's mother for example, helped Maya to create a card for Clara and Grace whilst Maya was in hospital. Maya's mother had used her mobile phone to photograph and email the card to the class teacher who then printed it out and shared it with Clara and Grace who consequently responded in some way with adult support. The findings support previous work on designing for care that positions care as a collaborative practice that develops over time (Brown & Choi, 2018). Based on these insights, **opportunities exist for strengthening the ways that children can enact these interconnected, ongoing care rituals** through technology, particularly when their friends, families and school networks are located far from them. Taking one existing technology solution as a starting point, currently, telepresence robots allow for people to access a situation when their physical bodies cannot be present. Building on this concept, telepresence might support children in sharing their multimodal meaning making in visual, auditory and tactile ways, and incorporating ways of building on what others are sharing over time.

A third way that children highlighted the importance of interconnectedness and belonging was through the ways that they practically co-created meaning with other children. Often, this was mediated via an adult, allowing for children to engage in shared experiences. For example, this was seen whilst participating in a game of tag with Grace and Oscar. Instances like these illustrated that children were deeply motivated to be embedded in jointly orchestrating experiences, rather than watching from the side lines. For Grace, the sensation of the unexpected, jittery wobbles of her wheelchair wheels clumsily bumping over the edge of the tarmacked climbing frame area added to the experiential qualities of shared play. At the same time, Oscar's weaving in and out through the pillars of the climbing frame at speed meant that Grace and the researcher also picked up speed, feeling gusts of wind, brushing passed other

children, dodging fast moving footballs, hoops and other objects in a bustling playground of activity. In this case, meaning making was unstructured and gradually unfolded as the participants were faced with different situations. Building on ways of supporting such experiences, **opportunities exist for designing ways of supporting the co-creation of meaning**. This could for instance, address full body experiences that children feel and share. Rather than relying on other people to support interactions (as in the case of Grace, Oscar and the researcher, above) this might for example be in the form of body suits that can be worn by different children, embedding different touch sensations (temperature, pressure, vibration etc) at different locations on the suit. Paired suits could allow for children to orchestrate different sensations involving more than one person. Rather than being contained and segmented messages, as different actions and modes are intertwined, both parties could constantly be engaged in exploration that gradually allows for new experiences to develop between participants.

3. Advancing involvement through play

In classroom situations, the adults of this study predominantly focused on the ways that children could accomplish learning goals and signal their understanding in normative, speech-oriented ways via augmentative communication, for example, through the use of Makaton signing and communication books. Conversely, children's goals were more varied and in addition to learning, encompassed wider purposes as evidenced through humorous and playful exchanges, for instance, as seen with Clara recounting her pretend play sequence to the class group, and also in Oscar's witty interjections within the registration routine. Beyond purely using established augmentative communication methods, children used multiple modes for meaning making, expressing themselves in richer ways with broader shades of intensity. Paradoxically, through playful conversations or actual play episodes, children demonstrated learning in ways that illustrated how they had transformed meaning (Kress, 1997) and applied it in their own ways. Rather than focusing on being able to carry out specific actions, for example, running in a game of tag or cartwheeling on the grass, children's actions suggested that participation in activities, through varied modes, was more important. Whilst overarching guidance from the World Health Organisation (WHO) reinforces this view of the importance of participation at activity level, this information has also been contradictory. For example, the International Classification of Functioning, Disability and Health (ICF, WHO) descriptors and the Gross Motor Function Classification Scale (GMFCS) for clinical descriptors of cerebral palsy both continue to reinforce a dominant focus on skill mastery. By measuring children's physical skills in ways that are comparable to able bodied people, such guiding perspectives has

prioritised a focus on designing assistive technologies that help children to walk, sit, stand, talk etc. In order to address this and rethink how technologies might support participation without a focus on skill mastery, **opportunities exist for designing with an attitude of advancing play, rather than addressing functional skills.**

The children in this study demonstrated that physical movement and participation in activities was not a case of either being able to do something or not. Rather, all of the children reached out to other people through their bodies or via assistive technologies in different ways and at different moments. This was also the case whilst engaging in play episodes. Children used their whole bodies to engage in activities, clearly letting adults know when they needed support (and equally so, rejecting support when it was not needed, as powerfully expressed by Grace through her comment “I do it!”). For design, this suggests that **opportunities exist in designing ways for children to both regulate external support** (connected with the first discussion point on regulating structures) **and also access varied experiences including play** that they may typically miss. For example, experiencing ways of manipulating real objects, movement sensations, rough and tumble play and other sensory experiences.

Conclusion to study two

This study reported on a qualitative field work study in a special school. The research aims were to investigate communication across wider contexts beyond formal teaching environments by attending to how children used the resources available to them for the purposes of meaning making. The second goal was to understand what children appeared to value based on what and how they communicated. Building on the first study which specifically examined conversations involving AAC devices from an observational stance, this study incorporated participatory mixed methods for investigating communication beyond AAC device use. An inductive social semiotic multimodal analysis was used to investigate communication from child-centred perspectives by attending to the ways that children created meaning about their interests. The findings generated insights that have both theoretical implications for understanding communication involving children with SSPs as well as practical implications for design and speech therapy through design opportunities. The study contributes to existing work in three ways. *First*, building on the first study, it develops a new theoretical perspective for describing communication involving children with SSPs without overly crediting the speech mode. *Second*, connected with the first study, it builds on a systematic and reflexive methodological approach for investigating communication in children

who use a range of modes to communicate. *Third*, it reveals a number of design implications for digitally mediated multimodal communication.

One methodological limitation faced concerned the challenges of representing child-centred perspectives. Due to the nature of qualitative observation-based work, the researcher's interpretive angle undoubtedly impacted on how children's views were investigated and presented. Also, some of the methods, including automatic photo capturing and using personas were not in keeping with the overall child-centred orientation of the doctoral work, as they overly credited the researcher's interpretive angle. To address this in the current study, the data generated using these methods were not included in the analysis. Instead, the analysis involved ongoing reflexivity and regular discussion with supervisors to discuss and develop the generated themes and insights. For example, in the case of video data, insights were generated through a lengthy and detailed process of watching and re-watching videos, and transcribing events multimodally in an attempt to best capture what was thought to be happening in faithful ways. Further, in an attempt to improve the rigour of the exploratory work, the study purposefully built on the findings of the first study for gradual knowledge development in line with what Stebbins has referred to as concatenative view (Stebbins, 2001).

A further aspect that can be interpreted as a limitation concerned the sample size. Whilst the data focused on a small population in one setting, a decision was made to investigate in detail the situated experiences of a small group, to allow for deeply engaging with methods that allowed for understanding child centred perspectives in children with SSPIs. Consequently, the issues raised were important in their own right, and offer a starting point for extending this kind of investigation with larger groups of participants.

Introduction

The overarching goal of this doctoral thesis has been to inform how designers conceptualise communication that involves children with SSPIs beyond a widely cited view that communication centres around speech and happens at the level of the individual through the transmission of information. Instead, by positioning communication as co-constructed, situated and multimodal, the goal has been to stimulate how one might approach designing for digitally mediated communication by applying multiple alternative frames that acknowledge these features. In order to do this, so far, this thesis has reviewed how theoretical and empirical findings from the fields of AAC and HCI have each separately studied and intervened in communication involving children with SSPIs. The thesis then contributed to this existing literature landscape through two empirical studies that adopted social semiotic multimodal theory to empirically show a new point of view on communication involving children with SSPIs.

In this chapter, the notion of 'frames' is a focal point. Frames have been described as 'providing an interpretive lens through which to perceive and make sense of facts and events' (Baumer, Snyder, & Gay, 2018, p.20:5). For Hey et al, frames expose the underlying assumptions that can guide which issues are relevant and what goals and values are important (Hey et al., 2007). In their work with design students, Hey et al noted that design team members held a range of implicit, individual ideas and values that formed the basis for how they worked on pairing problems with solutions. The authors recommended explicitly engaging with frames by distinguishing individual and team frames, negotiating conflicting perspectives as well as questioning the researcher's frame, instead of taking them at face value. Taking a cognitive view, frames provide a central way of reflection during the design process, by proposing different ways of seeing phenomena. As highlighted through these prior works, frames hold a central role in sense making and proposing solutions. In the case of designing for communication involving children with SSPIs, this is important as it allows for identifying different ways of construing communication beyond the traditional linguistically oriented view.

Prior to considering how designers worked through generating perspectives in the early stages of thinking about what to design for, the remainder of this introductory section considers the different research frames that informed what information would be shared with designers, based on prior work and generated through the empirical studies.

A review of existing research frames on communication involving children with SSPIs: From individual to co-constructed; deficit-oriented to distributed, and linguistic to multimodal

A review of literature on studying communication involving children with SSPIs revealed two main foci: studying communication at the level of the individual, and separately, studying communication as distributed amongst participants. The literature from the field of AAC revealed that the cognitive view of communication as information transmission has been less of a focus in work over the past two decades. There has been more interest in constructivist perspectives that acknowledge communication as situated and distributed amongst non-speaking and speaking participants (Smith & Murray, 2016). Despite this move towards co-constructed and situated communication, practical applications for education and therapy input in children continue to prioritise individual level, developmentally or deficit-oriented perspectives. For example, interpreting Light's communication competences framework (Light, 1989; Light & McNaughton, 2014) as addressing linguistic, operational, social and strategic competences that lie within the person who uses AAC, rather than seeing these competences as a relative and dynamic interpersonal construct that acknowledges the role of the environment and conversation partners (Blackstone et al., 2007). Examples from practical applications of this individual level focus have suggested ways of supporting communication by enabling young children with SSPIs to 'catch up' with peers of a similar age through augmentative technologies, for example by a focus on common vocabulary in early childhood (Banajee et al., 2003). However, developmental and deficit driven perspectives are problematic as they do not acknowledge the heterogeneity of children with SSPIs in terms of their exposure to learning experiences, their communication styles, or their unknown learning trajectories (Clarke, Price, & Griffiths, 2016).

With the move towards conceptualising communication as co-constructed, a key insight has been that conversations involving children with SSPIs and AAC should be treated as *aided* conversations, that distribute the ways that communication is accomplished by all participants involved (Clarke & Wilkinson, 2007). This move has acknowledged AAC use as shared, suggesting it is important to attend to the local ways that participants organise communication. For example, by studying how communication is organised around talk,

empirical studies have highlighted asymmetry in the range and length of linguistic turns in children with SSPIs (Clarke & Kirton, 2003; Clarke & Wilkinson, 2007; Light, Collier, & Parnes, 1985). This has in turn informed practical applications for studying communication and providing support, for example, by acknowledging the role of conversation partners in devising interventions for providing more positive interactions and making communication less challenging for both parties (Baxter et al., 2012).

Building on this distributed and situational view of communication, opportunities exist for examining how communication involving children with SSPIs is organised around other foci. Namely, rather than studying how communication is organised around talk, opportunities exist for understanding how children with SSPIs and their social groups co-construct communication in their own, individualised ways. Drawing on social semiotic multimodal theory to begin to unpack how communication manifests when the linguistic focus is removed (Bezemer & Kress, 2016; Kress, 2010; Kress & Van Leeuwen, 2001), there is a critical need to examine how communication is achieved on children's own terms. This is especially important in the case of children with SSPIs whose inherent minimal or absent use of speech suggests a different basis for communication. A move away from linguistic baselines is therefore needed to avoid exacerbating the deficit-oriented view that contemporary co-constructed perspectives have moved away from.

Alongside these theoretical and empirical insights on communication, design engagements have also shown that research frames have guided the ways that communication involving children with SSPIs and other groups of non-speaking children have been conceptualised and designed for. Connected with some of the discourses that have been described above, design frames have reinforced some of these perspectives, for example, through a focus on design that can alleviate bodily impairment at the individual level (Hayes et al., 2010; Madsen et al., 2008), support learning within a developmental frame (de Faria Borges et al., 2012; Zhao et al., 2018), but also enabling co-constructed, situated communication (Barendregt, Börjesson, et al., 2017; Black et al., 2012; Brederode et al., 2005). Interestingly, design thinking has also contributed to conceptualising and designing for communication by applying new frames that aim to foster empathy and aesthetic engagement between stakeholders (Durrant et al., 2013), promote reflexivity in the choice of methods for child led ideas (Frauenberger et al., 2017) and separately, critically challenging societal norms and expectations in designing for disability (McLeod, 2010; Pullin, 2013; Pullin & Cook, 2013; Sellwood, 2017). These engagements present design approaches that allow for thinking about communication situations in new

ways through multiple framings, which is helpful in this case as they offer opportunities for multiple and varied perspectives on designing for communication beyond a deficit orientation.

In addition to the frames discussed above, two major systematic reviews of the interaction design literature revealed that children with SSPIs have contributed to the design process in limited ways, owing to the challenges of involving them (Benton & Johnson, 2015; Börjesson et al., 2015). This has meant that children's contributions and consequently, design frames, have largely been informed by the voices of proxies whose interpretations provide a filtered account of children's contributions (Holone & Herstad, 2013). The impact of this has meant that children's accounts have been missing in these research frames on communication. Both systematic reviews revealed that existing work is yet to illustrate ways of involving children with SSPIs in the early stages of the design process, which has been problematic as children's contributions are yet to inform these design frames. In line with PD approaches that seek to distribute knowledge from residing solely with the designer to shared amongst all involved participants, a values-led PD approach offers opportunities to engage with children's priorities and motivations concerning communication and how to design for it.

Studying language focused technologies in structured teaching contexts

Motivated by the opportunities posed by research frames drawn from the AAC field and interaction design literature, the goal of the first study was to adopt a different theory for studying communication involving children with SSPIs and their social groups, away from linguistically driven perspectives. A social semiotic multimodal approach was used to investigate and present an alternative perspective on communication.

In line with prior literature illustrating that AAC technologies have been studied and largely used in formal or structured teaching contexts (Murphy et al., 1996), and considering the linguistic focus on studying and describing communication (Barnes & Bloch, 2019), the first empirical study investigated how existing language-focused AAC technologies were used by applying a situated, co-constructed and multimodal lens. The findings revealed that AAC devices themselves were largely underutilised in conversations and children would instead use a wider range of semiotic resources for communicating. AAC technologies were mostly used in adult-child interactions, and adults drew on these as teaching tools, exercising control over structuring conversations. AAC technologies were seen as a material object that was talked about, rather than through, and sometimes became a physical barrier for communication through its material form. Further, examining misalignments and breakdowns revealed challenges in engaging in child-initiated communication and interactions that involved peers

who also used AAC technologies. The empirical findings contributed new design implications for developing existing language-focused technologies; promoting child agency by allowing children to decide how and when to use these technologies to support their goals.

In addition to informing design opportunities for existing AAC technologies, the study highlighted that even when AAC technologies are present, multimodal communication happens around the technology. In line with the theoretical multimodal perspective identified in the literature review, the empirical study strengthened the view of a need for attending to multimodal communication that is currently not catered for in existing technologies in these situations.

Studying multimodal communication: Beyond technology use, beyond formal teaching contexts

Building on the principles of multimodal, situated and co-constructed communication identified in the literature review as well as the empirical findings from the first study, the second empirical study extended the investigation of multimodal communication. Taking the findings of study one as one starting point, the first goal of the second study was to investigate multimodal communication in a wider range of contexts beyond structured teaching contexts which included communication beyond AAC technology use. This addressed a need to study children's broader meaning making practices, connected with the prior insights that children's multimodal communication was not catered for through existing technologies. The findings of the second study showed that whilst adults were more likely to acknowledge children's communication attempts compared with the findings of study one, adult communication partners continued to organise the structure of interpersonal interactions according to adult goals. As before, the findings showed that material resources sometimes became barriers for peer interactions. Further, structural arrangements in the environment also inhibited communication opportunities. However, study two also revealed that children had some control to intervene in these structural arrangements, through full body communication to guide others in how best to support them. As in the case of study one, adults prioritised clear, *understandable* responses, often missing children's subtle communicative acts. However, unlike study one, children drew on multimodal ways of communicating on their own terms, demonstrating communicative agency in choosing modes that were quickest, most efficient and suited to the context. Through multimodal communication, children were able to communicate on their own terms and on a social level, this allowed for understanding how children asserted their membership to social groups through the roles they chose to take.

Engaging with children's values surrounding communication

The second part of study two investigated how children's contributions would provide another lens on informing design implications for new technologies. This was addressed through engaging with children's values connected to how and what they communicated. Values were investigated through observational and participatory methods that revealed different dimensions about what children expressed *about* and *through* their communication experiences. Whereas the first part of the study took a structural view on investigating interpersonal communication through observation, the second part of the study added a complementary lens by investigating the child's view. The findings revealed five themes that characterised the kinds of things that children in the study appeared to value. These were: 1. a desire for involvement, 2. enacting care, 3. doing things the same as everyone else, 4. regulating privacy, and 5. integrating play and playfulness in communicative episodes. Overall, the two parts of the second study presented a holistic methodological approach for investigating child-centred communication by first revealing interactional phenomena that characterised interpersonal communication involving children with SSPIs and their social groups, then second, presenting examples of the kinds of values that children in the study appeared to hold, based on their forms of engagement.

Moving from researcher frames to designer frames

With this holistic view of investigating child-centred communication, the underlying principles and empirical chapters generated research frames that incorporated three layers:

- children's choice of modes and values: presenting *a child's view* that focused on how children used the resources that were available to them and what this conveyed about their interests, motivations and priorities,
- children's interactions with other people and material objects including technologies: presenting *an interactional view* that focused on how children's meaning making practices occurred in concert with their environment, and
- the orderings of people, material objects and activities within environments – presenting *a structural view* that exposed the structural arrangements that created disability.

Using these layered research frames, in the current third study a design tool was created that could be useful for designers to think about new ways of designing for digitally mediated peer interaction involving children with SSPIs. The aim was to understand how this tool, a design

documentary, and design thinking could be generative in creating varied design frames at the fuzzy front end of the design process, i.e. the phase where designers are seeking to inform and inspire what is being designed for through open explorations (Sanders & Stappers, 2008). This is important as by introducing a new theoretical perspective, we can extend the functions that new communication technologies can serve beyond linguistic or deficit-oriented perspectives. An additional aim was to understand the sensibilities that designers would bring to designing for this situation, as people with an art school background who were unfamiliar with existing AAC technologies. By focusing on the development and use of a design documentary as the main design tool, the third study examines how this tool helped designers in creating new frames within the very early stages of a design process.

Research goal:

RG.1. To apply the findings of empirical work and prior literature to motivate new ways of framing the communication of non-speaking children with physical disabilities in their interpersonal communication with peers through design documentaries.

In order to address the research goal, this chapter discusses two main practices. First, the chapter reflexively discusses how I, as design researcher, created a design documentary and process, based on the earlier insights. This is focused on within the methodology section. Second, the chapter discusses how designers utilised the design documentary I created in the very early stages of the design process, informing their frames on communication, to create their own meanings and perspectives. The findings section focuses on how the design documentaries were used, and how design frames mapped onto the design concept that was presented by designers.

Methodology

Context

Following others who have suggested that the worlds of design and disability could both inspire each other (Pullin, 2009), one of the main goals of this work was to see how people from an arts school encountered disability utilising the points of departure identified in the background section. The methodological decisions that were taken therefore responded to these goals. The decision to work in an arts-based context as opposed to other contexts with established expertise and experience in assistive technology was an active choice, connected

with the view that designers with little prior exposure to assistive technologies can bring complementary perspectives through a design culture that has rich approaches and values (Pullin, 2009). Further, designers with little prior experience of designing for disability were more likely to approach the activities without fixed perspectives which might otherwise inhibit and limit design work that aimed to transcend the traditional ways of engaging with communication and disability. For example, empirical work from the field of HCI has highlighted a correlation between interpretation effects and framing when people hold strong ideological orientations to a topic. [Baumer, Snyder, & Gay \(2018\)](#) for example, looked at the effects of communicating frames by offering alternative text visualisations in the form of word maps and word clouds, as opposed to text in prose format. Participants who were presented with political issues surrounding healthcare through written prose documents were likely to interpret the communicated information within the pre-existing ideological views that they held. These findings suggest that for design, both the ideological orientations that people hold towards a topic as well as how information is communicated can largely influence interpretation.

Motivated by this desire to involve designers who were less likely to hold strong orientations to the topic area, the design study took place at the Royal College of Art (RCA) in the United Kingdom. The RCA is a prominent and internationally-recognised art school, widely considered as pioneering in its motivation to disrupt traditional ways of thinking about art and design. The workshops and meetings took place within the school of communication, as part of a master's degree module on design research methods. The study was presented as an 'opt in' activity for those undertaking the module and took place over the course of 13 weeks.

Participants

Participants were recruited by first contacting course tutors from five separate arts schools. As gatekeepers to design students, two of the five course tutors expressed their interest in taking part. Owing to practical issues and time constraints in carrying out the study within the timeframe of the doctoral project, the study was pursued with the arts school that was geographically closer and could practically take part within the proposed time frame. Further information about the workshop and researcher was then shared with design students on the master's degree module in the form of a workshop flyer, researcher bio, information sheet and consent form, communicated via the course tutor (appendix 3).

The participants were a self-selecting group in that they were invited to opt-in to attend the workshop and follow up activities. For the students who attended the initial workshop session,

informed consent was discussed by talking through the information sheet which they had previously received, and inviting participants to fill out the consent forms, signalling the degree to which they were happy for their data to be used. In total, eight participants took part in the initial workshop (seven students and one tutor). The participants were grouped into two smaller teams and, in the end, one of the two groups (a group of three participants) chose to pursue the design challenge beyond the initial workshop session. Participants who opted in to the initial workshop and follow-up sessions were master's degree students, with a professional background in design. A summary of their work experience and educational background is presented in table 6.1. This information was obtained by asking them to fill out a brief questionnaire about their experiences.

pseudonym	education	professional background
Amelia	BA Graphic Design	Theatre, freelance GD work (websites, books, branding)
Shannon	BA Graphic Design Communication	User experience design & design research
Abigail	BA Illustration & Visual Media	Freelance illustration, sculpture, editorial work

Table 6.01. Participant profiles

The questionnaire also asked participants if they had undertaken design work with their co-participants before, to understand about their working relationship. Despite being enrolled on the same course, none of the participants had worked with each other prior to the study. Two of the three participants stated that they undertook design-based work through collaborative workshop style activities on a monthly basis. The other participant also undertook similar collaborative design work, albeit less frequently; 2-3 times per year.

Although it was not within the selection criteria, during the design work, it became apparent that participants who decided to pursue the design project beyond the initial workshop session had personal experiences with disability which shaped their design thinking. They all, for example, had a close relative or friend whom they identified as being disabled. They did not however have prior experience in designing assistive technologies or any prior exposure to AAC which was important for motivating varied perspectives on designing for communication and children with SSPIs. Namely, they did not hold fixed orientations to the topic that might limit the scope of their interpretations. It was noted that as well as holding some personal experiences with disability, throughout the course of the study it became apparent that all three participants held a strong desire to 'do good'. This insight is discussed within the findings, in the context of discussing ethical and accountable design.

Materials

The materials that were created were informed by the findings of the empirical studies as well as principles drawn from prior work to communicate the researcher's frames on communication involving children with SSPIs. A **design documentary** was created as the central tool for communicating these frames, supplemented with a verbal, PowerPoint

presentation and regular opportunities throughout the workshop session to ask the **participant-researcher** questions.

The **design brief** motivated the call for action for participants to respond to the design documentary. The brief was supplemented with a **scenario** that provided additional information about the use case context. Each of these materials contributed different aspects of the layered research frames and are discussed separately.

Design documentary

Design documentaries are design tools that bring documentary film approaches and techniques into user research methods in HCI work (Raijmakers et al., 2006). They can facilitate reflection in multidisciplinary teams and can be useful in situations where designers are not able to be present 'in the field'. Acknowledging the significant amount of interpretive work done by the design researcher in creating and communicating these, design documentaries are intended to provide both information and inspiration through the ways in which the perspectives of the researcher and interpretive lenses inform the ways that information is communicated. By focusing on communicating rich and detailed instances of people's everyday life experiences without omitting idiosyncrasies and ambiguities, they are intended to open up multiple ways of understanding the situation being designed for by avoiding simplification (Raijmakers et al., 2006).

Design documentaries are typically used in the early discovery stages of the design process, prior to framing. Design documentaries were chosen as they allowed for conveying multiple dimensions of children's everyday lives beyond technology use. This was important as a central concern of the design study was to avoid simplifying or homogenising an extremely varied group of children. Raijmakers and colleagues proposed that design documentaries were intended to leave "the erratic, elusive fabric of the everyday intact", which was important in this case, as it meant that designers could draw on varied starting points for inspiration, beyond a focus on the task-based demands of communicating through speech. Other work on design documentaries has construed these as dialectical in facilitating encounters between designers and the communities being designed for through their interpretations (Green et al., 2015), which is helpful over neutral 'fly on the wall' approach for communicating information. Connected with this interpretational view, and motivated by a need for new conversations about the different roles that digital technologies can take in the lives of children with SSPIs, design documentaries were chosen as the central generative tool.

The decision to use design documentaries over other narrative methods developed through a process of trying other methods. For example, at the start, the plan was to create personas of and with children that depicted holistic and multi-layered accounts of children's communication experiences. However, whilst reflecting on having created two examples of these, it was felt that they did not capture enough detail about the multiple dimensions of children's lives, lending themselves instead to brief summaries. It was hoped that an adapted version of personas would convey richer details than that of typical personas which have been described as brief and task-oriented (Bødker et al., 2012). However, in practice it was difficult to convey multiple traits and perspectives through a one-page description with text and image. Furthermore, the creation of personas was heavily based on researcher interpretation owing to challenges of generating unprompted and previously unknown information about children's experiences and motivations. Further discussion on how personas limited children's opportunities to 'have a say' is discussed in the reflection on methodological choices in chapter seven.

Acknowledging that there are no typical cases of children with SSPIs, one design documentary was created that communicated a detailed account of one of the child participants in the study. Instead of amalgamating the different experiences of different children in the study, and to avoid oversimplification, a multi-layered and detailed account of one child reflected this diversity. Drawing from other work that has guided ways of communicating well-rounded characters for design purposes (McCarthy & Wright, 2007; Nielsen, 2002), a short video conveying the communication experiences of a primary school age girl called Grace was created.

Following Nielsen (2002), the design documentary sought to represent a 'well-rounded' character through detailed information that centred around a character rather than a plot, and documented multiple dimensions about Grace and her everyday life. Namely, this began with an introduction about her age, school setting, friends and family. On a physiological level, the video explained that she had experienced changes to her brain development following oxygen deprivation at birth which now impacted on her bodily movements, accounting for her SSPI. In line with prior literature on an interactional view on disability that acknowledges difficulties associated with bodily impairment as well as disabling barriers imposed by the environment (Shakespeare, 2014), the focus was on portraying multiple factors that caused disability. To minimise the chance of designers taking a deficit-oriented view or making generalisations about specific conditions, clinical/medical descriptors and diagnoses were not used throughout. Instead, the video documented what Grace *could do*, and what this meant on a

social and psychological level. The video captured short static and moving images of interactions with friends and school staff from study two, quotes about what others said about her (e.g. “You’re brilliant! You need to show everyone that you’re brilliant”), verbal commentary, captions and interpretations by the researcher (e.g. ‘power struggles’ / ‘the caring friend’), as well as researcher fieldnotes from a playtime interaction. The different representational modes were important for evidencing multiple interpretations about her communication experiences. For example, short video clips showed how she communicated through her whole body in class situations (as identified in both study one and two), whereas the fieldnote entry from a playground interaction evidenced co-constructed communication, as well as her personality and motivations for ‘doing things the same as everyone else’ as identified in the values-led findings of study two. The varied examples intended to highlight the different ways she communicated with different people as well as exposing the supports and barriers afforded to her by different situations. The written captions for example, were intended to highlight tensions that were raised in study one and two about power struggles during adult-child interactions, as well as highlighting some of the values she appeared to hold, for example, being a caring friend. On an affective level, the verbal commentary incorporated how she appeared to feel about using certain communication modes, like her existing AAC technology and other modes. The video also included photos of craft-based artefacts that she and her friends had created in the design workshops of the second study as well as a card that she received from a friend during the fieldwork period. Whilst detailed in places, the design documentary did not detail the technical aspects of her existing technology or her expertise relating to cognition, language levels or other normative features. This was in line with the motivation of study two for considering the broader ways that children co-construct communication multimodally, independently of developmental norms or linguistic reference points.

A script of the design documentary is available in appendix 4, owing to the challenges of anonymising the videos with children and their social groups, the design documentary itself has not been made publicly available.

Design brief & scenario

The brief supported the design documentary by providing a goal-oriented task for designers to respond to the video. It was bounded towards considering ways of designing for face-to-face communication involving the child depicted in the design documentary (Grace) and her peers. The brief asked:

“Drawing on Grace’s communication experiences as inspiration, design something for children with severe speech and physical impairments and their peers that motivates face-to-face communication.”

It was intended to prompt designers to engage with the research frames that were expressed in the documentary. The research frames, described earlier in the introduction section identified a layered view of children-centred communication, focusing on a child’s view, an interactional view and a structural view of communication.

The scenario provided space for emphasising the theoretical frame on communication, developed through the prior two empirical studies. Whereas the design documentary implicitly credited the value of multimodal communication by rejecting a focus on speech, for example, by stating that Grace had a speech generating device that she seldom used, the scenario made this research frame more explicit, inviting designers to consider broader ways of interpreting communication. The scenario therefore exposed the critical take on designing for communication and disability through linguistic or deficit-oriented ways. Further, building on parts of the documentary that discussed the importance of considering Grace’s values and priorities for communication, the last line of the scenario was intended to prompt designers to engage with what might be motivating from a child-centred perspective. The scenario described:

“For children who have limited or no functional speech, there are consequences to social interaction and overall quality of life. Communication is multimodal yet current technologies have focused on electronic voice output where the child has to come closer to normalised ways of communicating. What other experiences of communication can technology create where children would opt to want to use this technology?”

Presentation

As it was assumed that designers would have little prior exposure to designing for communication and disability, the presentation supplemented the design documentary by providing a context for discourses on design and disability. Specifically, the presentation described different frames that prior work has taken in designing for disability, as detailed earlier in chapter three. For example, design that can alleviate bodily impairment, design that can support learning and other frames. The presentation then introduced the design documentary, by detailing the data sources that were used from the earlier studies that informed how the design documentary was created. The presentation also included the workshop schedule and plan for follow up work planned to take place outside the workshop.

The participant-researcher as a resource

In addition to the material resources that were prepared, as a participant researcher in the earlier empirical studies, I was on hand to answer specific questions concerning the child and their existing communication systems, initiated by the designers. Although the aim was not to provide detailed technical descriptions about Grace's existing technologies, I responded to questions about what Grace's paper-based communication book looked like, the kinds of vocabularies that her paper and digital systems offered, and how she physically accessed these. Importantly, I acknowledged that my presentations of the data and motivations for the study were inextricably linked to my role as a doctoral researcher and speech and language therapist whose doctoral studies had been motivated by a disillusionment in the possibilities and affordances of existing AAC technologies that I had been used to working with in my clinical work. My responses to the participants' questions therefore highlighted both what Grace was able to access through her AAC systems, for example through written and spoken language, but also what her AAC systems did not provide, for example, access to movement, proximity, touch and physical play amongst other things.

Methods

The design study took place over the course of three sessions. The first session; the workshop session, was the focal point for the fieldwork reported in this chapter. The focus was on studying what frames the designers created based on the design documentary and the design process I introduced, and examining the process of how they generated these frames based on the elicitation materials. The second and third sessions provided opportunities for designers to reflect further on the frames that they had generated by presenting their idea (session two) and seeking child feedback (session three). As the focus was on studying and documenting how designers generated frames in the early stages, the thesis considers the data that was generated in the first workshop session.

Session one – The design workshop

The double diamond design thinking approach (Design Council, 2015) as shown in figure 6.1 was used to guide how the workshop activities were planned and carried out. Specifically, the focus was on supporting designers in understanding the situation through problem definition and proposing solutions. In both problem definition and proposing solutions phases, designers were invited to engage in activities that required divergent then convergent thinking by first generating many possibilities then refining these to focus on a chosen specific element. Within the initial stage, the designers therefore had opportunities to propose multiple frames, and

were encouraged to consider multiple possibilities for thinking about disability and communication.

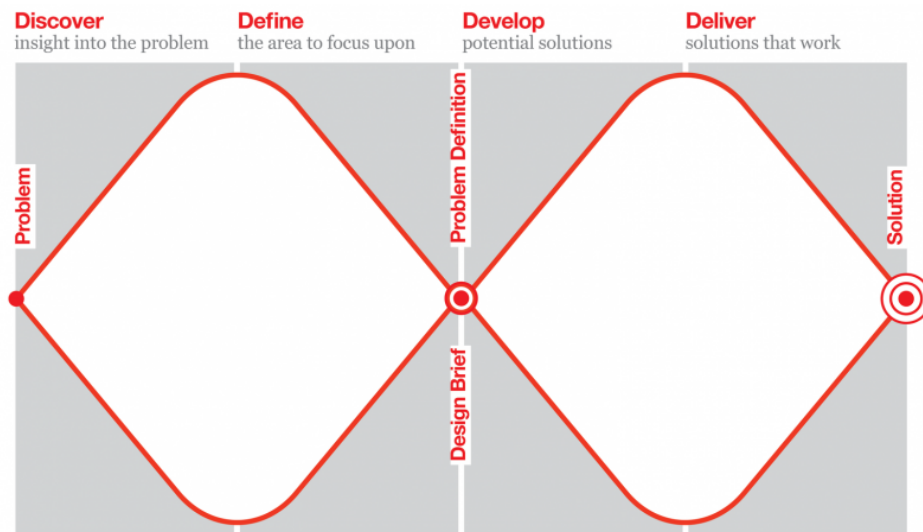


Figure 6.01. Double Diamond Design Thinking Model - Design Council (2015)

The double diamond model was used as it allowed for moving through the different design phases within the time and resource restrictions of the empirical study. Different activities were intended to allow participants to iteratively move through defining problems and proposing solutions through periods of convergence and divergence (Design Council, 2015). Activities were chosen based on how they would best address the research goals, in particular, considering the constraints posed by the structure of the master's module, the available time and resources and the tutor's local knowledge about the participants. The overall structure of the workshop was planned so that it would provide opportunities for understanding and defining a situation through problem framing, then ideating to propose solutions.

The methods for the study were planned in discussion with the course tutor, and separately, with my PhD supervisors. A three-hour workshop was planned which was comprised of: 1. a presentation of the research context, viewing of the design documentary, the brief and scenario as described above, 2. a disability simulation exercise, 3. small group activities, and 4. whole group feedback.

Following the presentation, all attendees were invited to experience what it might be like to communicate a written message first without speech, then second, without speech and gesture. Whilst it was acknowledged that this method can be controversial in only allowing for experiencing what an able bodied and speaking person feels when they suddenly cannot speak verbally or use movement and gesture (Bennett & Rosner, 2019), arguably privileging the

interpretations of the designer over the user, it was used alongside other methods that were intended to present the child's perspectives in varied and rich ways. For example, by prioritising the voice of the child themselves through sharing videos that were captured during fieldwork. Following the whole group presentation, disability simulation activity, and hearing the brief and scenario, participants were invited to work in smaller groups on a number of bounded activities.

In small groups, designers re-watched the design documentary and were asked to identify motivating areas for communication by listing five critical moments in the video that appeared meaningful to the character 'Grace'. Participants were asked to describe the situation so that they could begin to engage with why it was chosen as meaningful. Next, they were asked to form statements about what the identified moments could mean for technology, starting with the phrase "*Technology could...*". Lastly, they were asked to prioritise one critical moment and statement, explaining their choices for prioritising the chosen dimension. Participants were given 1hr 15mins for this activity before joining the whole class group for feedback.

The whole group discussion lasted 15 minutes, and was intended to be a mid-session brief reflection. Participants' responses were guided by prompt questions on what made them identify certain motivations; how they prioritised certain dimensions, and; how they used the design documentary to engage with the process.

Participants then returned to their smaller groups to work through the next activity. They were invited to brainstorm how they might design solutions for the motivations that they had identified, with space to revise their previous motivations and draw on the statements they had previously created ("*Technology could...*"). In order to support them in thinking through possible solutions in a short time frame, participants were offered a prompt sheet containing images of existing technology solutions such as shared active surfaces, augmented reality, robotics and a tangible computing example. Participants had 40 minutes for this activity before returning to the whole group again.

In the final plenary discussion, participants gave feedback about their proposed ideas. They were then invited to continue engaging with the design activities beyond the workshop session. The group that decided to continue working on the design brief beyond the workshop session, i.e. the focal group of participants within this chapter, was provided with a small tablet device containing a local version of the video file, which they agreed to store in a lockable space within the school over the course of the study until it was returned.

Session two – Presenting ideas

At the end of the first session, designers were asked to prepare their proposed idea in the form of a video blog or presentation with visual slides. They were informed that the children who had previously been involved in the earlier studies would be the ones reviewing their design ideas. The intention was that the video blog or visual materials would provide an accessible method for sharing their ideas with children. Between session one and session two, one of the groups continued working on the design brief. The second session was arranged for one month after the workshop, as negotiated by the designers and researcher during the workshop. The second session was significantly shorter than the first, lasting approximately 30 minutes and was comprised of an informal presentation, guided by the designers reporting their final design concept.

Session three – Researcher feedback of children's reviews

Between session two and three, I showed the design concept to the child participants who had participated in the earlier empirical studies. Discussions from the third session were included in the analysis as they provided insights on the kinds of practices that informed designing for communication. For example, knowing that children would be involved in reviewing their ideas greatly impacted on participants' engagements with the tasks. Similarly, their discussions in the final session identified the kinds of ways that designers engaged with the design documentary and other materials from beginning to end.

Methods and insights not reported on within the thesis

In keeping with the PD orientation of the thesis, study three also included further design work with children. Between sessions two and three, the design team's ideas were shared with the children who were involved in study one and two. This involved representing the team's ideas in the form of story about the character Grace (appendix 6). In line with the overarching goal of the thesis that focused on the early stages of the design process, it was beyond the scope of the study to analyse how children responded to design ideas. Instead, the focus was on developing ways of creating a narrative that foregrounded children's contributions and child centred perspectives within a design brief and design documentary. As the focus was on understanding design practices at these early stages, children's responses were not included in the findings.

Data collection

Two researchers delivered the workshop session. The doctoral researcher was assisted by their research mentor; a post-doctoral researcher from the same research lab. The assisting researcher supported in recording the sessions and made written notes about the discussions during the whole group activities and one of the groups' smaller discussions. Video recordings were made of the whole group discussions (i.e. the introduction and presentation, mid-session feedback and plenary discussion). The small group activities were audio recorded and photographs were taken of the written notes and sketches that the participants made whilst working through the activities.

For sessions two and three, the doctoral researcher met with the group at the arts school. Data comprised of audio recordings and a PDF file of their proposed design solution.

Analysis

In order to understand how participants responded to the research goal for examining alternative ways of designing for communication, the approach was to primarily use video and audio analysis. Images and written notes that were taken during the first workshop supplemented the audio and video analysis. The video, audio, textual and picture files were imported into NVivo 12⁶, a qualitative data analysis software tool. A whole-to-part inductive approach to video and audio analysis was taken (Derry et al., 2010; Erickson, 2006), whereby salient events concerning designers' interests and evolving frames were time marked then orthographically transcribed within NVivo. An inductive thematic analysis in line with a social constructivist theoretical perspective that motivated the whole thesis was used (Braun & Clarke, 2006). This acknowledged that knowledge was co-constructed and situated within the contexts that data was generated within. A flexible coding process was used whereby codes were iteratively generated and developed in an immersive process of watching and listening to the data many times. These coded patterns were gradually developed into themes which illustrated salient dimensions. As the research goal aimed to identify new and alternative design frames for communication involving children with SSPIs, attention was paid to understanding the process of how the design team used the design documentary to inform their perspectives. In order to apply a systematic and rigorous analysis, the coding patterns

⁶NVivo 12. v1.0.1.1 Produced by QSR International Pty Ltd - <https://www.qsrinternational.com/>

and developing themes were regularly discussed with the PhD supervisors, following viewings and discussions of parts of the data.

The findings generating five overarching design frame themes that accounted for the different ways that they responded to the brief. These were:

1. [Speaking out in public and proving herself](#)
2. [The importance of friendship](#)
3. [Invasive technology & space issues](#)
4. [Being included in play in common ways](#)
5. [Ethical, accountable design.](#)

In order to reach these frames, the analysis also investigated how designers used design documentaries. For this part of the analysis, a deductive approach was taken using four themes developed by Raijmakers et al (2006). This was useful as it allowed for building on existing applications of design documentaries. These themes were:

1. [Focusing on people, not just their needs](#)
2. [Providing solid ground for speculation](#)
3. [Hungry for everyday details](#)
4. [Stimulating team involvement.](#)

The findings that follow first describe the final concept that the design team presented. Next, the six design frame themes that were generated are described. Finally, the four themes that documented how the design team engaged with the materials are discussed.

Findings

Proposed design idea

The design team's final idea, 'Whisper', allows Grace to communicate in 'quiet ways'. Quiet ways of communicating are subtle and multimodal, allowing for Grace and her peers to creatively draw on different means, according to the situation. This includes a range of private channels, including whispering, hiding games, passing notes to her friends in class and more. Focusing on voice, in particular, one of the designers, Shannon, described the design concept as a contextual way of regulating voice: *"finding ways to allow Grace to control the volume she communicates at. Allowing her to speak more quietly or speak more loudly, depending on the situation"*. Further, 'Whisper' also incorporates co-constructed communication by allowing for

Grace to regulate the position of the device screen so that it can enable shared drawing on a flat surface or a two-way screen so that *“peers can nonverbally interact with Grace in real time.”* Thus, broadly the design concept is couched in the goal to provide Grace control in how she regulates the privacy of the diversity of activities involved in communication whilst also allowing for jointly constructed communication.

The design team’s proposed idea is presented in figure 6.2. ‘Whisper’ is motivated by cultural, social and developmental prompts that acknowledge the increasing presence of mobile technologies in young children’s lives, as well as a need for opportunities for children to understand *“the space between their inner world and the public world”* (p.1 of 6). By drawing on existing solutions for inspiration, ‘Whisper’ incorporates creative modes of communicating, such as drawing and playing games, whilst allowing for Grace to control the privacy of what others see (p.2 and 3 of 6). The design idea illustrates how the pivoting screen mechanism would allow for co-constructed communication, introducing the option of a curved screen for sharing, rotation, blacked out screen view for privacy and situated meaning making through location-based data (p.4 and 5 of 6). Finally, ‘Whisper’ also incorporates an alternative writing function that requires minimal eye movement, for practicing free-hand writing with less physical effort (p.6 of 6).



Whisper

Exploring the possibility of harnessing Eye Gaze technology with the aim of enhancing children with SSPIs capacity to speak, create and share quietly and privately.

We concentrated on exploring ways to provide Grace with more control over the volume with which she speaks, imagining tools that would allow her to communicate experimentally and forge her own ways to express her ideas as she grows older.

'Quiet' communication methods like whispering, hiding games, passing notes in class and sharing secrets are crucial to a primary age child's development of theory of mind, allowing them to form an understanding of the space between their inner world and the public world.

At a point where primary age children's access to smart phones and digital technology is exponentially increasing, many children are used to interacting digitally using private or semi-private channels. We felt it was particularly important to consider ways Grace could be provided with a similar option for privacy.



of children aged 9-12 in the UK have their own smart phone
PEW INTERNET, 2017

"For people without disabilities, technology makes things easier. For people with disabilities, technology makes things possible."
IBM TRAINING MANUAL, 1991

"In secret places we can think and imagine, we can feel angry or sad in peace. There is something to be said for just being, without worrying about offending anyone."
SOPHIE DAHL, THE SECRET GARDEN

"Secrecy contributes to the formation of our inner awareness and autonomy; it creates a space for the imagination; and, as well as being a weapon of exclusion, it is an essential tool for friendship."
TIFFANY JENKINS

Figure 6.02. Design team's proposed idea (page 1 of 6)



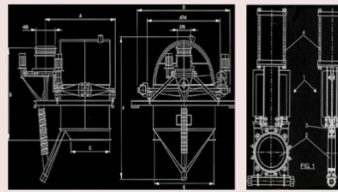
TOBII DYNAVOX

Tobii have created many innovative tools for augmentative and alternative communication, such as Indi, which offers features that go beyond speech communication, such as access to social media and file storage. Beyond the messaging aspect though, the devices remain personal, and don't promote collaborative use.



EYEWRIITER

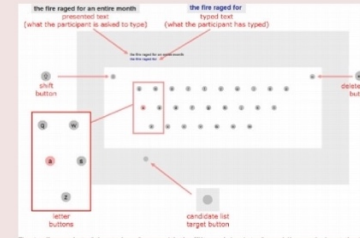
A low-cost, open-source wearable eye tracking system that allows physically impaired people to draw with their eyes. While most sophisticated Gaze systems come at exclusionary prices, this project proves it is possible to create a high functioning program for a lower budget, making the functions we imagine for Grace's system feasible to produce. Of course, for this project, the interaction should be seamless and a wearable not required.



EXISTING PLAN FOR PIVOTAL SCREEN SHOWING JOINTS ROTARY DEVICE



INTERFACE AND ONBOARDING GAMES OF MYGAZE



FILTERYEDPING - DWELL BASED EYE TYPING

A project that attempted to find a way to remove the virtual keyboard from eye typing in order to speed the communication process. Filtering is used to rank possible words based on their length and frequency of use, a little like predictive text. This approach has many drawbacks which the developers acknowledge, and potentially dangerous drawbacks when designing with a child in mind - as a sole method of communication, a predictive system could hinder creative writing and thought.



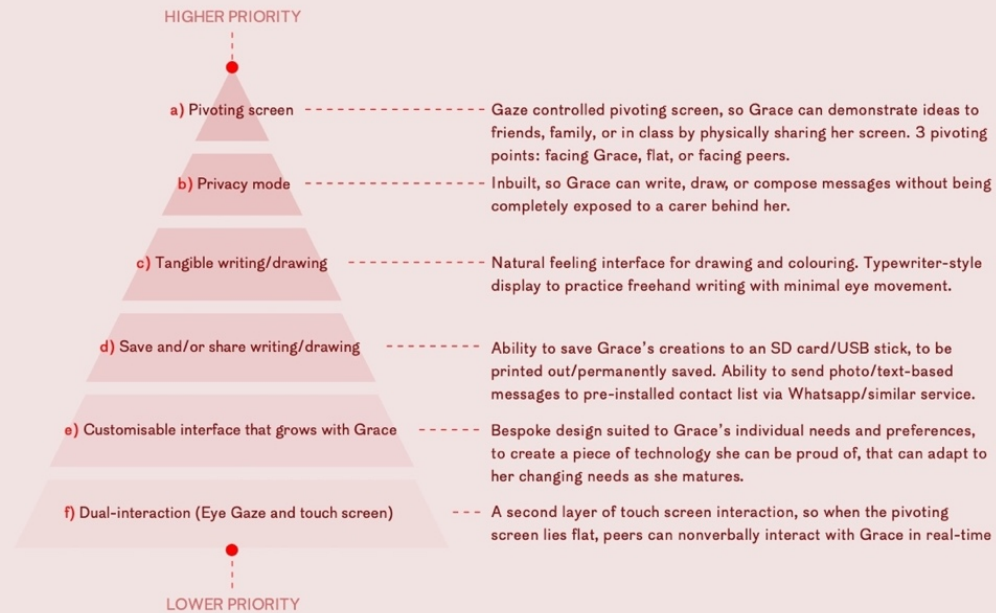
DELL LAPTOP WITH INBUILT PRIVACY FILTER

We were initially unaware of the fact that built in privacy filters has existed within some PC laptops for years already. This means the technology to switch an overlay on and off which blocks side views of onscreen information with a single button is already established.

Whisper - Technological Overview

Figure 6.02. Design team's proposed idea (page 2 of 6)

All of the following features would ideally be required, in the following order of priority:



Whisper - Desired Features

Figure 6.02. Design team's proposed idea (page 3 of 6)

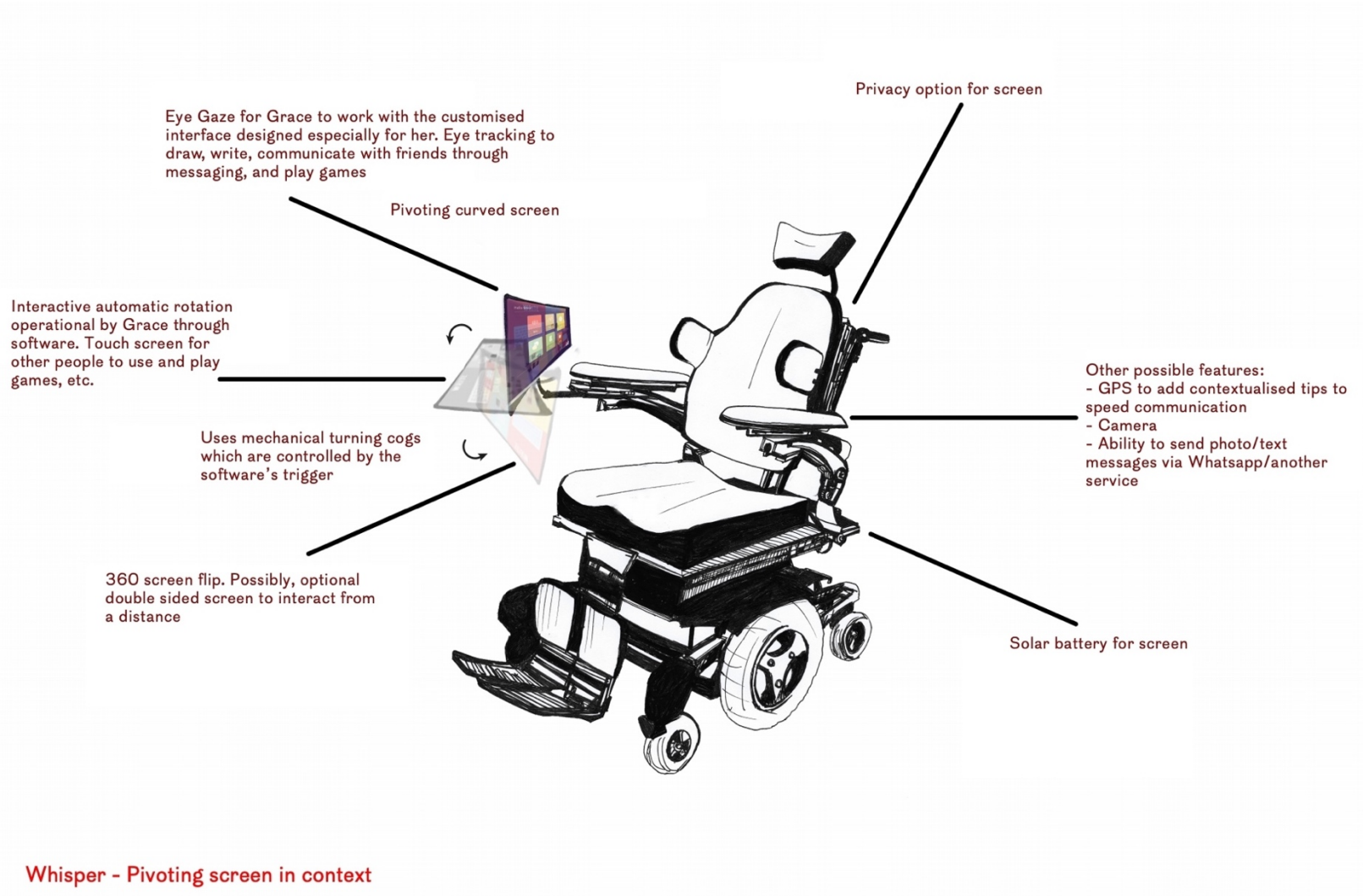
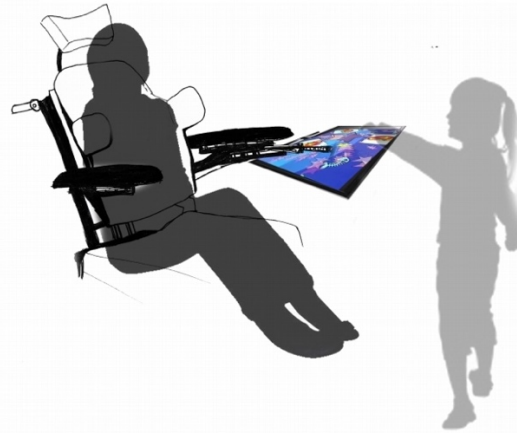


Figure 6.02. Design team's proposed idea (page 4 of 6)

Flat facing screen. Touch screen for peers to interact with messaging, drawing, or games.



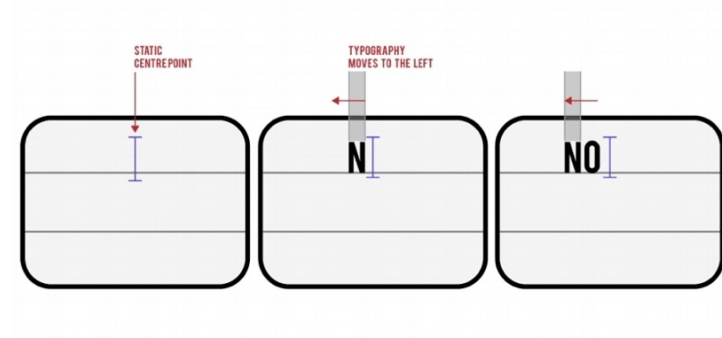
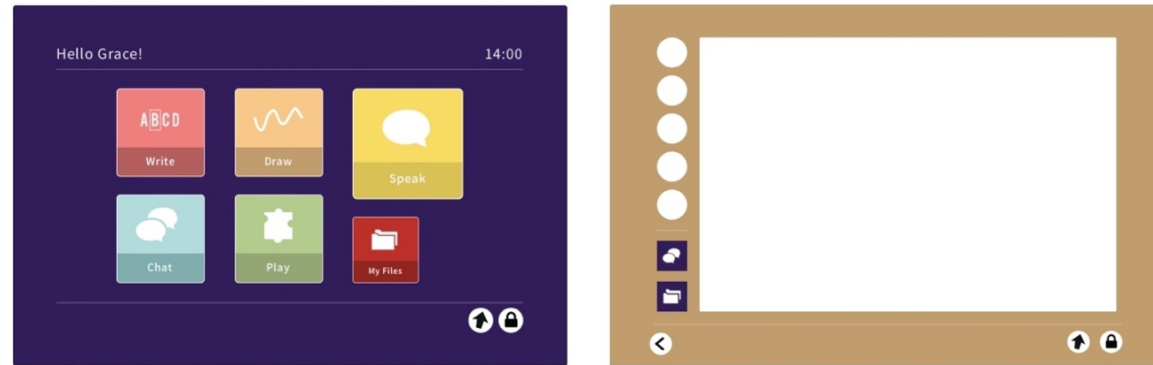
Communicating with a teacher in a classroom through software and flipped screen



Privacy mode to allow for undisturbed communication with friends.

Whisper - Pivoting screen in context

Figure 6.02. Design team's proposed idea (page 5 of 6)



Whisper - Interface development

Figure 6.02. Design team's proposed idea (page 6 of 6)

Designer frames

During the design workshop in session one, designers generated five overarching frames that communicated their perspectives and priorities of how to support communication in Grace's life. Each frame expresses the designer assumptions and key issues that they prioritised.

Frame 1: Speaking out in public & proving herself

The design documentary stimulated team members to attend to and reflect on the existing, imbalanced power dynamics in communication between children and adults, that are exacerbated by Grace's existing AAC device. In particular, the team used design documentary excerpts that alluded to Grace hating *"being put on the spot"* to use technology and needing to *"show that she's brilliant"*. The team proposed that Grace rejected her existing AAC system as it provided a means for adults to test her capability to respond to questions and take part in verbal conversations in normative ways. They also suggested that the affordances of Grace's existing device limited her control in communicating with other children on her own terms, through its restricted scope of modes and narrow volume range in regulating voice. One designer commented: *"imagine if the only way you could communicate is by having this robot thing shout out loud"*. This underscored their view that Grace's uses of her existing technology were mechanical and did not allow for regulation across people and places.

Whilst the design documentary promoted designer reflections on capability and control, the team also moved beyond the design documentary to consider alternative meanings about what it meant to communicate with friends in particular. By choosing to focus on private ways of communicating that go under the radar of adults who might otherwise assess children's functional communication capabilities, the team brought in new interpretations for communication, building a perspective that communicating through speech was not enough and there was a need for *"more channels away from speaking"* that could *"allow her (Grace) to be more creative"*. The team's discussions generated two connected ideas. They conceived a need for creative ways of having private peer interaction that might utilise different modes. In turn these ways would establish children's peer culture by allowing them to express themselves through different channels, compared with those they use when communicating with adults.

This view of privileging creative, regulated modes that were under Grace's control, was strongly expressed in the final concept that the group proposed. Namely, by focusing on the concept of *"Whisper"*, the group prioritised a need for quiet ways of communicating that

would mitigate instances of being judged or assessed by other people, whilst allowing the expression of a peer culture.

Frame 2: The importance of friendship

Prompted by the documentary that portrayed Grace as ‘a caring friend’ with multiple peer connections, the team developed narratives about Grace’s friendships that reflected this range and depth. They defined Grace’s friendships in terms of who her friends were, what their social activities comprised of, and how they supported each other on an emotional level. For instance, team members commented that Grace had an unexpectedly wide circle of friends: *“she had more friends than I had when I was that age”*. Also, that she held deep and established reciprocal connections: *“but it’s also [important] when her friend got sick, and she made her that card”*. Their reflections on the ways that Grace and her friends signalled support suggested that they treated peer support and care as a central concept in Grace’s friendships.

The view of friendship being reciprocal and shared was emphasised by their interpretations that friendship practices are enacted by being able to do things together in co-constructed ways that were *“good for everyone”*. For instance, this was conveyed in their final design concept that incorporated dual-interaction via eye gaze and touch screen access so that Grace and her friends could nonverbally interact together on a flat screen surface.

Prompted by the design brief, designers were asked to consider ways of facilitating peer communication. Connected with this call to action and the design documentary which expressed Grace’s friendships, “Whisper” was designed to advance and strengthen peer interaction through the private channels it offered to children as *“an essential tool for friendship”*.

Frame 3: Invasive technology & space issues

One of the central concerns of the team’s discussions was Grace’s underuse of her existing technologies, yet its obstructive physical presence. Using information in the video about Grace refusing to respond with her eye gaze when ‘expected to do so’ and ‘put on the spot’, the team conceived Grace’s existing technology as having an invasive presence in being imposed on her, as an expected main mode for communicating. For example, one designer commented: *“it’s interesting that she doesn’t even use that mainly – like that’s not her main way of communicating even though it’s always there. Seems really silly”*. The team reflected on the ways that Grace was *‘tied to technology’* by positioning that the device’s constant invasive presence distracted from the more subtle and wider range of modes she uses to communicate

and that Grace should be able to regulate the presence of the technology. Moreover, the design documentary showed that Grace's class peers' technology experiences were more varied and motivating, including playing games, recording and viewing pictures and videos, which prompted the designers to consider that Grace *"could see everyone else using technology for fun"* yet her own uses of technology were restrictive.

An additional dimension of invasive technology concerned how Grace felt about the technology. The team drew on information in the video concerning Grace's peer's interactions with mainstream technologies to identify differences and tensions in her own interactions with her device: *"she doesn't like it. She wants an iPad because it's like, ugly? – as in like, doesn't look cool?"*. These statements suggested issues with both the visual appeal of her existing technology, as well as alluding to it being different to the mainstream technologies that are more commonly used.

The team used information in the video about the family's small, temporary social housing to position that space was a key concern. Their discussions considered that as a girl with an SSPI that affected her whole body, Grace was likely to have lots of specialised equipment in her home and her AAC device added to this compromised space: *"Maybe the other equipment that [...] has to have is quite invasive. She has to do physiotherapy at home."* Beyond Grace's communication experiences, they considered her other daily activities and how all of her routines and assistive equipment each separately affected space. For example, they discussed that her chair and device were both cumbersome and didn't fit well in her home. The team moved away from considering the examples in the design documentary and specific communication challenges towards considerations for her whole environment, highlighting a need for compact technologies that could move in and out of view. Whilst considering practical solutions for allowing Grace to move around more freely in her home, one designer commented: *"it's just a massive chair"*. They reflected on ways of designing for smart homes that served many different functions that might include mobility, communication and more. They offered suggestions that would ensure *"everything is tucked away"*. These interpretations advanced one of their views for solutions that addressed the ecological rather than individual level.

Frame 4: Being included in shared play with common understandings

Taking the playground game of tag involving Grace, Oscar and the researcher as one focus, the team proposed two connected dimensions for this frame. The first dimension positions that play is a right, and the second argues that children with SSPIs should have the same play

opportunities as other children in creating bi-directional, co-constructed play. Considering the first dimension, the team prioritised the importance for Grace to engage in play experiences with other children owing to her being “*most engaged*” and “*excited*” when she was able to do so. By expressing that play was a key motivation for Grace, the team discussed the importance of enabling participation in play as a right. Taking the example of Grace’s delight in fitting into a small climbing frame gap, despite the size of her bulky chair, the team considered play involving children as a generational activity that helped to reinforce peer culture (also introduced in frame one). For instance, one designer commented: “*...being able to do the same things her other friends can; that seemed the most significant. Just fitting in the climbing frame gap, feeling like a normal kid*”. The second dimension, that concerned accessing social play opportunities, was evidenced in the ideal that children like Grace should have alternative ways of being involved in play. Their discussions acknowledged that it is not always possible for Grace to play in the same way as children without physical impairments, yet participation in play can take different forms. For instance, one designer identified it important to “*make her feel like a kid that could freely do what she wanted to do*”, within the constraints of her physical abilities. Informed by this assumption, the team proposed that participation could happen through observation and varied access methods. This idea was implicitly proposed through the team’s suggestions of “*a camera... that she could use to zoom in if she wasn’t able to move about physically*” or through the use of a drone where she “*could go off and see stuff... a 360 degree view of everything around her*”.

As well as prioritising alternative ways for Grace to access play activities, the team also considered how Grace’s new medium for playing could be open and inclusive for other children as well. For instance, one designer commented: “*we focused on all the possibilities you could do just with one screen, ...play music, ...games, battleship... a really useful extension other people could understand as well.*” These views underscored the importance of designing for common play that allows for Grace and her peers to create shared and bi-directional experiences, that are both meaningful for Grace and her peers by making Grace’s experiences understandable for others as well.

Frame 5: Ethical, accountable design

Unlike the other frames that were shaped by the design documentary, the team also took a new perspective on the design of technology for children with SSPIs that was informed by their desire to produce solutions that are practically achievable within the scope of existing technology opportunities and provided an impact on children’s lives. One designer commented: “*you don’t want to disappoint them ‘cause it’s for kids*”, which implicitly

suggested that designers did not want to let children down by making radical changes that they could not deliver on. This accountable stance through practically possible solutions was also evidenced in their final concept that closely built on existing solutions, for example for pivoting screens, privacy filters and ways of drawing through eye gaze access (figure 6.2, p.2 of 6). One team member commented: *"I think it's important for her to know that we didn't invent anything. We literally researched things that existed and put them together. We used them differently."*

The team were also motivated to produce useful solutions in terms of having an impact on how children communicate. In the context of discussing solutions that can impact on addressing social challenges in children's daily lives, one designer commented *"I really wanna do things that help people... how we can change stuff"*. Ethically engaging with the brief meant proposing viewpoints that prioritised the things that were important to Grace, which would consequently have a positive impact on her life. For example, the design team identified a number of critical instances that were important for Grace. Some of these included that: *"she didn't like answering questions when she's put on the spot... I think she wants more independence"* and *"she seemed the most engaged when (playing with Oscar)"*. By focusing on the emotional side of what the documentary conveyed about Grace as a person, rather than taking a technocentric view, the team prioritised a person-centred view. In reflecting on their own capability to propose solutions, one designer commented: *"I think we're quite well placed to talk about it though, as we're not techie people. In a way, that's a good thing. ...making an Arduino thing isn't gonna solve it. It's probably better to think of the emotional side of it"*. This suggested that their ideas were motivated by an accountable stance that acknowledged Grace's priorities, whilst considering what was achievable in the existing context.

Using design documentaries in early stages of the design process

Focusing on people, not just their needs

For Raijmakers et al (2006), applications of design documentaries involved looking beyond a set of needs and requirements that people being designed for might hold. In their work, designers appreciated access to incidental details that helped to develop an understanding of real people through their aesthetic tastes, daily activities and home life. This was reflected in the design of this documentary that aimed to represent children's social contexts, their relationships, their play opportunities and varied communication styles based on social contexts. In finding ways to make the character within the design documentary "come alive" (Raijmakers et al., 2006), the documentary utilised principles for constructing a 'well-rounded'

character (Nielsen, 2002) that focused on Grace's tastes, goals and values, as well as presenting polyvocal accounts of how other children and her teacher would perceive her.

During the workshop, the design team looked beyond a task-based focus on what made up the mechanics of communication for Grace. Instead, they focused on understanding her as a person, examining her interests, the people, places and activities that were important in her life, and her preferences and motivations for participating in daily activities. For instance, their discussions signalled that they defined her as being a compassionate friend; a member of a family unit; a sociable child; someone who valued her own independence, and; a child who was motivated to take part in the kinds of activities that her friends took part in. The ways in which they spoke about Grace suggested that they treated disability as being one part of Grace's life that cut across certain dimensions of her life, and as others have suggested, her disability did not define her as a 9 year old girl (Wickenden, 2011a).

The design team used the design documentaries in a number of ways to create these meanings. For instance, they identified critical incidents in the video that led to the view of Grace being sociable and holding compassionate relationships with her friends. One designer commented: *"...maybe playing with Oscar? She seemed the most engaged"*. Another team member identified that Grace receiving a card from a friend who had been out of school in hospital for some time as another critical moment. She commented: *"It's like they are very sort of extra compassionate kids, aren't they? I guess they've got a very grown up attitude to life."* These critical moments motivated their appreciation of Grace's social ties and her ability to access typical, everyday activities as well as expressing these social ties on an affective level.

In the example above, the design documentary was used to extract information for describing Grace. Separately, it was also used for leading to questions. The team used the video to generate questions that would enable them to imagine who she is, and why she and her friends communicated in certain ways. For instance, whilst discussing an excerpt from a playtime interaction involving Grace and her friend Oscar, where Oscar had moved away without the need to say goodbye, one designer asked: *"Is it because they're a child or because they have a disability?"* By questioning the reasons why children acted in certain ways, the designers attempted to understand children's lives by considering different interpretations.

Providing solid ground for speculation

Elsden and colleagues identify that speculation in design can serve many purposes (Elsden et al., 2017), including critique (Blythe et al., 2016), exploring emerging or future technologies

(Brandt & Grunnet, 2000) and expanding directions for new research (Hauser et al., 2014) . Helmes et al (2011) draw heavily on the use of speculation for promoting curiosity and discussion in designing for autonomy in interactive systems. Further, Gaver et al (2003) suggest that speculation can push designers to imagine how one might personally use products, and what one's lives would be like as a consequence of imagined possibilities. These presented examples suggest that speculation is helpful for creating a space for discourse, as well as understanding how people might interact with and experience new artefacts and designed situations that embed values within them (Elsden et al., 2017).

During the workshop, the design documentary elicited three different types of speculation. These were: 1. Speculating about how Grace might feel about her existing tech and new solutions; 2. Speculating about how Grace's life might be affected by their proposed ideas, and; 3. Speculating about contextual barriers that would impact on new ideas.

In the first case, designers used information in the design documentary to speculate about how Grace might feel or what she would prefer by making attributions. The design documentary implicitly suggested that Grace's device was too large and not always helpful, evidenced through subtle narratives that foregrounded her more dominant communication methods (for example, eye pointing, facial expression and tone of voice), as well as describing Grace as having *"mixed feelings about her eye gaze"*. Taking these implicit suggestions as inspiration, the design team attributed these *"mixed feelings"* to being connected with the invasive presence of technology that was imposed on her, as proposed earlier in frame 4. The design team speculated about Grace's aesthetic tastes concerning technology by drawing on their own opinions about her technology being dated and cumbersome. They postulated that Grace would be likely to prefer something: *"lighter", "modular", "less of this big, black scary box she has"* and *"evidencing her personality a bit more, so it didn't feel so separate from her"*. By considering these alternatives, the team drew on their own interpretations and knowledge about the possibility of mainstream technologies to create a broader narrative about what Grace's technology preferences might look like.

For Raijmakers et al (2006), their design documentaries allowed designers to concretely speculate about how individual people might be affected by their proposed ideas. Namely, by knowing about the person, designers in Raijmakers' et al's study were able to envisage how the person being designed for might use certain kinds of technologies which would support them in designing for clearly defined situations. During the workshop, 'what if' questions enabled designers to speculate about the impact of possible design solutions. Having established from the video some context about the kinds of activities Grace engaged in and

the possibilities available to her, the team speculated about the impact of how things could be different for Grace with different possibilities. Some of these possibilities asked: *“what if money wasn’t an issue?”*, *“what if she could have one of those smart homes?”* and *“what if her equipment could evidence her personality a bit more?”*. These ‘what if’ questions led to discussion about the possible outcomes and broader impact that new technologies would have on her life. For example, one designer commented that by focusing on ‘evidencing her personality’, new solutions could *“make (Grace) feel like she was being herself and wanting attention”*, as opposed to *“hating being put on the spot”*. They also considered that new lightweight and modular systems that Grace could independently regulate would *“give her back control”*.

The final type of speculation related to discussion about contextual barriers that might impact on Grace’s communication experiences. Using the design documentary as a starting point for establishing basic information about her school and home environment for example, the team discussed the resource constraints of these settings. One designer asked whether all of the students in the school were disabled in some way. This helped to establish the scope of designing for certain communication experiences that included children of mixed abilities, therefore acknowledging the range of children’s cognitive and physical impairments as potential barriers. Another designer suggested that the setting seemed like ‘a nice school’, which led to speculations about the environment and people within it as likely to be effective in supporting communication, which therefore meant that they did not pursue the idea of people’s motivational barriers as being an issue. The team also considered physical barriers that impacted on how Grace used her existing technologies. For example, using the video to identify key moments for making a card and using her communication book to communicate, the design documentary allowed the designers to form questions that could only then be probed by going to the proxy (researcher) for clarification and detail.

Hungry for everyday details

In their inception, Raijmakers et al (2006) described that design documentaries motivated designers to understand about the details of the individual’s everyday life by seeing and hearing about the ways they themselves communicated. The films were said to enable designers to get a better feel for the person, compared with other design tools such as personas, as the films offered new information about how ‘very normal events’ played out.

In the workshop, designers often came to the researcher to seek details about every day, mundane events, expressing a need for more information and *“not knowing enough about*

her”, despite the detailed information that was presented through the design documentary. Like in the case of Raijmakers et al, this suggested that designers were keen to understand the intricacies of Grace’s daily life that cut across different aspects of her life. For example, as described earlier in the context of speculation, after discussing video examples of Grace receiving a card from her friend, the group were keen to look for details about how Grace and other children with SSPIs practically achieved specific actions, like communicating messages in a communication book or understanding craft activities. Designers would direct questions to the researcher to understand the mechanics of how Grace constructed utterances with her communication book and AAC device. one designer commented: *“I wish I had seen technically how it works... how does the screen allow her to express an emotion... what it sounds like too, a robotic voice or does it sound like an actual, normal - normal? – child’s voice.”* By seeking such details, designers were motivated to explicitly understand about the intricacies of Grace’s daily life as a starting point for helping them to think about alternatives. Furthermore, it showed that the design documentaries also posed ambiguities and generated more questions. For instance, designers commented: *“I feel like I need to know more about her”, “this is such a big task to take on”, and “it’s hard to imagine for them, when you don’t know them, and you’ve never been in their situation”*. These comments suggested that designers wanted to legitimately engage in understanding Grace and consequently proposing solutions that could positively impact on her life, which connected with the fifth design frame on taking an accountable stance for impacting on children’s communication experiences.

Stimulating team involvement

A final dimension of design documentaries, was that they encouraged designers to tell stories about their own similar experiences involving friends or relatives (Raijmakers et al., 2006). By bringing in familiar examples from their own lives, designers created new meanings that supplemented the video.

In considering the role of the designer in ‘the making of futures’ for and with other stakeholders, Ann Light stressed an appreciation that designers are very much part of constructing outcomes and have a critical role in deciding when to disrupt or preserve through their interventions (Light, 2015). Drawing on established principles from anthropology, Light reflected on studying *with* people, rather than engaging in the study *of* people, as well as *flipping* between different ways of understanding and interpreting what is taking place. For design purposes, this is important as it acknowledges that designers bring their own ways of seeing a situation.

In the workshop, designers each brought along their own unique experiences that shaped the design process. For example, one participant identified friendship as a key social construct in their own life, choosing to focus on how friendship manifested for Grace. She commented: *“she had more friends than I had when I was that age.”* This prompted the design team to prioritise discussing friendship, as something that they could relate to.

Of the three designers, each of them had their own personal experiences with disability, connected with family members and friends. This also shaped how they defined their priorities of what to focus on. Taking the video as a starting point for identifying and building on examples of space issues in the home, one of the participants Amelia drew on a friend’s experiences as a wheelchair user. Seeing the issue as a practical challenge, she focused on how her friend moved around their home space and offered suggestions based on her friend’s experiences, commenting: *“I have a friend back home, who’s um- in a wheelchair, and like- her family’s really wealthy – they’ve decided when she gets her own place, they’re gonna set up an entire system that basically what erm - it’s attached to the ceiling so she can walk around the house – it’s like a thing she sits in – an’ like, she can move around. ...when you have the funds, you can do whatever you want...the whole house will be like made for her.”* The example led to the team discussing deeper issues about mobility and independence, showing that in this case, personal accounts on practical barriers were a hook for discussing deeper, more complex social issues. Equally so, the other two designers each talked about family member’s experiences that added new perspectives on other discussion points including financial issues, access to equipment, and emotions/affect. As identified in other work that has focused on team design work, each designer made a bid for what to discuss based on what they perceived as important (Brereton et al., 1996), then invited others in the group to engage in that focus point.

A different way that designers made sense of the situation was by drawing on meaningful examples from popular culture. On occasions, designers supplemented the available information sources with things they had experienced or read about, to enrich their perspectives. For example, whilst discussing the complexities and physical effort of Grace using her AAC system, one participant recounted the story of ‘The Diving Bell and the Butterfly’; a memoir of a man who, following a stroke, used a partner assisted AAC technique to write a about his experiences through the use of eye blinking to spell words (Bauby, 2008). Whereas the design documentary provided a starting point for discussing the effortful act of communicating with AAC, the story by Bauby helped to provide another perspective on the immense physical effort that was involved. By drawing on this example, the group discussed

issues of physical effort, control and the role of conversation partners. This discussion informed the group's decision to prioritise that Grace does not like being put on the spot to use AAC, and a need for her to maintain control in these situations.

Discussion

This chapter has investigated how research frames from the earlier empirical studies and prior work could be used to inform the creation of a design documentary and process for motivating new design frames. The focus was on conveying multi-layered and polyvocal accounts of the communication experiences of one child with SSPIs, in order to motivate designers to consider new ways of framing interpersonal, peer communication involving children with SSPIs. This was important for inspiring new ways of designing for digitally mediated communication that moves beyond linguistically driven and deficit oriented perspectives. Further, the design documentary was important for resolving some of the dilemmas of involving proxies instead of involving children themselves, as traditionally seen in design work with children who have SSPIs (Benton & Johnson, 2015; Börjesson et al., 2015). These alternatives are important as they contribute a critical perspective on the role that future digital technologies can take in the lives of children with SSPIs, generating new discussions about *who* informs the direction of *what* is design and *how* children's contributions inform these decisions.

This discussion section first reflects on the decision to use a design documentary as a design tool for engaging with understanding about children with SSPIs, whose communication experiences can be perceived as very different to that of designers. The section then discusses how generative the design documentary was for inviting alternative frames. Following this, the section then examines the role that the design documentary took in facilitating discussions amongst designers.

1. Reflecting on the choice of a design documentary

As a design tool, design documentaries can facilitate reflection in design teams, by exposing rich details about the everyday lives of people who are being designed for (Raijmakers et al., 2006). In doing so, it has been argued that design documentaries can motivate designers get closer to understanding about the nuanced experiences of people's everyday lives which is helpful for envisaging how new technologies might fit into people's lives, especially when access to a particular population is challenging and the situations that are being designed for are very different to the experiences of the designer. In order to provide these opportunities, I

created a design documentary that was intended to motivate designers to engage with the communication experiences of a child with SSPIs, through what would be an 'accessible' design language. Using the findings of the empirical work from the previous chapters, the design documentary expressed specific insights from these findings that focused on presenting one 'well-rounded' character of a child with a SSPI. The idea of presenting a well-rounded character was motivated by a need for understanding children's 'felt lives' (Wright & McCarthy, 2010) and consisted of conveying multi-layered and polyvocal accounts of some of the different dimensions of one particular child's life, by constructing a narrative that was centred around a character, rather than a storyline or 'plot' (Nielsen, 2002). By reflecting on specific experiences yet leaving many questions unanswered, the design documentary was intended to leave space for designers to interpret why the character might be feeling a certain way, or what their perceived requirements might be, therefore retaining some level of ambiguity. This ambiguity is viewed as an important resource for designers to personally engage with and interpret the situation for themselves (Gaver, Beaver, & Benford, 2003). A decision was made to use a design documentary over alternative design tools, as in this instance, it offered the benefit of communicating rich details about some of the varied facets of Grace's life, illustrating that her lived experiences of communication were inseparable from her situated physical, sensory and emotional experiences. The documentary allowed for different layered perspectives on friendship, participation in social interaction and other foci, foregrounding different dimensions through the use of different media methods. These methods included videos, photos, drawings, written captions, audio narration and sound effects. To give one example, an image of a card that Maya had created for Grace communicated that Maya valued Grace as a caring friend, whilst a powerful photo of Maya and Grace holding hands, despite the physical effort to do so, captured that their friendship was bidirectional. Without the need for words, both of these instances clearly signalled some of the individualised ways that the girls enacted friendship and communicated on their own terms.

As an alternative technique for helping to 'bring requirements to life' in the early stages of the design process, personas (Cooper, 2004) are regularly used for capturing the experiences of a typical user type of a product under development (Sharp et al., 2019). Personas are specific descriptions of hypothetical people who are deemed to represent actual users and what they want to accomplish. Typically, there is a set layout for personas, typically conveyed in a 1 – 2 page summary where the persona has a name, is accompanied by an image and several subsections that describe the persona's characteristics, goals and preferences (Nielsen & Storgaard Hansen, 2014). Whilst personas have their benefits in offering a shared language for

designers and stakeholders to discuss users that can be perceived as very different to the user groups being designed for (Nielsen & Storgaard Hansen, 2014), in this case, this tool (see appendix 5 for persona draft) was deemed to have limitations in bringing designers closer to the actual use situation (Bødker et al., 2012). This was because it was difficult to distil the complexity of children's rich communication experiences within 1 – 2 pages, as well as being unhelpful to present an archetypal user of such a heterogeneous population. As there are no typical cases of children with SSPIs who use AAC or other communication technologies, the design documentary was selected as a way of avoiding homogenising such a diverse user group, by embracing the rich and detailed, multi-layered accounts of one specific child.

2. How generative were design documentaries in inviting alternative frames?

One interpretation for the concept of being 'generative', concerns the idea of exploring a relatively uncharted (or novel) region of the design space, that can consequently produce transferable knowledge (Hoby & Löwgren, 2011). For Dorst (2013), being generative is concerned with applying multiple perspectives, or frames, to help in understanding complex social problems (Dorst, 2016). For instance, in one project entitled 'Designing out crime', Dorst described an instance of designing for minimising violence in a city centre in Sydney. Dorst describes how prior to the project, the local and state governments had introduced tight regulations with increased police presence; consequently treating revellers in the area as potential criminals. Conversely by proposing an alternative frame that treated the public as party goers at a festival (rather than criminals), Dorst described how the project was able to apply an alternative perspective that instead focused on *distraction*, i.e. by supporting party goers in 'unconsciously sobering' following a night out, and also *extraction*, i.e. for moving people out of the area safely (Dorst, 2016). Drawing on these examples and definitions for inviting alternative frames, the current study therefore examined the extent to which the design documentary was able to motivate alternative ways of seeing Grace's communication experiences, and produce novel transferable knowledge that could be used when designing for future communication situations. In line with Hoby and Löwgren (2011), novelty is appraised in terms of how far the design frames generated a new dialogue compared with the frames that are previously typically taken in HCI and AAC literature, as summarised in the introduction to this chapter.

To recap, existing research frames from the AAC literature base revealed a dominant, constructivist perspective on communication. This acknowledges co-constructed and situated meaning making by attending to how communication is organised around talk (Smith & Murray, 2016). Separately, the HCI community has produced frames that have also focused on

co-constructed communication (Barendregt, Börjesson, et al., 2017; Black et al., 2012; Brereton et al., 1996), but also frames that have focused on: alleviating bodily impairment or supporting developmental factors (de Faria Borges et al., 2012; Hayes et al., 2010; Madsen et al., 2008; Zhao et al., 2018); fostering empathy and aesthetic appreciation of children's experiences (Durrant et al., 2013), reflexivity in methodological choices (Frauenberger et al., 2017) and on a speculative level, critically challenging norms and expectations about designing for disability (McLeod, 2010; Pullin, 2009; Pullin & Cook, 2013; Sellwood, 2017).

Considering these established frames from the AAC and HCI/design communities, the findings revealed that the design documentary motivated designers to consider new frames that engaged with a humanist agenda. As argued by McCarthy and Wright (2010), this humanist agenda is concerned with acknowledging people's subjective experiences and feelings through 'aesthetic seeing' (Wright & McCarthy, 2010). Namely, by discussing what they perceived as being important in Grace's life, the design team's new frames addressed her discontent in having to loudly speaking out in public, whilst socially, allowing for Grace to be part of a peer culture through communication. For example, by focusing on designing for creative ways of supporting peer interaction in 'quiet ways' and through different modes, the design team prioritised a cultural dimension that has traditionally not been identified in previous HCI or AAC literature that has instead largely focused on prioritising ways of enabling communication through speech.

Equally, the team's design frame on invasive technology and space issues prioritised an emotional interpretation by proposing that Grace was frustrated by her technology being 'imposed' on her for the practical accomplishment of talking, compared with her friends' uses of technology, which were more varied, self-selecting and fun.

As identified in prior work, the design documentary offered a more 'dialectical' and 'interventional' approach by creating a narrative through the researcher's interpretive lens (Green et al., 2015). In order to generate new design frames that acknowledged a humanistic perspective, designers utilised the findings of the two earlier empirical studies of the thesis that focused on children's everyday meaning making practices as well as their expressed values. For example, attending to Grace's and her friends' multimodal ways of enacting friendship through co-constructed cards, collages and play sequences, as well as identifying her as a caring, compassionate and sociable 9 year old girl. By utilising these new frames, this chapter opens up new directions for engaging with designing for the wider ecology surrounding children with SSPIs and their social groups, through a focus on:

- Friendship – that advances its reciprocal and shared nature;
- Play – that focuses on ways of supporting common ground in ways that are both meaningful for Grace and her peers;
- Cultural relations – that cultivate ways of advancing children’s peer cultures that can be below the radar of adults, and;
- Social environments – that minimise the invasiveness of assistive technologies.

However, it was also observed that the PD orientation of the design work, that focused on the child centred perspective, had an impact on how frames were subsequently carried out into technology design. Namely, whilst the design team generated alternative frames, they also utilised existing technology solutions to address the various parts of their new frame. Through their design concept ‘Whisper’, the team focused on supporting shared and ‘quiet ways’ of communicating by incorporating existing technologies such as shared, table top surfaces, movable mounting systems, privacy features through a dark filter on screen and photo/text messaging features. By utilising these existing technology solutions, the team expressed that they were largely influenced by an accountable stance. This enactment of accountability reinforces prior PD work that has been centrally concerned with being transparent with decisions and outcomes, based on collaborative work (Frauenberger et al., 2015). In the current study, knowing that Grace and her peers would respond to their concept, and taking on board Grace’s priorities, the team decided to design something that was practically achievable with the options available to them.

Whilst their frames were generative by evidencing novelty, the final concept was in keeping with traditional design solutions. As a design researcher, the proposed idea “Whisper” was both an exciting idea, yet limited in its operationalisation. It was exciting to see that the design team had prioritised “quiet ways of communicating”, drawing on new perspectives of designing for peer culture and social relations. This suggested that design groups with little experience of designing for disability can add exciting and complimentary perspectives by drawing on social, cultural and aesthetic sensibilities that have received little design focus to date. However, the proposed idea was limited by an orientation to existing design solutions rather than exploring innovative solutions. For example, Figure 6.02 (p198) demonstrates that part of the design team’s recommendation was an existing AAC system that uses a grid layout for organising symbol icons for words. In keeping with traditional solutions, these recommendations reinforced existing tensions in designing for bodily impairment rather than for example, intervening at an ecological level.

This led to consider whether the logistical recruitment set up impacted on the outcomes of the design challenge. Namely, had a different group of experienced designers encountered the design brief and tools, would they have engaged with the activities differently? Arguably, being design students on a master's course, the team brought along different skills and sensibilities that impacted on the ways they responded, compared with more experienced designers.

3. The role of design documentaries in design work

Constraint versus openness

Raijmakers and colleagues suggest that design documentaries are able to create their own dialect by exposing both the perspective of the researcher and rich accounts of situated instances that are captured (Raijmakers et al., 2006). In the case of this study, a decision was made to foreground rich details of how Grace communicated with others, through videos segments that depicted how she used her whole body to communicate. A decision was also made to limit the focus of how she practically accomplished speech generation through her existing AAC technology. Through these arrangements, the design documentary purposefully promoted ambiguity by avoiding detailed accounts of how Grace carried out practical tasks, such as turning a book page. Further, instead of offering detailed explanations about Grace's underlying intentions, the documentary used insights from the fieldwork data to foreground the types of activities and interactions that were motivating or challenging in some way. For instance, a line drawing taken from a video still illustrated Grace refusing to respond to the teacher's question using her AAC device, by holding up her arm as a barrier between her and an adult. Whilst explicitly suggesting that Grace didn't like being put on the spot, this instance left many questions answered, such as why might she dislike being put on the spot? In this instance, it was hoped that the design team would begin to make inferences, adding their own level of interpretations. However, instead, designers wanted practical details, such as information about what her existing communication book and digital language display looked like, or how she was able to practically accomplish a craft activity like making a collage or greeting card. By seeking answers from the researcher to fill in the gaps about task-based activities, designers sought to closely understand Grace's life so that they could empathise and explore possibilities. Wright and McCarthy (2010) argued that in order to empathise and understand a person's experiences, designers should deeply engage with focusing on the whole person, imaginatively constructing the world from another's perspective (Wright & McCarthy, 2010). For the designers in this study, there was a need to feel confident with understanding the practical details of Grace's experiences, so that they could appreciate what it would be like to communicate as Grace does. This desire for practical detail impacted on the

extent to which the team embraced ambiguity as a motivating sensibility (Gaver et al., 2003). For example, by seeking detailed information about Grace's existing situation, the designers interpreted Grace's experiences in one way, which might have been different had the information been more ambiguous. For instance, in their hunger for everyday (specific) details, one designer commented: *"I wish I had seen technically how it works... what it sounds like too, a robotic voice or does it sound like an actual, normal – normal? – child's voice"*. By focusing on these technical aspects of Grace's existing technology use, the team arguably became stuck on her current solutions, which limited opportunities for different types of discussions. As a researcher, this raised tensions in knowing how to deal with these requests. Whereas the design documentary and supporting materials were carefully designed to regulate the amount of technical information that was offered, the design team directly asked for this information, which was perceived by the researcher as adding too much constraint and limiting opportunities for ambiguity. Consequently, additional technical information was provided about the mechanics of Grace's existing technology which may have impacted on the team's decisions to utilise existing technologies in their final design concept. Reflexively, it was hoped that designers would ask different sorts of questions and speculate about different interpretations. For instance, taking a different part of the design documentary, designers may have speculated about why Grace's friend Oscar *"did not need to say goodbye"* or what it was about Grace that made the teacher identify: *"you're brilliant! you need to show everyone that you're brilliant!"*. Rather than engaging with technical questions about specific tasks, it was hoped that the video would prompt new speculations on a broader social level, like for example, her skilfulness in establishing common ground or her expertise in negotiating environmental demands. Furthermore, considering the setup of the workshop, it is also possible that designers did not have enough time to deeply engage in alternative ways of seeing Grace's experiences. In the future, this might be extended to allow for longer periods of divergence in understanding the situation and defining problems before converging towards solutions. Future workshops might also incorporate other generative resources that can motivate discussions by proposing alternative ways of seeing the situation through polyvocal assessments of the situation. For example, Gaver (2007) argues that cultural commentators, being professionals who are able to inform public opinion through the ways they communicate information, can provide useful, alternative perspectives for designers in these early stages by motivating them to see users from a different angle (Gaver, 2007).

Design documentaries as a learning tool

For Yarosh and colleagues (2011), designer values play an integral role in motivating design decisions (Yarosh et al., 2011). However, values can be implicit, and difficult to explicitly engage with in the design process (ibid). Moreover, as individuals within design teams bring with them differences in ways of working and solution preferences (Brereton et al., 1996), supportive mechanisms are needed that allow designers to successfully collaborate by understanding each other's separate perspectives and experiences. In the current study, the design documentary was used as a resource for asking questions to join up understanding. As each team member brought with them their own set of values and experiences, the design documentary prompted questions that signalled team members' understandings about communication, disability, and Grace's experiences. For instance, as highlighted in the section on 'Stimulating team involvement' of the findings, prompted by the card that Maya had created for Grace, the team discussed the possibilities of children's range of emotions, exposing personal understandings about children with SSPIs. One designer asked: "*Can they be mean?*", which signalled that she interpreted children with SSPIs as having a different range of emotions. This question then led to further discussion relating to their own personal experiences with disability, and one team member drew on personal information from their own lives to clarify and share understanding. By asking such questions, designers were able to develop collective understandings, based on their personal experiences and knowledge.

Whereas in the previous instance, the design documentary prompted questions about things they knew less about, separately, it also allowed for connecting and synthesising previous knowledge. Motivated by instances within the design documentary, the team discussed various topics including the rate and quality of speech production through AAC technologies, physical effort and technology personalisation. In one example, when prompted by the design documentary to discuss Grace's physical effort in using her existing AAC technology, one team member brought in a familiar examples from a book she had read, to augment what they had been discussing. By drawing on Jean-Dominique Bauby's memoir 'The diving-bell and the butterfly', the designer connected the discussion about Grace's physical effort to Bauby's example of methodically eye pointing to letters to spell out words by closely working with a conversation partner to co-construct this. By drawing on examples like this, team members synthesised information about what they already knew, to support the team's understanding of Grace's ways of communicating. These insights suggest that beyond motivating team members to consider the rich details of people's lives, design documentaries can also take an instructional role in highlighting gaps in understanding, generating questions and motivating

designers to draw on their personal experiences and prior knowledge to advance team learning.

Conclusion to study three

This chapter reported on a qualitative study involving designers, that utilised the empirical findings from fieldwork with children who have SSPIs. The goal of the study was to motivate new design frames on communication involving children with SSPIs, when designers without fixed orientations to the topics of disability and communication were involved. Informed by the findings of the earlier empirical studies, a design documentary was created that captured multi-layered interpretations about the communication experiences of a girl called Grace. The design documentary was intended to provide information and inspiration (Raijmakers et al., 2006) by motivating designers to consider designing beyond the task based requirements of supporting speech generation, towards appreciating what Grace might want from a new digital technology, and by deeply engaging with understanding about Grace's *felt life*. The study investigated how a design team of masters students used the design documentary to generate frames within a workshop in the early stages of the design process. An inductive, video and audio analysis of the data generated five main frame themes that captured the different ways that the group interpreted the design brief and materials. In doing so, the findings showed that the design documentaries motivated alternative frames on designing for communication in children with SSPIs by acknowledging varied dimensions of a child's life.

This chapter contributes new directions for engaging with designing for the wider ecology surrounding children with SSPIs and their social groups, through alternative frames that concern:

- Friendship – by advancing its reciprocal and shared nature;
- Play – through focuses on ways of supporting common ground in ways that are both meaningful for Grace and her peers;
- Cultural relations – that cultivate ways of advancing children's peer cultures that can be below the radar of adults, and;
- Social environments – that minimise the invasiveness of assistive technologies.

Challenges identified included managing how to position myself as a participant researcher in designing for a marginalised population of children whose voices are seldom heard at the fuzzy front end of design. The design documentary was created by carefully balancing how much technical information to offer concerning Grace's existing communication technologies, to

prompt speculation with a healthy dose of ambiguity. However, designers prompted me for specific technical information about Grace's existing device and communication book system, knowing that I had access to this information as a participant researcher in the earlier fieldwork and being a clinician with experience in working with existing AAC technologies. At the expense of offering too much information that might exacerbated an existing linguistically-oriented focus for AAC technology design, I offered this information which may have impacted on designer interpretation.

Whilst the design documentary about Grace was intended to foreground her lived experiences, it also inadvertently generated mixed messages for designer interpretation. Namely, the introductory narrative about Grace's physical impairment described "there were complications which affected the oxygen flow to her brain" at birth. Despite an active decision by the researcher to omit medicalised language, the inclusion of this information was out of kilter with the rest of the narrative. Arguably, the inclusion of this information may have exacerbated the extent to which the designers sought functional information about Grace's existing assistive technology and therapeutic tools. In the future, it would more helpful to omit this information, instead focusing more on the social and affective aspects of Grace's communication experiences.

It was also recognised that the ways that designers engaged with the design documentary and brief may also have been connected with their work experience, as students on a master's programme, as well as their accountable stance for designing for what was possible in the short-term. In future work, it would be interesting to examine how design documentaries would be used with other groups of designers from different contexts, as well as extending the possibilities of the structure of the workshop, as discussed earlier in the discussion section. Moreover, considering ways of extending how to create design documentaries with children, narratives that foreground children's voices through first person narratives would add an important perspective. Whilst this would be challenging to capture with this population owing to the difficulties of capturing and interpreting faithful accounts, child-led narratives are crucial as they provide another lens on informing design frames from the child's view.

The study makes a methodological contribution to existing work by demonstrating how design documentaries can be used in a new application area, namely, in designing for communication that involves children with SSPs. By presenting child-centred perspectives through interpretive work carried out by the researcher, the study illustrates how design documentaries can be used to generate novel design frames on communication. These move beyond solely involving adult proxies in place of children with SSPs, and re-shifting the focus of possible

communication technologies from a linguistic or task-based focus towards one that appreciates the values and priorities that children appear to express.

Chapter Seven: A theoretical and methodological reflection on investigating children's voices

Introduction: Why voice?

In order to evaluate the participatory process of involving children with SSPIs in design-oriented research, this chapter critically reflects on methodological choices and how they allowed for promoting and listening to children's voices. In this thesis, the notion of voice is defined in line with the Scandinavian tradition of how PD treats voice, i.e. *having a say*, as a core ideal. As discussed previously within the literature review of chapter three, having a say, in its most fundamental sense, means having something to say as well as affecting outcomes and decisions with what you say (Bratteteig et al., 2012). Moreover, rather than solely 'tapping into the expertise of users' for the purposes of designing better future technologies, in this thesis, the focus was on understanding about the things that impacted on and mattered to people (Bødker & Kyng, 2018). The reason why voice was of central concern for this research, was that as identified in chapter three, to date, very little interaction design work has placed the voices of children with SSPIs at the centre of design work in the early stages where requirements are yet to be defined (Benton & Johnson, 2015; Börjesson et al., 2015). Instead, interaction design work with different groups of children with special educational needs and disabilities has been guided by the perceptions of the designer and adult/expert proxies in place of children themselves (ibid).

Throughout this research, engaging with children's voices meant accepting from the outset that children with SSPIs have something to say. The challenge was to find apt ways of engaging with children's voices so that their contributions would inform the outcomes, i.e. in this case, informing the ways of representing and communicating children's experiences to a group of designers. In order to achieve this, study one and two (described in chapters four and five) sought to democratise the voices of different stakeholders by foregrounding children's everyday experiences by primarily focusing on child centred perspectives rather than for example, consulting adult/expert proxies. The focus was on understanding the things that impacted on and mattered to a group of children with SSPIs. This focus formed the central concern for what was communicated to designers in study three (described in chapter six). Furthermore, as the literature review in chapter three identified that existing design frames on

communication involving non-speaking children have been limited in their scope of what to design for, the empirical studies were motivated to identify alternative frames by attending to the kinds of things that child participants prioritised for communication. This reflected the decision to pursue child-centred perspectives, that was defined as attending to the ways that children agentively used resources such as objects, technologies and arrangements available to them, to signal their interests.

In related work, scholars from the field of childhood studies have invested concerted efforts to investigate children's voices through examining the sociological and political perspectives that shape how the notion of voice is constructed (Spyrou, 2011). James (2007), for instance, urged researchers to critically reflect on their role in the construction of children's voices (James, 2007). Separately, Nolas and colleagues (2018) considered how researchers are at risk of 'listening without hearing' in participatory research with children (Nolas et al., 2018). Through ethnographic work, the authors considered ways of tuning in to understand what mattered to children by attending the embodied, affective and lived experiences of children's everyday lives (ibid). Furthermore, Spyrou (2011) invited researchers to reflect on the complexity surrounding children's voices, by attending to their multi-layered and non-normative characteristics. For Spyrou (2011), this reflexivity meant moving beyond claims of authenticity in portraying authentic accounts, towards considering the social, political and historical processes that impact on how knowledge concerning children is produced (Spyrou, 2011). Despite these advancements in participatory research with the broader population of children, very few examples exist of participatory work involving children with little or no verbal speech. With the exception of Wickenden (2011a), limited research with children who have SSPIs has embedded these important considerations as highlighted through the work that is described above. Rabiee et al (2005), for example, suggested that very little is known about how to obtain the views of children with significant communication impairments. Rabiee et al developed a tool for engaging children who have significant communication impairments in interviews using visual cards with pre-defined choices (Rabiee et al., 2005). However, more than a decade later, investigating voice in children with SSPIs remains a challenge, with very little work that has reflected on the multi-layered and non-normative characteristics of children's voices and forms engagement remains.

With these considerations in mind, this chapter reflexively considers the reality of what happened when the goal was to listen to and promote children's voices in empirical work involving a group of children with SSPIs. As the empirical studies involving children were situated within the early stages of the design process, it was not possible to identify how

children's contributions impacted on final design decisions and outcomes. This was because the goals of the studies were not to produce final prototypes, but to invest efforts in researching and understanding how communication manifests in these contexts. At this fuzzy front end (Sanders & Stappers, 2008), it was expected that children's contributions would inform decisions about what to prioritise within the early stages of design, by foregrounding children's values and experiences in everyday communication situations. I reflect on how voice was investigated in the cultural context of children's daily lives by focusing on specific instances from individual children in a bid to avoid *reducing* or *homogenising voices* of children with SSPIs.

The goal of this chapter is:

Research goal

To critically examine how methodological decisions of the researcher impacted on engaging with children's voices.

The approach for investigating voice

To reflectively evaluate the approach for involving children with SSPIs in design work, this chapter focuses on methodological decisions that were made by the researcher in chapters four and five; the two empirical fieldwork studies involving children with SSPIs. In line with the social constructivist orientation of this whole thesis, this reflective evaluation focuses on how children's voices were studied by attending to the distributed and co-constructed nature of communication. The distributed nature of children's contributions meant that children's voices were dependent on the contexts within which they were produced, and generating co-constructed voices meant treating children's contributions as collective knowledge that was informed and shaped by multiple participants.

Reflective practice was at the core of the whole PhD project and strongly influenced how both empirical studies were planned and carried out, from early planning stages right the way through to data analysis and communicating the findings. Using Schön's reflective practicum as a guiding framework for managing these reflections, reflection *in-action* was interpreted as the process for on the spot 'experimentation', i.e. observing phenomena within the moment, evaluating what was happening through proposing an interpretation on the situation, then testing new ways of addressing the situation before then re-evaluating it based on new moves (Schön, 1987). For example, in one instance during fieldwork when discussing consent with a

child, this involved forming an interpretation about why a child reacted to me in a certain way, deciding how to respond by testing this on-the-spot, then reviewing the situation again, based on how I acted in that moment. Reflection *on-action* referred to the evaluations that were made whilst no longer immersed in the event, for instance, looking back at what was done and evaluating retrospectively evaluating what this meant for the kinds of insights that were generated. For example, following the end of a workshop session, evaluating how children and adults responded to my choice of methods and considering alternatives for future workshop sessions.

The reflections were based on the running commentary of supervisory notes that were created over the course of the PhD as well as fieldnotes that were created during data collection. The reflections identified five overarching considerations for managing ways of hearing and promoting children's voices within the design process:

1. [Voices that are shaped by theory, epistemology and context](#): discusses how each of these areas impacted on what could be known;
2. [Incorporating multi-layered, polyvocal accounts](#): illustrates how representations of children's contributions were generated through varied sources and different lenses for studying children's experiences;
3. [Studying strong and prominent ideas](#): describes the importance of generating credible insights through triangulation;
4. [Hearing non-normative voices](#): captures values emerging from forms of engagement and meaningful peer moments, and;
5. [Promoting child-centred accounts through choice of methods](#): considers the challenges and limits of certain methods.

1. Voices that are shaped by theory, epistemology and context

The start of this chapter introduced the idea that voices are socially constructed and shaped by social, political and historical perspectives (James, 2007; Nolas et al., 2018; Spyrou, 2011). Expanding on this, Mauthner and Doucet (2003) argued that rather than being a stable and fixed entity belonging to individuals, investigating voice in research with children involves explicitly engaging with the theoretical, epistemological and ontological assumptions of the

researcher. In considering the possibilities for reflexivity in the context of their own qualitative research experiences, the authors showed that data analysis methods were not neutral techniques that are used by researchers. Mauthner and Doucet suggests one way of operationalising reflexivity through being transparent about the particular epistemological and ontological concepts and subjectivities informing their research practices (Mauthner & Doucet, 2003).

With this in mind, in both empirical studies involving children, the *ways* that children contributed and *what* they contributed were closely aligned with the context and opportunities that I orchestrated, as a researcher. Specifically, the underlying theoretical orientations that related to communication and participatory design (PD) impacted on how methods were planned, used and how data was interpreted. This was coupled with tacit knowledge (Schön, 1989) I held about working within the school ecology, as a clinician-researcher. Together, these theoretical and practical influences informed the kinds of evaluations and moves I made whilst generating data. First, I discuss how theoretical orientations impacted on the study design through epistemological decisions. Next, I reflect on my background as a clinician and how this affected my approach for engaging with children's voices. Finally, in this section I consider the practical and environmental influences on generating voices.

Theoretical influences

In the case of studying voice in non-speaking children where the role of conversation partners and environment are seen to be highly important, treating data as co-constructed and situated was more pertinent than ever. In both empirical studies, children's contributions were richer when children had opportunities to create meaning in a range of multimodal ways.

During the early planning stages, recursive discussions on communication theories affected how communication would be studied. I was initially interested in the affordances of framing communication from both anthropocentric and non-anthropocentric perspectives. For this reason, in the early research design stage, during planning meetings with my supervisors we considered how different theories of communication would affect how communication would be studied. For instance, we discussed what the analysis might look like when taking a human-centred, multimodal social semiotic approach (Kress, 2010; Bezemer & Kress, 2016) compared with a nonhuman-centred, material semiotic perspective, for example, through actor-network theory (Latour, 1999; Law, 2007). Each approach would offer a different perspective for communication by either centralising the agentive role of the child (social semiotic multimodal

theory) or distributing agency amongst many parts (actor network theory). Hypothetically, deciding to embrace a non-anthropocentric perspective through actor network theory would have meant treating everything in the social and natural world as being relational, and attending equally to all kinds of actors that include humans, objects, machines and other actors (Law, 2007). Instead, the supervision notes captured the decision to advance a critical, emancipatory perspective that credited the ways that children produced meaning through their actions. Focusing on child-centred accounts meant attending to the ways that children used resources such as objects, technologies and arrangements available to them, to signal their interests. This advanced an emancipatory perspective by focusing on how children agentively used resources for advancing their own goals.

Instead of considering how non-human actors (e.g. objects) have agency, a decision was made to take a social semiotic multimodal approach that treated objects and arrangements as tools that are selected by people (in this case, children with SSPIs), for carrying out semiotic work (Bezemer & Kress, 2016; Kress, 1997). Importantly, in embracing the view that children created meaning by drawing on the resources that are available to them, the analysis focused on the many different and legitimate ways that children expressed themselves, therefore rejecting the developmental view of children's 'divergent' communicative actions as delayed or disordered.

This multimodal social semiotic theoretical perspective largely informed the ways that the data was collected, analysed and represented. By acknowledging that the transcriptions themselves *transposed* meaning from one collection of modes (i.e. conveyed through video representations) into another collection (i.e. conveyed through print) (Cowan & Kress, 2017), the findings reflected that the decisions made by the researcher, largely informed how the data was represented. For example, the decision to transpose meaning from videoed representations of interactions to print transcriptions that conveyed the temporal unfolding of events through image and text was intended to highlight some of the multimodal complexities of interactions (Cowan, 2017). Through the interpretative task of transcription, certain features of children's contributions were inevitably emphasised whilst others were lost. To give one example of this, the timeline design transcription style used in chapter four focused on conveying longer periods of time through broader transcription capturing less detail. This decision was taken owing to the prolonged length of conversations that involve AAC technologies. In contrast, the transcription style used in chapter five was inspired by other works that have attended to capturing specific detailed accounts over shorter periods (for example, Bezemer, Murtagh, Cope, Kress, & Kneebone, 2011; Cowan, 2017). By deciding on

this detailed view, the transcripts in chapter five presented the ways that different participants simultaneously acted together. For example, in the case of Oscar, Andrew and the researcher, in transcript 5.01, the presentation of the data reflects that all parties were collectively responsible for orchestrating the direction of the interaction; jostling for the communication book, and acting in ways to advance their own interests whilst acknowledging the moves of others. Therefore, by embracing this co-constructed and situated view, the findings of the empirical studies highlighted that all participants' actions shaped child communication, as a collaborative process.

Alongside this social semiotic multimodal approach for communication, PD provided the other key theoretical influence. By deciding to take a PD approach, the nature of how children participated was closely linked with the political discourses that underpinned PD work. These discourses identify that intended users of a technology can and should influence the changes that the introduction of technologies bring (Bødker & Kyng, 2018). Studying ways of allowing for children to *have a say*, as one of the core ideals of PD (Simonsen & Robertson, 2013) was central throughout this thesis. Taking a PD orientation could allow for children to partake in shaping technological solutions and future developments for things that matter to them and their peers, as advocated for by the wider PD literature landscape (Bødker & Kyng, 2018; Vines et al., 2012). The methodological attitude of the study aimed to provide opportunities for children to express themselves in their own ways (as per [Freire, 1996](#); [Vines et al., 2012](#)) rather than imposing rigid rules for working with children or prescriptive ways of equalising power between adult and child participants. With these political discourses in mind, the assumption that children can and should contribute to the design process formed a basis for examining children's contributions in terms of how they could be involved at different stages and what this meant knowledge generation.

Being a familiar, clinician researcher

Separately, as a speech and language therapy practitioner, in embarking on this thesis, I had actively decided to take a critical perspective on how to involve children through participatory methods. Having experienced ongoing challenges in involving children in decision making about their interventions, I was motivated to understand how children's priorities and values, when not heavily informed by proxies, could inform interventions. In taking a participatory approach for investigating communication *with* children, I rejected existing linguistic and developmental frameworks that had guided my clinical work to date. Instead, I chose to investigate what children themselves prioritised by observing what their meaning making practices communicated about their interests. The impact of this meant that the analysis was

inductively driven and themes concerning communication were generated from actual observed events, rather than treating children's communication as differently disordered to typical language-based norms.

Having worked as a speech & language therapist within the school for eight years, beyond holding knowledge about the participants, I had experienced the community and culture of the school setting and everyday routines from within. This offered a rich background for developing an 'insider perspective' that is not always the case in ethnographic work undertaken by researchers who have 'outsider perspectives' (Cowan, 2017). Having this insider role meant that recruitment was more straightforward and the school senior leadership team, teachers and parents had confidence in my ability to plan and carry out class-based activities. However, for child participants and staff members who were used to me taking a different role, more work was needed to dispel ideas about my perceived authority and goals. In the early stages of fieldwork with one of the participants Clara for example, I assumed that she would be wary of me observing her, owing to her associating me with the National Health Service (NHS) in my previous role. I also perceived that she would most likely be anxious at the idea that I might share her data with other NHS staff, having known her in a clinical capacity. With this in mind, class-based sessions began with me tentatively attempting to gauge her reaction before choosing whether or not to continue. One instance of this was captured in the fieldnote entry below:

I walked over to the table where Clara was sitting and in the spirit of giving her a say about my presence, asked her if I was able to sit next to her at lunchtime to which she replied 'no' by shaking her head then pointing to the door. The SNA, who was supporting, her commented: "Oh, that's not nice, Seray just wants to sit and join us", but Clara was adamant that I leave. I suggested that I could sit with another child but didn't push this. Clara commented (by signing) that I could come back after lunchtime, so respecting her wishes, I left the room to return in the afternoon session.

Fieldnote 1. Clara expresses she does not want to be observed by the researcher

In this instance, I chose not to persist as I was concerned that it might be detrimental to future observations. In deciding to leave, I also tried to demonstrate to Clara that the power relationship was different. Namely, I was attempting to practically demonstrate the reality of reconstituting our relationship. Whereas from my previous clinical experience with Clara I gauged that I could have persisted in trying to convince her with other strategies, I was sensitive that this may also sabotage any chance of gaining her trust within my new researcher role. Equally so, being a familiar adult in this setting, I was aware that my reaction to let her decide might cause tensions with other adults in the room by setting a precedence for 'letting

her get away with it'. In the moment, the decision to honour her first request and leave the room expressed to Clara that I had 'heard' and acted on what she was saying. I learned that I would constantly need to rethink and adjust how I treated her actions. These on-the-spot decisions, that ultimately aimed to advance child-centred accounts, highlighted the relational nature of data generation that was comprised of my perception of the child's actions, my actions to build a (new) relationship with participants in a research capacity and my perception about what other people within the school setting would think and how they might respond.

The school setting

On a practical level, the decision to carry out fieldwork in a school setting was motivated by a desire to understand how communication manifested in children's everyday lives. The school setting as a formal or structured teaching contexts was chosen as a setting whereby children spent much of their day there and was a key setting where AAC technologies have been studied and largely used within (Murphy et al., 1996). The decision to research in schools was also affected by the logistics of carrying out a PhD research study with the available resources and timeframe. However, being an institutional setting with its own established routines for communication, I recognised that what and how children chose to contribute would be likely to be different compared with other settings. To begin to address this, the second study introduced a novel way of studying communication by focusing also on the spaces between formal and structured learning contexts, such as corridor, playground interactions and drawing on information from children's home lives. Whereas existing work described in the literature review in chapter two has shown that interactional communication studies involving children with SSPIs has largely taken place in formal or structured settings (for example, Clarke & Wilkinson, 2007; Solomon-Rice & Soto, 2011), informal settings within a school provided an alternative, complementary context.

2. Incorporating multi-layered, polyvocal accounts

In chapter three, the review of previous interaction design work with children identified that children with SSPIs are rarely involved in the early stages of the design process (Benton & Johnson, 2015; Börjesson et al., 2015). The impact of this has meant that technology solutions have largely been informed by adult/expert proxies (Börjesson et al., 2015; Holone & Herstad, 2013) with a limited scope in frames of what to design for. For instance, a review of existing design cases on communication and non-speaking children identified limited design frames, that largely targeted alleviating bodily impairment or supporting learning. The chapter review identified opportunities for exploring how designing for communication can serve a wider

range of purposes, by engaging with the voices of children with SSPs for understanding their priorities, values and interests. In the empirical studies, attempting to capture and faithfully represent what children might value or prioritise, meant developing rich interpretations that lie beneath what children expressed. By evaluating the kinds of knowledge that was being generated *in-action*, I was able to understand what children expressed about their communication on different levels.

Studying multi-layered and polyvocal accounts was conceptualised as studying different dimensions of children's lives beyond technology use. Drawing on previous work, this embraced the view of constructing a well-rounded narrative around a specific child, rather than focusing on the 'plot' surrounding their lives (Nielsen, 2002). Multi-layered perspectives were intended to reflect children's *felt lives* (Wright & McCarthy, 2010), by investigating their experiences on affective, physiological and social levels. In practice, this involved investigating children's communication experiences relating to people, places, activities, how they participated in social activities. At a deeper level, it also involved interpreting the attitudes and values that motivated what children expressed. These layered interpretations extended beyond studying individual participants alone, to studying polyvocality through identifying what others said about children, as well as identifying how children's communication experiences were connected with the experiences of their social groups. One example of this was seen in the case of Oscar, as he conveyed his strong desire to interact with other people. The example that follows demonstrates both what a polyvocal account is and how it was studied. In chapter five, we observed the ways that Oscar valued 'involvement', as he disrupted an existing interaction to signify his frustration at being excluded. In this situation, as a researcher, I needed to develop a deeper understanding of what was practically happening by examining different data sources. From observation, there was an indication that this instance was conveying complex and multifaceted dimensions about Oscar's communication experiences, by his frustration at being excluded from a conversation, yet these speculations needed further probing. In addition to the behavioural observations that were captured through the field notes, other data sources, such as discussions with teachers, and his collage from the design workshop helped to produce different dimensions on his desire for involvement. On one occasion, Oscar's teacher had mentioned to me that he enjoyed being with other children but this could sometimes be difficult. When I probed for more information, his teacher had commented that Oscar was often keen to gain other people's attention in any way possible, and would sometimes seek out a reaction from others by shouting, biting or spitting. His teacher commented that whilst his actions could appear quite negative on the surface, he was desperate to interact with the other children in the mainstream part of the

school and tried to do this in any way that he could. At this point, I had begun forming a view that Oscar's desire for involvement played out in different ways and sometimes the intensity of his actions could be misinterpreted by others as being aggressive or difficult. In this instance, acknowledging that I was yet to fully understand Oscar's perspective, I chose to join him in the playground, adding an additional perspective on his motivation to interact with other children. The fieldnote that follows captured my interpretation of an interaction involving Oscar and a group of children in the playground:

In the playground, he occasionally waved towards some of the mainstream school children and would then go over to greet them, attempting to join in their play. Some responded positively, letting him join in, others took a teacher role, instructing him to 'be gentle Oscar', or to 'slow down Oscar'. Others reacted more negatively, running away as if scared by him approaching them, reacting with fear in an exaggerated way.

Fieldnote 2. Oscar's playground interaction

Coupled with Oscar's collage output that showed a further dimension on being motivated to be involved in everyday, typical activities (e.g. supermarket shopping, going to the cinema and birthday parties), the mixed data sources revealed multiple dimensions of prominent ideas. Capturing these multiple perspectives through different data sources and employing reflective and rigorous techniques, revealed different layered accounts of communication and specifically, what *being involved* meant for Oscar. This allowed for drawing new interpretive conclusions that motivated new inquiries.

3. Studying Strong and Prominent ideas

Studying how children's ideas and contributions were pervasive across the different design methods and data sources was important for voice, as it allowed me as a researcher to develop a stronger case for understanding credible insights about children's communication experiences. For Lincoln and Guba (1985), credibility referred to how congruent the findings can be with reality, identifying this as a key indicator of trustworthiness in qualitative work through naturalistic inquiry (Lincoln & Guba, 1985). By evidencing the consistency between strong and prominent ideas across methods, the findings generated confidence that ideas captured children's true intentions and were thus credible (Shenton, 2004).

In the previous section, the example involving Oscar illustrated that developing a polyphonic view of Oscar's communication experiences, allowed for drawing new interpretive conclusions about what was happening. The varied methods prompted interpretations that: *i.*) Oscar was motivated to initiate communication with others and did so in varied ways (some more socially

brother at the weekend. This repeated referencing towards family-oriented activities signalled its prominence in Noah's life. When triangulating data sources by reflecting on the collage-making and persona-editing, I was able to understand about some of the different dimensions that characterised the importance of family and a sense of belonging for Noah. For example, Noah's collage suggested that he was interested in talking about his father. His collage depicted a muscular, athletic figure that was made up of a combination of picture cut-outs. The created figure took up approximately one third of the whole page on an A2-size sheet of paper. In keeping with the child-centred account of my research, it was important to evaluate if and how these prominent ideas were driven by the children. Children's needs introduced a facilitative role for the adult which impacted on the kinds of contributions that were produced. I reflected on whether the accounts that were being generated came from the child or whether they were significantly shaped by adults.

During the activity, I had asked Noah and the SNA to share information about what they had constructed. By asking these questions and reflecting on how the collage had been created in the moment, I was also able to gauge the extent to which Noah had participated in co-constructing the collage. As the aim was to advance child-centred accounts, probing questions helped me to understand about the ways that the supporting adult had drawn on prior knowledge about Noah and his relationship with his father, in the early stages of the activity. In terms of capturing how this legitimately represented Noah's ideas, through the co-construction task, adults provided a starting point and window into discussing one possible interest. For some children, this was expanded on and featured prominently, for other children who were less interested in the adult's initiation, their collages reflected a number of varied interests, conveyed through examples of different activities and events.

4. Hearing non-normative voices

In reflecting on the use of methods in participatory work with children, Gallacher and Gallagher (2008) suggested that children's active involvement through participatory methods could be problematic in allowing for children to exercise agency in research encounters (Gallacher & Gallagher, 2008). The authors suggested that such methods were not always aligned with the goal of child empowerment, owing to difficulties of interpreting what children express on a surface level. Instead, the authors advocated for an attitude of 'methodological immaturity' which involved privileging open-ended inquiries for what children's contributions might be conveying.

During the empirical studies, instead of taking children's contributions at face value, it was important to engage with understanding what children's forms of engagement might be conveying.

This section considers the relational aspects of children's interactions by trying to explain children's voices in the context of power dynamics involving adults and children. It also considers how children's forms of engagement signalled meaningful encounters with their peers.

Through children's behavioural engagements with the methods, I was able to advance an understanding of the deeper motivations that signalled children's values. In one striking example of this, one of the children, Grace, used bodily action to signify her values in response to my actions. On one occasion during a cooking class session, I observed and worked with Grace to make an omelette. As I attempted to physically support Grace in holding and stirring with a spoon (which was physically challenging) Grace tensed her body, turned her head to the side and pushed backwards in her standing frame, and shouted "I do it!". Although Grace was predominantly 'non-verbal', this phrase was one that had become intelligible to many people at the school and as illustrated in Fig. 7.02, was a common characteristic in her interactions with others.



Figure 7.02. Line drawing from video still of Grace (right) resisting physical help from the researcher (left), Grace vocalizes "I do it!"

Despite physical challenges, Grace's regular, physical persistence to carry out workshop activities and everyday classroom activities by herself signalled that she valued independence. Though her forms of engagement, her actions emphasised that the ability to carry out physical tasks were on a wider continuum, nestled within a complex arrangement of available resources and her interests and motivation. Figure 7.03 is taken from a video still whereby Grace is concentrating on turning pages in a catalogue to add to her collage. The catalogue is

resting on her lap and she is leaning forwards in her wheelchair. She is frowning as she is intently focused on holding and turning a thin, glossy page which is difficult to grasp.

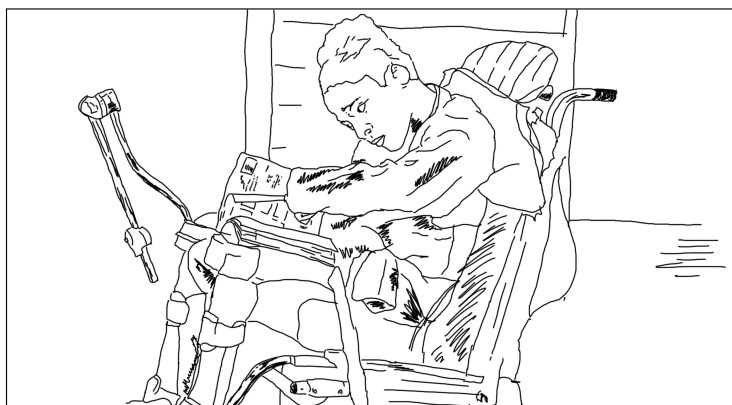


Figure 7.03. Line drawing from video still of Grace, intently focused on turning pages in a catalogue during collage making activity

In contrast, for Clara it was protecting her privacy that motivated how she engaged with the research. Earlier, in chapter five and in the first section of this chapter on ‘Generating interconnected, contextualised voices’ when discussing the ways that children signalled a desire for regulating privacy, an example involving Clara illustrated her refusing my entry into the classroom. For both Grace and Clara, it was their ways of engaging with methods that articulated their views.

As previously discussed in chapter five, Clara’s motivation for regulating privacy was clearly signalled through her actions. Whilst Clara had consented to be part of the study and often wanted to participate in fieldwork activities, she was also extremely cautious and sometimes anxious about how her contributions would be used. Two instances that reflected these interpretations were whilst discussing consent and during the collage making workshop. Figure 7.04 illustrates a discussion about consent for recording (left) and Clara’s rejection of the collage-making activity (right).



Figure 7.04. Clara's consent board using Talking Mats approach and collage materials

The discussion of a behavioural dimension for understanding children's forms of engagement so far have centred on trying to explain children's voices in the context of power dynamics involving adults and children. The values that were generated as a result were in the form of resistance.

By contrast, the storyboarding workshop was designed to promote children's participation where the adults took a facilitative role that was sensitive toward what children wanted to express. During the story-making workshop, children communicated with their peers and appeared to be fully engaged and motivated in constructing their stories together. For example, in one session, Grace and Clara were both very engaged in co-creating a funny story about fictional animal characters and people they knew. Through bodily actions, both girls suggested that they were motivated to self-direct narratives and interactions with their class peers and familiar adults and also to pursue creativity on their own terms. This was conveyed in a number of ways, including muscular tension suggesting excitement, children reaching out towards graphic image choices in their books to initiate, for example, as seen in figure 7.05 and also through the ways they listened to their peers and laughing reactively to other children's choices.



Figure 7.05. During story making workshop, Grace sits in semi-circle facing the researcher and reaches to her communication book to indicate what will happen next in the story. Image captured through lifelogging camera that Grace wore on her sweatshirt

In line with a developing body of research that is questioning how childhood researchers make sense of data on children's articulations, the insights underscored the importance of focusing on the affective, embodied and lived dimensions of meaning making (Nolas et al., 2018).

5. Promoting child centred accounts through choice of methods

In the previous section, investigating how children engaged with methods exposed some of the ways that children exercised agency in managing power dynamics involving adults and children. Whereas most of the methods used allowed for foregrounding children's voices in the analysis, photo capturing hindered this goal. Even though lifelogging acknowledged the effort of taking photos by automatically recording them, whilst offering a glimpse into the home context, it also took away control from children. It was anticipated that once we had captured images of children's daily lives, these would be discussed with children in order to reconstruct the meaning of the events captured, transforming children's passive everyday activity into active engagement. However, of the two children who agreed to wear the camera, neither wanted to explore the photos automatically captured. This may have been due to the volume of photos that were generated. Conversely, had I cut down the number of photos I would have made decisions on behalf of the child (Durrant et al., 2013). This would have been problematic, as deciding to reduce the number of photo choices could potentially have omitted important instances that children may have treated as significant, thus deciding on children's behalves. I identified that in this case, there was too much data to co-create the interpretive work with children.

In the absence of children's own accounts of their data, and in losing the insider perspective of being physically present as per other observation sessions, I faced tensions interpreting the photos in a credible way that reflected the reality of the situation that was photographed. For example, one of the images considered was of Grace sitting in her wheelchair at the edge of the living room whilst her younger brothers played and watched television on the floor on the other side of the room. The camera angle and the lack of sound or moving image, privileged a particular perspective adding distance between Grace and her brothers (Fig. 7.06). In lacking context, however, I questioned the credibility of this interpretation and it was difficult to move past my own subjective interpretation of the activity or what the situation might be signifying. Given these interpretive and also the epistemological misalignments with a child-centred approach, this method was removed from the analysis.

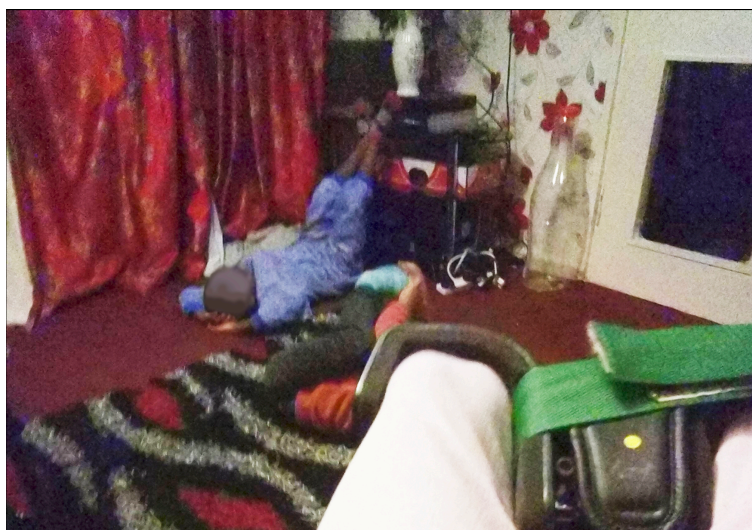


Figure 7.06. Life logging image captured of Grace at home. Grace sits in her wheelchair at the side of the room whilst her two younger brothers lie on the floor looking up at the TV.

Another methodological challenge that I faced concerned the use of personas and how faithful these could be in capturing and representing children's voices. The use of personas for promoting children's voices was problematic in two ways. First, the lean representation of the persona format was reductive in conveying the many dimensions of children's communication experiences. Second, the process of co-creating personas with children was problematic as in this case, required high levels of adult scaffolding.

Initially, it was intended that personas would play a larger role in eventually becoming design tools to be utilised in the third design study in chapter six. Moving away from the traditional use of personas which are created by designers to depict archetypes (Cooper, 2004), the intention was for personas to capture actual accounts of real children's experiences. As there

are no 'typical' profiles of children with SSPIs, it was hoped that varied, credible examples drawn from actual, anonymised children could highlight this diversity by capturing some of their very varied and individualised experiences. Whilst it was intended that personas could convey a multi-layered and polyvocal view on communication, as they would be co-created with children and intended to conveying varied insights that children had prioritised, in practice this was not the case. In creating individualised personas, it was difficult to represent the many aspects of children's lives conveyed through print alone. Whereas in practice, I observed children exercising agency by communicating in strategic ways with different people in different contexts, it was impossible to reflect this through a one-page summary of each child.

The initial decision to co-create personas with children was motivated by the idea that personas offered a similar format to communication profiles, which were visual tools that children in the study were used to creating with their teachers and therapists (Aitken et al., 2005). The expectation was therefore that children were familiar with the kinds of activities involved in creating these, owing to their parallels with communication passports. However, it became apparent that as personas had a different goal, i.e. to motivate future design, children were not used to being involved in design work in this way. Consequently, children were resistant to or did not have the resources to contribute to design oriented activities with an expectation that they would actively participate. In practice, children needed more time and opportunities to first learn 'the rules' of how they might participate. These experiences highlighted the value of building relationships with children as design partners over longer periods of time (Druin, 2002), particularly attending to how activities can be presented so that they are truly accessible and realistically offer deeper levels of engagement.

In attempting to co-create personas with children, during the persona editing workshops, challenges were faced in understanding and framing communication from children's own perspectives whilst they were being created. Despite my clinical knowledge and work-life experiences in communicating with children who have SSPIs, I found it difficult to apply communication strategies 'in the moment' that could motivate children to challenge what was already written on the page. On one occasion, in a discussion involving Noah, one of the child participants, and a Special Needs Assistant (SNA), I asked Noah and the SNA to look at Noah's persona draft to see if there was anything they wanted removed or changed. Following a short inspection, they both politely expressed that they liked it, which prompted me to consider that I needed another strategy for questioning the credibility of what was on paper. I directly asked Noah about other things he enjoyed, prompting him with choices in his communication book

and attempted to contextualise this by asking him about what he had done at the weekend. Consequently, I found myself asking Noah leading questions about the words he had expressed (“dressing up”), asking him what he dressed up as. I asked closed questions and offered suggestions, for example “Was it a spaceman?” / “Was it a robot?”. Noah smiled and agreed to all of the choices I offered him, which led me to believe that he was enjoying the conversation but was likely to be expressing something independent of what I was asking him. This example illustrates that my goal to create a more detailed, polyvocal account was out of sync with Noah’s goal to talk about the things he was interested in.

Given that the ultimate goal for using personas was to involve designers with no prior knowledge of the kinds of experiences I had hoped to convey, and as it was assumed that it would be difficult for designers to fill in the gaps in this instance, this method was abandoned.

Conclusion

Methodological reflexivity is critical in any research, and even more so when it comes to children with SSPIs where it can be difficult to identify if the findings reflect what child may be intending to express through their contributions. In the context of PD, many researchers have prioritised engaging with the voices of end users, by considering the realities of people’s everyday experiences so that technologies can positively impact on people’s lives (Simonsen & Robertson, 2013). In the case of PD with children, it can be difficult to engage with understanding children’s everyday lives, owing to challenges in managing power dynamics in participatory work with children as well as knowing how to manage competing stakeholder voices. These ambiguities are further exacerbated in interaction design work with children who have disabilities. In these cases, often children with certain disabilities, such as SSPIs, are rarely involved in the early stages where requirements are yet to be defined, and the voices of adult proxies have tended to inform decisions instead (Benton & Johnson, 2015).

In the introduction to this chapter, two challenges were identified in studying and promoting children’s voices in early stage design work with children with SSPIs. These were understanding what children express as important in their everyday lives, and identifying how to investigate children’s voices through methods and techniques. The methodological reflection identified that issues of listening and promoting voice were influenced by a number of considerations. These were comprised of:

- *defining voice* - that examined whose voice was studied and what layered dimensions it covered;

- *paying attention to voice* – through methods that allow for hearing non-normative voices; and
- *managing relational dynamics* – between the child and researcher in forming knowledge.

Reflecting on the earlier empirical studies, children's voices were defined as multi-layered and polyvocal. Specifically, interpretive work from different contexts of children's lives was needed to create holistic accounts that acknowledged the different dimensions on communication. The findings reinforced prior work that has suggested children's voices were not independent of the theoretical, epistemological and contextual influences at play (Mauthner & Doucet, 2003). Providing a new use case for studying voices in children with SSPIs, this work demonstrated the relational nature of situated, multimodal communication. It showed that by adopting a politically motivated PD perspective, it was possible to involve children with SSPIs in co-creating knowledge through active efforts to foreground what children express as important in their lives.

Equally so, by taking a situated, multimodal and politically motivated perspective for studying the ways that children agentively communicate on their own terms, it was possible to pay attention to how children chose to express themselves. In the context of this work, paying attention to voice, involved attending to the behavioural dimension of how children engaged with methods. It also meant reflexively applying mixed methods that allowed for strong and prominent ideas to be formed.

Lastly, the relational nature between the child and researcher was central in forming knowledge. In some cases, children exercised power over researcher-child interactions, expressing more about what was important to them through how they engaged with methods. In other cases, providing methods that allowed children to contribute in their own ways, and abandoning methods that limited this, produced useful insights about what they expressed.

These considerations contribute to the broader issue of involving children in participatory design research by proposing five main considerations for listening to and promoting children's voices. It is hoped that by providing a specific use case for researching with children with SSPIs, this work builds on ways of researching with children by acknowledging the challenges of studying voice in the broader population, as well as providing practical examples from empirical work that demonstrates how the contributions of children with SSPIs can inform design directions in the early stages of the design process.

Chapter 8: Conclusion

Designing technology that has a positive impact on people's lives is of central concern within the field of HCI as research moves away from studying human beings as subjects towards understanding and designing for people's contextualised interactions as human actors (Bødker & Kyng, 2018). Despite this central concern, within the context of assistive technologies for young people without or with limited speech, the abandonment rate for AAC devices continues to be high (Waller, 2018) suggesting a need for rethinking how these assistive technologies might reflect the contemporary concerns of people with complex communication needs and their social groups (Blackstone et al., 2007). Within HCI research, there has been a growing concern to contribute to the wellbeing and inclusion of children with disabilities by addressing some of the specific challenges posed by existing AAC devices. For example, addressing speed of speech generation through data-to-speech technology (Black et al., 2012), affordability and portability of devices (Sampath et al., 2012). However, by focusing on the challenges of existing AAC technologies that centre on speech generation, HCI research is yet to consider ways of designing for communication that can take alternative forms, beyond speech. By attending to communication in the context of children's everyday lives, HCI research can develop new inquiries into designing for communication that positively impacts on the lives of children with SSPIs and their social groups.

Whilst engaging with truly understanding the communication experiences of children with SSPIs is key, researchers have acknowledged the heightened difficulties of involving children with disabilities in design research (Benton & Johnson, 2015; Börjesson et al., 2015; Holone & Herstad, 2013). For instance, children with SSPIs have largely taken limited roles as testers of designed technologies, instead of guiding requirement gathering in the early stages (Benton & Johnson, 2015). Therefore, whilst technologies for communication can potentially have a profound impact on the lives of children who are at heightened chance of social risk factors associated with their SSPIs, involving children in design at the early stages, and broadening the scope of what to design for, has been limited.

The overarching goal of this thesis was to change how communication is designed for by expanding the possibilities for conceptualising communication. Whilst framing at the early phases is crucial for informing design, HCI research in this area has focused on the later stages by improving existing solutions. To address this, the central concern of this thesis has been to

produce alternative frames. This was achieved in a number of layered ways: *i.* by foregrounding the child; *ii.* by generating new empirical insights for communication, and; *iii.* by creating a new generative tool that builds on these insights.

In order to foreground children, the fieldwork and analysis adopted a social semiotic multimodal approach (Bezemer & Kress, 2016; Kress, 2010). This attended to how children agentively used resources for meaning making. In addition to this, PD methods were used that allowed for promoting children's voices, in line with the political conviction of PD for democratising having a say (Simonsen & Robertson, 2013).

By studying multimodal communication in children's typical daily lives, new empirical insights identified multi-layered perspectives on communication that focused on: 1. a child's view, by attending to children's values and choices of modes; 2. an interactional view that attended to how communication was co-constructed in situ with other people and material objects, and; 3. a structural view, that examined the orderings of people, material objects and activities within an environment.

These layered understandings generated new empirical insights that were used to inform the creation a design documentary. The design documentary served as a generative tool for inviting alternative interpretations on what to design for in face-to-face peer interactions involving a girl with SSPs.

The remainder of this chapter consolidates the main contributions that have been proposed in the earlier chapters. This doctoral thesis contributes to the fields of HCI, AAC and speech and language therapy in three ways. These are through:

- **A theoretical perspective on communication** - informing the fields of AAC and speech and language therapy practice by bringing a previously hidden practice to the foreground;
- **Design opportunities for new and existing technologies** - informing the fields of HCI and AAC through alternatives that are based on expanding the possibilities for how children communicate in multimodal ways, in everyday situations.
- **A methodological contribution for design work** - informing the field of HCI by introducing considerations for participatory work with children who have SSPs.

Contribution 1 – A theoretical perspective on communication

Whereas existing work has attended to the ways that conversations involving children with SSPIs and their social groups are organised around talk, the thesis introduces a new perspective for studying and describing communication by distributing the value that has been placed on linguistic modes. Using social semiotic multimodality as a theoretical underpinning, and in line with the paradigm shift proposed by this theory, attention is given to recognising the many, wide-ranging modes that people use for the purposes of meaning making. By acknowledging multiple modes and displacing the taken for granted centrality of language, this work demonstrates that when we focus on what children *can* do, rather than what they *cannot*, it is possible to expose typically unseen features of communication. These largely unnoticed features have the potential for disrupting what is understood about children's communicative capabilities in contexts of education, healthcare and importantly, within their everyday social experiences. The implications of these layered understandings are significant. Firstly, in the current landscape of communication research in the field of AAC, there are no established underpinning theories that have been proposed for explaining communication that involves people with SSPIs and their social groups (Barnes & Bloch, 2019). Instead, research on communication in these situations has focused on foregrounding the epistemological perspectives that researchers have taken through their methodological approach.

Instead of imposing binary grouping of communication being 'verbal' and 'non-verbal', this work has shown that by observing, analysing and documenting communication through a truly multimodal lens, we are able to attend to the multiplicity of modes and resources that are agentively used by children with SSPIs and their social groups for meaning making. Consequently, by attending to the affordances of a range of material objects and structures, it is possible to foreground children's capabilities in this co-created process of communication. These insights provide opportunities for researchers and practitioners to take stock of how one interprets what is happening and intervenes in any of these situations. For education and therapy purposes, this is important for ensuring that interventions are relevant by build on what children are doing. For this reason, the described application of a multimodal social semiotic theory offers an apt way of studying and describing communication from a clear theoretical stance.

Moreover, by engaging with children's values alongside a social semiotic view, it is possible to understand children's experiences more holistically; by providing an alternative perspective on communication. By attending to what children with SSPIs express as important for their

communication in the context of their everyday lives, it is possible to engage with understanding the motivators behind children's modes of conduct.

Building on interactional research from the field of AAC, the empirical fieldwork studies with children present new contexts for studying interaction. As existing AAC interaction studies have focused on conversations that involve people and AAC technologies, the thesis contributes new insights that are drawn from very typical, everyday interactions, with a significant focus on how communication manifests with and without AAC technologies. By investigating communication in the natural 'hubhub' of children's typical school environments, the findings show that structural arrangements of the environment and people's actions significantly impact on communication involving children with SSPIs. Building on existing AAC research that has examined communication competence (Light, 1989; Light & McNaughton, 2014) the findings demonstrate the importance of attending to the relational qualities of communication.

The second major impact of the theoretical insights relate to clinical implications for the field of speech and language therapy. In line with the World Health Organisation's guidance on classifying disability (World Health Organisation, 2018), speech and language therapy practitioners have recognised the importance of planning interventions that have an impact on how people with SSPIs are able to participate in everyday social activities. This has been evidenced through a move away from solely focusing on (re)habilitating at the level of the individual's bodily impairment, towards interventions that focus on enabling access to participation through conversation partner training and making adaptations within the environment. The empirical insights strengthen this view, demonstrating that therapy interventions should be designed to support communication on an ecological level, by increasing the focus on interactional dynamics and structural arrangements.

The third impact of this theoretical perspective has implications for education. In line with the growing interest of the tensions in quantifying and assessing children's learning (Cowan, 2017), this work highlights a need for rethinking the frameworks that are being used for measuring achievement, particularly when these heavily rely on developmental or linguistically driven perspectives. These perspectives are especially unhelpful in the case of measuring success in communication and learning in the case of children with SSPIs whose learning trajectories are unknown (Clarke et al., 2016). This work builds on the view of a need for attending to a wider range of modes and resources when measuring children's communicative capabilities in formal learning contexts. For example, in study one that focused on classroom interactions involving children, adults and AAC, the findings underscored the value of recognising children's social

and strategic competence, even when linguistic resources were not available to them. This supports the need for attending to how children demonstrate their communicative expertise and use strategies for communication on their own terms, as well as understanding how children communicate on their own terms in unstructured interactions, beyond the classroom. These insights can inform how communication competence is assessed by recognising the broader ways that children communicate multimodally. One way of fostering this, is to involve parents in sharing insights that can inform how children's communication profiles are assessed.

Contribution 2 - Design opportunities for new and existing technologies

A major goal of the two empirical studies involving children, was to inform interaction design by exposing instances of everyday communication that were treated generatively to support child centred communication. This was achieved by applying a multimodal lens on aided communication in formal teaching contexts involving teachers, across a more diverse set of school-based encounters between children, and an examination of the values children ascribed to communicating with peers and adults. Based on the insights, a number of opportunities for design directions were generated for supporting communication that is aided by technology. These opportunities are relevant for design research and provide an empirical basis for further developing design ideas beyond these early stages. A synthesised list of six design opportunities from both studies is summarised as follows:

Communication is embodied

The children in the study used bodily action to communicate more frequently than their AAC systems. When aided AAC systems were used, these were integrated as one type of resource alongside other semiotic resources. The prevalence of communication that happened through bodily action over spoken language highlights an important gap in technology design for children with SSPIs. Communication through the body can be quicker and less effortful in certain situations, yet can often go unnoticed. For this reason, opportunities exist for improving ways of attending to children's individualised communicative modes that occur through the body.

Respecting child competence and agency

Children's social and strategic expertise whilst using existing AAC technologies would sometimes go unnoticed in conversations with adult conversation partners. Instead, adults tended to focus on children's linguistic and operational use. In order to respect children's social and strategic agency and expertise in making timely decisions on what and how to communicate, new considerations are needed that allow AAC technologies to be personalised and grow in line with children's current expertise. Further, in the studies, adults inadvertently made judgments about children's privacy by using children's AAC as an archival resource and by assuming that children were happy for their contributions to be shared with others nearby. In line with promoting children's agency in regulating their privacy management, new ways are needed for children to regulate disclosure through AAC in instances where it is used as an archival object by naturally speaking partners.

Supporting child-initiated communication

In conversations involving AAC technologies in formal learning contexts, AAC use was predominantly organised around adult goals with instances of teachers teaching children how to respond to questions with specific types of answers. This rigidity meant that children had limited opportunities for experimenting with forms of communication and language and interacting with other children who also used AAC technologies. The findings suggest that opportunities exist for supporting child initiated communication that allows for children to establish common ground in aided conversations with their peers, and also to be able to self-clarify in situations where communication misalignments have occurred.

Regulating the orderings of modes and social structures

In the first study, the findings showed that AAC technologies exacerbated the ways that disability was socially produced. When AAC technologies were present, they were often explicitly talked about, rather than 'through' and at other times, they acted as physical barriers between the child with SSPIs and their social groups. In these cases, disability was produced through material structures that inhibited children from joining an interaction by hiding their attempts to initiate. In the second study, other material objects such as communication books and symbol boards, and structural arrangements of people and objects, also presented as physical barriers. Furthermore, naturally speaking adults organised the structure of interactions by setting up expected ways for children to respond, creating further orderings through fixed conversational styles. The findings of both studies therefore suggested that

opportunities exist for allowing children to regulate these orderings by regulating the presence of material objects like AAC technologies and being able to signal when structural arrangements stop children from visibly seeing and interacting with their peers. Moreover, considering structural barriers that were created by conversational styles, there is also a need to consider ways of recognising what children's intended meanings are, by 'waiting and wondering' rather than trying to predict or interpret these within rigid conversational structures.

Interconnectedness and belonging

In the second study, an investigation of children's values showed that children prioritised interconnectedness and belonging through the ways they signalled their interest and affiliation with their friends' lives. This was achieved through ongoing care practices that were scaffolded by other people and processes, as well as being able to do things the same as other children of their age. Children were keen to establish and maintain friendships by taking part in everyday, typical activities, providing opportunities for co-creating meaningful, shared experiences. Based on these insights, opportunities exist supporting the ways that children can understand about their peers' interests, so that these common interests can strengthen ties between children and their social groups. Opportunities also exist for strengthening the ways that children can enact these interconnected, ongoing care rituals, based on their regular encounters.

Advancing involvement through play

Children in the study demonstrated their communicative expertise through playful exchanges that conveyed wit and humour. These playful occurrences were part of communication instances within both formal learning situations and informal contexts throughout the day. In addition to this, children were motivated to access play opportunities which provided opportunities for social interaction, exploration and learning. The findings underscored the importance of play for many, varied functions. This motivated a new design opportunity that prioritises advancing play, and consequently, participation, rather than addressing functional skills. Furthermore, as opportunities for accessing play were situationally dependent, i.e. that children sometimes needed external support to physically access play encounters, opportunities exist to design for ways of regulating the amount and forms of external support offered to children with SSPs. This is in line with one of the earlier design opportunities for regulating social structures, whilst enabling children to access varied experiences that they may typically miss.

The empirical studies described in chapters four and five illustrated ways of studying and describing situated, multimodal communication, as well as generating design opportunities for existing and future technologies that are intended to support communication involving children with SSPIs and their social groups. These design directions underscore the importance of providing supports when they are needed and regulating forms of support so that they are in line with children's values and goals. The design directions offer a starting point for future interaction design research to continue developing these opportunities with children who have SSPIs and their social groups. Together, the identified opportunities open up possibilities for sensitively tuning into what children have expressed as important in their lives, drawing attention to social, affective, care-focused and protective dimensions that have yet to be central to designers undertaking this type of work.

Contribution 3 - A methodological contribution for design work

Involving children who have SSPIs in design

Involving children with SSPIs in design can be challenging as it can be difficult to directly engage in dialogue with children, owing to speech impairments. Instead, designers have tended to involve children with SSPIs by observing their responses to a prototype, once a technology has been designed (Benton & Johnson, 2015). Interaction design work with children who have SSPIs can also be difficult owing to challenges in managing power dynamics in a process whereby children may require a high level of support to participate in structured activities (ibid), as well as managing the competing voices of many stakeholders who are involved. For these reasons, there has been a lack of design research on involving children with SSPIs.

PD as a politically motivated approach, offers possibilities for engaging with end users whose lives will be impacted by intended technologies. Through a key focus on democratising having a say, PD critically engages with hearing and responding to marginalised voices (Simonsen & Robertson, 2013), which provides a helpful underlying perspective for designing with children who have SSPIs. Rather than solely involving users for the purposes of developing better technologies, PD can motivate design work that seeks to positively impact on children's lives by considering what is important to children as a central concern (Frauenberger et al., 2015). In related research from the field of childhood studies, researchers have invited others to reflect on the complexities surrounding children's voices, through attending to their multi-layered and non-normative characteristics (Spyrou, 2011). Also, by critically examining how the researcher orchestrates child involvement (James, 2007). The thesis has shown that it is

possible to involve children with SSPIs so that their involvement significantly impacts on outcomes, through the reflexive application of methods. By engaging with researcher decisions, this work has shown that it is possible to amplify children's voices so that perspectives, methods and techniques that promote rather than hinder voices are used. The key considerations in chapter seven identified that by engaging with child centred accounts, it was possible to understand how theoretical and epistemological choices impacted on the construction of voice in context. By adopting a reflexive methodological attitude to researching with children (Gallacher & Gallagher, 2008), children's contributions could be understood in terms of what constituted strong and prominent ideas. This also included attending to a behavioural dimension for understanding prominent ideas that were conveyed in non-normative ways. The reflexive attitude allowed for exposing and managing methods and techniques that hindered the goal to hear and promote child voice. The insights from the fieldwork studies involving children emphasised the interconnected nature of voice, underscoring the importance of attending to many contextual factors and treating knowledge as situated within that context.

In many forms of design research, it is useful to engage with understanding how the insights that have been generated can inform future work. Engaging with types of knowledge that have this transferable quality, Höök and Löwgren (2012) proposed the term *intermediate level knowledge* to reflect the types of insights that can transcend specific instances of design work. Examples of this kind of knowledge that can be abstracted from specific design outcomes, include methods and tools, guidelines and strong concepts, which have generative qualities and can be appropriated by design teams in new instantiations (Höök & Löwgren, 2012). For instance, in research from the HCI subfield of interaction design with children (IDC), Barendregt et al (2017) reviewed published papers from the IDC conference in a 13 year period and gave one example of a strong concept as 'head-up gaming' (Barendregt, Torgersson, et al., 2017). This was drawn from several IDC papers that focused on the ways that children performed tasks by moving around 'in the wild' through social interaction and movement in multi-player games, rather than through 'head down' and solitary ways. The empirical findings of the thesis generated knowledge in the form of design opportunities. Design opportunities were considered instances of intermediate level knowledge as they are able to be abstracted for different design purposes, including instantiations that extend beyond designing for communication involving children with SSPIs. For example, taking the idea of 'interconnectedness and belonging', new design scenarios and applications might include designing for supporting remote communication and social practices in a range of work, education and healthcare contexts. As the design opportunities that were generated are

currently in their infancy, opportunities exist for developing these further in a number of use cases. In returning to the value of involving children who have SSPs in design, the insights that were developed through participatory methods allowed for the development of this generative, intermediate level knowledge.

Involving designers in new ways

The thesis aimed to inform design with a new perspective on communication that is characterised by the use of multiple modes and situated social arrangements, highlighting children's interests and values. To achieve this, a narrative based method was used because of the importance of attending to and being able to communicate the richness and multi-layered qualities of children's communication experiences, whilst still retaining some level of ambiguity for motivating generativity (Gaver et al., 2003). The design documentary encapsulated a polyvocal and multidimensional account of the communication experiences of a nine year old girl called Grace. Through the presentation of a well-rounded character (Nielsen, 2002), the design documentary was intended to illustrate that Grace's lived experiences of communication were inseparable from her situated physical, sensory and emotional experiences, as well as leaving space for designers to interpret why certain things might be happening in a certain way. Using the design documentary, designers were able to imaginatively discuss and appreciate what it might be like from Grace's perspective, whilst appreciating that they held very different experiences themselves. The tool therefore offered designers with opportunities to move closer to empathising with Grace's experiences through conversations that allowed them to draw from their own experiences. It also contributed to their discussions by acting as a learning tool, as through their questions about the video content, team members signalled their understanding about communication, disability and childhood. By asking questions about the video and synthesizing information from additional sources, the design team were able to form collective interpretations and design for Grace's communication experiences. The tool therefore opened up opportunities for creating multiple new design frames, that related to friendship, play, cultural relations and social environments. One of the main challenges of using design documentaries was knowing how to position myself as a participant researcher, as I was actively involved in both generating data in fieldwork with children, as well as presenting the design documentary and discussing it with designers. Knowing that I had been closely involved in generating the data with children, designers were keen to ask detailed questions about Grace's life which could potentially limit any ambiguity that the tool was intended to leave space for. Further, as the design team were formed of a group of masters students with limited experience, it was unclear whether a

different group of designers with broader industry experience may have appropriated the tool differently. Despite these challenges, the design documentary provided a useful method for generating new frames on communication for designers who do not hold fixed orientations to designing for disability. The findings in chapter six illustrated that by engaging with a child's lived experiences beyond the task-based demands of speaking, new and varied design frames can be generated that closer align with what children may choose to prioritise for communication. This suggests that using narrative methods such as design documentaries can be useful for supporting discussions that transcend some of the traditional ways that communication has been typically designed for through speech generating AAC devices. In the thesis, design documentaries were useful in situations where designers knew very little about the specific situation they were designing for.

The findings of this study contribute to HCI research on design methods by showing that design documentaries can motivate alternative interpretations. As the literature review in chapter three identified a limited range of research use cases of design documentaries, this research builds on the work of Raijmakers, Gaver, & Bishay (2006), by examining the role that design documentaries can take in design work and by providing a practical application of a new use case.

Limitations and future directions

Contexts of study

Institutional settings like schools can pose certain structural influences that impact on how communication happens. Investigating communication within the school setting provided one lens through which to observe this, and investigating different contexts beyond school-based settings would inevitably have produced different insights. A decision was made to investigate communication within a school setting, as it provided opportunities for studying natural instances of communication which might not have been observable in a short-term fieldwork study within children's homes and other contexts. Connected with the overarching aims of being able to study situated communication in the context of children's everyday experiences, the school setting afforded opportunities to investigate how communication manifested across people, contexts and activities. Within schools, my presence as a researcher was also less intrusive than had I observed and recorded children's home lives. This was due to children being accustomed to frequent visitors and recording/observation in this setting. Conversely, it would have been more difficult to video naturally occurring instances of communication

without prompting or intruding on the typical sequence of a routine activity within a home or out of school setting. In order to build on further opportunities for investigating naturally occurring interactions beyond school settings, more work is needed that considers ways of faithfully capturing children's communication experiences beyond their school day. One direction for this, is utilising anthropological approaches that seek to understand what it is like from within the community (for example, Wickenden, 2011b). Alternatively, some HCI researchers have begun to look at negotiating ways of recording people's home life interactions in a minimally intrusive way, by regulating how and when a camera records (for example, Porcheron, Fischer, Reeves, & Sharples, 2018).

Participants: sampling and representation

One of the underlying ambitions of the empirical studies was to expose detailed accounts of how children's communication experiences manifested in different ways. A critical case sampling strategy was used that recognised the diversity of children with SSPIs and therefore purposefully sought to recruit 'information rich' participants through their varied profiles (Patton, 1990). Rather than forming archetypal representations or being able to show how children with SSPIs communicated in generalised ways, the aims were to highlight and celebrate the richness and diversity in communication instances across the heterogeneous population of children with SSPIs. By focusing in detail on each of the five children across contexts and using mixed data collection methods, the field work exposed detailed examples of the hugely varied repertoire of meaning making practices that children and their social groups engaged in. When considering ways of representing communication events, a decision was made to transcribe video observations multimodally as well as documenting through researcher fieldnote entries and photos of people and outputs of different activities. These ways of documenting conveyed my interpretation of the events yet through triangulation and team discussion with my supervisors, the intention was to convey multiplicity of how participants communicated. In order to build on ways of capturing and representing rich accounts, future work should continue to question how far chosen methods are appropriate for advancing child-centred perspectives. Whereas I used multimodal transcriptions in new ways to highlight the multiplicity of how children communicated by giving equal attention to different modes in their representation, future research can continue to expand on ways of representing real life situations. For instance, in the case of describing communication in children with SSPIs, language terms that are coined from other disciplines can be highly 'loaded' with interpretation, for example, the phrases 'looking behaviour', 'eye gaze' and 'uncontrollable movements' all offer some level of interpretation. Opportunities therefore

exist for developing terms that are harmonious with what transcriptions are aiming to represent.

Participatory work and participant gains

One major focus of interaction design work with children has been to identify how children benefit from being involved in design research (Bossen et al., 2010). Whilst PD work with users typically produces indirect gains for participants through developments for future technologies, researchers have argued for critically engaging with the more direct and personal gains for research participants (ibid). This has motivated recent PD research that engages with empowering children to develop the skills they need to make critical and informed decisions about the role of technology in their lives (for example, Iversen, Smith, & Dindler, 2018). As this thesis was focused on the early stages of the design process, it was difficult to ascertain how participants in the study directly and personally benefited from taking part. Even though on a practical level, I was in regular contact with children's families and school teams and regularly shared insights about children's communication, the study raised tensions concerning participant gains. As children were not involved in the process of making the technology, owing to this work being situated in the early stages, children were unable to engage with understanding how their involvement could transform the outcomes of design work. As participatory design researchers are increasingly reflecting on what children take away from being part of participatory design work (Bossen et al., 2010), opportunities exist for moving through the whole design cycle in PD work with children who have SSPIs. As part of this, future work should explicitly attend to supporting children in developing their skill sets in collaborating in design work so that they can also apply these skills in other situations. In the second empirical study, children were reluctant to engage in dialogue for editing and improving a persona that was created about children. This highlighted an important gap in supporting children to learn how to engage in such discussions about how these representations might better reflect them. This suggested that as the children taking part were not used to taking these roles, they had limited resources or were reluctant to contribute. This could be addressed in future work with longer and deeper relationships with children as design partners, so that they feel supported in taking design roles and contributing when they choose to.

Final comments

This thesis has contributed to existing work by drawing attention to the richness of how contextualised, everyday communication involving children with SSPIs and their social groups manifests. In turn, this has shown that multiple, alternative perspectives on designing for communication can be produced. Through a multimodal lens that distributed the value that has traditionally been placed on linguistic modes, the empirical studies demonstrated that if future communication technologies are to be successfully embedded in children's lives, they need to reflect child centred ways of communicating. Recognising children's communicative expertise is highly challenging, and requires a conceptual shift in attending not to adult goals, but instead inductively attending to child-centred accounts. By moving closer towards understanding children's communication on their own terms, designers can generate multiple and diverse frames on designing for communication that ultimately impacts on the lives of children with SSPIs.

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Appendices

Appendix 1: Parent / Carer Information Sheet

Project title:

Involving children with severe speech and physical impairments in the design and development of their augmentative and alternative communication aid technology.

Dear _____

We would like to invite you and your child to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. This information sheet tells you about the purpose of the study and what will happen to you if you take part.

If you are interested in taking part with your child after reading about the study, we will ask you to complete a formal consent form (a draft consent form is enclosed with this information pack). Once we have received this we will call you to discuss any questions you may have about the study and to arrange a time for you and your child to meet the research team at your child's school. When we meet we will be able to demonstrate the type of activities we would like to involve your child in and talk to you about the kind of discussions we will be having.

Purpose of the study

Young children with physical disability who have difficulty producing speech are often reliant on using different methods of communicating to help to get their message across. Children who can use pictures and symbols to communicate are usually assessed for an electronic communication device which helps them to generate speech. Usually, they press the buttons on their talking computer with switches, by looking at it or pressing onto the screen. Normally, they have a very large bank of words to choose from which are organised and grouped into folders in boxes. Some children start using these devices very early in childhood, sometimes before the age of 5 years, and for some children it can be difficult to learn this skill.

Up until now, most of the communication aids that are available to buy have been designed and developed by adults with little involvement from children. These aids typically organise

words in the form of symbols on a grid layout. For older children, this can be very useful but can be challenging for young children who need lots of support to learn this new skill. Our study will explore what children themselves want from their communication aids. We will involve your child in discussions and activities that encourage them to share what and how they want to communicate and how new technologies can support this.

If we can find out what children prioritise and value when communicating with their friends, families and others we hope that we can improve the design of devices so that young children and those new to using devices can use these more effectively.

We will use different methods to gather this information. First, we will observe how your child communicates throughout the day in varied ways, with and without their communication aid, noting how this varies with different people and places. Next we will invite them to directly tell us what they think about how they interact with others and communicate. This will be through different methods that do not place unnecessary strain on their verbal skills, e.g. depending on what is appropriate, they might choose to take pictures, draw, write, use symbols or other non-verbal methods to demonstrate this. During this process, we will talk to key people at school who know your child to gather more information about what typically happens on a day-to-day basis. Last, we will run a series of focus group workshops involving children who use communication aids to share their views and ideas of ways of communicating and how technologies can support this.

Our research team have years of experience in working with children with disabilities. In our experience children normally enjoy being given the opportunity to share their views about their personal experiences but if for any reason your child becomes anxious, distressed or overly tired we will stop our workshops and observations straight away and not continue unless you are happy to do so. Please be aware also that at least one other adult from your child's school will also be with your child during all activities.

Why has my child been invited to take part?

We are writing to you because your child attends a Haringey special school and the study is being partly carried out by a speech & language therapist who works at the school.

Please note that no one outside the care / education teams at your child school has had access to your personal details in preparing this invitation. Only members of the therapy and school team who work with your child directly, or researchers who are supervising this project will have access to personal details as part of your participation in this study.

What would participation involve?

If you are willing for your child to take part in the study, we would like to call you talk through any questions that you might have. We will then visit your child in school where we will carry out our activities. After we have collected and analysed the data we will provide you with a

summary of the findings of the project as well as inviting you to an event that exhibits what children shared in terms of their priorities and goals for communication and their technologies.

Our study is also collecting information on children's physical, speech, language and learning abilities. These sorts of information are normally collected by members of your child's care team at school. With your permission we would like to take a record of these skills.

More generally, sections of your child's school notes may be looked at by researchers who are also members your child's care team at school, or researchers who are working within the project.

Will you photograph and/or video record my child?

Yes, with your permission we would like to take photos and video record the activities. This will help us to see accurately how our child gets on. It is important for you to understand how the recordings might be used, before agreeing that your child can take part. Two different sorts of consent can be given. We have called these: research participation, and wider participation:

- **Research participation** level of consent means that the video recordings will be used for the research study only.
- **Wider participation** level of consent means that video recordings might be used for teaching (e.g. undergraduate and postgraduate students, and health and education professionals), and at presentations outside University College London, such as international meetings. The videos could also be used in electronic publications such as web-based teaching and research resources.
- **Level of granularity of images**– If you are happy for us to take photos and/or videos but you would like us to 'blur' these images when we present them to others (i.e. so that your child's face isn't identifiable), you can indicate this on the consent form.

It is important for you and your child to be comfortable with the level of consent that you give. You may change the level of consent or withdraw it completely at any time. However, we cannot accept liability if recordings have already been published. If you wish to alter the level of consent at any time, please telephone Seray Ibrahim at The Vale School (020 8801 5177).

Does my child have to take part?

It is up to you to decide. If, after reading this information sheet, you decide that your child can take part in the study we ask that you return the consent form in the envelope provided. We will then contact you to arrange a convenient time for you to meet the research team and for us to carry out our interviews with you and your child.

If I agree to take part what will happen if I decide not to carry on?

It is important that you are aware that your participation in this study is strictly voluntary. You are free to withdraw your consent at any time without giving a reason. Withdrawing your consent will not affect your child's care.

Will taking part be kept confidential?

Yes. We will follow ethical and legal practice and all information about your child will be handled in confidence. All data will be collected and stored in accordance with the Data Protection Act 1998.

What will happen to the results of the study?

The results will be interpreted by the student researcher who will write up the study as part of a thesis for completion of a PhD degree.

Who is organising the research?

The study is being carried out as part of a PhD research degree, Institute of Education, University College London. The student researcher is also a speech & language therapist within the local community health team.

Who has reviewed the study?

This research study has been looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The project has been given [a favourable review by Institute of Education, University College London Research ethics committee].

What if I have questions about the study?

Please do not hesitate to contact Seray Ibrahim at The Vale School (020 8801 5177 / s.ibrahim.12@ucl.ac.uk) if there is anything that is not clear, or if you would like more information.

What if I have a problem with the study?

Any complaint about the way you have been dealt with during the research, or any possible harm you might suffer will be addressed. Every care will be taken in the course of this study, however in the unlikely event that you or your child is injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. After discussing with the research team, please make the claim in writing to Dr Asimina Vasalou who is the Chief Investigator for the research and is based at the UCL Knowledge Lab, UCL Institute of

Education, University College London, 23- 29 Emerald Street, London WC1N 3QS. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff or about any side effects (adverse events) you may have experienced due to your participation in the research, the normal National Health Service complaints mechanisms are available to you. Please ask members of the research team if you would like more information on this. Details can also be obtained from the Department of Health website: <http://www.dh.gov.uk>.

What next?

After you have had an opportunity to read this information and are happy to participate in the study please sign and return the consent form to school in the envelope provided. In the meantime, if you have any concerns or queries please telephone or email XXX at The Vale School (tel / email). Once we have received your consent form we will call you to arrange a time to see you and your child.

Best wishes

Seray Ibrahim

Student researcher

Informed Consent Form

For parents / guardian for research involving children under 18 year

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project:

Involving children with severe speech and physical impairments in the design and development of their augmentative and alternative communication aid technology.

This study has been approved by the IOE UCL Research Ethics Committee

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I: **give consent for my child:** **to take part**
in this research.

- have read the notes written above and the Information Sheet, and understand what the study involves
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

- I consent to images of my child being used that are:
- I understand that my child’s participation will be photographed and/or video recorded and I consent to use of this material as part of the project;
 - Videoing and photographing for the research study as well as presentations outside

Fully visible (100%)

75% visible

50% visible

25% visible



Institute of Education, University College London



If you would like to limit how images of your child are shared, please indicate below:

- Videoing and photographing for the purposes of the research study only
- Videoing only for the purposes of the research study
- Photographing only for the purposes of the research study

(please tick or leave blank)

Signed:

Date:

Appendix 2: Study 1, list of 3 theme categories with 13 categories

Competence and agency in adult-child interactions

- Adult encouraging child competence with AAC
- Adult power over communication agency for teaching competence
- Adult competence expectations are violated and thus intervention happens
- Children often choose to use other communicative means rejecting
- Communication through technology dilutes other more strategic or clear communicative acts

AAC as a material object

- AAC shaped from a communicative tool to a disruptive object, assuming attention and changing child's role
- Tech sometimes has no utility in specific contexts
- The material form of AAC becomes obstacle in understanding context
- AAC can create meaning and context

Misalignments and breakdowns

- Sender-receiver set up of AAC limits situated and co-created meaning making. All interlocutors draw on other resources
- Interactional situations with more people with mixed capabilities are disrupted when technology is used
- Adult wants to create communicative situations between children, even those undermine AAC use
- Communication through technology prioritizes accuracy

Appendix 3: Workshop flyer, researcher bio, information sheet and consent form for design students

Research workshop: Communication (dis)ability design challenge

Seray Ibrahim

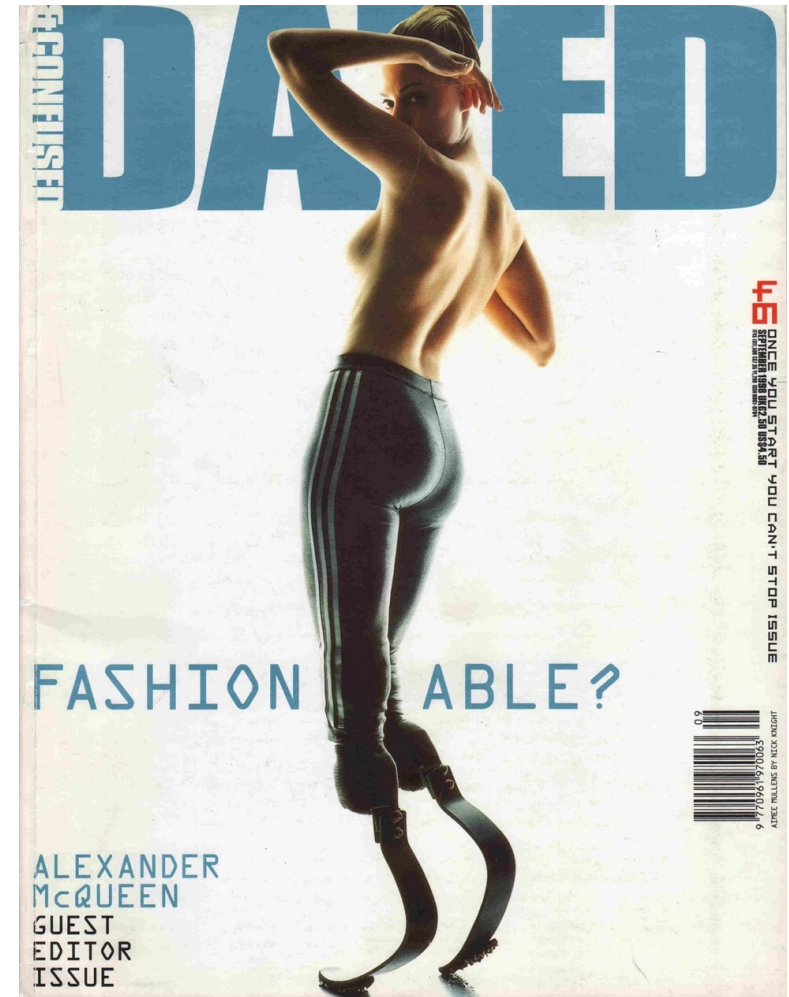
Friday 20th April, 13-16:00 / IED Lab

Outline

This workshop will explore disability and design in the context of designing to empower by extending beyond a focus on bodily impairment. We will begin with examining some of the tensions and values in designing digital technologies for disability and draw on these aspects in a design brief that responds to research data generated in an earlier phase of this project.

Practical workshop

We will work on a design brief based on research data with children who have severe speech and physical impairments, identifying and framing perspectives



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Bio

Seray is a third year PhD student supported through the economics and social research council. Her research takes a critical design-oriented perspective for communication by examining how digital technologies can be conceived to support communication that is socially constructed, multimodal and interactive beyond the transmission of information alone. She works with Dr Asimina Vasalou and Dr Michael Clarke and is based at the University College London Knowledge Lab. Before undertaking doctoral studies, Seray worked as a speech and language therapist in the NHS for +10 years with children who have little or no functional speech. Most recently, she worked as clinical lead specialist for augmentative and alternative communication in the Haringey community children's health team.





INFORMATION SHEET FOR DESIGN WORKSHOP ATTENDEES

Project title:

Design opportunities for communication, children with severe speech and physical impairments and digital technologies

Dear workshop attendee,

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. This information sheet tells you about the purpose of the study and what will happen to you if you take part.

If you are interested in taking part after reading about the study, we will ask you to complete a formal consent form (a consent form is enclosed with this information pack).

Purpose of the study

Young children with physical disability who have difficulty producing speech are often reliant on using different methods of communicating to help to get their message across. Normally, they have a very large bank of words to choose from which are organised and grouped into folders in boxes. Some children start using these devices very early in childhood, sometimes before the age of 5 years, and for some children it can be difficult to learn this skill.

Our study will explore multi-stakeholder perspectives of the design process for AAC, including what children themselves want from their communication aids.

If we can find out what children prioritise and value when communicating with their friends, families and others we hope that we can add to the wealth of information that shapes the design of devices so that they can be used more effectively.

We will use different methods to gather this information. First, we will involve children aged 5 – 16 years old through structured observations, discussions and activities to explore what they share about how they interact with others and how they choose to communicate. Next we



will represent this data and invite a wider community of people to explore and respond to these insights.

Why have I been invited to take part?

We are writing to you because we are keen to examine new ways of designing technologies that can advance communication. We are interested in involving students and practitioners who may approach design differently, for example by drawing on arts sensibilities instead of impairment-based solutions. This study is being partly carried out by a doctoral student who has contacted your institution and tutors.

Please note that no one outside the research team has had access to your personal details in preparing this invitation. Only members of the research team who are directly involved in the project will have access to personal details as part of your participation in this study.

What would participation involve?

If you are willing to take part in the study, we would like you to take part in the design brief workshop and challenge. After we have collected and analysed the data we will provide you with a summary of the findings of the project.

Will you record the workshop?

Yes, with your permission we would like to record the discussions through videoing and photography. This will help us to accurately record what is discussed so it can then be transcribed and analysed in a structured framework. Two different sorts of consent can be given. We have called these: research participation, and wider participation:

- **Research participation** level of consent means that the video/photo recordings will be used for the research study only.
- **Wider participation** level of consent means that video/photo recordings might be used for teaching (e.g. undergraduate and postgraduate students, and health and education professionals), and at presentations outside University College London, such as international meetings. The videos could also be used in electronic publications such as web-based teaching and research resources.

It is important for you to be comfortable with the level of consent that you give. You may change the level of consent or withdraw it completely at any time. However, we cannot accept liability if recordings have already been published. If you wish to alter the level of consent at any time, please contact Seray Ibrahim at UCL Knowledge Lab (s.ibrahim@ucl.ac.uk).



Do I have to take part?

It is up to you to decide. If, after reading this information sheet, you decide that you can take part in the study we ask that you return the consent form.

If I agree to take part what will happen if I decide not to carry on?

It is important that you are aware that your participation in this study is strictly voluntary. You are free to withdraw your consent at any time without giving a reason.

Will taking part be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Your personal details and details about the company that you work for will be kept confidential in the write up of the study. All data will be collected and stored in accordance with the Data Protection Act 1998.

What will happen to the results of the study?

The results will be interpreted by the student researcher who will write up the study as part of a thesis for completion of a PhD degree.

Who is organising the research?

The study is being carried out as part of a PhD research degree, Institute of Education, University College London.

Who has reviewed the study?

This research study has been looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The project has been given a favourable review by Institute of Education, University College London Research ethics committee.

What if I have questions about the study?

Please do not hesitate to contact Seray Ibrahim via email (s.ibrahim@ucl.ac.uk) if there is anything that is not clear, or if you would like more information.

What if I have a problem with the study?



Any complaint about the way you have been dealt with during the research, or any possible harm you might suffer will be addressed. Every care will be taken in the course of this study, however in the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) negligence then you may be able to claim compensation. After discussing with the research team, please make the claim in writing to Dr Asimina Vasalou who is the Chief Investigator for the research and is based at the UCL Knowledge Lab, UCL Institute of Education, University College London, 23- 29 Emerald Street, London WC1N 3QS. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

What next?

After you have had an opportunity to read this information and are happy to participate in the study please sign and return the consent form. In the meantime, if you have any concerns or queries please email Seray Ibrahim at UCL Knowledge Lab: s.ibrahim.12@ucl.ac.uk.

Best wishes

Seray Ibrahim

Student researcher

Consent Form

Design workshop attendee

Title of Project

Design opportunities for communication, children with severe speech and physical impairments and digital technologies

This study has been approved by the IOE UCL Research Ethics Committee.

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you. If you have any questions arising from explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I: **give consent to take part in this research.**

- have been informed about the project and understand what the workshop involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- consent to the processing of my personal information for the purposes of this research study and understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.



- understand that my participation will involve access to and the use of personal data relating to children, families and schools from an earlier phase in this project. I consent to accessing this data for the **purposes of the workshop only** and **will not share this with others** outside of the project.
- I understand that my participation will be photographed and video recorded and I consent to use of this material as part of the project;
 - For the purposes of the research study only
 - For teaching and at presentations outside University College London

(please tick or leave blank)

Signed:

Date:

Communication dis(ability) design challenge

Attendee questionnaire

What is your education background & qualifications?

(e.g. design, computer science, fine art, engineering etc. / BA, MSc etc.)

Can you briefly describe your professional experience?

How familiar are you with taking part in design-oriented workshops? (✓)

not familiar (I have taken part in 1-2 workshops over the past few years)

somewhat familiar (I take part in approx. 2-3 per year)

familiar (monthly, this is regularly part of my work/studies)

very familiar (this forms a large part of my work/studies)

Have you worked in joint projects with the people in your team before? _____

Gender? _____

Thank you

Appendix 4: Design documentary script

Grace is a nine year old girl who attends an inner city special school in the UK.

She lives with her mum, dad and two little brothers.

Grace has a severe physical impairment that affects her whole body including her natural speech. When she was born, there were complications which affected the oxygen flow to her brain, which meant that parts of her brain developed differently.

She mostly communicates using facial expression, eye pointing and tone of voice. She also communicates using graphic symbols in a communication book, and also organised in an eye gaze communication device that's mounted to her wheelchair. She likes to use her arms to point to things, although her uncontrollable movements can make gesturing difficult.

In school, her closest friends are Maya, Clara, and Andrew. But she has many other friends in other classes too. When Grace's best friend Maya was out of school recently for planned surgery, she asked about her all the time and was worried for her. She was really pleased when Maya started coming back into school.

Maya would also say that Grace is one of her best friends. Whilst Maya was in hospital, she made a card for Grace and Clara with some help from her mum.

The extract that follows is taken from a research diary entry whilst playing outdoors with Grace and a boy from another class.

I asked Grace if I could spend playtime with her, she agreed so we followed the class group out of the class and down the corridor towards the playground. Some other children were already outside sitting by a bench with adults, I asked Grace where she's like to go and she eye pointed to the far side of the playground towards the climbing frame and play shed.

We were about to move there when Oscar came over. He briskly and assertively walked over to us in his walking frame, greeting us with eye contact and a smile, then gestured that we follow him to the open space at the far side of the playground. He then leaned forward in his walking frame, grabbing hold of the bars in anticipation of a start gun ready to blow, I asked him "You want us to chase you?" "Yeah" he replied as he sped off before either of us could

answer. From behind Grace's chair, I leaned over to ask her "Shall we chase him?", she smiled and vocalised so we were off.

As I pushed Grace's chair picking up speed, I called out to Oscar "We're gonna get you!" to which both children giggled and shouted. We'd almost done a few circles of the open area when Oscar plunged under the bridge of a climbing frame. At that point, I wasn't entirely sure if Grace's chair would fit under the gap that Oscar had ducked under, but to our pleasure it did, at which point, Grace squealed with excitement and burst into giggles. The bumpy journey and jerky chair added to the fun of it as we negotiated the steep upward curve of the tarmac that lined the climbing frame.

This time, we were able to fit into one of those tiny and secure spaces of the school where only children go. As we came out of the other end and did a few circles around the frame, climbing over that bump repeatedly, the three of us were completely engaged in the game of tag. Without the need to say goodbye at the end of the interaction, Oscar moved away, finding another part of the playground to independently explore.

She hates being put on the spot, like being asked to respond to questions in front of her whole class, especially when there's an expectation that she'll use her eye gaze to do so. Grace has mixed feelings about her eye gaze device, apart from Maya, all her other friends use iPads and this is normally for fun stuff like playing games, recording and looking at pictures and videos. They're not asked to speak through a piece of digital technology. Their computers aren't attached to their chairs. When she's not in school, she'd love to do some of the things she enjoys like going to the cinema, play dates and friend's birthday parties but at the moment, things are a little tricky as they live in temporary housing accommodation which is too small and too stressful and packed with all of her special equipment so there's rarely time or space for friends to come around. In the evening and weekends, she mostly spends time indoors watching TV with her two younger brothers.

In school, her teacher tells her "you're brilliant! You need to show everyone that you're brilliant!" but she'd rather not have to show everyone that she's brilliant.

Appendix 5: Persona drafts

Maya



Maya is an inquisitive, sociable, smart girl. She enjoys being part of all sorts of activities, especially those that she can do and talk about with others. Maya is very caring and has a close relationship with her friends Grace and Clara. She is interested to know what they are doing and when she is not in school, Grace and Clara are keen to know where she is. She loves reading stories with her parents, sister and class team.

She especially loves Julia Donaldson stories like 'Room on the Broom' and 'The Gruffalo'. She likes all different kinds of games like activity card games (shopping, puzzles, lotto), imaginative play and crafts activities like sticking, cutting, painting and making things like butterflies and jewellery.

Maya uses her eye gaze device lots at home and in school, mostly with her parents and adults at school. She also uses an iPad for watching videos or plays games with her younger sister or an adult.



Profile

- 7 years old, girl
- Primary special school
- Sociable, bubbly and confident



Communication

- Eye pointing, symbols, written words and some facial expression/tone of voice
- Paper based symbol book, a letter and core word flip chart book
- Eye gaze device with language organised to mirror her paper based system (uses it mostly with adults). The device also has access to games, the internet and access to taking photos.



Likes

- All things pink
- Being with her friends
- Jokes and silly stuff in class
- Lots of TV programmes, Disney/Pixar films, especially Frozen, Inside Out and Paddington Bear, Pop music, CBeebies programmes,
- Spending time with her parents, sister, grandparents and family.



Dislikes

- Feeling poorly, chesty and tired.
- Being out of school for long periods.

Oscar



Oscar is "a real techie boy" and a risk-taker. He loves to be independent and to do things by himself. He attends different after-school activities including a local theatre company.

He will 'get stuck in' and is interested in doing things that all of the other children do at playtime, like using the climbing frame, ball games and cartwheels. He is motivated and persistent to participate in different kinds of conversations and activities.

Oscar loves physical games like chasing and playing tag. He mostly plays with adults in school and likes to be part of games with other children. He is very interested in what other children are doing and tries to be part of this. It can be difficult to get other children to understand what he is saying which limits how much he participates in shared games without getting annoyed.



Profile

- 8 years old, boy
- Primary special school
- Confident and independent



Communication

- Mostly uses gestures, facial expression, vocalising and symbols and some natural speech (few words)
- Has a paper based symbol communication book that he uses lots.
- Has an electronic touch screen communication aid device (symbol based) that he rarely uses.



Likes

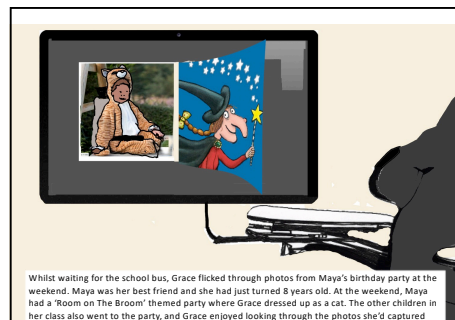
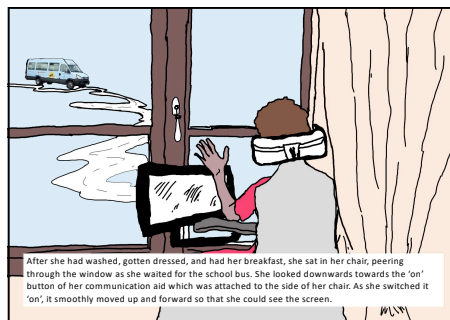
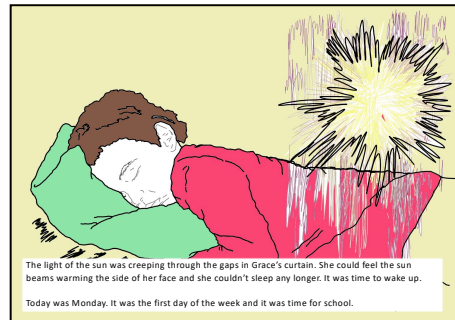
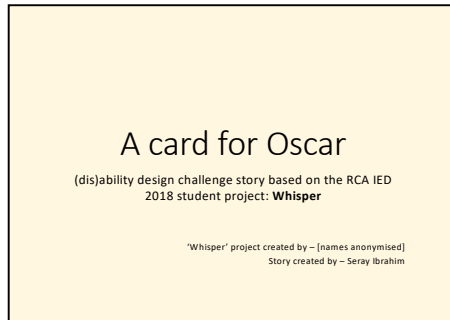
- Baking cakes at home
- Birthday parties, especially giving friends presents.
- Joking around
- Loves swimming
- Resting in front of the TV
- Computers
- Going to restaurants
- Toy shops

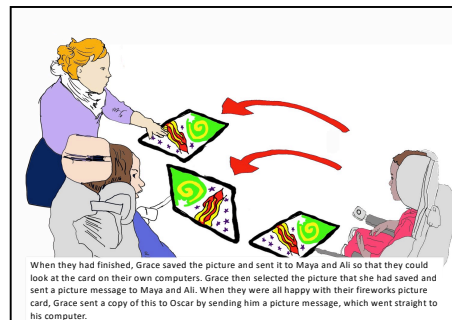
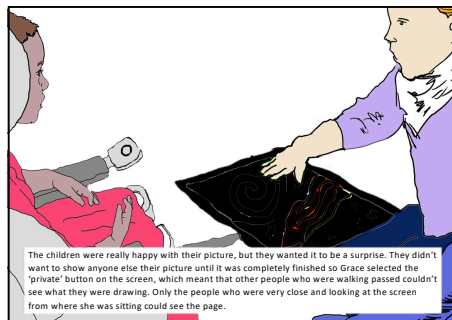
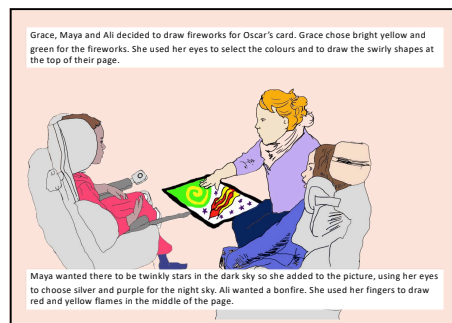
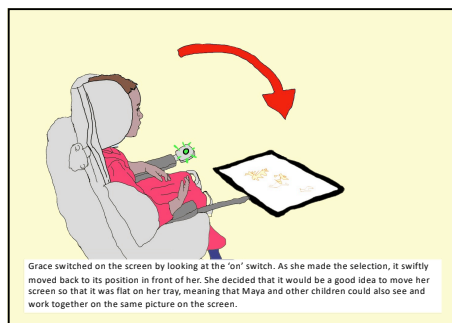
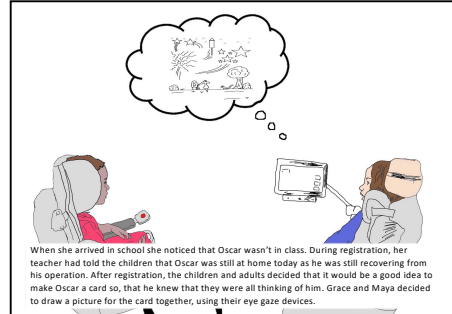
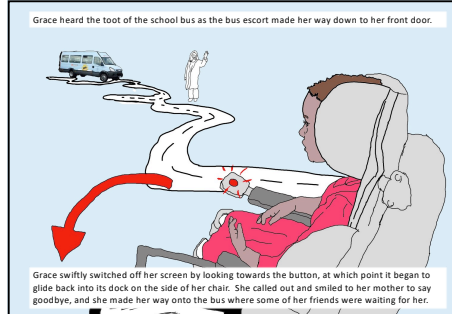


Dislikes

- Gets annoyed when adults talk amongst themselves in school.
- Having to wear 'special clothes' sometimes, like 'high-viz' jacket at playtime and helmet.
- Using his walker to get around.
- Going to the shops in the car.

Appendix 6: 'A card for Oscar' story. Based on 'Whisper' in study three.







The end