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Teenage worlds, different voices:
an ethnographic study of identity and the lifeworlds
of disabled teenagers who use Augmentative and
Alternative Communication

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Abstract

This study explores identity and the lifeworlds of disabled teenagers who use Augmentative and Alternative Communication (AAC). Drawing on theoretical influences from Childhood Studies, Disability Studies and Social Anthropology it uses ethnographic methods, to investigate the lives of nine key participants aged 10-18 years. Participant observation in schools, homes and clubs, and extended narrative conversations were conducted with participants over 18 months. Interviews and focus groups with parents, school staff and 15 additional teenage AAC users contextualize the data. Three adult AAC users contributed as research advisors.

Thematic analysis generated four main themes: Voices, Selfhood, Bodies and Personhood. These revealed that the participants view themselves principally as 'normal' teenagers, whose families and friends are important, and who aspire to live the same lives as their non-disabled peers. They paint positive pictures of themselves as sociable and competent without highlighting their impairments, although they acknowledge disability as part of their identities. They have pragmatic attitudes towards the effects of their impairments. Their main concern is to have appropriate, reliable technology, and friendly, respectful assistance, enabling them as much autonomy as possible.

Their self-perceptions are matched closely by the views of those who know them best. These people emphasise the teenagers' social relational selves rather than their impairments. In contrast, those who know them less well, over-emphasise their differences and fail to recognise their teenage selves. Judgments about who they can *be* are then made on the basis of what they can *do*. Thus for the participants there is an ontological dissonance between how they see themselves (selfhood) and the way they are often seen by unfamiliar others (personhood). They are annoyed and frustrated by these misattributions, but unlike disabled people without communication impairments, it is especially difficult for these young AAC users to resist and correct misunderstandings about who they are.

Dedication

To people who like talking

Acknowledgements

I would like to express my sincere and heartfelt thanks to all the teenagers, and their families and friends, as well as to staff at the schools and clubs, for welcoming me into their worlds and giving me so much of their time and of themselves. I would also like to thank the three research advisors for their enthusiastic support and interesting feedback, and for finding time to talk despite their busy lives. Their thoughts and insights were invaluable and improved the study in many ways. I learnt a lot from all of you, participants and advisors alike.

I owe a debt of enormous gratitude to my supervisors Professors Allison James and Sheila Wirz for their support during the rollercoaster of this project. Thanks to Allison for being inspirational and challenging as well as keeping me on the straight and narrow in patient and encouraging ways. Thanks to Sheila for her interesting questions, pragmatism and good humour. I would also like to thank Dr Kathy Boxall for her considered feedback and support, which was reassuring in the final stages.

Lastly thanks to my nearest and dearest relatives, friends and colleagues who have generally kept me sane in many ways during this adventure. You know who you are. Normal service will be resumed shortly.

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List of Abbreviations and Glossary of terms

AAC   Augmentative and Alternative Communication

BSL   British Sign Language

CM   Communication Matters (UK Organization for AAC users and professionals working with them)

ICF   International Classification of Functioning, Disability and Health (WHO 2002)

ISAAC   International Society of Augmentative and Alternative Communication (Global organization for AAC users and professionals, focusing on research, advocacy and service provision)

Low tech AAC   Systems of non-speech communication such as symbols, signs, gestures, communication books or board and objects of reference

LSA   Learning Support Assistant (person working with individual students in schools)

Makaton   Simplified sign language based on British Sign Language, used in many special schools, and mainly with people with learning disabilities

OT   Occupational Therapist

PA   Personal assistant (paid assistants who work with individuals in home, study, work and social environments)

Physio   Physiotherapist

RA   Research advisor

SLT   Speech and Language Therapist

VOCA   Voice output communication aid. 'High tech' computer aided device, which produces an artificial 'spoken' voice

1Voice   UK organization which supports young AAC users and their families

WHO   World Health Organization

Notation conventions

- All quotes from fieldnotes and from verbatim conversations with participants are presented in *italics*
- Words spoken with a voice output communication aid (VOCA) are in *CAPITALS*
- Words expressed with a sign or via a communication book are written in lower case but with the mode indicated e.g. *look (sign)*
- Words which are only partially intelligible or unintelligible are represented as (???) or (table ???) where a guess as to meaning has been made
- Non- verbal communication such as laughing, vocal sounds, eye gaze, mime, and signs (BSL or Makaton) appear in brackets eg. *(points at TV), look (sign)*
- Pauses are represented as **...**. Each **.** represents approximately 1 second

A note about presentation of verbatim conversations with participants using AAC.

When quoting the participants, I have sometimes included such detail as repetitions, pauses, misunderstandings, and words related to the AAC user selecting a category page in a communication book, or on a VOCA, using a manual sign etc. I have only used such detailed transcription when it seems important to illustrate the minutiae of the communication that occurred, rather than just the content of the message. This is mainly in Chapter Three which focuses specifically on the nature of the young people's 'voices'.

On other occasions for the sake of brevity, I have omitted these details and presented only the simplified message.   It will be clear on each occasion which approach is being taken, but it should be remembered that all the participants' communication proceeds at an extremely slow rate of about 5-20 words per minute compared with natural speaking rate which is around 150 words per minute.

Anonymity

The names of all children, family members, friends etc have been changed, and so have the names of adults, schools, clubs etc. Exceptions are the research advisors who are happy for their real names to be used, and the organization 1Voice which also gives permission for their involvement to be acknowledged with their real name.

I have referred to all the AAC users high tech communication aids just as 'VOCAs' (voice output communication aids), as using the product names for individual equipment might make individuals more identifiable.

Ages are those of the participants at the start of the project, by the end of course they were about two years older.

List of Boxes, Photos, Figures and Data Tables

Introduction

> 'When I was five I went to school but I couldn't speak to my friends and I felt dead. When I was nine I would lie in my bed and wish I could meet someone who would help me to speak…Before I had my Delta Talker I felt dead. NOW I AM ALIVE AND I CAN SAY WHAT MY BRAIN IS THINKING' Nicola Bush (Ford 2000)

This project investigated the identities and lifeworlds of disabled young people aged 10-18 years, who were born with neuro-developmental impairments. These teenagers have severe physical impairments which result in difficulty with moving and little or no speech[1]. They communicate using a range of 'low tech' communication systems such as signing, picture and symbol books, and 'high tech' computer aided voice output communication aids (VOCAs)[2]. These different methods of communicating, used alongside or instead of natural speech, are known collectively as 'augmentative and alternative communication' (AAC). People with severe communication and physical impairments and who have typically developing cognitive abilities may be viewed by onlookers as having 'a normal mind trapped in an abnormal body'[3].

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1 For further information see Appendices B and C, pages 329-330

2 'These include a range of electronic devices which produce spoken words or phrases using an artificially produced 'voice output'. A detailed description of Augmentative and alternative Communication (AAC) will be given in Chapter 3. A DVD is also provided with video clips of people using AAC in order to help the reader understand how this form of communication works (see appendix K page 349).

[3] It is important to note at the outset that the use of the terms natural/not natural, normal/abnormal, ordinary/extraordinary are controversial in the disability field (Brown & Smith 1989, Davis 2006). I have used 'natural' in relation to speech, to refer to physiological speech as opposed to that artificially produced (e.g. computer generated) by VOCAs.   Concepts of 'normality' and 'ordinariness' arose in the data from the teenagers, their parents, and others, and thus have been discussed in this context as part of the analysis, although my own understandings deter me from using this rather essentialising language as far as possible.

I was motivated to conduct this research by my interest in anthropological views of identity and the part played by narrative in the evolving self, together with previous professional experience of working with disabled children with communication difficulties. The possible disjuncture between these teenagers' 'bodies and minds' and their own views of their situation were the initial phenomena around which the research questions were formed.

The research set out to explore a core group of 10-15 young people's views of themselves, their lifeworlds and experiences. Using ethnography as the main underlying approach, the study was based in participants' schools and homes, and collected data about aspects of their identity, peer and other relationships, communication, support needs, aspirations and concerns. The research also followed them into other community settings (e.g. holiday schemes, clubs, outings), to gain an in-depth view of their lives in diverse contexts. It focussed on their own perceptions and endeavoured to explore how they see themselves in relation to other teenagers and society at large and to what extent they see their impairments as disabling. The study also contextualised the data from the teenagers themselves by asking others such as their families and school staff for their views, and by drawing on three adults with similar impairments for advice about the project.

The objective was to investigate how concepts of the self and social identity evolve when conventional ways of expressing thoughts and feelings through speech are not possible because of an 'impaired' body. For these young people, language cannot easily be expressed through speech. For non-disabled children, in contrast, the process of constituting ideas of self and other is mainly through talk, in the diverse contexts, experiences and environments of their lives (Goffman 1959, Bateson 1955, Ochs & Capps 1996, Nelson 2000). Children who cannot talk will also be experiencing their own similar set of relationships and situations, and this study aimed to uncover the ways in which they make sense of these in the absence of easy access to spoken conversations (Garfinkel 1967). Another key aspect of the process of identity formation is an individual's relationship with their body (Csordas 1994, Shilling 1994). Investigating the way in which having a 'different' body (including needing equipment, such as a wheelchair, to augment carrying out everyday

functions) plays a part in the young peoples' construction of self was therefore another objective of the research (Christensen 2000, James & Hockey 2007). For these young people, there are potentially both similarities to and differences from their peers in these processes of identity construction, especially as they are often at the margins of social situations and are immediately marked as different both by their physical appearance and their mode of communication. The significance of this in relation to identity construction is explored in this study.

Theoretical influences for the research are drawn from recent thinking in a range of disciplines; principally in Childhood Studies and the new childhood paradigm (James 1995, James, Jenks & Prout 1998, Christensen 1999), in Disability Studies and the social model of disability (Murphy 1987, Oliver 1996a, Shakespeare 1996, Morris 2003, Thomas 2006), and in communication sciences on AAC (Light 1997, Beukelman & Mirenda 1998, Blackstone et al 2005, Clarke 2003, Lilienfeld & Alant 2005). These in turn draw on work in sociology, anthropology (Goffman 1963, Douglas 1966, Geertz 1993, Cohen 1994, Jenkins 2004), psychology, and linguistics (Bateson 1955, Garfinkel 1967, Nelson 2000).

This study is therefore unique in setting out to integrate these different perspectives in the study of this particular group of young people. Children and young people who use AAC have previously been the *objects or subjects* of clinical, linguistic and psychological studies, rather than being seen as active *participants* in research processes and in the social world. The project is innovative in studying severely communication impaired teenagers in depth over such a long period (18 months), across settings, and in using ethnography, particularly participant observation, as well as a variety of other qualitative methods to amplify their own voices. It is unusual in focussing mainly on views from the young people themselves, rather than those mediated through others around them, and in including three disabled adults who use AAC as research advisors to inform the project.

Research Questions

1. How do young people with severe physical and communication impairments who use AAC see themselves (selfhood)?

2. How are young people who use AAC seen by others (personhood)?

3. What kinds of social relationships do young people who use AAC have?

4. What role does the body play in the development of selfhood, social relationships and personhood, for young people who use AAC?

5. What kinds of methodologies work best when doing research with young people with severe communication impairments?

Thesis structure

The thesis is presented as eight chapters. Chapter One introduces the project and provides a literature review of the key theoretical influences and issues. It aims to provide a backdrop for the six data analysis chapters by reviewing theory relating to: disability, children and young people, identity, and the body, as these are overlapping and interwoven themes throughout the study. Chapter Two describes the methodology and presents theoretical issues from the literature related to the methods used. Chapter Three on Voices provides a bridge between the methodology and the subsequent chapters by describing the process of AAC communication in detail. It aims to enable the reader to understand how conversations with AAC users work, and how this different way of communicating affected the type of data that could be collected. This is accompanied by a DVD with a video clip of an AAC user talking and a short video which I was involved in making during the fieldwork period. Chapters Four to Seven, on Selfhood (two), the Body and Personhood respectively, draw extensively on themed ethnographic material to analyse these aspects of the young people's identities and lifeworlds. Additional overarching themes were: disability issues, power, and structural influences on disabled people's lives. Discussion about these has been integrated into the chapters where relevant.

Finally Chapter Eight summarises the key findings and draws broader conclusions, which have important implications for the way in which these disabled young people are understood and for how services and support are provided and inclusion achieved for them, both by statutory services and by society at large.

Chapter One. Literature review

Introduction

The literature that informs this study is drawn from a number of disciplines, and indeed the topic itself demands a synthesis of ideas across boundaries between these. It necessitates bringing together ideas from Childhood Studies and Disability Studies, both of which, as relatively new academic arenas, themselves draw on theory from Sociology, Anthropology and Psychology. The study also draws on some research from human communication science. This chapter therefore begins with short overviews of key issues within these disciplines, before dissecting in greater depth the core theoretical topics of identity and the body. The review is intended as a general overview of the arenas of knowledge that contributed to my thinking. More specific interrogation of the literature where it is relevant to the analysis is included in each of the themed chapters.

Disability

In the last three decades there have been radical shifts in philosophy, concepts and language in the area of disablement. Ideas expressed both in the expanding academic field of disability studies, led originally by a small number of disabled activists (Oliver 1996a, Finkelstein 1999, Goodley & Moore 2000, Barnes 2003) and in the 'official' declarations of world bodies such as the United Nations (UN), World Health Organization (WHO) and the International Labour Organization (ILO), have resulted in changes in definitions and terminology. Importantly disabled people themselves have played a major part in establishing new ways of viewing disability. Key academic and policy work has both reflected and driven changes in attitudes to disability, many of these following in the footsteps of other human rights discourses in gender and race. Most recent and significant globally in the promotion of the rights of disabled people to equal recognition and participation, is the UN Convention on the Rights of People with Disabilities launched in 2006 (UN Enable 2006). Notably however, and of relevance to the present project, the needs and perspectives of disabled children and young people have been rather under-represented by this otherwise groundbreaking document (Landsdown 2009).

In 2001 the WHO produced a new conceptualisation of disablement; the International Classification of Functioning, Disability and Health (ICF)[4]. This attempted to answer criticisms that previous models had focused too much on the nature of the disabled person's individual corporal (e.g. physiological, anatomical, psychological) differences in relation to a 'normal' ideal. The WHO thus suggested the following revised terms and relationships:

- 'disablement' or disability as overarching terms
- 'impairment' the organic differences of structure and function (as before)
- 'activity' the restriction at a functional level (previously disability)
- 'participation' the level of social inclusion or exclusion (previously handicap)

Additionally and importantly two more factors not previously recognized were incorporated into the model:

- environmental
- personal (WHO 2001)

Although not universally accepted, and criticized still for being too 'medical' (led by the health condition), the model was innovative in attempting a more clearly multidimensional view of disabled people's situations (Bury 2000). The new conceptualization attempts to recognize that the extent to which someone with impairments is disabled is an interaction between their organic impairment, the restriction in their activities and their level of participation in society, in a particular environmental context and in consideration of personal aspects. Adding personal and environmental factors to the model, importantly acknowledges the influence of reactions and responses of the society around the person, as well as the contribution of physical and psychological factors unique to the individual. This revised version thus aims to take account of political, socio-economic and environmental influences on people's lives. Arguably therefore, for the first time, aspects of both structure and agency and their interaction are properly incorporated.

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[4] See Appendix A page 328

This work was a valiant attempt to establish uniform use of the various terms, but in practice only some professionals use them in exactly this way, and in particular, the terms disability and handicap are often still used inaccurately and what is more, interchangeably by the general public (Bury 2000). The ICF has also been interpreted and applied differently around the world (Ingstad & Reynolds Whyte1995). Disability activists have produced a number of alternative models and definitions in response to this model and there is still a lack of consensus about definitions and language use (French 1993, Oliver 1996b). However, broadly the move has been from 'medical' to 'social' models of disability, as described below. These models have had significant impact on the way that policy and service provision are justified and underpinned by theory.

The Medical (or Individual) model focuses on the nature of the impairment itself. It stands accused of having an interest only in finding causes for, and eliminating or curing impairments (Gordon 1988, Oliver 1996a). It is rooted in a scientific paradigm where 'normality' can be measured and defined and where the underlying assumption is that everyone aspires to be 'normal'. This model has difficulty with views which accept or celebrate difference (Davis 2006). The medical model offers prevention of the onset or exacerbation of some impairments, the minimizing of some and of course the relief of pain. It aims to improve people's function and consequently lessen the disabling effects of their impairment. Some detractors of the medical model of disability describe this approach as a 'tragedy' model, because it implies that disabled people are irrevocably deficient and not complete (French 1993, Barnes 2003). Traditionally this view is also linked to 'charity', wherein it is society's duty to help the person to become 'whole'. One of the key criticisms is that it is likely to reinforce the idea of the disabled person as being less human, because their impairment is viewed as a 'deficit' (Murphy 1987, Donoghue 2003). People are then likely to have diminished personhood and be objectified and dehumanized. Thus power relations between them and others mean that the disabled people themselves then have a weak voice and are disempowered and aspects of their identity are likely to be 'spoiled' (Goffman 1963).

In contrast the Social model sees the disabled person labeled as 'different' as a result of society's inability to accept diversity and lays the blame with health professionals and scientists particularly for promulgating the idea of abnormality. It explicitly celebrates difference and diversity. This stance is overtly political and emerged out of materialist stances. It sees the solutions to the stigma and isolation often experienced by disabled people, as lying within society rather than in changing individuals (Hunt 1966, Donoghue 2003,). This approach fosters independence and autonomy for disabled people. It regards the core issue as one of human rights. Zola (1993), who was one of the originators of the idea that disability was socially constructed, reminds us that we are all on a path towards disablement as we age, and are therefore only 'temporarily able' (Davis 2002). This is a powerful way of reconceptualising the negative way in which disabled people have been viewed and sets out either to make them less different and or to celebrate their difference (Turner 2001).

The 'frailty argument' has been criticized as unhelpful by Hughes (2007). He calls for a more 'critical social ontology' in relation to disability which would 'expose the forms of invalidation that lie at the heart of disabling culture' (p 673). Hughes' main objection is that the universal, vulnerability argument disallows a minority group status for disabled people, which he contends makes more phenomenological sense. Similarly, an 'affirmative model' has been promoted by Swain and French (2000), which further promotes positive attitudes and self-confident images of disability and tries to counter historically stigmatizing approaches. These ideas have had a powerful influence on the development of anti-discriminatory legislation about disability and the promotion of social inclusion for all as well as the development of rights based approaches to services. All of these approaches have an implicit or explicit ontological element to them as they try to address the social processes that may serve to invalidate disabled people's lives.

The more extreme proponents of the social model seem to deny the contribution of or impact of the person's impairment on their situation (Barnes & Mercer 1997). However, more moderate disabled writers insist that their experience of having a different body or mind is important in their lives and needs to be acknowledged as

part of the picture (French 1993, Thomas 2002, Shakespeare 2006). Thomas (2003, 2006) in particular argues that what she terms 'impairment effects' should be recognised as giving the person a different experience of life, which can sometimes be difficult or complicated. Some pragmatically inclined writers have argued for a more 'comprehensive' model which takes account of both individual and societal aspects of disability and suggests action at both the impairment and disability levels (Wyller 1997, Shakespeare & Watson 2000, Shakespeare 2007, Rhodes et al 2008). Certainly the social model of disability in its original formulation is now being challenged and reconceptualised by some writers and activists. The dualistic impairment/disability divide is being questioned and the role of the experience of impairment is now being brought back into focus (Shakespeare 2006, Thomas 2007). Gabel and Peters (2004) suggest that a more flexible, less dichotomized and more 'postmodern social model' needs to be developed which would better account for various types of resistance to oppression and the rapidly changing nature of disabled people's lives. In the UK there is an active disability lobby who fervently advocate for social model approaches and policies. Although they acknowledge that much progress has been made, they argue that there is a need for a still more inclusive society which genuinely welcomes all disabled people (Crowther 2007).

While the literature described above seems to suggest that there is an inevitable and irreconcilable gulf between the medical and social models of disability, this is a pessimistic, unnecessary and in many ways an unhelpful dichotomy. This great divide echoes other often debated dualisms: body/mind, structure/agency, nature/nurture which appear similarly difficult to resolve, combine or eliminate. As will be shown, the disabled people and their relatives whose views appear in this thesis suggest a 'both and' rather than an 'either or' view. This thesis demonstrates that, on the one hand, people with impairments experience real and important differences in their bodies or minds, which have practical consequences in their lives, and for which they need and appreciate 'impairment based' help. On the other hand, they also experience stigma and discrimination which is generated structurally, and so many would campaign for the more inclusive society which the social model advocates.

While national and international legislation is gradually improving disabled people's visibility in society by enforcing accessibility laws, and has undoubtedly helped to change attitudes, some disability academics emphasise that it is much harder to change underlying beliefs than it is to insist on the removal of physical barriers. Thomas (2004) cogently describes the effect of being stigmatized and excluded in subtle 'psychoemotional' ways, which she calls 'social-relational disablism'. Despite the increased inclusion of disabled children in mainstream schools and of adults in work or civil society activities, disabled people still regularly experience discriminatory practices which make them feel left out or in some way 'non human' as will be seen in the data to follow.

Interestingly, concepts from different disciplines converge in theorising these 'states of exclusion'. Thus in anthropology Murphy (1987) describes this as liminality, and Douglas (1966) emphasises impurity and fear of the unknown. Philosophy in parallel employs concepts of disavowal, threat (Shakespeare 1994) and the 'homo sacer' or bare life of a person without rights (Reeve 2008). Hughes and Paterson (1998) and Thomas (2007) use social psychological ideas, suggesting 'intercorporeal dys-appearance' and psychoemotional effects respectively. Thus there is agreement that the person with impairments is perceived to be different and treated as 'another type of person' or even non-person, who can then, perhaps legitimately be excluded, ignored or patronized. Such conceptualisations are useful, as all account for the 'existential insecurity' felt by many disabled people. As Thomas (2007) suggests this limits who they can *be* on the basis of what they can *do*, and Deal (2007) describes this subtle form of prejudice as 'aversive disablism'. Thus, although structural changes have been made through improvements in the legal position of disabled people, negative attitudes remain. The recipient is left 'feeling hurt' by the reactions of others (Reeve 2002, 2006).

There is a body of work, however which emphasises that the way disabled people see themselves is different, and that they do not necessarily internalize the negative judgments that are often made about them. Thus Watson (2002) and Reeve (2006), both disabled academics, explain that, to them, their body is 'normal' and that they do not necessarily categorise themselves as disabled, or do not see this as the most

significant part of themselves. Thus the way they are seen by others often conflicts with their own self concepts. Similarly Albrecht & Devleiger (1999) question why it is that disabled people report having a good quality of life, when outsiders observing their situation cannot see it as anything but deficient. They conclude that 'a good life' is linked more to 'a balance of mind, body and spirit' and the quality of relationships and support, rather than with aspects of the physical body. Thus it seems that non-disabled people tend to problematise those with impairments and categorise them as 'the other' in ways which exclude them and create categories that do not necessarily recognise them as people. This echoes work by Hacking (1986) which suggests that once a particular type of person has been identified as different, this category becomes reified. In a process which he calls 'dynamic nominalism', the category then creates the reality. Thus people with impairments find themselves recognised only as disabled rather than as members of a number of overlapping social groups. This places them outside society rather than part of it. These processes of exclusion arise in the data here and are explored further in the thesis.

Research with or about disabled people remains a contentious area, with some disabled activists being unsure that non-disabled people can legitimately be involved as researchers without perpetuating the unequal power relations that the social model of disability foregrounds (Barnes 1992, Zarb 1992, Stone & Priestley 1996, Barnes & Mercer 1997, Newell 1997). In the early 1990s these authors argued that non-disabled researchers were often part of the problem rather than part of the solution to disabled peoples' marginal position. They maintained that only research which explicitly positions itself on the side of the disempowered group, and aims to redress this balance, should be supported. This is termed 'emancipatory' research (Mercer 2002) and would dictate that all research activity should be 'potentially transformative', and that investigation for its own sake risks being oppressive (Oliver 1992, Barnes 1996, Priestley 1998a). However this is not a unanimous view. Shakespeare (1996 and Shakespeare et al 1993) take a more moderate stance, and as a disabled academic himself, Shakespeare does not claim to be emancipatory and furthermore denies the need to be. It seems that there is sometimes a collapsing of the terms 'participatory', 'action' and 'emancipatory' research in this debate which is potentially confusing and unhelpful (Zarb 1992).

This project's design and philosophy is avowedly participatory. It can also be seen as 'action' orientated, as it is iterative and aims to have some practical outcomes which can inform policy and practice about young people who use AAC. Following Balandin et al (2000) this research can thus be described as 'facilitatory'. Garland-Thomas (2000) argues that research which explores and exposes the real lives of disabled people is 'humanizing' and this is the perspective I set out to achieve (Mahon et al 1996, Priestley 1998b, Davis 2000, Goodley & Moore 2000).

Part of the argument in favour of disabled researchers doing the research, is that non-disabled people may misinterpret what they find, and misrepresent it, as well as pathologising and/or infantalising their participants (Jones & Pullen 1992, Davis et al 2003). These are indeed real concerns and there are examples of research that have, arguably, perpetuated negative stereotypes of disabled people (Bricher 2000). Anthropologists, who attempt to provide insider perspectives, have as yet only investigated disability to a limited extent (see Groce 1985, Murphy 1987, Murphy et al 1988, Shuttleworth & Kasnitz 2004). Murphy's work is particularly striking because it is auto-ethnographic, and this is a rarity. There have been a small number of interesting pieces of anthropological work, looking at cultural perceptions of disability in a variety of settings worldwide (Ingstad & Reynolds Whyte 1995, Keck 1999), but very few where the researcher has attempted real immersion into disabled people's lives.

Some writers argue that phenomenologically driven research that tells personal stories is not what is now needed (Barnes 2003). However the current move towards viewing the impact of impairment on individuals' lives from a social viewpoint, as conceptualised by the ICF (WHO 2001) model described earlier, has been helpful in improving public awareness of disabled people's lived experiences. Perhaps therefore this will encourage a move back towards viewing phenomenological work as useful. It seems that people with single 'visible' physical impairments (such as wheelchair users) are perceived as more easily researched, understood and included in the 'mainstream' than those with 'invisible' sensory, cognitive or communication impairments or complex combinations of impairments (Swain et al 1993, Moore et al 1998). Clearly there are methodological challenges with the latter groups, however their frequent exclusion from research reinforces a

'hierarchy of impairments' which excludes them from society to a greater extent than those with physical impairments. Thus those with cognitive and communication impairments are doubly discriminated against, in society and in research. Further discussion about methodological approaches in research with disabled people is included in Chapter Two.

Communication disabilities

Half of all disabled people have communication impairments as part of their pattern of difficulties (Hartley 1998). For most, this means that their speech may be difficult to understand, or they may have difficulty with understanding or producing language. The number of children in the UK whose difficulties necessitate them using AAC is unclear (Valios 2007, SCOPE 2007) and provision of services for this group is currently under review and likely to change (Bercow 2008)[5].

There is an extensive literature about the clinical, linguistic and technical aspects of communication impairment and about AAC. However this mainly explores psycholinguistic or psychomotor aspects of language use, choice, access methods and design of systems (Gerber & Kraat 1992, Beukelman & Mirenda 1998). Some studies do look at patterns of social interaction either between young AAC users and adults, or more latterly between disabled children and their peers (Collins & Markova 1999, Clarke 2003, Light & Binger 2003, Smith 2005, Blackstone et al 2005). However focussing purely on clinical aspects does not reveal the broader realities of their lives, as this study sets out to do, especially as these studies often do not take place in naturalistic settings. Nor do they easily uncover the participants' own ideas, as opposed to those of their parents, teachers or other professionals. There have been a small number of studies using narrative approaches to explore the experiences of learning disabled and communication impaired adults (Booth & Booth 1996, Balandin et al 2000) but very few with disabled children (Morris 2003).

'Cure' for AAC users' impairment is usually not a possibility and thus the ways in which society includes or excludes them becomes especially important. In line with the increasing emphasis on participation as suggested by the ICF (WHO 2001) and

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[5] See Appendices B & D pages 329 & 332.

the social model of disability described above, research foci are now broadening from aspects of the impairment itself and towards issues around the nature of peoples' inclusion (Davis 2000, Davis et al 2003). Some recent work on what participation might mean for the AAC user is thus welcomed (Granlund 2006). The present study takes this trend further in being informed by sociology and anthropology rather than psychology, and it is anticipated that it will complement and contribute to this increasingly human rights focussed agenda in disability research.

Katie Caryer, one of the disabled research advisors has expressed the view that this research needs doing, because using AAC as a way of life is so new and poorly understood. She feels that as wheelchairs have become more common and thus users of them more 'visible' in society, non-disabled people have become used to them and are increasingly more accepting and understanding of the adaptations needed to include users in all aspects of everyday life. However non-speech communication is still a novelty, and seen as extraordinary. Her experience is that people find it difficult to adapt to in conversations, and they are often so busy looking at the 'gadget' that they do not notice the person using it. Another research advisor Meredith Allan writes similarly that people are not 'well educated about what is happening when someone uses AAC and don't know how to react'. Because this is a very different form of interaction, people using it are not recognised as social actors (Allan 2006). Both Katie and Meredith then imply that as this form of communication becomes better known, it will become normalised and accepted, but at present it is difficult to have a voice without being problematised.

This is an argument for a project in which a non-disabled researcher facilitates these unusual voices being heard. Neither of these research advisors objects to a non-disabled researcher doing the work. In fact Katie commented that because people using AAC have not until recently had full access to education, there are probably few if any communication impaired people at present with the appropriate research skills. However the way in which this project 'gives AAC users a voice' is also an important consideration. Although using a high tech VOCA gives some communication impaired people a literal electronic 'voice', for many their method of

'talking' is more complex and multimodal than this suggests. Most non-speakers perform a highly skilled and subtle dance to get their message across, using a combination of signs, body language, low tech pictures or symbols and their high tech system. Thus looking purely at what is 'said' through the electronic voice would miss the point. Some of the previous research about AAC uses spoken conversation as its reference point. Arguably this is implicitly pathologising, because the AAC user cannot 'measure up' to natural speakers if considered in this way (Clarke & Leech 2003). It is necessary to look at ways in which the AAC user makes social relationships using a range of communication methods without stigmatising them by privileging speech. Allan (2006) suggests that the way that AAC users talk is an altogether different form of communication and it should be understood and celebrated for that rather than seen as diminished. For a non-disabled researcher who has always had the easy privilege of spoken language, some challenging questions are posed by people who cannot talk. As Billington suggests in relation to autistic children, this situation has the

> 'capacity to strike at the very heart of us, for they are questions which challenge us to contemplate our own mind and our own consciousness. When we meet an autistic child therefore we may not merely be confronted by their deficits or impairments but our own' (2006:16).

He goes on to argue that 'in autism the idea that the real experts are the people with autism' (Billington 2006:119) and this applies equally to the present group of young people. That is why we need to ask them for their views.

Disabled children and young people

The ways in which childhood and children are conceptualized has varied historically and evidence can be found in social histories, and fiction from past times to illustrate this (Opie & Opie 1959, Aries 1979). It is only quite recently, however, that children and young people have come specifically under social scientists' gaze (Hardman 1974, Corsaro 1992). Like women in previous decades, children are now recognised as a group who warrant particular study or tailor-made types of investigation (Oakley 1994), and consequently there have been some radical shifts in thinking about childhood and children (Jenks, James & Prout 1999, Christensen & James 2003).

The level of participation, control and choice given to children by adults has varied across time and also across cultures and follows on from how they are conceptualised. Certainly the predominant idea that children are 'work in progress' en route to becoming adults has meant that they have not been considered as having agency until recently (Christensen 1998). Their views, understandings and beliefs about the world have been regarded as embryonic and as Prout puts it 'leading toward a congruence with an adult consensus' (1986:113), thus not of interest in themselves. The rise of interest in children's rights and in giving children opportunities to participate is quite new and has perhaps been accelerated globally by the UN Declaration of Rights of the Child (UNCRC 1989), and in the UK by the Children's Acts (1989, 2004), and Every Child Matters (2003). Thus there has been a general movement towards the recognition of children themselves as having both the right and the capabilities to make contributions in a variety of arenas which affect them, including family decisions, policy making, law and research (Morrow & Richards 1996).

Out of the revolution in ideas about childhood has come an increase in research about children and more especially with them as participants (Mayall 1994, Morrow & Richards 1996, Hutchby & Moran-Ellis 1998), and many argue that anthropology and phenomenological approaches have much to offer in researching children's worlds (James 2001, Houtman 2004, Bluebond-Langer & Korbin 2007, James 2007). Ideas about the nature and status of the category 'child' have influenced whether and how they might become the objects or subjects of research (James 1995). There is increasing recognition that children and young people's own perspectives are generally under-researched (Mahon et al 1996). Historically children were regarded as people who could not or would not have views, and so effectively they had no voice that was separate from that of their families, school teachers or social workers, who might have been asked vicariously to say what children felt. Recognition that children are agentive, and are individuals, who make their own meanings, has resulted in them becoming more audible (Toren 2001).

Although there are some ethnographic studies of children in schools and about aspects of children's sickness and health (Prout 1986, Christenson 1998, 1999,

James 1999, Prout 2000), this field is still young and there is plenty of scope for development of innovative methods, in order to obtain a 'child's eye view' (Boyden & Ennew 1997). In relation to research with women, Oakley (1994) draws on Smith (1988) in suggesting that:

> 'It is essential to preserve the presence of subjects as knowers and actors, and to ensure that subjects are not transformed into objects of study by use of conceptual devices for eliminating their active presence' (Oakley1994:24).

I would argue that this should also be the aim for anthropologists researching children and young people and particularly for those with disabilities as they are so easily objectified (Tisdall & Davis 2004).

Bluebond-Langer and Korbin (2007) argue that in line with current more inclusive, multivocal, multi-perspective views of culture and society, it is logical and productive to integrate children's voices. They argue not for the privileging of these voices above others, but for their inclusion. However they also discuss the dilemmas in recognizing children's agency while still acknowledging their potential vulnerability in some situations. The UNCRC (1989) introduces the concept of 'evolving capacity' to suggest that young people should have increasing levels of autonomy and participation in decision-making as they grow older (Landsdown 2004). However this has proved a notoriously controversial idea, especially when the notion of adolescence is also contested (Fine 2004, Patel Stevens et al 2007).

James (2007) points out that in the rush to hear 'children's voices' there is a risk of cliché and tokenism and that as a powerful rhetorical device, there is a danger that adults in simplifying, clarifying or mediating may 'reinforce established prejudices' (2007:267). Clearly children's interests, concerns and ways of expressing themselves can be very different from adults'. Many authors have argued for the importance of children and young peoples' active participation both in community projects and in research. Given that unequal power relations between adults and children remain the norm, many have advised that this needs careful methodological and ethical consideration in order not to be tokenistic or to misrepresent them (Hart

1992, Prout 2000, Roberts 2000, Christensen & James 2003, Billington 2006, Hill 2006).

Arguably disabled children have largely been left out of the upsurge in participatory rhetoric and activity for children described above (Priestley 1998a). The concepts of 'competence' and 'evolving capacity' are particularly pertinent here, as disabled children are still generally regarded as incompetent, whatever their individual abilities and thus their views are not sought (Landsdown 2009). Indeed Jans (2004) challenges us to consider whether disabled children are regarded as citizens in the way that other children are, or indeed at all, since as a group they have been particularly excluded, arguably by the double disadvantage of being members of two under-researched groups, children and disabled. The power relations operating to silence both these categories of person justifies some 'catch-up work' which focuses on individuals' experiences, as this thesis will do.

To date there has been particularly little focus on severely disabled children's views of their lives and priorities. Furthermore, in-depth investigation of severe communication disability is as yet a rarity, especially using ethnographic methods. There has been considerable work in the field of deafness (Groce 1985, Sacks 1991, Jones & Pullen 1992), some on aspects of identity and stigma in relation to adults with physical disability (Murphy 1987, Fine & Asch 1988), and one study using narrative interviews of people with aphasia, a condition where speech is lost usually as a result of a stroke (Parr et al 1997). However, there is very little work with children or young people with communication disabilities, who are regarded as a 'difficult to reach' group (Morris 2001, Garth & Aroni 2003, Rabiee et al 2005), and none to date specifically on identity in this group. In fact, often in broader- based work with children, those who cannot talk are specifically excluded as unsuitable participants.

There have been investigations of parents' perceptions of health services and education for their disabled children (Calculator 1999, Marshall et al 2002, Schlosser 2003, Goldbart & Marshall 2004, Markham & Dean 2006). Some studies have asked non-disabled children for their views of non-speaking children (Beck et al 2000), but

only a few have asked AAC users themselves about their lives, and usually then using one-off interviews, which are methodologically problematic with this easily and often 'silenced' group (Clarke et al 2001, Morris 2002, 2003, Connors & Stalker 2003, Rabiee et al 2005, Nind 2008, Franklin & Sloper 2009). Recently developed technology now means it is somewhat easier for communication impaired people to 'talk', although it still requires some specific skills from their conversational partners, and a great deal of time for them to express their ideas in depth. Thus research methods need to be tailor-made in order for them to participate meaningfully.

Government legislation in England and Wales in relation to all children as mentioned above is evidence that there is a shift towards taking note of young people's views to inform health, social and educational policy and practice (Dept of Health 2002, 2003) and this is slowly expanding to include those with disabilities[6]. The present study could contribute to the currently evolving practice of consultation with young disabled people.

Social Identity: Selfhood and personhood

An interest in aspects of social identity, selfhood and personhood is a fairly recent development in sociological and anthropological arenas. The earliest approaches to the study of man, society and culture focus mainly on external structures and it was assumed that the individual was predominantly moulded by these (Craib 1997).

Cooley, writing in the early 20th century, was a pragmatist who introduced the idea of the 'empirical self', one who is necessarily interactional and always in the presence of others. He emphasises the influence that individuals have on each other and uses the term 'social mind' to describe these commonalities between people. Cooley uses the metaphor of mind as an orchestra with symbiotic relationships between members:

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[6] See Appendix D page 332

'Everything I say is influenced by what others have said or thought and in one way or another, sends out an influence of its own in turn' (cited by Jenkins 2004: 35).

Subsequently GH Mead (1934) argued that the nature of face to face interaction was all important and that the social development of the self grew from it. Mead, regarded as the father of symbolic interactionism, described his own view as 'social behaviourism' This new and pragmatic approach opened the way for exploration of the contribution of more internal processes and of attempts to get 'inside the person's head' to see how the world is experienced. In this more interpretative, interactionist approach, Mead differentiated between the 'I' and the 'me'. The former was the person's own conceptualisation of themselves, their 'ongoing moment of unique individuality', the latter being informed by external influences as the 'internalised attitude of significant others'. Mead was clear that both mind and selfhood are attributes of embodied individuals. He argues that there is no sharp line between individual psychological and social psychological elements, and that interaction produces consciousness not the other way around (Jenkins 2004).

Though influenced by Cooley, Mead was somewhat critical of him and aimed for a more systematic model of selfhood. He proposed a cognitive foundation for selfhood in which an 'internalised conversation of gestures, the origin and foundations of the self, like those of thinking are social'. He saw the self as more than 'the bare organisation of social attitude' 'a relationship between I and me'. His view seems to suggest plural selves. Importantly, 'reflexivity is of the essence for Mead', as he sees this as involving conversations 'with oneself' (Jenkins 2004:40).

Mead also proposes a 'generalised other' representing the organised community to which the individual belongs and against which s/he is poised and defined. This is not a series of 'me s', which would be unstable over time, but rather a degree of personal consistency in the self informed by taking on consistent attitude. Mead's 'me talk' of the internalised voice of a generalised other is different from Durkheim's idea of conscience collective. It is a product of ongoing encounters between individuals within group relations. Every person has their own generalised other, but also every group member will have much in common with every other. Without

the generalised other, the Meadian self is incomplete. He felt that this sense of the other was acquired early in childhood and was the 'parent of mind and self'. Jenkins explains then that for Mead as for Cooley, selfhood is 'intrinsically interactional', but additionally he claims that:

> 'Society is a conversation between people; the mind is the internalisation of that conversation; the self lies within and between the two'. (Jenkins 2004:42).

Later in the twentieth century these budding phenomenological ideas grew. More recently philosophers, sociologists and anthropologists have explored relationships between the body, mind and the outside world (Merleau-Ponty 1962). In anthropology the work of Geertz (1975) developed phenomenological ideas and moved things in a more interpretative direction by foregrounding 'subjective realisation'. He was interested in 'getting at meanings' and saw culture as only accessible through the 'conceptual world in which our subjects live so that we can in some extended sense converse with them' (Geertz 1975:24).
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Importantly for this study, Geertz saw language as key in this and was concerned to look closely at what people do, in order not to generalise 'across cases but within them' (ibid:26).   He thus uses 'thick description' and theory to 'ferret out the unapparent import of things' and to find 'cultural patterns, and organised systems of significant symbols' (ibid: 46). Geertz felt that:

> 'As culture shaped us as a single species – and is no doubt still shaping us – so too it shapes us as separate individuals. This, neither an unchanging subcultural self nor an established cross-cultural consensus, is what we really have in common' (1975: 52).

The concepts of self and mind are then inextricably linked and Geertz argues that such mentalistic terms have suffered from dismissive treatment by the physical sciences. The fear of being accused of being subjective encourages people to reduce the mind to pure behaviourist treatment. Geertz saw thought and symbol systems as essential, and culture as an ingredient of these, not supplementary to them. Thus language is fundamental, but, importantly when we are considering young people who cannot talk, he emphasises that thoughts need not be expressed through

speech. He gives the examples of people with aphasia or who are blind/deaf like Helen Keller, as successfully having meanings expressed through alternative symbol systems.

With his emphasis on the internal processes of people, Geertz saw culture more as a 'matter of thinking than doing' and thus the self as central. So culture provides conceptual and cognitive means and models by which to interpret the world. Geertz presents culture as a series of texts, which are available to its readers if we read carefully (or thickly) enough. This approach has subsequently been developed by others in the form of increased interest in 'reflexive' approaches and in extremis to postmodern anthropological trends. The 'reflexive turn' then urges researchers to think about themselves, in order to think about other people thinking about themselves (Cohen 1994). Similarly Berger and Luckman (1967) argue for people's creativity in the active process of constructing their worlds of meaning. They propose an endless cycle of externalisation, objectivation, and internalisation. There is a therefore a dialectal relationship between the person and the social world.

However alongside this tide of phenomenological and reflexive views, the structural tradition has continued with some authors. Giddens (1991) sees the concern with aspects of mind and identity as a modern or post-modern and peculiarly western trend. Both Cohen (1994) and Jenkins (2004) disagree. The former criticising Giddens for having a view of self which is too moulded by structure, and the latter arguing that historically and cross-culturally there are plenty of examples of people being interested in who they are.

Goffman (1963) is a towering figure of influence in the literature on the self but is a recipient of similar criticism. Although he is concerned with the individual he paints the person as a rather reactive entity. He describes the ways in which people need to 'optimise gain or minimize loss in their presentation of self', but this seems to operate rather mechanically. Goffman sees the individual as managing their presentation of their public and private selves, by playing roles that they can enact in the routines and rituals of everyday interaction. Using metaphors from drama such as 'performance', or as games, these are played out according to implicit and

explicit rules which form a basis for negotiation within particular 'frames'. Goffman does, however, allow the person an individual understanding of the frames and transactions at work. He sees the self as embodied, and the upper body and face as the focus and therefore the 'interaction presence of selfhood'. His 'interaction order' then is where all these elements combine in an attempt to 'bridge the gap' between the individual and the collective. However Jenkins (2004) is critical of this as being too 'scripted and ordered' an explanation, and making the individual involved in overly rational means-end calculations.

Cohen (1994) also criticises Goffman's conceptualisation of the self as it seems to suggest a 'performing self' who wins or loses rounds in society by virtue of their membership not as a result of their own conscious decision to participate. This makes for 'a peculiarly selfless society' where we get no sense of the person contributing internally to the process (Cohen 1994:27). Cohen argues that the individual has been 'colonised' and that there is then confusion with political agendas of 'individualism'. Goffman confines selfhood to the performance of roles, a matter of skills and performances, rather than anything more reflexive. Certainly the 'social relations' views of structuralist / deterministic thinkers tend to put people into their roles in the structure and do not see them as individuals. Bourdieu (1977) is clearly influenced by Goffman, but gives more importance to body/mind relationships and the improvisational nature of interaction which contributes to the self as a whole. His 'habitus' is an attempt to encapsulate the essence of the self, as both conscious and unconscious, neither deliberate nor automatic. It has elements that are collective and individual and necessarily embodied.

Cohen (1994) is the contemporary writer who has made the most overt plea for the recognition of the self and of self-consciousness as crucial to understanding society. He suggests starting from looking at the self to see if these internal reflections are indicative of society, rather than vice versa. He postulates not that the individual is a microcosm of society, but that the self is autonomous rather than contingent on society. The 'self is then informed by social engagement but not dependent on it' (ibid: 29). He accuses anthropologists of a tendency to emphasise the social at the expense of the individual and argues for the reversal of this.

Cohen addresses the issue of how selfhood is expressed publicly in different communities and this has direct relevance to my research. He looks to evidence from people's actions, and the imputed link between actions and beliefs. He feels that 'reading lack of selfhood from adherence to uniformities' is a mistake (1994: 51). Thus the public expression of selfhood or lack of it, cannot be conflated with its private importance:

> 'The development of the individual's self consciousness proceeds with the acquisition of experience. Indeed we may say that social experience augments and enhances the sense of self' (Cohen 1994:56).

This may be important when we come to think about communication impaired people who 'can't' express selfhood easily in conventional ways, so may then easily be regarded being lesser or different kind of persons. Anthropological studies show us that concepts of the person vary cross-culturally (Shweder & Bourne 1988), and so it might be appropriate to see AAC users as having their own 'culture' too.

If selfhood is about how the individual sees himself and personhood is about how others see him, then there is inevitably a dynamic tension between these two, and writers vary in their view of how they relate to each other. Cohen (1994) sees the public persona as only a 'cipher' of the self. He argues that 'it's not *not* me but may be is only a part of me', because it is selective and thus in some ways a distortion (1994: 57). There are at the same time two processes; the individual's process of making the self and the external process imposed by society. Cohen sees the self as assimilating personhood but not as being subordinate to it. He thus emphasises the 'authorial self' as opposed to social construction, his argument being that individuals are more than their membership of collectivities. Cohen justifies the consideration of the self by anthropologists, using the example of Brigg's (1979) work with the Inuit as an example of the kind of ethnographic attention that can be paid to individual consciousness. The study of culture remains the key anthropological endeavour and 'investigating self consciousness is another route to it, not an attempt to supplant it' (Cohen 1994:133).

So in using a reflexive approach we are using ourselves to think about others. Drawing on Boon (1982), Cohen says there is a tendency to exaggerate differences and in a very positivistic way invent categories. He points out that if we use our own self-consciousness we will be sensitized to that of others and will then be less likely to embue them with limited consciousness on the basis of observed external behaviours and social roles. Thus we should focus on the 'cultural agency of the individual as self-motivated rather than as social – (or other) driven' (1994:136).

This view of the authorial self as at least an equal partner in the process by which people become who they are contrasts with the concepts of 'socialisation' which come out of more structural and deterministic traditions. Cohen accuses this generalising approach of producing a 'neglected self', and suggests that this has only now been reduced with the adoption of more phenomenological approaches. He does not deny that there are common understandings and meanings between closely linked people. However he gives the influence of 'language, ecology, traditions of belief and ideology and so on' the role of 'affecting' personal interpretations and no stronger than that (1994:17). These issues around the relationship between the self and culture are directly relevant to the present study, especially in relation to language and communication and the attributions made by others about disabled people.

Like Geertz, Cohen emphasises the importance of language in selfhood, and he draws on Rapport's (1993) work in a northern English village as an example. Cohen underlines that individuals constitute themselves through language, but that there is variability in their meanings. People make their lifeworlds by narrating them in their own particular ways despite rather similar experiences. Evidently these diverse selves are formed within their cultural context and so will use idiomatic forms from that culture[7]. As Cohen says 'the self can be made competent by culture without being subjugated by it' (1994:117).

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[7] However for the participants in my study some of the most commonly used idiomatic forms may not be available to them (e.g. subtle body movements, long spoken sentences, quick-fire verbal repartee).

The importance of language and thought in this process of constructing the self leads to the question of what happens when someone cannot use language easily to show what they are thinking. Interestingly Cohen uses Rorty's (1989) work to look at the link between self-consciousness and the making of moral judgements. Rorty explicitly argues that the incapacity to take moral positions would dissolve selfhood (Cohen 1994:117). Thus being able to think is regarded as a vital part of the self. This leaves us with tricky questions about the selfhood and personhood of people with communication impairments. If you cannot talk, it may be hard to prove you are a thinker. Would someone in this situation then have different selfhood or be deprived of personhood? Jenkins reminds us that Mead said that 'out of language emerges the field of mind' (2004:37).

Rather similarly Berger and Luckman (1966) also emphasise the importance of language in selfhood and are particularly interested in the role of language in internalising of experiences and in its relation to subjectivity. They explain lucidly the curious paradox that we learn about ourselves partly through hearing what we say to others. Thus our own subjective meanings are objectified and so

> 'my own being becomes massively and continuously available to myself at the same time' (1966:38),

as it is available to our conversational partners in face to face interactions. They argue that language expressed out loud makes our subjectivity 'more real'. If, as it seems, social relations are to a large extent constructed through spoken language, then implicitly, much of the more subtle and nuanced aspects of our negotiation of our identity come about through informal and 'non essential' conversations. The nature of AAC communication (slow[8], laborious and restricted in range of vocabulary) means that often conversations are restricted to practical, instrumental topics. Additionally AAC users hear and see themselves using their own unusual 'voice' and it is interesting to hear how they construe this. This may mean that the AAC users construct their social world more from the sidelines, often being forced into the position of an observer rather than active participator, or perhaps they have

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[8] AAC users talk at about 5-20 words per minute, natural speakers at about 100-200 words per minute

to find alternative ways to make social relations and express their identity? The way that selfhood is constructed and expressed by those who cannot easily talk is then a key focus for this study.

Jenkins (2004) continues in Cohen's footsteps with his analysis of social identity, and he also emphasises the process of 'becoming' as ongoing and interactional. He prefers the term 'the human world', to society, and sidesteps dichotomous ideas about structure versus agency by suggesting, in parallel with Giddens' structuration theory, that this is a false division and that they are intertwined and arise simultaneously. Jenkins suggests a way of transcending these dichotomies and contends that the world is constructed of three aspects; 'individual order, interactional order and institutional order' all contributing to a continuous process of change (2004:17), which simultaneously occupy the same inter-subjective and physical space. He thus sees change and social identities as coming about within power relations but not solely because of them.

Jenkins calls his approach 'pragmatic individualism' and a key concept is that of 'the internal and external dialectic', contributing to social identity. He emphasises the process as being dynamic and multifactorially generated in a complex way which is unique for each person:

> 'Individual identity – embodied in selfhood – is not a meaningful proposition in isolation from the human world of other people. Individuals are unique and variable, but selfhood is thoroughly socially constructed' (2004:18).

In relation to the present study I find the ideas outlined above about identity, the person, and the self of Mead (1934), Goffman (1959), Cohen (1994) and Jenkins (2004) relevant and compelling, and they will be drawn on throughout the thesis. It should be acknowledged that there is now considerable dissent and confusion about 'identity' as a concept. This is partly because it is more commonly used in relation to collective identity, so applied in considering the politics of particular minority groups, most notably in race and gender studies, although increasingly in disability too. Thus it is a contested term, and types of, names for and definitions of 'identity' are many and various (Cerulo 1997 Brubaker & Cooper 2000). I would argue that

when the term 'social identity' is used to discuss the self-perceptions (selfhood) and perceptions of others (personhood) which go to make up the way a person 'is' in a phenomenological sense, it is a clear, important and unambiguous concept.

Children and identity

Work specifically on children and identity or subjectivity has sprung from a number of disciplinary roots (Mehler & Dupoux 1990, Meltzoff & Moore 1998, Damasio 2000). Developmental psychology, from Piaget onwards has tried to tease out how children's sense of themselves and others progresses, mainly by focussing on intersubjectivity in mother-child interaction (Trevarthen 1998), on aspects of language development (Nelson 2000), and most recently with the explosion of interest from cognitive scientists in 'theory of mind' (Baron-Cohen1993). Meltzoff and Moore (1998) have devised various experiments to investigate pre-verbal children's understanding of others. They conclude that infants are not generally behaviourists, as they do construe intention and motive in the actions of others. Notions of uniqueness in people are also seen as important, such that each has their own identity and intersubjective relations are specific to particular individuals. They conclude that by the end of infancy children:

> 'Appreciate that they are psychological beings among other psychological beings, different from others, yet neither alone nor unique in the world' (Meltzoff & Moore 1998: 62).

So, intersubjectivity is about the relationship between two minds, rather than being a function of one mind.

Sociologically focused writing about identity and the self specifically in young people is not yet very well developed, although there is plenty about other aspects of children and childhood. Older work in functional and structuralist traditions would suggest that young people are 'socialised' by society, implying a rather passive and uniform process, which attributes young people with little agency or individuality. In contrast, Jenkins (2004) suggests that some key 'primary identities' such as selfhood, human-ness and gender are robustly established early in life and that

these are embodied, and offer a template for subsequent identities. Other aspects are more 'changeable and mutable' (2004:19).

> 'Both mind and selfhood must be understood as embodied within the routine interaction of the human world, neither strictly individual nor strictly collective' Jenkins (2004:36).

Similarly, work from the sociology of childhood recognizes the child as an autonomous person who is able to influence their world and who actively constructs their identity. These understandings of identity are much more interactional and negotiated than previous behavioural descriptions allowed (Briggs 1979, Scheiffelin & Ochs 1995, James 1995, James 2000, Toren 2001). This approach emphasizes the child as a person who is a human *being* now, not as in the process of *becoming* (Qvortrop et al 1994). This seemingly self-evident statement leads to a number of more challenging questions about the status and autonomy of children and young people. A logical question might be if children are fully fledged people already, what is it that they become on achieving social adulthood? The new sociology of childhood generally draws less clear distinctions between adults and children and challenges older developmental views. These emphasise immaturity and growth for example, and constantly look forward to the 'next stage' in the child's life rather than exploring who they are in the present. James and James (2004) describe the ways in which children's identities are generally seen within developmental paradigms, being stereotyped as both carefree and powerless, and also centred around age based and kinship based status. This they argue often positions the child as object and with little space for individuality. Assumptions about vulnerability and dependence and a need for both protection and control leave the child as a product of culture rather than as participating and contributing to it.

Such developmental approaches have arguably had a particularly strong hold on views of disabled young people, who are easily infantilized and regarded as unlikely ever to 'grow up'. Perhaps they are never expected to 'become anybody'? This would match suggestions that disabled people are habitually denied their personhood in many ways, although most authors address this only in relation to adults (Murphy et al 1988, Shakespeare 1993, 1996).

There is a plethora of well theorized work considering transitions from childhood to adulthood, on non-disabled adolescence and identity, within the very particular frames of psychodynamic and developmental psychology[9]. However there is rather less from a social standpoint, particularly about younger teenagers and importantly for the present study, identity in adolescents with disabilities is an underexplored topic. Easily found are ubiquitous and arguably essentializing descriptions of teenagers as being in a state of 'turmoil', 'flux' 'emotionally vulnerable', 'difficult', or 'hormonal'. Anthropologically this period is seen as one of the best examples of a 'liminal phase' in the lifecourse and thus the individuals are regarded as potentially dangerous and unpredictable while in transition (Douglas 1966)

Hall in 1904 described adolescence as a time of 'storm and stress' (Patel Stevens et al 2007). The classic rebuttal of this is the work by Margaret Mead in Samoa and the subsequent debates surrounding it in Euro-American contexts. Popular assumptions about young people are that they are to a greater or lesser extent; unclear about their identity and busy 'finding themselves', 'pushing the boundaries', experimenting and exploring emerging sexuality and other aspects of their identity. Eriksonian approaches describe adolescence as *the* time when identity is formed, and resolving 'role confusion' as being the 'central task' in this age group (Kroger 2004). Commonly this is also described as a time when young people are very concerned about belonging to a peer group, and struggling to balance this sense of commonality with a need to express their individuality. Teenagers are seen as actively finding out who they are in relation to others, however one might question whether we aren't all doing that throughout the lifespan. This search for and establishment of identity is usually described as being expressed through behaviour, appearance, music and media, group activities, use of language and so on (Schwartz 2008). It seems clear that teenagers are very keen to separate themselves from children younger than themselves, and are extremely sensitive about any treatment from adults that they perceive as infantilizing or patronizing (Cohen 1994, James 1995).

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[9] This literature will not be discussed here but draws on the classic works of Freud, Piaget and Erikson and Hall (Patel Stevens et al 2007, Schwartz 2008) and tends to focus on particularly areas of 'identity development' such as ethnicity and sexuality or on collective identities.

Identity and disability

Discussion of identity and disability, and how they relate or interact, has become a 'hot topic' only very recently, and in line with other contemporary work in disability studies, broadly takes a social and cultural rather than psychological perspective. Much of this focuses on personhood rather than selfhood, and thus on the 'othering' of disabled people by society, rather than on disabled people's self concepts (Zola 1993). Key figures in this discourse, who, while talking about many aspects of identity, do focus more than most on the self are Shakespeare (1996, 2006), Watson (2002), Riddell and Watson (2003), Thomas (2007) and Reeve (2006, 2008). Attempts to essentialise 'disabled identity' are now rejected and challenged, although again this debate has taken place more in relation to adults than children (Watson 2002, Davis 2002, Hughes 2007). Shakespeare (1996) argues, for example that identity has political, cultural and personal aspects and that these are inextricably linked. However perhaps in children and young people the 'political' is usually a more latent than active force of which they are only partly aware. Arguably, stereotyped images of disabled children have remained, while disabled adults have managed to negotiate more nuanced understandings of themselves as people in the last decade or so.

Searches for parallels between issues in disabled identity and the 'big three' areas of identity politics reveal that disability has more in common with sexuality than with race or gender. If we consider the experience of a disabled person, often this will be akin to a gay person in that both may be isolated as 'the only one' in their family. However hiding their 'difference' or 'passing' as Goffman (1963) would call it, may not be a choice in the way it could be for the gay person. There is still a need for the disabled person to 'come out' and reject 'the burden of difference' that they may be carrying. Thus, where women, and black people are more likely to have support and role models in their family and community, the disabled person who is likely to be surrounded by non-disabled people, may feel isolated and have few others with whom to identify in relation to their disabled selves. Reeve (2006) draws on Agamben's concept of the homo sacer, the bare life, to suggest that the disabled person may experience being viewed as so far beyond the limits of 'normal' as to be denied basic rights as a person. She suggests that if the disabled person takes notice

of these judgments they may be 'internally oppressed' and thus see themselves as of less worth than other people because of their impairments. This is rather similar to Goffman's (1963) concept of 'spoiled identity' in the face of stigma.

Certainly, until recently, it has seemed that when a person has an impairment, this aspect of them easily becomes a kind of 'default identity' in the eyes of those around them. This becomes how are they seen and described by others, and their other aspects are overlooked. It is also assumed that this view is mirrored by the person's self-perceptions. Such assumptions arise partly out of historical lack of enquiry with disabled people themselves. Additionally MacKenzie et al (2007) interestingly suggest that because all life experiences are embodied, it is impossible for non-disabled people to imagine or understand fully the situation of someone with a very different body.   Thus there is an epistemic gap which may be revealed in the difference between disabled people's personhood and selfhood. The non-disabled person can try to imagine what it would be like not to be able to walk or talk, but their reference point will always be framed by their experience of doing these things. Thus their judgments about a disabled person will inevitably 'other' them. This has obvious implications for a non-disabled researcher like me and the ways in which I might interpret phenomenological data and will be addressed in the thesis.

Traditionally, disabled people themselves have not been asked questions about their 'selves'. Current evidence from research directly with them and from disabled writers suggests that their selfhood is not necessarily or predominantly linked to notions of disability and difference (Watson 2002). People may or may not include 'disabled' as part of their concept of themselves, and those with rather similar impairments may 'self identify' in different ways (Beresford 2000).   This must be a function of their different experiences and individual interpretations of these, as Giddens suggests:

> 'Self identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography' (1991: 53).

French (1993) emphasises the importance of narrative and disabled people's oral histories in making sense of their situations but again this raises the question of how aspects of identity construction evolve for those without easy ways to talk. Corker (1999) in analyzing the cultural category of disability rather than individual social identity relates the process of cultural representation back to the work of both Sontag and Foucault. She sees the label 'disabled' as being generated structurally out of prejudicial and stereotyping practices, which involve the use of particular types of language and meanings. These discursive formations are then 'processes of denial and subjection' of disabled people (1991:5). It may be that those with communication impairments are less able to challenge such discourses.

Mainstream writers about identity sometimes mention disability as an interesting or special case but rarely dissect the issue in detail (Giddens 1991, Cohen 1994, Craib 1997, Jenkins 2004). As described above there is a general agreement between these authors that identity is a multiple and ever-shifting phenomenon across the lifespan, unique to each person and is always forming in a dialectal way in a social context, in relation to other people. It seems that recognition that this flexible and evolving process is the same for disabled people has been slow to come.

The body

The participants in the study have an essentially physical impairment which affects the way their bodies move, and as a result they have poor or little speech. Additionally their impairment is very visible and the way that others respond to them may be influenced by the way they look. Having a different body might be important in relation to both selfhood and personhood. It is therefore necessary and important to investigate as part of the present study, relationships between social structures, individual agency and the body.

Only in the last 30 years or so has the body become a matter of specific interest in sociology although there is a longer tradition of its consideration by anthropologists (Csordas 1994). Arguably for a long period before this the body had been more or less absent 'in the wake of Cartesian privileging of the mind and its removal from theory (where it got in the way of thinking)' (Bell 2001:138).

Lock (1993) suggests that it has often been consigned to a 'black box', thus bracketed off and not reflected upon. Human embodiment has, in the last two decades, become a subject of sharper focus, especially as a forum for understanding relationships between nature, culture and society. This was probably driven both by the emergence of gender studies, and of medical anthropology as a subdiscipline (Skultans 2000). The body, perhaps previously seen as a purely 'natural' object, is now viewed much more as a product of culture too, even when it is being considered in 'scientific' contexts. Key writers who have addressed it, have been divided or undecided about whether the body should be treated as a purely physical entity or as a social symbol drawing more on ideas from semiotics than from physiology (Douglas 1970, Bourdieu 1977, Turner 1984, Frank 1991, Foucault 1994). It seems that in the context of the present research, both aspects will be relevant, or perhaps a collapse of this dualism is necessary as is attempted by phenomenologists (Merleau-Ponty 1962, Csordas 1994, Shilling 1994).

In the arenas of both childhood and disability, bodily features are often where recognition of membership of those groups begins and to a large extent it is through those external characteristics that the person is categorised by others, at least initially (Hockey & James 2003). A number of seminal works have tried to dissect the relationship between the body, the outside world and the self, with varying success and outcomes. Berger and Luckman (1966), for instance, remind us that everyday life is experienced through 'the here of my body and the now of the present' (p22). They go on to describe our experience of life as being at different levels of closeness, the nearest, being that which is 'directly accessible to my bodily manipulation, it is the world which I can reach and modify' (ibid: 22). Clearly the way that we interact directly with the world is through our bodies and the senses, and so however we see our 'selves', these are embodied. The body is then both a site of self and desire, and because it is the aspect of us that other people see and is on display all the time, it is often the part that is judged first. It is both our own body and at the same time what other people see of our personhood. As Bauman and May say, even if it is only the 'wrapping on our inner selves', it is the visible bit (2001:97).

Notwithstanding its physicality, society also affects the body and this has been theorized in several ways. For example, Foucault (1994) famously describes this as part of the 'technologies of the self' and the body 'as a task, as something to work on'. He suggests that there are 'discourses of improvement' within which there are ideas of pursuit of fitness, health and links with self-improvement. Thus how we manage our bodies is learnt and the way people's bodies are 'interpreted' is the result of common expectations and socialisation. Importantly then, bodily deviations in shape, style of dress, or how it moves may cause reflections or reactions from others. The body sends messages and these are described as 'written by our bodies'. This view, then, sees the body as a 'task that is performed' and therefore not purely natural but cultural as well. Our use and management of our bodies is culturally and socially determined and is therefore a site for potential security or insecurity about the self. Foucault (1994), Douglas (1970) and to some extent Turner (1984), seem almost to have discarded the actual physical body in favour of it being purely a social construct, a discourse and carrier of social meaning and symbol of society.

There has been a proliferation of theories suggesting 'multiple types of body' (Csordas 1994). Douglas (1970) and Turner (1984) both propose two: physical and social, and 'korper' and 'leib' (lived body) respectively. Schleper-Hughes and Lock (1997) outline three: the individual, social and body politic. These refer to aspects of individual bodies, representational uses of the body as a symbol of nature, society and culture, to regulation and control, and to models of the body writ large in social structures. However Csordas (1994) argues that many of these models take embodiment itself for granted and following Mauss, he says that they ignore the idea that 'human culture is grounded in the human body' (1994:6). He suggests that classical ethnographies should be reread with an eye for passages about bodily experiences 'within discussions of ritual and social organization' (ibid: 6). In relation to this research there are clear parallels between the contrasting discourses about the body as both physical and social, and the dichotomy in disablement literature between impairment (corporeal) versus disability (social) aspects of disabled people's experience. The physical fact of the teenagers' 'difficult' bodies cannot be overlooked, but the impact of these impairments evolves in a social world where

bodies act and are interpreted. As Csordas says the body is both 'as subject in everyday life experience and as object in science' (1990:35)

Similarly, Bourdieu (1977) with his notion of 'habitus', describes the body as representing our 'nature of being' in the world. Through repetitive experience or enactments we come to use our bodies in particular ways. He sees the body as coming to enact particular social principles and values and so we hold and move our bodies in ways which reflect our culture. This we learn to do through a process of experiencing our world. Phenomenological thinkers such as Merleau-Ponty (1962) insist on the physicality of the body as well as its role in conveying meanings for us 'the body must become the thought or intention that it signifies for us. It is the body which points out and speaks' (Bauman & May 2001:103).

Merleau-Ponty shifts the emphasis further from representation to lived experience. He uses the notion of experiencing the world through and in our bodies. In inhabiting our bodies we inhabit the world through a process of intersubjective engagement with others. The body then mediates all our actions and perceptions of the world and is a general medium for 'being in the world'. Merleau-Ponty uses the term 'lifeworld' to talk about immediate experience, and the way in which the self interacts with the world and others and the body is central to this:

> 'With the body being the prime, immediately visible message, the exhibit of the self displayed for public gaze and scrutiny, it tends to be loaded with enormous responsibility for the up and downs of social life. How aspects of our bodies are seen and endowed with particular significance effects how we see ourselves and how others see us' (Bauman & May 2001:105).

Csordas (1994) has taken these ideas and developed them to consider the way in which personhood is 'constructed through habitus'. The body as it is lived represents a person's particular view of the world, the body then is a vehicle for seeing. Csordas does not see the body as natural, but as part of social processes and thus in flux (Frank 1991).

> 'With the biology no longer a monolithic objectivity, the body is transformed from object to agent' (Csordas 1994:3).

These phenomenological perspectives which I see as pertinent in this project, view the body as ever changing, as representing and containing the self, and at the same time as the person's medium for interfacing with the world. Merleau-Ponty suggests then that we do not merely have a body, but that we 'exist or 'live' a body and similarly Csordas talks about the body being 'necessary to be' (1994).

Children and bodies

The way in which children use and think about their bodies has been considered by a number of researchers in recent years. Early writings took a naturalistic view of the biological body and saw society as written on it, but these are now seen as reductionist (Shilling 1994). These gave way to more social constructionist views where the body is seen as a product of social processes, constructed in terms of dominant practices and cultural norms. Shilling using the term 'corporeal realism' has suggested a synthesis of these two, with both biological and social elements being contributory and intertwined. Thus the body is unfinished at birth and is only completed *through* social relations. This acknowledges that, from the start, children's agency interacts with biology. Recognition of the child's agency in this process grows out of the new childhood paradigm described earlier. Work by Prout (2000), Christensen (1998), Hockey and James (1993), James (2001), Simpson (2000), and James and Hockey (2007) all recognizes that bodies and views of bodies are an important part of childhood and children's experiences. Rhetoric about sizes, shapes and competencies of bodies are regularly used to define and comment about children, and reinforce power relations between children and adults. Bodies are tamed, regulated and civilized during childhood (Simpson 2000), and children also use their bodies as tools for resistance, through clothing, use of space, and actions. The media is a powerful influence on children's ideas about what bodies should be like, and as will be seen in the data here, they inevitably compare their own bodies with those seen in public arenas such as the media.

The concept of the 'normal body' is important and contested both in work about children and in disability studies (Davis 2006). Positivist ideas which emerged in the nineteenth century established ideas about normality and the practice of measuring and standardizing the body, particularly during childhood. The physical

body appears to be a locus of identity and personhood and studies show the importance of conformity to 'normal shape and size' to children:

> 'Bodily changes over time during childhood are important in children's unfolding identity' (James & James 2004:142).

The body is 'chronologised' across the lifecourse in particular and expected ways (Hockey & James 2003). Bodies which do not conform to the 'ideal' are problematic and may be seen as unacceptable, inviting comment, or rejection. This implies therefore that disabled children and young people are almost inevitably in a vulnerable position in terms of developing positive self images, something which will be explored in this thesis. James and James (2004) found for instance that 'height in particular is a literal yardstick of progression towards adulthood' (2004:145)

A child in a wheelchair will not have the experience of getting taller in the same way, and may well have other ways in which his/her body does not match the ideal. As children grow there is a gradual shift from adult mediated views of them to their own internal moment, but these will be heavily influenced by social processes and influences around them. James and Hockey refer to this as the 'negotiated body' (2007:17). Societal views about what makes a body competent or incompetent and what a 'different' body represents will be all powerful (Murphy1987, Jenkins 1998. Kovarsky et al 1999, Davis 2006). If physical competence is usually a matter of pride, then the question of how needing help with the most mundane and personal of practical tasks impinges on young people's selfhood and personhood is an important one to consider, and so is explored in this study.

The body and disability

Research about the body and disability has until recently been scant, and this may be because many of the seminal writers in disability studies in the last 20 years have been keener to focus on social models of disability and to take emphasis away from impairments and the role of the body itself. Some would claim that discussion about the body is irrelevant to disability (Barnes et al 1993). Oliver as one of the

originators of the pure materialist form of the 'social model' of disability famously declared that 'disablement is nothing to do with the body' (1996:42).

More moderate voices argue for the re-entry of the body into the discussion (Hahn 1988, Murphy et al 1998, French 1993, Shakespeare 1994, 2006, Clear 1999, Thomas 2003, Reeve 2008). Shakespeare and Watson (1997, 2000) have argued, for example, that what is needed is a phenomenological theory of the body that can consider the impairment aspects of disability and this view has more recently gathered pace, under the influence of feminist scholars who highlight the subjective (Morris 1993a, Thomas 1999). Arguments and theory from the 'mainstream' literature on the body and identity are relevant here.

Foucault's discourses of improvement mentioned earlier imply a standard for 'normality'. As part of the definition of self, the body has the power to define the person. Deviations from the normal are then a sign on imbalance, disease or danger and impurity (Douglas 1966). The body as a form of communication is interpreted by others in ways which tend to privilege dominant ways of being. The implication is then that if there is 'something wrong' with the body and it is shunned, there is a problem with the guardian, keeper, and controller of the body (Bauman & May 2001).

Goffman's seminal works on identity and stigma (1959 and 1968) also clearly describe the body as a central mediator in the formation of self and social identity (Shilling 1994). He views the body as a component of action and as controlled by individuals in order to facilitate social interaction and so associated with human agency. In contrast to Foucault who sees the body as produced by social forces, Goffman refers to 'body idiom' as the range of conventionalized physical features and behaviours which communicate information to others. These 'shared vocabularies' give off information which leads to labels and categories. He hypotheses that embarrassment and stigma result when there is a gap between a persons 'virtual social identity, that is how they see themselves, and their 'actual social identity', that is how others see them. The way that others see them is through the medium of their body.

'The social meanings which are attached to particular bodily forms and performances tend to become internalized and exert a powerful influence on an individual's sense of self and feelings of inner worth' (Shilling 1994:73).

The body has the status of a resource which can be managed in a variety of ways in order to construct a particular version of the self. If a person's body image and management mean that others categorise them as a 'failed' member of society, they may internalize that label and incorporate it into what becomes stigma or 'spoiled identity'. Once so stigmatised, this will have damaging consequences for their self identity. If they hold the same general beliefs and standards as everyone else about bodies, they will see what others see as their failing, so inevitably agreeing that they fall short of what they ought to be. Meredith Allan (2006), one of the research advisors, draws on her own experience as a disabled woman in pointing out that disabled people have to do extra 'work' to be accepted as full members of society. Shilling is critical of Goffman's work because it suggests that the classifications used to categorise bodies exist prior to and independently of social encounters. There is no clear way to link the body management of individuals within the 'bounded sphere of the interaction' to wider social norms. Shilling argues that Goffman's notions are too vague and abstract to apply at a more structural level and that his view of how the body facilitates human agency is underdeveloped. Goffman's work however has been influential and clearly as Shilling says 'corporeality of body needs to be taken seriously' (1994:75)

Thus although biology is rather uniform, the ways bodies are managed, interpreted and socially classified, is different for individuals and across societies. Frank (1991) and others have built directly on Goffman's work looking at action as embodiment and concerns about the lived body particularly during illness.

'The stigmatising potential of illness, this has therefore, quite profound implications for identity and, indeed, for our very experiences of embodiment' (James & Hockey 2007:19).

The same must surely be true of disability. Theories which see the body in these phenomenological ways can usefully inform the current project.

The best known early anthropological work about disability and the body is that by Murphy (1987). He argues, compellingly and from personal experience that the 'well' body is not really present in conscious awareness, and is an 'experiential absence', unless and until it stops working properly. Illness however negates this lack of awareness of the body in guiding our thoughts and actions. It is only when we become ill or disabled that we have to renegotiate a definition of our bodies. Murphy argues that the physically disabled person then becomes a repository for other people's beliefs, and a cause of anxiety and discomfort to the onlooker. Lawton (2000) however criticises Murphy for being very cerebral about the situation. She feels that he does not address physicality sufficiently and just retreats into the mind. Her work in hospices looks at terminal illnesses and people who are close to death, and draws on Douglas (1966) to talk about the unboundaried body which is starting to lose control or leak for example. She theorises the effect on selfhood as being linked to loss of control and erosion of the self. The 'body subject' is then becoming 'body object'.

In contrast, the situation for a young person who has always had an unusual body, rather than experiencing it changing from 'normal' to 'deviant' may be different. Particularly, having a body, which needs help from other people to manage it, might result in different personhood or selfhood? Ongoing issues about boundaries of ownership and control of the body and privacy for someone with congenital impairments might well be different from those for an ill person. Sharp (2000) suggests that both pain and disability are often accompanied by 'a heightened thematisation of the body'' (2000: 290) which leads to 'commodification' over subjective experience. Therefore having a different body which attracts attention makes it difficult to assert yourself as a person rather just as a body because 'sense of self is obscured by the body' (Sharp 2000:290).

Sharp (2000) suggests that the 'natural body' is culturally sculpted and transformed' and has written about the commodification of the body, as a result of new technologies which split the body into 'parts' for transplant for example. A similar fragmentation into bits that work well and bits that do not might happen for the

disabled child who uses a wheelchair, leg or hand splints, headstraps and a high tech communication aid (VOCA).

A question for this thesis, therefore, is whether having a body which is in some senses fragmented threatens the integrity of the self? Garland-Thompson's (2006) work on staring makes a similar point and emphasises the need for the disabled person to develop strategies to control the situation. Goffman's ideas about 'passing', that is hiding one's negatively attributed difference is not a luxury open to those with physical impairments such as severe cerebral palsy. The person therefore is compelled to find other ways of managing the unwanted attention and misinterpretation of them as a person.

Classical anthropological ideas mesh neatly onto aspects of the disabled person's experience, although they have not thus far been applied to those with communication disabilities. French (1993), attempting to explain common responses to disabled people, suggests that often there is disgust and revulsion, coupled with fear. This links then with concepts such as impurity and liminality (Douglas 1966, Turner 1967). Douglas' (1966) concepts of taboo and pollution, particularly in relation to things that cannot easily be categorized, are also relevant to analyzing the responses of strangers to people with impaired bodies, as will be seen later. Thus the individual person disappears during these encounters, and becomes an objectified and dehumanized body which represents fearful things. Murphy (1987) is quite clear that disabled people do become liminal and are treated as 'other' in very particular ways, which may be impossible for them to overturn and so then they are liminoid (Turner 1974). He describes his own experience of increasing impairment and others reaction to him. Murphy felt he was living in a 'limbo' from which he had no possibility of escape. He and others have pointed out that bodily impairment may invoke feelings of vulnerability and a 'there but for the grace of god' attitude in onlookers (Hahn 1988, Shakespeare 1994, Thomas 2007). Shakespeare argues compellingly that the root of the exclusion of disabled people is in the tendency for them to be objectified as 'dustbins of disavowal', as cultural representations of strangeness, impurity, and darkness. He suggests that 'disabled people remind non-disabled people of their own vulnerability' (1994: 297). They

become liminal because of their essential 'otherness' and their otherness is clearly embodied.

Similarly Paterson and Hughes (1999) using a lifeworlds approach draw on Leder's (1990) use of the concepts of 'korper' and 'lieb', to argue that, in an absence of pain, most people's bodies 'disappear' from view and from attention. For the impaired person (who is not in pain), their body is brought back into view not by internal processes, but by external social factors which draw attention to their body and make it 'dys-appear', or become a focus of others' attention. This is a form of 'social reappearance' of the body, imposed from outside, drawn from the perspective of non-disabled people about what is significant. Paterson and Hughes say that the experience of impairment is not an 'intracorporeal one but intercorporeal, 'it is stunned into its own recognition by its presence-as-alien-being-in-the-world' (ibid 1999:603). They assert that this oppression implies a profound kind of 'being left out', which linking back to earlier anthropological ideas, could be described as liminality. Disabled people are then perpetually being reminded of their bodies as problematic, while they see them as normal.

Most recently there has been a turn in the disability literature back to recognizing the role of the body as part of disablement. As embodiment is recognised as necessarily inescapable, perspectives which include the personal experience of impairment, as well as disability become legitimate areas of concern and theorizing (Corker 1999, Thomas 2007). Indeed most disabled people outside the academy would not recognise any such dichotomy. Thomas critcises the 'refusal of leading social modellists to get entangled with either the corporeality or emotionality of disabled people's lives' (2007:120) and she trenchantly continues that the body should be 'brought back in'. As a corollary of this she argues that the consideration of impairment without society loses how the person 'lives in that body' (ibid).

She introduces and expands the concept of 'impairment effects'; the lived experience of having an impaired body as being 'thoroughly intermeshed with the social conditions that bring them into being and gave them meaning, as is disablism' (ibid: 153), and proposes that a lack of attention to these effects in the lived lives of people

ignores major aspects of their experience. Further she argues that there are real differences from the usual body in those of people with significant impairments, and that these have to be understood as being invested with constructed meanings and representations, which have social relational and psychoemotional consequences. Thus she insists that the body cannot be left analytically aside in the consideration of the disabled person's life:

> 'A sociology of impairment needs to be able to engage with the real materiality of bodies whilst at the same time understanding the ways in which bodies are simultaneously always interpreted. Those of us who live with marked impairments know that the body is 'real' however thoroughly it is culturally represented and positioned' (Thomas 2003:77).

Hughes and Paterson's work (1997) is also useful as it too deconstructs dualism and foundationalist views. They claim that the social model 'concedes the body to medicine...and leaves it phenomenologically dead' (1997:329). They point out lucidly that in fact the medical and social models of disability come to a curious consensus about the body, in that both regard it as 'a pre-social, inert, physical object, as discrete, palpable and separate from the self' (ibid:329) and thus both create a disembodied view of disability.

Their argument is for a more nuanced phenomenological approach to impairment and disability, dismissing dualist thinking and recognising the importance of 'lived experiences' as simultaneously bodily and social. They call their approach a 'sociology of impairment', which is perhaps unfortunate as that still implies some kind of contrast with models of disability, rather than encompassing both. However it does well at bringing the body back in and applies together the works of BS Turner (2001) and Shilling (1994), to provide a poststructuralist and phenomenological approach to disability in the broadest sense. They argue that because phenomenology views the body as subject as well as object, it provides a good position from which to view the experiences of those with unusual bodies, and this perspective needs to be added to the louder and longer disability discourse about structural oppression. Drawing on Crossley (1995:43) they argue in opposition to the most extreme materialist social model views, both that 'the social is embodied and the body is social' and therefore for an embodied 'social model of impairment' in

which 'disability is embodied and impairment is social' (Hughes and Paterson 1997:336). Thus anti-dualistic approaches such as post-structuralism and phenomenology are now gaining support and certainly in the present study seem to support the data more accurately.

The body, identity and communication

It is clear that the body and identity are linked, and many authors have recognised this and tried also to clarify links with language and communication. Jenkins (2004) sees 'selfhood as necessarily embodied' and 'the body as a canvas on which identification can play' (2004:19). As the process of identity formation continues, bodies remain relatively fixed and a kind of reference point of individual continuity and of collective similarity and differentiation. Thus in the process of becoming, both differences and similarities come into play, and some of these will be embodied. As Hockey and James explain:

> 'Categorical and cultural identity only acquires meaning from the ways in which it is embodied by individuals in social space and across time' (Hockey & James 2003:139).

It is self-evident that our intra and intersubjective lives are mediated via our bodies because our experiences are embodied. We both inhabit our own bodies and interact with other bodies. To a large extent this is through language, also an embodied phenomenon. Berger and Luckman (1967) point out that in spoken conversation there is inter-subjective and reciprocal closeness. Expressions of subjectivity are mediated via the body, whether this is while talking with speech, or other modes such as gesture, signing or writing. This link between the body and subjectivity may be the crux of the potential 'difference' for the communication-impaired person. How, therefore does lack of easy access to ways of expressing intersubjective self with language because of a speech problem, affect a person's sense of self? As Merleau-Ponty says :

> 'If we do not perceive our own bodies as objects, neither do we perceive others as objects. Another person is perceived as another 'myself' tearing itself away from being simply a phenomenon in my perceptual field, appropriating my phenomena and conferring on them the dimension of inter-

subjective being and so offering 'the task of pure communication' (cited in Csordas1990:35).

Both Martin (1992) and Csordas assert that 'the body' is currently going through a critical period during which it is being transformed. It can no longer be assumed to be a fixed immutable entity, but is subject to previously unimaginable influences and is thus the 'epitome of flux' (Csordas 1994:2). Their main evidence for this is the rise of medical technologies which enable new and extraordinary things to be done to and for the body, for example, dialysis and transplants, new ways of looking inside the body (MRI, PET scans), in genetics and immunology. So these techniques:

> 'Herald a radical paradigmatic shift in how we must now envision body transformations and associated forms of commodification… in essence certain biotechnologies now encourage self-objectification' (Sharp 2000: 297).

This is relevant to the current study as the use of VOCAs is part of the same revolution. Both the relationship between the AAC user and their VOCA, and how they conceptualise it are core aspects of the study. Several AAC users have already made it quite clear that they do not want their 'machine' to be seen as more important than the person using it:

> 'When people say 'oh what a fantastic machine', I am blunt in my reply 'the machine is boring, I am fantastic'. I do not care what people think of me for making that remark. The identity behind the machine is what is important' (Allan 2006:11).

Allan (2006) describes the way in which her electronic voice, produced by her communication aid is '*her* voice'. Others may view this electronic voice as odd and artificial, but for her it is part of her. Here is a potential site for interesting issues in selfhood and personhood when people have 'non-natural' bits of their bodies. With the development of new technologies the boundaries of nature and culture, are no longer secure and as Sharp suggests

'constructions of the human body and of human nature itself emerge as deeply troubled' (2000:295). The ways in which people who use high tech communication aids manage their own identity formation, and the ways in which others see their

different bodies is thus a matter of interest and conjecture in fast changing times. However as Bell reminds us:

> 'In the end, it seems, however much we might wish the body would disappear, there's more meat than we can repress or dream away or forget and we remain embodied – albeit in new ways' (2001:141).

There is a need therefore to consider in this very specific context 'the triangular relationship which exists between the body, self and society (James & Hockey 2007:39).

Conclusion

The study sets out to explore aspects of selfhood and personhood with a small group of disabled young people with severe physical and communication impairments who use AAC. This is a unique study because although there has been some research on related topics, such as other children's views of disabled children (Lewis 1995), and parents' and teachers' views (Goldbart & Marshall 2004), gaining the thoughts and views of disabled children and young people using AAC has rarely been attempted (Morris 2003, Soto 2005, Shakespeare et al 2000). This is not surprising since their combination of physical and communication impairments makes lengthy and probing conversations difficult and laborious at best. If, as the theorists above suggest, concepts of social identity and of the body are constructed through interactive and ongoing processes where the person is an active agent in his/her unique social context, one might expect disabled young people to have a sense of self which includes them being both similar to and different from others in some particularly unique ways. Like everyone else, their identity will be an assimilation of their understanding of experiences they have lived through so far, while all the time 'bounded by structural features of the milieux' (Hutchby & Moran-Ellis 1998:1) in which they live their lives. However the nature of their impairments will give them a particular way of 'being in the world'. Phenomenological, ethnographic approaches which focus on the young people's own perceptions seem to me to be the best way to explore these issues in depth (Geertz 1993, Csordas 1994, James 2000, Jenkins 2004). Thus, in line with contemporary discourses about both childhood and

disability, it is an aim of this research that the participants will have an 'authorial presence' (James 2000).

The stories they tell about their lives reveal key moments in this 'process of becoming' for individuals and both common threads and some disparities across participants. It is important to be wary of generalisations across such a small group, who although they have similar impairments, vary greatly in many other ways. In fact one of the outcomes of the present study may be to demonstrate how homogenised these teenagers tend to be when actually they are richly and interestingly different from each other. They show that, despite or notwithstanding their impairments, the practical obstacles these put in their way and the barriers erected by others, they are complex individuals with a kaleidoscope of different aspects to their identities. The study because it looks at the microcosm of these people's lives inevitably reveals diversities between them. The implications of this study at a 'macro' level are that if there are ways in which young AAC users' selfhood and personhood come into being in some distinctive ways, these can be better understood. Given the current emphasis in the rhetoric of both policy and practice, on the rights of children and of disabled people to be heard, this is an opportunity to give an often 'silenced group' a voice.

Chapter Two. Methodology

Introduction

It has been suggested that there are some groups of individuals whose voices are 'muted' (Hill 2006, James 2007). Children and disabled people are both often cited amongst these categories (Davis et al 2003). Disabled children, particularly those who cannot talk, are a particularly excluded group whose voices are not often sought or heard (Morris 2002, 2003, Rabiee et al 2005). They have been researched *on* or *about* as passive subjects, but it is a rarity for them to be active participants (Badham 2004, Cavet & Sloper 2004, Franklin & Sloper 2009).

> 'Most research on disabled childhood has failed to gather the views of disabled children themselves, relying on the perspectives of parents, professionals and other adults. This imbalance has the effect of objectifying and further silencing disabled children'
> (Shakespeare et al 2000:1).

The intention of the present study therefore was to allow these young people's hidden voices to emerge and for their own views of their lives and multiple identities to be represented. The study is fundamentally child-focused and uses a multi-sited mosaic (or distributed) ethnographic approach (Hockey 2002)[10].

This chapter presents theoretical background to the methodology chosen. It then describes the process of the study, the methods used, and reflections on the researcher experience. Finally, there is an overview of the data collected and the analysis carried out. Complementing this chapter is a detailed description and discussion of AAC methods and issues in Chapter Three.

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[10] See timeline for the whole study period in appendix J, page 348

Theoretical influences on the methodology

Anthropology

The main research method developed in anthropology is ethnography. This involves learning about a people through being immersed in their lives and hearing first hand how people see and experience that world (Geertz 1993). The current study is informed by phenomenological schools of anthropology which see experiences in the real world as key. Husserl, the father of this approach (Dowling 2006) emphasised, as did Csordas that analysis should focus on the 'lived world of perceptual phenomena' (1994:203). Thus people's real physical, social and emotional experiences are embodied in sensations and practical realities (Mead 1934, Merleau-Ponty1962). This view leads to methods which are based in natural settings, not manipulated or artificial ones, in which the researcher experiences the actual lives of his/her participants as closely as is possible.

The particular conceptualisation used here is the 'lifeworlds' approach described by Schutz (1967). This has increasingly been recognised as useful in disability research, where it allows that there is no one objective reality or fundamental truth to be discovered, but that the participants' understanding of the experience of their life is a valid and often overlooked one (Hodge 2008). In comparison with more prescribed 'quality of life' research approaches (e.g. Colver 2006, Ravens-Sieberer, Erhart, et al 2006) which try to assess people's lives through exploration of a number of pre-determined categories or parameters, 'lifeworlds' research leaves space for aspects of life which are important to the participants to emerge from the data. This methodology encourages the use of diverse qualitative methods, which can contribute to a comprehensive view of the person and their life. The present study is grounded in real experience within the contexts of home, school and clubs and it is the young people's own perspectives which are highlighted. The knowledge that is acquired about the participants is 'situated' and provided by them. The methods reveal detailed and contextual information, and have the ability to analyse the 'social being' not just the psychological or physical one (Paterson & Hughes 1999, Thomas 2003).

Childhood Studies

The new 'Sociology of Childhood' has emerged with important new ways of viewing and exploring children and childhood. It argues against purely developmental referencing, where children are seen as still maturing and therefore as somehow unformed, vulnerable and perhaps incapable. In contrast it proposes that we see them as competent agents who are able both to influence and reflect on their lives (Corsaro, 1998, James, Jenks, & Prout 1998). Many authors within this tradition have demonstrated that children are often denied an authorial voice (Hendrick 2003). The approach argues that children are 'human beings' rather than 'human becomings' (Qvortrop 1994), and thus that they should and can be consulted in matters affecting them and included in research in active ways (Christensen 2004).

Proponents contend that adults' interpretations of children's concerns may well be inaccurate because they can only be made through an 'adult lens', and that it is preferable, educative and revealing to ask young people themselves about issues affecting them (Mahon et al 1996, Alderson & Morrow 2004). Using proxies such as parents or teachers has been the most common way of researching disabled children to date. Mahon et al (1996) argue importantly that although participating in research should be a positive experience for participants, there should be a clear boundary between research and 'therapy', and that the indirect benefits of talking to someone cannot be the sole justification of a study.

There is still a debate about whether research with children necessitates using different methods from those used with adults, or whether essentially the same ones work equally well with young people, albeit with some adaptation to individual skills and preferences (Punch 2002, Hill 2006). In the present study my experience was that the methods and adaptations that I used were more influenced by the participants' skills (particularly communication skills but also physical capabilities) and interests than necessarily by their ages per se.

The relationship between adult researchers and young participants is also contested and views about this vary from handing the whole research process over to young people (Alderson 2003), to adults explicitly being sensitive to the power relations

inherent in situations where children and adults are involved (Christensen, 2004). In any event, the researcher's aim in any avowedly 'pro-child' project is to achieve as close to a 'child's eye' view of the world as is possible, but the way that this is represented, for instance as 'their voice' is then a matter for careful consideration (Alderson & Goodey 1996, Davis 1998; James 2007, Hill 2006, Thomas & 0'Kane 1998). Arguably, then the adult researcher is a conduit for children's perspectives, as well perhaps as someone who interprets and analyses data from children's worlds through an adult lens.

Disability Studies

In parallel with the empowering approach to children described above, a similar, although more overtly political movement, has risen in disability studies (Oliver 1996, Shakespeare 1994, Swain et al 1993). In relation to research, these authors argue strongly that the agenda should be set by disabled people, who should be involved in the whole process, and that the research should be *with* not *on* or *about* them. Their criticism was that previously much research had been either inherently pathologising, or irrelevant to disabled people's real concerns (Barnes 2003, Oliver 1992). The so-called 'emancipatory paradigm' proposes that all research should be empowering and actively contributory to the improvement of disabled people's lives. Some writers have argued, however, that guaranteeing such outcomes at the outset of a study is unrealistic, but that at the very least disabled people should feel that the study is worthwhile, not harmful, and must represent them accurately (Corker 1999, Shakespeare 1996b, Zarb 1992). Gradually disabled people have become more actively involved in research using a range of methodologies. Surprisingly however, given the recent emphasis on ethnography, there has been relatively little work with disabled people described in the anthropology literature. Most notable is the early work of Ablon described by Shuttleworth and Kasnitz (2004), and that of Murphy (1997) and Groce (1985). However there has been little exploration with people with communication impairments or with AAC users specifically (Parr et al 1997, Balandin et al 2000, Smith 2005).

Research with disabled young people

Listening to disabled young people's voices is a recent and arguably as yet still a quiet addition to the research agenda (Beresford 1997, Priestley 1998a, Stalker 1998, Shakespeare et al 2000, Pugach 2001). As Davis et al suggest:

> 'The voices of disabled children have rarely been heard in previous research or they have emerged only in studies preoccupied with issues of care and characterized by narratives of dependence, vulnerability and exclusion.... The picture is painted of a homogenous 'disabled child' who is often denied the same rights and choices as other children' (2003:206).

Inevitably perhaps, disabled young people are regarded as a particularly 'vulnerable group', and also as one whose views may be particularly difficult to access and represent accurately. In fact it has been assumed that it is not possible to ask certain children for their views and so they tend to be excluded at the planning stage of projects (Morris 2002, 2003, Davis et al 2003, Garth & Aroni 2003).

There have been some biographical or narrative based studies with disabled people (Smith & Sparkes 2008), specifically with children or adults who have learning disabilities. Some of the methodological issues with these participants are different from those in the present study, but nevertheless there are some similarities (Phillips 1990, Booth & Booth 1996, Atkinson & Walmesley 1999). Owens (2007), for example in her study of adults with learning disabilities argues that using narrative methods enabled her to 'liberate the voices' of her participants, by allowing them to tell their stories in their own way. Booth and Booth (1996) provide useful practical suggestions about the formulation of questions with this group. Daley and Weisner (2003) used 'explanatory models' (Kleinman et al 1997) as a way to explore disabled teenagers' views of difference and disability. However they excluded those who were nonverbal and 'graded' the quality of responses in a way which inherently pathologised those with communication impairments. It is undeniable, however, that there are methodological difficulties in carrying out participatory research with people with communication difficulties and some of the particular challenges in researching with children with these impairments have been highlighted recently (Morris 2003, Rabiee et al 2005, Nind 2008).

Identity and lifeworlds research

In considering how to investigate identity, my preference, which fits well with the Childhood and Disability Studies foci outlined above, is to agree with Cohen (1994) and Jenkins (2004) that identity is a constantly renegotiated process rather than being fixed. Selfhood and personhood interweave and are symbiotic. In aiming to investigate disabled young people's identities, it was important to find out both how individuals see themselves, in order to find out about selfhood, and also to ask others about them, to reveal personhood. Aspects of identity shift both across time and across contexts. Therefore, I needed to see the teenagers in a number of situations in order to achieve a broad picture of how they see themselves and are seen by others.

The lifeworlds approach was chosen first and most importantly because it allows the participants' lives to be seen to 'in the round' (Dowling 2006). Their roles, identities and relationships in school, home, and in activity clubs were likely to be different and varied over time as well as place. Ethnographic methods allowed me to see in depth what is important to them and how their social relationships work in different situations. Secondly, the long-term and naturalistic aspects of ethnography seemed to me to be perfect for researching this group of young people, for whom hasty conversations and instant answers to questions are impossible. Methods which provide quick snapshots or one-off interviews would be unlikely to collect much data at all, or any that would really reflect the young peoples' thoughts, or provide sufficient insights into rather complex and unusual lives. It takes time for listeners to 'tune in' to AAC systems and to 'learn their language' and it also takes time for AAC users to feel confident that the considerable effort needed by them to say things, is going to be worth it. Thus a research method such as ethnography, and particularly participant observation, which allowed me to spend considerable amounts of time with the participants, but in ordinary settings and to join in with everyday happenings, was well suited to my purposes (Van Maanen 1988, Hammersley & Atkinson 1995, Hammer 1998). This is not a conventional ethnography, since it is distributed around a number of schools and homes and other places; however it was designed to gain a 'thicker description' of the participants' lives than other methods would allow (Geertz 1993, Hockey 2002).

Finding the field: People and Places

Key Participants

I aimed to focus on a group of 10 – 15 young people aged 10-18 years who use AAC as the core group, and to carry out ethnographic fieldwork principally in their schools and homes, with some visits to other contexts that they might go to more intermittently. Data from these key individuals would be supplemented by that from people in their social networks (family, friends, school and club staff). The criteria for participants in the study are shown in Box 1. below.

The young people were therefore selected purposively. These guidelines generally worked well and were useful in describing the types of young people I was interested in inviting to join the project. In particular I avoided being specific about the type of medical diagnosis or specific impairment that the participants might have, as I was more interested in them as AAC users than them fitting into a particular medicalised description.

Box 1. Recruitment criteria for key participants

The young people would:

1. be aged 10-18 years
2. be of either gender, and any ethnic and social economic status
3. be attending any type of school (mainstream/special, day/boarding or split placement)
4. have communication impairments which necessitated augmentative and alternative communication systems, and using any combination of low and high tech systems and types of access
5. have cognitive skills broadly within the normal range (as judged by school staff)
6. be able to participate if they have other impairments (visual or hearing), if they have adapted communication systems/aids in place
7. be able to participate if they have additional medical conditions such as degenerative disease, feeding difficulties, or epilepsy, if judged by parents, healthcare, school staff to be well enough and able to participate.
8. be able to participate if they have autism, if willing and able to participate in simple conversations and understand writing, signs, pictures, or symbols
9. understand and be interested in the aims of the study (to find out about the lives of young people who use AAC), following appropriate introductory explanation

> Additionally there would be:
>
> - agreement initially from parents (written) and then from young people (verbal & ongoing)
> - assurance of confidentiality as far as possible and as negotiated with the young people and their families
> - understanding that the participants could opt out of particular activities or aspects of the study at any time (consent would be an ongoing & negotiated process)
> - agreement from schools, clubs, holiday schemes etc to allow the researcher to visit and participate on terms negotiated with staff and the young person on an ongoing basis, but with as much active involvement as possible

Finding Schools

My initial plan had been to find two or three schools in the south-east of England, with between three and five teenagers to study in each. If there were several participants in each school this would make it convenient and possible to spend substantial amounts of time in each location. In any one school I would have only a small number of individuals to focus on, which would make it easier to be involved in a broad range of activities that they might do during the school day. I would then visit them at their homes and activity clubs in the school holidays, all within a reasonably small geographical area, thus limiting travelling time and expenses. However, there are relatively few young people who fit the criteria I set[11]. In particular, finding appropriate candidates to fit my fourth criteria of broadly 'normal' cognitive skills was difficult, as these are exactly the group who are now increasingly included in their local mainstream schools, so are hard to identify, especially as there is no central record of such pupils. I had several offers of possible participants, but all of these had learning disabilities, and a study with this group would need a different approach and was not my current underlying interest. I was keen to find young people who would be able to understand and respond to questions about their lives and situations in a fairly sophisticated way, as my interest was in this very disjuncture: a lack of intelligible speech but an ability to understand and reflect using verbal language.

On recommendation I approached one appropriate special unit attached to a mainstream school, and initial discussions suggested that they might have suitable children who could be invited to join the project. However subsequent concerns

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[11] see Appendices B & C pages 329-330

amongst some staff about the extra workload they thought the project might generate and other perceived negative consequences of hosting it, resulted in this offer being withdrawn. I then approached two additional special schools for children with physical disabilities, both of whom were enthusiastic about the project and this resulted in a list of a possible eight or nine invitees.

National support group: 1Voice

Anticipating the possibility that some of the young people suggested by the schools, or their parents might not want to participate, I also approached a national voluntary organisation which supports families with children who use AAC (1Voice)[12]. This changed the nature of my recruitment strategy in some important ways:

1) Families involved in such an organisation might be from a smaller range of ethnic or socio-economic groups, and as people who have voluntarily joined such a group might have particular views about relevant issues such as disability, education, children and research. These views might be reflected by the young people as well as their parents.
2) This approach depended on active 'opting in' by families in response to my advertisement, rather than them being suggested by and invited via schools
3) As a national organisation members might live anywhere in the UK and therefore I might have a geographically very dispersed group of participants

However, I was aware that there were both potential positive and negative aspects of this recruitment strategy. The support group invited me to attend a residential family activity weekend, and I then had an opportunity to talk to a number of parents and teenagers about the project and distribute written information personally but informally. This resulted in four additional families opting into the project. The disadvantage was that they were indeed geographically very dispersed. Thus these children lived in different parts of the country and thus attended four additional schools, which created considerable logistical challenges during the fieldwork. Also as predicted many families were very clearly 'activists' and with a narrower range of ethnicity, socio-economic and educational background than perhaps would have been achieved by identifying children entirely through schools. One of the positive aspects of contacting IVoice was that I was invited by them to be

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[12] 1Voice have given permission for the real name of their organisation to be used.

involved in a number of their activities during the year. This then provided another site for ethnography in which a number of children, young people and adults using AAC gathered and proved an interesting context in which to see them and their families. While attending as a volunteer and then increasingly being involved in organising some of these events, I was able to meet and interact with a broader group of young people using AAC in addition to the nine key participants. In particular there were four who I met regularly and came to know well, so some data from them is included as 'additional participants'. Attending 1Voice events undoubtedly facilitated my acceptance into their community as an 'interested friend' and enabled me collect rich additional data.

Despite the difficulties with identifying suitable participants described above, there is, within the core group recruited via two schools and the support group, reasonable diversity of age, gender, severity of impairment, types of communication systems and types of schools attended, although they are a rather uniform group in terms of ethnicity and socio-economic status (see Table1.). As recruitment was voluntary it was not possible to control or balance these more precisely. Three children who were invited by their schools opted not to join in, though this may have been because of lack of parental consent, rather than refusal by the teenagers themselves. Clearly the issue of adults being gatekeepers to young people's participation in research described by a number of authors is particularly pertinent with disabled children (Christensen and Prout 2002, Stalker 1998, Thomas & O'Kane 1998, Thompson 2007, Gallagher 2008).

It is possible that the relative homogeneity of the group is an artefact of the school staff gatekeeping the recruitment of participants. They may have excluded particular families, or made judgements about whether individuals would be willing or interested in participating. In both schools I had a strong sense of this. Where staff decided who should have this opportunity, they clearly made judgments about which children might 'benefit' from being involved, or which families might be 'difficult' for them to ask or me to do research with. Table 1 summarises personal details for the nine key participants. Table 2 introduces the additional teenagers who were involved to a lesser extent (through the 1Voice group).

Table 1. Key Participants[13]

Name	M/F	Age	Type of school	Ethnicity	Communication systems	Physical skills	Med diags & other issues
Bryony	F	10	Main stream + special	White British	Some speech Gestures + signs VOCA, direct access Moderate literacy	Walks with help/Walker Wheelchair, Drives self Some hand function	CP
Jemma	F	12	Main-stream + special	Dual heritage	Some speech Gestures + signs VOCA , direct access Good literacy	Walks with help/Walker Wheelchair Drives self Some hand function	CP
Josie	F	15	Special	White British	Etran frame, Gestures Head spelling Mob phone texting e-mail VOCA, direct access Good literacy	Wheelchair Drives self Poor hand function	CP
Kate	F	13	Special	White British	Some speech Gestures + signs Mob phone texting e-mail VOCA, direct access Good literacy	Walks with help/Walker Wheelchair Drives self Some hand function	CP Deaf
Marie	F	12	Special	White Irish	Some speech Gestures + signs Comm book VOCA, direct access Poor literacy	Wheelchair Drives self Some hand function	CP Tube feeding
Nathalie	F	15	Main-stream	White British	Gestures + BSL signs Mob phone texting VOCA, direct access Moderate literacy	Wheelchair Drives self Poor hand function	CP Deaf
Ted	M	12	Special	White British	Eye pointing Comm book VOCA, headswitches Moderate literacy	Wheelchair Learning to drive (head-switches) No hand function	CP Tube feeding

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[13] Ages are those at the start of the study. All names are pseudonyms. Specific details about family size and structure, and makes/models of VOCAs have been excluded to protect confidentiality. Med diags=medical diagnoses, CP = Cerebral Palsy, VOCA = Voice output communication aid

| Terry | M | 14 | Special | White British | Eye pointing Comm board VOCA, joystick +knee access e-mail Moderate literacy | Wheelchair Drives self Poor hand function | CP Epilepsy |
| Toby | M | 14 | Special | White British | Eye pointing Comm book VOCA, headswitches Moderate literacy | Wheelchair Learning to drive (head-switches) No hand function | CP Tube feeding |

Table 2. Additional Participants

Name	M/F	Age	Type of school	Ethnicity	Communication systems	Physical skills	Med diags & other issues
George	M	16	Mainstream	Mixed heritage	Eye pointing Comm book VOCA, direct access with help Good literacy	Wheelchair Learning to drive (head-switches) No hand function	CP
Prakash	M	14	Special	British Asian	Eye pointing Signing VOCA, direct access Moderate Literacy	Wheelchair Drives self Some hand function	CP
Ruth	F	17	Mainstream	White British	Eye pointing Signing VOCA, direct access Limited Literacy	Wheelchair Drives self Some hand function	CP
Jim	M	14	Mainstream	White British	Eye pointing Signing Comm book VOCA, headswitches Good Literacy	Wheelchair Drives self Some hand function	CP Tube feeding

A group of older teenagers who use AAC

During the fieldwork, I met a manager from a specialist further education college for students aged 16-20 with physical disabilities. Our discussion resulted in the idea of collecting additional data from older teenage AAC users at the college. The aim was to expand on the material collected from the core group of nine and to see if the perspectives of some older adolescents would provide interesting additional data. I negotiated through college staff to carry out focus group discussions with any students who might be interested. Eleven students (aged 17- 20) volunteered, and were split into two groups to attend two focus group discussions each. Although

time constraints (for the students), meant I collected only basic biographical information from them, they were rather similar in profile to the core group, there being a mix of young men and women (three and eight respectively), of ethnicity (seven white British and two Asian), and a similar range of communication systems and mobility impairments (all were wheelchair and VOCA users with poor or no speech and little or no hand function). All were doing two or three year courses at the college studying for a variety of vocational and academic qualifications.

Research advisors: Three adults who are AAC users

In an effort to respond proactively to the criticism sometimes leveled at non-disabled researchers that they do not consult or include disabled people in the research process (Zarb 1992, Stone & Priestley 1996, Shakespeare 1996), I decided early on to try to include consultation with some adult AAC users as part of the project. During the year prior to starting my fieldwork, I attended several AAC conferences, support group meetings and disability advocacy events in order to familiarize myself with AAC users and their communities. This proved invaluable as I met two adult AAC users who were active in these groups, heard another give a paper about issues around identity and AAC, and was recommended a fourth person (two men and two women in all, aged 25-50 years). As a result I discussed with all four, either directly or by e-mail the role of being a research advisor to my project. This would draw both on their memories of being a disabled teenager (e.g. as peer derrieres), and also their perspectives currently, about what it would be appropriate for me do with the teenagers and subsequently about my analysis of the data. All four expressed interest in being involved. In fact, because of time and distance constraints, most of my subsequent contact and discussion has been with three of them. One in particular, Katie Caryer has been more actively and regularly involved as will be described. The three listed below are actively involved in disability activism, including published writing and public speaking and are happy for their real names to be used in the data and discussion. Table 3. below summarises who they are.

Table 3. Research Advisors

Name	M/F	Age	Ethnicity	Occupation	Communication systems	Physical skills	Med diags & other issues
Meredith Allan	F	40s	White Australian	Gov admin worker Writer	Gestures + signs Mob phone texting e-mail, computing VOCA, direct access Good literacy	Walks Good hand function	Acquired speech impair-ment as a child
Katie Caryer	F	20s	White British	Freelance disability trainer Student	Gestures + signs Mob phone texting e-mail, computing VOCA, direct access Good literacy	Walks with help Wheelchair Drives self Some hand function	CP
Allan Martin	M	40s	White British	Dancer & dance teacher Freelance Disability advocate	Gestures + signs Mob phone texting e-mail, computing VOCA, direct access Moderate literacy	Wheelchair Drives self Some hand function	CP

Ethical issues

Information and consent

University of Sheffield ethics clearance and CRB checks were completed before the information-giving, recruitment and consent process with schools and families began.

Following the preliminary discussions with school heads, and the 1Voice group, the process of gaining individual consent with parents and young people proceeded smoothly. All schools and parents received a written explanation of the project and the latter were asked to discuss with their teenage child, the option of joining in, and then if interested to sign a consent form[14]. In initial discussions with school staff, parents and extracurricular club organisers, I set out to explain the nature of

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[14] See appendix E for letter, form and information for young people, page 333.

ethnography as an approach and the role of a participant observer in particular. I found that some parents and headteachers were interested in the underlying aims and ethos of the research and its possible implications, whereas class teachers and club organizers were more concerned about how much help I would be in practical ways. I did not particularly highlight my previous professional background as a Speech and Language Therapist, though I did emphasise having considerable experience with working with disabled children and this helped significantly in gaining very broad and flexible access to the young people's worlds.

At the two schools where I had more than one participant, I made an initial informal visit, during which I had discussions with the headteacher and spent some time in classrooms observing lessons and talking to staff and pupils. I gave brief verbal descriptions of the project at staff meetings, and responded to queries. Staff's questions were mainly about confidentiality and anonymity in the report, where the report would be disseminated and about time constraints in school and pupils not missing lessons in order to talk to me. At the four schools where there was only one participant, I met key staff and discussed my role and ethics issues with them. The attitudes of the schools to aspects of ethics such as: confidentiality, anonymity, my role, access to information, and whom I would talk to, varied considerably. Some were very open, to the point of being apparently unaware of standard ethical concerns, others were highly prescriptive and regulatory in their approach.

Negotiating the role of participant observer

I described my proposed role in schools as close to that of a 'voluntary classroom assistant' who would be actively involved in a range of activities during the school day and broadly linked to the key participants. This included participating in lessons, sports, mealtimes and breaks, fieldtrips and outings, concerts, after school clubs and leisure time. In the event I was also sometimes involved in personal care tasks such as feeding and helping with toileting, or changing for swimming, although this varied across schools. I was careful to emphasise that I would not be involved in management, curriculum or therapeutic decisions or in disciplining children, although in some cases, I was included by staff in informal discussions or meetings about these issues.

All the parents had either met me at the support group meeting and or had received a written explanation and invitation letter via schools. I explained that I would like to be a regular visitor to their home and join in with a range of different activities, as chosen by the young people. Additionally I had phone discussions with some or met them informally at schools and further explained the aims of my visits. In some cases I was aware that during my initial meeting or discussion with parents and with schools, I was being vetted for my attitudes and approach to children and young people and to disability, and my general 'user-friendliness'. Sometimes I was asked about my professional background and my views on controversial topics such as inclusive education, disability activism, difficulties with provision of services, or pros and cons of different communication systems etc. Some parents were very active in disability activism and I felt under pressure to conform to their views and concerns and to emphasise that I would not be further pathologising their children. My aim was to be seen as someone interested in the teenagers as people first, as reasonably experienced and knowledgeable about disability issues, but as somewhat equivocal and open minded about the more controversial issues. I described my proposed role as 'an interested adult friend', who would be a regular visitor at home and at school for about an eighteen month period.

During the 1Voice group recruitment talk to parents and young people, one teenager emphasized that it should be the young people's choice to participate, and one adult enquired about how their children's views would be represented in the final report. Members of this group were concerned that the project should have a practical outcome in terms of advocating for disabled young people, with the possibility of impacting on policy and practice and on public understandings of communication disabilities. I reassured them that I intended to disseminate the outcomes widely and to a variety of stakeholders and agencies. In particular the idea of producing an accessible version of the results, which would be designed in consultation with the participants, came out of this discussion and is something I plan to seek funding for as public engagement activity to follow up the study.

One parent gave permission to be involved in the study at school but not to home visits. Initial home visits to the other eight revealed that the parents had understood the nature of participant observation and that I would not have a very specific agenda when I visited. All were welcoming and flexible in suggesting activities I might participate in, and a broad range of these arose during the year (eg shopping and bowling trips, hospital visit, walks around the area, sports events, and staying overnight with one family). I tried to fit into the demands of some very busy households, and although ideally it would have been good to visit on different types of days, varying between weekdays, weekends and holidays, in reality, Saturdays and the school holidays were the most convenient for most families.

Information, consent and choice for young people

The teenagers were introduced to the project initially through discussion with their parents who had written information to draw on for this. On my first meeting with them after this, I introduced myself and described the project with the help of a file of visual and written information designed specifically for them[15] (Nind 2008). They understood that I would be spending time with them both at home and at school and at other places that they might suggest. I emphasized that my visits should be with their agreement and that the option of discontinuing or banning me from certain events would be ongoing throughout. I was particularly keen to be clear about their choice of levels of participation, as disabled children are regarded as a particularly vulnerable to coercion and there is some evidence that power relations may make them more likely to acquiesce or be passive in their choices (Davis et al 2003, Nind 2008). They had an immediate opportunity to ask me questions and subsequently had time to think about whether they wanted to join in before the next meeting. Ten children agreed to join in[16], and one did not want to, so was not included further.

I did not ask the teenagers to sign a form, but regarded their consent as an ongoing verbal process (Thomas & O'Kane1998). I was careful to check their consent to continuing involvement regularly, especially if we were planning for me to join them in a different activity or setting that I had not entered before (e.g. outings, personal care, and sports events). Occasionally, the right to choose for me not to join in was

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[15] See Appendix E page 333
[16] One boy started but subsequently dropped out due to ill health

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exercised (e.g. a boy going to the medical centre at school for a checkup, a girl going to an important sports event where she didn't want any distractions, a boy about me using a photo in a presentation). In some cases, access to new settings was negotiated by the parents (e.g. for some schools and clubs), and sometimes through me approaching organizations directly.

Additionally, I was involved with a more specific and related project with the 1Voice support group. They obtained funding to facilitate a group of 12 teenage AAC users to make a DVD about themselves. I was invited and agreed to be a researcher/facilitator with this. Two teenagers who were already in my study were involved, but the issue of consent to use data from the other 10 arose. As I was going to work with the group quite intensively and was likely to have individual conversations with some, I felt that consent from them was necessary. Written information about the study was distributed and signed consent gained from all the parents to use any anonymised data. This was verbally explained and agreed with the young people. Their ages and levels of impairment are very similar to the nine key participants.

Fieldwork methods

Diverse methods and contexts

The main methods in this 'mosaic' or 'distributed' ethnography (Hockey 2002), with the nine key participants were participant observation and individual 'extended narrative conversations' supported by various visual techniques. The main contexts were the teenagers' schools, homes and extracurricular clubs. Some of the key participants (six) were involved in a 'photovoice' task (Darbyshire, MacDougall & Schiller 2005) in which they took photos of important aspects of their lives at home during half term[17]. The table below shows approximately how much time I spent with the key participants.

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[17] One chose not to do this and two agreed but did not complete the task

Table 4. No of sessions spent in each setting with key participants

	School	Home	Extra Curricular Clubs etc	Approx total no. of hours
Bryony	10	5	4	60
Jemma	20	5	2	80
Josie	15	3	2	60
Kate	8	6	5	60
Marie	20	-	4	70
Nathalie	8	5	4	50
Ted	15	3	1	60
Terry	15	3	2	60
Toby	15	3	2	60

NB 1 session = ½ day = approx 3 hours

In addition, I conducted interviews with parents, and focus group discussions with school staff, and with a group of older teenagers who use AAC[18]. I also attended four AAC-related conferences at which AAC users and carers, as well as professionals and academics were present, and a number of activity weekends and days for children and young people who use AAC run by 1Voice. One of these weekends involved the making of a DVD by 12 teenagers who use AAC. Throughout the project I consulted with the three adults, users of AAC, who acted as research advisors.

Communication methods

A detailed description of communication methods used by the participants and issues arising is given in Chapter Three. In summary each AAC user has a personalised range of 'low-tech' communication methods or 'modes' which may include some speech, gestures, sign language (e.g. Makaton), a communication book, eye gaze, and alphabet boards.

In addition they all use 'high-tech' electronic communication aids (VOCAs) which are controlled by switches that each person 'accesses' in a unique way depending on their physical skills. AAC users choose from moment to moment which of these low or high-tech modes to use to get their message across, and so their communication

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[18] See 4H page 343 for Topic Guides.

can be described as 'multimodal'. Their choice of mode will depend on a number of factors the most important of which are probably:

- who they are talking to (e.g. teacher, parent, friend, sibling, stranger)
- the setting (e.g. school, home, sports camp, shop, public or private)
- the topic and purpose of the talk (e.g. basic needs, feelings, opinions, jokes, schoolwork, gossip)
- the time available (plenty of time, urgency)

In every case the speed of conversation is extremely slow in comparison with natural speech. Communication is in any case inherently interactive and collaborative, but in conversations where one partner is using AAC, it's negotiated and sometimes ambiguous nature is magnified.

Direct and indirect methods of data collection

The methods used during my fieldwork which drew out the young people's views of themselves were diverse and varied with individuals and over time. The methods were designed to catch glimpses of their selfhood and personhood from a number of angles, and so to see the dynamic, shifting, evolving and contextual nature of identity (Jenkins 2004). In all cases, there was an initial period of general participant observation either at home or at school, before having more focused one to one 'extended narrative conversations' with each participant over several months. Underlying my approach was an emphasis on narrative, so I encouraged them to 'tell their stories' as a way of finding out about aspects of identity (Clandinin and Connelly 2000). The main topics were:

- my important people
- I am (self-description)
- my life story
- things I love and hate
- me and friends
- my treasure box (favourite stuff)
- people who help me
- my ways of talking
- my dreams for the future
- Four vignettes about dilemmas a teenager using AAC might have

These were a subset chosen by the participants from a longer list which I had generated as possible topics of interest. The vignettes were written by me, based on previous experience of dilemmas often facing disabled teenagers using AAC.

During these sessions we talked about various aspects of themselves in a rather unstructured way and often deviated off to other topics (e.g. school gossip, what we'd been doing since we last met, TV shows, jokes, family news etc). These were usually audio-recorded and also involved drawing a 'conversation mindmap'[19] on the topic chosen. For all except two of the nine key participants, physically drawing was not possible, so they were reliant on me to represent what was said. I know that on occasions they found my drawings and maps unsatisfactory! However these did provide a visual representation of the story, which was useful at the time for keeping us on track, and also subsequently, when they sometimes chose to change or add to their previous ideas or ask me to redraw the mindmap. In some cases they enjoyed looking back at these some months later and realizing that their priorities were the same or had changed. The young people always had a choice about which topic to discuss (or none) and the conversation would last anywhere from a few minutes to an hour. Some of the teenagers were very interested in these discussions and took them very seriously, while others were quite lighthearted or flippant about them, or preferred to change the subject to more general chat very quickly. Thus even their approach to such activities told me interesting things about them. For example:

> *Marie(12) although always keen to talk to me, usually started every conversation by saying the topic was 'boring' (which is her constant verdict on nearly everything at school), and asking me why I wanted to know, but once she realized that we had time to discuss it at length and that I was still interested in her ideas and prepared to put the time in to listening, she would persevere for a long time to tell me what she thought (fieldnote summary)*

I felt that in Marie's case this initial reluctance and even suspicion was related to the fact that she did not seem to have lengthy conversations with anyone at school and so it was a novel situation for her and perhaps potentially embarrassing or difficult. Also her family's relationship with the school (as reported by the latter) and with the local authorities was apparently a stormy and ambivalent one and she was

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[19] see Appendix F page 337 for example

perhaps wary that my questions were linked to this. However once reminded that I was 'just interested in her' she liked to talk at length.

The extent to which I directed the conversations varied between the participants. Some were relatively more skilled at taking a part in managing the conversations by changing the topic, indicating they were bored, or asking me questions. In every case the agenda was driven by them much more when we were at their home, than in school, and perhaps this reflects that in 'school mode' young people have less agency and feel more of an obligation to do what adults suggest. Nevertheless I tried hard not to ask too many very direct questions and to make it clear that they had choices to make about what to talk about. In this way I endeavored to emphasize that what we were doing was different from school work.

The focused nature of the narrative conversations was however essential, in addition to the general participant observation. This is because for AAC users there is much less incidental chat and gossip than there would be with natural speakers, especially compared with adolescents, who normally spend so much time talking (James 1986, Bohanek et al 2008). It was noticeable both in school and home settings that although they were socially present in family affairs, they were mostly verbally silent (although sometimes non-verbally active), and thus as a participant observer one could easily be left with the impression that they had nothing to say. However my individual sessions with them, when opportunities for them to talk were optimized, reiterated how wrong that general impression was. I realised that the extended conversations were important not just for their content, which was indeed more substantial and concrete than their incidental communication at other times, but also because we were learning from each other about how communication could work best. We were, in effect building our relationship through constructing conversations in a much more obvious and crucial way than natural speakers do. The extended narrative conversations were therefore not just a way of 'getting data' but also a way to get to know the young people, which does not happen easily with this group. I was aware over time of my relationship with the participants developing from a tentative one at first on both sides, to one of trust, friendship, mutual respect and fun in the later stages.

Strengths and weaknesses of the methods

The main disadvantage of the ethnographic research design is the long timescale and intensity, which calls for personal resilience from the researcher, as well as being financially challenging in a tightly budgeted research world. Additionally the distributed approach with the participants being geographically widespread, some several hours distance from each other, was challenging and made logistics and continuity difficult at times.

Shortage of time was a constant problem and time spent travelling felt like a waste of this resource. Ideally it would have been good to spend more time with families, but they are busy folk and I sensed in some cases that demands for more visits would have been an intrusion. It has been suggested that family or home based ethnographies are problematic or difficult to achieve (Aull Davies 1998). I did not find this, but this may be because I did not request too many visits. One parent commented at the end of the study that she was surprised how many times I came and that any more would have been too much. In school there were also limitations on the amount of time I could spend talking individually to the participants as timetables have few free spaces and the nature of the teenagers' impairment means that more of their 'free' time is taken up with personal care such as toileting, mealtimes etc with which they need help, than would be true of their non-disabled peers.

It is possible that the methods chosen failed to collect data on some difficult or sensitive topics. For the teenagers there were possibly some limitations in their willingness or ability to talk about topics such as their bodies, sexuality, their futures, difficult relationships, or school. I did gain some material on all of these from some participants, but sensed that for certain individuals and for some topics further probing would have been inappropriate and intrusive. Likewise in discussions with parents and school staff there may have been limits in how candid they were prepared to be. Again, I had many very open conversations but also sensed that some people remained more guarded in expressing their views.

A fourth disadvantage was the volume of data, which despite its richness made the analytic process long and difficult. This length and intensity of fieldwork may only be practicable during funded doctoral research. However, the core methods of participant observation used across settings and a series of extended narrative conversations could certainly be used in other shorter studies in the disability arena, where 'one-off' data collection approaches are often unsatisfactory both for the participants and the researcher.

Participant observation over an extended period allowed me the possibility of a thick description of the teenagers' lives. This is not to claim that I saw everything about their lives, but that through repeated visits at home and school and through the series of conversations I saw recurring themes that were important. As Geertz (1993) suggests this is a process of teasing out: who does what? with what?, when?, how? and what it means. Furthermore Geertz talks about finding 'webs of significance' in the community being explored, and I was very aware that I was searching for these webs for each young person, through asking them to tell me about themselves in various ways. This was for many of them an unusual experience, whereas for most natural speakers, talking about ourselves and our experiences is an everyday occurrence running in parallel with unfolding events and feelings. Most people 'narrate their lives' and in doing so continuously construct a view of themselves (Clandinin & Connelly 2000, Ochs & Capps 2001, Roberts 2002). Sometimes we construct these stories internally and without verbalising them, at other times we tell the story out loud and thus it may be negotiated and elaborated in conversation with others. There are two particular barriers which are constantly in the way for AAC users wanting to do this overtly with other people: time, and people not understanding their way of talking (Paterson & Hughes 1999).

It is sometimes not recognized that a disabled child, like any other, may decide not to talk, or may withhold information. Instead it may be inferred that they have nothing to say. In the present study, all the participants seemed genuinely delighted to have a chance to talk about what was important to them, and indirectly implied that this was a rarity for them. Only on one or two occasions did anyone say that they did not want to talk, or that a matter was too private too discuss.

Terry	*ITS GOOD TO ASK US*
Kate	*you should tell the schools what we say*
Josie	*I LIKE TALKING TO YOU*
George	*SOMETIMES I'M LEFT OUT … AND THAT'S NOT GOOD*

It was particularly important to use methods which allowed the participants a wide range of possible ways of responding and to value them all. As Booth and Booth (1996) argue when describing the adaptations to narrative interviewing that they needed to make when working with an 'inarticulate subject', in their case a young man with learning difficulties called Danny:

> 'There is a danger of allowing ourselves to be drawn by the tempo of our times into a kind of 'fast research' with a premium on quick results. Against this background, it is important to remember the virtues of an older, anthropological tradition which recognised that the task of learning to communicate with subjects takes a long time. Narrative researchers must go back to such basics in order to ensure that their scholarship does not continue to silence the stories of people like Danny' (1996:67).

Booth and Booth (1996) emphasise that it is important to talk to participants with learning difficulties 'over several sessions' and in different settings, and this applies also to the present group. This supports my long period of participant observation, the variety of context and flexibility in ways to talk to the teenagers. For instance, if a participant's high-tech VOCA was not working when we had planned to chat, I felt that it was important to continue to have our planned conversation using their other low tech modes if they wanted to, as I would otherwise have devalued their other ways of talking and thus privileged audible speech over language or indeed communication. Frank (1997) argues strongly for the place of narrative methods of investigation as giving the freedom for participants 'to tell their story in their way' and this resonates with what I aimed to do as far as possible (Clandinin & Connelly 2000).

Notwithstanding all the arguments above about the importance of narrative in the ongoing construction of identity, and the benefits of narrative methods of research, this was not without its complications in the reality of my fieldwork. For young AAC users, opportunities to use language to 'narrate' their lives are limited, not because they have no stories to tell, but because of the practical difficulties in expressing these. Firstly, I became aware of the extent to which time (or rather lack of it) was a constraint on having any kind of meaningful conversation with AAC users. Secondly, I realised that in inviting the young people to do a range of reflexive activities I was asking them overtly to define themselves. Of course my aim was to do this in non-directive and enjoyable ways. Nevertheless, sometimes I was asking them to verbalise how they saw themselves in rather explicit terms, which they may not have done before, and might be emotionally loaded. I realized during these conversations that 'giving voice' to these thoughts might itself be part of an important formative identity construction process.

Several authors have emphasized the collaborative nature of storytelling, it normally being a conversation rather than a monologue (Grove & Harwood 2007). The element of co-construction is much more obvious and prominent in conversations with AAC users, and will be described in Chapter Three. In any case the teenagers took the task seriously, thought carefully, and then with considerable effort told me how they saw themselves. I interpreted, clarified and I recorded it. There is, as Goffman (1959) emphasized a performative or dramatalurgical aspect to talking about oneself. For these young people however their performance of identity is heavily dependent on technology, and on mediators, not just on their own bodily actions. I realized that I had to be careful that through the way they were encouraged to talk and their stories were represented, that I did not reify any particular types of identities which were not significant or accurate for them.

Data from other people

The decision to include data from those around the teenagers, such as parents and school staff, as well as their own views needs to be justified. I am following Jenkins in seeing identity as an ever-shifting combination of selfhood and personhood and therefore 'an internal and external dialectic' (2004:18). Thus, if social identity is

socially constructed, it is important to present both the person's own view of themselves and the views of others, and perhaps to look for agreement or disjuncture between these two. I decided therefore to include as a part of the mosaic of methods, interviews with parents, and focus groups with school staff[20]. Ideally it would have been interesting to talk to other young people such as friends and siblings as well. Time, resources and ethical issues prevented this, although I do have a few incidental comments from siblings. Therefore I have collected data from familiar adults as a way of putting the teenagers' own views of themselves in context.

Researcher role, skills and relationships

Researcher reflexivity

The role, skills and attitudes of the researcher in this type of research are crucial in the building of relationships with participants during the fieldwork. When working with people with unusual communication skills this is particularly important to consider (Stalker 1998, Nind 2008). Rabiee et al. suggest that:

> 'the exclusion of disabled children from research and consultation says more about unsuitability of research and consultation methods and adults not knowing how to relate to them than about the limitations on the part of informants' (2005: 8).

Given the 'reflexive turn' in current social science research, there are many authors who argue for the explicit inclusion of the researcher's subjective experiences and interpretations as part of the study data and the importance of these, particularly in ethnographic work (G Watson 1987, Aull Davies 1998, Coffey 1999, CW Watson 1999). In addition, those researching childhood and disability have followed suit (Clough & Barton 1995, Davis1998, Davis et al 2003, Pillow 2003, Hodge 2008). As well as describing 'reflexivities of discomfort', Pillow (2003) warns against becoming 'overly self-reflexive' and the dangers of a confessional tone. Notwithstanding this, I feel that some self-consciousness about my role and

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[20] Consent was sought and gained from eight of the young people to talk to their parents. This was not sought about interviewing school staff as these focus group discussions did not relate to individuals but to issues for disabled children and young people more generally.

relationships with the participants, and my responses to what I was learning are part of the picture, and merit some description and discussion.

Adult – child relationships in research

Mandell (1991 cited in Hutchby & Moran-Ellis 1996) outlines three different levels of participation and control in research with children, and drawing on her categories, I aimed for my approach to be a 'marginal semi- participatory' one. This stance does not recognise an absolute distinction between the cultural worlds of children (or here young people) and adults but 'asserts that the age-based power relation' can never be transcended (Hutchby & Moran-Ellis1996:10). Thus I set out to be a 'different kind' of adult and to attempt to explore the 'social world of children from within' at least in part (Ibid1996:13).

I initially identified myself overtly as an anthropology student rather than as a speech and language therapist (SLT). Although my previous professional experience was known to some of the adults, I was keen not to be identified in this way to the young people, as I thought this might bias their response to me (either positively or negatively), and limit the ways in which we might relate to each other. In negotiating my role, my professional background undoubtedly helped me gain access to schools, but it was also clearly agreed that I was not working in the role of an SLT. Thus as an 'interested adult friend' without a prescribed relationship with the young people (e.g. not a parent, teacher, learning support assistant (LSA) or therapist), I was able to join in with their lives in ways which were different and more flexible than those of other adults. As Christensen argues:

> 'Children are very sensitive to adult-child differences precisely because they encounter them throughout their everyday lives. It is however possible to be a different sort of adult, one who, while not pretending to be a child, seeks though to respect their views and wishes. Such a role inevitably involves a delicate balance between acting as a 'responsible adult' and maintaining the special position built up over a period of time' (2004:174).

Similarly to this and despite feeling somewhat daunted at first, I positioned myself in relation to the young people as very interested in them as people, as well as a slightly silly, rebellious or subversive adult, as described here:

Assembly in the hall, practicing songs for the prize giving on Friday. I was sitting next to Toby(14) and Terry(14) and both were keen not to join in with singing (and actually don't really have a way to!). I colluded with this by saying to them that I was not a member of staff so I didn't have to join in either and just sang blah blah a bit and made a silly face. Distancing myself from staff and allying myself with them. They laughed (fieldnotes).

I aimed to convey the message 'you can say what you like, and I will listen'. I deliberately tried to ally myself with the participants, and over time noticed that indeed I was responding to incidents in a way that was closer to their perspective than to anyone else's. At schools and clubs I tried not to be involved in disciplining or other types of adult decision making, and tried to stay neutral or take the young person's view where this was possible. This was sometimes uncomfortable and challenging as I was also privy to adult perspectives both contemporaneously, and through memories of my previous work as a clinician in rather similar settings. Sometimes I felt cast in the role of teacher, LSA or therapist by adults and was also sometimes invited to make suggestions about young people's behaviour or learning. I tried to position myself differently, in order to enable the teenagers to show me a wider variety of selves than they would to those people. I had to 'bracket' much of this previous knowledge in order to distance myself from it as Husserl suggests (Dowling 2006).

My relationship with the participants was very different from that between a therapist and a client, or teacher and pupil, which are usually much more goal orientated. I was more like an older friend than a professional, although of course bound by an awareness of child protection and power issues and respect for the young people's privacy and our age difference. The issue of being 'a friend' to participants has been addressed by Stalker (1998) in relation to adults with learning disabilities. Some of her concerns about participants misconstruing 'friendliness' for a possible long-lasting friendship were also pertinent here, though I took careful steps to explain what my role would be over the course of the research. Because my participants do not have learning disabilities, I could be reasonably confident that they understood the time-limited and project-focused nature of our relationship. I

also regularly reminded them of this by telling them what the next stage was going to be. For example

> I will be:
>
> - coming in to school 3 days a week this term and on the school trip
> - coming to see you at home at half term
> - coming to the boccia[21] event with you in the holidays
> - not coming in to school next term because I'll writing up all my notes and listening to the tapes
> - coming back in a couple of months to tell you my ideas and see what you think
> - writing it all up for the university
> - eventually writing a booklet which you and the others will need to help me with (eg help chose what I say and photos)

During the initial period of getting to know them I deliberately suggested that we did informal activities without a need for too much talk or a potential emotional load for example, a tour round the school, house or bedroom, helping with activities in class, looking at photos and certificates. This period of familiarization helped both parties to understand each other and to see what methods might work in the future (Booth et al 1997, Stalker 1998). I had to learn about their modes of communication, to interpret non-verbal signals and the kinds of help they liked during talking, as well as their interests, sense of humour and for how long they could concentrate. In the meantime, they had to 'suss out' how good a listener I was, what kind of adult and no doubt much else besides!

An early routine was for me to ask them to show me how they liked to communicate best, how they indicated yes and no and to show me how they signed, used their VOCA or book to tell me a few basics such as their birthday and address, favourite football team or TV show, foods they loved and hated. This got the conversation off to a good start as they were then confident that I had at least some idea about how to communicate with someone with no speech, was interested in them as individuals, and prepared to learn how to tune in to their interests and ways of talking.

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[21] Boccia is a specially adapted disabled sport which is rather like bowls and is played highly competitively at special schools and nationally and is an international paralympic sport for physically impaired people. Some participants in the study were playing at national level.

My skills and experience as an SLT were invaluable in communicating well with the young people. In every case, I felt that during our initial meeting, they were making a careful assessment of me, and my 'userfriendliness', especially as they had not met 'a researcher' before. However they all seemed to understand the aims of the 'project' easily and regularly asked me how it was going. When I first visited Kate(13) at school she immediately introduced me to her teacher by saying:

> *THIS IS MARY...A RESEARCHER*

Though I was probably a 'good' communicator at the start, I was aware that my communication skills and relationship with each individual improved dramatically over time. My ability to wait, tolerate silences, understand unintelligible speech, switch modes, and particularly to read subtle individualized non-verbal communication increased greatly and in ways I had underestimated beforehand. The few qualitative studies that have been undertaken with children or adults with learning disabilities who cannot talk have discussed the issue of researcher communication skills to some extent (e.g. Morris 1998, 2003, Davis 2003, Rabiee et al 2005, Nind 2008). They have emphasised the need for time to get to know people and their systems of communication, and often focus on learning a sign language and I concur with the need for both. However my experience leads me to emphasise that there is much more to learn than this.

Being prepared to learn about each individual's complex and idiosyncratic system of communicating seemed more important than any specific skill. Importantly, I also learnt 'to be' in a different and certain way, which included not only adapting my communication, but my physical skills such as moving differently, steering wheelchairs, lifting people, noticing body movements, or waiting. There is also a way of talking to and being with AAC users which involves being aware of their extra needs for help, but at the same time being interested more in the content of what they were saying than paying undue attention to their 'difference'. This is a delicate balance. I noted many times in my fieldnotes a sensation of 'clicking into a different way of being' whenever I was in these environments and being increasingly

comfortable and accepted in them (Clark 2004). During the later stages of the project I was asked by several parents to accompany their teenage child somewhere, and by one of the research advisors to work as her personal assistant over a weekend. These requests felt like stamps of approval, and also when I accepted them opened up whole new levels of involvement, which were both demanding and illuminating in understanding disabled people's lives.

Over time then I moved from being a stranger who at times felt anxious and incompetent at conversing well and relevantly with the teenagers and without boring them, to someone who knew a great deal about them and could chat easily. Thus I switched from an 'outsider' to an 'insider', as has been recognised by many authors when describing ethnographic fieldwork (Geertz 1993, Clifford 1997, Aull Davies 1998). Thus I changed from someone who needed a 'translator/mediator', to providing this for other people who knew the teenagers or research advisors less well. In anthropological terms then, I became part of 'the tribe' and knew their 'language'. I also began not to notice what outsiders notice about these people, their messiness or slowness, and during encounters in public places I found that I began not to notice whether anyone else was staring. For example:

> *At the bowling alley on a 1Voice trip with a group of young disabled people and their families we were just busy with our own interactions, though I realised later that we probably looked like an extraordinary group to others (fieldnotes).*

Relationships with school staff

My relationship with the adults at schools needed as much if not more conscious working on, as that with the young people. I found schools welcoming and enthusiastic about my presence and very used to having visitors and extra adults around. However, I was very aware of having to negotiate my way round some complicated local politics, especially as someone with an unusual and perhaps, in their eyes, ambiguous role. After some very initial apprehension from some staff about what 'a researcher' might want to do, I was soon accepted as part of the scene in school. In one there was some suspicion that I was interested in staffroom rifts and rivalries, and I had to reassure people that my interest was the views and lives

of the young participants. I found that making very deliberate efforts to be chatty, uncontroversial and very practically helpful worked well in managing a certain amount of hostility and uncertainty. There was a palpable process of the staff learning about what my role was and what I was interested in doing and not doing. I was pleased when one of the classroom assistants said after a few days, when I'd offered to help take someone to the toilet and then to help with clearing up gym equipment

You're very hands on really aren't you?

Another said

we were a bit worried when you said you were a researcher, we thought you'd have a clipboard ! You're quite normal really! (fieldnotes)

The schools' acceptance of me, was partly as a result of my evident skill at interacting with the students, but was also motivated by their almost universal shortage of staff. For them, interest in facilitating my research was less important than the benefits of an extra pair of adult hands in demanding classrooms or sports fields. I was constantly aware of how busy and complicated schools are, and that the staff's main concern was that I didn't disrupt their work, either by my presence or by what I might say in my report. I was surprised at the generally low level of interest in what exactly I was investigating, although there were a few exceptions to this. Some staff asked me for my reflections on aspects of school life or about individual children in ways which suggested that they were hoping for validation of their own perspectives, concerns or curiosities. This was similar to the process described by Davis et al as 'attempts to resocialise the researcher' (2003:203). When asked about particular participants, I endeavored to respect confidential boundaries between their school and home lives, which I was in the privileged position of crossing, and which in some cases school staff were keen for me to break.

I carried out focus group discussions with groups of teachers, LSAs and therapists at the two special schools where there was more than one participant. In these I asked them to focus on how they thought being an AAC user affected the young people's

lives. However these were difficult to arrange, and not all of the key people I would like to have included found time to participate.

Towards the end of the fieldwork, I tailed off my visits to schools in a deliberate way in order to prepare the participants for the end of the project. When I had finished my intensive period of participant observation, I continued to visit the schools on an ad hoc basis, on the pretext of checking information with the teenagers, getting permission to use photos etc. By this time my relationship with the staff and participants was relaxed and informal as I had become 'part of the scene'. I was then given no special attention, which was useful as I could then confirm and add to some observations made at much earlier stages, but now with the benefit of hindsight and of being much less conspicuous.

Relationships with parents and families

Working with the parents was, in contrast, easier and generally very straightforward. All but one were interested in the research, very open, welcoming and willing to talk about their experiences, as well as facilitating their son or daughter spending time with me. Some were generous and imaginative in including me in family activities, with apparently no expectation of reciprocal gain, but a strongly expressed sense that more information about disabled young people's lives should be in the public domain. Many emphasised that it was unusual for someone to spend so much time finding out what their child thought. Parents, like school staff, varied in the extent to which they questioned me about methods, ethical aspects and what would happen to the data subsequently.

During home visits, and after initial introductory social chats with parents, they were generally happy for me to spend time talking to the adolescent alone or with siblings, sometimes in communal spaces or sometimes in a playroom or bedroom. Most parents understood that my main focus was on time spent with the teenagers, although some parents also wanted to have extended conversations with me or were initially keen to be around to facilitate their child's communication until they were sure that I would be able to manage without them to interpret. Most parents recognized a need for privacy and that the teenagers wanted to talk to me alone. On

several occasions young people very deliberately dismissed their parent from the room with a word or gesture or shut the door!

I decided to carry out interviews with the parents at the end of the period of fieldwork. The decision to do these late in the process was a good one, as by then we knew each other well, and so although the interviews were semi-structured rather than completely open-ended, the parents were very relaxed, open and honest in their responses. These interviews were carried out without the presence of the teenagers but with their knowledge and agreement.

Ending the fieldwork

At the end of the fieldwork period, on my last visit to schools or homes, we had 'feedback and thank you' sessions. I felt that it was important to mark the ending of this part of the project clearly for the key participants. At these I talked through a mindmap summary of the themes[22] and key ideas that had emerged at that point in my analysis, and gave them some examples of quotes that I might use. Some participants asked questions about my interpretations, but generally I found that their interest in the detail was quite limited, and they tended just to agree with my ideas. Given the suggestion that disabled children tend to acquiesce more than their peers (Basil 1992, Pennington & McConnachie 1999), I should be cautious about their apparent concurrence with my ideas, but given that I knew them all very well by this time, I would argue that in fact they did see my analysis as reflecting some version of reality for them. In the two schools with more than one participant, the sessions were done in a group with Katie (RA) as a special guest. All participants were presented with a file containing all their own conversation mindmaps, photos, a certificate of thanks, a £20 music/video token and a bar of chocolate. There are some individuals who I am likely to meet again (at 1Voice events in which I am still involved), and in all cases I left contact details so that they could stay in touch if they chose to (by e-mail). However this event was deliberately designed to mark the end of our 'official' work together.

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[22](see Appendix I page 347)

The data

A large amount of data in a number of formats was collected:

- Fieldnotes: hand written during or after participant observation (7 books transcribed into Word files)
- A Word file for each key participant: collating transcriptions and observations across settings for each (9)
- Researcher diary entries: more general or theoretical ideas not specific to settings, at least weekly. Transcribed.
- Audio recordings and subsequent transcriptions of:

  - Extended narrative conversations with key participants (approximately 10 hours per participant)
  - Small group discussions with participants (approximately 10 hours total)
  - Focus groups with older teenagers who use AAC (4x1hour)
  - Focus groups with school staff (6x1 hour)
  - Parent Interviews (8 x 40 minutes)
  - Discussions with research advisors

- Other written or transcribed materials: talks, articles, poems etc. by participants

- Visual materials
  - Mindmaps from extended conversations
  - Photos taken by me
  - Photos taken by participants

- DVD made by teenagers who use AAC (1Voice)

The amount of information about the key participants is variable because of consent or access issues. In one case I was not able to visit the teenager at home or interview the parents, and in three cases geographical distance or parents' commitments limited the number of visits. Data from the four additional teenagers, who were more peripherally involved in the project, is also more ad hoc, as I met them in a variety of settings (school or 1Voice events) but did not visit all at home or have extended (or recorded) conversations with them.

Prioritising different types of data

In coding, analyzing and interpreting the data I considered whether some kinds of data should be given more importance than others. It is tempting to see the transcripts of verbatim conversations with the teenagers as the 'most real' and

therefore as the most important, and in a sense this is true. However, as will be seen in the transcripts in the subsequent chapters, often what they actually say is rather elliptical or at least verbally unelaborated. There is also a great deal of time taken up with simply getting the message out and straight, so that the actual quantity of content is rather small. There is also a high proportion of talk from the conversational partner (usually me), as efforts are made to clarify, elaborate or expand on the few words 'said' by the AAC user.

There is always the danger of 'putting words into people's mouths', as Brewster (2004) warns in her discussion of methodology with those with learning disabilities. Bayliss (2007) discusses when and why one might 'tinker with transcriptions' and I would argue that such tidying up is essential in order to produce meaningful transcription of conversations with AAC users, but with the necessary caution and attention to authenticity of the message. This issue is discussed further in Chapter Three.

In transcribing AAC talk, one could be drawn towards conversational analysis (CA) or discourse analysis (DA) approaches (Clarke & Leech 2003), looking at the minutiae of the interaction, rather than looking more broadly at the underlying message that was being communicated. I have for the most part, resisted the CA or DA analysis options. In addition, because of the expanded role of nonverbal communication in AAC talk, my informal observations during participant observation are a more important adjunct to the teenagers' actual words than perhaps they would be with naturally speaking participants.

Additionally, when considering the prominence given to the different types of data collected there are some additional and particular issues. Because AAC users talk much less than other people, it may be tempting to pay relatively more attention to what other people around them say. For example, the actual volume of data from interviews and focus groups with adults could easily drown out the small amount said by the teenage participants themselves. Having adapted to the rate of talk produced from the AAC users, I was quite shocked at the ease of acquiring, and the amount I suddenly got from natural speakers when I interviewed them. I have been

cautious therefore in my use of this data, in order to keep the non-AAC speakers in the background, and to enable the young people's own voices to be the most prominent.

Unlike many other studies with children and young people, drawings were not an available method for this group, although sometimes written work was. Although writing (on a computer) is also a very slow process because of slow hand or head movements to control the mouse, it is for some a useful and rewarding mode, and less pressurizing than face to face talk. Therefore written pieces of work that some participants were willing to share are included. None of these were done at my request, but were shown to me by them as they judged them relevant.

The photovoice task, where the teenagers were given a disposable camera to use at home for two weeks, with the instruction that they could direct their families to take photos of anything they thought was important in their lives, yielded rather mixed results. Four of the group took considered and 'set up' shots to illustrate a variety of things (their favourite dinner, a group photo of friends, a mockup of a boccia game etc), whereas others took rather informal or spontaneous pictures, sometimes all at one event (at a football match). The resulting photos which were of varying clarity, were then used, as the conversation mindmaps were, more as conversational devices than in a formal analytical sense.

Data Analysis

The transcribed material thus comprised over 70 Word documents and these were entered into NVivo 7 (QSR 2006). Case nodes (individual files) were also created for each participant. The visual materials, such as photos, mindmaps and the DVD, were not analysed separately, but transcripts of conversations about these are included in the written material. The documents were coded using themes generated iteratively during the process (Miles & Huberman 1994). After an initial coding process which generated a tree structure of seven main themes, each with a number of sub branches, I reconsidered and reorganised these, and recoded or further coded some material. On several occasions I changed, moved or collapsed headings. Over time these gradually changed from being rather descriptive to more analytic in nature.

The coding and analysis process overlapped with the last five months of fieldwork, during final school or home visits and the parents interviews. Often during coding, a new interpretation of an event would occur to me and this then affected my observations and activities during subsequent fieldwork visits. I confirmed these ideas with the young people, with the research advisors or with some family members and school staff. Analysis was very much an iterative and inductive process, where issues gradually emerged from what the young people did and told me and my reflections on this. Thus, participant validation of my ideas was integral to the process rather than an additional stage at the end (Zarb 1992). The final analytical tree had seven main themes.

1. Me, selfhood and agency
2. Personhood and social relations
3. Physicality and practicality about bodies
4. Voices and communication
5. Structural stuff
6. The disability tribe
7. Research reflections and theoretical links

Themes Five, Six and Seven are perceived as being overarching and so data from these has been integrated where relevant into the five themed chapters of analysis and interpretation, which make up this thesis. Theme One had a large number of sub-branches and so has been split into two selfhood chapters for analysis and discussion. The themes were subsequently given more accessible names when they were presented back to the teenagers for comments, and so these names have been used as the chapter headings in the thesis as listed here:

- Whose voice is that? (communication issues as they relate to identity)
- Being a family person and being a teenager
- Me myself I (autonomous and disabled selves)
- Don't just see the chair! (the body, physical aspects of identity and the role of the kit)
- My family and others (the views of others and social relations)

Conclusion

The study used phenomenological approaches to explore social identity and the lifeworlds of a group of nine key disabled teenagers who use AAC, principally using participant observation to spend extended amounts of time alongside them in their homes, schools and other settings. An additional 15 participants were other teenagers with similar disabilities (4 at 1Voice and 11 in focus groups), family members, and school and club staff. Three disabled adults who use AAC who acted as research advisors and provided an additional way to validate the data and analysis. Informed by theory from Anthropology, Childhood studies and Disability studies, the methods used are all qualitative and were designed to optimise ways in which the 'internal' or unheard voices of young people who cannot talk easily might be both revealed and represented.

Chapter Three. Whose voice is that?

Silence can be a plan
rigorously executed

the blueprint to a life
It is a presence

it has a history a form
Do not confuse it
with any kind of absence

(Rich 1978 cited by M Allan 1998)

Introduction

This chapter will consider the process of communication with AAC users and the nature of the 'voices' that are revealed in this study. The word 'voice' can be used in both a literal and metaphorical sense. Both are important here. As the participants may be perceived as not having 'a voice' in the conventional physical sense, this chapter provides a description and explanation of the ways in which they communicate. It will show that they do have 'a voice' although it is rather different from that of a natural speaker. In the 1Voice DVD made by the teenagers they chose to use the phrase 'My voice is my power' repeatedly as a kind of rap to illustrate the importance for them of having an audible voice.

The chapter sets out first to give the reader an understanding of the process of 'talking' used by AAC users, especially the process of co-production and mediation with conversational partners. This is important as the subsequent chapters focus on what is said rather than the minutiae of how this has been achieved.

Secondly, the issue of whether and/or how the 'real' voices of young people who talk in unusual ways can be represented accurately and sensitively will be addressed. Finally, the concept of 'voice' and how it relates to issues of identity is dissected in order to explore the extent to which it is conventional meanings can apply to young

people who do not physically speak. This chapter addresses aspects of both the first research question about selfhood and the fifth about successful methodologies in researching children and young people who use AAC and, in doing so, forms a link between the methodology chapter and the presentation in subsequent chapters of themed analyses about the young people's identities and lifeworlds.

Excerpts from conversations with the participants used in this chapter will be presented using a more detailed transcription style than will be used subsequently. In later chapters I have deleted or 'tidied up' the hesitations, repetitions, misunderstandings, clarifications and long pauses, which regularly occur in AAC talk (Bayliss 2007). These are included here alongside an indication of the time taken for the excerpt, in order to give the reader a sense of the ways in which communication by and with AAC users is different from that of natural speakers. AAC users do have a very different kind of voice[23]. Other people conversing with them will be very aware of this difference, even though, as will be seen in later chapters, the content of what they say is rather similar to that of natural speakers of their age.

This chapter is accompanied by a DVD a videoclip of an adult advisor talking, and the 1Voice DVD made by the teenagers. This is intended to give the reader a flavour of conversations between a natural speaker and an AAC user, and what VOCA speech sounds like.

Augmentative and Alternative Communication: How it works

All the participants in the study use more than one method of communication, and usually individuals favour some over others. The types of system (modes) used evolve and change over time as children develop and mature, and as their levels of abilities and impairments become clear. All typically developing children learn early and spontaneously to use non-verbal means of communication before they learn to talk with words (Foster 1990), and those with physical impairments are no exception.

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[23] The transcription convention used throughout is that quotations from verbatim conversations and from fieldnotes are in italics. Talk produced with natural speech is transcribed in the lower case, whereas that said on a VOCA is in the UPPER CASE. Written material or gestures or signs are marked as such with brackets.

Thus, as young children, the participants will have developed informal ways of communicating with their families, using body movements, eye and hand pointing, vocalizations and possibly some speech sounds. Once it is clear, however, that speech is going to be difficult or impossible[24], more formal augmentative and alternative systems are often discussed and introduced. These can be both low and high tech, and it is usual to have at least one of each type, so that the young people will always have a way of communicating even if the high tech system is not working or is not practicable[25]

Some children develop enough speech (although perhaps very unclear or only single words), to use with family and close friends. The introduction of AAC does not prevent their use of these words, and indeed may enhance it. They gradually develop their own way of 'mode-switching' between their own speech and their aided communication systems as the need dictates and as they choose. Similarly, those with no speech learn to mix modes using low tech systems (e.g. gestures, eyepointing, communication book, chart) and high tech VOCAs which produce an electronic voice. Very often AAC users report that their low tech systems are much quicker and easier to use, so they opt for these when talking to people who know them well enough to understand the more elliptical style of these messages. In contrast the high tech VOCAs are slower but more comprehensible to strangers and are thus essential when there is no familiar person around to mediate for them.

The most common low tech modes used by the young people in the study were sign language, communication books or boards and eye-pointing frames. Sign language is

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[24] This becomes clear during the pre-school years, and is usually in the context of the obvious physical difficulties with body movements, and for which the child may be receiving physiotherapy, OT and other special help, equipment etc.

[25] The most important factors which determine the communication mode and choice of system used are: cognitive skills (eg understanding, memory, concentration, emerging literacy etc), physical skills (particularly head control and hand mobility, speed and accuracy of movement), as well as other aspects such as the child's interests and personality (eg social skills, perseverance) and child and family preferences. For children with very impaired physical skills the range of choices may be very limited, especially if they have very poor head control (which affects accuracy of eyepointing) and or very inaccurate hand movements. Children with poor memory or literacy will be unable to use systems which depend on learning complicated codes or on spelling. They need less complex picture or symbol based systems.

an obvious and natural alternative to speech, however for those with severe physical impairments it may be as difficult as speech. Four of the participants in this study use some Makaton signs, sometimes alongside speech. If speech is very unclear this can be helpful as it gives the listener an extra clue as to what is being said. Marie, Kate, Jemma, and Bryony all use this to good effect. Nathalie (who is also deaf) uses some British Sign Language (BSL) signs although she has very restricted hand movements. Using these formal sign systems as opposed to natural gesture depends, however, on the conversational partner knowing the sign language and being able to recognize rather inaccurately produced signs, in and amongst any other extraneous movements that the person with cerebral palsy often makes.

All the participants had past experience of using a communication book, and five still use one very regularly. This is an individually designed photo album style book of symbols[26] and pictures, organized thematically. The front page is an index of themes which are represented on the subsequent pages, such as: friends and family, school, food and drink, interests, emergency words, and feelings. The number of pictures or symbols per page will depend on the accuracy of the pointing skills of the user. Young children start with just a few pictures on a page, but a skilled user may have as many as 40 squares on the page and be very fast at navigating the symbols. The AAC user indicates to the listener which page to turn to by eye or hand pointing, and then, on the requisite theme page, to the target word. Some users and their carers learn to use this system extremely rapidly, using a series of colour and position coded points (eg top right, red) (Photos 1. and 2. below). Ted is a particularly fast eyepointer and at home uses his book in preference to his VOCA. Marie also often indicates that this is her preferred mode, by looking behind her to where her book is stowed at the back of her chair. She is able to point to the symbols with her finger. Toby, Jemma and Bryony use their books as a backup when their VOCAs do not work. The disadvantage of this system is that it takes a long time to construct a sentence with grammar, so often the

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[26] There are several commercially available sets of symbols, each of which has several hundred symbols for everyday vocabulary, and these are available for purchase on the Internet. These electronic formats, make compiling a communication book or board or adding to or and adapting it a faster and easier process than previously. It is also advantageous that most schools and SLTs will encourage the use of one of these sets of symbols, so that the AAC user's book is easily understood by many people in his/her environment. The book will also have a page with the alphabet and some key written phrases so that they have the ability the user can also spell out messages as necessary.

AAC user depends on their conversational partner to co-construct their intended meaning from a small number of key words, e.g. 'when, go, shopping?'

The final low tech option is an 'Etran frame' (Photo 3.).   The frame is a large perspex board with letters, numbers and punctuation arranged on a grid around the periphery. There is a rectangular window in the middle. The conversational partner holds the frame up so that the AAC user can 'eyepoint' at letters through the frame. After each letter point the partner says the lettername, and if it is right the user signals the next. If it is wrong she re-signals that letter until the listener says the target one. At the end of each word the AAC user looks directly through the middle at their listener, to signal the end of the word and then the partner says the whole word or sentence to recap. Once both are skilled with the system, a number of shortcuts start to develop e.g. the listener may guess halfway through a word or phrase what it is, and says it. This takes trust and good judgment about when to guess and when to wait. Once two people know each other well, this can be a very speedy process, and again can be much quicker and less effort than the high tech systems.   However it is still very tiring and requires intense concentration from both parties.   Josie uses this system for all her schoolwork, with an LSA she has worked with for four years. She also used it to sit her GCSE exams during the fieldwork period.[27]

There is a range of high tech communication aids (VOCAs) of different designs, and the decision about which is suitable for a particular person is complex and multifactorial. There has been a rapid improvement in the technology in the last 10 years, so that many devices are now computer-based and have huge memory capacity, so that the user can, if they have the cognitive skills to do so access many thousands of words and phrases, link to the internet, use e-mail and a mobile phone through the device.

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[27]   She was given double the usual amount of time for each exam, but this was still not really enough, and the way in which her helper supported her was highly restricted in this setting. This is a matter of some controversy between schools and exam boards.

Photo 1. Using a communication book with eyegaze   Photo 2. Page detail

Photo 3. Using an E tran frame

The quality of the electronically generated voices has improved greatly and most models allow the user to choose from a number of voice options (e.g. age and gender appropriate) and some also allow a choice of American or British accent and some other aspects of 'style'. However, because the voices are electronic, they do lack 'naturalness' and do not have the subtle individual variations in tone, volume and regional accent that physiologically produced voices have. Thus with the present level of technological advance they still have a 'robotic' quality.

The way in which the user 'accesses' the letters, words or phrases on the VOCA depends on each individual's physical skills. 'Direct access' refers to systems where

the person presses buttons or squares on a screen directly with their finger (or a headpointer or foot). The majority of the participants use this method, as illustrated below (Photos 4. and 5.).

If the user is unable to point accurately, other alternatives are to control a scanning system with a joystick or with knee or headswitches (so that a cursor moves across the items on the screen and this is stopped and selected as appropriate). In the current study, one boy uses a combination of joystick and knee switch (Photo 6.), and two others use head switches (Photo 7.). The latter work by having pressure sensitive pads in the head support attached to the wheelchair. One switch will move the cursor across and down the screen and the other will select an item. The joysticks, knee, head or footswitches can also be used to control a computer mouse and to drive a power wheelchair, as well as a number of other environmental controls.

The size and bulkiness of the VOCAs varies. The smaller ones can be moved around and used on a table, on the person's lap, or even hanging round their neck or holding it while walking. Most, however, are bigger than this and are usually mounted on a tray or bar attached to the person's wheelchair. This obviously restricts the range of contexts in which it can be used. For example if the user is sitting in another chair, swimming, lying in bed or on the floor, or of course doing sport or another activity out of their wheelchair, their VOCA will be unavailable to them. I witnessed numerous times when the teenagers did not have their VOCAs available because of pure impracticality during particular situations:

> *Photography club with Terry (15). We went out into the grounds and took pictures with a camera with a specially adapted switch on it. He directed me with gestures and sounds, not using his VOCA in that situation although it was there on his chair. Can't drive and talk because uses the same joystick for both! (fieldnotes).*

Photo 4. Direct Access with finger   Photo 5. Direct access detail

Photo 6. Indirect access with a joystick   Photo 7. Using headswitches

For most, the high tech system is very slow compared with natural speech or most of the low tech modes. Many AAC users use rather short utterances. Some go to great lengths to make these grammatically accurate, whereas others develop their own forms of ellipsis, using idiosyncratic shorthands, or sometimes only key words, and relying on a mediator to co-construct the full sentence for them. They may use pre-programmed phrases, which roughly suit the purpose but may be rather inexact. The result is that although English is being spoken, it is almost a different dialect, or perhaps a 'creole' with its own very particular rules, logic and idioms, generated in a particular context. It can therefore be difficult for a new conversational partner to understand. These shortcuts, which can be highly colloquial and individual, become part of the person's 'voice' and identity and characteristic of them as a person.

As the descriptions above demonstrate, although 'speaking' takes a variety of forms for AAC users, the kind of 'voice' they can have may be limited, unlike non-AAC users. For natural speakers, identity is partly reflected in the way people express themselves through their voice. Additionally, features such as style of communication and the language used contribute to the uniqueness of individuals, and people communicate in different ways on different occasions. Speakers adapt their grammar, vocabulary and non-verbal communication to suit the context. Different people might be very characteristically verbose, taciturn, grammatical or slangy, but will also vary their style according to the social situations. This natural 'online' flexibility is not always recognized, however, as either necessary or possible for AAC users. Thus, for example, their ability to adapt their style and content may be more limited for purely practical reasons, as an artefact of both their impairments and the technical capacities of their communication systems. AAC users say that they would like to be able to use intonation more and to have regional accents, and VOCA manufacturers are beginning to take notice of this and develop the technology to achieve these variations.

AAC users do choose, however, to adopt a range of different modes of talking to suit the context and from moment to moment and in this sense such choices can be said to reflect aspects of identity. Familiar conversational partners, for example, are expected to be very skilled at recognizing shifts of mode (eg use of eyegaze or a sign in the middle of a VOCA utterance), and at interpreting, even the less clear messages through a process of contextually appropriate guessing, and mediation, as exemplified by the following brief note about a conversation I had with Marie:

> *She pointed to 'DVD' in her communication book. I asked her if she had a DVD*
> *player at home. She nodded yes and then looked up to the ceiling. I did a series*
> *of guesses. It's upstairs? It's in your house? , it's in your bedroom? Yes she*
> *nodded (fieldnotes).*

Sometimes and especially initially however, the teenagers' chosen communication mode was completely non-verbal and unfathomable to me, as evidenced here:

> *Toby (15) and Terry (15) in Design and Technology class*
> *(special school, all the other children in the class can talk)*
>
> *Everyone in a good fun and a mellow mood today, doing carpentry. I worked*
> *with Toby mainly, though the two of them were sitting near each and there was*

a lot of non-verbal banter going on between them, which I got the impression, was partly at my expense. Neither of them had their VOCAs, so no verbal means of communicating. Lots of vocalisation and gestures and madness going on, with winking, giggling, making noises and body movements. They were having quite a conversation there, which was private and obviously very funny. They were probably being very rude, but how would we know? It was quite weird to be so excluded (fieldnotes).

The overall effect of such communication processes is a very different type of 'voice', something a newcomer needs to learn. During the fieldwork period, I became more adept at understanding these new languages, which were of course also different for each young person. As I came to know my participants, I became increasingly familiar with their individual styles of expression and began to see how much these represented their unique selves. As Smith (2005) describes, adolescent AAC users develop a different and highly effective set of metalinguistic skills to adapt to lack of vocabulary and to time pressure, but still to get their message across, often in highly creative ways.

Table 5. provides a summary of the modes used by the participants and their preferences for use, which were revealed during our conversations and through my observations of their interactions with a wide range of familiar and unfamiliar people.

Table 5. Summary of key participants' communication

Name (age)	Communication modes / Pattern of use
Bryony (10)	Some speech (single words & short phrases), gestures + signs, VOCA with direct access, moderate literacy. Prefers to talk, sign and mime. Feels that the VOCA attracts too much attention especially in public. Has to be persuaded to use it when speech is not understood. Tends to use single words or phrases only on VOCA.
Jemma (12)	Some speech (phrases), gestures + Makaton signs, VOCA with direct access, good literacy. Prefers to talk, but is also a confident VOCA user and mixes between the two often. Spells her own words and makes sentences. Keen computer user
Josie (15)	No speech. head spelling, Etran frame, gestures, mob phone texting ,e-mail, VOCA with direct access, good literacy. Uses her own headspelling system with family and close friends. Fast Etran frame user, supplemented by lots of facial expression and gesture. Depends heavily on others to know her systems and mediate. Very rarely uses VOCA – says it is too slow. Good computer skills.

Kate (13)	Some speech (phrases & sentences), gestures + Makaton signs, mob phone texting. e-mail, VOCA with direct access, good literacy Prefers to talk, but aware that this is difficult to understand. Confident and fast VOCA user, mixing between the two often. Spells own words and makes sentences. Uses pre-programming in advance to prepare things to say. Good computer skills including e-mail
Marie (12)	Some speech (words) ,gestures + Makaton signs, communication book, VOCA with direct access, poor literacy Likes to talk but very poorly understood. Uses comm book and signs, gestures & mimes expertly with people she knows well. Likes VOCA but not a flexible user. Uses set phrases and words but not sentences, cannot spell new words. Would like to use mobile phone and e-mail but poor literacy makes this difficult.
Nathalie (15)	No speech. gestures + BSL signs, mob phone texting, VOCA with direct access, moderate literacy Because of her deafness, needs a sign language interpreter to understand others well. This slows down and restricts her communication. Her own signs are difficult to read. Uses finger spelling of initial letters of words. Uses VOCA slowly, mostly single words and some phrases. Starting to use phone and computer more. Heavily dependent on mediation.
Ted (12)	No speech, eye pointing, communication book, makes sounds VOCA with headswitches, moderate literacy Fast and efficient comm book user via eyepointing with people he knows well. Would like to chat more. Likes his VOCA, but frustrated by the slowness of it and by it crashing. Makes long sentences and uses set phrases and pre-programmed jokes. Not good at spelling new words himself yet.
Terry (14)	No speech, eye pointing, communication board and book, e-mail, VOCA with joystick +knee access, moderate literacy Uses eyepointing, gesture and board with familiar people, and VOCA with others. A confident though slow VOCA user, mostly single words, short phrases. Relies heavily on conversational partner to mediate. Likes using computer to send e-mails and search on the net.
Toby (14)	No speech, eye pointing, communication book, makes sounds VOCA with headswitches, moderate literacy Uses eyepointing, gesture and comm book with familiar people and VOCA with others. A confident but slow VOCA user, single words and phrases. Relies heavily on conversational partner to mediate. Would like to use computer and phone more.

Here is an excerpt from a conversation[28], where Josie(15) used various different modes of communication to help me understand[29].   This occurred quite early in my

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[28] In this chapter I have indicated the timelines and more detail about the communication mode for quoted conversations, to underline their slow, laborious and multimodal nature.   Each **.** is approximately 1 second. The equivalent conversations between natural speakers would probably have taken a minute or two at most.

[29] The task was to decide what to put in an imaginary treasure box. This is halfway through the conversation. Josie communicates mainly by spelling out letters with low-tech eyegaze E tran system. Capital letters are those that Josie indicates and I call out.   She can move her eyes to point out letters very quickly. After each phrase I write down or draw what she has said on a mindmap for this topic. Josie is a thoughtful and academically able girl who is doing GCSEs this year. She drives a power wheelchair, is sporty, competitive, very sociable and fiercely independent, despite having very little useful hand movement and no speech.

fieldwork period so I was still learning to understand her communication system and subtle non-verbal messages.

MW   so mum dad, doll, CDs chocolate, what else ?... J no... S... O G no... M E,... SOM
        some O N someone... T O... someone to... T A L , talk to .. A T at S C H at school.
        Someone to talk to at school?
1.02 mins

MW   okay I'll just put a little face here for that okay...someone to talk to at school,...
        that's quite interesting , is that something that you think is missing sometimes
        ?
Josie   (nods yes)
MW   yes so like ...? what... because...? Because of time?.... Because   people...don't
        understand your system ?
Josie   (nods no)
MW   just thinking about that ...... so you're saying that you like to have someone to
        talk to at school
Josie   (nods yes,...... looks at chart)
MW   okay tell me...... G.. O.. go... F I N D... go find... T H E the go find the M... go find
        them... so you go and find somebody, so usually you manage to find someone?
        to sit and have a chat with you? and that's okay is it ?... you do manage to find
        somebody .....I'm not sure if you're saying that's a problem or not ...
2.26 mins

Josie   (nods no)
MW   you're not saying it's a problem..... you just have to find them? okay... so if you
        needed cheering up at school , you'd find somebody. Okay... A L I Ali... O no L...
        I Z... Liz, Ali Liz,... M I C A no H, Michele, Ali Liz Michelle... they're all people
        who are good to talk to ok?... so I'll put those in brackets here, Ali Liz Michelle,
        this treasure box might be getting a bit crowded! Josie   (laughs)
MW   okay so you're saying its important to have someone to talk to..? and you can
        usually find somebody?... Yeah?... okay brilliant, so anything else to go in the box
        ?
Josie   (indicates yes,...thinks...... looks at chart)
3.41 mins

MW   yep... H E L E N... Helen? she needs to go in the box, (xxxxx) lets put her in.. K A...
        K atie ? yes okay … ooh its gonna get crowded … has Katie got long or short
        hair? Long?..
Josie   (nods yes)
MW   long hair okay...?
Josie   (giggling and coughing … looking over to cupboard where there is a table with a
        computer and her school bag)
4.40 mins

MW   picture over there is there?...no...what? e-mail?....Internet?... something on there,
        msning ?... texting, phoning ? no... do you want something from your bag?
Josie   (nods no)

MW *no*

MW *hang on a minute while I draw Katie…(xxxxx) there she is … there… do you want me to get something from over there?*

Josie *(nods no but keeps looking that way)*

MW *so Katie, Helen, Mum and Dad, people at school to talk to, other things to   go in the treasure box ?*

Josie   *(nods and looks at spelling chart*

MW *C O T… no… M… E no P COMP U computer, you want to put the computer in, is that what you meant? sorry, okay lets put the computer in then!*

6.00 mins

Clearly, although Josie has no audible voice, she is able to tell me important things about herself. Sometimes she chooses to spell out whole words, but she also expects me to guess and finish words or phrases as much as possible to save her the effort. She knows that I know the people she is talking about and relies on me to use this contextual knowledge to make her task easier. She does not elaborate unless I have misunderstood. However she indicates very clearly with head nods and shakes whether I have guessed right or not. She is also happy for me to elaborate her short phrases into full sentences, but again, tells me if I have misinterpreted what she meant. At the 4.40 minute mark she switches mode (method of expression) and tries to tell me by looking over at the computer that she wants to put this in the treasure box too. I pick up the eye gaze but even after several near guesses do not get her exact message. She then reverts to spelling it out for me.

Having a conversation with a VOCA user demands a number of adaptations from the other person. Most obvious perhaps is having to wait patiently while the person constructs their message. This can be challenging initially as we are not used to long pauses and silences in conversation, and many people find themselves unsure about what to do during this wait. It can be unclear where to look, and whether it is rude to talk during this time. Some AAC users make noises and have extraneous physical movements while using their switches. Additionally some VOCAs, particularly if the user is using an indirect scanning system, make a series of bleeps and clicks while the person is selecting items. Some VOCAs also 'say' each individual letter or word, before the person has constructed the whole utterance. This can be disconcerting at first, as the listener can be confused about whether or not to respond to these interim sounds or words. Ted, for example uses a headswitch controlled scanning system, which announces the words he is passing by on the screen before choosing one. The listener

then has to learn to ignore these (they use a quieter voice than chosen words), focus on the person who is 'talking' and wait for his final utterance e.g. below is an example of us discussing when we will meet the following week. The scanned words are in brackets (   ), and his final phrase is unbracketed at the end of each of his utterances.

MW   *so what we'll do is we'll meet up again next week, is that alright?*

Ted: *(CLOSE SUNDAY SUNDAY WEDNESDAY WEDNESDAY THURSDAY) THURSDAY*
MW   *Ermm…?*
Ted   *(CLOSE CLOSE)*
MW   *Let me see which day I'm coming…mm?*
Ted   *(YESTERDAY MORNING…MORNING…..AFTERNOON) AFTERNOON*
MW   *Thursday afternoon is a good time is it?*
Ted   *(I…..TOO DON'T PLEASE WITH WITH ABOUT ABOUT BUT) BUT (I TOO DON'T DON'T DON'T NOT) NOT.. (GROUPS.. GROUPS TIME CLOSE SUNDAY JANUARY TODAY IS BEFORE BEFORE BEFORE) AFTER… (SPELLING SPACE A E T N H N LETTER SPACE SPACE SHIFT… BACKSPACE CLEAR BACK NUMBERS ONE HUN POINT QUESTION MARK EXCLAMATION MARK EXCLAMATION FOUR POINT QUESTION MARK EXCLAMA COMMA POUNDS COLON M D LETTER) THURSDAY AFTERNOON BUT NOT AFTER FOUR*
MW   *Are you talking about activity time?*
Ted   *(POINT POINT SPACE CLEAR DISPLAY DELETE AND BACK I .. TOO DON'T….. PLEASE WITH WITH WITH AND (AND) I TOO.. DON'T DON'T DON'T NOT)… NOT… GROUPS GROUPS TIME CLOSE.. CLOSE YESTERDAY MORNING MORNING) NOT MORNING.*
MW   *Not Thursday morning, cause you have physio? yeah*
Ted   *(TOO)*
MW   *mm next week I'm coming on Wednesday….*
Ted   *TOO*
MW   *No sorry, sorry, Tuesday, sorry coming on Tuesday.*
Ted   *(TOO…..IS ARE M ACTIONS CLOSE CLOSE CLOSE.. SPELLING CLEAR DISPLAY… GROUPS GROUPS TIME CLOSE SUNDAY JANUARY TODAY IS BEFORE BEFORE BEFORE AFTER) AFTER…. SPELLING SPACE A E T N H N N E.. SPACE BUT E E E R D SPACE SPACE SHIFT BACKSPACE …. SPACE BUT E.. E.. A R SPACE BROUGHT E E A SPACE BRANCH E T N.. H)….*
MW   *Can I guess Ted?... Is it after break?*
Ted   *H*
MW   *Yeah?*
Ted   *(C P K B R E A K).. BREAK*
MW   *yeah that's right, after break on Tuesday.*
Ted: *Nods yes*
4:30 mins

This transcription gives a sense of the amount of work Ted has to do to produce a short phrase such as 'not morning', and how easy it is for the speaking partner in the conversation to dominate the interaction, something which the young people

recognize as inevitable and of which they are generally rather tolerant, but also sometimes resist by continuing their utterance or indicating nonverbally that they are annoyed.

The nature of conversations: Negotiated and co-constructed meanings in AAC conversations

Meredith Allan (RA) has written about the way in which conversations between AAC users and others are different and complex, and demand adaptations from both parties:

> *We, as non verbal speakers, expect some Extra Sensory Perception (ESP) from others when we communicate with them, and seeing humans have not yet mastered ESP, we are doomed to others' interpretations (mainly misinterpretations) of our silence, our wants and our needs. AAC users must be ever mindful of not only of our own limitations but also the limitations of our listeners (Allan 1998.)*

It is useful to hear this worded from an insider perspective. For AAC users, external factors such to whom they are talking and about what, have a much larger impact on the type of 'voice' used than is typical for a natural speaker. Their communication is also always a much more negotiated process (Clarke 2003). However, the ways in which these types of interaction work, employing a different set of pragmatic rules, result in the AAC user generating unique modes of expression and types of 'voices' and their communication partner doing unique things in response.

The reciprocal and negotiated nature of all communication has, of course, been well documented in the psycholinguistic literature (Foster 1990, Garton 1992). There is always an active process of meaning making and interpretation and because of the abstract, symbolic nature of language there is always the possibility of misunderstanding in any conversation. However for natural speakers, there are ample and easy opportunities to clarify such occurrences. For conversations where one (or more) partner is using AAC this negotiation becomes massively slow and magnified, as well as being more crucial. The AAC user says much less and so there is less 'data' to use to work out meaning. There is little of the redundant information or

repetition which normally gives speakers and listeners extra opportunities to interpret each others meanings. A natural speaker who knows an AAC user well, may be cast in the role of a mediator between the user and others. A special set of skills are therefore needed by both parties in order for satisfactory, truly reciprocal and equal interactions to occur.

During all conversations, in addition to the negotiation about the meaning of specific utterances, there is also a constant process of relationship building. When people are in conversation, they are learning about how to communicate best with each other and are constructing their relationship simultaneously. My experience as an ethnographer with AAC users necessitated me learning new ways to have conversations, and I was very aware that my mastery of these skills would impact upon my relationship with the teenagers. As well as trying to narrow the gap between our ages and backgrounds, my task and responsibility was to learn a new language, both verbal and nonverbal, and a different 'way of being' like any other anthropologist entering a new culture.

Most natural speakers can start to talk without much thought about how what they say will come out, as they can easily edit, reformulate or expand it later. Additionally, they do not need to consider the effort involved, so most are not parsimonious in expressing their thoughts. However for the AAC user, every utterance takes physical effort and time, and it is clear that they consider carefully what to say and how. AAC users often become very adept at using a range of shortcuts in expressing themselves and expect their conversational partners to participate in the making of their meanings. They have to manage this in particular ways and make decisions about how much to expect the other person to do.

There are often long pauses before AAC users 'talk', which seem to be taken up with planning the most efficient way to say something. This then is a fine judgment and a risky one. If they truncate the utterance too much, so that it is just an eyepoint, gesture, single word or phrase, the listener may not understand, a misunderstanding might occur and then a further effort to clarify would be needed. If they opt for a longer phrase or sentence (perhaps using their VOCA), this will take greater effort,

and also risks the listener getting bored, filling in the answer for them or even walking away. Thus the AAC user has initially to assess the ability of the listener to cooperate and respond in helpful ways and about which mode will work best on each occasion.

This is illustrated in the excerpts below. As conversations proceed, both parties have to work hard in different ways. There is a constant and very visible process of co-construction of meaning in conversations, which often involves the natural speaker recapping what the AAC user has said and sometimes expanding this into a sentence, constantly checking back with them about meanings, and providing easy ways for them to elaborate, such as using yes/no questions or giving choices, for example by saying:

> *Do you mean this? ...X*
> *Was there anything else you wanted to say about that?*
> *Have I got that right?*
> *Tell me again, do you mean that X... or Y... or something else?*

The listener has to judge how much to interpret and elaborate, without over-interpreting and therefore irritating the AAC user by 'putting words into their mouth' or getting it wrong. Sometimes complete clarity is not achieved, and there is always a danger that either party might give up, as can be seen here with Marie(12):

> *Marie greeted me with a load of loud giggling and wanted to tell me about being 'in love with a boy' – not someone at school. I think at her respite care? Tape recorder not working but she did an elaborate multimodal sequence with speech, VOCA, gestures and pointing to symbols on her tray and book to let me know that it was something about this boy, who's name we didn't get to – then something about EASTENDERS, though we didn't get to the bottom of it. Lots of giggling. An example of unsuccessful communication, where I didn't know enough background or context to fill in the gaps and she couldn't give me enough clues and couldn't spell it. We agreed to leave it and she drove off giggling (fieldnotes).*

In contrast below Toby(14) has not got his VOCA, so is using his communication book to tell me about things he hates. So although he is nodding and eyepointing and using lots of facial expressions, only my voice interpreting this can be heard on the recording.

MW this page foods? yes , this square, this square , this square, this square, this square… sauce,? chips? no.. next page… this page… this one … this one?...okay… is it something you don't like?... I know you like chocolate… is it something you don't like? strawberry jam, biscuits, cake…   something else on this page?... This one , this one, you want to go back to this one? …Strawberry, chocolate ? you don't like chocolate?....uh?!... You don't like some kind of chocolate?! … you don't like it when you can't have chocolate? No?....you only like some kinds of chocolate ?... get cross when you can't have it ?....no… not quite it?...mmm?
2min pause
Okay?...we'll get there ..Go back to the other food page? …. ….this page, this page , this page, yes this one, down here,?...chips , next page, turn back, (cough) descriptions page … (turning pages)…(unclear)… people page? … this one, dad, mum… Mum? Back to menu … places page? . okay.. yes this one… ? out? Um… mum… out? Are we still talking about chocolate ?... yes? … when mum goes out?... no?... um …I'm, not getting it Toby?...something about mum and you and chocolate?... yes?... when mum doesn't give you any chocolate? Yes ! … oh when mum runs out of chocolate? Yes !! oh dear ! Goodness me Toby!
14 mins

On this particular occasion, Toby knew that we had plenty of time for the conversation, and also presumably judged both that the information was important and that I would eventually get the message. Here is another example where Marie(12) uses various modes (VOCA, speech, signs, mime) to describe her birthday.

> *Marie   EVERYBODY*
> *MW   Everybody was there? Great and what happened at the   party?*
> *Marie   ....THOUSAND*
> *MW   Thousand ? is that your fanclub? Lots of people!*
> *Marie   Big*
> *MW   Loads of people?*
> *Marie   Yeah*
> *MW   and …Did you have food?*
> *Marie   Yeah*
> *MW   Did someone make some party food? Like…. a cake?*
> *Marie   No*
> *MW   Snacks?*
> *Marie   No*
> *MW   And did you have music?*
> *Marie   yeah (mimes)… DANCE*
> *MW   Oh wow you were being a wild thing? You were doing dancing!*
> *Marie   L???*
> *MW   L ? Love music? Love? no , you're not saying love . you're   saying something else?*
> *Marie   L????*
> *MW   A band?... Singing?*
> *Marie   No (L????)*

> *MW   Lights? No?... does it begin with the L?*
> *Marie   yeah (gestures – hand up to ear)*
> *MW   L...love?, no listening? no*
> *Marie   (gestures ear)*
> *MW   mm? ....Music? dancing, your ears?   Listening? Phone? IPod?*
> *   Speakers?   something in your ear? Headphones?   no You're*
> *   doing a sign for your ear?*
> *Marie   L??? (sign for big)*
> *MW   Large? It was big? Is that what you're saying? Was it in your*
> *   house?*
> *Marie   (repeats gesture)*
> *MW   (copies sign) what's this? is that a sign? Are you doing a*
> *   makaton sign?... Loud!.. ah it was loud music! ... (laughs) okay it*
> *   was loud music, was it at your house or somewhere else?*
> *Marie   Home*
> **6 mins**

Making relationships through talking

During the fieldwork, I often witnessed instances with all the participants when they gave up on a conversation rather than persevering, having made a negative assessment of the utility of continuing. Often they would drive off in their wheelchair, which seemed to be clear way of the terminating the interaction without saying anything. This looked very clearly like the wheelchair users' equivalent of walking off, ignoring the person or turning away which one might see a natural speaker doing in an awkward or uncomfortable situation. This constant process of co-construction and negotiation demands trust, respect and good judgment from both parties. On occasions either may give up, and the consequences of this for the relationship between the two and on either's self esteem may be serious. Several of the participants told me that they hated it if people did not listen or wait for them to talk. Similarly, I felt guilty and incompetent when I failed to understand a conversation. The teenagers generally seemed to apportion 'blame' with the other person, though several said they would like to be able to talk better themselves too, so perhaps sometimes saw the communication breakdown as their fault too.

The importance of being able to say things for yourself varies amongst the participants. Some seem very comfortable and accepting of the mediation process and are experts at prompting familiar people to fill in the gaps for them. Ted, Josie, Bryony, Nathalie, Terry and Jim all did this extensively. For example when I visited them at home, all prompted their parents, with a pertinent single word or gesture, to

tell me stories about their lives that were relevant to our current topic. Others (Kate, Jemma, Toby, Marie) were keener to talk themselves, even if this took a long time, and often asked other people to leave us alone, so that they could do this. However for all, this choice of 'voice' (either their own or a mediated one) varied with context. Some of the teenagers (e.g.. Josie and Kate) and Katie (RA) were particularly skilled in making pragmatic choices about when it was good to talk for themselves and when to marshal help from others to talk for them. Bryony regularly quizzed me about what I was doing, using relatively few words but skillfully getting me to talk:

> She wanted to ask me about my 'B&B' on the VOCA so she fired questions: NICE HOTEL? wanted descriptions of it WHAT LIKE? and whether I SLEPT? well and what my ROOM? was like and did it have STEPS? What I'd had for BREAKFAST? Much more interested in this than in her literacy work which we were supposed to be doing! (fieldnotes).

Similarly I noticed that Josie who is a very sociable and skilled communicator

> Uses the rest of the class to do the interpreting for her ...has nonverbal strategies and cognitive abilities to manage the communication, although she doesn't speak, she is rarely left out of the banter in the classroom (fieldnotes).

Both Katie's and Meredith's (RAs) thoughts about this are interesting. Katie said:

> ITS FRUSTRATING... THE GAP BETWEEN MY SPEED OF THINKING AND SPEED OF SPEAKING – SO MUCH HAS TO REMAIN UNSAID.

and Meredith suggested that AAC users have to tolerate and

> 'embrace silence' and accept that often what they are thinking will remain unsaid and that you have to 'learn to put up with people's interpretation' (Allan 2006).

During further discussion, Katie agreed that it involves a great deal of trust, to allow the other person to summarise what she wants to say in the right way. She often then modifies their contribution with some extra words of her own to give it her own emphasis.   The AAC user has to learn, therefore, to 'manage' other people in conversations. Katie, for example, has a repertoire of pre-programmed phrases, which she uses skillfully for this purpose for example:

> ➢ *THAT'S NOT WHAT I MEANT*
> ➢ *CAN YOU SAY THAT AGAIN?*
> ➢ *THAT'S YUKKY!* (used for a range of occasions when she was shocked or disgusted and sometimes with irony)
> ➢ *CAN YOU READ THAT TO ME?*

The different participants' skill at this seemed to be more linked to their personalities (e.g. being outgoing and confident) and to the modes of communication available to them, rather than necessarily to age. However, the research advisors reflected that they had had to learn these skills, and had become better at them as they had reached adulthood, whereas, as children, they remembered getting frustrated and cross with other people.

Whose vocabulary is this?

Another interesting feature of aided communication is the way in which vocabulary is often very explicitly 'organised' or even censored by others (for example by a parent, teacher or SLT). This is unlike natural speakers who have a huge vocabulary of words stored privately and ready to use 'in their head'. For AAC users to express their internal thoughts, they have to choose from an externally organized set of words stored in a book or machine. Several times, I witnessed discussion between the teenagers and school staff about the vocabulary on their VOCAs, as I noted here after a discussion with Ted(13):

> *He had talked with Sue (SLT) about changing some items in his communication book and VOCA. He wants a symbol for 'it is the best food and I want more' and for different vegetables. On his 'Furry, feathery , slimy friends' page – he wanted to change Koala to Turkey! Though it's not clear why. So Sue went off to programme them into his system. A strange - concept having your vocab in your head represented on a page, and having changes in your ideas documented, negotiated and public. Of course this doesn't apply to people like Josie, Jemma or Kate where spelling gives them freedom to manage their own vocab privately in their heads (fieldnotes).*

Having someone else organizing and programming your vocabulary is potentially like having another person managing or editing your thoughts. This can be seen in the case of two of the older boys Terry(14) and Toby(14), when one day they managed to negotiate with the SLT to have swear words programmed into their systems. Similarly several of the girls gave examples of current teenage words that they liked to use eg:

'innit', 'bling bling' and 'whatever!' in a way which reflected the kind of language their peers use (Gee Allen & Clinton 2001). In both the boys and girls cases here, the adults agreed to add the words they wanted to their systems. Nevertheless the issue of external control of vocabulary and therefore of 'whose voice this is?' is ever present and it was clear that the young people had to negotiate their type of voice, in an explicit way. Other teenagers can just say what they like, whether adults approve or not!

Knowing each other

During the fieldwork, I became increasingly aware of the importance of the role of personal knowledge and contextual information in helping conversations to work well. This underlines how difficult talking to strangers in unfamiliar places is for AAC users, unless, and even if, they are very skilled VOCA users. There are two kinds of information that speed up and smooth the mediation process.

Firstly knowing an increasing amount about each young person's preferred communication modes, understanding their types of shortcuts and unique ways of expressing ideas is crucial. The quality and depth of our conversations improved greatly once I was more 'tuned in', and importantly, their confidence in me also increased. I was better able to recognise their idiosyncratic gestures and facial expressions, or when they were using Makaton signs or asking for their communication book with an eyepoint. It was very clear that by the end of the study, they were giving more nuanced answers to my questions and telling longer stories about their lives. They also became more confident about asking me questions and initiating conversations, as they knew that I would respond to minimal cues such as them pointing at me, which for Bryony, Josie and Terry meant "what about you?' 'tell me what you've been doing', or 'what do you think?'

Secondly, I had more contextual knowledge about their families, friends and schools as I gradually met more people and visited places. Thus, I was able to make more informed guesses to help 'fill in' in conversations and this was clearly helpful. This has been noted by other researchers looking at AAC interaction (Collins & Markova 1999). Over time, I saw that in each young person's life there was a hierarchy of people who

were able to provide this contextual information and mediation at different levels of sophistication.

As Clark (2004) (drawing on Geertz 1973 and Clifford 1997) describes, my acceptance and 'social arrival' in the field was made possible through developing a particular fieldwork practice or 'habitus' (Bourdieu 1977). I experienced that, gradually, my 'way of being' was attuned to theirs and I became more relaxed and unselfconscious in participating in these unusual conversations. I gradually moved from being 'an outsider' who needed the mediation help of others or maximum information from the teenager in order to understand, to the position of 'an insider', who could communicate quickly and smoothly with them and could mediate for others who knew them less well. For example during an outing to café with school:

> *I was sitting near Terry (14) and Polly, an OT assistant. She was asking Terry questions he couldn't answer without his VOCA which he didn't have there. She knew that moving house was on Terry's family's agenda and thought he already had moved. He wanted to say that no, he is going to but doesn't know when. I saw just how much he depends on people knowing the context and filling in for him, because explaining all that with the VOCA would take ages, and without it was almost impossible. He had judged that it wasn't worth the effort for him to try, so prompted me to explain by looking at me and then back at her. I was able to help out, so was cast in the role of mediator, as I knew some stuff she didn't. The person who communicates best or knows the most contextual facts becomes the intermediary, if they're not there, then the next best steps in etc. The AAC user themselves has to be skilled in managing this process so that they don't get sidelined (fieldnotes).*

This was directly analogous to the classic process described in anthropological studies in unknown cultures, where the ethnographer moves from a position of outsider to relative insider over the period of the fieldwork and becomes 'knowing' and embedded in the context, although of course never an actual 'native' (Aull Davies 1998).

However this process of 'familiarization' is controversial in the AAC arena. Professionals, such as Speech and Language Therapists (SLTs) and psychologists, tend to be cynical about the role of familiar conversation partners, who claim to 'know the

person well enough to know what they are saying'[30] because if overstated this could result in a very real and fundamental denial of AAC users' agency. This controversy emphasises the need for conversation partners to be circumspect in their interpretations of the AAC users' messages, and continually to check back with them for accuracy.

Notwithstanding these concerns, I grew to appreciate the skill involved in the nonverbal conversations between AAC users and their family members in particular, and to understand why formal communication modes such as communication books and VOCAs are used much less with very familiar people. Idiosyncratic nonverbal communication between people who know each other very well can be impressively fast and carry surprising amounts of concrete information. In the example below I am visiting Toby(14) while he is in hospital having minor surgery. He, his mum and I have been chatting. He is lying flopped out in bed so does not have his VOCA (which is attached to his chair parked outside the door) or communication book to hand:

> *A brisk and friendly nurse came and talked directly to him in a good way and knew about his yes and no eye movements, though not brilliant at interpreting these or at not asking open questions which he couldn't answer. Basically Mum was in major mediating mode and she does this amazingly quickly, noticing every little eye point that he does, either to the telly, to the window , to his arm which hurt etc. After quite a lot of chat about the op, he looked at the clock and the telly, and she said, 'so you want us to turn over and see the results?' (i.e. football), and then he nodded and looked at the phone, mum said 'or phone dad and ask him?' He nodded yes. A skilled performance by them both. The nurse looked amazed (fieldnotes).*

It is apparent that often those interacting with AAC users privilege instrumental, factual uses of language (e.g. do you need the loo?) rather than social-emotional functions (e.g. greeting, teasing, gossiping, reminiscing) which more commonly start and cement relationships (Dunbar 1996). This reductive range of conversation topics is mainly a function of time pressure. As Meredith Allan (RA) writes from her own experience:

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[30] The criticism and worry is that a parent, sibling or LSA for example may anticipate too much, and overestimate their own ability to 'know what is in the person's head'. Thus the communication may cease really to be mediated and negotiated, with the conversation partners making too many assumptions about the AAC users' intended meanings.

> *Gossip and secrets are an important part of forming friendships especially with females. It is part of the "joy of involvement" (Tannen 1993), that this involvement includes unimportant detail. AAC users skip unimportant detail, mainly because of the time involved and you know you are taking up the other person's time. It is hard to get beyond this initial "fear" of taking up too much time of the "listener" (Allan 1998).*

Several times, at the start of the project, it appeared that the teenagers did not have anything to say about a particular topic, and I was puzzled since they had initially seemed interested. However, it became clear that they were usually worried about time. Given reassurance that there was definitely more time available, they would chat. Time pressure on 'speaking' is thus a constant problem, especially in school. Terry(14) and Josie(15), both people who liked to talk, but who were also conscientious about being on time for classes, were constantly looking at the clock, seemingly needing to reassure themselves that we had time to talk. This time pressure is exacerbated also by the need for extra time for physical necessities such as getting between classrooms, going to the toilet or dressing. Paterson and Hughes have described time as 'the primary criterion of exclusion and discrimination' (1999:605) for disabled people, and this is amply demonstrated in this study.

Opportunities for 'idle gossip', which are arguably the social glue of societies (Dunbar 1996), are often missing for AAC users. On rare occasions when I saw two AAC users chatting together, of course the pace was slow from both partners and thus tolerated by both. Generally however, I noticed that 'chitchat', especially between peers, seemed to be a rare commodity, and indeed, sometimes efforts to chat were misconstrued or 'overmanaged' by adults when they did occur, as in this example with Ted(12):

> *We chatted again about Emily (care-staff) who he fancies. This is a bit of an ongoing saga with him which staff are trying to discourage. He talks about her a lot. He also talks about Pam (care-staff) who he doesn't like. Sue (SLT) told me that the staff are trying to ignore or discourage all this. Well what would happen with any other kind of kid? They would discuss who they fancy with a friend not with adults and it would not be a problem. He doesn't have much capacity/opportunity to gossip with or about other students so maybe this is a natural substitute? But staff see this as 'a tendency to try to 'play staff off against one another', whereas I see it as 'normal chitchat' but with the 'wrong people' (fieldnotes).*

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George(16) sums up the problem well. He recognizes that his form of communication does not make socialising easy because of the time it takes him to say anything, so his 'gossipy voice' is muted:

> *AT SCHOOL I HAVE FRIENDS AND PEOPLE ARE NICE TO ME, BUT BECAUSE THE SCHOOL DAY IS VERY BUSY I DON'T GET MUCH CHATTING TIME, PEOPLE SAY HELLO BUT NOT MUCH MORE.*

Some types of meanings and messages might be particularly under-represented or omitted in this co-constructed and time-limited process. Very personal or emotive topics might be hard to express through mediated conversations and so arguably some important, sensitive and subtle aspects of their inner worlds might remain hidden. Indeed my conversations with some adults (e.g. school staff) who knew the teenagers well suggested that there was a lack of recognition that AAC users have reduced opportunities for 'deep' conversations. This was confirmed in discussion with two of the research advisors.

Table 6. below summarises what does or may happen in AAC conversations. Sometimes the issues are rather similar and reciprocal for both parties, in others they are unique to one or other partner. There may be occasions when either party is less skilled than this suggests, or indeed in abusive or oppressive relationships there may be deliberate or unwitting misunderstanding of the AAC user, and thus a lack of any really reciprocal communication. I witnessed numerous examples of this process not working smoothly and successfully for both parties.

Table 6. Tasks, Skills, Challenges and Risks for AAC users and conversation partners in conversations

AAC users' tasks/skills	Conversation partner's tasks/skills
• Judge conversation partners' skill at constructing meanings from 'AAC speak' • Decide whether effort of talking is worth it this time. What is worth saying? • Choose which mode to use • Make 'shortcuts' strategically – how much to shorten the message (effort vs. understanding) • Hold the partners' attention while preparing message (eg by looking up occasionally) • Monitor partners' understanding • Switch modes to get message across as necessary (eg VOCA/gaze/sign/speech) • Decide to persist or give up during conversation • Accept meaning made for them or modify it	• Recognise methods used by each individual • Observe and listen carefully • Wait attentively for letter/word/phrase • Tolerate silence • Ignore bleeps, clicks, pre-selections and mis-hits on VOCA • Judge when to predict a word or sentence and when to wait for more info • Recap, expand and elaborate on what is said • Ask for clarification/confirmation • Give options for possible meanings (but also the option that its none of the above) • Adapt to different modes as necessary • Check that have understood correctly
Possible challenges and risks for the AAC user	**Possible challenges and risks for the conversational partner**
▪ Having enough time, feeling rushed ▪ Risking using shortcuts which if they don't work, will then involve more effortful elaboration ▪ Meeting and talking to new people ▪ Trusting people to mediate sensitively and accurately ▪ Dealing with unwanted attention ▪ Being misunderstood or patronized ▪ Starting a conversation, getting tired and then not being able to stop it ▪ Getting opportunities to initiate conversations and change topics, as well as to respond ▪ VOCA breaking down ▪ Being overly dependent on a few mediators	▪ Worrying about having enough time and rushing the conversation ▪ Being unsure if you have understood well ▪ Not having enough 'data' to go on to be sure of having understood ▪ Recognising when the AAC user switches modes (e.g. subtle nonverbals). ▪ Knowing and recognising the different systems used (signs, symbols) ▪ Anticipating meanings too early. Misunderstanding, misrepresenting or patronizing the AAC user ▪ Imposing own world view on other person or controlling the topic too much ▪ Asking and responding in ways which make conversation easy for the AAC user ▪ Being able to help when VOCA crashes

Glimpses of an AAC culture

It has been suggested that this very specific type of communication is established enough in its style and format to be recognized as an 'AAC language' or even as a 'culture' (Allan 2006). I glimpsed facets of this subculture when I attended events where there were many AAC users, such as conferences (ISAAC and CM) and family support weekends (1Voice). At these, AAC users and their particular style of communication were accepted and understood by many. For the most part, the natural speakers adapted their style of conversation to accommodate AAC users in a way that often does not happen elsewhere. This was true both in 1-1 conversations and, more impressively, in bigger discussions, where whole groups of people waited patiently and respectfully while AAC users composed their contribution to a debate. It was implicitly understood that extra time must be allocated and AAC users' contributions privileged in order to allow them to have 'a voice'. Thus the communicative rules and behaviours adopted by everyone in those settings suggested a 'subculture' of tolerance, acceptance and adaptation to different types of voices. However some of the adult research advisors and parents suggested that although this is true, some people in this environment, will only tolerate this adapted conversational style for short periods and that AAC users are still often patronized and denied a chance to speak or excluded. Paterson and Hughes argue that this is what happens in a disablist world. They suggest that 'norms of communication and norms of intercorporeal interaction reflect the carnal needs of non-disabled actors' (1999:604). Thus the verbal world and 'vocal bodies' are exclusionary because they powerfully structure society. Although none of my participants or advisors put their views as strongly or politically as this, many of them expressed frustration and anger about being excluded from conversations even in supposedly inclusive settings.

For the teenagers themselves, there was an atmosphere of 'solidarity' when they were at such group events, and this perhaps explains why all those who attended them (Kate, George, Nathalie, Bryony, Prakash, Jim) expressed great enthusiasm and a sense of belonging at them. Kate(13) expressed this particularly strongly by referring to places where she feels accepted as 'my world'. She underlined that this was not an argument for segregation, but recognition that there are some situations where she is more given time and opportunities to talk than others. Thus places where her type of

voice is recognized as valid are more comfortable and affirming for her. Many of the parents commented that, for their child going to these events always increased their VOCA use and efforts at independent conversations, and boosted their confidence. This underlines that the ways in which the AAC users' 'unusual voices' are received and responded to by others is likely to impact on the person's identity and these processes are, therefore, a key focus of this study.

Making conversations work

The participants all have views about what works best in conversations. A very common and consistent complaint is that people do not allow enough time for them to talk, and that often people misinterpret them or fail to check that they have understood correctly (Paterson & Hughes 1999). Many AAC users describe very clearly what they want other people to do in order for them to be able to contribute to conversations. All said that the most important was that people listen carefully to them, and give them enough time, as well as 'not being scared of me' and 'talk me like a normal teenager'.

Marie described how she judges, when meeting a new person, whether they are worth bothering to make an effort with or not. If they are a 'goody', that is a person who is likely to persevere and be flexible in understanding her, she will match this by persisting with a range of different modes and strategies because she knows the person will understand eventually. Conversely, 'baddies' are not worth the effort, as they probably will not get the message however much she tries different modes. In contrast, Josie is more positive and says:

> *I'LL ALWAYS GET MY MESSAGE ACROSS SOMEHOW.*

but also that she hates it when:

> *PEOPLE THINK THEY HAVE UNDERSTOOD, GET IT WRONG AND THEN DO IT.*

She means that they go ahead and act on misinterpreted information without checking with her.

Some other participants seemed more resigned to being misconstrued and there were various examples during the fieldwork, when in retrospect I discovered something which revealed that I had misunderstood a previous conversation, although the young person had kept quiet about this. While some clinical research has described this kind of behaviour as 'passive' (Pennington & McConnachie1999), it can be reconceptualised as agentic and pragmatic. The teenagers learn to make judgments about what is worth the effort and really important to say.

Participants views vary widely about whether the VOCA, as the most visible and 'least natural' mode, is useful and whether it is their mode of choice. In fact three people are overtly ambivalent about it, for example:

> Bryony (10)   *I love my voca and I hate my voca.*

Their views are partly determined by their level of impairment and thus their ability to use speech or signing, but nonetheless their advice to other people about how to make conversation easy is markedly similar across the group, although expressed with different levels of sophistication. The following is from a focus group discussion about the pros and cons of using AAC (16-20 year olds, mixed gender, who use AAC):

MW	*Ok. I'm quite interested in this idea that it's quite a lot of effort ?*
M	*Yeah!*
D	*(??)*
MW	*It is? Then maybe sometimes you might decide just to keep quiet?*
M	*Yeah*
MW	*Yes?*
M	*Yeah!*
MW	*So when would you decide just to keep quiet, that it's not worth the bother?*
S	*(? ?!) (dismissive gesture)*
MW	*It's all coming out now!.... I mean it could be particular situations,…. it could be particular people?*
M	*Yeah!*
MW	*Yes?... some particular people you don't bother with? Ok… It could be when you're in a particular mood?*
ALL	*Yeah!*
MW	*Yeah?... Ok, so sometimes you just think "Oh, I can't be bothered today".*

M	*Yeah!*
MW	*What sort of people might you choose not to bother with? ..... What sort of people might you just think "Oh, I just can't be fagged"?*
D	*ARSEHOLES*
MW	*D says "arseholes"; do we have any other descriptions of people?*
D	*PATRONISING*
MW	*People who are patronising?*
ALL	*Yeah.*
MW	*Ok; if they were patronising you'd just keep quiet and not bother?*
ALL	*Yeah!*
MW	*Okay?*
D	*PATRONISING GITS*
MW	*Gits? Oh, right; patronising gits. Ok...yep, fine. And you'd all agree with that?*
ALL	*Yeah! (nods and yes gestures from all)*
MW	*If somebody's patronising you, going "Oh hello, you're very nice" and patting you on the head, then you'd just not bother?*
M	*No*
MW	*Right, ok. Any other types of people that you would...? S, do you have any ideas?*
S	*IGNORE YOU.*
MW	*People who ignore you? Ok. So, somebody ignores you...then you would probably not bother with them?... Ok. Seems fair enough*
S	*People who (???)*
MW	*Tell me again?*
S	*People who (???)*
MW	*Didn't get it.*
S	*People...(N???)*
MW	*Argue? No. People who...nasty?*
SLT	*N N...O" (reading S's writing)....I think "narky"*
MW	*People staring?*
D	*(??) N*
MW	*Nosey? Nosey. Well done S!*
MW	*So people being nosy, you wouldn't bother with them if they were asking you things that were too personal?*
S	*Yeah*

It seems that communication that is supported and mediated by another person can be either oppressive or empowering, depending on how it is done. George (16) sums this up well:

> *There are certain people who make me feel more part of the community because of the way they are as people, like Julie asking how my GCSE exam went she'll ask: 'was it easy?' Then I can answer Yes or No? This makes communicating easier. Of course it's not always that simple....and I think some types of people are better at reframing speech than others; it really is a different way of communicating (written piece for DVD).*

Dilemmas in representation and authorship of voices

There are always dilemmas in seeking to represent accurately the meanings that have been expressed in a spoken form as written ethnography (Clifford & Marcus 1986, Watson 1999).   This is inevitably a subjective process of interpretation and translation. This is more of challenge, however, when communication is multimodal; much has been said with a very few words and with gestures and signs, and with in a highly negotiated and co-constructed form (Couser 2005, Bayliss 2007). The elliptical way in which ideas have been expressed, and then interpreted and reformulated by a second person, raises questions of authorship and authenticity. The risk is that any representation of these unusual voices may be biased or inaccurate, or at very least partial. Wallman suggests that there are two essential features of representations:

> 'They simplify the reality they represent and any meaning imputed to them is socially constructed' (1997:267).

She contends that there is always a danger that the contrasting and inconsistent nature of people and their multivocality might be under-represented. The way in which voices are written about can either conceal or reveal aspects of people's private lives. In the present study where the participants have voices, which are mostly unheard, it is even more important that the way they are revealed does not reify particular views of the teenagers. It would be easy to present, unwittingly, a uniform and thus homogenising identity for all disabled adolescents. James et al (1997) underline that all representation has elements of: 'interpretation, communication, visualization, translation and advocacy' (1997:2). Following this, I have remained aware of the situated nature of my understanding of the participants and that I may be contributing to their identities in ways which may be taken out of context once they have become text. This of course is true in production of any written ethnography but it is brought intensely into focus with these participants. Thus, as Atkinson and Hammersley (1995) emphasise, although with some caveats, there is the need for respondent validation as part of the process of fieldwork.

Due to the challenges in AAC 'talk' outlined above, I was concerned about the possible questions which might arise in reporting what the teenagers said:

What is said vs. what is meant
How can I know what was meant?
How can I represent what I have heard?

In order to tackle these uncertainties, I found that returning to previous topics with the teenagers and checking that what I had understood was right, and whether they wanted to add anything was a useful process. Generally they found it interesting, and sometimes amusing, to review my summaries of what they had said, and they usually agreed that they were more or less accurate. Sometimes they added extra information or an additional example to illustrate a point. This ongoing respondent validation was then essential in the process.

I also used the 3 adult research advisors as validators, although they had different degrees of involvement. Katie, in particular read draft chapters of my thesis and gave me useful feedback on my interpretations. I did not change my analysis in the light of her comments, but sometimes added in her perspectives or comments. Reassuringly, her response on first reading some sections of the Selfhood chapters was to say that they accurately reflected reality for her and she thought for other AAC users she knows. Most notably she was upset about one distressing episode in which I described a participant being humiliated and embarrassed. She questioned whether it should be included. My defence was that the incident was part of the reality of life for that individual and that if I did not report 'negative' events, then the analysis would be biased towards one view of their worlds, rather than representing its varied and sometimes contradictory or ambivalent nature. The contributions of the research advisors provided then an additional level of validation of my representations and analyses.

Voice, language and narrative as part of identity

As observed above 'voice' is a very individual aspect of a person, each speaker having their own unique and instantly recognizable features. Furthermore this becomes a 'social voice' through being overlaid with the individual's life experiences, much as Shilling (1994) argues that the unfinished natural body is 'completed' through social

action. Used philosophically or anthropologically the 'voice' is the expression of both internal and external dialogues, a representation of the person. Thus, the ways in which a person talks and moves (i.e. the latter as part of nonverbal communication) is like a 'fingerprint' of selfhood, simultaneously unconscious and conscious. This is usefully reflected in Habermas' (1984) recognition of the role of communication in intersubjectivity and Bourdieu's (1977) inclusion of it as a part of habitus.

Conventional natural speaking 'voices' are audible and physical, as well as social and metaphorical. However, for those who are non-speaking, 'voice' has only the latter two features, so 'having a voice' has a different meaning. Part of the uniqueness of an individual's voice arises out of their unique bodily features. Just as the body represents and reflects the self (Csordas 1994), so too does the voice. For someone using signing and gesture, their 'voice' is physically part of them but is silent, and for users of artificial electronic voices, there is an audible voice but it is not a 'natural' human one, and emanates 'from the machine' not directly from the 'speaker'. Thus, for the unfamiliar listener, there is a period of adapting to these unusual types of voices, and it takes time to see them as part of the person.

However, on several occasions, when I introduced AAC users to new people who were unfamiliar with alternative voices, a comment was made about 'the voice not being real or not really theirs'. As I had come to see their alternative voices as very much part of them, I was shocked by this and had to disagree. As will be illustrated, these alternative voices are indeed an aspect of the person and of how they see themselves. Someone talking in this way can chat, gossip, criticise, question, suggest, imply, and boast in complex and subtle ways, just as a natural speaker does. The only difference is the mode of expression not the content, or intent. The responses of newcomers to AAC users highlighted for me the very real denial of their personhood that a disabled person can experience, as a result of their perceived differences. As Murphy et al (1988) and Shakespeare (1996) have argued physical difference often seems to lead to social liminality. For AAC users the most obvious and potentially excluding differences are their voices. Nevertheless, I came to see these very methods and styles of producing 'voice' as integral parts of their selves, as illustrated by the following

excerpt from my fieldnotes, which are my observations after a conversation with Terry (15) early in the fieldwork period:

> *The effort of using the VOCA is enormous. He stabilises his body with his right hand by holding onto the mounting bar attached to his chair and he uses the joystick jerkily with his left hand. There is a series of bleeps as he constructs his utterance, moving the scanner across the screen with the joystick and then selecting an item he wants with a knee switch. He concentrates intently. If he lets go with the right hand, everything goes wobbly and it takes him a few minutes to gain control again. Sometimes his whole chair rocks and creaks as he struggles to get his limbs to obey him. Once he's got the message ready, he looks up at me, while the words are said. He rarely makes any kind of sound himself, except when very excited. Also he quite often switches off the electronic voice on the VOCA and indicates for me to read the screen, a privacy thing as the voice attracts a lot of attention and it is difficult to change the volume. The way that Terry combines his facial expressions, gestures and use of the VOCA is very much his own and I am slowly getting to understand how he combines them in his own way, especially his use of eyegaze and head nods which can be difficult to spot in between all the other movements (fieldnotes).*

The extent to which the teenagers saw their electronic voice as 'their own voice' varied across the group. Those who had some natural speech (Jemma, Kate, Bryony) were less inclined to see the electronic voice as inherently part of them, and regarded it more as a 'gadget' that sometimes helped out:

> *Jemma   my VOCA works hard for me… I DON'T LIKE THE AMERICAN VOICE.*
>
> *Kate   IT'S LIKE A SPECIAL COMPUTER!....IT GIVES ME A CHANCE TO SAY WHAT I   WANT*

However, those for whom it really is their main way of communicating (Ted, Terry, Toby, Nathalie, George, Prakash), the VOCA is an essential part of themselves, with certain pros and cons

> *Marie   ITS FANTASTIC*
>
> *Katie   ONE ADVANTAGE IS THAT I CAN TALK AND EAT AT THE SAME TIME!*

Some had very few 'low tech' options (such as signing) available for communicating because of the extent of their physical impairments, and without the VOCA were

limited to indicating 'yes' or 'no' with head or eye movements. Thus when the VOCA did not work, it was strangely as if the person had been 'unplugged'. In fact on several occasions, I heard an adult while trying to fix the technical problem say completely without irony

> *Right let's plug you in again*

The teenager sat patiently and waited to be 'given my voice back', as Jemma (12) put it when hers broke down for several days. Disconcertingly, their 'voice' was then a disembodied part of their physical selves, which could be separately dealt with by other people. In this sense, therefore, the 'voice' for AAC users, if it is an 'artificial' one, may not be regarded as physically representative of the person in the way a biological one is. All of the participants expressed anger and frustration about communication and particularly about times when their VOCAs did not work, suggesting that in these moments of losing their 'voice' they felt cut off from the world and denied personhood as Toby demonstrates in the following incident:

> *Today at the start of our chat session his VOCA crashed and I didn't realise for ages that that was the problem. I thought he just wasn't saying anything. He was frantically looking at the screen, to tell me it needed rebooting; he didn't have another way to tell me (fieldnotes).*

Narrating our lives

As outlined in the literature review, many authors have identified the link between identity or subjectivity and language. We are all 'performing' our identities by using various styles and voices at different times, and identity is therefore both interactive and mediated (Goffman 1959). Geertz (1993), Bruner (1991), Giddens (1991), Cohen (1994) and Jenkins (2004) have all argued for the importance of language in identity formation and more particularly that people are actively involved in realizing their selfhood partly through narrating it:

> 'A person's identity is not to be found in behaviour, nor - important though this is - in the reactions of others, but in the capacity to keep a particular narrative going' (Giddens 1991:54).

Ochs and Capps (1996, 2001), and Roberts (2002) underline, for example, the authorial nature of selfhood, explaining elegantly that in telling their life stories people are also describing themselves; and this is very much in evidence in the data here. Narrative approaches to phenomenological research have become increasingly popular, in recognition that this is a way of accessing, very directly, participants' own views of the world (Schutz 1967, Smith & Sparkes 2008).

> 'Humans are storytelling organisms who, individually and socially, lead storied lives' (Connelly & Clandinin 1990:2).

Telling stories about one's life is a way both of expressing selfhood and of clarifying the meaning of what has happened, and so in this sense, 'giving voice' to one's identity. Thus as Schieffelin and Ochs (1995) argue language is central in providing us with a logical scaffold for culture and so, in verbalising our lives, we impose order on them.

Social communication, and particularly talk which is declarative rather than imperative, is also fundamental to the formation of social relationships (Nelson 2000, Connelly & Clandinin 1990). Perhaps this is because talking is seen as proof of thinking. Although at first glance physical production of a voice may not seem significant in relation to personhood, it is important to be seen as someone who can produce words somehow, and therefore meanings. Voice, as a vehicle for language, can both generate and reflect power relations (Ng & Bradoc 1993) and thus someone without a voice or possessing a different kind of voice may be disadvantaged:

> "Language is not only an instrument of communication or even of knowledge, but also an instrument of power" (Bourdieu 1977: 648).

Voice is then both 'natural' and 'cultural'. When someone does not have a 'physical voice' of their own which would demonstrate that they have language internally, this .potentially leads to a lack of power. A person who has language but not speech therefore has to find other routes to express identity and find 'a voice'. The development of high tech VOCAs which enable people without speech to demonstrate that they have language, may be revolutionary in expanding the range of narratives and themes that they can express and, more importantly, are recognised as having.

Being able to tell one's own story is therefore an important part of selfhood and potentially empowering.

Adolescents have their own characteristic voice which is different from both older and younger people. They typically spend a great deal of time talking. They refine their particular voices, through negotiating, gossiping and telling stories (James 1986, Dunbar 1996, Rafaelli & Duckett 1989, Fine 2004). Bohanek et al (2008) argue that this is an important part of what teenagers do:

> 'Early adolescence is the time when children begin to form a more integrated life story in the service of constructing a sense of identity... narratives are the way in which we make sense of our experiences' (Bohanek et al 2008:154).

The teenagers in this study expressed a desire to do this like their peers.

Nathalie   *TALK TO ME LIKE A TEENAGE GIRL*

Jemma   *I like chatting about boys in the corridor!*

Marie   *talk better, talk to my friends (book & signs)*

The importance of having a voice is expressed clearly by Nathalie(15) in this poem which she wrote to underline the importance of her VOCA to her:

WITH AND WITHOUT

Without a voice I feel lonely
With a voice I can make friends

Without a voice I am vulnerable
With a voice I am safe

Without a voice I have no life now or in the future
With a voice I can enjoy and achieve

Without a voice I am excluded
With a voice I can be included in my community

Without a voice people think I am stupid
With a voice I can go to school and learn

Without a voice I would be so bored and frustrated
With a voice I feel good about who I am

Conclusion

This chapter provides an in-depth description of the types of communication used by the participants and an understanding of how this complex and mediated style of conversation works for both AAC users and their conversation partners. It also explores how conversation contributes to evolving identities.

It is clear that many different modes of communication (both low and high tech), are used by non-speaking young people, and that it is a challenge for the researcher to learn this new language, recognise different types of voices and represent them as authentically as possible. It is also recognised that representation can never be absolute. The ethnographer is always complicit in the production of the participants' voices as represented in the written account. This could either cement existing discourses about non-speaking young people and or it could disrupt them, and therefore challenge the reader to consider the AAC users' internal or otherwise unheard voices. However the ways and the extent to which this research really represents authentic voices is a matter for debate and concern. The ongoing use of

respondent validation methods with the teenager participants and the research advisors was designed to minimize misrepresentation of these complex voices.

The excerpts from conversations were chosen to illustrate the slow and negotiated nature of AAC talk, and to show that although the content of many conversations is very similar to that with other teenagers, the process is often very different. Thus, as Thomas (1999) suggests, a social-relational model of disability emphases that the important differences between disabled and non-disabled people are in their 'ways of doing' not their 'ways of being'. Connors and Stalker (2007) make a similar point in relation to children. This is pertinent here, as in considering aspects of identity, it may be that being seen as a person who talks less and differently, contributes significantly to both personhood and selfhood. A central question which this study asks is what happens when someone has an 'unconventional' voice? Are people still afforded the same kind of personhood by others if they seem not to be able to talk, and how do they see themselves?

The chapter has emphasised the central role normally attributed to language, as a reflection of thought and of the person, and the way that in telling stories about their lives people bring their self-identities into being. Underlying this is the notion that agency is usually demonstrated through talk, so differences in ways of talking may bring about fundamental differences in perceptions about the person. As Katie (RA) put it:

> *It is tempting to think that less talk means fewer ideas!*

Chapter Four. Selfhood: Being a family person and being a teenager

'Self-identity is not a distinct trait, or even collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of their biography' (Giddens 1991 :53).

Introduction

This chapter and the next use ethnographic data to consider how young AAC users see themselves and how they negotiate their identities, thus addressing my first research question[31]. These two chapters on selfhood focus on the participants' own views of themselves and their lives, rather than the roles and identities ascribed to them by others (personhood), which are discussed in Chapter Six[32].

The ways that the teenagers saw themselves were revealed to me, both directly and indirectly. Presented first are some initial impressions of the participants, and their responses to direct questions about themselves. However richer and less self-conscious data largely came out of many unstructured conversations and incidental moments during participant observation. These ideas about the self were then implied rather than explicit responses to any overt focus on identity per se. This chapter considers two broad aspects of the self that emerged as significant across a range of activities and settings:

- o Family self
- o Being a teenager

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[31] How do young people with severe physical and communication impairments who use AAC see themselves (selfhood)?

[32] In many ways it is artificial to divide these two intertwined aspects of identity, but for the sake of clarity when analyzing and presenting the data it is easier to separate out material from the young people themselves and that from others around them. This is particularly appropriate as my primary focus overall is the young people's own self perceptions.

These are aspects of the participants which are strikingly like those of other young people and so paint a picture of them as 'normal teenagers' as they say. I do not suggest that these 'different selves' are separate in any real sense, but are discussed separately here for clarity. Thus I have grouped material which is broadly similar together, but actually these are part of a complex whole, not compartmentalized or labeled explicitly by the teenagers, and there are many links and overlaps between their different selves.

Selfhood and 'the self' as concepts

> 'Selfhood is constitutive of who and where we are, which also implies some sense of what we are doing' (Jenkins 2004:46).

Here Jenkins draws on Mead and Goffman to describe individual identity as embodied in selfhood, and socially constructed in ongoing interaction, during which 'individuals define and redefine themselves and others throughout their lives' (2004:5). Identity is, therefore, never unilateral but always plural and he argues against the self being seen 'in bits'. Thus in contrast to psychological theories such as those of both Sigmund Freud and Eric Berne whose models present rather separate aspects of the person, Jenkins suggests that such compartmentalising is actually not too *complex*, as some critics have suggested, but too *simple*. For Jenkins selfhood is:

> 'A unitary thing for most of the time for most people and simultaneously cognitive and emotional, a rich amalgam of knowledge and feelings, both individual and collective and thoroughly interconnected and interdependent' (2004:45).

He calls this process, whereby all identities individual and collective are constituted, 'the internal external dialectic of identification' (2004:18). Thus although 'the self' is seen as private and 'the person' as public, nonetheless selfhood and personhood are completely implicated in each other and indivisible. He also emphasizes the processual nature of identity, as an ongoing project throughout the lifespan. As children grew older they gradually become more aware of the labels others give them and realise the ways in which they are (or are seen to be) the same and different from others. They may choose to accept the judgments of others into, or reject them from, their own construction of who they are. Certainly, in the present

study the participants' ideas about who they will be in the future emerge as being as important as their past and present selves. This incorporates their physical, social and emotional experiences and as well as their interpretation of other people's responses to them. Self identity is also necessarily embodied and therefore inextricably linked to gender, ethnicity and importantly here, as Thomas (2007) argues, also to impairment if this is present.

The process of developing selfhood then according to Jenkins is one of 'becoming', something which he calls 'pragmatic individualism' and which involves a complex dynamic interaction between three 'orders' in the world: individual, interactional and institutional. Similarly Bourdieu's habitus is another conceptualisation of the 'presentation of self' that is simultaneously collective, individual and implicitly embodied. It will be seen, that embodied ways of self-expression are particularly important for people who cannot speak and so use their bodies to talk, even more than those who can speak naturally..

Lastly, it is important here to clarify the relative merits of the terms 'selfhood' and 'self'. Jenkins suggests that 'the self' is in danger of being reified too easily into a singular and rather static phenomenon rather than an ongoing part of being human. Thus 'selfhood' captures the process and emphasises 'the complex consistency or consistent complexity' of individuals (2004:51). However the term 'self' still needs to be used for specific aspects of embodied individuals or 'empirical selves'. Thus in this chapter and the next, I will talk about individual selves and types of self, but always remembering that these are actually meshed together in selfhood.

Initial impressions of the teenagers as people

I was struck on meeting all the young people by their very apparent strong 'sense of self' expressed in a myriad of mainly non-verbal ways. In each case I felt immediately that this was a person who had things 'to say'. This was mainly because those around them who knew them well were tuned in to their 'code' and often responded by verbalizing for the teenager what they thought had been meant by a movement of eyes, face, hand or a sound. It felt as if the people around them were

interpreting an unknowable and secret language, and made it very clear that these were people with individual opinions and ideas.

The teenagers mostly show initially a certain wariness of new people expressed by looking away or at a familiar adult and not 'saying' anything either non-verbally or on their VOCAs. As a newcomer, these initial encounters were daunting, as I sensed the young people looking intently at me watching my every move and hanging on my words, as they 'sized me up'. When I knew them better, most confirmed that they were often concerned when meeting new people about whether they were going to be treated as 'a person or 'as a wheelchair' and they took steps to show they were a person 'with an inner self' (my words), as quickly as possible.

> *Terry sat quietly and still all the time (during my intro talk), but seemed interested, listening and was looking at me intently, without looking away… I had been told he was a big football fan, so when I asked him which team, he immediately told me on his VOCA and smiled. He's a Birmingham City supporter and Toby is Man U. When I asked a closed question (about which class and house he was in), Terry told me very quickly and clearly by responding to my guesses with his head shake for no and a kind of forward movement for a nod to say yes (fieldnotes).*

In many cases they followed up my initial introduction with a question:

> *Ted asked 'WHEN'? immediately after I had mentioned the possibility of coming to his house, and when I said 'probably in the holidays' and asked if that would be okay with him, he did a massive 'yes' movement.*

> *Bryony almost immediately after we'd sat down on the floor said 'what' and pointed to my bag which was bulging with interesting looking coloured stationary. She then insisted on inspecting everything I had in there, including my pencil case and audiorecorder and continued to fire single word questions at me eg 'who' which I guessed was 'who else is in the project?', 'school' when are you coming to my school?*

The young people's behaviour left me with a sense of urgency about getting to learn their communication systems quickly and a responsibility to listen hard and attentively to them (Christensen 2004).

Initial self-descriptions

During early conversations with the key participants I asked them directly to describe themselves and what is important to them[33]. Their initial responses although appearing rather list-like, are almost verbatim, and reflect the nature of much of their verbal communication. As suggested in Chapter Three, for the AAC user this elliptical style is enforced and may make them more selective about who they respond to and how. The words they used to describe themselves are largely positive and rather broad personality traits (nice, mad, kind, funny, fun, chatty, sociable, good) or refer to aspects of physical appearance (handsome, tall, beautiful, nice legs, sexy, fit, smart, clean, boyish). They also often included specifically competent aspects of themselves e.g. sporty, clever, good at: ICT, athletics, or science. Some also chose to describe things they liked doing or planned to do (go to college or university, play sports, watersports, shopping, parties, eat chocolate, pray, watch TV, play IT games, go to football matches or musicals, go out with friends, family events). A few mentioned more specific personality traits, which they were later keen to demonstrate in action (e.g. determined, likes to talk and listen, to be independent, have my own ideas, stubborn, do my own thing).

These responses seemed to me to more systematically positive than one might expect from a group of young teenagers, few of them expressing any neutral or 'negative' attributions. Many non-disabled teenagers in doing this self-description task would in a spirit of modesty and or self-deprecation include at least some less 'desirable' aspects of themselves, albeit possibly just to avoid being accused of being bigheaded (Martin 1996). Here the exceptions were both Jemma and Josie saying they were worriers, Toby that he was grumpy and moody, Kate saw herself as stubborn, Terry described himself as scruffy and Josie rather jovially as both messy and often late. However self-descriptions such being 'scruffy', 'messy' and 'late' are ambivalent or even positive terms, as they also represent the attractive teenage traits of being 'laid back' or rebellious. Indeed I felt that both Terry and Josie were keen to cultivate that sort of image, this being observable in their dress: hippy, goth or sloppy looking clothes, and the way both drove their wheelchairs.

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[33] See Data Tables 2 & 3 in Appendix G, pages 338-344

However, as a group, these adolescents were above all concerned to describe themselves as 'a nice person', demonstrating that for them their relationships with others are important (e.g. family person, kind, helpful). The characteristic that was mentioned most often was 'having a good sense of humour', both in relation to themselves as people who were fun or funny and made people laugh, and in relation to others who made them laugh. Other related words which seemed to have similar meanings were 'mad' and 'whacky'. Many said while explaining why they liked particular friends or relatives that it was because they were funny, silly or 'a laugh' and they liked to see themselves in this way too.

From these early self-descriptions it seems that this group of teenagers had rather high self esteem, were 'happy in their skins' and perhaps rather unusually unselfcritical[34] and in general this overwhelmingly positive attitude predominated throughout the study. There are several possible explanations for this.

Firstly it might be that their self-esteem is indeed very high. It might be that the aversive disablism which is definitely at work in society (discussed further in Chapter Seven) has not impacted on them yet. It could be that they are not yet very aware of the negative stereotypes that society might apply to them, and so are not experiencing the social relational disablism that Reeve (2002) and Thomas (1998) talk about, although this seems unlikely.

Secondly, if they are aware of such stereotypes, they are working hard assertively to counter them. Their very positive descriptions echo the sentiments of the Swain and French's (2000) affirmative model of disability, which suggests an integration of their impairments into their view of the world and the presentation of a positive outlook and optimistic views of who they were and what they can do. So they are able to resist more negative views by feeling good about themselves. Their very positive responses might be a 'self-protection' mechanism against more fundamental implied criticism which they all later expressed as something they hated (e.g. being treated as a non-person, being seen as incompetent).

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[34] As I got to know them better some of them did express some more neutral or nuanced views of themselves and so perhaps this is something that can only be done when you trust someone more?

Thirdly, it may also be that these young people constantly receive very positive feedback in the form of complements and encouragement about what they do, and perhaps less negative criticism and incitements to' do better' than other teenagers. I observed that they were often praised just for 'having a go' in ways that sometimes sounded patronising. Hence they are curiously excused from having to be 'good at' things which their siblings and peers are often under pressure to be. This may be an example of the compensatory mechanism suggested by Thomas (1998) as being used by parents and carers, and which acts as a kind of 'buffering' of the label 'disabled' thus constructing a 'protective capsule' around young people. Disabled teenagers may therefore be unused to receiving the more usual mix of 'positive' and 'negative' feedback from others, and so when asked to describe themselves, tend to echo the adults around them by using a range of overwhelmingly positive vocabulary.

Family self

As described in Chapter Two, fieldwork took place in the participant's homes as well as at schools and seeing them at home revealed surprisingly different physical and social selves. Wearing scruffy holiday clothes, rather than school uniform and not being in their wheelchairs, transformed them visually into different people. They were less 'ordered' and more relaxed, and of course I was seeing them in the context of their families. When visiting Toby(14) at home, I started to understand how he was and wasn't involved in family life, and confusingly, he seemed simultaneously both more and less disabled in this situation:

> *A houseful of children in holiday mode. All shorts and t-shirts and general mayhem. Toby lounging in relaxed way on a big comfy chair in the living room his arms and legs splayed over the chair and flayling around in a way that he can't in his wheelchair. His younger brother Rob and a friend, two sporty looking types bouncing around the room, lots of talking all at once. A roomy child- friendly house full of TVs, playstations, videos etc and a garden full of trampolines and bikes. His sisters and a friend were getting ready to go out shopping. At one point one of them sort of jumped on him, and his brother 'cuffed his head' in a fake fight way. No one took much notice. Toby was included in the general discussion of arrangements, by being asked to indicate yes or no to various things. Talking just non-verbally, his VOCA was miles away, attached to his power chair, parked in the corner of the room. He looked very*

relaxed and floppy lying in the chair but also very small and skinny and young not sat up in the chair (fieldnotes).

He seemed less disabled in the sense that he was so very obviously part of the scene at home and was being included in the conversation and the mock fights, so he was socially very present. However physically he looked so frail and he had no active form of communication, so compared with his school self, where his body is 'organised' by his chair and he can use words on his VOCA, he seemed much younger and more dependent in this context. He was actually the oldest of the children there.

I had similarly mixed impressions and thoughts when I visited the others. In every case the very fast non-verbal communication that goes on in families, where the VOCA is used much less, is impressive. Demonstrably people in close social networks understand each other well, no-one is self conscious and no-one pays excessive attention to anyone in particular.

For all of the young people, being part of a family was important and a strong part of their self identity. When asked to name their most important people they all listed nuclear family members such as parents and siblings first, usually closely followed by grandparents, aunts, uncles and cousins. Often a few close family friends were mentioned as important too, and were almost honorary family members. Often these were friends of their parents whom the teenagers had known from birth. Most, however listed relatively few people in addition to family members and school staff, or only when prompted by parents to mention other friends. This very marked privileging of family was repeated throughout the fieldwork. Arguably, this contrasts with non-disabled teenagers who spend a great of time talking about and to their friends and are in many senses gradually shifting their focus away from their immediate families.

All talked of family trips, holidays and get-togethers as important landmarks in their lives. They showed me photos of family occasions and told anecdotes about memorable and usually funny incidents, and which had passed into family mythology. They often used a few key words to prompt their parents to tell me the story. For example looking at old photos with Kate(13):

MW	*I like your dad's shirt!*
Kate	*Ah (laughs and looks at mum)*
MW	*Very funky*
Kate	*BEFORE BORN*
Mum	*Yes, that shirt is famous, we've had it since before you were born!*

Siblings as friends and rivals

Spending time with siblings was mentioned by most as one of their favourite pastimes, and for two of the boys, their brothers were also their best friends. Significantly neither Toby(14) nor Terry(14) named any other boys of their own age as friends, so it appeared that they were heavily dependant on their brothers, who were four or five years younger as peers. Unlike other young people perhaps, they seemed very comfortable with having their brothers as their 'best mate'.

Very striking also was the normal physical and verbal 'rough and tumble' of sibling dynamics, with several of the participants saying they favoured some siblings over others. As can be seen below, some preferred their same sex or nearest aged sibling perhaps as the sibling with whom they had most in common. For others preferences seemed more linked to their siblings' view of their disability, especially if they felt helped, hindered or overshadowed by some siblings more than others.

> *Toby(15) named brother Rob(11) and his friend Mark (11) as the people he likes to spend time with. The 3 boys spend a lot of time at weekends and in the holidays, playing sports related virtual games on the computer and being rude about their younger sisters. I witnessed this on several visits and was made to join in with their playstation games. The two 11 year olds play in the local boys' football team and Toby is there at every match as 'the manager'. Toby gets very cross if they go somewhere without him, which does happen sometimes (fieldnotes summary).*

> *Bryony (10) has a much younger sister Nancy (2). On several home visits I witnessed rivalry and struggles for attention between them. One day Bryony had her VOCA on the floor near where we were lounging and talking, Nancy came over, sat down and started pressing random buttons on the VOCA, but chatting in toddler talk at the same time (the ultimate insult!). Bryony looked distinctly cross but didn't do anything about it, till her mum intervened and took Nancy off to do something else. Bryony indicated to me that we should go in her room to chat, to get away from her sister. She very deliberately shut the door (fieldnotes).*

Nathalie (15) who has 5 siblings, seemed to be both in the middle and at the periphery of what was going on in her family. During the constant comings and goings of a busy household, she was nearly always in the kitchen/dining room where all the action was, and the other children often hugged her or said things to her in passing as they got on with their various pastimes, sports, schoolwork etc. However I also sometimes got a sense of her as perhaps paradoxically isolated in the midst of all this action. On schoolday evenings she has a personal assistant (a young woman in her early 20s) to help her with homework etc. This somehow made her different from the others, because of needing an adult to help her get on with what she needed to do (fieldnote summary).

Jemma's(12) older sister Angela, only 14 months her senior is very much her role model. Jemma expects that anything Angela is doing now, she should be doing soon and announces this often. Jemma also colluded with her sister in having a supercilious attitude to their younger brother. Several of the group talked about the birth of a younger sibling or cousin when telling me their 'life story'

Jemma	*I remember dad picking me and Angela up and taking us to Aunty Sue's because mum was having Neil. We had the day off to see the baby. I went with dad to buy a baby car seat and a present. I was 6.*
Toby	*SISTER ALICIA BORN*
MW	*ah you remember her being born! What did you think?*
Toby	*WANT BOY!*
MW	*You would have preferred another brother?*
Toby	*(nods) yes*

In general the participants rarely compared themselves with their siblings, in either favourable or unfavourable ways, suggesting an acceptance that everyone is different. The exception to this was Bryony(10). Her teacher June told me:

She is not using the VOCA as much as before – used to make long sentences but now tends to try her speech first, though we try to get her to use the VOCA at school. We wonder if this is because Nancy (2) is beginning to babble and talk so Bryony thinks if she can do it, so can I. She is vocalising a lot. A sensitive issue. She said 'everyone says Nancy is clever , what about me?'. She will also be being overtaken in physical skills, walking, running, jumping etc soon. How does this feel as a big sister? (fieldnotes).

Two of the teenagers had had a sibling who had died, both when they were too young to remember the event. Another girl had recently experienced bereavement when a lifelong family friend of her own age had died unexpectedly. In each case they told me this, without much elaboration, but with a strong sense of it being sad family business. If their mothers were nearby during these conversations, the young people called them over and urged them to fill in the details for me. Very noticeably, the short phrases used by the young people echoed the longer narrative told by the mothers. These glimpses into the importance of family culture and stories confirm Bohanek et al's (2008) findings that parental narratives, and mothers' expressions and explanations in particular, play an important part in young people's positive self-esteem, and that the telling of these stories is a key element in identity development

> 'Early adolescence is the time when children begin to form a more integrated life story in the service of constructing a sense of identity' (Bohanek 2008:154).

The centrality of the family is encapsulated by Nathalie(15) who in an RE lesson had to define some words including love, faithfulness, patience, etc. She said:

LOVE MEAN FAMILY

Thus these young people are very much 'family people'. As Toby(14) said:

AT HOME CAN BE MYSELF

This suggests that at home these young people can be themselves, in a way which in other contexts can be problematic and may have to be negotiated by them or for them. Closs (1998) in discussing the quality of life of children with life-threatening conditions, uses Bronfenbrenner's (1979) social ecology model of inter-reacting concentric circles of social networks. She finds that their inner circle of close family ties is particularly strong and influential, whereas the mesosystem of more distant friends, relative, neighbours etc is depleted. Blackstone et al (2005) had similar findings in their work on the 'social networks' of children using AAC. This is

certainly replicated in the present study, where the family is a key reference point, place of security and centre of their lives for all the teenagers. Thus for them 'family' is generally a place where they can be sure of being understood and accepted in ways they prefer.

Being a teenager

All the young people liked and did a range of 'teenage' things and the mass of evidence generated in relation to their teenage selves suggests that this is the most important and significant aspect of their selfhood and the one they most want to emphasise. This shows their identification of themselves clearly and more than any else apart from as family member, as 'ordinary teenagers'. Some interests were almost universal across age and gender, such as IT and media related interests (computers, music, TV), and trendy appearance. Also common was the importance of pets, mascots and memorabilia such as photos, medals and certificates as objects of pride and proof of achievements.

The participants wished to identify themselves positively as teenagers as opposed to younger children, who they tended to regard with a mixture of amusement and contempt. This is exemplified below in a (special) school assembly when I was sitting with Marie(12) and Jemma(12):

> *First the early years group did a fantastic 'Mr Gumpy's outing' with puppets on sticks stuck on their wheelchairs and lots of switches with prerecorded sayings to press. The older girls seemed to enjoy watching this, smiling and saying it was sweet but also smirking superiorly (fieldnotes).*

Being a cool teenager is definitely a status to be proud of. Jemma on her thirteenth birthday, was beside herself with excitement and pride at having reached this milestone:

> *Several times during the day she spun round in her chair, did wheelies and with one arm up in the air triumphantly said in a loud voice ' I am a teenager'. This is important to her, maybe because she has a sister who is only a year or so older, but looks much more teenagery than her. I asked her if being a teenager made a big difference to her and she said yes! She and Marie were being unusually chummy today and affectionately high fiving each other. Various*

people were teasing Jemma about how much trouble she'd be now, she said 'yes like KEVIN, FROM HARRY ENFIELD' (fieldnotes).

They had clear ideas about what a teenager should be doing (e.g. 'being moody', 'going to the pub', 'being free', 'going out', 'going to clubs')   In fact some of their 'hates' were related to not being able to do these things:

Josie(15)   *I WOULD LIKE TO GO OUT ON MY OWN MORE*

Toby(14)   *I CAN'T WATCH TV ARGUE MUM*

Being treated like a younger child was mentioned as annoying by nearly everyone at some point during the study. Marie, when she got cross shouted repeatedly:

I not a baby!

and as Nathalie(15) put it:

TALK TO ME LIKE A TEENAGE GIRL (on DVD)

Being cool with technology

Various IT gadgets act as badges of membership of the 'teenage clan', and in some cases it seemed to be more important to own a mobile phone, or have the *theoretical* capacity to send e-mails (from their VOCAs) than actually to do it. In fact for the majority of the group, physically using an unadapted mobile phone or iPod is difficult or impossible. Ling (2004) and others (Katz & Aakhus 2002) suggest that for contemporary teenagers the mobile phone both enables them to be constantly in contact with their peers and also represents symbolic affiliation with their age group and status. However for many of these participants practical difficulties with using the phone make it more the latter than the former.

Music and media

Individual choices of music and particularly of TV and film genres appeared to be gendered. Only a few people mentioned specific bands, films or TV programmes by name, although this may have been an artifact of their communication systems, in

that spelling out names of films or bands would take time. However, despite this, when asked directly they were quite prepared to express an opinion about types of music or TV shows:

> *In a communication skills class Toby and Terry were asked to think how they would argue or persuade someone about their choice of music. They were given different tracks to listen to, the first was Irish folk:-*
>
> *Toby   IT'S RUBBISH' ......CAT*
> *MW   Cat?... You mean it sounds like a cat?... Like a cat's chorus?*
> *Toby   (nods yes and laughs)... HELP!*
> *MW   does that mean turn it off?*
> *Toby   yes......IRISH ....MUM*
> *MW   yes you're right it is Irish.... Does your mum like it?*
> *Toby   (nods yes) (pulls a 'yuk' kind of face)*

Two of the boys preferred watching sports programmes above anything else on TV, and five girls mentioned watching soaps, cartoons, Harry Potter and Dr Who. The latter two characters had a cult following at the time especially amongst young teenagers. Jemma(12) when listing key events in her life said

> *The return of The Doctor after 15 years!*

Very frequently Jemma brought Dr Who into our conversations declaring undying love for him. This was a very important part of how she saw herself. To be a Dr Who fan was the coolest thing to be. Marie was also very sure of her taste:

> *Went to the HMW shop to spend a voucher she'd been given. She knew her way round the shop and what she was interested in buying very well (even though she can't read well), I had trouble keeping up with her as she whizzed round the different areas (though she wanted me follow, to help with getting things off racks) checking out what the latest CDs, DVDs etc. She finally settled on a DVD of a favourite cartoon character and a keyring with some funky media characters on it. She was very clear about her choices and didn't need any help with this, although she needed help with knowing how much money she had left and with paying etc (fieldnotes).*

Bryony had very clear stereotypical 'girly' taste in musicals and romantic comedy shows.

> *Her bedroom was a pink and purple palace of girly stuff including pink walls,*
> *carpet and TV.   She was very smiley and keen to show me 'her stuff'.   Lots of soft*
> *toys, books, games and posters of Grease, John Travolta, Princess Diaries and*
> *Harry Potter (fieldnotes 1ˢᵗ home visit).*

All the girls mentioned specific media celebrities whom they 'fancied', and had posters of on their bedroom walls. As other teenage girls do, they talked about aspects of fashion, shopping and doing things with friends more than the boys did (Carter 2005, Goodwin 2006).

The data suggests therefore, that the participants know as much about 'teen culture' as any of their peers. In fact, since they may spend relatively more time watching TV or on the internet than other children, they may know more (Gee, Allen & Clinton 2001, Huffaker & Calvert 2005).

> *Terry's father told me that he let him spend more time on the playstation and*
> *watching TV than his other children, because there were other things they*
> *could do (fieldnotes).*

This observation could be construed as revealing in Terry's father a rather passive attitude to what his disabled son can do. However subsequently he talked about how liberating the internet and virtual reality sports games were for Terry and how much pleasure he got from them. Both his parents said that before he had learned to do these things himself, they had struggled to find things to interest him and that he could do without help. They saw it as a sign of his growing independence and expression of his teenage self that he spends long hours on the computer, doing similar things in the virtual world as his siblings, either with them or alone.

In contrast when

> *Marie reported that she'd done nothing interesting at weekends except watch*
> *TV and said 'boring' very loudly*

my impression was that she literally did nothing else at home and unlike Terry was not able to choose what to watch. She has very limited literacy skills, as do many of her family, so opportunities for computer based activities in her household are

probably limited. She enjoys computing at school but needs adult help with this. For her the idea of using the computer and mobile phone are more an ideal than a reality. She is however an expert on what is happening in Eastenders and several other soap operas!

Fashion

Everyone, regardless of gender, was very interested and concerned to look fit, trendy and beautiful/handsome and to have the right clothes, haircut, and jewellery and to be seen as 'cool'. All had an individual style and 'look' which they were clear about. Kate(13), who likes bright colours and shopping, when asked to think of an object that represented her, chose her favourite highly decorated boots:

> *My ultra cool Lelli Kelly Boots…. I have lots of interesting reasons for choosing these. Some features of the boots are similar to some things about me!' eg they are pretty and funky! (DVD script).*

Ted's mum emphasised his strong views on what he wears:

> *Mum   He does like to wear… to church… does not want to wear his school sandals. We've got trainers, normal trainers that he wears to church, and he hates his ankle huggers, which he wears at school, because he thinks that people see them and he won't look normal, but…*
> *MW   Is that why he doesn't like them? I thought they were uncomfortable?*
> *Mum   I think its two things. He doesn't like the restriction of them but he also thinks that they don't look normal.*
> *MW   Oh, okay. So, he'd rather be wearing some trendy trainers?*
> *Mum   Yes. Clothes matter to him. He's always been interested in clothes, so it takes quite a while to get him ready in the morning because we have to go through about five different outfits for him… to decide which he's going to wear. So I think… if he wears the clothes he wants when we go out, and the shoes he wants, he feels quite good about himself.*

Evidently these adolescents, like their same age peers, 'use style as their compass points' as Cohen suggests (1994:67), to anchor themselves in a world where they may feel uncertain or marginal (James 1986).

Language

That style is important can also be seen in the participants' language use and vocabulary, despite their restricted range of ways to talk. There were numerous

occasions when they showed that they were keen to use the 'cool' language of their peers and some were very clear about why this was important:

> *Jemma*   *I use slang like 'innit'*
> *MW*   *why do you use that?*
> *Jemma*   *because everybody uses it, it's the language of young*
>   *people… so I have to use it!*

In class, Toby(14) was tasked with thinking about how well he had done at a recent assignment:

> *MW*   *so how do you think you did?*
> *Toby*   *PANTS! (giggles)*
> *MW*   *okay so you thought you were pretty rubbish then?*
> *Toby*   *(nods yes)*
> *MW*   *I wonder what word you'd say if you thought you'd done it well?*
> *Toby*   *SOCKS! TROUSERS (laughs)*
> *MW*   *(both laugh) right, okay! (the conversation continues with various silly suggestions about what you could do with clothing vocabulary, doing 'cool' gestures and both giggling).*

Evidently even if you do not use many words, it is important to use the right ones and these examples show that the young people have an awareness of which words are 'right' (Opie & Opie 1959, Hoyle & Adger 1998, Goodwin 2006).

As noted in Chapter Three, AAC users even if they are very proficient, have only a restricted range of vocabulary that they can access quickly. Thus the question arises as to whether and which 'naughty' words or phrases are programmed into VOCAs for instant use. This has been debated in the linguistic literature on AAC especially in relation to swearing, age appropriate vocabulary, and freedom to say what you want (Caryer & Herd 2006)[35]. This issue arose in a discussion with Toby(14), Terry(14) and their speech and language therapists (SLTs):

> *Conversation got round to swear words on VOCAs. The boys both interested in having some swear words. I asked Toby which ones? He could have spelt them out, but this would have taken ages and he indicated with a gesture to me that I should suggest some. I think he also relished the idea of getting me to say them*

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[35] Most often new words or phrases are programmed into the VOCA by an adult (e.g. parent, SLT, teacher), and so the issue of censorship or control of 'suitable' vocabulary comes to the fore. There have been examples of adults refusing to programme swear words in for teenagers.

first! So I started listing them – from the mildest first. He kept saying no and giggling, until I got to 'fuck' and then he said yes with a massive head gesture and laughed. The two SLTs who were happy to programme them in, then discussed putting them on a button (control on the VOCA), but without an obvious label on it (so that no-one else looking at their screen would see it). The boys were keen on this and said they also wanted football slogans, and that the main place where they hear swearing is at football matches. Toby wanted 'you'll never walk alone' and Terry wanted his team song 'Goodnight Irene' so that they would be able to use these at matches as well as some swear words! (fieldnotes).

For both boys being able to use these words thus represented joining in, was part of being 14, being at a football match and being one of 'the lads'. Katie (RA) has argued strongly in a conference paper (Caryer & Herd 2006) for the right for AAC users to have complete freedom of expression.

Sporty self

Sport was another important part of their identity for more than half of the teenagers and most especially for the boys. In fact, even those who were not particularly involved in doing sport themselves outside compulsory school sessions (Nathalie, Ted, George) still named a football team that they supported. Being associated with sport, and particularly a football team is an essential part of these young people's identity, and seems to represent being part of a community and being strong and cool, both of which are key aspects of teenagerhood (Messner 2006). The extent of their involvement in attending matches and owning supporters gear varied greatly. When asked about a favourite object or one that represented them, Toby and Terry chose items related to their football teams such as posters or T-shirts, and Josie who is very sporty, chose her Boccia equipment. During the photovoice task, she also arranged a photo of herself all set up with her Boccia ramp and balls. Interestingly she also described herself as 'boyish' and this seemed to be linked to being good at sport and being competitive. Sporting events and sporty possessions represented very positive aspects of their lives. Several parents mentioned their child's involvement in sport, (sometimes through virtual sports games on the computer), as being beneficial in various ways. For example Terry's parents:

> MW   Is that relatively new, that he's been into football?
> Mum Two years.
> Dad Um. I mean, the football is good... I mean, the life saver for us is the X-Box. You know. It just makes life so much easier for us here ... I mean, he can, he sits on the X-Box, it's Sky TV or...
> Mum Well, he plays with his feet...

Toby(14) plays an important part in his younger brother's local team. He is regarded by the other boys as 'the manager' and chooses who plays where on the team. Toby, Terry and Josie all chose the colour of their new wheelchair acquired during my fieldwork, to match their football team. For most, sport is then less about being a performer than being part of the collectivity of supporters of a team, alongside their families or friends, and so is an important part of their selfhood.

For some, however, their interest in sport did include their own active involvement (including gymnastics, archery, canoeing, boccia, disabled athletics, wheelchair football, riding) and four young people dreamt of being in the London 2012 Paralympics, either as a competitor or as a helper. In all cases their parents invested considerable amounts of time and money in taking their children to competitions or clubs, and some were modestly optimistic that their child might possibly reach the London Paralympics. In one or two cases this is a real possibility, so the teenagers saw themselves as current or potential champions.

For Josie, Terry and Kate being involved at a competitive level in disabled sports was one important reason why they liked their special schools, and the older two have chosen to go on to a specialist college for physically disabled students in the hope of continuing their sports. For Kate, who changed from a mainstream to a special school that specializes in disabled sports, this was one important positive aspect of her move:

> Kate I DO BOCCIA AND ARCHERY AT SCHOOL
> MW   What do you like about doing sports?
> Kate Being competitive... like my dad

Thus my data showed that nearly all the participants are interested in and sometimes actively involved in sport. This echoes the literature about sport being an

important aspect of identity both for boys, for teenagers generally and for many disabled people (Hargreaves 2000, Sherrill 1997).

Rebellious and resistant self – How to be 'bad'

Being rebellious and resistant to authority is often regarded as 'normal' and indeed as characteristic of adolescence (Patel Stevens et al 2007). However for many physically disabled teenagers, it is practically quite difficult for them to be for example, naughty, messy or late, because many aspects of their lives such as their possessions, physical appearance and movement from place to place, are highly managed by others. Having communication impairments also makes being verbally 'bad' an additional challenge. My recognition of this was stimulated by the following incident when I met George(16) for the first time at his home

> *His mum showed me into his bedroom, where he was sitting in his high-tech chair, looking very immobile and staring at me intently.*
>
> *MW   what an amazingly tidy room! It's fantastic!*
> *Mum   well he can't really make it messy can he?*
> *George   (laughs)*
> *Mum   I expect he'd like to make it messy but I suppose it's me that's the tidy one!*
> *George   (nods – yeah! laughs)*

I realised that, although the content of the young people's bedrooms very clearly reflected their personalities and interests, the actual arrangement of their possessions was mainly physically beyond their reach. Thus the stereotypical messy (or not!) teenage bedroom, which usually reflects young people's evolving styles was absent. Additionally, bedrooms normally become increasingly private spaces for teenagers, their territory where they can do as they please. This is generally not a luxury that is available to physically disabled people, and opportunities to construct their own space may be limited, although I learnt that dissension is nevertheless achieved in subtle and varied ways. As shown below, although these adolescents' lives are relatively more managed and mediated by adults than most of their peers, they still find ways to dissent.

On several occasions, for example, I witnessed the young people vicariously enjoying experiencing another child being subversive, and there seemed to be an element of supportive encouragement of their peers in the ways they did this. I also saw the teenagers enjoying hearing stories about other young people's 'bad' behaviour and also liking to fantasise about possible future 'transgressions' that they might commit given the chance.

Physically and communication impaired people undoubtedly have a narrower range of options about ways to express anger or rebellion and yet most of the teenagers had a repertoire of ways of doing so. Very often this is through non-verbal communication such as a body movement or facial expression, much of which is quite subtle and inventive. Interestingly most of these acts may be invisible to or misunderstood by onlookers who do not know the person, as exemplified in the following extract:

> *Interview with Toby's mum about going out in public*
>
> *Mum   Yeah but, then, what Toby does... if there are people going in a lift that can quite happily walk, if Toby's legs are free, he kicks them. Yeah. And they turn around and they say,' oh, sorry', and they let Toby on. And it's usually teenagers that shouldn't be going in there, anyway and the lift's going down...*
> *MW   He just deliberately kicks them?*
> *Mum   He looks at them and kicks them. Yeah. And I say, 'I'm sorry, he just wants to get in the lift', and they always say, 'that's fine, in you go'. And I make a joke out of it and Toby smiles at them*

Toby's mum emphasised that his intentions are sometimes understood by people who know him, but also may not be. Parents confirmed that these teenagers can be as 'naughty' as any other:

> *I was waiting with Terry(14) in the school entrance. He was going to an interview at a further education college. His parents arrived at his boarding school to pick him up and take him. It was looking like rain, and Terry had chosen not to wear his school uniform, had on a pair of raggy hippy trousers and an old t-shirt.*
>
> *Mum   are you going like that?*
> *Terry   (nods) yes*
> *Mum   right...haven't you got a coat?*

Terry	*(gestures) no*
Mum	*you need to go back and get one*
Terry	*(gestures) no*
Mum	*so what happens when it rains?*
Terry	*(gestures with eyes - I'll borrow yours) (laughs)*
Mum	*uh! so nothing changes then!*
Mum	*(turns to MW) just like his brothers!*

This sounds like a rather stereotypical conversation between a teenage boy and his mother, although his rebellion is expressed in a different way[36]. Over time I began to see how the teenagers did 'being bad' in different contexts. George(16) described his own way of causing trouble at his mainstream school:

> *Some of the girls are shy too and I think they want to talk and listen to me but they are scared, I'm very good with my eyes! (written).*

As the following examples show, participants could express dissent very effectively often without words. They did this with their bodies, including their use of their wheelchairs as extensions of their bodily communication. The way different people drive their wheelchairs is, for example, an embodied expression of selfhood in a way that is analogous to an ambulant person's style of walking. While this is partly determined by the level of physical skill and impairment they have, additionally there is a voluntary and expressive aspect. Each young person drives in characteristic ways. Some are reckless or swervy (Terry, Josie, Marie, Prakash), while others are rather cautious and careful (Bryony, Ted, Jemma, Ruth), or have an air of sensible self-confidence (Nathalie, Kate), all which I came to see was important parts of who they are. Prakash(14) spelt this out clearly in his choice of favourite object, which sums up his physical presence and desire to be seen as 'devil may care', as well as brave and sporty:

> *Prakash* MY DAD'S BMW ...BECAUSE IT'S A FUN CAR AND I ENJOY FUN, AND I ALSO GO VERY FAST IN MY POWERCHAIR .....I GET CALLED SCHUMACHER, AS WELL AS BEING KNOWN AT SCHOOL AS A CHEEKY CHAP *(written for DVD script)*

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[36] Even though I was used to this difference it sometimes caught me off guard, as my reading of his non-verbal communication was not yet good and I would have missed the meaning of Terry's cheeky 'banter' if his mum had not interpreted it so clearly.

Josie's driving was rather similar, as described by her mum with a hint of criticism:

> Mum   she is a reckless driver and often barges into things at home and
>   bashes into doors, knocks over linen baskets etc
>
> Nathalie's mum told me that a way she shows she is cross is to drive into things
> and people. Her mum said she always tells her off when she does this because
> its just as rude as the other kids saying something rude, her dad then joined in
> and said ' well she doesn't have so many ways of showing she's cross does she ?'
> (fieldnotes).

This very physical expression of emotions is not necessarily directed at anyone else.
Here Marie is just rejoicing about the end of the school day:

> She was in her manual wheelchair waiting to go home, freewheeling the chair
> with her foot, in an exuberant carefree way, flicking herself round and round
> doing wheelies, ignoring various instructions from adults to line up, get ready
> etc. Adolescent carefree rebellious fooling type behaviour (fieldnotes).

A stranger observing these physical expressions might think that the person could
not control their movements and was moving randomly or involuntarily, and
possibly that the teenager did not understand what they were doing or the situation.
On the contrary, these were very specific and subtle types of resistance and so
evidently an important means of expression and autonomy[37].

However, the sobering fact is that disabled teenagers have fewer ways to express
their disenchantment. Although I witnessed surprisingly few outbursts, some of the
parents described episodes of anger, either as something that happened frequently
in the past or currently, for instance Terry's parents:

> MW   How does he let you know if he's cross then?
> Mum   effectively!... gets mad with his brothers doesn't he, I mean, he
>   uses his eyes now. Shouts. You know, sort of, if someone's winding
>   him up. And the shout is a, sort of, butt out! [laughter].
> MW   A frustrated, get off my case, kind of thing?

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[37] However I sometimes felt that the young people themselves did not see that they could be
misconstrued and a false picture of them conveyed, in just the ways they also objected to. This is
perhaps not so different from the adult discourse around non-disabled adolescents attitudes and
behaviour and the stereotyping of them as unthinking, rebellious etc (Patel Stevens et al 2007).

Mum	Yeh… Off my case. He tells me I'm completely stupid. But then that's typical of all the boys versus me… Mum, why are you so stupid, do you? Well, his best one is, um, he pats his eye and mouths obscenities at me.
MW	What does that mean?
Mum	are you blind or what? … kind of thing
	And…its, are you, are you blind, Mum, you're blind. [laughter].
MW	What? Because you can't see what he's….?
Mum	Because I can't see something specific, as in, not necessarily visually see, but, um…
MW	Yes, you can't see what it is he wants, kind of thing?
Mum	Yes. Correct. He goes.. you blind? ooooh…he's being a typical teenager!(interview)

Some parents were very aware of the differences in the way that they responded to their disabled teenagers' behaviour in comparison with others of that age. This means that because of the disabled child's physical needs for support, opportunities to be a 'normal' teenager and therefore to change or opt out of things, are restricted. Toby's mum described a major row they had had. He 'threw a tantrum' and physically fought being moved. The problem was that unlike any other 14 year old, he could not be left at home alone:

Mum	he just, well, he just basically screams and screams.
MW	Okay. To make it impossible.
Mum	Yeah. And even when I try, I mean, I don't do now, what I said, all right, we're going anyway, which I do with the others, lift him up to put him in his chair – rigid, screaming.
MW	So, he's getting big enough now to physically resist it?
Mum	Yeah..To say no. And then, Rob, who's ten, says, mum, when I'm 14, if I don't want to do something, you can't make me, can you? That doesn't help, Rob, at this minute in time.
MW	Is he saying that to support Toby, then?
Mum	Yeah. Because Toby… and then, at the end, we didn't go, but then I didn't let Toby play in the week. I told Toby I just told him, you spoilt it for the other three
MW	And why do you think he didn't want to go?
Mum	We'd been watching Rob play football in the morning. I think he just wanted an afternoon of doing nothing.
MW	Oh, okay.
Mum	And, if he was a normal 14-year-old, I'd say, okay, you stay here, so… it's that fine line of accepting he's 14 and he may want to do nothing all weekend because he's been busy at school – because he does work hard – but, on the other hand, he's got to be part of

> *the family and I can't give up everything for Toby to stay in on a*
> *Sunday afternoon (interview)*

Rather similarly, while Terry's parents recognized his particular frustrations, for them it was a challenge to mediate or moderate these and to try to make him aware of what were acceptable and unacceptable ways of exercising his autonomy:

> *Father*   *Yes. I mean, there's things out there he doesn't like. He doesn't*
> *like people parking on the pavement.*
> *Mother*   *Parking on the pavement is a nightmare because he actually*
> *drives his wheelchair deliberately close to the car and threatens*
> *to scratch the car for parking on the pavement.*
> *MW*   *That's fair enough... I think I'd do the same if I was in his...*
> *Mother*   *I know, but, you know, if you can avoid it is better to avoid it. You*
> *just don't need the flap when the man comes out of his house. I*
> *say ...I know you feel like hitting the car... but please don't.*

Despite the preponderance of examples of non-verbal rebellion, there were also some examples of the teenagers being verbally cheeky and challenging, given the chance. These were rarer, because using AAC does not generally allow a quick repost and so the moment is lost. Sometimes by the time their comment had been constructed the target person had left. However I saw various examples of them using spoken language to rebel. Often they did this with very few words, which served the purpose perhaps as well as a whole sentence could:

> *Ted in a literacy session with Sally his SLT- a new programme with his VOCA for*
> *doing spellings. Had to rearrange letters to make words. He was very slow with*
> *this and kept wanting to gossip about other things. Sally said 'hurry up or you'll*
> *only have done one word in the whole lesson! he laughed and said 'COOL*
> *COOL'– being rebellious! (fieldnotes).*

Katie (RA), as a young disabled adult who is active in disability advocacy, makes a point of resisting and challenging negative attitudes to disabled people. Some of the participants met her, and were interested in her wheelchair stickers:

> *Watch ya toes, crip chick coming through!*
> *Walking is over-rated*
> *If you stare long enough, I might do a trick!*
> *Not being able to talk is not the same as having nothing to say*
> *(KC's stickers)*

She also has a number of t-shirts which challenge the onlooker:

> *You're all laughing at me because I'm different, I'm laughing at you because you're all the same!*

These are much more defiant, shocking, and outwardly confrontational than anything the young teenagers do or say. They laughed when they read them and judged them 'good' and 'funny'. For Katie these provocative statements are both a declaration of her intelligent sense of humour and her much more developed sense of disability politics than the young people have as yet. She deliberately identifies herself as disabled, whereas most of the participants are concerned to identify first as teenagers and to challenge anyone who denies them this status. Perhaps being overtly subversive about disability is difficult during adolescence and something that is more possible once you have achieved adulthood?

Nevertheless, an early stage in the process of learning to resist disablism is to deal with being stared at in public. Nearly all the teenagers mentioned hating this unwanted attention, but they were not always or easily able to counter it directly.

> *Josie and her mum usually counter undue attention by going into a kind of role play double act, where her mum asks her a complicated question loudly and Josie answers it with her amazing head spelling system, showing everyone that she is a person with opinions. This sometimes works but sometimes the 'message' was lost on the observer. Her mum said she often just wants to tell people to 'get a life' (fieldnotes).*

Usually there is little time for the AAC user to say anything. Occasionally, however, it is possible, as exemplified here by Nathalie (15) at her new school

> *A load of people waiting in the school corridor were staring at her so she laboriously typed out*
>
> *WHAT ARE YOU STARING AT?*
>
> *and said it several times, which made them look embarrassed and turn away. She thought this was very funny and hasn't been bothered by staring at school since (story told by her LSA).*

Katie (RA) is a very skilled AAC user and has some preset phrases at different levels of rudeness, ready to use e.g. 'can I help you? , 'what's your problem?', 'up yours', 'I think I'm going to be sick', 'you're patronising me' and 'fuck off'. I saw her using these with varying degrees of effectiveness, the problem being that saying these phrases with an electronic voice then attracts more attention!

Some of the young people said that they would like to be able to challenge people who stare, pat them on the head, or talk to them as 'if they were eight', but often they had to 'ignore it' or 'just drive off' (the equivalent of walking away), as a show of dissent. These are important ways of showing who they are and to counteract being seen as 'the other', especially in public settings where they are not known (Garland Thomson 2006). In many ways however these also look like variations of rather typical teenage forms of defiance.

The individuals who were most frustrated about not always being able to express their views were the youngest (Bryony and Ted) and those with the slowest or least clear communication systems (Toby, Ted, Marie). Arguably, learning a repertoire of effective ways to confront is part of any teenager's agenda and perhaps as they get older they become more skilled at this. The older teenagers generally had more subtle and sophisticated ways to make their views known, and perhaps also accepted that some battles were too difficult to fight. Some were very aware of the need to be clear and assertive, and particularly those with parents who were actively engaged in the disability rights movement, appeared more aware that they would need to be strong fighters as adults. Marie, coming from a rather different social background than the others, had her own plans for rebellion as an adult:

> MW   *What sign is that? Taking things? Shopping? What sign...are you doing... shopping? No, you're doing taking things, getting things for yourself? No? Can you tell me another way? What sign are you doing? Eating? No. I'm probably being a bit thick, aren't I, Marie? I know; sorry. You'll have to tell me clearly, because I'm not going to get it. This page? No. This one? Not this one... Over,.. yep.*
> Marie *No...bad*
> MW   *Uh?. .. Bad? Being bad? Oh, that's what you're looking forward to, being bad? (laughs) What does "being bad" mean?... Taking stuff? In shops?*

> *Oh...that's what you want to do? Get out of paying for things? Oh, I see;*
> *you think that's what the older ones do? If you haven't got any*
> *money...What would you take, from a shop?*

Marie   *Phone.*

MW   *Phone? Ok; so you'd want to have a phone. I think that would be quite a*
difficult thing to nick, because they have quite good security in those
shops, Marie

Marie   *(laughs) (shakes head)(mimes)*

MW   *Don't think that would be that easy (laughs). Oh I see, you'd drive*
out....do you think you could get away fast enough... in your chair?

Marie   *yeah ...(mimes fighting and driving away)*

MW   *you'd bash them up?*

M   *(?)*

MW   *You'd go in the shop, you'd bash somebody up and you'd nick the phone?*
And drive off

Marie   *yeah!*

It is clear that these disabled teenagers are able to rebel against and resist situations and to challenge authority in various subtle or not so subtle ways. Often they do this through movement rather than language and this can be very effective and well understood by people who know them. However the intentionality and meaning of these body actions may be under-recognised by strangers, and thus this aspect of their selfhood (as a rebel) is easily denied.

Gendered self, sexuality and teenage friendships

An increasingly strong sense of gender identity and emerging sexuality and romance is a key part of adolescence (Kroger 2006). Within the group there was a wide range of ages (10-17), and reflecting this, these aspects were expressed variously. As already described there were some very strong specifically gendered aspects of their selves, as well as some rather universal ones. Both boys and girls wanted to be seen as friendly people and signs of emerging sexuality were clear in both genders too. The difference between the boys and girls is perhaps best represented by the activities that they chose to do with me when I visited them at home. Generally the boys wanted me to play virtual sports games on the computer, either on their own or accompanied by a brother, whereas the girls wanted to talk for hours to me on our own, without their parents listening!

For nearly all the boys (aged 12-17) their interest and involvement in sport was gendered, as this was something they did mainly with their fathers and brothers. As described earlier this did not necessarily involve playing sport, but the importance of their symbolic identification, particularly with football and a good team was a recurrent theme. Being linked to sport thus represents masculinity, and their confidence about themselves as young men.

Rather stereotypically perhaps, the boys were less comfortable talking about feelings and relationships than were the girls (Martin 1996). As a gender group they named fewer friends by name, and talked less about the issue of getting friends or what friends meant to them. Their football team acted as a virtual group of friends and worked as a strong and stable reference group and they expressed less concern about having more actual friends. Many were content to spend time alone, with their fathers, brothers or one friend and talked less about the importance of groups of friends than the girls. However it may be that boys just 'do' friendship, rather than talking about it as the girls do. Toby's mother described his friendships as follows:

> Rob and him are very… maybe it's because it's boys and it's football and he loves Rob's friends and it's the PlayStation… it's a boy thing…They're all… well, they're split into categories. You have the sporty ones and you have the geeky PlayStation and computer ones, so they both, they fill a need for Toby. The sporty ones come and they talk to Toby about sport (interview).

The boys talked very little about possible close friendships or sexual relationships. The exception was Ted(12) who had 'crushes' on several different female care-staff at school, and talked a lot about them. Mostly the other boys were apparently not interested or willing to discuss this aspect with me. Toby(14) is very physically immature for his age[38] and really only expressed the kinds of views of girls that are typical of younger boys ('girls are silly', 'they don't know about football' etc). Terry(14) is popular amongst the girls at school and seemed to be interested in them as friends in a laid back way. He invited a girl in his year to the school prom

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[38] This is obvious from his appearance generally. He is very small in height for his age and very skinny. He showed as yet no signs of the onset of puberty.

but paid little attention to her once the event started. He was reticent to talk about relationships but was very keen to 'look cool'. Terry then was perhaps rather like many other boys of his age in beginning to be interested in girls but being as yet inexperienced in relating to them socially and sexually. George(16), the oldest boy, but with the most severe physical difficulties, hinted at his interest in girls but also at his frustration about a lack of social contacts and opportunities. He was the only boy who mentioned a fantasy female figure, Kylie Minogue.

The girls (age 10-16) were also interested in sport and being active and outgoing, but with one exception (Josie) were not particularly interested in football. In fact Kate declared:

> Kate   *I hate football. It's boring. And so is rugby!*
> MW   *Why don't you like them?*
> Kate   *cos they only use one ball … boring! Its just men running around in shorts (giggles)*

Kate is an active Boccia player and this uses many balls! She did admit later that she supports Chelsea, but only because her dad does. Her protestations about 'men's sports' and those of some of the other girls are suggestive of their mostly strong and positive identification as young women, and in critical opposition to boys and men. Although both Josie and Kate were involved in sport in highly competitive ways, the girls' general attitude to sports was more focused on fun and participation than winning or on the team affiliation aspect that is so strong for the boys. Thus their image of their sporty selves was one of being sociable, willing to have a go and physically competent.

In contrast to the boys, many of the girls liked having conversations both amongst themselves, and with interested adults, about different aspects of relationships. There were, however, various rather sensitive topics: wanting more friendships with girls of their own age, what worked best in friendships, things friends might do together, and problems with making friends. Some of the girls had experienced difficulties with other girls and were keen to discuss these in detail with me. Kate had been excluded and bullied at her old school, Bryony had dealt with a girl

patronizing her, and Marie had an ongoing rivalry with a girl in her class. They all emphasised liking to do things with other girls, either at school or clubs and liked to be part of a gang of girls of their own age. Many wanted to go out more often, particularly shopping or to the cinema with other girls.

Although the teenagers, and more overtly the girls, valued friends, the reality was that all had very small numbers of really strong and reciprocal friendships. Josie was able to explain to me very clearly what a good friend would be like and how she would be a good friend to someone else:

> MW   So if a new girl came in your class, how would you make friends with her? What sort of things would be important for you two to be friends?
>
> Josie   ASK HER IF SHE IS OKAY (ARE THEY FEELING ALRIGHT IN THE NEW SCHOOL)
> A FRIEND WOULD BE THERE FOR ME IF I NEEDED TALK AND CUDDLES
> IF SHE WANTED TO FIND OUT SOMETHING ABOUT SCHOOL I COULD TELL HER (GOOD AND BAD AND GOSSIP!)
> WHAT DOES SHE LIKE – MUSIC, SHOPS?
> IF I HURT HER SHE WILL STILL BE FRIENDS
> ABOUT HER FAMILY?
> CAN I HAVE A LAUGH WITH HER?
> DON'T FORGET HER (IF SHE LEAVES)
> CAN I TALK TO HER IF I AM UPSET?
> WHAT DOES SHE DO AT HOME? HOBBIES, SPORTS ETC (DOESN'T HAVE TO BE SAME AS ME)
> DOES SHE TELL ME THINGS?
> IF SOMEONE TRIES TO BREAK UP FRIENDS WOULDN'T LET THEM (Loyalty)

However, despite her thoughtful insights into friendship, Josie asked me later how she could get more friends, and explained that although she had a few good friends at her boarding school, she had only one at home. She really wanted to be asked out by friends but this did not happen. Despite her considerable physical and communication difficulties, she was very confident that she could communicate with other people, and so it seemed that the problem was more with others' perception of her than anything else. Thus, here it can be seen that selfhood and personhood contrast with each other, and this will be discussed further in Chapter Seven.

Bryony had recently made a very significant 'real' friendship, which she and her dad described in stark contrast to another peer relationship at school:

MW   *What do you like about Rachel?*
Bryony   *WE PLAY*
Dad   *we went bowling*
            (banter between Bryony and Dad about who won)
MW   *and did Rachel do well?*
Bryony   *yeah!*
Dad   *she was doing lots of fancy dancing every time she threw the ball*
Bryony   *FUNNY*
Dad   *she makes you laugh?*
Bryony   *SILLY... FRIENDS... RACHEL... SHE'S FUNNY*
Dad   *I think one of the things that I notice about Rachel the same with the others in that lot is that... she doesn't treat you any differently from everyone else? she doesn't talk to you like a baby, isn't that one of the things you like about her ?*
Bryony   *Yeah... NOT LIKE LESLEY*
Dad   *yeah yeah not like Lesley... 'Hello... Bryony... are... you.. all... right?!!' (dad exaggerates a patronizing tone with a pat on the head)*
Bryony   *(laughs hysterically)*
MW   *is that an adult or a child?*
Bryony   *she's not my friend (signs)*
Dad   *well I think she is still your friend really*
Bryony   *she's not!*
Dad   *well... it was a bit awkward wasn't it, because she sent you that note didn't she, to apologise and I think she was a bit confused and self conscious about it*
Bryony   *(frantic gestures – pointing to self)*
Dad   *oh right, she wants to be your friend but you don't want to be her friend*
MW   *oh right you've chosen*
Bryony   *Rachel, I would (???????) with Rachel... and Isabel*
Dad   *you'd rather be friends with Rachel... and Isabel...*
Bryony   *I WOULDN'T WANT TO BE LESLEY*
Dad   *you wouldn't want to be Lesley?*
MW   *why? .. you wouldn't want to be like her.. why isn't she a very happy person or something?.... not your type maybe?*
Bryony   *mm*
Dad   *well and also she irritated the pants off Isabel and Rachel and everyone... and you, but not just you, but everyone was quite narked with her*
            (more discussion about this being similar with other kids)
Dad   *you dealt with the whole sort of business with Lesley very well, because you did explain to her that you didn't like her treating you like a baby... and she hadn't realized*
MW   *and she got the message did she?*

Dad	*well as much as she was capable of doing…*
MW	*you think she didn't get the message?*
Dad	*mm*

In a subsequent interview Bryony's parents explained more about what was significant about her friendship with Rachel

MW	*So would you say that Rachel is….the most noticeable friend she's had…?*
Mum	*Yeah, it's definitely the strongest friendship she's ever had.*
MW	*There hasn't been anybody like that?*
Dad	*I mean, she's had friends previous to that but not with the same sort of depth. It's like there is something there…*
Mum	*An equality actually. I think it's… other friends that Bryony has had,… it's been more a case of people being sort of supportive of her and giving to Bryony but not expecting her or allowing her to give anything back to them.*
MW	*Right, so a bit of an unequal thing?*
Mum	*Yeah, whereas with Rachel I think it's much more on an equal footing so that Rachel will talk to Bryony about things that are worrying her and Bryony worries about Rachel just as much as Rachel worries about Bryony, and that's a much more ordinary friendship and I think it's the first time… so she's had people who she's been friendly with where it's been almost there's been an imbalance, I think…*

Some parents made specific efforts to encourage friendships by organising for same aged friends to come to the house or go on outings. However this often had a rather 'stage-managed' feel to it, and several mentioned that it was disheartening that these initiatives were rarely reciprocated. Previous literature on disabled young people's participation in leisure activities suggests that often parents put in extra investment of time and money to facilitate their disabled children's inclusion in sports and leisure, but that generally they still do less of these than their peers and more family based activities (Cavet 1998). Similarly Smith found in two surveys about adolescents using AAC that parents are:

'Frequently concerned by the limited opportunities for social interaction available to young people with communication impairments' (2005: 69).

Often the friendships the teenagers mentioned most were those with adults (Ted, Terry, Kate, Josie). One could question the truly reciprocal and equal nature of these

friendships. Very clearly these would not be typical of their non-disabled peers for whom friendships with people of their own age usually dominate (Rawlins 1992, James 1999).

The girls were much more interested than the boys, in talking about potential or fantasy sexual relationships with boys or older male heroes such as film, TV or popstars. However only Jemma(12) had an actual 'boyfriend', Lee a boy in her class at mainstream school, with whom she had a strong and reciprocated friendship. In this excerpt he had come to sit with her for lunch for the first time, and had chatted amiably to me sitting nearby and the LSA who is helping Jemma with eating.

> *After Lee had left, Jemma turned to me and Emma and said 'well do you approve?' and we both said 'yes, a very good choice' 'he seems like a very nice boy'. She looked pleased and then banged her fist on the table and said 'dam' at least I thought she was saying dam, as we had had a joke about saying dam earlier. She didn't correct this but after a minute I realized she was saying 'stamp' i.e. stamp of approval' (fieldnotes).*

She gave me regular updates on the friendship although this had not extended outside school yet, and my impression was that it had not developed into anything physical. Jemma was always keen to talk about boyfriends and had a strong idea of what sexual/loving relationships should be like. This is perhaps influenced by her having an older sister. For Jemma the idea of 'having a boyfriend' was important, and she often asked newcomers such as Katie (RA) if they had one. Other girls mentioned boys they 'fancied' at a distance, in ways that seemed very typical of young teenage girls, but any mention of actually meeting them or talking to them reduced them to giggly shyness. Ruth(17) the oldest girl, was the only one who mentioned wanting any physical sexual involvement:

> *Ruth is very interested in boys, there's a number of boys she fancies, and really wants to be kissed, be close to and have a soul-mate (written by her mum for DVD script, agreed by Ruth)*

On the whole, in interactions between boys and girls in school contexts, there was a general acceptance of each other and the kind of camaraderie in the classroom that is common with many same age peers. Often these young people had been in the

same class for several years, so knew each other well and were generally fond of each other. This was particularly obvious in the special schools. When anyone was away with illness or for a hospital appointment (a common occurrence), sympathy and concern were expressed across gender boundaries. For example when Toby had to go into hospital for a few days, I heard the rest of his class discussing making a card for him and wondering if he was okay.

In contrast, there seems to be a gender bias at Jemma's mainstream school where she is the only disabled child and therefore very visibly different from her peers. The girls are generally supportive and accepting of her, although to different extents, but the boys are generally apparently hostile to her:

> *The teacher wanted them to circulate round the room to look at different pictures. Some confusion about who was working with whom and not clear who Jemma was going with, though it was eventually settled. Emma (LSA) felt that it was the boys trying to avoid Jemma and without some adult intervention she would have been left out (fieldnotes)*

Jemma is someone who very definitely sees other girls as her reference group, and makes overt moves to cement this:

> *Jemma insists on changing for PE in the changing room with the other girls, rather than in the disabled loo, even though she has to use this at other times for actual toileting. She wants to 'be with the gang', and 'compare underwear and stuff' (fieldnotes).*

Mostly, close social relationships and friendships were within gender groups rather than across them. This was less true of the older teenagers where mixed activities (e.g. in GSCE drama and English) seemed to work on an equal and friendly footing:

> *Josie working with Joseph (another boy with no speech) in media studies, on a plan for a comedy sitcom series. It was about a 'seaside saga'. .Lots of in jokes between them about making names of people like those in the class, using a mixture of e-tran and eye-spelling while Joseph uses his spelling board. 'The normal weird sisters, weird normal sisters', 'Fighting solves nothing' – was Josie's moral of the story. No speech but lots of verbal (spelt) and non-verbal chat and humour going on (special school) (fieldnotes).*

There was some good humoured asexual banter as well as some hints of sexual flirting and teasing between boys and girls.:

> *(Josie's GCSE science class). Boys in the back row looking louche, and 'keeno' girls near the front. Lots of banter, Josie drove in and barged into a stool, one of the boys said 'you really are a woman driver aren't you'… she just laughed. The boys kept up a continuous stream of cheeky chat including insults and put downs mostly aimed at the girls. A group of rather diligent girls sat quietly at the front. Josie as a rather 'boyish' girl and a bit of cool character chose to sit in the middle, so that she could hear both the boys and girls conversations and throw in the odd nonverbal comment, using facial expression and eye pointing, which was well understood by both groups. She was definitely doing a good job of providing feisty reposts to the boys insults, while the other girls just rather haughtily ignored them (special school)(fieldnotes).*

Being a teenager involves negotiating a position as a person who is sufficiently like others of the same age to be accepted, while at the same time expressing increasing individuality and autonomy (Kroger 2006). The participants all have distinct interests, tastes and priorities which are very much their own, but also many that are common across their age group and gender, and mirror closely those one might expect from their peers. Thus like other teenagers they are striving for a balance between the reassurance of conformity and a sense of uniqueness. Being accepted and belonging to a larger 'virtual group' of teenagers, and having friends who accept them as such is extremely important to them.

The changing self through the life-course

Over the course of the fieldwork, I caught glimpses of the participants changing selves over time, their views of both their pasts and futures and their awareness of being in a transitional state as teenagers.

Views of the past

Of course no-one can remember directly very much of their very early lives, and we are all dependent on stories we hear about these times. However these young people's narratives about their birth and early childhood were particularly vivid and noteworthy. Nearly all recounted the dramatic incidences that had occurred around their birth (which for those with cerebral palsy are quite likely to have been the

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cause or effect of their impairments). It was clear that they had heard the saga of their birth and infancy and the numerous health problems which accompany cerebral palsy recounted many times by their parents, and probably often overlaid with strong emotions. This was reflected in their own telling of their stories, though in many cases they could not or did not want to tell me much detail. Often they way that they worded the events directly echoed their parents' phrases:

> Terry   I DIDN'T BREATHE FOR 23 MINUTES

Strikingly this phrase was used by his mother when I interviewed her months later. Likewise Marie told me, accompanied by a dramatic mime that she:

> died three times (signs)

and Jemma, although she said she did not want to talk about it, said:

> I WAS RUSHED TO HOSPITAL WHEN I WAS 2 WEEKS

Stories about early childhood were similarly full of anecdotes that they had heard within the family, and several prompted their parents to tell me the details. When her mum was telling me about her early life Nathalie interrupted often with single words or signs to remind her mum about particular events:

> *Nathalie jumped in with prompts about things: her twin who had died, things she remembered from her first school (a bad experience), weeing herself because no one understood her communication about wanting to go to the loo, about it being boring and not learning anything, having rests at lunchtime instead of being active etc. This whole story was very much mediated and managed by her mum and it was quite hard to hear Nathalie's voice through all this. Overlaid with her mum's narratives (fieldnotes).*

The young people's knowledge of and stories about themselves as babies were unusually dramatic and graphic, and seemed better rehearsed than one might expect of other teenagers. Arguably this is the result of their lifetime of regular visits to professionals who ask their parents for their 'history', while they listen. In contrast

non-disabled children may not hear much about their birth or infancy except the occasional anecdote. Josie related a story about the family moving to America when she was six months old and how they had better physiotherapy there, and Terry proudly told me about getting his first wheelchair at about four years old:

> Terry   THEY THOUGHT I NOT DRIVE... BUT I WENT STRAIGHT OUT
>   THE DOOR!

In both cases these were stories received from family mythology rather than clearly remembered, but nevertheless they reflect important aspects of the young person's sense of self. As Ochs & Capps suggest:

> 'the activity of narrating with a family member, friend or neighbor, or perhaps a healer serves as a prosaic social arena for developing frameworks for understanding events. Narrative activity becomes a tool for collaboratively reflecting upon specific situation and their place in the general scheme of life' (2002:2).

Unusually, Kate(13) has given a number of talks about herself at AAC events. Her parents had clearly helped her to prepare these, and so it is uncertain how much of this is her own memory and conceptualization and how much is theirs, but it has become her narrative here:

> Kate   At 4 I felt sad and alone, I wanted other people to understand me.
>   I could read at nursery but school didn't think I could as they
>   didn't understand me so made me start again which was boring
>   At 7 I thought in pictures and the sounds went up and down like
>   words.
>   At 8 I wanted to spell so I really liked it when Mum found word
>   prediction on my dynavox
>   When I was 9 I got a sound box in school but when I was 10 I got
>   hearing aids – it was like the birds had started to sing in my life
>   (oral presentation – delivered on VOCA)

Subsequently I heard her talk reflectively and perceptively about how she had changed during the previous year, mainly as a result of having had some difficult relationships at a school where she was bullied, subsequently changing school and

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thus regaining confidence and self-esteem. She was perhaps unusual in the group, in so clearly expressing her past, present and future selves as a chronological narrative.

Jemma(12) also had a change of school during the year, transferring from being part-time in two schools, one special and one mainstream, to full-time in the latter. I noticed marked changes in her during this time, although she did not explicitly acknowledge them in the way that Kate did:

> *A picture of herself which we had drawn together at the beginning of the year, with her sitting in her wheelchair, was updated at the end, with one of her standing in her new school uniform, next to her new friend Asha. (fieldnote summary).*

Changing physical selves

The participants had explicit awareness of their changing physical selves and how they had grown and changed and would do further. Despite spending most of their time sitting in a wheelchair, many talked about getting taller, i.e. taller than their mum, and about wanting to look big and 'grownup'. Many of the girls were aware of their changing bodies and were looking forward to these developments. Both Kate and Jemma talked very specifically about 'becoming a woman' and Jemma eagerly anticipated 'getting boobs and having periods'. This was at the beginning of my eighteen months contact with her, and at the end when we reviewed this she said:

> *Jemma*   *I've got them now…boobs*
> *(and we proceeded with a hushed conversation whispering and with the VOCA on silent, so out of her mum's earshot about where to buy sexy underwear[39]).*

Two of the older boys changed the preset voices on their VOCAs to deeper ones during the year[40], to simulate their voices breaking. It was not clear whether they

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[39] It is possible to turn the 'voice' off on the VOCA, so that the listener has to read the screen, and thus this is the equivalent of whispering, as bystanders can't overhear the conversation. Skilled AAC users often use this to preserve privacy.

[40] All VOCAs have a number of different voices available, so the user can chose between different pitches, and qualities. There are a number of children's, and adults' (male and female) options. VOCA users often enjoy experimenting and playing with these as they can be selected quite easily with a click of a button.

had initiated this or whether their speech therapists had suggested it. In any case, both had obviously agreed to the change. At first this took listeners by surprise, particularly in Toby's case, as he still looked very 'little boyish', and of course the change of voice was sudden and complete, rather than gradual as it would be normally. They seemed to enjoy the attention this provoked. There will be further discussion about the participant's views of their bodies in Chapter Six.

Views of the future

Overall the teenagers had a range of ideas about their futures, some idealistic and others down to earth. This may be typical of many non-disabled teenagers, whose ideas about their futures are also in flux. Additionally, however the participants' visions of themselves and what they might do, were clearly strongly influenced and mediated by their families and their socio-economic background. Similarly, their attitude to their impairments and how these might affect what they could do or be seemed also to be influenced by that of their families and I often heard similar ideas from the adolescents and their parents. For instance both Terry and Toby's parents were rather pessimistic about their sons having a job, whereas Kate's, Jemma's and Nathalie's parents all felt they could and would do anything they liked, albeit with support. These parental views were echoed by the teenagers when we talked about their plans for adulthood.

Although there was some diversity in terms of social class across the whole group of participants, Marie was from a much poorer background than any of the others. It is noticeable that her ideas about what a teenager and indeed an adult might or should be diverge from the others. This demonstrates the stark reality that class, income and parental education are strong influences on what young people think about in the present and aspire to do later.

Also interesting is the varying extent to which they took their impairments into account in their ideas. This was a partly a reflection of age and maturity, so that generally the older participants had more focused and pragmatic ideas, whereas the younger ones were more fantastical. Ted and Toby, who have the most severe impairments, which thus also affected their methods of communication, were the

least sure about their futures. Those with the fewest physical difficulties and therefore the most independence currently, and the faster communication (Kate, Jemma) were the clearest in expecting 'mainstream' lives where they would participate on equal terms in work, social and family arenas.

Generally the girls' ideas were specific, practical and based in reality. They seemed to treat questions about the future, even when phrased in a very open way (such as 'what are your dreams?), as about the real world and what they want to do in it.

MW	*so what else about 5 years time? What will you be like? Will you be the same as you are now? Or what will you be like?*
Jemma	*an independent woman*
MW	*an independent woman… what does that mean Jemma?*
Jemma	*I'll (??) by myself*
MW	*you'll what by yourself?*
Jemma	*out*
MW	*go out by yourself… where would you want to go?*
Jemma	*with my friends*
MW	*with your friends?*
Jemma	*letting me go and be independent and not moddle coddle me!*

The girls included ideas about independent living, types of job and social life, and holidays. In comparison the boys tended to say rather general or idealistic things:

MW	*so what would be different about being a teenager and being an adult do you think?*
Terry	*(long pause)…..BE FREE*

The idea that adulthood was about freedom to do what you want (e.g. go to the pub, drink beer, have money) was mentioned by several boys. The boys were also less clear about how or where they would like to live in the future, more suggesting rather more dependent living arrangements than the girls. However this may be because by chance in this group, the boys had more severe impairments than the girls.

Toby's dreams were all linked to his interest in sport and despite me asking about the future in different ways at different times, he tended to say similar things:

> *MW   so what would you dream of doing in the future?*
> *Toby   BE MAN CITY COACH, BE ENGLAND COACH, GO TO WORLD CUP*
> *AND WE WIN, BE REF IN WORLD CUP*

Toby(14) took a question about 'dreams' literally, whereas the girls were more pragmatic, with the exception of Bryony(10), the youngest in the group:

> *I asked her about her dreams, she said she wanted to write a story, so she dictated this to me over about an hour or so.*
>
> *'One morning mummy got me ready for school. I went on the bus to Woodbury school and when I got there, there were lots of adults and children. Some who are always there and some others! All my friends coming to one school! I said 'what's happening? How did you lot get here?' Some famous people from TV like Harry P were also there! Then everyone did their schoolwork. Also there were other people. People in different classes. In my class was Anna (LSA), and also Rosie, me, and Sue and Jenny. WOW!'*
>
> *It subsequently emerged in conversation with her mum that she is finding attending two different schools (one mainstream, one special) very stressful and that what she wants is for all the people she likes to be in one place (fieldnotes)*

For Bryony, her dream story was a clear indication of what her parents said was her current confusion about her identity and about her wishes for the future. The older girls were more settled and clear about who they were and what they might expect to do, although there was still an element of perhaps normal fantasizing, ambition and conjecture (eg run a health club – bathe in champagne, travel the world, win the Paralympics). It seemed that the girls had more emotional maturity to think practically about their lives, whereas boys of the same age or older were still more interested in fantasy than reality.

Nearly everyone talked about having a job of some sort, although again there were gender differences. Most of the girls had strong ideas about what they might do, including more than half wanting to do some kind of caring role such as looking after babies, children or disabled people. Some realised that these ambitions might involve doing well academically and going to university. Five had hopes of continuing with further studies. With the exception of George, the boys generally had less focused ideas, although Terry(14) was interested in wheelchair design and Ted(12) was inspired by his mum being a nurse. However neither of them had a

clear idea of how they could follow up these interests. Josie(15), who was due to leave school and go to college soon, planned to study IT and drama, though she said that the whole idea of leaving school was 'SCAREY'. Toby and Terry were also moving on to a specialist college soon and both expressed a mixture of anxiety and excitement about this, but had rather unclear ideas about what they would study and why.

Everyone anticipated living independently as adults, or with friends or siblings rather than with their parents. With one exception their vision was of living in their own home, though most also recognised that they would need some help to do this, either from paid carers, or from parents who they generally expected would live nearby.

Ted(12) was the exception, and he described living in a more institutional setting and wanted to live with other disabled people. This is not to suggest that Ted had a negative view of disability or of himself, but that he recognised that he needed a great deal of physical assistance, and it did not occur to him that he might be able to have this in a non-institutional setting. This may have been strongly influenced by his awareness that his mother gets very tired and not wanting to burden her. Ted's view of himself is greatly influenced in contrasting ways by his strong individual and family's Christian faith. So although it had helped him to accept his disability:

GOD WANTS ME TO BE LIKE THIS

he also had faith that

GOD WILL MAKE ME WALK AND FEED MYSELF

I sensed that it also gave him a stronger idea that he would be 'looked after' by others and perhaps fewer aspirations for independence than the others.

For most participants the best thing about living independently would be freedom to do what they liked, and usually involved sociable activities, such as 'going out', and 'having parties'. Marie's was the most dramatic example:

> MW   *So we're thinking about living in a house, a place on your own? What would be good, or what would you do there?... (looks in comm book) Over. No? Over. No? Ah, it's not in Activities, is it, what you wanted?... Is it in Actions? ... Next... Something you do in the house?*
> Marie   *Yeah.*
> MW   *Back to the beginning of that (?). Yeah? Let's have another look, shall we? No? Another look? Is it on your VOCA?*
> Marie   *No. (looks at book)*
> MW   *No. (turns pages).... Music... so you could have your own music? yeah. Ok, ...*
> Marie   *(points to dancing)*
> MW   *dancing? (laughs) So you're having parties in your house, With all Marie's friends coming along? Ok... What else would be good about having your own place? you could have parties whenever you wanted.... Who would you invite along?*
> Marie   *Some boys.*
> MW   *Some boys. (laughs)*
>   *(further discussion)...*
> MW   *.....just you and a load of boys?*
> Marie   *yeah ! (laughs)*

In relation to emerging sexuality, although this group of teenagers had increasing expectations of sexual and close emotional relationships as they get older, they appeared much less experienced in these than their non-disabled peers would be. This was not something that they talked to me about explicitly, although I took what the girls said about wanting 'more friends' actually to mean boyfriends in some cases. The girls seemed to have a clearer idea than the boys about what was cool, and 'sexy' and what was expected of older teenagers or adults. They certainly talked about these more:

> Jemma   *(typing and giggling) CLUBBING*
> MW   *You wanna go clubbing?... mm what is clubbing exactly? Do you know what it is? What do you do when you go clubbing do you think?*
> Jemma   *Dance*
> MW   *Dance mm?*

Jemma	*and drink*
MW	*dance and drink okay… I think Marie would be into doing that wouldn't she!*
Jemma	*(laughs) yeah!*
MW	*have you talked about that with her? She always says she wants to go dancing and clubbing and drinking*
Jemma	*yeah*
MW	*what would you drink Jemma… what would be your tipple?*
Jemma	*I don't know*
MW	*you don't know… have you tried any alcoholic drinks? …*
Jemma	*juices…coke*
MW	*coke… okay clubbing dancing and drinking… right.. any others?*
Jemma	*LIMO FOR BIRTHDAY… 18*
MW	*you want to have a limo for your birthday…. For your 18th… what colour would that be … pink, white, black, silver? Have you seen them in town?*
Jemma	*yeah*
MW	*and who would come in the limo with you?*
Jemma	*my girlfriends*
MW	*your girlfriends…and would Lee be allowed in?*
Jemma	*yeah*
MW	*and what would you wear? In a limo… you couldn't wear your tracksuit bottoms and jumper!*
Jemma	*nice*
MW	*something nice?*
Jemma	*(gestures being posh and mincing about)*

Looking further into the future, the girls expressed a stronger expectation of themselves as sexually active adults than the boys. Four said they would like to marry and have children. However this imbalance in the data may again reflect by the lack of ease with which boys might discuss the topic with a female researcher, a factor also identified by Martin (1996) in talking to this age group.

Conclusion

This chapter shows that teenagers who use AAC see themselves above all as family people and as ordinary teenagers. Like other teenagers they are interested in and influenced by their same age peers and by sport, fashion, IT and media. Their social networks and close relationships outside the family, are for the most part, more limited than those of other teenagers, and the reasons for this will be discussed in Chapter Seven. They have a strong sense of their own lifecourse; in the past as babies and children, in the present as changing during adolescence, and of

themselves in the future as competent adults. The narratives they tell about themselves are both clearly influenced by their families' worldviews and at the same time demonstrative of their own individuality and emerging sense of their own autonomy.

Chapter Five. Selfhood: Me myself I

Introduction

This chapter builds on the previous one in looking at further aspects of the participants' selfhood. In particular it focuses in more depth on their views of themselves as social-emotional, autonomous and independent selves and the extent to which they view their disabled status as an important aspect of their identities. It contrasts with the previous chapter, which described the young people's 'ordinariness' as teenagers, in exploring ways in which they may see themselves as 'different' or as sometimes struggling to be seen as 'normal'.

Social-emotional self

The teenagers reveal various aspects of their social and emotional selves, which are perhaps the parts of them that are most under-recognised by others. They are concerned to be seen as people who have sensitivities, thoughts and feelings which are similar to their peers. As described earlier, they often express these non-verbally, as well as being adept at expressing their feelings through very short spoken phrases, where a natural speaker might have produced a paragraph. Many of them use hyperbolic exclamations such as 'terrible' 'horrible' 'I hate it', and 'fantastic', 'really cool', 'wicked', without any other elaboration, when asked for an opinion. George(16) emphasizes his keenness to have his emotional self recognized:

> *George*   *I experience a wide range of different emotions the same as any other man, maybe I even have deeper feelings than other people (written self description).*

Talking about sensitive and difficult topics was something I felt the young people wanted to do more, but this is often problematic, mainly because of time pressure. AAC conversations proceed so slowly, that often anything more than a superficial greeting, or an essential exchange of information is cut short. This can have the side effects both of depriving the AAC user of chances to have 'deeper' conversations, but

also it also easily gives the impression that they do not have such thoughts and feelings. One day at school Terry(14) attracted my attention and said:

> *I WANT TO TALK*

It emerged that his very good friend (an adult his dad's age) who had been ill for sometime, had died at the weekend:

> *He wanted to talk about Andy but also didn't in a way – so we had a chat about this. I asked if he was going to any kind of ceremony – he said yes and then 'NOT DRIVE CHRISTMAS EVE' which I think was about Midnight mass. WALK VILLAGE CHURCH. Had that sad and faraway look on his face, so we talked a bit about feeling sad about someone, and what he would remember Andy for? 'FESTIVALS' (fieldnotes).*

This precipitated me into thinking further about whether people using AAC feel that their emotional and reflective selves are overlooked by others as suggested by George above. He was the most able and explicit in voicing this. However most of them said variations of:

> *'TALK TO ME AS NORMAL' (Prakash 14)*

They are asking for recognition of their inner lives, which are easily overlooked because of the attention drawn to their different outward appearance. Reeve (2006) argues that for many disabled people, this denial of their subjectivities which can be called 'psycho-emotional' disablism, undermines their inner well-being and sense of worth, and can be more disabling than the structural barriers that are often given prominence in the disability rights discourse. This will be explored further in Chapters Six and Seven.

Being sensitive and caring

One common feature of the teenagers' self descriptions was their very obvious concern about other people, and their perception of themselves as caring, kind and able to be active helpers, not just recipients of help. Many of them were keen to be helpful, for example Marie's self-description included:

Marie	*kind... helpful*
MW	*okay... that's good.. who do you help?*
Marie	*mum*
MW	*how do you help her?*
Marie	*bus (book) look (sign)*
MW	*bus, look...you look out for the bus?*
Marie	*yeah!*
MW	*and tell her when its coming?*
Marie	*yeah!*

and

> *Toby* *I WILL HELP ANYWAY I CAN*
> *(offering to help his friend who was campaigning to be elected head boy)*

About half of the group had career plans that involved 'helping others' in some way as exemplified by the excerpts below in separate conversations.

Nathalie	*WANT WORK WITH CHILDREN...IN SCHOOLS... TELL ABOUT DISABILITY*
Jemma	*I wanna be a midwife*
MW	*be a midwife?.... And why do you want to do that? Why do you like that idea?*
Jemma	*I like helping people*
MW	*you like helping people ... people?...Or children?...or babies or everybody?*
Jemma	*(long pause) every people*
MW	*What do you imagine you'll do after school?*
Ted	*NURSE- I WANT TO BE THAT AFTER SCIENCE CLASS. HELP SICK PEOPLE AND I THINK I LIKE IT. DAY NURSE. I WANT TO BE IN A HOSPITAL.*
	I HAVE WARM HEART.... CARE ABOUT PEOPLE
Terry	*WHEELCHAIR DESIGN.... WANT TO MAKE BEST CHAIR*
Kate	*I WANT A JOB WORKING FOR A COMMUNICATION AID COMPANY ... TO MAKE THEM BETTER*

Some young people were explicitly concerned about those they regarded as 'less fortunate' disabled children than themselves, for example those who did not have

the right equipment. For example Nathalie(15) was very concerned about those who did not have VOCAs and so could not talk. She was involved in helping her mother in campaigning, including giving an interview on the radio, and reciting a poem about the importance of AAC at a lobbying meeting about improved services. Kate's mother was also very involved with lobbying for resources and disability rights and thus her daughter had a strong awareness of this:

> Kate   *EVERYONE SHOULD BE ACCEPTED FOR WHO THEY ARE NO MATTER WHAT THEY ARE*
> MW   *what about if people treat someone differently because they look different or...?*
> Kate   *totally totally wrong. I want to say that to everyone!*

Generally therefore these young people did not see themselves as passive receivers of help but as people who could help others, and who had the confidence and experience to help in a variety of ways. Jemma told me many times that she wanted to be a midwife and on one occasion at her house said this again in front of parents:

> *They both laughed and immediately teased her about this and said 'Jemma... you can't be a midwife ... you'll drop the babies!' This was obviously a recurrent family joke which they were happy to have in front of me, but Jemma ignored this and insisted that this was her ambition and that she would be good at it (fieldnotes)*

> MW   *you need science to do that you know*
> Jemma   *well I'm quite good at science! And I like babies*

In some cases (Ted, Jemma, Nathalie, Kate), their parents were working in 'caring professions' such as nursing, teaching or advocacy work, and so one might hypothesise that their children's choice of work was partly affected by this. As well as seeing themselves as kind and caring people, they had the influence of educated, assertive and politicised views of disability modeled for them by their parents. As middle class young people, they have already learnt to fight not only for their own rights but to be philanthropic towards others. Arguably this emphasis on care and caring contrasts with their non-disabled peers, who as a group might be generally sensitive to others, but do not have such a strong interest in these matters.

For some who expressed an interest in 'caring' roles, family influence was not so apparent, and it may therefore be that their own experiences of professional care (or lack of it) have influenced their interests. Sometimes it seemed that they were drawing on their own knowledge of a great many specialist services, and thus had a strong idea of how things could be done well or better. The three who specifically mentioned working in disability- related fields that are close to their own experience (Terry – wheelchair technology, Kate – communication aids, Nathalie – teaching children about disability), all said in different ways that they wanted to 'make things better' for the next generation of disabled children. Some of their concerns are about availability and development of technology, others related to the 'attitudes', which are discussed further in Chapter Seven. However the element that was common was their perception of themselves as caring people who could change things.

Being a good judge of others

Many of the teenagers implied that they were good at judging other people's characters and could tell quickly when they met a new person what they were like. Conceivably this is because they are often cast in an observer role on the edge of social groups and so are in a good position for a 'ringside view' of what goes on. My observation was that these young people spend much more time waiting and watching than others of their age and this was confirmed by their parents:

> *Natalie's mum   She's spent her whole life waiting*

Marie(12) described deciding quickly whether newly met people were 'goodies' or 'baddies' as she put it, especially in the way they related to her:

> *In a long and elaborately mimed and multimodal conversation, she said she likes to talk to people who understand her, but not many people do. At school people who do are me (mw), Bob (LSA) and Sally (SLT) and at home her (younger) sister Noreen is best and she translates for the others. She likes to use the VOCA and (communication) book if people know how. She said that a lot of people are useless and don't listen. She doesn't mind saying things many times if the person is trying to understand. Then it's worth trying a lot of different ways because the 'goodies' will hang on in there to get the message.*

> *She explained that some people (baddies) weren't worth the bother, and she can tell quickly who is what! (fieldnotes).*

Thus Marie uses her judgment about other people to decide whether or how she will communicate with them. This strategic behaviour in relation to communication is an important part of AAC users' armoury in maintaining their own sense of self.

When I first met her, Kate(13) was happy at home, but very unhappy and losing confidence at her mainstream school, and during the year changed to a special school where she was instantly more relaxed:

> *MW   so how is school now?*
> *Kate   FEELING LIKE A NEW WOMAN!*
> *MW   hey that sounds good... why?*
> *Kate   THEY GIVE ME THE HELP I NEED*

Later in the same conversation:

> *MW   cos when you first went there, you must have been wandering what they'd be like?*
> *Kate   yeah*
> *MW   and did you find out very quickly that they.....?*
> *Kate   in the one hour*
> *MW   just one... one hour!*
> *Kate   (??????)*
> *MW   what ? ..*
> *Kate   I SAID IN ONE HOUR. I SAID I WANT TO BE HERE*
> *MW   in just one hour after going there... you said I want to be here?*
> *Kate   yeah!*
> *MW   okay so you made a pretty quick decision... you sniffed it out pretty quickly!*
> *Kate   yeah!*

It seems that achieving recognition of their social and emotional selves can be a real difficulty for these teenagers despite their self-expressed sociability and sensitivity. Of course these qualities are recognized by close family and very familiar school staff and peers, but breaking through the barrier to meaningful and affirming relationships outside these settings and with same age peers can be extremely challenging.

Autonomous and independent self: being your own person

Negotiating agency

Having 'agency' is commonly regarded as having the ability to affect change. It is closely linked to individual rights and describing someone as 'agentive' or autonomous suggests that they are able to make choices and to show who they are as a person (Mackenzie & Stoljar 2000). AAC users' repertoire of ways to show who they are, are somewhat different from those of other people. However most of the group were very clear about who they wanted to be. They knew what they wanted to be in control of and expressed concern about situations when they felt they did not have choices or a voice (Watson 2006). Ted's mum in describing him said:

> *He likes to be in control and directing things,*

and Ted(13) himself then added:

> *I LIKE IT IF PEOPLE TAKE ME SERIOUSLY.*

Later on, his mum said she was not a mind-reader and could not always guess what he wanted, when he retorted:

> *I THINK WHAT I THINK!*

Thus he emphasized that even if other people did not understand him, he was sure of his own ideas. For him this was about 'being your own person'. Terry's parents discussed how much autonomy he has compared with his brothers. They felt that in practice he could not have as much except in particular situations:

MW	*...does he ever do that? Go into a shop on his own?*
Mum	*No never*
Dad	*Well, he does, when we go to the Festival, which we'll go to in the summer, on a Festival site, we do just let him go.*
Mum	*He's been on his own since he's nine.*
Dad	*And we just let him go. I mean, he takes a purse with some money in, I mean, whether they rip him off or not, I don't know*

> MW He comes back with stuff though, does he?
> Dad Oh yeah!...he came back with purple hair one time!

I witnessed numerous examples of the teenagers very clearly expressing who they are, sometimes in conventional and sometimes more unusual ways:

> *Marie (13) has a collection of keyrings, and on one of them it says 'get out of my way, I'm fabulous'… she regularly waves it at people and giggles (fieldnotes)*
>
> *Kate (13) in art lesson - working on a painting inspired by Van Gogh's sunflowers. The teacher introduced the task as being about 'representing you'. She matched up the colours for the yellow background and splodged this on and then the detail of the white centres of the flowers. She wrote 'Vincent' on the pot and then 'by Kate' at the bottom. She pointed to herself, said on her VOCA 'SECOND VINCENT' looked at me and laughed (fieldnotes).*

They were all quite persistent at explaining to me aspects of themselves which they perhaps thought were under-recognised. If their suggestion was rebuffed or challenged, they generally reiterated the description:

> *Jemma (12) fit*
> *MW and how else would describe yourself then?*
> *Jemma (puts VOCA on silent and types - giggling) SEXY*
> *MW sexy … (laughs) fit and sexy .. oooh!*
> *Jemma (squeals) yeah !....(types) NAUGHTY SCHOOLGIRL*
> *MW You think you're a naughty school girl?... but Jemma whenever I see you in school you're always very good…you're not very naughty at all!*
> *Jemma (squeals and laughs)*
> *MW but you like to think of yourself as naughty do you? … what do you do that's naughty?*
> *Jemma (typing and laughing)*
> *MW would you like to be more naughty?*
> *Jemma (types silent mode) CHATTING*
> *MW chatting? … you think you're quite chatty? Like?*
> *Jemma chat a..(???) boys*
> *MW chat with boys?... No?*
> *Jemma chat (a???)… (types silent mode) ABOUT BOYS (laughs!)*

Seeing how the young people asserted their agency and had a great deal of self belief regularly surprised and impressed me. This kind of selfconfidence about what they could do or get done was evident with nearly all of the nine key participants but also with the most of the wider group of 15 teenagers. What Josie says below in relation

to communication shows a remarkable resilience considering the complexity and 'effortfulness' of her communication methods:

Josie	*I ALWAYS GET MY MESSAGE ACROSS SOMEHOW*
MW	*do you ever give up?*
Josie	*NO*

These examples show that the teenagers are as keen to exercise control over their lives and express their own opinions as might be expected at their age. However their physical dependence on others and their communication methods often make it much more difficult for them to achieve this. This was revealed as a source of anger and frustration by all of them as evidenced here:

Nathalie	*I HATE PEOPLE NOT TALKING TO ME AND IGNORING ME*
Bryony	*WHEN PEOPLE JUST SEE THE WHEELCHAIR*
Josie	*I HATE NOT GOINH OUT WITH FRIENDS*
Terry	*WHEN PEOPLE PATRONIZE ME*
TOBY	*NOT GOING OUT PLACES*
Ted	*I WANT TO FEED MYSELF AND DRESS MYSELF*
George	*WHEN PEOPLE THINK I DON'T UNDERSTAND*

Being independent and negotiating help

Having to rely on others for help with many practical aspects of life, and yet at the same time negotiating a sense of agency, is a very complex and multilayered process. Issues around the amount and type of help that is needed and wanted are sensitive, and are often sites for contest between young disabled people and those who support them either within the family or in paid positions.

The participants' attitudes to assistance varied greatly and were linked both to their personalities and their ages. The two youngest (Bryony and Ted), were the most adamant about wanting to do things for themselves, and were the most likely to get very cross if this was not possible. Both expressed a desire to do more themselves, whereas the older ones seemed to accept that this was sometimes too difficult and talked more about the nature of the help they wanted. I saw this contrast in the attitudes of Ted(12) and Toby(14) to driving their wheelchairs. Both use head switches to do this, so for both it requires very considerable physical effort and is a

very slow process. However there is an option to allow someone else to 'drive' the chair for you:

> *Toby is happy to let people drive him sometimes, or to do some of the typing on the computer for him to save time, whereas Ted gets really cross and wants to do it all himself even if he knows that will make him late and very tired (fieldnotes).*

This was not laziness on Toby's part, but a pragmatic attitude of accepting help and being clear that this does not make him less of person. Sometimes he judged that it was more important to get to class on time than to drive himself there. Perhaps this pragmatic and self-accepting approach is something that comes with experience and disabled teenagers gradually learn. Certainly the younger ones expressed their frustration at not being 'in charge' in more dramatic and overt ways, such as shouting and physically resisting things they did not like. It appeared that as they got older they discovered ways to claim agency and express choices in non-conventional but 'acceptable' ways, using a body movement, or a short but pithy phrase on their VOCA as recalled by Bryony's father here:

> *Probably the best example of it, in a very busy department store, with a couple of people stood in the isle blocking Bryony's path and she is in her powerchair and so she's got her VOCA and typed in the word 'MOVE'. And they didn't hear it, but she bumped against them and they sort of... they turned round and you could see that it registered that there was a little girl in a power wheelchair looking annoyed at them, but... that's okay, you can just ignore that, so they turned round to talk to each other again so she turned the volume up and said, 'MOVE NOW', and I said, Bryony, that's not very polite, so she bumped the volume up a little bit more and said, 'MOVE NOW PLEASE', and then drove into them and they moved out of the way.*

Several parents recalled that their son or daughter used to have more 'tantrums' about being helped, but that as they had got older these had stopped and they had learned to express their need for help or wish to do something themselves more clearly and assertively. As Josie's mum put it:

> *She is happy in her skin, and she knows what she can do and what she can't.*

Similarly

Terry and I talked about who helps him and how – he was quite interested in this and said that the people he likes to have helping him are people who want to help – who aren't just doing it for a job – and 'who care', later on he said that trust is important and people not thinking he's a baby. He was very clear about this.

Toby's mum described his insistence during a family holiday in a hotel that he should be carried upstairs with his (very heavy) powerchair to where his siblings and cousins were playing:

We said, look, Toby, it's four flights of stairs, we can't do it… he would have… I think, we would have had to get everybody else downstairs, I think, because it wouldn't be fair. But because he knew how many stairs there were, he knew his dad was there, and his uncle was there, it was a case of… he said with his eyes…I've worked out how you can do it, we're doing it. And … we did… yeah!

Similarly, I noticed that when a new task was introduced in class, Jemma would very quickly decide whether she would be able to manage on her own or would immediately say:

I WILL NEED HELP WITH THAT

in order to secure the help of one of the scarce resource of adults in the classroom before someone else got them. Amongst the group there was a variety of ways of asking for help. Some people (Jemma, Kate, Josie, Marie and Terry) were very skilled at this and seemed very able to 'recruit' the adults around them, to get help when they needed it, and also conversely could show when they wanted to do things for themselves. Thus they were able to demonstrate their agency in various ways. However for some of the others this was not so easy.

Bryony(10), Ted(12), and Toby(14) struggled more to get the balance of help and 'independence' that they wanted. I saw all three of them getting very agitated on various occasions and it usually emerged that they were being helped either more or less than they wanted. Bryony and Ted were both particularly sensitive about the amount of help they needed. Bryony often liked to do tasks herself, but then in an upsetting 'double bind', would often be unhappy with what she had achieved. She

would often say 'its rubbish' about how she'd done something, but also be unhappy if she was helped as then she felt she hadn't done it herself:

> *Bryony – in IT class today, the task was to make a mother's day card on the computer using a drawing package. She had a very clear idea of what she wanted hers to look like, but got very agitated with Sue (LSA) and with herself, because it didn't come out right. She wanted it to be neater. She was using a specially adapted mouse, but even so her hand movements are quite unsteady, so the result was too wobbly looking. She thought it looked babyish, but at the same didn't want anyone else to do it for her or tidy it up. A constant dilemma (fieldnotes).*

She seemed to be struggling with various aspects of how she saw herself at this time, and this was summed up by her saying:

> *LIFE IS NOT EASY FOR ME*

and

> *I WANT TO DO THINGS MYSELF*

For disabled young people, part of the identity development they need to do is to resolve the dilemma of being someone who needs help with being a 'good enough' person and being able to integrate these into their selfhood. These kinds of conflicts have been explored in relation to disabled adults (Shakespeare 2006), but not to date about children and young people.

Independence and what it means

The word 'independence' was often used in conversation and emerged as a recurrent theme both in the discourse from adults around the young people and also from them directly. The issue of relationships between them and people who help them will be discussed further in Chapter Seven, but here it is important to deconstruct 'independence' as a concept, because it appears to link closely with selfhood and the ways in which the teenagers wanted to see themselves. Nearly all the teenagers mentioned liking to be 'as independent as possible' both presently and in the future. Superficially this was often linked to having particular equipment, or to skills which they felt they needed to achieve 'being independent'. Frequently this

was in relation to practical aspects of daily living such as toileting, dressing, eating and drinking, or moving around. There was a link with very specific actions such as: learning to 'drive my power wheelchair', 'to transfer from the chair to the loo', 'use my hands for eating', 'play with playstation with my feet', or 'write letters to boys'.

Independence however, was also mentioned in more impressionistic ways, when thinking about the future, where they might live or work, and other activities such as shopping, going out alone, or travelling. As Kate(13) succinctly expressed it:

> *I DON'T LIKE IT WHEN I HAVE TO DO EVERYTHING WITH MUM OR DAD. I WANT TO BE LIKE MY FRIENDS. I WANT TO LIVE INDEPENDENTLY WHEN I'M OLDER SO I NEED TO PRACTISE NOW.*

This was echoed by several others who had been on trips away without their parents or school staff and all emphasized that what they liked was going 'on their own'. They said this made them feel 'more independent'.

Kate although not one of the oldest, has clear ideas about what independence means for her. She has relatively good physical skills, so the possibility of doing many practical tasks herself is realistic. However, she also has an understanding of what she needs help with. She wants to 'manage' this help, and decide how it will happen. Her thinking about how she can maintain her sense of self, and at the same be helped may have been precipitated by her unhappy experiences at a previous school, where she said 'they didn't help me at all!' and 'they expected me to do things I couldn't do'. At her new school things are better and she feels in control:

MW	*care? … so that's stuff like helping you wash or go to the loo or have lunch and stuff.. and how do people do that in a good way ? how do you like it to be done*
Kate	*they tell me what they're doing*
MW	*mm? …so they say… now we're doing to stand up or pull your knickers down, or wash your hands… so they give you some warning?*
Kate	*yeah*
MW	*so that's useful… so you like to know what's happening?*
Kate	*'I tell them'*
MW	*you tell them… what you like?*
Kate	*yeah*

Young people with disabilities have therefore to learn the skill of managing adults who 'manage' them, to make sure that things get done, for example reminding people to put their tray back on, do straps up, bring their equipment, or charge it up at the right time. I regularly saw the frustration which resulted when these things did not happen.

Despite all the rhetoric about independence being an important and achievable goal there was, often some confusion about whether this necessarily implied doing things yourself or alternatively being in charge of getting them done.   The latter interpretation is the one used more commonly in the literature on 'the independent living movement' (1993b), but it is easily misunderstood.   However it was sometimes the former expectation which prevailed.   This resulted in adults encouraging young people to do things for themselves which were actually rather difficult and perhaps unachievable, and leading to occasions when children were labeled as 'lazy' or 'not taking responsibility' if they did not physically do things themselves.

The use of the term 'independence' in relation to practical living skills appeared to have the status of a mantra, promulgated by adults. Parents, therapists and teachers often use 'so you'll be more independent' as the reason why the teenager should do particular activities. It is certainly true that the young people themselves seemed to concur with these aims and saw them as important. They were generally very accepting and uncomplaining of going to therapy to practice skills and saw the sessions as enjoyable and useful even if painful or boring at times. They appeared to 'try hard' to do what was required of them, spurred on by the ultimate goal of 'independence'.   However some teasing out of the difference between 'physical' independence and real autonomy and choice is pertinent here. Some post-structuralist disabled researchers would see this emphasis on physical independence as evidence of the young people's subjugation to the all powerful medical model of disability, as it tends to have an underlying message about 'getting better' (Thomas 2006). Such debates have been rehearsed at length in relation to

adults with disability, but have not been considered carefully enough for disabled children. Of course a disabled child is at risk of being seen as dependent both because of their disabled and their child status (Alderson 1995, Alanen & Mayall 2003, Christensen 2004). For them, because of the power imbalance between them and adults, there is the possibility that people who ostensibly 'care' for them, deny them choices about exactly *how* to be independent, and over-emphasise individual physical or verbal competence rather than autonomy. The following notes about Marie and Jemma illustrate the point that this varies between individuals:

> *Then I helped Marie to finish making a 'little mermaid' mobile. She has a strong sense of colour and is very insistent about getting the colours matched up just right, matching the shades of blue and green for the fish etc. Indicating all this nonverbally but clearly. Happy for me to do the actual painting because she wants it to be neat, but resting her hand on mine, to be part of it. Unlike Jemma who definitely wants to do it herself, even if it's a bit messy (fieldnotes).*

> *Jemma –I was pushing her in a manual chair to the physio room. As I pushed her she was 'bossily' telling me where to go (pointing and saying 'there'). I said 'okay left here boss' and she giggled and wrote OKAY BOSS on her VOCA and kept pressing it multiple times, enjoying bossing me and laughing (fieldnotes).*

Parents, even those who were not particularly active in disability politics tended to have a more nuanced and realistic understanding of how their son or daughter could be 'independent' than professionals did, and expressed more clearly that what was important was their sense of self, rather than necessarily practical abilities.

Interestingly the girls in the group express this desire to be autonomous and 'independent' much more clearly than the boys as these conversations with all show:

MW	*What will you be up to? in 5 years time?*
Jemma	*uni*
MW	*uni.. okay... (discussion re mindmap)*
Jemma	*(??) with my friends*
MW	*doing what with your friends?*
Jemma	*LIVING*
MW	*living with your friends... or thinking about it?*
Jemma	*living with ... when I'm 18*
MW	*when you're 18 you'd like to move out of home and live with friends...would be that be near mum and dad or far away from them, or what do you think?*

Jemma	*remember there's going to be the Olympics?... they are gonna make new homes*
MW	*you think you might get one of those?*
Jemma	*yeah*

Josie talking (by headspelling) about her power wheelchair:

Josie	*INDEPENDENT*
MW	*so your chair gives you independence and … that makes you feel?... better ? yes ? anything you want to add about that?*
Josie	*H A T E hate I B E I being I N in M Y M A N E U*
MW	*(recap)...ah manual, you hate being in your manual okay...because... It's someone else being in charge of you … ?*
Josie	*nods yes*
MW	*so in your electric you can zoom about and... bash into people...and … cause havoc in whatever way you want?*
Jose	*nods yes and giggles*

Marie (using her symbol book) thinking about the future	
MW	*What would you do...? you would have cool things? Ok. Like..?.*
Marie	*(?)Gestures*
MW	*Like what?*
Marie	*(?? ? ??)*
MW	*Is that in your book? I'm not getting it, Marie. Transport...yes, transport?*
Marie	*No.*
MW	*No. Wheelchair. What about your wheelchair? Electric. You'd have your electric; would you have it at the college? Tyres?.. so you could go outside, you mean? Ok, so you'd be zipping about, going out to places in your electric?*
Marie	*bed (sign)*
MW	*And having a bed there, yes. Electric chair with tyres, bed, yep; what else would be cool? Tyres are for outdoor, aren't they, going on the road? Is that what you want to do?*
Marie	*(?)electric bed*
MW	*electric bed?*
Marie	*Yeah.*
MW	*(laughs) Like so you can get in and out of bed on your own? Yes, ok. So is that about more independence too?*
Marie	*Yeah*

It seems, therefore, that the teenagers are in a 'catch 22'. They have extra needs to be agentive and assertive, in order to manage their bodies and their choices, and to get people to help in ways they like. However they are inevitably more dependent and restricted in the ways they can make this happen.

Their regular use of the term 'independence' in our conversations suggests that this behaves as a proxy for some more complicated and subtle desires and feelings. Although it was superficially linked to practical competence, it was actually about selfhood and personhood. As described above, a sense of being in control and able to affect change emerged as important. When describing things they did not like, they all included aspects such as: not being listened to, being misunderstood, not having choices, being stared at in public, being left out, being patronized, or being treated as stupid etc. Thus their use of the word 'independence' could be interpreted as a way of countering some of these experiences, more than necessarily about being able to perform practical acts of self care etc. They are saying something important about agency, autonomy and recognition of themselves as real people (Hughes & Paterson 1997). Feeling in control and being perceived as such by others is arguably more fundamental in terms of identity than *doing* things. It may be verbalized as 'independence', but this is not a profound enough word for what they are saying, as shown here:

> Jemma *I like doing it my way*

and

> George *IF THEY GIVE YOU A CHOICE YOU FEEL MORE IN CONTROL OF DECIDING THINGS*

This recalls Thomas' (1999) 'social relational' model of disability which suggests that 'barriers to being' are the main difficulty, not 'barriers to doing'. 'Independence' is more about being able to show what sort of person you are, than just about getting practical things done. However for all of them being able to express who they were was in itself dependent on technology.

Private selves

Clearly all children as they reach adolescence start to want to have more private lives, both physically and emotionally. Both aspects of privacy are complex and important for those with physical disabilities and for those using AAC. They have at the same both less physical privacy because of their need for support with everyday tasks and because of their method of communication, and also more 'emotional or

psychological' privacy because their thoughts and ideas may not be expressed as readily.

Physical privacy is something that these young people will never have completely, as they will continue to need help with ordinary self-care tasks normally done independently. Much of the work of occupational and physiotherapists aims to develop disabled people's skills in these areas as far as possible, but all of the participants will continue to need lifelong physical assistance. Thus they have no choice but to accept the regular involvement of others in intimate aspects of daily life. To a large extent they accept this and are more concerned about the nature of the help they receive than the fact of needing it. Styles of caring and relationships with carers will be addressed further in Chapter Seven. One might surmise, however, that as they have always had this level of physical support, they have little idea of what it would be like to do these things alone. Indeed, most expressed little concern about physical privacy per se.

Occasionally, I was involved in helping some of the girls with toileting and changing for swimming. Their regular carers' approach was always very matter of fact, chatty and jovial, but I felt very aware of the dependency of the teenagers in these situations. They did not express concern about this. However, one incident in relation to physical dependency and privacy stands out. This was on a residential fieldtrip when Toby(14) was out of his normal routine and being helped by different carers:

> *After the (evening) game, I took Toby down to the bedrooms (pushed his manual chair), as everyone was gradually turning in and he said he was tired. On the way we met Susie (SLT), wheeling Adam, going to the same room. When we got there, there was no-one else to help with getting Toby out of his chair and onto the bed, so Susie and I lifted him. While doing this we immediately realised that Toby had pooed himself badly (there had been some jokes during the game earlier about a smell, which everyone else had assumed was just a bit of wind). It was all leaking out of his nappy through his trousers, onto the bed etc. It was difficult to tell how he felt about this as he was lying down so had no access to communication except facial expression, but I guess he didn't have much choice about what happened or the luxury of being embarrassed. He must have been distressed but this was hard to know. A few minutes later as we cleaned him up the school nurse came in and started to tell him off for not*

saying he needed the loo earlier, in a way that I thought was quite punitive and insensitive to his situation (fieldnotes).

It may have been that the teenagers did have more views about physical privacy issues, but that they chose not to discuss these with me, or the context did not make this appropriate, especially with the boys. Only Kate(13) and Marie(12) expressed specific concerns about who did what with them:

> *MW   is there anything you don't like… like when you're having care done… that you'd like to ask people not to do*
> *Kate   no*
> *MW   so at school they do it well?*
> *Kate   yeah … I don't like it when (????) … DADDY HAS TO DO IT*
> *MW   when daddy has to do it … okay… why is that?*
> *Kate   HE'S A BOY*
> *MW   he's a boy and… it's a girly thing?… yes.. I can understand that.. and you're a teenager… girls and boys do things separately don't they?*
> *Kate   yeah*

Kate was just reaching puberty and had not started her periods, but perhaps was anticipating this. Also, perhaps she felt confused by the contradiction that at school the rules about which staff helped with 'care' meant that a man would never do this with her, and yet her father sometimes did at home. Her comment suggests a growing awareness of herself as a woman rather than a girl and the gender boundaries which this implies. Marie also hated having certain things done for her by people that she had not chosen or approved:

> *At the beginning of the lesson Marie had shown great distress about something – it emerged that it was about having her tube-feed – which she is always given sometime during the first lesson by one of the nurses, and usually with little fuss or attention. Her anguished cry and physical signals of refusal paralysed the class for a few minutes – a feeling of empathy from everyone. I think it was about who was going to give her the feed, as the usual nurse wasn't there. Holly (LSA) took her out for a few minutes and some negotiation went on about who would do the tube feeding. Then she was relaxed and happy again (fieldnotes).*

Quite understandably in both cases, the two girls want to retain some control of the situation, and this may have been true of the others but I did not witness it so clearly. In Marie's case, her communication difficulties mean that she often chooses to express this anger about changes of the routine through non-verbal means, and I

rarely saw her get so upset about anything else. Her message was very clear: that she did not mind having these things done, but they had to be done by the right person, in the right way.

In contrast to physical privacy, 'emotional or social privacy' seemed to be much more of an issue, or perhaps one that participants were happier to discuss with me. Two rather different underlying reasons for this concern emerged from the data, first related to communication, the second to age and status.

Being an AAC user makes confidentiality in conversations difficult. Using low tech AAC such as signing, gestures or a communication book, renders communication visible and 'readable' by inquisitive onlookers[41].

I witnessed numerous occasions when the participants had just said something (on their VOCA), and then someone who was not involved in that conversation looked over their shoulder at their screen, to see what had been said. Sometimes the observer then made a comment about what they had read, which I perceived as a gross violation of the AAC user's privacy, and often the comment was inappropriate and out of context:

> *Terry who was playing argy bargy, queue jumping other people in his chair. He still had 'church' on the screen on his VOCA from our previous private and sad conversation about a family bereavement. One of the care staff looked at this and said 'church?' what's that a spelling mistake? Terry just nodded. Private lives and thoughts made into public worlds. Previous conversations and thoughts on display for all to see and no easy recourse (fieldnotes).*

Terry seemed resigned to this and did nothing to explain, but some of the other teenagers expressed irritation about this happening and at the misunderstandings and misrepresentation of them that follows. There has been some discussion in the AAC clinical literature about the ethics of therapists or researchers having access to

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[41] A natural speaker can talk quietly or metaphorically to disguise the message from unwelcome listeners. This is not as easy for an AAC user, having to give their message slowly and in edited form. When using a VOCA, privacy may also be compromised by the unusual voice which attracts attention, by its loudness (which is difficult to change quickly) and also by the visual readout of the message which stays on the screen after the spoken message has been delivered.

AAC users' output records [42]. Some users argue, quite rightly in my view, that this is an invasion of privacy. I saw several of the teenagers and the research advisors (Katie and Alan) switching their VOCA to 'silent mode' and encouraging selected conversational partners, to read their screen, as a privacy measure. Paradoxically, for an AAC user, although what is said is more public and observed in some ways, this mode of communication also potentially gives more and sometimes unwanted 'psychological' privacy. This is because many thoughts and ideas may never be expressed, as a consequence of the limitations of the communication systems available. I often had a sense that the teenagers were thinking more than they were saying, and as mentioned earlier, made strategic choices about what was worth the effort of expressing, and when I asked them about this many agreed that they were pragmatic about who to talk to about what. Additionally, as described in Chapter Three, for those who were very reliant on someone mediating their communication (interpreting or rephrasing it), their actual thoughts may not be well represented and therefore much of what might be expressed easily by a speaking person remains private and unheard.

These teenagers have to be quite assertive if they want to talk in private or about not wanting to discuss some topics, and this may be no different from their non-disabled peers. However it seemed that there was a tendency for their business to be public in a way that is perhaps more accepted with younger children. In our conversations either at home or at school, nearly all the participants made it clear on occasions that they wanted us to talk in private and took action to ensure this:

> *Mum sitting on the sofa while we were starting a conversation mindmap about*
> *her life story on the floor:*
> *Kate   what are you doing mum?*
> *Mum   writing my shopping list, why? Do you want me to go out?'...*
> *Kate   yes*
>
> *Mum went out, Kate laughed and very firmly shut the door (fieldnotes).*

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[42] It is possible with many VOCAs to get a readout of all the utterances the user has made, hence a 'transcript of their speech' over a certain period eg a day or a week. This is called LAM – Language activity monitoring. Researchers claim that this is useful 'data', but it is not something you can do so easily with a speaking person (Hill 2004), and the ethics of it are hotly debated.

Similarly, others deliberately sent their siblings, parents or friends away so that we would not be overheard.

In relation to private topics, only Marie overtly indicated that some issues were too private for us to discuss, and she normally did this by doing a 'shh' gesture and saying 'secret'. She was quite private about her home life, and I was not able to visit her at home. It seemed as if her school and home lives were very separate and she was clear about keeping it that way. Marie also had strong views about her right to privacy in public arenas, and this was expressed rather similarly by many of the group:

> *Marie mentioned that she didn't like people who are nosey, with a dramatic gesture – pointing to her nose, and laughed. She was talking about people she meets in shops and in the street who ask nosey questions (mostly to her mum not to her- which made it worse) (fieldnotes).*

This was echoed by several of the others, who described how strangers in public spaces deny them privacy by staring or asking inappropriate questions. This lack of recognition of boundaries of the self was then an invasion and an infantalising process which the young people found very annoying. They described ways of resisting and challenging this intrusion which will be described in Chapter Seven.

Disabled selves

The literature suggests that often disabled people do not regard their impairments or their disabled status as the most important or dominant aspect of themselves (Watson 2002, Reeve 2002). This study supports this notion, as the teenagers varied in the extent to which they mentioned their disability as note-worthy and in the manner in which this was expressed.

Being aware of labels and categories

All the participants knew the terms 'disabled', 'cerebral palsy' and 'AAC', although they rarely used them spontaneously. Their views of themselves did not tend to foreground anything about their impairments, or about disability, although it

became clear that they all knew that they were placed in the category 'disabled' by others:

> *They had to fill in some forms about a community arts project. I did them with Marie and Jemma together. Had to tick boxes for various categories. Both individually agreed that they should tick the disabled box, but with no particular discussion. Both also ticked specific boxes for their ethnicity, using categories that I did not know about either of them (fieldnotes).*

When I told the teenagers vignettes about imaginary disabled teenagers who were deliberately rather like them and when I used words like disabled or cerebral palsy or VOCA, many of them pointed to themselves or said 'like me' in a matter of fact or an excited way and were keen to discuss the dilemmas described.

For many, although they are aware of their social categorization as disabled, they do not particularly see this as potentially stigmatizing or negative at the moment, although Bryony is the exception and will be discussed below[43]. Using a wheelchair and VOCA are practical things to be dealt with, rather than major aspects of who they are. Some parents suggested that this was something that had changed as their children grew older, and that when younger they had asked very direct and practical questions about why they had cerebral palsy or why their legs did not work. This excerpt from Ted's mum was particularly stark:

> *Mum   At this point he is quite comfortable with being in a wheelchair and having cerebral palsy.*
> *MW   You say at this point? Is that something that's changed or been..?*
> *Mum   Well, when he was about eight there was a bit of a crisis, which is quite young to recognise how different you are from others. But that was worked through at his mainstream school that he was at, and currently he's definitely happy enough with it. Even last week… no… I was saying that in an ideal world we'd still have his brother who died, and we would still have Dad, and Ted wouldn't have cerebral palsy.*
> *MW   You said that?*
> *Mum   I said that and… he reacted to that*
> *MW   Oh, did he? Okay. That's interesting. What did he say?*
> *Mum   He felt that it was okay to have cerebral palsy, he was accepting of that. I think because he has a very strong Christian faith he, he has grown to*

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[43] Although again it is possible that they didn't want to or didn't have the language to talk about this.

> *see it that God has allowed this and that he is in part the person he is because of his cerebral palsy.*
>
> MW   *Right. So, he didn't like the fact that you'd, you'd put it with two other very sad things?*
>
> Mum   *No. He didn't like that.*
>
> MW   *Interesting. You were surprised by that really?*
>
> Mum   *Yes. I was. Yes.*
>
> MW   *It's good actually, isn't it?*
>
> Mum   *It is good. It is good. He's, I'm sure that there will be other times when he has to reface issues as he gets older, but right now he's …okay with it.*

Interestingly, however, many of them have ambivalent views about other people (particularly children) that they encounter, who have disabilities. Several told me that they were glad that they did not have various other impairments, such as learning difficulties, or behaviour problems and felt sorry for people who did. In parallel with other authors focusing on identity in disabled adults, I found that the young people did not see the disabled community as their reference group (Watson 2002). Additionally they were keen to distance themselves from those with 'low status' impairments, and so a hierarchy of different impairments is active *between* disabled people as well as in 'mainstream society'[44] (Deal 2003). Often those with communication disabilities figure in this hierarchy as an especially 'marginalised' category. However the participants here did not see themselves as part of this. Ted, notwithstanding his mother's report of his positive self image in relation to cerebral palsy, was very anxious about possibly being seen as having learning difficulties:

> *Sue (SLT) said she had done an assessment of language understanding[45] with Ted and he'd scored very low for his age. She said he had recently asked again about the issue of being cured and had said 'but God will change me to walk, but now I don't know what'. This was after she had fed back to him about the test and suggested that sometimes he might have trouble with understanding. He had reacted badly to this and said 'handicapped in the head' and was worrying about being 'not good' at some things (fieldnotes).*

George(16) also emphasized this, although as a more politically aware young man he expresses it more subtly:

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[44] The literature suggests that those with learning and behavioural difficulties and mental illness are more excluded and stigmatized than other impairment groups (Deal 2003)

[45] TROG (Test for Reception of Grammar. Bishop 1983) a test regularly used to compare children's understanding of language structures with that of other children of the same age.

> *There is a marked difference between physical disabilities and learning difficulties. I think this should be made clear in the DVD. Everyone has different abilities to a greater or lesser degree and being less able to move doesn't mean that you are less able to think!*

Thus for him, proving that he is able to think is most important. It seems that many of the young people made normative societal judgments about disability and applied these to others, though not to themselves. Katie (RA) confirmed that she herself had done this as a teenager. She remembers being rude and dismissive about other people who 'walked funny' and suddenly becoming aware that she looked like that herself and being confused by this.

The extent to which the participants were aware of broader aspects of 'disability politics' varied greatly. The two girls who had parents who were involved in disability activism, were very aware of the arguments rehearsed in these arenas. The girls had overheard discussions about 'the social model of disability' and though neither of them used this term themselves, they talked about 'not feeling disabled' in certain situations, which suggested that they understood the term from this perspective. Thus they had an idea that disability was a socially constructed entity rather than anything to do with them as people. The others had a less explicit or verbalised understanding of this, but certainly all of them believed that although they were different, they had a right to do the same things as other young people and were indignant when they could not.

One world or two?

Although not able to generalize too strongly from such a small group, the participants who attended special schools appeared to have a stronger sense of a 'disabled identity' as being part of themselves. This had both positive and negative aspects. Thus they were all sure that their school suited them because it offered them opportunities that a mainstream could not: Josie, Terry and Kate emphasized the disabled sports opportunities, and Terry, Toby and Ted, the special technology and the therapies that helped. Marie felt that no-one would understand her at a mainstream school and that she would be bullied. There was for her then an element of refuge and protection, which sounds rather old fashioned in the present

pro inclusive education climate. Shakespeare (2006) however, has suggested that this sense of a 'haven from a hostile world' is still important for some. Ted's mother's interpretation of what he wanted for the future echoes this, although it is unclear whether this is really his idea or hers:

> Mum   He realises that he would need carers helping him, yes. He knows that and he knows that there really needs to be someone around all the time. But if it were the right person or people then he would be quite happy with that. So I don't think it's a worry to him at this point.
>
> MW   So you… imagine that rather than him living here with you…, until he was 30 something, or 50 something or whatever?
>
> Mum   I would rather he didn't. [laughter]. I find him tiring now and emotionally, and physically, and… I have back problems periodically, and the last time I did my back, it's nearly better. He's only going to get bigger.
>
> MW   what sort of place do you imagine him living in? what kind of setup? what does he?…
>
> Mum   With people like himself. Probably partly because he realises it's hard work for me but there's the people he relates to, so he would like five or six of them in a home with the, the right number of carers but not too far from wherever I am.

This did not mean that any of these young people did not also see themselves as part of the 'mainstream' world. In fact, Josie expressed some ambivalence about her special school and the specialist residential college she was due to go to. Her concerns were about her social life.   She would rather have gone to a local mainstream college near home, but had been persuaded that they would not have good enough facilities for her.

The extent to which the world is distinctly dichotomized seemed to vary for the young people. The three who attended mainstream schools (although Jemma and Bryony were only part-time) were perhaps least comfortable with their disabled identities taking precedence, and talked more actively about trying to integrate the 'two worlds' or not wanting to do 'disability' things. They had a clear idea about wanting to be seen as 'normal teenagers':

> Jemma went to gymnastics club with her sister, and to an outdoor pursuits centre, where although there was a special needs support worker to work with a number of disabled members, she preferred to try to manage without this help and do exactly what the non-disabled children did. She definitely allied herself

with the 'mainstream' group. I heard a boy asking her which school she went to, and she replied by naming only her mainstream school not her special school, although she attends both.

Nathalie   *PEOPLE SHOULD TALK TO ME LIKE A TEENAGE GIRL*

Bryony   *I WANT TO PLAY MORE WITH OTHER KIDS*
               I AM EQUAL, STOP JUST SEEING THE WHEELCHAIR

In contrast, is Kate, who previously attended a mainstream school and has recently changed to a special school. Interestingly she refers to places where she feels comfortable and understood as 'my world'. This could be interpreted as a rather pro-segregation stance, but she is clear that what she means is that anywhere where people give her the chance to be herself and time to communicate can be 'her world'. When we deconstructed this further she emphasized that she is 'not disabled' when she is in this kind of world.

MY WORLD…MAKES ME FEEL STRONG AND CONFIDENT

Her aspiration is that it could and should be like this everywhere, for everyone no matter what they are like. Some of the others expressed rather similar though not as well rehearsed views about the ease with which they can be themselves in different places. All had a small number of familiar places they visited, where relationships were easy and people knew them (e.g. family events, clubs, local pub, village shop). In these places they had an identity that was not just about being disabled. Some felt that it was considerably more difficult to go to new places, and to establish new relationships without their disabled identity being to the fore. Others felt that given the opportunity, they could do this, as Jemma says:

Some parents are scared to let disabled kids join in but I think they can do loads of different activities and shouldn't be scared.

The participants' views then varied about whether they saw their disabled and other worlds as integrated into one or rather separate, and of course for each individual this shifted depending on the context, showing that they have multiple and

contrasting and sometimes contradictory selves, of which their disabled self is only one.

> *Jemma*   *I've got my wheels in two camps!*
>
> *Bryony*   *I want everyone to be in one school*
>
> *Josie*   *I WOULD LIKE TO HAVE MORE LOCAL FRIENDS*
>   *MY DREAM IS TO BE IN THE PARALYMPICS*

Being different and what it means

Some authors have pointed out that an obvious and integral part of the process of identifying as disabled or not, must be about noticing difference in the first place. Post-structural analysis of disability tries to demolish dichotomies such as that between 'normality' and 'abnormality' and look at people's social experiences more broadly (Davis 2002, Shakespeare 2006, Thomas 2007). However reflection on what young people usually value reveals that belonging is of great importance. James (1993) argues that children aspire to 'sameness', across various domains such as physical size, gender, fashion sense and behaviour, so that success is about being conventional in relation to their peers (cited in Cohen 1994:67). This explains why the disabled teenagers here so clearly prefer to identify as the same as other teenagers, rather than disabled and therefore different. Many of them gave examples of times when they were regarded as 'other' and thus felt marginalized.

> *George* *when I'm out people look at me and I think they may be thinking that because I am a wheelchair user and non-verbal that I haven't got anything to say at all! So until they are told and understand I'm not deaf and can understand everything you say they'll often talk to my PA instead of directly to me! This can make me feel like I'm on the sidelines. It isn't good (written).*
>
> *Kate*   *YOU CAN FEEL LEFT OUT IF PEOPLE DON'T GIVE YOU TIME TO TALK*

Bryony's dad expressed this for her thus:

> *correct me if I'm wrong Bryony but when you're out there in the world at large, and at home a lot of the time as well... you went through a phase recently of not wanting to use your VOCA... because you think that attracts too much attention*

> *and makes you seem different at school...so you wanted to use your own voice*
> *rather than the VOCA...Is that right?*
> *Bryony   yeah!*

George explained to me that he feels that his disability is a distraction for other people who inevitably focus on what is different about him:

> *SEEING MYSELF ONE WAY, BUT BEING AWARE THAT OTHER PEOPLE   SEE*
> *ME ANOTHER*

He is thus aware that because of the nature of his impairments which are both very visible and affect the nature of interaction, it is extra hard for him to overcome those 'other' impressions. If you can't talk fast, it is not easy to express quickly who you are, and so your disabled self is the only one that people see:

> *My disability is a very complex one. If the DVD[46] can help to alter attitudes,*
> *perceptions and assumptions about disability and communication that would*
> *be good (written).*

This disjuncture between how the teenagers see themselves and how they are seen by others, will be returned to in Chapter Seven.

Celebrity and heroic self

Very few of the young people expressed overtly negative feelings about being disabled, apart from Ted, who as a committed Christian maintained a firm wish and belief about being 'cured' by God, and Bryony who showed overt frustration at not being able to do some things. On the contrary, more often they had a sense of celebrity, and had proud, heroic feelings about themselves and what they had achieved or overcome.

Many had appeared in the media, perhaps more often than their non-disabled peers. Sometimes this was linked to appeals for resources or as part of lobbying activities, in which their parents were involved. Otherwise it was because they had won a prize or participated in a project or event at school, or club. Many showed me with

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[46] This conversation was part of our preparation for the 1Voice DVD. The teenagers' aim was to express their thoughts about how they would like to be perceived, how important communication was for them and how other people could facilitate easier communication with them.

pride, trophies and photos or videos of themselves winning awards and meeting famous people. They talked about these experiences with an intensity and gravitas which suggested strong and significant feelings and some of them described themselves as 'competitive' 'a fighter', or 'strong'. Often these descriptors were also used by their parents.

As described earlier, narratives about survival against the odds were particularly prevalent, especially in their descriptions of their birth, early lives and in having overcome illness or being brave after operations. They nearly all gave a strong sense that they could overcome adversity or other people's underestimations of them:

> *Terry (14) - his life story. He quite liked the idea of it and started off by saying 'I was very very ill' etc. Then he said that when he first got his wheelchair everyone thought he wouldn't be able to drive it and he proved them wrong by 'driving straight out'. A hero narrative for him, about him proving what he could do (fieldnotes)*

> *Kate(13) ALL CHILDREN WITH SPEECH DIFFICULTIES AND WALKING DIFFICULTIES HAVE TO BELIEVE IN THEMSELVES. I BELIEVE IN MYSELF, I CAN DO ANYTHING IF I WANT! 'MY BODY MIGHT NOT ALWAYS DO EVERYTHING I WANT, BUT I AM NOT DISABLED!' 'NO-ONE HAS THE RIGHT TO MAKE ME FEEL INFERIOR UNLESS I CONSENT' THAT'S FROM ELEANOR ROOSEVELT THE PRINCESS DIARIES (CONFERENCE TALK DELIVERED ON HER VOCA)*

Similarly I noted that many talks given by disabled adults at conferences also had this element of heroism. This kind of rhetoric has been described as part of a stereotyping process which dichotomizes disabled people as either 'brave superheroes' (supercrips) or 'tragic victims', rather than ordinary people with a range of attributes (Grewel et al 2002, Oliver 1996b). However, this is usually in relation to other people's classifications. When this sense of celebrity and heroism is part of the disabled person's self-perception, one might hypothesise that it provides self-affirmation and a feisty response to the possible negative attributions of others. Reeve (2002), Hughes (1999), French (1994) and others have described ways in which adults learn to resist negative disabled identities. Perhaps the first stage in

learning to do this during adolescence is learning to be assertive and self-congratulatory in the ways exemplified here.

At the end of the fieldwork I arranged to do final school visits, including feedback sessions giving participants a summary of my initial analyses and an award ceremony thanking them for participating. In discussion with Katie (RA) we decided it would make this more of an occasion if she came along as a 'special guest'. We anticipated that the teenagers would be interested in meeting an adult who used AAC , something some of them had not previously experienced. They all agreed to meet her.

In the event, what happened at these visits was thought provoking for me in relation to disabled identities. The students were intrigued by Katie and in fact they stared at her in the way that they say they dislike themselves. They asked her many questions (about her schooling, studies, work, travel, where she lived and whether she had a boyfriend), in ways that suggested that they saw her as a positive role model. She was upbeat and chatty and deliberately made links between herself as a teenager and them. However by the end of the meetings, I had a strong feeling that, for some of the teenagers at least, this had been an uneasy session. In introducing them to someone who was by implication 'an older version of themselves', we had actually reified an identity which they were not particularly interested in or didn't recognise. Certainly they were interested in her trendy and rebellious wheelchair stickers, and her very speedy VOCA use. However perhaps they had not yet really visualized themselves as looking or more importantly being 'like this' in a few years time. So this experience had for some confronted them with the reality of their future, and of the continuity of their present selves, rather than any fantasy they may have had about being different later in life.

Subsequent discussion with the research advisors revealed that they all felt that they had not really embraced and integrated a 'positive disabled identity' into their picture of themselves until they were in their twenties at least. In fact they reported that this was something they still struggled with at times.

Conclusion

This chapter has presented data showing how the participants see themselves as socially and emotionally competent people who want to be autonomous and independent. Each individual has a number of shifting and overlapping 'selves', which come to the fore in different contexts, of which a disabled identity is only a part. Any division between these selves is artificial and for convenience only, and in fact they are often at the same time complementary and conflicting with each other.

For most of them, most of the time, their main perceptions and descriptions of themselves are drawn from images of 'normal' teenagers, who they wish to be like. They are busy negotiating increasingly autonomous and assertive selves and ways in which both to incorporate and resist the influence of their parents, teachers, friends and others. Islam (2008:42) suggests in her study of Asian disabled teenagers that their worlds are made up of 'multifaceted realities' rather than one unitary identity, and this seems an appropriate description here too. Thus like anyone else, disabled teenagers will adhere to various reference groups at different times (Davis 1998, Islam 2008, Watson & Cunningham-Burley 2000). A participant might be 'a big brother or sister', 'cool', 'good on computers', 'a Chelsea supporter', ' a member of class nine', 'a good laugh', or 'a good driver'. The aspect of themselves which is prominent in each situation varies, and they have a sense of 'belonging' in different ways at different times. Thus, as exemplified by their rather diverse descriptions of themselves, the way they express the essence of their selfhood is complex and ever-shifting.

In summary, Chapters Four and Five have shown that when the young people talk about positive aspects of themselves and their lives, they give only fleeting glimpses of their disabilities. Their interests constitute a classic catalogue of teenage culture, interspersed with relics from their younger selves. They know about 'teenage stuff', through the same channels as other young people: media, siblings and peers. In contrast to this teenage knowledge, their opportunities to *do* teenager things (with the exception of computer based activities for some), are more restricted and this is something that concerns them, especially the older participants. Closer examination of their 'hates' reveals the times when they feel excluded from their rightful teenage

activities: being left out of chat and gossip, being seen as younger, incompetent or dependent, being ignored or misunderstood and not being in control. All of these are major affronts to their teenage selves.

Much of what has been said above about people's shifting and diverse identities arguably applies to any or all individuals. However the ways in which selfhood may be different or more difficult to express for these disabled young people needs careful consideration. Shakespeare (1996) argues helpfully against an essentialist disabled identity and suggests that there must be a variety of disability identities that coexist with other types of self. This view is indeed reflected here. Teenagers who use AAC, like those with other impairments, may sometimes self-identify as disabled, but there is no simple binary opposition between 'disabled' and 'non-disabled' and this part of their selves will be more or less in focus at different times (Rhodes et al 2008). It may also be both a positive or a negative or indeed a rather neutral, matter of fact description. The extent to which their worlds are dichotomised into disabled and non-disabled varies, but the fact that some young people talked about having 'a wheel in two camps' or wanting 'to bring their two worlds together', suggests that two separate worlds do exist, at least sometimes. It appears that this bifurcated world is one that is structurally imposed, whereas a more unified view is held by those experiencing opportunities to be autonomous in a range of settings. This is most clearly expressed in conversations about different types of schools. Additionally, it is often when they are in unfamiliar places that their disabled identity is most highlighted by others and thus reified for them. Their 'hates' suggest that it is when they are in the position of an 'unknown' or unusual person, and therefore of being judged by physical appearances as 'other' that they feel most 'disabled' and therefore excluded. Then they are forced into a minority group position which they may not have chosen or have little control over. Opportunities for them to show their multiple and mostly non-disabled views of themselves may then be missing.

Chapter Six. Bodies and the Kit:

See me, don't just see the chair!

Introduction

> *'I ALWAYS THOUGHT AND THINK MY BODY IS LIKE EVERYONE ELSE'S UNTIL I SEE SOMEONE ELSE WITH CEREBRAL PALSY AND THEN I SEE THAT IT'S NOT. ITS WEIRD, IT FEELS NORMAL TO ME'. (Katie Caryer RA)*

An important aspect of the current study is that the participants have physical impairments that affect their corporeal bodies and these have very practical impacts on how they do ordinary tasks. However, these differences in how their bodies work and look, also have inescapable consequences for less concrete and more negotiable aspects of selfhood and personhood, such as how the teenagers see themselves and appear to others, how they communicate and how they are judged. Thus it is likely that at the root of their constitution of selfhood and personhood will be some very particular bodily experiences and views of bodies, as well as views about the equipment or 'kit' they use in order that their bodies can be managed better. Thus, a pure materialist approach to disability which ignores what Thomas (2003) has called 'impairment effects' evidently would not accurately represent the lifeworlds of the participants in this study (Paterson & Hughes 1999).

As originally conceived, this study set out to explore identity issues for any young AAC users, and I intended to include both participants using AAC who had physical impairments and those who did not.[47,48] As I reflected on these interwoven

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[47] Most nonspeaking young people with no cognitive impairment, have physical impairments too, Cerebral Palsy being the most common cause. However there are a number of other medical diagnoses which can include lack of speech, but without more generalised physical difficulties e.g. autism, dyspraxia.

[48] My recruitment criteria did not specify this aspect, and anticipated that I would have a mixed group, some with physical impairments and some without. However, all the participants (except one who withdrew due to ill health) have visible and considerable difficulties with a range of body movements, of which poor speech is one consequence. All, though with individual variations, share some broadly similar embodied experiences such as: being able to sit but not walk, having poor control of hand movements, using wheelchairs and other physical aids from an early age, having a

categories I realized, however, that the experiences and perceptions of these two groups might vary greatly. Whether or not someone had a visibly 'different body' as well as no speech, might have varying impacts on both selfhood and personhood. Thus at an early stage I included the fourth research question:

> What role does the body play in the development of selfhood, social relationships and personhood, for young people who use AAC?

Indeed, as will be illustrated, for these teenagers, their physical impairments and in particular being a wheelchair and VOCA user, were important aspects of how they saw themselves. The chapter presents data, therefore about both the body and the 'kit'.

Overall, there are for these teenagers a number of contradictions and conundrums about the body which are not easily resolved, something which mirrors the ongoing debates within the disability literature as outlined in Chapter One (e.g. Shakespeare 1994, Oliver 1996a, Hughes & Paterson 1997, Paterson & Hughes 1999, Thomas 1999, 2007, Reeve 2008). In summary, the role that the body plays in identity processes, for physically disabled teenagers using AAC is simultaneously both like and unlike those of other young people. Their desire to be as like others as possible in appearance through activities and fashion (Gilbert 1998), and wanting access to 'ordinary' places, parallels their non-disabled peers. In contrast their need to make use of helpers and 'kit' in order to do things and their relationship with these constantly reminds them and signals to others that they are different. They are simultaneously and paradoxically more dependent (on other people and equipment) because of their particular bodies, and also enabled to be like others by their kit and by their skill at managing those who help them with their bodies.

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body which sometimes moves uncontrollably, needing physiotherapy and help with a range of tasks such as dressing, feeding, toileting, living in a house with special adaptations etc

Embodiment

Like everyone, the teenagers' identities are necessarily embodied and they express aspects of themselves through the way they use their bodies (Csordas 1994). However their dilemma and a cause for some consternation is that their external appearance is a marked one, so that very often, their disability is the part of them which is noticed first and becomes essentialised (Watson 2002). Yet it may not be so significant for them. They are often regarded as 'other', because of their bodies, whereas they see themselves as 'the same'. This is succinctly expressed by Meredith (RA) in a written piece:

> '*We are identified by our bodies firstly and foremostly. We are perceived as a group member of disabled beings. We have little choice in how we are perceived. Conscious of our own self identity, we strive to make sense of the myriad complexities of our social experience and break through the disability barrier to be accepted as ourselves' (Alan 2006:12).*

The feelings that this quote and the one at the start from Katie (RA) express are strikingly similar to those to be found in many accounts by disabled writers and theorists (Murphy 1987, Shakespeare 1996, Watson 2002, Reeve 2006). However, it could also be argued that this is the same for everyone, impaired or not. As Merleau-Ponty writes, our own embodied perception of our physical selves is inevitably different from that of an outsider looking at it (Merleau-Ponty 1962, Crossley 1995). However, for these teenagers it is clear that this ordinary disjuncture between their own and others' perceptions is exaggerated. Importantly the implications and impacts of this are at the root of many of disabled peoples' experience of negative and stigmatizing encounters.

As noted in Chapter One, phenomenological approaches to the body often attempt to collapse the Cartesian duality of body versus mind, by using the concept of 'embodiment' to emphasise the essentially physical and sensory nature of experience. Thus as Berger and Luckman suggest, everyday life is experienced through the body in the

'here of my body and the now of the present (1967:22).

Hence the body, selfhood and personhood are inextricably linked and the body as part of our social identity becomes a basis for prediction about people. Jenkins (2004) emphasises that identity is about similarities and differences, and so the question arises, what happens when, like these teenagers, someone has a very different body?

Also pertinent to this discussion is the fact that while identity is a process of becoming, some aspects of bodies, such as physical impairments, can be relatively fixed and while Bauman and May suggest that the body is the site of representation of ourselves, they go on to say that it is also

'the prime possible source of trouble' (Bauman & May 2001:105),

because of its immediately visible message. As the self is displayed for public gaze, the body tends to be held responsible when things go well or badly, because it is part of how we constitute ourselves through our actions and the reactions of others. In summary:

'How aspects of our bodies are seen and endowed with particular significance effects how we see ourselves and how others see us' (Bauman & May 2001:105).

In this respect Bourdieu (1977) and subsequently Csordas (1990) have shown how embodied actions and social experience constitute the process whereby the body comes to enact particular social principles and values through a 'way of being' in the world. Csordas (1990) particularly emphasises the idea that personhood is constructed through 'embodiment and experience' and so agency is performed through our ways of inhabiting our bodies.

Phenomenological approaches to thinking about the body see it as a very real and corporal thing, through and in which we experience the world and also engage intersubjectively with others. The body then is central to social processes and this approach is useful for the present study, as the data suggests that the teenagers do

not experience their lives dichotomously in relation to body and mind, or through the social and conceptual categories of impairment and disability. What is unusual and potentially confusing for these teenagers, is that unlike those with 'unmarked' bodies, their bodies constantly 'speak out'. Rather than being able to take their bodies for granted as Csordas suggests the healthy or non-disabled person does, they are constantly reminded of its difference.

My body and how I see it

When I asked the teenagers directly about their bodies and how they felt about the way they looked, there was near unanimity that they looked fine. Their self-descriptions (as discussed in Chapter Four) often spontaneously include aspects of their bodies and appearance like: 'cool', 'trendy' 'sporty', 'fit', 'pretty', 'handsome' or 'smart'. They tended, perhaps as we all do, to highlight aspects of their bodies and appearance which could be changed as part of 'managing the project of the body' (Shilling 1994). They expressed, for example, strong views about clothes, jewellery and haircuts; and many of their parents reported rather stereotypical 'adolescent negotiations' about what they wanted to buy and wear on different occasions as part of their image management. For example Terry(14) liked to gell his hair and Nathalie(15) wanted to shave her legs and have a good tan.

The young people had less to say overtly about actual body size and shape. Nonetheless, their incidental comments reveal similarities with other work on children's perceptions of identity and bodies (Prout 2000). For example, James' (1995) work shows the importance for children of being the same, especially in relation to size and competence, which Cohen suggests reveals the role of peer influence in identity construction:

> 'Children socialize each other, as well as socialize with each other' (Cohen 1994: 66).

Cohen suggests that aspirations for normalcy must necessarily be preceded by awareness of differences, and then followed by efforts to conform, and likewise for these young people, there sometimes emerged a sense of group identity and solidarity about their shared bodily experiences, as in the following example:

> *Josie's GCSE science lesson (special school). The teacher was explaining about the properties of elastic and how it goes back into place if you stretch it. One of the boys shouted out. 'that must be what the physios think when they do that to us' everyone laughed. A united front against a common 'enemy' (fieldnotes).*

Everyone (aged 15-16) in that class has physical disabilities, so all could relate to a joke about physios, suggesting that the teenagers' shared an identification as having different bodies in a positive and supportive way, something which the participants who went to mainstream schools may have missed out on. Indeed, one might predict that those attending mainstream schools might have a stronger sense of wanting to have 'normal' bodies, because they spent more time with non-disabled peers, but I did not find this particularly. Those at special schools were equally concerned about looking good and being able to do physical things.

The idea that young people usually want to achieve median size in height and weight was clearly evident in my data, and echoes James (1995) finding that this was particularly linked to wanting not to be seen as small and therefore younger. Many young people with cerebral palsy (and in this group) are small in height for their age and rather underweight (because of difficulties with eating), so this, in combination with a tendency for anyone with a disability to be infantilised and patronised, may make them particularly sensitive to judgments about looking younger:

> *Toby (15) is very skinny and rather short for his age (he wears 8-10 year clothes) and there has been discussion for some time about whether he should be tube fed, as he cannot eat well enough to get the nutrition he needs. Staff say the extra nutrition would accelerate his growth and help him to 'hit puberty'. His mum told me that previously they (Toby and parents) have generally been reluctant to do this, but that now the decision has been made, and this is partly because Toby himself wants to 'fatten up' and 'look bigger'. It has been decided to do it this year, which involves a minor operation, so he is hoping that he will look taller and older before he starts college next year (fieldnotes)*

Similarly, Ted(13) was keen to look 'trendy and tall', Jemma(12) was looking forward to 'getting boobs and periods'.

In relation to how their bodies worked, as opposed to how they looked, some of the group did occasionally express concern about particular aspects which they would ideally like to change:

> Ted   *I WANT TO USE MY HANDS TO FEED MYSELF AND WALK*
> Bryony   *I WANT TO WALK BETTER*
> Nathalie   *MY ARMS ARE ANNOYING (they don't move where she wants them to sometimes)*
> Kate   *I want to stop dribbling*
> Terry   *I WANT TO RUN*
> Marie   *I like my legs, I would change my talking, TALK more, then I wouldn't need the VOCA, I would like to write – letters to boys (book and signs)*

At the same time, as described earlier, about half the group were actively involved in disabled sports activities such as boccia, athletics, gymnastics, riding and archery and were proud of their physical achievements in these.

Although some of the parents recalled that when they were younger, their children had expressed distress and concern about not being able to do certain things, as teenagers they mostly understand that these goals might be unrealistic and accept their bodies as they are in rather pragmatic ways. However several parents conjectured that another phase of self-doubt and dissatisfaction might arise as their son or daughter moved into their late teens, when issues around dating and sexuality would be more prominent. This was confirmed by comments from Allan and Meredith (RAs) who recalled considerable 'angst' about their unusual bodies as young people.

Who controls this body?

A recurrent observation was the extent to which these young people's bodies were organised and ordered by other people, and the varying extent to which the participants exercised their own control of this, or indeed, at times, resisted such management (Davis & Watson 2002). Here Ted(12) and two other boys with similarly very severe physical impairments are having a physical 'chill-out' time in the soft play room with the physios; a rare opportunity to get out of their

wheelchairs in school time. However, none of them can crawl or sit up on their own, so are dependent on the adults to help them have physical fun:

> *Ted was very giggly and full of fun, and Angie positioned them all so they could move towards each other, touch etc. In roly-poly tunnel – a sense of danger and freedom, in the ball pool with physio holding him up, relaxation and being supported. Ted could propel himself around along the floor a little bit but couldn't roll over. He enjoyed lying on the floor and being pelted with balls! They use a sling to lift the kids into and out of the ball pool and up to the top of high soft climbing frame structure and then to slide down with help. For this lot soft play is the equivalent of other children being in an adventure playground. Feeling what you can do with your body and freedom and some sense of riskiness, though not much chance to be really naughty and or to chose something dangerous or original to do. All controlled by the adults in health and safety mode, and of course no verbal communication because VOCAs are attached to their chairs, lots of nonverbals though (fieldnotes).*

Their lack of easy control of their own bodies, in comparison with their non-disabled peers' unthinking bodily freedom, often struck me. For someone who cannot walk or use their hands well, there are many decisions to be made during the day; for example about which chair to be in (or walker or standing frame), when to go the toilet (needing help), or have a tube-feed.   There are also some detailed considerations about the exact position of the body (legs, hands, head) in the chair or frame, which straps to use, heights and angles of chairs, trays, and switches. The amount of time that all this physical organizing took during the day was obvious. Once when I was shadowing Ted for the day at school, he spent almost two hours in the morning trying to get a problem with his wheelchair sorted out. He regularly missed both class and socialising time because of this. The three students (Nathalie, Bryony, Jemma) who were in mainstream school, all left each lesson early and arrived late at the next, because of the extra time needed for them to get between classes, to the loo, or to eat. At special schools, this extra time is factored into the timetable. Thus aspects of their physicality were much more present than for their peers. As several authors (Csordas 1994, Murphy 1987, Paterson & Hughes 1999) suggest, we are usually unaware of our bodies, until they become problematic. For these teenagers their bodies are much more likely to demand this externally precipitated awareness.

Although the participants were often consulted, many decisions about their bodies were made by adults who 'knew best'. The extent of this ordering by others varied both across individuals (related to their level of impairment and personalities) and the context. Simpson (2000) suggests that (non-disabled) children's bodies are 'tamed 'regulated' and 'civilised' by adults, but that they find ways to resist this, and arguably young people with physical disabilities are more regulated and have fewer ways to resist than their able-bodied peers. Their bodies do not conform to what is expected, especially in school or in public places. Although there was clearly understanding and tolerance of their different bodies, so that they were not necessarily admonished to 'sit up straight', as others might be, there was a whole repertoire of other expectations about how their bodies 'should be' (e.g. head up, arms not flailing about, legs bent, feet on footplates). At home this physical regulation was less prescriptive, so they were freer to choose what to do.

Bryony(10) who attended two different schools was much more actively 'organised' by teaching staff at her special school than at the mainstream one. A physio had told the teachers about the ideal positioning of her legs, so they were constantly reminding her of this and physically moving her legs to 'sit properly'. I saw her moving much more freely and in her own way at home and at her gym club. Similarly at school I only saw Toby in his chair or standing frame which controlled his body and provided great stability for him, and was therefore surprised, when I visited him at home, to see how different he looked. In his case, the chair, which tamed his lack of control, enabled him to be more autonomous at school, as he could move around by driving and use his VOCA. He could do neither of these, sitting floppily on a beanbag, as he often did at home.

I went to physio sessions with six of the participants on various occasions, and saw that they were both fond of their physios and very relaxed in this setting. I was shocked at how floppy and helpless they looked when lying on the floor or trying to sit without the support of their wheelchairs. All have been having physio since they were babies, and consequently had a matter of fact attitude towards it. Here Jemma who has recently had major surgery on her legs, is having very intensive physio every day:

Bob (LSA) started putting the sling ready to lift her up, to practice walking with support, jollying her along, and she was bantering back. Clare the physio took over getting her to practice on the parallel bars. A lot of faffing with the various slings etc, which she was resignedly patient about, and wanting to chat and gossip at the same time. Had to walk up and down the bars with Clare and Bob encouraging her to keep her legs straight etc. She worked hard at it but didn't say much, think it was hurting a bit but she didn't complain. Rather a business like attitude to it all. Accepting people manhandling her, pushing her hips and knees, rearranging her shorts etc. I was thinking about her being such a sporty person in her head during all this, and how she says she'd like to be a runner (fieldnotes).

Generally the young people's bodies were less managed by others at home, where their parents had evolved the quickest and easiest ways to get essential tasks such as dressing, toileting, or feeding done, albeit sometimes in ways of which physios would disapprove. Mostly, parents were not constantly organising their children's positions and movements as school staff did. Two parents mentioned this difference between what happened at home and at school, and both said:

She's my child, I'll do it how I think best (Nathalie's and Jemma's mums)

Clearly much of this ordering of their bodies is done with the best of intentions. For instance the physios are very clear that moving in the 'right way' will prevent the teenagers developing additional impairments[49] later in life and also gives them more efficient function and comfort. However it also has implications for young people's autonomy, choice and control. Adults' approaches to including young people in decisions about their bodies varied. Some discussed what should happen and gave the person choices, whereas others more overtly imposed external control in ways which appeared to regularize and order the teenager a great deal. This was received varyingly by the young people. Some would argue, complain, or try to negotiate, for example for less time in the standing frame, to have legs out of straps. However, on occasions, I saw the teenagers relinquish control of their bodies with no resistance

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[49] E.g. 'contractures' which are permanent tightening of the muscles over time, and result in stiff fixed positions which are painful and restrict movement a great deal in older people with CP or those who have not had physiotherapy or good 'positioning' early in life

at all. This was the case in the following example of Marie who usually had very strong views about what happened:

> *Tim (helper) wanted to clear her nose of grunge which certainly needed doing – very blocked up and she submitted to this – he did it in a kind and gentle way – but still? humiliating for a 13 year old or maybe not for her? (fieldnotes).*

The teenagers were, of course, used to this external control, having had a body that needed help all their lives, so their apparent dependency and lack of choice may not be something that matters to them and is accepted[50]. Kate and Jemma were both very assertive about how they liked things done and were good at saying verbally (with speech or their VOCA) what they needed.

> *Jemma*　　　*I should go in my walker now*
>
> *Kate*　　　*I need my hearing aid bit*
>
> *Kate*　　　*Can you move the table up?*

Equally, Terry, Josie, Nathalie and Marie would show clearly, with non-verbal skills such as eye-gaze, when something needed doing. It was the two youngest, Ted and Bryony who were generally more passive about expressing their needs or views, but both would also get frustrated and angry when things were not comfortable. Then a complicated guessing game of finding out what was wrong would ensue, because they would then be too agitated to communicate easily with either their low or high tech systems. However, on one occasion when Ted was obviously distressed and uncomfortable because of muscle spasms, he very laboriously spelt out:

> *I WANT TO GO TO PHYSIO BECAUSE I'M REALLY TITE*

He was very able to express his own understandings about his body and what would make it feel better, i.e. getting the physio to help relax his tight muscles.

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[50] I found observing this lack of physical autonomy quite distressing at times, but this is my own reaction to it and was not obviously matched by the teenagers' feelings. This difficulty for non-disabled people in imagining the situation for someone with a very different body has been highlighted by Mackenzie and Leach Scully (2007), who argue cogently that our embodied experience colours our interpretation of other people's situations and may lead us to misinterpret what we see.

As they grow older then, it seems that disabled teenagers become more adept at managing other people who organise their bodies. They remind people to put their powerchairs and VOCAs on charge, plug things in, do up straps, move trays, and bring equipment from one class to another. However, my conversations with the teenagers revealed a mostly pragmatic attitude to their bodies and needing help with them. They had little to say about the fact that they needed help, or that they could not do some things. Mostly they were more concerned about *how* the help was done (discussed in Chapter Seven), and that the right equipment was available and worked well. What these examples reveal however are the ambiguous boundaries of ownership and control of the disabled body.

Unclear boundaries were also revealed in relation to privacy (discussed in Chapter Five), since the young people were so often unable to be private about their bodies in ways that most of us take for granted. For example, one day in the middle of maths (special school):

> *Martin (another boy in a wheelchair but who can talk) asked to go to the loo and Ted(12) then indicated to me that he wanted to go too, but Steve (teacher) and Trudy (LSA) both said 'no' that this is just Ted trying to get out of class: 'trying it on'. Tracey said 'he wears a pad and doesn't need to go'.*

In this example, the LSA's knowledge about Ted's body and the fact that he wears a pad means that his claim to need the loo can be countered. He has less chance of escaping from maths on this pretext, than a child whose body is under his own control. Here the adults claim to know more about his body than he does and make decisions for him.

Similarly, on a school trip there was an optional boat ride out to sea. Each student was given the choice of going on the boat or going into town to go shopping. Toby(15) was very clear about his preference, and was adamant that he did not want to go on the boat. As the following account reveals the staff were very unaccepting of this and critical of him for 'opting out'. They did not respect his judgment about what was right for him and his body:

He was scared of the whole boat thing. He's a vulnerable sort of character, or may be because of his physical situation, it's hard to be confident about new experiences, especially physical ones. He is very wobbly so he probably knew he'd feel really unsafe (or perhaps he's been in a boat before and didn't like it?). Also a matter of trust and of not wanting to be in that kind of out of control situation. Whereas for most of us a bit of fear is exhilarating, for him may be its just fear? He knows he can't save himself. Anne the nurse said he was given loads of chances to decide either way and he decided not to do it. (that seemed to mean, they tried very hard to persuade him). She said 'well, it was his decision, though it was a shame coz he missed out, but they've got to get used to making choices' . Interesting, she is implying that he made a bad or wrong choice, but for him at that moment, with his body, it was the right choice, why should he regret it? I took him into town and we had a nice time eating chocolate ice cream and looking round! For him that was the right decision (fieldnotes).

Having a body that needs so much help from others may mean that it becomes objectified, and although it is still 'the property' of the person, somehow other people have a delegated right (or responsibility) to organise it. In this way, it could be suggested that deciding when to have a tube-feed, or to stand up to have a stretch becomes a matter of what to do with this object/body rather than an embodied experiential part of the self. Tremain (2002:42) argues that, 'the impaired body is produced, disciplined and governed (via direct regulation and self-regulation) by technologies of power' (cited by Thomas 2007:126) and this resonates with some of my findings.

Clearly, complete privacy and control over one's body is something that most teenagers gradually acquire (Patel Stevens et al 2007), but these young people never will. They will always need physical help with practical bodily tasks. However, if they are to have a sense of autonomy and of their body being theirs, they have to develop ways of controlling what happens. For example, it was clear that those with less severe physical impairments and faster communication had more chance of real agency and autonomy. Thus Jemma and Kate as the least physically impaired were able to influence what happened, whereas Toby, Ted and George as the most physically impaired sometimes had their wishes overridden or were not consulted. James and Hockey (2007) describe in children a gradual shift towards their own 'internal moment' and thus their own identification. However, it is interesting to

reflect on how far this shift is possible if other people are controlling your body. As Castaneda (2002) says :

'The child's ever-changing body is slowly transformed into the comparatively stable, physically mature and culturally inscribed adult form.' (2002:4)

Potentially, if the body remains 'childlike' in the sense that it is dependent on help, there is risk that the embodied person will also be infantilised. This explains why many of the participants were (as described in Chapter Five), keen to be as 'independent' as possible in order to counteract any passive or incapable impression that a newcomer might get from a superficial, external view of their body. Many of them said that they hated it when people assumed they could not do things or as Bryony put it:

SEE ME, DON'T JUST SEE THE CHAIR

Other peoples' views of bodies

The responses of others emerged as an important issue, as all the participants and indeed their parents expressed concern and anger about being too visible and thus being identified as 'other'. Several gave examples of people pitying or patronising them in public. This was something they talked about more than the fact of having a physically different body. This suggested not only that other people's reactions could be distressing and hurtful, but more importantly, that the teenagers interpreted this as a lack of recognition of their real selves. As Reeve (2008) suggests, a visible impairment easily becomes the most noticeable thing about the person. Once the negative connotations of 'not normal' have been applied, other assumptions then quickly follow such as not human, not clever, or not sentient. Reeve (2008) draws on Agamben's idea of the

'Homo Sacer'……someone whose entire existence is reduced to a bare life stripped of every right' (2008:206)

to suggest that people with visible impairments are subject to staring which is so humiliating and disconcerting that they are left in 'psychic state of exception' and thus feeling disempowered. This is expressed by the teenagers:

> *Josie*   I HATE IT WHEN PEOPLE STARE AND THINK I CAN'T DO   THINGS
>
> *Prakash*   PEOPLE SHOULD UNDERSTAND THAT MY BRAIN WORKS FINE
>
> *George*   TREAT ME AS SOMEONE WHO CAN UNDERSTAND
> AND HAS THINGS TO SAY, TALK TO ME 'AS NORMAL'

Even when structural barriers such as spatial restrictions in the form of physically inaccessible buildings and transport are remedied by law, psycho-emotional disablism remains. This is much more difficult to legislate against, leading Hughes (1999) to describe society as inherently 'oculocentric': physical appearance is the dominant aspect, and 'perception' and 'perfection' are both tyrannical in his view. The responses of onlookers to disabled people are discussed further in Chapter Seven, but it is important to emphasise here that many of these reactions are precipitated by different bodies .

The Kit: being technology enabled and technology dependent

All the participants use a daunting array of 'kit', which help their bodies to move, talk, control a computer, open doors, or hear. Technology has changed and advanced so much in the last ten years that the present generation of disabled teenagers use many more high tech types of assistance than was ever possible previously, and of course more developments are constantly emerging. This group have, like their peers, grown up with technology and they expect to have it and for it to work well for them. This emerged clearly in the data, as they all emphasised how annoying it was when a piece of kit was not available, did not work or was too slow. I witnessed their irritation about this on numerous occasions. Their annoyance was not linked to any sense that it might represent something negative about them as people, but purely to the practical fact that when it was not available there were things they then could not do. This is somewhat in contrast to the adult research advisors, who though they appreciate the aids they have now, had had no such technological assistance as young people. The adults noted with regret what was not available when they were young, and admitted to a certain amount of envy at what the young have now. The most important aspect of all the kit was what it

enabled people to do, and more especially, do without help as the following example demonstrates succinctly:

> Kate NOW THAT I'VE GOT MY VOCA (AND CAN SPELL) I CAN BE INDEPENDENT, I CAN GO SHOPPING ON MY OWN. I CAN ORDER FOOD AND DRINK IF I GO OUT. IF I'M ILL, I CAN TELL THE DOCTOR WHAT IS WRONG WITH ME.

Wheelchairs

Everyone in the larger group of 24 teenagers regularly used a wheelchair. In their initial self-descriptions most key participants mentioned their chair at some point, but often not until they had told me a number of other things about themselves. Thus they saw moving in a different way as important to mention. For example Josie(15) said when initially describing herself

> Josie looks at alphabet board (starts spelling by eye pointing)
> MW M A D…mad… that your mad?… okay that would be the   first thing you'd say (laughs) okay (discussion about being mad) …. do you want to go onto something else?... still thinking' ..
> MW L I K E like T O like to T A L talk, like to talk, so that's a separate one from mad, okay, would almost say a chatter box actually !
> Josie (laughs and spells out)
> IS IN A WHEELCHAIR AND HAS A VOCA … ALL THE TIME (PERMANENTLY)…. I DRIVE IT MYSELF – IMPORTANT, LIKE TO BE INDEPENDENT…DON'T LIKE THINGS DONE FOR ME

So for Josie it is important that she is 'in a wheelchair' but also to qualify this by adding that this is permanent, so it is definitely part of her. Also, driving it herself is significant because it gives her independence. Subsequently she added:

> I HATE BEING IN MY MANUAL

This happens, for instance, if the powerchair is not working or she goes somewhere inaccessible. Being pushed is an affront to her sense of who she is, in a way that the powerchair is not. Others also expressed a strong dislike of having to be in a manual chair and as fieldnotes made at a special school record, the young people appeared very different when they were in this situation:

Children in manual chairs pushed from one class to the next look passive, and stuck where they are put, others driving themselves have more choice about how and where to go, fast, slow, whether to dawdle, stop to chat on the way, jump the lunch queue, race someone, and where to position themselves in class or move about during lessons (fieldnotes)

Some participants had first acquired their powerchair (as opposed to a manual one) at a young age and had learnt to drive at nursery or primary school (Josie, Terry, Kate, Marie, Prakash). All have strong memories of how important this milestone had been in terms of their autonomy. Others in the group had acquired powerchairs more recently (Jemma, Bryony, Ted, Toby):

Jemma   *THE CHAIR GIVES ME FREEDOM TO MOVE*

Some have only recently started learning to drive themselves and are still perfecting this (Ted, Toby, George). The method of driving is determined by their level of physical impairment, so these three boys all have to use headswitches whereas the others use a hand operated joystick, which is easier, faster and more flexible. In addition to the style imposed by the type of control they use, the way in which each of them drive is very much an embodied expression of themselves.

Being able to drive yourself gives immediate and very concrete autonomy, and some teenagers personalise their chair, by choosing a colour to match their football team, or putting stickers or other decorations on it. This suggests that the chair is regarded by them as an extension of their body. Like their physical bodies it is adorned to achieve a certain 'look'. Marie who likes girlie pink stuff, has various bits of jewellery and coloured keyrings dangling from hers, as well as a sparkly handbag, Jemma has Dr Who stickers, Toby's is red and covered with Manchester United regalia.

Sometimes the reality of this extended body boundary is demonstrated by a dislike of people touching or leaning on their chair. This is then an invasion of their extended body space. Marie, for example, is very particular about who does what to her or to her chair. For her, the chair really does appear to be part of her, and she is

very adept at both driving her powerchair and propelling herself along with her foot if she is in her manual one. She drapes her legs over the side quite often and is able to do wheelies and spins with a great 'devil may care' attitude. She also objects strongly if anyone leans on her chair, as if they are leaning on her body without permission.

Others (Kate, Bryony, Jemma), however, regard their chairs in a more detached way, more as a useful gadget rather than as part of themselves. Interestingly these three girls are all able to walk short distances with a walker, and crawl well, so they spend less time in their chairs, especially at home. Thus, for them perhaps, the wheelchair has not become so much an embodied part of themselves as it has for the others and they see themselves as people who sometimes walk and sometimes drive. These three are relatively less physically impaired and so as well as sometimes walking, they have more use of their hands. This, by implication, is also important as they describe many things that they can or would like to do (eg writing, drawing, making things) that are not possible for the others. None of these three mentioned their wheelchairs in their self descriptions, whereas those who use wheelchairs all the time seem to invest more in them, by personalising them as described above.

Nevertheless all regard the chair as an important way for them to be autonomous. I was there on the day when Jemma(12) got her long awaited powerchair:

> *MW   how does it feel to be in your new chair?*
> *Jemma   WICKED*
>
> *She went to fetch the register from the office on her own with her new chair. Relishing the independence of getting about. Drove round the classroom to put her drinks packet in the bin with a flourish and beamed. She is busy experimenting with the controls quite a lot and moving around to different places in the room, backing up, twisting around, but in a cautious and serious sort of way (fieldnotes).*

I also went with Terry (14) to collect his new chair. This was a replacement for him, and he had chosen some extra features which his old one did not have, as well as it being bigger, in fact adult sized.

I went up to the wheelchair clinic with him, a whole herd of people – OTs, physio, technicians, people from the company, quite a gang, but he knew them all and was quite confident. He was practically exploding with impatience and couldn't sit still, wanted to get in it straight way, while they were doing last few adjustments. The adults' attitude was all very positive and included him in the discussion. Finally they got him in and fiddled about some more, with footplates, headrests, angles and pads etc. They didn't get his VOCA positioning right, but he didn't care about this and was eager to get off out of the door and start driving. It has more power than the old one and he knows this, so he is hoping to go really fast! He went off down the corridor with it on the slowest setting. I walked down with him/ behind him as he went back to classroom. He met a couple of people as he went and stopped to see if they'd notice the chair, but indicating it with his eyes and of course they did. Saying things like, 'hey cool', 'looks so grownup', 'we'll never catch you now' etc. He looked pretty pleased with himself, and when he drove into the class, everyone stopped what they were doing to admire it, and the colour - blue for Chelsea of course (fieldnotes).

VOCAs

Voice output communication aids are the other important piece of kit that everyone in the study uses at least some of the time. The teenagers' attitudes to their VOCAs are rather similar to their wheelchairs, in that they generally think they are wonderful because they enable them to do things they otherwise could not. Like the wheelchairs, however, for some this is a really essential piece of equipment as they have no natural speech and few other movements to use for non-verbal communication (Ted, Toby, George, Nathalie, Prakash). For others, the VOCA is a useful addition to their other modes of communication (Josie, Jemma, Kate, Bryony, Marie, Terry). In all cases it enables them to talk with an audible voice, which can be understood by strangers and this is for them a most important advantage. However, like being a wheelchair user, having a VOCA raises some dilemmas in relation to identity. In fact Bryony expresses this ambivalence starkly:

I love my VOCA and I hate my VOCA

As someone who desperately wants to use her own speech then, it represents both the fact that she cannot do this, and also a way to say what she wants. As the youngest in the group she is perhaps only just discovering how useful the VOCA could be.

Those who have some natural speech very much prefer to use this if possible, but are also aware that they might not be understood. Some, (Bryony, Jemma, Ted, Toby) feel that the VOCA attracts undue attention because it is very visible (it looks like a kind of laptop attached to the wheelchair) and has an unusual voice. They sometimes therefore choose not to use it in public unless they absolutely have to, and rely instead on a familiar person accompanying them to mediate for them.

I was interested in exploring the extent to which they saw the VOCA as part of themselves, in the way that some saw the wheelchair as part of their body, or alternatively as a rather separate 'gadget'. This proved quite difficult to discuss, but not because of embarrassment or reluctance, but just because they did not know. Many had not thought about it specifically before and so their answers were often a thoughtful 'not sure', or 'a bit of both'. However, it was clear that those who had some speech saw the VOCA more as a tool to be used, whereas those for whom it was their main form of communication saw it more as part of themselves as the following discussion demonstrates.

All types of VOCAs allow the user to select from a number of different preset voices, and the teenagers had all been involved in choosing which one they thought suited them best. In some cases they had chosen very grownup, adult voices (Kate, Terry, Toby, Nathalie) and at first I found these voices rather surprising. As noted earlier two of the older boys had switched to men's voices in the last year, but because they both looked quite small for their ages, the deep pitch was a shock at first. On the other hand some still had very childlike voices (Ted, Jemma, Bryony) which actually sounded too young for them, and seemed surprising considering their sensitivity described earlier about being thought of as children rather than as teenagers.

The electronic 'robotic' quality of electronic speech means that the young people's voices lack natural intonation or any kind of regional accent. These features which would normally contribute to a person's unique identity are then missing. Katie (RA) is very keen to have a London accent as soon as the technology is able to achieve this. Meredith (RA) uses a voice which is called 'Betty' by the manufacturer. Other

people using the same type of VOCA may also be using 'Betty', so their voices will be the same. However she is keen to point out that her linguistic style of using 'Betty' gives her electronic voice its own identity despite its artificial and thus standardised production. For instance she might use particular phrases or words that are distinctively hers. I noticed this also with the young people, and as I became familiar with their style of language use, the lack of other markers became less problematic. Thus the electronic voice *becomes* the person's voice, and the AAC system part of their bodily identity. The fact that other people may be using the same VOCA voice is of course not a problem unless two meet each other, when it can be quite confusing. Indeed I witnessed several amusing incidents of this kind at AAC users' gatherings.

That some teenagers regard their VOCA as an external object or even possibly as a person, but under their control is illustrated in the following exchanges:

> *Jemma*   *MY VOCA WORKS HARD FOR ME*

and with Kate when at one point the VOCA was making a buzzing noise:

> *Kate*   *shut up! (laughed)*
> *MW*   *isn't it allowed to talk by itself then?*
> *Kate*   *'no… only when I tell it*
> *MW*   *oh I see, you're in charge!*
> *Kate*   *yes!*

The notion that physical prosthetics, which augment people's bodies, can be seen as extending subjectivities and or as types of cyborg (Haraway 1985, Dery 1995) has been discussed by Cromby and Standen (1999). The latter authors suggest that in the case of mobility aids, aside from the practical benefits of being able to move:

> 'the subjective awareness that independent movement is easily possible is hugely significant' (1999:3)

The AAC users' positive comments quoted earlier about their VOCAs suggest that this anticipated use applies also to communication devices. Thus having the

possibility of saying something may be as important as actually talking at any particular moment. As the examples have shown, the boundaries between the body, the self and 'the kit' do become blurred, especially when other people are involved in plugging in systems or programming words. There were several occasions at the start of the fieldwork when I was not very familiar with the participants' non-verbal communication when, for example, I failed to pick up their messages about what was happening with the VOCA, as is illustrated here with Toby:

> *Today at the start of our chat session his VOCA crashed and I didn't realise for ages that that was the problem. I thought he just wasn't saying anything. He was frantically looking at the screen, to tell me it needed rebooting, I felt really bad when I realised, this kind of thing must happen all the time (fieldnotes).*

Similar incidents occurred with Ted, whose system crashed or ran out of charge with frustrating regularity.

Thus, although the teenagers are enabled by their technology in some very positive ways, as was reflected by their verdicts that VOCAs were 'magic', 'fantastic', 'great', and 'help me say what I want', they are also simultaneously very dependent on the technology and sometimes at the mercy either of it, or the people who manage it for them.

A small number mentioned their use of AAC in response to general invitations to describe themselves, but again not until they had said many other things. They were quite specific in describing their particular ways of communicating when asked this in a different context. Terry's response here is rather typical. Many of them were very keen to emphasise that they communicated in several ways:

MW	*How would say you communicate with other people? What are the ways you do it?*
Terry	*USE VOCA*
MW	*okay... anything else?*
Terry	*E-MAIL, COMPUTER*
MW	*okay great!*
Terry	*MY EYES... HANDS*

Four of them can use some speech of their own (Kate, Jemma, Bryony, Marie). Again these girls saw themselves as 'people who talked' at least as much as they saw themselves as 'AAC users' and thus did not choose to mention this as a core part of themselves. It is interesting that in the excerpt from Josie above (page 244) she mentions her VOCA, almost as an aside, as part of her 'kit', but does not elaborate about what is important about this. Perhaps significantly she was the participant who used her VOCA least, and she had many highly effective low tech ways of making herself understood with people who knew her well. However she was aware that she would need to use her VOCA more with people who do not know her, but had not been in this situation very much yet.

That some young people did not say anything about their physical or communication impairments or the equipment they used as an aspect of themselves might have different explanations. One is that, by implication, their view of the world through the lens of a 'different' body was indeed truly embodied and did not need describing, so it did not occur to them to elucidate it (Merleau-Ponty 1962, Crossley 2001). The other is that they deliberately did not mention this aspect of themselves, either because it is obvious or it is something they do not want to talk about. In any case, the result is that they highlighted ways in which they are physically like other teenagers rather than ways that they are different.

Other bits of kit

In addition to wheelchairs and VOCAs, the participants had a number of other aids and appliances, both low and high tech. They had a matter of fact attitude to all of these, which arises, I suggest, from its familiarity and their understanding of its utility. Thus, like corporeal bodies which disappear from our attention until they are problematic, the kit is also taken for granted until it goes wrong. Sharp (2000), however, highlights the increasing likelihood of commodification and fragmentation of the body, so that it is regarded as its constituent parts rather than as a whole. He sees the development of medical and assistive technologies as part of this trend:

> 'The medicalization of life, the fragmentation of the body and subjectification of colonized subjects all potentially dehumanize individuals and categories of person' (2000:283).

The teenagers had, for example, lifts and hoists in their homes, specially adapted computers, foot-operated Playstations, adapted calculators and cameras. Kate(13) had strong ideas about what she would like her ideal place in the future to be like:

> *My own home with lots of environmental controls, a handheld AAC system and lots of stuff on the computer. I'd be able to do my e-mails and would have my own personal assistant (written piece)*

Two teenagers wore special close fitting body suits ('second skin') during the day. These are a relatively new innovation which provide extra core body stability and enable them to sit up and use their hands and arms much more. Both were very positive about the value of these, again because they could then do more for themselves. When I first saw Bryony in hers, when changing for swimming, I was struck by its cyborg like nature:

> *Quite a contraption with all its zips etc from elbows to knees (fieldnotes).*

But she was completely unselfconscious and at ease in it, in a way that suggested that it was perhaps just a part of her body. Similarly for Terry, his second skin is so much part of his body that both he and his dad both expressed great concern that the funding for it may run out when he leaves school next year and that he would then be without it.

When I visited the young people at home, I realised how much their houses were adapted to help with the physical practicalities of life. All either lived in bungalows, or houses that had been extensively adapted for them. I saw at first hand how stressful it was when the technology failed, as in this example at Nathalie's (15) house:

> *Dad was out and Kathy (Mum) was back and was going to take Nathalie upstairs to bed. However there was a panic because her special lift didn't work, it didn't stop at the top so she ended up coming back down again. She was laughing but Kathy was swearing like a trooper 'bugger bugger bugger, we've just fixed it, we're so dependent on technology!' She was envisaging us having*

*to carry Nathalie up between us. However after some more pressing of buttons
it worked and she was off upstairs (fieldnotes).*

Being comfortable

As a group the teenagers have strong views about aspects of physical and bodily
comfort, and some of these somewhat parallel the priorities of their non-disabled
peers, but with some additional significance.   For instance, they are very interested
in food and drink, and in places where they feel comfortable, accepted, and where
they can physically 'chill-out' and relax.

Their particular interest in specific foods reflects that, for many of them, eating and
drinking are difficult tasks. Being undernourished is a constant concern for and
about many people with cerebral palsy. Foods that are easy to eat, like Toby's
chocolate minirolls (of which he ate an astonishing number every day!), are both an
important source of nourishment, and enjoyable in ways that many foods are not, if
chewing and swallowing are problematic. Three participants have extra nutrition by
tube-feed in order to keep them growing well, so for them the kinds of additional
foods they can eat are important.

Also emphasised are other aspects of physical comfort which might seem ordinary,
but are magnified for this group. Comfortable clothing, for example, allows freedom
of movement and the young people like not always being restricted by the
equipment which they have to use for much of the day at school:

> *Ted likes his slippers because they are soft and don't have the restrictive straps
> he has to wear in the day (fieldnotes)*

Furniture, such as their own adapted bed or a beanbag is also especially important
for people with physical disabilities, as they are often uncomfortable in standard
chairs or beds.   There is also a sense of relief when they can get out of their
wheelchair, take off their special boots and flop!

> *Terry was sitting in a very relaxed and loungey way on a beanbag playing with
> his playstation with his feet. His dad had rigged up the controls on a special*

board for him to do this. He looked very laid back and different from how I knew him at school (fieldnotes, first home visit).
(Bryony) when I visited her at home liked to lie on the floor, all floppy, while we chatted and moved herself around on knees or crawled. Often she leaned on me or her mum, and moved about constantly, much more than she can in her chair. I never saw her in her wheelchair at home whereas at school she was almost always in it (fieldnote summary).

There are contradictions and ambivalences about how they view their 'kit'. Many of them told me that there is freedom in being in a wheelchair (especially a powerchair that they can drive themselves), but also freedom in being out of it. However moving around without it is something that most of the teenagers only did in the familiarity, safety and privacy of home.

The data shows that the use of 'kit' is simultaneously practically useful and allows independence, but also potentially poses a risk to the users' sense of self, by highlighting their difference. This is raised in work by Lupton and Seymour (2000) who investigated issues about technology with adults with physical disabilities:

> 'technologies could serve to mark out people with disabilities as 'different' or 'lacking', acting as a barrier to the achievement and presentation of their preferred body/self' (2000:1851).

There are however subtle variations in the ways in which different individuals perceived different kinds of kit and the extent to which they are part of the embodied self. Most of the participants, for example, mentioned being a wheelchair user before they talked about being an AAC user. They were generally more interested and willing to talk about their chair, than about their body, for as I have shown this is less controversial and personal, also however powerchairs have the cuedos of being high-tech and therefore in some ways 'trendy', an acceptable part of themselves. Similarly perhaps talking about using a VOCA was easier and less difficult than talking about not being able to speak? Seeing the VOCA as part of themselves seemed to be less common than seeing the wheelchair in this way. Perhaps this is because the person's thoughts and language are still 'in their head', so the VOCA is only a medium for these to be expressed and thus not a fundamental part of them. This complex issue was not easy to explore with the teenagers and remains a matter of conjecture.

One interpretation of this difference between attitudes to chairs and VOCAs may be that these youngish teenagers are still moving in familiar circles, where their low tech and esoteric communication modes are understood. They may not yet have realised how challenging communication will be with strangers, nor the extent to which their VOCA may become more significant and essential later. This analysis is supported by the data from discussion with the nine older college students in a focus group, who did see their VOCAs as important, especially for going out independently. For example, they underlined the need to be able to get messages across in places like the cinema, the pub or music/video shop. Their experiences of less protected and more challenging environments, such as college, work placements and independent living settings might account for their different and more nuanced attitudes to communication and to VOCAs, as well of course to their more mature years.

Interviews with parents also revealed some interesting observations about the implications of using 'kit' and the assumptions about the body and identity that are made by people about someone who is visibly different. Several parents related experiences in public where they felt that the kind of wheelchair and VOCA that their child had, directly impacted on how they were treated by strangers. Kate's mum felt that when her daughter was in a manual wheelchair, people assumed that she had learning difficulties and so spoke directly to her less, and patronised her more. In contrast when she was driving herself in a powerchair and also using the VOCA, which looks complicated, she was treated in a more respectful and grownup way. The visible cues that she was cognitively able to drive type and spell affected people's perceptions of and interactions with her. Bryony's parents felt that when she used her VOCA in public, it was simultaneously a negative and positive experience for her. It attracted unwanted staring, which distressed her in just the way that Reeve (2008) has described. At the same time, people were impressed by the technology and her ability to use it, and so were positive and complementary. Here Bryony's father explains:

There was a small crowd of people looking and you can see that they were recognising this is somebody using a communication aid, this is a thing to communicate with people, but that doesn't seem to happen very often and I think it is a case that the general public just don't know what the funny box is and the funny box on the wheelchair just... that just means that, you know, we can't think about that, and they'll disengage

but on occasions when she does use it and people do realise what it is, they then... get a, a very sort of quick shift from thinking, oh well, the poor bairn's got a little box and it probably means that she can say that she needs the toilet or what have you. And then Bryony will display that she can actually use it and construct a sentence and they recognise that that's possibly harder than any sort of computer technology they use at home and that the implication is that Bryony is obviously quite clever because otherwise she wouldn't be able to do that. And a few times I have seen that happen and I can see people suddenly think, oh, well, right, yeah, you know, I've just been completely patronising you and I should probably apologise.

Conclusion

The data here aligns very closely with the recent literature on the body in the disability arena particularly that of Hughes and Paterson (1998), Watson (2002) Thomas (2007), Reeve (2008), and Hughes (2009), all of which suggests that the body should be seen as part of the experience of disability, as well as of impairment.

It shows that young people with visible impairments are like other teenagers in wanting to be seen as physically 'normal', and that they are busy developing their own bodily style through fashion. They have an awareness of their changing size and shape during puberty and are keen to be recognised as teenagers rather than as younger children. Expressions of their individuality extend beyond their physical bodies to their style of use and decoration of their 'kit'. In some cases their wheelchairs and VOCAs become very much part of themselves, in others they are regarded as useful gadgets of which they are in charge, and which help them to do what they want to. With age they have an increasingly accepting and pragmatic attitude to their bodies and what is possible for them to do. Some are keen to push their own boundaries by being involved in sport, which gives them a strong sense of physicality and success.

Issues around control and agency are important and there is evidence that during the teenage years these young people have to develop ways of managing the tension between wanting to be seen as autonomous, but at the same needing considerable amounts of help with physical tasks. Expression of identity is often technology dependent for them and that is perhaps why they have strong views about availability and efficiency of their kit.

An analysis of what 'agency' or autonomy actually means becomes complicated, when one considers people who have both physical and communication impairments and therefore a constant physical dependency on other people or on technology for almost everything they do. It raises the question of whether agency is, at heart, a physical phenomenon. While on first consideration it appears to be a cognitive/emotional and social entity, it is expressed and put into action largely through communication which is, in turn, dependant on physical action. The body itself is communicative in many ways and therefore subjectivity is mediated via the body (Berger & Luckman 1967). Thus, while someone might have the cognitive desire and capacity to be autonomous, if they cannot play this out physically in ways which others recognise, then their status as agentive and independent selves may be denied. As Hughes and Paterson (1999) emphasise, vocality is usually particularly privileged. Thus for those with communication impairments the key way in which society expects subjectivity to be expressed is restricted. Someone who doesn't *seem to talk* is at risk of being marginalised and dismissed as strange or incompetent, in a way that someone who cannot walk is not. It is clear from my data that the attitudes of others towards the teenagers, precipitated by their visible differences, are a cause of concern and sometimes anger for them. This unease was mentioned by all of the young people albeit in a variety of ways.

As outlined in Chapter One, theoretical approaches that account for people with physical disabilities' frequent sense of exclusion, such as: liminality (Murphy 1997), impurity (Douglas 1966), disavowal (Shakespeare 1994), 'intercorporeal dys-appearance' (Hughes & Paterson 1998), psychoemotional disablism (Thomas 2007), and homo sacer (Reeve 2008), are all relevant and applicable to my data with young people, although stemming from a variety of disciplinary roots. Rarely have these

explicitly been applied to children or young people, although there are plenty of examples of their use in describing disabled adults' experiences in the work cited above. The use of liminality as a helpful concept in relation to inclusion by Ytterhus (2004) and Connors and Stalker's (2003, 2007) application of psycho-emotional disablism are exceptions to this relative paucity of application of theory in the literature on disabled children.

Watson (2002) describes the difference between how disabled people see themselves and are seen by others as a kind of 'perceptual dissonance', and I would contend that it is actually more than this: an ontological dissonance. Newcomers make assumptions about them by looking at their bodies, rather than getting to know them as people. They are easily objectified, and this feels uncomfortable because their selfhood and personhood are at odds. This will be explored further in Chapter Seven.

Similarly Thomas (2007) suggests that disablism results in 'existential insecurity', by limiting who people can 'be' not just what they can 'do'. The present generation of physically disabled teenagers has experienced far fewer structural or physical barriers than previous ones. Although they have the same impairments (and thus similar corporeal bodies) as their predecessors, because of their experience of high tech equipment from an early age, they have been enabled to 'do' much more. Their 'kit' should then be able to contribute to their bodies being seen as competent. However their social bodies are still viewed as problematic by others. As Jenkins reminds us:

'selfhood is necessarily embodied' (2004:329),

so even though their self-perception of their bodies is positive, the attitudes of others to their different bodies may still serve to restrict who these young people can 'be'.

Chapter Seven. Personhood and social relations:
Me and other people

Introduction

This chapter considers how young AAC users are seen by others and explores their social relationships. It discusses the ways in which these aspects of their lives contribute to the teenagers' identities and lifeworlds. Personhood as described in Chapter One and drawing on Cohen (1994), Jenkins (2004) and others (Giddens 1991) is the aspect of identity which arises out of other people's views. It then contributes to an individual's dynamic and evolving identity throughout the lifecourse. It is suggested that the attitudes of others if accepted, are internalized into individuals' perception of themselves (Mead 1934, Skultans 2000). If we are all essentially social beings, as Mead suggests, then:

> 'Selves can only exist in definite relationships to other selves'
> (Mead 1934 cited in Bagatell 2007:413)

However as Cohen reminds us (1994:57), personhood is 'a cipher of me' not the whole me, as it is a selective or partial view. So the self assimilates personhood and is affected but not subordinated by it (ibid).

The ethnographic examples presented below support the argument that personhood and selfhood are inextricably intertwined (Cohen 1994, Jenkins 2004). In an early task the teenagers listed the most influential and important people in their lives. As described in Chapter Four, these are firstly their families, and secondly, people at school, and interestingly and perhaps unusually, the latter are predominantly adults rather than peers. The young person's self descriptions are both influenced by and in turn have influence on how other people view them. This is evident in the data, since the ways that the teenagers are described and viewed by those who know them well often mirror their self-descriptions.

In contrast, it can be seen that the way they are seen by strangers does not align closely with their own views or those of familiar people. Thus those close to them view them as they see themselves; as 'normal' people, whereas strangers see them as essentially 'different'.

The idea of a fundamental 'ontological dissonance' for the participants, between their own (as well as familiar people's) views of themselves, as opposed to those of unfamiliar people is explored here. Two visual representations of how their various identities may interact for AAC users are presented in the concluding section of the chapter.

The contribution of familiar people to the teenagers' personhood

Parents

It is clear that the parents' perceptions of their children are often similar to the teenagers' views of themselves. The close relationship between these two views suggests that they influence each other, and further that this effect is bidirectional. This of course is likely to be true for any parent-child dyad, and perhaps more so in younger children, and indeed traditional power relationships between children and adults mean that parents may have a great deal of influence on who their children can be. Teenagers however may gradually break away from this symbiosis and develop views of themselves which diverge from their parents. It may be therefore, that because, as this thesis has shown, disabled children are more embedded in the family and have fewer external social links (Blackstone et al 2005), that the influence of these parents on their children endures for longer and is stronger than for their non-disabled peers.

The participants' parents' views of them are generally positive and affirming, and focus on the teenagers as people in a social relational sense, rather than on their impairments and things that they can or cannot do. As the teenagers themselves do, parents emphasise their social-relational selves, especially within the family and with friends, as well as stressing positive qualities such as: a sense of humour, being caring, determined, strong-minded, perfectionist, feisty, resilient, or patient. In

addition and in parallel with their children, many parents mention their child's unease about other people's attitudes to them and anger at being patronised. Their language and examples often very closely mirrored the teenagers' self descriptions and concerns, e.g. Toby's mother when describing him says*:*

> *He's got a very good, wicked sense of humour. He loves playing practical jokes on people. He's quite emotional. He's quite emotional about other people getting upset, I suppose he has empathy with other people. He'll want to help them and he... I think somebody at school was ill and we'd been shopping and he'd had a chocolate bar and he took it in to give to somebody.*

Jemma's mother:

> *She is quite a caring person, she likes to care...she's quite motherly. I think she's lively, outgoing, nosey – the most nosey person you can ever imagine, she's a real busybody – and she's just delightful really.*

and Terry's parents

> Mum   *Always looks on the bright side. Nothing seem to faze him,*
> Dad   *No. I mean, he just seems to enjoy it, and just wants enjoy it, anyway that he can enjoy it, he'll do so.*
> Mum   *He takes every day at a time. Um, he has certain things that he follows, like football*
> MW   *Why, do you think... the way you've described him, what have been the main influences on him do you think?*
> Mum   *He was born like that.*
> MW   *He's born like that? That kind of character?*
> Mum   *It's tenacity, um, I come from a strong family. His dad comes from a strong family. He's just so... you know, he's, he, he's just going to be strong.*

These examples reveal shared family narratives about the teenagers and their lives, reflecting jointly constructed consensuses about them as people (Clandinin & Connelly 2000, Bohanek et al 2008).

Being a 'normal' family

There was a notable variation in the way that parents across the group conceptualized the impact on their family of having a child with a disability. However detailed analysis of this issue will not be presented in this thesis.

Essentially though, many families emphasised strongly that they were a 'normal' family in which their disabled child was included, even if this needed extra effort or some adaptations. Their parents demonstrated a 'can do' attitude and several explicitly used this phrase. Many said 'we do normal things' to describe their family life and attitude to their son or daughter:

> *Josie's mum: If someone was going to the cinema, we'd would go, so all those kinds of things, she's just been out in the world...So, if actually then that child isn't part of that wider world, so how can they have some of the skills they're going to need to ever be part of that?(interview).*

> *Toby's mum: I think having siblings has made him normal, if there's such a thing. It's made him realise that... it's made him experience things that, if we just had Toby, I don't think we would. Like on Sunday morning, Rob was playing football at 8 , so 7.30 we had to leave, in the rain, with coats on, umbrellas, push him through a field, stand there watching a match, and he loved it. But if we didn't have normal, in inverted commas, siblings, we wouldn't have. He wouldn't experience these things. So I think that fact, that he's had normality, from a normal family life, has made him, I think, happier in his mind and in his life he does what everybody else does. There's nothing, really, that he can't do, or we can't get around in some way (interview).*

> *Kate's mum: she has her own Solo card. She pays for everything herself, ... And that's a typical, normal thing for a teenager to be doing... So... for us that is a typical, normal thing to do, so she should do it. Now that's because we believe she's able to (interview).*

This replicates similar findings by Traustadottir (1991). She found a pattern of mothers of disabled children, in particular, taking the lead in actively constructing this 'normal' life for the family, both by taking on more of the responsibility of caring for the disabled child in order for normality to happen at home, but also negotiating normality outside the family.

In most cases the parents were not very interested in or aware of disability politics or such dichotomizing discourses as the 'medical versus social model' debate described in Chapter One. However, unwittingly, many of their views and experiences reflect these contrasting approaches, although some also evidenced pragmatic combinations of the two. For example they did not deny the real 'impairment effects' of having physical and communication difficulties, but were also

clear that it was often 'society's attitudes' which made the biggest difference to their child's life (Thomas 2007). Here Terry's parents are talking about taking him out:

> Mum Church is fine. There are 500 people there but, you know, they're familiar with him. The main reason if I don't go somewhere with him, it's because of the practical logistics of that wheelchair in and out of the van on my own, the access.
>
> Dad That is the reason we won't go rather than anything else, but otherwise we've always felt we can take him anywhere. And he behaves appropriately wherever we take him, and if people are positive and it works well, we'll go again.

Paradoxically however, although many families emphasised their 'normality', they also highlighted the difficulties they had in securing the extra resources they needed in order to be 'normal' (e.g. adaptations in the home, or funded personal assistance). Some felt that if they appeared 'too normal' to the authorities they would not get the help they needed; so ironically, they had to be 'abnormal' to be normal, as Jemma's mum suggests:

> We're not very needy you see. So I sort of felt like actually, maybe what I need to do is like become a drug addict and a single mother and God, then Jemma can have some extra support. You know, I felt like we're a bit too normal (laughs) which is a shame.

As can be seen below, mostly there was an explicitly inclusive attitude, which reflected a desire for their disabled teenager to have the same life chances as his or her siblings and peers. As their children grew physically bigger and thus more difficult to lift, the physical strain on parents was a factor, but this was usually overcome. More important were economic or attitudinal barriers to social inclusion, as these were more difficult to negotiate.

The question arose with many parents, of whether they regarded their family as 'a disabled one' (Goodley & Tregaskis 2006), either in parallel with being 'normal' or in contrast to this, and the extent to which having a disabled child had affected the family as a whole. This study supports previous evidence that parents of disabled children do regard themselves as having extra stresses in their lives, particularly physical and financial ones and of constantly having to fight for resources on their

child's behalf. Again like other studies it emerged that emotionally there are some paradoxical effects, both of strain, tiredness and worry, as well as joy, optimism and love for their child, and also a sense that the child had contributed to the family and given the family a different worldview (Voysey Paun 1976, Larson 1998, Kearney & Griffin 2001, Green 2007). Thus it appears that maintaining a 'normal' life and having a 'can do' attitude can be challenging at times. During a group discussion with parents about securing resources and trying to change attitudes at the 1Voice group someone said:

> *I wonder why disabled children always have angry parents? (everybody laughed).*

Thus parents saw both themselves and their children as fighters and as very resilient in the face of adversity (2001). Similar results are reported by Ryan (2008) about the experiences of parents of children with learning difficulties.

Only one parent mentioned the impact that his son's communication impairment specifically had had on them. Terry's dad reflected that the nature of their relationship was different from that with his other sons, although as can be seen his wife was less sure about this:

> *Dad*   *certainly from my point of view, the hardest thing of all is the fact that he cannot talk. You can't have a conversation with your son. Not a real conversation. Just bits and pieces of it.*
>
> *MW*   *Yeah, well, you have to work very hard, don't you?*
>
> *Mum*   *And he gets so frustrated as well.*
>
> *MW*   *Does he? with the talking or the?*
>
> *Mum*   *well, with us, well, lack of us not being able to understand, or maybe we do understand a phenomenal amount?*
>
> *MW*   *Yes. So, if, it's interesting that you said that's a thing that you, that you regret. Is that that you can't have a conversation with him?*
>
> *Dad*   *Mainly, yeah.*
>
> *MW*   *So that you can't have a father to son, man to man chat about stuff?*
>
> *Dad*   *No. No.*
>
> *Mum*   *I don't know... I think you can. He understands everything...what's going on*
>
> *Dad*   *maybe?*

Parents tend to use rather heroic narratives about their child, and one might question why this is. Arguably, and one parent implied this, it was in a deliberate effort to nullify the more common negative narratives that they experienced especially from 'outsiders', as will be demonstrated later. Indeed, Goodley and Runswick-Cole (2009), drawing on Hochschild's (1983) concept of 'emotional labour, suggest that mothers of disabled children have to:

> 'induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others' (Hochschild 1983:7),

and thus 'be nicer than natural' (ibid), particularly in public spaces. One mother for example suggested that other people's positive responses to her daughter are produced through her own (i.e. the mother's) efforts to 'model' for them how they should behave towards a disabled person. Arguably, then, these parents are more active in 'constructing' their disabled children's personhood than would usually be true. Potentially then parents act as mediators not only in communication and by arguing for practical resources, but also in the negotiation of identity, when they try to correct the misapprehensions made by others.

Being a normal sibling

Although I did not interview siblings specifically, I observed their relationships with the disabled teenagers in various naturally occurring family contexts. Parents reported mixed views from their other children about having a disabled brother or sister, again echoing other studies (Connors & Stalker 2003). Some parents emphasised that different siblings dealt with the attention their brother or sister attracted in public in various ways, as these examples show. First Nathalie's dad is talking about their other children:

> MW   *what's their response if somebody is coming up and being very curious? How do they respond to that?*
>
> Dad   *I think in some ways that's when they're at their best, I think, our kids, you know. it's a time in which they will stop and things will go at Nathalie's pace. They'll try to explain in an appropriate way if somebody is asking a question or is maybe being a bit inappropriate in terms of their approach*
>
> MW   *They might step in and protect her?*

> *Dad   They would protect her. But not, you know, they're not overprotective are they? I think it's one of the times when they're quite good, you know, our kids. It brings out the best in them, really (interview)*

and Toby's mother talking about her younger children:

> *Mum   Rob (10) is very... wherever he goes, he wants Toby to go too. So, if we're going into town, if I'm in one shop, Rob will now say, I'm going into the games shop with Toby and he'll take him there, and he interacts, he's very good. Maya (8) is more... self-conscious of people looking. She's more aware of...*
>
> *MW   People's curiosity?*
>
> *Mum   Yeah. She gets embarrassed... well, not, no, she gets embarrassed, but she, I don't know, it takes her longer, I think. She sees the disability more than Rob does, I think. Ally (4) just rides on his chair. ...Jumps all over him. She'll hold his hand and pull him (interview).*

Some discussion with siblings arose spontaneously, and it seems that their relationships with their siblings are both 'normal' and 'different'. They are different in that they are aware of the need for special arrangements, equipment, and more time in order for their sibling to be part of what happens. Siblings, for instance, help with practical tasks such as moving equipment, feeding and mediating in conversations, often in unselfconscious and matter of fact ways. This is then part of normal family life. Attitudes vary from siblings being vehemently protective and sensitive, to seeing their sibling as a playmate, as fun and funny, as a nuisance or a competitor for attention. However in all cases, the disabled sibling is viewed as part of their family and 'normal' to them. These findings match closely those of Connors and Stalker (2003):

> *Angie (16), Jemma's older sister*
>
> *MW   what are they thinking about you then? – like people on the bus, do you think?*
>
> *Angie I don't really care.*
>
> *MW   Oh, you don't?*
>
> *Angie No, she doesn't...because Jemma's just Jemma to us!*

However in contrast I noticed in many households that rather ordinary instances of sibling rivalry occurred in a different way, where because of the disabled teenager's slow communication, parents were more often recruited as mediators. Here parents seemed to be compensating for the AAC users' difficulty with fast repartee. After

one such incident Nathalie's mum commented to me that she felt that it was her job to intervene, but was aware that the other children might accuse her of constantly 'taking Nathalie's side' in such disputes. In a sense then, a teenager needing to use a parent to mediate for her is an example of 'abnormality'.

In summary all the teenagers were physically surrounded and emotionally supported by their families in ways that showed obvious understanding of their impairments but did not emphasise these unduly. It was taken for granted that they needed extra help with certain tasks and 'talked' in a different way, and that sometimes 'normal things' had to be done differently. These then became normal for them. Simultaneously and therefore perhaps paradoxically, the disabled teenagers needed extra help and adaptations but were also just 'one of the gang' and so were not given any special status or attention. Several parents used phrases like 'we just get on with it' and 'we try to treat him/her just the same as the other kids as much as possible' and this was very much the impression I had while with them at home. Non-disabled children similarly described their disabled sibling as 'just my brother'. The participants' own desire to be seen as ordinary teenagers rather than extraordinary, encouraged their parents to see them like this, and the parents reciprocally aimed to be a 'normal' family, but sometimes through making extraordinary things ordinary.

Familiar people outside the family: their role in construction of personhood and social relationships

From the teenagers' point of view, the second biggest influence on their lives after their families was people at their schools (both past and present). However, unusually, they listed more adults than children, which is different from other young people. This may be because staff act as valuable or essential supporters and mediators in communication. Nevertheless, the data from school staff[51] shows that often they had rather incomplete views of the teenagers, which although to some extent echoing the teenagers' self-descriptions, are limited because they were drawn

---

[51] teachers, LSAs, care-staff and therapists

just from staff's experiences of the student in the school context, and with little knowledge of and some misconceptions about the rest of their lives. Generally, the teenagers felt that people at school, as well as paid personal carers at home, were kind and helped them:

IN A GOOD WAY

as Josie said.   Most of them listed these professional helpers amongst their important people and some named a few as their 'best friends'. Skar and Tamm (2001) in a study about physically disabled children's relationships with their assistants found similarly that these adults were seen simultaneously as a friend, as parent-like and as a helper, but also that they were sometimes too intrusive and could block friendships with other children, and deny the young person autonomy. My observations are similar, but the additional communication impairments that these teenagers have, entail the adults regularly acting in the role of communication mediator as well as physical helper. It is this extra role that increases, I suggest, the chances of disruption to ordinary social relationships with peers. Skar and Tamm's (2001) participants suggested, for example, that if they used the assistant as a way into social situations, there was a danger that the adult might be included in place of the young person.   This certainly rang true for these AAC users, as I regularly observed assistants being drawn into conversations which were originally directed at the teenager. Thus their relationships were often mediated through adults in a way that would be very unusual and probably not tolerated by most other adolescents, i.e. the adult 'speaking for' the youngster.   Indeed this comment by a non-disabled child in Jemma's class reflects this:

> *As we were walking over to the hockey pitch with Jemma in a sports wheelchair, another girl from the class came up and asked me 'are you Jemma's boss?' and then we got chatting, and she said to Emma (LSA) 'are you her minder?' and later ' I think she would like to be free' (fieldnotes).*

Differences between the ways in which help is given perhaps reflect the assistants' underlying perception of the disabled teenager and attitudes to disability more broadly. Thus the degree to which helpers recognized the participants' desire to be an autonomous person who wants control and choice varied. The three who were in

mainstream school and thus had one-to-one assistants were particularly at risk of spending much more time with adults than with classmates. Some staff, though not all, were careful not to be 'overprotective' or to block social interaction with peers by being ever-present. However several were aware that disabled students often spend more time talking to adults than to peers, but they felt that this was because

> *Adults take the time*

and

> *Other children are too impatient (focus group)*

Some staff recognised that sometimes they needed to 'back off' in order to let the teenagers have a chance to interact with other students without adults in earshot, and some deliberately engineered such occasions.

There was also awareness that the type of 'kit' that the teenager used could create a barrier to socializing. The physios for instance felt that this was a dilemma, as part of their raison d'etre was to provide and encourage the use of equipment, while knowing that this could be counterproductive socially:

> *Physically big bits of kit are a social barrier, eg the tray etc I know parents of one child who want to get rid of the tray, because they think it makes her unapproachable., if it was a normal little wheelchair , people would come up and talk, but not when you see kids with all this kit on, they think it might break or something (Physio in focus group).*

Kate(13) talking about her change of school, was very clear about the way she wanted to be treated as a person by helpers, and how this had not happened at her old (mainstream) school.

> *I enjoy everything about my new school which is a school for children who have physical and mental conditions. They really understand me and what I need. It's so much better than my last school, where they kept trying to make me type faster and did things for me. I like all of the teachers at Valley because they are patient (written).*

The problem for her was that the teachers at her old school had perceived her personhood in a way that mismatched her selfhood. They were trying to make her

'normal' (e.g. write fast, talk and do not use VOCA) in ways which she could not do, and at the same time were denying her autonomy to do other things that she felt she could. Here interestingly, she does not deny that she is different but wants acceptance of this, rather being punished for what she could not do in the same way as her peers. This negative experience had given her a major crisis of confidence about who she could be, which had precipitated the change of school. Thus the staff's perception of her had had major consequences.

Jemma and her mum were able to explain how other people could contribute to her being the kind of person she wanted to be:

> MW   *I'm trying to get at what's a good way to help and what's irritating*
> Mum   *people often think they're helping by sort of grabbing... they've got much better now.. but they used to be going .. oo come on come on...when she wants to be left alone to do herself*
> MW   *so... fussing?*
> Mum   *yeah fussing is a bit...isn't it Jemma do you remember when people used to fuss, when you were thinking , just let me get on with it... they still fuss by talking a lot to you but not so physical... what else is a good way of helping you?*
> Jemma   *LETTING ME GO AND BE INDEPENDENT*
>   *Don't moddle coddle me! (speech) NOT VERY PC!*
> Mum   *We like the ones like Bob (LSA) who say. .. come on you cripple get out your chair .. you know what I mean because actually he's saying it in a really nice way and its funny and we can all laugh.....however if someone says that in a nasty way.. she may learn to laugh it off... and just go ..actually you don't know what you're talking about!*

The teenagers themselves were very sensitive to the way people interacted with them as they recognized it as a reflection of how they were perceived, as George(16) so cogently puts it

> *THERE ARE CERTAIN PEOPLE WHO MAKE ME FEEL MORE PART OF THE COMMUNITY BECAUSE OF THE WAY THEY ARE AS PEOPLE*

Several participants said that on meeting a new helper, they were often anxious, to see if they would be someone who would as Ted says

> *TREAT ME AS A PERSON*

Several told me that they knew new people needed time to learn about them and so they would tolerate a period of uncertainty while they got to know each other. Terry said

HAVE TO TRUST THEM

They were aware that some people were nervous about how to be with them, whereas there were others that they could trust straight away. The teenagers' sense of the adults' anxiety was confirmed by their helpers themselves. Several teachers at mainstream schools who had no prior experience of working with disabled children and in particular with AAC users, told me that they were worried about having the child in their class and about how to help and behave:

> *Jemma's ICT teacher. Wanting to help but actually rather tentative about moving her chair and setting up her equipment. He said self-consciously to me 'I haven't done this before'. People's nervousness about getting things wrong, concern for the child and embarrassment? (fieldnotes)*

Jemma expressed her irritation one morning on arrival at school:

> *She said suddenly 'I FEEL LIKE A BABY IN THE CAR', this is about the two women who escort her to school in the taxi. She thinks they are pair of old witches who patronize her a lot. We had a funny conversation about putting up with them! (fieldnotes).*

Thus Jemma's escorts are constructing her as a younger and helpless person. She resists this by asserting that they are wrong, and she is mature enough to dismiss their judgment of her. Nevertheless it is irritating for her to be so misconstrued and her way of dealing with this is to be rude about them.

However, many school and club staff who knew the teenagers well had attitudes and perceptions of them, which matched those of their parents. Perhaps because having worked with them over a long period, they had grown to know them as 'people'. Any negative attributions precipitated initially by their impairments had been overridden by experience of their social-relational selves. Some of these very familiar professionals made criticisms of other staff, who they felt were patronising and did not give the students enough opportunities to talk and make choices:

> *Alex (SLT) said she thought that the care-staff are 'rough and ready' and 'insensitive with the kids' and 'do the care tasks at great speed' and 'are patronising'. She thinks they don't treat people like Toby who are small for their age, in age appropriate ways and forget that he is 15 because 'he looks young and can't talk' (fieldnotes).*

Those who are paid to help can become 'like parents' in taking on important mediating and negotiating roles, and so contribute to the construction of the disabled young person's personhood, in a way which more closely matches their selfhood.

Nevertheless, Shakespeare (2006) suggests that the dominant discourse about disabled people is often about their impairments rather than about them as people, and this was certainly true of some of the staff in schools. Although there was obvious affection and dedication to doing the 'right thing', there were constant conversations about tasks the adolescents could not do and needed to 'practice'. This contrasted greatly with their families' views of them as competent social beings. There was a tendency to pathologise them by focusing on their differences, and to assume that their home lives were in some way impoverished. For instance one OT said when the discussion turned to how AAC users could converse with other people:

> *Well of course they never hear normal conversation (focus group)*

This statement is puzzling since she was talking about Toby and Terry , both of whom she knew had siblings and who regularly talked at school about family activities like camping trips, local football matches and family parties,. There was plenty of evidence that the boys had opportunities to witness and join in, in their own way, with ordinary family chitchat and interaction.

Thus I saw many situations where, although the teenagers were well supported physically by staff, they were excluded from conversation or social interaction, by a lack of the adaptation (described in Chapter Three), to their type of talking which is necessary in order for them contribute. In this sense they were being perceived as

people with bodies which needed organizing, rather than as social-relational beings. Their personhood then was a 'not normal' one, as shown here on a school fieldtrip:

> *We all walked/wheeled through woods and along a stream. Beautiful spring day. I pushed Terry and tried hard to talk about stuff as we trundled. Very aware of how difficult it is for him to make active conversation in this setting , as he didn't have his VOCA so really has very little means of initiating any unpredictable conversation. He is at the 'pushers' mercy in terms of where he goes, along a bumpy path. Lots of chat going on between the adults, their own agendas, but not much to the students or between them, as there would be with speaking teenagers. It feels as if they adopt a rather passive 'wheelchair' role in that situation – nothing they can do about it. I wondered if they were bored or were enjoying the new and different environment, despite not really being able to comment on it or direct anything. Difficult to know. I asked Terry later and he said it was ok but not sure it was!*

Just like everyone else, the disabled person has to find ways to impress on others who they are and how they would like to be seen, and this is something that teenagers are busy experimenting with. However for the study participants this is a more difficult task, both because of how they look and their slow communication. The skills needed to 'manage' their assistants and so to contribute to the construction of a personhood they recognise are probably learnt gradually. I sensed that the participants in this study were at different stages in this process. For example Toby's mum indicates that now at age 15 he is already able to achieve this quite effectively within a family environment, but elsewhere it is more problematic:

> *Mum   if he knows the people, he's quite good, but he's not fantastic, I would say. But if he was sitting there and wanted to get from A to B and needed help, then he would ask. I think he would ask a female before a male.*
> *MW   Would he?*
> *Mum   And he would ask a child first.*
> *MW   If he thought the child would get the message, kind of thing?*
> *Mum   Yeah. He would ask for it yeah, because I'm thinking that when we go away –the children go swimming or bowling or whatever, Toby will decide which group of boys or girls he wants to go with and he will... if they're going bowling, he will want to go bowling and he will want me or Pete (dad) to stand behind him, so that the children move him not us; the children do everything for him, because... he'd want to know that we're there, but, I don't want you to do it for me, I want them to do it, because I'm with them. But with strangers, he's still not... if strangers ask him questions, he'll eye-point up and down, across, yes or no. He will be fine, but if... he will never... I don't know how he would ask a stranger for help (interview).*

No-one in the present study goes out anywhere completely on their own, although Kate(13) and Nathalie(15), both have funding for a personal assistant (PA) at home, and do go out accompanied by them (e.g. shopping, to cinema). On these outings they may be joined by a sibling or friend but more often they are just with their PA. This is then 'symbolically alone' as they are not with their family and they are 'in charge'. Potentially therefore the PA can be seen an extension of themselves in the way that Meyer et al (2007) and Shakespeare (2006) suggest. I met a number of PAs working either for disabled adolescents or for adults and I noticed that the extent to which PAs facilitated real autonomy for the disabled person, acting as a physical and communication supporter rather than their 'minder', varied greatly. The PA's style of engagement has an important effect on the self identity of the person they work for. Kate for example was very clear about how her PA could support her in being independent in a way that was different from her parents:

> *For me independence means going out with my friends, doing things on my own, being like other people. Often I need my personal assistant Kath to come with me to help with doors, cutting up food and carrying things (written).*

In essence the teenagers are noticeably more comfortable and confident with people who know them well, than with strangers. With these familiar people there is no need for them to negotiate who they are or overcome misperceptions People who know them well, whether family, friends or helpers contribute positively to their identity, via personhoods which are broadly congruent with their selfhood, though perhaps a cipher of these.

Otherness and personhood: the views of strangers

> *Being with Katie (RA) in new places (eg a shopping centre or restaurant) and in the role of her PA and therefore her mediator/advocate is an enlightening experience. She is often treated as a child because she does look young for her age, and also because of an instant infantilizing process, which seems to be particularly linked to her not talking. This is quite weird to witness, particularly now I know her well, and know what she would be feeling about this. I introduced her to people at one of the schools and they initially spoke to her as if she was about 12! She has a routine when this happens of throwing in bits of conversation (on her VOCA) to show that she is: an adult, my research advisor, has a degree etc. However quite often the stranger is so busy being amazed by her that this message is missed. Katie then expects her assistant to*

put the person right by saying something to correct the impression they have, like 'actually she's twenty-five and is going off to do a Masters degree soon'. There is a careful judgment to be made (by the assistant) every time, about how soon to jump in, whether to ignore it etc (diary).

In contrast to the way that the young AAC users are perceived by familiar people described in the previous section, the personhoods ascribed to them by those who know them more distantly or by strangers, are rather different. Thus unlike the generally positive and 'non disability focused' selves portrayed in Chapter 4, and similar views echoed by those who know them best, they are seen in more objectified and sometimes pathologised ways by 'outsiders'. This section on the responses and perceptions of more distant acquaintances and unknown people is divided into those of adults and children

The responses of adults

As demonstrated by the diary note above, I experienced vicariously in public places, how being visibly different attracts mostly unwanted attention from strangers. Many of the parents, school staff and young people mentioned experiences with strangers, where there was a mixture of curiosity, intrigue, sympathy or pity, and being patronised, as well as some positive types of support, for example here with Nathalie's parents:

> MW   How do you think she comes across to strangers?
> Dad   As a curiosity, a lot of the time. People are curious but a lot what people think is…
> Mum   Oh bless! (exaggerated intonation)
> Dad   There's a range of things
> Mum   It's all right dear!
> Dad   It depends a lot on their personality.
> Mum   Ah ha, what a shame!
> MW   Okay, do you hear people saying that actually sometimes to her?
> Mum   Very rarely, but when I do I put them right!
> MW   Okay, what do you say?
> Mum   I say that Nathalie has a better life than 99% of the kids in this   town!
> MW   right.
> Mum   and then I tell them what she does [laughs]. But they don't mean it in a nasty way….Very rarely do people say that, though sometimes they speak to me, 'well what's wrong with her?' I say there's nothing wrong with her; she's just disabled!

It is not uncommon for parents to be asked by strangers for an explanation of their child's difficulty, something which Garland-Thompson (2000), drawing on Goffman, sees as a legitimate search for a narrative to explain the situation, despite the invasion of privacy it entails:

> 'In social relations, disabled bodies prompt the question 'what happened to you?' The disabled body demands a narrative, requires an apologia that accounts for its difference from unexceptional bodies' (Garland Thomson 2000: 334).

I was given various examples of these kinds of questions and generally parents and teenagers seemed to concur with Garland-Thompson that this kind of curiosity was understandable. They reflected that asking questions wasn't necessarily perceived negatively, but what was crucial was the manner of asking. The advantage of direct questioning is that it gives them the opportunity to provide accurate information, for instance about the person's impairments and about the communication aid, as evidenced here by Bryony's parents talking about interest in her VOCA in public places:

> Mum   *I think people just don't know what it is so they...*
> MW   *Do people come up and say, what's that?*
> Dad   *Some people do, yeah.*
> Mum   *And that's great actually; I like it when people do that because then you can actually... you know (explain?)...it's not the wrong thing to do*

They were aware that strangers who do not ask questions may make various often inaccurate inferences, drawn from visual cues and from what the young person seems on first appearances able to do. Here Marie(12) describes disliking being stared at, and being aware of the assumptions that she thinks are being made about her[52]:

> Marie   *(looks at book)*
> MW   *Bodies page....Transport page... chair?*
> Marie   *(points to self and back to the book)*
> MW   *you? Yes? In your chair?*

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[52] This is a multimodal conversation using her communication book, some speech and gestures. She did not think that she could explain it using her VOCA.

> Marie   yeah (points to book)
> MW: Places page, shops
> Marie   No like (speech)
> MW   You don't like? in your chair? In shops? You mean you don't like going
>   in shops in your chair?
> Marie   Yeah! (points back to book)
> MW   places page, school, school? Speech?
> Marie   no
> MW   you've got no speech?
> Marie   no (points to school again)
> MW   no school? They think you don't go to school?
> Marie   yeah! (gesture? points to head)
> MW   so you mean you think that they think you're stupid or something?
> Marie   yeah!

Similarly Ted's mum said:

> Mum   I also think Ted is content in himself, he contributes in his own ways
>   and he is not to be pitied. And I think some people treat him, the way
>   they speak to him, they treat him younger than he is, you know, …
>   there is an assumption that he will have a mental handicap as well,
>   with a lot of people which he doesn't, so quite often I briefly explain
>   that he understands the same as others of his age.
> MW   I presume that annoys him, if he feels he's being patronized?
> Mum   Yes. yes, . He wouldn't like that

As described in Chapter Five, it was often clear that judgments directly linked to 'looking disabled' or the type of 'kit' the young people used, lead to particular assumptions about their intelligence or competence. Some adults and teenagers mentioned strangers being curious or fearful and being unsure about how to react to them. Often then people will ignore them or be anxious about any interaction that might ensue.   The teenagers were keen to dispel this fearful response:

> Prakash(14)   DON'T BE SCARED OF ME, TALK TO ME AS NORMAL

> Josie(15)   JUST TALK TO ME

Several parents emphasised that because their sons had 'nice', 'normal looking' faces, they felt that they got a positive response:

> *Toby's mum*
> Mum   *I think they see him as being quite happy. Particularly when we are away...I think he's quite approachable. He will smile as well, smile at girls, he will smile at people and he will show an interest in things. I don't know, actually.*
> MW   *What sort of response do you get if you go somewhere like a shopping centre, or something like that? Do you feel that they're...?*
> Mum   *It's all positive, because, I think, Toby's face looks completely normal.*

Here the parents' perception of how strangers respond is influenced by how they as parents see their child. However it is true that for the most part the participants faces do not reveal their impairments, which are more clearly signaled by their 'kit' and sometimes by lack of movement or unusual movement in their limbs. The implication of the parents' interpretation is important however, as it supports Hughes' (1999) assertion that society is 'oculocentric' and that judgments about 'perfection' or difference are 'tyrannical' and therefore disrupt social relationships.

Parents noted that as their children grew older and looked 'more adult' the nature of the attention they received from strangers had changed. Toby and Terry's parents said that when the boys were younger they were often described as 'sweet' and likewise Bryony's mum recognized that she is going through a transition to being seen in a different way by strangers*:*

> Mum   *She's not so much public property now. I always felt when we went anywhere with her that we were never just kind of one of the crowd. It's like you're almost public property. If you've got a child in a wheelchair, people feel that they have the right to come up to you and talk to you and fuss over your child, and I used to think...*
> MW   *It's a bit like having a small... a small baby or a dog!*
> Mum   *A brand new baby with you, then people do that, yeah. Its not so much now*

Supportive reactions from strangers were also mentioned by most of the parents, sometimes combined with a sense of compassion. The subtleties of how this is expressed were important and thus the parents' and children's responses to it varied. Here Ted's mum is very clear about what she and he like and do not like. Interestingly, she is the only person to suggest 'revulsion' as a possible response although this is postulated in some of the disability literature (Shakespeare 1994, Clear 1999).:

Mum   No, I feel the general feeling is compassion, not really revulsion... But a lot of people stop to say something, you know, I don't think, he frightens people. It's more a compassion and a curiosity thing as to why a boy that...looks okay is in a wheelchair and sorrow that he is. I think that's what that seems to be...People are generally very sympathetic and kind. We often get doors opened for us without being asked. Some people, sort of, bend down and talk to him, who don't know him. They're usually people, probably, who have some sort of special needs grandchild or some sort of... background. There are some people that have said, oh, what a shame, you know, he's so nice looking, what a shame he's in a wheelchair.

MW   Do they say that to you or to him, or in his hearing, or?

Mum   In his hearing.

MW   Right. How does that go down?

Mum   I don't like it, and I don't think he does either.

MW   Do, do you say anything back, or do you just, sort of, smile sweetly and go away, sort of thing?

Mum   It's usually a passing comment so we tend to just move on. Sometimes people stop and are interested, and ask a few questions. ...I don't think generally he's ever viewed negatively

Again in considering their children's experience of meeting strangers, parents described the way in which they too had to tolerate and correct inaccurate assumptions about their child. Because of the AAC users' slow responses and different communication modes, a stranger may not understand, and then the parents or assistants are drawn into participating in a three-way construction of personhood:

Jemma's mum: An ed psych I remember her seeing. He came to the house and she had some toys out... but he got out some little dolls and beds and stuff like that...... he was quite amazed, he said, oh, she's absolutely cognitively, you know, way up there. And I always think people assume the worst, whereas I treat other people the other way.

Charitable and pitying approaches to disability still exist, and several young people or parents told me anecdotes about being offered money or even cures by strangers in the street. Some were infuriated by this and others saw the funny side of it:

One parent, said they were on holiday in Barcelona and an American woman came up and gave €50 to her son. Her other children were indignant and said

they wanted a share of it! She said 'its not as if the money will take the disability away! (fieldnotes from AAC conference)

Jemma's mum tried to encourage her daughter to accept such 'compensatory' approaches in this lighthearted way, but was also clear about which were well-meaning and which annoying and intrusive:

> *I tell you what is quite funny, is when you go to cash machines and the tramps are sitting there? If you go on your own, they always ask you for money. If you go with Jemma, they're like, oh hello, ain't she lovely, what a lovely little girl. They'll never ask you for money... when we walk to school, there's this really old lady – she must be about 100, she always says hello to us, and when we used to pass her regularly, she used to give her little packets of biscuits and things. Jemma doesn't like them, and tried to say, I don't like them. I'd say, look, she's really old, just say thank you very much and you know... [laughs]. That's quite funny... and others come up and say to you, oh God bless her, she's lovely and all things like that. And they don't mean any harm at all and they don't mean to interfere ... and they don't stare and they're not meaning be horrible at all. And you just get other people that just look, other people that don't quite know what to do, and then other people that pretend they do and they're probably the most annoying*

Some school staff were similarly scathing about public attitudes, as shown here by Emma, Jemma's mainstream LSA:

> *The taxi driver had then gone into a diatribe about how these kind of children shouldn't be going to mainstream schools, that they'll disrupt other kids etc and Emma then gave him an earful about how nice the other kids are and how they regard Jemma as part of their class, and that she is not disruptive at all ! Emma was very indignant and protective (fieldnotes).*

There is a difference between those who are 'well-meaning' and supportive, and the intrusive staring, incomprehension or pity of others. Both the teenagers and those who know them well who are also recipients of these attributions, feel very differently about these different types of attention. This variation in responses sometimes influences choices about places where they are happy to go. If they have had a particularly negative experience, the teenagers do not want to go again, like Terry(15) here as described by his mum:

> *Mum   Oh, they stare. He gets cross.*
> *MW   Like in shopping centres and things?*

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> *Mum* Yeah, but he doesn't get as cross (now). He doesn't really notice it, if it's not pointed out to him. Well, he does, but he ignores it. We were out one time and granny says, why are all these people staring? so then he realised that they were staring, so then he got cross.
>
> *MW* Would he try and, sort of, say anything to you or to them about it?
>
> *Dad* Um, I think he would get up and hit them if he could!. He got really cross. Frustrated and just, sort of angry
>
> *MW* what does he think about that?
>
> *Dad* It depends, depends how condescending they are.
>
> *Mum* As long as they talk to him
>
> *MW* So, if they talk to him, that's better, but if they come up and said something to whoever's with him, you know?
>
> *Mum* He might just drive off!
>
> *Dad* He doesn't like condescending people. He doesn't like people patronising him.
>
> *Mum* The worse thing is if people come and pat him on the head. He gets mad.
>
> *Dad* The village shop… Well, she gives him sweets free. And he won't have it. She talks to him like he's a five year old. He won't go in there

However, despite the negativity of such experiences the teenagers and their families had ways of dealing with such attention such as: 'ignore it', 'get on with living our lives', or more actively, 'explain that he's got cerebral palsy' , 'engage in an intellectual conversation together loudly to show them' or 'drive off'!' They had thus developed a resilient and resistant attitude but accompanied by varying levels of irritation and indignation.

A child with disabilities often receives compassion and 'charitable' responses, whereas an adult may be judged more harshly as a liminal person who is potentially polluting or dangerous (Douglas 1966, Murphy et al 1988, Shakespeare 1994). As teenagers, the participants in this study are perhaps in a transition period where they receive some of both of these types of responses and learn gradually, with support from close relatives and friends, about ways to handle what can be very intrusive assaults on their selfhood. It appears for example that the older teenagers have more strategies for dealing with this, including having responses preprogrammed into their VOCAs, which they could use to answer people's questions or indeed to tell them to go away! Bryony is just developing this as her parents describe:

> Mum   *More recently, you know, if people that she's never met before either come in and start talking to her in an inappropriate way, you know, talk to her like she's younger than she is or, you know, not ... as good at understanding as she is, she will actually say to them, 'please don't talk to me like a baby'*
>
> Dad   *That's one of Bryony's main bugbears, is people who treat her younger than she is.*
>
> Mum   *yes ...She's got a 'tetchy' page[53].*
>
> Dad   *And she very rarely uses it but she likes to know it's there, and it's graded in response from a polite request, you know, please stop talking to me as if I'm a baby...*
>
> Mum   *But it's good to have it on one button, isn't it?*
>
> Dad   *right the way down to fairly impolite, you know, sort of bog off'! (laugh).*
>
> Mum   *But she... I mean, she is confident at using that and she uses it quite often!*

However, despite the development of these assertive attitudes, some of these incidents were upsetting, and so it regularly requires 'emotional labour' on the part of families and professional assistants 'to manage' what happens, both on behalf of the child or young person, or for themselves as people who are emotionally involved (Hochschild 1983, Davis, Watson & Cunningham-Burley 2003, Goodley & Runswick-Cole 2008). The parents expressed a sense of weariness at having to deal with being seen as 'exceptional'. Thomas' (2004) definition of the psycho-emotional effects of disablism, which suggests that there is an attitude which restricts who you can *be*, not just what you *do* is reflected in some of this data. Some young people and their parents say that it is whether they are treated 'as a person' that really matters and that practical issues such as physical access can usually be overcome. However in either case, if the disabled person or indeed their family feel that they are being excluded, then their personhood is threatened by them being placed in a liminal position and regarded as an unusual category of person. This awareness that they are being seen as the 'other' arises frequently, as illustrated by this interchange between two young adult AAC users at a conference, where the man approaches with an ordinary chat up line:

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[53] i.e. a page of words for 'being tetchy' on her VOCA. A 'button' means an individual item of vocabulary or phrase programmed into the system, which she can access by the press of one button on the screen.

> Man   *HI, CAN WE TALK?*
>
> Woman   *NO….THAT'S WHY THEY ARE HAVING A CONFERENCE ABOUT US!*
>
> *(everyone, including bystanders collapsed with laughter)*

Thomas (2004) and Reeve (2002, 2006) argue that this causes existential insecurity which is as personally oppressive as more structural forms of exclusion, such as poor physical access or restricted education or job opportunities. Garland-Thomson suggests that:

> 'disabled people in public are noticed by everyone and acknowledged by no-one' (2000:239)

and thus are 'socially invisible'. This is confirmed by Jemma's mother who resents other people's assumptions about how their family life is experienced:

> Mum   *Ooh, the outside world are…. They're sympathetic towards us as parents, which is… it must be a real burden for you! Yeah, they think it's… ooh, she's hard work. And you think, well, how would you know, actually? Yes, she is, but it's not for people to assume and …people that don't know her, never look at her to talk to. They all say, ooh, would she like a sweet, looking somewhere else, and I sort of say… why don't you ask her? don't ask me! You know, so people assume, because she finds it difficult to communicate, that she doesn't understand. I think people don't, …see her. Lots of people don't see you if you're disabled. And I still think that happens.*
>
> MW   *And do you think she (Jemma) thinks that, that happens? Would you ever talk about that?*
>
> Mum   *Yeah, I do think she thinks it. She knows, because she gets angry.*
>
> MW   *Would she say anything?*
>
> Mum   *Yes, she's, oi, I'm here! You know what she's like; she's a real strop. So yes, she will, but it doesn't mean that they, they listen to her!*

Perceptions of and social relationships with other young people

Bryony's mum reflected that:

> *Often young children are the best, kind of kid… people to talk to because they'll come up and say, why is she in a wheelchair and what's that? And you can actually talk to them, whereas adults feel they, they don't dare ask; it's not appropriate, you know.*

There seemed to be agreement across the group that other children and young people who they met in public generally responded in better ways to them than adults, and this was because they were seen to be openly curious rather than judgmental, anxious or embarrassed (Lewis 1995). Sometimes though, adults accompanying children restricted the forming of spontaneous social relationships between disabled and non-disabled young people, because of their own unease or fear or over-caution, as Jemma's mum describes:

> Mum   *Children are really interesting, because lots of children come up to   look at her.*
>
> MW   *Right. What they come right up close and?... touch her?*
>
> Mum   *Some of them do. They love touching her walker. And their parents in that situation are quite funny, because if the kids come up and touch the walker, and Jemma will look at them and I'll just say to them ooh, don't touch her walker, she doesn't like it, but by all means chat to her. And the parents: ooh, no, no, don't touch, ooh that little girl, ooh, no, no, like she's got some sort of disease. and they panic more. And I'm sure they don't mean it like, she's got a disease, but they panic, they worry that if somebody touches her that maybe she'll fall over and then they'll get the blame*

Similarly Nathalie's parents drew a distinction between children's and adults' reactions to her:

> Mum   *You know what makes me laugh though is when she's coming down the street or on a path, or in a shop. the parents, there's like a little child who might be stood in the way, not in the way but just standing and watching. And they will say get out of the way, you know, move over. Like Nathalie's got this sort of tank and this sort of... but, you think, my God, it's just a wheelchair.*
>
> MW   *So the child is standing there curiously?*
>
> Mum   *Yes, quite innocently......And the parent say oh Michael, you know, move to the side, let her through. I mean they're probably right because she'd knock him over, but [laughs]. It's like; they're like getting out of the way rather than sort saying oh...*
>
> MW   *So the parents are worrying that they'll do the wrong thing or something?*
>
> Mum   *Yes.. I don't know*
>
> Dad   *I think a lot of people are curious and they'll be interested, you know, they'll probably think, I wonder what that girl's disability is. I'm not so sure... this is something that goes an awful lot further than that. I mean, you might sometimes get people approaching but they tend to be the extroverts or people who might have some knowledge of disability, i.e.*

> *they're sort of converted already. Or some slightly more extrovert kids*
> *who will come up and be really interested in the VOCA or something like*
> *that.*

MW　*what does Nathalie feel about that if somebody comes up and is very,*
　　　wanting to press buttons or?

Dad　*It depends, I mean, she's not keen on that. But if somebody's just*
　　　genuinely interested, she can quickly tell the difference between
　　　somebody who's interested in the machine, as opposed to somebody
　　　who's interested in her, and the fact that she might have an alternative
　　　way of communicating.

MW　*Yes, and how would you know that she's judging that? She's making a bit*
　　　of a

Dad　*The eye contact, the look she gives us!*

Generally there was a consensus from families that curiosity from other children was not necessarily negative, and could lead to non-disabled children understanding more about people who are different from them.

In summary, relationships with unfamiliar children and young people, if they are allowed to develop with minimum or no adult interference, tend to be more relaxed, spontaneous and less complicated by assumptions and preconceptions than those with newly met adults. However it is difficult for these to develop beyond a level of superficial acquaintance unless the non-disabled young people have time to understand AAC modes of expression and thus find out more about the disabled teenagers' interests. Opportunities for spontaneous meeting of new friends are often limited, perhaps because the disabled teenager needs to have assistance, and this can easily form a barrier to peer relationships, as I noted here at Bryony's Guides meeting:

> *She was very keen for me to come to see what she did at guides, so I went along*
> *with her and her mum, who stays to support her and act as her assistant. She*
> *was clearly accepted and welcomed into the group, and joined in actively in all*
> *the activities, including the very physical running about games which the older*
> *guides seemed to be very keen to adapt so that she could be involved, so they*
> *whizzed her about in her manual chair. However I got a sense of their anxiety*
> *about doing 'it right' and being gentle, when what she wanted was to be in the*
> *rough and tumble the same as the others. During a small group discussion with*
> *4 other girls she was very active in making suggestions about what they should*
> *do using speech, signs and VOCA, and the others generally waited for her to say*
> *her bit. However her mum was also busy 'interpreting' for her and explaining*

what she meant and this was clearly necessary, but at the same she resented it, as she wanted to do this herself, and in some ways resented having to bring her mum along, when everyone else was there by themselves (fieldnotes)

Therefore really meaningful social interaction is often confined to family and some school settings, in contrast to the large, fluctuating and constantly renegotiated social networks that most young people have, especially as they move into the middle and older teen years.

Conclusion: Towards a model of selfhood and personhood in the context of disablement

This thesis has argued that young AAC users are seen in two contrasting ways by others, closely reflecting Thomas' (2004) 'being' and 'doing' dichotomy as described above.

Firstly, the personhoods constructed about them by their families, close friends and often by other children, are principally as social beings, irrespective of what they do. The effects of their impairments and their disabled status are just parts of their identity and usually not the dominant ones when they are in familiar company. Familiar people have a 'way of being' which is adapted to the needs and particularly the pace of the AAC users 'communication. Some parents said their worldview had changed through their experience of having a disabled child and there were hints of this from siblings too. This is reflected in other work with disabled children and their families (Voysey Paun 1975, Traustadottir 1991, Thomas 1998, 1999, Dowling & Donlan 2001, Connors & Stalker 2003, Fisher 2007). Bourdieu might have described this 'way of being' as a particular habitus, that is a 'way to be a disabled family' or 'way to be with an AAC user in public'. Rather paradoxically then, this different worldview allows familiar people to see the disabled person as 'the same' or as 'normal' and in social-relational ways within that normality. Thus these people because of their different worldview, contribute to the construction of the personhoods of the disabled young people in 'non-disablist' ways. Familiar people privilege aspects of them which emphasise their similarities to other people, over their impairments which make the disabled person different, or other. The disabled

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person is then seen not primarily as that, but as an individual with many facets. These familiar people can, by the way that they interact with the disabled person, deliberately demonstrate for strangers how the person would like to be seen and responded to. Families, close friends and very involved professional helpers then contribute significantly and positively to the identity construction process.

In contrast 'outsiders' tend to emphasise or draw attention to what the young person can or cannot *do* rather than who they *are*. In contexts where they are unknown they are then 'othered'. Because strangers focus on what is different about the disabled person they often seek a coherent explanation for this by asking sometimes intrusive questions such as 'what's the matter with him?' (Couser 2006). They also stare and make assumptions about what kind of life the person has (Shakespeare 1994, Albrecht & Devleiger 1999, Clear 1999, Garland-Thompson 2006). Thus a worldview which focuses on *doing*, makes the disabled person abnormal, because what is most obvious at first is what they cannot do.

Although physical and structural barriers to 'doing' still exist, to a large extent these are often now legislated against and furthermore some are resolvable with the aid of technology. There are still many practical tasks that someone with physical impairments cannot do, but the importance of these may be overplayed by outsiders. Therefore the strangers' view of them is one which emphasises their 'incompetence' and essential difference from 'normal'. These attitudinal barriers to disabled people's perceived differences, and assumptions about who they can 'be', are more difficult to challenge or change through legislation. It is unfamiliar peoples' negative attributions about the teenager as a person (or rather as not a person) which are the most hurtful to deal with. These kinds of responses are described by Thomas as 'psycho-emotional disablism':

> 'disablism is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas, 2007:73)

Supporting this, a disabled academic colleague whose impairments are rather similar to those of the participants in this study recently reflected in a conversation:

> 'It's pretty impossible to legislate about attitude!'
> (Lang 2009 personal communication)

The stark contrast here between, on the one hand the young people's views of themselves (selfhood) alongside the parallel views of them (personhood) of familiar people, and on the other hand those of strangers, allows us to see where there is room for confusion for the teenagers about who they are. Here then is kind of 'ontological dissonance' for them. This is played out in practical ways in the contrasting and sometimes paradoxical real life experiences they have. For instance they may have the opportunity to go to a mainstream school or local club, but then have difficulty making friends, or not be given enough help to join in fully. Equally, they may go to a special school or special disability focussed club where many of the practicalities are easier (physical access, people understand AAC), but where they do not necessarily feel they fit in as they don't see themselves as disabled, but as normal teenagers.

Several writers have reflected on the existential insecurity of being seen in a way which does not reflect one's own perceptions (Reeve 2002, 2006, Watson 2002, Hughes 2007). Three of the adult research advisors told me that they had not really realised how differently they were seen by others until they reached early adulthood, and that this had then been a considerable shock to them. They recounted the difficulty of having to reconcile these alternative views of themselves and in some cases felt that this took many years to achieve or was still work in progress.

The very positive and optimistic self-perceptions of the teenagers in this study suggest that they are as yet somewhat unaware of the 'invalidation' or stigma that they may encounter more as they leave school and spend more time away from home. At present they are buffered from these paradoxes to a large extent by familiar people who see them as they see themselves. Essentially then there is a

problematic contrast between being 'normal' at home (and sometimes at school), and being seen as 'other' elsewhere.

Social psychologists suggest that humans have a tendency automatically to group others into 'like me' and unlike me' (or ingroup and outgroup) categories (Allport 1954, Brewer 1999), although it is now recognised that this might be too essentialist a view and that often such categorising is more fluid and shifting.

Figure 1. below is an attempt to represent how such processes of social categorizing might happen particularly in relation to AAC users and perhaps to disablement more generally. In 1a. non-disabled people, particularly those with little direct experience of AAC or disability, might view most other (non-disabled) people as falling into a number of different and sometimes overlapping categories, such as gender, race, sexuality, class, as represented by the dotted shapes, and of which they themselves are also members. However there is a tendency to view the disabled person as some 'other kind of person' and so to deny them full membership of these other groups. Their diminished personhood then places them in an opposing category which is altogether different, extraordinary and liminal. They are then objectified and dehumanized. We can see here Hacking's (1986) dynamic nominalism at work. Once someone or a group of people are perceived to be different, the category becomes firmly boundaried and on the outside. Therefore being 'normal' and being disabled are, or are almost, mutually exclusive.

In contrast perhaps, disabled people's selfhood tells them something different, as represented by 1b. In considering themselves and others, they do not see two opposing or mutually exclusive categories of 'normal' versus 'not normal'. They see themselves as disabled *and* normal. There is no simple dichotomy for them, as being disabled is one of a number of negotiable descriptors, as part of the same network of overlapping categories as everyone else. Disability is just one of their multiple identities recognised alongside their other memberships. This view which was evident in my data supports poststructuralist approaches which propose multiple identities rather than one dominant one, and builds on positive notions of difference,
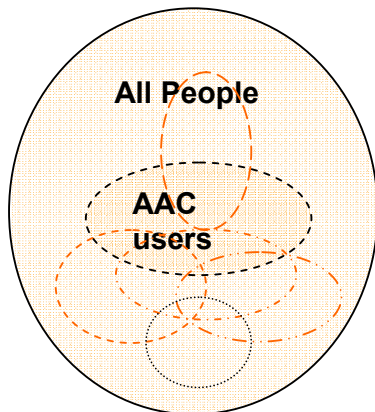
rejecting essentialist categories or one 'disabled identity' (Priestley 1998b Shakespeare 2006).

Figure 1. A representation of how AAC users may be viewed by unfamiliar others in contrast to their own view (and those of familiar people)

a. Unfamiliar others see
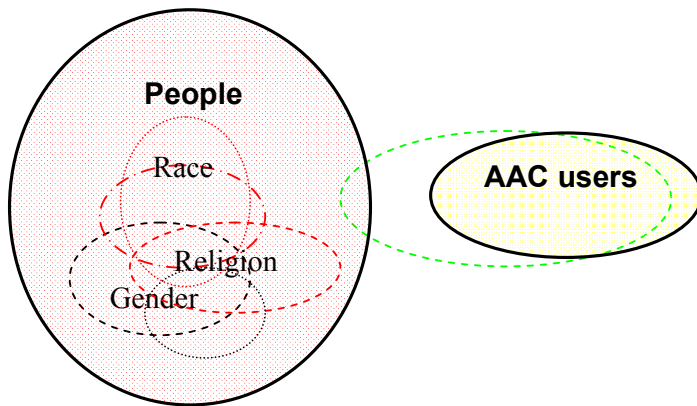

b. AAC users and familiar people see

As illustrated, the boundaries around their disabled status may be more fluid and perforated from the point of view of the AAC users as they move in and out of seeing themselves as part of this category as well as a number of others. Whereas non-disabled people without experience of AAC users perhaps see those with impairments in a circumscribed and separate category of which they themselves are never a member. Of course there is a danger in proposing such a model, as it could

contribute to the essentialising of these supposedly opposed views. Thus it is important to remember that many people have less exclusionary views of disability than this model suggests, so Figure 1a. could be drawn with more permeable dotted lines? This may be too extreme and dichotomized a view, but my data suggests that it reflects people's experience some of the time. With changes in attitudes to people with certain types of impairments at least, for example those using wheelchairs but having no other difficulties, some of those in the excluded area might also be recognised for their other aspects, so be seen as having other identities too, (hence the green dotted line) bringing some disabled people into the 'mainstream'. However, Alan (RA) commented when he saw the model, that this exactly represented the exclusion of disabled people from many arenas of life, and he felt that the boundaries were quite impermeable and solidly drawn at present. Of course this is just one person's experience, but given that, like the young participants in the study, he has very significant communication impairments, it may be that it is they in particular who experience exclusionary attitudes from others.

Further, the ontological dissonance between selfhood and personhood that is felt as unease by the participants can also be represented visually as below. I have expanded this to suggest that it may apply to disabled people with different impairments rather than just those who use AAC, though this would need further exploration to verify.

Figure 2. The relationship between selfhood and personhood for non-disabled and disabled people: An explanation for disabled people's unease
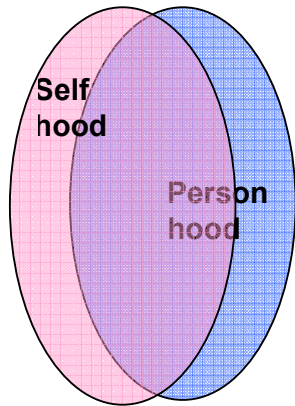
a. Non-disabled people's identities   b. Disabled people's identities
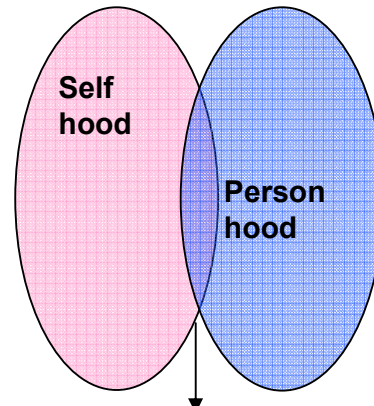
Ontological dissonance

For non-disabled people then (Figure 2a.), the way that they see themselves (pink) overlaps to a large extent with the way that others see them (blue). In contrast (Figure 2b.) disabled peoples' views of themselves (and those who know them very well), can be very different from the way they are seen by outsiders. This disjuncture between selfhood and personhood may be confusing and unsettling, as the person often feels that they are being misunderstood. If they chose to accept the inaccurate or negative judgments of others then this may impact on their selfhood and result in low self-esteem. In this study there is some evidence of the negative effect of these external judgments, as some parents reported that their son or daughter had gone through a period of unhappiness, self-doubt and questioning, particularly when they felt they were not being understood as a person. Conversely the teenagers all felt confident about themselves when they were with people whose views of them coincided with their own, such as within the family or in settings or events that are well catered for in terms of disability access and awareness of AAC.

Arguably, this process could occur for anyone (disabled or not) who feels that they are not the person they are perceived to be by others. However, the possibility of being misconstrued is magnified for the disabled person, and therefore they have constantly to work harder to enable others to see them in different ways, which

match their own self-perceptions and thus recognise their social-relational selves. Arguably these misattributions more often arise for people with visible physical impairments. Some are able to correct the judgment made of them verbally. However for those with communication as well as physical impairments, like the young people in this study, it is particularly difficult to counter these views, and for all the facets of their identity to be recognised by others. Although mostly their positive sense of self seems unaffected by these negative attributions, such attitudes are, nonetheless, a source of frustration and annoyance for them. Indeed Alan (RA) commented that he felt that very few people really knew and understood him as a person.

Chapter Eight. Conclusions

Introduction

The study set out to explore the identities and the lifeworlds of disabled teenagers who use AAC. The topic arose out of broader reflections on aspects of children and young people's agency, on disability, and through an interest in social identity as it is conceptualized in anthropology.   I was interested in how having communication impairments might impact on identity. In reflecting on different types of communication difficulty, I decided that AAC users in particular would be an interesting group to investigate because of their 'extreme' situation brought about through the added complications of physical impairments, almost total lack of speech and the necessity of using VOCAs and other non-speech communication modes.   Thus the common perception that these were young people with 'normal' minds in 'abnormal bodies' struck me as a disjuncture worth dissecting. I wanted to explore how a person's mode of communication, particularly absence of natural speech might impact on both selfhood and personhood. In this chapter the five research questions will be revisited individually, and overarching links will be made between them and the key themes which emerged.

The research questions:

1. How do young people with severe physical and communication impairments who use AAC see themselves (selfhood)?
2.   How are young people who use AAC seen by others (personhood)?
3.   What kinds of social relationships do young people who use AAC have?
4.   What role does the body play in the development of selfhood, personhood and social relationships for young people who use AAC?
5.   What kinds of methodologies work best when doing research with young people with severe communication impairments?

Me, myself, I: young AAC users and selfhood

The participants see themselves in positive, social–relational ways which emphasise a number of diverse aspects of themselves, rather than foregrounding their disabled identities (Thomas 2006). They emphasise being normal family people and gendered teenagers, as well as sociable and funny, and also variously sporty, clever, caring, good-looking and sexy. Their reference points are drawn therefore from the same teenage cultural milieux of fashion, sport, IT and media as their non-disabled peers, and their aspirations for the future also reflect this 'mainstream' worldview. However their physical and communication impairments do impact on their view of themselves, so that, although their bodies are 'normal to them', they are aware that they are viewed as different by others (Watson 2002, Reeve 2006), perhaps because there are some things which are difficult for them to do, and for which they need special equipment such as wheelchairs and VOCAs.

Their disabled status is, for them, linked with being 'interestingly different' as Josie(15) put it, rather than having a deficit. Their views of their lives are overwhelmingly positive and this finding echoes the 'disability paradox' described by Albrecht and Devleiger (1999), wherein disabled people report high quality of life despite others viewing their situation negatively. The teenagers' concerns and wishes in relation to their impairments are that they should have access to appropriate and reliable technology and respectful assistants who treat them as people. They see these as essential in facilitating them being independent and autonomous. For these young people then, the contradictions inherent in developing independence and needing support which is said to characterize adolescence as a life-stage (Fine 2004, Kroger 2006), are amplified and problematised (Smith 2005). Part of 'growing up' for these teenagers is learning how to manage other people who assist them. They learn these skills in both implicit and explicit ways. For them, the tendency for people to patronise and infantalise them means they often feel they have to fight to be recognized as a 'proper human being' despite needing help (Meyer et al 2007).

Who are you? Personhood

There is a clear contrast between the way that the participants are seen by those who know them well, and less familiar people or strangers. Familiar people such as family members, close friends and selected professional helpers view them in ways that are similar to the way they see themselves. Thus the teenagers' individual qualities as people are highlighted rather than aspects of their impairment. These are both positive attributes such as being fun, feisty, clever, beautiful, patient and caring, as well as and more unusually some negative ones such being scruffy, lazy, cheeky, or stubborn. Who they *are* as people is emphasised, rather than what they can *do.* This thesis provides clear support for Thomas's (2006) suggestion that this distinction is important for disabled people. Descriptions of the participants by people who know them best focus on diverse aspects of them, rather than on 'deficits' or 'missing' functions. For these familiar people then, the teenagers' disabled identity is neither a negative aspect nor a dominant one.

In contrast, newcomers and strangers tend to view the teenagers in altogether different ways. Their responses are influenced by first impressions, where their attention is drawn immediately to the participants' visible physical differences and unusual ways of communicating. Thus the young people often experience being stared at as objects of curiosity (Hughes 1999, Garland-Thomson 2006). Reeve (2006) points out that dealing with the curiosity of others is part of the disabled person's life and they are aware that others may be frightened or embarrassed to talk to them, or may ask inappropriate questions. Responses to them often focus on their impairments and what is different about them, rather than recognizing them as individuals.   This is part of a process of 'othering', which potentially puts them in liminal positions outside the norms of society (Murphy et al 1988, Clear 1999). They often feel that they are patronised or pathologised and treated with sympathy, compassion or pity, though to varying degrees. The teenagers sense that it is often assumed initially that they cannot understand (have learning disabilities) and this attribution may be linked to their evident lack of speech. There is confusion for the uninitiated between being able to talk and being able to think. These assumptions are particularly hurtful to them.   Exceptions are the responses of unfamiliar

children, who although they might be curious, were perceived to be more open-minded and slower to make negative judgments than newly met adults.

This treatment as the 'other' leaves disabled teenagers 'feeling hurt' undermined and excluded by the reactions of others (Reeve 2006:96). This kind of psycho-emotional disablism is quite a subtle form of prejudice, in contrast to the overt structural oppression which has, in the main, now been legislated against (Deal 2007). Many of the participants and their families reported hating this kind of misattribution by strangers which diminishes their worth as people, and potentially denies them citizenship as ordinary young people (Jans 2004). They then have to find ways to deal with this ontological dissonance (represented visually on page 292), wherein there is a mismatch between how they see themselves and how they are perceived by unfamiliar others. For example parents, other familiar adults or siblings often find themselves protecting the disabled youngster from the negative reactions of strangers and finding another 'way of being', which resists these misattributions and helps to maintain the young persons' identity as a 'normal' person (Fisher 2007). Often this means choosing to ignore unwanted attention, mediating on behalf of the person, deliberately demonstrating their competence as a thinking person, or quite simply avoiding the place or person who fails to recognise them as a social being.

As older teenagers and young adults, the participants will move from the protective environments of home and school and will have to learn to use some of these strategies for themselves. Both they and their parents acknowledged and anticipated this with a mixture of excitement and anxiety. Steps towards independence and negotiation of autonomy are thus more complex and daunting for these teenagers than for their non-disabled peers, as well as for their families.

Them and us: social relationships

Within their families and close friendships, teenagers who use AAC have rich social relationships which are very important to them and are fully reciprocated. As described above they are seen by these people as 'normal' and as social beings who

contribute actively in the social worlds of familiar environments (Larson 1998). In contrast their social networks outside this home territory are reduced, as making and maintaining friendships on their own terms is quite difficult, even if they see themselves as friendly and social people. The teenagers have a very small number of good friends of the same gender, some with disabilities and some without. Often these friendships are longstanding and started at primary school or through family connections. Very few of them however, have recently formed friendships initiated themselves rather than mediated by their parents. Making new social relationships completely independently is something that many of the teenagers have limited experience of, outside the protected environment of school. This is a matter of concern and worry both for many of them and for their parents.

Physical appearance can be a barrier, and this is difficult for young people to counteract, because using a wheelchair and a communication aid is part of who they are and is therefore not negotiable. Additionally because friendships usually depend on fast and subtle verbal communication, there is often insufficient time for AAC users to show who they are and reveal their interests and opinions. Often conversation is mediated by adults who are assisting them and this can easily form a barrier to friendships. Many of the participants expressed a wish for more friends, especially non-disabled ones and more of a social life outside home. This finding supports previous work showing the reduced social networks experienced by disabled people, particularly those with communication difficulties (Hahn 1998, Grewal et al 2002, Blackstone et al 2005).

The body and the kit: don't be scared of me

Direct discussions about aspects of the body were difficult to have, but participant observation revealed rich data on the topic. In relation to their self-image, the teenagers have mostly positive views of how their bodies look and what they can do. Both boys and girls have strong opinions about style and about how they want to look (clothing, haircut, jewellery). This is echoed by their ways of individualising their wheelchairs and VOCAs. These pieces of kit are then, to a greater or lesser extent, regarded as part of their body and are part of their expression of identity.

All are aware of their bodies changing during puberty and like others of their age, are keen to look like adolescents not like children (James 2000). Some mention features of their physical bodies which they do or do not like, although it was rare for them to mention their physical impairments or what they could not do specifically. Rather, they talked about aspects which they could change such as being less skinny, more tanned or gelling their hair. Regarding what they can *do* with their bodies, all accept in matter-of-fact ways their need for physiotherapy, doing exercises and using kit to help them do practical physical tasks more easily. Many are involved in disabled sports and are proud of their achievements in these. This was facilitated very actively by their parents, who in this study were a predominantly middle class group who therefore had the resources to do so. In general then the participants' attitude to their bodies is that they are 'normal' to them (Watson 2002).

In contrast and as described above in relation to personhood and social relationships, outsiders' views of impaired bodies are influential and can have a major impact. The young people experience a variety of reactions to how they look, and are aware that although their bodies are normal for them, they do attract attention from others. They are implicitly aware of 'public narratives of normality, truth, beauty and perfection' (Reeve 2006:164 citing Hughes 1999), but paradoxically have positive self-images despite often encountering disablist responses to how they look. Thus the body as an unavoidable external representation of the internal self can mislead onlookers. All the young people however are confident that once someone gets to know them, they will be seen as a person 'not just as a chair'.

Individual and group identities and disability

The way in which social identity and disability issues intersect was a major focus in the study and questions around these two concepts are woven into all the chapters and themes. Of the key writers on identity, Goffman (1963) is the main one who explores disability to any extent and although the concept of stigma is still important, the contemporary discourse on disability has moved on beyond this

(Hunt 1966). For the participants in this study the idea of 'passing', that is of hoping to hide or disguise one's impairment is almost irrelevant as their difficulties are so immediately visible and audible. Additionally 'social model' thinking has influenced attitudes at least to some extent, such that hiding one's impairment is now not seen to be necessary or desirable. However the teenagers' desire to focus on their 'normal teenage selves' rather than on their differences could be regarded as a variation of passing. Jenkins (2004) discusses the ways in which identity and difference may be related and this is an important theme in this study. Individual identity embodied in selfhood must involve elements of similarity with and also differences from other people. However Jenkins suggests that the latter have been privileged over the former. The study confirms this for disabled teenagers, as has been shown in the ethnographic examples. Clearly people have both individual and collective identities, which are based on different types of belonging and distinctiveness. However it may be that certain types of people are prone to being distinguished by others, for their distinctiveness or otherness, more than their belonging.

For most people identity is asserted through a personalised and unique use of verbal spoken language and non-verbal communication. For young people using AAC, in addition and somewhat in contrast, the expression of identity is also dependent on technology and the skills of a mediator who may or may not accurately represent them. Many AAC users use different communication modes in different settings and so different kinds of selves may be seen. For instance at home, with family and friends, a complex but very individual form of non-verbal communication may be used in ways which enable the person to be 'a rebellious teenager', 'a family person', or 'the joker'. Whereas with strangers they may have to use a slow and less subtle high tech system, which casts them in the role of 'other' much more clearly and inescapably.

Using AAC can make it difficult for people to overcome exterior impressions and negotiate a picture of themselves with which they are happy, and which is who they really are. Their predicament is in not having easy and quick ways to correct first impressions and represent themselves accurately. Thus for many non-disabled

people, selfhood and personhood may be rather closely aligned, but for those with physical and communication difficulties the two aspects of identity may be unreconciled or in conflict with each other. However these teenagers, given time and opportunity are able to express the richness of their various selves, and clearly if identity creation is a reflexive, ongoing and negotiable process through the lifespan, their identities will continue to evolve as they find out who they are, and construct new selves in their various social worlds (Cohen 1994, Jenkins 2004, Hockey & James 2003).

Shakespeare (1996) suggests three different aspects of disability identity: political, cultural and personal. The present thesis only addresses the last in depth although aspects of the other two arise sporadically throughout the data. Echoing the identity theorists described above he suggests that the 'process of positive self-identification is difficult and complex' and ongoing for disabled people (1996:100). As outlined in Chapter One, individual social identity can be seen as connecting the personal and social through the reciprocal interaction between selfhood and personhood. Additionally, personal identity informs and is informed by collective identity. Thus during the study, I was led to question the extent to which the participants felt themselves to be part of a 'disability culture' or an 'AAC culture' as opposed to or in addition to any other group with which they might identify. Shakespeare (1996) draws on Weeks (1990) work on gay identity, when considering this and suggests that collective identity is about 'shared feelings'. So having a sense of belonging to a particular group might then lead to joining with others and to building a specific political or cultural identity. Clearly there exists a collective 'disability community' with which some adults with impairments chose to engage. This is then a positive choice in identity making which Shakespeare suggests is about 'transforming selves' from a passive to an active position. All of the adult research advisors, can be described as disability activists and have much to say both about what has changed in the last decade as well as what remains to be done. This generation of 20-40 year olds have in their lifetime witnessed a revolution in terms of concepts of and attitudes to disability.

It is unclear to what extent children or young people feel they are part of this collective identity currently or want to be in the future. Of the participants in this study, it was clear that their involvement in wider 'disability' or 'AAC group' activities was to a large extent governed by their parents. Three of the girls are active members of the 1Voice group. Bryony(10) very much enjoys the social aspects of it, Nathalie(15) and Kate(13) are both more active in awareness-raising activities. At organisations like this and at special schools, there is then a sense of 'culture' and of being member of a 'tribe'. In these settings the teenagers are visibly comfortable, in that they do not have to negotiate about who they are. There is an assumption that everyone there is a member of the tribe or an ally. Within 'the tribe' everyone's communication style is adapted to the AAC users, and like being at home with family, it is something of a haven from an outside world that can be quite unforgiving. An important question might be whether this feeling of acceptance can be accomplished elsewhere? Katie (RA) noted that wheelchair users attract much less attention now than they used to, presumably because as physical access has improved they are seen out and about more. AAC users will always be a small group, but again, perhaps as they access mainstream settings more, they will be seen as less unusual and thus will be less quickly categorized as the 'other'.

Evidently now that 'mainstreaming' is so clearly on the agenda, disabled children have inherited the idea that they can and should be part of the ordinary rather than being relegated to the sidelines. The extent to which they will find it attractive or necessary to join disabled collectivities is unclear. It seems likely though that they will, like older AAC users, still have to manage the constant struggle between wanting to be seen as the same as others, but being viewed as different.

Interestingly, Meredith (RA) suggests that there is an emerging 'AAC culture' (2005), although AAC users are not 'a community' in the usual sense, as they are not regularly in physical proximity with each other. They are not brought up by or with others using this communication method. It is unlikely that their parents would be talking in this way, as these are not usually inherited impairments, unlike deafness, which may be. The types of communication and ways of constructing selves that they witness vicariously use the spoken language of the talking majority. Other

children around them will be using speech to play, to explore feelings and ideas about themselves, and to negotiate and build relationships (Ochs & Capps 1996, Nelson 2000). A communication impaired child might know a few others like themselves, especially if they go to a special school, or to disability focussed clubs. Certainly there are now more events which facilitate meeting others using AAC. However numbers are very small and whether one would regard this as enough to develop a 'culture' is questionable. An AAC user attending a mainstream school may never meet anyone else using a similar system. Debates about what constitutes a culture are important here. Allan's (2006) postulated 'AAC culture' might imply and necessitate celebrating and 'cultivating' difference', by seeking out others who are similarly different. This would encourage AAC users to get together in ways which inclusive education doesn't necessarily facilitate (Armstrong, Armstrong & Barton 2000). It could be argued that the different interaction style used by AAC users, which demands adaptations in communication by their conversational partners, as described in Chapter Three, makes AAC conversation a particular form of language use, with different and specific pragmatic rules (Nippold 2000). This reflects 'difference rather than deficit' arguments which are current in much of the contemporary disability discourse, however it is also in some senses more 'separatist' than most. It has some parallels with the issues around deafness and 'Deaf' (with a capital D) culture (Davis 2002). The latter movement has now positioned itself largely outside the disability arena and has become highly politicised. Deaf people, at least those who are born deaf and who sign, view their differences as cultural not corporeal. They see it as legitimate and indeed sometimes necessary to be somewhat exclusionary of people who talk (Jones & Pullen 1992).

The situation for people who use AAC is somewhat different. Their numbers are much smaller, so they are more geographically and socially separate from each other and the likelihood of whole families and local communities using AAC is tiny. Can a 'culture' develop despite this? It may be that electronic communication methods (e-mail, social networking sites) can enable an online culture or community to emerge without the members meeting physically, although there is at present lively debate about this (Argyle & Shields 1996, Bell 2001). A geographically dispersed AAC culture may therefore develop electronic links between users at a distance. In fact

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communication which does not necessitate physically meeting or talking removes some of the potentially problematic aspects of interpersonal interaction for the AAC user. This would be a special case of the disembodiment which is debated in the cyberculture literature and referred to as 'leaving the meat behind' (Bell 2001:137). Certainly all three of the research advisors use e-mail, and social networking sites extensively and the teenage participants are beginning to or learning to do so.

It seems therefore that issues around growing up using a minority communication system are very different for the AAC user from those for a deaf person, and I believe drawing analogies between these two groups is therefore of only limited value. Members of these two groups have very different experiences of the body and the way that identity and the body may be related, because of the visibility of the difference for the AAC user, as discussed in Chapter Six. Advances in technology have been useful to both groups, but arguably the implications are very different for the two. For people who cannot physically talk, electronic communication may become an important way of building identity and relationships which have hitherto been extremely difficult.

Inclusive research methodologies

People with communication impairments, as well as those with cognitive impairments, are often excluded from research, even that specifically aimed at investigating disability issues. This is probably because of perceived methodological difficulties in including them. Conventional qualitative methods such questionnaires, interviews and focus group discussions, and 'child-friendly' methods such as drawing, role-plays and written tasks were all problematic to use in this research, because of the participants' slow communication and limited physical and literacy skills. Thus other kinds of methods needed to be explored and adapted to include these young people.

In the present study, ethnography has proved to be an excellent method for countering or sidestepping some of these difficulties. There are two main features which suit this population particularly. First is the long timescale, which allows both the researcher to learn to communicate effectively with each of the participants and,

reciprocally for them to gain trust and confidence in the investigator. Thus it becomes possible for rich data to be collected, which faster methods would not have achieved. Particularly when investigating a topic as subtle as identity, ethnography allows a gradual unfolding of different aspects of the person, as part of the developing relationship between the researcher and participant in different contexts.

Secondly the flexibility and diversity of situations that the ethnographer witnesses allow for a broad view to be obtained and for triangulation and validation of data to occur. This was important as it was not always easy to ask participants directly for clarification or elaboration. The research design also allowed the participants to suggest additional contexts where I should see them, and indeed some of them took advantage of this by inviting me to new places. The longitudinal and multi-sited nature of the study therefore provided opportunities for the teenagers to give as full as possible a picture of themselves as people and for them to have some influence on the settings.

Ethnography and lifeworlds approaches are useful because they provide detailed and contextual information, and have the ability to analyse the 'social being' not just the 'psychological being'. The person is thus seen within the contexts of family, friends, and school and it is their own perspectives which are highlighted. Through becoming a 'fly on the wall', as well as talking to them directly over a long period, I had the privilege and advantage of seeing their different 'selves', in different settings and with different people (Hockey, 2002).

As a researcher with a previous clinical background, I found this approach liberating and enlightening. As an adult without a disability I cannot claim to have been completely 'inside' the world of a teenager who uses AAC. However, the process of becoming immersed in their world gave me understandings that my previous work with disabled children and their families had not. My experience as a participant observer closely mirrors that described in the literature, in the sense that I felt increasingly identified with the teenagers and their families rather than with the other people around them (Clifford1983, Coffey 1999).

Evidently since I was part of, and not outside the process of researching, my observations and interpretations are just one interpretation of reality. They are however, validated by looking for similar evidence on other occasions or settings, and by asking for feedback on my perceptions both from the teenagers and the research advisors. In general I found that they agreed with my interpretations, although they were not afraid to tweak them for accuracy on occasions. The ethnographic process of using relationships which develop 'in the field' was highly effective in investigating this 'hard to research' group (Coffey 1999, Goodley 1999).

The participants themselves, when asked to review the experience of being involved in the project, said:

> *'ITS FAB',' FUN', 'AWESOME', 'I LOVE IT', 'I LIKE TALKING TO YOU', 'IT'S GOOD THAT YOU'RE ASKING US', 'YOU SHOULD TELL THE SCHOOLS WHAT WE SAY', 'THE BOOK YOU WRITE SHOULD HAVE OUR PICTURES ON IT, AND NOT BE BORING!'*

Thus they and the research advisors have given the work an important 'phenomenological nod'. My intention is to follow up the study with accessible public engagement activities for both adults and children who may have little knowledge about teenagers who use AAC.

The study's contribution to the field

In relation to the three disciplinary backdrops for this study, I would argue both that all have been important influences on my thinking and that the project contributes to and expands these fields of knowledge in important ways.

Firstly in embedding the study within a Childhood Studies perspective, there have been bidirectional benefits. The discipline has encouraged me to see the participants as young people rather than as disabled, and sensitised me to think of them as people who would have interesting things to say about their lives, which might be different from what adults might predict or say for them. This has resulted

in work that the research advisors say is 'true to life' and does not patronise or infantilise the participants. In addition I have brought teenagers who use AAC into the 'mainstream' childhood research world, from which they are still mostly excluded. Although there are increasing efforts to include disabled children in research and policy about children generally, those with more complex impairments are still often excluded (Connors & Stalker 2007). The data suggest strongly that these teenagers have more commonalities with their same age peers than they have differences.   Publishing and publicising this work in 'childhoods arenas' will therefore be important both from the academic and policy and practice points of view.

Secondly Disability Studies has contributed to my thinking particularly about identity and the body in more nuanced and flexible ways. It has challenged my assumptions and led me to consider ways in which the project could be emancipatory rather than pathologising. However it is clear from the relative absence of recent and in-depth literature about the lives of disabled children, that the main focus in this arena is still very much on adults, and on those with physical and sensory impairments rather than the more marginalized groups, of which AAC users are one. Thus the present study contributes to the small but growing body of work which engages actively with disabled children and young people, and particularly with those at the bottom of a suggested 'hierarchy of exclusion' which differentially marginalises certain impairment groups.

Lastly, anthropology has contributed theory about ethnographic methods and the benefits of in-depth and reflective analysis, as well as encouraging me to see teenagers and disability as social and cultural phenomena. Thus using a lifeworlds approach has led to me to look at the participants lives in processual way and in the round. Again, anthropological work in disability has been limited mainly to work with adults, so my contribution is to bring together anthropological perspectives on children and on disability and so to counter some of the liminalising of this group which ironically happens within the academy as well as in society.   If, as suggested by Garland-Thomas (2000), this kind of research, which explores and exposes the real lives of disabled people is 'humanizing, then I hope that is what I have achieved.

Ideas for further research

A similar study with older teenagers and young adults who use AAC would be able to explore how some of the dilemmas in adolescence that emerged here are resolved in subsequent years. In particular issues around negotiating autonomy and relationships with assistants, developing social networks, friendships and sexuality for those using AAC would be interesting as these are as yet unresearched arenas. The research advisors agreed that these are neglected topics, and in addition suggested projects involving AAC users in design of VOCAs and in AAC as an emerging culture. One disabled adult also highlighted the lack of knowledge about changes across the lifespan for people with cerebral palsy. The intersections between social class and or race, and the experience of people with very marginalized types of impairments are also poorly understood and neglected research topics.

Methodologically, having shown that ethnographic methods are ideal for those with communication impairments, there is certainly potential for the expansion of these methods with other marginalized groups of disabled children or adults, such as those with learning or behavioural difficulties.

Additionally an adapted and expanded version of the present study comparing the experiences of children and young people with severe physical and communication impairments, living in different cultural settings (eg in the global south), would reveal how concepts of culture, disability and identity interweave.

Key messages

In summary, the study revealed that teenagers with severe physical disabilities who use AAC view themselves principally as 'normal' teenagers, whose families and few close friends are very important to them, and who aspire to do the same kinds of things as others of their age and gender. In general they paint positive pictures of themselves as sociable and competent teenagers, and they do not particularly highlight their impairments, although they acknowledge that disability is part of their identity. They have pragmatic attitudes towards the effects of their impairments and their main concerns in relation to these are that they have

appropriate and reliable technology, and friendly, respectful assistance, which allows them as much autonomy and choice as possible.

Their perceptions of themselves are matched closely by the views of those who know them best, who also emphasise social relational aspects of them rather than highlighting their physical and communication impairments. These views contrast strongly with the perceptions of people who know them less well, and strangers, who tend to over-emphasise their differences and fail to recognise their ordinary teenage selves.

Thus for the young people there is a ontological dissonance between the way they see themselves (selfhood) and the way they are often seen by others (personhood). Judgments about who they can *be* are often made on the basis of what they can *do*. They are annoyed and frustrated by frequently being patronised and misunderstood. Unlike disabled people who do not have communication impairments, their use of AAC to talk makes it particularly difficult for them to resist and correct these misunderstandings about who they are, and for them to be seen as people who are in essence very much like everyone else.

This study has important implications for policy and practice in the health, education and social care arenas, as well as in other domains in society. As the UNCRPD (UN Enable 2006) begins to have an impact both on legislation and on attitudes, the concept of disabled people's inclusion in all areas of mainstream life will become more accepted and acted upon. Policy makers and practitioners need to think about ways of including and providing appropriate services for the whole range of disabled people, not just the 'easy to reach'. Seeking greater understanding of the perspectives of people who are 'hard to reach' and including them in research is part of this process of improved inclusion for all.

Those with severe communication impairments, alongside people with learning difficulties, are often viewed as the most difficult to include. They are at the bottom of a 'hierarchy of exclusion' so are often discriminated against and stigmatised even within the disabled community (Deal 2003). This may be because, to include people

using AAC, requires more adaptation and change from non-disabled people than does providing for the needs of those who have relatively straightforward physical difficulties.

There are perhaps some fundamental reasons why people with cognitive, behavioural and communication impairments are particularly excluded, related to common perceptions about the nature of such individuals and the ways that they may be viewed as 'different from normal'. Physical differences are relatively easy to understand and with which to empathise. Non-disabled people can imagine what it might be like not to be able to walk. However, if an individual's behaviour and communication appear very different, this strikes at the heart of other peoples' ability to see them as someone with ordinary feelings, aspirations, and experiences. Thus such people become categorized as another type of person altogether, and may be denied humanity or citizenship. Mackenzie and Leach Scully (2007) argue cogently that there is a lack of moral imagination of people without impairments to understand or imagine what it is like to be different. Additionally, it seems that it is difficult to see that someone so different could have a 'good' or worthwhile life (Albrecht & Devlieger 1999), or indeed might have views about that life. It is clear from the present study that these teenagers who use AAC, like their non-disabled peers have plenty to say. They see themselves as able to have good and worthwhile lives especially if they are given the equipment and assistance they require and are treated as ordinary young people. As George, a thoughtful 16 year old AAC user succinctly puts it:

> *I FEEL JOYOUS WHEN A BREAKTHROUGH IS MADE. WHAT ARE WE TRYING TO BREAKTHROUGH TO? LESS PREJUDICE AND MORE POSITIVE PROMOTION OF PEOPLE LIKE ME!*

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Appendices

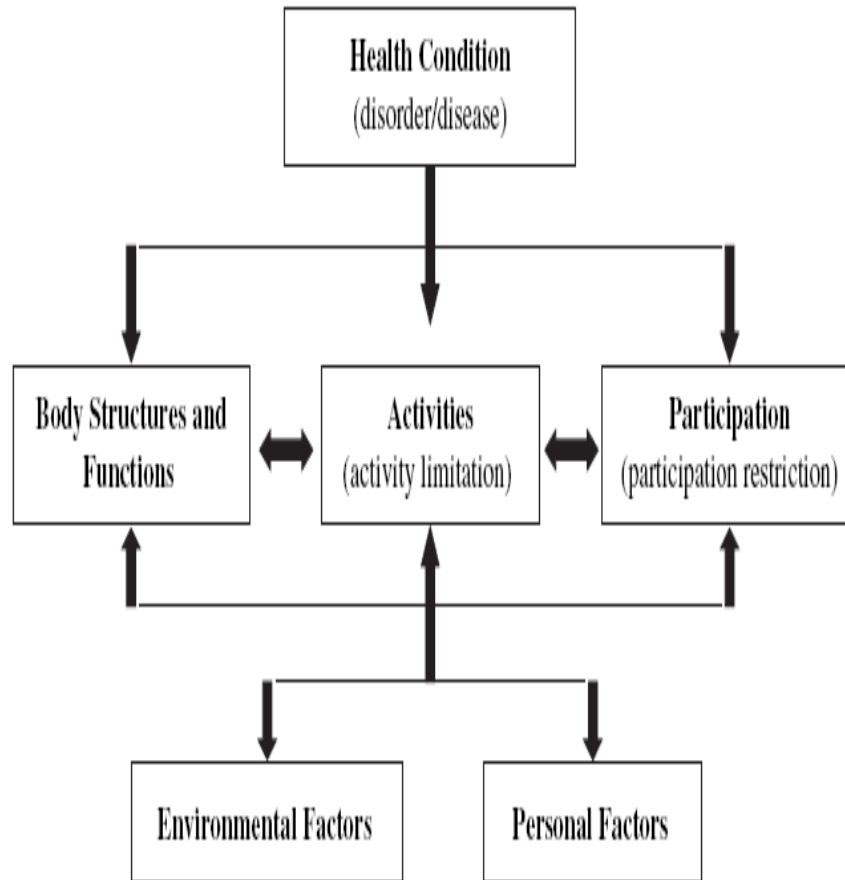## A. International Classification of Functioning Disability and Health (ICF) WHO 2001

Fig. 1. International Classification of Functioning, Disability and Health (ICF). (Adapted from WHO, 2001).

B. Prevalence and incidence of communication impairment and AAC use in the UK

Estimates for the incidence of people with communication impairments are around 4-5% of the population (just under 50% of the total disabled population, which may be near to 10% of the general population (Hartley 1998).

Accurate statistics about the number of children and young people using AAC in the UK are not available, mainly because the way in which assessment and diagnoses are provided varies across the country and there is no national reporting system. The incidence of cerebral palsy is around 1/400 births, or about 1800 new cases each year (SCOPE 2007). SCOPE, the national support organisation estimate that there are over 113 000 people with cerebral palsy across all ages in the UK. However, only a proportion of these will have severely affected speech. Athetoid cerebral palsy is a type which is particularly likely to affect speech and this occurs in about 10% of cases. Additionally there are children and young people with other conditions or uncertain medical diagnoses who have very severe speech impairments and who thus also use AAC. A review of the government funded 'CAP' project which until 2004 provided AAC technology to children, found that 802 young people with cerebral palsy were referred to the service between 2002 and 2004, across 6 regional centres (Wright et al 2006). These probably represent only a proportion of the total cases, as some parents or professionals will have arranged for provision of AAC equipment via other funding sources such as local health or education authorities, charities or privately. A very rough estimate therefore is that there are several thousand children and young people using AAC in the UK. In addition there are probably considerably more who would benefit from AAC but for whom it has not been suggested or provided.

C. Types of impairment: AAC users' communication and physical skills in childhood

The young people in this study have cognitive skills and verbal understanding which are broadly similar to their typically developing peers. They can see and hear normally. However they have severe physical impairments (caused by cerebral palsy). They have had this since birth, and the effect of the neurological damage is to make coordinated and fine movements difficult throughout their bodies.

The exact pattern of difficulties with movement will be individual and variable. Most have difficulty walking and controlling their hands and head movements and are wheelchair users. Nearly all are dependent on help from others with daily tasks such as dressing, toileting, eating etc.

These physical difficulties also have a severe effect on their ability to talk and although they may be able to say some words, these are very unclear, such that their speech is only understood by those who know them best. Therefore they use a range of 'augmentative and alternative communication' (AAC) systems to communicate. These may be 'light tech' such as picture or symbol boards or books and signs or gestures, and or 'high tech' computer based systems (Voice Output Communication Aids or VOCAs) which produce a 'voice output' in the form of an electronic voice when the user presses a sequence of buttons or pads. There are different ways of 'accessing' the buttons, for example with a finger, whole hand, or head pointer, to chose what to say.

High tech communication aids are used by both children and adults, with a range of different types of communication impairments and health conditions. The best known example in public life being Prof Stephen Hawkins. In his case, as with many adults, the speech impairment was acquired in adulthood (e.g. as the result of a stroke or degenerative disease), when the person already has established literacy skills and a pre-existing 'non-disabled identity'.

However children with congenital impairments are in a different situation. They have to acquire language and literacy through the medium of AAC, as an ongoing process. A teenager may have had a number of different VOCA systems during their lifetime (Beukelman & Mirenda 1998). Changes to the system are made as the person's skills improve or as the technology advances. Many people use a combination of their own speech, body language, light and high tech systems, depending on the context and on the skills of their conversational partner (Light 1997, Light & Binger 2003). However, generally the overall result is slow and effortful conversation.

Severe Cerebral Palsy is usually identified early in babies' lives, and parents will have been given a great deal of advice and information in these early stages. However it is difficult to predict early on how well the child will walk and talk as s/he grows up. It can be assumed therefore that the extent of these young people's communication impairments will have emerged gradually over time, and their families will not necessarily have known during the early years that a different form of communication would be necessary. Thus the ways in which the participants are disabled by their impairments will have emerged slowly during their childhood. This is probably important when considering the process of unfolding identity.

D. Government legislation in relation to children and young people and about disability in England and the UK

The Dept of Children, Families and Schools' green paper Every Child Matters' (2003) was groundbreaking in England, and part of this and subsequent legislation addresses the needs of disabled children (Aiming high for disabled children 2007). Additionally a consortium of organisations concerned with disabled children has launched a campaign highlighting their particular needs: 'Every Disabled Child Matters' (2006). Broadly similar legislation and campaigning groups are active in Wales, Scotland and Northern Ireland.

A Cabinet Office report covering the UK but with some slight variations across the devolved countries, on 'Improving lives of disabled people' (Life Chances) (Prime Minister's strategy unit 2005) has produced 5 key recommendations. Two were particularly concerned with disabled children and young people in transition to adulthood. This specific evidence of government recognition that issues about disabilities needed more focus was arguably precipitated by the UN Convention of the rights of persons with disabilities (UN Enable 2006) which the UK ratified in June 2009. The 'Life Chances' recommendations have been acted upon in the form of the recently opened Office for Disability Issues (Office for Disability Issues 2007) which aims to consult with and advocate for disabled people , including children and young people.

E. Ethics Information and Forms

Parents' Invitation letter and consent form

Dear Parent,

Research project 'Giving children who use AAC a voice'
I am a research student studying at Sheffield University, as well as working at the Institute of Child Health, University College, London. I am planning to carry out a project during 2007 with a small number of children (aged 10-18) who use AAC (high and low tech communication aids) as their main way of communicating. I am writing to you in the hope that you and your child may chose to join in.

About the project
The aim of the project is to get a 'child's eye view' of the experience of having difficulties with talking and of using high and low tech communication systems. I want to find out what the children think is easy and hard about their lives, what would make things easier, what they enjoy, what others could do to help them communicate etc. I plan to do this in very informal ways by getting to know the children over a fairly long period of time by spending time in their classes during one school term. I would also like to visit them at home on a few occasions, if you were happy with this, and possibly go to any clubs or holiday schemes that they attend, to see how they manage in different situations.

About me – the researcher
I have 20 years of experience of working with children with disabilities. I have lots of skills in getting children chatting and enjoy finding out what individual children have to say. I have developed this project because I feel that children with severe communication disabilities have very few chances to express their views and opinions. The project is funded by two research funding bodies, who recognise that my findings may help people working with disabled children (e.g. teachers and health-workers) to provide better services in the future.

What will the project involve?
If you agree to join in, I would be helping in out in your child's class on a regular basis during the spring term of 2007. This would give me a chance to see how your child manages communicating with the other children and the staff. I would also do some individual and small group work with your child and one or two others. During these sessions we would use symbols, pictures, speech, computers, voice output aids etc to talk together about what makes life easy or hard if you have a disability. I hope to make these activities fun for the children and an easy way for them to express their views.

After half-term I would contact you to arrange to visit you at home a few times, either in term-time or in the holidays. This would involve your child showing me how s/he manages at home. It would also be great if I could talk to you and other family members informally about how life is at home with a child who has communication disabilities. This is the first time that a study has been done that aims to find out in detail about children who use AAC systems. It is especially unusual to focus mainly on the children's own views rather just asking parents or teachers.

What will happen to the information found during the project?
The findings from the project will be written up as a study report, which will be part of my PhD work. I will change the name of the school and all the children and adults involved, so that it will not be possible for readers to identify anyone. I may give talks to various meetings and conferences, and may publish a book based on the study at some time in the future. Again no real names would be mentioned in any of these. If you are interested in what I find out, I will be able to provide a summary of the findings or talk to you about it, at the end. I will finish the whole project early in 2009. I will be feeding back my findings to the school staff, as this may well help them in their work with your child or others.

What happens next?
First of all, I will need to get permission from both you and your child. I will be talking to the children at school about it in a few weeks time. However you may have more questions about it before you decide. I am very happy to meet you at school to discuss the project further, or to talk to you on the phone if that is easier. If you and your child agree to join in, and then change your mind later, it would be absolutely fine to stop being involved at any point or to opt into some activities and not others.

If you agree to give permission for your child to be involved in the project please sign the consent form attached and send it back to school.

Many thanks for taking the time to read such a long letter. I hope you will chose to join in with the project and look forward to meeting you if you do!

Yours sincerely
Mary Wickenden
m.wickenden@ich.ucl.ac.uk

Consent form for Research Project

'Giving children who use AAC a voice'

Name of Child …………………………………………………………………………..

Name of Parent/s ……………………………………………………………Print Please

Please tick to show that you understand and agree with each section.

- o I understand that the aim of the project is to find out how children who use AAC   systems of communication see their lives.

- o It will involve observing with and working with my child in school during day to day activities. It will also involve my child doing some individual or small group with Mary during the school day, when this is seen as appropriate by the staff.

- o I will also be willing to arrange for Mary to visit our family at home at times convenient for us.

- o It is okay for Mary to audio or videotape my child as long as these tapes are erased when she has finished listening to or watching them.

- o I am happy for Mary to use information she finds out from my child in her study report and other publications. I understand that the name of the school and names of all children and adults will be changed.

- o I know that I can contact Mary via school, for more information about the project either before, during or after it, if necessary.

- o I understand that if I or my child change our minds, we can withdraw from involvement in the project at any time.
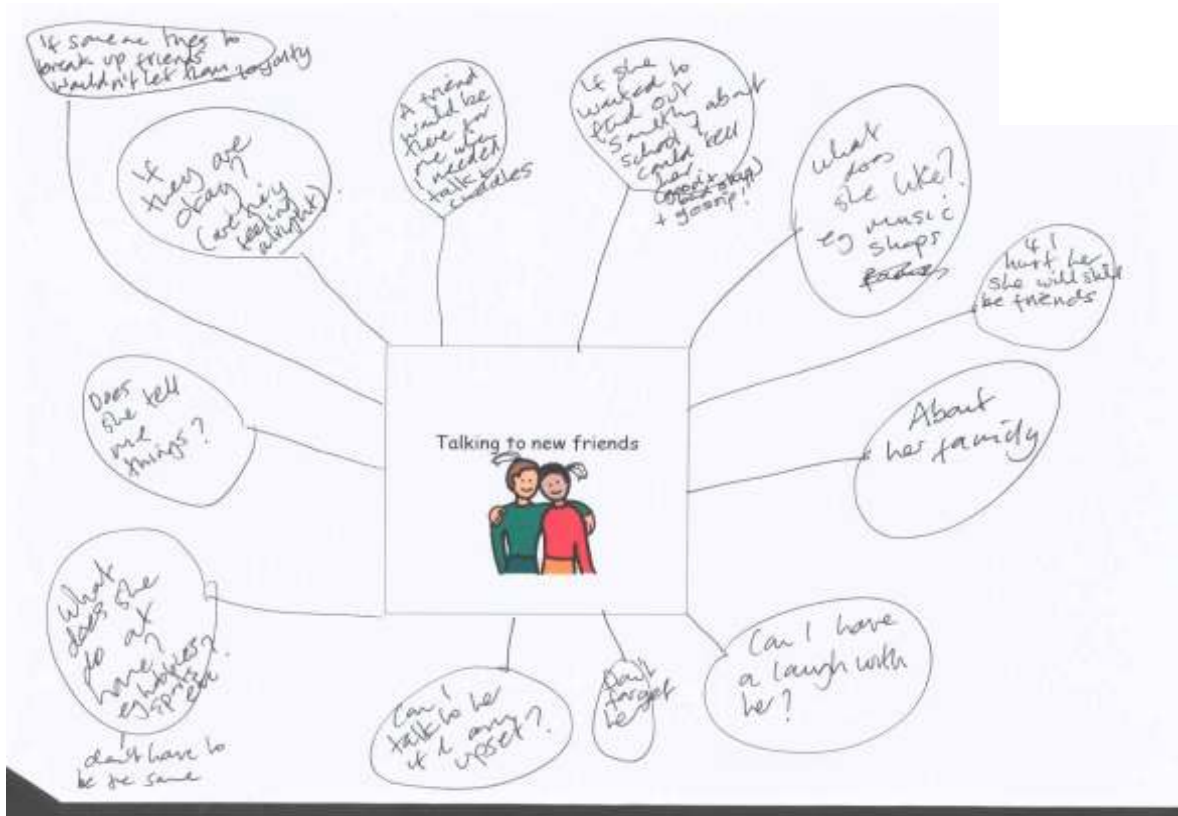
Signed ……………………………………./…………………………………………………

Many Thanks. Mary Wickenden.

E. Recruitment and consent information for young people

F. Example of visual data

1. Mindmap from conversation about friendships

G. Selected Tables of data

Data Table 1. Participants' view of AAC and advice for others

Name (age)	Views of AAC and using a VOCA	Advice for other people about talking to me
Bryony (10)	▪ I love my VOCA and I hate my VOCA ▪ I want to talk ▪ The VOCA draws too much attention from other people	▪ See me, not the wheelchair ▪ Listen
Jemma (12)	▪ Its brilliant ▪ I like the VOCA, but also like to talk with my voice. I don't like the American voice.	▪ Listen to me. Talk to me ▪ Learn how to use the communication book
Josie (15)	▪ I use whatever is fastest at the time ▪ The VOCA is the slowest of my systems ▪ I use 'facetalk' always ▪ I always get my message across somehow	▪ Listen ▪ Talk to me
Kate (13)	▪ My VOCA gives me a choice of how to communicate. I feel this gives me the chance to get my message across, though it is rather big, and ideally would be smaller and fit in a handbag ▪ My voice makes people stop & listen ▪ I can prepare speeches to give in class and I don't have to worry about it. I can communicate! I'd rather talk! ▪ "Sometimes the American voice [the sound of the recorded voice) makes the words come out a bit funny. If I don't spell quite right it can sound a bit strange, but it usually makes sense in a sentence. ▪ I haven't given it a name. It is just called the VOCA.	▪ Look at me ▪ Pay attention to what I say ▪ Don't shout ▪ Make it easy for me to ask for help ▪ Don't look over my shoulder ▪ Don't guess what I'm saying ▪ Don't talk to my assistant instead of me ▪ Don't look bored when I'm making my sentence ▪ I hate it when people speak like I'm a baby ▪ Please wait for my reply ▪ What I don't like is if people look over my shoulder when I'm typing and guess what I'm going to say before I finish
Marie (12)	▪ It's fantastic ▪ I would like to talk ▪ In order of preference 1 talking myself, 2 VOCA, 3 signing and my hands, 4 my communication book.	▪ Listen ▪ Some people are good, some people are terrible. ▪ With the good ones, I'll try different ways. With the bad ones, I don't bother! ▪
Nathalie (15)		▪ Talk to me like a teenage girl
Ted (12)		▪ Talk to me, bad if they don't ▪ People should take me seriously ▪ People should take time

Name (age)	Views of AAC and using a VOCA	Advice for other people about talking to me
Terry (14)	▪ It's fantastic	▪ When people misunderstand me it makes me angry
Toby (14)	▪ Great	▪ Don't be scared (of me) (have a go)
Ruth (17)	▪ I like chatting to people ▪ I like to use my mobile phone and texting	▪
George (16)	▪ It's all about having a voice, gaining independence, feeling empowered and satisfied you did your best communicating. ▪ It does make a big difference to my life when people take the time to care, to listen and to understand. ▪ Of course, communication aids help me - they are great. I am getting a new VOCA, I hope it will be mounted on to my wheelchair, then I'll be able to communicate better with preprogrammed messages	▪ Treat me as someone who can understand and has things to say, talk to me 'as normal' ▪ Don't ask too many questions at once, one at a time is best, yes/no works well ▪ Give choices for me to select from. But you need to give a range of options and always give the option of 'none of these' in case I am thinking of something you haven't thought of! ▪ If possible, give me a chance to prepare in advance, which cuts down waiting time for you ▪ Look at me: ▪ 2 reasons – to show that you are listening to me not my helper, and ▪ I might tell you something with my eyes or another movement and if you don't look at me you might miss it
Prakash (14)	▪ The VOCA is too slow ▪ People in my family listen patiently most of the time, Mum is the best at this. and also my SLT and people at the adventure playground ▪ At school, people in class don't wait for me to talk very well ▪ I get frustrated when the VOCA doesn't work. ▪ It is really annoying when it breaks down. ▪ I have a communication book, which I can use in emergencies but normally rely on the VOCA for most talking ▪ My spelling is sometimes a problem, if I don't know how to spell something, the VOCA doesn't help and it may sound funny.	▪ People should understand that my brain works fine ▪ Its important that they are patient ▪ They should listen carefully ▪ If they haven't understood my VOCA voice they should ask me to repeat it ▪ It's annoying if people read the screen before I have said something ▪ Being given options to choose from can help me sometimes ▪ Don't be afraid of me ▪ It is useful to pre-programme things to say in advance when this is possible

Data Table 2. Key participants' self-descriptions

Key participants	Self descriptions
Jemma(12)	1.Nice, fit, is going to university, likes watersports 2. Cool, loves parties, likes to have a good time, likes boys, likes summertime, fit, sexy, naughty schoolgirl, likes chatting about boys, sporty-likes running and gymnastics Good at science 3 I'm a worrier
Kate (13)	1. Determined, stubborn, quick, enthusiastic, positive 2. Good at ICT and boccia. Sporty, Competitive like my dad.
Marie (12)	1. Nice. Good. Friendly and sociable. Use a comm book and a VOCA to talk. 2. Like going to cafes. Love boys. Like my legs. 3. Want to go to college, In a wheelchair. Want money to spend on clothes. Nice person. I help other people. Bad at getting up in the morning
Nathalie (15)	1. Nice, kind, beautiful, funny 2. Clever, trendy
Bryony (10)	1. I am beautiful, I have friends I am funny. I am equal
Josie (15)	1. Mad, likes to talk and listen, In a wheelchair – all the time –drive myself I like to be independent Don't like things done for me I am a worrier – people say I worry about silly things-Worry about being late A family person A girl – but boyish Likes a laugh, likes to be with friends 2. Sporty, messy, late
Ted (12)	1.Pretty/handsome, fun, nice, smart, clean, cool, good, right, (wrong?), excellent 2. peculiar, whacky, different likes designing showers and kitchens 3. Have a warm heart Likes fun, Likes to be in control, Think what I think
Terry (14)	1.Mad , a wheelchair user, (dirty) scruffy , sporty – athletics and boccia Football -Birmingham City supporter not in a wheelchair – friends know me as a person 2 Calm, cool 3 I like design and technology and ICT. Like football
Toby (14)	Boy who is 15 Smart, Nice, Grumpy, Do my own thing, Moody Tall, In between fat and thin, Not handsome, not ugly I'm in a wheelchair – electric Into football – Man U. Hi tech games – like wii, ICT.A few friends home & school

NB Words are listed in the order in which they appeared during an initial conversation on the topic. Numbers 2/3/4 are additional descriptions used by the teenagers on subsequent occasions.

Data Table 3. Participants' Loves, Hates and Important Things

Key participants	I love	I hate	Important things
Jemma (12)	1.Craig (boy in her class) Athletics and watersports Shopping, Dr Who 2.Lee (boy in new sch)	1. When my VOCA is dead	Photos of (grandad who died), other grandad, new baby cousin, cousins, 2 gmas, my uncles, laptop, baby photos of me and sibs, graduations certificates(future), DVDs of Dr Who, tickets for 2012 Olympics, my whole school tutor group, the tardis, Lee, Hotel in Egypt
Kate (13)	1.Cinema, arts and crafts, stationary, monsoon clothes, DVD, boccia, athletics 2.School – everything, Boccia, Shopping –B shopping centre Giving talks at conferences. 3.Archery, Riding	1.Apples (hard for me to eat), viruses on the computer, football - boring & rugby also boring! My old school where they didn't help me 2.I don't like it when people look over my shoulder when I'm typing and guess what I'm going to say before I finish	1.Mum, Dad, Carol, Toby. Fish & Chips, ice-cream, money box with lock, teddy and Dumbledore toy, Harry Potter and Daniel Radcliffe. 2. Trendy colourful boots.

Marie (12)	1.Harry Potter, A car I can drive Boys –their hair, Making things, Beer Eastenders, Babies Halloween-spooky stuff DVDs about nasty and scary things. Buffy 2. I love boys. Football. Phone shopping and catalogues Going to cafes for tea Going to the park Presents and my birthday. Loud Music. Red wine. Rednose day Friends come round for tea. Watching movies Keyrings. Anything pink Mobile phones. Dancing Parties. Eating Chocolate. Sweets Makeup. Art lessons	School work. Especially PE. Boring stuff. School because of not talking Older rough boys, Old people on TV. Fat people. Waking up in the dark for school Mary (? Mother of Jesus?) People treating me like a baby People staring at me in shops. People who think I'm not clever People who shout and fight. Don't like hospitals – boring, though I like the people, but I nearly died. I hate thinking about saying goodbye to everyone when I leave school.	Toys and games at home paper for writing MP3 player. Mobile phone Boyfriends and girlfriends. My bedroom My guitar Talking on the phone Power wheelchair. VOCA is fantastic
Nathalie (15)	Cinema, holidays Shopping in Primark, being warm, milkshakes chocolate, watching TV-Hollyoaks Jason – film star –poster Ice-cream, Going on safari, holidays Funny things and people Working with young children	People not talking to me and ignoring me Baked beans, Broken VOCA or lift or chair, Being angry, Arguing with my mum	Handbags, and fashion stuff Holidays Pets
Bryony (10)	1.Musicals and DVDs – Annie, Grease, Mary Poppins, Harry P, Sound of Music. My friends Playing with other kids 2.People who make me laugh Gym & Athletics ,Guides Going to shows	My VOCA People looking at me in public When people just see the wheelchair Not being able to eat independently When people treat me like a baby	My VOCA, My accessible bedroom Pink things Beads & jewellery Arty crafty things Soft toys computers
Josie (15)	1. Food – roast dinners Fruits – strawberries & bananas, Talking to people, When friends ask me out Computer – games, e-mail, internet, Swimming with gran Boccia Family get-togethers	1. Mondays – go back to school People who don't talk to me directly, People who think I can't do stuff People who think they know what I am saying, 2.People who talk for me People getting my message wrong	Mum, Dad Hayley & Katie - old friends Someone to talk to (like Anna & Lucy LSAs) favourite doll chocolate – galaxy favourite CDs My chair Computer - to be on my own away from people.

	Fridays – go home from school Relaxing, chilling out Having a moan or gossip TV and music 2. Football matches with dad	Grumpy adults Not enough room in shops for my chair Being in my manual chair Not being able to go out with my friends	Box of pictures and stuff I made with Katie – old memories - about life Mobile Phone
Ted (12)	1.School – good get help and I am myself and people who like me. Blocks and Lego – building all kinds of things Goat's milk God – I go to Kings Church. Good Hugs Breakfast – bacon Emily – people I like 2.Talking to people Going on trips Visiting & meeting people Pizza hut Playing games with my sister	People who say 'oh my god' When no people in vehicle (being in car on my own) Drink at night (people who go out and drink) My feet in my straps Dogs – bit scary Sad people - prefer jolly people I don't like people who says 'I don't like you' When VOCA breaks	Mummy, Emily (carer at school) Ruth (sister) Restaurant with bacon, cookies and goats milk Comfy slippers Bed My bedroom at home A little house – because no cold God
Terry (14)	1. Football team and all sports - Birmingham city Going to the folk festival Competing in Boccia and athletics competitions ICT and techy stuff. Computer games .Music 2. My new wheelchair Going out - meeting people Going to the pub in the village	My friend Andy who being ill (died during the year) People who patronize me	1.Parents and godmother favourite uncle - funny Geoff –ad friend The local folk festival Wheelchair and charger Football team - poster/shirt/calendar Xbox 360, Sky box and hd TV, Ipod Fish tank at home, My bed 2.Boccia and athletics medals 3.Hippyish clothes Gelling my hair
Toby (14)	1.Chocolate minirolls Playstation Football team – Man City Travel – holidays – Going to Grans Camping. Beach Watching TV – sport and cartoons. (a good day is when?) Girl' (likes me?) I get good grades Do well at something (eg ICT) Chilling out with Rob – playing games Playing with my new wii – computer games	1. Nothing 2. Disgusting school food RE teacher, VOCA not working, Being poorly 3. When my VOCA doesn't work or my chair control doesn't work When I want to watch TV and can't When people don't know how to use my chair and VOCA Arguments about TV with sisters and mum and dad Arguments with Rob	1.Desserts Chocolate minirolls Chocolate Ice-cream Chocolate minirolls 2.Playstation, wii, TV Football posters Breakfasts Bean bag (at home)

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	2. Going on trips out to places like theme parks	about wii and playstation Not being able to go out to places – would like to go out more When I run out of chocolate When there is no football on TV or I have to miss it	
Additional participants	**I love**	**I hate**	**Important things**
George(16)	1. The natural world – anything about birds and animal. Tigers Music - pop-classical -Kaiser Chiefs and Kylie Football – Liverpool Writing poetry Travelling to new places Bowling & Cinema Woodcraft folk,	When people think I don't understand. When people leave me out of the conversation	Tiger things and bird things Music CDs, DVDs Audio-books Posters
Ruth (17)	1. Boys, love, kissing, flirting, dancing, funloving. Pink and pretty stuff in her room Into magic at the moment and has a wand which she likes and takes with her to school daily. Makeup, perfume and jewellery. Enjoys drama and dance and singing	People not waiting and don't listen enough	Magic wand Photos Funky clothes, Jewelry and bags etc Music Mobile phone for texting
Prakash (14)	1.Horse riding Fast cars Football – Man United Playing computer games and playstation Going on holiday Listening to music Chilling out with sister Walking dogs in the park Other local trips Adventure playground for disabled kids	VOCA when it doesn't work or is too slow When people don't listen patiently	Dads fast car Rosettes and certificates

H. Topic guides for Interviews and Focus Group Discussions

Parent Interview Topic Guide

Introduction
- Recap re the aims of the study and about anonymity and confidentiality for the child, the family and anyone else they mention.
- Ask for permission to audiorecord the interview.
- If anything arises in the interview which they would prefer me not to use as data, they can ask me to delete it from the transcription.
- There are four broad questions. There are no right or wrong answers and these are only to guide our conversation, so it is fine to stray away from the question somewhat, if you think of something you think would be of interest me.

1. **If you had to describe (name of child) to a stranger who hadn't met him/her, what would you say?**
2. **Why do you think he/she is like that?**
   What have been the main influences on who s/he is now?
3. **How do you think other people who meet him/her see him/her?**
   What is their impression do you think? Why is that?
   Do you think the way his/her body is has any effect on what people think?
4. **What do you think s/he will be like in the future, as an adult, in 5 or 10 years time? What do you imagine s/he will be doing? What will be easy or difficult about that?**

School Staff Focus Group Discussion Topic Guide

Introduction
- Recap re the aims of the study and about anonymity and confidentiality for the children and families, schools and anyone else they mention.
- Ask for permission to audiorecord the interview.
- If anything arises in the interview which they would prefer me not to use as data, they can ask me to delete it from the transcription.
- Four broad questions. There are no right or wrong answers and these are only to guide our conversations, so it is fine to stray away from the question somewhatN, if you think of something that you think would interest me. The questions are about children and young people who use AAC generally, not about individuals in particular. If you want to use examples of individuals, that is fine, but I will change their names.

1. **When you think about the young people you know who use AAC, how do you see their social relationships working?**
2. **How do you think others see them?**
3. **How do they see themselves?**
4. **How do you think having bodies that are different affects their social relationships?**

Older teenage AAC users at College. Focus Group Discussion Topic Guide

Introduction

- Introduce myself. Explain about anthropology and research
- The aims of the study and what I have been doing with the younger teenagers in schools etc.
- Confidentiality and anonymity issues
- Permission to audiorecord
- Broad questions with no right or wrong answers. Interested in their ideas and experiences of being an AAC user

1. **Student introductions: Names, age, how long they've been at college, where they live and what they are studying**
2. **What can you remember about how you communicated with people when you were younger? Can you remember when you first started using AAC? and what it was like?**
3. **What is easy or hard about being an AAC user for you?**
   What is good? What is not so good?
4. **How do you think other people see you? How do they react to you using AAC?**
5. **How do you choose which type of communication to use with different people?**
6. **What can other people do to make socialising or communicating with you go well? What doesn't help.**

I. Mindmap used to feed back to participants

Mindmap of things you all told me

1. Me myself I

My life history and memories
Stuff at home
The future
Being in or out
What I love and what I hate
Independence + dependence
Children's competence
Boys and girls
Privacy
Doing it my way

Being a teenager – what's cool?
    Food and other creature comforts
    Going out, shopping and hanging out
    IT computers, phones and techy stuff
    Love stuff
    Music and media
    Sport
    Trips and holidays

2.   Me and other people

My family and other animals
Being in school
Friends
Other children, school or other
Parents
How people who help me
Professionals
    LSAs and Care staff
    Teachers
    Therapists
Strangers and the public

3. Physicality and Practicality

Me and my body
Doing is being
Practical stuff to do with everyday life
The kit –equipment
Time is an issue

Being a teenager who uses AAC

5. Who said that? – stuff about talking

AAC
Chit chat + goss
Communication and language
Saying what I need to and saying what I want to

4. The Disability Tribe

Being different and being the same
Having CP
Ways to be
Who controls what?
Speaking up and going places
Power struggles
School politics and resources
Types of schools

J. Timeline for study

Year 1
Oct-Dec 2006
Recruitment of participants and advisors:
Contact suitable schools and national support group, negotiate participant observation / researcher role, and discuss research with parents, relevant healthcare and education staff.
Gain university and school ethics approval.
Consider adaptations of qualitative methods for communication aid users (e.g. symbols systems).
Preliminary visits to school, meet possible participants informally. Arrange information sessions and consent procedures for young people, parents and other adults.
Meet and discuss project with 3-4 disabled adults who are AAC users, who will form research advisory group.

Jan – Sept 2007
Participant observation fieldwork
Spring term: School A (2 young people – 2 days/week) + Home visits
Easter Holidays: Home visits (School A young people + 4 others)
Summer term: School B (4 young people 3-4 days/week)
July: National support group weekend - Research role with AAC teenagers making DVD
Summer Holidays: Home visits and activity club visits
September: AAC conference- consultation with advisory group and others. Conference paper on methods and preliminary themes.

Year 2
Oct-Dec 2007
Participant observation in 4 separate schools, home visits and various club visits (4 days/week).

Jan – April 2008
Additional home visits and club visits.
Focus groups with older teenagers and with groups of professionals & assistants.
Individual interviews with parents.
Data transcription and coding.

May 2008 – Sept 2008
Data transcription and analysis
Data transcription and initial analysis
Individual interviews with parents
Participant feedback sessions (July)
Data analysis and writing up
Conference presentations: Sheffield (Childhood –July 08) and Montreal (AAC- August 08 - Poster) and Lancaster (Disability Sept 08)

Year 3
Oct 2008- Sept 2009
Analysis and Writing
Consultation with research advisors
Journal article submission (Communication Disorders Quarterly – Jan 09, in press Oct 09)
Conference presentation: Communication Matters UK (AAC Sept 09)

ESRC Assistive technology day Nov 09
Thesis submission (Nov 09)

K. Accompanying DVD

NB the electronic copy does not include the DVD. This is available with the University of Sheffield library copy. However the 1Voice video can be access via U-tube as detailed below.

On this DVD are two short videos, each of under 5 minutes.

In order to play these, it may be necessary for you to install the VLC video player file on to your computer first (included on the DVD). Click on this before playing the two videos. This will take only a few minutes.   The two DVD files should then play automatically.

1.   Katie Caryer (RA) talking to MW about her experiences in the first few weeks of studying for an MA at Leeds University. It is important to know that Katie uses a large downward gesture with her left hand to mean 'yes', and a shake of the head for 'no'. She is a very fast and skilled user of her VOCA and which uses a system of 'icons' or symbols in combination to produce pre-programmed words or phrases. She can also choose to spell out letter by letter more unusual words, although she does not do this during the clip. Katie has been using the same system since she was eight, although with progressively updated versions. She is also a fast and competent user of a mobile phone and computer with adapted mouse, so is a regular user of e-mail and social networking sites.

2.   1Voice DVD: Listen to me. Made over a single weekend with support from a team of AAC researchers, musicians, and professional film-makers.   Some of the young people in the DVD are key or additional participants in this study but not all.   This video is also available on U-tube and has been widely circulated.

      http://www.youtube.com/watch?v=vLf7RCWKhrU

Filename: Teenage worlds different voices electronic mw
Directory: C:\Documents and Settings\My computer\Desktop\All phd
    stuff\Final versions
Template: C:\Documents and Settings\My computer\Application
    Data\Microsoft\Templates\Normal.dot
Title: Teenage worlds, different voices:
Subject:
Author: My computer
Keywords:
Comments:
Creation Date: 4/18/2010 8:23:00 PM
Change Number: 7
Last Saved On: 4/20/2010 11:36:00 AM
Last Saved By: Sop06jmw
Total Editing Time: 144 Minutes
Last Printed On: 4/24/2010 11:09:00 AM
As of Last Complete Printing
    Number of Pages: 350
    Number of Words: 111,130 (approx.)
    Number of Characters: 633,443 (approx.)