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How I use the internet and online social  
media: Experiences of young people who use  
Augmentative and Alternative Communication  
(AAC).

**Amanda Hynan**

A thesis submitted for partial fulfilment of the requirements of the  
Manchester Metropolitan University  
for the degree of Doctor of Philosophy

Department of Health Professions

**2013**

*“My laptop is completely lifeless, flatlined, I feel sick. If I don’t have my computer, then I can’t send text messages or emails, do college assignments or finish off the work I bring home... I can’t laugh and joke with my friends online, tell them about my day and ask about theirs. I can’t describe to them how I’m feeling or make plans to meet up. My physical world might still be limited ... but there are parts of my life that know no boundaries... All I’ll have to communicate with now is a battered old alphabet board that won’t reach around the globe the way I need it to.”*

**(Martin Pistorius, 2011).**

## **Abstract**

This thesis addresses a specific gap in the literature base regarding the self-reported experiences of using the internet and online social media by adolescents and young adults (young people) who use augmentative and alternative communication (AAC) within the UK. The research took a socially constructivist approach and used a qualitative methodology to conduct semi-structured interviews with twenty-five young people (aged 14-24) with complex communication needs. The data was collected over a period of eighteen months within a mainstream school, two specialist schools, four specialist colleges and an adult residential centre.

The study is based within the context of adolescent development for young people who use AAC. Peer relationships are important to adolescents (Helseth & Misvaer, 2010) and Smith (2005) identified establishing friendships is difficult for young people who use AAC in light of their physical and complex communication challenges which increases the risk of loneliness. Using online communication technology can help mitigate feelings of loneliness with people who use AAC (Cooper, Balandin & Trembath, 2009), although significant barriers for access have been identified (McNaughton & Bryen, 2007). The views of young people who use AAC are under-represented on the topic of the internet and online social media. There are important legal obligations to seek the views of young people with disabilities (Article 12, United Nations Convention on the Rights of the Child, 1989; Article 21, United Nations Convention on the Rights of Persons with Disabilities, 2006) but progress has been slow to include the voices of young people with significant communication impairment (Morris, 2003; Rabiee, Sloper and Beresford 2005; Wickenden, 2009).

A grounded theory approach to data analysis generated nine categories, from which the core category identified was the desire to use the internet and online social media. A theoretical grounded theory is proposed which is also refined to offer a more accessible practical application version. The proposed ground theory is then used to explore whether outcome measures, focused on social inclusion within community

environments, may be applicable to perceptions of social inclusion within virtual communities.

The key message of the thesis is that young people who use AAC have a clear desire to use the internet and online social media, as it is perceived to offer tangible benefits that are synonymous with identified outcome measures for community-based social inclusion, but they also face many challenges, especially regarding accessibility.

## **Dedication**

For Dermot, Veronica and Jonnie.

Without all of you, this thesis would never have been possible.

Thank you.

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First and foremost I would like to thank all the young people who gave their time to this research. Their determination to take part in the interviews took great personal commitment and effort and was inspirational. Their insights are extremely valuable and I hope by creating this written story together, we will be able to ensure their voices are heard by a wider audience than just me. I would also like to thank Rohan Slaughter, Tom Kipling, Gemma Mitchell, Laura Day, Tom Kelly and Gregor Gilmore. I would also like to extend my gratitude to all the people that I cannot name for their support, enthusiasm and expertise.

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# Table of contents

Abstract.....	1
Dedication.....	3
Acknowledgements.....	4
Table of contents .....	5
List of Figures and Tables.....	12
Chapter 1 – Introduction .....	13
1.1. Structure of the thesis .....	13
1.2. Impetus for the study .....	14
1.3 Significance of the study .....	16
1.4. The research aim.....	17
1.5. Philosophical position .....	17
1.6. Terminology .....	18
Chapter 2 – Literature review .....	20
2.1. Introduction .....	20
2.2. Part One: An overview of AAC .....	20
2.2.1. Introduction .....	20
2.2.2. The mode .....	21
2.2.3. The means.....	23
2.2.4. Representation system .....	23
2.2.5. Interactional strategies within face-to-face conversations .....	25
2.2.6. Time considerations within AAC-mediated face-to-face conversations.....	27
2.2.7. Narrative and humour .....	28
2.2.8. Summary .....	29
2.3 Part Two: Historical development of AAC .....	30
2.3.1. Introduction .....	30
2.3.2. Historical context .....	30
2.3.3. Development of voice output Apps on mainstream devices.....	32
2.3.4. The reaction of the AAC industry and the development of VOCA devices.....	35
2.3.5. The future?.....	36
2.3.6. Summary .....	37



2.4. Part Three: The internet and online social media within the lives of young people, including those with physical disabilities, within westernised societies .....	38
2.4.1. Introduction .....	38
2.4.2. Rights of people with disabilities .....	38
2.4.3. Internet use by youth populations .....	40
2.4.4. Social capital and internet-based research.....	41
2.4.5. Online social ties of young people .....	44
2.4.6. Online self-representation .....	46
2.4.7. Self-determination .....	49
2.4.8. Potential risks within online environments .....	52
2.4.9. Summary .....	53
2.5. Part Four: The internet and online social media within the lives of young people who use AAC .....	54
2.5.1. Introduction .....	54
2.5.2. Use of computers, the internet, online social media and mobile phone technology by people who use AAC .....	54
2.5.3. Challenges for using the internet and online social media.....	57
2.6. Summary of the literature review chapter .....	58
2.7. The research objectives .....	59
Chapter 3 – Methodology .....	60
3.1. Introduction .....	60
3.2. Theoretical framework .....	60
3.2.1. Disability studies .....	60
3.2.2. Feminist research principles and disability studies .....	61
3.2.3. International Classification of Functioning, Disability and Health (ICF).....	62
3.2.4. Challenges of internet-focused research .....	63
3.2.5. Summary .....	64
3.3. Methodological underpinnings.....	65
3.3.1. A socially constructivist/constructionist paradigm.....	65
3.3.2. A qualitative research approach .....	66
3.3.3. Discussion of three common qualitative approaches.....	67
3.3.4. Traditional Grounded theory .....	70
3.3.5. Constructivist Grounded Theory.....	71
3.4. Preparation .....	73

3.4.1. Ethical approval.....	73
3.4.2. Researcher positionality .....	74
3.4.3. Pilot Investigation .....	74
3.4.4. Pilot investigation participant.....	75
3.4.5. Pilot investigation data collection.....	75
3.4.6. Pilot investigation data analysis.....	75
3.4.7. Reflective learning from the pilot investigation .....	77
3.5. Procedure.....	79
3.5.1. Recruitment .....	79
3.5.2. Inclusion criteria.....	80
3.5.3. Ethical variations.....	81
3.5.4. Participant information.....	81
3.5.5. Informed consent.....	85
3.6. Study design.....	86
3.6.1. Introduction .....	86
3.6.2. Data collection .....	87
3.6.2.1. Settings .....	87
3.6.2.2. Semi-structured interviews.....	88
3.6.2.3. Total communication and low tech AAC.....	88
3.6.2.4. Group meetings .....	89
3.6.2.5. Demonstrations .....	90
3.6.2.6. Summary of data sources .....	90
3.6.3. Data Analysis.....	92
3.6.3.1. Transcription .....	93
3.6.3.2. Concurrent data collection and analysis.....	93
3.6.3.3. Initial coding.....	95
3.6.3.4. Focused coding .....	95
3.6.3.5. Theoretical coding.....	96
3.6.3.6. Memo writing .....	97
3.6.3.7. Theoretical sampling.....	98
3.6.3.8. Theory generation.....	98
3.6.4 Summary .....	99
Chapter 4 – Data interpretation .....	102

4.1. Introduction .....	102
4.2. Explanatory notes on data presentation .....	106
4.3. Desire to use the internet and online social media .....	108
4.3.1. Desire to be online .....	108
4.3.2. Desire to extend use .....	109
4.3.3. Summary .....	111
4.4. Reported use of the internet and social media .....	111
4.4.1. The internet .....	112
4.4.2. Online social media sites.....	113
4.4.3. Email.....	117
4.4.4. Texting and mobile phones.....	117
4.4.5. Frequency of use.....	118
4.4.6. Summary .....	119
4.5. Describing support .....	120
4.5.1. Introduction to and training to use the internet and online social media .....	120
4.5.2. Collaboration.....	123
4.5.3. Challenges regarding support .....	125
4.5.4. Summary .....	131
4.6. Online challenges.....	132
4.6.1. Online safety awareness .....	132
4.6.2. Resilience .....	135
4.6.3. Restrictions to use.....	139
4.6.4. Reduced privacy .....	140
4.6.5. Summary .....	140
4.7. Access technology.....	141
4.7.1. Computer access without additional equipment .....	141
4.7.2. Computer access with additional equipment .....	142
4.7.3. Challenges associated with access technology.....	144
4.7.4. Summary .....	146
4.8. VOCA issues.....	146
4.8.1. Advantages of integrated VOCAs.....	146
4.8.2. Disadvantages of integrated VOCAs .....	147
4.8.3. Cameras on VOCAs.....	149

4.8.4. Repairing VOCAs and future planning .....	152
4.8.5. Summary .....	152
4.9. Self-determination .....	153
4.9.1. Autonomy and authorship .....	153
4.9.2. Enhanced privacy .....	154
4.9.3. Summary .....	155
4.10. Self-Representation .....	156
4.10.1. Information about self .....	156
4.10.2. Conversational equality .....	159
4.10.3. Expressing humour .....	160
4.10.4. Narrative record of activities .....	161
4.10.5. Summary .....	161
4.11. Online social ties .....	162
4.11.1. Bonding social ties .....	162
4.11.2. Maintaining social ties .....	164
4.11.3. Bridging online social ties .....	166
4.11.4. Summary .....	168
4.12. Memos .....	169
4.13. Generating the grounded theory of internet and social media use by young people who use AAC .....	176
4.13.1. Nature of the theory .....	176
4.13.2. Central phenomenon .....	177
4.13.3. Causal conditions .....	177
4.13.4. Limitations for achieving the central phenomenon .....	177
4.13.5. Context .....	178
4.13.6. Interaction/actions .....	178
4.13.7. Strategies .....	178
4.13.8. Consequences .....	179
4.13.9. Summary .....	179
Chapter 5 - Discussion.....	181
5.1. Introduction .....	181
The research objectives: .....	182
5.2 Central phenomenon .....	183

5.3 Causal conditions .....	184
5.3.1. Access methods that facilitate the use of mainstream computers .....	185
5.3.2. Availability of mainstream technology on integrated VOCAs.....	186
5.3.3. Human support to access and use digital technology and online social media ..	187
5.3.4. Requesting to use the internet and online social media .....	189
5.3.5. Evidence of use of the internet and online social media.....	190
5.3.6. Summary of causal conditions .....	191
5.4. Limitations for achieving the central phenomenon.....	191
5.4.1. VOCAs and mainstream computer issues .....	191
5.4.2. Limited use of mainstream mobile technologies and Apps.....	193
5.4.3. Restrictions on use.....	197
5.4.4. Limited technical support from personal staff .....	200
5.4.5. Parental technical knowledge and skill limitation .....	203
5.4.6. Individual skills .....	204
5.5. Interaction and action.....	205
5.6. Context.....	208
5.7. Strategies .....	208
5.8. Consequences .....	212
5.8.1. Self-determination .....	212
5.8.2. Enhanced self-representation.....	214
5.8.3. Social capital .....	216
5.8.4. “Talk to everyone” .....	217
5.8.5. Reduced isolation.....	218
5.8.6. Resilience .....	219
5.8.7. Dating opportunities .....	222
5.9. Relevance and significance of the grounded theory of internet and online social media use by young people who use AAC.....	223
Chapter 6 - Conclusions .....	227
6.1. Conclusions .....	227
6.2. Strengths and limitations of the study.....	229
6.2.1. Strengths .....	229
6.2.2. Limitations.....	230
6.3. Methodological considerations .....	231

6.4. Potential areas of further study.....	232
Chapter 7 – Practical applications and concluding comments .....	234
7.1. Practical applications of the proposed grounded theory .....	234
7.2. Concluding comments .....	237
References .....	239
Appendices.....	277
APPENDIX A - THEMES AND QUESTION GUIDE.....	277
APPENDIX B – DETAILED INFORMATION SHEET .....	279
APPENDIX C – BRIEF INVITATION .....	282
APPENDIX D – DIFFERENTIATED INFORMATION SHEET .....	283
APPENDIX E - STANDARD CONSENT FORM.....	284
APPENDIX F – DIFFERENTIATED CONSENT FORM.....	285
APPENDIX G – APPROVAL OF ETHICAL VARIATION TO INCLUDE 14 YEAR OLD .....	286
APPENDIX H – APPROVAL OF ETHICAL VARIATION TO INCLUDE PARENTS AND SCHOOL STAFF.....	287
APPENDIX I: QUESTIONS SENT VIA EMAIL TO 2 PARTICIPANTS (pre-prepared answers on VOCA and blog) .....	288
APPENDIX J – JOURNAL ARTICLE OF PILOT INVESTIGATION.....	289
APPENDIX K –JOURNAL OF INITIAL FINDINGS .....	290
APPENDIX L – THEMATIC NETWORKS FROM PILOT INVESTIGATION .....	293
APPENDIX M – ANONYMISED VERBATIM TRANSCRIPT 1 .....	297
APPENDIX N – ANONYMISED INTERVIEW TRANSCRIPT 2 (excerpt) .....	306
APPENDIX O – CHILD LANGUAGE TEACHING AND THERAPY ABSTRACT .....	307

## List of Figures and Tables

<b>Table 1:</b> Table illustrating the distinctions of three common qualitative approaches and areas of flexibility with other qualitative approaches (Adapted from Holloway and Todres (2003)).....	67
<b>Table 2:</b> Issues identified within the current project and the suitability of constructivist grounded theory (Charmaz, 2000, 2006, 2008, 2009).....	72
<b>Table 3:</b> Participants' who use AAC demographic information.....	83
<b>Table 3a:</b> Additional adult participants.....	84
<b>Table 4:</b> Table outlining literacy, access methods of participants and how they use mainstream technology (n=25).....	85
<b>Figure A:</b> Schematic representation of the steps suggested by Charmaz (2006) for conducting a constructivist grounded theory study.....	87
<b>Table 5:</b> Table showing data sources and quantity.....	92
<b>Figure B:</b> The schematic representation of data collection occasions over eighteen months.....	94
<b>Figure C:</b> Constructing a grounded theory through constant comparison.....	101
<b>Table 6:</b> Identified categories and supporting raw data excerpts.....	103
<b>Table 7:</b> Component elements of the categories .....	105
<b>Figure D:</b> Proposed grounded theory of internet and online social media use by young people who use AAC.....	180
<b>Figure E:</b> Practical applications of proposed grounded theory of internet and online social media use by young people who use AAC .....	236

# Chapter 1

## Introduction

This thesis adds new knowledge to the field of augmentative and alternative communication (AAC), firstly by re-dressing the specific gap within the United Kingdom literature base for the self-reported experiences of using the internet and online social media by young people who, due to physical disabilities and complex communication needs, choose to use AAC to support their total communication strategies. Secondly, through the development of a grounded theory of internet and online social media use by young people who use AAC to explore whether outcome measures focused on social inclusion within community environments may be applicable to perceptions of social inclusion within virtual communities.

### *1.1. Structure of the thesis*

The thesis is divided into seven chapters. Chapter One informs the reader of the structure of the thesis and provides an explanation of the impetus and significance of the study. It also articulates the research aim and philosophical position taken before finishing with an explanation of why particular terminology is used within the main body of the thesis. Chapter Two reviews the literature within a quadripartite format: part one gives an overview of the field of AAC to contextualize issues of communicative interaction within face-to-face environments. This will orientate the reader to factors that impact on the research design and illustrate how online communication may be of particular relevance for people who use AAC. Part two outlines the historical development of AAC to place the specialist communication technology within the broader societal frame of mainstream technology. Part three traces issues relating to internet and online social media use by young people, including those with disabilities, in order to: draw attention to the rights of people with disabilities to access mainstream technology, indicate how popular the internet and online social media are within youth populations, and offer a brief exploration of certain psychological and sociological topics from an online perspective. Part four gives a summary of the small literature base that is beginning to develop within different countries looking specifically at self-reported experiences of using the



internet and online social media by people who use AAC. Chapter Two concludes with a summary of the literature review and states the research objectives.

Chapter Three describes the methodology. It starts by setting out the theoretical framework and methodological underpinnings before moving on to describe in detail the procedural factors relating to the overall study design including the data collection and analysis process. Chapter four presents the data interpretation by revealing the nine categories that emerged from the data (supported by transcript excerpts) and then moves on to demonstrate how a core category was identified. A proposal is then made for a new theory (grounded in the data) of internet and online social media use by young people who use AAC.

Chapter Five discusses the significance of the findings in relation to existing literature in order to illustrate the relevance and contribution of the grounded theory proposal. The layout of this chapter is based on the theory elements which are presented in diagrammatic form at the end of chapter four. Chapter Six outlines the conclusions drawn from the study, the limitations and strengths that have been identified and areas for potential further research. Finally, chapter seven outlines the practical applications of the grounded theory. A refined grounded theory was developed in order to provide a more accessible version for those seeking to apply the grounded theory on a more practical level; the theory has been re-focused to more prominently consider facilitators and barriers relating to use of the internet and online social media by young people who use AAC. The chapter then closes the thesis and the research story by offering a short section of concluding comments.

## ***1.2. Impetus for the study***

The fledgling field of AAC matured and gathered during the eighties and nineties to become a scientific and clinical discipline (Higginbotham, Shane, Russell & Caves, 2007). The aim of AAC is to support people with physical disabilities and complex communication needs to express themselves and has increasingly moved over the past few decades into developing specialised communication technology. The desire to harness technology to support people with complex communication needs established

the basis for the development of computer based communication aids that have pioneered many innovations, such as word prediction software to increase the speed of communication. The challenge for the industry has always been to balance the enormous potential of computer technology against individual characteristics such as motor, sensory and perceptual skills as well as cognitive and linguistic demands (Higginbotham et al. 2007). As society has hurtled through a digital communication ‘revolution’ since the mid-nineties (that shows no signs of slowing), using technology to communicate has become an accepted and essential aspect of most people’s lives. For many years, people who used AAC technology to communicate were noticeably unique whereas nowadays people are glued to handheld communication devices wherever you go.

The initial seed of this research project was sown through my undergraduate research project to look at the social opportunities of adolescents who AAC in 2008. By 2010, the implications of the rapidly developing world of social networking through online social media sites (such as Facebook) led me to want to explore the ramifications of this ‘brave new world’ for people who used AAC devices. I was particularly keen to look at this in relation to adolescents and young adults as the popularity of the internet and online social media is apparent within this age demographic (Ofcom Consumer Experience Report, 2012).

This research desire was shaped by literature highlighting factors which may be relevant for young people who use AAC during adolescent development. Young people with cerebral palsy have fewer opportunities for social experiences with friends than their peers (Kang, Palisano, Orlin, Chiarello, King & Polansky, 2010). Smith (2005) identified via a literature review that very little research has been carried out within the field of AAC that addresses issues of adolescence. She identifies many areas of adolescence that may be challenging for young people who use aided AAC, for example,

*“establishing secure social networks may be particularly difficult ... The physical movement required to be part of a group requires independent mobility. Having to rely on an adult to physically locate a student within a group may be unacceptable both to the student and to the group” (p. 69)*

This has implications for emotional and mental health which is known to be supported by strong social networks. Brage and Meredith (1994) found loneliness is directly associated with adolescent depression. Smith (2005) and Light, McNaughton, Krezman, Williams, Gulens, Galskoy and Umpleby (2007) both stress the importance for young people who use AAC to be able to establish intimate friendships and access emotional support during adolescence.

Cooper, Balandin and Trembath (2009) found that AAC and other communication technologies helped to mitigate feelings of loneliness. McNaughton and Bryen (2007) within their review of published research into how AAC can increase societal participation reported the internet and online communication were useful for supporting social networks. However significant technical, policy and financial barriers have been identified for people who use AAC in terms of using the internet (DeRuyter, McNaughton, Caves, Bryen & Williams, 2007).

### ***1.3 Significance of the study***

Having established that adolescence may be challenging for young people who use AAC in terms of creating social networks it was important to establish the significance of conducting research within this area. Over the last decade it has been recognised that the AAC database needs strengthening around issues of social inclusion. Alant, Bornman and Lloyd (2006) suggested the importance of research within the AAC field is growing in light of the push towards evidence-based practice, especially from the viewpoint of understanding communication contexts and environments. Blackstone, Williams and Wilkins (2007) suggested six key principles that members of the Rehabilitation Engineering Research Center in Communication Enhancement (known as the AAC-RERC) believe should be addressed in terms of research and practice within the field of AAC. Principle five states there is a need to focus on societal roles, relationships and opportunities that are made possible by the use of AAC. This study seeks to address these factors by exploring how the internet and online social media use impacts on the social inclusion of people who use AAC within a specific communication environment and context.

The stance taken by this study is to create an opportunity for the views of young people who use AAC to be represented. This has been influenced by the growing legal obligations to create platforms for the voices of children and young people to be heard (Article 12, United Nations Convention on the Rights of the child, 1989; Article 21, United Nations on the Rights of Persons with disabilities, 2006; Every Child Matters: Change for Children, 2004) and the evidence that progress to include the voices of young people with significant communication impairment has been slow (Morris, 2003; Rabiee et al. 2005; Wickenden, 2009).

#### ***1.4. The research aim***

This general aim of the current research is to look at how the growing popularity within westernised societies of the internet and online social media for social communication may be influencing the social inclusion opportunities of young people who use AAC. The specific research objectives (section 2.7) will be outlined in more detail after the literature review.

#### ***1.5. Philosophical position***

I interpret the aim of this research as facilitating an opportunity for adolescents and young adults who have physical disabilities and complex communication needs to offer their insights and experiences of using the internet and online social media. I believe by embracing a social constructivist paradigm the research will remain open to the creation of new knowledge and interpretations through an interactive process. This is important as the cultural backgrounds of the participants (adolescents and young adults who use AAC) and myself (a female speech and language therapist in her late forties) vary in terms of age, physical and communication abilities but may also overlap in terms of using the internet and online social media. I interpret my researcher voice as that of a

*“passionate participant” as facilitator of multi-voice reconstruction”* (Guba & Lincoln, 1994:112)

Methodologically, the thesis predominantly utilizes a constructivist grounded theory approach based on the writings of Kathy Charmaz (2000, 2006, 2008 & 2009).

However, it also takes a hybrid slant by pulling in some of the conceptual grounded theory ideas outlined by Corbin and Strauss (1990) and interpretations of their work from lecture material offered by Graham Gibbs (Gibbs, 2010). The data collection was through qualitative methods, mainly through face-to-face interviews but in line with a grounded theory approach other sources were identified and sought as theory generation progressed.

## ***1.6. Terminology***

Terminology within the field of disability is a contentious issue and subject to much academic discussion. There is on-going debate about the following terms: ‘physically disabled people’ and ‘people with physical disabilities’. The former is associated with the UK understanding of the Social Model of Disability as outlined by the UPIAS document, *Fundamental Principles of Disability* (1975). The latter is the term often used in other countries, such as the USA and Australia, which broadly speaking believes in prioritising the person rather than disability (Shakespeare & Watson, 2001).

Many opinions are voiced around the terms and a few of the different perspectives are offered here. Oliver (1983, 1990) acknowledges the issue of putting people first but states the preferred terminology within the disabled movement is ‘disabled people’ as it makes a political statement that people are disabled by society’s response to their differences. Koca-Atabey (2013) discusses how the term ‘people with disabilities’ struck her on her first visit to the USA. She was used to the UK term and the American term reminded her of a comment by Davis and Green (1999, cited by Koca-Atabey, 2013) that it makes disability sound like a piece of luggage to be carried around. Shakespeare and Watson (2001) within a broader discussion about whether the UK social model is outdated, question whether the term ‘disabled people’ risks imposing the term ‘disabled’ upon people who may not see their impairment as the defining aspect of their identity.

Another terminological factor within this thesis is related to the terms for communication challenges. The phrase ‘complex communication needs’ was

suggested by Balandin (2002) to replace ‘severe communication impairments’. In their 2011 paper, von Tetzchner and Basil (2011) describe how the term ‘complex communication needs’ has been widely adopted within the AAC literature base but feel despite being well intentioned it is rather vague. They also outline the variety of terms used to describe how people use AAC such as: ‘people who use augmentative and alternative communication’, ‘aided communicator’, ‘aided speaker’ and ‘AAC user’ which philosophically attempt to capture what a person can do.

Within this study, I will use ‘people with physical disabilities’, ‘people with complex communication needs’ and ‘people who use augmentative and alternative communication’ or ‘people who use AAC’ as well as occasionally ‘AAC users’. I have a sympathetic view towards the political and philosophical British social model stance of ‘physically disabled people’, but wish to maintain consistency with the field of AAC and put people first across both physical and communication descriptions. I am using the term ‘complex communication needs’ as it is not the intention of this study to define individual communication impairment, however, within the participant information section it was deemed useful to offer a broad description of the degree of physical and communicative impairment. In order to respect the stance of quoted or discussed authors then ‘disabled people’ may be used if it is clear that this is their preferred term.

Finally, I will use the term ‘young people’ as this acknowledges the adolescent/young adult threshold that is crossed by this study (age range 14 to 24 years) and fits with how the participants primarily view themselves. My main interest is in capturing the views of the young people on the topic area but in order to contextualise and co-construct these views it is sometimes necessary to describe the physical and communicative issues that challenge and support them.

## **Chapter 2**

### **Literature Review**

#### ***2.1. Introduction***

This thesis examines the intersection between: physical disability and complex communication needs, AAC, and the internet and online social media through an adolescent/young adult lens. This necessitates exploring theoretical perspectives from different disciplines: disability studies, the field of AAC, speech and language therapy, sociology and psychology. This chapter presents the epistemological canvas from which the research objectives were conceptualised.

This chapter will take a quadripartite form; the first section gives an overview of the field of AAC to contextualise issues that are relevant to the research objectives, data collection methods and factors that impact on the use of the internet and online social media by people who use AAC. The second section will provide an overview of the historical development of technology within the AAC field and how this intersects with mainstream technological advances. The third area will consider internet and online social media research for young people within westernised societies, including those with disabilities, in regard to issues surrounding: accessibility legislation, the popularity of the internet and online social media, online social ties, self-representation, self-determination and the potential risks posed by the internet. The fourth section will discuss the literature base in regards to the use of the internet and social media by young people who use AAC.

#### ***2.2. Part One: An overview of AAC***

##### ***2.2.1. Introduction***

Severe motor impairment (most commonly caused in childhood by cerebral palsy) can make it difficult to use natural speech (Fauconnier et al. 2009). Total communication strategies focus on maximising and developing an individual's ability to integrate natural speech with forms of AAC (Marshall & Goldbart, 2008; Clarke, Newton,

Petrides, Griffiths, Lysley & Price, 2012). AAC can augment (add to) or act as an alternative to natural speech and writing, and understanding communication needs will guide different strategy decisions (Alant et al. 2006). This section will give an overview of the field of AAC in order to explain how it works. It will also look at the impact that using AAC has on face-to-face interactions and outline some of the resulting conversational challenges. It is necessary to raise these issues in order to orientate the reader to topics that arise within the course of the thesis and to give context to how they relate to the internet and online social media, as there are overlaps with AAC equipment (section 2.2.2), access technology (section 2.2.3) and language representation (section 2.2.4). Issues of interactional strategies (section 2.2.5), time (section 2.2.6) and narrative challenges (section 2.2.7) are relevant to the data collection, transcription and data analysis sections and contextualise how being online intersects with issues of face-to-face communication for people who use AAC.

AAC is described on the Communication Matters website

([www.communicationmatters.org.uk](http://www.communicationmatters.org.uk)) as using techniques which support or replace spoken communication. Murray and Goldbart (2009) provide a summary of four interconnected components that are useful to consider when thinking about an AAC system:

- the **mode** - meaning what type of AAC system a person is using
- the **means** – referring to how someone accesses their communication mode, they can either do this via direct connection with a device or indirectly through some kind of scanning system and one or more switches
- the **representational system** being used – is it written language, symbols, photographs etc.
- the **interaction strategies** - e.g. starting conversations, changing topics, repairing communication breakdowns

### 2.2.2. *The mode*

Many young people with physical impairments and complex communication needs that prevent them using natural speech often develop effective non-verbal forms of communication with people who know them well. At some stage a decision may be



reached to introduce some form of AAC in order to support their total communication. In England and Wales intervention usually falls under the remit of a speech and language therapist (Clarke, McConachie, Price & Wood, 2001). Introducing AAC has been shown to support language, communication and literacy (Light & McNaughton, 2012) without adversely affecting natural speech development (Millar, Light & Schlosser, 2006; Schlosser & Wendt, 2008). The following outlines the modes or types of AAC that can be considered.

AAC is differentiated between ‘unaided’ or ‘aided’ communication depending on whether a person uses additional equipment. ‘Unaided’ forms refer to gesture or sign language (within this thesis some participants used Makaton signing (<http://www.makaton.org/>)). ‘Aided’ forms fall into two categories: low tech (not requiring an additional power source), for example, books, charts and boards. The other category of ‘aided’ AAC falls into ‘light-tech’ (simple, single message devices) and ‘high-tech’ (complex, flexible computer-based devices) all of which require a power source. Most of these will have a form of voice output either digitised (recorded speech) or synthesized (produced by text-to-speech software). These are known as Voice Output Communication Aids (VOCAs) in the UK and Speech Generating Devices (SDGs) in the USA. Low and high-tech forms are not exclusive and most people who use AAC use a mixture of modes. It is sometimes impossible to use a high-tech form in certain contexts, so a low tech form is an essential backup. Attitudes vary across different cultures in terms of preferences for varying forms of AAC (Beukelman & Mirenda, 2005) and are affected by cultural values placed on attributes such as independence, equality, privacy, time perceptions, achievement and assertiveness. Low tech may be regarded as faster by a person who uses AAC and familiar communication partners whilst high-tech forms may be easier for strangers to understand but possibly slower to use. McCord and Soto (2004) found in interviews with Mexican-American families who had developed communication strategies (before the introduction of high-tech AAC devices) that they did not perceive high-tech devices increased the speed or fluency of a conversation and may interfere with the dynamics and intimacy of family conversations. Low tech AAC was preferred at home but high-tech was considered necessary within educational settings as it was perceived teachers were more comfortable with a digitised voice output. The crucial

aspect for considering the mode of communication is to adopt a holistic view known as total communication which values and respects every method used by an individual to communicate and receive messages.

### 2.2.3. *The means*

Identifying the best way for a person to access AAC can be very complex if a person has significant motor impairments. Dowden and Cook (2002, cited by Beukelman & Mirenda, 2005) describe the two broad categories of access as ‘direct selection’ or ‘indirect selection’ (more commonly in the UK called direct and indirect access). Direct access (selection) is through four routes: *physical contact and force* (to operate a touchscreen, mouse, keyboard, joystick, etc.), *pointing with no contact* (including systems which use some form of eye gaze), *pointing with contact but no force* (communication books or alphabet boards), and *picking up and exchanging* (symbol cards or photos). Colven and Judge (2006) describe how indirect access (selection) refers to the need for an intermediate step to be taken before an individual can make a selection on a device. They describe how a wide range of disabilities can

*“affect a person’s interaction with technology”* (p.7)

such as motor control problems, visual problems, cognitive involvement and developmental needs which necessitate some kind of switch/scanning method of access to a computer. They explain an onscreen selection set (for example, an onscreen keyboard, a grid, a page) is presented and then a cursor scans through the information either in groups or one at a time and when the desired item is reached the user indicates their choice through using some kind of switch selection (there are many types available).

### 2.2.4. *Representation system*

This area is of particular importance within the context of the current research as the internet and online social media are predominantly text-based environments. O’Keefe, Kozak and Schuller (2007) carried out focus group research with AAC users aimed at identifying research priorities for the field of AAC, one of which was to

*“determine the best teaching methods for developing reading and writing skills in people who use AAC”* (p. 94).

The representational system explains the way that language is represented within different AAC modes, for example in written form, symbols or photographs. For people who may have limited exposure to literacy there will be significant implications for how they can engage with an online environment.

Representational systems on high-tech VOCA devices require management strategies to address the formulation, storage and retrieval of messages (Beukelman & Mirenda, 2005). Literate individuals may create messages on a letter-by-letter or word-by-word basis or retrieve complete sentences. Non-literate individuals can use symbols and there are many types of symbolised vocabularies available. Symbols are described at one end of the scale as *transparent* (easily guessed) and at the other end as *opaque* (abstract). Light and McNaughton (2012) discuss the difficulties of representing vocabulary and language concepts graphically and how there is no empirical basis for many of the systems available which are often based on ideas of representation from the symbol developers.

Developmental stage and individual skills in areas such as attention, language and literacy impact on the type of representational system chosen. People with complex communication needs often face challenges in areas such as literacy (Smith, 1992; Browning 2002) and language domains (Sturm & Clendon, 2004). Brekke and von Tetzchner (2003) describe how language is created through the shared

*“communicative activities of the members of a culture”* (p. 176)

and discuss how the developmental pathways for achieving proficiency are different for hearing children who lack the motor skills to use natural speech. One pathway is for children to use pictographic representations that gradually become more complex with the goal of achieving orthographic writing. They discuss how this approach requires language to be taught in a formal way via collaboration between a professional (who does not require a graphic system personally) and a child (who may become more skilled with the graphic system than the professional) to teach/learn the graphic system. It is important to note these issues in order to appreciate the diverse profiles of the participants within the current study (section 3.5.4.) who had differing types of language representation and language generation.

### *2.2.5. Interactional strategies within face-to-face conversations*

This area has been considered as the data collection method involved face-to-face conversations and because the use of the internet and online social media has significance for reducing the challenges that people who use AAC may have in negotiating face-to-face conversations. Murray and Goldbart (2009) describe how conversational management strategies such as repairing misunderstandings, changing topic, starting conversations and turn-taking are different within face-to-face conversations when one partner uses AAC. They suggest this means formal training is often needed as skills within this area can impact on the success of face-to-face conversations and the speaking communication partner can adopt a supportive role by using strategies such as: understanding verbal and non-verbal productions of yes and no, asking open questions, trying not to second guess and/or appear impatient.

Exploring one of these issues, turn-taking, will put into context how the use of the internet and online social media may change the intrapersonal perceptions of communicative skills and interpersonal communication dynamics for people who use AAC. Goffman (1964) stated turn-taking within conversations is socially organised and ratified by those involved and interference can disrupt the success of the conversation. Sacks, Schegloff and Jefferson (1974) proposed a model for turn-taking organisation, which they believed had robust cross-cultural validity. One of their observations was that turn transitions are characterised by no overlap or gap, or very slight overlaps and minimal gaps. People rarely speak at the same time and if this occurs one of them will drop out quickly. Gaps between turns are usually minimal and a variety of non-verbal, vocal and linguistic signals are used to signpost transition points. For example intonation may fall towards the end of a turn, the speaker may prolong eye contact to indicate they are going to stop soon, or use other postural and gestural cues.

Clarke and Wilkinson (2008) discuss the evidence that shows adults tend to control conversations with children who used aided communication and a picture of dominance emerges. This dominance, although viewed as well intentioned to keep the conversation going, has been suggested to possibly increase a child's passivity and is

viewed in rather a negative light (von Tetzchner & Grove, 2003). Bloch (2011) states research to look at AAC talk-in-interaction is still in its infancy and discusses the value of Conversational Analysis (CA) as a

*“systematic, data-driven study of naturally occurring talk-in-interaction”* (p. 261) that is useful for understanding AAC-mediated communication. Clarke and Wilkinson (2007) used CA to look at the interaction between children who used VOCAs and speaking peers. They found a shared responsibility was taken for turn construction and suggested this is advantageous to both communicators. The VOCA becomes a resource and both partners provide locations for its use within the exchange. This allows minimal input from the person using the device to be understood in terms of both humour and competence. Bloch (2011) also used CA to look at turn-taking for AAC-mediated conversations within case study research between a person who used AAC and a speaking partner who knew each other well. He found they tended to co-construct a conversational turn by joint production of an utterance initiated by the person who used AAC. This may be the production of one word or letter which the speaking partner then takes over in order to confirm their understanding. Bloch states some people who use AAC may have a negative reaction to this and interpret their turn as having been interrupted. He concluded overall that utterance completion cannot be judged as good or bad as in some cases it assists the exchange of meaning but can also lead to a breakdown which takes more time and energy to fix than would initially have been required.

Gandell and Sutton (1998) used a case study design to look at the difference between face-to-face interactions and those using a specialised form of email with symbolised vocabulary (they call telecommunication). The case study participants were a person who uses AAC and a speaking communication partner (well-known to each other) who interacted within two conditions, face-to-face and via telecommunication. Analysis of the two types of data found using telecommunication alleviated the pressure of negotiating face-to-face turn-taking and changed the dynamics of the interaction. In the telecommunication condition the person who used AAC produced proportionally more utterances and the speaking partner produced proportionally fewer statements than they had in the face-to-face condition. Gandell and Sutton suggest this facilitated a greater participation in the interaction by the person who

used AAC. The most notable difference in the telecommunications condition was how the person who used AAC used a greater variety of utterance types including 'wh' questions. In the face-to-face condition more statements were used by both parties with the person who used AAC using the same strategy noted by Bloch (2011) of initiating a topic via a statement and then waiting for the communication partner to guess. Using telecommunications meant the person who used AAC had to produce complete message forms which Gandell and Sutton suggest may support the development of literacy and language skills.

It must be remembered that misunderstandings and communication breakdown can still occur through the exchange of electronic messages especially due to the lack of non-verbal communication cues which can make expressing emotions, especially sarcasm, problematic and also increase the risk of 'flaming' where arguments, abuse, harassment, or slander flare up either intentionally or due to misunderstandings (Mann & Stewart, 2000).

#### *2.2.6. Time considerations within AAC-mediated face-to-face conversations*

Murray and Goldbart (2009) also emphasize another important conversational strategy is to give the person using AAC additional time. Typical conversational speaking rates vary between 150-250 words per minute (Goldman-Eisler, 1986, cited by Beukelman & Mirenda, 2005). Measuring rates for people who use AAC is dependent on a multitude of personal and technical equipment factors but speeds of between 2-15 words per minute are average (Higginbotham, Shane, Russell & Caves, 2007). Extended time lapses between turns are a defining aspect of AAC-mediated conversations. Todman, Alm, Higginbotham and File (2008) say perceptions of people who use AAC often focus negatively on their slow rates of communication, and opportunities to tell stories or talk about things that are important are often denied within fast-moving interactions. Many research areas within the field of AAC focus on speeding up conversational rate (Todman et al. 2008).

Mathias, Sutherland and McAuliffe (2010) investigated the effect of pause time in conversations with young people who use AAC and reported typically speaking

communication partners often take a dominant position making the interaction asymmetrical and placing the people who use AAC into a passive role. The typically speaking partner is likely to: ask more closed questions, be less responsive to communication attempts, have decreased expectations of communicative competence and give insufficient pause time between turns. Their study found when typically speaking communication partners extended the time they paused between turns, sometimes for as long as 45 seconds, young people who used AAC showed a greater number of conversational responses. Extended pause time within conversations may be one of the most difficult aspects for a typically speaking partner to feel comfortable with. Extended pauses of longer than 2-3 seconds challenge pragmatic conventions within conversations and unless sanctioned in some way can lead to feelings of discomfort and also lower perceptions of social competence (McLaughlin & Cody, 1982; McCarthy & Light, 2005; McCoy, Bedrosian, Hoag & Johnson, 2007; Todman et al. 2008).

Another implication for the time taken to have face-to-face conversations is the challenge it presents for attention skills. Thistle and Wilkinson (2012) describe how carrying out the dual task of following a conversation and operating a technical device creates additional pressure for people who use AAC as they have to focus on typing text (or locating symbols) whilst following the thread of a conversation which in certain situations can also change direction during the composition of their intended message. The communication partner also has to maintain attention and stay focused on the thread of the conversation, as depending on the complexity of the message, it may take people who use AAC a considerable time to prepare their message, especially if it is a novel message that has not been pre-prepared.

#### *2.2.7. Narrative and humour*

One of the challenges of using AAC is the creation of personal narratives and being able to express humour (Grove & Tucker, 2003). Waller (2006) discusses how discourse can be described as taking two forms,

*“transactional (expressing concrete needs/wants and transferring information) and interactional conversation (telling jokes/sharing experiences, discussing philosophy etc.)”* (p. 221).

Narratives and storytelling support friendships and expressions of identity as well as making sense of experiences and Waller (2006) explains people who use AAC can have pragmatic difficulties in terms of knowing how to structure a story and operational problems in terms of speed and physical exertion. Narrative-based intervention for young people with complex communication needs using scaffolding strategies which were developmentally appropriate had positive results (Grove & Tucker, 2003; Waller & O'Mara, 2003). Aside from intervention, another area of investigation is harnessing computational power to create algorithm based programmes that can generate simple forms of humour (Ritchie, Manurung, Pain, Waller, Black & O'Mara, 2007) or narratives from collected sensor data and stored personal information (Coles-Kemp, Reddington & Williams, 2011; Black, Waller, Turner & Reiter, 2012; Reddington & Tintarev, 2011) but there are hurdles to overcome in relation to personal data protection (Coles-Kemp et al. 2011).

This section has been included in the overview of AAC as it is important to recognise the relevance of self-expression through interactional communication, as Grove and Tucker (2003) explain having the ability to self-report and share personal experiences is crucial for the development of a social identity. Although there may be huge computational advances in the future for VOCAs, one of the present advantages of online social media sites as explained by Livingstone (2008) is the

*“exciting yet relatively safe opportunity to conduct the social psychological task of adolescence – to construct, experiment with and present a reflexive project of the self in a social context”*(p. 396)

#### 2.2.8. Summary

This section has given an overview of how AAC supports people with complex communication needs and addressed factors such as literacy, face-to-face communication, time, and the expression of self-identity through narrative and humour. It is necessary to consider and understand these factors in order to theorize how the internet and online social media may intersect on the everyday experiences of people who use AAC in terms of (a) challenges of engaging in a predominantly text-based environment if not literate, (b) implications for social relationships and (c) perceptions of self-representation. Little is known about the impact of the internet and



online social media on communication experiences from the perspective of people who use AAC.

## ***2.3 Part Two: Historical development of AAC***

### *2.3.1. Introduction*

This section considers the technological development of AAC within the broader mainstream development of communication technology to conceptualise the research interest to look at the use of the internet and online social media by people who use AAC. DeRuyter et al. (2007) state the ‘digital revolution’ over the last twenty years within mainstream technology and the development of wireless connectivity is going to have far reaching consequences for people who use AAC.

### *2.3.2. Historical context*

The AAC-RERC (2011) white paper describes how the roots of AAC developed from the desire to help people with complex communication needs to express themselves. Hourcade, Pilotte, West and Parette (2004) describe how intervention evolved within the speech and language therapy profession during the 1970s with an initial focus on an ‘unaided’ approach using gesture and sign language to support the development of speech. Disadvantages remained for those whose motor abilities prevented accurate sign production and the limitation of other people’s knowledge of sign language. Vanderheiden (2002) explains how three distinct threads helped form the basis for the field of AAC during the 1970s: early electromechanical communication and writing systems, research into the development of language and work to develop communication and language boards. He describes a major step in the field of communication boards occurred in 1971 when a Canadian group led by a teacher called Shirley McNaughton started to use the Bliss symbol system developed by Charles Bliss to help children to communicate. The early pioneering work within these threads then combined with the work being done with sign language and the field of AAC began to take shape. The formation of the International Society of Augmentative and Alternative Communication (ISAAC) marked the beginning of a

formally organised field bringing together people from many different disciplinary backgrounds.

‘Aided’ communication tended to be in the form of communication boards (with pictures or writing) and was considered a last resort as there was a concern that use of these would impede the development of speech production (Vanderheiden, 2002). There was also a belief that ‘unaided’ and ‘aided’ systems should not be used simultaneously (Hourcade et al. 2004). A move in the philosophical basis of speech and language therapy intervention to recognise the functional use of language made ‘aided’ AAC practices more attractive (Hourcade et al. 2004). The goal to acquire natural speech was no longer considered a priority although there was a growing recognition that ‘aided’ AAC could support the development of speech. Many aided language representation systems were developed in the form of stylised symbols and early forms of electronic communication devices emerged which produced messages on a screen or printed onto paper and some early advances in switch and scanning technology occurred.

Vanderheiden (2002) says the development of the Apple II (1977) was when computer support for people with disabilities really was considered in earnest. During the 1980s/90s, in response to computer advances, speech synthesis technology and alternative access methods, a small dedicated AAC industry developed producing computerised devices. Chapple (2011) charts how early devices in the 1980s were basic computers with a voice synthesizer attached. Using a basic keyboard people could create novel messages one letter at a time or store whole phrases under two or three letter combinations. Later in the decade he explains how communication devices shifted to being language-based and were pre-programmed with words and sentences which were often represented by pictures or icons within a static display.

During the 1990s, Chapple (2011) says interest shifted to dynamic displays where vocabulary was broken into categories which allowed users to select a button which would then change the screen to a new selection of pictures or words within the new category. Another development was alternative access through head pointer sensors or external trackers that opened up possibilities for people to make selections using a

cursor that reacted to movement. Two of the most important advances at this time were the ability to interface with a computer which allowed the use of email and word processing via pictorial language systems and the options to interface via USB ports and wireless technology (initially radio and infrared technology, subsequently Bluetooth technology and more recently 3G mobile phone technology dongles or wireless connection through WiFi).

In 2000, a device appeared which Chapple (2011) says was truly revolutionary. Firstly, it combined static overlays with dynamic touch screen displays which increased speed dramatically, secondly it ran on a Windows CE format which opened up the use of address books, calendars and some computer games, and thirdly it allowed mobile phone calls to be made and received though the device via an Air card and SIM card and paved the way for current devices on the market today to receive text messages. By 2007, totally integrated communication aids were available from many manufacturers meaning single machines could operate as a communication device and a personal computer or continue to interface with an external computer.

DeRuyter et al. (2007) summarised how AAC technology had integrated mainstream technology through three primary approaches:

*“(a) “dedicated” AAC systems housed in specially designed hardware, (b) proprietary AAC software functions on a mainstream operating system and housed in specially designed hardware, and (c) proprietary AAC software functioning on a mainstream operating system and housed in a mainstream device” (p. 262).*

They concluded (in 2007) that many features important to those who use AAC could cross into larger markets (e.g. older adults) and the AAC industry must make mainstream manufacturers aware of this and also ensure access to email, mobile phones and all the services provided by the internet are available within communication devices.

### *2.3.3. Development of voice output Apps on mainstream devices*

Within the last few years the mainstream mobile technology industry has indeed ‘woken up’ to AAC. Voice output Apps have been developed which can be used on Apple and Android based devices and people who use AAC now have the possibility

of using mainstream mobile technologies and having access to communication based AAC software within the same mainstream device. This initially started on the Apple platform and Higginbotham and Jacobs (2011) explain how Apple's development of the iPad, and the emergence of non-iPad tablets, has not only changed the face of mobile technology, but by supporting voice output Apps, has also changed the face of AAC with increased choice for: cheaper products, alternative access options, and standard or specific software applications.

The literature base is proliferating around the use of mobile technology and Apps within the field of AAC. Some Apps have been judged appropriate for people with autism who use AAC (Sennott, 2011) whilst others may not have been developed around principles of language acquisition and research evidence (Light & McNaughton, 2012). Researchers are attempting to develop frameworks within which Apps can be evaluated in relation to individual need (Gosnell, Costello & Shane, 2011a, 2011b; Alliano, Herriger, Koutsoftas & Bartolotta, 2012). Hershberger (2011) warns ill-considered App solutions may lead to people who use AAC and their families losing faith in the potential support of AAC. He suggests, in line with McBride (2011), that whilst remaining enthusiastic about mobile technologies for people with complex communication needs, AAC procedures must be applied to evaluate individual needs and guide decisions about technological solutions. Many Apps targeted at mass markets may not be specific enough for people with complex communication needs (Beukelman, 2012, cited by McNaughton & Light, 2013). McNaughton and Light (2013) state the goal of any device must be to focus on communication rather than the technology. They also outline how the cost of follow-up technical support is included in the price of traditional AAC devices which is not the case with AAC Apps on mobile technologies (there is little, if any, technical support available post purchase).

Since the release of the iPad there has been a proliferation of competing products. Higginbotham and Jacobs (2011) describe how Android (developed by Google) is significantly different from Apple iOS as it is an open source operating system and therefore available to software developers to use in their products. This will mean that within small programming communities, like those in the world of AAC, individual

AAC developers will be able to share creative innovations across the Google platform. The lowered costs of mainstream devices may enable AAC consumers to use multiple devices across different aspects of their lives. Vocabularies could also be stored within Cloud (online) storage systems and synced across the different devices. However, they also warn that the very nature of the open-source approach, which is so different to Apple, may provide challenges as there is no standard system for developers to refer to so Apps may be compromised in how they can interact with each other. The impact of mobile technologies is recognised as causing a large shift within the AAC industry. McNaughton and Light (2013) summarise the impact of mobile technologies as

*“increased awareness and social acceptance of AAC in the mainstream, greater consumer empowerment in accessing AAC solutions, increased adoption of AAC technologies, greater functionality and interconnectivity, and a greater diffusion of AAC research and development” (p. 108)*

So to sum up this section, there have never been so many opportunities available to the people who use AAC and those who support them. People with complex communication needs have a right to use new technologies to access education, social networking, games, entertainment and information sourcing and it is vital their perspectives are heard. Two people who use AAC have written eloquently about the impact mobile technology and Apps have had in their lives. McLeod (2011) speaks about how the advances in technology have impacted on his life. He has used AAC for 25 years, since he was six years old, and has witnessed at first hand the remarkable changes that have swept through the industry. Using AAC has supported his career as presenter and writer. He describes using many devices to suit his communication needs and gives an interesting perspective on the emerging App market. Although he still uses two traditional VOCAs he is glad to have an App which he can use on a mobile device. He likes the long battery life as traditional VOCAs struggle with battery life. He says it acts as a valuable backup but has not become his main communication aid as it has some limitations when compared to his VOCA. For example, it cannot speak each word as he types it and he has to compose the whole message first which he says may lead people to lose interest in what he is saying, and it has word prediction limitations. He particularly likes the low cost and says when

App improvements are made he can see this being his main communication aid. Hyatt (2011) speaks about how buying an iPad has changed her social communication opportunities and describes using it within a hotel bar with her friends. She liked the back light and clear display in the dimly lit environment and the good typeface size of the App made reading at a distance possible. She described how accessing the internet over the hotel WiFi system allowed her to share a depth of communication about areas of her life which would not have been possible on her single-function VOCA.

#### *2.3.4. The reaction of the AAC industry and the development of VOCA devices*

As DeRuyter et al. (2007) identified, the high cost and long term procurement of VOCAs means they may remain in service for longer than mainstream technologies and can be difficult to update as technological advances are made. They also state

*“many AAC technologies have focused primarily on supporting face-to-face communication”* (p.259)

meaning the focus has not always been on the convergence of communication functions within one device.

However, since 2007, the situation has been changing rapidly and traditional VOCA manufacturers have been responding to the increased market pressure created by the mainstream mobile technology market and the development of voice output Apps. On the hardware side, integrated VOCAs are becoming far more powerful as computers and some of the latest models (as of 2013) are lightweight, have front and back facing cameras and full access to the internet and mobile phone technology which enables users to access, produce and share content on social media sites. Software is developing to embrace the Apps market and facilitate the use of a wide range of social media sites. There is also a growing assortment of mainstream Apple and Android accessories to support access (wheelchair mounting, switch access solutions, protection cases, speakers, etc.). The strength of traditional VOCA manufacturing companies is their experience of the AAC field and in-depth knowledge of the type of challenges people with physical and complex communication needs might face, especially in terms of access and robust design.

### 2.3.5. *The future?*

Shane, Blackstone, Vanderheiden, Williams and DeRuyter (2012) paint an optimistic view of the future where they suggest that advances in technology may produce personalised solutions for alternative access for people who use AAC in the future. Some of the areas they discuss are the on-going progress with Radio Frequency Identification (RFID) which is the wireless non-contact technology used to transfer data by the recognition of tags attached to objects. They suggest, for example, it might be used to recognise an AAC user and then, in terms of their location, present them with context relevant vocabulary, e.g. a doctor's surgery. They also discuss the promise of the Raising the Floor project called the global public inclusive infrastructure (GPII)<sup>1</sup> which is aiming to provide accessibility to any device, anytime, anywhere by storing a person's individual computer requirements in the 'cloud'. This means any device could become a portal through which individualised services can be delivered. The Cloud4all project<sup>2</sup> is based on a European Grant to develop key parts of GPII. Another area of possibility Shane et al. (2012) mention, is the potential for camera detection and microphones which will be able to use any type of motion to control a computer and they suggest

*“an individual could approach any computer, anywhere and, without touching it, have the virtual assistive technology and virtual interfaces called up from the cloud, adjusted to their exact setting, and available for them to use”* (p. 9).

They also allude to 'crowd sourcing' where human and computer based assistants could be called up through devices by sending a message 'into the cloud' and asking other people for help. Finally, they speak about Near Field Communication (NFC) which allows machines near each other to connect and this could help people with physical disabilities to, for example, pay for things without having to enter pin numbers on a terminal.

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<sup>1</sup> GPII is a Raising the Floor project ([www.raisingthefloor.org](http://www.raisingthefloor.org)) dedicated to making the internet accessible to everyone. It is made up of organisations from academia, industry, consumers, non-government organisations, activists etc.

<sup>2</sup> The Cloud4all project (<http://cloud4all.info/>) is funded by the 7<sup>th</sup> Framework Programme of the European Union in order to develop key parts of GPII by building algorithms, developing the knowledge base and evaluating the ability of the concept to work across platforms.

The other side of this bright view of the future is discussed within the 2012 State of the science conference in AAC: ARC-RERC final report (AAC-RERC, 2012). It outlines how technical innovation can influence how disability may be experienced and also extended. They discuss how the rise of voice controlled technology and also movement sensor operating systems may prevent people with physical disabilities and complex communication challenges from accessing mainstream technology, thereby heightening the risk of exclusion. Wise (2012) warns this may mean that communication systems break down rather than improving. It is vital in order to strike a balance between the promises and possible limitations offered by new technology that the views of people with disabilities are sought in order to understand their perceptions, especially those who are traditionally under-represented.

### *2.3.6. Summary*

The description of the changes from the 1970s to the present day (and maybe beyond) shows how enormous philosophical and technological shifts have occurred over the past few decades in regard to AAC, particularly in terms of technological advances over the past twenty years. This has resulted in an AAC field which supports people with physical impairments and complex communication needs to engage in many aspects of the modern digital age. VOCAs have evolved from being very bulky and primarily designed to support face-to-face communication to sleek lightweight mobile technologies which can connect with the internet and online social media through wireless technology. Recently mainstream technology has also embraced the concept of AAC and voice output communication Apps and mobile technologies are creating a paradigm shift within the traditional field of AAC which has been described as the ‘democratization’ of AAC (Rummel-Hudson, 2011). People within modern society, especially the younger generation, expect to be able to use the internet and online social media and Soderstrom (2009) says young people who are unable to engage with online activity are at risk of being marginalised and excluded from their peer communities.

There is a growing body of evidence, especially within educational fields, that it is vital to include the voices of students as they can have insights which may differ from the views of professionals (Jenkins, 2006; Cook-Sather, 2009). Boggis (2012) has



carried out one of the rare studies which have sought the views of children who use AAC within the UK. She carried out research exploring the views and experiences of children about high-tech AAC devices and found they had insightful information about the limitations of their VOCAs which they felt sometimes had little value to them. They had limited inclusion in service provision decisions over choice of equipment, how the device was organised or the vocabulary available. There is a startling lack of evidence within the United Kingdom on the experiences of using the internet and online social media by young people who use AAC so many of the issues highlighted above have been reported by professionals and developers and the perspectives of those who use AAC is required.

#### ***2.4. Part Three: The internet and online social media within the lives of young people, including those with physical disabilities, within westernised societies***

##### *2.4.1. Introduction*

This part will consider issues regarding the use of the internet and online social media within westernised societies, in order to consider some of the popular perceptions of online technology for youth populations, including those with disabilities. It will start with an overview of UK legislation recognising the rights of people with disabilities to access cultural materials; it will then examine data on the use of computer technology by young people with and without disabilities, to illustrate how ubiquitous use has become for young people. It will move onto giving a brief outline of social capital and the implications for social ties and self-representation within online environments. It is recognised these are vast areas and so information given will be targeted specifically to the online technology research agenda.

##### *2.4.2. Rights of people with disabilities*

The UK Equality Act (Home Office, 2010) requires that school and higher education institutions when regarding accessibility for students with disabilities must work towards

*“improving the delivery to disabled pupils of information which is readily accessible to pupils who are not disabled”* (Home Office, 2010, Chapter 15, Part 6, Chapter 1, Section 88, Schedule 10).

In 2009, the United Kingdom ratified the UN Convention on the Rights of Persons with Disabilities (Office for Disability Issues, HM Government, 2009). Article 30 of the convention states the right for people with disabilities to participate in cultural life, recreation, leisure and sport, specifying a member state takes

*“appropriate measures to ensure that persons with disabilities:*

*a) Enjoy access to cultural materials in accessible formats”* (United Nations, 2006).

Figures released in the 2012 Ofcom Consumer Experience Report show only 46% of people with mobility challenges had home access to the internet. A lack of practical attention to access can risk favouring already privileged groups (Clayton & Macdonald 2013) and people unable to digitally engage may feel increasingly isolated (Goggin & Newell, 2003). As discussed previously, access technology refers to the additional adaptations people with disabilities may require to access ‘off the shelf’ equipment (Watling, 2011). People with disabilities on limited budgets can encounter high costs, lack of support and inaccessible internet sites (Lewis, 2010; Watling, 2011; Macdonald & Clayton, 2012).

Within the Ofcom report (2012) on home internet use by a single disability group, age was a significant variable; among the 15-34 year age group percentages were comparable, 92% of non-disabled and 90% with mobility challenges had home access to the internet (Ofcom, 2012). In light of the popularity of being online within this age group it is important to seek the views of those with mobility challenges about their experiences of using the internet and online social media. There is a growing legislative requirement and philosophical recognition of the need to ensure the voices of people with disabilities are better represented within the research process (Farmer & Macleod, 2011) but as Franklin and Sloper (2009) point out the progress to include the voices of young people with complex communication needs has been noticeably slower than in other populations of people with disabilities.

### 2.4.3. *Internet use by youth populations*

According to Lathouwers, Moor and Didden (2009), little data is available on use of the internet by disabled young people as most research has focused on non-disabled adolescents and the evidence that is available is sometimes conflicting from different countries. They cite Clancy (2002) and DeBell and Chapman (2003) as finding reduced internet use within different groups of young people with disabilities (physical, visual or hearing) in comparison to non-disabled peers in the USA. This was also suggested by Raghavendra, Wood, Newman and Lawry (2012b) who found reduced internet use by Australian adolescents with physical disabilities in comparison to peers without disabilities. In contrast, Lidstrom, Ahlsten and Hemmingsson (2010) compared questionnaire information from 215 Swedish children and youths with physical disabilities (mean age 12.10 years) with data from the 'Kids and Media 2006' (a survey by the Swedish Media Council), (Mediaradet 2006, cited by Lidstrom et al. 2010), to compare reported activities outside of school. They found a higher proportion of children with physical disabilities were engaged with ICT activities as they had a more uniform profile than children without disabilities who were engaged in a broader range of activities outside school. This higher level of use was also found within hearing impaired young people in Israel who used the internet for significantly longer each week than hearing individuals (Barak & Sadovsky, 2008).

Gross (2004) says, within westernised societies,

*“the increasing pervasiveness of the internet in the lives of adolescents is now well established”* (p. 634).

Valkenburg and Peter (2009) review research looking at the social consequences of internet use by adolescents. They note that in the 1990s much research suggested that being online had a negative effect on the social connectedness of adolescents. They suggest the reasons for these findings may be firstly, very few adolescents were online then, so those that were, had little access to the remainder of their offline social networks and, secondly the types of sites available did not encourage social connections in the way instant messaging and social networking sites (like Facebook) currently do. The current prevalence of use indicates adolescents are likely to have

good online social connections to their peers. Lenhart, Purcell, Smith and Zickuhr (2010) reported 93% of young people in America had access to the internet and 73% used social networks. Figures are similar in the UK, 93% of 12-15 year olds are reported to have access to the internet with 75% having an active social networking profile (Ofcom, 2011). Survey data collected from 25 European countries (n=25,142 children and parents) shows on average 50% of children (9-16 years), have access to the internet in their bedroom and 40% via a mobile device and these figures are higher for Northern European countries (Livingstone, Haddon, Gorzig & Olafsson, 2011). Opportunities for online entertainment and social communication are strong motivators for digital engagement among young people (Livingstone & Helsper, 2007). Mesch and Talmud (2010) conclude young people evaluate a wide range of options when considering keeping in contact with their peers and online and offline communication converges with choices made over

*“face-to-face, email, instant messaging, chat rooms, phones, SMSs – according to their communicative needs” (p.95).*

The issue to bear in mind according to Livingstone and Helsper (2007) is that simply using the internet is not a goal in itself and research must try to understand how using the internet links to the broader social inclusion/exclusion agenda. They warn of the risks of a digital divide developing amongst young people that threatens opportunities for inclusion as most young people expect their peers to be online and social media use is integral to their relationships.

#### *2.4.4. Social capital and internet-based research*

The concept of social capital has been utilised by researchers when looking at the value of the internet and social media in regard to social ties (Valenzuela, Park & Kee, 2009). Social capital is an influential concept that has gained ground over the latter half of the last century and emphasises the reciprocal nature of social relationships and the importance this has for achieving mutual goals. Schuller, Baron and Field (2000) discuss how the concept has a broad appeal although it is not without critics. They discuss how in terms of origin there are texts that: mention the term directly, others which use the key concepts of trust and networks, and those that are related to social capital but do not explicitly refer to it by name. MacGillivray and

Walker (2000) say the three widely acknowledged developers of social capital theory are Pierre Bourdieu, James Coleman and Robert Putnam. Schuller et al. (2000) map their contributions as follows:

- Bourdieu defined social capital as the collectively-owned capital generated through the actual or potential resources available to all members of a recognised and durable network and placed particular emphasis on how elite groups used their contacts to perpetuate privilege.
- Coleman's work on social capital was particularly influential and brought together the disciplines of sociology and economics and emphasised the benefits of acquiring educational credentials which facilitate the actions of actors either at an individual or a collective level and extended to non-elite groups.
- Putnam has been the most successful author to popularize the concept globally and at a policy level. He defined three key social capital features as: networks, norms and trust. His work was criticised, like Coleman's, for failing to recognise issues of power and conflict which he denied by suggesting inequality by default cannot support social capital. His recent work has identified social capital solely with networks.

Putnam introduced two basic forms of social capital: bridging and bonding which support different needs (Field, 2008). Bridging attempts to explain how external assets can be utilised to encompass broader identities, whereas bonding aims to represent in-group loyalty. The concept of social capital is in many spheres regarded as positive and has had huge influence on social policy developments. However, any type of group has the potential to alienate other groups, allowing malevolent practices to flourish and promote inequality by advancing their own interests. Holt (2008, 2010) argues social capital can be envisaged as embodied which she suggests is helpful for recognising how disadvantage is

*“embedded in everyday practices within specific social networks”* (2010, p. 26).

She suggests many social commentators are disturbed by the neoliberal undertones of social capital theory.

Whilst noting these criticisms and having reservations about the neoliberal overtones of social capital theory, especially as reinforcing disadvantage in regard to disability politics, I have chosen to include social capital theory within this discussion of the literature as some recent work has attempted to utilise notions of bridging and bonding capital in regard to internet-based research. Williams (2006) suggests the established social capital frameworks traditionally used in television research are outdated in terms of the online era and developed a new quantitative measurement tool (the Internet Social Capital Scales, ISCS) to consider bridging and bonding social capital across online and offline contexts. He argues there is confusion surrounding social capital as a cause or an outcome and he chooses to regard it as an outcome rather than a description of a network. He suggests concepts of bridging and bonding social capital can be used as measurements of the consequences of online and offline social networks. He suggests that his validation of the ISCS scale challenges criticisms of bonding social capital as creating out-group antagonism. Within an online environment, he suggests this may be due to concepts found in the work of Galston (1999). Galston suggested the low level of social cost surrounding entering and exiting voluntary online communities lessened group power dynamics of in-group benefit and thereby the production of out-group antagonism. Ellison, Steinfield and Lampe (2007) created a questionnaire to look at the relationship between Facebook and social capital among a cohort of undergraduate students within a university setting by adapting items from Williams' (2006) scale. They created a novel measure identified from their pilot interview data of *maintained* social capital. They discuss how their results showed Facebook had an impact on bridging capital offering opportunities to overcome barriers by providing more information and opportunities, especially for students with low self-esteem. There was a weaker effect on bonding social capital as it was more useful for supporting weak social ties than the type of close relationships associated with bonding social capital although it did help maintain pre-existing close relationships. Finally, they found the intensity of Facebook use predicted increased levels of maintained social capital. Keeping in touch with old friends played an important role for students to maintain social capital through capitalising on the value of old friendships and offsetting distress that might be caused by losing touch. They also found Facebook use intersected with measures

of psychological well-being and may support perceptions of self-esteem and life satisfaction.

There are interesting implications for the fact that online social media sites such as Facebook can support social capital. Within the next section it will be illustrated that people with physical disabilities often find it difficult to establish and maintain social ties (Imms, 2008, Kirk, 2008), especially when their life situations change and they geographically move to new situations.

#### *2.4.5. Online social ties of young people*

As the previous section (2.4.3.) has shown, one of the main interests of young people is to use the internet for social communication (Livingstone & Helsper, 2007). The growing popularity and integration into young people's lives of online communication is opening up new dynamics for social participation and inclusion within adolescent peer groups. Livingstone (2008) discusses how adolescents are not necessarily using online social media to displace face-to-face communication but find it adds an additional dimension to existing local ties. Vallor (2011) has written a discussion paper on the value of friendship and new social media using an Aristotelian theory of the good life, which holds that

*“human flourishing is chiefly realized through ‘complete’ friendships of virtue”*  
(abstract).

She looks at Aristotle's four values of *reciprocity*, *empathy*, *self-knowledge* and a *shared life* and examines each in relation to new social media. She concludes there are many ethical questions about what we value and define as true friendship in a virtual world but that online social media is certainly influencing friendship maintenance and allowing people to connect and collaborate in new ways that are yet to be fully understood or realised. Young people share a wealth of candid and intimate information online about interests, extracurricular social activities and family dynamics within virtual communities, which support, reinforce and enrich their offline social relationships (McMillan & Morrison, 2006; Williams & Merten, 2008; Mesch & Talmud, 2010). Livingstone et al. (2011) found young people reported they often found it easier to be themselves online than in face-to-face situations.

People with disabilities have the same aspirations for friendship, participation and recognition as other people (Watson, 2002; Soderstrom, 2011). Young people with physical disabilities have lower social participation opportunities across a range of domains (Imms, 2008; Fauconnier et al., 2009; Parkes, McCullough & Madden, 2010; Raghavendra, Olsson, Sampson, McInerney & Connell, 2012a) so it is important to consider opportunities for social participation and inclusion through digital technology. Soderstrom (2009) suggests the long distance social ties of disabled young people are enriched through the use of social media. Seymour and Lupton (2004) suggest being online may have benefits for addressing the complex issues for social participation faced by people with physical disabilities by offering opportunities to build and enrich relationships beyond the confines of temporal, spatial and physical challenges and was invaluable in helping to

*“maintain and develop significant friendships” (p. 299)*

and manage intimate relationships. Priestley (2003) says,

*“Participation in youth culture involves the maintenance of peer friendship networks and close personal relationships. Yet there may be many physical and social barriers to such relationships for young disabled people” (p. 91)*

Many people with physical disabilities find it difficult to keep in touch with old acquaintances as they move through their life. Kirk (2008) explored the perceptions of young people aged 8-19 years with complex healthcare needs in relation to various issues but with a particular focus on transitions. She found participants felt

*“feelings of loss because of their relationships with trusted professionals coming to an end” (p. 571).*

The perceptions of transition for people with disabilities into adult services is often overlooked when they have complex communication needs and they can be excluded from transition planning with little attention given to their friendship and leisure needs and often enter a period of loneliness as they lose contact with peers (Rabiee, Priestley & Knowles, 2001; Beresford, 2004).

The internet and online social media is incredibly popular within youth populations and is shown to support friendships and offer opportunities for sharing intimate and candid information that enriches peer relationships. As people with physical



disabilities and complex communication needs will have the same aspirations for friendship but face challenges for maintaining social ties, especially during periods of transition, examining their perceptions of the role of the internet and online social media may play in supporting their social ties is crucial.

#### *2.4.6. Online self-representation*

In order to consider aspects of self-representation for the participants of this study, this section will initially discuss research that has suggested adolescence and young adulthood are developmental stages for identity exploration before touching upon the issue of identity theory within disability studies. This is necessary to contextualise the literature looking at online representation from adolescent and disability perspectives.

Identity formation is an important component of psychological and sociological theory in respect of adolescents and young adults (Mesch & Talmud, 2010).

Adolescence is often regarded as a key stage for identity exploration (Smith, 2005) and Arnett (2004) suggests this continues into young adulthood with the time between 18-25 years of age being very significant. Erikson's (1963, 1968) theory of psychosocial development (considering both psychological and social aspects) suggests the exploration of *ego identity* happens in developmental stages across the life span and involves the competent resolution of various conflicts. He suggests that during adolescence (12-18 years) the exploration of identity versus role confusion is a key factor characterised by an exploration of a sense of self. Young adulthood (19-40 years) is characterised by intimacy versus isolation where the development of close relationships with others is deemed important to counteract isolation and loneliness. Marcia (1980) suggests adolescent identity should be seen as a self-created internal concept which takes into account aspects of ability, personal characteristics and personal history. He says if this is well-developed it leads to a sense of stability and internal validation in relation to external circumstances and if under-developed may lead to confusion and a need to externally validate a sense of self. He does not feel identity formation happens only within the adolescent period but that this period is important as it is the first time an individual can physically, cognitively and socially begin to examine childhood constructs and create their own passageway to adulthood.

Goffman (1959) discussed the presentation of self in everyday life as individual performances that can be broadened into team or region behaviour and manipulated accordingly to affect audience reaction. Central to Goffman's discussion is the idea that an individual plays a part and creates a performance which s/he hopes observers will take seriously. Goodley (2011) speaks about how Goffman's later work (1961, 1963) has been hugely influential in permitting analyses of the ways in which disabled people are labelled and pressurised to accept conceptualisations of themselves through the expectations and interpretations of others. Goodley argues Goffman's work helped to close down long-stay hospitals and position disability as a sociological problem. Watson (2002) describes how many disputes have arisen within the field of disability studies over theories of identity. He explains those which focus on the fact that identity formation is built on fixed concepts of shared experience can be oppressive when disability forms the foundational basis. He discusses his interview study of disabled people's accounts of self-identification that found they primarily did not see themselves as disabled and their views were spread over the following positions: some felt their impairment did not make them different, some focused on what they could do as the essential component of identity and others rejected a social construction of normality. Watson (2002) talks of the importance of being able to exercise choice over one's identity and the ability to create a personal narrative.

As previously stated, the development of the internet has provided a theoretical space within which researchers can consider and debate identity theory. Much research has started to look at the implications of online identity formation. According to Livingstone (2008), a consistent observation about young people is the attention they pay to the presentation of self. She suggests online social media sites, due to the convergence of multimedia such as email, music, photographs, website linking etc., are offering young people opportunities to construct their presentation of self in ways not seen before. Much has been made of this phenomenon in the popular press and concerns have been raised that adolescents lack the judgement skills to protect their own and others' privacy. Gross (2004) re-examined some early internet identity theories (Turkle, 1995 and Sweeny 1999, both cited by Gross, 2004) which suggested adolescents use the internet for anonymous identity exploration. She collected questionnaire data from 261 adolescents, aged 12-13 years olds and 15-16 year olds,

in Californian schools. Of those who answered questions regarding typical internet use, 49% reported they never pretended to be anyone but themselves and 41% said they had done it a couple of times, and of the remaining 10%, some said occasionally, a few said pretty often and a very small number said all the time. Pretending behaviour was usually to appear older, occasionally to be of another gender or sexuality and in some cases to be a celebrity. The majority of those who admitted to pretending did so within the physical company of a friend and their motivation was usually for a joke. Only 2% of those who said they pretended did so in order to explore a new identity or self.

Zhao, Grasmuck and Martin (2008) investigated identity construction on Facebook. Within their literature review they discuss the work of Stone (1981) who, in similarity with the ideas of Goffman (1959), suggests individuals make ‘announcements’ which are then ‘placed’ by others and identity is established when the two coincide (Stone, 1981, cited by Zhao et al. 2008). Their paper is part of a wider study that carried out content analysis on the Facebook profile data of 63 university students. The conclusion drawn was that a Facebook identity is formed around a continuum ranging from the implicit visual end where the self is portrayed as a social actor predominantly through photographs, the ‘watch me’ self which effectively shows without telling. At the other end of the continuum is the explicit narrative ‘first person self’ where descriptions are used to illuminate information. The mid-point is where Zhao et al. place the enumerative (or ‘self as consumer’), the space on Facebook where an individual lists what they like in terms of cultural material (music, books, films, etc). Users also control their audiences through filters on the website but Zhao et al. suggest that despite some deviance most people tend to present a ‘hoped for’ self that is socially desirable. Among other things they conclude

*“the Internet provides new resources and opportunities for identity production that can be used to overcome some limitations inherent in face-to-face situations” (p. 1831)*

They suggest these ‘digital selves’ are real in many ways to Facebook users and can enhance a person’s self-image and increase chances to make connections in the offline world that have concrete consequences. They also suggest being able to perform acts of resistance through a Facebook profile and use the ‘hoped for’ self to influence and

convince others of what to think about the individual. Livingstone (2008) suggests (in line with Mead's (1934) distinction between 'I' and 'me') that online social media is definitely about 'me' as it reveals the self as it is entrenched within a social peer group rather than the personal representations of 'I' which tend to remain private.

These debates about online identity formation have also filtered into the disability research arena. Some researchers have expressed that being online can be a 'levelling ground' offering people with physical disabilities the opportunity to show their abilities without being defined by their bodily appearance (e.g. Bowker & Tuffin, 2002). This idea is also discussed by Seymour and Lupton (2004) who found 'body-less' communication was valued by participants as offering the opportunity to escape the visible body as an identifier of disability and facilitated communication on more equal terms. However, it was also acknowledged within their study that losing the nuances of non-verbal communication online can lead to misunderstandings. It is important to understand that escaping definitions of bodily appearance is desired in order to challenge societal perceptions of ability and must not be confused with ideas of lowered self-concept. Shields, Murdoch, Loy, Dodd and Taylor (2006) carried out a systematic review to examine the literature base for evidence of the assumed lowered self-concept of young people who have cerebral palsy. They found there was insufficient evidence to conclude young people with cerebral palsy have lower global self-concept than peers without disability, although a small amount of evidence suggested young girls with cerebral palsy may be at a slightly higher risk of lowered self-concept.

As noted previously within this review, very little research has been carried out with young people with physical disabilities and complex communication needs in relation to self-representation within online environments.

#### *2.4.7. Self-determination*

The potential benefits of the internet and digital engagement have been well documented across areas such as education, health, employment, public services and leisure and the UK government believes it can increase social inclusion opportunities (Champion for Digital Inclusion, 2009). People affected by unemployment, low

income, social deprivation or disability have been identified to be at a seven-fold increased risk of digital exclusion (Helsper, 2008; Watling, 2011). Clayton and Macdonald (2013) suggest that being online does not necessarily increase social inclusion; much depends on the context of engagement as without knowledge, connections and reasons to engage, individuals may struggle to maximise potential benefits and they suggest being wary of the role technology can play in

*“tackling entrenched disadvantage” (2013:18).*

Self-determination is a recognised component within measures of social inclusion for people with disabilities. Milner and Kelly (2009) identified five fundamental antecedents for community participation and inclusion by people with disabilities one of which was self-determination. Smith and Murray (2011) used these concepts and built upon them by incorporating the outcome literature of authors such as Granlund and Blackstone (1999) and Lefebvre, Cloutier and Levert (2008). Smith and Murray (2011) were interested in building a framework to measure the goals and outcomes of AAC intervention. They describe building a sense of

*“self determination [sic] and self-efficacy” (p. 294)*

through the perception of individual skills is an important outcome measurement for the success of AAC intervention. Mahar, Cobigo & Stuart (2013) conducted a narrative literature review to establish social belonging outcome measurements that could be useful when considering community-based programmes for people with disabilities. They also identified five themes, one of which was self-determination.

These studies show that self-determination was an important antecedent for feeling a sense of social inclusion. The internet has been reported to offer people with physical disabilities an increased sense of belonging within online communities (Obst & Stafurik, 2010). Finn (1999) reviewed information on an online self-help forum on issues of disability and found the online group provided

*“many of the processes used in face-to-face self-help and mutual aid groups, with an emphasis on mutual problem solving, information sharing, expression of feelings, catharsis, and mutual support and empathy” (abstract, p.220)*

If being online is going to be valuable for building perceptions of social inclusion and a sense of belonging for people with disabilities then offering increased opportunities

for self-determination is an important aspect. Ritchie and Blanck (2003) discuss the role of the internet to support people with physical disabilities who live within Centers for Independent Living (CILs) to access information on a range of subjects and access consumer services. One of their conclusions was,

*“accessible technology for persons with disabilities has the potential to enhance independence in life. Its future development holds promise for a wide range of persons with disabilities, including those with communication disabilities who use symbol language”* (p. 24)

Self-determination may be widely hailed across the disability field as desirable but has also received concerned criticism within critical disability discourses. The desire expressed by people with disabilities to author their own experiences is clear but as Maskos (2006) argues absolute self-determination is problematic. Steiner (1999) says

*“Self-determination is never an all-or-nothing principle or even a synonym for self-realization. Self-determination is, to choose one way ... in the absence of institutional constraints and patronizing professionalism”* (online, no page number)

This sentiment is echoed by Petersen (2009) who found when self-determination was *“articulated as a particular set of skills to be acquired...the democratic intent of self-determination was undermined”* (abstract).

Williams and Merten (2008) point out in a discussion about adolescent perceptions of internet communication,

*“symbolic interactionists would argue that blogging is as meaningful to adolescents as they believe it to be and plays as large a role in their life as they allow”* (p.255).

Soderstrom (2011) demonstrated how self-determination is best judged from an individual's perspective in her study of the perceptions of the mobile phone's significance in the lives of mobility disabled and non-disabled adolescents in Norway. She suggests the conceptualisation of the mobile phone is different for each group. For non-disabled adolescents the mobile phone is essentially a social mediator; however for the young people with mobility challenges, the vital characteristic of the mobile phone was as a safety net with which to summon help in case of mobility accidents. Rackensberger, a young woman who uses AAC to support living independently, says

*“being able to be independent and having the freedom to control my own destiny are the most important things to me” (Rackensberger 2006, cited by McNaughton et al. 2012, p.51).*

Using the internet and online social media can also support self-determination in terms of employment. O’Keefe et al. (2007), through focus group discussions with people who use AAC, discovered finding jobs was one research area they felt should be prioritised. McNaughton, Light and Arnold (2002) found employment opportunities for people who use AAC could be improved by being able to use the internet, as employers rated this as a valuable skill. Benefits of employment for people who use AAC are increased social interaction, personal enjoyment and financial gains (McNaughton, Light & Gulla, 2003) but transportation needs can be a major barrier (Magill-Evans, Galambos, Darah & Nickerson, 2008). Being able to use the internet and online social media may offer opportunities to people who use AAC in terms of employment by overcoming the need to travel (McNaughton & Arnold, 2010).

#### *2.4.8. Potential risks within online environments*

Alongside the opportunities for enriching friendship networks, there are concerns of harm for young people. On 11<sup>th</sup> August 2013 the BBC news website (BBC News 2013) reported on a forthcoming survey (due for publication in November 2013) that has been carried out by the National Society for the Prevention of Cruelty to Children (NSPCC). The BBC reported the survey contains information from 1,024 11 to 16 year olds and showed one in five children who use social networking sites has suffered a negative experience during the last year with bullying and trolling listed as the most common bad experiences (BBC News, 2013). Livingstone et al. (2011) discuss the issue of risk compared to actual harm and say increased use of the internet correlates with higher exposure to risk. They found on average 21% of 11-16 year olds had seen potentially negative online content but many children did not report feeling harmed by it. Cyber bullying was fairly uncommon but young people said they found it very upsetting. The survey also revealed 34% of 9-16 year olds had added people they had not met face-to-face to their address books, but that it was extremely rare for an unaccompanied meeting offline to occur and even rarer for this to result in a negative outcome. Conclusions drawn by Livingstone et al. were that reducing

online risks for young people was important and training in online safety was highly recommended. They felt as long as the risk encountered does not exceed the individual's capacity to cope, then risk exposure can help to build resilience and awareness. There are similar concerns for the safety of young people with disabilities and Lathouwers et al. (2009) suggest young people with physical disabilities might face tighter parental controls over online activity.

#### *2.4.9. Summary*

It is important both morally and legally that the views of young people with physical disabilities and complex communication needs are sought on issues that concern their lives. Much of the research to date with children and young people with disabilities has tended to focus on those who are verbally articulate or relies on adult perceptions (Morris, 2003; Rabiee et al. 2005; Wickenden, 2009; Boggis, 2011). The use of the internet and online social media is without doubt a defining aspect of young people's lives supporting friendships and relationships. Peer friendships, as shown by Priestley (2003), are a vital aspect of participation in youth culture. Seymour and Lupton (2004) suggest the internet has specific implications for young people with physical disabilities in terms of increased opportunities for strengthening and maintaining relationships. There are interesting opportunities offered by online social media for choice over self-representation for all young people and engaging in this exploration is an important aspect of adolescent development. Enabling digital inclusion is a focus of social policy as it is perceived to increase social inclusion and self-determination. It is important that this does not become a pressurizing concept for people with disabilities or become a measure of ability. Young people face increased risks through online environments and people with physical disabilities may experience higher levels of protection from parents (Lathouwers et al. 2009).

As can be seen much of the literature concerns non-disabled adolescent populations. It is imperative that niche populations of young people are included in the research base so that factors that are specific to their use of the internet and online social media are revealed. The next section will look more specifically at the research evidence surrounding the use of mainstream technology to access the internet and online social



media by people who have additional complex communication needs and already use digital technology in the form of AAC devices.

## ***2.5. Part Four: The internet and online social media within the lives of young people who use AAC***

### *2.5.1. Introduction*

Smith (2005) argues adolescence is a key developmental stage and young people who use AAC are likely to have the same aspirations and face similar challenges as their peers but have to cope with additional physical challenges and complex communication needs. Wickenden (2009) conducted an ethnographic study with young people who use AAC and found they were

*“more interested in the ways that they are like others than anything else and identify themselves most importantly as teenagers rather than disabled”* (p. 1).

Morris (2003), Rabiee et al. (2005) and Wickenden (2009) all comment on the lack of direct research with disabled young people with complex communication needs and say many qualitative studies on a range of topics have collected proxy interview data with family or caregivers. The following section outlines the literature found that contains self-reported experiences of using computers, the internet, online social media and mobile phone technology by people who use AAC.

### *2.5.2. Use of computers, the internet, online social media and mobile phone technology by people who use AAC*

Research looking at the use of computers, the internet, online social media and mobile phone technology is patchy and scattered across different countries. Raghavendra, Newman, Grace and Woods (2013) state there is very limited research with young people with physical disabilities about internet use. Raghavendra et al. (2012b) conducted qualitative interviews in Australia with a cohort of 15 children with physical disabilities (five with communication difficulties, one of whom used a VOCA). They found that they were using the internet for a variety of purposes but the extent and frequency of use was lower than their peers. Friends were the main people

contacted online and the digital skills of parents, siblings and friends were significant influences on levels of use.

Garcia, Loureiro, Gonzalez, Riveiro, and Sierra (2011) looked at the use of computers and AAC devices by thirty children and young people (aged 3-22 years, mean 13.3 years) with cerebral palsy of whom twenty nine had complex communication needs (ranging across dysarthria, anarthria, delayed language development and cognitive difficulties). The data was collected via questionnaires with the people who use AAC and educators within a special educational centre in Spain. They concluded that the use of Information and Communication Technology (ICT) required a high level of support from professionals. Seventeen of the participants were using computers within the centre but only four of these were also using a computer at home (despite nineteen participants having computers within their home setting) which was due to a lack of appropriate assistive technology. All the participants using computers expressed satisfaction and showed a positive interest in using them. It was suggested that there was a lack of personalized assessment and training within the home and insufficient financial support for assistive technology. There was also a lack of use of ICT translating through from the computer room to the classroom settings and the reason for this was lack of knowledge from the general educational staff. It was suggested there needed to be greater interaction between professional groups within the centre, better training protocols, and more attention when evaluating assistive technology for the impact of social, physical and personal factors. The study also found the level of satisfaction from the young people who used AAC regarding the *“use of computers were positive in all cases (very good or good)”* (p. 144).

Phillips and Zhao (1993) and Pape, Kim and Weiner (2002) found assistive technology can often be abandoned which has implications for computer access and communication support.

Moving back to Australia, the research carried out by Cooper et al. (2009) explored the loneliness of six people with physical disabilities who use AAC via in-depth interviews. They described support networks, use of AAC devices, access to the internet and good technical advice all helped mitigate feelings of loneliness. The internet itself has also been used to carry out research on a more global level; Dattilo,

Estrella, Estrella, Light, McNaughton and Seabury (2008) used an online focus group study to explore perceptions of leisure for people who use AAC. They recruited by posting information about the research on Augmentative Communication On-line Users Group (ACOLOG) (<http://aac-rerc.psu.edu/index.php/projects/show/id/18>). Eight adults (aged 27-44, 4 men and 4 women) took part in the study and identified using computers created increased opportunities for leisure with one participant saying,

*“having access to the internet has opened up my world”* (p. 25)

A focus group study with seven people who used AAC found that being able to use email and online forums are beneficial for accessing support from other AAC users (Rackensperger, Krezman, McNaughton, Williams & D’Silva, 2005). Atanasoff, McNaughton, Wolf and Light (1998), through survey information collected from seven college students who used AAC, found that those participants who communicated by email

*“rated this the most effective way of being understood by others”* (abstract).

Cohen and Light (2000) found email was a useful tool for mentor/protégé relationships between AAC users. Both parties (in a spooky pre-empting of Facebook and Skype) expressed *“an interest in the use of live chat on the internet [and] photograph and videotape exchanges, and World Wide Web pages”* (p.236).

Sundqvist and Ronnberg (2010) found that a software programme that supported symbol-based email exchanges enhanced social contact for children, aged 6-13 years, who use AAC. They suggested that using email helped to reduce the pressure to respond quickly (p. 256) and alleviated the unequal turn-taking that can occur within conversations between speaking people and those who use AAC (Light, 1988, cited by Sundqvist & Ronneberg, 2010). The children who took part in the study reported

*“they liked writing and receiving email messages; they thought it was fun to get to know and write to new children”* (p. 263)

Moving to individually expressed views, Krogh and Lindsay (1999) presented case study data from ‘Lesley’ (a 32 year old woman who used AAC) about using computer mediated communication. ‘Lesley’ said using personal and group instant messaging and email did not to replace face-to-face interaction but supported her

*“desire to meet new people, interact with them in a variety of ways, and to ultimately meet with them off-line” (p. 231)*

Stevens (2011) writes, as a person who uses AAC, about his experiences of using mobile phone technology through his hybrid VOCA and talks about his iPad. He had previously used a smart phone but quickly realised the new hybrid VOCA was more accessible than his smartphone as it had big buttons and was designed to be easy to use. He comments that using both the VOCA and the iPad has

*“revolutionised my mobile telephony and enabled me to conquer an area of communication I was previously simply coping with” (p.7)*

but the iPad has not totally taken over from his VOCA as a communication aid because

*“it is not as easy to type with” (p.7)*

He describes many advantages for the hybrid VOCA: it is useful as a phone, he is proud that it has features that interest “*non-speech impaired people*” (p. 7), and has a nice design. He says all of this is important because it is fundamental to his sense of dignity and self-worth.

### *2.5.3. Challenges for using the internet and online social media*

Accessibility appears to be the major challenge for the use of online technology by young people who use AAC. There are not only physical challenges which require alternative access support via equipment such as switches or eye gaze (Chapple, 2011), but also cognitive challenges in relation to language and literacy abilities. Smith (1992) reports literacy problems are common among non-speaking people affected by cerebral palsy and Sturm and Clendon (2004) report people who use AAC often have difficulties across multiple language domains which impacts on their ability to use language effectively and acquire literacy skills. To gain a fuller understanding of challenges within any field it is important to hear from the people that systems have been designed to support (Jenkins, 2006). The voices of people who use AAC is alarmingly muted on an issue that is impacting on the lives of so many people in the 21<sup>st</sup> century.

## ***2.6. Summary of the literature review chapter***

The literature review has illustrated there is evidence which supports how aided AAC can support people with complex communication needs within face-to-face conversations and social relationships (Branson & Demchak, 2009; Light & McNaughton, 2012). The rapidly moving digital revolution within society is intersecting with AAC technology and causing a seismic shift within this highly specialised field and much has been written over the last few years about the symbiosis of these two areas (DeRuyter et al. 2007; Higginbotham et al. 2007, 2011; Shane et al. 2012). The integration of mainstream media tools into dedicated AAC technology, and the appearance of voice output communication Apps within the mainstream mobile technology field (AAC-RERC 2011), has created opportunities for people who use AAC to engage with the internet and online social media in new and exciting ways. The views of young people who use AAC are under-represented in relation to these recent changes within the AAC industry.

There is a thriving literature base regarding the use of the internet and online social media by young people within westernised societies, much of which has looked at issues of online social ties, online identity formation and self-determination although not much attention has been focused on young people with physical disabilities (Soderstrom, 2009; Bowker & Tuffin, 2002; Ritchie & Blanck, 2003). The literature base is practically non-existent for the use of the internet and online social media by people who have additional complex communication needs (Raghavendra et al. 2013).

As the aim of using AAC is to support people with complex communication needs to express themselves (section 1.3.2) it is crucial their experiences are considered within the new landscape of digital online communication. The UN Convention on the Rights of Persons with Disabilities (2006) places an obligation on researchers to examine the ways that people with disabilities are being supported to access cultural materials. The internet and online social media could be regarded as one of the most pervasive cultural materials within current westernized societies. McNaughton and Bryen (2007) reviewed research which explored how AAC technologies might enhance social participation and societal roles. They said research and development

needed to look at the ability of AAC devices to interconnect with mainstream devices and allow people to use internet and mobile communication opportunities. Newell (2008) in his discussion paper on the accessibility of technology for people with disabilities says it is vital to collect data from specific disabled groups to encourage designers to take a more nuanced view of access problems and possible solutions. The way technology is evolving within the AAC field, especially in regard to mobile technologies, has enormous potential to empower people but it is imperative that key stakeholders are aware of the very real challenges which exist for alternative access methods (Chapple, 2011).

This review of the knowledge base has identified a particular gap into the *self-reported* use of the internet and online social media by young people who use high-tech AAC, especially within the United Kingdom. They are known to be a particularly marginalised population in terms of research knowledge (Morris, 2003; Rabiee et al. 2005; Wickenden, 2009).

## ***2.7. The research objectives***

Four research objectives for the current study have been developed, firstly through my personal interest in the field of AAC and my previous experience of exploring social opportunities for young people who use AAC, and secondly as a consequence of the issues identified within the literature review in relation to the internet and online social media.

The four objectives are as follows:

1. To investigate the self-reported experiences of the accessibility of the internet and online social media by people who use AAC
2. To investigate the self-reported use of the internet and online social media by people who use AAC
3. To explore the perceived role and importance of the internet and online social media for self-determination and self-representation
4. To establish how online social media is perceived in terms of social ties for people who use AAC

# Chapter 3

## Methodology

### ***3.1. Introduction***

Although progress has been made, the inclusion of the voices of young people with disabilities within the research process is still slow and those with complex communication needs are noticeably absent within the literature base (Morris, 2003; Rabiee et al. 2005; Mitchell, Franklin, Greco & Bell, 2009; Wickenden, 2009; Franklin & Sloper, 2009). As demonstrated in the literature review, research into the use of the internet and online social media by young adults with physical disabilities and complex communication needs who use AAC is very limited globally. There is a specific gap within the existing United Kingdom literature regarding self-reported experiences. The intention of this thesis is to provide an opportunity for their views to be represented. This chapter will describe: the philosophical positioning of the study, the methodological underpinnings, ethical approval, preparation through a pilot investigation, the procedure, and study design in terms of data collection and data analysis methods.

### ***3.2. Theoretical framework***

#### *3.2.1. Disability studies*

The political challenges made by people with disabilities to issues of social exclusion has radically changed the way disability is viewed globally and led to many legislative changes to recognise the rights and voices of people with disabilities within society (Oliver, 1990). The British approach grounded within the social model of disability (also known as the social barriers approach) argues disability is a social construct that oppresses people through societal forces such as discrimination, isolation, lack of employment, access and institutionalisation.

Goodley (2011) describes disability studies as

*“a new interdisciplinary sphere for scholarly work” (p.3)*

which seeks to challenge the view that

*“disability equates with personal tragedy” (p. xi).*

Hotly debated within disability research practice are issues of ownership, involvement and application. Prominent activists have argued non-disabled researchers should not seek to pursue an ‘independent’ academic status in regard to disability, which is probably impossible to achieve, and should seek to work with disabled people to overcome oppression (Barnes, 1996) and develop theory which aims to tackle disabling practice (Shakespeare, 1997). In 2003, Barnes evaluated the position of disability research and suggested much progress had been made over the previous decade in light of the social model of disability and the emancipatory research paradigm. However, he also identifies it is not easy for researchers to achieve an emancipatory position and careful consideration should be made before claiming such an approach. As Oliver (1997) pointed out

*“one cannot ‘do’ emancipatory research” (p.25)*

as this can only be retrospectively judged, but one can

*“engage as a researcher with those seeking to emancipate themselves” (p.25).*

Engaging people with complex communication needs in the research process is recognised as difficult, especially if they are young (Morris, 2003). Rabiee et al. (2005) point out there is a growing body of evidence that young people with communication impairments are willing and keen to be involved and they cite the Scope report (Morris, 2002) which was produced by people with complex communication needs. The project identified that people had strengths for engagement such as: determination, patience, good interpretation skills, being able to indicate what they need and finding creative ways to express themselves via other means than speech. Being aware of these issues informed the decisions within the current research to: use a self-report methodology in the form of interviews, carry out a pilot investigation to establish if interview topic themes were relevant (Appendix A), produce inclusive materials (Appendices D & F) and seek feedback to ensure accurate representation (Appendix J, K and L).

### *3.2.2. Feminist research principles and disability studies*

Wendell (1996) reports how Hannaford (1985) and Fine and Asch (1988) were influential in bringing feminist analyses to the forefront when looking at the socially



constructed nature of gender and disability. Garland-Thomson (2005) suggests as feminism seeks to challenge entrenched belief, its role within the field of disability studies can be supportive within five areas: (i) by understanding exclusion and stigmatization experienced by people with disabilities, (ii) exposing communities that produce prejudiced perceptions of disabled bodies, (iii) revealing discrimination, (iv) suggesting disability is a social construct and (v) by looking at the effect of power relations on experiences of disability. In seeking to take an interdisciplinary perspective within this research study (Goodley, 2011), the principles of feminist research have been considered: involvement, sharing rather than imposing meaning, transparency, empowerment, transformation, and rendering visible ‘power’ discourses (especially the power relationship between the researched and the researcher).

### *3.2.3. International Classification of Functioning, Disability and Health (ICF)*

The International Classification of Function, Disability and Health (ICF) (World Health Organisation, (WHO), 2001) (and the subsequent development of the Children and Youth version (ICF-CY) (WHO, 2007)) has extended health classification beyond medical and biological definitions to incorporate new inter-related dimensions based on the social model of disability. Raghavendra, Bornman, Granlund and Bjorck-Akesson (2007) describe how the ICF includes

*“contextual factors as a major classification”* (p.350)

and explain how there are two contextual factors: the environment and personal.

Personal factors are not classified due to the complexity of variance but environmental factors are outlined by Raghavendra et al. (2007) as having

*“an impact on all components of functioning and disability and are organised in sequence from the individual’s most immediate environment to the general environment”*(p. 350)

Lidstrom (2011) describes this bio-psychosocial approach (medical term to illustrate the joint consideration of biological, psychological and social factors) as a

*“unified and neutral descriptive framework to understand health in relation to functioning and disability with children and youths.”* (p. 4)

and gives an example of the immediate environmental factors in terms of things like assistive technology devices and the more distant as encompassing issues such as systems, policies and societal approaches.

Participation in everyday life situations is an important environmental health indicator within the ICF-CY (WHO, 2007). Looking at participation is a relatively new research context for disabled children and adolescents (Parkes et al. 2010). Raghavendra et al. (2007) and Lidstrom (2011) both point out simply supplying technology will not necessarily negate participation barriers. Exploring implications at an individual and societal level are important as, explained by Raghavendra et al. (2007), they exist at a practice, attitude, knowledge and skill level and they suggest the ICF-CY is useful to the field of AAC but may also need refinement. Rowland, Fried-Oken, Steiner, Lollar, Phelps, Simeonsson and Granlund (2012) present their development of the ICF-CY for AAC and suggest the ICF-CY is good for AAC because it separates speech from communication functions. Their AAC focused code set has four categories: restrictions on participation caused by communication limitations, communication limitations, functional impairments that limit communication and environmental factors that serve as barriers or facilitators for communication.

In this thesis the focus is on participation from the viewpoint of using digital technology and social media. This activity has arguably become an important component of the everyday life for adolescents and young adults within westernised societies and facilitates novel forms of social inclusion (Notley, 2009). However, some populations are in danger of having limited access to an online environment as illustrated in the literature review (section 2.5.3.).

#### *3.2.4. Challenges of internet-focused research*

Many challenges exist for conducting internet-focused research. Researchers have used approaches such as monitoring computer and content use (sometimes with specialist software to log activity) or using online questionnaires and surveys (van Deursen & van Dijk, 2009; Wright, 2005), but limitations have been identified for measuring communication skills or understanding why people make choices over

content. Livingstone (2004) also identifies issues such as invasion of privacy, difficulty capturing experiences which may seem trivial to users, revealing information about transgressive material (e.g. pornography), researcher unfamiliarity with certain aspects of technology and concerns about harm. The lack of available research into exploring online behaviour with people who use AAC required remaining open and flexible to new obstacles.

Building awareness of possible challenges helped the navigation of hurdles that arose especially in relation to the potential invasion of privacy and alternative data collection methods. When considering how to collect data it was tempting to consider doing this through online methods considering the focus of the research topic. However, collecting data through engagement with participants through online social media sites such as Facebook was discounted as it raised ethical concerns around consent and privacy for family and friends on the site and was judged to potentially transgress agreed professional boundaries with educational settings. It may have also made my position as a researcher unclear, especially around ‘friendship’ and negotiating exit strategies. Using email with participants was considered acceptable as it does not have the associated social boundary ambiguities as other forms of online social media. Using email as the main data collection method was briefly considered but was discounted as it was judged not to offer the benefits that face-to-face interviews gave in terms of:

- reaching a deeper level of understanding about the implications of communicating through VOCA devices
- building rapport with participants
- the opportunities to follow up issues in real time
- the validity of self-report

### 3.2.5. *Summary*

These theoretical influences guided my thinking and planning. During the remainder of this chapter issues raised within the literature review and these philosophical foundations will be discussed where relevant. It is important to state this study did not set out to produce information that can be generalised but rather to gather detailed

individual information from a group of young people who use AAC in order to understand their experiences of using the internet and online social media. Whilst predominantly using an interview methodology, there was recognition of the challenges of this data collection method for people with complex communication challenges and data was also gathered from other sources such as demonstrations given by the young people, observational field notes from researcher experience within the field, and explanatory conversations with people who were trusted and known by the participants within the interview settings.

### ***3.3. Methodological underpinnings***

Creswell (2003) suggests a researcher should always address what knowledge claim is being made and the decisions used to guide the approach and methods of data collection and analysis when designing a study. The current research claims are based upon a socially constructivist/constructionist paradigm.

#### *3.3.1. A socially constructivist/constructionist paradigm*

The terms constructivist or constructionist are often used interchangeably when speaking of this paradigm approach depending on how radically the epistemological position is viewed as either an individual construction of knowledge ('v') or a societal construction ('n'). Both terms refer to the idea that learning, either individually or socially, is constructed by learners rather than just being received (Kim, 2001). The term will be used interchangeably within this thesis in order to adhere to the point being made by a quoted author. However, my preference is for constructivist (the individualised level) in order to align the thesis with the constructivist grounded theory approach (Charmaz, 2006) discussed later, although she also uses the term constructionism on occasion (Charmaz, 2008).

Social constructionism is sometimes linked in the literature to interpretivism and hermeneutics (Denzin and Lincoln, 2000, Ponterotto, 2005). Schwandt (2000) gives a nuanced account of these three epistemological stances outlining their different philosophical approaches to interpreting human behaviour as:

- interpretivism - the inquirer finding meaning in human action in much the same way as a subject gains knowledge about an object
- hermeneutics - recognising the inquirer's personal beliefs will affect interpretation and understanding so knowledge is negotiated
- social constructionism - taking a stance that knowledge should not be viewed as discoverable but as socially constructed during the research process

Guba and Lincoln (1994) explain constructivism as:

- Ontologically - stating reality is comprehended through social constructions
- Epistemologically - stating findings are jointly created
- Methodologically - taking a hermeneutical approach.

My interpretation of the theoretical perspectives and influences described within the literature review and at the beginning of this chapter suggests a socially constructivist approach is considered the best fit for the current study. Any emergent knowledge will rest on the differing, and yet also shared, historical, contextual and cultural perspectives that all parties bring to the research process.

### *3.3.2. A qualitative research approach*

It would be impossible within the confines of this thesis to appraise in full the three main social science approaches: quantitative, qualitative or mixed methods. However, a brief outline of each will be given to contextualise the decision making process.

Burke Johnson and Onwuegbuzie (2004) explain a quantitative approach is traditionally characterised by

*“deduction, confirmation, theory /hypothesis testing, explanation, predication, standardized data collection and statistical analysis” (p. 18)*

They describe a qualitative approach is characterised by

*“induction, discovery, exploration, [and] theory/hypothesis generation” (p. 18)*

with data collection and analysis being conducted via the researcher(s). Finally, they argue the value of mixed methods, as they suggest being purist to either a qualitative or a quantitative approach can blinker a researcher to seeing the benefits of taking a more pragmatic stance. They suggest a mixed approach can help to corroborate or test qualitatively generated theory or enrich and illuminate quantitative statistical analysis.

Giddings (2006) expresses concerns and criticisms over a mixed methods approach. She acknowledges it may have potential for creating more complex research designs but voices concern that whilst being hailed as a third way it is actually a disguised form of positivism, although she concedes within a more modest postpositivist shape. Denzin and Lincoln (2005) suggest it may side-line qualitative techniques to a secondary position by moving away from the interpretive foundation.

In the current research project, the exploratory and inductive nature of a qualitative approach was considered the best fit for the research aspiration to explore the experiences of young adults with physical disabilities and complex communication needs for accessing the internet and online social media. Bryman (2001) discusses the merits of a qualitative approach when studying attitudes as people are capable of attributing meaning to their environment and collecting rich data from their perspective is vital for creating understanding within a contextual framework.

### 3.3.3. Discussion of three common qualitative approaches

Holloway and Todres (2003) consider the distinctions and flexibility between three common qualitative approaches, phenomenology, grounded theory and ethnography. Table 1 is a summarised adaptation of their table that appeared in the *Qualitative Research* journal.

**Table 1: Table illustrating the distinctions of three common qualitative approaches and areas of flexibility with other qualitative approaches (Adapted from Holloway and Todres (2003)).**

Phenomenology	Grounded Theory	Ethnography
The goal: to describe linguistically actual situations at a general and unique level.	The goal: to develop a theory grounded in the data which explains how activities fit together and how participants take an active role	The goal: to describe and understand a particular cultural setting through the diversity and voices of the participants

<p>Research questions: try to elicit descriptions of the structure or 'lived experience' that are internally meaningful.</p>	<p>Research questions: aim to elicit how participants actively influence their environment and attach meaning to their circumstances</p>	<p>Research questions: to understand significant relationships between people within the studied setting especially power structures, values, knowledge and shared beliefs</p>
<p>Data collection: expose depth of internal experience (interviews and narratives). Questions need to encourage recall of specific times and situations.</p>	<p>Data collection: a variety of methods that can change to pursue emerging theory ideas by progressive focusing and theoretical sampling ( a method specific to grounded theory to obtain data to explicate categories)</p>	<p>Data collection: immersion in the setting, intensive interviews with key individuals, observation and sometimes visual data</p>
<p>Analysis: part and whole relations without over emphasising the role of constituent parts. Emphasis on moving back and forth within the data. Computer aided analysis or content analysis may be problematic.</p>	<p>Data collection and analysis develop concurrently via constant comparison. Focus on ideas that are important to emerging theory. Analysis identifies categories that can be linked to develop theory.</p>	<p>Analysis: coding and identifying patterns from thick descriptions. Aim to find central tenets of culture.</p>
<p>Results: show the essential components of the phenomena, textured with specific examples of the unique experiences of individuals.</p>	<p>Results: elements of a model showing how they fit together to form an explanatory theory</p>	<p>Results: show how participants make sense of community through cultural and social activities and the meanings attributed</p>
<p>The knowledge claim is cautious. By staying close to the words of individuals it aims to show essential qualities of experiences contextually but not to explain overall cause</p>	<p>The knowledge claim is a theory which can be tested in other contexts</p>	<p>The knowledge claim is an understanding of a particular cultural group and how they perceive themselves and others</p>

<p>Flexibility with other approaches can be seen in the way: Coherent narratives are generated and reference is maintained to specific experiences meaning phenomenological analysis can be useful for revealing meaning within the texts of other approaches</p>	<p>Flexibility with other approaches can be seen in the way: Theoretical sampling can give direction to other forms of qualitative research. Coding and categorisation techniques and the idea that theoretical ideas which emerge are provisional and open to change can be used within other approaches.</p>	<p>Flexibility with other approaches can be seen in the way: Researchers approach their participants with an open mind, theories can emerge and be tested in much the same way as grounded theory and the data analysis of other approaches can be mindful of the multiplicity of voices and perspectives</p>
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I decided I was interested in pursuing one of these approaches and the following outlines my critical appraisal of each in relation to this project, drawing on my personal experience of working with people who use AAC.

When considering ethnography although I would see participants within their individual settings, likely to be an educational setting or personal home (the logistics of seeing them in an alternative venue would be too difficult), I knew immersion within these settings would be difficult as young people with physical disabilities are subject to high levels of protection (Wickenden, 2009). In addition, I also considered lengthy ethnographic observation to be ethically inappropriate in terms of exploring internet and online social media use which are often considered to be private activities, although there is an irony within this as data is potentially in a public domain and open to exploitation. At an interpersonal level it is considered socially unacceptable to stand and view someone's activity on a 'personal' computer. There is also a tension regarding whether people who had accepted the participants as friends within their own social media forums would expect data to be shared by the participant with a researcher. Although on some occasions during the research process participants did choose to demonstrate how they used social media (as it was often difficult for them to explain what they did), I took great care never to read or record any personal conversations with friends and the observation always centred on



processes, types of sites used or the participant's own profile information.

Observation also limited exploration of the meanings that people who use AAC may attribute to their online activities (Bryman, 2001).

When considering phenomenology, as outlined in the earlier section on narrative and humour (section 2.2.7), without prior preparation it is difficult and time consuming for people who use AAC to create extensive narratives around their experiences in an interpersonal situation, further confounded by possible challenges structuring language and limited experience of speaking about themselves. Therefore, although it was important to use interviews to satisfy the research objective to capture self-reported experiences of the internet and online social media use it was recognised these may not satisfy the expectations of a phenomenological approach which seeks richly textured personal narratives.

The main attraction within the context of this study for using grounded theory was the focus placed on theory generation. As little is known on the specified topic, the research goal was to generate theory within this area and the flexibility regarding data collection methods to pursue emergent categories was also considered desirable. Further explanations of the suitability of this approach are outlined below in Table 2, but firstly the origins of traditional grounded theory will be explored in more detail.

#### *3.3.4. Traditional Grounded theory*

Traditional grounded theory was developed by Glaser and Strauss (1967) and has dual roots in symbolic interactionism (Strauss) and positivism (Glaser). Symbolic interactionism has three main foundations: American pragmatism, German neo-Kantianism and German historicism. Alvesson and Skoldberg (2009) summarise these respectively as: the practical use of truth, the in depth study of individual cases and prioritising a qualitative approach. Skeat and Perry (2008) summarise symbolic interactionism as a philosophy that seeks to find meaning in social situations through three core principles: people ascribe meaning to social reality; meaning is expressed through symbols (language) and symbols are interpreted and modified by people's thoughts. They suggest that grounded theory is often summarised as an inductive approach to theory formation from data. By using constant comparison to extract

concepts for further exploration, the on-going data collection aims to form a ‘core’ category explaining the field under exploration. Their review of eight speech and language therapy studies using grounded theory found that it is a suitable qualitative methodology within the field because of the focus it provides for

*“the underlying processes of human action and interaction [and] its emphasis on the ‘core concern’ of participants” (p. 107).*

### 3.3.5. *Constructivist Grounded Theory*

Many innovations of grounded theory have emerged over the years and there is a clear lineage of development (Morse, 2009), one of which is known as constructivist grounded theory developed by Kathy Charmaz (2006). Charmaz (2009) describes how she developed the symbolic interactionism of Glaser and Strauss’ grounded theory to incorporate a constructivist perspective. She outlines how her contemporary revision

*“assumes a relativist epistemology, sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance” (p. 129)*

and opens the approach to other

*“theoretical starting points [such as] feminist theory, post structuralism, Marxist theory” (p.134) .*

Within the current research study a constructivist grounded theory approach (Charmaz, 2000 2006, 2008, 2009) will be followed and Table 2 outlines the rationale for this decision.

**Table 2: Issues identified within the current project and the suitability of constructivist grounded theory (Charmaz, 2000, 2006, 2008, 2009)**

<p>Issues for current project:</p>	<p>Suitability of constructivist grounded theory (Charmaz, 2000, 2006, 2008, 2009)</p>
<p>Using literature to identify topics regarding internet use by mainstream and disabled youth populations</p>	<p>Theoretical sensitivity - A traditional grounded theory approach contends a literature review might prejudice a researcher (Skeat &amp; Perry, 2008). Charmaz’s constructivist approach asserts a focused literature review often “strengthens your argument ... without letting it stifle your creativity” (2006:166).</p>
<p>Each participant has unique characteristics regarding physical access challenges and language/literacy/cognitive ability</p>	<p>Charmaz (2000) states a constructivist approach to grounded theory entails coding a participant’s language with an active intent to “keep life in the foreground”(p. 526)</p>
<p>Extremely limited data exists regarding the self-reported experiences of how young people who use AAC are utilising the internet and online social media</p>	<p>A constructivist grounded theory approach is useful when little is known as it can assist researchers to learn how “<i>participants make sense of their experiences [and] begin to make analytic sense of their meanings and actions</i>” (Charmaz, 2006:11)</p>

<p>Using a high-tech AAC device is tiring and takes time. Conversational breakdowns are common and repairs can be difficult. Relevant topic vocabulary may not be available on a device. Participants may find it difficult to convey detailed thoughts. The roles and interactions of communication partners will require reflexive analysis to reveal meanings which may not be overt.</p>	<p>Charmaz emphasises the importance of researcher and participant co-construction. When analysing text “<i>the ‘discovered’ reality arises from the interactive process and its temporal, cultural and structural contexts</i>” (2000:524). Also reflexive, refined coding helps to analyse participant perspectives and may “<i>assume much more than what is immediately apparent</i>” (2006:47) making reflexivity explicit especially in regard to the researcher’s actions (2009)</p>
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### **3.4. Preparation**

#### *3.4.1. Ethical approval*

Ethical approval was gained from the university Faculty Academic Ethics Committee and required evidence of: how participants with physical disabilities and complex communication needs would be protected from harm, debriefing arrangements for participants within educational settings, information and consent forms (appendices B, C & E) and differentiated materials for people with complex communication needs (appendices D & F). There was also a requirement to identify appropriate protocols to ensure my physical safety and emotional well-being. As explained in more detail later two ethical variations were applied for. The first was to include a participant under the age of 16 (14 years old) (appendix G). The second (Appendix H) was to include school staff and/or parents as some data information needed clarification beyond participant explanation. My enhanced Criminal Records Bureau (CRB) check was applied for through the university.

### *3.4.2. Researcher positionality*

Interpretive researchers recognise the interactive shaping of their research through the ways their own experiences and perceptions of social constructs interweave with those of their participants (and others in the studied environment) to create shared meaning (Denzin & Lincoln, 2005). This on one hand acknowledges the implausibility for a researcher to achieve objective neutrality but on the other hand can risk reinforcing the researcher's own position and relegating participants to the role of exotic 'other' (Vidich & Lyman, 2000). It is therefore difficult to know how much information a researcher should include so I have chosen to give a brief outline of myself so that readers can contextualise my interpretations.

I became interested in the field of AAC through my training to become a speech and language therapist and my original career as a specialised computer graphics operator in the television industry. AAC captured my attention as it appealed to my interest in communication and specialised technology and this research project grew from that foundational basis. In terms of the current project, I started to consider how as a society we are engaging with technology in ever evolving ways to communicate socially and wondered what impact this societal shift would have for AAC technology. I became increasingly interested in how young people who use VOCAs might be interfacing with the internet and online social media.

As a woman in her late forties, I cannot be described as young and have never had mobility or communication challenges, so I cannot understand what it is like to be one of the participants of this study. Any interpretation I bring to the topic will always be from the position of an outsider although we do share common cultural experiences of the internet and online social media, especially Facebook. Although I did not conceal my training as a speech and language therapist (appendix B), I predominantly positioned myself as a researcher.

### *3.4.3. Pilot Investigation*

A pilot investigation was conducted in order to support my skill development (van Teijlingen & Hundley, 2001) as the conversational partner of a person who uses AAC

and to explore whether the topics identified from the literature review and the research aims were of relevance to people who use AAC.

#### *3.4.4. Pilot investigation participant*

A male adult, (aged 30+) who was a proficient user of a high-tech VOCA and accessed a home computer and mobile phone, agreed to act as a participant for the pilot investigation. He used direct access to his technology and had good literacy skills although he used a software programme called Penfriend™ that he explained was

*“for it’s word prediction feature which speeds up my typing... [and also has] the voice feature turned on”.*

This enabled him to hear what his written material sounded like. He operated his mobile phone with the knuckle of a finger on his right hand which limited his choice of device as touch screen phones were not suitable and he did not access the internet this way.

#### *3.4.5. Pilot investigation data collection*

The interview was conducted in the participant’s home and his personal assistant was present initially and post interview for the debrief session but during the main part of the interview she was not in the room. The interview was semi-structured following a topic guide (Appendix A) based on the literature review to establish how he accessed the internet and online social media, what sites he used, the role the internet and online social media played in his life and his online relationships. The interview lasted for two hours with a short refreshment break.

#### *3.4.6. Pilot investigation data analysis*

Braun and Clarke (2006) give an account of thematic analysis and offer a description of some other qualitative analytical methods which are available and suggest these methods fall broadly into two camps. In the first camp are ones that stem from an epistemological stance such as Conversational Analysis (CA) or Interpretative Phenomenological Analysis (IPA), and those taking a methodological perspective such as grounded theory, discourse analysis and narrative analysis. The second camp

encompasses methods which are independent and can be used across a range of theoretical and epistemological stances. They say thematic analysis falls within this second camp and offers flexibility to the researcher. They say it is a useful method by which to create a rich thematic description of the entire data set.

The data from the pilot investigation was coded through a six step approach of thematic network analysis described by Attride-Stirling (2001). She explains how her approach is based on some of the principles of argumentation theory (Toulmin, 1958, cited by Attride-Stirling, 2001). Argumentation theory seeks to explore meanings within explicit and implicit statements by deconstructing the elements of a negotiation to examine how the original statements (data) are moved forward to make a claim (thus revealing the logic behind that progression). Her thematic network analysis uses this theory as the background but has redefined and adapted the method to create a qualitative data analysis system that seeks to explore

*“the signification of an idea, rather than to reconcile conflicting definitions”*  
(p. 387).

The decision to use thematic analysis at this stage of the project was based on the desire to create a rich analysis of the pilot data rather than a substantive grounded theory (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). As explained by Attride-Stirling (2001) this approach is useful for seeking the significance of ideas. The transcript was coded to reveal meaningful segments of text which were marked according to the issue addressed and called quotes. During the second stage, these quotes were checked and amended or re-labelled if necessary. During the third stage the data was re-assembled by using the quotes to create Basic themes, these were then grouped under more abstract Organising themes, which were finally grouped under the umbrellas of Global themes which reflected the outstanding issues within the data.

Stage four involved the creation of four thematic networks with their relevant Global, Organising and Basic themes (appendix L). These were shared with the participant who confirmed they were a good representation of the interview and had relevance for people who use AAC. They were also presented at the annual Communication Matters conference (Hynan, 2011a) with supporting quotes and the audience was

invited to feedback alternative interpretations. An article was also published within the Communication Matters journal (Hynan, 2011b) inviting further feedback (Appendix J). The aim of both these feedback exercises was to establish the credibility of the analysis by using reviewers who were external to the study (Creswell & Miller, 2000).

Stage five involved considering the main themes against feedback from the conference. Audience feedback confirmed the interpretation within thematic network 3 that being online supported independence and within thematic network 4 that social friendships were supported by Facebook, especially as non-literate people who use AAC could share photographs. Stage six involved using the significant themes to explore the research objectives and establish their relevance for taking forward into the main data collection exercise. As the aim of the pilot investigation was to establish the appropriateness of the interview topic theme guide and on a broader level the research objectives, this data analysis method was considered to be a good fit.

#### *3.4.7. Reflective learning from the pilot investigation*

As identified within the literature review (sections 2.2.5 and 2.2.6.) conversations between naturally speaking partners and AAC users have been well documented as presenting many challenges. Being aware of these issues in theory is one thing but experiencing them is another. Despite carrying out previous research with people who use AAC, my experience of talking to people who use AAC was limited and I was keen to further my skills in this area. The pilot investigation proved invaluable as I found it more difficult than anticipated to feel comfortable with the extended pause time between turns. I noticed this made me feel nervous and I tended to ask the questions in a hesitant rambling fashion. I asked the participant if this made it difficult and he confirmed it had. As explained within section 2.2.6. attention can be a factor for people who use AAC so unclear questions can add to the attentional load and make response planning difficult. Moving forward into the main study I tried to keep my questions simple and direct and tried to remain calm.

The other main area of insight was in relation to the topic guide (appendix A) which contained twenty five questions. Kvale (2007) describes how semi-structured



interviews are based around a topic guide with some suggested questions. He says depending on the study these will either be followed quite strictly or treated with more flexibility. Interview questions should also be evaluated in relation to:

*“both a thematic and a dynamic dimension: thematically with regard to producing knowledge, and dynamically with regard to the interpersonal relationship in the interview” (p.57)*

A good interview question should relate to both with the importance placed on the dynamic side to keep the conversation flowing through questions that are simple to understand. I had designed the questions with both thematic and dynamic views in mind, but on the day I stuck too rigidly to these questions rather than letting the flow of the conversation develop naturally. This is illustrated by the following quote from the original data:

*Amanda: I've actually realised trying to stick to just this one theme about accessibility.... I have realised it doesn't work because I don't know if you use Facebook 'cos I haven't asked you about that*  
*Frank: (laughs)*  
*Amanda: so maybe it's better to move into talking about what you use the internet for*

Realising I had to take a far more flexible approach was important as data collection continued as interviews proved to be varied and challenging on many levels. People who use AAC are an extremely diverse population and this was reflected across the participants in the current study (section 3.5.4.). Apart from one occasion where I met a group of five participants prior to their individual interviews (section 3.6.2.4.), each interview was also the initial meeting with the participants and their communication partners. This meant we were unfamiliar with each other's communication techniques. Following a semi-structured approach predominantly worked well but sometimes the interviews became unstructured (where questions were aimed at encouraging the participant to talk) or pursued a more structured method (where questions were closed and were more concerned with repeating or clarifying points raised). Guidance about carrying out interviews with people with complex communication needs stresses the need to remain flexible and open to adaptation (Booth and Booth, 1996).

### ***3.5. Procedure***

#### *3.5.1. Recruitment*

Young people who use high-tech AAC are a small population with the UK. The Office of the Communication Champion Report on AAC (Gross, 2010) estimated 0.05% of children and young people in England require high-tech AAC provision (approximately 6,200). However, under-identification is also an issue, Gross (2010) reports an example of two AAC users identified within a county with a child population of 70,000, whereas an incidence level of 0.05% should have predicted 35 individuals. In order to reach this small community, the standard and differentiated recruitment materials were distributed nationally through AAC-focused organisations, AAC-focused literature, Royal College of Speech and Language Therapists (RCSLT) literature and special schools and colleges with AAC clients. The overall recruitment period lasted for eighteen months with a second phase of information distributed after 12 months. Some educational settings that had not initially responded showed interest in the project during the second phase. Low (2006) discusses, when carrying out research with people with complex communication needs, recruitment and response times can take longer than anticipated.

The recruitment strategy resulted in two different approaches, I was either contacted by educational staff suggesting young people who had shown interest in the project from their settings or I was contacted directly via email by young people, or their parents, who had seen recruitment literature from sources such as AAC manufacturers or charitable organisations. LeCompte and Schensul (2010) say interest in an ethnographer's research problem will make access to community members easier, but if deemed irrelevant it may be seen as a potential threat.

Negotiating to see the young people took time because, although most were over the age of sixteen, educational settings have strict legal obligations to protect young people with disabilities on their premises. This placed the young people within the current study into a similar situation as that faced by children in terms of contributing to research. Powell and Smith (2009) discuss the difficulties of balancing the rights of

children and young people to be consulted on matters that concern them and their rights to be protected. They say children and young people may sometimes feel they have had limited opportunities to be heard.

Recruiting within educational settings can also lead to concerns of whether participants are willing interviewees as teaching staff occupy specific power positions. Conversely opportunities for inclusion may be constrained by decisions about suitability. When children or young people are denied knowledge of research that may be relevant to them because of concerns for their safety, their ability to decide for themselves is denied (Campbell, 2008). Boggis (2011) in her research with children who use AAC suggested it was ironic how they

*“were last in this complex chain of consent [and their voices] were only heard once many layers of adult consent were negotiated”* (web resource, no page number).

Although it is impossible to find out if any young people who might have elected to participate were excluded, I felt confident educational staff were interested in the topic area and keen to offer participants the opportunity for involvement. This is supported by the following example; two students declined to take part once they had met me which shows they had been given the opportunity to know about the project but also did not feel obliged to comply with staff expectations.

### *3.5.2. Inclusion criteria*

Initial inclusion criteria required participants to be over 16 years of age, use AAC and have access to the internet or some form of online social media. It was assumed the requirement to access the internet and online social media would self-screen for independent use based on literacy and cognitive abilities. One of the first approaches I received was from a speech and language therapist in a special residential school and adult centre asking if low cognitive and literacy abilities would exclude people from participating in the study as she reported potential invitees within her educational setting were using online social media with support. In line with the theoretical influences outlined earlier (sections 3.2.1 & 3.2.2), I decided it would have been unethical and undesirable to exclude people on the basis they did not use the internet and online social media independently. Although at the time this seemed to be a

relatively small decision to make, it had an enormous impact on the data and illuminated many areas that may have remained hidden if inclusion had been limited to participants who were independently using the internet and online social media.

### *3.5.3. Ethical variations*

As mentioned previously, an ethical variation was applied for after an approach to join the project was made by a 14 year old boy in mainstream school. Ethical approval was granted (Appendix G) on the basis he was capable of making an informed decision (Gillick versus West Norfolk and Wisbech, 1986), was keen to be involved and had full parental assent. Historically within the legal view, young people under the age of sixteen were considered to be unable to make independent decisions and so parents would take decisions on their behalf. The Gillick ruling (commonly now called the Fraser guidelines) changed this legal distinction and was incorporated into the Children's Act, 1989 (Coppock, 2010). Although applying this is not always a straightforward legal process, the test considers a child is competent of consent if they have the capacity to fully understand what is proposed and sufficient discretion to make a decision regarding their own interests (Morrow & Richards, 1996) and moves the focus away from chronological age to establishing a precedent for self-determination (Masson, 1991).

A secondary ethical variation was applied for (appendix H). It became clear during the data analysis that certain alternative data sources needed to be targeted to develop emerging theory. This is a process specific to grounded theory known as theoretical sampling and is explained more fully later (section 3.6.3.7.). It was identified that interviewing key members of staff within educational settings about issues of implementing the use of online social media and equipment use was required.

### *3.5.4. Participant information*

Despite the challenges outlined regarding recruitment, interest in the project was healthy. The study involved twenty-five participants aged between 14 and 24 years (13 male, 12 female, mean age 20.04 years) who use VOCAs (Table 3), two heads of technology within college settings and a quality assurance manager (Table 3a). There

were variations regarding physical access methods, cognitive and literacy abilities, the types of AAC equipment used and levels of support required at interview from communication partners (See Table 3).

**Table 3: Participants' who use AAC demographic information**

Pseudonym	Age	m/f	Total Communication System	Interview setting	Med Diag	GMFCS	Comm. Support in interview
PETER	17	M	VOCA, head switches on wheelchair moderate literacy	Special School, FE Unit	CP	5	Yes
MARY	17	F	Small amount of natural speech, VOCA, Direct access, moderate literacy	Special School, FE Unit	CP	5	No
CAROLINE	21	F	VOCA, Head switches mounted on wheelchair, literate, sign language	n/a – data via blog site	CP, Hearing impairment	5	n/a
NICHOLAS	23	M	VOCA, direct access, not literate	Special Adult unit.	CP	5	Yes
CAROL	19	F	VOCA, direct access, preferred using Makaton, not literate (some initial letters)	Special Adult unit.	CP	5	Yes
GEORGIE	19	F	Eye Gaze (E-tran frame, VOCA not wanted), not literate (some whole word recognition)	Special Adult unit.	CP	5	Yes
FIONA	23	F	VOCA, head switches on wheelchair, not literate	Special Adult unit.	CP	5	Yes
MOIRA	22	F	VOCA, direct access, literate	Special college. Group and individually	CP	5	No
OLIVIA	21	F	VOCA, head switches on wheelchair, literate	Special college. Group and individually	CP	5	No
MADDY	20	F	VOCA, direct access, literacy unknown	Special college. Group only	CP	5	No
XAVIER	19	M	VOCA, head switches on wheelchair, literate	Special College. Group and individually		5	No
SIMON	21	M	VOCA, head switches on wheelchair, not -literate	Special College. Group and alone with STA	CP	5	Yes
KEITH	19	M	VOCA, direct access, literate	Special College.	CP	5	No
DAVEY	21	M	VOCA, direct access, not literate	Special College.	CP	5	Yes
BEN	14	M	VOCA, direct access, literate	Mainstream School.	CP	5	Yes
HARRIET	22	F	Alphabet board, literate (VOCA broken)	College setting (has left) Part of dyad	CP	5	Yes
WILL	19	M	VOCA, head switches on wheelchair, literate	College setting (as left) part of dyad	CP	5	Yes
KEVIN	21	M	VOCA, head switches on wheelchair, not literate	Special college. (within computer skills class)	CP	5	Yes
FAITH	21	F	VOCA, direct access not literate	Special college. (within computer skills class)	CP	5	Yes
RICHARD	21	M	VOCA, direct access, not literate	Special college. (within computer skills class)	CP	5	Yes
JACK	20	M	VOCA, direct access, early emerging literacy	Special college. (within computer skills class)	CP	5	Yes
ERICA	21	F	VOCA, head mouse camera , literate	Special college.	CP	5	Yes
NANCY	21	F	VOCA, head mouse camera, literate	Special college.	CP	5	No
KEN	21	M	iPad, direct access, some speech, literate	Special college.	CP	5	No
SEAN	19	M	VOCA, direct access, literate	Special college.	CP	5	No

M/F: Male/Female; FE: Further education; VOCA: voice output communication aid; Med Diag: medical diagnosis; STA: specialist teaching assistant; CP: cerebral palsy; GMFCS: Gross Motor Function Classification System (Palisano, Rosenbaum, Bartlett & Livingston, 2007); Comm. Support in interview: Communication partner during the interview. All ages relate to interview date. To further protect identity ethnicity is not specified and VOCA manufacturer is not disclosed

**Table 3a: Additional adult participants**

<b>Role</b>	<b>Gender</b>	<b>Setting</b>
Head of technology department	Male	Specialist college
Head of technology department	Male	Specialist college
Quality assurance manager	Female	Specialist educational setting

Table 4 summarises how literacy and access methods impacted upon the use of mainstream computers and the circumstances requiring collaboration. Five participants with direct access skills and literacy were able to use independent mainstream computers. One participant with direct access skills independently used a computer but needed literacy support for Facebook. Five literate participants could use mainstream computers if they had relevant access equipment. One participant could access a mainstream computer but needed support for literacy to post content and another used switches to access a computer but as he was not literate he used Skype or had support to create content. Five participants used the integrated computer within their VOCA which opened up opportunities for two to use their personal communication packages. Four participants with no literacy but direct access required the collaboration of parents or personal/educational staff to use a mainstream computer in order to access, share and create content on the internet and online social media. Online access was not available on their VOCAs. One participant who was literate but required indirect access was waiting for a 3G dongle for her VOCA to be able to link up the college WiFi system. She worked in collaboration with her personal assistant to access, share and create content on the internet and online social media through her family computer at the weekends. Two participants with indirect access to their VOCAs (but no internet connection) were not literate. They both collaborated with family and college staff to use mainstream computers mainly to Skype.

**Table 4: Table outlining literacy, access methods of participants and how they use mainstream technology (n=25)**

Access methods to mainstream technology	Literate	Emerging literacy	Not literate
Uses hands to access an independent computer (some use key guards)	5	1 (mum helped to read complex text)	
Uses form of access technology to independently access computer (joystick/switches to control computer, or Bluetooth/USB cable via communication aid to control computer)	5	1 (needed support to read and create content)	1
Direct access via head mouse. Full computer use on integrated VOCA	1		
Indirect access (scanning). Full computer use on integrated VOCA	2		
Indirect access (scanning). Uses texting and email on integrated VOCA via symbolised vocabulary			2
Direct access to VOCA. Collaborates to use computer			4
Indirect access to VOCA. Collaborates to use computer	1		2

### *3.5.5. Informed consent*

The process of gaining informed consent for this project was sensitive due to the complex communication needs of the participants and mediation via educational staff and/or parents. The differentiated information and consent forms (appendices D & F) were sent to the educational settings in advance of the interview date. On the day of the interview, when I initially met with the potential participants, I would explain the research project, their rights and role in the process and check whether they were happy with audio and video recording techniques. This often took considerable time and meant the interview slot was shorter than anticipated but my priority was to ensure I had informed consent. I believe this strategy was successful as two participants who had consented via the paperwork decided to decline on the day and one participant who had previously declined changed his mind and asked to take part.

About a third of the way into the data collection phase, a participant indicated she wanted to be acknowledged rather than anonymous. Guaranteeing anonymity and



confidentiality are central to issues of participant protection within the university ethical application process. I had not given enough attention to an alternative scenario and when this arose I realised I had not explained the potential range of academic dissemination. The focus of the information was on identity protection and the ramifications of identity disclosure had not been discussed. After a discussion on this topic, the participant indicated she would like to be acknowledged but not have her personal data identified. This led me to alter the way I discussed anonymity with future participants by checking whether they wished to be acknowledged or not.

As previously discussed in relation to recruitment (section 3.5.1.) although the current participants are young adults, research within the childhood research literature base is helpful to consider in terms of informed consent and anonymity. Lansdown (2005) discusses the rights of children to participate and says that adults often fail to recognise the capabilities of children by not creating appropriate environments for them to express their views. Priestley (2003) suggests that social constructions of childhood and disability are often built around frameworks which fail to recognise ideas of independence and competence. Therefore both groups may be at risk of being considered incompetent and/or dependent and their inclusion may be limited within research. Komulainen (2007) suggests a nuanced approach to vulnerability and competence can support approaches to informed consent. Huber and Clandinin (2002) discuss their narrative research with children (aged 9-10 years) and speak of the need for a researcher to move beyond legal boundaries of rules and regulations and consider the nature of a narrative relationship and fully respect the joint construction of a research project.

### ***3.6. Study design***

#### *3.6.1. Introduction*

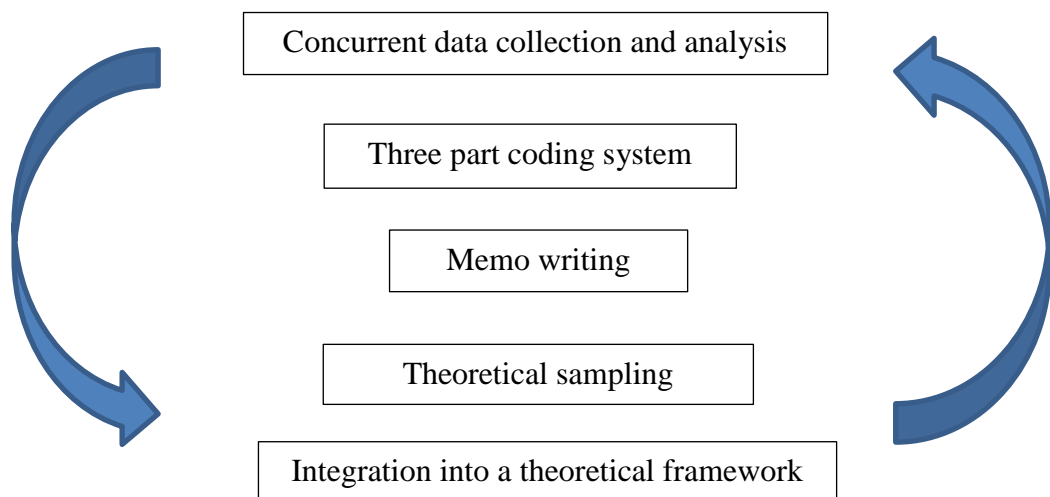
Globally, researchers are trying to explore the rapidly evolving ‘digital revolution’ and the relationships between society and technology. Research theories are proliferating within many different areas with much focus on the way that online social media is amplifying how humans socially interact with one another. Generating theory is vital to support understanding of this phenomenon, especially within niche

populations that are at risk of being overlooked. As argued within section 3.3.3., the strength of grounded theory via concurrent data collection and analysis to drive forward the construction of theory, and its usefulness in areas where little is known (Charmaz, 2006), make it an attractive and suitable approach in the context of this research.

### 3.6.2. Data collection

As outlined earlier (section 3.3.5.) a constructivist grounded theory was perceived as the best fit for the present study. The steps suggested by Charmaz (2006) for carrying out a constructivist grounded theory study are presented in Figure A (not linear, steps move back and forth as data is collected and analysed simultaneously).

**Figure A: Schematic representation of the steps suggested by Charmaz (2006) for conducting a constructivist grounded theory study**



Strands of grounded theory from the writings of Corbin and Strauss (1990) have been integrated into the study (referenced) as the information given on how to carry out the procedures and techniques of grounded theory can be useful for a novice researcher (Charmaz, 2006).

#### 3.6.2.1. Settings

All the data was collected within eight educational settings as follows: one mainstream secondary school, two specialist secondary schools, four specialist

colleges and one specialist school and adult residential centre. These were geographically wide spread across the United Kingdom.

#### 3.6.2.2. Semi-structured interviews

Data was collected through semi-structured interviews lasting between 30 minutes to 2 hours and guided by topic themes (appendix A) identified from the literature review and substantiated by the pilot investigation. Of the twenty-five participants, fifteen were supported within the interview environment by a familiar communication partner: a speech and language therapist, parent, teacher, personal assistant or the head of the technical department. Sometimes more than one communication support partner was present. The heads of technology within two of the special colleges and the quality assurance manager from a special school and adult residential centre took part in semi-structured interviews (lasting between 30 minutes to 1 hour) to clarify issues emerging within the data in order to help develop emerging theory (see section 3.6.3.7. on theoretical sampling).

#### 3.6.2.3. Total communication and low tech AAC

Within the field of AAC problems with equipment are not uncommon. This impacted on the interviews as follows: one participant used an alphabet board as the joystick that drove her VOCA broke off her wheelchair before the interview. Another participant had a last minute technical problem but did not want to cancel. As no low tech AAC was available at short notice, we used yes/no questions (at his request) and the interview was supported by his father. A second interview was arranged and he requested that the questions be sent by email so he could pre-prepare answers on his VOCA. One participant did not want to use her VOCA and chose to use a low tech form of AAC (an eye transfer frame, see footnote entry within Figure B in section 2.6.3.2.). All participants used total communication strategies and utilised body language, facial expression, gesture and on occasion Makaton signing (<http://www.makaton.org/>).

#### 3.6.2.4. Group meetings

On two occasions, nine of the twenty-five participants were also seen within group settings. On the first occasion (mentioned in section 3.4.7.), five participants were seen prior to their individual interviews to build rapport and discuss interview topics and strategies. Nearly all of the participants within the group had complex medical issues and some of the participants were unable to keep their subsequent individual interviews and these had to be re-arranged. One of the participants, despite being unwell, was determined to take part in the research at considerable personal effort. As noted earlier, within the Scope project (Morris, 2002) (section 3.2.1.) determination was identified as one of the strengths that people with complex communication needs demonstrate in terms of research engagement. Unfortunately, one of the participants within the initial group could not be seen on subsequent occasions for an individual interview due to health complications (see Figure B, section 3.6.3.2. for details of data collection occasions).

The second time participants were seen in a group situation was when four interviews were arranged by the college staff to take place within a computer teaching session (see Figure B, section 3.6.3.2, occasion 10). When the session started I thought it might be advantageous because participants would have time to prepare answers on their VOCAs whilst I moved flexibly within the group. However, in reality it became confusing and created communication breakdowns. As will be discussed in the data analysis, moving between participants meant some concepts that were difficult to understand were not allocated the time and attention they may have required. It was only during the transcription process I was also able to see on the camera recording how severely communication attempts may have broken down. This issue is discussed in depth in section 4.12.

The other problem was the atmosphere that this approach created for the participants. Some participants got 'stuck' with a prepared message whilst waiting for me to return, which complicated and curtailed their ability to interact with the other people who were in the classroom. Not being able to play messages to me when they were ready meant they sometimes got deleted. Some participants rebuilt them but I cannot know

whether some participants did not bother to do this. Although messages can be pre-stored on devices this can entail entering an extra level of programming. The other consideration was that the scheduled class timetable slot was the usual one for training to use the internet. The participants were keen to get online and speaking to me (and then waiting for me) clearly tested their patience. Two of the four participants lost interest and terminated the interviews.

#### 3.6.2.5. Demonstrations

During the group meeting to build rapport and discuss strategies, two of the group indicated they wanted to give me a demonstration of using the internet and online social media. The demonstration data was unexpected and unplanned and I had to adjust my thinking in relation to my previously outlined reservations about the ethical nature of observation for internet related activities (section 3.3.3). In line with my aspirations to follow feminist research principles (section 3.2.2.) which emphasise sharing rather imposing meaning, I needed to negotiate this development with subsequent participants and offer them this choice during their interviews. Five participants, four of whom used integrated VOCAs and one who used an iPad, chose to supplement their interview data by giving me demonstrations. I chose to restrain the scope of how I recorded this data. I made field notes on the basis of the explanation it offered about the participants' use of social media, social ties and self-representation but did not record or read any information about the people I saw in passing on the screen. I felt reading or recording details of social media content via a process of 'looking over the shoulder' of someone who had permission to see that information was not acceptable from a personal ethical stance.

#### 3.6.2.6. Summary of data sources

The main data source was semi-structured interviews with additional data from field notes including descriptions of participants' demonstrations of using equipment, a blog entry created specifically for the project and video recordings of the interviews which illuminated non-verbal information missed in real time and policy documents on social media. Table 5 illustrates the data sources and their quantity. The blog entry was submitted by a participant whom it was not possible to meet up with. She was

unsure of how she wanted to take part and asked me to send her questions by email (Appendix I). She emailed me to say she had created an entry on her family blog site and she gave me the web link for the entry in her email. She confirmed in the email that the data was to be used as part of this research project.

**Table 5: Table showing data sources and quantity**

Type of data	Quantity
Interview transcripts with people who use AAC	24
Interview data from heads of technology in two special colleges, one quality assurance manager in a special school and adult residential centre	3
Participant demonstrations of using social media	5
Internet blog created by a participant who could not be seen in person. Email questions sent by researcher as a guide.	1
Video recordings of interviews	22
Policy documents on social media use in educational settings	3
Field notes	Several notebooks and voice memos

### *3.6.3. Data Analysis*

As stated earlier (section 3.3.5.) this study predominantly adopted the constructivist grounded theory approach of Charmaz (2006). Some of the techniques of data analysis outlined within the grounded theory approach of Corbin and Strauss (1990) were also used. I decided to synthesize the grounded theory approaches of Charmaz (2006) and Corbin and Strauss (1990) as it is difficult to establish clarity across the different authors of grounded theory (Eaves, 2001). I predominantly followed the underlying philosophical guidance of Charmaz (2006) and used her methodological techniques. However, I found combining this with some of the more prescriptive directions for execution given by Corbin and Strauss (1990) was very helpful and I adopted and adapted the guidance given by them for axial and selective coding (which compare with Charmaz's focused and theoretical coding stages). This is compatible with the writings of Charmaz (2006), as she herself suggests researchers may find axial coding helpful and outlines the principles within her 2006 book.

### 3.6.3.1. Transcription

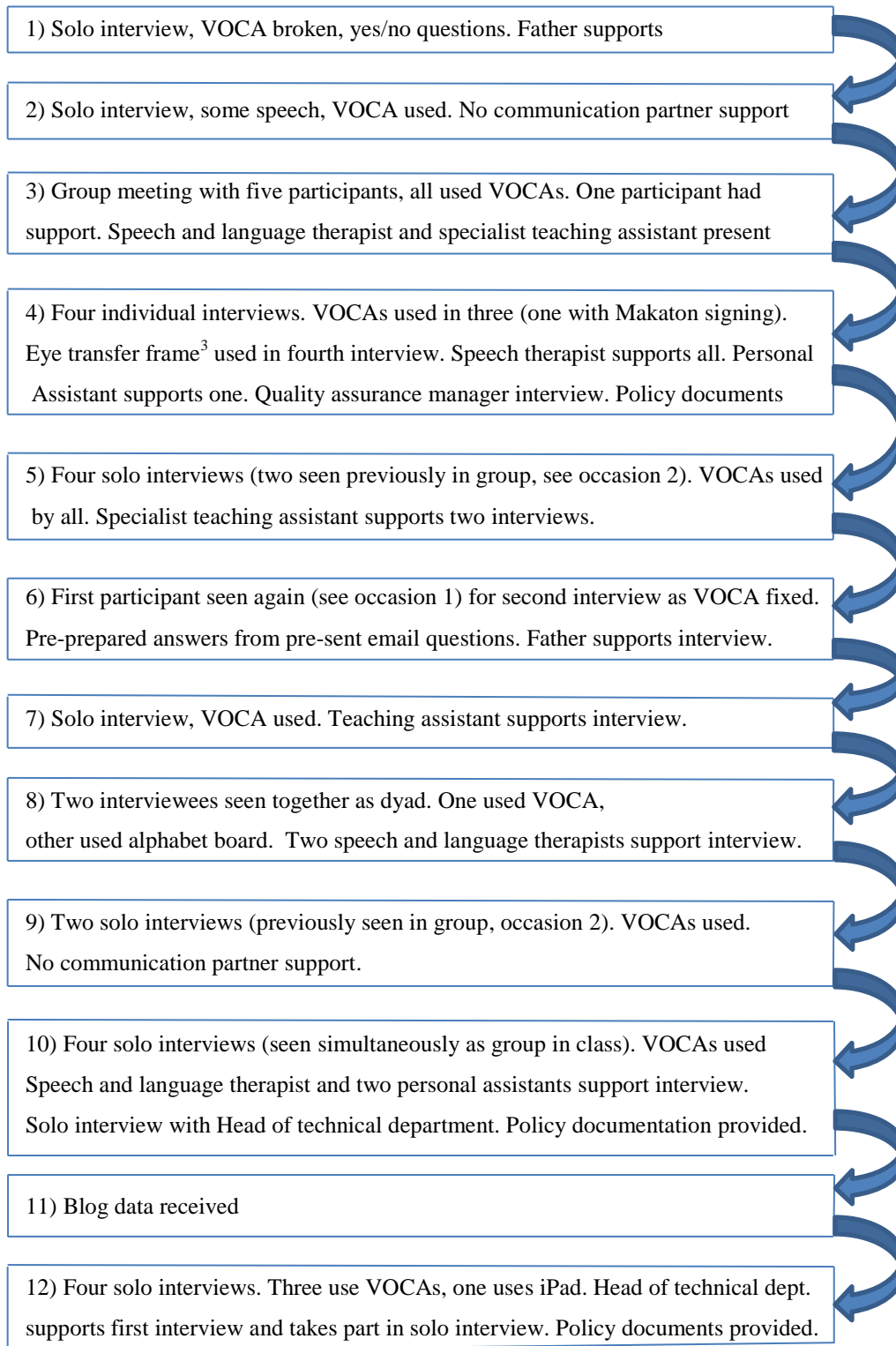
Each interview was transcribed verbatim; two anonymised transcripts can be seen in Appendices M and N. The transcripts have been prepared using the guidelines given by von Tetzchner and Basil (2011) for the notation of conversations with AAC. Manual signs are capitalised e.g. FRIEND (Makaton sign), naturally spoken words are italicised e.g. *naturally spoken speech* and machine-produced digitized or synthesized speech (aided speech) e.g. “*words and sentences spoken by a machine*”. Non-verbal gestures are represented by the indicated meaning in quotation marks with an description of the corresponding non-verbal gesture given in brackets e.g. ‘no’ (shakes head). Responses that have been spelt by individually indicating letters on an alphabet board are indicated in the following manner e.g, s-p-e-l-l-e-d w-o-r-d-s . Alphabet boards also have high frequency whole words available and these are represented by an underline e.g. yes

### 3.6.3.2. Concurrent data collection and analysis

A fundamental characteristic of grounded theory is that analysis begins as soon as the data collection begins (Birks & Mills, 2011). Interview data was concurrently collected and analysed and subsequent interviews focused on emerging theoretical categories. Figure B offers a schematic representation of the data collection occasions (explaining who was seen, what equipment was used, and communication partner information) to illustrate how the concurrent data collection and analysis was carried out.



**Figure B: The schematic representation of data collection occasions over eighteen months**



<sup>3</sup> Eye transfer frame (also known as an E-tran frame) is a Perspex sheet with a hole in the centre. Symbols or text are arranged around the outside of the frame. A communication partner holds the frame in front of the individual who uses AAC who will then indicate areas of the frame through eyepointing. The communication partner will follow this lead and verbalise their interpretation which is then agreed with or not. A communication book is commonly used in combination as the individual who uses AAC will indicate on the frame which page of the communication book should be accessed.

#### 3.6.3.3. Initial coding

Each transcript was analysed using the initial coding described by Charmaz (2006). She says this is the stage where the researcher seeks to begin to understand what the data is describing, what does it suggest and from what point of view. She suggests working at a word-by-word and line-by-line basis to find actions within the data whilst staying as closely as possible to the participants' voices. A global issue for all the transcripts related to the nature of AAC-mediated conversations. As well as working at a close level to preserve the actions of the participants, it was also necessary to take a pragmatic approach. People who use AAC tend to create short phrases in real-time conversations. This can mean that reaching a joint understanding of an event sometimes spreads across several conversational turns. Creating meaning may require input from a supporting communication partner who is familiar with the total communication of the person using AAC. As the participants were present when conversational partner comments were made it is assumed there was agreement (unless stated otherwise).

The advantage of initial coding identified by Charmaz (2006) is that it allows a researcher to think about material in new ways. As it is being scrutinised at such a minute level it can help avoid seeing the obvious superficial meaning of text. Charmaz (2006) urges a researcher to remain open minded and sensitive to the data and let knowledge flow. She states the necessity to set aside any prejudice that may have arisen from the literature review. I had an advantage in this regard as there is a lack of data on this specific topic. The nature of AAC-mediated conversations described earlier (sections 2.2.5 and 2.2.6.) is reflected within the transcripts as participants' responses often contained single words or very short phrases so working at a word-by-word level was important as meaning was often hidden within unexpanded dialogue. Emergent initial codes were carried through to subsequent interviews.

#### 3.6.3.4. Focused coding

Focused coding is explained by Charmaz (2006) as the second major phase of the coding process. She says this is the stage where the researcher starts to explore

bringing the fractured data together to build more conceptual ideas and bring coherence to the initial codes. At this point the data was downloaded onto Nvivo 9.0 (a qualitative software programme). Some commentators have reservations about using computer analysis for grounded theory research as they fear it may crystallise forms of tacit understanding of textual material (Kelle, 1997). However, many researchers also support the use of computer software as it can be very useful for organisational, ordering and structural management.

The advantages I found from using Nvivo 9.0 were two-fold. Firstly, it allowed me to identify the frequency of issues arising in the initial codes and to start conceptualising my emerging ideas. Secondly, I was able to easily display the data on multiple levels and cross-examine the codes between different interview transcripts. It also allowed for easy manipulation and movement of coded data and I found this supported raising the initial codes into higher categories to create the focused codes.

#### 3.6.3.5. Theoretical coding

Charmaz (2006) describes theoretical coding as the process by which the focused codes are brought together to express the possible relationships that exist between them to create explanatory categories. This is the stage when the researcher begins to generate the story of the data. Charmaz (2006) describes how the earlier substantive analysis through initial and focused coding can help to indicate the kind of theoretical codes that will be invoked. She explains emerging categories can draw from many areas of the data, they may be fairly explicit in what they describe or they may be more abstract referring to a sociological concept. The theoretical codes should be reflective and interpretative of all the data. Charmaz (2006) describes theoretical codes as

*“integrative; they lend form to the focused codes you have collected”* (p.63).

Corbin and Strauss (1990) use alternative terminology for Charmaz’s (2006) theoretical coding stage defining it as ‘selective coding’. They describe it as the process by which

*“all categories are unified around a central “core” category [which] represents the central phenomenon of the study. (p.424)*

The core category is the one that represents the central phenomenon, around which all of the other categories can be understood, the driving category which stands out as the defining factor of the data set. Corbin and Strauss (1990) explain this may be an abstract concept which has not appeared as an actual category but which pulls the story of the categories together. They suggest it is identified by considering what is the main idea within the data, can it be summarized within a few sentences, what is driving the interaction and action of the participants, and what explains any variation seen. Glaser and Strauss (1967) see this as the explanatory part of the process where the researcher can raise their work past being merely descriptive to a level where it can add to the knowledge base. Birks and Mills (2011) propose three factors that are necessary for a grounded theory: an identified core category, an accumulated bank of analytical memos, and theoretical saturation of major categories. The first of these objectives is supported by the theoretical coding process.

Within this research study, the process of creating theoretical codes led to the identification of nine categories. One was then identified as the **core category** around which the remaining eight categories could be understood.

#### 3.6.3.6. Memo writing

The second factor identified by Birks and Mills (2011) as necessary to a grounded theory is a bank of analytical memos. Memos form a vital part of the analysis process and memo writing is a technique specific to grounded theory. Memos vary in form depending on the stage of the analysis and can become more complex as theory emerges (Corbin & Strauss, 1990). Charmaz (2006) explains how they act as a pivotal stage between collecting data and writing up the final report. She says they help a researcher to stop and analyze ideas that are emerging during the coding process. The process of writing memos allows the researcher to make and interpret comparisons and variations.

Memos proved very useful within this research. During the transcription of the interview data, the video footage often revealed several points that had been missed at the time of the interaction. These were related to non-verbal communication gestures

that had been missed during the interview that shed light onto possible communication breakdowns that had occurred. These instances either confirmed or shed doubt onto what had been understood by the researcher at the time of the interview and using memos was an ideal way to explore these issues. As has been previously discussed many AAC-mediated conversations involve the naturally speaking partner interpreting short phrases or yes/no answers. Within the time constraints of a face-to-face conversation it is sometimes difficult to reflect on alternate meanings. By viewing the interaction in minute detail on video it was possible to reflect on alternative interpretations. Charmaz (2006) stresses the importance of memo writing as a process which allows you to stop and analyse your own ideas about the codes

*“in any-and every-way that occurs to you during the moment” (p.72).*

#### 3.6.3.7. Theoretical sampling

The third factor identified by Birks and Mills (2011) is the theoretical saturation of major categories. Theoretical sampling is a key concept within grounded theory and is best explained as the recognition during analysis of what kind of future data needs to be collected, and from where, to develop emerging theory. Within the current study, it was recognized that some of the technical details of access, and the implications of using the internet and online social media within educational settings, were difficult to explore solely through self-report with the participants. Therefore extra data was collected, from the heads of two college technical departments and from the quality assurance manager within a special school and adult residential setting, in order to illuminate issues and develop theory.

#### 3.6.3.8. Theory generation

In order to generate the grounded theory, I decided to synthesize the grounded theory approaches of Charmaz (2006) and Corbin and Strauss (1990) (section 3.6.3.). This synthesizing process led me to draw upon lecture material delivered by Graham Gibbs on the axial coding of Corbin and Strauss (Gibbs, 2010). Corbin and Strauss (1990) use a technique called axial coding which they place as the second level of coding, comparable to Charmaz’s focused coding. In other words it takes the medial position within a three stage coding process. Gibbs (2010) outlines the model that Corbin and

Strauss proposed in order to identify relationships within an axial code. They suggest asking what are the causal conditions affecting the identified phenomenon within the emerging code, what is the context that the phenomenon occurs within, what are the intervening conditions, what action or interaction is needed to achieve the phenomenon and what are the consequences of achieving the phenomenon. Axial coding is a contested area within grounded theory (Kendall, 1999; Charmaz, 2006) due to the perception that it can be too prescriptive and constrict a researcher's openness to emerging theory. However, it is also acknowledged that it can be useful, especially for novice researchers as it can act as a framework within which to carry out analysis (Charmaz, 2006).

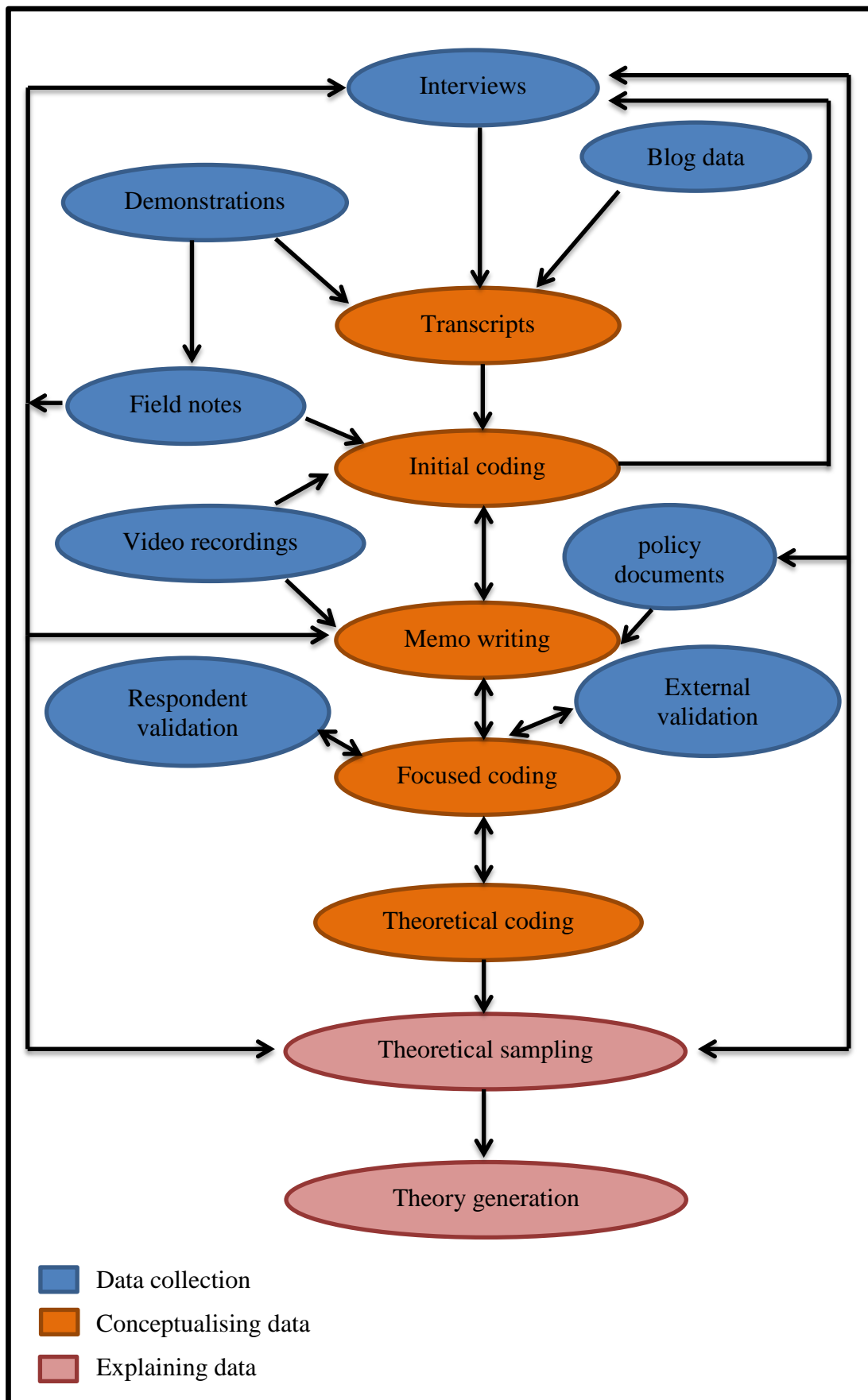
I adapted this technique by moving it up to the theory generation stage. I created a series of memos around the core category (central phenomenon) which I had identified during the theoretical coding stage (section 3.6.3.5.). I used the same axial coding questions to explore how the relationships between the core category and the remaining eight categories could be articulated as a grounded theory. I asked what elements could be considered causal conditions of the core category. I then asked what limitations impacted on both the core category and the causal conditions. I considered the context within which the core category operated: what interaction and action had to take place in respect of achieving the core category, where and when did these take place, and what strategies were required, and what consequences arose for the participants of achieving the central category. This led to a grounded theory which was also expressed in diagrammatic form (section 4.13.9).

#### *3.6.4 Summary*

Generating a constructivist grounded theory required collecting rich data and employing an iterative analysis and coding of the data to establish a co-constructed interpretation of the studied phenomenon (Charmaz, 2006). The aim was to seek patterns and connections rather than establish causality (Charmaz, 2006). The initial codes revealed what had been observed; the focused and theoretical coding subordinated the initial codes into categories. Through ongoing analysis and comparison, the categories were interrogated and conceptual relationships were established (Corbin & Strauss, 1990). This revealed underlying processes which could

offer explanations for generating theory. The framework of the theory was devised from creating memos and concept mapping the categories using mind maps to answer questions about the relationships between categories. This process of looking for relationships led to the generation of the grounded theory. The emergent grounded theory was then considered in relation to wider theoretical concepts of social inclusion to establish the significance of the theory within a societal context. Figure C offers a visual summary of constructing the grounded theory through constant comparison, interpretation of which must also consider the non-linear conceptualization of grounded theory expressed by Figure A in section 3.6.2.

Figure C: Constructing a grounded theory through constant comparison





# Chapter 4

## Data Interpretation

### ***4.1. Introduction***

This chapter will present my analysis of the data based on the methods outlined in the previous chapter and summarised in Figure C. I will describe the characteristics of the nine categories that were identified accompanied by extended excerpts of data. I use my interpretation of the data to begin to address the four research questions as follows:

1. To investigate the self-reported experiences of the accessibility of the internet and online social media by people who use AAC
2. To investigate the self-reported use of the internet and online social media by people who use AAC
3. To explore the perceived role of the internet and online social media for self-representation
4. To establish how online social media is perceived in terms of social ties for people who use AAC

The nine categories are: (core category in bold)

- 1. Desire to use the internet and online social media**
2. Reported use of the internet and online social media
3. Describing support
4. Online challenges
5. Access technology
6. VOCA issues
7. Self-determination
8. Self-representation
9. Online social ties

Using the theoretical coding as described in the previous chapter (section 3.6.3.5.), I interpreted the *desire to use the internet and online social media* as pervading all the

other categories and have given it the position of core category; however the remaining eight categories are not hierarchically ordered within the list. At the end of the chapter, I will describe how I used the methods outlined in the last chapter to interpret and understand how the categories relate to each other and reveal a substantive grounded theory of internet and online social media use by young people who use AAC.

Before discussing the categories in detail two tables have been inserted (Table 6 & 7), table 6 gives an overview of the categories to show how they are understood and supported within the raw data and table 7 illustrates the component elements of the categories.

**Table 6: Identified categories and supporting raw data extracts**

<b>Identified categories</b>	<b>Participant quotes</b>
<p><b>Desire to use the internet and online social media</b>            Unanimous agreement across all the participants of their desire to use the internet and online social media.</p>	<p><b>Feelings about being online</b>  <i>“with Facebook I want to use more”</i>  <i>“now I’m starting to use it more, very excited”</i>  <b>If online access was unavailable</b>  <i>“I would be very upset ... I’d be lost without it”.</i></p>
<p><b>Reported use of the internet and online social media</b>            A range of internet based activities and types of online social media sites are used that are typical of young people</p>	<p><i>“I use the internet to look at websites like doctor who, watch programmes on BBC iPlayer, and for shopping on Amazon”</i>  <i>“At home I like to use the computer to go on Skype with my granddad”</i>  <i>“It’s easier for college work”</i>            Amanda: <i>“And do you use anything other than Skype, Facebook, email and texting?”</i>            Nancy: <i>“MSN”</i>            Amanda: <i>“So have you got control of being able to type things into YouTube so you can find any topic”</i>            Erica: <i>‘yes’ (nodding head)</i></p>
<p><b>Describing support</b>            Participants describe how they have been helped to set up and use the internet and online social media by staff within educational settings (including using specialist teaching tools such as InBook), family (especially siblings)</p>	<p>Jack: <i>“InBook”</i>            Amanda: <i>do you use it at home</i>            Jack: <i>‘no’ (shakes head)</i>            Amanda: <i>no so do you use it at college</i>            Jack: <i>‘yes’ (nods head)</i></p>

<p>and friends. Collaboration is a major part of this category as individual challenges meant some participants could not use the internet and social media independently.</p>	<p>Amanda: <i>“has anyone ever helped you to do it?”</i>  Keith: <i>“my sister”</i></p> <p>Amanda: <i>can go on Facebook by yourself</i>  Mary: <i>‘no’ (shaking head)</i>  Amanda: <i>no so mum’s always with you when you go on Facebook is she</i>  Mary: <i>yeah</i></p>
<p><b>Online challenges</b>  Challenges exist for the young people in an online environment but there is evidence of resilience and an ability to cope</p>	<p><i>“one of the people wasn’t very nice to me, I told them off”</i></p>
<p><b>Access Technology</b>  Methods of access affect participant choice over which types of equipment are used</p> <p>Challenges with scanning access technology</p>	<p>Keith: <i>“I don’t need that one”</i>(referring to integrated VOCA)  <i>“special switches eight at home”</i>(describing accessing a computer)  <i>“need my cable to computer”</i>  (connecting VOCA to computer)</p> <p><i>“trouble it’s the lack of information”</i>  (parental report)  Email question: <i>What problems do you have using the internet?</i>  Peter: <i>“Access is slow”</i></p>
<p><b>VOCA Issues</b>  Participants described advantages and disadvantages for using the internet and online social media through integrated VOCAs.</p>	<p><b>Advantages</b>  Amanda: <i>“Right has that made you happy being able to use the internet through your communication aid”</i>  Xavier: <i>yeah</i></p> <p><b>Disadvantages</b>  <i>“I can’t play a game”</i>  <i>“It’s hard”</i></p>
<p><b>Self-determination</b>  Perceived control over independent access to information and self-organisation of activities are interpreted as improved self-determination in terms of autonomy and authorship of activities. Another aspect of self-determination was interpreted as enhanced personal privacy.</p>	<p><b>Authorship of activities</b>  <i>“It gave me more independence. I can organise things like meetings myself”</i></p> <p><i>“planning trips with my P.A.”</i></p> <p><b>Enhanced privacy</b>  <i>“Main thing about Facebook is I can send a message to either my brother or my dad if I have a problem and they get it on their phones”</i></p>

<p><b>Self-Representation</b> Increased capacity for self-representation online which compensates for some of the challenges within face-to-face environments due to complex communication needs.</p>	<p><b>Information about self</b> Amanda: <i>what kind of things do you tell people about</i> Will: <i>“What I think”</i></p> <p><i>“I like Facebook because I like seeing me holding Pikachu”</i></p> <p><i>“people understand me better in writing”</i></p>
<p><b>Online social ties</b> Young people expressed the main benefit of being online was the increased opportunity to “talk to people” which enriched existing relationships with family and friends. They also spoke of the value of re-establishing and maintaining old friendships which had altered due to life changes. There was evidence of new friendship opportunities being created and support for dating.</p>	<p><i>“for talk to people”</i> <i>“it me in contact with everybody”</i> <i>“I can talk to people on it”</i></p> <p><b>Keeping in touch long distance</b> <i>“yes, especially when I am here”</i>(residential college) <i>“my old teachers”</i> <i>“I send them a text. I find them”</i> (finding old school friends on Facebook)</p>

Table 7 has been inserted illustrating the component elements of the categories in order to orientate the reader through the chapter contents.

**Table 7: Component elements of the categories**

<i>Component elements</i>	<i>Categories</i>
1.1. Desire to be online 1.2. Desire to extend use	1. Desire to use the internet and online social media
2.1. The internet 2.2. Online social media sites 2.3. Email 2.4. Texting and mobile phones 2.5. Frequency of use	2. Reported use of the internet and social media
3.1. Introduction to and training to use the internet and online social media 3.2. Collaboration 3.3. Challenges regarding support	3. Describing support
4.1. Online safety awareness 4.2. Resilience 4.3. Restrictions to use 4.4. Reduced privacy	4. Online challenges
5.1. Computer access without additional equipment 5.2. Computer access with additional equipment 5.3. Challenges associated with access technology	5. Access technology

6.1. Advantages of integrated VOCAs 6.2. Limitations of integrated VOCAs 6.3. Cameras on VOCAs 6.4. Repairing VOCAs and future planning 7.1. Autonomy and authorship 7.2. Enhanced privacy 8.1. Information about Self 8.2. Conversational equality 8.3. Expressing humour 8.4. Narrative record of activities 9.1. Bonding social ties: “to talk to everyone” 9.2. Maintaining social ties 9.3. Bridging social ties	6. VOCA issues  7. Self-determination  8. Self-representation  9. Online Social Ties
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#### ***4.2. Explanatory notes on data presentation***

Some transcription issues are specific to individual participants; Peter was seen over two interviews as on the morning of the first occasion his VOCA had broken. He was keen to continue and his father, Paul, suggested the interview took place with his assistance and the use of closed questions requiring a yes/no response. As Peter’s answers could not provide cues to guide the direction of the subsequent questions, the solution was to follow the advice of Booth and Booth (1996) and offer a variety of suggestions for him to agree or disagree with. The concern in this situation is acquiescence, the tendency to answer questions positively regardless of their content, but Peter demonstrated he was prepared to say no. Once the second interview had been arranged, Peter asked for the questions to be sent to him in advance so he could prepare his answers to play back on his VOCA. To provide Peter with the opportunity to elaborate on the first interview many of the original questions were asked again. Peter’s responses are reported with reference to which interview the data came from either *Interview 1* or *Interview 2* as in between his interviews Peter had started to use Switch XS™ software that enabled him to use a computer independently. As the responses in the second interview are more detailed and sometimes differ in detail it was deemed important to signify to the reader which interview the data is quoted from.

Georgie did not want to use her VOCA within the interview and used eye gaze on her Eye-transfer frame (E-tran Frame) which was supported by the speech and language

therapist (SLT). She also did not wish for a video camera to be used so non-verbal communicative acts had to be described by the researcher and their appearance within the transcript can sometimes appear out of context with the conversational flow.

Faith also did not want to be on camera and her transcript will refer to (an unrecorded non-verbal response) which is followed by a description of what that response was,

Faith: *(makes unrecorded non-verbal response)*

Amanda: *yeah* (interpreting response)

Caroline contributed to the research through a blog site as it was not possible to meet up; her comments have been lifted from a continuous transcript and contain no question references as she is responding to research questions sent to her by email (Appendix I).

Harriet's joystick control had snapped off her wheelchair and she could not use her VOCA during the interview. She used an alphabet board and spelt her answers by pointing to each letter in turn which the speech and language therapist (SLT) vocalised. This interview was transcribed using the guidance outlined earlier of von Tetzchner and Basil (2011), (section 3.6.3.1.) to illustrate how each word has been spelt manually e.g. s-p-e-l-l-e-d w-o-r-d-s.

The thesis is now going to move into data analysis with supporting excerpts from the data transcripts. This is structured around the nine categories outlined previously:

- 1. Desire to use the internet and online social media**
2. Reported use of the internet and online social media
3. Describing support
4. Online challenges
5. Access technology
6. VOCA issues
7. Self-determination
8. Self-representation
9. Online social ties

The core category will be explored first: *The desire to use the internet and online social media*. This is the category which has been judged as the central core category around which all the other categories are unified and that explains the central phenomenon expressed by the participants of this study.

### **4.3. Desire to use the internet and online social media**

#### *4.3.1. Desire to be online*

This category encapsulated the emotions expressed by the participants about using the internet and online social media. Across all the interviews every participant expressed a desire to be online as it provided feelings of happiness and excitement and most importantly a sense that life had been improved.

Amanda: *how it makes you feel to use Facebook or the internet*

Faith: *“Excited”*

Amanda: *Faith was just telling me about how using InBook or Facebook made her feel and I was wondering how do you think it makes you feel*

Jack: *“happy and excited”*

Amanda: *some people said they felt excited about it others said it made them feel happy. Um can you think of any adjective?*

Sean: *“fun”*

Amanda: *What difference do you think it has made to your life being able to use it*

Moira: *“it has changed my life better”*

Amanda: *and do you like using Facebook*

Fiona: ‘yes’ (raises brows and smiles broadly)

Amanda: *yes. Does texting make you happy*

Fiona: ‘yes’ (raises brows and smiles broadly)

Caroline’s blog

*I love Facebook!*

[not consecutive]

*The internet and social media are an important part of my life. I cannot imagine life without that*

Amanda: *do you like Facebook?*

Mary: ‘yes’ (nods head)

Amanda: *yeah, how does using Facebook make you feel*

SLT: *Amanda is testing me to see whether I know where all these are Georgie!*  
Amanda: *She has found a feelings face* (description of Georgie's eye gaze instruction)  
SLT: *give me a colour Georgie, so it's in this corner*  
Georgie: *yeah*  
SLT: *red, happy*  
Georgie: *yeah*

*1<sup>st</sup> interview*

Amanda: *are you glad you found Facebook?*  
Peter: *yeah*  
Amanda: *would you say that it has added something to your life that you're happy that you've got access to Facebook?*  
Peter: *yeah*  
Amanda: *so it's about a year you've been using Facebook. Did you like it when you first saw it*  
Peter: *yeah*

*2<sup>nd</sup> interview*

Email question: *How did you feel when you found out about the internet?*  
Peter: *"Now I'm starting to use it more, very excited"*

Amanda: *And do you feel Facebook has made a difference to your life?*  
Nicholas: (laughs)  
Amanda: *Do you like using it*  
Nicholas: *"yes"*

Amanda: *you use Facebook more, so you prefer Facebook*  
Carol: 'yes' (nods head)  
SLT: (using Makaton signs to support speech) *wait, so is Facebook your favourite*  
Carol: 'yes' (nods head)  
Amanda: *Does Facebook make you happy*  
Carol: 'yes' (nods head)  
Amanda: *yeah, so it's very important for you to have Facebook*  
Carol: 'yes' (nods head)

#### *4.3.2. Desire to extend use*

Some of the participants spoke about how they wanted to extend their use of online social media

*2<sup>nd</sup> interview*

Email question: *Is there anything I have not asked you about that you think is important for me to know?*  
Peter: *"I am going to try the iPhone with my communication aid to send and read texts. I think this will be useful when I go to college"*



Caroline's blog

*I want to try talking to my One Voice friends and maybe (New York friend). I have not tried Twitter yet, but maybe I will try in the future.*

Olivia: *"with Facebook I want to use more"*

Olivia works collaboratively to use Facebook and texting as she does not have the relevant equipment to work independently. She can only use Facebook at weekends with her home "carer" (her description). She wanted to have the internet and texting set up on her VOCA in the educational setting, but to do this she required a dongle

SLT: *Xavier uses a dongle to link up to our networked computers so if you want to make a word doc or a poster or read your college emails you use your dongle*

Amanda: *Right*

SLT: *Which is something we are getting Olivia sorted out on*

I saw Olivia on two occasions over a few months and she had not achieved this by the last time I saw her.

Olivia: *"I do, I do, I can't, I do, I can use it when I get set up"*

Amanda: *yes. You can use it when you get set up and is that something you are looking forward to*

Olivia: *yeah*

Moira wanted to have an 'app' loaded onto her mobile phone

Moira: *"I would like a voice on my phone if I have no talker"*

Amanda: *Cos there are Apps which you can download onto your iphone which can give you a voice, but have you not got them on your phone at the moment. It's difficult to keep up with technology cos it moves so fast, it's hard finding what's available.*

Moira: *"I don't know how to use"*

Amanda: *Right, so you probably need some help to get it sorted out*

Moira: *yeh*

In Peter's first interview an issue occurred to Amanda which might impact on whether or not he could extend his use of Facebook. Peter appeared happy with the suggestion made

*1st interview*

Amanda: *and on your (VOCA) have you got a symbol for Facebook, have you got anything programmed in so can you use your (VOCA) to tell people you are on Facebook*

Peter: 'no' (shakes head)

Amanda: *no, would you like to be able to have it programmed onto your (VOCA), would that be helpful*

Peter: 'yes' (nods head)

Paul: *Right well we can do that can't we. You don't think about these things*  
Amanda: *no, no. So I suppose that would be helpful cos then you could ask somebody if they were, if you had something on your (VOCA) saying 'are you on Facebook'*

Peter: 'yes' (nods head)

Amanda: *and then somebody could tell you if they were and you could say 'would you like to be my friend on Facebook'*

Peter: 'yes' (nods head)

Paul: *hmm yeah, hadn't thought of that*

Simon is hoping to get a camera and Skype set up on his VOCA so he can extend his use of Skype to his residential college setting

Amanda: *Now have I heard that you would like to use Skype* (choice of hands offered for eye gaze answer)

Simon: 'yes' (gazes at left hand)

Amanda: *so who would you use Skype to talk to?*

Simon: *"my dad and my mum"*

#### *4.3.3. Summary*

The participants had a diverse profile in terms of individual skills which is reflected within their transcripts and will become clearer as this chapter continues. However, regardless of whether they used the internet and online social media independently or through collaboration with another person, they were unanimous in their desire to be online. The evidence for establishing this as the core category is justified by the way it extends into all other categories. The desire to be online is triggered through the perceived consequences for self-determination, self-representation and enriching and maintaining online social ties. The desire to be online is also the driving force behind reported use, responding to support, dealing with online challenges and finding ways to use access technology and integrated VOCAs to go online.

#### ***4.4. Reported use of the internet and social media***

A range of activities was reported in regard to engaging with digital technology. The internet was used to follow hobbies, share and access information, play online computer games, carry out academic study and for two participants it provided an employment opportunity and supported charity work. The most popular reported use was for the social opportunities offered by online social media sites such as Facebook.

#### 4.4.1. *The internet*

*2<sup>nd</sup> interview*

Email question: What do you use the internet to do?

Peter: *“To keep in touch with friends, planning trips with my PA, emailing, updating my website. I also use video calling to talk directly with people like my grandparents”*

Amanda: *What kind of things do you look at on the internet, what do you use the internet for?*

Mary: *“Picture”*

Amanda: *Right, um so you like looking at pictures, um, of things that you’re interested in*

Mary: ‘yes’ (nodding)

Amanda: *Yes, so would you use Google images?*

Mary: *yeah*

Amanda: *do you use the internet for other things?*

Mary: ‘yes’ (nodding)

Amanda: *can you tell me some of them, maybe?*

Mary: *“look up”*

Amanda: *so look up information*

Mary: ‘yes’ (nodding)

Amanda: *about things that you’re interested in*

Mary: *“Yorkshire”*

Amanda: *Oh Yorkshire, so you like to look up things about Yorkshire. Why are you interested in Yorkshire?*

Mary: *“Because I love the hill”*

#### Field notes

Speaking to Mary’s mother post interview uncovered that Mary likes to make PowerPoint montages of photographs and uses Google to find images she can use. Her mother says she likes to express her moods and emotions through the images. She also takes her own photographs to show her visual perspective of the world from a wheelchair.

Amanda: *do you have favourite hobbies that you follow on the internet*

Moira: ‘yes’ (nods head)

Amanda: *would you be happy to tell me about some of the things you are interested in*

Moira: *“I am interesting about Boccia”* (a game that resembles Bowls)

#### Caroline’s blog

*I use the internet to look at websites like doctor who [sic], watch programmes on BBC i-player, and for shopping on Amazon.*

Amanda: *and do you link up on the PlayStation games with your friends or*

Ben: ‘yes’ (nods head)

[not consecutive]

Amanda: *yes and so you can play online with them*

Ben: 'yes' (nods head)

[not consecutive]

Amanda: *which games do you play?*

Ben: *"MW3, Black ops, FIFA"*

Kevin: *"I don't use the internet at home but I like using it at college, to use and go on YouTube and sometimes for my work"*

Amanda: *Some people have told me that they like being online. What do you think about that?*

Nancy: *"It's easier for college work"*

Amanda: *What things would you use the internet to do?*

Harriet: F-a-c-e-b-o-o-k, s-h-o-p-p-i-n-g a-n-d I b-u-i-l-d w-e-b-s-i-t-e-s

Amanda: *What kind of websites do you build?*

Harriet: A-n-y-t-h-i-n-g i-t d-e-p-e-n-d-s o-n t-h-e c-u-s-t-o-m-e-r

Amanda: *Ah, right so do you earn money from building websites*

Harriet: Yes (whole word available)

Amanda: *Is it very important to you to be able to use the internet and things?*

Xavier: *yeah*

Amanda: *yup and er..*

Xavier: *"especially with my (name of charity) work and everything"*

#### 4.4.2. Online social media sites

Field notes were taken from a volunteering experience at an AAC focused charity event. The young people who used AAC built a presentation to illustrate what they considered to be an important aspect of communication in 2012. Facebook was the central topic of the presentation and materials were created to illustrate how it was considered useful for talking with friends, sharing interests, photos and videos, and networking in order to share information and news.

Within the current research Facebook was by far the most popular social networking site with the majority of the participants reporting they used it,

Amanda: *Do you use Facebook*

Carol: 'yes' (nods head)

Amanda: *Eh ha, and how long have you been using Facebook?*

Carol: (holds up 2 fingers)

SLT: *Two years*

Amanda: *Two years, so you've been using Facebook for two years*

Carol: 'yes' (nods head)

*1<sup>st</sup> interview*

Amanda: *do you use Facebook to contact your friends?*

Peter: 'yes' (nods head)

Amanda: *Okay and do you use Facebook?*

Mary: *Yeah*

Amanda: *Okay and*

Mary: *N (starts to type on VOCA) "as new"*

Amanda: *But new, so you've only just started using Facebook*

Mary: *Yeah*

Fifteen young people mentioned they liked Skype,

Rick: *"At home I like to use the computer to go on Skype with my granddad"*

Amanda: *Let me see, have you got the names for Skype, email and Facebook on your talker?*

Nicholas: *No*

Amanda: *Shall I give you a choice*

Nicholas: *Yeah*

Amanda: *Is Facebook your favourite*

Nicholas: 'no' (shakes head)

Amanda: *No, is Skype your favourite*

Nicholas: 'yes' (nods head) *yeah*

Amanda: *It is, okay*

Amanda: *have you used Skype at home, yes or no (choice of hands)*

Simon: 'yes' (looks at left hand)

Amanda: *so did you learn about Skype at home*

Simon: 'yes' (looks at left hand)

Amanda: *So when you Skype do you use the texting facility that Skype has got*

Harriet: D-e-p-e-n-d-s w-h-o I-'m S-k-y-p-i-n-g

Amanda: *Okay and if you weren't using the texting facility on Skype and your (VOCA) isn't working, how would you get somebody to assist you with what you wanted to do?*

Harriet: I-f I-'m S-k-y-p-i-n-g m-y p-a-r-e-n-t-s c-a-n u-n-d-e-r-s-t-a-n-d m-e

Eight mentioned using You Tube and Erica gave me a demonstration of using it on her VOCA,

(video springs to life on VOCA of a presentation Erica gave a few years ago at an event for people who use AAC)

Amanda: *right so that's on YouTube so you access stuff on YouTube.*

[not consecutive]

*So have you got control of being able to type things into YouTube so you can find any topic*

Erica: 'yes' (nods head)  
Amanda: *okay oh and then you've got buttons for storing your favourites*  
Erica: "object"  
Amanda: *are right yes so you've got Saturday Kitchen, oh excellent I love Saturday Kitchen. Oo and One Direction*  
Erica: (starts playing One Direction video on VOCA)  
Amanda: *is this one of your favourite songs*  
Erica: "object"  
Amanda: *Who's your favourite, nod your head when he comes on*  
Erica: (turns excitedly)  
Amanda: *ah ha that's my niece's favourite one. Is that Harry Styles?*  
Erica: 'yes' (very excitedly nods head and smiles)

Mary, Ben and Nancy said they used MSN,

Mary: "MSN"  
Amanda: *Oh I know, MSN, instant messaging, so you use MSN*  
Mary: *yeah*  
[not consecutive]  
Amanda: *Did you use MSN before you used Facebook?*  
Mary: *yeah*

Amanda: *So do you use anything like MSN as well?*  
Ben: 'yes' (nods head)

Amanda: *And do you use anything other than Skype and Facebook and email and texting? Do you use twitter*  
Nancy "MSN"

Moira used other online social media sites as well as Facebook mentioning Bebo and MySpace.

Moira: "well I use Bebo and like Facebook"  
Amanda: *oh you use Bebo as well*  
Moira: 'yes' (nods head)

Amanda: *and do you use MySpace*  
Moira: 'yes' (nods head)  
Amanda: *right so use quite a... is there any other social things like that which you use, Bebo, Myspace and Facebook any more*  
Moira: 'no' (shakes head)

Twitter was mentioned by Keith, Moira, Harriet, Will and Erica and received a mixed reaction

Amanda: *right and what do you like about Twitter*  
Keith: "I can write short phrases"  
Amanda: *right so would you, do you prefer Facebook or Twitter or do you think they are so different that you can't compare them*

Keith: *"I like Facebook more than Twitter"*

Amanda: *Do you know why*

Keith: (uses intonation) 'I don't know'

Amanda: *you don't know*

Keith: *yeah*

Amanda: *why would that be, can you explain why you wouldn't prefer Twitter to Facebook or Bebo or Myspace or those kind of things*

Moira: *"it is different"*

Amanda: *okay different as in it's not as social*

Moira: 'yes' (nods head)

Harriet: I k-e-e-p f-o-r-g-e-t-t-i-n-g a-b-o-u-t m-y T-w-i-t-t-e-r

Amanda: *Now that's really interesting*

SLT: *Hang on, right so is that yes, you forget about Twitter 'cos you use other things,*

Harriet: *yeah*

Amanda: *I find Twitter really hard to use and I find it quite hard to understand with all the hash tags and the @'s and the abbreviations. Will you are madly saying yes, yes, yes, so I presume you are agreeing with me*

Will: 'yes' (raises brows)

Amanda: *so what kind of things do you use, I mean I know you use Facebook 'cos you just mentioned that but do you use anything else*

Erica: (opens up VOCA to show Twitter)

Amanda: *Oo, twitter*

(Erica gives a demonstration of how she creates a tweet)

Erica: *"tweet submit tweet"*

Amanda: *so you sent that to Harry from One Direction*

Facetime was being used by Ken,

Amanda: *so what sort of things are you interested in apart from Facebook. Facebook and...*

Ken: *"Facetime"*

Amanda: *Oh I know Facetime and that's where you have a camera link up isn't it?*

Ken: *yeah*

Erica mentioned Facetime, although it is not clear if she accessed it personally or whether she was in the room when her female friend was using Facetime on an Apple device.

Erica: *"(female name) say to (male name) with me"*

[not consecutive]

Erica: *"me on Facetime"*

#### 4.4.3. Email

Sixteen participants said they used email,

Xavier: *"I get emails about it"*

Amanda: *ah okay the same way I do and if you did have a comment that you want to make, you would do the same thing I would do is send an email and then it gets posted onto the forum*

Xavier: 'yes' (nods head)

Caroline's blog

*I email people in my family to say thank you for presents, and friends to arrange to meet*

The main endorsement for using online social media sites was through the advice offered to other AAC users

Amanda: *maybe you have advice to give to somebody who uses AAC about if they were thinking of using social media or Facebook or anything like that.*

Will: 'yes' (raises brows)

Amanda: *Yeah*

Will: *"Use demo first"*

Amanda: *there's not much research about people who use AAC about the internet and email. So what do you think would be important to tell the world if anyone reads the research*

Sean: *"try it"*

Amanda: *would something you'd be interested in saying to people who support people who use AAC that social media is a good thing*

Harriet: 'yes' (nods head)

Amanda: *so now that communication aids can link in with computers and things, do you think it is an important thing to start working on with people who use AAC*

Harriet: 'yes' (nods head)

#### 4.4.4. Texting and mobile phones

Mobile phone technology was used for texting in a variety of ways and was affected by motor skills and literacy level. Peter, Harriet and Olivia, who were all literate, said they used a mobile phone but needed someone to operate it for them as they could not operate one directly. Mary, Keith, Moira and Sean all said they used a mobile phone independently and Carol, Georgie, Fiona, Will, Erica and Xavier used texting via their VOCAs. Two participants gave me demonstrations of this, Xavier typed a text and sent it to one of his contacts using his VOCA and Fiona demonstrated the creation of



a text using symbolised vocabulary that was then converted to a standard written text by her VOCA. When she received a reply the VOCA turned it into a spoken message for her to listen to. Georgie liked texting on her VOCA because she could do this independently,

Amanda: *Right okay and which do you prefer Facebook or, shall I put my hands up, Facebook or texting which do you like best*  
Georgie: (looks to Facebook)  
Amanda: *Facebook*  
Georgie: (looks to texting)  
Amanda: *oo both. Do you like both the same, (decides to double check) this is Facebook and this is texting (holding up hands again)*  
Georgie: (looking at texting hand)  
Amanda: *so texting, you like texting best*  
Georgie: *yeah*  
Amanda: *and is that because you can do it yourself on your talker*  
Georgie: *yeah*  
Amanda: *so that means you can do it when you want to do it*  
Georgie: *yeah*  
Amanda: *yeah, okay so that's important*

*1<sup>st</sup> interview:*

Amanda: *right so, um, at the moment you use texting sort of via your dad's phone*  
Peter: *yeah*

Amanda: *so do you use a mobile phone?*  
Mary: 'yes' (nods head)

Amanda: *How do you keep in touch with your family when you are here is it by email or text*  
Sean: *"phone"*

#### 4.4.5. Frequency of use

Frequency of use varied considerably ranging from once a week to daily

*1<sup>st</sup> interview*

Amanda: *so you go onto Facebook at home, so that would be maybe at the weekend when you've got time, on a Saturday or a Sunday?*

Peter: *yeah*

*2<sup>nd</sup> interview*

Email question: *Can you try to describe how using the internet fits into a typical day*

Peter: *"Now I am able to access it myself I go on every day. I mainly use Facebook to catch up with friends"*

Olivia goes home at the weekends and describes how she uses Facebook on the family computer with the support of her carer (her term)

Amanda: *and when you use Facebook with your carer at home*

Olivia: *yeah*

Amanda: *is that on the computer, do you have a computer at home*

Olivia: *yeah*

Amanda: *is it your family's computer or is it your computer*

Olivia: *"we share"*

[not consecutive]

Amanda: *So you can catch up with Facebook every weekend so you don't have to wait too long to find out all the news, and but it would, am I right in saying it would make a difference if you could find out things during the week when you were here*

Olivia: *yeah*

SLT: *Georgie can I just tell Amanda quickly about what you talked about with your texting, about how many times a week you like to text*

Georgie: *yeah*

SLT: *Georgie has asked for her targets to be 3 times a week that she texts*

Amanda: *okay so is that more than now, is that increasing*

Georgie: *yeah*

The other issue that impacts on frequency of use is speed. As Caroline explains

Caroline's blog

*I can do email independently on the (VOCA) email browser. That#s [sic] good but slow. It takes all afternoon to write all my news.*

#### 4.4.6. Summary

The internet is used for entertainment, research, academic and social activities that are typical of online interests in the participants' age demographic (mean age 20.04).

There was a small amount of evidence it supported paid employment and charity work which is an area the young people will be considering as they near the end of their educational careers. The evidence for the popularity of Facebook is not surprising considering the worldwide appeal of the site. Despite some signs of waning in early-adopter countries, the UK was listed as the having 29.8 million users logging onto Facebook over the course of June 2011 which represents 58% of the 51.4 million who are listed as being online (Arthur, 2011). Skype can offer opportunities to participants who might not be able to use text-based communication independently or temporarily do not have access to their VOCA equipment as it offers opportunities to communicate with familiar others who can interpret total communication strategies.

Twitter did not seem to be as popular with the participants as Facebook and email and was described by Moira as “different”. This may indicate a preference for using online social media sites that support more social interaction and self-representation opportunities which links into the self-representation and online social ties categories (sections 4.10 and 4.11).

#### ***4.5. Describing support***

Participants described educational staff, personal staff, family and friends have often introduced them to the internet and helped set up online social media accounts and Olivia describes requesting to use Facebook herself.

##### *4.5.1. Introduction to and training to use the internet and online social media*

Olivia describes how she asked to use Facebook after finding out about it. She thought this was through school, but couldn't quite remember.

*Amanda: How did it [using Facebook] start with your carer?*

*Olivia: “I asked”*

Georgie describes how she learnt to use Facebook in her class at school,

*Amanda: where did you learn to use Facebook*

*SLT: down here*

*Georgie: yeah*

*SLT: give me a colour, (name of class), so it was in (name of class)*

*Georgie: yeah*

*SLT: yup this corner, give me a colour (name of teacher) red*

*Georgie: yeah*

*SLT: (name of teacher) Georgie's old teacher.*

Simon is being taught how to use email at his special college

*Specialist Teaching Assistant (STA): Simon can I tell Amanda about the computer and how you like the computer, yes or no (choice of hands)*

*Simon: ‘yes’ (looks at left hand)*

*STA: Simon really likes the computer and he really likes doing jobs on the computer sending emails, don't you, but he finds it very difficult to access the computer*

Information about two specialist teaching tools emerged from the interviews within three of the special college settings,

STA: *so each user has their own account and they can put on there their photos, it's like a blog page, a lot of users write their diaries what they done at college or use it like a CV to show what they have done at college and it's been spread out across lots of different colleges*

Amanda: (turning to Simon) *so do you like InFolio yes or no* (choice of hands)

Simon: 'yes' (looks at left hand)

InFolio is an accessible open source e-Portfolio which allows students to either load their own material, or have it loaded on their behalf, onto simple online pages and it also has a picture based log on system for those who might find using a user name and password difficult.

Amanda: *do you use Facebook when you're at college*

Faith: (makes unrecorded non-verbal response)

Amanda: (forgot to repeat what she had indicated but from context of the next comment presumes it is a head shake meaning no)

Personal Assistant: *you use InBook when you are at college*

Amanda: *okay so you use InBook when you are at college*

Faith: (makes unrecorded non-verbal response)

Amanda: *yeah* (interpreting response)

Jack: *"InBook"*

Amanda: *so you use InBook as well* (referring to information given by other group members). *Okay and do you use that at home or college or both*

Jack: (looks to Personal Assistant, PA)

PA: *no good asking me she's asking you*

Amanda: *do you use it at home*

Jack: 'no' (shakes head)

Amanda: *no so do you use it at college*

Jack: 'yes' (nods head)

InBook is a secure online social media site designed as a teaching tool to help students learn the principles of online social networking so they are empowered and informed before they use unsecured mainstream online social media sites.

Erica's interview revealed how she is liaising with one member of the college technical staff to prioritise access to computer game technology

Amanda: *what about computer games do you use them at all*

Erica: 'no' (shakes head)

Amanda: *No, what would be the reason for that*

Erica: (draws attention to screen of VOCA)

Erica: *"Andy"*

Amanda: *oh right Andy* (seeing what Erica is selecting on her screen. *Andy is one of the technical team*)

Erica: *"not it"*

Amanda: *Andy not it! Er, has Andy not set up computer games on here*

Erica: 'yes' (nods head)

Amanda: *or he has*  
 Erica: 'no' (shakes head)  
 Amanda: *no so he hasn't set up computer games on there right*  
 Information Technology Manager (IT): *do you want some help Erica*  
 Erica: 'yes' (raises eyebrows and nods head)  
 [not consecutive]  
 Head of technology: *you ranked the things that you were interested in doing and I'm pretty sure if I remember rightly that you put games as pretty low and there were other things you liked to do first. Is that right*  
 Erica: 'yes' (nods head)  
 Amanda: *right. So they are not a priority for you, you do play them but because they are not a priority you may not play them very often?*  
 Erica: (no response, looks at Information Technology Manager)  
 Head of technology: *what I'm thinking is that we haven't got to that yet because we are working on environmental control*  
 Erica: 'yes' (raises eyebrows)  
 Head of technology: *and you will get to games it's just that you want to get your environmental control stuff working first*  
 Erica: 'yes' (smiles and nods head)  
 Amanda: *okay. Erica are you happy that that is a good explanation*  
 Erica: 'yes' (nods head)

Family and sibling support is described

Amanda: *So is that where you learnt about Skype, at home? Is that where you learnt about Skype at home, yes or no* (choice of hands)  
 Simon: 'yes' (looks at left hand)

*1<sup>st</sup> interview*

Amanda: *and was it your dad that helped you set up Facebook*  
 Peter: *no*  
 Amanda: *was it somebody at school who helped you set up Facebook*  
 Peter: *no*  
 Amanda: *was it another member of your family who helped you*  
 Peter: *yeah*  
 Amanda: *was it your sister*  
 Peter: *yeah*  
 Amanda: *so your sister came up with the idea of using Facebook*  
 Peter: *yeah*  
 Amanda: *and is your sister older than you*  
 Peter: *yeah*

Amanda: *did you just teach yourself how to use the internet and Facebook or has anyone ever helped you to do it*  
 Keith: *"my sister"*  
 Amanda: *right she was the one who told, was she the one who told you about Facebook in the first place. Was that how you learnt about Facebook?*  
 Keith: *yeah*

Amanda: *yeah, your sister. So is your sister older than you or younger than you?*

Keith: *“younger”*

Amanda: *who helped you to um set up was it at school, was it at home, college who helped you to*

Ken: *home*

Amanda: *at home and who helped you at home*

Ken: *my sister*

Ben describes using computer games

Ben: *“I used to share with my brother”*

Friends are also mentioned

Amanda: *so who helped you, did you teach yourself or did somebody help you to start using ‘cos your parents don’t use it so what happened*

Sean: *“best mate”*

Amanda: *okay was that your best mate at school or at college, sorry did you say yes, was it your best mate at school*

Sean: *yeah*

Peter revealed in his second interview other sources of human support are NHS staff

Email question: *Where do you and your family get technical support and help from?*

Peter: *“(names his local NHS support department)”*

Will’s mum showed how VOCA manufacturers are also important sources of human support

Will’s Mum: *we’ve emailed (the VOCA manufacturer), we don’t know if iPad is compatible with his (VOCA name), so that’s the next thing that he wants*

#### 4.5.2. Collaboration

Collaborating was a major element of describing support in terms of accessing, producing and sharing online content. Challenges regarding literacy and other individual skills meant for some participants it was not possible to use the internet and social media independently.

Amanda: *when you go in your room you can go on Facebook by yourself*

Mary: *‘no’ (shaking head)*

Amanda: *no so mum’s always with you when you go on Facebook is she*

Mary: *yeah*

Amanda: *and is that, do you like having your mum with you when you’re looking at Facebook*

Mary: *yeah*

Amanda: *yeah so that is something you kind of do together*  
 Mary: *yeah*  
 Amanda: *do you ever do Facebook when you are on your own*  
 Mary: 'no' (shaking head)  
 Amanda: *no, will you use MSN on your own*  
 Mary: 'yes' (nods head)  
 Amanda: *yeah*  
 Mary: *easy*  
 Amanda: *easy*  
 Mary: *than Facebook*  
 Amanda: *oh is Facebook a little bit hard*  
 Mary: *yeah*  
 Amanda: *oh okay can you just tell me what is hard about it 'cos that's interesting. What do you find difficult with Facebook*  
 Mary: (unintelligible, starts typing on VOCA)  
 Amanda: *did you say to read*  
 Mary: 'yes' (nods head)  
 Amanda: *ah so to read the things that people have written*  
 Mary: 'yes' (nods head)  
 Amanda: *okay, so with MSN you can do that on your own*  
 Mary: *yeah*  
 Amanda: *and you find you can read*  
 Mary: *yeah*  
 Amanda: *the comments 'cos they're small*  
 Mary: *easy*  
 Amanda: *they're easy to read but sometimes on Facebook it's more complicated the writing*  
 Mary: 'yes' (nods head)  
 Amanda: *and then it is difficult*  
 Mary: 'yes' (nods head)

Amanda: *you said you used Facebook at home*  
 Olivia: *yeah* (coughs)  
 Amanda: *you okay?*  
 Olivia: *yeah*  
 Amanda: *so can you tell me about how you do that*  
 Olivia: "my carer"  
 Amanda: *so you do it with your ca....oops* (realising Olivia is still composing her message)  
 Olivia: "writes what I want to say"  
 Amanda: *your carer writes what you want to say. Oh that's interesting*

SLT: *So does (name of personal assistant) help you use Facebook*  
 Carol: 'yes' (nods head)  
 Amanda: *and when you are at home, your mum?*  
 Carol: 'yes' (nods head)

Faith: "when I at home I use the computer with help from my mum"  
 (pause) "I use the computer at home to go on Facebook"

Amanda: *okay*  
Faith: *"I like looking at photos with my mum"*  
Amanda: *do you put things on to your communication aid, do you tell your mum things that you want to put on Facebook*  
Faith: (makes unrecorded non-verbal response)  
Amanda: *yeah* (interpreting response) *and then will your mum put it on for you*  
Faith: *"laptop"*  
Amanda: *okay so your mum uses a laptop*

Faith and her personal assistant later offer an explanation about why she needs support

Faith: *"confused"*  
Amanda: *oh confused. What sometimes when you are looking at Facebook you feel a bit confused*  
Personal Assistant: *there's loads of things on there*  
Amanda: *ah is that why cos there's loads of things to look at. Is that why 'cos there is so much on there sometimes*  
Faith: (makes an unrecorded non-verbal response)  
Amanda: *yeah* (interpreting response)

#### 4.5.3. Challenges regarding support

It was revealed during Will's interview how difficult it might be for staff to gauge and measure the level of support required. Will has left college but has returned for the interview. He is an experienced and competent user but within his interview the following issue regarding his knowledge of his equipment emerged

2<sup>nd</sup> SLT: *So you use it* (referring to his VOCA) *connected to a computer to use Skype but have you never used that* (pointing to his VOCA) *just to Skype*  
Will: 'no' (shakes head)  
2<sup>ND</sup> SLT: *No, okay*  
(Will looks at the principal Speech and Language therapist)  
SLT: *What did you know you could Skype with someone*  
Will: 'no' (shakes head)  
SLT: (addressing second Speech and Language therapist) *No, didn't know that*  
2<sup>nd</sup> SLT: (addressing Will) *Sorry*

Another issue is the inability of educational settings to provide the same level of support after transition

Amanda: *technical support is through the college at the moment but when Xavier leaves where would technical support come from?* (addressing specialist teaching assistant - STA) *do you know?*



(STA): *no, we tend to keep learning support links so we will help where we can but any kind of major thing I'm not sure how that would, generally falls to parents I think*

Xavier: *"that difficult"*

Amanda: *So is there anyone in your circle of friends or family who are good with technical issues*

Xavier: *"mum"*

A potentially difficult issue that emerged was the technical knowledge of support staff. As collaboration is often required, the ability of staff to use digital technology and online social media themselves will impact on participant use of online social media.

SLT: *I can tell you who doesn't help you use Facebook*

Carol: (smiles)

SLT: *Who here doesn't help you*

Carol: *S* (makaton sign)

SLT: *'S'?* (says female name)

Carol: 'yes' (nods head)

SLT: *Does she not like computers?*

Carol: 'yes' (nods head)

SLT: *And I know someone else who doesn't, (another female name). (female name) is the senior in the bungalow*

Amanda: *Oh okay*

SLT: *(female name) hates computers so Carol is not only teaching her signing but also about VOCAs and computers. So (first female name) and (second female name) do not like computers.*

Fiona's interview was one of the most difficult in terms of communication breakdowns. There were four of us present, Fiona, myself, the speech and language therapist and Fiona's personal assistant. If Fiona wanted to use Facebook she had to work collaboratively with someone. She had a collaboration issue which was preventing her using Facebook and she was keen to try to explain this within the interview. She used non-verbal communication and the available phrases on her VOCA strategically and eventually managed to indicate she would like her personal assistant to explain in more detail. The following excerpt is very long but it was deemed important to be able to show how difficult it was for Fiona to communicate this and how important it was for her to have succeeded.

Amanda: *so do you use Facebook here*

Fiona: (sighing sound)

Amanda: *yes?*

Fiona: *"message"*

Amanda: *Does Fiona go home?* (addressing SLT)  
 SLT: 'yes' (nods head)  
 Amanda: *do you use Facebook at home*  
 Fiona: 'no' (raises eyebrows without smiling)  
 Amanda: *no*  
 Fiona: *"functions, vocabulary"*  
 Amanda: *do you think she is trying to get a message ready?* (addressing SLT)  
 Fiona: *"what am I doing today, tonight, what am I doing tomorrow, where we going, who is working today, tonight, what, who, what, who, what, message, what"*  
 SLT: *Any ideas (PA's name)*  
 PA: *Nope*  
 Fiona: *"message"*  
 SLT: *we're a bit stuck Fiona, is this anything to do with Facebook*  
 Fiona: 'yes' (raises eyebrows and body and smiles)  
 SLT: *yes, is it to do with you using Facebook*  
 Fiona: (makes long sighing noise)  
 SLT: *is it to do with what you are using it for?*  
 Fiona: *"what"*  
 SLT: *is it to do with who you talk to on Facebook*  
 Fiona: 'yes' (raises eyebrows and body and smiles)  
 SLT: *Right*  
 Fiona: *"what"*  
 SLT: *do you mean what kind of help*  
 Fiona: *"message, what"*  
 SLT: *Amanda said do people help you to use Facebook*  
 Amanda: *Ah so maybe what kind of help, do you use Facebook with your PA?*  
 Fiona: 'no' (raises eyebrows without smiling)  
 SLT: *Can (PA's name) explain Fiona?*  
 Fiona: *"message"* (raises eyebrows and smiles)  
 SLT: *yes (interpreting Fiona's non-verbal expression)*  
 PA: *It's kind of tricky with Facebook at the moment isn't it Fiona, cos Fiona has got a Facebook account but her old key worker who set it up for her we don't have the password for the account name*  
 Amanda: *Ah*  
 PA: *So I don't know whether she's trying to, are you trying to say something to do with that?*  
 Fiona: 'yes' (vocal noise and raises eyebrows and smiles)  
 PA: *so at the moment we're not really, we're not using it because we can't get onto it, but if we do when we find out what the stuff is then yeah I would, we would help you Fiona on there, which ever PA's working with you at the time*  
 Amanda: *And are you going to be able to get the information?*  
 PA: *Hopefully, um I'm also going to ask around for it 'cos I'm hoping that she can remember*  
 Amanda: *Right and could you set up a new Facebook page?*  
 PA: *Could do but we'd have to find out what her old one is set up under 'cos you need an email address don't you? So it might mean setting up a whole new email*

Fiona attempts to illustrate how important getting the problem resolved is for her

Fiona: *“quick chat, quick chat, hello, goodbye, I’ve got a problem, how are you, thank you, sorry, thank you, sorry, thank you”*

SLT: *That’s alright Fiona. Would you like to finish Fiona is that what you’re saying*

Fiona: *“message” ‘no’ (raises eyebrows without smiling)*

SLT: *I can’t, do you want to finish the session Fiona? Yes or no?*

Fiona: *‘no’ (raises eyebrows without smiling)*

PA: *are you saying thank you for trying to fix the problem with Facebook?*

Fiona: *‘yes’ (smiles very broadly and raises eyebrows)*

Across the settings there were different levels of practice regarding the collaboration of staff to use of the internet and online social media and it was clear this is a difficult area to navigate. Extracts from the policy documentation of an educational setting show the typical guidelines that staff are expected to work within.

*8.1. Staff and students can use the computer systems and the Internet for educational and business purposes without unreasonable restrictions.*

*8.2 Staff and students can use the computer systems whilst minimising risk by observing the principles of e-safety.*

*All staff who support students to access IT or the internet have a responsibility to ensure that students use the IT responsibly, appropriately to the session or personal development goals and above all safely.*

#### ***Electronic communications***

*This includes e-mail, chat rooms, social networking sites, instant messaging, forums and the like. Apart from email all of these are barred to staff. Certain students will be allowed to use these services on an individually risk assessed basis.*

The head of technology explained how the risk assessment for the use of the internet and online social media services is organised within the college

*“the e-safety challenge is something that faces all educational establishments I think and we’ve got an additional duty of care cos of the vulnerable nature of some of our students. I feel there are huge opportunities to be had from having access to social media and the internet generally and unfortunately there are a number of schools and colleges that basically just say no you’re not doing it and block it or attempt to anyway. We take a slightly different view and we use a highly person centred approach*

[not consecutive]

*So the risk assessment uses the exact same format as any other risk assessment in the college, we haven’t created another system*

[not consecutive]  
*the risk assessment process allows us to be highly granular about students having access to one thing and not another. And the other thing we do at the risk assessment process is have a look at the student's profile and just talk through with them the security options*

[not consecutive]  
*and students have been involved in creating a code of conduct''*

As can be seen from the data, within some settings, requests to use social media from students has led to personal staff helping students to use online social media sites such as Facebook. Despite careful policy development, no amount of planning can foresee every eventuality. Interviewing the quality assurance manager within an educational setting helped to explain this issue in more detail.

*Quality assurance manager: our young people and their inability to quickly express what they need and how they feel, um there has been a lot of work done both with the local safeguarding board and a lot of work done with Roger Morgan who is the director of children's rights, around the rights of young people to access social media balanced with the reasonable safeguarding requirements that such or any young person needs. So we've had to take it from a quite formal point of view where we have to have quite a formalised system of consent from parents where parental consent is required and balancing that then with the requests of the young people to access social media against sometimes parent's natural emotions around safeguarding their child as to whether they should go onto Facebook, they should Twitter or whatever, so some of the major stumbling blocks that we have had have not been with the young people they've actually been with the parents allowing young people to access social media in that way.*

[not consecutive]  
*Quality assurance manager: I think it probably needs another set [speaking about limitations of existing policies] it is far more about how we as (an educational setting) engage with other bodies, how staff use Facebook and Twitter, I think and stuff like that. I think very much we need to do more in terms of working with groups of young people to shape protocols far more around what they want and how they want to access it, and what part it plays in their everyday life rather than in the life of the (educational setting)*

[not consecutive]  
*Amanda: do you feel that there is a strong desire from the young people within the*  
*Quality assurance manager: yeah, there's quite often, it comes up the most every time they come back from holidays*  
*Amanda: right*

Quality assurance manager: *because obviously they've been with families, they've been with um siblings who are texting, using Facebook, using any form of social media*

[not consecutive]

Amanda: *what happens in the relationship and where you maybe train, or counsel or talk to personal assistants about how they deal with things*

Quality assurance manager: *it's one of the things we've struggled with our Ofsted inspectors and local authorities, it's very much about that personal assistant or carer knowing their young person really well and having good links with the family. Also its quite a complex role really cos they have to have a safeguarding hat on as well*

Amanda: *yep*

Quality assurance manager: *but our young people can't be given traditionally the privacy that you or I would have to close the door on a telephone booth or close our bedroom door and be on our own*

Amanda: *yep*

Quality assurance manager: *so for them it's very much the boundaries around um how they manage the situation whilst having as much privacy as possible because they become privy to some very personal bits and pieces that they may well otherwise not be privy to during the day and we had one incident last year where a carer did come to see me because she was concerned about not the Facebook relationship that this young person was having with a member of the family but concerned for that member of the family*

Amanda: *right*

Quality assurance manager: *and that was one we had never had to face before um because the impact of the worry on the person she was caring for was impacting their day to day life*

Amanda: *right*

Quality assurance manager: *so we had to pick our way very carefully through a minefield cos the young person was under the age of consent as full parental responsibility was in place*

Amanda: *right*

Quality assurance manager: *and the member of the family was an adult who obviously had profound problems which they were sharing on Facebook and was impacting on the young person. So we had to look very carefully there at the boundaries around confidentiality. And we decided that we would treat something like that in the same way as we would treat a disclosure so that it was I need to take this to my designated person to help support you to support that member of your family. So we treated it that way, we kept it low key but made sure that the young person then got support in order to deal with the family member*

Amanda: *right*

Quality assurance manager: *so that brought something up that we had never had to deal with before*

Amanda: *gosh that's very interesting*

Quality assurance manager: *mm and it was quite upsetting for the carer*

Amanda: *yep*

Another area where challenges for support were seen is around parents' lack of technical knowledge which limits how far they may be able or willing to get involved with the use of technology and/or online social media as illustrated by Will

Amanda: *do your parents use computers*

Will: *(shakes head – no)*

Amanda: *No, so maybe that's so maybe it's cos your parents aren't very technical?*

Will: *(raises brows – yes)*

Amanda: *Ah yes so it's not because you don't want them on Facebook with you it's because they're not interested in using Facebook,*

Will: *(raises brows – yes)*

#### 4.5.4. Summary

A small amount of evidence exists for self-requesting to use the internet and online social media but predominantly participants described being either introduced through their educational setting and receiving training or being shown by family (particularly siblings). The evidence of collaboration was an unexpected outcome of the research project. The initial proposal had envisaged that only independent online users would respond to the research invitation but interest from educational staff within educational settings led to the inclusion of participants who were working collaboratively with personal staff or family members to produce and share content on the internet and online social media sites. The reason for this was either due to individual skill challenges or lack of relevant equipment to work independently. This in turn brought up that staff within educational and residential settings and/or parents may lack the necessary knowledge (especially about assistive equipment) and/or not like using computers themselves and therefore may not be able and/or willing to work collaboratively. Staff turnover can also create problems for collaborative working as new staff may inherit problems that they are unable to solve due to lack of handover information about social media accounts.

It is clear that collaboration to use online social media adds a significantly new dimension to the job role of personal care staff within settings. There are not only issues of technical skills and motivation to use computers, there are potentially huge ramifications in terms of appropriate use policy guidelines and professional boundaries. The interview data from the policy documentation and the quality

assurance manager revealed that balancing the rights of young people to use social media, the wishes of parents, the legal obligations to protect young people and the need for policy development is problematic. Working as an advocate to facilitate the use of a personal social media account has ramifications for the traditional employment role of personal staff. As literacy skills are a major challenge for young people who use AAC and they have a clear desire to engage within online environments which are predominantly text-based, the role of support and collaboration for online social media is likely to continue to be a key factor within personal care relationships. There are also implications for educational settings to prioritise the development of literacy skills and the fact that online social media could be a motivational support for young people who use AAC to engage with literacy teaching.

The other area illuminated is how to assess the knowledge of young people who use AAC in regard to internet and online social media to establish if there might be gaps in their knowledge, especially if they appear to be competent users. Another difficult issue is how the use of the internet and online social media will be supported post transition in adult services.

## ***4.6. Online challenges***

### *4.6.1. Online safety awareness*

Online safety awareness training was reported to have been received from various areas: families (especially siblings), educational settings and from a national e-Safety training day run by Communication Matters (<http://www.communicationmatters.org.uk/>), the UK chapter of the International Society for Augmentative and Alternative Communication (ISAAC), (<https://www.isaac-online.org/english/home/>) which works to improve the lives of people with complex communication needs.

*2<sup>nd</sup> interview*

Email question: *How did you learn about keeping safe online?*

Peter: *“Home and school”*

Caroline's blog

*My parents help me stay safe on-line. Now I can do more things independently I have to think about safety. I went to a communication matters day about that*

Teaching Assistant: *what did you learn in IT in year 7*

Ben: (starts to construct something on talker and then turns to look at TA)

Teaching Assistant: *you know when we did about internet safety*

Ben: 'yes' (nods head)

Teaching Assistant: *and you had to do a booklet and posters about how to stay safe online, yeah*

Ben: 'yes' (nods head)

Teaching Assistant: *yeah, so you did get taught it in school*

Amanda: *your sister uses Facebook, and um so how did you learn about the privacy settings and safety and things like that. Did your sister teach you how to set up your Facebook account*

Keith: *yeah*

Amanda: *Do you use Twitter?*

Mary: *No, I don't want to.*

Amanda: *No, why?*

Mary: *'cos... rude people*

Amanda: *Rude people, ah okay. Yup, right, so do you find rude people on Facebook?*

Mary: 'no' (shaking head)

Amanda: *No, but Twitter yeah. So you don't like Twitter because of rude people*

Mary: *yeah*

Amanda: *was somebody rude to you on*

Mary: *no*

Amanda: *no but you heard, did somebody tell you that there were rude people on Twitter?*

Mary: *yeah*

Amanda: *ah who told you that? Your, was it your mum?*

Mary: *Lucy*

Amanda: *ah Lucy, ah I see so your sister said it's not very nice. Does your sister use Twitter*

Mary: *no*

Amanda: *No, so she doesn't like it either?*

Mary: *no*

Amanda: *did she try it?*

Mary: *no*

Amanda: *no, but she said there's rude people on it. Ah, that's sensible, you don't want to be in contact with rude people do you?*

Mary: *no*

Amanda: *Oh, what about online safety and things like that, did you have to learn about that from somebody else or did you teach yourself or is it not*



*something you really worry about. Whatever you feel like talking about in terms of online safety*

Will: *"when here"* (referring to special college setting)

Amanda: *Whatever you feel like talking about in terms of online safety*

Harriet: I d-i-d a B-T-E-C i-n IT (Information Technology)

Amanda: *So there you learnt all about issues*

Harriet: 'yes' (nods head)

Amanda: *did you receive some training from college as part of being set up about being safe online*

Erica: 'no' (shakes head)

Amanda: *no!*

Erica: (gestures head towards the Head of Technology)

Head of technology: (nods yes and laughs) *I was just about to say!*

Amanda: (looks round at Head of technology and then turns back to Erica)

Erica: (nods head yes vigorously and then starts laughing lots)

Amanda: (laughing) *so not only did you get technical support to be online (both Erica and Amanda really laughing now) you also got um you know were warned about things to put on and how to keep safe*

Erica: (head down giggling)

Amanda: *okay moving swiftly on*

Head of technology: *Erica are you laughing 'cos it was me that did that*

Erica: (nods head yes and really laughs)

Amanda: *that was a good joke. I'd love to have seen his face it was a shame I was looking at you*

The participants showed a good level of understanding about online safety and used strategies to protect themselves

Amanda: *So, if this is too personal then I wouldn't expect you to answer it but what would your reason be for not wanting to have a picture of yourself and preferring to have jokey keep calm picture*

Moira: *"because the strange people keep to add me"*

Amanda: *Oh er have you had a picture of yourself in the past*

Moira: 'yes' (nods head)

Amanda: *and then you've had requests from people who you don't know saying that they would like to add you as a friend*

Moira: 'yes' (nods head)

Ken and Jack were both aware of protecting their passwords when demonstrating how social media worked on their devices and checked I was not watching them enter their passwords

(Jack turned to look at me, aware of password privacy, to check I am not looking)

Amanda: *Oh, look I'm hiding not going to watch you put your password in.*

Amanda: *Is there anything you would like to show me about how you use it*

Ken: *yeah*

(Ken starts to swipe touch screen and then shields password from me. I look away to reassure him of his privacy)

#### 4.6.2. Resilience

Some unpleasant incidents associated with online social media were reported, however, these were met with resilience. The participants appeared to have effective emotional coping skills to deal with them

Amanda: *Has anything sort of embarrassing or frightening or horrible ever happened to you from using Facebook or*

Keith: *“younger” ah (clears display) “one of the people wasn’t very nice to me”*

Amanda: *oh no, what did you do?*

Keith: *“I told them off”*

Harriet: Y-o-u k-n-o-w m-y b-r-o-t-h-e-r d-i-d t-h-a-t f-i-l-m

SLT: *Yeah*

Harriet: a-n-d p-u-t i-t o-n Y-o-u-T-u-b-e. P-e-o-p-l-e k-e-p-t f-i-n-d-i-n-g m-e o-n F-a-c-e-b-o-o-k a-n-d m-e-s-s-a-g-i-n-g m-e

SLT: *Do they*

Harriet: *Yea*

Speech and Language therapist: *Is this good or bad*

Harriet: (Vocalises and shakes head)

SLT: *Bad (interpreting vocalisation) okay*

Amanda: *Is this people you know*

Harriet: ‘no’ (shakes head)

Amanda: *people you don’t know. Right, okay so*

SLT: *Shall I explain for a bit now*

Harriet: ‘yes’ (nods head)

SLT: *Did your brother do it for television?*

Harriet: U-n-i-v-e-r-s-i-t-y

SLT: *Cos your brother was doing a film course wasn’t he*

Harriet: *Yea*

SLT: *so for his final sort of film made it about you*

Harriet: *Yea*

SLT: *and about his relationship with you and the way he talked to you and what you thought about everything to do with you wasn’t it*

Harriet: *Yea*

Amanda: *Right, did he ask your permission before he put it on YouTube?*

Harriet: ‘yes’ (nods head)

SLT: *Yeah, but I don’t think you expected that part of it*

Harriet: ‘no’ (shakes head)

Amanda: *No, so neither of you expected the response that you’ve had*

Harriet: ‘yes’ (nods head)

Amanda: *So have you had some negative and positive posts and messages or is it the fact that you don't like getting all these messages all the time 'cos it's just annoying?*

Harriet: 'yes' (nods head)

SLT: *Yeah it's just the fact that you don't know them*

Harriet: 'yes' (nods head)

Amanda: *So would that make you, would you put anything on YouTube again*

Harriet: 'yes' (nods head)

Amanda: *You would, so it hasn't frightened you from using YouTube maybe you'd not put such personal stuff on*

Harriet: *Yeah*

Ben said nothing negative had happened to him but his teaching assistant disagreed with him and reported an incident where someone had criticised his online gaming skills which she claimed had upset him. However, Ben did not perceive this in the same way and clarified the situation after she had reported the incident.

Teaching Assistant: *it's just showing that bad things can happen on something that is supposed to be quite good*

Amanda: *yeah*

Ben: *"I blocked him"*

Amanda: *have you ever had anything kind of upsetting happen from using social media, email that sort of thing*

Sean: *"my ex friend hacked in"*

Amanda: *oh your ex-friend hacked into your Facebook account*

Sean: *yeah*

Amanda: *and did they put some stuff up that you did want up there*

Sean: *yeah*

Amanda: *wow, so how did you deal with that, you just stopped being friends*

Sean: *yeah*

Amanda: *yeah right and did anything else happen*

Sean: 'no' (shakes head)

Amanda: *so that was the only thing that happened and how did that make you feel. Were you cross*

Sean: *yeah "now we don't see"*

Erica reported an incident which she was still upset about and it was fortuitous that the college Head of technology was present in the interview as he was able to check whether or not it was a potential safeguarding issue.

Erica: *"(female name) say to (male name) with me"*

Amanda: *er.. so (female name) said that you and (male name) were going out together*

Erica: 'no' (shakes head)

Amanda: *(female name) said to (male name) with me...mmm sorry maybe you hadn't finished I might have jumped in too quickly*

Erica: *“me on Facetime”*

Amanda: *(female name) say to (male name) with me on Facetime*

Erica: ‘yes’ (raises eyebrows)

Amanda: *So was it something not very nice that (female name) said to (male name) and you saw it when you were on Facetime*

Erica: ‘yes’ (raises eyebrows)

Amanda: *okay so and it was something that upset you and um and you haven’t managed to sort it out, okay*

Head of technology: *when did this happen Erica*

Erica: *(gestures)*

Head of technology: *recently*

Erica: ‘yes’ (raises eyebrows) *“time upstairs”*

Head of technology: *are we confusing the previous question with what you are answering now? Are you saying that (female name) has got Facetime on her iPad upstairs*

Erica: ‘no’ (shakes head)

Head of technology: *no*

Erica: ‘no’ (shakes head)

Amanda: *no I think the problem happened upstairs*

Erica: ‘yes’ (raises eyebrows vigorously)

Amanda: *cos the time bit is the end of the Facetime okay. So that’s where, where did it happen – upstairs, I think (Head of technology name) said when*

Erica: *“in my room”*

Amanda: *okay in your room*

Head of technology: *when did this happen*

Amanda: *do you think it was last week*

Erica: ‘yes’ (nods head)

Head of technology: *have you told any staff members Erica*

Erica: ‘yes’ (nods head)

Head of technology: *yes who did you tell*

Erica: *“(name) and (name)”*

Amanda: *so are they helping you to sort it out*

Erica: ‘yes’ (nods head)

Head of technology: *they are area staff*

Amanda: *yes, okay are they helping you to sort it out do you think*

Erica: (shakes head but inclines to one side)

Amanda: *not yet? Okay*

Head of technology: *okay do you want me to help with this*

Erica: ‘no’ (shuts eyes and shakes head)

Amanda: *so is it something you feel can be sorted out*

Erica: (no facial response)

Amanda: *just wondering is it something that you would like to share with me because you want me to know that some things can happen which aren’t very nice*

Erica: ‘yes’ (raises eyebrows and nods)

Amanda: *and that maybe you would need to sort it out and things like that but*

Erica: ‘yes’ (raises eyebrows)

Amanda: *er and er you don’t necessarily want (Head of technology’s name) help now to sort it out now*

Erica: 'no' (shakes head)

Amanda: *no but you're it's almost like you're trying to tell me to give me an example of things that can happen. People can say things that are a bit mean and then maybe you need to sort it out or you need to get help to sort it out but it could be a bit upsetting and that's one of the things that can happen*

Head of technology: *is it worth saying that these are all students at college that we are talking about here*

Erica: 'yes' (raises eyebrows)

Amanda: *yea*

Head of technology: *apart from (male name) who left last year*

Amanda: *yea er can I just check cos I have heard that this can happen I mean things happen with my friends online and stuff. Would you say is this something that has greatly upset you or do you think that this is something that can happen with your friends when you're online? Ooo sorry I've done an 'either' 'or' there! Is this something that you're really upset about*

Erica: 'yes' (raises eyebrows)

Amanda: *okay yes. Is this something that you think can be a problem online*

Erica: 'yes' (nods head)

Amanda: *yes. Do you need from having shared this now help with taking this further now*

Erica: 'no' (shuts eyes and shakes head)

Amanda: *no okay. So I understand where you're coming from it's not necessarily something that can be solved but it is a potentially upsetting thing that can happen on the internet which you wanted to let me know about*

Erica: 'yes' (nods head)

Amanda: *is that a good explanation*

Erica: 'yes' (raises eyebrows)

Amanda: *okay thank you*

The Head of technology had to make absolutely sure this was not a safeguarding issue so he continued the conversation

Head of technology: *okay are you very upset by what happened*

Erica: 'yes' (nods head)

Head of technology: *do you want me to help you*

Erica: 'no' (shakes head)

Head of technology: *no. Do you think your area staff will sort this out*

Erica: 'no' (shakes head)

Head of technology: *no. So you just want to let it go*

Erica: 'yes' (nods head)

Head of technology: *yes. okay. Can I just ask Erica do you think this is like something like you've just fallen out with one of your friends and it'll be alright in the long run*

Erica: 'yes' (nods head)

Head of technology: *is that what we're saying*

Erica: 'yes' (nods head)

Head of technology: *it's not about anyone from outside college*

Erica: 'yes' (nods head)

Head of technology: *(male name)*  
 Erica: 'yes' (nods head)  
 Head of technology: *okay. Right so I have to ask is anyone at risk at the moment. Is anyone else upset*  
 Erica: 'no' (shakes head)  
 Head of technology: *just you*  
 Erica: 'yes' (raises eyebrows and nods head)  
 Head of technology: *right. So you don't want any help with this. Do you think it's worth you talking to (name) again?*  
 Erica: 'yes' (nods head)  
 Head of technology: *are you going to do that*  
 Erica: 'yes' (nods head)  
 Head of technology: *okay. I won't ask you about it again then. You're going to deal with it yourself. Okay*

#### 4.6.3. Restrictions to use

Another online challenge is connected to restrictions of use either within college settings or due to parental concern.

SLT: *I mean there was, Xavier and Moira could probably tell you I think that Facebook was or it used to be restricted didn't it to outside of classroom hours*

Specialist Teaching Assistant: *it's not anymore*

SLT: *I don't think so*

Specialist Teaching Assistant: *Mr X manages it in my session regularly*

SLT: *yeah there's space for mischief with that*

Amanda: *and people have said how they would feel if they lost access for some reason which would be unlikely but if something happened*

Erica: *"in my home"*

Amanda: *in your home you don't have access to the internet?*

Erica: 'yes' (raises eyebrows)

Amanda: *oh okay, that's interesting would you be able to explain why*

Erica: *"mum say not Facebook and YouTube"*

Amanda: *so mum says not Facebook or YouTube, okay and do you use them at college?*

Erica: *"YouTube I went to my room"*

Amanda: *you went to your room*

Erica: 'yes' (raises eyebrows)

Amanda: *at home*

Erica: 'yes' (raises eyebrows and nods)

Amanda: *so mum didn't know that you went on YouTube so you did it in secret*

Erica: 'yes' (makes huge smile and nods, then laughs)

#### 4.6.4. *Reduced privacy*

Finally, another online challenge relates to the fact that when participants have to collaborate this reduces their privacy.

*Amanda: As much as you love your dad and you don't mind him seeing everything on your Facebook do you ever hope that you could do something on your own so that it could be a bit private?*

*Peter: 'yes' (nods head twice)*

#### Caroline's blog

*The problem is that#s [sic] not private, my mum sees everything.*

*Amanda: right mobile phone, so you don't text from your talker, sorry I should say, do you text using your talker*

*Olivia: "not"*

*Amanda: does somebody help you to text from your mobile phone*

*Olivia: yeah*

*Amanda: okay, can you text from your mobile phone on your own*

*Olivia: 'no' (shakes head)*

#### 4.6.5. *Summary*

E-Safety training has been given in school and college settings and there is support from within families, again especially siblings, and the Communication Matters training day. The participants within this study all showed a level of resilience through the strategies they used to protect themselves and the reactions they had to negative incidents. The incident with Erica showed although there was on-going distress for her she knew how and where to access support and was clear she did not need further support in dealing with the issue. Restrictions on use were as expected within educational settings and the use of mobile technology within educational settings is an evolving issue across education which will be explored further in the next chapter. The reduced privacy from collaboration must be balanced against the benefit of being online and it was evident from the desire to be online category (section 4.3.1.) having to compromise in terms of privacy is accepted by participants. However, the desire to extend use category (section 4.3.2.) showed if it was possible to use the internet and online social media independently due to equipment provision or symbolised vocabulary (section 4.4.4.) this was the preferred method.

## **4.7. Access technology**

This is a huge area and it is beyond the scope of this research project to explore in detail but the participants and their communication partners discussed some of the aspects relating to access technology in terms of support and challenges. Participants' descriptions of how they accessed technology revealed the impact it had on choice of equipment and activities.

### *4.7.1. Computer access without additional equipment*

Direct access means people can control equipment without an additional switch/scanning device and this means they often reported using computers and VOCAs independently of each other as explained by Keith, Mary and Ben,

Keith: *"I don't need that one"*

Specialist Teacher Assistant (STA): *no, you don't need it. That might be quite important actually that um with this one (pointing to an integrated VOCA) we could have got him using social networks and things but there was no need because he can use a stand alone*

Keith: *"this typewriter"* (his term for his VOCA)

STA: *typewriter*

Keith: *"I can use this typewriter"*

STA: *Yeah and you can access a computer can't you*

Keith: *yeah*

Amanda: *you don't use the internet on here (pointing to integrated VOCA) even though you can use the internet on here*

Mary: *yup* [cross talk]

Amanda: [cross talk] *you don't use it on here. Why is that?*

Mary: *"because think is my talker"*

Amanda: *Oh, because you think it is your talker*

Mary: 'yes' (nods head)

Amanda: *Right and so you wouldn't want to mix using it for the internet*

Mary: *yeah* [cross talk]

Amanda: *so* [cross talk] *this is your talker and this is the internet (gesturing two separate things)*

Mary: *yeah*

Amanda: *would you like to tell me about how you use technology in your life?*

Ben: *"I have my computer which I use it for work and Facebook"*

Amanda: *Okay and is your computer at home?*

Ben: *"Yes"*

Amanda: *And do you have access to the internet on your communication aid?*

Ben: *"No"*



#### 4.7.2. Computer access with additional equipment

There are numerous technological options and combinations for people who use AAC to access computer equipment. The participants described some of the ways they achieved access to mainstream computer technology. Nicholas uses a series of switches to control a computer.

Amanda: *and how do you use Facebook, do you use it on your talker?*  
Nicholas: *No*  
Amanda: *No*  
[not consecutive]  
Nicholas: *No, "eight of special switches eight of"*  
Amanda: *Oo, could you play that again*  
Nicholas: *Yeah "special switches eight of (unintelligible)"*  
Amanda: *special switches aid the ho, what did?*  
SLT: *eight, Nicholas can I just have a quick peek at that last word (SLT looks at VOCA screen)*  
Amanda: *That last word was a bit difficult to understand*  
SLT: *Special switches eight at home (reading from screen)*  
Amanda: *Ah right okay*  
SLT: *Does that mean they are at home Nicholas*  
Nicholas: *Yeah*  
SLT: *Ah, you've left your switches at home*  
Nicholas: *yeah*  
Amanda: *Ah but you would have special switches to use a computer*  
Nicholas: *Yeah*

Another option is to use a VOCA to remotely control a computer as demonstrated by Will via a Bluetooth connection,

Amanda: *So in fact, you're not restricted to just your home computer because for instance coming here you can go on any computer 'cos your communication aid is like a controller and then the Bluetooth allows you to go onto any computer*  
Will: 'yes' (raises brows)

#### Fieldnotes

*Will has full control of the mouse and can type in anything he wants using the keyboard on his VOCA*

Nancy and Sean use a similar system except they control a remote computer via a USB cable connected to their VOCAs

Amanda: *would you mind just showing me how you do it would that, is that something you wouldn't mind*  
Nancy: *"need my cable to computer"*

Amanda: *Right I've got you so um your you would use this (pointing to VOCA) as a mouse control*

Nancy: 'yes' (smiles and nods)

Amanda: *do you use this (pointing to VOCA) as a mouse and then you connect onto a computer with a USB cable is that right?*

Sean: *yeah*

As mentioned previously, Xavier uses his integrated VOCA to access all his computer needs in college, however he also described a method he uses at home which uses switches and a programme called EZ keys (a type of software programme which superimposes a switch enabled keyboard over the top of a mainstream computer screen)

Xavier: *"EZ keys at home"*

SLT: *that was Xavier, EZ keys at home*

Xavier *"EZ at home"*

Amanda: *EZ keys at home. Right on the computer*

Specialist Teaching Assistant: *what's EZ keys Xavier. I've not come across that one*

Xavier *"a programme"*

SLT: *EZ Keys is a programme*

Amanda: *Right so it's a programme*

SLT: *so you can access your computer but I'm not ever so up on it in all honesty*

Specialist Teaching Assistant: *is it like an on screen keyboard, you do it from your aid*

Xavier: 'no' (shakes head)

Specialist Teaching Assistant: *no not from your aid, is it with switches*

Xavier: 'yes' (nods head)

Harriet describes a similar access method to a mainstream computer but instead of the switches used by Xavier she uses a joystick to control the onscreen keyboard.

Amanda: *I'm a bit confused about the joystick conversation we had earlier, (reporting joystick was broken) did you use the joystick to access, you used the joystick for your communication aid*

Harriet: 'yes' (nods head)

Amanda: *but with your computer do you just use the keyboard*

Harriet: 'no' (shakes head)

Amanda: *No, how*

Harriet: I h-a-v-e a d-i-f-f-e-r-e-n-t j-o-y-s-t-i-c-k

Amanda: *Right*

Harriet: a-n-d a-n o-n-s-c-r-e-e-n k-e-y-b-o-a-r-d

Amanda: *Okay, so could you just say that again*

SLT: (repeats the whole phrase she has interpreted from alphabet board) *I have a joystick and an onscreen keyboard*

### 4.7.3. Challenges associated with access technology

Participants also described the challenges associated with access technology. One element is having sufficient information about what is available. As Peter's father explains in his first interview they have recently discovered a software programme called Switch XS™ through a visit to a further education college.

*1st interview*

Paul: *yeah we've asked and I've sort of said it, I think we've had a bit of a lapse with the school, I hate to say, I think they lost the ball a bit with communication and er when you know that this stuff is there as I said having been up to (college name) on a visit and then when you see this stuff in place and being used and it works and they say that yes he will just be able to just access he will just be able to come in and plug in then you know its*

Peter: *yeah*

Paul: *you then start looking at but until somebody tells you this is the trouble it's the lack of information*

Amanda: *exactly*

Paul: *and er I think we need if we had this you know somebody come along I mean at school to some extent like this or any special school really, SEN school, especially where children are having to rely on communication aids should have somebody in that school who is a bit of a geek you know who likes all the sort of bits and pieces and can find out about all this sort of stuff and then passes it on. Or even trials it you know. Cos a lot of these websites you know it's like the active the keyboard thing, Switch XS™ you can go on and download it for free for about 30 days so you can trial it before you buy it [not consecutive]*

Paul: *this is the big leap that we want to make*

Amanda: *yeah, it's going to be*

Paul: *is so that he can do it*

Amanda: *yeah, but it's nice 'cos you know the things you want to, so you are beginning to feel that you know what is available on the internet and you want to be able to do it yourself*

Peter: *yeah*

[not consecutive]

Paul: *I mean until you've got, so you will be able to sit in front of a computer yourself and do it, you've got to still wait for me or mum haven't you*

Peter: *'yes' (nods head)*

By the time Peter's second interview takes place, Switch XS™ has been set up and he reports using it and finding it beneficial.

*2<sup>nd</sup> interview*

Email question: *What helps you to use the internet?*

Peter: *"Switches, interface and special software. I use Switch XS™"*

An aspect of indirect access technology which affected participants was the speed of scanning.

*2<sup>nd</sup> interview*

Email question: *What problems do you have using the internet?*

Peter: *"Access is slow"*

Caroline's blog

*Mouse scanning is slow and quite difficult, but that's [sic] like everything with my switch, I am used to that!*

Switch access also had an impact on access to computer games on mainstream computers as Will and Peter explain

Amanda: *What about those war kind of games, shoot 'em up kind of games*

Will: 'no' (shakes head) *"I cannot play"*

Amanda: *You cannot play, what the shoot 'em up kind of games*

Will: 'yes' (raises brows)

Amanda: *Right, I've got you, and is that because the controls are too sensitive or you have to use too many controls at the same time*

Will: 'yes' (raises brows)

[not consecutive]

Amanda: *So with something like golf there would be a definite switch that you would hit as the swing comes down*

Will: 'yes' (raises brows)

Amanda: *Yup, right okay I've got you, so depending on the complexity of the game it would dictate what kind of game you could do*

*2<sup>nd</sup> interview*

Email question: *Are there ways you would like to use the internet which you cannot do at the moment?*

Peter: *"Switch access makes it slow so difficult to play games"*

During the course of Peter's interview the topic of funding arose in relation to additional access technology

*1<sup>st</sup> interview*

Paul: *Peter will hopefully have control and be able to use more but um it's like the software packages are £250 a go*

Peter: *yeah*

Paul: *and so you want to make sure you get the right one*

Amanda: *can you get help with funding*

Paul: *with some things*

*2<sup>nd</sup> interview*

Email question: *Do you have to fund equipment yourself, or do you receive help with this?*

Peter: “*Access to communication and technology (ACT for short) fund (VOCA) and access switches and wiring. Home computer and software funded by me*” (ACT is an NHS department which aims to empower people with disabilities)

#### 4.7.4. Summary

Access technology makes a huge difference to the level of choice available to use the internet and online social media. For those who could operate an independent mainstream computer this was the preferred method to go online and their integrated VOCA was conceptualised as a face-to-face communication device rather than an online tool. For those participants requiring additional equipment to access a computer there was a range of methods illustrated that all involved using an interface to operate a mainstream computer. Access technology was described as challenging in two areas, the first was finding information about what was available and the second was in terms of switch/scanning access being very slow which significantly impacted on the ability to play computer games. These factors supplement the next category VOCA issues (section 4.8). The topic of funding was raised by one parent and it was felt important to include this as it is an acknowledged challenge within the field of AAC which will be discussed in the next chapter.

### 4.8. VOCA issues

#### 4.8.1. Advantages of integrated VOCAs

Having the internet available on a VOCA, however, is still an advantage for people with direct access who use a stand-alone device as revealed in Moira’s interview.

Amanda: *but having said that if you were on holiday or something and you didn’t have your PC or something like that then it’s very useful to be able to, to have the capability*

Moira: ‘yes’ (nods head vigorously)

Amanda: *so you do like having it available on your communication aid*

Moira: ‘yes’ (nods head)

Amanda: *but it’s not your preferred way of using it*

Moira: *no*

Xavier uses indirect switch/scanning and the specialist teaching assistant revealed the integrated computer is especially beneficial in terms of having access to email more frequently

Specialist Teaching Assistant: *it may be that he is now accessing it differently to before. He might not have had a computer whereas now that might be different*

Amanda: *Ah right so (STA name) suggested that maybe you used to use the internet on a separate computer*

Xavier: *yeah*

Amanda: *whereas now you're able to do it through your communication aid. Right has that made you happy being able to use the internet through your communication aid*

Xavier: *yeah*

Amanda: *yes so that is quite an important, you would say*

Xavier: *"especially with email"*

Amanda: *right so that means presumably you can use your email much more regularly than you know cos it's with you all the time. That might be a similar thing to the way that I have started using email, cos I've started using it through my iPhone and that's really changed my life you know that I don't have to wait til I'm back home to look at my emails and things, I can just look at them whenever I like so it must be very similar*

STA: *We use that a lot at college. I'll email Xavier in the morning quite often and then he can know what's happening during the day when he's down the bottom and he gets it before he comes to class*

Xavier: *"fast"*

#### 4.8.2. Disadvantages of integrated VOCAs

A limitation of having an integrated VOCA was noted when Xavier, Erica and Fiona were demonstrating how they used the internet and mobile phone software through their VOCAs. Without toggling back to the voice output software they were unable to communicate with me except through gesture. The VOCA would still 'voice' the commands it was carrying out, for example 'home' 'tweet' 'object' and the participants could have 'spoken' by entering what they wanted to say me into an email or a text message format but the ability to compose a face-to-face message was gone as they were not on that page. This had implications for the interview and impacts on day to day life requiring participants to choose between communicating face-to-face or operating the computer.

##### Fieldnotes

*Xavier spent approximately 45 minutes showing me how his (VOCA) worked. He was not able to answer questions whilst doing this as it would have meant toggling backwards and forwards between his communication page and the pages he was demonstrating. He demonstrated using email, Facebook, texting, making a mobile phone call, using his MP3 player and how he could use the remote environmental controls to operate his television.*

Will confirmed this was also a limitation for him on his VOCA

Amanda: *Another person I was talking to when they went into the computer on their communication aid then they lost the ability to communicate because the aid no longer could have a spoken voice so they either had to be showing me how the computer worked or switch back into the communication aid mode to be able to talk*

Will: 'yes' (Raising eyebrows constantly during my utterance)

Amanda: *Now you're saying yes a lot, is that something that would apply to you*

Will: 'yes' (raises brows)

Amanda: *Do you find that annoying?*

Will: 'yes' (raises brows)

Amanda: *Would, yes, so actually you wouldn't really like it to toggle you'd prefer it so you could still speak whilst you were in computer mode*

Will: 'yes' (raises brows)

Amanda: *That's interesting. Have I got all that right?*

Will: 'yes' (raises brows)

The issue was not only confined to VOCAs though. Ken had a similar problem and he used a communication app on an iPad.

Amanda: *can I have a quick look at your profile page, would that be alright about how someone would see you*

Ken: (goes onto profile page)

Amanda: *oh yes. Oh that's nice. Oh that's a great photo. Where are you there?*

Ken: (no response)

Amanda: *ah now you haven't got your communication aid have you whilst you're in Facebook*

Ken: 'no' (shakes head)

Another limitation of having integrated VOCAs and mobile phone technology is if a participant would like to use a 3G dongle and an eye gaze system simultaneously as reported during Erica's interview

Erica: *"not on text"*

Amanda: *is that because you are not interested in texts*

Erica: 'no' (shakes head)

Amanda: *is that 'cos it's not set up*

Erica: 'yes' (nods head)

Amanda: *okay so it's not set up*

Head of technology: *do you want me to explain that*

Amanda: *Right*

Head of technology: *Erica is looking at me*

Erica: 'yes' (raises eyebrows)

Amanda: *okay*

Head of technology: *The wireless dongle that we were supplied um draws so much power that you can either have the wireless dongle with the 3G Sim card*

*in it or the head mouse but you can't have both 'cos it draws too much power off the device and it breaks it, well it doesn't break it, it just stops so um the so obviously Erica needs the head mouse to access her device so it's basically a weakness of the amount of power that's generated by that back box that's on there so we can't do both at the same time*

A potential limitation that did not affect Erica but could affect other integrated machines in regard to college internet domains was also revealed

Head of technology: *yeah and Erica's got direct access to the file stores on the servers so all Erica's files that she stores on the college network can be accessed through this device*

Amanda: *okay so they are saved on a hard drive and then they can be pulled*

Head of technology: *saved on a server and pulled down to here*

Amanda: *yeah server. Right that's excellent news and I've not come across that at all in my research so far*

Head of technology: *it's not that common because a lot of the communication aids are supplied with Windows XP home which can't connect to the domain*

Moira highlights a limitation of an integrated VOCA in terms of computer games

Moira: *"because it is difficult to use"*

Amanda: *okay, so this is difficult to use. Right that's interesting, um can you explain more about why it is difficult to use compared to your computer is it possible to explain that*

Moira: *"I can't play a game"*

Amanda: *Right, oh right so the capabilities of what you can do on your PC are not the same especially with playing games*

And Caroline highlights an issue with her integrated VOCA

Caroline's blog

*The (VOCA) browser does not cope with attachments like photos.*

#### 4.8.3. Cameras on VOCAs

Skype was popular with participants for whom other forms of social media were not accessible due to literacy and/or other individual skill challenges. Davey and Simon were interested in having Skype set up on their VOCAs. They had used it at home on the family computer and wanted to use it on their VOCAs so they could contact their families from the educational setting

Amanda: *that's great and er do you like Skype*

Davey: *yea*

Specialist Teacher Assistant (STA): *I think you use Skype at the moment on your computer at home don't you*

[not consecutive]



Amanda: *right, so Davey wouldn't use texting or anything through here would he*

STA: *I don't think Davey would but other users could. I think we are just sticking to Skype*

Amanda: *just sticking to Skype 'cos that's easiest with the camera*

Davey: *yea*

Amanda: *and I think (technical support name) was saying that you might have a camera so you could take pictures going around to show mum*

Amanda: *is Skype going to be set up on the Communication Aid*

Simon: 'yes' (nods head)

STA: *I think it is possible to but I'm not sure if Simon will access, that is something we need to work on with (name of IT support Manager)*

In Rick's interview, the Head of Technology at his college confirmed they are looking to set up Skype on his VOCA

Amanda: *Do you need help to set up Skype?*

Rick: *yeah* (raises hand towards Amanda's video camera)

SLT (SLT): *Rick does someone help you at home. Who goes on Skype with you*

Rick: (pointing at Amanda's video camera)

SLT: *or do you do it by yourself*

Rick: (still pointing at Amanda's video camera)

SLT: (looks around room) *Oh are you pointing at Ted. Did (Ted – Head of Technology) help you set it up*

(Ted happens to be in the room at the time of the interview)

Rick: *yeah*

Ted: *We're looking at setting it up on Rick's Communication Aid*

Erica had demonstrated using a wide range of social media on her VOCA and also wants to use a camera. As most mainstream computers have cameras it is understandable that a person using a VOCA as their sole computer might desire access to one.

Erica: *"would like"* (turns and looks at Amanda and raises eyebrows very high)

Amanda: *er would like... would like what*

Erica: *"a curly c"* (the VOCA gives a voiced prompt when 'c' is selected by Erica)

Erica: *"it starts with a curly c"* (looks at Amanda again)

Amanda: *okay.... I would like a*

Erica: *"c"* (due to the predictive text capability on the VOCA the word 'camera' comes up on screen and Erica looks at Amanda)

Amanda: (looks at screen) *ah camera. I would like a camera*

Within the educational settings where the participants said they wanted cameras, it was possible to speak with the Heads of the technical departments about this issue.

They revealed some of the implications go beyond the technical side of setting up the equipment. As the Head of technology with Erica explained it is not that students are disallowed access to cameras; they can use netbook computers in special areas. The challenge is having a mobile camera on a VOCA which is difficult

Head of technology: *yeah our support team have raised issues with having mobile web cams especially on the living areas (cameras would be mounted on VOCAs and these in turn are mounted on wheelchairs)*

Amanda: *yeah*

Head of technology: *because it's one thing for your room mate or friend to see you in a certain situation but it's not okay to broadcast it to the internet*

Amanda: *no, no*

Head of technology: *um I'm talking about perhaps accidentally seeing someone in their dressing gown or something like that*

Amanda: *yeah that's what I heard before 'cos in a way you would have like a roving camera I suppose*

Head of technology: *and there is also an issue with like individual, it's beyond stuff like the potentially like the incident I described, it's also around the fact that people aren't consenting necessarily to having their picture broadcast to the internet so having a mobile camera is a bit tricky but we don't ban the use of Skype, we have several areas where the machines are set up for it to be used and the students can make use of it and we also have all the student living areas have access to a library of loan netbooks which have integrated cameras so it's entirely possible for students to access Skype if they want to. It's putting it on a mobile device is a little bit tricky*

The Head of technology at Rick's college explained their planned policy position on any equipment that is capable of supporting camera use (for example iPads) as being more to do with when it would be appropriate to use cameras during the college timetable

Head of technology: *I don't think that any of the communication aid devices have got cameras at the moment but we do have some students that are starting to use iPads as communication aids*

Amanda: *okay*

Head of technology: *so again that's bringing a new dimension to it. Everything's built in, it's got Facetime which is the equivalent of Skype, it's got a camera at the front as well as the back so that could be an issue but generally devices are usually used in session times with support by members of staff*

[not consecutive]

Head of technology: *yes, we are looking at having an acceptable use policy for students so that when they, er, if they are bringing their own devices into college making sure that they are using them at the right times. You know not using them in the middle of a session when they should be doing something else and making sure that they understand the consequences of if they do, if*

*they are using it for that purpose then we'd have to say well we'd have to stop the internet access to your device between certain times or you know make it clear to them that it's got to be used within the right sort of um situation*

#### 4.8.4. Repairing VOCAs and future planning

Technical staff within educational settings not only helped set up VOCAs they also helped with repairs.

*Amanda: do you ever suffer from technical problems when everything breaks down*

*Xavier: yeah*

*Amanda: yeah, is it quite quick to resolve are there people that can help you to fix it*

*Xavier: 'yes (nods head)*

*Amanda: yeah*

*Xavier: "(college staff name)"*

Educational staff are also aware that having set up VOCAs it was important to plan for when students leave and to consider how to give subsequent support.

*Amanda: so is that going to have ramifications though for when Erica leaves college eventually?*

*Head of technology: no because we'll take it off the domain when Erica leaves and make sure all the security stuff is set to automatically update off the internet so we will put it into a state where it can work independently of us*

Harriet left college last year but has returned for the interview and during the discussion the following observation was made by the SLT

*SLT: So your communication aid is like Will's, so you could do that with it then (referring to the way he remotely controls a computer)*

*Harriet: 'yes' (nods head)*

*SLT: So a Bluetooth connection is another way to go, so we've got to look into that (referring to the earlier conversation when it was established that the joystick controller had broken)*

#### 4.8.5. Summary

Even if a participant prefers to use a mainstream computer independently, integrated VOCAs can still be useful as they effectively become mobile devices which can be used when a mainstream computer is unavailable. Some participants found the availability of the internet and online social media on their integrated VOCAs opened up more frequent access to resources such as email. For example, although Xavier used a mainstream computer with 'EZ keys' software he clearly preferred the

convenience of having all his internet and online social media resources as well as environmental controls available in one place and effectively with him at all times. The main disadvantage which appeared to be the most frustrating was the necessity to toggle between programmes that essentially meant participants were ‘voiceless’ when they were working online unless they toggled back into their voice output software. Other limitations mentioned although inconvenient could often be worked around or accepted, for example, Erica was not too bothered about texting as she had other means of communicating through online social media sites such as email or Facebook. The lack of access to cameras was a big issue for the participants, especially if text-based communication was difficult and Skype was desired, but created concerns over consent, privacy and appropriate use within educational settings. This is particularly pertinent as most mainstream devices have cameras and their use is becoming ubiquitous. Within the minority world the issue of camera use in educational institutions has been widely discussed and will be covered in more detail in the next chapter (section 5.4.3.). Three further issues that arose within this category were problems interfacing with college domains for the Windows XP Home operating system within many integrated VOCAs, the frustrations of not being able to play computer games and the uncertainty about how young people access support and repairs once they leave educational settings.

#### ***4.9. Self-determination***

The participants gave various descriptions of how they felt using digital technology and online social media had improved opportunities for self-determination. An important aspect of self-determination is the ability to use individual skills to carry out self-chosen activities.

##### *4.9.1. Autonomy and authorship*

*Xavier: “It gave me more independence. I can organise things like meetings myself”*

*2<sup>nd</sup> interview*

*Email question: How do you feel using the internet has changed your life?*

*Peter: “I can keep in touch with friends and family easily. I can plan my leisure time myself”*

Email question: *How do you feel losing access to the internet would change your life?*

Peter: *"I would lose touch with people I don't see. I would have to rely on others to find things out for me. I would have less independence"*

Harriet: I h-a-v-e t-o r-e-l-y o-n s-o-m-e-o-n-e t-o t-e-x-t f-o-r m-e a-n-d t-h-e i-n-t-e-r-n-e-t I c-a-n d-o m-y-s-e-l-f

Caroline's blog

*My (VOCA\*) is a computer too. For ages I wanted to access the internet independently, but I use a switch with scanning and I did not know How to do that. In September the (VOCA manufacturer) rep showed us How to use mouse scanning on websites. Now I can write a message on the (VOCA) then post it on Facebook. I was really really excited the first time I did that independently. Mouse scanning is slow and quite difficult, but that#s [sic] like everything with my switch, I am used to that!*

*\*name of VOCA removed to protect identity*

Amanda: *in summary would you say that you got support and help with the technical side of access*

Will: 'yes' (raises brows)

Amanda: *but then once you had that you could just be away and do it and you didn't need help to actually use social media*

Will: 'yes' (raises brows)

Will's mum: *for Will IT (information technology) and technology is a big thing.*

#### 4.9.2. Enhanced privacy

Despite decreased privacy being a limitation of collaboration, Harriet who can access online social media independently reports it has enhanced her privacy.

Harriet: M-a-i-n t-h-i-n-g a-b-o-u-t F-a-c-e-b-o-o-k i-s I c-a-n s-e-n-d a m-e-s-s-a-g-e t-o e-i-t-h-e-r m-y b-r-o-t-h-e-r o-r m-y d-a-d i-f I h-a-v-e a p-r-o-b-l-e-m a-n-d t-h-e-y g-e-t i-t o-n t-h-e-i-r p-h-o-n-e-s

[not consecutive]

Harriet: B-e-c-a-u-s-e I c-a-n-'t a-l-w-a-y-s t-e-l-l t-h-e p-e-r-s-o-n w-i-t-h m-e

SLT: *Yeah but you could tell someone close to you*

Amanda: *And right, okay and would that be because it might be something personal*

Harriet: Yeah, o-r i-t-'s t-o d (SLT1 is struggling to interpret word)

2nd SLT: *Or it's to do* (has understood what Harriet is hand typing on her alphabet board)

SLT: *Thank you*

Harriet: o-r i-t-'s t-o d-o w-i-t-h m-y s-t-a-f-f

Amanda: *Ah, right*

SLT: *It might be to do with them*

Amanda: *Ah, it might be to do with them and you can't tell. Right, so it's if one of your staff want to talk to you about something that they don't necessarily want one of the other staff to hear about and if it was a phone call it would not be very private so with Facebook, okay that's.. Yes, so you*

SLT: *Can I say about what happened before 'cos this is really relevant isn't it?*

Harriet: 'yes' (nods head)

SLT: *Cos what Harriet used to find before is that when you used to have new carers or agency carers that sometimes they made assumptions about you didn't they?*

Harriet: 'yes' (nods head)

SLT: *And it was just awful and you used to get really upset going back at half term if you had new carers 'cos they just used to treat you in a way that wasn't right*

Harriet: *Yea*

SLT: *So this way is much easier 'cos now you can have frank discussions about it*

Will confirmed this was also applicable to him too

Amanda: *would you agree with Harriet about what she was saying, that with Facebook she might be able to talk about something that's private or something that's actually to do with her personal staff that she can communicate to friends and family*

Will: 'yes' (raises brows)

Amanda: *So yes, you're saying yes, yes, yes to all of that you would agree with that* (referring to the fact Will was continually raising his eyebrows as he listened)

Will: 'yes' (raises brows)

#### 4.9.3. Summary

Being able to use the internet was perceived as supporting the ability to plan leisure time and take authorship of activities. This was also expressed within the category Use of the Internet (section 4.4.1.) where data showed participants used the internet to follow hobbies/interests, shop online, carry out academic work/research and support employment opportunities or charity work. An aspect of self-determination is the ability to engage privately with others which can be challenging when personal staff are present twenty-four hours a day. This is especially important if there is an issue with a staff member and the ability of online social media to link quickly and privately to family and friends is of great relevance. This is likely to be of particular relevance for participants who been given the opportunity to text using symbolised vocabulary on integrated VOCAs (section 4.4.4.).

## **4.10. Self-Representation**

As outlined in the literature review much has been written about self-representation on the internet and online social media sites. The participants within this study predominantly described that being online offered heightened opportunities for showing other people aspects of themselves which may be challenging for them to share in face-to-face situations due to their complex communication needs.

### *4.10.1. Information about self*

Participants described being able to tell people about themselves online

SLT: *What is good about Facebook?*

Carol: (points to self)

SLT: *about you*

Amanda: *oh because you can give news about you to your friends*

Carol: 'yes' (nods head)

Amanda: *would you be sad if you couldn't use Facebook*

SLT: *SAD* (Makaton sign)

Carol: 'yes' (nods head)

[not consecutive]

Carol: *"rebound"*

Amanda: *rebound?*

SLT: (using Makaton sign to support speech) *what about rebound, it's something else that you like*

Carol: (nods head – yes)

SLT: (using makaton signing to support speech) *and that you might talk about on Facebook*

Carol: 'yes' (nods head)

*1<sup>st</sup> interview*

Amanda: *do you load photographs of things that you've been doing?*

Peter: 'yes' (nods head and looks to dad at same time)

Paul: *Yeah, we put them on there don't we?*

Peter: 'yes' (nods head)

[not consecutive]

Amanda: *so can we talk about your website. Can you tell me about it, um what, er do you put information on your website*

Peter: *yeah*

Amanda: *is it information about yourself*

Peter: *yeah*

Amanda: *is it information that you think will be useful for other people*

Peter: *yeah*

Amanda: *and is it different to your Facebook information*

Peter: *yeah*

Amanda: *so it's not as personal*

Peter: 'no' (shakes head)

Amanda: *no, so is it more technical information*

Peter: *yeah*

*2<sup>nd</sup> interview*

Email question: *Tell me about your profile on Facebook, for example what photograph do you use of yourself?*

Peter: *"I have a photo of me at Chelsea which my sister took. I include things I like, where I live, places I have been"*

Email question: *Have you added any description about yourself onto your profile? For example about your interests, things like music, sports that you like?*

Peter: *"Yes I have included things I like such as cricket, Chelsea, theatre, family information, where I have been"*

Caroline's blog

*I like choosing different photos for my Facebook profile. I used to have photos of my Ginger cat, now I have doctor who [sic] characters.*

Amanda: *do you have a photograph of yourself on Facebook? Some people would have a photograph of themselves but other people might have a picture of Homer Simpson or you know or like a cartoon. Have you got a picture of yourself*

Nicholas: *No "basketball"*

Amanda: *You've got a picture of a basketball, brilliant, why a basketball, is it 'cos you like basketball?*

Nicholas: *yeah*

Amanda: *On your Facebook profile have you got your own picture*

SLT: (using Makaton signs to support speech) *your own photo*

Amanda: *your own photo or do you a different photo*

Carol: *FRIEND* (Makaton sign)

SLT: *friend, a photo of you and a friend*

Carol: 'yes' (nods head)

[not consecutive]

Amanda: *do you put photographs on Facebook*

Carol: 'yes' (nods head)

Amanda: *of things that you have been doing*

Carol: *"prom 2011"*

Amanda: *do you think Facebook has changed the way you socialise with people*

Xavier: (makes gesture)

Specialist Teaching Assistant: *yes* (interpreting non-verbal gesture)

Amanda: *do you think you contact people more because of Facebook*

Xavier: 'no' (shakes head)

Amanda: *so it's not necessarily that you contact them more, do you think that it is you can know more about them*

Xavier: *yeah*



Amanda: *yeah and do you feel that it gives you the opportunity to tell people more about your life*

Xavier (makes head movement)

Amanda: *was that a yes?*

Xavier: 'yes' (nods head)

Amanda: *what have you got as your profile picture*

Keith: *"I got a picture of Pikachu"*

[not consecutive]

Keith: *"I like Facebook because I like seeing me holding Pikachu"*

[not consecutive]

Amanda: *what information do you tell people about yourself, how much do you tell people*

Keith: *"a lot"*

Amanda: *do you have a photo of yourself as your profile photograph on Facebook*

Ben: *"one I was on holiday"*

Amanda: *oh that's nice*

Ben: *"on dodgers"*

Teaching assistant: *on dodgers, car dodgers*

Amanda: *ah okay, brilliant. So they are of when you are out doing fun things that you are proud of*

Ben: 'yes' (nods head vigorously)

[not consecutive]

Amanda: *have you got profile information*

Ben: 'yes' (nods head)

Teaching assistant: *what have you got on it sweetheart*

Ben: *"Like I know French, English, Portuguese"*

Amanda: *okay and what about your profile picture what do you choose to have as your profile picture. Some people have got things like they are at a concert or they are on holiday or some people just have a photograph or some people don't have a photograph of themselves*

Moira: *"Sometimes I don't like to put a picture of myself"*

Amanda: *Okay so what would you put instead would you just leave it blank or would you put a picture of a tree or something what would you do yourself*

Moira: *"Keep calm picture"*

Amanda: *Oh a keep calm picture I know the ones you mean Oh I like those, keep calm and carry on*

Moira: *yea*

Amanda: *what kind of things you put on, some people might not put anything on at all and just want to look at what their friends have been doing*

Moira: *"anything, well I am mixed person"*

Moira: *okay so sometimes you might just go on and look at what your friends have been up to and then other times you might think oh I feel in the mood for putting a lot of things up about how I feel*

Moira: 'yes' (nods head)

Amanda: *do you feel you are quite a political person do you like protesting*

Moira: (no response)

Amanda: *or are you like more of a jokey person*

Moira: 'yes' (big smile and nods head)

Amanda: *Do you use Facebook to tell people about your news*

Olivia: *yeah*

Amanda: *Do you use as part of your business. Do you have any customers from your websites on there?*

Harriet: 'yes' (nods head) I h-a-v-e o-n-l-y j-u-s-t s-t-a-r-t-e-d m-y b-u-s-i-n-e-s-s

Amanda: *Right, so it's quite a new area. So you wouldn't necessarily use Facebook as part of your business. Is Facebook more a personal*

Harriet: I d-o a-d-v-e-r-t-i-s-i-n-g

Amanda: *Ah, so you do advertising through Facebook as part of your business*

Harriet: O-n m-y s-t-a-t-u-s

Amanda: *On your status, on your profile status*

Harriet: I h-a-v-e a-l-l t-h-e j-o-b-s I h-a-v-e d-o-n-e

Amanda: *Okay and with your status, what kind of things do you tell people about*

Will: *"What I think"*

Amanda: *Do you think Facebook is a place where you can show people your personality*

Nancy: *yeah*

Amanda: *what kind of thoughts would you have on that*

Nancy: *"it good show pictures"*

#### 4.10.2. Conversational equality

There was also descriptions of how being online improved the ability to be understood and reduce isolation

*2<sup>nd</sup> interview*

Email question: *What advice would you give to someone who uses AAC about using the internet and Facebook?*

Peter: *"It's a really good way for people to get to know you better and understand you. With the right advice and help, most people can do it. It helps independence and can stop people feeling isolated"*

Nancy: *"people understand me better in writing"*

Amanda: *okay, so can I just check that I've understood that so you're saying when you can write things down you can give people more information and they can understand you better*

Nancy: *yeah*

[not consecutive]

Amanda: *So have you ever used email or Facebook if you've been in a face-to-face conversation and you feel that you haven't had a chance to say everything that you wanted to say would you maybe send somebody an email or say something to them on Facebook later*

Nancy: "yes"

#### Caroline's blog

*I read what everyone is up to, I like or write comments, and look at photos. I like that because I communicate equally with everyone.*

Amanda: *and I sometimes wonder whether with things like live chat and things when lots of people are all chatting at the same time and with MSN it means you've got time to get your message ready and to be able to join in conversations*

Ben: 'yes' (smiles and nods head)

Amanda: *does that make it um does it make it easier for you to feel that you've got time for you to say what you want to say*

Ben: 'yes' (nods head)

Amanda: *and you can make your message as long as you like*

Ben: 'yes' (nods head)

Amanda: *so do you think it's added more to the amount of things that you can talk to people about*

Ben: 'yes' (nods head)

Amanda: *when you say it helps you to talk to people, you can say more, you can say it faster, you can have time to do it, I mean what sort of things about it do you like*

Moira: "It shows people that how they have to wait to hear what I say"

#### 4.10.3. Expressing humour

It was evident from some descriptions that online social media was helpful for expressing humour

Harriet: I a-l-s-o p-u-t s-i-l-l-y s-t-u-f-f o-n m-y F-a-c-e-b-o-o-k  
[not consecutive]

Amanda: *Yes, cos some people might have a photo of Homer Simpson or something like that but you've got a picture of yourself*

Harriet: I-t-'s m-e l-e-a-n-i-n-g o-n s-h-o-p-p-i-n-g t-r-o-l-l-e-y  
[not consecutive]

Amanda: *And are your parents friends on Facebook?*

Harriet: T-h-e-y j-u-s-t l-a-u-g-h

Amanda: *Some people have told me that they feel they can show their humour online*

Erica: 'yes' (raises eyebrows)

#### 4.10.4. Narrative record of activities

Harriet mentioned the timeline feature of Facebook as useful for keeping a record of old activities which was confirmed by Will and Erica

Amanda: *I don't know if I've created a timeline or not?* (interview took place as this feature was being launched on Facebook and people had been invited to create a timeline themselves before Facebook started automatically creating one)

Harriet: I l-o-v-e i-t

Amanda: *You love it, So you've fully created. I must get into Timeline then*

Harriet: Y-o-u c-a-n l-o-o-k r-e-a-l-l-y o-l-d

Amanda: *you can look at really old stuff, oh I know what you mean without having to plough through all the old posts and everything, so it's much quicker to scan down quickly and get to stuff*

Harriet: 'yes' (nods head)

SLT: *Oh gosh, I don't use any of this stuff*

Amanda: *What about you Will have you got a timeline?*

Will: 'yes' (raises brows)

Amanda: *Yup, okay and do you love it too*

Will: 'yes' (raises brows)

Amanda: *some people have found the timeline on Facebook really useful cos they've said it's a space where they can record old stories*

Erica: 'yes' (raises eyebrows)

#### 4.10.5. Summary

Being able to represent themselves more fully was the main thrust of the self-representation category. Photographs were particularly important to show activities that participants were proud of and helped to establish a desired self-image which gave a sense of satisfaction and pleasure but also as seen in the Use of the internet category (section 4.4.1.) to express internal emotions. The opportunity to express opinions and follow up and repair conversations which may have been challenging within face-to-face interactions was also valued. Participants showed how conversational equality was perceived through feeling online communication helped other people understand, feeling better understanding through writing and also challenging other people's perceptions by showcasing an underlying ability and humour which may not be so evident from face-to-face conversations. Of particular interest is the narrative record offered by the timeline feature of Facebook that will be discussed in the next chapter. One area of difficulty for AAC assisted communication

is the challenge for creating personal narratives about life experiences on VOCAs as they tend to be stored as monologues or in chunked sequences (Reddington & Coles-Kemp, 2011), are time consuming to prepare and need to be constantly altered to mark the progress of time (e.g. yesterday, last week, last year).

#### **4.11. Online social ties**

##### *4.11.1. Bonding social ties*

Participants reported keeping in touch with parents, siblings, other family members, friends from old schools and colleges, old teachers and personal staff, and also people within settings they saw on a daily basis. Online social media is interpreted as enriching social ties and affording participants the opportunity to share more with those they are in contact with. One of the key advantages expressed for using the internet and online social media was to “talk to other people”.

*Amanda: So what do you like most about Facebook, what's the reason for using it?*

*Ben: “For talk to people”*

*[not consecutive]*

*Amanda: do you feel it's really been a valuable thing that's in your life*

*Ben: ‘yes’ (nods head vigorously)*

*[not consecutive]*

*Amanda: has it made you feel happy that there are other ways that you can communicate with your friends and things*

*Ben: ‘yes’ (nods head vigorously)*

*Amanda: Xavier you were saying you can do everything on your communication aid, is that right, so what can you do*

*Xavier: “Internet, mobile and talk”*

*[not consecutive]*

*Xavier: “it me in contact with everybody”*

*[not consecutive]*

*Amanda: okay and what do you find most valuable about Facebook*

*Xavier: (laughs) “talk a moment and take a nosy”*

*Moira: “it helps to talk everyone”*

*Amanda: what do you think is most valuable about Facebook to you. You know, what do really like about it*

*Keith: “I can talk to people on it”*

*Olivia: “to talk to everyone”*

Harriet: S-h-e c-a-n t-a-l-k t-o m-e o-n F-a-c-e-b-o-o-k

Amanda: *What are your interests and things you might follow on the internet?*

Will: *“talk friends”*

Amanda: *what sort of things do you follow online, what are your interests*

Nancy: *“talk friends”*

[not consecutive]

Amanda: *and the difference it has made to your life what would you tell me about it*

Nancy: *“good I can talk family”*

*2<sup>nd</sup> interview*

Peter: *“I like using live chat”*

Caroline’s blog

*I like chatting on Facebook. Usually I chat with friends who used to be at school or college with me.*

[not consecutive]

*The internet helps me stay in contact with people and the world. That’s really important.*

Amanda: *what is it that you like about Facebook and Facetime. What is the main thing that you like about it*

Ken: *“talking to people”*

Mary described how she used MSN to speak with her sister when they were in the same house as they both have computers in their bedrooms

Amanda: *So has she got a computer in her room?*

Mary: *yeh*

Amanda: *Yeah, so the two of you might be in the house, in your rooms and you talk on MSN*

Mary: *yeah*

Amanda: *Okay, that’s a good idea. Why would you talk on MSN is it because you like using MSN?*

Mary: *‘yes’ (nods head)*

Amanda: *So, do you find it easier to talk to her*

Mary: *yeah*

Amanda: *through MSN than in the same room*

Mary: *yeah*

Amanda: *and is that because you can type, you can use text*

Mary: *yeah*

Amanda: *so do you find it faster than using your talker?*

Mary: *‘yes’ (nods head)*

[not consecutive]

Amanda: *can I just check that I understood, you said you like using the MSN with Lucy*

Mary: *yeah*  
Amanda: *when you are in the same house*  
Mary: *yeah*  
Amanda: *cos you find it easier to talk to her with MSN than using your talker, is that right*  
Mary: *yeah*  
Amanda: *and that's because it's quicker, is that right*  
Mary: *yeah*

#### 4.11.2. Maintaining social ties

Maintaining social ties was identified as a benefit of using the internet and online social media, especially over distance. Many people with physical disabilities who use AAC are at a heightened risk of losing touch with people as they move onto new situations.

*1<sup>st</sup> interview*  
Amanda: *do you use it to keep in contact with people you don't see anymore?*  
Peter: *Yeah*  
[not consecutive]  
Amanda: *So you keep in contact with granddad*  
Peter: *'yes' (nods head)*  
Paul: *and your sister cos she works in (place name)*  
Peter: *yeah*  
*2<sup>nd</sup> interview*  
Email question: *Do you feel using the internet or Facebook has changed how you socialise with your friends, if so can you describe what is different*  
Peter: *"Yes it's difficult to meet up as we live all over the county and some friends are away at college. It makes it easier to stay in touch"*

#### Caroline's blog

*I post status updates and my friends and cousins and aunties write comments. I stay in touch with people I do not see often, like my One Voice friends and my family in the south of England, France and Canada.*

[not consecutive]

*Usually I chat with friends who used to be at school or college with me.*

[not consecutive]

*I have a email pen friend called (female name) in New York state. She uses a (VOCA) too. We email every week. We have been pen friends for 4 and a half years.*

Amanda: *and do you use it to keep in touch with people who you might have known in the past, say from school or from home?*

Nicholas: *yeah*

Amanda: *do you keep in touch with friends from your old school on Facebook*

Carol: *'yes' (nods head)*

Amanda: *has Facebook changed the way you socialise with people*  
Xavier: 'yes' (nods head "especially when I am here" (referring to the residential college)

Keith and Nicholas explained how they use Facebook to keep in touch with friends from old school

Keith: *"school"*  
Amanda: *okay, that's your old school*  
Keith: *yeah [crosstalk]*  
Amanda: *or [crosstalk] people here*  
Keith: (points to the distance)  
Amanda: *right people in your old school*  
Keith: *yeah*  
Amanda: *so you use Facebook to keep in touch with people who you don't see anymore, people who were in your school but they're doing different things now so you keep in touch with people you don't see everyday*  
Keith: *yeah*

Amanda: *and do you use it to keep in touch with people who you might have known in the past, say from school or from home?*  
Nicholas: *yeah*  
Amanda: *yup*  
Nicholas: *"old school"*  
Amanda: *old school, yup, so it's very useful for that*  
Nicholas: *yeah "(name of old school)"*  
Amanda: *oh okay that's the name of your old school*  
Nicholas: *yeah*

Keith also describes how he finds his old school friends and initiates contact with them

Keith: *"I send them a text"*  
Amanda: *Oh okay. Do you find your friend on Facebook and then send them a message or do you send them a text on a telephone. I don't quite understand what you mean sorry*  
Keith: *"I find them"*  
Amanda: *Right, so you find them on Facebook and then you send them a text on Facebook*  
Keith: *yeah*

Amanda: *who do you use Facebook to keep in contact with*  
Olivia: *"my mates and my old teachers"*

Harriet: I c-a-n g-e-t i-n t-o-u-c-h w-i-t-h f-r-i-e-n-d-s I k-n-o-w i-n  
(country name).  
Amanda: *Right, did you used to live in (country name)*  
Harriet: 'no' (shakes head)  
Amanda: *Have you got family in (country name)*



Harriet: A-t m-y o-l-d s-c-h-o-o-l t-h-e-y l-e-a-r-n g-a-p w-i-t-h s-t-u-d-e-n-t-s f-r-o-m (country name) a-n-d (country name)  
Amanda: *Right so gap year students from (country name) and (country name) used to come to your school*

Nancy: *“can talk dad for in Spain”*  
Amanda: *oh right you can talk to your dad ‘cos he’s in Spain. So you can talk to him on Skype and on Facebook*  
Nancy: *yeah*

Amanda: *who do you keep in contact with on Facebook for instance old friends or just people you know here or family or people from abroad*  
Ken: *both*  
Amanda: *both so people from your old school*  
Ken: *yeah*  
Amanda: *and from your family*  
Ken: *yeah*  
Amanda: *and are in contact with people here at college on Facebook*  
Ken: *yeah*

Amanda: *what do you use the internet and/or social media to do? Are you using them and if so what do you do with them*  
Sean: *“talking to family in Scotland and Canada”*  
Amanda: *Do you keep in contact with people from your old school*  
Sean: *yeah*

#### 4.11.3. Bridging online social ties

There was a very small amount of evidence that using online social media also creates opportunities for developing new acquaintances and possibly widening social circles and to support romantic relationships.

##### *1<sup>st</sup> interview*

Paul: *and then you start getting bits where people, you know, there’s people who you probably contact very, you know, now and again, you know, who are friends of friends as it were sort of thing*

##### *Field notes*

*Ben’s teaching assistant tells me on our way out of the school about an aspect of Facebook she has perceived in regard to Ben. She says he has linked up with her sons on Facebook due to their connection through her. She says they share information that she believes they would not have had the opportunity to do under traditional circumstances.*

Will describes linking up with people through online computer games

Amanda: *Do either of you play computer games?*

Will: 'yes' (vigorously raises eyebrows) *yea* (everyone laughs because Will is so enthusiastic)

Amanda: *And do you just play them on your own or do you interact with your friends and play?*

Will: 'yes' (raises brows)

Amanda: *So you connect online*

Will: 'yes' (raises brows)

Amanda: *what kind of games do you like playing?*

Will: *"golf"*

Amanda: *Golf. Okay, are you good at it?*

Will: *"It's hard"*

Amanda: *It's hard, I bet it is. I was just thinking do you join up with friends you know*

Will: 'yes' (raises brows)

Amanda: *Cos you can join up with people round the world can't you? My nephew joins up with people in America*

Will: 'yes' (vigorously raises brows)

Amanda: *So do you join up with people round the world*

Will: 'yes' (raises brows)

The InBook project had been run between colleges and has given students the opportunity to meet new people and to stay in touch with them online.

Amanda: *was that how you met the new people*

Jack: 'yes' (nods head)

Amanda: *is that where your new friends have come from this other college*

Jack: 'yes' (nods head)

Personal assistant: *use your speech aid*

Jack: *"InBook"*

InBook may also be giving the students within the college the opportunity to pursue romantic relationships which it may be difficult to pursue on a physical level within the college premises.

Amanda: (a commentary on the actions being taken) *Right so now we are going into one of Jack's friend's pages and can keep track, you can see the photograph, see what she's been up to, see her name and then you can see all of her pieces of news that she's put in. And it's a really nice set out screen, it's nice big graphics, clear not too much information on here and no advertisements like you get on Facebook. Oh I think, (Jack is pointing to one of the staff) who do you want Jack? Do you want (staff name), do you want (staff name)*

Jack: 'yes' (nods head)

Amanda: (addressing staff member) *Sorry, Jack was asking if, he was pointing at you I think he wanted to talk to you*  
(female staff member comes over and looks at Jack's screen)

PA: *Oh never! I know but does Amanda know (Jack shakes head). I don't know if we can sign it. This is a.... very good friend we'll say (laughing)*

Jack: 'yes' (smiles and nods head)

PA: *Kathy*

Amanda: *would it be your girlfriend by any chance?*

Jack: 'yes' (nods head vigorously and smiles)

Amanda: *ah brilliant. Is that what you wanted me to know*

Jack: 'yes' (nods head)

Amanda: *So this is great news Jack cos this means you can keep in contact with your girlfriend all the time and read what she has been up to. Is she at this college*

Jack: 'yes' (nods head)

Amanda: *But is she, do you have any groups together and things like that*

Jack: 'no' (shakes head)

Amanda: *Is she in a different group to you*

Jack: 'yes' (nods head)

#### 4.11.4. Summary

“Talking” to other people was the term used by the participants and within this category came up repeatedly across the interviews. As the participants have challenges for using natural speech it was clearly one of the most important perceived benefits of using the internet and online social media. In a society which could be seen to privilege speech (Bourdieu, 1991) the participants expressed how the internet and online social media helps them redress this imbalance which in turn enriched existing social ties. Within social capital theory the ability to strengthen close social relationships is known as bonding social capital.

Being online offered benefits for maintaining social ties with people who it may have been difficult to see due to life changes and living away from home. There was also a small amount of evidence that opportunities to meet new people could be created through linking up with other settings. One aspect of having physical disabilities is the difficulty of spending time alone with other people with physical disabilities as both parties are often in the company of personal staff. The demonstration of using InBook to keep in touch with a girlfriend showed how a private communication space could be created online to support intimate relationships. The perceived support for social ties offered by online activity also overlaps with issues within the self-determination category for enhanced privacy (section 4.9.2) and the self-representation category of sharing personal information (section 4.10.1) and conversational equality (section 4.10.2.)

#### **4.12. Memos**

Charmaz (2006) stresses the importance of memo writing. An interview was conducted within a class setting with four participants. Moving between the four participants meant the transcript was disjointed and it was decided to lift each participant's data out separately to create four individual transcripts. Two of the participants had declined to be on video which meant that a camera placed on one of the participants kept rolling even when he was not being spoken to. During transcription this footage was viewed for the first time and a potentially major communication breakdown that had been completely missed at the time of the interview was revealed. A memo was created to discuss emerging theoretical thoughts about what the data might in fact be revealing about dating.

#### **Dating Memo (November 2012)**

The following data when looked at during transcription made the researcher wonder whether Faith was trying to indicate that being in contact with boys was what was 'exciting' about using Facebook/InBook.

#### **Original Interview Transcription Data**

(SLT tells researcher that Kevin would like to have a word with her having earlier decided he did not want to take part. SLT asks Kevin if he would like to do it now and he says yes. Amanda leaves Faith but the audio recorder picks up the following conversation)

SLT: (speaking to PA who has returned to work with Faith) *I think there's still a thing that Faith is trying to explain but I couldn't quite work it out*

PA: *is it why she felt excited*

SLT: *yeah it was around why she felt something but not quite sure what..or was it another way that it makes you feel... No. It's something about being excited and why you feel excited*

Faith: (makes unrecorded non-verbal response)

(It is assumed Faith pointed towards Rick to make sense of what SLT says next. Also it would explain earlier incident when Faith pointed towards Rick

in relation to same question but Amanda thought she wanted the SLT who happened to be sitting next to Rick).

SLT: *Is it something to do with Rick?*

(Rick happens to be on camera at this point and is watching Faith. Although no-one is with him, he reacts by smiling and appears excited when he overhears this exchange)

Faith: (makes unrecorded non-verbal response)

SLT: *ohh* (SLT intonation is one of understanding)

PA: (addressing Faith) *you've got your friend's page on there*

SLT: *ah that's a good idea*

(SLT then goes to join Rick but does not follow up on Faith's comment and reverts to task she was working on with him previously. Amanda is still busy talking to Kevin)

(Amanda returns)

Amanda: *Hi Faith*

Faith: *"friend, Kevin, Rick"*

Amanda: *okay so these are the friends that you're linked up with and it's great because you can find out what they are doing and things and does that mean when you are not with them that you can see what they have been doing 'cos you see them here don't you but then when you go on InBook*

Faith: *"Xavier"*

Amanda: *mm mm fantastic so you've got lots of friends and you're all on InBook together*

Faith: (makes unrecorded non-verbal response)

Amanda: *yeah* (interpreting response) *So the other thing I was going to ask you is how do you use the internet, do you use it using your communication aid*

PA: *you've got it written in there haven't you Faith*

Faith: *"Peter, friend, Kevin, Rick, Xavier, Peter"*

Amanda: *mm mm*

PA: *is it in college, remember where it is*

Amanda: *I'll come back in a minute* (Rick is waiting to talk to Amanda)

### **Amanda's memo thoughts on the transcription data**

Rick's reaction captured on camera when she points to him was very animated. The SLT and PA did not follow up why she pointed at Rick and the PA suggested she found her friend's page on her VOCA. When I return to speak to her she selects various friends and I do not notice at the time they are all male friends. Is there a 'blindness' in the SLT, PA and I about the subject of dating or contacting boys? It is very natural for Faith to be interested in boys. Was Faith trying to tell everyone that Rick is her boyfriend or was it that he was the only male in the room in her line of sight? Is the well documented 'asexualisation' of people with disabilities the reason this was not even on our radars so we failed to follow it up? Why did I assume the first time Faith pointed to Rick that she wanted the SLT? Was my focus on the 'process' of making the VOCA work and not on thinking about the 'content' of her intended message? Why did I not ask did she mean the SLT or Rick? Why did I assume she wanted technical assistance? As I was not present when Faith re-pointed at Rick (when he was sitting on his own) I can never know whether I would have followed up on this.

An alternative scenario may be that the SLT or PA did not feel it was their place to disclose that there might be a romantic link between Faith and Rick? It is easy for communication partners to take over situations and maybe reveal information the person using AAC did not want to share and communication partners sometimes err on the side of caution rather than reveal a detail they know about with a relative stranger. Later on the same day one of the male participants asked his PA to tell me about the picture he was showing me. She laughed and said she was a good friend. As he was so keen to show his friend to me I asked if she was his girlfriend and he enthusiastically confirmed she was.

Could there be a reticence to mention a possibly 'personal' subject within the setting? Do we feel inhibited? Have we made an assumption that we cannot be sure this is what Faith is trying to tell us and so avoid initiating the subject? Do we think we are protecting her by not making such a suggestion? Do we feel the setting would not want us to bring it up? Is the SLT constrained by staff guidelines within this area? Am

I constrained by the thought that I have to be on my 'best behaviour' as I have been given permission to come into the setting?

Why does Faith not have any vocabulary available on her VOCA to talk about this topic? She still tries to give me the names of boys on her VOCA after I think I have understood and ask her a question about how she accesses the internet. Her PA at that point is trying to move her on to an answer she knows is pre-programmed on her VOCA. I then get called away. Would Faith have persevered if I had stayed? Would she have ignored her PA's advice? Once I had gone, the moment was lost and it would have been very difficult for Faith to re-visit. Were we on the brink of a communication repair moment that was lost forever? How frustrated would this have made Faith feel? Was she irritated that no-one picked up her cues? Did she give up when I returned? Looking at the incident from a different perspective reveals a potentially serious communication breakdown. If Faith has been trying to tell us something about dating it is of interest that no-one picked up on what are in hindsight clever strategies.

More evidence to support this dating conjecture interpretation of the situation is seen in Rick's interview data. The interaction with Faith has already happened and he has observed her using male friend's names to try to explain why she feels excited. Rick has been asked the same question and is working with the SLT to access the feelings page on his VOCA. He has already selected 'excited' but when I came over he deleted it by mistake. They had been working to get it up on the screen again but this time Rick starts to add female names. Why is it deemed important by the SLT and me that he gets the word 'excited' back on his VOCA so he can say it to me face-to-face. She knows he wants to say that. Are we both caught up in the idea that for the research to be valid the suggestion has to be seen to have been said by Rick? Again is this an over-focus on the 'process' of apparently 'helping' the AAC user to create a message on a VOCA completely ignoring the much more important 'content' of the communication message. See the following conversation

Original Interview Transcription Data

Rick: "Julie"

SLT: *do you want Julie on the internet? Okay Rick have a think where is the feelings page, that's it well done, is it a good or a bad feeling, well done, I think it's just that same button again that one that you had on before*

Rick: "excited"

SLT: *well done*

Rick: "Sally"

SLT: *is that someone from Eastenders*

Rick: (gives non-verbal signal to SLT which she appears to understand)

SLT: *or Coronation Street*

Rick: (uses non-verbal signal with SLT which she understands as yes)

SLT: *oh okay right. Do you watch Coronation Street on the TV or do you sometimes watch it on the computer*

Rick: 'no' (shakes head)

SLT: *no on the TV*

Rick: 'no' (shakes head)

SLT: *on the computer*

Rick: 'no' (shakes head)

SLT: *do you ever watch it*

Rick: (gesturing and pointing to aid)

SLT: *oh you want to watch it on here (pointing to aid)*

Rick: 'no' (shakes head)

SLT: *or right. You probably could use the internet on here you know Rick but you're not doing it at the moment are you. We'd have to find out at home if you've got wireless internet set up and if you have then you might be able to. You've also got your little laptop that you use at home have you not got any more*

Rick: (goes to construct an answer on his VOCA)

SLT: *Rick hang on a second she'll be back with you in a second. Rick do you want to tell Amanda what message it is that you have*

Rick: "grandma"



SLT: (Rick wipes VOCA) *oh no. Right, Rick come on* (Rick holds head in ironic despair and is laughing)

#### Amanda's memo thoughts on the transcription data

It would appear that the SLT has thought that Rick is trying to explain about a television programme. Maybe the female names are on a page of vocabulary related to television programmes (?) It appears when SLT starts to ask if he watches these things on the telly and he says no that she becomes confused and then asks if he ever watches it. Again he says no. What is he trying to say? Then he points at his VOCA and she thinks he is trying to say about watching it on the aid to which he says yes. Maybe he is trying to get her to think the answer is on the aid. She thinks he wants to watch the internet on the aid. He goes to add something onto the aid and she worries because I am coming back he is going to lose the phrase 'excited'. He adds grandma. Is he accessing the only female names he has available? As I arrive his message gets completely wiped and he appears to gesture despair and laughs. Was he realising how hopeless it was going to be trying to show SLT and me that the reason he feels excited is because of girls? Was he trying to use the same strategy as Faith to explain? However, later in the interview the following data appears

#### Original Interview Transcription Data

Rick: "*grandma*"

SLT: *are you saying it makes that person feel excited if you give her a call on Skype*

Rick: 'yes' (nods head)

SLT: *okay so let's go back out* (presses button on VOCA) *Rick, where's those feelings. Rick have a look* (points to aid)

Rick: "*granddad*"

SLT: *okay so it's grandma and granddad* (long pause) *Rick have a look in this one* (pointing to button)

Rick: (presses button)

SLT: *that's it, well done*

Rick: "*excited*"

Amanda: *okay so it makes you feel excited. Good, well that's what a lot of people have told me that it makes them feel happy and excited to*

Rick: *“grandma granddad excited”*

Amanda: *oh and your grandma and granddad are excited as well*

SLT: *if you give them a call on Skype does that make them feel excited do you think*

Rick: ‘no’ (shakes head)

SLT: *or it makes you feel excited* [cross talk]

Amanda: *it makes you feel excited* [cross talk]. *So it’s definitely made a change you’re pleased that you’re able to use Skype*

Rick: *yeah*

#### Amanda’s memo thoughts on the transcription data

So.... now was it a mistake by Rick to press the names Julie and Sally? Was he trying to select Grandma and Grandpa? mmm.... Or did he decide it was too difficult to repair the communication breakdown and decided instead to try to tell the SLT and me how it was exciting for him to communicate with people. He knew he had already told us he spoke to Grandma and Granddad on Skype. He does not confirm it makes him feel excited to talk to them as suggested by the SLT and me.

So was he using it as a strategy to show us that it was not about television programmes? The SLT had guessed before it was about communicating with other people who were close to him? Maybe what we missed earlier was that he was also trying to show that included girls...??

Unfortunately, this interview was the final one to be carried out and the potential revelation only came during the transcription process. The limitations of the research time frame meant this newly emerging insight could not be carried forward into fresh interviews.

#### Memo (December 2012)

##### Educational setting constraints

I found it difficult to reconcile my position as a researcher in an educational setting I had been given permission to work in by staff. The educational staff were present in the interviews and on a couple of occasions when I would have liked to follow up

more strongly some of the technical limitations the participants alluded to, I felt uncomfortable in case I appeared to be criticising the setting. The main times this happened were when participants said they wanted cameras on their communication devices so they could use Skype or Facetime. This is tricky because most digital devices nowadays have inbuilt cameras (phones, laptops, desktops, iPads). The participants really seemed keen to have this. I knew it is an issue for residential settings and educational colleges in terms of personal care and also as pointed out by the Head of technology about consent. So I felt it was difficult to pursue this with participants in establishing how much they might want it, why they wanted it etc. without it becoming potentially pressurising for the setting who may be seen as not providing it. Also one college setting said they were working towards trying to put cameras in devices which seemed at odds with what I was told by other colleges.

#### ***4.13. Generating the grounded theory of internet and social media use by young people who use AAC***

The section explains the process by which the following proposed grounded theory of internet and online social media use by young people who use AAC was generated. This follows the process described in the methodology chapter (section 3.6.3.8.) to answer specific questions around the core category. This was identified as the desire to use the internet and online social media. As explained earlier, theoretical thinking has developed using a hybrid approach; firstly by following the guidance outlined by Charmaz (2006) to seek to construct a story which explains the data. Secondly, utilising suggestions for the axial coding of Corbin and Strauss as outlined in the lecture material delivered by Graham Gibbs (Gibbs, 2010). The proposed grounded theory of internet and online social media use by young people who use AAC as a schematic representation of the information is presented below (Figure D).

##### *4.13.1. Nature of the theory*

To answer my research questions I am posing the following grounded theory about the use of the internet and online social media by the participants. It is grounded in and constructed around my interpretation of the data and is an interpretative theory. It

is reflexive as it relies on a subjective interpretation of the data which has sought to explain the connections, context, conditions, interaction and actions within a theoretical framework symbolic interactionism in order to explore concepts of social participation and inclusion (Charmaz, 2006).

#### *4.13.2. Central phenomenon*

The identified core category was the desire to use the internet and online social media. Across the interviews the consistent emotion expressed was the happiness and excitement that using the internet and online social media offered. The desired goal was often to have independent access but working collaboratively was also appreciated and desired. The desire for use was perceived to have been generated by the exposure to a variety of causal conditions.

#### *4.13.3. Causal conditions*

This part of the proposed theory explains the variety of conditions which have created the desire to use the internet and online social media. The first of these is the access technology that allows the participants to use mainstream computers. Secondly, an alternative route is the increased opportunities to use mainstream internet and online social media tools within integrated VOCAs. Human support seen for the introduction of the internet and online social media through family, friends or educational settings was also an important causal condition. Some participants requested to use the internet and online social media and some were supported through collaboration to create an online social presence. Once online the participants reported using a variety of internet and social media for a variety of activities which further fuelled the desire to continue using the internet and online social media.

#### *4.13.4. Limitations for achieving the central phenomenon*

The three way arrow within the model expresses how the causal conditions and central phenomenon are confounded in many ways by limitations for use. Limitations in terms of technology within VOCAs to interface with mainstream technology and mainstream technology design flaws can frustrate use in a variety of functional or operational ways. There is limited evidence within the data for the use of the newly

emerging mobile technologies which have voice output Apps despite great expectations expressed within the literature base. Parental and staff technical knowledge and motivation to use technology can also impact on whether the central phenomenon is achieved. A lack of response to participant requests and/or difficulty in communicating desires can also impact on success. Frustrations in terms of lack of privacy if collaborating, funding constraints and technical support post transition from educational settings can also be an issue

#### *4.13.5. Context*

This element of the proposed theory expresses the context within which the central phenomenon is achieved. The internet and online social media are used within home, educational and residential settings and frequency of use ranges from once a week to daily depending on individual circumstances.

#### *4.13.6. Interaction/actions*

This section of the proposed grounded theory expresses who else is involved in achieving the central phenomenon and why and how they are involved. It also seeks to explore if participants can act alone to achieve the desired outcome. The data revealed a wide range of people are involved within the visited educational settings, family and friends and other agencies such as the NHS, communication aid manufacturers and the Communication Matters AAC national charity. The reason for the involvement of outside agencies is to support and respond to the desire of the participants to use the internet and online social media which is achieved through advice, training, funding, collaboration, equipment supply and set up. The participants illustrated how they can work independently provided the correct conditions have been established for them to do so.

#### *4.13.7. Strategies*

The strategies employed by participants and their communication partners to bring about the central phenomenon are outlined within this part of the proposed theory. These relate to sourcing information about and availability of access technology, requesting technology (for example cameras), learning how to use equipment, having

equipment set up by technical teams and receiving and responding to training. Strategies which support independent use in addition to having the correct equipment are becoming literate. If not literate, then using symbolised vocabulary software within VOCA devices to access hotlinks to social media tools or finding suitable partners to collaborate are alternative strategies.

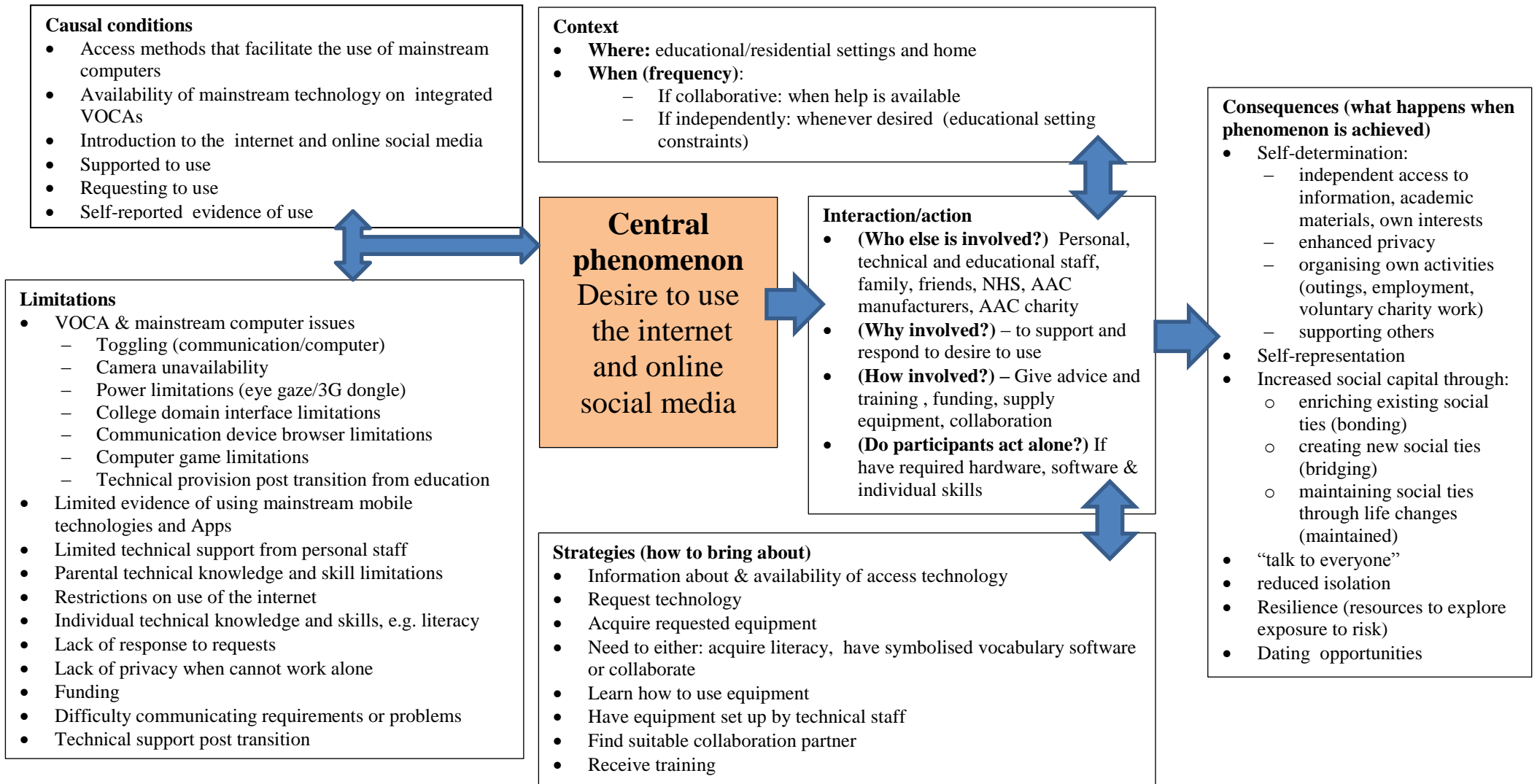
#### *4.13.8. Consequences*

The participants and their communication partners identified consequences of achieving the central phenomenon through their descriptions of self-determination, self-representation, increased social capital opportunities which had advantages associated with feeling able to “talk” to people and feel less isolated. Using the internet and online social media were also important resources for demonstrating resilience and there was a small amount of data which may suggest that the dating opportunities are supported.

#### *4.13.9. Summary*

The sections of the proposed grounded theory of internet and online social media use by young people who use AAC discussed in detail above are summarised in diagrammatic form in Figure D (presented below). Chapter Five will discuss the significance of the findings within the context of the existing knowledge base and examine the relevance and contribution of the proposed grounded theory of internet and online social media use by young people who use AAC in terms of social inclusion.

**Figure D: Proposed grounded theory of internet and online social media use by young people who use AAC**



## **Chapter 5**

### **Discussion**

#### ***5.1. Introduction***

This chapter illustrates how the research objectives have been addressed by the proposed grounded theory of internet and online social media use by young people who use AAC. Each area of the grounded theory developed within the preceding chapter will be discussed within the context of existing knowledge and the significance and relevance of the contribution of this thesis will be described.

The primary purpose of the current research was to explore self-reported factors surrounding the use of the internet and online social media by young people who use AAC. This topic was distilled from broader concepts regarding the need to include the views of young people with disabilities within research (Morris, 2003; Cavet & Sloper, 2004; Farmer & Macleod, 2011) and a desire to explore the impact of communication technology on social interaction issues from the viewpoint of young people with complex communication needs. The research project evolved to focus on how self-reported experiences of internet and online social media use may be impacting on the social relationships and self-identity of young people who use AAC.

Although the literature base for the use of the internet and online social media is broad and descriptively rich for adolescent populations, this study is distinctive in its examination of how young people who use AAC are engaging in an online environment as the literature base is extremely limited for this specific group (AAC-RERC, 2011; Raghavendra et al. 2012b). As described previously the proposed theory is grounded in the qualitative data from twenty-five interviews with people who use AAC, three interviews with educational setting staff members, video recordings of the interviews, participant demonstrations, field notes and policy documents (section 3.6.2.6.). The proposed grounded theory was developed by asking questions of the nine categories that had emerged from the coding process to create a coherent story. These questions were drawn from lecture material delivered by Graham Gibbs on the



axial coding of Corbin and Strauss (Gibbs, 2010) and the guidelines of Charmaz (2006) related to,

*“seeing possibilities, establishing connections, and asking questions....the content of theorizing cuts to the core of studied life and poses new questions about it” (p. 135, emphasis given by Charmaz)*

Respondent validation was carried out through sharing a summary of the findings via email with some of the interviewees. Creswell and Miller (2000) and Pickl (2011) both discuss the importance within qualitative research of seeking the views of experienced people within the field of study who are not connected to the research project. Within this study, feedback was sought from audiences through presentations given at the annual UK Communication Matters AAC conference (Hynan 2011a, 2012b), with follow up articles appearing in the Communication Matters journal (Hynan, 2011b, 2013) (Appendix J and L), and a paper presented at the 15<sup>th</sup> biennial International Society for Augmentative and Alternative Communication (ISAAC) conference (Hynan, 2012a). The theory establishes a construct-focused framework for understanding the interrelated factors that young people with physical disabilities and complex communication needs navigate in order to achieve their desire to use the internet and online social networks whilst outlining the perceived consequences.

*The research objectives:*

1. To investigate the self-reported experiences of the accessibility of the internet and online social media for people who use AAC
2. To investigate the self-reported use of the internet and online social media by people who use AAC
3. To explore the perceived role of the internet and online social media for self-representation
4. To establish how online social media is perceived in terms of social ties for people who use AAC

The areas of the theory that address the first two research objectives to investigate the self-reported experiences of (1) the **accessibility** and (2) the **use** of the internet and online social media for people who use AAC, are: *the causal conditions, the*

*limitations, the interaction/action, the context and the strategies.* Research objectives (3) **online self-representation** and (4) **offline/online social ties** are predominantly addressed within the *consequences* part of the theory although elements of research objectives (1) and (2) come into play here as well.

Within the following discussion, the names of specific VOCAs and their manufacturers have been omitted. The purpose of this research is not to favour or critique particular types of VOCAs. It has been necessary however, to name companies such as Apple and Google in order to explain certain phenomena. Due to the enormous size and global reach of these companies, the issues of naming them are not considered comparable with the concerns of naming specific VOCA manufacturers within a small specialised field.

## ***5.2 Central phenomenon***

The central phenomenon of the proposed grounded theory identified was that young people who use AAC have a *desire to use internet and online social media* due to perceived positive benefits but many challenges exist for achieving access and use, especially independently. Research has shown that the current generation of young people have a strong interest in online activities and using the internet is thoroughly embedded within their lives (Livingstone et al. 2011). Sociological theories report adolescence is a time when bonds to parents weaken and peer relationships become more significant (Mesch & Talmud, 2010). The internet and online social media are playing an increasingly important role in the lives of adolescents (Subrahmanyam & Greenfield, 2008) with many claiming they could not live without the internet and love how new technology helps them communicate with people (Hulme, 2009). Helseth and Misvaer (2010) found that psychosocial elements, in particular peer relationships, were how adolescents evaluated their quality of life rather than through traditional health related concepts.

Within the current study, the desire to use the internet and online social media (especially Facebook) was unanimously expressed which supports previous findings within the AAC literature base. McNaughton and Bryen (2007) stated

*“individuals who use AAC have clearly spoken to their interest ... to use their AAC device to ‘communicate’ with personal and mainframe computers as well as other devices” (p. 223).*

Cooper et al. (2009) in their interview study on the loneliness experienced by people who use AAC noted

*“all of the participants spoke about their experiences of using communication technologies such as mobile phones, telephones, the Internet, and email, and agreed that they were beneficial to maintaining positive friendships and relationships”*

(p.159)

although Cooper et al. noted there were mixed experiences of success based on challenges for access and usability. The three-way arrow within the proposed grounded theory (Figure D) attempts to reflect the co-dependent relationship between the causal conditions and limitations and their impact on the central phenomenon. A desire to use the internet has to be fostered by exposure to and use of the internet and online social media yet, once achieved, this very desire can also be frustrated if it cannot be enacted to a perceived satisfactory level.

### ***5.3 Causal conditions***

The causal conditions within this grounded theory that have set the stage for using the internet and online social media were identified as:

- the access methods and technical innovations that have increased the opportunities to access and use mainstream digital technology and the integration of this into AAC devices
- the human support received from families, friends and educational settings
- requesting to use and evidence of using the internet and online social media by young people who use AAC

These were evidenced by the self-reported engagement with various online activities that has fostered the desire to use the internet and online social media. Each participant has a unique profile in terms of individual motor skills, cognitive ability and language/literacy development that has a bearing on how they engage with digital technology. In terms of motor skills, some participants were able to operate

equipment directly using touch or eye pointing systems and others required an additional piece of technology (for example a switch) to control a scanning system. Cognitive, literacy and language skills also had an impact on the level of support required in order to use the internet and social media sites. Ellcessor (2012) discusses within the conclusion of her thesis ‘Access ability: policies, practices and representation of disability online’ that,

*“Differences in access, and in the accessibility of media technology and content, may lead to particularly interesting innovations, negotiation, and reconfigurations of the experiences of media production, consumption, and interaction. ... Even when accessible conditions exist, differences at the point of entry mean that it is impossible to discuss accessibility without reference to individual needs and circumstances”* (p. 341)

### *5.3.1. Access methods that facilitate the use of mainstream computers*

Some of the participants with direct access and literacy skills reported preferring to use mainstream computers for their internet and online social media requirements although most of them owned integrated communication devices. Despite much progress being made recently in the design of VOCAs that have integrated computers, the literate participants with direct access reported they perceived these to be useful as a form of mobile device but not as the preferred method for going online. This finding supports existing knowledge; DeRuyter et al. (2007) point out the considerable challenges that AAC manufacturers face in terms of facilitating connection with the world through VOCAs such as: anticipating and funding new features, the relatively small market for recovering development costs, the physical difficulties of adjusting hardware and problems of incorporating AAC software into mainstream devices which might need modifications. They say AAC manufacturers tend to be

*“in a “catch-up” mode”* (p. 262)

in relation to the fast moving mainstream technology market and may not be able to supply AAC users with features found in mainstream computer devices.

Participants’ access methods varied, they either used mainstream computers through switches that controlled mouse movements, switch accessible onscreen keyboards or used their VOCAs to drive external computers. Chapple (2011) explained VOCAs can link up to independent computers either through a cable into the USB port or

wirelessly through Bluetooth technology allowing the VOCA to act like a remote control. All of the participants, except one, using these types of access methods for mainstream computers were literate.

There is a substantial body of research that has identified the importance of literacy for people who use AAC across many fields (Light & McNaughton, 2012). Literacy is a key skill and focused teaching has been identified as vital for those who use AAC (Horton, Horton & Meyers, 2001; Sturm, 2002; Sturm & Clendon, 2004; McNaughton & Bryen 2007; Light & McNaughton, 2012). Randy Horton comments that non-disabled children get intensive literacy training in schools which was not his experience within his special educational setting (Horton et al. 2001). Kelford and Smith (1993, cited by Beukelman and Mirenda, 2005), found self-help and communication skills can often take priority over literacy training for children who use AAC.

This study illustrates that literacy can increase opportunities for using the internet and online social media which supports previous research suggesting targeted literacy training should be an issue of prioritisation within the AAC field (Horton et al. 2001; Smith, 2006; Light & McNaughton, 2012). Trembath, Balandin, Stancliffe and Togher (2010) found

*“literacy was a major factor determining the extent to which the participants were able to express themselves clearly”* (p. 82)

making it easier for people who use AAC to initiate and engage with volunteering activities. Light, Stoltz and McNaughton (1996) found it increased employment opportunities.

### *5.3.2. Availability of mainstream technology on integrated VOCAs*

Four participants who relied on indirect access reported using the integrated computers on their VOCAs. Chapple (2011) describes how the integration of mainstream computer technology within the VOCA device market started tentatively during the 1990s and in 2000 with the [named VOCA] that ran under the Windows CE format and offered mobile phone integration. It provided the first step towards the fully computer integrated VOCAs that are seen on the market today. He explains at

the beginning of 2007 that totally integrated communication devices really started to make their mark within the AAC industry which had particular significance for individuals with severe mobility challenges. This technical development has particular significance within the current study for two participants who had additional literacy challenges by providing them with their first chance to use texting and email independently as their integrated VOCAs allowed them to use their language programmes and personalised access methods to create text messages or emails with symbolised vocabulary.

As identified in the literature review, Brekke and von Tetzchner (2003) discuss how one pathway for people who use AAC is to use pictographic representations that gradually become more complex with the goal to achieve orthographic writing, requiring formal teaching. This difference in approach to language acquisition and possibly literacy development means that conventional instruction for teaching reading and writing skills may not be applicable to people who use AAC who can experience severe delay or never achieve literacy skills (Beukelman & Mirenda, 2005; Erickson & Clendon, 2005).

It is important to remember that people who use AAC often have good comprehension of spoken language but challenges in terms of literacy. The development of software that allows users to access the functions of a computer on their VOCA through symbol or text based vocabulary is opening up opportunities for many people who use AAC to use online communication for the first time independently. The software accesses a wide array of programmes such as text messaging, email, music, games, internet browsing, and popular social media sites. It is the reason why many of the participants within this study can now access the internet and online social media through their VOCAs, which is revolutionising access for those who have literacy challenges and limited mobility skills.

### *5.3.3. Human support to access and use digital technology and online social media*

An important causal condition is the human support given to people with complex communication needs to use digital technology and online social media. Many of the

participants described finding out about and being helped to start using online social media either through educational settings (teachers and technical staff), family (especially siblings) or friends. As shown in the literature review, Raghavendra et al. (2012b) found the digital skills of parents, siblings and friends were significant influences on levels of computer use.

Participants also spoke about working collaboratively with family or personal staff to access, share and input content onto the internet or online social media sites such as Facebook. Naslund and Gardelli (2013) present empirical data from a study carried out with youths and young adults with learning difficulties/disabilities to focus attention on access to and use of information and communication technology (ICT) to support agency. They discussed the importance of working collaboratively with experienced partners as this

*“inspired and motivated the participants to act and use their abilities in meaningful way” (p.10).*

This was certainly the case in the current study, for some participants their initial engagement with online social media was facilitated through collaboration. This not only fuelled their desire to use the internet and online social media but led in some cases to an exploration of whether they could extend their use to other contexts or become independent through hardware and/or software modifications.

Support for internet and online social media use was also identified from NHS agencies and AAC manufacturers. Traditional AAC manufacturers and developers have a good track record in after sales support. The Communication Matters charity has worked collaboratively with educational settings to organise and run training days on e-Safety. Communication Matters also organises national road shows at different locations around the United Kingdom which AAC manufacturers support (in addition to running their own awareness and training days). The author has attended several of these events and field notes confirm social media tools are being incorporated into hardware and software to enable access to social media sites.

The use of two training tools emerged from within the data; an e-portfolio tool called InFolio (<http://www.jisctechdis.ac.uk/techdis/learnersandstudents/infolio>) and a

secure social networking tool called InBook (<http://inbook.jisctechdis.ac.uk/>). InBook was running as a pilot scheme during the data collection period and reports will be issued in due course by the project co-ordinators. The training resources are not intended to be alternative social media sites for people with disabilities, but have been designed to enable educational settings to teach young people (particularly those with disabilities or learning difficulties) how to use social media safely before moving onto mainstream unprotected sites. The training witnessed with the current research is a relevant causal condition as Hoppestad (2013) states many people with developmental disabilities such as cerebral palsy are often overlooked for training in how to use computer technology despite the fact that being online may offer tangible benefits in areas such as

*“learning, entertainment, socialization or self-expression”* (p. 191).

Seale and Cooper (2010) warn that the legal imperatives to ensure e-learning technologies and content are accessible often places emphasis on the accessibility of resources rather than the role teachers can play in adjusting online learning environments. They state it is important to address pedagogical issues as well as technical ones when it comes to supporting disabled learners. The InBook training witnessed and reported on by the participants in the current study highlighted the pedagogical nature of the approach. The project is not designed as a technological exercise to replace existing social networking sites but to allow educational staff to support students to learn the principles of how to use social media effectively and safely so they have a more empowered approach when they leave the ‘walled garden’ environment of the training site.

#### *5.3.4. Requesting to use the internet and online social media*

The issue of requesting to use technology was identified as a causal condition for the use of the internet and online social media although it will also be revisited as a limitation later as some requests were unsuccessful (Strategies - section 5.7). Seale, Draffan and Wald (2010) argue that by applying an

*“expanded, conceptual framework to the analysis of a study designed to explore the e-learning experiences of disabled students [they identified two important concepts] digital agility and digital decision making”* (p. 458).



They argue these are significant as they encourage a viewpoint of empowerment towards the digital inclusion of disabled students that is not based solely through a deficit and barriers perspective. They state that recognising how disabled students can use

*“digital agility to ‘break in’ on their own terms”* (p. 459)

is important for recognising the goals a student may wish to pursue. Digital decision making refers to the recognition of agency by disabled learners to make their own decisions about technology including when they do not want to use digital tools.

The relevance of these concepts is illustrated within the current research as participants demonstrated how they requested access to digital equipment and online social media. For some this created a situation where they worked collaboratively with family or care staff to go online or requested assistive tools to enable independent access. Participants also demonstrated digital decision making by evaluating the strengths and weaknesses of AAC specific and mainstream technology. Decisions were taken depending on requirements, for example, some participants preferred to use an integrated computer on a VOCA due to the increased ability for constant access to social sites such as email, whereas others found integrated aids limiting as their main interest was to play computer games so they preferred more powerful mainstream computers.

### *5.3.5. Evidence of use of the internet and online social media*

The young people (age range 14-24 years, mean 20.04 years) in the current study spoke about using the internet for: interests and hobbies such as fashion, music, sport and theatre, sharing information about joint activities, playing online computer games, academic study, planning trips, shopping online, catching up on television programmes, watching videos, listening to and downloading music and in some instances were able to pursue opportunities for employment and charity work. Using online social media was also very popular; Facebook, Skype, You Tube, MySpace, Bebo, Twitter and Facetime were mentioned as was the use of instant messaging (MSN), email and using mobile phones and texting. These are all activities which are typical of the range of activities described widely in the literature for this age demographic (Mesch & Talmud, 2010) and opportunities for online entertainment and

social communication are known to be strong motivators for young people to digitally engage (Livingstone & Helsper, 2007).

#### *5.3.6. Summary of causal conditions*

The causal conditions for creating the central phenomenon of *desire to use the internet and online social media* are: technical innovations which support access, human support in terms of technical knowledge and training and the digital agency and digital decision making of participants to use technology in ways that suits their requirements. The reported use of the internet and online social media sites across the diverse profile of participants shows options are increasing for people who use AAC. The causal conditions are also a site of tension as limitations within them can disrupt digital engagement.

### ***5.4. Limitations for achieving the central phenomenon***

#### *5.4.1. VOCAs and mainstream computer issues*

Many of the limitations described relate to the integrated VOCAs and/or mainstream technology. Issues seen were: losing the ability to communicate whilst using computing programmes (integrated VOCAs and the iPad), cameras being unavailable on VOCAs, power limitations of VOCAs (3G dongle and eye gaze system could not be used simultaneously), problems linking into college domain from particular mainstream operating systems, processing limitations on some VOCAs to handle photographs or computer games, switch access making it difficult to play certain types of computer games, and the issue of on-going support and technological provision after transition from educational settings. In addition, many of the participants within the current research had older models of VOCAs rather than the new powerful VOCAs described within the literature review which could be why if they had access to mainstream computers they preferred to use these for their internet and online social media requirements.

The importance of collecting this kind of information from specific groups is discussed by Newell (2008). He points out that although progress has been made in

addressing the difficulties people with disabilities have in using computer technology there is a long way to go and different groups are sometimes prioritised by accessibility researchers over other groups. He also warns of the dangers of pursuing the ‘design for all’ approach as it is likely to be unrealistic and may lead to box ticking exercises and ill thought out solutions rather than really examining the needs of specific disabled groups. Pullin and Newell (2007) suggest an alternative design approach to “universal accessibility” should be for projects to start with the needs of specific groups and consider their applications to broader audiences later. This they suggest would encourage innovative and more appropriate solutions to accessibility. An area of frustration for the young people within this study who relied on switch access was the difficulty of choice over, and the challenges of playing, certain types of computer games. Computer games are an area of interest to the young people in this study which explained why limitations were a cause of frustration. Chantry and Dunsford (2010) carried out a systematic review of the contemporary literature pertaining to computer use by children with severe and complex disabilities and its impact on children’s participation. They cited the work of;

- Langone, Malone and Kinsley (1999); Brodin (2000); Lindstrand (2002) and Brodin and Lindstrand (2004) which showed computer technology had opened up opportunities for disabled children to engage in play
- Reid (2002a, 2002b) and Tam, Schwellnus, Eaton, Hamdani, Lamont and Chau (2007) who found virtual computer reality games enabled non-threatening and enjoyable participation by bringing families and peers together in newly collaborative ways

Chang, Chen and Huang (2011) discuss how

*“enhanced hardware or software assistive technology can repurpose many commercial high-technology products”* (p. 2569)

A UK based charity (founded in 2007) called SpecialEffect ([www.specialeffect.org.uk](http://www.specialeffect.org.uk)) supports people with disabilities to play video games by using technology to find ways for them to play to the best of their ability. Fundraising enables them not to charge for the work they do and as Mike Donegan (founder and director) explains on the website

*“anyone, anywhere in the UK can ask us for help and, if appropriate, we’ll buy and lend the necessary video games and access technology to try out for themselves”*  
(website).

Hopefully the view of the future outlined within the literature review by Shane et al. (2012) that technology will evolve to fully recognise the needs of individual users and innovations will offer affordable assistive solutions for overcoming the limitations of computer game playing or mainstream manufacturers will respond to disability rights legislation and start to create fully accessible games.

The observation about the accessibility of computer games leads into another area where the issue of access appeared to have an impact on the technological opportunities for the participants of this study. As illustrated within the literature review, there has been much written about a newly emerging area within the field of AAC in terms of mobile technologies and Apps. The evidence within the grounded theory shows that instead of what may have been expected in terms of benefit there appears to be significant access barriers for the participants within this study.

#### *5.4.2. Limited use of mainstream mobile technologies and Apps*

As discussed in the literature review (section 2.3.3.), the emergence of mainstream mobile technologies and Apps has produced an enormous shift of focus within the AAC field and has been suggested as increasing opportunities for the use of mainstream digital technology by people with complex communication needs. McNaughton and Light (2013) say AAC has been propelled into the mainstream and due to being relatively inexpensive, widely available and popular there is widespread adoption by people who use AAC and their families. Hershberger (2011) discusses how the clinical model of AAC intervention delivery that requires assessment, prescription and funding is moving to a consumer led model where individuals and their families can take over AAC decisions purchasing equipment at much lower costs.

Despite the huge potential and impact of this paradigm shift in the world of AAC, within the current study mobile technologies were not a major influence on the use of the internet and online social media. The use of Windows-based static computers and

mobile phones was evident whereas the use of mobile technologies such as iPads, iPhones, and tablet computers was very limited. Only one participant was using an iPad to access the internet and online social media and support his communication. It was puzzling why there was such limited evidence for the use of mobile technologies and Apps within the data. Some participants directly mentioned their desire to use these mainstream products and the reasons given for not using them were access concerns and a lack of knowledge on how to implement the use of Apps. There was an underlying interest in mobile technologies detected within the data, supported by participant descriptions of wanting to have cameras on their VOCAs to enable them to access social media sites such as Skype and Facetime with friends and family. This was also supported by the two heads of technology who reported netbook computers were available within one residential college setting and students were beginning to bring mainstream devices into another non-residential college setting.

The low level of reported use would support findings within the literature base of access problems to mainstream devices by people with physical disabilities (Goggin & Newell, 2003; Harris 2010; Macdonald & Clayton, 2012). Knowing how to establish access can be difficult, for example switch access for the iPad, iPhone and iPod market are only recently becoming established and it takes time for information to become widespread. The internet can be a source for distributing information as evidenced by Jane Farrall's blog site (29.10.12) which described two sorts of switch access to iPads: "switch access to individual Apps which have built-in scanning and switch access to iOS through Voiceover" (Farrall, 2012). The first description refers to an external switch which is linked to an iPad via a bluetooth connection with an iPad switch interface. Into this interface external switches can then be connected and used to select items within a specific 'app' which has been created as switch accessible by the app creator. This means it is necessary to establish whether a desired app is switch accessible. The other option for switch access to iOS through Voiceover describes how Apple have recently added a feature to Voiceover allowing control with a keyboard, a Braille keyboard or a large button controller (connected via Bluetooth). Again, it depends whether the desired Apps are compatible with Voiceover and another issue can be that Bluetooth switch interfaces also drain the battery power of an iPad. Farrell has also created a blog (9.6.13) which gives

information about switch accessible Apps for iPads and iPhones (Farrall, 2013). The latest news is that iOS 7 (the latest launch from Apple) has incorporated ‘switch control’ as standard into their accessibility settings (ablenetinc, 17<sup>th</sup> September, 2013). Ablenet have provided a YouTube video which explains how to set up switch control (<http://www.youtube.com/watch?v=fqWkNx27DM>). This is being predicted as a huge game changer and the access challenges reported within this research could be completely changed by this innovation.

Fager, Beukelman, Fried-Oken, Jakobs and Baker (2012) in their review of access interface strategies outline the rapidly expanding options for people who use AAC such as head/eye movement, head pointing, recognising residual speech, brain computer interface and gesture recognition yet conclude that access technologies although developing are still the main barrier preventing the use of iPads and other mobile tablets for individuals with severe mobility challenges. Chapple (2011) describes the lack of alternative access for AAC users within the mainstream device market as

*“stepping back into the Stone Age”* (p.36).

As Ellcessor (2012) warns the focus on whether technology can overcome disabling hurdles may create additional pressure on disabled individuals. Excluded groups may find

*“their relative position in society will worsen”* (van Winden, 2001:867)

and Cook (2011) suggests it is how well innovations are applied to enhance communicative opportunities that is important for people with complex communication needs. McNaughton, Bryen, Blackstone, Williams and Kennedy (2012) suggest access solutions need to identify person-centred solutions as people who use AAC are a ‘diverse’ population and it is unclear whether Apps will address the needs of all people with complex communication needs, especially those with cognitive difficulties.

The fledgling interest expressed for the use of mainstream technologies within this study may support the literature base that shows AAC users can find their specialised devices unattractive. Smith (2005) commented for many adolescents and young adults who use AAC the look of a device is important and a traditional VOCA may be

rejected because it is not perceived to be cool. Clarke et al. (2001) found some young people who used AAC devices thought they looked stupid and were embarrassing to use. As Pullin (2009) says

*“All the qualities of a communication aid – its sounds, appearance, and interactions - contribute to the shared experience of its use”* (p. 6)

and Higginbotham (2010) concurs

*“Pullin’s book and design philosophy have a lot to offer AAC research ... attraction to the iPhone and iPad appears to be based not only on cost and function but also on visual attractiveness and identification with other users of this “cool” technology”* (p.228)

The lack of evidence supporting the use of mainstream mobile technologies within this study is a source of tension in regard to the central phenomenon relating to the *desire to use the internet and online social media*. It is also worrying if the underlying reason for the lack of more extensive use is due to the issues alluded to by two participants about access factors and lack of knowledge. People with physical disabilities and complex communication needs could become increasingly isolated and frustrated if they cannot achieve the same online access as the majority of society. Livingstone and Helsper (2007) warn a digital divide amongst young people who can and cannot access digital resources threatens social inclusion as most young people expect their peers to be online and social media use is integral to their relationships. Soderstrom (2009) says young people who are unable to engage with online activity are at risk of being marginalised and excluded from their peer communities.

This situation revealed within the current study also has implications in terms of the UN Convention on the Rights of Persons with Disabilities which places an obligation on member states to ensure people have access to cultural materials (United Nations, 2006). The AAC-RERC White Paper (2011) states, people who use AAC

*“have a need for, and a right to, the same range of communication options available to everyone else”* (p.3)

and Williams, Krezman and McNaughton (2008) are emphatic about the fact AAC must offer full participation in 21<sup>st</sup> century life and enable people to use: the internet,

computer games, multi-media formats and social media to maintain their social relationships. Hyatt (2011) discusses

*“Being able to whip out my iPad from my handbag and having a choice of communication methods for when I’m on the go is life changing. Technology is finally catching up with my needs” (p. 26)*

Bednarska (2009) questions (on a wider disability discourse platform than the field of AAC) whether many disablement issues are being side-lined in the excitement generated by technological solutions. She warns technology may not universally serve everyone’s needs and time constraints for access and increased expectations of productivity can create new areas of pressure for people with disabilities and also lessen the availability of human support.

#### *5.4.3. Restrictions on use*

The inclusion of ‘restrictions on use’ within the limitations part of the grounded theory is debatable as Livingstone, Bober and Helpser (2005) revealed parental internet restriction may not produce a negative outcome in terms of developing internet literacy. This ‘catch 22’ is accommodated within the grounded theory by the three way arrows between causal conditions, limitations and desire to show the interrelated nature of the grounded theory elements. The main restrictions of use in the current study relate to the regulations within educational settings on when the internet and online social media can be used and the small amount of evidence that emerged for attempted parental restriction over the use of social media sites. There is however, a less concrete form of restriction exercised through the act of collaboration.

Firstly, the discussion will deal with the restriction on use of the internet and online social media described within school and college classroom time. This is a challenging issue within education as seen from Campbell’s (2006) discussion on the use of mobile phones within classroom settings. He points out social perceptions towards whether the use of a device is acceptable relates in some ways to perceptions of private and public spaces. His survey data from mainstream students found some participants had strong attitudes towards classrooms as places where people could



reasonably expect not to be distracted along with concerns about cheating but also evidence of more tolerant attitudes amongst younger generations.

The special educational settings within the current study face a particular challenge from mobile camera technologies as they have heightened responsibilities to protect pupils considered to be vulnerable. It was clear that participant requests for cameras on VOCAs, and the incidental introduction of cameras through iPads being used as communication devices, was being addressed through policy development. This is a broad issue within society with camera/smart phones becoming ubiquitous for most people and often regarded by parents as security for their children (Parry, 2005). A Google search on the use of phones in schools produced a plethora of policy documents issued by schools and local councils. The content of most documents reveals the acknowledged benefit to education of photographing pupil's activities and achievements but also the risks of material being misused. Policies exist to protect staff, guide parents on what is acceptable and outline whether devices can be allowed onto school premises. The National Union of Teachers (26 October, 2012) have issued a document relating to the health and safety issues of mobile phone photography in schools. They point out the rise in smart phone use has exposed schools and teachers to increased risks and policies must be developed to address the threat. The document points out the risks for sending offensive pictures and messages and the dangers of taking photographs surreptitiously, which can then be manipulated and sent to websites and be very difficult to track down and delete. The document also outlines the distressing practice of 'happy slapping' where a bullying incident is filmed and distributed. The suggestion is for two main strategies: one a complete ban on all mobile phones or allowing phones on school premises but requiring them to be turned off and kept in bags. They suggest the use of camera detectors may help enforce policies but because parents can see phones as a form of security it can be difficult to enforce policies. Parry (2005) discusses the law and practice related to camera/video phones in schools and the article concludes due to the widespread use of devices, educational authorities should be wary of outright bans and work to create appropriate policies and agreements on use.

Moving onto parental (or personal staff) concerns, Mesch and Talmud (2010) speak of the adjustment families go through when the internet comes into the home environment. They say the family becomes “*exposed to large amounts of information*” (p. 37) that may be positive and negative and parents may try to mediate by either explaining media content to guide children and teens or by reducing access and trying to prevent exposure to unwanted content either through parental rules or restricted access to web pages. Springhall (1998), cited by Richman (2007) argues that historically the views of entertainment in childhood often vary between older and younger people. Older people can have sentimental ideals about what type of entertainment youth should engage with which may well be at odds with the interests of young people.

Livingstone, et al. (2005) revealed survey data from parents relating to internet rules and regulations revealed two categories of *restriction* (protecting privacy and restricting activities to connect to peers) with evidence of less restriction on older adolescents (16-17 years) than younger children (9-15 years). Peer restrictions reduced risks but also opportunities because of less time spent online possibly affecting internet literacy. The attempted parental peer restriction in the current research supports Dutch research by Lathouwers, et al. (2009) discussed in the literature review. Their large comparison study of internet access and use between 1566 non-disabled and 97 adolescents with physical disabilities found similar online interests but young people with disabilities faced tighter parental controls and were warned more about online activity. The current study illustrates how the technical knowledge and support offered within special residential college environment enabled many of the participants to have increased digital independence.

The ‘catch 22’ restriction on use mentioned earlier relates in the current study to the act of collaboration. Livingstone et al. (2005) identified two types of parental monitoring: supportive (which includes overt monitoring and co-use of computers) and checking up (covert monitoring of computer use). The act of collaborating for the young people within this study places them within the supportive category where their co-use of the internet leads to overt monitoring by parents or staff. Livingstone et al.

(2005) questioned whether parental intervention can make a difference. They concluded there was

*“no simple direct relationship between implementing more or less parental regulation and the opportunities or risks that children encounter”* (p. 19)

but peer restrictions and supportive practices had a direct influence on opportunities and risks. Whereas peer restrictions reduced risks but also opportunities because of less time spent online, supportive co-use practices increased opportunities and were unrelated to risks. No evidence of covert monitoring emerged within the data but as it was based predominantly on the self-report of young people who use AAC it would seem logical that participants would not be aware if they were the subject of this type of protection.

Raghavendra et al. (2012b) mentions parental reports of covert monitoring where social networking is checked for who is known and where from and more overtly agreed rules where restrictions are placed on only contacting people known to the family, computers are located in central areas where they can be monitored and rules are made around online purchases, time limits, use of approved sites, appropriate postings and parental passwords. The mean age of participants in their study was 14.6 years and within the current research it is 20.04 which may be of significance. Within the current research, the data revealed acceptable use of the internet and online social media within educational setting may be considered especially within teaching timetables and the suggestion was made that abuse may lead to restricting internet access. This may indicate that educational settings would need to (or already do) monitor or block internet content. Raghavendra et al. (2012b) found school IT classes were often vital to learning how to use email and websites but school rules often limited use, especially for social networking and entertainment, but these tended to vary between schools and grade levels.

#### *5.4.4. Limited technical support from personal staff*

There was a small amount of evidence within the data that participants experienced a lack of support from personal staff in terms of collaborating to use the internet and online social media. A lack of interest in computers by personal staff was one reason given and the other was to do with staff turnover and losing access details to a

participant's Facebook account which had not been rectified by new staff. However, it is difficult to make general judgements based on isolated incidents observed during the research process as Slater (2013) warns researchers must be wary of making

*“snap judgements about an organisation”* (p. 126).

Many of the participants could only access the internet and online social media through collaboration. Field notes from observations and discussions with staff within the researched residential educational settings showed much of the onus to collaborate on the use social media use falls on the personal assistants. As seen within the data, there was no universal approach to how social media collaboration was implemented across the research sites. Each setting had differing policy guidance and sometimes policies had evolved in reaction to unforeseen incidents. The main priority was ensuring the safeguarding of young people who use AAC and management teams described working collaboratively with staff to develop policies that protected their privacy and safety but also recognised the positive aspects of social media to support social relationships. Personal assistants were asked about their Information Technology (IT) skills at interview, and training could be provided, but it was not a compulsory skill. Challenges identified for personal staff when working collaboratively to input and share content on social media sites were: professional boundaries between home and educational environments, entering into potentially private relationships with families and friends and knowing how to handle, report and negotiate disclosure of potentially negative content. Collaborative social media use may be a newly evolving role for the personal care workforce. The National Survey of Care Workers (Hall & Wreford, 2007) revealed the following demographic profile from data collected from 502 care workers between September 2006 and July 2007,

*“71% of care workers were female, 24% were under 35, 51% aged between 35 and 54, and 25% aged 55 or over. 94% were of a white background and 60% were in the lower social grades of C2DE ... the average hourly wage was £6.87”*

There may be challenges for the personal digital technology skills of this work force based upon this demographic profile. Morris, Goodman and Brading (2007) found computer use was less popular among the older generation and Clayton and

MacDonald (2013) report digital access opportunities are influenced by socio-economic status.

The limited database surrounding the use of online social media by people who use AAC has impacted on the ability to relate this finding to previous research within the field of AAC but the following issues identified for the use of Information and Communication Technology (ICT) by staff in residential and day care centres for people with learning difficulties/disabilities may be of relevance in this study.

Parsons, Daniels, Porter and Robertson (2008) found the provision of equipment and training was not sufficient to ensure the use of ICT with and by people with learning difficulties/disabilities. Factors identified as important for implementation were primarily: time, training and budget but on a secondary level the beliefs of staff and the organisational culture were relevant. Some staff expressed concern about the suitability of ICT for older and less-able service users and worried it negatively impacted on interpersonal communication. It was also noted despite similar levels of equipment, training and support that ICT use differed across different sites.

Some participants within the current study were using the internet and online social media through their integrated VOCAs. Personal staff may not have the knowledge or training in relation to these more specialised pieces of technology and so they may find it difficult to support internet and online social media access through this type of integrated VOCA. Stancliffe, Larson, Auerbach, Engler, Taub and Lakin, (2010) found staff knowledge about specialised AAC devices can impact upon use by suggesting

*“our results are consistent with the existence of a systemic weakness in staff knowledge and skills concerning AAC that likely greatly hinders service users’ communication opportunities (p. 93)*

Demetriadis et al. (2003) evaluating an ICT secondary school teacher training project in Greece found teachers expressed an interest in ICT but needed training and consistent support as many were novices to ICT. Interest was high for commonly used tools but not so high for specialist applications. Negative attitudes were seen in relation to bad experiences of previous training, reluctance to work outside their

scheduled timetable, feeling ICT was not their responsibility and took up too much of their time and a lack of confidence in their own ICT skills meant they avoided working on projects alone.

#### *5.4.5. Parental technical knowledge and skill limitation*

Parents were sometimes shown by self-report and description from AAC users to lack the technical skills to support use of the internet or online social media or were not interested in using sites such as Facebook. Siblings were mentioned more frequently than parents as supporting online social media use. Raghavendra et al. (2013) reported on an intensive intervention programme to teach internet skills to young people with physical disabilities which suggested benefits in terms of increasing social participation. They also suggest there is great variability between families and friends in terms of technical knowledge and digital literacy abilities for supporting the use of internet by young people with physical disabilities within the home.

Within this study, accessing information was also mentioned as a problem by one source and participants reported receiving information and training through schools, colleges or AAC manufacturers. A new knowledge base resource (<http://www.aacknowledge.org.uk/>) has recently been launched on the Communication Matters website (the first of its kind in the world) which aims to empower AAC users, parents, support staff and professionals by offering up-to-date information across a range of areas. As outlined in the literature review, Garcia et al. (2011) found low levels of computer use within the home environments of young people with physical disabilities and complex communication needs in Spain. They suggested this was due to lack of parental knowledge about assistive technology and the financial costs. McNaughton, Rackensperger, Benedek-Wood, Krezman, Williams and Light (2008) in their focus group study with parents of individuals who use AAC also commented that

*“one cannot help but be struck by the frequency with which parents’ efforts to obtain information and services were frustrated”* (p. 54)

Within the UK there is a recognised problem within the AAC field regarding the lack of a nationally co-ordinated strategy for the provision of AAC and there has been a

ten year co-ordinated campaign to try to change this situation which has made significant progress recently. The National Lottery Funded three year Communication Matters AAC Evidence Base research project carried out by the University of Sheffield, Barnsley Hospital NHS Foundation Trust and Manchester Metropolitan University published their final report in April 2013. The University of Sheffield and an honorary researcher from the Barnsley Hospital NHS Foundation trust carried out research into the prevalence of need and service provision of AAC within the UK. They estimated that 0.05% of the population would benefit from powered communication aids but acknowledge this is likely to be a low estimate in the face of advancing technology. In terms of equipment provision they found there is a lack of consistency for service provision across the UK.

Within the current research study a small amount of evidence arose that funding access equipment was a concern and the fact this was not pursued further by the author in subsequent interviews was in retrospect an oversight. The Communication Matters (2013) qualitative research project revealed funding was one of the most commonly raised issues from within the field of AAC. The Clinical Advisory Group for Prescribed Services Report (DoH, 2012) suggested that VOCAs should be nationally commissioned from April 2013 and if this is implemented by the UK government there may be a considerable increase in the amount of centrally available information for parents.

#### *5.4.6. Individual skills*

Individual skills impacted on whether the internet and online social media could be accessed as fully as desired as many websites do not accommodate individual challenges. Some participants identified that social media sites such as Facebook were difficult to read and understand. Hollier (2012) reported that the internationally definitive standard for web site accessibility, Web Content Accessibility Guidelines (WCAG) 2.0, requires twelve different criteria under four broad headings of perceivable, operable, understandable and robust should be applied to all websites. He cites research carried out by Boudreau (2011) that showed many social media sites such as Facebook and Twitter fall short of expected standards and concludes that in practice this means that most social media tools will have some level of accessibility

limitation for consumers with disabilities. Lewis (2010) found frustrations with the design of websites by exploring the use of online social networks through qualitative interviews with people affected by cerebral palsy. The current research found that some of the participants found Facebook too confusing to navigate on their own and needed the support of their parents to be able to use it.

### ***5.5. Interaction and action***

This area of the grounded theory explains how the participants enact the desire to use the internet and online social media by describing the interaction/action required to achieve the central phenomenon. It also addresses research objectives 1 and 2 in relation to accessibility and use of the internet and online social media. Craddock (2006) explored the impact on assistive technology (AT) on quality of life and self-esteem, and also the satisfaction of using AT, by students with disabilities. He found that those who used technology extensively had more than just technical skills; they also had an emotional attachment to devices in terms of what they enabled them to do. He pointed out people are less likely to speak about the design and capabilities of a device and are far more likely to describe the benefits and context of how a device is used (where, when, how and with whom).

This area of the grounded theory is where questions are asked of the data in relation to who is involved, why and how are they involved and can a participant act alone to achieve the central phenomenon? In terms of who is involved, the data revealed parents, family members (especially siblings), personal staff, teaching and technical staff within educational settings, health professionals, AAC manufacturers and AAC based charities. How they are involved is predominantly to provide support by giving advice or training, supplying and repairing equipment or by working collaboratively to co-create, share and exchange content information and ideas. Approximately two thirds of the participants at the time of the interview had received the relevant hardware for access, software to enable them to create content, and had the individual skills to create, share and exchange content so they could act alone although they may have needed help to make cable connections in order to get started. It was apparent they had received help and training in reaching this stage. The other participants



ranged from needing support for their literacy skills but otherwise operated the equipment independently, to needing the full support of a communication partner to operate equipment and create, share and exchange content. As Skype does not require text input some participants once they had received help to log on and set up could communicate with family and friends using their individual total communication strategies.

Collaboration to set up and use technology has been documented as effective for people with disabilities; as previously mentioned, Naslund & Gardelli (2013) studied communication technology (ICT) use by people with learning disabilities. They reported introducing computers through collaborative working supported the communication of the participants and facilitated the use of new tools. Raghavendra et al. (2012b) found participants with physical disabilities had emphasised that their siblings and friends were heavily involved in teaching them digital skills and had showed them how to use the internet and helped them to use certain sites and also connecting with them online. Raghavendra et al. (2013) reported participant perception of an internet intervention programme described it as beneficial because

*“it was on their own computer, and in their home environment”* (p. 558).

Brekke and von Tetzchner (2003) outline a case study describing how a young man was helped to use his VOCA. The focus was on his independent use, which was unsuccessful due to his motor impairment issues, and led to frustration rather than success. They suggest if he had been supported by an adult who had operated the VOCA under his direction this might have supported his communication repertoire by increasing his exposure to communicative situations. Within the context of the current study, it was evident that working collaboratively to use mainstream technology with a literate adult on motivational activities (such as Facebook) has enhanced the opportunity for orthographic exposure.

Despite the known difficulties outlined earlier in relation to the difficulties people who use AAC have in acquiring literacy, Beukelman and Mirenda (2005) say in recent years

*“we have made considerable gains in understanding the literacy learning process for people who rely on AAC”* (p. 352)

but that there are still limited resources and research to support implementation of programmes. Smith (2006) states it is possible for people who use AAC to acquire literacy. She discusses two compilations of essays that contain reflections of learning to read and write by or with people who use AAC; *Waves of words* (Erickson, Koppenhaver, & Yoder, 2002, cited by Smith, 2006) and *Speak up and spelling it out* (Fried-Oken & Bersani, 2000, cited by Smith 2006). Smith (2006) outlines some of the salient points relating to literacy instruction for people who use AAC as: find ways of incorporating independent communication, take advantage of motivational activities and raise expectations of literacy achievement, ensure exposure activities are relevant and meaningful, build goals around reading, writing and spelling, use VOCAs and other technologies, and be flexible and able to adapt to goal achievement. (Nunes da Ponte, 2002, McNaughton, 2002, Gandell & Filippelli, 2002, Wershing & Hughes, 2002, Hogan and Wolf, 2002, Bialik & Seligman-Wine, 2002 are cited by Smith, 2006 as having used examples of these strategies respectively). Smith also outlines how the acronym SCRAWL can help to introduce these factors in practice: **S**hared stories (constructing narratives), **C**omprehension (exploring written texts supports vocabulary, syntax and morphology), **R**apid recognition (exposure to high frequency words encouraging whole word recognition), **A**nalysis and articulation (exposure to articulatory characteristics of sounds), **W**riting and finally **L**anguage, literacy and literature.

Many participants within the current study worked collaboratively with parents and personal staff to access the internet and online social media sites. There may be implications from the collaborative use of online social media that impacts on the emerging literacy skills of people who use AAC. Sitting beside a literate companion and having the opportunity to co-create content, watch that content being constructed, observe the written responses and hear them being read may fulfil many of the elements suggested by the SCRAWL acronym within a highly motivational environment. The high level of interaction was particularly evident within this study in the educational settings. Teaching and technical departments worked closely with the young people to help them develop the necessary skills and acquire the relevant equipment in order to use the internet and online social media. This poses different

questions not considered within this thesis regarding the level of support post transition into adult services.

## **5.6. Context**

This part of the grounded theory addresses the issue of where and when the interaction/action to facilitate the use of the internet and online social media occurs. As stated in the literature review, since 2010 the UK Equality Act states schools and higher education institutions have a responsibility to improve “*the delivery of information to disabled pupils*” (Home Office, 2010, Chapter 15, Part 6, Chapter 1, Section 88, Schedule 10).

As illustrated within the other sections many of the participants were engaging with the internet and online social media within their educational settings but also at home with family, friends and/or personal care staff.

In terms of the context of ‘when’, defined within this study as frequency, this was highly dependent on whether use was collaborative or independent. For those working collaboratively they would have to wait until help was available, in some cases this was only at the weekend when they went home and were able to work with personal staff or parents, which could also be subject to shared resources within the home. Raghavendra et al. (2012b) reported competing uses at home could create a barrier as children and parents often vied for access, especially when families only had one shared computer (also mentioned in this study). For those able to work independently, they were technically free to use the internet and online social media when desired within the limitations of educational setting restraints and parental limitations (as previously discussed).

## **5.7. Strategies**

This part of the grounded theory refers to the strategies that participants and others have to engage with to bring about the desired use of the internet and online social media. Many issues within this part of the grounded theory overlap with other areas but the *focus* is on what factors the young people have to either initiate proactively or

respond to in order to experience using the internet and online social media independently or collaboratively.

Clearly, having the right information is important as was demonstrated by Peter's visit to a further education college which revealed how he could use a computer independently through Switch XS™ software. As discussed in 'Requesting to use the internet and online social media' (section 5.3.4.) some of the young people negotiated the desire to use the internet and online social media by requesting equipment or assistance. Although there are examples of success there were some examples when making requests for equipment were unfulfilled. As discussed in section 5.3.4. attending to conceptual factors such as digital agility and digital decision making and recognising young people who use AAC as empowered is important. It was not clear from participant report why there had been a failure to respond to their requests and these issues would need to be explored more with technical departments. These departments undoubtedly work very hard to support students and field note data revealed sometimes colleges and schools have to rely on outside agencies for equipment supplies or repairs as well as individual funding packages. Therefore the reason some of the students did not appear to have the equipment they wanted may not be down to staff within educational settings. However, whatever the reason, the outcome is that lack of access heightens the risk of digital exclusion and a small number of participants articulated they had challenges in relation to using the internet and online social media to the extent they desired.

Other vital strategies are learning how to use access technology, having equipment set up and receiving training. As discussed in section 5.5, most of the participants within this study acknowledged they had required help to initially set up their use of the internet and online social media but once online many of them were able to teach themselves how to use websites and services. The CEG report (2009) said

*“lack of awareness about the access technology available, and of the ways in which it can help break down the barriers to the Internet, is another key issue in looking at the low take up for disabled people” (p. 2)*

A clear picture emerged within this research that literacy skills were an important strategy for independent use of the internet and online social media as many physical limitations could be overcome with appropriate access technology. Although the development of the software programme described earlier is having an enormous impact and allowing participants without literacy to use online social media for the first time, it is still clear that a lack of literacy skills had the biggest impact for preventing sophisticated and broad internet and online social media engagement. This supports the research of Raghavendra et al. (2013) who found for some participants *“literacy skills were a bigger barrier than their primary disability or technical issues”* (p. 558).

By building on the motivation to use social networking and scaffolding reading and writing with screen reader and word prediction software, Raghavendra et al. (2013) enabled successful social media engagement. They showed by case study data that one young man who had been working collaboratively was delighted after 11 months of intervention when he could independently post and share information on Facebook due to the technical support he had received to overcome his literacy restrictions. Research with a different population of people who have literacy challenges due to dyslexia also reported challenges for making sense of web content as web pages sometimes contained too much information and links and destinations were not always consistently labelled or clear (Freire, 2012). Gillette (2006) showed how the use of hardware and software technology (such as text to speech) helped a young man with learning difficulties/disabilities to improve his literacy skills.

Being able to use symbolised vocabulary on integrated VOCAs was a major strategy for enabling young people with low or non-existent literacy skills to use texting for the first time. Participants were clearly encouraged by this and enjoyed the increased privacy and contact this provided with family and friends. This specific area is being explored extensively by traditional AAC manufacturers who are producing a host of social media tools at software and hardware level. I was supplied with documentation outlining a project (initiated by the requests of students) within one of the educational settings to use a specific AAC software programme to build accessible access to Twitter, Facebook and Skype. This reaction from the manufacturers and colleges in relation to the desires of young people to use the internet and online social media

supports the findings of Harris (2010) who explored why devices are sometimes abandoned by people with disabilities. He concluded that the role of advanced technology should be to

*“enhance independence and provide mainstream solutions that disabled people request”*. (p.427)

As discussed within the previous chapter (sections 4.5.3. & 4.5.4) and within this chapter (sections 5.3.3; 5.4.4.; 5.4.6. & 5.5) collaborating to use the internet and online social media is a hugely complicated issue for: educational settings to address, personal staff to facilitate, parents to manage and young people to navigate. Young people need to navigate the challenges for finding suitable partners to collaborate with. They have to negotiate balancing issues of privacy against being able to communicate with family and friends through a third party. The young people also have to negotiate the lack of knowledge of potential collaborators as reported by the SLT in the raw data, one participant was teaching her personal staff about signing, VOCAs and computers. There are numerous resources produced by local authorities and government departments illustrating the strict guidelines on personal social contact between care staff and their clients. One such example is the ‘Guidance for safer working practices for adults who work with children and young people within educational settings’ published by the Department for children, schools and families (DCSF, 2009).

*“Communication between pupils and adults, by whatever method, should take place within clear and explicit professional boundaries. This includes the wider use of technology such as mobile phones text messaging, e-mails, digital cameras, videos, web-cams, websites and blogs. Adults should not share any personal information with a child or young person. They should not request, or respond to, any personal information from the child/young person, other than that which might be appropriate as part of their professional role. Adults should ensure all communications are transparent and open to scrutiny”* (p. 16)

The educational settings within the current research were keen to support their staff within this area and as discussed in section 5.3.3. are actively working on many levels to navigate their way through the factors of introducing the internet and online social media into settings and supporting young people who use AAC. Colleges can draw much support from JiscTechDis (<http://www.jisctechdis.ac.uk/techdis/home>), a UK

based advisory service on technologies for inclusion and accessibility, who run an Online Accessibility Self Evaluation Service (OASES) which describes itself on their website as a free online tool that can,

*“help staff in different roles understand and appreciate their influence on inclusive accessible practices”*

[http://www.jisctechdis.ac.uk/techdis/news/detail/2011/OASES\\_Award](http://www.jisctechdis.ac.uk/techdis/news/detail/2011/OASES_Award)

## **5.8. Consequences**

The Consequences box of the grounded theory illustrates consequences that occur when the central phenomenon of desire to use the internet and online social media is enacted. Again the observation outlined earlier by Craddock (2006) (section 5.5) is of relevance as he states people are

*“more likely to describe the benefits or otherwise, the effects, the purposes”* (p.22) of a technological device if asked how it is used within their lives. This study found being online was self-reported to offer perceived benefits in areas such as self-determination, self-representation, social capital (bonding, maintaining and bridging social ties), reduced isolation, building resilience and possible dating opportunities.

### *5.8.1. Self-determination*

Self-determination was identified by Milner and Kelly (2009) as one of five fundamental antecedents for creating a sense of community participation by people with disabilities due to being able to use their own skills to achieve autonomy in self-chosen activities. They identified a vital aspect for an experience to feel qualitatively different is the degree of authorship felt. Although their research concentrates on inclusion within a physical community, the conceptual basis they outline is suitable for understanding some of the perceived online benefits revealed for self-determination within the grounded theory of internet and online social media use by young people who use AAC. Smith and Murray (2011) also reiterate the impact for self-efficacy and self-determination as valuable outcome measurements for evaluating interventions for the use of high-tech AAC technology.

In the current study, the participant descriptions of having more perceived control over independent access to: information for academic materials, following own

interests, self-organisation of activities and supporting others have been interpreted and expressed within the grounded theory as indicators of a perceived increase for self-determination due to the internet and online social media supporting the autonomy and authorship of these activities. As shown in the literature review judging self-determination is best done by the relevant individuals as it can run the risk of being democratically undermined, therefore it is important that the participants self-reported they felt more independence from using the internet and online social media.

Cheatham (2012) carried out a review of quantitative research which sought to measure the effects of internet use on well-being among adults with physical disabilities. They identified six studies which matched the inclusion criteria they had set and noted the small sample size was related to the difficulties of internet quantitative research design within controlled settings for this population. One study concentrated specifically on individuals with physical disabilities and found a significant positive relationship between internet use and perceived independence (Grimaldi & Goette, 1999, cited by Cheatham, 2012). Abascal and Nicolle (2005) state if people are digitally excluded then their ability to live a social and independent life is curtailed. DeRuyter et al. (2007) identified

*“access to email, cell phones, digital music stores, e-commerce, digital photo albums, and e-books are all activities that require digital independence [and] are fundamental communication activities in the twenty-first century”*  
(p. 268).

Evidence emerged within the data that the internet could increase the possibility of pursuing self-directed activities such as employment opportunities and voluntary charity work. Duckett (2010) discussed the barriers and opportunities for work and employment within emerging Asian countries (not specified by Duckett) for people who use AAC and compares this with American and European experiences. He points out the development of VOCAs that can interconnect with the internet is a real positive bonus for enhancing employment opportunities. He acknowledges that even in advanced AAC countries, such as the USA, there are still considerable challenges within the employment market. He points to opportunities (be they paid or unpaid) within emerging Asian countries as just beginning for people who use AAC and



suggests part-time positions, taking more control over running personal care teams, voluntary work, mentoring younger people who use AAC or working as motivational speakers or disability advocates are all areas for consideration. These possibilities were seen within the current study with participants describing how using the internet and online social media was widening opportunities in these areas.

Another facet of self-determination articulated within this study was communicating through various forms of online social media offered enhanced privacy in personal relationships. The necessity to have high levels of personal care, coupled with complex communication needs, means it can be very difficult to conduct private conversations with family and friends. As was shown within the data, being able to use online social media to contact family, friends and staff members was considered beneficial for enhanced privacy. McNaughton and Bryen (2007) discuss the desire for privacy by people who use AAC and cite the following research that shows the importance of private conversations for (i) closeness in personal relationships (Smith, 2005) and (ii) reporting illegal activity or abuse (Bryen, Carey & Frantz, 2003).

Evidence also surfaced within the data that participants sometimes had better technical knowledge and skills than parents or personal staff and in one circumstance this was helping personal staff to learn about technology. Raghavendra et al. (2012b) reported parents of children with physical disabilities were only just beginning to take steps to learn more about the internet's potential and were either formally or informally trying to develop skills. They often found support from younger family members and their children with disabilities. This is a phenomenon noted on a broader scale within mainstream society. Mesch and Talmud (2010) discuss how the balance of power is changing in many families as adolescents become the technical experts within the household.

#### *5.8.2. Enhanced self-representation*

Evidence arose from the data to show that the participants enjoyed the amount of information they could give their friends through online social media sites, especially Facebook. Opinions were expressed about how online social media might challenge the time constraints of face-to-face interaction and allow a person who uses AAC to

reveal more about themselves to other people. Another aspect of a Facebook identity is the ability it offered the participants to show their humour, create personal narratives through representing significant aspects of their lives of which they were proud and using the timeline for creating an historical framework. As illustrated in the literature review (section 2.2.7) by Waller (2006), this is an area of difficulty for those who use AAC as intervention has largely focused on transactional rather than interactional communication which tends to be more complex and adhere to strict conversational conventions. Waller discusses the importance of interactional conversation for people as it allows them to share life narratives and develop a personal identity suggesting people who use AAC are at a disadvantage in this regard. She cites her previous research (Waller, 1992) that showed many people who use AAC rely on close communication partners to tell stories on their behalf once they have indicated a topic area.

These findings also support the research of Goffman (1959) and Zhao et al. (2008) discussed within the literature review. Participants discussed enjoying putting things on Facebook of which they were proud which supports ideas outlined by Goffman (1959) that individuals create a performance which they hope observers will take seriously. Zhao et al. (2008) also suggested Facebook users liked to control what they showed others to promote their 'hoped for' self which they suggest enhances a person's self-image in order to have concrete consequences within the offline world.

Within the data of the current study, there was also mention of the sense of equality from being able to express yourself in the same way as peers. Bowker and Tuffin (2002) found online benefits for people with disabilities in areas such as choice over self-representation. Clarke et al. (2001) spoke about the importance of communication technology to support participant perceptions of being able to say what they liked and tell jokes. Within this study participants described feeling they could use online social media to give voice to their opinions, follow interests and some said they felt other people could understand them better in writing. As outlined within the literature review face-to-face conversations introduce considerable time pressure for people who use AAC. Being able to use social media tools (such as email) can support communication and also offer an opportunity for a particular conversation to be

followed up later. Larned (2012) discusses his personal perspective as a person who uses AAC on the empowerment of writing saying

*“I discovered writing has a power all of its own to change hearts and win friends”*  
(newsletter).

During the data collection, a few participants asked if email could be used either pre or post interviews to provide the research questions or to follow up on issues raised within the interview. The benefits of using email were noted in the literature review to support mentor/protégé relationships between people who use AAC (Cohen & Light, 2000) and via symbol-based email to enhance social contact for children who use AAC (Sundqvist & Ronnberg, 2010). Another positive benefit discussed was the possible ability of email to alleviate unequal turn-taking within conversations as the pressure to respond quickly is removed (Gandell & Sutton, 1998, cited by Sundqvist & Ronnberg, 2010).

### *5.8.3. Social capital*

This area of the grounded theory reflects findings that emerged in relation to concepts of social capital theory discussed in the literature review (section 2.4.4). Participants within the current research described the ways that internet and online social media increased the bonds of social ties with family and friends, maintained distant ties with old school friends or people who had moved on to, or away from, college settings and created the possibility for bridging social capital by creating new social ties through inter-college online links or through friends of friends.

The current study never intended to measure social capital quantitatively but considering the conceptual elements of social capital is useful in evaluating the value of the perceived benefits of the internet and online social media for the participants in this study. In relation to concepts of bridging social capital, the opportunity seen to make contact and socially network with people who are ‘friends of friends’ may be important for building a social presence in ways that may not have been open to the current participants through traditional means as the reduced opportunities to network in real world environments is well documented. Guo, Bricout and Huang, (2005) found a positive relationship between internet use and improved frequency and quality of social interactions for disabled people in China although there were

concerns around socio-economic digital divide issues. Raghavendra et al. (2013) illustrated through targeted intervention with adolescents with physical disabilities (including a sub group with complex communication needs) that providing relevant equipment and instruction on how to use the internet and online social media sites increased the number of online communication partners and offered a new way to extend social connections.

Another aspect of the current study in terms of a social capital perspective was the evidence that bonding social capital was influenced by the ability to use the internet and online social media to maintain close relationships more intensely especially from within residential college settings and evidence of bridging social capital in terms of helping to remove barriers and create opportunities to contact other AAC users in the same setting and also from other college settings.

As discussed in the literature review (section 5.4.4.) the application of social capital theory into online research environments by Williams (2006) and Ellison et al. (2007) showed social media sites can support forms of bridging, bonding and maintained social capital. This was supported by findings in the current research as participants described how they used online social media, especially Facebook, to contact friends and teachers from old schools and to keep in touch with friends who had moved onto college. They also described keeping in touch with family and friends in different countries and searching for people they had lost touch with online. As noted previously many people with physical disabilities find it incredibly difficult to keep in touch with people when they move on. VOCAs may have the names of old friends and teachers no longer seen programmed within the vocabulary items. Online social media is changing the dynamics of maintaining social ties for young people who use AAC.

#### 5.8.4. *“Talk to everyone”*

One of the main descriptions applied to the benefits of the internet and online social media by the participants was the opportunity to *“talk to everyone”*. As discussed in the literature (section 2.2.7) Grove and Tucker (2003) and Waller (2006) describe the importance of interactional communication for developing friendships. For the

participants within this study the issues identified by Seymour and Lupton (2004) are in some ways similar yet subtly different. The desire to “*talk with everyone*” appears to supersede concerns of being misunderstood in text based communication. The references to anonymity made in relation to profile photos “*sometimes I don’t like to put a picture of myself*” were explained to discourage undesired contact from strangers rather than altering perceptions of a physically disabled identity suggested by Seymour and Lupton. The value of using online social media centred around issues such as “*people understand me better in writing*” and being able to comment and look at photos means it is possible to “*communicate equally with everyone*” and using social media is a “*really good way for people to get to know you better and understand you [and] stop people feeling isolated*”.

Participants primarily wanted to have cameras, not to prevent misunderstanding through text based communication as suggested by participants in Seymour and Lupton’s study, but to compensate for literacy challenges that prevented the use of text-based communication. By being on camera individuals could communicate with their family and friends using mutually understood total communication strategies and the voice output on their communication aid. As discussed in the literature review (section 2.2.5), Gandell and Sutton (1998) showed communicating through a telecommunication medium allowed for a greater variety of utterances (especially an increased use of ‘wh’ questions) by the person who uses AAC and gave them a greater ability to control the interaction. They discuss how this has important implications for intervention as assessments of communicative skill are often carried out face-to-face so may give misleading information on utterance variety.

#### 5.8.5. *Reduced isolation*

The current thesis shows the participants’ improved opportunities for talking to people and keeping in touch with family, friends and old acquaintances from previous life situations were perceived to have potential to “*stop people feeling isolated*”. This supports previous literature by Ballin and Balandin (2007) who found increased levels of loneliness in adults with cerebral palsy in part due to difficulties accessing communication technologies such as telephones and internet sites. Cooper et al. (2009) identified loneliness as a common experience for people who use AAC and

can be psychologically demoralising. They indicate communication with others can help to ease feelings of loneliness. As shown in the literature review (section 2.2) challenges with face-to-face communication situations can occur for people who use AAC.

#### *5.8.6. Resilience*

Having the opportunity to use the internet has provided the young people within this study with an important resource to experience resilience and risk. Resilience is a controversial concept as will be demonstrated shortly when discussing the literature. This is especially true in relation to disability where it risks being seen as an individualistic attribute of success. The current participants reported being assertive in relation to unkind online comments, blocking people from sharing material online, reacting to an invasion of privacy by severing a social relationship, using Facebook to privately discuss issues with staff, and accessing social media despite parental wishes. By asking for equipment to extend their use of social media (for example, dongles or cameras), or requesting to use equipment either collaboratively or via access technology, they have demonstrated their awareness of the resources they wish to access.

Much of the research into resilience has focused on its developmental nature and been studied through childhood. Luthar, Cicchetti and Becker (2000) offer a critical appraisal of theories relating to resilience by exploring how they have been understood as exposure to adversity and adapting to the challenges during developmental stages. They outline how resilience theories were formed, (citing authors such as Anthony, '71; Garmezy '71, '74; Murphy & Moriarty, '76; Rutter, '79; Werner, Bierman & French, '71 and Werner & Smith, '82), showing much of the early work was based within the schizophrenia literature and focused on the personal characteristics of resilient children. As resilience research matured, three guiding perspectives can be traced which all have at their core an appreciation of multiple, rather than individualistic, levels of influence.

1. The first (Garmezy, 1985) considers the protective and vulnerability factors that surround an at-risk child within three levels: (i) attributes of the individual child, (ii) aspects of their families (iii) wider societal elements.

2. The second perspective is based upon ecological (Bronfenbrenner, 1977) and ecological/transactional (Cicchetti & Lynch, 1993) influences that consider factors within proximity to an individual. Over time these can affect development: socio-economic disadvantage, parental mental illness, maltreatment, poverty, violence and catastrophic life events.
3. The third is the structural-organizational perspective (Cicchetti & Tucker, 1994) which suggests there is coherence to the way that competence and resilience develop over time, so that contextual factors are affected by individual choice and self-organisation.

These perspectives all recognise the need to understand *how* protective factors work in order to develop intervention and prevention strategies.

Luthar et al. (2000) discuss the scientific concerns that have arisen around resilience as a scientific concept based around difficulties of measurement, the dangers of positioning resilience as a personal trait (where a person may be seen as failing to overcome adversity), and a lack of consensus around terms such as ‘protective’ and ‘vulnerability’. Masten (2001) suggested resilience should not be seen as a special characteristic that emerges in extraordinary circumstances but is better conceptualised as an everyday phenomenon demonstrated by people within their communities.

Ungar (2004) suggests that the ecological perspective is the most dominant and sits within a positivist paradigm which is underpinned by a focus on the predictable nature of risk and protective factors. He suggests a constructionist, postmodern approach to resilience is one that considers the negotiation of resources by an individual in relation to their environment. He critiques ecological interpretations which seek to compensate through: challenging (inoculating against future risk), protecting (reducing potential risks) or compensating (neutralising identified risks) as being  
*“plagued by cultural hegemony”* (p. 342)

He suggests a constructionist interpretation recognises the multidimensional nature of resilience and recognises the uniqueness of each context for an individual or their group. He suggests that negotiating resilience through individual challenges and the construction of protection through personal resource management has implications for

altering the ways that that resilience is viewed and understood within research or intervention.

Runswick-Cole and Goodley (2013) explore concepts of resilience from a disability studies perspective suggesting historical attempts to place resilience within individualistic accounts are not helpful. They applaud the socially constructionist view that locates resilience within a framework of resources such as relationships, community resources and social justice. Runswick-Cole and Goodley (2013) propose a 'networks of resilience model' that creates interconnections between resources suggested by Ungar (2007, cited by Runswick-Cole & Goodley, 2013). They adjust one of Ungar's resources 'cultural adherence' into 'community participation' as they feel the original might champion ideas of 'normal' which disability studies seeks to challenge. They define the resources within their model (based on Ungar, 2007) as follows: (i) material resources (access to medical, educational, employment resources), (ii) relationships with significant others, (iii) identity (a positive personal sense of self), (iv) bodies and minds (what affects the ability to take advantage of social and cultural assets), (v) power and control (the ability to self-author change), (vi) community participation (what activities are meaningful), (vii) social justice (a sense of equality and purpose) and finally (viii) community cohesion (feeling part of a community).

Within this study, data emerged which demonstrated how using the internet and online social media created access to many of the resources articulated by Ungar (2007) and Runswick-Cole and Goodley (2013) allowing participants to explore resistance and resolution of potentially negative experiences. Participants showed they considered in what ways, and from whom, assistance could be sought. Glasby (2011, cited by Runswick-Cole & Goodley, 2013) suggests segregating people is not the way to keep them safe; the key is to build confidence and skills so they can engage positively within community activities. The social media teaching tools being used within the educational settings aim to help build resilience skills so the young people will have the necessary resources to cope within publicly open forms of social media. Livingstone et al. (2011) suggested risk exposure online can be beneficial for adolescent development if not outside an individual's ability to cope. According to



Seymour and Lupton (2004), exposure to a ‘world of strangers’ is not without risk but exposure to the

*“wild woods of everyday social relationships will build confidence and selfhood.*

*Exposure to danger has transformative power”* (p. 301).

Tavares and Peixoto (2003) outline one of the challenges faced by young adolescents who use AAC is having limited access to a variety of conversational partners. Also they face a decrease for interventional support as the focus is primarily during their early years and tends to become limited during adolescence. They suggest conversational skill development will depend on the communication experiences available and a significant aspect of having varied conversational experiences is the opportunity this offers to negotiate conflict and disagreement between peers.

#### *5.8.7. Dating opportunities*

The data revealed a very small amount of evidence that using online social media was providing one participant with an opportunity to keep in contact with his girlfriend as their paths rarely crossed within their college environment. The memo created in relation to a possible communication breakdown within the group interview situation shows how the transcription process revealed an issue not apparent in real time. This may be an area of importance for young people who use AAC but due to the time constraints of this project it was not possible to take this forward as this was one of the last data collection sessions and the issue did not reveal itself fully until after the final interview opportunity. Whitty (2008) suggests that the internet can provide a unique environment for people to learn about and experience relationships and sexuality. Greene, Derlega and Mathews (2006) discuss the importance of self-disclosure for achieving romantic closeness. For people who use AAC being able to ‘talk’ online may have significant ramifications for intimate relationships. Also people with physical disabilities have few opportunities to be alone as they tend to have personal assistants in attendance. This is likely to have a major impact on the ability of adolescents who use AAC to spend private time together so having an online connection may be highly significant. Bryen (2008) suggests many adults who use AAC do not have the relevant vocabulary to reflect life roles and one area of particular concern is having the vocabulary available to express sexuality, both in

terms of expressing intimacy (Bryen et al. 2003) but also for reporting abuse (Bornman & Bryen, 2013).

This is an area where category saturation was not achieved. Future research should examine this area as its emergence within the data suggests it might be an area of significance. It was unfortunate that the timing of the disclosure meant it could not be explored within the current project due to the time constraints of the doctoral process.

### ***5.9. Relevance and significance of the grounded theory of internet and online social media use by young people who use AAC***

The final process was to consider the broader structural relevance of the analysis. According to Corbin and Strauss (1990), the analysis must not be

*“restricted solely to the conditions that seem to have immediate bearing on the phenomenon of central interest”* (p. 422).

The antecedents of social inclusion and participation within community settings proposed by Milner and Kelly (2009) and Mahar et al. (2013), identified within the literature review (section 2.4.7.), were used to consider the relevance and significance of the proposed grounded theory within the broader knowledge base of social inclusion.

Milner and Kelly (2009) identified five fundamental antecedents for community participation and inclusion by people with disabilities. These are: self-determination, social identity, reciprocity and valued contribution, participatory expectations, and psychological safety. A brief outline of the five antecedents follows and have been supplemented with evidence provided by Smith and Murray (2011). As mentioned earlier, Smith and Murray (2011) used Milner and Kelly’s (2009) paper and the research of Granlund and Blackstone (1999) and Lefebvre, Cloutier and Levert (2008) to develop their own outcome measurement metaphor for AAC intervention.

- **Self-determination:** Having the autonomy to use own skills to carry out self-chosen activities, participants valued being able to

*“decide where, when and with whom they were”* (Milner & Kelly, 2009, p. 56).

- **Social identity:** This is built up over time through on-going interpersonal contacts (Milner & Kelly, 2009). A recognised social status is important (Lefebvre et al. 2008) and is facilitated by family and other social networks (such as being part of a local church movement).
- **Reciprocity and valued contribution:** Milner and Kelly (2009) describe being valued and perceived as contributing help to challenge perceptions of dependence and create a sense of supporting the lives of others. Smith and Murray (2011) suggest reciprocity implies a sense of equality.
- **Participatory expectations:** Milner and Kelly (2009) describe limited expectations of participation from non-disabled people as one of the most disabling barriers for a sense of community participation and the support and encouragement from other people with disabilities was one of the most empowering. Smith and Murray (2011) discuss the importance of feeling able to challenge assumptions and attitudes.
- **Psychological safety:** Milner and Kelly (2009) describe the sense of safety and belonging that is experienced with trusted members of a community where what you say and can contribute is valued by other members. Smith and Murray (2011) speak about becoming “*incorporated into the social history of the particular community spaces*” (p. 294).

Mahar, et al. (2013) conducted a narrative literature review

“*to develop a transdisciplinary conceptualization of social belonging*” (p. 1026) to guide outcome measurements of community-based programmes for people with disabilities. They also identified five themes which are important for perceiving a sense of social inclusion: subjectivity, reciprocity, groundedness, dynamism and self-determination. Although using different terminology these map closely to the research of Milner and Kelly (2009) as illustrated by the brief description given below:

- **self-determination** (a sense of power over choice of interaction). Milner and Kelly (2009) identify a key attribute of self-determination is self-authorship of activity.

- **groundedness** (having a referent group that one belongs to). Milner and Kelly (2009) refer to this as a recognised social identity built up over time within community settings.
- **reciprocity** (connectedness to a group, a sense of shared history, feelings of social acceptance). Milner and Kelly (2009) suggest reciprocity and a sense of belonging is important to counteract feelings of dependence.
- **dynamism** (the dynamic interplay between physical and social environments that either support or undermine a sense of belonging). Milner and Kelly's (2009) participatory expectations show how being undermined or encouraged are important elements of perceptions of social inclusion.
- **subjectivity** (individual psychological perceptions of value and fit). Milner and Kelly (2009) call this psychological safety and describe it as feeling reassured that individual views can be expressed freely within a trusted community.

I suggest that these outcome antecedents or measures can be mapped into the grounded theory of internet and online social media use by young people who use AAC through the consequences area. I am posing this as evidence that using the internet and online social media can support perceptions of social inclusion.

- **Self-determination:** I suggest this emerged from the data through evidence of: an ability to self-author activities, seek information, follow own interests, participate in academic studies, employment opportunities, voluntary charity work and being able to support others.
- **Social identity/groundedness:** I propose these are seen in descriptions of improved opportunities for self-representation. Being able to build up a narrative history of identity within a Facebook community of friends I would suggest helps to build a sense of belonging in the sense suggested by Milner and Kelly (2009) of belonging within a local church movement.
- **Reciprocity and valued contribution/reciprocity:** I would suggest is also achieved through using online social media groups to maintain close social ties with families and friends in home and college settings and having a sense

of social acceptance and connectedness. Participants spoke about feelings of equality in terms of being able to do the same things on Facebook as friends could and spoke about how being online made them feel more independent.

- Participatory expectations/dynamism: I believe this is seen through the perception that the internet and online social media allows the participants to “talk to everyone” and enhances feelings of social belonging. Support and encouragement can also be found through closer social contacts but importantly the participants felt they could challenge perceptions others may have by being able to explain more about themselves. This is also reflected within the evidence that using the internet provides an important resource for demonstrating resilience in the light of negative online experiences.
- Psychological safety/Subjectivity: I would argue that reducing feelings of isolation through engagement in online social media communities in part satisfy the implications of this antecedent. Also the descriptions of being able to express humour and opinions through Facebook pages would suggest that it offers an important space in which opinions are valued by others.

I suggest that this thesis has added to new knowledge by demonstrating through empirical evidence that using the internet and online social media may have important implications for increasing feelings of social inclusion for young people who use AAC. The proposed grounded theory of internet and online social media use by people who use AAC (Figure D) illustrates how consequences identified for using the internet and online social media can be mapped into outcome measures for social inclusion within community settings. Measures of social inclusion are increasingly being recognised as the principles of the ICF are shaping areas of policy across many different parts of society.

## **Chapter 6**

### **Conclusions**

#### ***6.1. Conclusions***

This research shows a strong desire among young people who use AAC to use the internet and online social media. It has shown that despite much diversity in individual profile there are many different levels at which young people who use AAC can digitally engage through collaboration and technical support. The issues and arguments for using the internet and online social media for distance communication mirror many of the issues that arise in discussions of VOCA technology for face-to-face communication. The AAC field is certainly starting to take the issue of interconnectivity with the wider world very seriously but little research has sought the perspectives and experiences of using the internet and online social media by young people who use AAC.

The long fight to have the right to communicate recognised as fundamental for people who use AAC by the Department of Health (2012) is very important. Steps must ensure that the scope of communication within the 21<sup>st</sup> century, where being digitally excluded puts people at a heightened risk of being socially excluded, is considered within this new framework of intervention. Evidence is important for people who use AAC, their families, professionals and organisations when seeking to justify the funding of equipment and will be increasingly relevant to ensure the recommendation of The Clinical Advisory Group for Prescribed Services Report (DoH, 2012) that VOCAs should be nationally commissioned from April 2013 becomes a reality.

The new knowledge that has emerged from this study has demonstrated the perceived benefits the internet and online social media have for perceptions of social inclusion. It was possible to map the outcome measurements devised within studies of community inclusion suggested by Milner and Kelly (2009) and Mahar et al. (2013) and demonstrate crossover within their five antecedents into the consequences perceived from being online. The ICF-CY seeks to understand how environmental factors impact on the ways in which young people live and conduct their lives

(Lidstrom, 2011). The development of the ICF-CY for AAC (Rowland et al. 2012) has refined measures to code areas where environmental factors may serve as barriers or facilitators for communication. I propose this research has revealed there is a need for outcome measures which look specifically at online social media use by people who use AAC, in order to consider whether the inferences drawn for the benefits of social inclusion (when referenced against community participation antecedents) can be validated more formally.

Young people were not always satisfied with the response to their requests for equipment. This study has identified the internet and online social media supports total communication strategies and participants within this study indicate this is important to them. They identify the value of online social media to “talk with everyone” and being online must not be considered a luxury within their lives but rather should be regarded as a necessity.

Literacy challenges as identified by Raghavendra et al. (2013) are a major barrier to internet and online social media use. Literacy training must be targeted as a matter of urgency. This is an area which has long been identified of intense importance and concern within the field of AAC. The growing popularity and necessity to be online within the digital society, makes this issue even more pressing if young people who use AAC are not going to be additionally marginalised within this area.

The findings have practical applications in terms of barriers and facilitators which will be of interest to SLTs and educational professionals. The original presentation of the grounded theory takes the form of a theoretical expose but the following chapter will present a refined form of the grounded theory in order to offer an accessible version for those who seek a more practically focused perspective (Figure E).

This research made an original contribution to knowledge by identifying and attempting to redress the gap within the literature base for the self-reported use of internet and online social media use by people who use AAC within the United Kingdom. It has led to the creation of a conceptual grounded theory contextualising relevant issues within empirical data. A secondary benefit is that it acts as an

exploratory step to examine whether outcome measures that have traditionally focused on community participation may be applicable for exploring perceptions of social inclusion within virtual communities.

## ***6.2. Strengths and limitations of the study***

### *6.2.1. Strengths*

1. This research has provided new knowledge for an identified gap within the literature base for the self-reported experiences of internet and online social media use by young people who use AAC within the United Kingdom.
2. The relatively large sample size (n=25), variety of geographical locations and wide age range of the participants was a relative strength in terms of qualitative research. This research does not seek generalisation but instead may be useful for analytical application of understanding within alternative situations and different populations (Kvale, 1996).
3. The relatively wide age range of the participants and the broad heterogeneity in individual skills offers a broad perspective across the range of supports and barriers for the use of the internet and online social media within a diverse population.
4. Establishing the validity of the study was fairly robust within two measures suggested by Creswell and Miller (2000). The first was the feedback sought from audiences at national and international conferences and via a journal article in an AAC focused magazine. Secondly, the attempt to find disconfirming evidence led to a category that had initially been identified and presented at the 2012 Communication Matters conference being down-graded in status. It was decided the category of 'time' had been overstated from the initial analysis of the data and under closer scrutiny could not maintain its original hierarchical status. Morse, Barrett, Mayan, Olson and Spiers (2002) say this type of investigator responsiveness is a necessary ingredient of qualitative research validity. The ability to relinquish a theoretical idea which seems exciting is a sign of strength within a study. They also identify the strength found within concurrent data collection and analysis which was a technique employed during this research. Finally, as stated by Morse et al.



(2002) it is important the research question has a good fit with the method. This thesis clearly outlines how and why the methodological course chosen was a good fit for the research objectives.

### 6.2.2. *Limitations*

1. Challenges posed by technical equipment, available vocabulary, communication breakdown, participant fatigue and time pressure meant the interview data was not as exhaustive as was hoped for. Difficulties within the interviews arose in terms of the participants being able to discuss their experiences in depth and often responses were short or consisted of yes/no replies. Moves were taken to counteract this by asking shorter questions to clarify previous points made. As the interviews progressed and I became more knowledgeable about the topic under study and more aware of the dynamics of AAC-mediated conversations I was able to target more relevant questions and be more supportive as a communication partner.
2. The relatively wide age range of the participants and the broad heterogeneity in individual skills may have affected the findings as participants may have had different interests making it difficult to draw conclusions.
3. The range of settings was mainly restricted to special schools and colleges with only one participant seen within a mainstream setting. This will have affected the findings in terms of offering a rather narrow perspective on the use of the internet and online social media by young people who use AAC.
4. There was reduced potency for three qualitative validity elements suggested by Creswell and Miller (2000). These are: member checking, rich, thick description and prolonged engagement in the field. The email responses in relation to the findings summary were lower than would have been hoped. It is assumed this may be due to the fact that constructing messages on computer devices takes a large amount of physical effort for people with physical disabilities. The tendency of people who use AAC to produce short phrases also affected the volume of data and the potential for rich, thick description. Finally, due to recruitment within educational settings, prolonged engagement within the field was also problematic.

### ***6.3. Methodological considerations***

1. Using narrative techniques to explore the experiences of people with complex communication needs may have seemed counterintuitive (Booth and Booth, 1996). Consideration was given to creative activities (art, photography, dance) which have been used successfully with research participants who experience communication challenges by supporting abstract discussions within concrete contexts (Greenstein, 2013). However, the severe physical mobility impairments of the young people and the physical requirements for operating VOCAs raised concerns that using creative methods may have introduced novel disabling factors. Observation could not have captured the meaning that participants may attribute to their experiences. Some participants did want to demonstrate how they used online social media and this data was useful for demonstrating process issues.
2. Collecting data through engagement with participants on the internet or through online social media sites such as Facebook was discounted as it raised ethical concerns around consent and privacy for family and friends on the site, potentially transgressed agreed professional boundaries with educational settings and could have made my position as a researcher unclear, especially around 'friendship' and negotiating exit strategies.
3. Using email with participants was considered acceptable as it does not have the associated social boundary ambiguities as other forms of social media. The over-riding reason for not pursuing this route as the main data collection method was because it was considered important to have face-to-face meetings with the participants in order to contextualise the factors involved for face-to-face conversations. This enabled a clearer understanding and perspective from which to reach a co-constructed interpretation of the implications for using the internet and online social media.
4. Using a survey based methodology may have alleviated the challenges of interviews but may have raised alternative challenges. The language and literacy challenges of the participants may have produced problems for understanding survey questions and rating scales. Also it would have been

difficult to judge whether the responses were solely the views of the participants.

5. Overall, despite the challenges of interviews, they are still believed to ‘best-fit’ the research objectives to gather self-report data of the perceptions and experiences of using the internet and online social media. An improvement would have been to have spent more time with the participants to become familiar with each other’s communication strategies and build rapport. It would also have allowed follow up of issues which may only have become clear during transcription. This may have proved impractical though within the constraints of time pressure within educational settings and the risk of participants missing valuable educational sessions.

#### ***6.4. Potential areas of further study***

1. Utilising outcome measures from studies of community participation appears to show there are important antecedents within the use of the internet and online social media for improving perceptions of social inclusion. This is an important finding in terms of the ICF-CY which seeks to understand how environmental factors impact on the ways in which young people live and conduct their lives (Lidstrom, 2011). As suggested in the conclusions (section 6.1) future research should look to develop outcome measures which are specifically orientated to consider the environmental consequences for social inclusion within virtual communities.
2. An exploration of the internet and online social media use by an older age group who use AAC within the United Kingdom is recommended, as the young people within this study had high levels of technical, human and funding support within their educational settings. Figures within the Ofcom Consumer Experience Report (2012) illustrate that figures for the use of the internet within the home for the 15-34 age group are roughly comparable between people with and without mobility challenges. The figures show less parity of home internet use by older generations of people with mobility challenges.

3. This study helps to give voice to a small population of young people who use AAC but future research must look more closely at the other parts of the jigsaw to give a fuller picture of the issues alluded to within this research which affect the achievement of the desired goal. There is evidence that supporting people with complex communication needs to digitally engage presents many challenges for different actors, especially personal staff. Investigating factors for training and policy development is suggested as collaborative practice is putting personal staff into novel positions in terms of traditional job specifications.
4. There was also evidence that educational settings are working hard to collaborate and explore the issue of social media provision and seeking more in depth data from education settings about the benefits and challenges of responding to client demand for online social educational settings is suggested.

## Chapter 7

### Practical applications and concluding comments

#### *7.1. Practical applications of the proposed grounded theory*

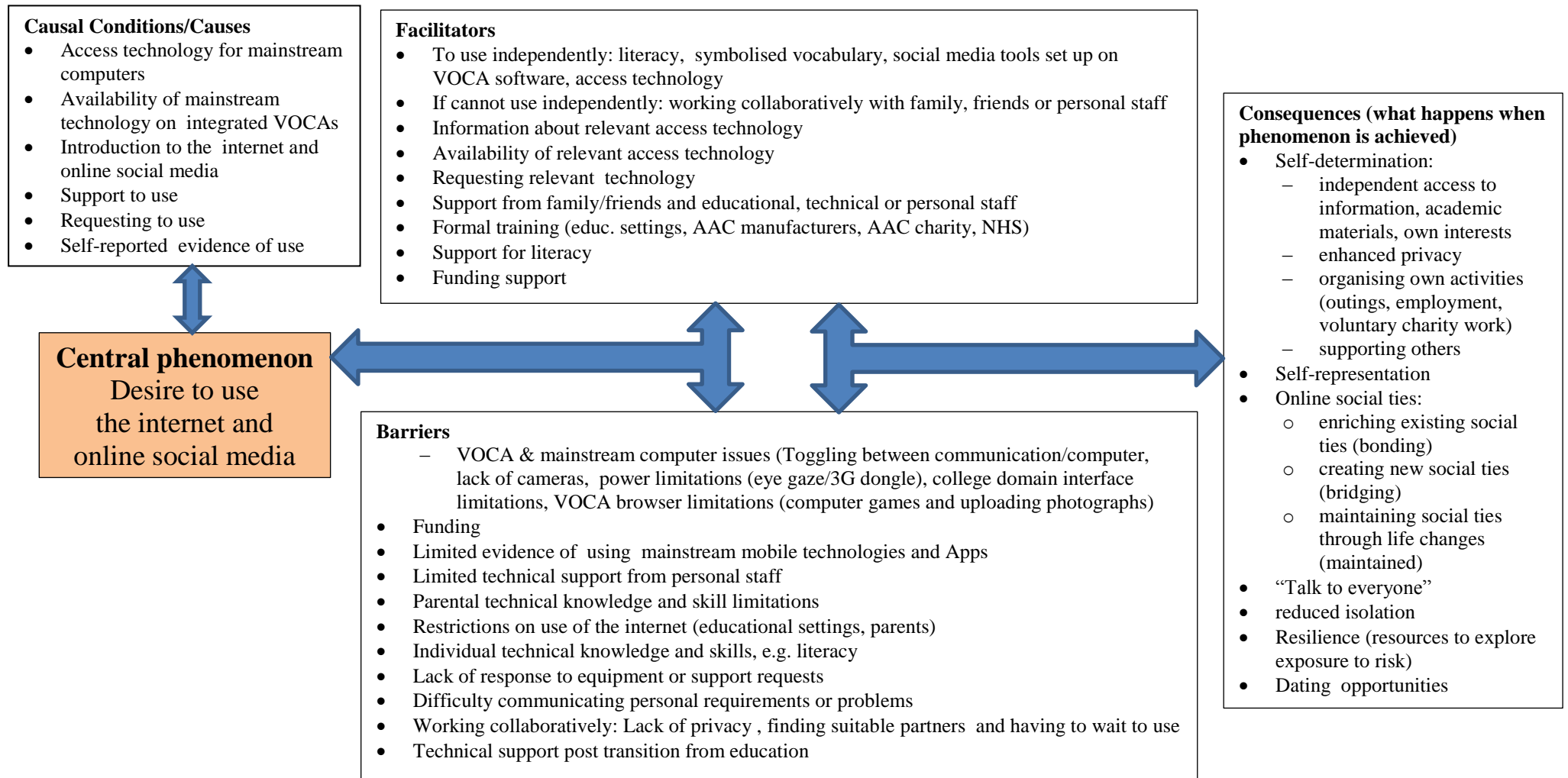
As this refined grounded theory is based on the original presented (section 4.13. and Figure D) I will not re-iterate all of the information covered there again. The new diagrammatic form of the practical applications grounded theory (Figure E) maintains the same causal conditions, central phenomenon and consequences as established within the theoretical grounded theory (Figure D, section 4.13). The refinement is achieved by moving the conceptual focus away from separately considering limitations, context, interaction/action and strategies and synthesising and refining these into a new conceptualisation of facilitators and barriers. As outlined in section 1.1. a refined grounded theory has been developed as it is felt that the original level of theoretical detail is not helpful for those seeking a more practical application of the grounded theory. The new theory has been developed to consider the facilitators and barriers relating to use of the internet and online social media by young people who use AAC.

The facilitators identified can be conceptualised in terms of the ICF-CY framework as focusing on personal characteristics which facilitate access such as mobility, cognitive, sensory and perceptual abilities as well as language and literacy skills. From an immediate environmental perspective then factors such as: suitable language programmes (symbolised vocabulary), targeted access technology and training are important. From a more distant environmental perspective, issues such as parental and personal staff acting as collaborative partners, funding, equipment supply and support from educational settings, NHS, AAC charities and specialist centres, and AAC manufacturers' commitment to training, equipment provision and inclusion-focused policies are all relevant to success.

The barriers are mapped within the same personal and environmental constructs but in opposite ways. Personal skills which can on one hand be strengths and facilitate use, may also be barriers when there are challenges in terms of mobility, cognitive,

sensory and perceptual abilities and language and literacy skills. Difficulties reporting problems (for example through a lack of appropriate vocabulary) can also prevent access and create frustrations for privacy, self-determination, self-representation and reduced social capital in terms of online social ties. Environmental factors impact through lack of equipment (dongles, onscreen keyboard software, cameras) or equipment limitations (togglng, power limitations, interface problems, browser limitations). From a wider environmental perspective, barriers seen were: the technical knowledge of staff and parents that might limit available support, funding for equipment, a lack of information on what is available, policy restrictions within educational settings, technical support post transition and the lack of evidence for the use of mainstream mobile technologies and voice output communication Apps.

**Figure E: Practical applications of proposed grounded theory of internet and online social media use by young people who use AAC**



The following is a summarisation of the practical applications grounded theory. The exposure to the internet and online social media through technological advancements, personal request and introduction through supportive partners remains the trigger for the desire to use the internet and online social media. The theory then shows how the facilitators and barriers to using the internet and online social media are mirrored in many ways in relation to personal characteristics, available support and the provision of relevant access technology. A person-centred approach is imperative for considering the full range of resources at both an individual and environmental level to enable a person who use AAC to use the internet and online social media with relevant support and access technology. A key attribute for internet and online social media access on a rich and broad platform is to have good literacy skills. Training in literacy is already a recognised as an urgent requirement within the field of AAC but the pressure to achieve optimal results must be maintained as society hurtles ever faster into the digital future.

## ***7.2. Concluding comments***

My proposed grounded theory of internet and online social media use by young people who use AAC can be expressed by the following statement:

**People who use AAC have a clear desire to use the internet and online social media, as it is perceived to offer tangible benefits that are synonymous with identified outcome measures for community-based social inclusion, but they also face many challenges, especially regarding accessibility.**

The thesis provides a detailed explanation of: the literature which contextualised the research questions, the methodological approach taken to address the questions and the data analysis process that answered them. The thesis also illuminates many of the methodological issues that arose from following a qualitative interview-based approach with adolescents and young adults who have physical disabilities and complex communication needs. The complexities of carrying out the research were evident throughout the thesis but the value of seeking the views of young people with complex communication needs is self-evident. Future researchers can be encouraged by the current participants' determination, eagerness, and ability to engage in the



research process and offer both concrete and abstract insights into internet and online social media use. The opportunities for people with complex communication needs to take part in research are slowly increasing but they are still a sadly under-represented population. This must continue to be addressed.

The thesis has sought to socially co-construct a grounded theory model of internet and online social media use by young people who use AAC and offer a theoretical level of analysis accompanied by practical applications. It is hoped this contributes to developing a deeper understanding of the potential for social inclusion through virtual communities for young people who use AAC. The heuristic nature of the model is recognised and this thesis can only ever claim to be a version and not the whole.

Further dissemination of the thesis is in hand. A paper has been submitted for the special 30<sup>th</sup> anniversary edition of the Child Language Teaching and Therapy journal: ‘The relevance of the digital age in understanding and supporting children and young people with speech, language and communication needs (SLCN)’. It has been anonymously reviewed and is being re-submitted with requested revisions at the end of October 2013 (Appendix O). It is hoped the story thread that has been started, a co-constructed glimpse into the lived experiences of using the internet and online social media by young people who use AAC, will be expanded upon and continued by future research.

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## Appendices

### *APPENDIX A - THEMES AND QUESTION GUIDE*

<b>Accessibility</b>	<b>Use of the internet and online social media</b>	<b>Role</b>	<b>Online friendships</b>
Can you tell me about how you access your computer?	Can you tell me about what you use the internet for?	Do you feel using the internet is an important part of your life?	Has using the internet changed the way you socialise?
Could you describe things that help you access the internet	How would you describe your use of the internet for social purposes? (for example, email, forums, blogs, Facebook, Twitter)	How do you perceive the internet has changed your life?	What are your feelings about offline and online friendships?
Could you describe things you find challenging when using the internet	Describe how you use the internet other than for social purposes (for example, business, study, politics)	Do many of your friends use the internet or online social media?	Do you have any friendships that only exist online?
Can you describe how you first learned to use the internet	Tell me about how you represent yourself	How would losing access to the internet affect your life?	Have you ever met with anyone you first made contact with online?



<b>Accessibility</b>	<b>Use of the internet and online social media</b>	<b>Role</b>	<b>Online friendships</b>
How do you feel about changes made to websites?	Do you share different types of information with different people online?	How do you feel using the internet might support or hinder your communication with others?	Do you use the internet or online social media sites to stay in touch with old acquaintances?
How do you manage your safety and privacy online?	What advice would you give to someone who was just starting to use the internet and online social media	Can you explain the role technology plays in a typical day for you?	
Do you need help from someone else to use the internet or online social media sites?			
How do you solve technical problems?			



**How I use the internet and social media: Experiences of young people who use augmentative and alternative communication**

*This is an invitation for a research project. This leaflet is to tell you what the study will involve. This is to help you decide whether you want to take part.*

*Read the following information carefully and feel free to discuss it with others. Please contact me if you need more information or explanation. Take as much time as you need to decide whether you would like to be involved.*

**Why is this study being done?**

The internet is increasingly becoming part of everyday life for many young people. Some people who use augmentative and alternative communication (AAC) may use a computer through their communication aid or use one in a different way. This research project wants to find out about the experiences of young people who use AAC and how they use the internet for social purposes (for example, Facebook, Twitter, email). It is being carried out as part of my PhD with Manchester Metropolitan University.

**Why am I being invited to take part?**

As someone who uses AAC, your experiences about using the internet for social purposes are important and it is vital your views are heard.

**Do I have to take part in the study?**

No, taking part is voluntary.

**What if I don't want to carry on with the research study?**

You can leave the study at any point. You do not have to give a reason and nothing negative will happen to you. Eventually your data will be made anonymous and after that you will not be able to withdraw it.

### **What happens if I decide to take part?**

You need to contact me (Amanda Hynan) and together we will organise a convenient time for an interview at a location of your choice. You will be sent information about the interview topics so you can have time to think about them. The interview will not be longer than two hours but this is only a guide and you will be able to stop whenever you want to.

### **Who will see my data?**

Any information that identifies you will only be seen by people from the university who are involved with the research project. Data will be stored and protected under the rules of the Data Protection act. Any data used in the public domain will be anonymous.

### **Are there any benefits to taking part?**

It is hoped the project will help inform other people about the challenges and opportunities of using the internet by young people who use AAC.

### **Who is in charge of the study?**

The study is being carried out by **Amanda Hynan**. I am a qualified speech and language therapist currently studying for a PhD.

I can be contacted through Manchester Metropolitan University (MMU)

-*email*: (email address)

My **supervisor** can also be contacted at MMU by:

- *telephone*: (phone number)

- *email*: (email address)

- *post*: Dr Janice Murray,  
(postal address)

**How do I know it is safe for me to be involved in the study?**

The research has been approved by the Faculty Research Ethics Committee, Faculty of Health Psychology and Social Care, MMU. Their role is to protect your safety, rights, wellbeing and dignity.

**What if I have a complaint or concern about the research study?**

If you have any concerns you can talk to me (Amanda Hynan) or my supervisor, Dr Janice Murray.

If you are unhappy with me or Manchester Metropolitan University you can also contact Communication Matters – ISAAC UK (email address). Communication Matters is a charitable organisation for people who use AAC and they have agreed to act as an independent advocate for my study.

**What if I still have questions about the study?**

Contact me via email: (address)

## APPENDIX C – BRIEF INVITATION



### **An invitation to be involved in a Research Project**

*Hi, my name is Amanda Hynan. I am a PhD research student at Manchester Metropolitan University.*

### **My research project**

*Listening to Young People who use Augmentative and Alternative Communication:  
Topics around using the Internet for Social Purposes*

### **Please will you help me?**

*If you are aged 16-20 and use AAC, I would like to talk to you about whether you use the internet and are interested in social networks (for example: facebook, twitter, email)*

*If you would like to be interviewed you can choose where this will take place. The interview will not be longer than two hours but this is only a guide and you will be able to stop whenever you want to.*

*The questions will be around the following topics:*

- *How you access the internet?*
- *In what ways do you use the internet socially?*
- *Other ways you might use the internet?*

*If you would like to take part, I will send you a more detailed leaflet with important information to help you decide.*

*My project has been approved by a research committee that protects your rights, safety and privacy.*

**How you can contact me:** (email address)

**How you can contact my project supervisor:**

*Dr Janice Murray at Manchester Metropolitan University  
(email address)*

## INFORMATION SHEET

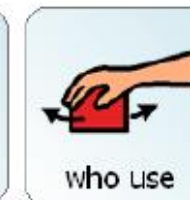
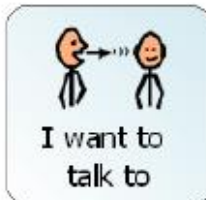


**I am AMANDA HYNAN**

I am doing a study at Manchester Metropolitan University



I want to talk to people who use communication aids



about using the internet and social media



*If you are interested, please contact: (email address of author)*

APPENDIX E - STANDARD CONSENT FORM

Listening to young people who use augmentative and alternative communication: topics around using the internet for social purposes



Researcher: AMANDA HYNAN

Supervisor: Dr JANICE MURRAY

Email address of author

Email address of supervisor

Participant Identification Number for this project:

Please initial box

- 1. I confirm I understand the information about this project.
- 2. I have had the opportunity to ask questions about the project.
- 3. I understand taking part is voluntary and I am free to withdraw at any time until my data has been made anonymous. I do not have to give a reason and nothing negative will happen to me.
- 4. I do not have to answer any questions I do not feel happy about.
- 5. I give permission for members of the university research team to have access to my data. No one else can see it without my permission.
- 6. I understand audio recordings will be made and I give permission for these to be reviewed by members of the university research team.
- 7. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in any reports that result from the research.
- 8. I agree for the data collected from me to be used in future research.
- 9. I agree to take part in the above research project.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher


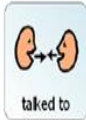

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

APPENDIX F – DIFFERENTIATED CONSENT FORM

**CONSENT FORM (Page 1)**

I talked to Amanda Hynan on .....

 I
  talked to
 
  
**AMANDA HYNAN**

I understand the information

 understand
  information
  yes  no

I know I can ask questions

 know
  can
  ask
  questions
  yes  no

I know I can leave if I want to


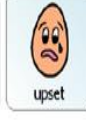
 know
  can
  leave
  yes  no


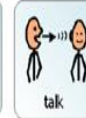
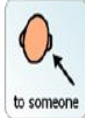

**CONSENT FORM (Page 2)**

I am happy to be recorded on camera

 I
  happy
  video camera
  yes  no

If I get upset, I understand there will be someone I can talk to

 I
  upset

 can
  talk
  to someone
  later

 I
  understand
  yes  no

Signed:



*APPENDIX G – APPROVAL OF ETHICAL VARIATION TO INCLUDE 14  
YEAR OLD*

**MANCHESTER METROPOLITAN UNIVERSITY  
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE**

**M E M O R A N D U M**

**FACULTY ACADEMIC ETHICS COMMITTEE**



To: Amanda Hynan (MMU ID 0528179)

From: Prof Carol Haigh, Prof Jois Stansfield

cc Emma Reilly

Date: 20 January 2012

Subject: Ethics Application 1120

Title: Listening to Adolescents who use augmentative and alternative communication

---

I can confirm that the ethics committee have approved the minor amendments made to your original approved ethics application.

We wish you every success with your project.

A handwritten signature in blue ink, appearing to read "A. Emma Reilly".

Prof Carol Haigh and Prof Jois Stansfield  
Chair and Deputy Chair  
Faculty Academic Ethics Committee

*APPENDIX H – APPROVAL OF ETHICAL VARIATION TO INCLUDE PARENTS AND SCHOOL STAFF*

**MANCHESTER METROPOLITAN UNIVERSITY  
FACULTY OF HEALTH, PSYCHOLOGY AND SOCIAL CARE**

**M E M O R A N D U M**

**FACULTY ACADEMIC ETHICS COMMITTEE**



To: Amanda Hynan (MMU ID 0528179)

From: Prof Carol Haigh, Prof Jois Stansfield

cc Emma Reilly

Date: 05 March 2012

Subject: Ethics Application 1120 (Minor amendments)

Title: Listening to Adolescents who use augmentative and alternative communication

---

I can confirm that the ethics committee have approved the minor amendments made to your original approved ethics application.

We wish you every success with your project.

A handwritten signature in black ink that reads "Emma Reilly".

Prof Carol Haigh and Prof Jois Stansfield  
Chair and Deputy Chair  
Faculty Academic Ethics Committee

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*APPENDIX I: QUESTIONS SENT VIA EMAIL TO 2 PARTICIPANTS (pre-prepared answers on VOCA and blog)*

- How did you find out about using the internet?
- Do you access the internet through your Communication Aid or do you use a separate computer?
- If you use your Communication Aid, do you need extra equipment in order to use the internet?
- Do you have to fund equipment yourself, or do you receive help with this?
- Where do you and your family get technical support and help from?
- Can you describe to me how you use the internet, for example, directly by yourself or with help from someone?
- If someone helps you, can you describe for me how they do this and how you let them know what you want to do?
- Do you (or did you) receive help from school to use the internet, if so can you describe how?
- What do you use the internet to do? For example, do you use it for your hobbies or your own web page, blogging, forums, email, playing games?
- How did you feel when you found out about the internet?
- How do you feel using the internet has changed your life?
- How do you feel losing access to the internet would change your life?
- How did you learn about keeping safe online?
- Has anything embarrassing/frightening/unpleasant ever happened to you from using the internet? If so, would you feel comfortable to give me more information about what happened?
- Can you try to describe how using the internet fits into a typical day?
- What do you think the most important thing is about using the internet?
- What problems do you have using the internet?
- What helps you to use the internet?
- Do changes made to websites affect you in any way?
- Do you use Facebook, Twitter, email, blogs, forums or any other form of online social media?
- If not, what are your reasons?
- If so, can you tell me about what you use and describe how you use it and what you use it for?

**If you use Facebook please look at the following questions. If any of the questions I have asked about Facebook are relevant to an alternative form of social media you might use online, could you use them as a guide to describe how you use that particular form of social media.**

- Tell me about your profile on Facebook, for example what photograph do you use of yourself?
- Have you added any description about yourself onto your profile? For example about your interests, things like music, sports that you like?
- Do you ever change your profile information on Facebook?
- What do you find most valuable about using Facebook?
- How do you decide who you will be friends with on Facebook?
- Do you use Facebook to keep in touch with people you might not see anymore?
- Are you linked with many people from your family or are you mainly linked to friends?
- Have you changed your mind about using the internet or Facebook?
- Do you feel using the internet or Facebook has changed how you socialise with your friends, if so can you describe what is different?
- How do you feel using the internet or Facebook affects your communication with other people?
- Do many of your friends use the internet and Facebook?
- Are there ways you would like to use the internet which you cannot do at the moment?
- What advice would you give to someone who uses AAC about using the internet, online social media and Facebook?

**CLOSING QUESTIONS**

- Is there anything I have not asked you about that you think is important for me to know?
- Are these interview questions what you expected?

# APPENDIX J – JOURNAL ARTICLE OF PILOT INVESTIGATION

PAPER PRESENTED AT THE CMC2011 NATIONAL SYMPOSIUM, UNIVERSITY OF LEICESTER, SEPTEMBER 2011

## “How I use the internet and social media”

### Findings from a pilot investigation with an AAC user

AMANDA HYMAN

Manchester Metropolitan University, Elizabeth Gasford Campus, Manchester M13 9PL  
Email: amanda.hyman@mmu.ac.uk



This paper presents findings from a pilot investigation I have carried out as part of my PhD research. I am looking at how technology can potentially support social participation for young people who use AAC by looking at how the internet and social media are utilised. I use the term ‘social media’ to describe any website that allows social interaction, for example:

- social networking sites (e.g. Facebook, MySpace, Twitter)
- online gaming
- second life sites
- video sharing (e.g. YouTube)
- email and instant messaging (MSN)
- Skype
- blogging to forums
- blogging

#### ADOLESCENTS, SOCIAL MEDIA AND RESEARCH

Lenhart et al. (2010) reported 92% of young people in America have access to the internet and 73% use social networks. In the UK, Livingstone and Bober's (2007) study reported 73% of young people had access to the internet at home, rising to 92% through school, and highly valued being in constant contact with their local friends. Recent data reports 91% of 5-15 year olds in the UK have access within the home with 26% using social networking (Ofcom, 2011). Young people are the first generation to have grown up ‘digitally’ and mainstream research is increasingly exploring the positive and negative effects of internet exposure. O’Keefe et al. (2011) reported much adolescent social

development is occurring online for benefits for communication, social skills, education and health awareness but concerns for cyber bullying, inappropriate exposure and personal safety. I am interested in the implications for young people who use AAC of this rising use of mainstream technology for social participation.

#### DISABLED PEOPLE, SOCIAL MEDIA AND RESEARCH

Research in areas concerning internet and social media use by young disabled people has some findings show:

- Online interests are similar to non-disabled peers (Lathouwers et al., 2009).
- Safety issues are highlighted more intensely and access may be controlled by parents (Lathouwers et al., 2009).
- Girls are more interested than boys in using the internet as a social tool (Sims et al., 2010).
- Long distance friendships are easier to maintain (Soderstrom, 2009).
- Characteristics of offline social ties reflect on how disabled young people use online social media (Soderstrom, 2009).
- Being online offers choice about management of identity (Soderstrom, 2009).

Since 2007, high-tech communication aids have integrated computers, and many young people who use AAC have access to mobile phones and traditional computers. However, there is a gap in the literature on how people with

complex communication needs might be accessing and using the internet and social media.

#### RESEARCH AIMS

My research aims to investigate the experiences of young people who use AAC in four areas:

- The accessibility of the internet and social media. As Newell (2008) argues a blanket approach to accessibility for disabled people is not sufficient, and data is required from specific groups.
- The ways the internet and social media are used. As Lathouwers et al. (2009) found, physically disabled young people have similar online interests to non-disabled peers but might face lighter parental control. Sims et al. (2010) suggest gender influences content choice.
- The perceived role and importance of the internet and social media and how this relates to Bowker and Tuffin's (2002) discursive work on the ways disabled people might position themselves in the online social world.
- How existing social ties affect online friendships. As Ahn (2011) and Soderstrom (2009) claim existing social, psychological and emotional characteristics are brought into online communities and influence networking and communication.

#### PILOT INVESTIGATION

In order to explore the relevance of these issues for people who use AAC and develop my skills as a communication

partner, I spoke to an adult male who uses a Liberator 14 with an integrated computer, as well as a home computer and mobile phone. When conducting a qualitative interview, Kvale (1996) suggests ‘thematizing’ forms the ‘why’ and ‘what’ of the investigation and helps objectives in focus. While Paton (2002) says it ensures enquiry lines are consistent between participants, my thematic interview guide was built around the research objectives outlined above.

#### DATA ANALYSIS

I analysed the pilot data using a thematic network approach described by Atkinson-Stirling (2001). This builds thematic networks by successively coding the data into basic, organising and finally global themes. Figures 1-4 show the networks but in order to fully reflect the data I will discuss some of the issues raised in more detail and illustrate points using the participant's own words.

#### Thematic Network 1 – Accessibility

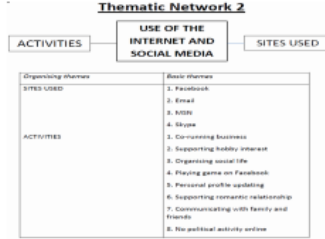
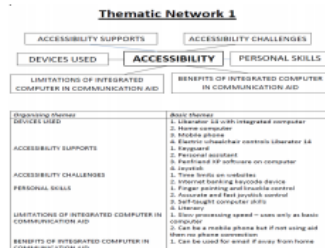
Reading the participant's own literary skill, he identified Freedom XP software as a support for access. It acts as a word prediction programme and he says, ‘it's like my best piece of software’ because it ‘makes my work on the computer fast’. He also finds the voice feature to check individual words and completed sentences useful as it ‘can tell off what you are typing sounds right’. He discussed a limitation to access in connection with online banking. He said, ‘I do my banking online, but to get in to it, you have to use a card reader which I can't do myself’. He also identified he can have problems accessing websites ‘if you have a time limit’. Newell argues this level of detail is required to illustrate the disablement of different populations online.

When speaking about his communication aid computer he reports, ‘this is not very powerful as a computer’ and when asked if he could use any additional software on it, he replied, ‘I could but saying the program in this is a bit of a strain’. He says he only really uses the computer component to pick up email when he is able.

He felt accessibility issues were the easiest theme to explore and it made me reflect on how this is somehow ‘safe’ territory.

Thematic Network 2 – Use of the Internet and Social Media

The participant creates an online business and identified he ‘used to be heavily



into communication radio and I used the net to find things out’. However, he also reported a range of hobbies which he did not supplement with online activity. He also uses Facebook to play an online city building game but not interactively and when asked if he used the internet for political activities said no because ‘they are all the same’. He did not mention using interactive gaming, blogging, or second life sites, forums or posting videos but I did not ask about these directly.

In future interviews, I need to explore ‘use’ more extensively to look at issues of content, online safety, and content to establish if unique characteristics exist for young people who use AAC including gender differences. However, this will be a difficult area to investigate, as questions have the potential to invade privacy. Livingstone (2004) discusses the methodological difficulties of internet-based research saying people often use it in a private space to explore personal concerns, such as health or sexuality. She also notes not people are producers as well as receivers of information which makes content analysis

COMMUNICATION MATTERS | VOL. 26 NO. 3 | NOVEMBER 2011

29

30

VOL. 26 NO. 3 | NOVEMBER 2011 | COMMUNICATION MATTERS

PAPER PRESENTED AT THE CMC2011 NATIONAL SYMPOSIUM, UNIVERSITY OF LEICESTER, SEPTEMBER 2011

difficult and participants may find it hard to recall potentially novel details.

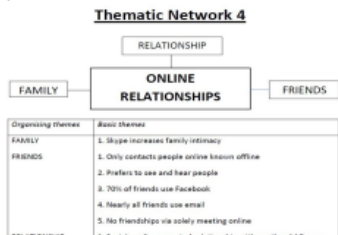
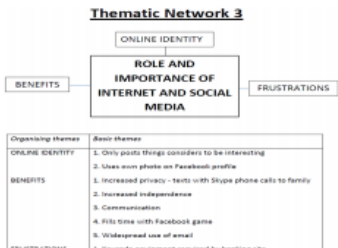
#### Thematic Network 3 – Role and Importance of the Internet and Social Media

There is concordance between the participant's online and offline identity management. He uses a photograph of himself on Facebook and says he shares news and photographs with friends if he is ‘doing something out of the ordinary’. He goes onto say he ‘can't see why people write things like I am eating a bar of chocolate’. Online identity management is something I am keen to look at, as Bowker and Tuffin (2002) and Soderstrom (2009) both discuss how disabled people sometimes find being online offers them freedom to focus on different aspects of their identity other than their disabled status. In future interviews I will try to explore online identity representation in more detail.

Benefits and frustrations were identified for privacy and independence. He said, ‘I could ring mum but how could I have a private conversation when I have twenty four hour care’. He enhanced privacy by teaching his family to use Skype and said, ‘I can write messages’ explaining he now has the immediacy of video yet privacy through text. A frustration, as previously mentioned, is online banking and he says, ‘I ask my staff but they could get to see how much I have’. He identified a city building game on Facebook (of which I was unaware) as beneficial and said, ‘when I am quiet I can just play a game’ and called it ‘too good for addictive’. At first, I thought he meant a second life game and although he indicated my error he found it easier to wait until I mentioned Facebook again to say, ‘like I said about building’ to correct me. This exchange showed me how difficult conversational repair can be and provided valuable information for future interviews.

#### Thematic Network 4 – Online Relationships

The participant reported he only contacted people online who he knew in the offline world and he had not made friends with anyone he only knew in an online context. How widespread an application was appeared to dictate how useful it was for supporting online friendships. When asked if he could only keep one form of social media, he identified it would be email. He reported using social media to support a relationship he had with another person who used AAC and when asked what difference he felt there were between offline and online relationships he said ‘always better seeing and hearing the person’.



Soderstrom (2009) feels her data revealed that disabled participants had special characteristics within their offline social ties that influenced how they managed online social ties. This particular area was difficult to explore and I have to reflect on how to frame questions in future interviews to look more closely at the characteristics of offline and online friendships and perceptions of social participation.

#### FEEDBACK

The participant thought I had good interview skills but he said he could

about how many questions I ask in one turn. The audience at the conference presentation session gave me the following feedback:

- Facebook was identified as important for one young boy by his mother because he can interact with friends independently when online. She said at school the presence of his personal assistant impacted on his social interaction with peers.
- Facebook was reported as rewarding for a child with low literacy as he enjoyed looking at friends' photos and posting his own.

PAPER PRESENTED AT THE CMC2011 NATIONAL SYMPOSIUM, UNIVERSITY OF LEICESTER, SEPTEMBER 2011

A 25 year old speech therapist felt there were differences in how she used Facebook compared with her brother aged 18 and 16. As this pilot investigation forms a basis for my on-going project, I would welcome feedback via email.

#### CONCLUSION

At the CMC2011 National Conference, Tom Griffiths and Scott Stack discussed the Communication Matters ‘Safe Social Networking’ project for colleges, and explained it had evolved in response to the desires of young AAC users to engage with social media and many presenters' suppliers demonstrated how they are integrating social media access into their devices.

However, the most powerful words for me came from the conference plenary speaker, Martin Parron who, in his 2011 book *Chad Ray*, has written a chapter about his laptop. He explains the screen, page and physical actions he felt when he did and he realised his only communication tool was a ‘thumbs off’ elevator board that won't reach around the globe the way I need it to. (p. 154)

If you want to take part in this research, are aged 16-20, and use AAC and social media, please contact me by email: amanda.hyman@mmu.ac.uk

AMANDA HYMAN  
MANCHESTER METROPOLITAN UNIVERSITY

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There are a number of subsidised places for people who use AAC and the family members. Book now to avoid disappointment.

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COMMUNICATION MATTERS | VOL. 26 NO. 3 | NOVEMBER 2011

31

VOL. 26 NO. 3 | NOVEMBER 2011 | COMMUNICATION MATTERS

# How I use the Internet and Social Media

## Experiences of young people who use AAC

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### INTRODUCTION

This article summarises the presentation I gave at the 2012 Communication Matters National Conference and the 15th Biennial ISAAC Conference. It contains research data collected between November 2011 and June 2012 regarding the experiences of using the internet and online social media from young people who use AAC in the United Kingdom.

### BACKGROUND

Young people are at the forefront of technological changes within society that are altering the ways people communicate with one another. Research has shown they share candid and intimate information online about their interests, social activities and family dynamics, which support, reinforce and enrich their offline social relationships (Mesch & Talmud, 2010). Adolescence is a key developmental stage and young people who use AAC are likely to have the same aspirations and challenges as their peers, only with additional communication considerations (Smith, 2005).

Being online may address complex factors for social participation and inclusion by offering opportunities to build and enrich relationships beyond the confines of time, space and physi-

cal challenges (Seymour & Lupton, 2004). Opportunities to use online technology are increasing in the AAC field as communication aids become multi-purpose and language applications are developed for mobile technologies, e.g. iPads (Chapple, 2011). Research carried out in Australia indicates that young people who use AAC reported that access to the internet and good technical advice helped mitigate feelings of loneliness (Cooper, Balandin & Trembath, 2009).

There is a specific research gap in the United Kingdom for the self-reported experiences of using the internet and online social media by young people who use AAC. My research aims to capture their experiences of access to and use of the internet and their perceptions on how this impacts on self-representation and friendships.

### METHODOLOGY

The research is following a constructivist grounded theory approach (Charmaz, 2006) which is a method of carrying out qualitative research following a set of consistent procedures to collect and analyse data with an aim to develop theory.

At the time of the presentation, seventeen young people aged 14-24 who use

AAC had taken part in face-to-face semi-structured interviews lasting between one and two hours and on one occasion five people were seen as a group prior to their individual interviews.

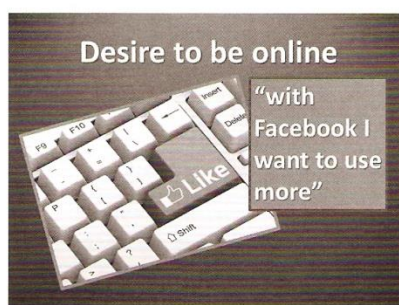
In ten of the interviews, a communication partner supported the young person. All interviewees used high-tech communication aids except for two who chose not to, and two due to technical problems. In these cases, low-tech alternatives were used (Makaton signing, communication book, alphabet board, E-tran frame). There was a wide range of ability in areas such as literacy and many variables regarding accessibility.

On most occasions the interview was the first opportunity for everyone to meet and challenges existed in terms of technical equipment, available vocabulary, communication breakdown, fatigue, illness and time, but despite these limitations many important points were raised.

The information represents initial themes seen within the data. Grounded theory ultimately aims to identify a theory within the data; however, at the time of the presentation data analysis was still ongoing. In order to protect privacy I have used pseudonyms and not identified what brand of communication device is being used.

## THEMES

## Desire to be online



The most powerful theme to have emerged is the desire to be online. The young people unanimously say they are interested in using the internet and online social media. They expressed views such as "wanting to use it more", being "excited" and "happy", having their lives made better and how sad they would be if access was removed. Olivia says Facebook is "fun" and Georgie used an E-tran frame to say Facebook makes her feel happy. Xavier told me without the internet "I would be very upset, I would lose independence, I'd be lost without it".

## Independence

Independence was identified as an important aspect of being online as it lessens the impact of having to rely on others and offers more control. Xavier identified "I can organise things like meetings myself" and Peter says he uses the internet for "planning trips with my personal assistant". Harriet runs her own business and advertises this via her status on Facebook.

Independently following interests online is a big bonus. Peter says he used to "have to rely on others to find things out" and Nicholas likes looking at newspapers and following his basketball team and shows they are "special" to him by posting information about them on Facebook. Will likes to look into alternate access to mainstream technology, Moira loves the Paralympic sport of Boccia and Becky likes sharing news about Rebound therapy, which is a form of trampoline exercise to support movement.

Independent access to entertainment is also enjoyed. Will loves playing online golf and linking up with other virtual players but as an indirect switch user is excluded from lots of online games explaining "I cannot play" due to intricate controls. Peter uses games on a BBC

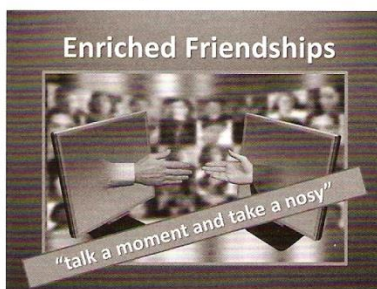
website for young children as the controls are simpler but often finds them childish and wishes more mature games were available with simplified controls. Moira (who has direct access) says she likes to play "anything" but doesn't want to link up with virtual players and finds the integrated computer on her communication aid limiting as "I can't play a game".

Privacy is an important aspect of independence and being online can be supportive. Harriet says her father and brother have Facebook 'apps' on their mobile phones and she can message them confidentially if she has an issue with her staff. She also communicates privately between different staff members and explains they can "talk to me on Facebook". Some people used the text facility on Skype to increase their privacy and prevent their phone calls being overheard by support staff.

## Personal Representation

Carol signed during the interview and explained her love of Facebook by passionately pointing at herself. To clarify, I asked if she meant telling people about herself and she nodded 'yes' vigorously. Facebook helps people express their personality and humour and share their views. Keith says, "I like Facebook because I like seeing me holding Pikachu" and Will says he uses it to tell people "a lot" about himself and to show people "what I think". Profile pictures are used to show activities such as bungee jumping. Harriet uses hers to make people laugh although she joked new friends "would probably run" when viewing her page. Facebook can also act as a repertoire for memories and the timeline feature was particularly popular for the speed of sharing "really old" events.

## Enriched friendships



Being able to communicate with friends was identified as incredibly important.

A wide range of methods are used to keep in touch: texting, Facebook, email Bebo, MySpace, You Tube and Skype. Facebook was particularly popular and Twitter, although used, did not appear as popular and was described as "different" and not as social as Facebook.

Xavier says Facebook allows him to "talk a moment and take a nosy...especially when I am here" referring to residential college. Carol used the Makaton sign for 'friends' when asked why Facebook was her favourite social media site. Keith uses Facebook to keep in contact with people from his old school and Georgie links up with everyday friends and her sister. Many people said keeping in touch with staff from previous schools or friends who had moved on was great as well as supporting long distance relationships in places such as New Zealand and Canada.

## Online challenges

Although everyone desired to be online and most said nothing unpleasant had happened, some potentially negative factors were reported but had been met with resilience. Bertie's teaching assistant said she thought he'd been upset by one of his friends criticising his online computer game skills. He was adamant this wasn't negative and said "I blocked him" and when I asked if he sorted online problems out for himself said "yes". Keith said "one of the people wasn't very nice to me" on Facebook however "I told them off" and they are still friends.

Moira doesn't have her photograph on her Facebook profile because strange people have tried to befriend her and she uses a funny slogan. Harriet reported receiving unwanted friendship requests on Facebook after a video with her real name was posted online by her brother. He had her permission but neither had anticipated the outcome. She was not frightened but is cautious about posting personal information. All independent internet users said they had online safety training from their educational settings and received advice from family or friends.

## Time

Having more time available when online was perceived as beneficial for showing communicative ability. Moira said it shows people they "have to wait to hear what I say". Real time opportunities were also popular with Fiona saying she likes a "quick chat" on Facebook.

## Role of technical and human support



Technical support within educational settings was excellent but some barriers were identified. Moira lost WiFi access when she moved flats and had to wait for wider college coverage. Simon and Davey used Skype at their family homes and wanted it on their communication aids but having potentially roving cameras was a major obstacle for the college and it was not clear if this could be resolved. Olivia wanted Facebook and texting set up on her communication aid but after five months was still waiting.

Outside of educational settings, family support was important. Peter's sister suggested using Facebook when she moved away and his dad helped him until acquiring 'SwitchXS' meant he could "go on everyday" independently. Mary's family all had computers and she uses MSN with them. She likes connecting with her sister from their respective bedrooms and was advised by her sister not to use Twitter because of the "rude people".

Lack of technological knowledge amongst parents and personal assistants can also be a barrier. Peter's dad found it difficult to access technological information and Fiona (via limited pre-stored vocabulary) managed to say she had a problem with Facebook. Her personal assistant (PA) clarified that a previous PA had set up her account but when she left the password was lost. The current PA was unclear about whether she could rectify this. Carol told me several of her staff didn't like computers and couldn't help her to use Facebook.

#### Accessibility

This is a difficult area to explore via self-report. Nicholas said he used "special switches eight" and Xavier demonstrated using social media on his communication aid but was unable to use his voice software simultaneously.

The young people with direct access and good literacy skills used the internet and online social media via a desktop

computer, multi-purpose communication aid or hand-held device (e.g. mobile phone). They used a wide range of sites and, as Moira reported, this supported communication, friendship and entertainment opportunities.

People with good literacy and indirect access (scanning/switch access) faced stronger challenges for going online. Satisfaction was reported with multi-purpose communication aids and other types of assistive technology such as Bluetooth.

Xavier said he could go online more frequently now he had a multi-purpose communication aid and Peter was able to achieve independent access from the suggestion by a special college to investigate 'SwitchXS'.

Access constraints and low literacy skills impact on independent online activity but collaborative access was very popular among the ten young people who went online with support from others. Some social media sites were easier to use than others: Mary said MSN was "easier than Facebook" which she said was difficult to "read" without her mum.

#### CONCLUSION

Data collection continued until December 2013 and a further eight people were interviewed but their data is not represented here. Additional information has also been collected from manufacturers, technical departments, educational support staff and parents to contextualise factors raised by the young people. The thesis is due for submission in September 2013. ✱

Amanda Hynan, PhD Researcher

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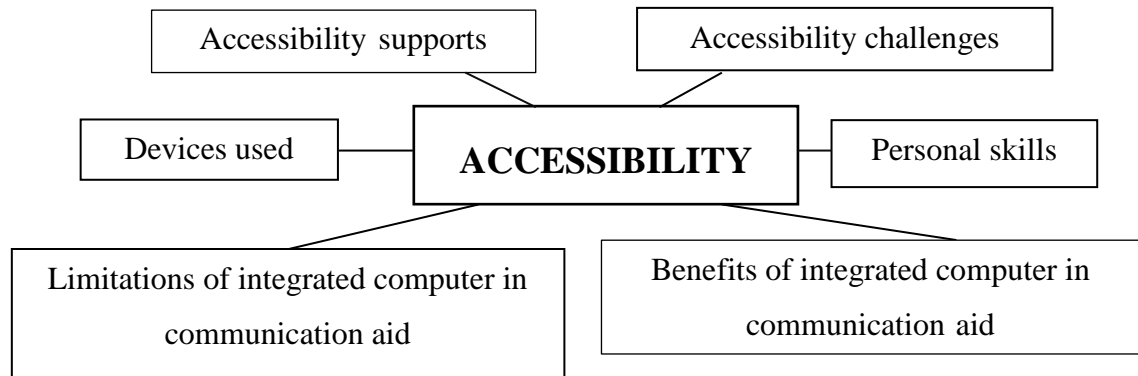
The DVD is an introduction to AAC, and celebrates and promotes communication in all its forms. It is of general interest, and in particular to service managers and purchasers who have responsibility for AAC services. Preview it online at: [www.communicationmatters.org.uk/powerofcommunication](http://www.communicationmatters.org.uk/powerofcommunication)

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APPENDIX L – THEMATIC NETWORKS FROM PILOT INVESTIGATION

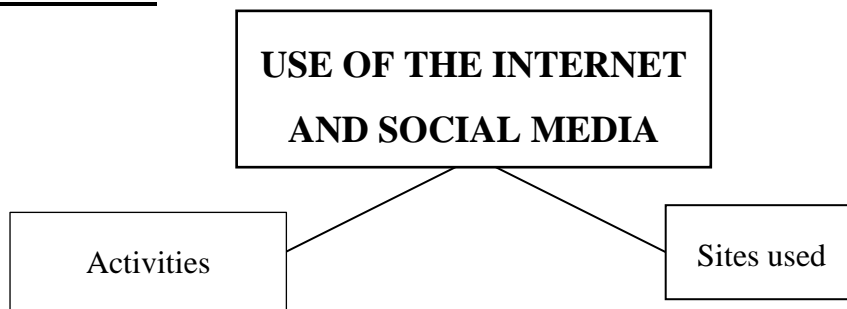
**Thematic Network 1**



<i>Organising themes</i>	<i>Basic themes</i>
DEVICES USED	<ol style="list-style-type: none"> <li>1. VOCA with integrated computer</li> <li>2. Home computer</li> <li>3. Mobile phone</li> <li>4. Electric wheelchair controls VOCA</li> </ol>
ACCESSIBILITY SUPPORTS	<ol style="list-style-type: none"> <li>1. Keyguard</li> <li>2. Personal assistant</li> <li>3. Penfriend XP software on computer</li> <li>4. Joystick</li> </ol>
ACCESSIBILITY CHALLENGES	<ol style="list-style-type: none"> <li>1. Time limits on websites</li> <li>2. Internet banking keycode device</li> </ol>
PERSONAL SKILLS	<ol style="list-style-type: none"> <li>1. Finger pointing and knuckle control</li> <li>2. Accurate and fast joystick control</li> <li>3. Self-taught computer skills</li> <li>4. Literacy</li> </ol>
LIMITATIONS OF INTEGRATED COMPUTER IN COMMUNICATION AID	<ol style="list-style-type: none"> <li>1. Slow processing speed – uses only as basic computer</li> <li>2. Can be a mobile phone but if not using aid then no phone connection</li> </ol>
BENEFITS OF INTEGRATED COMPUTER IN COMMUNICATION AID	<ol style="list-style-type: none"> <li>1. Can be used for email if away from home</li> </ol>

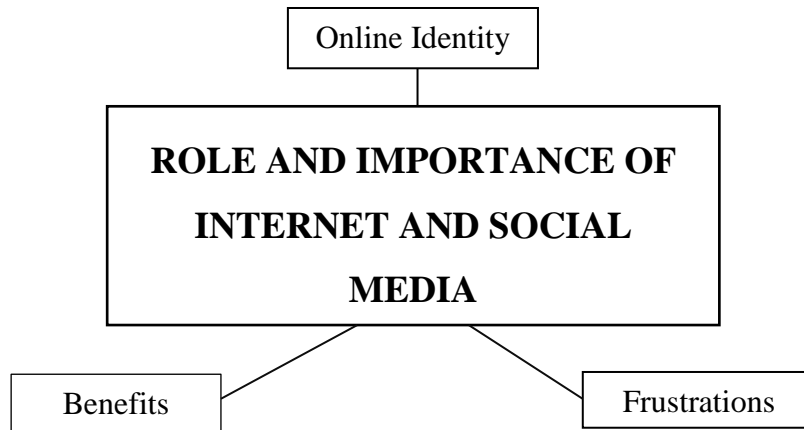


**Thematic Network 2**



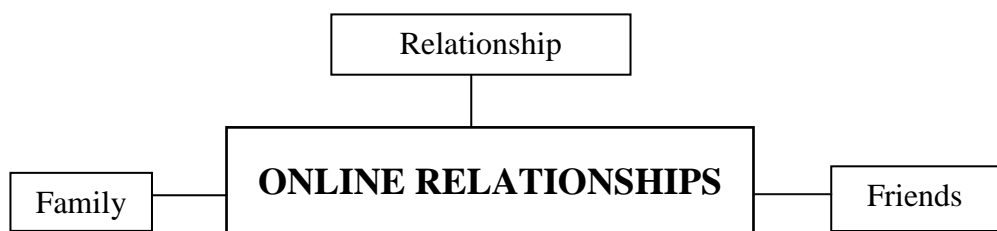
<i>Organising themes</i>	<i>Basic themes</i>
SITES USED	1. Facebook
	2. Email
	3. MSN
	4. Skype
ACTIVITIES	1. Co-running business
	2. Supporting hobby interest
	3. Organising social life
	4. Playing game on Facebook
	5. Personal profile updating
	6. Supporting romantic relationship
	7. Communicating with family and friends
	8. No political activity online

**Thematic Network 3**



<i>Organising themes</i>	<i>Basic themes</i>
ONLINE IDENTITY	1. Only posts things considers to be interesting 2. Uses own photo on Facebook profile
BENEFITS	1. Increased privacy - texts with Skype phone calls to family 2. Increased independence 3. Communication 4. Fills time with Facebook game 5. Widespread use of email
FRUSTRATIONS	1. Keycode equipment required by banking site 2. Requiring help for online activities from staff

**Thematic Network 4**



<i>Organising themes</i>	<i>Basic themes</i>
FAMILY	1. Skype increases family intimacy
FRIENDS	1. Only contacts people online known offline 2. Prefers to see and hear people 3. 70% of friends use Facebook 4. Nearly all friends use email 5. No friendships via solely meeting online
RELATIONSHIP	1. Social media supported relationship with another AAC user

APPENDIX M – ANONYMISED VERBATIM TRANSCRIPT 1

Amanda = Researcher, Nancy = female VOCA user, indirect access via headswitch.  
Uses gesture for yes (opens mouth wide or smiles) and shakes head for no. Uses natural voice to say yeah

Transcription: Naturally spoken words are italicised e.g. *naturally spoken speech* and machine-produced digitized or synthesized speech (aided speech) e.g. “*words and sentences spoken by a machine*” and non-verbal expressions are presented in quotation marks with an explanation given in brackets e.g. ‘no’ (shakes head).

Overall interview time: 30 minutes 9 seconds.

- Amanda: *I was wondering do you use the internet could you tell me about that first*
- Nancy: (starts typing on communication aid)
- Amanda: *what you like to use, oo sorry I went too quickly I'll wait*
- Nancy (53 second pause) “*I like use Facebook Skype*”
- Amanda: *Okay that's interesting and do you use the internet as well for example um do you go and look at YouTube*
- Nancy: *yeah*
- Amanda: *yup and how do you access things on the internet and social media. Do you use it on your communication aid*
- Nancy: *yeah*
- Amanda: *so you can access it on here*
- Nancy: *yeah*
- Amanda: *would you mind just showing me how you do it would that, is that something you wouldn't mind*
- Nancy: (23 second pause) “*need my cable to computer*”
- Amanda: *ah. Right I've got you so um your you would use this (pointing to communication aid) as a mouse control*
- Nancy: ‘yes’ (smiles)
- Amanda: *and you would have like a USB cable onto a computer*
- Nancy: ‘yes’ (opens mouth wide)

Amanda: *okay that's fine I understand now. Cos the last person I was speaking to she had her Facebook and everything in the room (pointing to the communication aid screen) but that's fine, we don't need to see it, it's just great to know how you do it. Um so how do you think it makes you feel, people have told me it makes them feel excited or happy or they'd feel lost without being online and things but how do you think you feel about being online and using*

Nancy: (60 second pause) *"can talk dad to (60 second pause)"for in Spain"*  
(60 second pause) *"can talk dad for in Spain"*

Amanda: *oh right so you can talk to your dad cos he's in Spain. Right, so do you talk to him on Skype and on Facebook*

Nancy: *yeah*

Amanda: *so how does that make you feel*

Nancy: (26 second pause) *"good"*

Amanda: *so would you feel sad or sorry I don't know what you would feel! What would you feel if somehow you weren't online and able to use the internet, what would it make you feel*

Nancy: (20 seconds) *"feel frustrated"*

Amanda: *mm do you think it gives you more independence to be online or to be on the internet*

Nancy: *'yes' (opens mouth wide and makes a low sound)*

Amanda: *yeah?*

Nancy: *'yes' (opens mouth wide)*

Amanda: *what sort of things do you follow online what are your interests*

Nancy: (34 second pause) *"talk friends"*

Amanda: *mm hmm and who are your friends online? Is it friends from college*

Nancy: *yeah*

Amanda: *have you got friends from your old school as well*

Nancy: *'yes' (opens mouth wide) yeah*

Amanda: *and are you connected with your family? I know you can talk with your dad but is there anybody else*

Nancy: *yeah*

Amanda: *um*

Nancy: (60 seconds) “mum”

Amanda: *right your mum okay. Have you got any brothers and sisters*

Nancy: *yeah* (23 seconds) “mum, my step brothers are called (name) and (name)”

Amanda: *do you speak to them online*

Nancy: *yeah*

Amanda: *do you use email*

Nancy: (made a response very faintly)

Amanda: (not sure of response) *sorry do you use email*

Nancy: *yeah*

Amanda: *and do you use texting*

Nancy: *yeah*

Amanda: *and I know it’s a bit.... some of the questions sound a bit sort of obvious but um with texting have you got a mobile phone that you use or do you do texting through a computer*

Nancy: (27 seconds) “phone”

Amanda: *okay have you got what they call a smart phone is your phone connected to the internet*

Nancy: (shakes head very slightly)

Amanda: *was that a no?*

Nancy: ‘no’ (shakes head no)

Amanda: *okay so right if you use the internet you’ll do it via a computer but then you use your phone for texting or making a call or something.*

Nancy: ‘yes’ (opens mouth wide)

Amanda: *Um how er, I think we’ve covered most of (consulting notes)... Oh, who gave you help to go online, where did you get most of your help was it at home with your family, or was it at college or was it at school. Who helped you to get set up?*

Nancy: (60 seconds) “school and home”

Amanda: *okay so you were already used to being online when you came to college is that right*

Nancy: ‘yes’ (opens mouth and smiles)

Amanda: *yeah, okay. So were you helped with online safety and things like that when you first got told about how to go online*

Nancy: *yeah*

Amanda: *did people tell you about safety*

Nancy: *yeah*

Amanda: *okay and do you feel that is there anything not very nice that has ever happened to you online or anything like that*

Nancy: *'no' (shakes head)*

Amanda: *has everything always been alright when you've been online*

Nancy: *yeah*

Amanda: *so you haven't ever had any experiences that have made you unhappy*

Nancy: *no response*

Amanda: *oh sorry I'll make that a ... er a yes or no question have you had any experiences that made you unhappy*

Nancy: *'no' (shakes head)*

Amanda: *no okay good. Um oh how do you like to represent yourself on Facebook and things? Do you have a photograph of yourself*

Nancy: *yeah*

Amanda: *yeah, are you doing anything in the photograph? Is it just a picture of your face or is it on holiday or... can you remember*

Nancy: *'no' (shakes head)*

Amanda: *no so it's just a photograph of you that someone took. And some people have told me that they um like using Facebook cos they feel it's a chance for them to tell people about themselves, they like the timeline, they can share memories, they like to be able to show their humour, they like to be able to show places that they've been or holiday and things. Do you have any thoughts about that?*

Nancy: *(no response)*

Amanda: *Do you think Facebook is a place where you can show people your personality*

Nancy: *yeah*

Amanda: *what kind of thoughts would you have on that*

Nancy: (starts working on communication aid, 1 minute 50 second pause) “*it good show pictures*”

Amanda: *okay that’s my favourite thing. I like looking at pictures, I love looking at where people have been and stuff. Um do you um so it’s good to show pictures and share things with people do you um.. one girl was saying to me that she felt that sometimes people didn’t really understand her under lying ability and that they didn’t give her time to talk and to say things and she felt that because she was able to show people what she thought on Facebook or using email cos she had more time to get messages ready that she thought it showed people that they had to give her more time to say things in face-to-face conversations. What do you think, would you agree with that*

Nancy: ‘no’ (shakes head)

Amanda: *no so it doesn’t seem to, you don’t feel that it makes much difference that you can either tell people face-to-face or doing things online doesn’t make much difference*

Nancy: ‘no’ (shakes head)

Amanda: *okay, did you understand what I meant*

Nancy: ‘yes’ (nods head)

Amanda: *yeah but that’s not something that’s important to you*

Nancy: ‘no’ (shakes head)

Amanda: *okay, what do you think the main benefit of being online is, what do you think the most important thing is*

Nancy: (1 minute, 10 second pause) “*people understand me better in writing*”

Amanda: *okay, so can I just check that I’ve understood that so you’re saying that when you can write things down you can give people more information and they can understand you better*

Nancy: *yeah*

Amanda: *so in a way it’s a little bit like the same thing that other girl I was talking about she was trying.. I think she was trying to say the same thing that by being able to write things down people can understand her better and she can show people more. So do you think there is something about time that is important*



Nancy: *yeah*

Amanda: *does being online give you more time to write about things*

Nancy: *yeah*

Amanda: *and that makes people understand more*

Nancy: *yeah*

Amanda: *is it that*

Nancy: *yeah*

Amanda: *can you.. I was just wondering would you be able to tell me something about what you think about time in what you were saying that people can understand you better in writing. Is it to do with time is that what you mean*

Nancy: *“yes”*

Amanda: *okay and is that because do you think people aren't as patient when you're speaking to them like you and I are talking now. Is that why it is sometimes better to talk to them in an email or something*

Nancy: *“sometimes”*

Amanda: *okay I suppose it depends how busy people are, oh sorry you haven't finished, sorry*

Nancy: *(pause with Nancy looking at me and not using communication aid)*

Amanda: *oh so you have finished! So depending on the situation, sometimes. So have you ever used email or Facebook if you've been in a face-to-face conversation and you feel that you haven't had a chance to say everything that you wanted to say would you maybe send somebody and email or say something to them on Facebook to them later*

Nancy: *“yes”*

Amanda: *okay. And do you use anything other than Skype and Facebook and email and texting? Do you use twitter*

Nancy: *(10 seconds) “MSN”*

Amanda: *oh yeah that's good, it's nice and instant isn't it. Do you use Twitter by any chance*

Nancy: *‘no’ (shakes head)*

Amanda: *have you seen Twitter*

Nancy: *‘yes’ (nods head)*

Amanda: *why would you not use it*

Nancy: (20 seconds) *“got Facebook”*

Amanda: *so you prefer Facebook, is that right do you prefer Facebook*

Nancy: ‘yes’ (nods head)

Amanda: *why do you prefer Facebook*

Nancy: (30 seconds) *“don’t know”*

Amanda: *Mmm, I wonder if it’s cos you said you like showing pictures I wonder if it’s...*

Nancy: (no response, looks away from Amanda and then turns and stares)

Amanda: *I guess there’s more you can do with Facebook than Twitter, it’s just like one comment on Twitter*

Nancy: (smiles)

Amanda: *I prefer Facebook as well I think cos I like to see more about people. So what else have people told me that I’d like to double check with you. Oh some people have told me that they like being online because they can find out information for themselves so they feel more independent. What do you think about that*

Nancy: ( 52 second pause) *“It’s easier for college work”*

Amanda: *mm that makes sense. Yes cos I was talking to (head of technology) earlier and he was saying you are all on a college domain so you can have all your college files and everything all stored on and then you can access straight through here (pointing to communication aid) into your college work and college files. So um so we’re just coming to the end of our time together what um if you were wanted to give me one sentence that summed up all your thoughts about being online and the difference it has made to your life what would you tell me about it. If I was an alien who had come down from outer space and I didn’t know anything about it*

Nancy: (30 seconds) *“good I can talk family”*

Amanda: *okay yup, especially when you are here I imagine*

Nancy: (smiles)

Amanda: *Does it make a big difference*

Nancy: ‘yes’ (nods head)

Amanda: *and the one other thing I wasn't quite clear about was do you use the internet as well for research and finding things out and shopping and things like that*

Nancy: (4 seconds) *yes*

Amanda: *and what are the main things you are interested in*

Nancy: (12 seconds) *"games"*

Amanda: *oh my goodness you've just reminded me of a whole thing I wanted to ask you about!. I wanted to know about computer games what kind of things do you do?*

Nancy: (15 seconds) *"bubble island"*

Amanda: *so that's one of the main things that you enjoy using the internet to do is computer games.*

Nancy: *'yes' (nods head)*

Amanda: *Okay, do you play any other games apart from bubble island*

Nancy: *'no' (shakes head and smiles)*

Amanda: *okay and I'm gonna have to, I don't know bubble island I'm gonna have to*

Nancy: (25 second pause) *"cards"*

Amanda: *oh yeah like card games where they flip over the cards and things*

Nancy: *'yes' (nods head and smiles)*

Amanda: *oh I got completely addicted to Solitaire when I first found that, I couldn't stop playing*

Nancy: (smiles) *yeah*

Amanda: *um oh do you play Scrabble or anything like that online*

Nancy: (glances at clock and suddenly switches her power supply over from her communication aid to her wheelchair control)

Amanda: *oh do you want to finish now*

Nancy: *yeah*

Amanda: *okay well it's really nice to meet you Nancy and thanks for your help it's been really interesting what you said. Let me open the door, nice to meet you. Bye*

Personal assistant: *ah Nancy*

Amanda: *oh hi, sorry I kept you a little bit too long*

PA: *No, no, we're not ready, not at all. I was just coming to intercept*

Amanda: *oh well nice to meet you Nancy. Are you okay by the way, did everything go alright*

Nancy: *yeah*

Amanda: *right okay, alright bye*

(Total interview time: 30 minutes and 9 seconds)

APPENDIX N – ANONYMISED INTERVIEW TRANSCRIPT 2 (excerpt)

AMANDA: *what things would you use the internet to do?*

HARRIET: F-a-c-e-b-o-o-k, s-h-o-p-p-i-n-g a-n-d I b-u-i-l-d w-e-b-s-i-t-e-s

WILL: “Anything”

AMANDA: *Right so you would use the internet to do anything (addressing WILL).  
What kind of websites do you build? (addressing HARRIET)*

HARRIET: A-n-y-t-h-i-n-g i-t d-e-p-e-n-d-s o-n t-h-e c-u-s-t-o-m-e-r

AMANDA: *Ah, right so do you earn money from building websites*

HARRIET: Y-e-s (whole word available on alphabet board)

AMANDA: (addressing WILL) *Would you like to say something about.*

WILL: ‘no’ (shakes head)

SLT1: *I thought you said yes*

WILL: ‘no’ (shakes head)

AMANDA: *What are your interests and things you might follow on the internet*

WILL: “Talk”

AMANDA: *Right, to talk with other people, that’s the main*

WILL: ‘yes’ (raises brows)

*APPENDIX O – CHILD LANGUAGE TEACHING AND THERAPY*

*ABSTRACT*

(Suggested revisions from anonymous reviewers. Re-submission to editors at the end of october 2013)

“Happy and excited”: perceptions of using digital technology and social media by young people who use augmentative and alternative communication

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**Abstract**

Research indicates young people are increasingly using digital technology and social media within their everyday lives, especially for communication and entertainment. Using digital technology may support social inclusion opportunities but challenges for access mean people with physical disabilities are at risk of digital exclusion and contextualising their experiences is vital for understanding opportunities and barriers.

People with physical disabilities and complex communication needs use total communication strategies to support or replace their natural speech with forms of augmentative and alternative communication (AAC). One high-tech form, a voice output communication aid (VOCA), is a computer that creates a synthesized or recorded voice. Recent technological developments within this specialist field and the mainstream arena have created increased opportunities for people who use augmentative and alternative communication to engage with digital technology and social media.

This paper discusses the results from qualitative interview research carried out with 25 adolescents and young adults with physical disabilities and complex communication needs (aged 14-24) about their experiences of using digital technology and social media. Findings indicate a strong desire to be online and increased social inclusion opportunities. Frustrations exist in terms of alternative access to mainstream devices heightening the risk of digital exclusion. Collaboration and technical support from educational settings, families and friends are important aspects in overcoming challenges.

### **Keywords**

Augmentative and alternative communication, AAC, voice output communication aid, VOCA, complex communication needs, adolescents, young adults, physical disabilities, grounded theory, qualitative, interview, digital technology, social media, social inclusion, social participation, social exclusion