‘I want to be me’:

Learning from teenagers diagnosed with autism using collaborative, participatory research

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Statement of authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

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Abstract

An increasing number of children are being diagnosed with autism. While much literature exists about autism, a literature review highlighted that research about children and young people diagnosed with autism is predominantly within etic or adult expert research. The experiences and voices of children and young people are largely missing from research literature and from policies based on research. Some researchers who have sought to be inclusive of diagnosed children’s views have reported difficulties in using traditional research approaches. Others have excluded those unable to articulate their views verbally.

The dual aims of this research were to a) learn about the lives of a small group of teenagers diagnosed with autism, and b) develop an inclusive qualitative research approach that would enable meaningful engagement of individual young people with a range of cognitive and communication abilities.

The theoretical framework for this research was informed by a constructionist paradigm drawing on concepts and principles from the ‘new’ sociology of childhood and the social model of disability. A collaborative participatory approach, informed by phenomenological and ethnographic traditions, was used. Consultations were conducted prior to the main data collection stage, first with parents and then with teenagers. The consultations involved establishing rapport, asking for consent and obtaining information about individual teenagers’ communication abilities and preferences. In the main stage of the study, participating teenagers were engaged individually using research methods of their choice.

Study participants included six teenagers, aged 13 to 18 years, and 11 parents. While broad question topics framed the research, the views and interests of individual participants generated the interview questions. Face-to-face interviews were favoured by most participants initially, but email interviews were also used with some participants. Semi-structured interviews were adapted to suit
individual teenagers and to include their own communication strategies. Participant observations were used with one young person combined with structured interactive communication strategies. Between two and five research visits were conducted with each teenager.

An interpretative framework was used for the data analysis process. Recurrent or strong themes produced the key themes. During the research process, research visits were analysed reflexively highlighting key issues for inclusive research. Two categories of findings were produced. One category pertains to methodology, the other to young people’s knowledge about their lives.

Implementing a collaborative participatory research approach was found to be important in being inclusive of individuals who had diverse cognitive and communication abilities. This approach was time consuming and required considerable resources, but it allowed for individualising research engagement. For myself as the researcher, it was important to be sensitive to individual communication styles and flexible in the use of research methods. Through consultation I found that most parents and young people decided to participate in this particular research because it resonated with important issues in their lives and provided an opportunity to be heard. Involving parents alongside their children during consultations had the effects of both facilitating and limiting the extent to which young people’s voices could be heard. To hear the voices of these young people I found theoretical insights from both childhood sociology and disability studies valuable.

The findings highlight that the lives of young people living with a diagnosis of autism are not homogeneous. The young people in this study were individuals with a range of views and experiences. Still a central theme was produced from engaging directly with individual teenagers. This theme, ‘Negotiating identity’, was integral to four other key themes around experiences of teenage-hood and autism: 1) Identifying self through a period of change; 2) Indicating the significance of a diagnosis for sense of self as different; 3) Indicating the importance of control and social identities; and 4) ‘Just want to be me’ and be accepted as ‘me’. These findings illustrate that many of the experiences of these particular teenagers reflect those of teenagers more generally, and
that having a diagnosis of autism was not necessarily the most important aspect of their lives. Where
the young people had common views and experiences related to autism these typically involved
experiences related to negative stereotypes lingering in society. Such experiences had significance
for the way the young people felt about autism and the extent to which they identified with the
label.

It is important for social policy makers, practitioners, educators and researchers to consider that
there are both positive and negative implications for young people’s identity when a label is applied
to them. Taking into account the increasing number of children and young people being diagnosed
with autism, I suggest that further research is necessary to better understand their lives. However,
researchers need appropriate time and resources in order to be inclusive of children and young
people with a diverse range of abilities and requirements. In order to change negative stereotypes
and attitudes towards those carrying diagnostic labels such as autism, I propose that significant steps
should be taken to develop programs that increase awareness and understanding about impairment
and disability. It is important to include young people’s views in developing such programs in order
to make appropriate decisions about processes that affect their lives.
PART ONE: BACKGROUND
Chapter 1: Positioning the study
1.1 Introduction

Autism as a disorder has received much attention in research and public debate over the past decade. This attention has sparked recent changes to social policy in Australia (Australian Government, 2008a) with significant implications for individuals diagnosed with autism, especially children and young people. Despite this attention, diagnosed individuals have had little opportunity to contribute their knowledge and experiences to social policy research. In order to address this lack of knowledge in the literature, this doctoral study has focused on learning, from their perspectives, about the lives and experiences of a small group of teenagers diagnosed with autism or autism spectrum disorders (ASD). To be inclusive of the young people’s views, this study used a collaborative participatory approach based on theoretical perspectives in contemporary childhood sociology and disability studies. This research approach includes children as *subjects in research* rather than *objects of research* and applies a lens that takes account of children’s views (Mason & Urquhart, 2001). A collaborative participatory approach is rarely used in research involving children and young people diagnosed with autism. Placing the participants’ own views and experiences at the centre of this research has produced different knowledge about diagnosed young people and their lives with autism than that produced using traditional approaches.

This chapter provides background information about the study. First I explain how the direction and approach of the research were influenced by my own experiences as a mother of two children diagnosed with autism. A short discussion is included around the use of terminology, followed by an outline of the key issues that have framed autism as a social problem. Thereafter I provide a rationale for including young people’s own views and experiences in research and policy. The chapter concludes with an overview of the structure of the thesis.

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1 In Australia, the term ASD includes autistic disorder or autism, Asperger’s syndrome (AS) and Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) (Autism Spectrum Australia (ASPECT), 2009). To simplify the reading of this thesis I use the term autism unless another term is more appropriate.
1.2 Selecting the research direction

1.2.1 Choosing the topic

This study was initially motivated by my own experiences as a mother of two children diagnosed with autism and out of my concern for their rights as people. I commenced this doctoral program after completing a bachelor degree in occupational therapy with honours. My undergraduate studies had been an endeavour to gain knowledge in order to understand the diagnosis with which my sons had been labelled. I also wanted to find the best ways to support them when dealing with the normative structures and expectations they encounter in their everyday lives.

Many children who fall outside of social and educational norms face disabling social attitudes and barriers on a daily basis (Connors & Stalker, 2007; Davis, Watson, & Cunningham-Burley, 2000; Kelly, 2005). Those of us who parent such children are often disabled by these same attitudes and barriers. We experience stigma when our children display ‘odd’ behaviours in public. Through connections with other parents, I know that many of us feel powerless in dealing with authorities and are often pressured to ‘make’ our children conform and ‘fit in’. Having these experiences meant that at an early stage in developing my thesis proposal I considered studying the challenges from a parent’s perspective. Conversely, I found that parents still have a more privileged position than children in terms of making their voices heard. Children’s lives and experiences are most commonly defined by adults, especially those children with diagnoses that define them as being less competent than others. I have observed how my children’s feelings and experiences have been negated by adults who felt their adult viewpoint was more valid than that of the child. I have learned from other parents how their children and young people diagnosed with autism have been excluded from schools because their right to have their views heard on equal terms with others has been disregarded.

The lack of attention to the voices of children diagnosed with autism is reflected in the literature, as discussed in Chapter 2 of this thesis. More parental accounts about living with autism exist in both
academic and grey literature than accounts by children and young people to whom this diagnosis is applied. Therefore I felt that to make a contribution to existing literature it was important to focus my research on the views and experiences of children and young people rather than those of their parents. My interest in the rights of children and young people to participate and be heard increased as a result of preparing for and engaging in this study. As I became more familiar with childhood and disability literature, it became particularly important for me to be inclusive of young people in a way that was considerate of their individual abilities and preferences. In the next section I outline how I initially approached the study and how the iterative process of thinking and engaging in the study has influenced the writing of the thesis.

1.2.2 Choosing the research approach

The process of conducting this project has taken me on a journey exploring different research approaches. Coming from an occupational therapy background, I commenced this study using an approach arising from a medical perspective on autism. I soon found that alternative approaches arising from sociological perspectives on childhood and disability had more resonance with my personal viewpoint. These alternative approaches helped guide the research design so that it centred on the young people’s experiences. I did not start out with a postmodern approach. However, once I started analysing data produced from engaging with the young participants, I began to understand how developing postmodern ideas within childhood and disability literature link with the complexities of teenage-hood and autism. Additionally, much has changed in research literature and Australian social policy since I started this study in 2006. In short, my personal journey has had some parallels with the developments in the literature. This research journey has challenged and extended my thinking as well as my writing, particularly as I am not writing in my first language. The experiences on the journey have offered me an abundance of new knowledge, albeit through a steep learning curve.
The change away from traditional and medical approaches in the research process is congruent with my position as a mother. In the early years of receiving my sons’ diagnoses, I relied mostly on medical knowledge. Unfortunately, the medical model places many pressures on parents with a newly diagnosed child. Some parents may be distressed and relieved at the same time, but certainly most parents are vulnerable when dealing with professional authority as they try to understand the implications of this new diagnosis (Hodge, 2005). However, as time went on, I became aware that my knowledge and that of my children could make an important contribution. Sometimes our experiences challenged or contrasted with medical knowledge. Thus, in some respect, my research journey began at the crossroads of controversial and competing knowledges.

The complexity of different knowledges is reflected throughout the autism literature. The particular concerns within and around the different knowledges and perspectives on autism are taken up in Chapter 2. The next section demonstrates how terminology produced by contrasting knowledges has implications for the way young people are referred to and defined in terms of the diagnosis.

1.3 Finding appropriate terminology

Currently no agreement exists about the best language to use when talking about people who are diagnosed with autism. Different terms are used when talking about autism to reflect the thinking within particular professional fields, organisations or population groups. For example, within Australian Government departments and disability organisations person-first language is preferred (i.e. ‘a child with autism’, ‘a person with a disability’). This terminology is considered the politically correct way to talk about persons with impairments in these organisations (Department of Ageing Disability and Home Care (DADHC), N.D.; Queensland Government, 2005; Western Australia Government, 2008). Person-first language was promoted in an effort to shift attitudes, remove stereotypes and acknowledge the person as being more important than the impairment (Queensland Government, 2005).
The use of person-first language has been contested by disability writers and activists. For example, Oliver (1992) argues that the use of person-first language is a ‘linguistic attempt to deny the reality of disability’ which downgrades disability to an insignificant appendage (p. 21). The argument against person-first language is that it emphasises problems associated with disability as belonging to the individual person. While people may have impairments that interfere with their everyday life experiences, the barriers individuals face to community participation and inclusion are typically caused by social structures and attitudes rather than the impairment itself (Oliver, 1990, 1996). Within disability studies, the terms ‘disabled people’ or ‘disabled children’ are used as recognition that disability is a form of social oppression imposed on top of impairment rather than belonging to the individual (these concepts are discussed further in Chapter 3).

Following the lead of disability activists, some autistic self-advocates have been equally critical of the use of person-first language. They contend that autism is not something they have but an integral part of who they are (for example Bradley, 2008; Sinclair, 1993). In his much quoted paper ‘Don’t mourn for us’, Sinclair (1993) describes autism as ‘a way of being’ which ‘colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence’ (no page). In a later paper, Sinclair (1997) states: ‘I am autistic because I accept and value myself the way I am’. He reinforces autism as a positive, not a negative, aspect located within a person, which cannot be separated from being that person:

We talk about ‘male’ and ‘female’ people, and even about ‘men’ and ‘women’ and ‘boys’ and ‘girls,’ not about ‘people with maleness’ and ‘people with femaleness.’ We describe people’s cultural and religious identifications in terms such as ‘Russian’ or ‘Catholic,’ not as ‘person with Russianness’ or ‘person with Catholicism’ (Sinclair, 1999)(Webpage)

Other self-advocates agree with using the autistic label. For example, on her website, Alison Bradley (2008) states that ‘... a person is no more “with” their autism than they are “with” their gender or race’ and that using the term ‘with autism’ ‘would imply that somehow because you are “with” then you could be “without” i.e. simply have it taken away or choose not to live with it’. 

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The adoption of the label of autism is a conscious and often political choice by individuals. The label expresses how they understand the diagnosis as an integral part of their being and identity. Recently, active members of the Autistic Community have taken note of the movement within the Deaf Community and made the choice to use a capital A for *Autism* or *Autistic* (as I have in this paragraph). This change was an effort to bring awareness to their different needs and preferences and to establish their rights to being the way they are, but also to highlight that Autistic people are deserving of opportunities equal to the rest of the population (Bradley, 2008; Sinclair, 1997). Thus, referring to people as Autistic implies that they have accepted the diagnosis and identify with autism as signifying difference.

In writing this thesis, I have chosen to use the terms ‘disabled people’ or ‘disabled children’ because of the strong influence of a disability studies perspective on my work. However, in terms of autism, I use the phrase ‘diagnosed with’, especially when talking about children and young people, because I feel uncomfortable using the label *Autistic* in the same way as those who actively self-advocate. First, my understanding is that autism is essentially a socially constructed concept, which is applied to a person rather than something that is ‘discovered’ (Biklen, 2005). The dominant construction of autism is highly medicalised and is typically discussed in terms of difficulties and deficits. Some people may not identify with the characteristics associated with autism and choose not to use the label publicly. Further, some children and young people are sometimes unaware of having a label or unsure about the exact meaning of the diagnosis applied to them (Connors & Stalker, 2007). As will be discussed further in Chapter 2, autism as a label is associated with a set of symptoms or characteristics that have been defined by adults. The children to whom the label of autism is applied have had little opportunity to contribute their knowledge or perspectives. Thus children and young people may be unsure about or unwilling to identify with the autism label. In fact, few young people I have come across both in doing this research and elsewhere use the term *Autistic* to identify themselves in a political manner or in relating autism to their lives. Although some young people indicated the significance of autism in their lives, most tended to refer to autism as a condition they
‘had’. Thus, in taking young people’s views seriously, I feel it is inappropriate to use the label ‘Autistic’ about them unless they choose it. In the next section, I outline the rationale for focusing this research on hearing the views of young people diagnosed with autism.

1.4 Research rationale

As explained previously, this research was initially motivated by my own personal journey as a mother who wanted to hear children’s views on autism. I wanted to also learn about the issues that were important in their everyday lives. While my research journey did not start out with a social policy focus, I was aware that children and young people were rarely heard in relation to the policies that affect their lives. I had struggled to find literature that took account of children’s views and experiences. During the early stages of the research journey, my personal interest turned to a focus on children’s rights to be heard on issues affecting their lives and ways in which these rights can be respected. With a new Australian policy on autism (Australian Government, 2008a) launched during the later stages of my research, the absence of children’s and young people’s voices became even more apparent. I briefly explain these aspects in the next sections.

1.4.1 The absent voices of children and young people

Children and young people diagnosed with autism are commonly the objects of research, theory and public debate. In exploring the literature about autism I began to understand how autism has been defined as a social problem by dominant perspectives through a deficit-focused medical model. As I discuss in Chapter 2, much of the available research involving children has focused on diagnosis and remediation. In recent years the focus of research using a medical approach has been on early diagnosis and early intervention. This focus is reflected in the recent Australian autism policy (Australian Government, 2008a) and will be discussed later in this chapter. Less attention has been paid to the full lives of children diagnosed with autism or the issues that are significant for them as they grow older.
A recently emerging body of knowledge within the social sciences has challenged the dominant paradigm. This literature presents alternative ways of understanding autism by drawing on autobiographical literature and social theories (Davidson, 2007, 2008; Dawson, Soulieres, Gernsbacher, & Mottron, 2007). Yet the experiences of children and young people diagnosed with autism are still largely missing from this literature.

In social care research, writers have identified that children and young people diagnosed with autism are rarely involved in research or consulted about their experiences of services (see Beresford, Tozer, Rabiee, & Sloper, 2004; Preece, 2002). Typically when children and young people are seen as a social problem this is a perspective of adult experts who attach labels to them. In this process young children are rarely provided opportunities for choice or contribution (Ho, 2004; Hodge, 2005).

Only a small number of studies were identified that had sought the perceptions of children diagnosed with autism (these are reviewed in Chapter 2). These studies focused on children’s perceptions of specific topics such as school and friendship. These studies tended to use the diagnosis to draw assumptions from children’s contributions about their abilities, competencies and deficits. Little emphasis has been placed on finding out what carrying a label of autism means to young people themselves, how they apply knowledge about their diagnosis to themselves or whether living with such a diagnosis is at all important to them.

The dearth of children’s voices in the literature generally may reflect the limited significance that has been placed on young people’s views about autism. Another reason for this gap is that researchers have struggled to find appropriate ways to be inclusive of young people diagnosed with autism (see Chapter 2). Some researchers have purposely included only the most verbally articulate representatives (for example Carrington & Graham, 2001). Others have reported ethical and methodological challenges which limited the inclusion of less verbally articulate children diagnosed with autism (Beresford, et al., 2004; Preece, 2002). The absence of children’s voices in the autism
literature contrasts with research generally in childhood studies where the focus is on children’s rights to be heard.

1.4.2 Respecting children’s rights

New and emerging research approaches seek to be inclusive of the views and experiences of children in order to shift away from traditional approaches which have excluded children’s voices (for example Davis, 1998; Mason & Urquhart, 2001; Mayall, 2002; Prout, 2002; Prout & James, 1990; Waksler, 1991). A major impetus for this shift was the implementation of the United Nations Convention on the Rights of the Child (CROC) (Lansdown, 2000). The CROC was adopted by the United Nations General Assembly in 1989 and ratified in Australia in 1990. The CROC defines children as people under the age of 18 years and sets out the civil, political, economic, social and cultural rights of this population (United Nations, 1989). The following articles from the CROC are those typically of interest to researchers who seek to take account of children’s views. The convention requires the states or countries that are party to it to:

... assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance and maturity of the child (Article 12(1)).

The convention also requires that:

[t]he child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child’s choice (Article 13(1)).

While the principles of the convention apply to all children, article 23 refers to the rights for disabled and ill children specifically. Article 23 (1) has a particular focus on children’s rights to health care:

State parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.
These principles imply that children and young people are active participants in their lives. They have the right to be involved in decision making that affects them. This acknowledgement has resulted in social researchers increasingly recognising the significance of hearing the views of children and young people and moving beyond adults’ perceptions of children’s lives. This move has been the focus of research applying the concepts central to the ‘new’ sociology of childhood (further details in Chapter 3).

The CROC formally recognises children as a minority rights group (John, 1993). While children were obviously included in the UN Universal Declaration of Human Rights (UDHR) (1948) in terms of their basic rights and needs, the CROC specifies that children have a right to seek information about, and be heard on, issues concerning their lives. This convention has been instrumental in stressing the importance of children’s participation in decision making that concerns their lives. The interest in children’s participation in research has developed as a result of the increasing recognition of these rights. Additionally, researchers in the ‘new’ sociology of childhood acknowledge children as social agents with competence to contribute their views (Christensen & Prout, 2002).

The rights of children and young people diagnosed with autism are now given further emphasis by the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). This convention was adopted by the UN to help ensure that all ‘persons living with disabilities’ enjoy full and equal human rights and basic freedoms. Again, disabled people were essentially protected by the UDHR. However, except for article 23 in the CROC, no other human rights convention specifically mentions disabled people. This has meant that monitoring of their rights and reporting on the application of human rights conventions in local policies has been poor (Disabled Peoples’ International (DPI), 2006). Driven by a socio-cultural perspective on disability, the development of the CRPD promotes respect for the inherent dignity of all people living with disability. In doing so, the CRPD takes a broad approach to disability and embraces civil and political rights as well as the economic, social and cultural rights of disabled people. Article 7 of the CRPD is particularly relevant
to children diagnosed with autism. This article stipulates the rights of ‘children with disabilities’ to enjoy all human rights on an equal basis with other children, the right to ‘express their views freely on all matters affecting them’ and the right to appropriate assistance to realise that right.

1.4.3 Influencing social policy

Australian social policy has ignored children diagnosed with autism until recently. This situation changed in 2008 with the introduction of a new policy ‘Helping children with autism’ (Australian Government, 2008a). This policy has increased awareness around autism, but did so by defining children diagnosed with autism as a social problem. The policy appears to have been guided predominantly by medical assumptions which characterise autism as an especially ‘challenging’ condition (Macklin & Shorten, 2009). The wording within the policy refers to children diagnosed with autism as ‘deficient’ and needy (Australian Government, 2008a). With its focus on remediation and specialised education, this policy document seems to counter the more general Australian policy promoting social inclusion as an explicit social policy goal (Australian Government, 2008b).

One of the main aims of the social inclusion policy is for all Australians to have a voice so they can influence decisions that affect them (Australian Government, 2008b). This aim is in line with international human rights agendas. However, there is a danger that the current Australian policy for children diagnosed with autism (Australian Government, 2008a) will have the effect of marginalising them as subjects that do not have knowledge or views on their lives. The policy can be critiqued using the argument made by Scott-Hill (2002) in relation to disability that the use of unitary discourse in policy and law ‘produces the very subjects it claims to protect or emancipate’ (p. 401). If the policy goal of social inclusion is applied to young people with diagnoses such as autism, their inclusion as subjects of policy is important at the research level.

In summary, three main issues form the rationale for this research. Firstly, the shortage of literature including the views and experiences of diagnosed children and young people helped form the focus of the research. Secondly, children diagnosed with autism have a right to be heard on issues
concerning their lives. This right is determined through two UN Conventions, the CROC and the CRPD. Finally, children diagnosed with autism have long been ignored by Australian social policy. Now that a policy has been developed to help children diagnosed with autism, it is disconcerting that the same policy defines them as a social problem and neglects taking into account their views and experiences. The broad research aim that responded to these issues, and thus shaped the study, was:

To learn about the views and experiences of young people diagnosed with autism using an inclusive research approach.

1.5 Significance of the research

Including the views and experiences of young people diagnosed with autism in research is significant for several reasons. Firstly, this research contributes to the limited literature on the lives of children and young people diagnosed with autism. This research expands existing knowledge in the fields of childhood, disability and autism around children and young people diagnosed with autism by adding the views and experiences of those so labelled. Secondly, in developing an approach that is inclusive of the voices of teenagers diagnosed with autism, the study adds knowledge to the literature on research methodology that takes account of the views of children and young people with a range of abilities and preferences. Finally, and arguably most importantly, by achieving the research aims, the study responds to the rights of children and young people who are diagnosed with autism or otherwise experience disability to be heard on issues that affect their lives. It is my hope that this research will open a space in the literature for hearing the views and experiences of children and young people diagnosed with autism so that their voices can become part of the broader discussion on autism. While I am hopeful that this research will provide input into studies wanting to make contributions to policies for children diagnosed with autism, I also hope this research provides a foundation for studies involving young people from other population groups.
1.6 Structure of the thesis

The thesis is divided into four parts comprising nine chapters. **Part One** forms the background to the study and includes Chapters 1 (this chapter), 2, 3 and 4. In **Chapter 2** I explore different bodies of knowledge pertaining to autism and outline the way medical and social sciences literature has conceptualised autism. I also explore the way researchers are beginning to take account of emic knowledge in personal accounts and autobiographical literature by those diagnosed with autism. The chapter highlights the fact that missing from these personal accounts are the voices of children. **Chapter 3** explores the issue of the limited focus on children’s knowledge in the literature and the challenges reported by previous researchers when trying to include the voices of children with autism in research. The chapter concludes with the specific objectives for this research. **Chapter 4** explores the epistemological underpinning of and the conceptual framework for the study. The chapter outlines key concepts from the constructionist paradigm and the fields of disability studies and childhood sociology. The chapter discusses how these key concepts from childhood and disability theories may relate to researching the lives of young people diagnosed with autism.

**Part Two** of the thesis pertains to the methodology of this study and consists of Chapters 5 and 6. **Chapter 5** outlines the considerations for the methodological approach as drawn from contemporary qualitative research in childhood sociology and disability studies. The chapter discusses how using a collaborative participatory approach is significant for addressing ethical concerns in research with children and young people. **Chapter 6** describes the research design and process including the methods and communication strategies used within a collaborative participatory approach.

**Part Three** of the thesis contains the findings and consists of Chapters 7 and 8. **Chapter 7** reports the findings related to implementing the research approach with teenagers and their parents. **Chapter 8** reports the findings that emerged from directly engaging with individual teenagers. An outline of the key themes is followed by a detailed presentation of the young people’s contributions.
Finally, **Part Four** focuses on the discussion and conclusion of the thesis. **Chapter 9** discusses the findings and the possible implications of this research for education, theory, policy and practice and concludes the thesis with reflections and further questions for this area of research.

### 1.7 Summary

In this chapter I have introduced the doctoral study presented in this thesis and the background for the topic of focus. I have outlined how the research was motivated by my personal experiences and explained how dominant knowledge about autism has been generated within a medical framework, which tends to focus on deficits and as such has framed autism as a social problem. This approach is reflected in new Australian social policy as it begins to focus on children diagnosed with autism. Research taking into account the everyday lives and experiences of children and young people diagnosed with autism is sparse. Despite their right to be heard on issues affecting their lives, little is known about what is important in these young people’s lives or how they experience living and growing up with a diagnosis.

In this study, the premise has been to acknowledge that different types of knowledge about autism exist within various fields because of alternatives ways of generating such knowledge. It is important to engage with these different types of knowledge in order to understand the implications they may have for the lives of children and young people diagnosed with autism. In Chapter 2, I explore the different perspectives on autism that exist in various academic disciplines as well as popular literature and media.
Chapter 2: Mapping literature that conceptualises autism
2.1 Introduction

In Chapter 1 I highlighted how autism is increasingly perceived as a social problem. The tendency of policy makers to rely extensively on medical research on autism was also discussed. The purpose of this current chapter is to map out the existing literature that has influenced the way autism is conceptualised. The literature on autism is rich, voluminous and now spans more than 70 years (see Nadesan, 2005; Wolff, 2004). I have not attempted to be exhaustive in reviewing this literature. Rather, the purpose of this chapter is to present key issues within the extant literature and capture some of the changes that have occurred in literature around autism, especially in recent years. Different literature uses different approaches to producing knowledge. Therefore different literature contributes various perspectives on autism that complement, compete, contrast with or challenge each other. These differences highlight the complexity of autism as a concept.

This chapter has three main sections. The first section pertains to the foci of knowledge around autism research within the dominant medical sciences literature. The second section provides an overview of emerging alternative approaches to understanding autism. Most of this has been produced by social sciences disciplines. The third section maps out the relationships between literature pertaining to personal or emic knowledge of autism and current academic research. Before exploring these sections, I briefly explain how the approaches used to conceptualise autism may differ within literature produced by medical sciences and social sciences scholars.

2.2 Approaches to conceptualising autism

In literature conceptualising autism, medical sciences research and research using the medical model dominate. The medical model uses a positivist approach which can also be defined as an etic or top-down approach (Finch, 1986). Etic views are ‘the views of those with power and access to control the naming process, even when being outsiders to marginal lives’ (Lincoln, 1993, p. 29). These views typically define those with a diagnosis as deficient and as objects of research. Because positivist or etic approaches are most commonly used in the medical and health sciences,
researchers in these fields have a strong influence on public perception and policy making around autism.

Etic approaches to knowledge have traditionally been used in the social sciences. In recent years however, alternative approaches to researching and conceptualising autism have emerged in the social sciences literature. These approaches have highlighted that there are variations to the way autism is identified, perceived, represented and remediated (see for example Foss, 2009; Nadesan, 2005; Silverman, 2008; Waltz, 2005). Some authors even suggest that autism may be performed by those so labelled depending on the context within which they act (Nadesan, 2005). Some researchers using alternative approaches are beginning to pay attention to emic knowledge. Emic knowledge can be described as the insiders’ perspectives or perspectives that are meaningful to the members of a given society (Lett, 1990). Here emic knowledge refers to accounts by individuals diagnosed with autism produced through published literature, as well as those that are accessible through online media. These approaches provide some insiders’ perspectives on autism and present knowledge different from that produced in the more traditional medical sciences literature. Literature pertaining to emic knowledge of autism is presented in Chapter 3. In this chapter I present the literature using mainly etic approaches to conceptualising autism.

2.3 Medical sciences approach to conceptualising autism

The medical sciences took the lead with autism literature and thus have a much longer history than other bodies of literature. Since the 1940s, the medical sciences approach to conceptualising autism has dominated within psychology and education literature. This literature has informed public awareness of and Australian policy on autism (Australian Government, 2008a). Three main topics are evident in the medical sciences literature on autism: 1) the definition and diagnosis of autism; 2) the cause of autism; and 3) intervention strategies to remediate children diagnosed with autism. Each topic has led to ongoing contentions and debates around autism. The disputes in the literature relate to the lack of unambiguous diagnostic categories of the autism spectrum disorders, the
confusion around the notion of autism as a continuum, the lack of a clear cause and the lack of clarity around what constitutes effective intervention programs. The key foci of research and associated controversies are reflected in the following sections.

2.3.1 Definitions and diagnosis

Autism is a label that is applied by specialist practitioners to children whose behaviour is considered socially awkward, inappropriate, stereotyped, repetitive or even dangerous. The language and social skills of these children are described as not matching those defined as normal or typical for children and young people at a similar age (Happé & Frith, 1996; Rutter, 2005b). Current medical literature defines autism as a neurologically based developmental disorder affecting the central nervous system (Happé & Ronald, 2008; Roberts & Prior, 2006). The neurological deficits are thought to influence the way diagnosed individuals process and store information (Frith, 2003; Jordan & Powell, 1995; Wing, 1993, 1996). Several different theories have been attributed to autism since it was conceptualised as a ‘disorder’ in the 1940s, while the construction of autism as a ‘concept’ dates back to the early twentieth century.

Bleuler (1916) derived the word autistic from the Greek word autós, meaning self. Bleuler used the word autistic in his early descriptions of schizophrenia to describe the way his patients withdrew from the external world into a private world during psychosis (Bleuler, 1916). The work of psychiatrist Leo Kanner (1943) and later Hans Asperger (1944) provided the foundation for the diagnoses of autism and Asperger’s syndrome as ‘mental disorders’ separate from schizophrenia. In his paper, Kanner described 11 children who had a distinct preference for being left alone. In discussing his observations, Kanner’s views contrasted with the prevailing psychiatric theories on psychosis. Kanner emphasised that the children were not withdrawing from formerly existing participation. In his opinion, the children shut ‘out anything that comes to the child[ren] from the outside’ from the beginning and whenever possible (Kanner, 1943, p. 242). Kanner described all the children as having a delayed, absent or peculiar spoken language, but noted that eight children
acquired language over time. He also observed that most of the children acquired several normative skills as they got older and typically had strong rote memory.

Hans Asperger (1943) described four teenage boys in similar ways to the children in Kanner’s paper in terms of social interaction and communication. Despite perceiving their speech and social skills as unusual, Asperger did not describe delayed language development or cognitive impairments. In contrast, Asperger described the boys he observed as being ‘very intelligent with extraordinary originality of thought’ (Asperger 1979 in Nadesan, 2005, p. 12). Although Asperger used the term ‘autistic psychopathy’ to describe the boys’ collective characteristics, he understood these as signs of a ‘personality disorder’ (Asperger, 1943). Asperger’s work did not receive much attention beyond Austria until the 1990s, at which time his paper was translated into English and published in the book *Autism and Asperger Syndrome* by Uta Frith (1991).

Lorna Wing (1981a) was the first author to use the term ‘Asperger’s syndrome’ (AS) in the literature. She described children who demonstrated ‘normal’ intellect but had difficulties understanding and relating to others. However, Wing disagreed with Asperger’s classification of the observed characteristics as a ‘personality disorder’. After comparing Kanner’s and Asperger’s work, Wing argued that AS belonged on the autism continuum, but as a separate category. This classification, she argued, would have some value for the diagnosis, management and prognosis of the overall condition (Wing, 1991). Since Wing’s first use of the term Asperger’s syndrome much debate has taken place around defining the exact criteria for diagnosing autism. Uncertainty remains in differentiating the various sub-categories.
2.3.2 Diagnostic criteria

The diagnostic criteria for autism and the definition of newer sub-categories such as Asperger’s syndrome have been the focus of much research and debate (see for example Cohen, 2003; Freeman, Cronin, & Candela, 2002; Gernsbacher, Dawson, & Hill Goldsmith, 2005; Gillberg, Gillberg, Rastam, & Wentz, 2001; Leekam, Libby, Wing, Gould, & Gillberg, 2000; Lord, Leventhal, & Cook, 2001; Lord, Rutter, & Couteur, 1994; Lord, et al., 1989; Mayes & Calhoun, 2001). Disputes remain around the diagnostic criteria. Currently no biomedical markers can confirm a diagnosis. The diagnostic assessment of children is based on developmental history and clinical behavioural observations (American Psychiatric Association, 2004; Klin, Lang, Cicchetti, & Volkmar, 2000). Further, there is not one universally agreed or prescribed set of criteria for diagnosing autism. A range of formal and informal diagnostic criteria exists, which means that a diagnosis largely rests on the judgement of individual clinical specialists.

Typically autism is diagnosed according to a ‘triad of impairments’ (Wing, 1981b). The triad of impairments includes three observable core characteristics. These are:

- difficulty with two-way social interaction (for example, difficulty reading social cues, difficulty understanding jokes and (unwritten) social expectations)
- difficulty with comprehension and use of language (verbal and non-verbal)
- idiosyncratic, repetitive and stereotyped behaviours (for example, flapping arms, spinning or lining up objects), which are thought to substitute difficulties with flexible imagination activities.

The ‘triad’ has been adopted as the basis for most psychiatric diagnostic tools including two formal diagnostic manuals, the DSM-IV-TR (American Psychiatric Association, 2004) and the ICD-10 (10th revision of the international classification of diseases and related health problems (World Health Organisation (WHO), 2007)). The inclusion of autism as an independent disorder in these diagnostic manuals has legitimised it as a distinct diagnostic category.
Autism writers explain that children are diagnosed with autistic disorder or childhood autism when all three core characteristics are observed. They add that these children often present with delayed speech development and a measured cognitive impairment (Attwood, 2007; Jordan & Powell, 1995). To qualify for a diagnosis of Asperger’s syndrome, according to both the DSM and the ICD-10, individuals must not have a history of delayed speech or delayed cognitive development. A diagnosis of Asperger’s syndrome is only given once a diagnosis of autism has been ruled out (American Psychiatric Association, 2004; World Health Organisation (WHO), 2007). Attwood (1998) explained that children are usually diagnosed with autism (or autistic disorder) around the age of two or three years, while Asperger’s syndrome is typically not diagnosed until the child commences school or later in life.

The criteria for diagnosing autism have received much criticism from authors writing within the medical sciences, as well as those holding alternative perspectives. Over the years, clinical problems in diagnostic congruency have arisen when using different diagnostic tools to differentiate between autistic disorder and other categories on the autism continuum (Volkmar, et al., 1994; Woodbury-Smith, Klin, & Volkmar, 2005). Some authors have suggested that the individual criteria of the triad lack clear definition (Alderson & Goodey, 1999). Each criterion gives little exact indication of the level at which a diagnosis is warranted or can be separated from other clinical disorders.

Several authors have suggested that differentiating Asperger’s syndrome from autistic disorder is particularly problematic. For example, Woodbury-Smith and colleagues (2005) reported difficulties in replicating diagnoses of Asperger’s syndrome using the DSM-IV in children already diagnosed using the ICD-10. Allred (2009) asserted that current diagnostic criteria for Asperger’s syndrome ‘lack reliability and measurement validity’ (p.345). Ambiguities exist in the definitions of individual categories and several diagnostic criteria overlap (Allred, 2009). With such ambiguities, there is concern that diagnosis may be left open to interpretation by individual practitioners (Allred, 2009; Frith, 1991).
A range of alternative instruments has been developed to diagnose and differentiate Asperger’s syndrome. These include, but are not limited to, the Asperger Syndrome Diagnostic Scale (Myles, Bock, & Simpson, 2001) and The Asperger Syndrome (and High-Functioning Autism) Diagnostic Interview (ASDI) (Gillberg, et al., 2001). However, in several studies attempts to replicate a diagnosis of Asperger’s syndrome using different instruments have revealed a discrepancy between methods of assessment, showing low agreement between diagnoses of the same subjects (Freeman, et al., 2002; Leekam, et al., 2000; Mayes, Calhoun, & Crites, 2001). Authors have noted that the use of diagnostic tools is at the discretion of the individual practitioners and that some clinicians rely on other means when diagnosing children with Asperger’s syndrome (Klin, et al., 2000; Leekam, et al., 2000).

Some authors question the value of separating out the diagnostic categories. Leekam and colleagues (2000) argued that there is little clinical value in differentiating between autism and Asperger’s syndrome because interventions are the same. They noted, however, that there may be personal or political value in a label that indicates less severe impairments. Other writers have suggested that the value of differentiating is lost over time as the characteristics associated with autism may change with age (Freeman, et al., 2002). For example, differentiating between the categories later in life can be difficult as differences in language and cognition may diminish (Leekam, et al., 2000; Mayes, et al., 2001). Currently the medical sciences literature is divided on whether autism and Asperger’s syndrome are in fact the same or separate diagnoses (Freeman, et al., 2002).

Some authors have argued that the diagnostic boundaries have blurred over time because of the consistent changes to the diagnostic criteria and categories (Gernsbacher, et al., 2005; Nadesan, 2005; Wolff, 2004). Gernsbacher, Dawson and Hill Goldsmith (2005) and Nadesan (2005) outlined in detail how diagnostic sub-categories have been added and individual diagnostic criteria have been loosened in the DSM. These changes have occurred since 1980, allowing more people to be diagnosed (Gernsbacher, et al., 2005; Nadesan, 2005; Wolff, 2004). For example, the 1980 DSM-III
lists the obligatory criteria ‘gross deficits in language development’ and ‘if speech is present, peculiar
speech patterns such as immediate and delayed echolalia, metaphorical language, [and] pronominal
reversal’ (American Psychological Association (APA), 1980, p. 89). In the DSM-IV, these criteria were
replaced with more subtle versions: finding it difficult to ‘sustain a conversation’ or ‘lack of varied ...
social imitative play’ (American Psychological Association (APA), 1994, p. 70). With each revision of
the DSM, it seems the criteria have been loosened and new sub-categories have been added
(Gernsbacher, et al., 2005).

The addition of the term autism spectrum disorders (ASD) reflects this broadening of the diagnostic
categories and loosening of criteria. The term ASD was also coined by Lorna Wing (1981b) to allow
children who did not fulfil all diagnostic criteria to gain access to funding and services (Tongue,
2002). This term has reinforced the notion of autism existing on a continuum with hazy distinctions
between categories. At the same time, relaxing the criteria and adding categories have been
suggested as the main reasons for the upsurge in autism prevalence (Gernsbacher, et al., 2005).
Gernsbacher and her colleagues (2005) pointed out that while children diagnosed with autism using
the early versions of the DSM would still fit today’s criteria, the same would not necessarily apply for
children diagnosed today using the original criteria.

A range of other characteristics is commonly associated with autism in the medical sciences
literature. Many of these characteristics do not necessarily occur in every diagnosed person
(Bogdashina, 2006; Frith, 2003; Jordan & Powell, 1995; Wing, 1993). Characteristics associated with
autism include but are not limited to: sensory hyper- and hypo-sensitivities (for example, dislike or
preference of noise, light, certain tactile experiences, food textures or sounds); lack of eye contact;
lack of joint attention (pointing or showing to share); concrete thought processes; preference for
sameness; and intense interest in certain subjects (Jones, Quigney, & Huws, 2003; Smith Myles, et
al., 2004; Talay-Ongan & Wood, 2000). Some characteristics may be noted equally across the
spectrum. Other characteristics can be observed as weaker or stronger in individuals who are then
classified as being at the higher or lower end of the spectrum. Other characteristics again are observed in children and not in adults, which, as noted earlier, complicates the diagnosis process across the lifespan (Herbert, 2009; Molloy & Vasil, 2002).

In short, a wide range of characteristics is associated with a diagnosis of autism. A lack of clarity continues to exist around the exact diagnostic criteria for autism and associated sub-categories. Although some characteristics may be more common than others, many of these are not part of the formal diagnosis. Some authors have pointed out that so many characteristics are associated with autism that it would be impossible for one person to display them all, and most people in the general population would present with at least one characteristic (Alderson & Goodey, 1999). With this range of characteristics associated with the condition, the complexity in accurately diagnosing autism is perhaps not surprising. Similar complexity exists around finding a cause of autism. The range of characteristics associated with autism is thought to be symptomatic of various underlying causes (Happé, 1999; Happé & Ronald, 2008). The causes associated with autism are the subject explored in the next section.

2.3.3 Causes of autism

Identifying a clear cause of autism has been one of the primary agendas of medical researchers. However, when various theories are discussed in the literature pertaining to a cause of autism, these views are speculative due to the lack of supporting evidence. Early formal theories conceived during World War Two defined infantile autism as a childhood version of schizophrenia, despite Kanner’s insistence that autism was not a form of psychosis. While this definition remained until 1980, during the post-war period the psycho-pathology of autism in children was cited as a result of maternal deprivation (Nadesan, 2005). This understanding was in part based on Kanner’s notes on parents of children with autism as being preoccupied with careers and material things (Wolff, 2004). Later, Bettelheim’s theory of ‘refrigerator mothers’ was outlined in his best seller of the time The empty fortress (Bettelheim, 1967). With this text, Bettelheim had significant influence on the general
understanding of autism. Autism was seen by medical professionals as the child’s form of defence from a negligent mother by withdrawing into a protective shell (Nadesan, 2005; Waltz, 2006). Some authors have suggested that Bettelheim’s professional status as a childrearing authority at the time, and his reputation for ‘curing’ severe autism, allowed parent inadequacy to be accepted as a plausible cause of autism throughout the 1950s and 1960s (DeMaria Severson, Aune, & Jodlowski, 2008; Waltz, 2006). Bettelheim’s theory was eventually discredited with the rise of the cognitive paradigm (Nadesan, 2005). By the 1970s most researchers were beginning to understand autism as a neuro-developmental disorder (Rutter, 2005a).

Cognitive neuropsychology and neuroscience theories formed about the development of the brain became popular in the 1970s. In relation to autism, theories can be traced in articles by Francesca Happé and Uta Frith (Happé, 1999; Happé & Frith, 1996), Simon Baron-Cohen and colleagues (Baron-Cohen, 1999, 2001, 2002a; Baron-Cohen & Hammer, 1997; Baron-Cohen, Knickmeyer, & Belmonte, 2005; Baron-Cohen, Leslie, & Frith, 1985), Michael Rutter (Rutter, 2005a, 2005b) and Lorna Wing (Wing, 1981b, 1993, 1996). Research goals within these sciences have been to identify causal links between biology, cognition and behaviour in diagnosed children, leading to specific theories being developed around how the structure and the function of the brain may relate to behaviour in autism (Happé & Frith, 1996). One theory describes children with autism as having a weak *theory of mind* (TOM), which involves the ability to reflect on the content on one’s own and others’ minds (Baron-Cohen, 2001; Baron-Cohen, et al., 1985). This perspective includes the notion that the autistic mind lacks empathy, such as the awareness and appreciation of other people’s perspectives. This theory has met both support and criticism in the literature. For example, Smukler (2005) and Bogdashina (2006) have potently noted that this theory fails to equally consider the perspective of the person with autism questioning whose theory of mind is more important.

Another theory, the *weak central coherence theory* (Frith, 1989), posited a detail-focused cognitive style in people diagnosed with autism. In the early days, the theory indicated that deficits in central
processing were resulting in failure to extract global information, whereas updated research has indicated that perhaps the focusing on detail is a particular cognitive strength of autism (Happé, 1999; Happé & Frith, 1996; Happé & Frith, 2006). However, despite the advances in neurosciences, researchers have reported that current theory and descriptions of cognition and behaviour exceed identification of specific brain abnormalities (Hill & Frith, 2003). While research has recognised some atypical brain development in some younger children diagnosed with autism, specific patterns of brain development have not yet been identified or related directly to function that can be applied across diagnosed individuals (Happé & Ronald, 2008; Sparks, et al., 2002).

A third theory, the extreme male brain theory of autism (Baron-Cohen, 1999, 2002a; Baron-Cohen, et al., 2005), was formulated on the premise that there are some generalised psychometrical differences in the functions of male and female brains. This later theory by Baron-Cohen built on earlier suggestions by Hans Asperger that autism is an extreme version of the male brain, which has a tendency to be more mathematical and systemising than the female brain. In contrast, the female brain is associated with language abilities, social judgement, empathy and cooperation (Baron-Cohen, 2002a). While this theory has not been refuted or supported, it backs another popular theory that autistic people are best understood as having extreme versions of a brain type that is common in the population at large, particularly among men.

In the past two decades, academic as well as popular literature has linked the onset of autism with a range of systemic and environmental causes. For example, some authors have noted that dietary and metabolic problems are more frequent in children diagnosed with autism (Valicenti-McDermott, et al., 2006). Wakefield and colleagues (1998) suggested that inflammation of the gastrointestinal system was a main contributor to the onset of autism but that the condition was caused by the Measles Mumps Rubella (MMR) vaccination. Their investigation of 12 children was based on reports from parents who stated that their children’s skills and behaviour started deteriorating a few days after the immunisation (Wakefield, et al., 1998). It was noted in the literature that the claims against
MMR immunisations sparked significant public debate about the safety of mass immunisations, causing a decline in MMR immunisations, particularly in the UK (Pareek & Pattison, 2000). Wakefield’s findings have not been confirmed in other research and his study has since been discredited (Herbert, Sharp, & Gaudiano, 2003). Other updated studies have suggested that exposure to mercury can cause immune, neurological, motor, sensory and behavioural dysfunctions similar to traits defining or associated with autism in individuals whose bodies were unable to process heavy metals (Bernard, Enayati, Redwood, Roger, & Binstock, 2001). Biomedical approaches aiming to address toxicity and metabolic problems are commonly discussed in online forums. Anecdotally, some children have been reported to ‘recover’ from autism through the alteration of their diet and nutritional supplements. However, the same interventions seem to have little effect on others. So far no direct links have been established between the cause of autism and specific dietary problems, immunisations or family history of autoimmune disease (Black, Kaye, & Jick, 2002; Farrington, Miller, & Taylor, 2001; Taylor, et al., 2002; Valicenti-McDermott, et al., 2006).

Most recently, medical sciences researchers have focused on identifying a genetic link to autism. Some studies have suggested that siblings of children diagnosed with autism are likely to be diagnosed with Asperger’s Syndrome, PDD-NOS or atypical autism, and that milder symptoms are commonly identified in other family members (Bailey, Palferman, Heavey, & Le Couteur, 1998; Le Couteur, et al., 1996; Piven et al, 1997; Rutter, 2005b). Studies involving twins and several members of families indicate that genetic factors may be influential in the onset of autism (Le Couteur, et al., 1996). However, the genetic involvement is different for each diagnosed person. Currently no complete picture of the biological basis for autism can be established. Studies focused on the genetics of autism have yet to demonstrate that the associated impairments and many varied behaviours can be loaded on a single factor (Happé & Frith, 1996; Happé & Ronald, 2008). Thus, as the cause of autism cannot be pinned on a single theory, the current dominant approach to autism aetiology is that perhaps a number of causes exist of biological, environmental and cultural origin (Happé & Ronald, 2008; Nadesan, 2005).
In summary, there is currently no clear cause of autism. Many theories have been posited in the medical sciences since the 1940s, none of which can explain autism in all diagnosed individuals. While some theories have been discredited, others remain at least as possible explanations for the condition. While autism is still most commonly described as a neurological disorder, current research indicates that autism may have different causes in different people (Happé & Ronald, 2008). Wolff (2004) emphasised that shifts in scientific thinking have influenced cultural beliefs and the way autism has been conceptualised as a disorder. She pointed out that both cultural shifts and research literature have had effects on the interventions and education offered to children with autism. These are the issues to which I now turn.

2.3.4 Interventions for children diagnosed with autism

Identifying interventions and matching them to the diagnosis of autism has been another focus in the medical sciences literature. The interventions developed and applied to children diagnosed with autism have multiplied and changed over the years. Some authors suggest that these changes have occurred according to the shifting theories about the origin of the diagnosis (Wolff, 2004). Until recent years, approaches to intervention were based primarily on notions of cure. However, most interventions have been criticised in the literature. The intervention approaches reported in early medical literature reflect the theory of autism as a shell (thanks to Bettelheim's empty fortress) from behind which the ‘real child’ had to emerge or was to be retrieved (Waltz, 2008). Waltz (2008) noted that some intervention programs have responded to the notions of children diagnosed with autism as ‘wild monsters’, ‘sub-normal’ or ‘less than human’, such as the early versions of Applied Behavioural Analysis (ABA).

The ABA program has been led and promoted by Ivar Lovaas as the only ‘proven’ method to recover children from autism since the early 1970s. The ABA approach is still often claimed to be the most effective for treating and even curing autism and it is widely used (Lovaas Institute, 2005). While it is possibly the most researched intervention approach related to autism, the claim of recovery remains
controversial (Gernsbacher, 2003; Herbert, et al., 2003). Critics note that research claiming promising effects of ABA lack sound research methods to support the approach and that reported improvements are limited to children with less severe impairments (Herbert, et al., 2003). This means that while the ABA approach has been effective in developing social behaviours in some children, the approach may not be suitable or effective for all children (Roberts & Prior, 2006).

The ABA approach has been criticised by autistic self-advocates (Aspies For Freedom, 2004) because of the rigor and time required for a full program (20–40 hours per week), the focus on restricting autistic stimming (non-harmful repetitive or unusual behaviours that individuals have reported to enjoy or find relaxing) and the dehumanising methods used in the earlier versions of the approach. Early methods reported in the ABA approach included aversive treatment of children, such as withdrawing affection, shouting at, shaking, slapping or conducting electric shock therapy to eliminate undesired behaviours and promote compliance (Lichstein & Schreibman, 1976; Lovaas & Simmons, 1969; Risley, 1968). Although contemporary methods of the ABA approach are less callous, the method is still used to discipline ‘undesired behaviours’ such as stimming, rather than to understand the meaning of them. However, the program now also focuses on the development of social skills through intense learning programs (Roberts & Prior, 2006).

Parent writers have also criticised programs based on the ABA approach for their high cost. In online blogs on autism websites, it is not uncommon to read how parents agonise over having to pay out large sums in attempts to help their children. Several authors have voiced their concern for desperate parents who are seduced by promises of costly treatments, such as the ABA approach, that later prove to be ineffective (Herbert, et al., 2003; Wolff, 2004). The treatment intensity required in such programs is relatively expensive, so parents may be left out of pocket without seeing the desired improvement in their child. It is thought that parents of children with autism are more likely than others to try treatments that promise cure. As children diagnosed with autism
rarely look any different from other children, parents are drawn to treatments that promise recovery in the attempt to draw out the ‘normal’ child trapped within (Herbert, et al., 2003).

Other intervention approaches have received similar criticism. Biomedical approaches promoted by organisations such as Defeat Autism Now! (DAN) are one example. DAN is a research and intervention group that trains its own doctors. These treatments are equally expensive as they involve complex testing of the children, programs of food elimination and vitamin/mineral supplementation. Biomedical approaches have been cautioned against in the literature because of the dangerous or fatal side effects that have occurred with approaches involving high amounts of supplements and heavy metal detoxification methods such as chelation therapy (Metz, Mulick, & Butter, 2005; Shannon, Levy, & Sandler, 2001). Many more such treatments can be identified in the literature. Autism has attracted many fad interventions, most of which are promoted on a commercial basis and have little or no scientific study behind them (Metz, et al., 2005).

Other interventions have been developed in response to theories of autism as a neurological developmental disorder. Sensory Integration Therapy (SIT) is commonly used by paediatric occupational therapists with children diagnosed with autism (Schaaf & Miller, 2005). SIT was developed by Jean Ayers (1979) to address underlying neurological impairments that affect sensory-motor skills. The methods involve tactile activities (joint compression, pressure vests and using brushes on the skin) and whole body movements (such as balancing activities, swinging in hammocks and spinning on chairs) designed to stimulate tactile, vestibular and proprioceptive systems in order to improve the child’s capacity for learning new (Herbert, et al., 2003; Schaaf & Miller, 2005). Although some degree of effectiveness of SIT has been reported in over 80 studies, similar to other interventions for children diagnosed with autism most of these studies lack rigorous research methods and the substantial sample sizes required in the medical sciences (Schaaf & Miller, 2005).
Limited evidence exists for the majority of interventions targeting autism. Reports of recovery are typically based on anecdotes (Herbert, et al., 2003). Few treatment methods have produced changes in the core characteristics of autism, although some methods have sometimes shown to improve single symptoms (Roberts & Prior, 2006). For example, some individuals have reported that psychotropic medications may be useful for specific symptoms such as depression and anxiety, although these may or may not be directly related to the diagnosis of autism (Grandin, 1995; Roberts, 2003). Also research has shown that psychotropic medications may reduce certain symptoms in one individual while exacerbating the same symptoms in another (Herbert, et al., 2003).

The main assumption in the medical sciences literature has been that the intervention needs of children diagnosed with autism are somewhat homogeneous, although individuals diagnosed with autism are constructed as occupying a broader spectrum (ASD) of impairments and abilities. Few reviews of autism interventions have found sufficient evidence to support any one single intervention method as the most effective or suitable for all children diagnosed with autism (Perry & Condillac, 2003; Roberts, 2003; Roberts & Prior, 2006). Thus in recent years guidelines have stipulated the need to understand children’s individual needs and abilities.

Detailed guidelines were required for the diagnosis of autism and intervention of young children in the development of the Australian Government’s autism policy (Australian Government, 2008a). Despite the lack of empirical evidence for most of the interventions reviewed, Roberts and Prior’s (2006) review recommended the following guidelines for the management of young children:

- the importance of early diagnosis of children by specially trained professionals and provision for early intervention of very young children
- the need for implementing a range of intervention methods with a focus on the core characteristics of autism, noting the importance of accounting for individual strengths and weaknesses
- the importance of a specialised teaching environment that can deal with the need for predictability and routine, and with challenging behaviour, obsessions and ritual behaviours and an autism-specific curriculum focusing on attention, compliance, imitation, language and social skills (Roberts & Prior, 2006).

The recommendations reflect the medical model’s focus on deficits and the remediation of children, as discussed in the first part of this chapter. The guidelines appear to be in favour of specialist services, special education environments and special education practices. The guidelines contrast with the Australian Government’s more general goal of social inclusion, as the approach in the autism policy risks the long-term exclusion of diagnosed children from the mainstream.

This first part of Chapter 2 has illustrated the approach to constructing autism in the medical sciences literature. This approach has predominantly focused on defining diagnostic criteria, identifying causes and developing interventions for autism. The chapter has highlighted that this literature is fraught with contention and that much uncertainty remains around what actually constitutes the diagnosis, its cause and intervention. This first part of the chapter has also indicated that scientific theory has significant effects on cultural beliefs and consequently the way autism is defined and treated (Wolff, 2004). Currently the medical sciences literature defines individuals diagnosed with autism as deficient and as such they are commonly the objects of research seeking to remediate them. Within this literature, expertise and authority dominate while individual views and experiences, especially those of children, are rarely taken into account.

In the next part of the chapter I turn to the social sciences literature. The attention given to autism within social policy and public debate has meant that social science scholars have increasingly become interested in the topic and are beginning to bring different foci of knowledge to the debate about autism. For example, different views have emphasised the way cultural and political shifts have strongly affected how autism and its boundaries are viewed and the significance of identity
politics in relation to autism as a personal label. The next part of this chapter explores the contribution from the social sciences to the knowledge and perspectives on autism.

2.4 Social sciences approach to conceptualising autism

Only recently has autism received attention from the social sciences. Some of this literature was published during the period of this doctoral research program (2006–2010). The attention of social scientists has been stimulated by the increasing public interest in autism resulting from the number of children being diagnosed. In this part of the chapter I identify the primary theme in the social sciences literature as a critique of the central elements of the medical sciences approach to constructing autism as a disorder (Allred, 2009; Biklen & Kliewer, 2006; Billington, 2006; Molloy & Vasil, 2002; Nadesan, 2008). The main tenet of this critique is the way the medical approach ignores the social context in which certain behaviours manifest and in doing so focuses on deficiencies within certain individual children. Related to this critique are four other themes. The first of these themes identifies the socio-political context in which autism and Asperger’s syndromes became useful labels. The next theme focuses on the socio-cultural aspects of the definitions of the diagnosis and management of autism. The final two themes deal with the role of metaphors in the construction of autism and the children so diagnosed, and how media representation enforces metaphors and stereotypes attached to autism.

2.4.1 Autism as a social construction medicalising children’s behaviour

The social sciences literature has drawn attention to the way autism has been constructed by the medical sciences (for example Allred, 2009; Biklen & Kliewer, 2006; Broderick & Ne’eman, 2008; Molloy & Vasil, 2002; Nadesan, 2005; Waltz, 2005). Within different disciplines, authors have emphasised that autism and the differential categories are not ‘real’ on their own, but are arbitrary constructions that take on the meanings people attribute to them or derive from them (Biklen & Kliewer, 2006; Molloy & Vasil, 2002; Nadesan, 2005). These authors assert that the focus on deficits within medical sciences research and theory has constructed the human differences associated with
autism as disordered neurological development (Allred, 2009; Molloy & Vasil, 2002; O'Neil, 2008). This construction problematises human diversity and places ‘the problem’ on the individual, rather than on social expectations or educational practices (Molloy & Vasil, 2002; Waltz, 2005). Much of this literature has been influenced by the field of disability studies based on the social model of disability (Oliver, 1990), which emphasises the concept of disability as socially constructed.

Disability theory is explored in more detail in Chapter 4, but, briefly, the literature central to the social model distinguishes the characteristics of disability (structural barriers and oppressive social practices or attitudes) as opposite to impairment (physical, cognitive or sensory limitations experienced by individuals) (Goodley, 2001; Morris, 2001a; Oliver, 1990). While individuals may experience personal difficulties, restrictions or pain, disability writers using the social model emphasise that it is typically social barriers and attitudes that disable and exclude them from full participation in society (Oliver, 1996). In terms of autism, some children may have significant sensitivities and impairments that have implications for their responses and behaviour in educational settings. Some authors have suggested, however, that the beliefs and assumptions others draw from the label are often what marginalise children with diagnoses such as autism and Asperger’s syndrome (Alderson & Goodey, 1999; Molloy & Vasil, 2002).

Other authors have described the arbitrary creations of social norms as the main cause of the medicalising of children’s behaviour (Coppock, 2002). Arguments have been made for the need to integrate alternative perspectives into the medical approach to labelling and defining child development (Timimi, 2004). Timimi’s (2004) statement below makes this point clear:

In my clinical practice I often come across children and adolescents who are labelled autistic. When I focus on their abilities I often find much about them that does not fit the autistic discourse. Once I reopen the question of diagnosis many adolescents ask me to officially ‘undiagnose’ them, which their parents are usually very pleased about. ... We can and should do better than this relentless medicalisation of children and must become more competent at integrating medical theory with other perspectives, otherwise we will soon have a grown up generation of children (mainly boys) who have become unnecessarily convinced that they are somehow deficient and incapable (Timimi, 2004, p. 226).
Calls have been made for Asperger’s syndrome to be ‘demedicalised’ in a similar fashion to the gay right activists’ challenge to the medicalisation of homosexuality (Allred, 2009; Aspies For Freedom, 2004). Allred argued that Asperger’s syndrome does not qualify as a category of mental disorders as described within the DSM-IV and ICD-10 because the key definitions for a mental disorder rarely apply to diagnosed individuals. On the basis of such findings, others have questioned whether clinicians in fact use the set criteria when handing down a diagnosis of Asperger’s syndrome, whether they refer to non-clinical literature, or whether they rely on professional assumptions and popular beliefs about the diagnosis (Mayes, et al., 2001).

Another argument relating to the DSM-IV diagnostic criteria for Asperger’s syndrome concerns the fact that these criteria have been defined for younger children (Molloy & Vasil, 2002). Several of the criteria for Asperger’s syndrome are often not met in older children and adults. This change in characteristics over time raises questions about the value of diagnostic criteria. A similar question can be raised in terms of the early diagnosis of children (Herbert, 2009). Although there is general agreement among the medical profession that autism is a lifelong condition, the diagnosis has no formally established trajectory or prognosis. A person simply has to meet the diagnostic criteria for autism at one point in their life time to be labelled. With the uncertainty around diagnostic criteria, Herbert (2009) questioned whether a person who meets these criteria at one point and no longer meets them later in life ‘really’ met the criteria in the first place.

2.4.2 The importance of socio-political context in the construction of autism

A major theme in the social sciences literature associated with its critique of the medical model is the way the construction of autism and the individual sub-categories have been influenced by the contexts in which the medical diagnosis occurs historically, geographically and socially (Alderson & Goodey, 1999; Molloy & Vasil, 2002; Nadesan, 2005; Waltz, 2006). Alderson and Goodey (1999) brought attention to the way formulation of scientific theories is influenced by their time and place. For example, autism was conceptualised during World War Two, when European physicians in
particular were influenced by the Nazi regimen’s obsession with racial hygiene (Alderson & Goodey 1999). In her book, *Constructing autism: Unravelling the ‘truth’ and understanding the social*, Nadesan (2005) provided a detailed outline of autism in historical context as it relates to the history of the specialised fields of psychiatry and psychology. In these fields in the early twentieth century, the definitions of normative child development and the formalisation of standards of normality were the foci. New diagnoses were constructed for those who did not fit within the norms implied by these standards (Nadesan, 2005). Nadesan contended that autism and theories around interventions must be contextualised within an understanding of the part they played in the development of various medical practices and the construction of psychiatry as an authority on child development. In brief, Nadesan suggested that the early definitions of autism as a disorder sprang from, firstly, the focus on autism as a symptom of withdrawal in studies on schizophrenia and, secondly, the focus on intelligence in the definitions of normal child development. Nadesan drew attention to the following statement made by Hans Asperger in 1979 (before the term Asperger’s syndrome was coined), in which he observed that his own research was a reflection and extension of the investigation of children emerging in psychiatry and psychology in the 1930s, but that he felt limited by the focus within his own discipline:

*Let us remember the early thirties. At that time psychological problems in children had become fashionable. Karl and Charlotte Buehler and the pupil Hildegarde Hetzer did some pioneering and fundamental work and Piaget had made himself known. Tests were coming into use for getting to understand anomalies of the intelligence. But none of this helped with the children I am about to describe or clarify. The disturbance was not so much intellectual, but lay more in the child’s relationship with other human beings; in his lack of contact. But at the time this lack of contact was not recognised and it had no name. So how was a doctor trained to observe and categorise, to describe the peculiarities of these children? (Asperger 1979, p. 46 cited in Nadesan, 2005, p. 26).*

Other authors noted that in the post World War Two climate a focus on mental hygiene was prevalent in many countries. This focus turned to childrearing and the bringing up of healthy, normal and resilient children, while maternal deficiency was cited as a primary determinant of psychopathology in children and young people (Coppock, 1997). Within psychiatry, this focus
produced the notions of bad mothering as a cause of autism, as led by Bettelheim (Waltz, 2008). Following mass education and the increasing monitoring of children in the 1960s, parents became more sensitive to and aware of any ‘delays’ in their child’s development (Nadesan, 2005). Thus, Bettelheim’s theory of ‘refrigerator mothers’ reinforced the political agenda of the time. With the rise of the cognitive paradigm and more recently the focus on bio-genetics, the ideas of Bettelheim and others with similar viewpoints were dismissed (Nadesan, 2005).

The distinct value and purpose a diagnosis may have for clinicians, the education system and parents have been highlighted in literature describing autism as a social construction (Molloy & Vasil, 2002; Nadesan, 2005). The value and purpose lie within the context in which these groups operate. When applied to individuals, diagnostic categories provide a lens through which interpretations can be made about the body and mind. Consequently these categories also promote the drawing of assumptions about the lives, experiences, competence and abilities of those being labelled (Broderick & Ne’eman, 2008; Molloy & Vasil, 2002; Nadesan, 2005; Waltz, 2005). Molloy and Vasil (2002) noted that the educational context has particular implications for the diagnosis of Asperger’s syndrome as this diagnosis is commonly prompted by a child entering the education system. The medical model is implicit within special education, where it is typically understood that a child’s poor performance at school is due to an internal problem rather than a result of educational practice (Molloy & Vasil, 2002). Molloy and Vasil suggested that Asperger’s syndrome as a sub-category of autism was conveniently adopted ‘because of its value as a category of special education’ (p.659).

Asperger’s syndrome emerged in the literature as a distinct diagnostic category at a time where, in many countries, specialised education services were undergoing profound changes (Molloy & Vasil, 2002). Molloy and Vasil (2002) noted that at the time schools entered into contractual networking with specialist services such as educational psychologists, occupational therapists and speech therapists, some of whom may have provided parents with the diagnosis of their child. For practical reasons, the diagnosis provided a common language to discuss the child’s ‘needs’ between the
school, parents and various specialist services. Thus, they claimed, the diagnosis worked for the schools’ need to maintain order, for the parents’ need to make sense of their child’s behaviour and for the networking disciplines’ need to have a common language and methodology to support their practice (Molloy & Vasil, 2002). Nadesan (2005) also noted that being able to explain a child’s behaviours through a diagnosis also replaced questions of parents’ moral integrity with a medical pathology, which had the function of transforming parents from being ‘failures’ to being ‘objects of sympathy’ (p. 197).

The significance of the socio-political context of education in the definition of Asperger’s syndrome as a disorder has been highlighted by several authors (Allred, 2009; Molloy & Vasil, 2002). These authors argue that what is perhaps neurological difference has been socially constructed as a neurological disorder. Instead, they suggest, the diagnosis could be seen as a product of inflexible educational practices (Allred, 2009; Molloy & Vasil, 2002). In exploring the social construction of autism further, critics have scrutinised the diagnostic criteria. Rather than providing answers, this has brought about further questions about the socio-cultural context, as highlighted in the next section.

2.4.3 The significance of socio-cultural norms for the construction of autism

As discussed in earlier sections of this chapter, the core criteria for diagnosing autism have been contested within literature produced within the medical sciences because of the ambiguity in their definition and the difficulty this ambiguity then presents for differential diagnosis. The diagnostic criteria have met similar and additional criticism in literature in the social sciences. Some writers have suggested that the ongoing contentions surrounding the origin and diagnostic criteria for autism have made definitions of the diagnosis incoherent (Alderson & Goodey, 1999). Others have highlighted how the inclusion of autism and sub-categories in formal diagnostic manuals such as the DSM-IV provides an idea of an ‘official status’ of that particular definition of autism, which may conceal the lack of agreement about the criteria for diagnosing autism (Molloy & Vasil, 2002, p. 664).
The diagnostic categories are thought to be consequences of the construction of ideal norms from which they may deviate (Biklen & Kliewer, 2006). Biklen and Kliewer explained that socially constructed norms and expectations define acceptable and deviant behaviour but that the boundaries of these may be blurred. Other writers have asserted that particular contexts typically frame ‘abnormality’ as belonging within diagnostic categories. For example, Alderson and Goodey (1999) demonstrated in their study, conducted within segregated and inclusive schools, that ‘autistic’ behaviour could be reinforced or diminished depending on the educational context within which diagnosed children were placed and the assumptions attached to the diagnosis by authoritative adults:

> Autistic tendencies of isolation and self-absorption are more noticeable in the segregating education system itself, which appears to project and enforce these characteristics on to the pupils we observed (Alderson & Goodey, 1999, p. 260).

The idea of autism purely as a disorder has been critiqued as a simplistic view, in that typically a diagnosis is given when there is a focus on deficits rather than abilities (O’Neil, 2008). O’Neil (2008) acknowledged that people diagnosed with autism may experience significant impairments and distress, but pointed out they may also demonstrate superior strengths such as rote learning, visual memory and the ability to focus on details. In her article, which focuses on the strengths of people diagnosed with autism, O’Neil (2008) examined a range of the instruments with which language and intellectual abilities are typically being measured. She argued that these types of tests tend to put less emphasis and value on areas of ability that often are the strengths for children diagnosed with autism, such as those that draw on visual memory, are rule-based or require the ability to be systematic.

The idea that particular measurement instruments underestimate the intelligence of autistic children has been raised by others. Some authors have suggested that the foci of these instruments are perhaps measures of the instruments’ weaknesses rather than that of the children they are used with (Dawson, et al., 2007). When using instruments that do not rely on social interaction between a
child diagnosed with autism and a stranger (the assessor), such as in the commonly used Wechsler scale, individuals diagnosed with autism may test 30 to 70 points higher on levels of intelligence (Dawson, et al., 2007). These differences suggest that perhaps autism involves a different nature of intelligence, rather than a different level of intelligence (Dawson, et al., 2007).

Not all characteristics associated with autism, and Asperger’s syndrome in particular, can be defined as impairment. Some authors have argued that these labels may be better defined as neurological human difference rather than neurological disorders (Allred, 2009; Molloy & Vasil, 2002). Molloy and Vasil (2002) asserted that some characteristics associated with Asperger’s syndrome may contrast with social norms and expectations, but do not necessarily qualify as impairment. For example, one such characteristic is that people diagnosed with Asperger’s syndrome often have a preoccupation with a particular topic or hobby. Although the perseverance of these persons may be seen as strange, even irritating, to some people this characteristic can hardly be defined as impairment, unless it is harmful or injurious (Molloy & Vasil, 2002).

Other writers have noted that spending time on certain particular interests, such as mathematics, solar systems, transport vehicles and plastic bottle design, is considered disordered. In contrast, spending copious amount of time on other interests is not considered unusual, such as passionately following sporting events or the latest fashion trends (Allred, 2009; Baron-Cohen, 2002b). Spending time on ‘unusual’ interests is perceived as particularly disordered in childhood, whereas such specialised knowledge is valued in adult occupations such as engineering, computer sciences and chemistry (Allred, 2009; Baron-Cohen, 2002b; Molloy & Vasil, 2002). These differences attest to the relation between the diagnostic criteria and characteristics that are accepted as social norms and fuel scepticism in the constructionist literature about autism, and especially Asperger’s syndrome, as a medical disorder.

Researchers in the social sciences literature have considered the diagnosis of autism as being ethnocentrically framed and have focused on the meaning of the diagnosis within other cultural
contexts (Daley, 2002; Dyches, Wilder, & Obiakor, 2001; Silverman, 2008). While there is an
acknowledgement within the literature that autism needs to be understood across cultural beliefs
and practices (Silverman, 2008), the literature exploring different cultural perspectives on autism is
still sparse (Dyches, et al., 2001). The existing cross-cultural research on autism is limited as
literature on autism is predominantly written from a Western perspective and provides little
guidance for families facing cultural challenges (Daley, 2002; Dyches, et al., 2001). While
approximately 80 countries have national autism organisations and several other countries have
recorded individuals with a constellation of characteristics that in the Western world is known as
autism, the precise degree of fit has not been explored (Daley, 2002). In her review, Daley noted
several challenges to exploring autism in a cross-cultural context. Firstly, most cross-cultural
research on autism exists in dissertations that have never been published. Secondly, the socio-
cultural frameworks of individual countries differ. Often tension exists between the Western
biomedical systems of medicine and spiritual-religious beliefs within individual countries. Because
autism is presumed to be of biological origin, there is perhaps a perception within Western culture
that the diagnosis will present the same across cultures. However, the degree to which the diagnosis
of autism is consistent internationally is still unclear (Daley, 2002).

The different concepts of health and normalisation apparent between cultures have been shown to
have implications for the diagnosis of autism and subsequent intervention practices (Welterlin &
LaRue, 2007). Welterlin and LaRue (2007) found that characteristics which are typically pathologised
as part of the autism diagnosis in Western societies were not necessarily seen as even unusual in
other cultures, including immigrant families in Western countries. Different perspectives on
normative behaviour determine whether immigrant families seek intervention services for their child
and whether they agree with the type of intervention offered (Welterlin & LaRue, 2007). Therefore
the cultural understanding of symptoms and characteristics associated with autism has implications
for the boundaries between biological and cultural aspects of the diagnosis in terms of service
provision (Daley, 2002; Silverman, 2008).
In this section, I have outlined literature that emphasises the significance of social and cultural norms for the construction of autism. The understanding of autism across cultures is important for the way the diagnosis is portrayed and described in the literature. Within Western societies, metaphors are commonly used to describe people with autism and have implications for the way diagnosed individuals are perceived and treated. The use of metaphors in the construction of autism is the focus of the next section.

2.4.4 The role of metaphors in the construction of autism

The use of metaphors in relation to autism has been significant in the construction of autism as a deviant and perplexing medical disorder. Metaphors have provided linguistic images through which assumptions have been drawn about the person so labelled (Broderick & Ne'eman, 2008; Waltz, 2006). Social sciences writers have noted how in medical (as well as personal) accounts, some of the most powerful metaphors are used to describe autism (Waltz, 2005, 2006b, 2008). Waltz (2006) contended that some metaphors were invented within the medical profession to support theories about the nature and cause of autism. Using a cultural studies framework to analyse case studies, Waltz demonstrated the way authors have manipulated the text with metaphors to construct diagnosed children as ‘others’.

The dominant discourse of autism has been developed from a small set of selected case studies, the most influential being by Kanner (1943) (11 children), Bettelheim (1959) (‘Joey’) and Klein (1989) (‘Dick’). Bettelheim had a particular preference for using ‘emotionally stirring language’ which had dramatic effects on his audience (Waltz, 2006, p. 2). For example, Bettelheim created dehumanising analogies of the boy named ‘Joey’ such as the ‘boy-machine’, a ‘robot’ and a ‘machine-powered body’ (Bettelheim, 1967 cited in Waltz, 2005). In his book The empty fortress, Bettelheim (1967) suggested that autism was a problem within the child, who created a barrier as a means of protection against neglectful or abusive parents (Waltz, 2005, 2006b). Waltz has suggested that despite the now discredited theories of Bettelheim, the metaphor the ‘the empty fortress’ has been
influential in the way other metaphors have been created around autism since then within the medical and popular literature, as well as the media, as listed here:

*These [metaphors] include the essential emptiness, otherness, or non-humanness of people with autism; the idea of a ‘real’ self that is hiding, missing, estranged, or asleep in people with autism; military metaphors; and the concept of autism, or the person with autism, as an enigma or puzzle. (Waltz, 2006, p. 2)*

The use of metaphors creates distortions that function to exert power ‘to include or exclude, to ignore or treat, and even to control or harm, first by positioning autism as a medical condition in need of cure and, second by rendering its “sufferers” less than fully human’ (Waltz, 2008, p. 14).

Metaphors can be found within autobiographical literature and other personal accounts by people diagnosed with autism and their parents. It is likely that some of these metaphors have been created in response to the distorting metaphors in the dominant medical paradigm (Broderick & Ne'eman, 2008; Foss, 2009; Waltz, 2006). For example, it has been suggested that some of the early personal accounts by parents were deliberately phrased in response to the evocative dominant metaphors such as ‘the Fortress’ (Waltz, 2006). The fortress metaphor implied that the child was trapped within him or herself as a result of neglectful parents. This metaphor invited ‘heroic treatment decisions’ to conquer and overcome the barrier of autism (Waltz, 2006, p. 5). The military metaphor used in Clara Claiborne Park’s much debated biography *The siege* (Park, 1967) and the name for a current biomedical research and treatment group ‘Defeat Autism Now!’ (DAN) are testaments to the heroic theme.

Some of the most frequent metaphors used within medical accounts, parent accounts and accounts by people diagnosed with autism have been noted as spatial and based on separateness (Broderick & Ne'eman, 2008). For example, the ‘fortress’ metaphor illustrates a barrier from the ‘real world’. The ‘autistic person as alien’ metaphor invokes images of a person arriving from one world to another entirely different world, where they are perceived as ‘... culturally, neurologically and otherwise different and distinct from dominant neurotypical conceptualizations of “normalcy” …’
(Broderick & Ne’eman, 2008, p. 464). While ‘alien’ metaphors have been used in medical, parental and personal accounts, different meanings have been attached to them. For example, the ‘alien’ metaphor in the parental account by Maurice (1993) illustrated the perception of the child as strange and not belonging to the family. The mother explained that in receiving her daughter’s diagnosis of autism she suddenly found the child to be alien and felt ‘stripped’ of the illusion of having a normal child. Some accounts by people diagnosed with autism have used the alien metaphor in a similar way to illustrate their day-to-day feelings of being excluded, marginalised and discriminated against (for example O’Neill, 1999). Borderick and Ne’eman also noted that most metaphors tend to rely heavily on the binary conceptual divide between ‘normal’ and ‘abnormal’.

In summary, writers have highlighted the significance of metaphors used within various autism discourses based on the medical paradigm. Although theories and definitions of autism have changed over the years, many stereotypes developed as metaphors in early literature still tend to dominate the representations of autism and the understanding of the diagnosis in wider society (Broderick & Ne’eman, 2008; Waltz, 2008). In the next section I discuss social sciences literature that demonstrates the way autism is typically represented in the media and understood in the public domain.

2.4.5 The construction of autism in public representation

There is an increasing awareness among some social scientists that the focus on deficits and the use of dehumanising metaphors in the literature have also dominated the way young people diagnosed with autism are most often portrayed and represented in the media. This has been represented by Jones and Harwood (2009) who, in their analysis of the Australian print media between 1996 and 2005, found the dominating theme to be ‘autism as a problem’ (p. 6). Within this theme, people diagnosed with autism, especially children, were polarised into two main categories, one of ‘dangerous and uncontrollable’, the other of ‘unloved and poorly treated’ (Jones & Harwood, 2009, p. 5). These findings, Jones and Harwood argued, reflect the dominant paradigm’s discourse of
tragedy, incompetency and need for a cure. Jones and Harwood emphasised the lack of helpful information provided in the media portrayals with regard to increasing understanding of the individuality and ‘multidimensional’ lives of individuals diagnosed with autism (p. 15). Their concerns included that the only positive portrayals of people with autism tended to be those that sensationalised savant skills. These portrayals have also been prevalent in the fictional media, such as in the movies *Mercury Rising* and *Rainman*, wherein the person with autism displayed extraordinary skills in providing mathematical calculations and solutions. While the characters in these films were created in consultation with adults diagnosed with autism and their families, the Rainman character was drawn together using the most unusual characteristics from three different individuals to reach an ‘acceptable’ level of otherness (Waltz, 2005).

Today’s media continues to emphasise ‘stereotypes’ of children diagnosed with autism that are essentially created through the medical sciences literature (Bagatell, 2007; Jones & Harwood, 2009). As with disabled children and young people more generally, those diagnosed with autism are likely to be exposed to portrayals suggesting that they are a burden to their families and their community (Jones & Harwood, 2009; Kelly, 2005). These portrayals reinforce the notion for young people that there is a need for ‘curing’ their condition in order for them to lead happy and worthwhile lives (Jones & Harwood, 2009). Thus, such normative accounts may have an effect on the way young people perceive themselves and construct their identity (Bagatell, 2007). Broderick and Ne’eman (2008) have stated that the two main messages represented through the media are that autistic people are Rainman and possess superhuman skills or that autism is a horrifying condition that pushes families to the edge. It is not surprising that many parents opt to support the more negative portrayal as this is what sustains fundraising money. Any positive attention to the diagnosis may take away the public pressure on medical research (Broderick & Ne’eman, 2008).

In short, the main influence in the public representation of autism comes from the focus on deficits and otherness in the medical sciences. While this representation of autism fuels fundraising for the
benefit of children diagnosed with autism, at the same time it may have the effect of disempowering and excluding them from mainstream society. Additionally, a focus on deficits provides a limited portrayal of the lives and experiences of those diagnosed with autism and may negatively affect diagnosed individuals’ sense of self and the way they construct their social identity (Bagatell, 2007). These portrayals are also likely to have implications for the way people understand autism and apply the diagnosis to themselves. The next section of the chapter explores literature that has taken account of knowledge produced by individuals diagnosed with autism.

2.5 Emic knowledge and its relationship with academic literature

Personal knowledge and experiences of autism have been used sparingly in the medical sciences, although at times extracts from personal writings have been used to support or illustrate theories, characteristics and symptoms (for example Jones, et al., 2003; Jones, Zahl, & Huws, 2001). The narration of experiences is a literature phenomenon to which social sciences scholars from various disciplines have very recently started to pay attention (Davidson, 2007; Davidson & Smith, 2009; Foss, 2009; Nadesan, 2005; Waltz, 2005). However, as pointed out by several authors, the already existing multitude of personal accounts continues to increase, which makes it difficult, if not impossible, to conduct a complete review of this literature. Analyses of selected autobiographical accounts and personal blogs in online autism communities have been carried out by a small number of authors. I draw on these analyses for the next two sections. In the final section I look at the limited research that has sought directly the views of people diagnosed with autism.

2.5.1 Autobiographies and published accounts

The insiders’ experiences of living with autism have largely been provided through non-academic emic literature such as book-length narratives of living with autism by diagnosed individuals, predominantly adults, or parents of diagnosed children. Such narratives have multiplied at an astounding rate over the past 30 years. These are not to be confused with the numerous guidebooks
on autism written by professionals for a non-professional audience, in which authors sometimes claim to have a knowledge of autism that positions them as authorities on the topic (Smukler, 2008).

The role of published autobiographies has been significant in developing the social and cultural understanding of individuals diagnosed with autism (Hacking, 2009). Third-person accounts written by parents and occasionally by other family members emerged in 1967 with Park’s landmark account *The siege* (Park, 1967). This book drew much attention as it was the first non-medical account of autism. First-person accounts by people diagnosed with autism began with *Emergence: Labelled autistic* (1986) by the now internationally renowned author and cattle yard designer, Dr Temple Grandin. Grandin’s book was similarly remarkable as it provided the first understandings of how autism was experienced ‘from the inside’ (Hacking, 2009). Hacking (2009) has suggested that personal accounts have provided a way of describing insiders’ experiences for which there was no language previously. At the time of Grandin’s first published account there had been no previous insider’s narrative of autism, as the medical dogma for decades had understood those labelled as autistic to lack inner life (Hacking, 2009).

Analyses of autobiographical accounts have highlighted that some individuals diagnosed with autism have described social experiences and interactions with others as different and sometimes difficult (Davidson & Smith, 2009; Williams, 2004). Some examples include, ‘feelings of distance from others’ or a ‘sense of alienation’; the need for social ‘coping strategies’ or ‘coping and controlling emotion and space’; a ‘desire to connect with others’ but ‘inaccessibility to social and emotional cues for interaction’; and ‘difference in emotional expression’ as well as ‘perceptual differences and sensory distortions’ (Davidson, 2007; Davidson & Smith, 2009; Williams, 2004). A wider ‘more-than-human’ world is described in some accounts of social experiences. These experiences included particular emotional connections with animals, trees, plants and rocks rather than people (Davidson & Smith, 2009). These experiences indicated a particular openness to seeing and hearing a more nuanced visual and auditory world through the use of a wider register of senses.
The descriptions above contrast with notions of autistic people as lacking inner life and emotions. Rather they indicate that perhaps it is what is understood as ‘typical lives’ that may be restricted (Davidson & Smith, 2009). Davidson and Smith (2009) have noted that the social experiences described within such accounts may add to notions of difference and otherness, but assert that they challenge the dominant understandings of sociality and the popular ideas of autistic people as non-social beings. While the behaviour of people diagnosed with autism is often dismissed as bizarre and pathological by others, it makes sense in context of their perceptually overwhelming worlds (Davidson & Smith, 2009; Williams, 2004).

Traditional medical definitions of autism are sometimes challenged through the experiences described by authors of autobiographies. For example, several authors have described a strong desire to communicate and connect with others (Davidson, 2007; Davidson & Smith, 2009; Williams, 2004). Others have expressed the importance of and flair for storytelling and imagination (Hacking, 2009). These are characteristics not typically associated with autism. In fact, the first contrasts with the core notion of autism as being the withdrawing from social contact. The second is in conflict with one of Wing’s criteria for the ‘triad of impairments’, which stipulates a lack of imagination as an explanation for stereotypical behaviour (Hacking, 2009). These findings show the potential of emic knowledge to expand and change the way autism is conceptualised and understood if included in academic literature.

In contrast to adult accounts, few personal accounts are written by children and young people. One exception is Luke Jackson’s *Freaks, geeks and Asperger syndrome: A user guide to adolescence* (Jackson, 2002). Jackson wrote his book at the age of 13, having accepted the diagnosis of Asperger’s for himself, and his book addresses other young people who are learning about having a diagnosis of Asperger’s syndrome. While Jackson draws much on medical terminology and definitions of Asperger’s syndrome, he adds his own views and experiences on significant topics such as finding
out about having a diagnosis, dealing with challenges and his everyday relations with family and friends.

Experiences of childhood and youth are more often provided retrospectively in personal accounts written by adults who have accepted the label of autism. Retrospective accounts of childhood and adolescence are more likely to focus on particular events rather than overall everyday life experiences. Arguments have been made elsewhere about the differences between memoried childhood and the present experiences of being a child (Oakley, 1994). These events are interpreted through the eyes of the adult in light of later acquired knowledge and new experiences. This idea was noted by Grandin (2005) in the second edition of her book Emergence: Labelled autistic:

*Today my childhood memories are like a rich tapestry. I can still picture some parts of the fabric quite well. Other parts are faded. The incidents I recall tell a fascinating story on how autistic children perceive and respond in unusual ways to the strange world around them ... (p. 11).*

Grandin and other adult authors tend to look at their childhood through an autism lens, focusing on incidents of divergence rather than on their lives in general. While the experiences of adults with autism have contributed considerably to the understanding of the diagnosis, childhood sociologists emphasise the importance of listening to children’s own views and experiences of their lives (for example Alderson, 2001; Fattore, Mason, & Nixon, 2005; Prout & James, 1990). Significant changes have also occurred in society in the past 20 years, which means that children’s experiences today are likely to vary somewhat from those 20 to 40 years ago. Additionally, more public awareness exists about autism per se than when Grandin and other adults first wrote about their experiences; most people have now at least heard the term autism. Advances in technology have made significant differences to the way children gain information and socialise with others (Prout, 2005). Thus to understand the lives of children and young people today who have been diagnosed with autism, it seems imperative to learn directly from their experiences.
Analyses of published accounts and autobiographies also suggest that a shift has occurred between 1967 and 2007 in the way authors living with autism position themselves in narratives about autism (Foss, 2009). Foss (2009) has suggested that patterns of early narratives reflected medical definitions of autism at the time. These were the definitions influenced by Bettelheim’s theories. The early narratives moved writers from living in the darkness of autism towards a brighter position connected with recovery or cure. In later narratives, the writers’ positions move from unknown feelings of otherness to discovery of autism through diagnosis; thereafter, difference is accepted as a fundamental part of self (Foss, 2009). The shift in the writers’ positions between early and later accounts is more marked in the autobiographical accounts than in parental accounts. Early parental accounts described despair as the child was diagnosed and used metaphors that indicated the child was stolen away or locked inside a shell from which he or she needed to be recovered. In later accounts, some parents describe an acceptance of the child and the diagnosis, although some parents still express hope for improvement in the child’s condition and recovery from autism. Foss (2009) has suggested that the shift in the writers’ positions is perhaps a reflection of changing political and cultural contexts related to autism in the past decade and the emergence of international autism communities. In all research articles cited above, the authors tend to acknowledge that there is an emerging autistic culture which promotes and supports self-advocacy and with which many diagnosed adults are now identifying. With this culture, other ways of conceptualising autism are emerging. In the next section I explore how the literature has taken account of the personal narratives by those diagnosed with autism rapidly emerging online.

2.5.2 The autism community and online culture

Blogs and discussions in online communities have become an important aspect of contemporary emic knowledge on autism. In recent years social sciences writers have begun to pay attention to the discourse around autism that is emerging in cyber-space (Broderick & Ne’eman, 2008; Brownlow & O’Dell, 2006; Davidson, 2008; Foss, 2009; Jones, et al., 2003; Jones, et al., 2001). Early discussion forums within internet advocacy groups were initiated by parents of children diagnosed with autism
and professionals specialising within the field. These advocacy groups have been concerned with creating awareness of autism in the wider society, providing mutual support for parents of children diagnosed with autism and raising funds for interventions and cure (for example Autism Speaks, 2009). More recently autism-specific websites and blogs in virtual internet communities have opened up a public (cyber-) space for diagnosed individuals to share their experiences and life stories informally. Early use of such internet blogs was predominantly by diagnosed individuals to describe their inner selves and the way they experienced the world through having autism. Many of the described sensory and perceptual experiences were perceived as being different from the norm (Jones, et al., 2003; Jones, et al., 2001). As such the early use of the internet was similar to autobiographical material albeit not formally published. More recently, individuals diagnosed with autism have claimed these communities as their rightful place to contribute their views and knowledge (Davidson, 2008). For these individuals, writing to share their experiences of and reflections on learning and living with autism has become widespread practice. As navigating the numerous personal as well as community websites dedicated to the discussion of autism is a huge undertaking, I draw key points from research that has examined online writings related to autistic culture.

Online autism communities have become popular for several reasons. Firstly, the ease of access to the internet has made autism websites and personal blogs common spaces for members of autism communities to air their knowledge and perspectives, as well as to connect with similar others (Broderick & Ne'eman, 2008; Brownlow & O'Dell, 2006; Davidson, 2008). Using a critical geographical approach, Davidson (2008) found that a virtual community allows members to circumvent the geographical constraints of the material world, but also to characterise it and to assert some agency in defining their own position within it. As such the community and their members are mutually constitutive. Secondly, authors have noted that the internet appears to be particularly suited to accommodate people on the spectrum who dislike direct interaction
(Brownlow & O'Dell, 2006; Davidson, 2008). Additionally, distinctive Autistic\(^2\) styles of communication are present online and the internet has the facility to bring together Autistics in groups which may help them to claim a voice in society (Brownlow & O'Dell, 2006; Davidson, 2008).

Many people diagnosed with autism discuss their lives and identities online in chat groups and forums. These individuals have their own agendas and use insider jargon (Brownlow & O'Dell, 2006). In browsing through autism websites, it is clear to see how Autistic self-advocates and other members of their communities use this online space as a medium to unite internationally and discuss their agendas. Through the analysis of postings in a chat group over a period of four months, Brownlow and O'Dell (2006) identified two major themes. First, the people in the chat group were relatively knowledgeable about research on autism, but they often questioned the usefulness of much scientific research in relation to their own lives. There was a tendency to prioritise first-hand knowledge over scientific knowledge held by professional clinicians and academics. At the same time, obtaining a diagnosis from a professional was important. The second theme evolved around distinguishing between people diagnosed with autism (AS) and ‘neuro-typicals’ (NT=non-autistics).

To most individuals, accepting a diagnosis for oneself was important. Brownlow and O'Dell found that there was general consensus in the group that AS people are significantly different from NT people: ‘The difference is seen as real, and weight is given to the position by reference to neurology’ (Brownlow & O'Dell, 2006, p. 318). For self-advocates in these community groups, using the label ‘Autistic’ is typically a political choice. The label is powerful in constructing an identity of self as different from social norms, and its purpose is to emphasise difference as positive and taking pride therein. There was a tendency from some chat room members to construct NT in a negative light in contrast to the positive attributes of being AS. While these expressions were not necessarily aimed at ‘NT bashing’ (Brownlow & O'Dell, 2006, p. 319), members stated that in order to accept themselves as AS they needed to understand exactly how they differed and find the positive aspects of these differences.

\(^2\) Capitalised to reflect the terminology preference of self-advocates within the Autism Community.
Currently tension is rife between various online advocacy groups and organisations around what the most important agenda is for people with autism (Broderick & Ne’eman, 2008). In recent years, the debate has polarised between autism advocacy groups on the basis of whether they are ‘pro-cure’ or ‘anti-cure’ (Broderick & Ne’eman, 2008). Members of one of the dominant autism communities, the US-based Autism Speaks!, are predominantly ‘pro-cure’. This advocacy group has developed into a major charity organisation asserting to be the voice of autism. The organisation is run by medical professionals and parents, with the aim being to raise funds almost solely for the prevention and cure of autism (Autism Speaks, 2009). Members of the self-advocacy movement have challenged the ‘pro-cure’ view on autism as a disorder that needs to be eliminated. One of the cornerstones of the movement is ‘No need for a cure’ (Aspies For Freedom, 2004; Broderick & Ne’eman, 2008). These individuals emphasise autism as a fundamental part of their self-concept rather than a ‘hindrance to a more normal life and self-realization’ (Foss, 2009, p. 2). For those who see autism as part of their identity, a cure would mean the destruction of their original persona (Broderick & Ne’eman, 2008).

There are now a growing number of self-advocacy organisations challenging the cultural dominance of ‘pro-cure’ organisations. Self-advocates contend that ‘pro-cure’ organisations appear to run scare campaigns about autism for their own benefit.

The single most important contribution of the self-advocacy movement is said by some authors to be the concept of ‘neuro-diversity’ (Broderick & Ne’eman, 2008). Ne’eman, an academic Autistic self-advocate, President for the Autistic Self-Advocacy Network (ASAN) and Asperger autistic defined ‘neuro-diversity’ as an ‘idea that asserts that atypical (neurodivergent) neurological development is a normal human difference that is to be tolerated as any other human difference’ (p.470). The hope expressed by the ASAN president was that the counter narrative within the Neuro-diversity movement may promote more inclusion of personal knowledges on autism within public debate and policy (Broderick & Ne’eman, 2008).
The views of the ‘Neuro-diversity movement’ have been criticised by other online autism communities. Some writers criticise ASAN for talking exclusively on behalf of adults diagnosed with Asperger’s syndrome or High-functioning variety of Autistic disorder. These writers consider that ASAN is ignoring the problems experienced in families where children may have more significant impairments (for example Doherty, 2009). In autism blogs, some parent advocates have also suggested that the neuro-diversity view is ideological and may have the effect of depriving diagnosed children of treatment. With the ‘Neuro-diversity movement’, self-advocates argue for a social understanding of autism as human difference rather than the medical definition of autism as a disorder (Broderick & Ne’eman, 2008). Broderick and Ne’eman (2008) have suggested that if ‘autism as neuro-diversity’ was a more culturally dominant metaphor than ‘autism as disease’, it might inform differently the development of socio-political decisions related to appropriate responses to autism.

While the concept of ‘neuro-diversity’ is mostly discussed within autism communities, the construct of ‘neuro-diversity’ is beginning to capture the interest of writers in different academic fields (Baker, 2006; Brownlow, 2010; Fenton & Krahn, 2007; Jurecic, 2007; Ortega, 2009). The neuro-diversity construction is said to produce a discourse of otherness, which involves self as other from notions of social norms, and neuro-typicals as other from notions of autistic norms. Acknowledging ‘neuro-diversity’ as a concept defining neurological human difference may have wide ranging implications for the construction of autism (Brownlow, 2010).

So far I have looked at how research on personal experiences with autism has been produced through the analysis of commercially published autobiographies and texts publically available online. Some authors have argued that these methods of analysing written accounts are more suitable in understanding autistic experiences because several individuals who self-identify as autistic have expressed a preference for communicating in text (Davidson, 2007). The limitation of these analyses is that autobiographical accounts by people diagnosed with autism are typically by those who write
and like writing. These individuals have the resources and abilities to express their knowledge and experiences in a written medium. Those who do not fall into this group are still excluded from being heard. Only a few autobiographies are by people with more significant cognitive and communication impairments. Such texts were not included in any of the located analyses. The use of informal communication styles also means that the lives of these individuals are usually interpreted through parental accounts.

Similar limitations apply to the accounts by children. Some autism websites have allocated specific forums for children and young people diagnosed with autism. These are predominantly provided for young people to connect with one another, but otherwise seem to have little influence on agendas within the individual communities. In fact, one of the ongoing debates online remains as to who is better equipped to speak on behalf of autistic children: their parents or autistic adults. To this point I have not located research taking significant account of emic knowledge by children and young people such as Jackson’s book or online accounts. Additionally, there is limited research that includes persons diagnosed with autism as participants in order to learn directly about their lives. Such research is the focus of the next section.

2.5.3 The direct inclusion in research of people diagnosed with autism

Only a few studies have sought accounts directly from individuals diagnosed with autism. Of 11 publications located for this review, six included adults (Cesaroni & Garber, 1991; Hurlbutt & Chalmers, 2002; Portway & Johnson, 2003, 2005; Sperry & Mesibov, 2005; Volkmar & Cohen, 1985). Five publications focused on children. These are more recent and will be reviewed in more detail in Chapter 3. This dearth is surprising as researchers have been fascinated with what goes on in the minds of individuals diagnosed with autism since the conception of the diagnosis (Cesaroni & Garber, 1991; Volkmar & Cohen, 1985). However, while early researchers were interested in the ‘experience of autism’ through first-hand accounts, this interest was mainly manifest in the use of personal accounts to draw conclusions about functioning and prognostics in relation to those
diagnosed. In this section I outline how early studies have mainly employed etic approaches to researching personal experiences, while the views of individuals included in research have been considered valuable knowledge only in more recent studies.

The general perception in the medical sciences has been that those labelled autistic have little to offer about their diagnosis (eg. Cesaroni & Garber, 1991). The dearth of available research may be understood as a result of this perception. While the researchers in early studies acknowledged the value of first-hand accounts in developing an understanding of the experience of autism, they focused on identifying characteristics of autism and presented the participants as clinical case studies (Cesaroni & Garber, 1991; Volkmar & Cohen, 1985). Participants’ scores on clinical assessment tools and developmental history were presented along with detailed descriptions of their behaviours and impairments. Volkmar and Cohen (1985) presented a three-page life recount by a 31-year-old male, which details his personal thoughts, emotions and difficulties, but equally outlines experiences of being excluded and discriminated against. The focus of the authors, however, was less on the experiences of the participant and more on how to determine diagnostic and prognostic indicators of autism from his account. Cecaroni and Garber (1991) focused their study on learning about their participants’ perceptions of characteristics such as ‘memory’, ‘sensory processing’, ‘social interaction’ and ‘stereotypical behaviours’. Although the authors pay much attention to their participants’ own experiences and descriptions of these characteristics, assumptions drawn from the interviews about the functioning of their participants are scattered through the text and often generalised to the population of people diagnosed with autism. It can be argued that in these early studies participants were objects to be analysed rather than people with knowledge to contribute. More recent studies recognise the value of knowledge about autism held by individuals and the importance of the meaning their experiences bring to the autism discourse (for example Hurlbutt & Chalmers, 2002; Portway & Johnson, 2003, 2005).
Where there has been research on ‘experiences of autism’, it has typically focused on individuals described as ‘higher functioning’ and has mainly included those able to articulate their experiences through verbal or written accounts (Cesaroni & Garber, 1991; Hurlbutt & Chalmers, 2002; Portway & Johnson, 2003, 2005; Sperry & Mesibov, 2005). Some authors have conceded that the ‘linguistic and cognitive deficits of such persons generally preclude clinicians and investigators from having direct verbal access to their experiences’ (Volkmar & Cohen, 1985, p. 47). Consequently, few studies have included the experiences of autism by individuals with cognitive and communication impairments.

All five publications located for this review focused predominantly on the challenges encountered by individuals diagnosed with Asperger’s syndrome or those understood as having higher functioning autism. As with Cesaroni and Garber’s (1991) study, findings in most studies were generalised to the sample, if not to the entire population. Common findings were reported in these studies. For example, many participants were reported to experience feelings of being different from others and not fitting in. Problems with social interactions often involved misunderstanding and being misunderstood by others (Cesaroni & Garber, 1991; Hurlbutt & Chalmers, 2002; Portway & Johnson, 2003, 2005; Volkmar & Cohen, 1985). Reportedly, many participants experienced bullying, ridicule and exclusion leading to feelings of loneliness and depression. Thoughts and attempt of suicide were mentioned by a number of participants, especially young males (Portway & Johnson, 2003, 2005; Volkmar & Cohen, 1985).

Most adults in these studies reflected on the teenage years and transition into adulthood as being particularly challenging. Some of the reasons involved increasing self-awareness as well as increasing academic and social demands (Hurlbutt & Chalmers, 2002; Portway & Johnson, 2003, 2005; Volkmar & Cohen, 1985). Some difficulties associated with autism had persisted into adulthood: for example, social interaction remained especially difficult, including developing and maintaining romantic relationships. Some individuals had made a conscious decision to live alone while others remained hopeful of finding a partner (Hurlbutt & Chalmers, 2002). Common misunderstandings of the various
relationships that also exist in a work environment had made obtaining and sustaining employment difficult, despite individuals holding adequate technical and academic skills (Hurlbutt & Chalmers, 2002; Sperry & Mesibov, 2005).

Some authors described the challenges and difficulties experienced by participants as risks associated with having an ‘invisible disability’ (Portway & Johnson, 2003, 2005). The authors highlighted that people diagnosed with Asperger’s syndrome do not appear obviously different to others but that they ‘don’t quite fit in’. They also suggested that risks of anxiety, depression and suicide were increased when a diagnosis was not obtained until later in life because the ‘unique’ needs of the diagnosed person are not met.

Adults in all four studies expressed frustration with expectations that they had to change themselves in order to fit into society. The participants explained how they were typically expected to change or suppress certain behaviours, while also learning suitable social and communication skills. Many participants felt that efforts of mutual understanding were not proportionate. Some of the adults interviewed noted that although people with autism are reported to lack empathy and the ability to understand others’ viewpoints, they rarely experienced others as trying to understand their point of view (Cesaroni & Garber, 1991; Hurlbutt & Chalmers, 2002).

Adults in one study expressed a wish to be involved in decision making on issues related to autism as they felt they had experiences and expert knowledge to impart (Hurlbutt & Chalmers, 2002). These adults noted that few people make an effort to really listen to and understand the perspectives of individuals diagnosed with autism. This view is reflected in the way some researchers draw assumptions from personal accounts about the individual abilities of people diagnosed with autism. This notion is equally true about children and young people.

In general, children tend to be seen as less competent and therefore less knowledgeable than adults. This view has particular relevance for autistic children. Their views are largely absent in both the
medical and social sciences literature, as well as within the written work of different autism advocacy groups. It is only in very recent years that researchers have sought to involve children diagnosed with autism in research. The studies located for this thesis are reviewed in Chapter 3.

2.6 Summary

This chapter has mapped out the literature on autism across the medical and social sciences literature. In mapping out this literature, it was evident that while autism has a long documented history it has predominantly been conceptualised through etic knowledge generated in the medical sciences literature. This chapter has highlighted the ongoing conflicts in the medical sciences literature around identifying a cause of autism, definitions of the criteria for diagnosis and the development of interventions. It also pointed to the fact that, in spite of these conflicts, the medical sciences continue to dominate policy and public debates on autism in Australia.

Social sciences researchers have provided alternative approaches to conceptualising autism. These approaches have challenged the way autism has been defined traditionally by emphasising that the diagnosis is a social construction which emerged as a result of specific social and political contexts. Social sciences writers have also shown that diagnoses of autism and its criteria have changed over time and are influenced by changing socio-cultural norms. These changes add to the notion of autism as a social construction.

Emic literature has provided another approach to conceptualising autism, identifying how diagnosed people themselves understand autism. This chapter has shown that emic knowledge exists mainly in the form of grey literature, such as autobiographies and other publically available emic accounts. Additionally, only a few research studies are available that have sought the views directly from those diagnosed with autism. Early research on the ‘experiences of autism’ took an etic approach to knowledge, with the researchers as experts placing their own interpretation on the lives and experiences that those diagnosed with autism shared with them. Some very recent studies have begun to acknowledge the importance of the views of those diagnosed with autism. As yet, these
studies have had little impact on the way autism is conceptualised in medical sciences literature and public policy.

Even more recent has been attention by researchers to children’s knowledge and experiences of autism. While researchers have begun to analyse adult accounts for the benefit of academic literature on autism, few researchers have paid attention to the knowledge and accounts provided by children and young people. In Chapter 3 I focus on children and young people diagnosed with autism and review in detail studies involving them as participants. I also outline the research aims and objective for this study.
Chapter 3: Research on views of children diagnosed with autism
3.1 Introduction

In the previous chapter I highlighted how etic and emic knowledges have contributed different constructions of autism. The chapter highlighted that the views and experiences of children and young people were rarely a part of these constructions. As this chapter will show, the views of children with autism have only been included in the literature in very recent years and examples are therefore still sparse.

The views and experiences of children and young people diagnosed with autism are of particular interest to my PhD research. In this chapter I provide a review of the extant research that has sought the experiences of children and young people by involving them directly in research. Firstly I outline methods used to identify relevant studies. Thereafter I provide an overview of the key characteristics of the studies, followed by a critical analysis of the research trends and approaches used to involve children and young people. The analysis shows that, despite attempts by researchers to understand the lived experiences of children and young people diagnosed with autism, etic research approaches predominate in most of these studies. These approaches seem to influence the extent to which the views of children have been included and heard. Finally I outline the implications of existing studies for developing the focus and methodological approach for my research. The chapter concludes with a statement of the research question and aims of the project.

3.2 Identifying research inclusive of children diagnosed with autism

A comprehensive search of the literature was conducted in early 2006 at the outset of this PhD program and repeated on several occasions during that year. The aim of these searches was to identify research literature that included the subjective views and experiences of children and young people diagnosed with autism. Therefore the searches focused on qualitative research.

Initial literature searches included various combinations of the following terms: autism? [autism, autistic], Asperger(‘s) AND child? [child, children], teenage(r), adolescence,
adolescents], young people, youth AND view(s), experience(s), perspective(s), perception(s), account(s), insider, ‘lived experience(s)’, inclu? [including, inclusion, inclusive], consult? [consulting, consultation(s)], involv? [involve, involving]. Additional terms were added in later searches, including qualitative AND research, methods, methodology. The main databases searched included Google Scholar, ProQuest and PubMed. Detailed hand and online searches were conducted of autism-specific journals and journals focusing on children and disability issues.

Five publications were identified from the initial 2006 searches (Beresford, Tozer, Rabiee, & Sloper, 2004; Carrington & Graham, 2001; Carrington, Papinczak, & Templeton, 2003; Carrington, Templeton, & Papinczak, 2003; Preece, 2002). Three publications reported on two studies that included young people diagnosed with Asperger’s syndrome (Carrington & Graham, 2001; Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003). The other two publications (Beresford, et al., 2004; Preece, 2002) focused on methodological issues in including children diagnosed with autism in social care research. The latter studies had implications for developing the methodological approach used in my research, which I discuss later in this chapter.

In October 2009 the search strategy was repeated, yielding four new publications (Beresford, Tozer, Rabiee, & Sloper, 2007; Howard, Cohn, & Orsmond, 2006; Humphrey & Lewis, 2008; Huws & Jones, 2008). One of these later publications (Beresford, et al., 2007) reported findings linked with one of the previously identified studies on methodology (Beresford, et al., 2004). As these publications were located after the completion of the current study, they did not influence the development of the research questions or design. However, I mention these new publications here because some of the themes they report on have relevance for the findings of my research. Additionally, these recent studies have doubled the extant literature which indicates that there is an increasing interest in research focusing on the views and experiences of children and young people diagnosed with autism. The next sections outline and discuss in more detail the publications located for this review.
3.3 Overview of reviewed studies

The results of the literature search show that research taking account of the views of children and young people diagnosed with autism is recent and sparse. The nine publications identified for this review reported on seven studies that included children and young people diagnosed with autism (Beresford, et al., 2004, 2007; Carrington & Graham, 2001; Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003; Howard, et al., 2006; Humphrey & Lewis, 2008; Huws & Jones, 2008; Preece, 2002). Earlier studies were conducted in three countries, with the same authors listed on several publications. Since 2006, studies including children and young people diagnosed with autism have been conducted and reported on more frequently and by a wider range of researchers.

In reviewing these nine publications, I have summarised their individual research characteristics in a conventional manner in Tables 3.1, 3.2 and 3.3. The tables show individual study designs, sample sizes, participants and the reported key findings. Table 3.1 illustrates three early publications reporting on two studies about the perceptions of school, friendships and social relations by teenagers with Asperger’s syndrome. Table 3.2 outlines two publications focusing on methodological issues in including children with autism in social care research. Table 3.3 provides details of the four recent publications that were located after the completion of the project. In the next sections I present my critical analysis of the research approaches used in these nine publications.
### Table 3.1 Publications reporting on the perceptions of teenagers with Asperger’s syndrome

<table>
<thead>
<tr>
<th>Authors</th>
<th>Research focus</th>
<th>Participants</th>
<th>Research design &amp; methodological approach</th>
<th>Reported key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carrington &amp; Graham 2001 Australia</td>
<td>Challenges faced by children diagnosed with AS and their mothers</td>
<td>Two boys (13 yrs) and their mothers</td>
<td>Qualitative Inductive–descriptive Case studies Semi-structured interviews</td>
<td>[Findings from parents and teens reported together, but more parents’ views]</td>
</tr>
<tr>
<td></td>
<td>Selection criteria: Ability to talk about their experiences and their diagnosis</td>
<td>Consent from parents and teenagers</td>
<td></td>
<td>Parents described teenagers as:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• having developmental differences from a very young age</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• having specific social and communication problems which were associated with AS.</td>
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<td></td>
<td>• having obsessions with special interests</td>
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<td></td>
<td></td>
<td>• needing routines in everyday life</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• using ‘masquerading’ (presenting a ‘normal’ facade) to cope with own social deficits and</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>to fit into peer group</td>
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<td></td>
<td></td>
<td></td>
<td>Teenagers talked about:</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• the importance of particular interests</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• difficulties finding friends</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• stress related to social and academic demands at school</td>
</tr>
<tr>
<td>Carrington Templeton &amp; Papinczak 2003 Australia</td>
<td>Perceptions of friendship by teenagers diagnosed with AS</td>
<td>One girl, Four boys (15–18 yrs)</td>
<td>Interpretative sociology – Phenomenology Multiple case studies Semi-structured interviews</td>
<td>Teenagers with AS are described as:</td>
</tr>
<tr>
<td></td>
<td>Selection criteria: Ability to talk about their experiences and their diagnosis</td>
<td>Consent from parents and teenagers</td>
<td></td>
<td>• having difficulty describing their understanding of friendship and what is a friend</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• having less difficulty describing what is not a friend and what is an acquaintance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• using ‘masquerading’ as described in 2001 study</td>
</tr>
</tbody>
</table>

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3 AS= Asperger’s syndrome
<table>
<thead>
<tr>
<th>Authors</th>
<th>Research focus</th>
<th>Participants</th>
<th>Research design &amp; methodological approach</th>
<th>Reported key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carrington, Papinczak &amp;</td>
<td>The social worlds of five adolescents with AS</td>
<td>As above</td>
<td>As above</td>
<td>Teenagers described:</td>
</tr>
<tr>
<td>Templeton 2003</td>
<td></td>
<td></td>
<td></td>
<td>• social experiences</td>
</tr>
<tr>
<td>Australia</td>
<td></td>
<td></td>
<td></td>
<td>• satisfaction with current friendships</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• hostile encounters with peers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• use of ‘masquerading’ as in previous publications</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Teenagers described as:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• not comprehending ideas of friendship</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• having limited social interaction with friends outside of school (reasons not explored)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• developing friendships around shared interests</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>• common targets of bullying</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• unwilling to break (school) rules for the sake of making friends</td>
</tr>
<tr>
<td>Authors</td>
<td>Research focus</td>
<td>Participants</td>
<td>Research design &amp; methodological approach</td>
<td>Reported key findings</td>
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<td>--------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Preece 2002</td>
<td>Consultation with children diagnosed with autism about their experience of short-term residential care</td>
<td>Three boys aged 7, 12 and 14 attending short-term respite care in same centre</td>
<td>Qualitative</td>
<td>The consultation process:</td>
</tr>
<tr>
<td>UK</td>
<td>Focus on: The effectiveness of the consultation process</td>
<td>Also Parents of participants, teachers, respite staff (number not stated)</td>
<td>Case studies</td>
<td>• Open-ended questions not suitable</td>
</tr>
<tr>
<td></td>
<td>The child’s ability to participate</td>
<td>Consent from parents, assent from individuals</td>
<td>Semi-structured interviews</td>
<td>• Visual methods strengthen communication</td>
</tr>
<tr>
<td></td>
<td>The child’s experience of short-term care</td>
<td></td>
<td>Observations</td>
<td>• Need for triangulation (other informants)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Individual communication strategies</td>
<td>• Need for individualisation (No single method suitable for all children)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Parent interviews</td>
<td>• Relevance of questions to children important for engagement</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Teachers’ notes on interviews and observations</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Staff File Notes</td>
<td></td>
</tr>
</tbody>
</table>

- **The consultation process:**
  - Open-ended questions not suitable
  - Visual methods strengthen communication
  - Need for triangulation (other informants)
  - Need for individualisation (No single method suitable for all children)
  - Relevance of questions to children important for engagement

- **The child’s ability to participate:**
  - Impairment in social interaction -
    - Aloofness (not engaging)
    - Social anxiety (in interviews) shortened consultation time
  - Children were calmer when with known persons
  - Impairment in communication -
    - Limited and idiosyncratic use of language
    - Phenomenon of recency
    - Poor memory
  - Need for routine -
    - Dislike of change and choices

- **The child’s experience of care:**
  - Importance of consistency in approach taken across care environments
  - Staff familiarity with child important for positive care experiences
<table>
<thead>
<tr>
<th>Authors</th>
<th>Research focus</th>
<th>Participants</th>
<th>Research design &amp; methodological approach</th>
<th>Reported key findings</th>
</tr>
</thead>
</table>
| Beresford Tozer    | Developing an approach to involving children with ASD$^4$ in a social care project | 26 families recruited from social care service, 5 children interviewed (4 diagnosed with autism, 1 with AS) 16 other informants (teachers and mental health professionals) Consent from parents and children, assent assumed where consent not deemed appropriate | Mosaic approach. One semi-structured interview each with parents and other informants Observations of children in school settings One semi-structured interview with children, use of social stories and poster making activity using photographs taken by child | Focus on methodology:  
- Parental gate keeping reduced number of children interviewed  
- Some children reluctant to participate  
- Nature of autism complicates research more than with other groups  
- Open-ended questions unsuitable  
- Need to restrict conversation to here and now  
- No single method suitable for all children  
- Need for flexibility and willingness to adapt and change aspects of the research project to accommodate participants  
- Researchers reported a struggle with the flexibility needed to be inclusive of all children  
- Social story with photo was useful to inform children of visits  
- Poster making useful for interaction with four children  
- Time and resources needed to be inclusive of all children |
| Rabiee & Sloper    |                                                                                  |                                                                              |                                                                                                         |                                                                                                                                                      |
| 2004 UK            |                                                                                  |                                                                              |                                                                                                         |                                                                                                                                                      |

$^4$ ASD= Autism Spectrum Disorder
Table 3.3 Overview of recently published studies

<table>
<thead>
<tr>
<th>Authors</th>
<th>Research focus</th>
<th>Participants</th>
<th>Research design &amp; methodological approach</th>
<th>Reported key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Howard Cohn &amp; Orsmond 2006 USA</td>
<td>The experience of friendship</td>
<td>One boy (12 yrs, 8 mths), diagnosed with AS, and his mother</td>
<td>Qualitative Grounded theory Single case study</td>
<td>Qualities of friendship described as:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Home schooled</td>
<td>Two semi-structured interviews with child, using items (unspecified) from a youth survey(^5) and friendship scale(^6) as guide for interviews</td>
<td>• Shared interests and proximity</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Consent from child and parent</td>
<td></td>
<td>• Mutual help and support</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Caring and responding</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>• Forgiveness</td>
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<tr>
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<td></td>
<td>• Reciprocity</td>
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<tr>
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<td></td>
<td>• Negotiating focused interests in friendships</td>
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<td></td>
<td>Support of family:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Parent facilitates friendships (rather than prohibiting and monitoring)</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>• Parent provides advice on being a good friend</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
<td>• Brother identified as best friend</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Friendships are desired and enjoyable</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Wanting to connect with peers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Willing to learn social interactions</td>
</tr>
</tbody>
</table>

\(^5\) Youth Quality of Life Instrument-Research Version (Patrick et al., 2002)

\(^6\) Friendship Qualities Scale (Boivin et al, 1994)
<table>
<thead>
<tr>
<th>Authors</th>
<th>Research focus</th>
<th>Participants</th>
<th>Research design &amp; methodological approach</th>
<th>Reported key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beresford, Tozer</td>
<td>Exploring desired outcomes [of social care services] for children and adolescents with ASD</td>
<td>See 2004 study</td>
<td>See 2004 study Further comments on methodology:</td>
<td>[Parents’ desired outcomes reported in much detail] Children’s desired outcomes:</td>
</tr>
<tr>
<td>Rabiee, Sloper</td>
<td>Focus on positive aspects of their lives</td>
<td>Additionally 12 teenagers in a therapeutic discussion group</td>
<td>• Children with autism have different capacity for expressing desires and aspirations</td>
<td>Mental health (one person only):</td>
</tr>
<tr>
<td>2007</td>
<td></td>
<td></td>
<td>• For some children questions about desires and aspirations are meaningless</td>
<td>• Desire not to be bullied</td>
</tr>
<tr>
<td>UK</td>
<td></td>
<td></td>
<td>• Lack of adequate communication makes accessing views about abstract or future issues difficult</td>
<td>Safety:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sense that repeat visits would have provided fuller picture of children’s lives and aspirations</td>
<td>• Wanted to be able to deepen friendships</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Wanted to feel able to cope with new situations</td>
</tr>
<tr>
<td>Humphrey, Lewis</td>
<td>The views and experiences of pupils with AS on mainstream education</td>
<td>20 pupils (11–17 yrs)</td>
<td>Transformative framework, interpretative phenomenological approach</td>
<td>School and academic achievements:</td>
</tr>
<tr>
<td>2008</td>
<td></td>
<td>Drawn from four schools, individually approached and invited after consent from school and parents</td>
<td>Semi-structured interviews Pupil diaries (for a month) Pupil drawings (incidental by one participant who enjoyed drawing)</td>
<td>• Mixed feelings about school</td>
</tr>
<tr>
<td>UK</td>
<td></td>
<td></td>
<td>Interview schedules sanctioned by participants</td>
<td>• Place for socialising rather than academic attainment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Wanting to do well academically</td>
</tr>
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<td></td>
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<td></td>
<td></td>
<td>Friendships:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Important and desired part of life</td>
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<td></td>
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<td></td>
<td></td>
<td>Interests and favourite activities:</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td>• Important part of life</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Important for experiencing success, achievement and feeling valued</td>
</tr>
<tr>
<td>Authors</td>
<td>Research focus</td>
<td>Participants</td>
<td>Research design &amp; methodological approach</td>
<td>Reported key findings</td>
</tr>
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<td>-------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Huws &amp; Jones</td>
<td>Young people’s view on their diagnosis</td>
<td>9 college students (16–21 yrs, 3 females, 6 males)</td>
<td>Interpretative phenomenology Idiographic analysis</td>
<td>extra support accentuated their differences)</td>
</tr>
<tr>
<td>2008 UK</td>
<td></td>
<td>Drawn from one college for young people diagnosed with autism</td>
<td>One semi-structured interview with each participant</td>
<td>• Negotiating difference (most participants felt different from others, context is important to whether difference is accepted and rejected)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Purposive selection: Individuals with HFA(^7) or AS able to verbalise experiences of being diagnosed</td>
<td></td>
<td>Themes:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Verbal and written consent from students</td>
<td></td>
<td>• Delay between time of diagnosis and disclosure to young person (time of non-awareness)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Diagnosis providing explanations of previous life events (explaining difficulties and difference)</td>
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<tr>
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<td></td>
<td>• Positive and negative effects of labelling (understanding/discrimination)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Diagnosis causing disruptions and providing opportunities (disruption of plans/access to services)</td>
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<tr>
<td></td>
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<td></td>
<td></td>
<td>• Acceptance and avoidance of diagnosis</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Call for further exploration around disclosure of diagnosis and effects of diagnosis</td>
</tr>
</tbody>
</table>

\(^7\) HFA=Higher Functioning Autism
3.4 Critical analysis of research seeking the views of children diagnosed with autism

The studies identified for this review are significant in that they recognise the importance of involving and focusing on children in research literature about autism. In analysing the significance of this focus I link my analysis with the discussion in Chapter 2 about etic and emic approaches to the production of knowledge. Recapping from Chapter 2, etic approaches to knowledge production have been dominant in the literature about autism and the children so labelled. Etic research presents the views of those in power as expert knowledge. In terms of knowledge about autism as discussed in Chapter 2 and this chapter, etic views about children tend to be those of professionals, particularly medical researchers and, in recent research, parents, teachers and diagnosed adults. Emic knowledge refers to knowledge held by person(s) in question – the ‘insider’s view’. Emic research approaches take account of individual views and experiences. In research with children, an emic approach requires adult researchers to not only focus on children’s views but also to recognise children as experts in their own lives (for more detail, see Chapter 4). This last point is central to the analysis presented in this chapter.

The broad aims of the identified studies were to explore ‘insiders’ experiences’ and to present the views of children. To achieve these aims the researchers used qualitative methodologies with somewhat different interpretative frameworks. As I examined these studies, I explored the approaches to knowledge making that characterised them and which seem to influence the findings produced. Despite the attempts in these studies to understand children’s experiences, etic approaches were dominant. There was a tendency to privilege adults’ views over those of children. Children’s views were often obscured by adults’ views, both those of the researchers and sometimes those of the parents.

The following key characteristics identified etic approaches to research across the studies. Firstly, there was a reliance on medical definitions of autism in all the studies. Secondly, there was a distinct
tendency to limit research to include young people who were able to verbally articulate their experiences. Only two studies sought to include children with a broader range of cognitive and communication abilities (Beresford, et al., 2004, 2007; Preece, 2002). Where children with more diverse abilities were included, researchers were confronted by methodological challenges. Thirdly, in some studies there was a focus on children’s perceptions on topics defined by adults as problematic for children diagnosed with autism, such as friendship and school. The focus of research varied across the studies and two studies focused on particular contexts about which children were consulted. One study consulted children on their experiences of respite care, while the other consulted children and adults on their desired outcome of social care services. In the more recent studies, it appears that researchers have attempted to move towards an emic approach in the way they include and present the views of children and young people diagnosed with autism. For example, a later study focused on young people’s views on and experiences related to having a diagnosis of autism. In the sections below I outline these research characteristics in more detail.

3.4.1 Medical definition of autism dominant in research with children

The medical definition of autism dominated research literature located for this review, especially the early studies. As outlined in Chapter 2, the way autism is defined in the medical sciences carries particular assumptions about those diagnosed. These assumptions may have consequences for the way diagnosed people are viewed and treated. In the paragraphs below I show how the dominance of the medical conceptualisation of autism in these studies had implications for the interpretation of children’s views and sometimes for the practical aspects of the research process.

Early studies tended to focus on ‘deficits’ associated with autism. The children and young people involved were characterised primarily in terms of impairments and characteristics associated with autism. Four studies focused on children’s perceptions of topics that were presumed to be particularly problematic for those diagnosed with autism, such as friendships and school (Carrington & Graham, 2001; Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003; Humphrey
& Lewis, 2008). The researchers in these studies seemed to assume that children’s lives were predominantly challenging and that any problems experienced by young people were associated with their diagnosis. These assumptions were also reflected in the way findings were presented.

The findings in early studies typically centred on identifying deficits rather than understanding meanings in the responses from the young people. For example, the overall aim of Preece’s (2002) study was to understand young people’s experience of respite care, but the article focused predominantly on how autism may affect the consultation process. Some of the themes in that study were titled ‘aloofness’, ‘social anxiety’, ‘limited and idiosyncratic use of language’ and ‘poor memory’. Preece deemed some children’s responses to be ‘factually incorrect’ as they did not correspond with adults’ responses. He also stated that the children had poor memory as they did not seem to recall recent activities or people at the respite centre. In other literature, however, researchers have suggested that children and young people in general may place importance on different aspects of events than adults (Beresford, 1997). Beresford (1997) noted that while young people may recall events differently to what adults expect, this difference does not invalidate their responses or make their recollection inaccurate.

Children’s responses to research questions were frequently interpreted and presented as examples of ‘deficits’ even in studies attempting to use sociological interpretations. For example, Carrington and colleagues (2003) suggested that ‘the adolescents’ words in this study indicate a lack of insight into what constitutes friendship and a general difficulty in using and understanding the language to describe friendship issues’ (p. 216). These authors also stated that they were ‘speculative of the nature of friendships described’, although the participants named friends and described activities they engaged in together (p. 216). This statement implies that young people’s views were not taken seriously. From their findings, these authors generalised that ‘they [individuals with Asperger’s syndrome] do not seem to comprehend the nature and reciprocity of friendship’ (p. 216).
Generalising statements were frequently made about individuals diagnosed with autism. Although most researchers acknowledged that people diagnosed with autism have individual differences, there was a tendency to generalise characteristics across the population. For example, in drawing on previous research, Preece (2002) stated that people with autism ‘have little intrinsic motivation to communicate or interact’ and ‘difficulties comprehending abstract concepts such as emotion, space and time’ (p. 98). Other researchers generalised characteristics from their own findings to populations of those diagnosed with autism. For example, Carrington and Graham (2001) stated that ‘children with Asperger’s syndrome tend to be egocentric’ (p. 41), while Howard and colleagues suggested that young people’s social deficits are characterised by ‘a lack of social or emotional reciprocity’ (Howard, et al., 2006, p. 619). Some researchers acknowledged that ‘true generalisations’ of their findings were not possible because of the small sample sizes. In one study, a specific attempt to make ‘fuzzy generalisations’ was made in place of ‘true generalisations’ (Preece, 2002, p. 101). Generalisations can be problematic in qualitative research. They tend to create collective notions of people’s lives and topics explored, with little consideration for their experiences as being individual or contextual (Greenwood & Levin, 2008). Greenwood and Levin (2008) suggest that taking a positivist approach to generalisation is to ‘lose sight of the world as lived in by human beings’ (p. 73).

The focus on deficits and the tendency to generalise suggest that some of these researchers held preconceived assumptions about children and young people diagnosed with autism. Such preconceptions have implications for the way young people’s voices are heard and understood. However, few researchers acknowledged up front how their own assumptions might influence the research process or their interpretations of children’s views. One exception was a study by Howard and colleagues (2006). These authors noted how their own expectations of early adolescence as a particularly challenging time for someone with autism had possibly influenced the way they interpreted their data. In the other studies these assumptions were merely implied through the way autism was conceptualised in the focus of research.
The methodological approaches used to research the views of children also highlighted the dominance of the medical definition of autism. In most studies, those unable to verbalise their views or considered ‘lower functioning’ were excluded (see Section 3.4.3). In two publications, the research was designed with particular considerations for the characteristics associated with autism (Beresford, et al., 2004; Preece, 2002). For example, Preece (2002) suggested that the research process would be affected by Wing’s ‘triad of impairments’, the children’s lack of intrinsic motivation to communicate and interact, and their difficulty in comprehending abstract concepts. In addition to these issues, Beresford and her research team (2004) anticipated that children diagnosed with autism would be more reluctant to participate than other children. Thus, as a part of their preparation to consult children diagnosed with autism, Beresford and colleagues undertook courses to learn more about the characteristics of the diagnosis.

In both of the aforementioned studies, the methods for data collection were selected based on the impairments and characteristics associated with autism. Preece used visual communication resources such as photographs and pictures during observations and interviews. Beresford and colleagues considered the concrete and literal cognition style and strong visual skills associated with autism. They also considered how the children would respond to abstract questions about their lives, desires and aspirations.

In their considerations for the diagnosis, Beresford and colleagues used the Mosaic approach\(^8\) (Clark & Moss, 2001) which was designed to consult very young children on their experiences in day care facilities. They asked children to take photos of people and places that were significant in their lives. These photographs were then used in a poster making activity to facilitate communication with the children. Before the interviews, a story illustrated with photos was sent to each of the families to inform children of the upcoming visits. In accordance with general assumptions about children diagnosed with autism, the methods and strategies used in both studies had the potential to engage

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\(^8\) The Mosaic approach includes a range of methods (observations, interviews and drawings) and participants (children, parents and day care staff) to achieve an all-round picture of children’s lives in day care.
some children in research. However, the explicit focus on the diagnosis also influenced the expectation of these children as somewhat homogenous in terms of participation. This expectation seemed to be partly responsible for methodological challenges encountered in being inclusive of the children’s views. These challenges are described in Section 3.4.3.

The interpretation of children’s abilities and responses purely through a diagnosis invariably reinforces the medical construction of autism and objectifies children. As shown in the paragraphs above, the medical definition of autism dominates most of the studies reviewed to date. The way these studies focused on impairment as the primary cause of social problems had implications for the way participating children were included in research and how their views were understood and presented. Typically, this approach resulted in a focus on impairments and seems to be based on the assumptions that challenges arise from the diagnosis of autism and that the diagnosis affects all aspects of individuals’ lives. Even in later studies, which were less focused on defining deficits, similar underlying assumptions seemed to imply that the lives of children and young people diagnosed with autism are necessarily challenging (Howard, et al., 2006; Humphrey & Lewis, 2008; Huws & Jones, 2008).

The approaches used in the studies reviewed indicate that research about children diagnosed with autism is not following developments in contemporary research with disabled children more generally (see for example Connors & Stalker, 2007; Davis & Watson, 2000; Kelly, 2005; Morris, 2003; Priestley, 1998). Impairments and challenges may well be part of the everyday experiences for children diagnosed with autism. However, explicitly presenting young people diagnosed with autism in this way and drawing generalisations from these presentations negates the purpose of seeking insider experiences. Billington (2006) argues that studies that follow such ‘models of social deficit’ are presumptuous and ‘impaired in their ability to conceptualise individual experience’ (p. 2). Perceptions are likely to differ between researchers and their participants. However, it is imperative not to confuse these differences with impairments when seeking the experiences of individuals with
diagnoses such as autism (Billington, 2006). A deficit approach places constraints on the understanding of diagnosed children as people with individual experiences, views and feelings.

3.4.2 The foci in studying children’s lives

The lives of children diagnosed with autism have been researched in two ways. First, many of the studies reviewed for this research focused on specific topics to which children were asked to respond. In five studies, researchers assumed that because of their diagnosis the children would have different, unusual and even impaired perceptions of topics such as school and friendship from those of others without a diagnosis (Carrington & Graham, 2001; Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003; Howard, et al., 2006; Humphrey & Lewis, 2008). Second, previous research has focused on particular social services or contexts that have direct implications for children’s lives and on which children and young people were consulted for their views and experiences. In two studies, children and young people were consulted on their experiences of respite care (Preece, 2002) and their desired outcome of social services (Beresford, et al., 2004, 2007). I explore these two foci of research below.

Specific topics

The approach to researching children’s perceptions of specific topics reflects how medical definitions of autism are dominant in currently available research about the lives of children so diagnosed. Because social situations are commonly understood as particularly problematic for children diagnosed with autism, the assumption is that these problems are caused by impairments associated with a diagnosis. Of the publications located for this review, five focused on young people’s perceptions of friendship (Carrington, Templeton, et al., 2003; Howard, et al., 2006), school (Carrington & Graham, 2001; Humphrey & Lewis, 2008), and social experiences related to friendship and school (Carrington, Papinczak, et al., 2003). Difficult experiences with friendship may indeed be commonplace for children diagnosed with autism. However, assumptions that difficulties rest purely on the diagnosed individual add to generalised notions about their inability and unwillingness to
socially interact with others as described in the observations of children discussed in Chapter 2. In terms of school, issues related to academic and social matters are typically perceived as problematic for young people diagnosed with autism and Asperger’s syndrome. In the past decade, the practical inclusion of children and young people diagnosed with autism in mainstream schools has been a complex and much discussed issue (see, for example, Alderson & Goodey, 1999; Barnard, Prior, & Potter, 2000; Biklen & Kliewer, 2006; Cooney, Jahoda, Gumley, & Knott, 2006; Ochs, Kremer-Sadlik, Solomon, & Gainer Sirota, 2001). The increasing number of children and young people who are diagnosed with autism has implications for both mainstream and specialised educational institutions. However, by looking at the issues related to social interaction and school in isolation, the broader and varying contexts of children’s lives are ignored.

One of the later studies focused specifically on young people’s views on and experiences related to having a diagnosis of autism (Huws & Jones, 2008). While still being focused on a narrow aspect of the young people’s lives, this study brought up some important issues around the understanding of autism by those so labelled. It also highlighted the implications for some young people when a diagnosis of autism is disclosed to them. These issues have relevance for findings in my study and will be discussed later in the thesis.

Within most of the current research, lingering assumptions imply that the lives of young people diagnosed with autism are mostly homogenous and that the same issues are of importance to all. These assumptions persist despite the acknowledgement of diversity among diagnosed individuals. Asking children to respond to specific topics sets parameters to what they can talk about. There is a lack of research taking account of the broader lives and experiences of the children and young people who are labelled with autism.

**Consultation with children and young people**

Two of the reviewed studies sought to consult children on their views of social care. These UK-based studies were conducted on the principle that children who receive services from a social services
department should be consulted on their views of these services in accordance with the *UK Children Act 1989* (Department of Health, 1997). The inclusion of children’s views in UK-based social service development is reflected in the increasing research that now focuses on children as direct participants (more details in Chapter 4). One study focused on children’s experiences of short-term respite care (Preece, 2002). Another study was concerned with the desired outcomes of social care services by children and their families (Beresford, et al., 2004, 2007). The latter was part of a larger project that included groups of children with other impairments as well as chronic health issues. These studies were significant for several reasons. Firstly, while children diagnosed with autism are commonly consumers of health services, it is rare that these children are consulted on the services they access (Beresford, et al., 2004; Preece, 2002). Secondly, these studies moved beyond asking children to respond to specific topics. Finally, these studies explicitly considered methodological aspects of consulting young people diagnosed with autism, including those with more complex impairments. These studies highlight that inclusive research with children and young people with more complex impairments challenges positivist or etic research approaches. The last point is significant in that current research seeking the views of children diagnosed with autism has mostly been limited to include those who communicate verbally.

### 3.4.3 Research focuses on young people who communicate verbally

Most of the reviewed studies focused on young people diagnosed with Asperger’s syndrome or those diagnosed with autism who were considered to be ‘higher functioning’ and able to communicate verbally (Carrington & Graham, 2001; Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003; Howard, et al., 2006; Humphrey & Lewis, 2008; Huws & Jones, 2008). Authors provided different reasons for focusing on these populations. For example, Humphrey and Lewis (2008) argued that these young people are increasingly identified in mainstream education but not always included in schools in ways that are in their best interest. In most studies, however, participants were selected if they were able to articulate their views and experiences in a semi-structured interview (Carrington, Papinczak, et al., 2003; Carrington, Templeton, et al., 2003). Huws
and Jones (2008) purposively selected such participants on the premise that ‘higher functioning’ individuals were more likely to have the ‘memory’ and ‘cognitive capacity’ to recall their experiences.

Two studies included children with a broader range of cognitive and communication abilities, as mentioned in the previous section (Beresford, et al., 2004, 2007; Preece, 2002). Preece’s (2002) study included three boys diagnosed with autism (aged 7, 12 and 14) attending the same short-term respite care centre. One of these boys was described as having ‘severe learning disabilities’, no speech and ‘extremely restricted’ communication (p.98). The other two participants were described as having some speech but using other communication resources. Beresford and colleagues (2004) involved 26 parents and 16 other informants but only gained access to interview five children. In this study, the young people were described as having special learning needs but the authors made clear that none of the children had severe learning difficulties. As noted earlier, in both studies efforts were made to engage children by using research methods and communication strategies considered suitable for children diagnosed with autism. Both studies also included parents and other informants as a means of producing a wider understanding of the children’s lives and experiences. However, in both studies methodological challenges were encountered in attempting to engage the children in research. Descriptions of these challenges were helpful in the planning of my own study.

Particular ethical and methodological challenges to attaining the views of children with more complex impairments in research were reported by Preece (2002) and Beresford and colleagues (2004). Preece suggested that ‘the characteristic impairments of ASDs impacted upon all three children’s abilities to participate in the consultation process’ (Preece, 2002, p. 101). More specifically, Preece expressed the view that limited speech, limited social interaction with others and social anxiety during consultation presented barriers for the children’s participation. Beresford and colleagues found that parental gate keeping reduced the number of children interviewed. Some
children were also said to be anxious and reluctant to participate. Only five children from a possible 26 were involved directly.

In the study by Beresford and colleagues (2004, 2007), the children were found to have different capacities for expressing desires and aspirations. Some children were described as lacking adequate communication which made accessing views about abstract or future issues difficult. For some children, questions about desires and aspirations seemed to be meaningless. In both studies, children were found to have difficulties with open-ended questions and making choices. Taking together the challenges described above, Beresford and colleagues suggested that researching with children diagnosed with autism was more problematic than with other groups of children in their study, including those others not using speech for communication. The research team suggested that traditional approaches to research may not be appropriate with children diagnosed with autism due to the complex nature of the diagnosis (Beresford, et al., 2004).

What ended up happening in the project reported in this paper was that different research questions and methods were used with the children with autistic spectrum disorders compared with the other groups of disabled children taking part. Taking this approach can feel like going against all that is taught about the qualities of ‘good research’, where consistency of method and research tools within a research project is advocated. However, there is a balance to strike between ‘methodological rigour’ and facilitating the direct participation in research by the groups who are the focus of the research (Beresford, et al., 2004, p. 184).

The struggle to include the views of a broader range of children diagnosed with autism seems to be the reason for their exclusion from research about their lives. This struggle is also indicated in the passage above. The diversity among children diagnosed with autism means that etic research approaches may exclude their views as no single method is suitable with all the participants. Thus it seems that the inclusion of children diagnosed with autism who have more complex impairments requires challenging the dominance of etic research approaches, as Beresford and colleagues (2004) do in their study. Additionally, while it may be helpful to consider the effects of impairments, it is
necessary to refrain from explicitly seeing children through these or through their diagnosis and to include participants as individuals.

3.4.4 Difficulty hearing the views of children and privileging adults’ views

In the research including children and young people reviewed for this study, it was sometimes difficult to distinguish the children’s views from those of adults due to the way findings were reported. As mentioned earlier, some researchers tended to judge the views of children and young people as unreliable or inaccurate. These judgements also relate to the way children’s views are heard by adults. Where adults were involved as co-informants, their views were typically privileged or reported in more detail than those of the children. In the early studies, it often seemed that the researchers had difficulty moving away from the etic research approach in order to understand or explore the ‘insiders’ experiences’, to ‘empower’ children and to ‘understand meanings’ in their experiences. These issues are outlined below.

In some studies there was a tendency to assess the views of children. Statements by authors implied doubts about the reliability and truthfulness of their participants’ responses. For example, Preece (2002) noted that ‘where answers were obtained, it remained difficult to ensure their validity’ (p.100). Carrington and colleagues (2003) expressed that they felt speculative about the ‘true’ nature of friendships described by their participants generally (p. 216). Such statements indicate that the young people’s views were not seen as credible.

Children’s views were typically less prominent in studies where adults were also participants. More weight and attention were often given to the views of parents, teachers and professionals than those of the children. For example, in two studies including children diagnosed with Asperger’s syndrome, mothers were included as co-informers to draw on parental perspectives on the children’s lives (Carrington & Graham, 2001; Howard, et al., 2006). In these studies, the themes generated were reported as the views of the children although on closer examination most views reported were those of the parents.
In one study, the presentation of parents’ views overshadowed those of the children because of methodological challenges in accessing children’s views due to parental gate keeping (Beresford, et al., 2007). While most parents had been willing to participate themselves, some parents did not perceive the study questions as meaningful to their child with autism. Other parents had expressed the view that research visits in their home would be too intrusive and disturbing for the child (Beresford, et al., 2004). Although children’s views were presented sparsely and lacked the detail of adults’ views, the report clearly indicated that children typically had different views and priorities for service outcomes than their parents. This difference is an important reason to ensure that children’s views are the focus of research about their lives and not obscured by those of adults. As noted earlier, the currently available research with children diagnosed with autism lags behind research with disabled children and indeed children generally. Contemporary research approaches seeking to understand the lives and experiences of children diagnosed with autism need to be open to hearing children’s views and inclusive of those with a range of cognitive and communication abilities.

3.4.5 A shift towards a more emic approach

More recently published studies show that researchers are beginning to take seriously the need for emic knowledge about autism. These studies illustrate how researchers with an etic research background are acknowledging their own assumptions about diagnosed children. For example, at the beginning of their article Howard and colleagues (2006) note how they assume that young people diagnosed with Asperger’s syndrome have difficulty developing social relationships. In the effort to listen to the views of one young person labelled with autism, these researchers recognised how their own understanding of autism may have significance for the interpretation of data. This acknowledgement is significant as such preconceptions may influence the research findings. Although the findings are to some extent compared to the characteristics associated with Asperger’s syndrome, the authors attempt to focus on the views and experiences of their participant. In their conclusion, these writers also acknowledge the importance for researchers of not letting general and
preconceived assumptions about those diagnosed with Asperger’s syndrome dominate the views of participants.

A similar approach was taken by Humphrey and Lewis (2008). These authors indicated their belief that children diagnosed with autism spectrum disorders have ‘special educational needs’ compared to other students. However, rather than employing an etic, deficit-focused approach as in most earlier studies, these authors sought to examine the function of environmental inequities in the social exclusion of diagnosed children within the educational context. Another recent study examined the views on autism of diagnosed college students (aged 16 to 21) (Huws & Jones, 2008). In that study, the authors were interested in what autism meant for these young people and asked them to describe the diagnosis and their experiences in their own words. In both the latter studies, the researchers also checked that the questions asked were relevant and meaningful to the participants before engaging the young people in interviews.

These recent studies indicate that the way young people are being included in research is changing. Researchers are beginning to take seriously the views and experiences of young people diagnosed with autism. They are acknowledging that young people’s views may contribute to the way the diagnosis is conceptualised (Howard, et al., 2006; Humphrey & Lewis, 2008; Huws & Jones, 2008). However, despite attempts to be more inclusive of children and young people’s views, these studies still mainly include people who are able to verbally articulate their experiences. The centrality of the medical definition of autism and traditional positivist, etic ideas about the application of research still have the effect of limiting or excluding some young people.

3.5 Summary

This chapter has presented an analysis of available studies including children and young people diagnosed with autism. The analysis indicates that etic research approaches dominate despite attempts to explore the ‘insider’s view’. Researchers focusing on children diagnosed with autism have been slow to move away from the dominant positivist, etic approach that focuses on deficits,
towards an approach that is inclusive of children’s knowledges. This struggle can be seen particularly in the early studies, but to some extent across all the studies.

In brief, medical definitions of autism are dominant in current research. These definitions have implications for assumptions drawn about diagnosed children and young people and the way they are included in research about their lives. The foci in studying children’s lives have been on eliciting children’s views on specific adult-defined topics or their experiences within particular contexts. This focus has limited the inclusion of children’s own views on issues of importance to them. Thus it seems that the research about children diagnosed with autism lacks behind research on children more generally.

Research about young people diagnosed with autism tends to include young people who communicate verbally. Similar to studies with adults, young people considered to be higher functioning and those able to verbally articulate their experiences have been privileged over those with more significant communication impairments and those using other forms of communication. Only two studies have sought to include a more diverse range of children diagnosed with autism. In studies seeking the views of children with a wider range of cognitive and communication abilities, researchers have been confronted by ethical and methodological challenges. The reviewed studies show that research approach and methodology is significant in terms of whether children and young people diagnosed with autism are included or excluded from research.

In several studies the views of adult participants were usually privileged over children’s views. While researchers were interested in involving children and young people, the research approach used often caused the researchers’ views to overpower those of the participants, especially the children. Where parents or other adults were also participants, their views were typically heard more clearly than those of the children. This overpowering of children’s views can be attributed to common assumptions about children generally and about children diagnosed with autism in particular. These
assumptions are explored in Chapter 4. This difficulty in hearing the voices of children points to the need to do research that wholly centres on the views and experiences of young people.

The analysis showed that later studies have been more diligent in presenting the views of young people. However, most studies still exclude those who do not use speech to communicate. This continued shortfall in the literature is likely due to challenges in accessing, engaging and communicating with a more diverse range of children, as reported in the studies by Preece (2002) and Beresford, Tozer, Rabiee and Sloper (2004). To address the resulting gap in knowledge, it is imperative to identify a flexible approach that allows inclusion of the views of a broader range of young people diagnosed with autism.

3.6 Identifying the ‘gap’ and the implications for research

The review of extant studies indicates that research including children and young people diagnosed with autism is still sparse. As adult-defined topics have been the main focus in existing research, there is a need to understand the broader lives of children who are diagnosed with autism, the implications of being diagnosed and/or ‘growing up’ with a label and the issues that may be of particular importance for, or of concern to, children and young people.

When considering the scarcity of research including children with more complex impairments and the methodological issues discussed in the studies by both Preece (2002) and Beresford’s research team (2004), there is still a need to identify a research approach that is inclusive of the broader range of children who are labelled with autism.

The dominance of etic research and medically defined assumptions about children diagnosed with autism highlight that there is a need for researchers to be aware of their own assumptions and be careful that their practices are not limiting children’s opportunities to contribute their views.
3.7 Research aims and objectives

To address the gap in the literature about the lives of children and young people, the main aim for this study was:

**To learn about the everyday lives and experiences of teenagers diagnosed with autism.**

To address some of the methodological challenges reported in the literature for involving children and young people diagnosed with autism, and trying to include those who do not use speech for communication (Beresford, et al., 2004; Preece, 2002), a second aim was:

**To develop a research approach that would be inclusive of young people diagnosed with autism.**

In Chapter 4, I outline some of the methodological considerations for this study. In particular, I explore the theoretical aspects of developing a research approach that is inclusive of a diverse range of children and young people who are diagnosed with autism.
Chapter 4: Towards a methodology: Theories informing research directions
4.1 Introduction

The previous chapter focused on research that included children diagnosed with autism as participants. A search of the literature to identify research including the views and experiences of young people diagnosed with autism highlighted the following key issues. First, research focusing on the views and experiences of diagnosed children and young people is limited. Second, where these studies exist they tend to focus on specific aspects in young people’s lives. Third, with the exception of two studies, researchers tend to privilege children who are able to verbally articulate their experiences. Fourth, traditional, etic research approaches dominate most research. Fifth, two studies attempting to be inclusive of children with different abilities reported challenges when using traditional research approaches despite adapting research methods according to the characteristics associated with autism (Beresford, Tozer, Rabiee, & Sloper, 2004; Preece, 2002). In attempting to design an inclusive methodology, I built on the findings reported in these two studies (Beresford, et al., 2004; Preece, 2002). I found it necessary to go beyond identifying creative research methods that took account of characteristics associated with autism. I felt it was important to develop a research approach that would be considerate of young people and their families throughout their participation, as well as being sensitive to individual participants’ abilities and preferences for engagement in the research.

In this chapter I outline the development of the conceptual framework that guided the methodological approach used in this research. I describe the overall epistemological stance from which I derived my methodology. I also outline the way in which a constructionist paradigm was central to my adoption of the two theoretical approaches informing my research approach: the ‘new’ sociology of childhood and the social model of disability.

4.2 Considering theory for selecting the methodological approach

Research methodology comprises the principles and theoretical perspectives that underpin research. Eventually these principles and perspectives come together as the research design (Crotty, 1998).
Crotty has argued that in developing research methodology it is necessary to face the ‘assumptions about reality that we bring to our work’ and that ‘to ask about these assumptions is to ask about our theoretical perspective’ (Crotty, 1998, p. 2). Various researchers have emphasised that bringing one’s assumptions to the forefront is crucial when seeking to hear those who are typically silenced in research (Lincoln, 1993). Alderson and Morrow (2004) have argued that it is not possible to avoid having one’s own ‘beliefs and theories about what children are and ought to be like’ when engaging in research (p. 22). When involving children directly in research, Fattore, Mason and Watson (2007) have argued that the epistemological approach required is one that takes their views seriously, places them centrally in the research and attempts to understand their viewpoints. In relation to children’s wellbeing, the same authors have demonstrated that research driven by a child-centred epistemology and methodology produces different knowledge than that produced in traditional positivist approaches (Fattore, et al., 2007). The beliefs we hold shape the methodological approach and consequently the research design, which has implications for the choice and use of methods during the data collection process. More significantly, the methodological approach determines the position of the researched individual within the study and the way researchers position themselves in relation to that individual.

The purpose of this doctoral research was to understand the everyday experiences of young people diagnosed with autism. The research was based on the premise that the voices of the young people involved should be heard on matters that are important to them. My key assumption was that the young people would be able to express their opinions on particular issues in their lives if given the opportunity. Another assumption was that, in order to facilitate young people voicing their opinions, considering their diagnosis and impairments was not sufficient in terms of being inclusive. I would need to take into account individual abilities and preferences for interaction and allow these to direct the research process. The first assumption was central to the primary aim of my research. The second purpose was to develop an inclusive methodological approach for providing adequate opportunities for individual participants to contribute to the research. This approach needed to
engage with some of the challenges reported in previous research with children diagnosed with autism. As discussed in Chapter 2, these challenges included the need to gain access to children’s views through parents, the children’s dislike for change in daily routines, their reluctance to interact and the difficulties for researchers in using the same method of data collection with all participants (Beresford, et al., 2004; Preece, 2002).

An overall research approach was needed that was respectful of teenagers and their families. This approach needed to address parental gate keeping, as well as making sure that the young people were comfortable when interacting with me. Additionally, the research methods needed to be meaningful to individuals. The methods had to be flexible enough to engage young people with a range of abilities and to be inclusive of different preferences for participation. The decisions made were based in part on my own experiences as a ‘protective’ parent and my experiences of dealing with other adults who paid little attention to the way my younger son communicates. From the outset my approach contrasted with traditional research with children and young people diagnosed with autism by ‘presuming competence’ (Biklen & Kliwer, 2006) and believing that the young participants would be able to contribute their views if given the opportunity to do so. The focus of the research was on finding out about meanings participants attributed to their experiences rather than identifying deficits.

In recognising the knowledge held by those diagnosed with autism, this research project fitted well within the constructionist paradigm, as articulated in the social science disciplines of the new childhood studies and disability studies. In the next sections of this chapter I outline the key concepts of these theoretical frameworks and how they have informed this project.

4.3 The value base: Constructionist paradigm

As noted in Chapter 2 in relation to autism, the constructionist paradigm takes a critical stance towards assumed knowledge and questions how individuals are categorised. Social constructionists identify truth and knowledge as products of interaction between people, rather than a reality
derived from nature (Burr, 1995). As such, constructionism focuses on language and interactions as processes of social practices, rather than looking for answers in the psyche of individuals or socially defined structures (Burr, 1995). A constructionist perspective may also be used to analyse how young people engage in constructing meaning and individuality and, as such, can reveal the discourses of which they are part (Burr, 1995; Firestone, 1990).

Crotty (1998) has pointed out that ‘there is no meaning without a mind. Meaning is not discovered, but constructed’ (p. 8). This position acknowledges that different people construct different meanings, and indeed knowledge, in different ways when discussing the same phenomenon (Crotty, 1998). This notion was explored in Chapter 2 in looking at the different meanings and knowledge held by individuals and groups about autism. For example, the literature review highlighted that some groups constructed autism as a disorder because they focused on a set of deficits when engaging with the concept of autism. Others defined autism as a different way of being in the world. These authors explained that while characteristics associated with the diagnosis may be perceived as different or unusual behaviours, these differences may be associated with both strengths and weaknesses depending on the context and the norms within it. The latter aspect reflects how social constructionism is also related to the influence of culture on the way we make sense of our experiences. As Crotty (1998) expressed it:

... social constructionism emphasises the hold our culture has on us: it shapes the way in which we see things (even the way we feel things!) and gives us a quite definite view of the world (p.58)[Crotty’s brackets].

In other words, a constructionist approach recognises that meanings are constructed by human beings as they engage with the world they are interpreting (Crotty, 1998) and that individuals seek understanding of the world within which they live (Cresswell, 2003).

When using a constructionist approach in research, it is not appropriate to generalise from findings but rather to understand the meanings within them. This means paying attention to individuality.
Individuals develop subjective meanings of their experiences that may be many and varied, and which lead the researcher to look for complexity of views rather than simply categorising views into a few ideas (Cresswell, 2003). This approach helps in understanding that multiple lived realities exist, and that these are constructed between people and the meanings they contribute to their individual lives and experiences.

The constructionist framework has underpinned the development of conceptual frameworks for contemporary research within childhood studies and disability studies. Both disciplines have focused on hearing the voices of those who are the subjects of research within their areas of study. As the conceptual underpinnings of both childhood sociology and disability studies are central to my research, I will provide an overview of their significance here.

4.4 The ‘new’ sociology of childhood

From the early 1990s a paradigm shift occurred in the sociology of childhood. Childhood research shifted away from a reliance on developmental psychology. The new approach challenged the dominant positivist approach to conceptualising childhood and researching children, creating a space for childhood within a sociological discourse. The application of sociological theories to children’s lives using social constructionist perspectives resulted in the reconceptualising of childhood in terms of social dichotomies such as, for example, the ‘nature vs. culture’ debate on childhood and whether children should be understood as ‘becoming vs. being’ and ‘passive vs. active’ within their social contexts (Prout, 2005). Below I outline these dichotomies.

Nature vs. culture

Traditional approaches to researching children tend to view the child as developmentally immature and therefore less competent than an adult. With the emergence of the ‘new’ sociology of childhood, positivist approaches were criticised for this exclusive focus on children’s development from a biological and psychological perspective (Christensen & James, 2000b). Early childhood writers within the new paradigm argued that childhood was more than a biological phenomenon.
Rather, they suggested, it was a socio-cultural construction that provided a framework for interpreting and contextualising the first years of life in humans that was not to be understood in a vacuum away from other social variables such as gender, class and ethnicity (Prout & James, 1990). While children could perhaps be considered biologically immature when compared with adults, the view within childhood studies pertained to the way different cultures interpret this immaturity (Prout & James, 1990). The concepts of nature and culture have particular implications for understanding the views of young people to whom a label is applied, especially where the label assumes social and behavioural immaturity based on biological impairments.

**Becoming vs. being**

Research using a traditional perspective on childhood has explored children’s lives from an adult standpoint, with an overall goal of developmental research being the examination and documentation of children’s competencies as achievements towards adulthood (Hood, Kelley, & Mayall, 1996). The perspective that children were becoming adults positioned them as ‘marginal to society’ and as ‘awaiting integration as adults’ (James, Jenks, & Prout, 1998, p. 208). The *becoming* child was understood as still lacking competencies of the adult, which he or she would gain once they became an adult (Uprichard, 2008). In contrast, the ‘new’ paradigm in childhood sociology asserted that children’s lives and social relationships were worthy of study in their own right, away from the views and concerns defined by adults (Prout & James, 1990). For childhood sociologists, the epistemological difference in studying childhood then became the focus on children’s own experiences of ‘being a child’ in the present, rather than the accounts of adults (James, et al., 1998, p. 208). Consequently, the *being* child was seen as a social actor active in the construction of his or her own childhood (Uprichard, 2008). Thus while the traditional perspectives on childhood see children as incompetent on the basis of their immaturity, perspectives in contemporary childhood studies have emphasised the importance of including children’s own views in research about their lives and valuing their knowledge. The latter has implications for researching with young people.
diagnosed with autism. If we assume they have competence in telling us about their lives, we can continue to look for ways to include their views in research.

**Passive vs. active – structure vs. agency**
The ‘new’ sociology of childhood acknowledges children and young people as active in the construction of their own social lives (Prout & James, 1990). Contemporary childhood writers have asserted that children are not merely passive subjects of social practices and structures, although they are often denied their role as social actors within an adult-defined society. Recognising children and young people as social actors in their own right involves acknowledging that children can deploy their own knowledge in order to create spaces of autonomy and resistance to adult-imposed structures such as, for example, educational institutions (Hutchby & Moran-Ellis, 1998). This conceptual change within childhood studies has repositioned children as subjects rather than objects of research (Christensen & James, 2000b; Mayall, 1996; Woodhead & Faulkner, 2000). Contemporary researchers have shown that there are different versions of children’s worlds and these differences can be tracked through children’s use of words, and application of values and ideas of acceptable behaviour (Mayall, 2000). From this perspective, there is not just one homogenous voice of children or just one concept of childhood, adolescence or youth. Writers in the ‘new’ paradigm usually emphasise children’s heterogeneity by referring to their views in a plural form and paying attention to individual voices in research. They emphasise that children’s views should be understood within the different contexts they influence and are influenced by. These contexts include their family and educational settings and when with their peers. As such, children’s voices may be differentiated in terms of age, gender, class, ethnicity and ability, but they may also be distinguished individually within and across these social categories (Prout & James, 1990). In terms of researching with young people who may be labelled with the same diagnosis, their lives, views and experiences are likely to differ. As individuals they belong to different families and cultures and move in different social contexts.
4.4.1 Critiques of the ‘new’ sociology

The ‘new’ sociology of childhood has been critiqued by postmodern writers in recent years. Prout (2005) has stated that ‘the sociology of childhood established itself within and not beyond the oppositional dichotomies of modernist sociology’ (p.62). While these dichotomies have provided new and expanded ways of understanding childhood, postmodern sociologists have pointed out that such dichotomies have presumed a chasm between nature and society (Urry, 2000 cited in Prout, 2005). The boundaries between these socially constructed concepts tend to be blurry at best. The ambiguity relates to age ranges, but more so in terms of how the roles and images of young people described using these terms have been influenced by social and cultural changes over time (Prout, 2005).

Prout (2005) has identified that a problem within the sociology of childhood is the way in which it is grounded within the dichotomous oppositions of earlier approaches to childhood. He has argued that essentially the biological reductionism of childhood had been replaced with a sociological reductionism. As childhood is now becoming more diverse and ambiguous, there is a need for theory to move beyond dualistic formulations. Future thinking in childhood studies needs to consider the ‘excluded middle’ of current opposing dichotomies. Finding ways of talking about childhood is important so that hybridity and complexities can be explored without resolving to one side or the other of the dichotomies (Prout, 2005). Other writings about childhood have made similar suggestions, in particular in relation to the being and becoming debate (for example Lee, 2001; Uprichard, 2008). Lee (2001) has argued that children as well as adults need to be understood as both being and becoming on the basis that socio-cultural changes related to family situations, education and employment have changed not only childhood but also adulthood. For example, it is no longer taken for granted that adults entering into marriage or a career will maintain these as lifelong choices; rather, they may change partners and re-skill to change jobs. Thus as there is no finished human end product, like children adults may also be considered becoming. Uprichard (2008) has suggested that it is more relevant to understand children as both being and becoming
because of the temporality associated with both concepts. She has argued that constructing children as either becoming or being without considering the other is problematic as the two concepts are mutually constituent. What one expects of the future may determine the choices made in the present and vice versa.

4.4.2 Applying new childhood studies to young people diagnosed with autism

The concepts related to childhood generally are rarely considered in studies involving children and young people diagnosed with autism. Mostly their lives are interpreted in light of their diagnosis. However, I believe these issues to be relevant for understanding everyday issues in the lives of young people so labelled. Other authors have demonstrated that, as with children generally, the way in which disabled children are treated by adult society is dominated by issues of power and control (see for example Cocks, 2000).

In my research I have chosen to focus on older children. Because of the focus on early diagnosis and early intervention, older children are commonly overlooked within the autism literature. I am aware that in Western cultures, the term ‘children’ typically includes young people up to 18 years of age because this cut-off denotes young people who are legally dependent (Alderson & Goodey, 1996). However, as I explain below, the boundaries are less clear in terms of describing when individual young people might be treated as independent and therefore when their Childhoods end. Within the literature, the boundaries for children’s development towards independence and maturity are ambiguous. For example, the term ‘adolescence’ is often used to refer to older children but may mean those above the age of 10, 11, 12 or 13. Adolescence is typically linked with a life stage between childhood and adulthood. This stage carries the connotations of particular processes of physiological and psychological development, although the boundaries of when ‘adolescence’ begins and ends are unclear. The concept of adolescence can be understood as a social construction that can be attributed chiefly to Eriksson’s developmental theories. Therefore, the construction of adolescence occurred within the disciplines of developmental psychology and clinical medicine.
Rather than the term ‘adolescents’, I use the term ‘teenagers’. This term simply refers to young people between the ages of 13 and 19. This choice of terminology was based on observations that many young people use the term teenager to describe themselves. In Australia the teenage phase tends to run parallel with secondary education. This means that in this country ‘being a teenager’ often begins and ends with culturally constructed transitions in and out of high school. Young people may have reached the age of legal majority before they finish school, but many still reside with their parents. Consequently these young people may be considered dependent, both within the educational system and within the family.

In Australia, the transition from high school as an adult is significant for young disabled people who want to or need to access post-school programs. For example, to be eligible for the NSW Government’s ‘transition to work’ program, young people are required to remain in high school until they have completed the final year (Year 12) (NSW Government, 2008). Other young people have a number of options once they have completed Year 10. This requirement to remain in a secondary education setting elongates childhood. Therefore concepts in the sociology of childhood have implications for researching with young people who may not be considered children in a legal sense. The elongation of childhood has been also linked to notions of disability and impairment (Priestley, 1998). Priestley (1998) has argued that the structured dependency of disabled adults resembles that of children as they too are often denied their role as social actors. While for most individuals childhood is considered a temporary stage, some disabled people are viewed and treated as children through their lives.

Until recently childhood research overlooked issues of disability and disability studies took little notice of children’s lives. While theories within childhood studies are evidently about children, the theories within disability studies have been defined by and around the lives of adults. However, researchers from each of these fields have in recent years found that using an approach that incorporates both theoretical frameworks is valuable when researching the lives of disabled children
(Cocks, 2006, 2008; Connors & Stalker, 2007; Davis, Watson, & Cunningham-Burley, 2000; Kelly, 2007; Kelly, McColgan, & Scally, 2000; Morris, 1998, 2003; Priestley, 1998). In recent years researchers have begun to apply theoretical concepts from both childhood sociology and disability studies when seeking the views of disabled children (Cocks, 2008; Connors & Stalker, 2007; Kelly, 2005). The next section outlines some of the major concepts within disability studies and the implications of these for my PhD research.

4.5 Disability studies

The term ‘disability studies’ refers to an increasing body of contemporary literature that in the past three decades has challenged the way conventional thinking has represented disability as a social problem. Since the 1970s, this area of study has been generated on the basis of the activities of what is commonly referred to as ‘the disabled people’s movement’. The movement has included various organisations run for and by disabled people. Examples include the Union of the Physically Impaired Against Segregation (UPIAS) in the UK and others in the USA and Canada, as well as a small group of influential disabled writers and activists (Barnes, Mercer, & Shakespeare, 1999). The ‘disabled people’s movement’ drew attention to the way ‘people with accredited (or perceived) impairments’ were being ‘disabled by society’s blatant failure to accommodate their needs’ (Barnes, et al., 1999, p. 2). In the UK, the activities and thinking generated by the movement, and by UPIAS in particular, resulted in the articulation of ‘the social model of disability’ (Oliver, 1990).

4.5.1 The social model of disability

The development of the social model of disability is mostly commonly attributed to the work of Mike Oliver (see for example Oliver, 1990, 1996), although a number of other writers have also contributed knowledge. The social model enforces the point that disability is a socially constructed concept and often confused with that of impairment. As described briefly in Chapter 2, the primary aim of the social model is to separate impairment from disability. From the perspective of the social model of disability, impairment refers to the functional limitations of body and mind. On the other
hand, disability occurs from the social factors and attitudes that create barriers and deny opportunities. Although the social model focuses on disability as oppression, it does not disregard the importance of impairment in people’s lives or the importance of medical and educational services that may improve individual people’s intellectual and physical potential. However, the social model emphasises that social barriers are imposed ‘on top of impairment’ (Barnes, et al., 1999). This perspective emphasises disability as social oppression, rather than belonging to individuals. The perspective of the social model contrasts with the individual or medical model of disability which has otherwise dominated the definition of disability (Oliver, 1990).

Within the medical model impairments are viewed as the primary cause of individuals’ failure to conform to social ‘norms’. This view emphasises disability as belonging to the individual person because of their impairments (Oliver, 1990). Consequently within the medical model the disability discourse has focused almost exclusively on cure and rehabilitation. Writers within disability studies have suggested that an exclusive focus on correcting impairment has the effect of overlooking society’s responsibility to address the social and structural barriers disabled people face in their everyday lives (Shakespeare & Watson, 1998). Consequently the central aim of the social model has been to deal with the barriers of social oppression.

The key aspect of the social model of disability that distinguishes between impairment and disability was significant in terms of developing the methodological approach for my study. More specifically, it was important that my approach or personal assumptions did not create barriers for the participation of individual participants but that it considered how to best include them. In order to be inclusive, it was important that the approach was flexible enough to take into account the abilities and preferences of individual participants, rather than assuming strengths and weaknesses on the basis of the diagnosis. However, I found that the social model of disability alone did not fully explain the issues that emerged from involving young people diagnosed with autism in this study. More recent developments within the field of disability studies have highlighted the need to further
develop the social model so that it accounts for the experiences of the wider population of disabled people and those living with diagnosed impairments. I outline some of these developments below.

### 4.5.2 Expanding the social model

The social model of disability has been further developed by a number of writers on disability. Some writers have suggested that the dichotomous distinction between impairment and disability is a little too rigid and that it over simplifies the complexities in the everyday lives and experiences of disabled people (Corker & French, 1999; for example Crow, 1996; Llewellyn & Hogan, 2000; Shakespeare & Watson, 2001; Thomas, 1999). Post-structuralist/postmodern authors have suggested that the concepts of disability and impairment are more complex and multifaceted, that disability needs to be understood within different social and cultural contexts, and that they need to be seen in light of political and socio-cultural changes (Shakespeare & Watson, 2001). Several authors, and particularly feminist writers, have also highlighted the importance of acknowledging the various individual experiences of living with impairment and how these experiences may be significant aspects of disability in relation to difference and identity (for example Corker & French, 1999; Reeve, 2002; Thomas, 1999). I briefly outline these aspects below.

**Impairment**

In recent years disability researchers have begun to analyse the experiences of living with impairment. One argument has been that the focus on the collective experiences of disabled people within the social model has valorised disability while marginalising and silencing impairment (Corker & French, 1999). Others have argued that the social model of disability has to engage with impairment in order to challenge disablism (oppressive practice related to disability) (in Thomas & Corker, 2002). Thomas (1999) has asserted that the experience of impairment is significant in disabled people’s lives both at a biological level as well as a social level and, as such, should be theorised as a bio-social phenomenon.
The concept of ‘impairment effects’ was introduced by Thomas (1999). Impairment effects refer to the results of living with impairments but are not necessarily associated with social relationships. These effects may include pain, fatigue or discomforts that arise as a direct result of particular impairments or conditions. Consequently these effects may place limitations on the individual’s involvement in social, educational and employment activities. Thomas’s thinking has also extended the social model to include the notion of disability as rooted in social relational issues. With her social relational model of disability (Thomas, 1999), Thomas has posited that the restrictions experienced by disabled people may be described as ‘barriers to doing’ and ‘barriers to being’. ‘Barriers to doing’ refers to the social model’s definition of disability – the physical, structural, economic and material barriers, including lack of suitable transport and inaccessible buildings. ‘Barriers to being’ refers to actions by others that may include hurtful or hostile attitudes, exclusionary practices and inappropriate responses from others that may have negative effects on an individual’s sense of self-worth. Thomas has underlined that such personal experiences of living with impairment and impairment effects must be acknowledged in research so that these can be better understood. Additionally she has stressed the importance of analysing the similarities and differences in disability experiences associated with the full range of impairments (Thomas & Corker, 2002). This notion leads me to discuss another critique of the social model which relates to impairment but has evolved specifically around the issue of ‘learning difficulties’ (Chappel, Goodley, & Lawthorn, 2001; Chappell, 1998; Goodley, 2001).

**Learning difficulties**

Commonly, ‘learning difficulties’ is used as an umbrella term in the literature and sometimes interchangeably with the term ‘learning disabilities’ or ‘learning disabled people’. The choice of terminology usually depends on the theoretical perspectives of the authors or individual organisations. The term ‘learning disabled’ tends to reflect the preferences of writers who have adopted the perspectives of the social model of disability. The term ‘learning difficulties’ is used on the basis of research indicating that this term is preferred by self-advocates who may not necessarily
identify themselves as disabled (Goodley, 2001). In relation to ‘learning disabled’ children, Kelly (2007) has noted that terms such as ‘learning difficulties’ and ‘learning disabled’ are broad and may refer to varying concepts of ‘developmental’ delay, ‘intellectual’ disability or ‘cognitive’ impairments. Additionally, these terms may be used about a range of other impairments sometimes categorised under labels such as Down’s syndrome, autism, ADHD and dyslexia (Kelly, 2007). While some commonalities are likely among children labelled as having ‘learning difficulties’, it is important to also consider the diversity and complexity of their lives.

Until recently, people labelled as having learning difficulties were largely ignored by the disabled people’s movement. They were afforded little consideration within the social model of disability (Chappell, 1998, 2000; Goodley, 2001). Goodley (2001) has explained that part of the reason for the exclusion of people with learning difficulties within disability studies was related to the reluctance to engage with impairment. The concern was that bringing impairment into focus would ‘water down’ the strength of the social model by bringing back notions of tragedy and suffering. Increasingly authors have argued, however, that impairments, including those related to learning difficulties, need to be theorised as part of the social model of disability (Chappell, et al., 2001; Chappell, 1998; Corker & French, 1999; Goodley, 2001; Thomas, 1999). Goodley (2001) has asserted that ‘learning difficulties’ is a social construct like disability and impairment. As a construct, ‘learning difficulties’ has emerged on the basis of political and cultural definitions of normative development. Those living with ‘learning difficulties’ and physical impairments may equally be subjected to or resist oppressive and disabling barriers. However, some authors have argued that while experiences of oppression may be common among people with impairments, their experiences of living with various impairments differ (Corker & French, 1999; Thomas, 1999).

Issues related to impairment and learning difficulties are significant in terms of young people diagnosed with autism. While the diagnosis denotes certain impairments, the ways in which these impairments present are diverse. Some impairments are visible to other people, while other
impairments are hidden. Some impairments are seen as learning difficulties, while others may be understood as differences rather than impairments (Kelly, 2005). Therefore experiences of living with a label such as autism may differ according to the way impairment or difference is felt and understood by individuals.

Disability and difference
The term ‘difference’ has had particular relevance to the development of this study, partly because difference is frequently discussed in published personal accounts by adults diagnosed with autism (as discussed in Chapter 2). Within disability studies difference is commonly debated in relation to disabled people more generally. The recognition of difference has long been the opportunity for ‘denial of human and civil rights’ (Morris, 2001a, p. 12). For example, disabled people still do not have the same access to education, housing and employment as non-disabled people on the basis of their perceived or accredited differences. Thus as a concept difference also complicates the dichotomous distinction between impairment and disability. Morris (2001a) has explained that having an impairment makes one significantly different from those who do not have one, but that the way others may recognise and respond to difference may cause one to deny it exists. Reeve (2002) has noted that the person who is unable to hide their impairment may be exposed to others making assumptions about them. Their impairment becomes the most significant personal characteristic and an object of public gaze (Reeve, 2002 drawing on Foucauldian themes). A visible impairment creates difference by providing the observer with privileged information about that body. Thus the power of the gaze may result in experiences that contribute to ‘psycho-emotional dimensions of disablism’ associated with negative feelings of self-worth (Thomas, Reeve, 2002; 1999). Someone with a hidden impairment (for example, individuals labelled as learning disabled or with autism) may be less subjected to the power of the gaze (Reeve, 2002). However, Thomas has suggested that within the act of trying to ‘pass as normal’, a person may be subjected to the fear of being discovered, resulting in ‘the negative psycho-emotional aspects of concealment’ (Thomas, 1999, p. 55). As such, the psycho-emotional aspect of impairment, disability and difference may have
significant implications for the way disabled people construct their identity. The concept of identity is commonly discussed in relation to disability.

**Disability and identity**

Identity as a concept is commonly debated within disability studies. Shakespeare (1996) suggests that identity related to disability is significant because it is an area in major conflict with mainstream social sciences. As a concept, identity has different meanings in different contexts. Watson (2002) has explained that two main perspectives on identity exist within social sciences: some writers maintain that identity is ‘based on shared social experiences, origin or structure’ (p. 509), while others claim that identity only ‘exists as opposites’ and is both ‘multiple and temporal’ (p. 509). Within disability studies, however, identity as a disabled person is typically based on shared experiences and in this way has been presented as something static (Watson, 2002). For example, Oliver (1996) understands disabled people as identified through ‘the presence of impairment’, ‘the experience of externally imposed restrictions’ and ‘self-identification as a disabled person’ (p. 96). Thus, within the social model of disability, disabled people are defined as those who identify as such or who can be identified as such (Oliver, 1996).

Some authors have noted that the social model perspective can be problematic because it demands that disability becomes the dominant identity, and some people with impairments do not identify as disabled (Shakespeare, 1996; Watson, 2002). As disabled people are not homogenous, there is no core identity that separates disabled people from non-disabled people (Watson, 2002). Additionally, as Shakespeare (1996) has pointed out, disabled people are also men and women, straight or gay and belong to various ethnic groups; therefore to discuss their identity purely in disability terms would be to ignore their full lives. This notion is equally significant for researching the lives and experiences of young people diagnosed with autism. While children and young people may have a label of autism, they are not simply autistic and they may not identify as such. Nevertheless, the concept of cultural identity has been discussed in relation to disability (Lawson, 2001; Shakespeare,
1996) and more recently also specifically within the autism discourse, as noted in Chapter 2. Chapter 2 also highlighted an apparent increase in voices publicly identifying with the diagnosis of autism and the characteristics associated with it, although these voices rarely include those of children and young people.

While the concepts discussed in the sections above have been defined for and by disabled adults, they have equal resonance with disabled children including those labelled with autism. The wide range of impairments and characteristics associated with autism implies that individuals with the same diagnosis may relate to it in different ways. Therefore, the notions of impairment, difference and identity are relevant for understanding how young people experience autism and relate the diagnosis to their lives.

4.5.3 Bringing together disability studies and childhood studies

The sections above illustrate that several parallels can be identified between the developments in childhood studies and disability studies (Priestley, 1998). Both disciplines have been chiefly mutually exclusive until recently. The concepts discussed in the previous section have also only in recent years been explored in research including the views of disabled children and young people (Barnes, et al., 2000; Connors & Stalker, 2007; Davis & Watson, 2000; Kelly, 2005; Morris, 2003). For example, Davis and Watson (2000) illustrated how disabled children faced discriminatory notions of ‘normality’ and ‘difference’ in various school settings and how their experiences related to cultural practices of both adults and children. Kelly (2005) explored the implication of adult discourses around disability on the way children viewed their impairments and constructed their self-identity. Lately, Connors and Stalker (2007) have found that using Thomas’s (1999) concept of ‘barriers to being’ may be particularly relevant in exploring disabled children’s understanding of disability and difference. The concepts at the centre of these studies are less understood in relation to young people living with specific diagnoses such as autism. The reason for this gap is perhaps that few diagnosis-specific studies have applied theoretical frameworks from childhood sociology or disability studies, or
perhaps because disability studies have until recently refrained from studying specific diagnostic groups. Perhaps this void reflects the criticism of early studies into experiences of childhood disability for being impairment specific (Priestley, 1998). The argument behind such criticism was that focusing on certain impairments could create barriers to the development of generalised understanding of common issues (Priestley, 1998 citing Philip and Duckworth, 1982). At the time, disability studies were following the main aims of the social model, which focused on exploring the disabling barriers of society, leaving little space for understanding individual experiences of impairment.

Disability research has mostly focused on disabled children’s collective experiences and less on the individuality of their lives (Davis, Watson, Corker, & Shakespeare, 2003). Some writers have argued that using this focus exclusively is problematic because social model perspectives on social policy then present disabled children as a homogenous group (Davis, et al., 2003). These writers have suggested taking account of individual experiences of disability and impairment in order to respond to the complexities and diversities of disabled children’s lives (Davis, et al., 2003). These points have implications for exploring the experiences of young people living with specific impairments and labels, especially when, as in the case of autism, these are frequently the focus of public debate.

4.6 Summary
This chapter has outlined the epistemological foundation for this study, as influenced by a social constructionist paradigm and theory drawn from both childhood sociology and disability studies, which have been fundamental to this study. The epistemological framework described provides the basis for developing a methodology and for making sense of the findings. The theoretical concepts in childhood sociology and disability studies were discussed in terms of how they may relate to the lives of young people diagnosed with autism.

Chapter 3 showed how much research involving children diagnosed with autism focuses on their commonalities, their abilities and characteristics. In this chapter, I outlined the significance of
researching experiences of children and young people diagnosed with autism for also understanding individuality, diversity and complexity in their lives.

In researching individual lives and experiences, theorists from both childhood studies and disability studies have identified a qualitative research framework as best practice. In Chapter 5, I outline how research using the epistemological framework informed the qualitative methodological approach for this study and my focus on collaborative and participatory research methods for researching with young people.
PART TWO: METHODOLOGY
Chapter 5: Methodology: Designing a research approach
5.1 Introduction

In Chapter 4 I outlined the epistemological framework underpinning this research. Chapter 4 also described the theoretical framework for this study as informed by childhood sociology and disability studies. This current chapter builds on Chapter 4 but is concerned with the research design. In this chapter I describe the qualitative research approach designed for this PhD study. As qualitative research is understood in different ways within different paradigms, I first point out some of the contrasting perspectives on the use of qualitative research. Thereafter I outline how qualitative research has informed this study with reference to phenomenological and ethnographical traditions. I also outline the benefits of using a collaborative participatory approach for my study. This choice was based on the recent research developments within the field of childhood sociology where researchers are seeking new approaches to involve children in directing the research process. The last part of the chapter considers data collection methods to include young people with a range of cognitive and communication abilities. I also identify communication strategies that may support the process of recruitment, consent and data collection. I conclude with considerations for my roles as a researcher. I outline what these roles mean in terms of preparing research and when engaging with young people.

5.2 Designing the elements of a qualitative framework to research disability and young people’s lives

In terms of designing research and selecting methods, there is no one ‘right way’ to research with children (Mason & Urquhart, 2001). However, there is a general consensus for using qualitative approaches with children in order to be inclusive of their views rather than being dominating and exploitative (for example Alderson, 2004; Christensen & Prout, 2002; Davis, 1998; John, 1993; Mason & Urquhart, 2001; Waksler, 1991). Within the fields of childhood sociology and disability studies, qualitative research approaches are continually being developed to find the best ways of including children that respond to their individual abilities (Alderson & Goody, 1996; Christensen, 2004; Clark & Moss, 2001; Davis, Watson, & Cunningham-Burley, 2000; Garth & Aroni, 2003; Kelly,
McColgan, & Scally, 2000; Morris, 2003; Rabiee, Sloper, & Beresford, 2004). Several studies now illustrate that qualitative approaches can be successful in finding out about the views of children (Davis & Watson, 2002; Kelly, 2005; Morris, 1998; Rabiee, Sloper, & Beresford, 2005), including those with cognitive and communication impairments (Fattore, Mason, & Watson, 2007; Mandell, 1991; Mason, 2008; Waksler, 1991). Researchers have used various techniques and methods to include children’s views. These have been applied in ways that are flexible, respectful and meaningful to children and young people.

A qualitative research approach was selected for this project. I considered qualitative research to be useful because I was interested in learning first-hand about the ‘social worlds’ of teenagers diagnosed with autism. Qualitative research is concerned with finding ‘meanings’ in the data (Denzin & Lincoln, 2003; Finch, 1986), rather than identifying ‘causes’ (Barnes, 1992). Denzin and Lincoln (2003) describe qualitative research as attempting ‘to make sense of, or to interpret, phenomena in terms of the meanings people bring to them’ (p.5). More flexibility in the use of methods is possible in qualitative than in quantitative research because there is an acknowledgement that knowledge is made through subjective interaction (Barnes, 1992; Denzin & Lincoln, 2003). The characteristic features of qualitative research arise from both research epistemology and techniques (Finch, 1986).

Finch (1998) explains that at the epistemological level qualitative research implies a different ‘way of knowing’, which looks to uncover from the ‘actor’s point of view’ the meanings of ‘lived experiences of human society’ (p.7). Denzin and Lincoln (2008) point out that the word ‘qualitative’ itself implies a focus on ‘... qualities of entities and on processes and meanings that are not experimentally examined or measured (if measured at all)⁹ in terms of quantity, amount, intensity, or frequency’ (p. 15). No single set of research methods is privileged in qualitative research as the approach is based on the interaction between researcher and the researched (Denzin & Lincoln, 2008). This interaction emphasises the socially constructed nature of reality (Denzin & Lincoln, 2008). Thus within a

⁹ Authors’ brackets.
Qualitative framework, human actions are constructed by the actor rather than being a moulded ‘product of external forces’ (Finch, 1986, p. 7).

Qualitative researchers do not necessarily agree on the exact dimensions of qualitative research (Denzin & Lincoln, 2008). Denzin and Lincoln (2008) outline how researchers working within different paradigms may view qualitative research. For example, qualitative researchers within a positivist paradigm tend to assert that their approach is rigorous science which is free of bias and subjective opinions. They contrast their approach to qualitative interpretive research which they maintain is not reliable and objective (Denzin & Lincoln, 2008). Countering these claims, some postmodern researchers emphatically reject positivist criteria in relation to their own work on the grounds that its rigidity excludes or ‘silences too many voices’ and produces knowledge which is irrelevant to their work (p. 16). Other postmodern researchers may reject the use of positivist methods and assumptions. They may understand them merely as one way of generating knowledge about societies, which is no better or worse than other methods but which generates different knowledge. In between these opposing views some, more lenient, post-structuralist qualitative researchers may use statistical measures and methods as a way of locating a group of subjects within a population, although they rarely use these methods to report findings (Denzin & Lincoln, 2008). Despite the history of multiple uses within multiple disciplines, qualitative research is essentially grounded in the constructionist paradigm within which contemporary social research has reacted strongly against the rigidity of positivism and its limitations (Denzin & Lincoln, 2003; Finch, 1986).

Researchers in the two distinct fields of childhood sociology and disability studies have made conscious efforts to develop qualitative methodologies that are inclusive and participatory (Mason & Urquhart, 2001; Thomas & O’Kane, 1998; Veale, 2005). Researchers who span both disciplines have sought to refine qualitative approaches from both fields to be inclusive of disabled children (Aldridge, 2007; Beresford, 1997; Davis, et al., 2000; Kelly, 2007; Kelly, et al., 2000; Morris, 2003).
Being inclusive often involves reflexivity and flexibility on the researchers’ behalf (Davis, 1998; Davis, et al., 2000; Kelly, et al., 2000; Morris, 2003). As such, inclusive research approaches challenge traditional approaches because they are subjective and flexible. No single research method is best suited to learn about children’s opinions (Davis, 1998). However, some writers argue that participatory methods are preferable as they ‘facilitate the process of knowledge production’ rather than simply gathering or eliciting knowledge (Mason & Urquhart, 2001; Thomas & O’Kane, 1998; Veale, 2005).

In preparing this study, I was aware that more than one method of inquiry would be appropriate, if not required. As discussed in Chapter 3, Beresford and her colleagues (2004) found that no single research method is suitable with all children diagnosed with autism. These authors reported that their research with children diagnosed with autism was somewhat restricted by the limitations of applying research in traditionally accepted ways. Thus, in anticipation of including a diverse group of young people, I expected to draw on a range of methods (Morris, 1998, 2003). I sought information from traditions of inquiry that have primarily shaped and facilitated participatory research methodology within the disciplines of disability and childhood, namely phenomenology and ethnography. The influences from these traditions are described briefly in the next sections.

5.2.1 Phenomenology

Phenomenology is a philosophical approach that sociologists use in theorising about the way the social world works and has a focus on personal life experiences over time (Grbich, 2007). The aim of phenomenological research is to describe structures of consciousness of everyday first-hand experiences (Grbich, 2007). A phenomenological approach requires the researcher to become aware of their own experiences of the phenomenon under study and to let go of these:

*It [phenomenology] is an attempt to return to the primordial contents of consciousness, that is, to the objects that present themselves in our very experience of them prior to our making sense of them at all. Sense has been made of them, of course. Our culture gives us a ready-made understanding of them. So we need to lay that understanding aside as best we can.* (Crotty, 1998, p. 96)
Some writers consider a phenomenological stance to be advantageous when researching with children (Waksler, 1991). As a phenomenological approach involves setting aside beliefs and doubts in what is real (ontological matters) and what is known (epistemological matters), phenomenology allows researchers to see children simply as social actors in the world. This perspective provides the opportunity to apply a range of sociological theories to children’s lives and experiences traditionally only applied in the adult world. Waksler (1991) argues that, most importantly, phenomenology encourages researchers to take children seriously as sociological subjects. This approach contrasts with the application provided by psychological theorists (such as Freud, Piaget and Eriksson) and widens sociological knowledge about children (Waksler, 1991).

5.2.2 Critical ethnography

Classical ethnography is a philosophical perspective originally stemming from anthropology that enables researchers to study people, their lives or particular phenomena in context (Silverman, 2001). In contrast to classical ethnography, contemporary approaches to ethnography, such as critical and interpretive ethnography, aim to learn about the culture of others by embracing a subjective way of knowing (Crotty, 1998; Foley & Valenzuela, 2008). Critical ethnography emerged in the 1960s out of growing disappointment with positivist objective social science that supposedly produced value-free research. Early critical ethnographers rejected positivism and the focus of their approach became on narrowing the divide between ‘the powerful and the powerless’ (Foley & Valenzuela, 2008, p. 288). Since then, researchers have found critical ethnography particularly useful when examining issues of power relations within cultures and societies (Grbich, 2007).

Ethnography is commonly used in contemporary childhood and disability research (for example Baker & Donelly, 2001; Christensen, 2004; Davis, 1998; Davis, et al., 2000). The flexibility of contemporary ethnography allows the researcher to observe and interact with participants in social settings and invites participants to partake in directing the research process. In researching with children, various writers have also suggested that the flexibility of ethnography positions researchers
so that they can take account of shared meanings within children’s cultures. This position means that researchers can learn about the diversity of children’s lives, including the meanings children as individuals contribute to their everyday experiences (Christensen & James, 2000a; Davis, 1998).

Contemporary approaches to ethnography can address the goals of emancipatory disability research (Davis, 2000). These approaches acknowledge participants as experts on their own lives and thereby change the relations between the researcher and the researched (Davis, 2000). Like phenomenologists, ethnographers are required to acknowledge their own assumptions and experiences. Ethnographers use their assumptions in the research process so that they can learn how their own culture differs from or is similar to that of the culture observed (Crotty, 1998; Davis, et al., 2000). Davis and colleagues (2000) have suggested that, by using a reflexive approach, ethnographers can also become aware of how both their academic and personal preconceived assumptions may influence the research process.

The philosophical stances within both phenomenology and ethnography value children as competent social actors and consider them experts in their own lives. In using such qualitative approaches, the importance for me as the researcher was to be reflexive in my practice when engaging directly and openly with the ethical and methodological issues that are connected with being inclusive of children’s views and choices. This meant involving children in the development and direction of the research process. Children’s participation and collaboration in research is the focus of the next section.

5.3 Collaborative participatory research

The past decade has seen participatory methodologies increasingly being used and encouraged in childhood and disability research (Alderson & Goodey, 1996; Chappell, 2000; Davis, et al., 2000; Fattore, Mason, & Nixon, 2005; Fattore, et al., 2007; Kelly, et al., 2000; Mason & Urquhart, 2001; Mauthner, 1997; Morris, 2003; Thomas & O’Kane, 1998; Ward, 1997). Alderson and Goodey (1996) have emphasised the need to understand and treat children as social actors throughout the research
process, while Christensen and Prout have emphasised the importance of employing practices in participatory research that are in line with the experiences, interests, values and everyday routines of children rather than those of adults. Such practices involve including children in decision-making processes at the beginning and during the research process. This approach fits with a collaborative model of children’s participation, as outlined by Mason and Urquhart (2001).

Children’s participation in welfare practice and research has been said to occur through three different models (Mason & Urquhart, 2001). According to Mason and Urquhart (2001), a number of important dimensions differentiate these models along a continuum. At one end of the continuum is a model referred to as ‘adult-centric’ (or ‘adultist’), a term which indicates the adult-defined boundaries of participation. This model involves children at very superficial tokenistic levels. At the other end of the continuum is a child-directed model in which children dominate through initiating research and directing decision-making processes. This model uses an approach that empowers children and recognises them as expert on their lives, while challenging the power of adults over children (Mason & Urquhart, 2001).

The collaborative model of participation is placed in the middle of this continuum (Mason & Urquhart, 2001). In this model, decision making is child-adult shared. This model resembles Mary John’s concept of building a bridge for participation by underlining the ‘individual, collaborative and negotiative elements’ of the research process (John, 1993, p. 21). The collaborative model has adults taking roles as initiators of and leaders in research but understands children as co-constructers of knowledge. This model involves considering significant aspects of research which include negotiating with gate keepers, giving time for establishing respectful relationships between researchers and children and sharing control with children during the research process (Mason & Urquhart, 2001). As such, the collaborative participatory model addresses the need to balance uneven power relations between adult researchers and child participants in childhood studies. Participatory approaches have particular implications for the way ethical issues have been negotiated between researchers
and the researched in disability studies. Ethical considerations for research are outlined in the next section.

5.3.1 Ethical considerations in research with children and young people

Ethical considerations were at the forefront of this project from the outset. To uphold general principles of integrity, respect, beneficence and justice, this research program was developed and conducted in accordance with the following guidelines:

1. The Australian National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council (NHMRC), 1999)
2. The University of Western Sydney Research Code of Practice (University of Western Sydney (UWS), 2005)
3. The Research and Ethics Review Committee Guidelines of Autism Spectrum Australia (ASPECT) (ASPECT, N.D.)

However, while official ethical guidelines are necessary in research, they rarely provide adequate guidance to the dilemmas researchers face during the process of a project (Morrow & Richards, 1996). As asserted by Morrow and Richards (1996), ethical considerations do not just arise at the beginning of the research process. These considerations are ongoing, as dilemmas may arise at any stage. In conducting qualitative research, writers within childhood sociology and disability studies have reported particular ethical dilemmas related to informed consent, privacy and confidentiality, and protection (for example Beresford, 1997; Davis, 1998; Mauthner, 1997; Morris, 2003; Morrow & Richards, 1996).

Ethical dilemmas may arise because of unequal power relations between adults and children as children’s competencies are questioned. Children are sometimes assumed to lack the ability to understand and contribute to research on the basis that they are younger and therefore less
knowledgeable than adults (Christensen & Prout, 2002). Consequently tensions are created between
the rights of children to participate in research and their carers’ responsibility to protect them. To
counter these assumptions, and to be inclusive of children’s views, researchers have sought to
identify and develop suitable research methods. These have been in line with activities in which
children usually participate, such as drawing and writing (Christensen & James, 2000a). In
considering ethical issues in research, however, Alderson and Goodey (1996) have questioned
whether research methods necessarily have to be different for children and adults if children are
acknowledged as social actors in the research process.

Most ethical dilemmas are not unique to children. Considering ethical issues is significant in doing
social research with people of any age (Alderson & Goodey, 1996; Thomas & O’Kane, 1998). For
example, consent must always be obtained. Confidentiality and privacy is always relevant.
Researchers have a responsibility to ensure that research with children upholds the principles of
privacy, confidentiality, authenticity, credibility and trustworthiness (Lewis, 2002). Increasingly,
social researchers agree that children should be entitled to the same ethical and methodological
considerations as adults (Alderson, 2004; Alderson & Goodey, 1996; Morrow & Richards, 1996;
Thomas & O’Kane, 1998). These considerations involve developing research approaches that are
respectful of children. Respectful research approaches need to offer adequate information about the
research and what it involves. Opportunities and tools must be provided for children to dissent and
end participation, as well as to decline participation in particular aspects of the research (Alderson,
2004; Alderson & Goodey, 1996; Beresford, 1997; Morrow & Richards, 1996). Christensen and Prout
(2002) followed this idea when they proposed the concept of establishing ‘ethical symmetry’
between adults and children in research (Christensen and Prout, 2002, p. 482). From their point of
view, the relationship between researcher and participant is the same whether participants are
children or adults. Christensen and Prout outlined three points that have implications for achieving
‘ethical symmetry’. First, similar ethical principles apply whether a researcher involves adults or
children. Second, each right and ethical consideration in relation to adults has a counterpart for
children. Third, any differences between carrying out research with children or with adults should be allowed to arise from this starting point rather than being assumed in advance. The latter implication is particularly significant in terms of researching with disabled children because they are frequently assumed to be less competent than other children.

Disabled children’s competencies are sometimes questioned because their impairments or their diagnosis lead to assumptions about their capacity (Davis, et al., 2000; Davis & Watson, 2000). In Chapter 3, such assumptions were noted in research including young people diagnosed with autism. When including children with significant cognitive and communication impairments in research, particular considerations are required. However, these should involve how to best inform children about research, ask for their consent and include their views (Morris, 2003). Researchers have suggested that a sound methodology that is respectful of children’s competencies may help to improve ethics (Alderson, 2004; Morrow & Richards, 1996; Thomas & O’Kane, 1998). Participatory research gives children control in the research process (Thomas & O’Kane, 1998). Thomas and O’Kane (1998) have argued that when research methodology is ‘in tune’ with the way children see and relate to the world it augments ethical acceptability (p. 337). In disability research, writers have also asserted that participants should not only be taken seriously with regard to their involvement but play an active part in directing the course of the research (Stone & Priestley, 1996). In preparing my research, I hoped that using a collaborative research approach would enable me to address the problematic ethical issues of inequality in researcher-participant relations associated with more traditional research approaches. Addressing these issues was very important to my attempt to conduct ethical research in situations where unequal power relations were likely to have great significance, such as researching with participants who were both children and individuals diagnosed with autism. I also hoped that using a collaborative research approach in this study would help address the methodological problems reported in other research using more traditional and rigid research approaches with children diagnosed with autism.
A collaborative participatory model with the benefits outlined above was the model selected for this PhD research. In taking the views of young people seriously and involving them in directing the research process, the model addresses the goals in the fields of childhood sociology and disability studies that pertain to developing empowering and emancipatory research. The model allows adult researchers to assist children to contribute their individual knowledges to research in ways that are meaningful to them. In extending a collaborative participatory approach to parents as well as to the young people, I hoped to achieve a number of objectives. I hoped that involving parents as consultants at the beginning of the study would acknowledge my respect for the adults in their roles as parents of children diagnosed with autism, while at the same time confronting the issues related to parental gate keeping as discussed in the literature. In particular I wanted young people to be involved in making decisions about participating in the study and about the ways in which they wished to participate, interact and communicate.

5.4 Methods for including children and young people diagnosed with autism

The main methodological issue in the proposed project was providing the young participants with opportunities to participate in ways that were comfortable and meaningful to them. In considering the data collection methods for this study, the methodological challenges reported in previous research involving children diagnosed with autism were taken into account (Beresford, Tozer, Rabiee, & Sloper, 2004; Preece, 2002). Research in this field has highlighted the importance of finding a sense of balance between the rigours of conventional approaches and applying methods in ways that facilitate direct participation of the individuals who are the focus of research (Beresford, et al., 2004; Morris, 2003). Key challenges highlighted in these studies included the finding that no single method was suitable for use with all participants, that some children had been reluctant to interact with strangers (researchers), and the fact that open-ended questions had been unsuitable in interviews with most children.
To address some of the challenges noted above, I examined literature that reported on research with disabled children, including those with cognitive and communication impairments. Additionally, I searched literature on communication strategies from a range of fields such as speech therapy, occupational therapy and education. Semi-structured interviews and participant observation emerged as being appropriate for use with most children and young people if their individual communication style and abilities were considered. To promote inclusiveness, it was important that the methods were flexible. Being able to adapt the methods was important so that they were meaningful to teenagers of different ages, with different cognitive abilities and different communication requirements (Morris, 2003). Furthermore, it was important for me to be well prepared in order to maximise opportunities for communication with young people with a range of abilities. Below I outline the implications of these considerations for research methods and communication strategies.

5.4.1 Semi-structured interviews

Semi-structured interviewing was selected as a possible method of inquiry in this study. Semi-structured interviews are commonly used in research with children and young people (Beresford, et al., 2004; Kelly, 2005, 2007; Morris, 2003). This method enables the researcher and participant to engage in a more natural conversation than structured interviews (Minichiello, Aroni, Timewell, & Alexander, 1995). Usually semi-structured interviews consist of a series of open-ended questions to allow participants to talk freely about the issues they connect with the overall topic. Because questions are typically broad, they allow children to direct the research topics, which make the interviews meaningful to individual participants.

In using semi-structured interviews, researchers avoid asking leading or closed questions. This strategy is seen as good practice as it circumvents placing limitations on the participants’ answers (Silverman, 2001). However, in research with children diagnosed with autism and other learning difficulties, researchers have found that open-ended questions are sometimes limiting (Beresford, et
al., 2004; Kelly, 2005, 2007; Morris, 2003). Therefore in designing questions for this research it was important to consider different ways of talking about the topics of interest.

Morris (1998, 2003) has found that while interviewing is suitable for children with different communication abilities, it could be challenging when cognitive impairments are significant. Morris (1998) has suggested that researchers build rapport with participating children in order to ensure that interview questions relate to the context of their lives. Questions should be asked in a way that is easy to understand and communication strategies should be identified that are appropriate for individual participants. These guidelines to asking questions were used to direct this research.

5.4.2 Participant observation

Participant observation is commonly used in research involving disabled children (Cocks, 2008; Davis, et al., 2000; Morris, 2003; Ward, 1997). This method is said to have several benefits for inclusive research. Firstly, participant observation does not exclude participants on the basis of cognitive or communication abilities (Ward, 1997). Secondly, participant observation allows for learning about individuals within their natural settings (Denzin & Lincoln, 2003). The way participant observation has been implemented in contemporary research with disabled children involves the researcher as ‘observer participant’. The ‘observer participant’ takes part in the everyday lives of the participants, while both researcher and participant are aware of the research relationship (Barnes, 1992).

In their renowned ethnographic study, Davis, Watson and Cunnigham-Burley (2000) illustrated the advantages and challenges associated with applying participant observation in the everyday school lives of disabled children. This method allowed the researchers to interact with children and staff in the field over a period of five months. The method also facilitated the children’s inclusion in directing the research process through self-reflexivity and negotiations with both adults and children (Davis, et al., 2000). The ethnographic process enabled the researchers to understand meanings through the cultural relations between children and other actors in the setting.
Morris (2003) has used the term ‘being-with’ to describe a similar research relationship. She has suggested that ‘being-with’ is useful when being inclusive of participants with complex cognitive and communication impairments. While participant observation is a classical ethnographic method, the concept of ‘being-with’ is derived from phenomenological philosophy. Moustakas (1995) has used this term for one of three processes that contribute to the development of relationship and receptivity: ‘Being-With means listening and hearing the other’s feelings, thoughts, objectives, but it also means offering my own perceptions and views’ (p. 84). Being-with teenagers involves natural interaction and participation in their everyday activities. In this way, the researcher becomes ‘a participant in their world’ (Gubrium & Holstein, 1997, p. 35).

In the process of participant observation, communication and interaction techniques already used in the daily environment may be useful for the researcher (Morris, 2003). Strategies may include particular routines, schedules, photographs, comic strips and Social Stories™, Board Maker™ and Talking Mats™. These communication strategies can assist in exploring individual perceptions and experiences in various situations. For this study, additional strategies for communication were explored. These strategies are outlined in the next section.

5.4.3 Strategies for communication

Preparing a range of communication strategies for including the views of participants with different preferences and abilities has been used in recent studies (Kelly, 2007; Kelly, et al., 2000; Punch, 2002). In these studies, it was found that while the individual participants’ own style of and preference for communicating would guide the engagement process, having additional strategies on hand was likely to help reduce barriers to inclusion. Previous research has reported that children with autism dislike face-to-face interaction (Beresford, et al., 2004; Preece, 2002). Therefore strategies such as email interviews or other internet-based communication were considered as possible alternatives to traditional interviews in this study.
A range of strategies deemed suitable for communicating and interacting with children diagnosed with autism has been published in clinical and educational literature. Other writers have noted the usefulness of this literature in the process of identifying communication strategies for use in research (Beresford, et al., 2004). For the purpose of the current study, it was important to consider that each strategy needed to respond to the individual in question in order to facilitate the inclusion of their views. One major consideration was that most communication strategies reported in the literature have been designed for young children. Although Beresford and colleagues (2004) noted that strategies for communicating with pre-verbal children may have been useful with some of their participants, in my view not all strategies were necessarily appropriate for older children and young people. I chose to include strategies that were simple to use and individually adaptable. Below I briefly outline the strategies I considered relevant to this study.

**Email interviews**

Conducting interviews by email was likely to be appropriate for some participants. As mentioned in Chapter 2, some individuals diagnosed with autism find writing easier than talking face-to-face. Writing takes the pressure off deciphering social cues while providing an answer (Davidson, 2008). There are several benefits of using email compared to face-to-face or phone interviews, both for the participant and the investigator (Meho, 2006). For example, email interviews allow for extra time to think and respond. Participants and the researcher can communicate at a convenient time. There are additional advantages for researchers in using email, but these had little significance for selecting the strategy for this particular research. For example, as a method, emailing is efficient and cost effective. Researchers can engage several participants at once and it requires no travel time or other resources. The data that are generated are already written, eliminating the need for transcription (Meho, 2006).
Social Stories
Social Stories™ was a communication strategy developed by Carol Gray (Gray, 2002; Gray & Garand, 1993). This strategy has been found valuable in explaining social and novel situations to children and young people with various learning difficulties (Gray & Garand, 1993; Rogers & Myles, 2001; Sansosti, Powell-Smith, & Kincaid, 2004; Swaggart & Others, 1995). In research including children diagnosed with autism. Social Stories has been used to prepare children for receiving a visit from a researcher (Beresford, et al., 2004). I considered using Social Stories in a similar manner but also as a possible resource for ongoing consent.

Comic Strip Conversations
Comic Strip Conversations™ is another invention of Carol Gray (1994). This strategy involves hand drawing and writing a conversation between two or more people with an emphasis on illustrating the thinking of individuals. Drawing stick-figures, or sometimes favourite cartoon characters, and speech/thought bubbles is useful to convey feelings, perceptions and ideas (Gray, 1994). Colours can be used to illustrate questions, ideas and emotions (i.e. green = happy, red = angry, black = facts). I have used the technique with my own children occasionally to help tease out complex situations (such as describing the consequences of a series of events) and abstract issues (emotions and thoughts) that they found difficult to express verbally. In figure 5.1 I have provided hand drawn examples of how Comic Strip Conversations may be used.

Figure 5.1 Example of Comic Strip Conversation
Talking Mats

The Talking Mat™ (Cameron & Murphy, 2002) is a low technology visual strategy designed to help people with verbal language impairments communicate their feelings and views about a particular topic. The strategy involves setting up a felted or laminated mat with options to indicate ‘yes’, ‘no’, and ‘don’t know’ or ‘like’, ‘dislike’ and ‘so-so’. A selection of simple pictures or photographs relevant to the person and the topics is then presented. Talking Mats can be used with people of different ages to enable responses to visual images. Talking Mats have been shown to assist with communication with elderly people diagnosed with different stages of dementia (Murphy, Gray, & Cox, 2007). They were also used as a research tool in a recent study including children who did not use speech for communication (Rabiee, et al., 2004). The researchers in the latter study illustrated how the strategy could be adapted for use with children with various cognitive and communication abilities and in conjunction with their individual communication methods. Rabiee and colleagues (2004) noted the ease of using this strategy and have stated that the young people involved found the method fun and enjoyable. An example of the Talking Mats is provided in Figure 5.2.

Figure 5.2 Example of Talking Mat¹⁰

¹⁰ Image freely available from the Joseph Rowntree Foundation website for non-commercial purposes (Murphy, Gray, & Cox, 2007)
**Picture Exchange Communication System**

The Picture Exchange Communication System™ (PECS) (Bondy & Frost, 1994) provides thousands of images of everyday items and activities. Traditional PECS images were mainly drawings; however, more recently, real life photographs are used as well. These images are often printed and laminated for use as visual cue cards. The images can be used with different communication strategies, such as the Talking Mats described above. The system is commonly used in schools and childcare settings to assist in communication and choice making and for designing visual schedules for children diagnosed with autism (Magiati & Howlin, 2003). Examples of PECS cards are illustrated in Figure 5.3.

**Figure 5.3  Example of PECS cards**

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**Emoticons**

Emoticons or ‘Smileys’ are textual facial expressions representing the face of a writer’s mood. These facial expressions are now commonly used to express emotions when using computer-based communication technology such as chat rooms, email or mobile phone text messages. Emoticons are generally familiar to individuals using computer-based technology to interact and socialise with others (Opdenakker, 2006; Walther & D’Addario, 2001; Yuasa, Saito, & Mukawa, 2006). For the

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11 The Picture Communication Symbols ©1981–2011 by Mayer-Johnson LLC. All Rights Reserved Worldwide. Used with permission. Boardmaker® is a trademark of Mayer-Johnson LLC. These images are publically available communication resources from Spectronics, New Zealand (Spectronics New Zealand, 2006).
The current study, 25 commonly used emoticons were printed at the size of a palm and individually laminated. Figure 5.4 provides examples of emoticons easily and freely accessible online.

Figure 5.4 Examples of emoticons

The communication ‘toolbox’
A communication ‘toolbox’ was assembled with resources for employing the strategies described above. The ‘toolbox’ included a range of tangible resources to enable participants to express their views creatively through drawing or writing or, for example, by making posters, mind-maps or mini movies. These resources included paper, cardboard, coloured pencils and digital cameras (still and video) (see Figure 5.5). A range of laminated communication cards was also included to assist with verbal communication or various activities. Some of these cards were the emoticons described above, while others had single words printed on a coloured background (such as ‘yes’, ‘no’, ‘stop’, ‘go’). The toolbox was intended as an aid to maximise opportunities for communication rather than as a stand-alone research tool.

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12 Emoticons are freely available on various websites. These examples are from the Open Clipart Library, which allows individuals to share images (Open Clipart Library, N.D.).
5.4.4 The roles of the researcher: Reflexivity and skills

The role of the researcher must be considered carefully in all research. Some qualitative researchers have explored the ‘least adult’ and ‘non-authoritarian’ role in gaining trust and participation from children (Mandell, 1991). Others have noted the importance of the researcher being a respectful learner in research that aims to understand lived experiences where participants are considered the ones with expert knowledge (Davis, 2000). When including children, the roles of the researcher can be many and varied. However, in listening to children, it is important that the researcher’s role facilitates children contributing their views and does not prioritise the views of the researcher (Davis, 1998). In practice, this means employing self-scrutinising practices that analyse whether children’s participation is being facilitated or hindered (Morris, 2003). The facilitating role of the researcher hears individual voices and is not deafened by a rigid ideology that sways the researcher’s understanding in one direction (Davis, 2000). Lincoln (1993) argues that silencing is created when:

*those who are subjects of research have little or no power in the construction of accounts, no access to text and no avenues into the corridors of knowledge production power (p. 32).*
The importance of a reflexive stance has been emphasised by researchers who have included silenced groups such as children (Christensen, 2004; Davis, 1998, 2000; Kelly, 2007; Mason & Urquhart, 2001). As discussed earlier, self-reflexivity in research is consistent with both phenomenological and ethnographical philosophies. Reflexivity can be expressed as ‘the process of reflecting critically on the self as researcher’ (Guba & Lincoln, 1981). Thus reflexivity should be applied by the researcher throughout the research process. In practice, this can be said to involve adult researchers questioning their attitudes and assumptions when interpreting children’s contributions, as well as the language and processes they use as academics and as members of the culture of adulthood (Mason & Urquhart, 2001). When including children and young people with different cognitive and communication abilities, reflexivity is imperative in order to help facilitate individual views being heard in the research because of the assumptions about the participants’ competency and position as other (Davis, et al., 2000). Davis and colleagues (2000) illustrated how reflexivity was significant in terms of negotiating the researcher’s role when engaging disabled young people in research within school settings where adults typically assumed an authoritarian role.

In this study, it was important that I as the researcher attempted to leave behind any assumptions about young people diagnosed with autism while still remaining sensitive to their individual requirements and preferences. It was important for me to be able to understand how I personally could reduce barriers to communicating with individual participants. Other researchers have found it useful to conduct team training before engaging in field work. For example, Morris (2003) highlighted the importance of being familiar with the social model of disability before involving disabled children in research. Similarly, Beresford and colleagues (2004) ensured that they learned about autism and the issues that are commonly problematic for children so diagnosed. Refreshing my knowledge on these aspects was important in preparing for this research. To reduce communication barriers, I decided that it was important to be familiar with communication methods other than speech. This learning process involved spending time as an aide in a school for children
diagnosed with autism and undertaking workshops run by the Australian Deaf Society. The workshops helped me to learn some basic sign language and to understand some of the common issues faced by deaf people when dealing with hearing people. For me, the process of skill requisition was useful for being reflexive, for understanding my own communication limitations and knowing how to make changes in the research process.

Researcher reflexivity is equally important in the writing process. Writing in a counter-hegemonic manner includes hearing the individual voices of participants (including the non-verbal ones) as well as that of the researcher. Individual views are contrasted in the text and there may be conflicts, but authority is not given to one view over another (Davis, 2000). This suggestion is congruent with Lincoln’s (1993) statement earlier in this section. Within anthropology, this approach is understood to help disperse the author’s authority by offering the reader different perspectives, values and voices within the final text (Davis, 2000). The author’s voice is not excluded from the text but serves to highlight how different voices compete and perhaps contrast with the author’s own voice (Davis, 2000 drawing on Fisher, 1986). The strength of counter-hegemonic writing is that it emphasises the plurality of children’s voices and experiences so that the individuality and complexity of children’s lives may be understood.

5.5 Summary

This chapter has outlined the rationale for the methodological design used in the current study, which was influenced by a social constructionist paradigm and theoretical concepts drawn from both childhood sociology and disability studies. In being respectful of young people and parents, a collaborative participatory approach was selected for this study. This approach is based on contemporary research developments in the fields of childhood sociology and disability studies. A qualitative framework informed by critical phenomenology and ethnography philosophies was selected to guide the research design and methods. The chapter also outlined the research methods considered suitable for this study. Data collection methods included semi-structured interviews and
participant observation. In using these methods, a range of communication strategies was outlined that was likely to be suitable with a diverse group of participants. The chapter concluded with a discussion about the variable and flexible roles of the researcher and the importance of employing reflexivity when engaging with young people. In Chapter 6, I describe the process of the study and how the aims were addressed using this collaborative participatory approach.
Chapter 6: Engaging with parents and young people: Research methods
6.1 Introduction

In the previous chapter, I explained the rationale for using a collaborative participatory research approach. In this chapter, I describe the research methods used with young people and their parents. The approach and methods discussed respond to some of the ethical and methodological challenges reported in previous studies (Beresford, Tozer, Rabiee, & Sloper, 2004; Preece, 2002).

6.2 Research design

A collaborative participatory approach was used in this study. As outlined in Chapter 5, this approach is appropriate where projects may be initiated by researchers but where decision making at various stages is shared between the researcher and the participants. While the research was my initiative, there were several opportunities for collaborative decision making over a 15-month period during 2007 and 2008. Collaboration occurred in three main phases, as follows:

- **Phase One** involved consultation with parents. The purpose of this phase was to gain access to teenagers, explore the parents’ views on their child’s participation and inquire about individual young people’s communication requirements and preferences.

- **Phase Two** involved consultation with prospective teenage participants and their parents about research engagement. The purpose of this phase was to establish rapport with the young participants, inform them about the study and seek their consent to participate in the project. These meetings allowed me to seek the young people’s input about their preferred methods of communication.

- **Phase Three** involved engaging with teenagers individually using methods of their choice. In this phase, most of the data were collected using interviews and observation, as well as a range of communication strategies.

Each phase was planned separately. However, the three phases merged and overlapped. This overlap occurred partly because dialogue with parents and teenage participants often developed
quickly, and partly because consultation with young people was an ongoing process during the data collection phase. This overlap meant that distinguishing between methodology and findings was sometimes difficult, creating some ‘messiness’ in writing up the thesis. Messiness is not unusual in research involving adaptation to methods and the generation of various types of data (Lewis & Kellett, 2004). To clarify the research process I have provided an illustration (Figure 6.1). Thereafter the process is described in a linear fashion from recruitment to analysis.

Figure 6.1 The research process
6.3 Recruitment methods

The recruitment methods were determined by my desire to gain access to a diverse group of teenagers diagnosed with autism. At the same time, it was necessary to bear in mind the requirements of two ethics committees\textsuperscript{13} to obtain consent from the parents of those below 18 years of age. The invitation to participate was addressed to parents in order to involve them as consultants to the study. Involving parents in the early part of the study was not to privilege their knowledge over their child’s; rather, the recruitment of parents enabled access to teenagers through significant gate keepers. The process of negotiating access through gate keepers can sometimes be complex and difficult when including young people with communication and cognitive impairments (Beresford, et al., 2004; Morris, 2003).

For recruitment I used two primary methods: the internet and paper fliers. An open call for participants (see Appendix A) was placed on the website and in the school newsletters of Autism Spectrum Australia (ASPECT).\textsuperscript{14} Using the internet for recruitment had the potential to provide access to a large population (Hamilton & Bowers, 2006). Using an autism-specific website for recruitment was likely to draw a range of respondents from the desired population.

A 1-page information sheet was printed in school newsletters. These printed materials were intended to reach families that did not use the internet. The information sheets were printed in the newsletters for three consecutive terms to families of children attending autism-specific schools or satellite classes run by ASPECT around Sydney and along the east coast of NSW. Some snowballing occurred through these methods as other schools printed the letter of invitation in their newsletters.

\textsuperscript{13} The University of Western Sydney Research Code of Practice (University of Western Sydney (UWS), 2005). The Research and Ethics Review Committee Guidelines of Autism Spectrum Australia (ASPECT) (ASPECT, N.D.)

\textsuperscript{14} ASPECT provides education, support and services relevant to families and individuals with ASD in NSW, Australia. Information about these issues as well as key information about international research are available on the website. www.aspect.org.au
Private people also forwarded the invitation to individuals or organisations they thought might be interested in the study.

This opt-in method was intended to help protect the privacy of individuals should several teenagers from the same ASPECT school participate. Opt-in methods of recruitment are considered to be more respectful of privacy and free choice than opt-out methods; however, they do involve some risk of generating a lower response rate (Alderson, 2004).

6.3.1 Recruitment of parents

Parents inquired about the study by phone or email. With some parents, several phone calls and/or email exchanges took place. A detailed research information package was posted to parents willing to proceed with the study. The package included a detailed information statement about the study (Appendix B) and a simplified version of the information statement (Appendix C) that parents could share with their son or daughter if they found it suitable. The information statements included the key aspects of participating in the research. These aspects were in line with those outlined by Morris (2003) as being important for young participants, including their right to decline, stop and end participation. The package also included initial consent forms for parents (Appendix D). The parents were asked to share this information with their son or daughter in a manner they found appropriate. I offered to create additional and particular resources for parents that would help with presenting the information to their teenager if required. A visit was arranged with the family following the initial consultation with parents and once teenagers had agreed to meet me.

6.3.2 Recruitment of young people

Recruitment of young people took place during a visit to their individual homes in Phase Two of the study. During this visit I informed the young people about the research and encouraged them to ask questions of me. I explained my role as being that of a student interested in learning and finding out about the lives of young people who had a diagnosis of autism. We discussed how collaboration would work in terms of how they were in a position to choose methods and topics for the study.
Methods of agreeing, disagreeing and ending participation were also discussed. I practised these methods with those who were unsure. We also talked about issues related to privacy and confidentiality, their right to stop the interview and to refuse particular questions or activities if they felt uncomfortable with any aspect of the process. During the consultation participants able to do so signed a consent form. The standard form for the young people was designed to include short and concise statements (see Appendix E) with boxes next to them, which were ticked when the participants understood and agreed with the statement. Section 6.7 describes in further detail the process of consultation and obtaining consent from young people.

### 6.4 Participant sampling

The participants in this study were those who opted in as a result of reading the open invitation to participate. The aim was to include six to eight young people aged between 13 and 19 years of age (teenage) diagnosed with different forms of autism. I did not intend to recruit a representative sample but rather a diverse range of participants. To achieve this diverse sample, the goal was to include young people who were using speech and forms of communication other than speech, participants diagnosed with a (measured) cognitive impairment and participants diagnosed with Asperger’s syndrome.

The number of participants was planned considering the overall research approach. Ongoing collaboration, as well as the flexible and eclectic application of research methods, was expected to require more time. The numbers in previous qualitative research projects were also considered. Those projects conducted by a single researcher and directly inclusive of children and young people with ASD and/or learning difficulties have typically included one to five participants (Carrington, Papinczak, & Templeton, 2003; Garth & Aroni, 2003; Preece, 2002). Studies including larger numbers (up to 60 participants) have commonly been completed by research teams of two or more people (Barnes, et al., 2000; Beresford, et al., 2004; Carrington, et al., 2003; Connors & Stalker, 2007; Minkes, Robinson, & Weston, 1994).
6.5 Study participants

In total, nine individual parents inquired about the study. After 12 months of recruitment, just six teenagers had agreed to participate and were included in the study. Amongst the six young people recruited to this study, there was some diversity of family, social and local community circumstances. The participants comprised four males and two females and their ages ranged from 13 to 18 years. The gender ratio of four males to two females was expected, as males are typically diagnosed with autism four times more often than females (Fombonne, 2005). The young participants had been diagnosed with different autism spectrum disorders (ASD). The young people’s individual diagnoses were disclosed by parents and/or the teenage participants themselves. They referred to diagnostic categories such as autism, higher functioning autism (HFA) or Asperger’s syndrome (AS). These six participants were labelled with a range of other diagnoses as listed in Table 6.1. Having multiple diagnoses is not uncommon for people diagnosed with autism (Ghaziuddin, 2000; Gillberg & Billstedt, 2000).

Of the six participants, five participants were able to communicate verbally. Only one participant did not use speech or other formal methods of communication, despite the invitation having been designed to explicitly call for teenagers with a range of abilities. It would have been desirable to include more than one participant with complex cognitive and communication impairments, as these young people are typically those excluded from or silenced in research (Beresford, 1997; Davis, Watson, & Cunningham-Burley, 2000; Morris, 2003; Preece, 2002). In an attempt to recruit more such participants later in the study, principals of ASPECT schools distributed a letter of invitation to participate in the project directly to families of teenagers attending their schools. This action did not result in further inquiries.
Table 6.1 Participant demographics

<table>
<thead>
<tr>
<th>Details</th>
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</thead>
<tbody>
<tr>
<td><strong>Gender:</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
</tr>
<tr>
<td><strong>Age:</strong></td>
<td></td>
</tr>
<tr>
<td>Dylan, 13</td>
<td>1</td>
</tr>
<tr>
<td>Anna/Lucas, 16</td>
<td>2</td>
</tr>
<tr>
<td>Kim/Ian/Andrew, 18</td>
<td>3</td>
</tr>
<tr>
<td><strong>Family situation:</strong></td>
<td></td>
</tr>
<tr>
<td>Both parents living at home</td>
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</tr>
<tr>
<td>No siblings</td>
<td>1</td>
</tr>
<tr>
<td>One sibling</td>
<td>2</td>
</tr>
<tr>
<td>Three or more siblings</td>
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</tr>
<tr>
<td><strong>Geographical location:</strong></td>
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<tr>
<td>Metropolitan</td>
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</tr>
<tr>
<td>Rural</td>
<td>3</td>
</tr>
<tr>
<td><strong>School setting:</strong></td>
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<tr>
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</tr>
<tr>
<td>Boarding school</td>
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</tr>
<tr>
<td>Special school</td>
<td>1</td>
</tr>
<tr>
<td><strong>Autism Spectrum Diagnosis:</strong></td>
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</tr>
<tr>
<td>Autism</td>
<td>2</td>
</tr>
<tr>
<td>Higher Functioning Autism (HFA)</td>
<td>2</td>
</tr>
<tr>
<td>Asperger’s Syndrome (AS)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Additional diagnoses:</strong></td>
<td></td>
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<tr>
<td>Attention Deficit Hyperactivity Disorder (ADHD)</td>
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</tr>
<tr>
<td>Language Disorder</td>
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</tr>
<tr>
<td>Hearing Impairment</td>
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</tr>
<tr>
<td>Vision Impairment</td>
<td>1</td>
</tr>
<tr>
<td>Depression</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2</td>
</tr>
<tr>
<td>Unspecified genetic disorder</td>
<td>2</td>
</tr>
<tr>
<td>Down’s Syndrome</td>
<td>1</td>
</tr>
</tbody>
</table>

There were other differences in the participant demographics, such as geographical location, family composition and school settings. While the participating families all lived within the state of NSW in Australia, their individual geographical locations included both metropolitan areas (inner city and suburban areas) as well as rural areas. Three teenagers were members of large families and had several older and/or younger siblings, while two had one sibling and one had no siblings. All the

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15 Pseudonyms used for all participants
young participants attended secondary education, which in Australia includes Years 7 to 12. One participant was enrolled in a ‘special’ school (School for Specific Purposes (SSP)). The other five participants attended mainstream high school settings with varying educational supports. One of these five had recently transitioned from an autism-specific primary school class to a mainstream class in high school. Another participant was attending a boarding school and was only home during school holidays and some weekends.

6.6 Phase One: Consultations with parents

Parents were consulted formally in the first phase of the study. This first step took place prior to involving the young people. Further consultation was sometimes useful in later stages of the process when participants’ circumstances changed or if young people found it helpful to involve their parents in the interviews or in the planning of a subsequent interview. With most parents, rapport was established easily and early in the first phone contact.

The main aim of consultation was to gain access to young people through their parents so that they individually had opportunities to decide whether they wanted to participate in the study. In research involving disabled children, the role of parents has often involved being a proxy for their children’s views (Russell, 2004). The parents’ knowledge was not the focus of this study and it was not privileged over that of the young people. Rather, the knowledge held by parents about their children was useful for negotiating access and gaining consent to meet with the young people.

Another aim of this consultation was to explore parents’ views on their children’s participation and find ways to address any parental concerns. In particular, the aim was to focus on those concerns that would present barriers to my meeting their children. Some researchers have suggested that parents may decline participation on their children’s behalf based on the parents’ concerns about the researcher’s expectations about their child’s ability to provide verbal answers (Kelly, McColgan, & Scally, 2000; Morris, 2003). In one study including children diagnosed with autism, some parents were concerned that a visit from a stranger (the researcher) would upset their children (Beresford,
et al., 2004). With consideration for these issues the consultations included providing parents with information about the research focus and the methodology. Additionally, it was hoped that gaining preliminary information from parents about individual teenagers’ communication abilities and preferences would help me prepare adequately to meet their children.

The consultations were informal but guided by questions that opened a space for parents to discuss issues they felt were important or relevant to their children’s research participation. Some questions were designed to find out how I could best prepare to meet the young people in terms of their preferences for social interaction and requirements for communication. Other questions related to individual families’ general situations. Specific questions focused on the parents’ views on their children’s participation. These included:

- What made you decide to participate?
- What do you expect or hope that your son/daughter will gain from participation?
- What are the benefits or drawbacks of listening to young people’s views?

This consultation with the parents provided preliminary information about the communication requirements of their child and likely preferences for interaction during the consultations involving young people. Consultation was conducted with the mothers of seven teenagers. All gave their consent for me to visit their homes and meet their children.

6.7 Phase Two: Consultations with young people

6.7.1 Consulting young people

Phase Two involved face-to-face consultations with six teenagers and their families. One teenager declined participation after receiving the information package even though his mother had consented. In this study, consulting young people was the first step in developing collaborative research partnerships with them. Other researchers have emphasised that consulting with children and young people prior to research engagement is beneficial in overcoming common
communication barriers (Morris, 2003). The main objectives for developing collaborative relations with young people involved developing rapport, gaining consent and setting up individual interviews with those who agreed to continue participation. The objectives were achieved through providing information to the young people about the research project and receiving information from them about their interests, preferences and requirements.

The families chose to have the consultations conducted in their individual homes. The consultations were conducted as informal conversations using a topic guide to ensure that key issues related to the purpose of the consultations were discussed. This format was useful in generating conversation and including the perspectives of both parents and teenagers. The entire interview, including the process of consent, was recorded with permission from teenagers and the family members present.

The duration of the consultations varied between 45 minutes and 2.5 hours, depending on internal family relations and the dialogue that was established with the family members. Lengthy consultations sometimes occurred because the topics of interest to the families led to internal discussions or because there were other distractions in the home environment such as curious pets, playful babies, sick siblings, phone calls and unexpected visitors. Although these events sometimes led to sidetracking, they also contributed to a greater understanding of the everyday life of the young people.

### 6.7.2 Methods of gaining consent

Consent was treated as an ongoing process rather than a one-off event. Ongoing consent is increasingly used in research with disabled children (Kelly, 2007; Morris, 2003). Several participants needed further clarification of the meaning of particular words. Once they were clear on the meaning of the information, these participants were able to sign consent forms. On each subsequent occasion I ensured that participants were still happy to be involved in the study and I reminded the participants that they could ask questions or make suggestions.
Consenting methods had to be individualised with one participant, Andrew. It was difficult to know to what extent Andrew was able to understand the research and the implications of his personal involvement. For Andrew, attaining assent was appropriate. Assent involves gaining the individual’s agreement to participate in the process when others (in this case his parents) have given consent (Lewis, 2002). Other researchers have also suggested that with some participants obtaining their willingness to interact is more appropriate than using formal methods of consent (Beresford, et al., 2004). In preparing for the first meeting with Andrew and his family, I had emailed a visual social story to Andrew’s mother (on her suggestion) to inform Andrew of my visit. In being inclusive of Andrew throughout the research process, it was appropriate to provide information in small sections at times where it had a direct meaning and application. At the same time, it was appropriate to ask Andrew’s permission for one issue or activity at a time to avoid confusion, so that he could indicate ‘yes’ or ‘no’ using his own gestures or the communication cards if he wished to do so. I developed a few simple visual resources (see Figure 6.2) for specific questions that I asked often, such as asking permission to take photos, and to make sure Andrew understood what I meant before he agreed or disagreed. After a while, I only needed to hold the camera up and Andrew would show agreement by either posing or pushing away the camera.

Figure 6.2 Example of visual consenting strategy

_Lise [photo of me] would like to see Andrew at school today. Is this OK?_  

Andrew can say **YES** or **NO**

_Can Lise take photos of Andrew?_  

**YES** or **NO**
6.7.3 Developing rapport and ‘setting up’ individual interviews

Once the young people had decided to participate in the study the consultation centred on developing rapport with each individual and setting up their participation in the study. An important aspect of developing rapport and setting up the research involved finding out about the young people’s communication preferences and abilities. The importance of approaching people with consideration for the way they communicate has been emphasised by other writers (for example Davis, et al., 2000; Morris, 2003). While parents had provided basic information about their son’s or daughter’s communication during telephone consultations, meeting with the prospective participants in their homes added further information about their communication style. Questions could be asked directly about the way the young people preferred to participate and let me know about their lives.

Additionally, the consultation visits provided opportunities to observe individual teenagers in their home environment and how they communicated with family members. My view was that knowing how teenagers interacted with familiar people would be useful in learning how they communicated in everyday life. Experiencing individual ways of communicating was particularly important when communication involved methods other than speech. The observations gave information about the way individual participants used vocabulary and tone, their use of particular expressions or gestures and the way they responded to questions or directions from their parents. In the meeting I also introduced the communication ‘toolbox’ described in Chapter 5 so that the participants had an opportunity to consider different ways of contributing their views and experiences.

‘Setting up’ visits and preparing young people individually for research engagement is an aspect that Morris (2003) has emphasised as particularly important when involving participants with different cognitive and communication abilities. Aside from identifying individual communication requirements and preferences, ‘setting up’ the research engagement with the participants in this study included discussing the best methods for participation, as well as considering issues of privacy,
credibility and trustworthiness. The young people were asked where they wanted participation to occur and whether they wanted to meet with me alone or have a family member present. For example, two young people wanted to meet me outside of their homes. One participant selected cafés where we could talk. With another participant, plans were made with his school to observe and interact with him there. The young people also decided how they wanted me to check my understanding of their contribution and how they preferred to receive/give feedback about the study.

Part of developing rapport and ‘setting up’ the research involved identifying topics that were interesting or important to the participants. The participants also asked questions about me and my family. The reciprocal exchange of personal information with participants early in the research process has been suggested as a fair and respectful approach to developing rapport (Kelly, 2007). This aspect of the visit was useful in getting a sense of the issues young people were interested in before engaging in research with them. Most of the young people were enthusiastic in beginning to tell me about themselves and often data collection commenced during the consultation phase.

6.8 Phase Three: Data collection and research engagement with teenagers

The third phase of the research process involved data collection with individual young people. The overall research aim was: To understand the everyday life experiences of teenagers diagnosed with autism. A set of broad topics guided the research. These topics were designed to explore:

- young people’s views of themselves and their lives
- issues/aspects of the current stage in their lives that were important for young people
- young people’s thoughts and feelings (if any) about the future
- young people’s thoughts and feelings (if any) about autism/having a diagnosis of autism.

In the topic guide, the questions were ordered so that they allowed young people to talk about issues that were important in their lives first. To ensure that I did not project to the young people
that autism was the most significant issue in their lives; the topic related to autism was approached last in the interviews unless young people brought it up beforehand. The research process and methods were individualised to enable the young people to contribute further to the research on aspects of their lives that were important to them.

Between one and five visits took place with each participant. The number of visits to each participant was influenced by the information gained each time, by the individual teenager’s willingness to continue participation and by the individual participant’s changing circumstances. With Kim, participation included a single but longer visit, due to her geographical location and the constraints on her time as a boarding school student. With two participants, emails replaced face-to-face visits after the first individual interview as their lives became busier. The duration of each visit ranged between one and six hours depending on the individual teenager, the research method and the setting. For example, when observing within a school setting, a four to six hour visit was not unusual, while face-to-face interviews were typically between 45 and 90 minutes long.

As outlined in Chapter 5, I had identified a range of creative methods that could be implemented in this study. In keeping with each teenager’s preferences, abilities and availability, the research methods used in this study were essentially based on two primary methods: semi-structured interviews and participant observations. As stated previously, the application of these methods was significant as they were adapted to individual participants’ communication abilities and preferences. Below I describe the processes of engaging with the young people through interviews and observation.

**6.8.1 Participant observation**

Participant observation was used with one person where more formal semi-structured interviews did not seem appropriate. This key method in ethnographic research approaches was used in two different ways. Firstly, **straightforward participant observation** involved observing the participant partaking in classes and participating in assemblies and sporting events. During this time I would
simply observe and take brief notes. Secondly, ‘being-with’ the participant enabled me to directly observe, interact with and participate with the participant in his everyday activities. In this study, ‘being-with’ involved partaking in activities with the participant at his school, at school functions, on outings and in his work experience placement. For example, when going on the work experience placement, I was packing and stacking boxes just as he and the other students were doing.

When confronted with issues that arose in the environment I was observing at the time, I tried to take mental notes of my own reactions and thoughts. As I was often actively involved in activities, it was not appropriate to take notes at the time. Usually I spent an hour immediately after a visit writing down details from the day while sitting in my car. During the time of observing and ‘being with’ the participant, I sometimes took photographs or made short video clips of him with his permission. These photographs and video clips were later useful for communication, for generating resources for meaningful interactive activities and for the purpose of providing feedback (see Section 6.9).

6.8.2 Interviewing

*Face-to-face interviewing strategies*

Traditional face-to-face interviews were favoured by the five teenagers who were able to communicate verbally: Anna, Kim, Dylan, Ian and Lucas. Although several of these young people used internet chat and email to socialise, they did not choose to use these methods for research participation initially. Semi-structured interviews were used both in face-to-face interviews and in email interviews. Where semi-structured interviews were used within this research, open-ended questions were employed initially as is common with this method of qualitative research. Some of the young people disliked open-ended questions. While I learned this through the way some participants answered the questions, Kim stated straightforwardly that she felt the questions emailed to her ahead of the interview were too broad:
Difficulties with open-ended questions have been reported in previous studies that included children diagnosed with autism (Beresford, et al., 2004; Preece, 2002), as well as in research with disabled children more generally (Kelly, 2007; Morris, 1998). In response to these studies, I had initially prepared a few slightly more focused questions under each broad topic in order to start the interviews. However, sometimes it was necessary to break down questions further so they could be answered with a yes or a no. This approach contrasts with what is typically suggested for qualitative research interviews. However, in responding to challenges reported in previous research, I decided to use these questions if appropriate. Often these questions were more successful in generating conversation and in-depth answers than the ambiguity of open-ended questions.

In conducting the interviews I considered the divergent ways in which the five participants verbalised. Occasionally the diversity made it a little tricky knowing how to pitch and phrase questions. It was necessary to be considerate of the vocabulary used by individual participants. Some participants used a rather complex vocabulary. For example, Lucas often used jargon when referring to aspects of his interest in computers or his favourite online communities. With Dylan and Anna, it was most useful to use uncomplicated terminology and sometimes clarification of words was necessary to ensure reciprocal understanding. In interviews where parents were present, they could sometimes be a useful resource in restating a question using a word or phrase that was more meaningful to the participant; at other times, I needed to think of different ways of talking about the topic. Sometimes participant responses were ambiguous as they used words such as ‘maybe’ or ‘sometimes’. These responses typically indicated that I had asked a question that was unclear to the participant or that the participant was perhaps reluctant to answer the question. At other times I encountered silence from the participants after asking a question. When this happened, it was tempting to try to fill in the silence. However, as others have also found, it was important to wait
before saying something again (Morris, 2003). It was not unusual for some young people to take some time to think about the questions and formulate a response.

**Participants’ strategies for enhancing communication**

Few participants expressed interest in using the resources provided in the ‘toolbox’ such as writing, drawing or using the cameras. When I went through alternative methods or options for communication, the participants typically declined, saying things like ‘I can say it’ and ‘I’ll be fine with just talking face-to-face ... like I am cool with that’ or by asking ‘Can I just speak to you?’ However, some young people used their own particular strategies to assist them in communicating their views.

A range of strategies was introduced by individual participants to communicate their views and experiences. Kim made a written personal profile available that outlined details of her characteristics, strengths, weaknesses and things that made life harder or easier. Ian and Anna provided handwritten pages with answers in response to the questions I had emailed prior to the interviews. In his answers, Ian had drawn a diagram (the ‘Me tree’, see Figure 6.3) to illustrate his personal traits and identity, as well as the things in life that were important to him. Lucas seemed a particularly keen and competent computer user. In one interview, he booted up his laptop, informing me ‘I can show you what I mean on my computer’. He showed me examples from internet websites to illustrate issues of particular importance to him. This activity created an in-depth dialogue that provided rich information about issues of particular importance to him. Meanwhile, Kim stated that it was important for her to have her mother present during the interviews so that she could help express her thoughts and views. Between them, this strategy worked well especially when discussing more complex issues. The individual initiatives described above show how the young people engaged in the study and took ownership of the methods and strategies that were suitable for them. The use of strategies that were meaningful to each participant also significantly increased their enthusiasm and the depth of the answers they provided.
Using alternative communication strategies

With Andrew, using a number of alternative communication strategies was appropriate. Andrew had significant hearing and vision impairments. While he did understand some speech, Andrew used no formal method of communicating such as sign language or Makaton. Rather, he used a combination of gestures and facial expressions. In the beginning Andrew’s parents were a useful source of information. They described to me how Andrew showed agreement and disagreement and explained some ways Andrew showed his intentions. For example, when Andrew was clear about what was being asked of him he would use a thumbs up gesture to say ‘yes’ or agree. To say ‘no’ or disagree he either shook his head vigorously or simply turned away. His mother added ‘You’ll definitely know when there is something he doesn’t want to do’, which I experienced for myself during subsequent visits.
The methods employed during the research process were adapted to suit the context of different settings, Andrew’s methods of communicating and his changing personal circumstances. Initially, participant observation, including the process of ‘being-with’, was the most appropriate method in the school environment as there were few opportunities to engage directly with Andrew in a focused and structured way. Unfortunately Andrew was hospitalised for several weeks and did not make it back to school before his graduation. A final visit was made to Andrew at home to close off his participation. In this last visit, two communication strategies were used as the opportunity arose and Andrew seemingly enjoyed the activities.

Using the Talking Mat activity was appropriate at one time in the last visit in Andrew’s home. Andrew was enjoying looking at photos I had taken during visits to his school. During the last visit, these photos provided an opportunity to ask more detailed questions about particular situations. For this purpose, the Talking Mat was valuable in clarifying Andrew’s views on everyday situations, as well as on tasks and activities he engaged in regularly (see Figure 6.4). Sometimes Andrew’s views contrasted with statements by teachers or parents about the things that he liked. For example, using the Talking Mat, Andrew told me that he did not enjoy ten pin bowling as much as his teacher had indicated that he did.

**Figure 6.4 Andrew’s Talking Mat**
A significantly adapted version of the Comic Strip Conversation was also used with Andrew. I prefer to call this activity ‘illustrated conversation’ as many of the techniques for Comic Strip Conversations were not practical or appropriate at the time. This strategy provided more direct knowledge about Andrew as I was able to ask him questions about himself. I was also able to clarify questions that his parents had been unsure about. The activity involved writing single words or short sentences, along with simple symbolic drawings. These were not pre-empted words, sentences or drawings, but those that were relevant as I interacted with Andrew at that particular time. Simply using the pen and paper, questions were asked about particular topics similarly to other semi-structured interviews. For example, using this technique, Andrew was able to indicate that he was 18 years of age, that he was a teenager, that he was able to talk and that he wanted to talk. Figure 6.5 is an example of the illustrated conversation between Andrew and me.

**Figure 6.5 Illustrated conversations**

Andrew seemed to enjoy the more structured activities, as he was particularly focused and kept looking into my eyes as if he wanted more questions. Unfortunately this direct engagement was interrupted once his father entered the room. However, being able to draw on these activities was useful in facilitating Andrew’s views in ways that I would not have learned through traditional observations or interviews.

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16 These illustrations have been reproduced to protect the participant’s identity.
The use of email

Email communication was used in a number of ways. Firstly, email was the preferred way of keeping in contact with participants throughout the research process. Additionally, and as indicated above, most of the participants requested that some questions be emailed to them before the first interview so that they could prepare themselves. Email was also used as a means of data collection. After the first face-to-face interview, two participants requested to continue participation using email because it suited their new circumstances better. Once the participants got used to communicating with me using emails, they elaborated on their perspectives and sometimes wrote quite long, emotional answers. Lucas even surprised himself by how much he wrote: ‘Wow – I wrote a lot then, but I stand by every word of it strongly’.

Using email interviews is a fairly new research method and currently there is no standard way of conducting these. In using this method I had to develop my own guidelines, informed by the way individual participants communicated. The strategies I used included asking a maximum of four questions per email. Each main question included one or more sub-questions to ensure clarity and to help the participant think about different aspects of each question. Mostly these questions followed a topic discussed during the face-to-face interview; thus, for each question, I would remind the participants of the topic so that they knew why that question was being asked. I responded to the participants’ responding emails as soon as practically possible in order to maintain connection, continuity and motivation. Both participants expressed the view that emails were suitable for them at this time of the research process, but only because we had already met face-to-face.

The previous sections have illustrated how the use of research methods was individualised with the young research participants. Facilitating communication with some participants involved drawing on a range of strategies. This point has been raised in other research including children and young people with cognitive and communication impairments (Kelly, 2007; Morris, 1998). The examples show that it is possible to find engaging techniques that allow for individuality. While the same detail
was not achieved in all interviews, paying attention to the strengths of individual communication styles helped me to understand the views of children and young people despite the absence of formal communication methods. Additionally, the flexible approach allowed for changing the research methods and adapting communication strategies when appropriate. This flexibility also allowed for the changing circumstances in young people’s lives and the identification of more suitable methods if found necessary through reflexive analysis of the process.

6.9 Data analysis

Analysis of the data collected in this study was complex and time-consuming because of the varied nature of the information gathered and the different methods used. Observational data were documented in field notes. Audio taped data were collected from six family interviews (1.5–2.5 hours each) and nine individual face-to-face interviews (1–2 hours each). Written data were produced through the use of email interviews. Handwritten notes were produced in key points as a record of phone conversations. Other data sources provided by participants included handwritten notes, drawings and a typed personal profile created by a participant and her mother for another purpose. Photos and video clips were used as a means of facilitating communication rather than for analysis purposes. All recorded interviews were transcribed as soon as possible after each visit. I had assistance from professional transcribers to ensure that I did not fall behind with interviews, but always double-checked transcripts against recordings for accuracy. Along with email trails, the field data were organised using the Nvivo7 computer software package (QSR, 2006).

Analysis of data and research engagement occurred at various intervals throughout the study. During verbal interviews, I consistently double-checked with participants my understanding of their views. Some participants specified that they wanted me to rephrase their answers and repeat them back to them. After each visit, I read through the transcripts and field notes. This activity provided opportunities for preliminary data analysis and for reflecting on the way communication and interaction with participants had occurred. Immediately after each visit, as I took down notes of the
topics discussed, observations made, the usefulness of the methods and any issues that may have emerged, I reflected on the overall process and the information contributed by individual participants. These notes were used to develop a reflective log. Informed by the reflexive approach used by Davis and colleagues (2000), issues of concern were discussed with the supervisory panel and notes were made of the subsequent interpretations made or actions taken. I engaged in consistent dialogue between visits with academic colleagues and my supervisors about the usefulness of methods and application of strategies, as well as my feelings and responses to dilemmas in the process and how to proceed. This activity facilitated reflexivity in terms of my role as a researcher, as well as in relation to my experiences and observations of the participants’ interaction with me, peers, parents and teachers.

On completion of the data collection, all data were analysed in a systematic way to explore whether themes occurred that related to the broader research question topics and the theoretical underpinning of the project (Richards, 2005). Firstly, each transcript was read and then re-read in detail. The same process was carried out with observational and other written data. Sections were highlighted to indicate strong or recurring topics. Annotations were made to develop points for further investigation. As several transcripts were processed, initial broad themes were developed and listed, and possible connections were made with theoretical concepts. Links between individual themes were explored and documented. This process was reiterative and included engaging with the text and making sense of what the participants had said or done.

The analysis process involved more than simply identifying themes. The young people’s opinions and ideas were important aspects of the further development of the interview questions and the research process. Therefore the issues raised by the participants became integral in directing the analysis process. Common and divergent perspectives were identified within and across interviews. Observations highlighted that participants’ perspectives were sometimes contradictory and sometimes similar across their experiences.
Various strategies were employed to ensure authenticity and trustworthiness of the interpretations of the qualitative data, in terms of its representation of the young people’s views, were at the centre of this study. The participants verbalised in diverse ways, which meant that there was significant difference in the depth and density of content in the transcripts. This divergence had implications for the analysis process, as I found some transcripts were more complicated to analyse than others. Thus, as part of the analytical processing of these instances of complexity, I found it helpful to discuss particular extracts of transcripts and field notes with the supervisory panel.

The young people were encouraged to provide feedback on the research process and on summaries of the findings in order to comment if they wished to do so. Three participants opted to have brief typed summaries which were emailed to them towards the end of the entire research process. Two participants declined typed summaries because this involved reading, a task they disliked. When I explained that I wanted to ensure that they agreed with what I had written, one of these participants stated that a summary of my findings was not necessary because he already ‘trusted’ that I would write the right things about him. These participants also stated that they were not really interested in what other young people had to say. One participant was said to have limited reading skills and did not engage in writing or typing himself. As a typed summary was not an appropriate way of obtaining feedback from these participants, I created alternative techniques to present at the completion of our last meetings, which included the preliminary findings.

One technique was what I termed ‘profile mapping’, an activity similar to making a concept map (a modified example is provided in Figure 6.6). The profile mapping involved writing out the information contributed by the participant in key points under headings of the question topics. Using a handwritten map kept the activity informal. This technique was helpful in drawing information together and summarising it for the participants in an interactive and visual manner that did not involve a great amount of reading. I read through the key points with each participant and encouraged them to make comments and to change, withdraw or add points if they wished to do so.
With Andrew, the profile map was supplemented with photographs and video clips taken during the observation visits. Using some of the concepts from the Talking Mat technique and the participant’s own communication symbols helped clarify likes and dislikes, as well as issues of importance.

Figure 6.6 Profile map example

6.10 Summary

The research approach used in this study was designed to develop collaborative participatory research relationships with the young participants and their parents. This chapter described in detail the design and the process of the research in a linear manner to provide an overall image of the research structure. I outlined the purpose and the process of the three major phases of the research, namely the consultation with parents, the consultation with young people and their parents together and the individual research engagement of the young people. The chapter described the participants and the process of providing information and gaining consent, as well as how a range of research methods was applied in engaging with them according to their individual preferences and abilities. The chapter also showed that some of the young people had ideas of their own for how to tell me about their lives.

In the next two chapters, I begin to report on the findings produced from this research. For clarity and knowledge-building purposes, I have attempted to separate what I am defining as ‘findings’ learned by applying the above described research approach from findings that have been produced
through the knowledge contributed by the young participants. In Chapter 7, I focus on the findings that contribute methodological knowledge. These relate to recruitment, the consultation with parents and teenagers and the use of methods and strategies for consent and research. These findings are potentially useful to others researching in similar areas, as well as for practitioners and policymakers wanting to employ inclusive strategies with young people who may communicate and interact in a range of different ways.
PART THREE: FINDINGS
Chapter 7: Applying a collaborative participatory approach: Key findings from engaging with young people diagnosed with autism and their parents
7.1 Introduction

In this chapter, and in Chapter 8, I document the findings from the research as they relate to the two aims of the project: learning about the lives and experiences of teenagers diagnosed with autism and developing a research approach to facilitate the inclusion of their views. In this chapter I report specifically on the key findings from employing a collaborative participative research approach. The findings are important in light of the challenges facing researchers who want to be inclusive of young people diagnosed with autism and/or cognitive and communication impairments. Some of the findings also have implications for research involving children generally.

Findings are presented according to the stages of the research process and include references to literature that supports, explains or contrasts with the findings from this research. I begin with a summary of findings from the recruitment stage. Thereafter I present issues that emerged during consultations with parents and young people. In that section, I highlight reasons parents and young people gave for participating. I show how involving parents and young people as partners in the research process had implications for gaining consent and engaging with individual young people, as well as for my role as a researcher. Finally I demonstrate how a flexible research approach enabled the inclusion of, and collaboration with, young people.

7.2 Recruitment as a difficult process

Recruiting an adequate number of participants for this study was difficult. The overall number of inquiries from parents was low, with few inquiries from parents of teenagers with more complex impairments. No selection criteria were applied. The six participants were those young people who volunteered after initial inquiry.

Eleven inquiries were received. Nine inquiries were from parents and two from organisers of support groups. Of the nine parents, two chose to not participate. Communication was lost with one mother after an initial email inquiry, despite my attempts to contact her. Another parent expressed a desire
to receive behaviour intervention for her son. She declined participation as the aims of this study were not a priority for her at that time. One teenager declined participating in the initial consultation meeting, despite his mother’s hope to include him. After receiving the information package, the mother phoned to inform me that her son was not interested in partaking in this study. He disliked the autism label and rejected talking about it in relation to himself. Although that young person may have contributed interesting views, his right to decline was acknowledged. The organiser of one support group commenced initial preparation for me to engage with a small group of teenagers diagnosed with autism. However, a series of concurrent events meant that these young people were unable to participate.

The difficulty in recruiting the desired number of participants reflects findings in previous research involving children diagnosed with autism (Beresford, Tozer, Rabiee, & Sloper, 2004) and with disabled children more generally (Connors & Stalker, 2002). The small number of inquiries may have been because of the recruitment methods used, gate keeping by adults or decisions around participation made by the young people themselves. These reasons remain unknown because using the opt-in method for recruitment is respectful of individuals’ privacy. Such methods do not allow researchers to find out about those who dismiss research recruitment or those who may read a call for participation but never inquire (Hill, 2006). Other research has suggested that some parents may not see any benefit from participating in research or may see participation as too time consuming (Connors & Stalker, 2002). Connors and Stalker (2002) highlight that parents of disabled children often have to deal with large amounts of paperwork. Parents and children also have high levels of contact with professionals, which can be time consuming and tiring.

Findings from my research indicate that young people may control access to knowledge about their lives and experiences. Not all young people whose parents inquired agreed to participate. Perhaps some young people may not understand certain research as significant or of value to them and therefore decline participation even when their parents consent. It has been highlighted elsewhere
that some young people are simply not that interested in participating in research (Edwards & Alldred, 1999). Even if research such as this does resonate with issues in young people’s lives, it is possible that some will decline because they do not wish to talk about their diagnoses or impairments. Researchers have suggested that sometimes disabled children and young people resist the identity imposed on them by others that may relate to stereotypes of impairment and disability (Davis & Watson, 2002). In this research, these reasons can only be guessed at; however, it was possible to investigate reasons parents and young people chose to participate.

7.3 Reasons for participating in research: Views of parents and teenagers

Both parents and young people gave their reasons for participating in this research. Parents reported three main reasons for wanting their son or daughter to participate. These reasons can be categorised as making a contribution to research, advocating for their children and empowering their children. The young people also expressed a desire to be heard. Their two main reasons for participating were feeling empowered and having control over the way they could participate. In the following sections, I present these reasons in more detail.

7.3.1 Parents wanting their children to participate: Making a contribution to research, advocating for their children and empowering their children

Making a contribution to research

Typically, the parents wanted to make a contribution to research. There seemed to be a consensus among parents that children and young people labelled with autism are poorly understood by others, both adults and children. They described children diagnosed with autism as different to, and often more vulnerable than, other young people. They expressed the view that more knowledge was needed for the general public to understand the issues associated with living with autism.

One parent expressed that his endorsement of this research related to his awareness of the scarcity of literature around the personal lives and experiences of individuals with ASD:
I guess I am sort of looking at this as a really good thing to do. Doing research in an area where there is little. So I am quite pleased about it.

A perceived ‘duty’ to be involved was a reason given by another parent. This parent stated the importance of sharing with others their experiences of living and learning with a child diagnosed with autism:

_We have an enormous amount of information we've learned through experience ... [We are] always willing to share and learn more ourselves._

The parents also wanted to involve their children in research to help raise awareness of issues experienced by young people. Therefore this research complemented the way they were already advocating on their children’s behalf.

**Advocating for their children**

Advocating for their child was the second main reason given by parents for participating. Parents who allowed me to meet the young person expressed the view that this research resonated with their own efforts to advocate for their children. Three parents felt that the differences associated with autism marginalised their children. Every parent had at least one story where their child had been excluded, misunderstood or ridiculed because they were seen as different from others. Two parents expressed concern about the rights and security of children and young people diagnosed with autism. They gave examples of severe bullying incidents at school and while on public transport. One parent expressed the view that a lack of awareness around the views and experiences of children diagnosed with autism placed young people’s safety at risk:

_The general public needs to know that these kids see the world from a different perspective. No one understands how to support them and keep them safe._

Some parents described feeling powerless in their advocacy efforts to promote an awareness of issues faced by their children. Such powerlessness is evident in the extract below. The parent first expresses her frustration in negotiating the educational system. She then states her belief that the
teachers dealing with the children directly need to be better educated in teaching and caring for young people diagnosed with autism:

_We’ve called on the area department for help in various ways; however, I don’t think teachers are very well educated in the abilities and limitations of kids like [name] ... Teachers just don’t understand ... ASD._

These parents expressed the hope that including young people’s own views and experiences in research would bring about awareness of the issues associated with autism, while also empowering young people in the process.

**Empowering their children**

The third reason raised by parents for wanting their children to participate was to empower them. Some parents explained that their son or daughter liked to talk with people about the things that were important to them. One parent explained that the prospect of empowerment had motivated her son to participate in the research: ‘[he] was interested once I told him he could express his opinion ... [and] be heard’.

Empowering children and young people diagnosed with autism was important to these parents because the young people were often marginalised. Another parent stated that it was time these young people had ‘... a chance to tell it like it is’.

A third parent felt that autism not only set children and young people apart from other children but also from disabled children more generally:

_Kids with physical disabilities have a platform, but kids with ASD are often not heard or accounted for._

This parent added that she hoped participation in the research would be both therapeutic and empowering for her daughter:

_[She] may understand that she is not the only one, that other children have similar issues and that they have a voice. It [participation] may even empower her._
These accounts show that the parents were enthusiastic about their children’s views being heard. This finding contrasts with the reports from other research that parents can be reluctant to let their children participate (Beresford, et al., 2004; Connors & Stalker, 2002; Morris, 2003). Considering the few inquires received, however, it is possible that these parents were particularly proactive. The parents’ efforts to be heard and struggles with the education system that motivated their participation reflect findings in other studies focusing on parent views (Fong, Wilgosh, & Sobsey, 1993; Renty & Roeyers, 2006; Stoner, et al., 2005). The parents in my study expressed the view that young people’s personal experiences could make important contributions to research and the way that autism is understood by society. The parents also indicated that the focus of the research supported their own efforts to advocate for their children and the need for young people to be heard. In some families, however, the parents’ enthusiasm exceeded that of the young people. The young people’s perspectives on participation are explored in the next section.

7.3.2 Young people wanting to be heard: Feeling empowered and having a sense of control over participation

During the consultations, it became apparent that the young people had different motivations for participating in this research. Most of the young people indicated that the focus of the research was relevant to their lives. Four of the young people were enthusiastic about being research participants. Two were a little hesitant. Being heard was important for all the participants. However, for those who were more enthusiastic, participating seemed to be about empowerment arising from having one’s views heard on particular issues. For the other two, being able to control the ways in which they participated was more important. I explore these views below.

Feeling empowered

Four young people expressed a desire to be heard on issues important in their lives. While three of these participants had been encouraged to take part by their parents, the focus of the research seemed to have relevance for them. For example, after reviewing the information statement, Ian reflected that: ‘I’ve always wanted to be part of something like this’. Lucas was eager to make his
views known on a political issue. Being listened to and recorded seemed to be significant for him. At one point, Lucas wanted to make sure that his views were captured clearly on the recording and pulled the recorder closer as he continued talking: ‘I have one more statement ... cause it’s kind of interesting to be recorded ... to sort of get it out there’.

Kim had initiated participation herself. After finding the call for research participants on the internet, she asked her mother to volunteer on her behalf. Kim told me how she was exploring the meaning of autism for herself. She felt her knowledge and experiences would contribute to the research. She explained that she was currently struggling with issues that affected the way she felt about her diagnosis of autism. For Kim it was important to capture and articulate these feelings at that particular time.

**Having a sense of control over the way of participating**

For two participants, having a sense of control during research participation seemed more important than the focus of the research. These two participants were initially hesitant to communicate with me and to make a decision about participating. Initially both Andrew and Anna agreed to meet me because their parents had approved the research and arranged the consultation. Andrew was reluctant to interact with me in our first meeting. His parents had expected this reluctance. They informed me that, at home, Andrew usually liked to ‘do his own thing’ and disliked interruptions to his home routines. Andrew’s mother expected that he was likely to enjoy participation if it took place at school, as he enjoyed socialising outside of the home. Anna was not reluctant to interact with me as such. However, she was quiet during the consultation with her parents present. She also hesitated to make a decision about further participation in the study, stating that she was ‘just not sure’.

With both Andrew and Anna, my initial feeling was that they were trying to decline participation. However, both these young people agreed to take part in the research once they were assured that they could participate outside of their homes (for details see Section 7.4). It is difficult to know
whether they were concerned about privacy and confidentiality in their own home or just more comfortable interacting with a stranger outside their home. It did, however, seem important for these participants to have some control over the way they participated.

The findings reported in this section responded to the aspect of the research which was concerned with learning about the views on research participation by parents and young people. These findings indicate that the parents and some young people agreed to participate because the research focus resonated with current issues in their lives. Parents indicated that the research had the potential to assist them with advocacy and their child’s right to be heard and understood. It seemed that for these parents, the focus of this research was timely and meaningful. Similarly, most of the young participants who agreed to the research did so because they had something to contribute and wanted to be heard. Even though two of them were reluctant participants initially, they willingly contributed their knowledge and experiences once they felt comfortable with the research process and methods.

The significance of participating in research that was meaningful and empowering for these young people reflects findings in previous research with children and young people. Edwards and Alldred (1999) argued that children’s views on research are strongly linked with the meaning the research topic has for the ‘personal, local and wider societal contexts of their lives generally’ (p. 277). For some participants in this study, the context was the opportunity to express their views on autism, as well as their views on other important issues in their lives.

It is likely, however, that the way these young people interacted during consultations and made decisions about participation was influenced by the involvement of parents as partners in the early stages of the research. In the next section I present findings that indicate the inclusion of some of the participant’s views were influenced by parents.
7.4 Involving parents in the research process: Implications for young people’s participation

Involving parents as partners in this research had both benefits and disadvantages for the goal of involving young people as participants. Mostly the parents acted as facilitators and advocates for their children. In some cases, the parents’ involvement supported the young person’s engagement in research. At other times, their involvement seemed to compromise hearing the young person’s views. In the next two sections I outline these aspects of the research process.

7.4.1 Parents as collaborators and facilitators of young people’s participation

Parents facilitated participation of young people in two ways. Firstly, they initiated the first contact and organised the first meeting with the young person in their home. They also facilitated the subsequent interviews, setting aside time and providing a private space – usually in their home – for the interview to take place. One parent willingly transported her daughter to the locations requested for participation. Secondly, the parents facilitated hearing the young person’s views by sharing their knowledge about their son or daughter, promoting and sometimes assisting with communication. For example, the parents were usually keen to involve their son or daughter in the consultation process. Some stepped back and allowed their son or daughter to speak. At times, parents and teenagers supplemented each other in remembering details and contributing information. Some parents were helpful in terms of assisting with strategies for communication by discussing with their son or daughter ways most suitable for participating in the project.

One parent was directly involved in the facilitation of her daughter’s views through a joint interview (details of the process are included in Section 7.5). The extract below from the consultation with Kim and her mother illustrates how they worked together. Here the mother considers the implications of Kim’s uneasiness with the use of communication cards. After I showed Kim the communication ‘toolbox’, a few communication cards were left on the table between us and the mother encouraged her daughter to speak out:
Mother: (To Kim) Are you happy having the cards sitting there? [laughs]
Lise: Are they distracting you?
Kim: I won’t use them.
Lise: No. You don’t think so?
Kim: No ... Like ...
Mother: Go on, you can say whatever you like.
Kim: You know when I was getting the special help when I was younger ... I found it very patronising with all these cards and things.
Lise: That is fine. I’m happy to take them away. (I quickly remove the emoticon and communication cards.) OK.
Mother: Yeah, yeah, she was probably never taught how to use them properly, I think. So it became more of an issue of feeling like an idiot rather than ... you know ...
Lise: Oh OK. Yeah. That’s fine, I understand ... and that certainly wasn’t the intention.
Mother: No, I just knew Kim was going to have a reaction to having a look at these cards, ‘cause that is what she said, she used to hate, you know, those PECS cards and Board maker ... she just hated it ...

The extract shows the significance of the mother’s involvement and her knowledge of her daughter’s views and feelings. It is possible that Kim would not have said anything about the cards on the table on her own. Perhaps she would have completed the consultation with their uncomfortable presence. This example shows how involving parents sometimes facilitated communication between me as the researcher and the young person. However, there were also times when some parents’ involvement and enthusiasm for the study almost compromised the young people’s views. I turn to this aspect of the research in the next section.

7.4.2 Engaging young people with their parents present: Tensions and constraints

From my research, it seems that the parents’ role as partners in researching with their children at times had the effect of limiting young people’s voices from being heard. Despite my intentions to the contrary, in some families it seemed that the parents’ role in the research strained the research relationship. Occasionally tensions stirred between family members, which had implications for the young person’s opportunities for being heard and making decisions. Mostly these tensions occurred in the initial consultations where the parents were present alongside the young person. In some families the parents were particularly keen to contribute their own views: so much so that their voices almost imposed on the young people’s views. For example, in one family, a parent was unintendedly competing with the young person for the most talk time and often answered questions
on the young person’s behalf. In another family, the teenager was reluctant to talk about his interest in computer games because he knew that one parent did not appreciate it. Occasionally parents raised issues that the young person did not want to talk about. On these occasions, it was necessary to negotiate individual research relations and important for me to focus on the young person and be inclusive of their views.

**Implications for making decisions**

The parents’ presence sometimes had implications for the way young people made decisions about participation. While some young people indicated early their own interest in participating, parents sometimes took on the role of advisor. Some parents sent clear signals to their son or daughter that they wanted them to participate. Usually, however, parents also signalled that the final decision was up to the young person. The following statements from one of the fathers illustrate both kinds of signals:

*I guess I am just sort of looking at this as a really good thing to do; doing research in this area where there is little. So I am very pleased about it.*

*As far as I am concerned, it’s great. It’s a great idea, you know, um it’s gonna [sic] be ... it’s not a huge amount of work for him ... or for us.*

*It sounds pretty good, Ian, but it’s up to you.*

In the first two statements the father indicated to me his support for the research. The father made his own position clear by stating that the research was ‘a really good thing to do’. Then he emphasised his view by pointing out a positive aspect about the investment in the research: ‘it’s not a huge amount of work ...’. In the final statement, the father addressed Ian, his son. Here he indicated first his support for the research – ‘it sounds pretty good’ – but also provided space for his son to reject participation in the project.

Another young person’s freedom to refuse participation was limited. In this case, the tensions at play between the teenager and her parents presented a dilemma in the process of ensuring willing
consent from the young person. I referred to this aspect of the research in Section 7.3.2 when discussing the importance for some young people of having some control over their participation. Below are extracts from a scenario that unfolded between Anna and her parents during the consultation in their home as she hesitated to consent to participation:

Anna: I don’t know yet …
Lise: Ok … do you need a little more time to decide …?
Anna: Yeah …

Mother: This is research that might help you …
Father: And other people …

Mother: This research could help you really … other people don’t understand how you think …
Father: … my attitude would be that, there would have to be strong reasons why not to participate …
Mother: Well it’s not up to you …
Father: I understand that, I’m simply … I’m just saying so that everyone here knows what the views are … I’d like to think that she can … and that if you need to speak directly to Lise to discuss it in more detail so you do understand … I think it is a very positive thing what she is doing and it is going to help a lot of people including you … and you know what we are like as a family … I’d like you to think very carefully about it and … it is an important part of the people we are, isn’t it?

The extract illustrates another process where parents may negotiate or provide advice on decision making with their children. The parents did not merely indicate their approval of the research, they argued for it: ‘it might help you’. The mother went on to highlight the perceived benefits for her daughter: ‘other people don’t understand how you think’. However, the mother retreated as the father became more coercive. In the last, long statement the father drew on the apparently well-known family values to emphasise his views: ‘… you know what we are like as a family’, which left little option for his daughter to refuse participation. The mother later suggested that the interviews could be carried out in a café, where Anna could talk to me alone. This suggestion seemed important for Anna. She decided to partake and signed the consent form. After making up her mind, Anna seemed comfortable and enthusiastic about participating. However, because her parents’
enthusiasm was so persuasive, I questioned whether the teenager’s agreement to participate was voluntary. This scenario indicates something about the relations within the family. It also shows that the role of parents as advisors sometimes involves the expectation that children do what their parents see as the right thing. This situation had implications for my role as researcher which I discuss in Section 7.5.2. The tensions experienced in the family consultations were less marked in the subsequent individual interviews, although occasionally the parents’ presence still had implications for hearing some young people’s views.

**The influence of parents’ presence for hearing young people’s views**

The young participants expressed differing views on having their parents present during their individual interviews. Some young people were not concerned whether their parents were able to overhear their interviews. For example, Ian said ‘That’s ok. Well there is nothing that I haven’t already told them’. Kim chose to have a parent present during interviews as she felt she needed assistance with communication (for more details, see Section 7.6). When I was interviewing Lucas, his father was in the room working on a laptop. This seemed of little concern to Lucas. However, the mother was asked to go to another room. Sometimes it was not so easy for the participant to choose who was present as some houses had open plans, which meant that different people walked through at different times.

The way some young people engaged in the interviews was influenced by parents being present. When interviewed alone, most teenagers were more talkative. Some participants talked more freely about home or school concerns. Once a parent entered the room, some participants changed the topic, started laughing or telling jokes. Others became quiet and disengaged. For example, during a visit to Andrew’s house, his father was present but not always in the room. During this visit I had a rare one-on-one opportunity to engage with Andrew directly in a structured activity using alternative communication techniques (as described in Chapter 6). The activity led to a brief dialogue about his ability and desire to speak. As Andrew did not use speech to communicate, the moment
became very intense and very exciting. Unfortunately, I was unable to clarify Andrew’s issues around speech. In the same moment Andrew expressed that he would like to speak again, Andrew’s father entered the room and commented on Andrew’s answer. This interruption, although unintentional on the father’s behalf, altered the engagement. I was not able to re-establish that same connection with Andrew again, as he immediately changed his attention from the activity to his father. He and his father joked around for a little while before Andrew ended the visit by leaving the room to watch a movie.

In these sections I have illustrated how research relations with parents were significant in accessing and hearing some young people who may otherwise be excluded from research. These parents became involved according to the aims of the project as facilitators of their children’s participation and as partners in research, moving beyond just initial engagement in the research. At the same time, involving parents as collaborators in reaching the young people may have limited the extent to which young people’s voices could be heard. I felt that these participants were genuinely interested in participating by what they were saying in the consultations. However, adults’ consent to children’s involvement in research before children themselves are consulted can place constraints on children’s decision to refuse or voluntarily participate in research (Abramovitch, Freedman, Thoden, & Nikolich, 1991). Even when involving older teenagers it is important to consider that when parents have approved participation in research, their children are more likely to agree although they are theoretically free to refuse.

The situations discussed above give some indications of individual relationships between family members, an aspect of the research which sometimes required me to negotiate family and research relations. In research including children generally it is not unusual for the adult researcher to confront power relations and generational issues (Mayall, 2000). Below I describe the implications for my researcher role of involving both young people and their parents as partners in research.
7.5 Implications for the researcher role when partnering with both young people and their parents

My role in this research was influenced by partnering with both parents and teenagers. My primary role was to facilitate and hear the views of young people while being considerate of them and their parents within the collaborative research process. In negotiating research relations between myself, the parents and the teenagers, these considerations sometimes required me to challenge my own parental role. Similarly my efforts to maintain a non-authoritarian role in relations with teenagers were sometimes compromised by my status as a parent. I explain these issues below.

7.5.1 The significance of the insider researcher

My status as a parent seemed to have some resonance with the participating parents. I sensed that my being a parent of children diagnosed with autism may have had some effect on the participating parents’ positive attitudes towards the research. In conversations with the parents, they often indicated that they saw me as an insider. Several parents made comments such as ‘you know what it’s like’ or ‘I am sure you know what I mean’. While I often could identify with their concerns and experiences, it was important not to assume I automatically knew what they meant. Once the consultations with teenagers began within the homes of the families, I often felt that the parents invited me into their homes and treated me like a welcome guest rather than a tolerated investigator. For example, several parents (and some of the young people) were interested in my personal situation and asked questions about my children. Similar experiences have been described by other parent researchers, such as Russell (2004) whose research focused on the experiences of parents of disabled children. Although the foci of the studies differ, they both show that the role of the parents in facilitating access to their children (even older children) makes collaborative partnerships with them significant. However, when establishing these partnerships with parents, it was important for me to consider how these relationships might influence my relationship with their son or daughter.
7.5.2 Negotiating research roles and relations

I found that there was a need to negotiate the research relations within the context of the consultations with both parents and teenagers as partners. On several occasions I felt the need to reiterate to young people that the decision to participate was theirs. One situation presented a predicament for me, when the parents were strongly coercing their daughter to participate (as described in Section 7.4.2). While I wanted the young person to participate I also wanted to make sure that this was a willing choice. Although Anna agreed to participate, I still felt that her decision had been forced. At the time, I carried on with the consultation as with other young people who had willingly agreed by setting up the subsequent interviews.

After the meeting I consulted with my supervisor about my position. We agreed that ongoing consent should be sought in such instances, throughout the research process. In subsequent meetings with Anna, I reiterated her right to withdraw from the research and not answer any questions without consequence. While Anna maintained that she wanted to participate, during the interviews she exercised her right to decline talking about some experiences in detail.

When designing the research, my relationships with the parents contrasted with my expectations around asking for consent. I had anticipated some scepticism and was prepared to be scrutinised, so these parents’ enthusiasm was surprising. The role of parents as gate keepers for children and young people in research has been widely written about, as stated in previous chapters. In particular, parents of children with cognitive and communication impairments often have reservations around their children’s participation in research (Beresford, 1997; Beresford, et al., 2004; Morris, 1998). In this study, it is likely that without the involvement of the parents some of these young people may have been excluded from participating in the research in the first place. However, involving both parents and young people together may also complicate research relations and require the researcher to take on the role of negotiator in the process of facilitating young people’s views.
The complex relations between young people and adults were highlighted by using a child-centred approach to researching with young people. The approach also emphasised the importance of establishing collaborative relationships with young people. In the next sections I reflect more directly on engaging the young people in the research and consider significant aspects of being inclusive of their individuality.

### 7.6 Collaborative participation promoted inclusive research

The collaborative participatory approach used in this research was successful in engaging young people and being inclusive of their views, albeit to a greater extent with some young people than with others. In this section, I first describe the value of consultation before research engagement and the importance of facilitating decision making. Thereafter I illustrate how the research approach enabled individualised research engagement through flexibility in the use of data collection methods and sensitivity to individual communication requirements and preferences. Finally I discuss how using a flexible research approach may add necessary complexities to the research process that need to be considered in inclusive research involving collaborative participation.

#### 7.6.1 Consultation and facilitating decision making with young people

The consultation with young people prior to the main research engagement was a valuable step in collaborating with them and being inclusive of their views and preferences. As anticipated (see Morris, 2003), consultation helped to establish an initial rapport with young people and a space for developing ongoing dialogue. Getting to meet and learn about the young people also highlighted their diversity in terms of interests, abilities and preferences for communication. Paying attention to this diversity was important throughout the research process, as I will discuss in the coming sections. However, a significant discovery in the consultation process was the need to facilitate decision making with most of the young people.

Facilitating decision making became an important aspect of my role during consultation in order to be inclusive of individual young people’s preferences. Few of the participants seemed accustomed to
making decisions or being asked for their opinion. While setting up the subsequent individual visits with the young people, most appeared a little overwhelmed by the prospect of making decisions related to participation. Typically the young people expected me to tell them what to do and needed encouragement to state their preferences. Lincoln (1993) has suggested that participation in research by those who are in focus involves tasks that they may not have undertaken before and that they may need some ‘coaching’ in how to be ‘collaborators in their own stories’ (p. 41). This statement certainly applied to my research. However, with further clarification and assistance during the consultation visit, the young people were able to make some initial decisions about participation. As described in Chapter 6, during and in between subsequent interviews several of the young people developed their own ideas or made suggestions for ways of contributing their knowledge. The research approach allowed for individualising research engagement in this way, but also provided the flexibility to change research methods and communication strategies along the way.

7.6.2 Flexibility in the use of research methods

The research methods were selected and used in a flexible manner. Initially the participants favoured direct face-to-face interaction over other less socially demanding forms of communication, such as using the internet or telephone. This preference for direct interaction and communication contrasts with findings related to research engagement in previous studies in which some children and young people diagnosed with autism found direct engagement stressful (Beresford, et al., 2004; Preece, 2002).

During the research process, data collection methods were changed with three participants. The main reason for these changes was to allow the young people to continue participation despite their changing lives and circumstances. After I conducted the initial individual interviews with Ian and Lucas, both participants had time constraints due to the need to study for exams. These participants found email interviews to be more convenient than meeting face-to-face. Both Ian and Lucas were
accustomed to emailing and communicating in writing in their everyday lives. They were confident and comfortable with written communication. These young people’s appreciation of this flexibility is clear in the email responses below:

Ian: Email would be great as I am busy TRYING to study. Send me the questions and I will answer them ... it would be good to think about something different for a while! [Participant’s capitals]

Lucas: I am happy to communicate on here [meaning email].

After completing the interview, Lucas explained:

[Being] interviewed in person was good for the first two introduction and preliminary questions, while email made things soo much easier for time limits and events ...

With Andrew, both the research methods and location were changed. During the course of the research Andrew became ill and needed surgery. He was hospitalised for several weeks. Andrew’s hospitalisation occurred at the end of the school year which meant that he was not able to return to high school before his graduation. Andrew’s mother was enthusiastic about letting him complete his participation in the study. To enable his participation, a final visit was arranged in the family’s home a few weeks after his return from hospital. The flexibility applied to research methods was equally important in being sensitive to individual participants’ communication style, as I explore next.

7.6.3 Being sensitive to individual communication styles

There was great diversity in the way these young people communicated, reflecting findings by Beresford and colleagues (2004). Therefore being sensitive to individual communication styles and preferences was important. With Andrew, the research methods and communication strategies were also changed to better facilitate his views and experiences. Observing and being with Andrew gave me opportunities to experience and understand about his everyday life but also to learn to communicate better with him. Andrew used body language such as facial expressions and hand gestures when responding to others. Through observation I learned how Andrew interacted with peers and teachers, expressed joy, responded to requests from others and asserted agency when
disagreeing with actions by others. He used similar strategies to let me know when he was happy to receive a visit and spend time with me. The extract below is from the field notes from my third visit to Andrew’s school. This visit occurred during a school fete. The extract reveals how Andrew shows his excitement in anticipation of the upcoming activity:

The teacher suggests that Andrew and I go down to line up in one of the queues forming in front of the two jumping castles. Andrew immediately grabs my arm and drags me along toward the two jumping castles. I am pleasantly surprised at this gesture. As we walk along he squeezes my arm really tight. He puts his head on my shoulder for a moment, then turns his head and plants a light kiss on the sleeve of my jacket. He doesn’t look at me but seems to be absorbed in his own thoughts. He is wearing a big smile. His bouncy body movements tell me he is excited about what is about to happen.

However, I felt that Andrew had opinions about issues in his life that were rarely explored in the school context. The use of communication strategies in school appeared to be limited. I planned to engage in more structured activities with Andrew when visiting his home after his illness. For that visit, the interactive communication strategies described in Chapter 6 were used to engage and hear Andrew more directly.

With five of the six participants, being considerate of their diversity in using speech was important. Ian and Lucas were particularly verbose and sometimes talked for several minutes at a time, especially when they had a particular interest in the topic. Ian was comfortable talking to people and was aware of his ability and tendency to talk for a long time: ‘Yeah well ... I always like to express myself [laughs]. I always have ... we’ve always said that I uh yeah ... sort of gift of the tongue I suppose [laughs again].’ In contrast, Dylan and Anna usually used brief sentences or single words to answer questions. Typically they awaited questions from me rather than freely elaborating on any of the topics. In general, the participants were more talkative when a topic held personal interest for them.

With Dylan, it became necessary for me to ask quite specific questions. In the early interviews a typical response from Dylan was ‘I don’t know’. Such answers were less likely when questions were
asked in a more specific way. It was also important for me to understand the way Dylan provided his answers. Sometimes it seemed as if he was rapidly changing the subject we were talking about. At other times, it was difficult for me to distinguish whether Dylan was answering my question or having a joke. As his mother had informed me, Dylan did not enjoy being ‘serious’ for too long. Importantly, I learned that Dylan often responded by giving specific examples of his experiences, using physical terms. Below is an example of a response given to a question I asked him about how high school was different from primary school:

**Dylan:** The way you work and it hurts your arm.
**Lise:** It hurts your arm?
**Dylan:** Well, it can.
**Lise:** Oh, because of all the work you have to do?
**Dylan:** Yeah, well it can hurt your arm.
**Lise:** Is that from all the writing?
**Dylan:** Yeah.

For Kim, it was important to have her mother present during the interviews so that she could help Kim express her thoughts and views. The significance of this parent’s involvement was discussed in Section 7.3.1. In the extract below, Kim and her mother explain the usefulness of the strategy they had developed for understanding and expressing Kim’s views. The mother explains how it is necessary for her to be reflexive in the interpretation of Kim’s views so that she does not make assumptions about the underlying meanings of her daughter’s words:

**Kim:** I need Mum to speak for me soo …
**Lise:** That’s OK.
**Kim:** She’ll be able to translate … what I’m trying to say … Yeah. It is much easier.
**Lise:** Do you find that your Mum is pretty good at understanding what you want to say most of the time?
**Kim:** Yes. Especially in doctor’s appointments and stuff like that. Sort of someone … to talk sort of … so it comes through more clearly. I have the ideas and I’ll sort of say the key words and Mum can sort of say what it is. Personal translator … [laughs]
**Lise:** How are you finding that [addressing mother]? Do you find that you can pick up fairly easily what Kim means?
**Mother:** What I … certainly a lot better these days because I ask questions. I used to assume a lot and just … yeah, assume something was going on but not really understanding what was really going on underneath. So now I’ve gotten into the habit of asking questions to find out what it is that she is really saying. What it is she is feeling? Sort of teasing it apart to get a bit deeper than the surface thing might be. Whatever Kim
says, there is always something a little bit more underneath it all. Yeah, so I guess it is more that I’ve started to get an idea of where … what her experience is, I suppose.

The mother added that while Kim would be able express herself well some days, at other times it was as if the right questions had to be asked: ‘It is like … it is like she can’t put it into words until the question has been phrased. It has to be the right question being phrased first before she can say ‘well that is it, or no, that is not it’. Kim indicated that her ability to express herself differed according to her mindset and circumstances. Kim explained that she had found participation hard, though the difficulty she referred to was not related to the process itself. Kim explained that the ‘state’ she was in currently meant that she found it difficult to express her thoughts. Although she felt that perhaps she could have expressed herself more clearly at another time, she still thought the interview had been worthwhile. She said that important issues had been raised because of her current ‘state’ which she would not otherwise have thought to talk about:

Lise: Was this hard to do … did you find it hard?
Kim: Yeah, sometimes. I guess because of in the state that I am at that moment, I couldn’t really make it … I didn’t feel like I could make it clear and sort of. As good as I normally can but yeah …
Lise: So if I had spoken to you at some other time it might have been easier, do you think?
Kim: Yeah ... but still it is important that if you do stuff that has come out of this one that wouldn’t have come out at that one. So …

In the previous sections, I have shown how flexibility in the collaborative research approach enabled individualised research engagement with young people at various levels. As planned, the research approach enabled teenage participants to select how and where they wanted to participate in the beginning of study. However, flexibility in approach also allowed for change or use of more than one method and changing locations when necessary. I also gave examples of how the approach permitted sensitivity to individual communication styles and requirements, as well as changing methods and strategies along the way where necessary or appropriate. Overall the young people indicated that they were satisfied with the methods used because they fitted well within their preferences and the circumstances of their lives. However, while the flexibility enabled me to be
more inclusive of young people, it added complexities to the research process. I outline these complexities in the next section.

7.6.4 Inclusive collaborative research required time and resources

The individualised research approach complicated the research process in two ways. Firstly, more time and resources were required in order to be inclusive of young people with diverse cognitive and communication abilities. For example, extra time and resources used with Andrew were important for developing rapport and learning more about different ways to communicate with him. If I had only made the one visit to Andrew at home, my understanding of his life would have been quite limited because, as a stranger, I was intruding on his private time. After my first meeting with him and his family, Andrew was no longer reserved when I visited. Additionally, while participant observations provided the opportunity to interact with Andrew in natural everyday settings, further knowledge was obtained directly from him using other strategies. Similarly, when interviewing Dylan, more visits and extra attention to communication strategies were required for me to be inclusive. However, without spending extra time with these participants, their views would have been excluded. Thus, the flexibility of methods was a unique aspect of this study which allowed me to be sensitive to the participants’ individual and changing circumstances.

The need to allow time and resources reflects findings in previous research including children diagnosed with autism (Beresford, et al., 2004), but also in other research engaging disabled young people, particularly those with cognitive and communication impairments (Minkes, Robinson, & Weston, 1994; Morris, 1998, 2003). Also, despite the extra efforts to engage with young people, research may yield only small amounts of information. However, including the views of these young people is important to help understand the broader experiences of childhood and those that relate more directly to diagnosis, disability and impairment.

The research approach also had implications for analysis and reporting of the findings. The range of methods and strategies used produced a range of data. While different levels of analysis are
common in qualitative research, data collected in this study had varying levels of depth because of the different communication styles and methods used. In conducting inclusive research the process of collating and analysing this varied qualitative data required careful consideration. Similar complications applied to the process of reporting the findings, where it was sometimes difficult for me to ensure that the voices of all the participants were heard.

Using a collaborative participatory approach was important for promoting inclusiveness in this research. The findings reported in this last section show the importance of considering the participants’ requirements, abilities and preferences individually and not assuming these on the basis of their diagnosis. The findings also show that in this study inclusivity was not necessarily related to age, ability or impairment. Young people’s lives are fluid and their situations may change, sometimes rapidly. The flexibility of the approach allowed research participation to fit in with their lives. The approach enabled both the young people and me to change methods during the research process when their individual circumstances rendered this necessary or appropriate.

In this study, using principles from the sociology of childhood and the social model of disability was helpful in achieving collaborative research relationships and engage with the young people. As outlined in Chapter 4, childhood sociology principles emphasise the importance of valuing the knowledge held by young people and placing their views at the centre of the research. The social model of disability emphasises the importance of separating disability from impairment when being inclusive of young people with diverse cognitive and communication abilities. This separation enabled me to respond to individual requirements and abilities in implementing research methods and communication strategies. These principles resonate with other research that includes disabled children (Kelly, 2007; Morris, 1998), but are not often applied in research focusing on children diagnosed with autism.
7.7 Summary

The findings presented in this chapter describe how and why young people diagnosed with autism and their parents participated in research as collaborative partners. First, I presented the reasons that parents and young people gave for participating in this research. Second, I showed how involving parents as partners in research had implications for young people’s participation; and third, how partnering with both young people and their parents had implications for the researcher role. Finally I reflected on the importance of using a collaborative partnership approach to promote inclusive research with young people diagnosed with autism. I conclude this chapter by briefly summarising these findings.

Parents and some young people agreed to participate in this study because the research focus resonated with current issues in their lives. Parents indicated that the research had the potential to assist them with advocacy and their child’s right to be heard and understood. For these parents, the focus of this research was timely and meaningful. Similarly most of the young participants who agreed to the research did so because they had something to contribute, even though two of them were reluctant initially. For these two young people, participation was subject to having control over the way of engaging in the research.

Involving parents as partners in the research along with their son or daughter had implications for the young person’s participation. Parents had an important role in providing access to the young people. In some cases, they facilitated communication in the early stages. At the same time, in some families the parents’ presence caused tension, influenced the way young people made decisions and affected the extent to which the young people’s views could be heard.

My role as a researcher was also influenced by involving young people and their parents together. My status as a parent of children diagnosed with autism seemed to have some significance to parents. However, generational tensions within some families required me to assume various
research roles. These roles included being a collaborator and partner with parents and teenagers, but also involved negotiating the best way of being inclusive of young people in this study.

The findings show how important it is that researchers avoid making assumptions about young people’s preferences and abilities on the basis of diagnosis. Rather, by applying an individualised approach to research engagement, it was possible to include participants with a diverse range of abilities. Individualising research engagement involved consulting young people prior to the research, facilitating their individual decision making when selecting methods and being sensitive to their individual abilities and preferences for communication. It was equally important to maintain an individualised approach throughout the research process that allowed for flexibility and sensitivity towards young people’s changing circumstances.

This study shows that the views of children and young people diagnosed with autism can be included in research if they are given the same considerations as in contemporary research with children more generally. However, it is important to acknowledge that communicating with some young people diagnosed with autism can be difficult and may require extra time, especially when formal methods of communicating have not been developed.

In the next chapter I present the findings that emerged from young people’s knowledge and experiences through using this methodological approach.
Chapter 8: Negotiating identity in relation to life changes and being recipients of a diagnosis
8.1 Introduction

The previous chapter reported key findings in relation to practically engaging in research with young participants and their parents. The chapter showed the value of drawing on principles from both the sociology of childhood and the social model of disability in being inclusive of young people diagnosed with autism. I illustrated how using a collaborative participatory approach allowed me to individualise the research engagement in order to be considerate of six individuals who had diverse abilities and preferences for communication. This chapter reports the findings produced from the knowledge contributed by these six participants. In this chapter I also refer to existing literature that explains, reflects or contrasts with the findings produced.

In reporting the findings it is important to acknowledge three key points. Firstly, in this chapter, I have not limited the themes to issues that may signify or be particular to young people diagnosed with autism. Many issues expressed by the participants as being important were similar to those of other young people going through teenage-hood. However, several participants also had experiences that perhaps are less common for young people without a diagnosis or labelled impairments. Secondly, in presenting these findings I have included quotes from the data from which the themes emerged to let the voices speak for themselves as much as possible. Thirdly, the key themes reported were not expressed with equal significance or depth by all participants. When presenting the themes, I attempt to juxtapose individual views in order to be inclusive of all six young people who participated in this study. As noted in Chapter 7, Andrew’s situation was quite different from that of the other participants. However there were similarities between issues in his life as I observed them and those expressed more directly by the other young people. I have added observations and interactions with Andrew (and occasionally the views of his parents) to sections where these complement or contrast with the views expressed by the other participants. In the next section I present a brief overview of the key findings from this research.
8.2 Key finding: Negotiating identity

Negotiating identity emerged as a central theme. Negotiating identity was reflected in young people’s discussions of the way they understood themselves in relation to others, and how they experienced teenage-hood and the diagnosis with which they were labelled. These aspects of negotiating identities were fluid and overlapping. However, for the ease of reading, I outline four key themes that illustrate how these participants negotiated their identities. Each key theme has two or more sub-themes which are labelled as follows:

1. Self through a period of change
   - The changing self: ‘Turning into a man’ or woman
   - Changes in social relations
   - Changes in views: Sense of morality and social responsibility

2. The significance of a diagnosis for sense of self as different: Individual stories
   - Kim’s story: Autism ‘means difficulties’
   - Ian’s story: Diagnosis legitimised problems and helped find inner self
   - Anna’s story: Diagnosis validated feelings of being different
   - Lucas’s story: Taking pride in diagnosis and difference
   - Dylan’s story: Autism means being treated differently

3. Control and social identities
   - Being an adult: The importance of having control in one’s life
     - Notions of age and competency
     - Struggles for autonomy
     - School as a context for feeling controlled
   - Negotiating impairments: Taking control of oneself

4. ‘I just want to be me’ and be accepted as me
   - Accepting difference, resisting disclosure
   - We are all different: Resisting negative attitudes and stereotypes

These themes are reported in detail in the coming sections.

8.3 Self through a period of change

In responding to questions about themselves, the participants expressed feelings about being in the process of change. Most participants understood this process as being related to teenage-hood. This
process included experiences of change within themselves, in their relations with others and their views about the world. These data did not seem related to autism per se, but highlighted these young people’s own experiences as teenagers and the ‘ending of childhood’.

8.3.1 The changing self: ‘Turning into a man’ or woman

The young people’s experiences of change had implications for the way they understood themselves as becoming adults and ‘being teenagers’. For example, when asked about how he saw himself, Andrew pointed to the word ‘teenager’ from a selection of words that included ‘child’, ‘boy’ and ‘man’. While it was difficult to know what Andrew understood by being a teenager conceptually, others articulated their understandings in detail. For Ian, being a teenager was the process of becoming an adult and meant that he was still ‘in between’:

Um ... well I think all that sort of change and stuff ... I like to say that I’m in that category, that I’m just learning now and I’m not a child but I’m not an adult either.

Lucas referred to being a teenager as ‘a transition between childhood and the adult years’. For Lucas, this transition was associated with the progression towards adulthood and reaching age-related privileges and milestones. These milestones included being able to drive, get a job, vote and drink alcohol. Ian and Lucas explained how they saw teenage- hood as a social structure for finding out about themselves and learning about the world and how they fitted in it:

Ian: ... it’s like an experiment in a way. You have this little period in your life, where you just are purely discovering about life, discovering your potential, discovering who you are, and discovering how you can help other people. I think in a way, it makes teenagers unique in that way.

Lucas: The role of being a teenager is to decide where you will go in life, through trial and error.

Both Lucas and Ian described the role of teenagers in terms of what Mayall (2002) refers to as an ‘apprenticeship’. They saw themselves as learners working out where they wanted to go in life and what they needed in order to get there.
For Dylan, ‘being a teenager’ clearly marked the end of ‘being a child’. He was the youngest of the participants having recently turned 13. For Dylan, turning 13 seemed to be pivotal in where being a child ends and being an adult begins. For example, when he referred to situations that made him feel like a child, he stated ‘I feel like I am still 12’. He explained that becoming a teenager meant that he was ‘turning into a man’ and indicated that with this change he was now entitled to the rights he ascribed to the status of an adult:

... you don’t have to listen to your mother anymore and you can do whatever you want ...

Being a teenager also involved feeling changes within oneself. Most of the young people observed changes in the way they were thinking, as well as in their bodies. The physical changes were not discussed in detail but were often implied in reference to ‘hormones’ and physical growth. Rather these young people focused on the way their views and feelings were changing along with certain expectations they associated with being teenagers. For example, some young people felt that being a teenager involved having more responsibilities than being a child. More was expected of them. For example, Dylan now had the responsibility of managing his pocket money. For most young people school work had increased and was harder than when they were younger. This point is illustrated explicitly in the following extracts:

Lise: Ok ... is there anything that is easier or harder being a teenager?
Anna: Um ... yeah the workload at school ...
Lise: So they are asking more of you now than when you were younger?
Anna: Yeah.

Dylan: The way you work and it hurts your arm.
Lise: It hurts your arm?
Dylan: Well, it can.
Lise: Oh, because of all the work you have to do?
Dylan: Yeah, well it can hurt your arm.
Lise: ... from all the writing?
Dylan: Yeah.

With Andrew, changes that involved added responsibility and increasing academic demands were less marked. Despite Andrew’s obvious physical growth and development, my observations within
the school context did not reflect that he was faced with the increasing academic demands and expectations described by other young people. Aside from participating in a work placement program once a week, it seemed that Andrew was rarely expected to actively participate in class discussions or academic activities. On a few occasions I observed how Andrew (and others not using formal communication methods) was handed an activity to complete on his own. For example, he was asked to put coloured pegs into a plastic frame, while the class carried on with academic work. His mother felt that Andrew was more capable than they as his parents, teachers and other adults gave him credit for. She explained that he liked being independent in his daily activities, but it was sometimes quicker to do things for him. At home Andrew was not expected to help out with chores, but his parents encouraged Andrew to do the things for himself that he was capable of. During one of my visits to his home I observed Andrew’s competence in the kitchen where he confidently cooked pasta for himself.

For Kim, the notion of being a teenager was connected with the school context. She indicated that the term ‘teenager’ allowed adults within the ‘school zone’ more control over older students. Kim said that she felt older and more mature when with her friends outside of school:

Lise: Would you describe yourself as a teenager?
Kim: No.
Lise: No? How would you describe yourself?
Kim: As a young adult now – most of my friends are adults so I guess sort of coming out of the teenage. Outside of the school zone, I am more of a young adult than a teenager. Does that make sense? [laughs]
Lise: Mmm ... others have said that school tends to ...
Kim: Make you a teenager longer ...

For Kim, feeling younger within the context of school related partly to the systemic aspects of control over children that exist within that particular environment:

Lise: What do you think makes you feel like a child or a teenager when you are at school?
Kim: Just that School ... School is like ... you still have to wear a uniform and like ... everyone else ... You still have to behave in a certain way ... certain manners and like ...
Lise: Mmm. OK. So does wearing a school uniform make you feel different?
Kim: It makes me feel younger.

Kim’s account suggests that she understood teenage-hood as an adult construction that had the power to control young people for longer. She identified that in schools this power was enforced through the use of symbols that separated young people from adults. For example, formal rules and the use of uniforms separated the two groups. Issues related specifically to control are reported in detail in Section 8.5. These restrictions by adults sometimes resulted in conflict, and social relations with others became more important. Thus teenage-hood also involved negotiating a range of social relations in everyday contexts including at home and school.

8.3.2 Changes in social relations

Several young people discussed how the changes they were experiencing at this time in their lives had consequences for the way they understood themselves in relation to others, particularly adults. For some participants, changes in the way they viewed the world caused them to have conflict with their parents and siblings. Despite these conflicts, most of the participants noted that family remained important in their lives. Family provided a sense of security, stability and belonging. In the example below, Ian expresses clearly that family was a dependable part of his life:

Ian: Well, yeah, the people that are closest to me would have to be my family, I’d say.

... it’s not just a bunch of people living together who have learned to cope with each other. They are linked, like they’ve seen so much of each other, that they’re no longer ... they’re no longer afraid of anything that’s unknown about other people like they know each other inside out. They know exactly what to expect. It doesn’t matter how much they say ‘I hate you, get out of my life’, you know that always in your life you can depend on these people. They’ll never let you down. And I ... that’s what I find is the best thing about family. The fact that they know everything about you and they’re willing to accept it ...

Social relations outside of the family seemed to be increasingly important for these young people as they became older. Friends were important for company, for providing a sense of belonging and being liked or feeling popular. Usually the number of friends was not important, but the qualities of a friend were. Such qualities included similar interests, honesty and loyalty. Social interactions with a
number of friends, individually or when ‘hanging out’ in groups, were often more important than developing specific friendships.

Four participants indicated that having friends and interacting with others was essential for a positive sense of self. For Ian, feeling accepted by others and having friends to talk to were important in order to feel good about himself. This need was increasing as he became older. Ian understood this need to be more social as a part of the changes he was experiencing as a teenager:

Lise: Why do you think feeling popular is so important to you?  
Ian: I need friends, (not just family), because I have to have somebody to relate to, otherwise I feel sad and want to ring up just plain anybody for a chat. I guess that being social is part of growing up.

The importance of social interactions with friends for Andrew was difficult to ascertain. At school, I often observed Andrew sitting or standing amongst his classmates. However, he rarely interacted directly with them. At times he seemed to seek solitude, removing himself from his peers. However, he willingly engaged with his peers during practical structured class activities. Andrew seemed to have fewer opportunities for developing social relationships outside of school. Andrew and his family lived in a rural area without public transport and community facilities nearby. Andrew was transported to and from school by his parents in their car or by a special bus service for disabled children. His mother told me that she occasionally invited a friend and her children, who were younger than Andrew, to visit and play. However, apart from attending a structured leisure activity (martial arts) once a week, Andrew did not engage with other young people of the same age on a regular basis. His mother reported that Andrew preferred to be with other young people when the opportunity was there. She added that as he became older, he seemed less interested in spending time with his parents. Andrew’s opportunities for social interaction were perhaps further reduced because he did not speak or use a mobile phone or computer like other young people.

For Lucas, the methods of communicating and socialising with others were more important than the people themselves. His reasons for preferring to socialise online will be discussed later in this
chapter. Lucas had recently begun to make some changes in his life and was enjoying having interests in common with some of his friends. However, Lucas clearly indicated that his online interactions remained more important than face-to-face communication with friends and peers:

... recently with Halo 3 on the Xbox, me and a couple of school friends have had a few social team matches where we verse another group of friends, and recently I have also been seeing movies with a few friends of mine. I feel both me and my friends wanted me out and about. Not really important, I’m still a resident of the Internet.

The importance of internet chat rooms, networking communities or social internet games was also noted by Dylan and Anna. On the contrary, Kim and Ian preferred to spend time interacting with their friends directly in cafés, watching a movie or going shopping.

Ian, Lucas and Anna explained that they were now focusing on achieving romantic relationships rather than seeking friendships. Ian found a girlfriend during the course of the study, while both Lucas and Anna felt that finding the right person was difficult. In the extract below, Lucas illustrates clearly the emotional implications of his unmet desires:

Lucas: To make more relationships, I will focus on a seriousness of a relationship, what I’m talking about is Love, I really want a girlfriend, but I’m not interested in anyone of our year, I like more mature people and I have a particular interest in Asian girls as well. I know I don’t need to worry about this until later on, but I see a particular friend of mine, who has someone, he doesn’t hang with us anymore and the relationship they have is intimate, and when I see them get intimate I really feel depressed and lonely as I don’t have someone, sometimes I feel like saying ‘oi, there are people less fortunate over here’, I have dreams and desires, and that’s all I have and it gets so frigging depressing and aggravating. But that’s just Hormones I guess.

Kim viewed romantic relationships during her teenage years as a ‘waste of time and energy’ because ‘they are not going to last anyway’. She already had the experience of having a boyfriend but ‘got bored’. Kim explained that friendships were worth investing in. Her friendships were ‘constructive’, ‘meaningful’ and likely to last:

Friendships are more better [sic] and more constructive and ... It’s much better when you can have a nice friendship with them that can last – yeah. It is cool.
Between them, these young people had different experiences with social relations, different preferences for social interaction and different opportunities for establishing friendships. However, there were some similarities in the importance placed on these changes during the teenage years. These young people described similarities in the way their views on the world were changing.

8.3.3 Changes in views: Sense of morality and social responsibility

Four of the young people said that their views on life were changing, which had implications for their interests. Some individuals explained that they were now relating to the world in a different way from when they were children. In the example below, Ian explains how he was becoming interested in what he understood as adult issues. At the same time he was experiencing physical and cognitive changes:

We’ve sort of been discovering more about how sort of the adult society works. I think that a lot of the times, little kids will think ‘oh this is boring, it’s about stuff I can’t relate to’, but all of a sudden, when I look at it now, I see it as all that stuff affects me. And just in that huge learning process of everything, as well as physically turning into an adult.

For some participants, part of the new way of relating to the world was living as a ‘good person’ and thinking about what this meant for their lifestyles. Most of the young people articulated a strong sense of morality. They were trying to live their lives according to moral beliefs. This philosophy included being a good person, helping and listening to others and, for some, living a Christian life. For, Ian living a Christian lifestyle was imperative for his sense of self and the way he wanted others to see him:

Ian: I think the most important thing in my life would have to be is living the way God wants me to be so living a life of loving other people, making people feel good about themselves and helping where they’re is suffering. So yeah ... that would probably be the most important thing in my life. Just living the way God wants me to, and making sure the relationship is kept good...

Ian explained that his religion provided a guide for living a life of good and could help him adopt the social identity he desired for himself:
And I figured out sort of that’s my little meaning for life, sort of thing. If I can get that right, everything else doesn’t matter, it’s just if I get that right, everything is good and everybody will like me and I think it would be good.

Four participants expressed a strong sense of social responsibility. Some discussed global concerns such as environmental issues and the prospects of terrorism and war. Others discussed more specifically the marginalisation of people experiencing diversity and disadvantage. For example, Lucas had strong concerns about racism. On several occasions he expressed frustration with the way some people discriminated against others because of their race and culture:

I really despise … racist people … Well I just think that, you just don’t need racism anymore. … xenophobia shouldn’t exist anymore really. It’s – I just don’t understand why they still do it. They still – it is just the appearance. Why does appearance matter?

Three of the young people indicated that these interests had developed as a consequence of their own sometimes difficult experiences. For example, Ian explained that he had developed a ‘deeper sense of respect’ because of his own experiences of living with his ‘illness’:

I have come to develop a new understanding of what some people have to go through with these sorts of illnesses and have subsequently acquired a deeper sense of respect for the people who have to suffer even more than I had to. I feel that in developing this new respect, I have learned that it is possible to become, and remain, content with whatever it is that I have.

These young people also felt that their interest in and views on social injustice were stronger than those of their friends, as here stated explicitly by Kim:

I feel more strongly about these things. My friends don’t care … about [things like that].

The significance of these interests was illustrated in the way four participants exercised social responsibility at different levels. For example, Anna applied her beliefs in everyday life. She explained that she was not shy about challenging others if she thought they were doing the wrong thing to other people or to animals. For some of the older teenagers, exercising social responsibility involved becoming more engaged in organised groups and activities. For example, Ian was an active
member of his church and an environmental group at school. Lucas had become involved in internet
groups that exposed people engaging in racist activities. Kim was engaged on a global level with a
larger human-aid organisation. She was due to travel with them to provide support to a community
in a developing country once she had completed school. Both Lucas and Ian expressed a desire to
carry their interests in social issues into their adult lives through future education and possible
career paths.

The findings in the sub-sections 8.3.1 to 8.3.3 show how these participants had some experiences in
common that they related to teenage-hood. The findings also suggest that these young people
understood ‘being a teenager’ as a time of change connected with biological development as well as
with socio-cultural structures and normative expectations of what becoming an adult is about. These
findings seem similar to those reported in research with children and young people generally. They
support Uprichard’s (2008) argument for the understanding of children and young people as both
‘being’ and ‘becoming’.

These findings indicate that that both the biological changes and experiences as teenagers
influenced the young people’s views, interests, actions and relations with other people. The
importance of good social relations with family and friends for feeling secure and having a positive
sense of self is an important finding. Together with findings from a recent study of one teenager
diagnosed with autism (Howard, Cohn, & Orsmond, 2006), the findings challenge common
assumptions about the asocial nature of people diagnosed with autism derived from the medical
sciences definition as discussed in Chapter 2. Related to this was the finding of the importance the
young people placed on social responsibility for others. This finding contrasts with the idea that
those with autism lack the ability to understand other people’s circumstances and point of view.
Both findings align with research with children more generally about their understandings of
wellbeing (NSW Commission for Children & Young people, 2007).
Findings presented in Sections 8.3.1 and 8.3.2 reflect suggestions by Priestley (1998) that young people seen as having cognitive impairments tend to be more protected. They may be treated as children for longer than young people generally. Andrew in particular seemed to be restricted in his opportunities for attaining independence and developing relationships with other young people. He was often closely observed by adults. Other young people expressed the view that having a diagnosis of autism in itself implied difference, which meant that they were seen and treated differently by others.

8.4 The significance of a diagnosis for sense of self as different: Individual stories

The individual participants’ experiences of being diagnosed – or learning about having a diagnosis – had implications for the way they understood and related autism to themselves. Ian and Kim discussed their experiences of being diagnosed, while Anna and Dylan described how they learned about having a diagnosis. Kim, Ian and Anna described how their experiences had implications for the way they understood themselves as different. In contrast to these three participants, Dylan expressed the view that the diagnosis had more significant implications for the way others understood and treated him as different. Lucas stated that he had always known about having autism. The label had been a part of his childhood and had significance for his self-identity. The five short stories below outline the participants’ individual views on autism and their experiences of learning about the label for themselves.

8.4.1 Kim’s story: Autism ‘means difficulties’

When I first asked Kim what autism meant for her, she promptly said ‘it means difficulties’. For Kim, being diagnosed with autism had been a confronting experience with unpleasant consequences and lasting emotional implications. Kim was diagnosed shortly after starting school. Much of her childhood had involved learning about having a diagnosis. With help from her mother, Kim described
how the consequences of receiving a diagnosis of autism had highlighted that she was different in ways that others found necessary to change:

Mother: Kim has in the past said that up until she was eight ... she didn’t think she was different at all. She just lived in her own little world and was quite happy doing what she was doing. But then as soon as the intense intervention sort of stuff happened, evolving around ASD specifically, all of a sudden there was a label and that is when you started hating ...
Kim: Yeah, the label and what came with it ...
Mother: The fact that there was so much focus put on her all of a sudden ... And she was ... yeah would that be right?
Kim: Yeah ...
Lise: Were you told of it [autism] then?
Kim: I was probably told but I just didn’t understand what it meant until like the end of last year.

While Kim indicated that she had not fully understood the label of ‘autism’ at the time it was applied, the differences associated with the diagnosis were undesirable for her. She disliked the focus on ‘correcting’ her differences. The particular context of early intervention presented Kim with her first experiences of feeling different as the effects of both impairment and disabling attitudes. She explained how her limited speech made her feel like an outsider:

Lise: Did you feel different?
Kim: Yeah ...
Lise: From other people?
Kim: I felt it ... but like I didn’t notice it until that – just special things – at intervention and places ... And then I felt different and it was ... like an outsider sort of ... I don’t know why, I couldn’t fit in. I couldn’t fit in ... I couldn’t talk ... I got lost ...

Kim’s negative experiences were further compounded by the way she was treated by health practitioners:

Kim: ... I found it very patronising with all these cards and things.
Mother: So it became more of an issue of feeling like an idiot rather than ... cause that is what she said. She used to hate you know those PECS cards and Board maker she just hated it!
Lise: OK, so what do you think would have been helpful for you?
Kim: I don’t know. I really – I just didn’t like the patronising manner. I still cannot stand being spoken down to. I like being spoken at the same level and I try to do it to every age group that I do.
Further to the patronising aspect, Kim felt that the interventions were meaningless for her. Firstly, Kim explained that she was not informed about the purpose of intervention. Secondly, she felt that therapy was applied based on assumptions about her needs, rather than being suited to her as an individual. In the example below, Kim expresses how strongly she still feels about these experiences:

*Mother:* ... and once you said to me, that it was like they tried to get you to work on areas that weren’t relevant. Like you didn’t necessarily have trouble with some areas but it would have been helpful if they had helped in other areas.

*Kim:* Yeah.

*Mother:* It was then I thought, you didn’t get a chance to sort of say ... Oh I don’t know.

*Lise:* Would you have liked the opportunity perhaps to have said to the therapist ... this is what I need help with? ...

*Kim:* Like I didn’t even know ... Like you just don’t know until it is spelt out to you or you need something to relate to or something. You know that something is not right ... you have a feeling of frustration because ... it is frustrating. It is just frustrating and it is not something that you enjoy. But it is not helpful ... not helping ... it is just making me angry but ...

*Lise:* And did it not do anything for you?

*Kim:* Well I didn’t feel like it was doing anything. It probably did something but really ... it wasn’t suited to what I needed so ...

*Mother:* ... Kim got to the point where she said ‘no more ... I’ve had it’.

*Kim:* I hated doing it ... I didn’t like it.

In these examples, Kim highlighted how the approach to intervention by those who were supposed to help her had negative emotional implications. Her initial feelings of incompetency led to frustration, anger and eventually resistance, both towards the intervention and, essentially, the diagnosis per se. As she explains below, Kim made efforts to deny the diagnosis for herself, because of the meaning it had for her:

*Kim:* I just wanted to shut it off because I didn’t like it. Yeah, I didn’t want anything to do with it because of what it meant\(^\text{17}\) ... it made everything so much harder.

*Lise:* What part made it harder ... ?

*Kim:* Living with it ... Knowing that I was different and knowing that I had limitations that I didn’t want.

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\(^{17}\) My bolding: she stresses the pronunciation of this word.
Kim and her mother explained that no matter how hard Kim tried to counter her diagnosis, she felt that autism was something that would stay with her throughout her life. Although she explained that some impairments had decreased over time, her feelings about the diagnosis remained. For Kim, the normalising socio-cultural processes associated with having a diagnosis generated particular feelings and understandings about impairment and difference. These had ongoing negative effects on the way she related to autism. When I asked if there was something she wanted to change in her life or about herself, Kim clearly stated that having [a diagnosis of] autism complicated her life:

Kim: I wish I didn’t have autism. Things would be a lot easier and a lot more efficient.

At the same time, Kim indicated that the different experiences related to having autism had some implications that were significant for the way she structured her identity. She indicated that she was quite pleased about these differences:

Lise: Is there anything about having autism that you quite like?
Kim: If I didn’t have it, it wouldn’t have made me the person that I am today.

8.4.2 Ian’s story: Diagnosis legitimised problems and helped find inner self

Similarly to Kim, Ian learned to see himself as different through the experience of being diagnosed. However, Ian’s experiences with diagnosis and intervention contrasted with Kim’s. He expressed that these events had made positive changes to his life. Ian was diagnosed with Asperger’s syndrome only two years prior to the interview. He had experienced increasing problems in a number of areas of his life that eventually led to the diagnosis. Receiving the label had made Ian reflect on his life through the diagnosis. Here he explains how this reflection changed his self-concept and his perspective on norms and differences:

Ian: ... um I started to look at my life completely differently ... Well, I noticed that um ... but I never really looked at it ... but all throughout my life ... I was sort of ... I was always a bit weird, and I noticed I had little habits and things ... and this thing that I eventually was diagnosed with ... that condition ... looking back on my life and thinking yeah I saw a lot of it there, where previously I just thought it was normal.
Lise: Right. So once you were diagnosed, you saw things that were different?
Ian: Um yeah ... I had symptoms back then which I didn’t know I had ... so little habitual things and little patterns and things ...

Being labelled had provided a sense of security for Ian, although he now understood certain personal characteristics as being symptoms of his diagnosis. At the time the diagnosis was given, Ian was not concerned about the way others perceived the label. Rather Ian explained that for him the label itself had legitimised the problems he was experiencing. The diagnosis offered strategies for dealing with his problems:

But when she ... like she [his specialist] diagnosed me with Asperger’s and stuff and just. It just put everything into perspective for me because ... um ... a lot of people think ‘oh, it’s a label’ and all of a sudden it has to be some sort of prejudice – but I think that is sort of like a secure sort of thing for me. And just finding out that problems that I was dealing with were real problems and that they actually had names and labels and that they have diagnosis and treatments for that sort of thing. And that was a really secure thing for me. I wanted to be labelled because I suddenly knew what I could do and I knew there was a way I could cope with that problem once it had been identified. It was like a diagnosis in a way, saying that oh for this certain thing like you use this certain method and it works well.

As well as helping Ian to better understand his problems, the diagnosis provided a sense of belonging with others who had experienced similar issues:

It was really helpful because I suddenly understood myself a bit more. Because I read these books about heaps of people who had Asperger’s in their lives or that – and I found out that there were certain similarities that all Asperger’s people had with each other.

Ian explained that diagnosis and intervention helped him find his identity. Despite having to cope through trials with different medications, which Ian expressed as ‘a scientific shot in the dark’, the medications eventually reduced his anxiety issues and provided some clarity in his life:

Well, yeah – the little pills that they gave me started to work pretty good – it started to relax the system – most of the OCD left, which is great. And the Asperger’s started getting really sort of in control and I started to work on social issues again which I didn’t really previously thought possible, like just starting to talk to people, like, which I found so hard before. It just became so much easier.
Ian highlighted how the diagnosis and intervention had implications for his sense of self and the way he interacted with other people:

And I think that, um, just finding my true inner self in a way – my own personality and the fact that I wasn’t this sort of little jittery person that would run away from society – that I was really the person who could reach out to people and help them, and they could help me and my life would suddenly just work again.

With the changes, Ian began to structure a new social identity. While Ian still perceived himself as different, he did not identify with the symptoms of his diagnosis once he learned that they could be reduced through/by using medications:

I think that just um … that sort of got me thinking that my identity wasn’t with that Asperger’s traits anymore, it wasn’t with the OCD, it wasn’t with all the little problems that I had before, but that was all part of the diagnosis of a condition that I had and that the real person inside me could do anything.

Although Ian initially embraced the diagnosis, he eventually found that he could detach himself from it. In a later email interview, Ian explained that in addition to the effects of medication, he felt his differences were less apparent once he began to spend more time out of school. In the account below, Ian indicates his understanding of school as a context for restricting social relations which may compound feelings of being different:

I don’t really think I am all that different after all, as I have recently found a nice group of people at church who will accept me for who I am. Not to say I don’t have to try my best anymore, but rather, I can be allowed to contribute to other people just like I have always wished I could. Other than the example of church, there have been some other areas within my new life that have revealed to me that I am probably just as normal as the next teenager. One more of these areas can be found in the form of my current employment – it is here that, once again, people enjoy my company and make me feel very valued. I have begun to think that my life has been very limited at school and I just haven’t been able to experience many friendships beyond my peers.

8.4.3 Anna’s story: Diagnosis validated feelings of being different

Anna’s story was similar to Ian’s. Although she was diagnosed at a young age, Anna had only recently been told of her diagnosis. Anna explained that she had always felt different from other people. Finding out about her diagnosis had been helpful. The diagnosis confirmed her feelings. Anna
expressed that while she sometimes did not understand social situations, she also felt that others did not always understand her point of view. In the interview, Anna focused on the fact that she had not been told about her diagnosis until recently. She resented the fact that her parents had kept this knowledge from her for years. She felt that knowing about the diagnosis sooner could have spared her some recent difficult experiences:

Lise: How long ago was it that you found out about having Asperger’s syndrome?
Anna: Three months ago …
Lise: How did you feel about that?
Anna: Well … I felt angry at her [the mother] because she said she had known for a while …
Lise: Alright …
Anna: I had just been through months of problems and questioning why … [things were happening] she had known long enough …
Lise: So you feel that it would have been helpful to know about …
Anna: Yeah …
Lise: Do you think things would have changed much for you if you had known earlier?
Anna: Yeah … it would have … if I’d known before …

For Anna, the diagnosis provided validation of her difficulties. Having a diagnosis explained why she felt differently from her friends about many issues. However, while Anna accepted Asperger’s syndrome as an explanation for some of her differences and the difficulties she had experienced, she described herself as an otherwise ‘average teenager’. She did not always feel different: ‘Sometimes I forget that I have it’.

8.4.4 Dylan’s story: Autism meant being treated differently

In contrast to the other four participants, Dylan did not feel that the diagnosis made him much different from others. He explained that his sister had told him about the diagnosis when he was nine years old. Although he had inquired about the meaning of the diagnosis at the time, he explained that he knew little about autism. While Dylan did not feel that he was much different from his friends, he thought that the diagnosis was perhaps the reason he was being treated differently:

Lise: Do you think it [autism] makes you different from your friends in any way?
Dylan: No.
Lise: No? Just the same?
Dylan: Pretty much.
Lise: Do you think that it means that some things are harder for you?
Dylan: No. Although I think I get a bit of easier work.
Lise: Yeah? At school you mean?
Dylan: Yeah ...

Dylan was not particularly concerned about being treated differently. While he understood that allowances were made for him on the basis of his diagnosis, Dylan did not see this as a negative experience. He was content with the arrangements made for him at school:

Dylan: ... I like being in my maths classes and I'm in the bottom maths class. I'm happy in the bottom maths class. I don't want to be into the higher maths class ...

Dylan expressed the view that going into a higher class meant that others would have higher expectations of him. These expectations required more effort from him. Although the diagnosis meant that sometimes he was treated differently, at no point did Dylan suggest that the label had negative implications for his sense of self. Rather, Dylan saw some allowances made by his mother as a benefit of his diagnosis, as he expressed in the example below:

Lise: Do you think it [autism] makes some things easier for you?
Dylan: Yeah ... Well I know that if I wasn't autistic my Mum wouldn't let me get away with much stuff.
Lise: Like what?
Dylan: Well ... when I was ... I get money for doing nothing. Like I get $25.00 a week for not doing anything!
Lise: OK. Who doesn't get that?
Dylan: Well normally people have to do some things to get money.
Lise: So they have to do ... like ... chores you mean?
Dylan: Yeah.
Lise: ... and you don't?
Dylan: Not really ...

Dylan did not express autism as a significant part of his self-concept. He used the terms ‘having autism’ and ‘being autistic’ interchangeably about himself and mainly related the diagnosis to being given certain allowances.

8.4.5 Lucas’s story: Taking pride in diagnosis and difference

For Lucas, autism and ‘being different’ were fundamental parts of his self-concept. He expressed a distinct sense of pride in the diagnosis and being exactly as he was. Lucas spoke of autism as
something he had ‘always’ known about. The diagnosis had formed a significant part of his
career. Lucas structured his identity around this difference and through his objects of interest, as
the extract below illustrates. His views are expressed clearly in the response to a question of
whether there was ever a time when he wished away autism from his life:

**Lucas:** Never, I believe that it was pure chance and genetics that I am this way, and it gives
my class group a more serious look on things, my friends notice two sides to me, the
more proactive and punctual Lucas, and the mysterious out-of-school Lucas, I say
mysterious, as few people think I work for ASIO.\(^\text{18}\) This may be because I have an
interest in the subject of Intelligence and that I can say things and know a lot about
security subjects, and the fact that I disappear when I’m not on school grounds. This
two sided me is a trait of Autism, and I feel my peers admire me because of it.

**Lise:** What do they do or say that indicates this to you?

**Lucas:** Well, for starters, when I’m in a relaxed environment the real me comes out, and I
think they are taken by that, also general comments like ‘my gosh Lucas, you are soo
mysterious’.

Lucas’s account shows how he asserted his identity within his own interpretation of the diagnosis.

Lucas chose to focus on aspects that contributed positively to his identity, including characteristics
such as ‘proactive’, ‘punctual’, ‘knowledgeable’ and ‘mysterious’. He expressed the understanding
that this identity was accepted socially:

... it doesn’t bother me at all, my friends have some idea about me being unusual, but
I’m not sure that they know a complete diagnosis, and I don’t think it really matters
...

Despite his positive identification with autism, Lucas did not deny experiences related to
impairment. However he resisted focusing on these in the interview, expressing that he would
rather not talk about it.

It was not possible for me to include Andrew’s views on having a diagnosis. His parents said they had
not made specific efforts to talk with Andrew about the diagnosis as they were unsure whether he
could relate to the concept. For Andrew, the autism diagnosis had been applied in his early teens,

\(^{18}\) ASIO= Australian Security Intelligence Organisation

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secondary to his Down’s syndrome diagnosis. When I mentioned autism to him during our interactive activities he did not respond with any recognition or interest.

The young people’s stories illustrate that they hold different knowledges about autism and that a range of experiences may be associated with being diagnosed with autism or learning about having a diagnosis. However, from these stories three important aspects emerged about being diagnosed with or having a label of autism that are rarely explored in research with diagnosed children and young people. Firstly, for these young people, the diagnosis was significant for their understanding of themselves as different from others or for understanding why they were being treated differently by others. Secondly, the accounts suggest that living with, and learning about, a diagnosis had positive and negative significance for these young people’s sense of self. For Kim, being diagnosed had been a negative experience with ongoing consequences for her sense of self. That diagnosis carried assumptions about her needs and subjected her to intervention regimes she found oppressive. For Ian and Anna, who were older when they first learned about their diagnosis, the label provided some clarity to their lives. The diagnosis helped them to look at their lives in a different light. Experiences similar to those of Ian and Anna were reported recently in a study involving college students diagnosed with autism (Huws & Jones, 2008).

Third, and as a consequence of individual experiences, being defined by a diagnosis had significant implications for the way some young people constructed their social identity. Yet for others, the diagnosis was merely an appendix that had less significance for the way they saw themselves. The significance of diagnosis for social identity is reported in more detail later in the chapter. However, these findings illustrate the conundrum surrounding a diagnosis of autism. As also noted by Ho (2004), a diagnosis or label may be seen as negative because it defines young people as different and inferior. However, at the same time, a diagnosis may legitimise difficulties faced by individuals and help them to deal with problems. For these young people, it was typically the negative experiences
associated with the diagnosis that had implications for their sense of self-worth over which they sought to take control.

8.5 Control and social identities

These young people indicated that having a sense of control was important for the way they negotiated their identities, both in terms of sense of self as well as the way in which they projected their social identities. Several young people discussed control in terms of their experiences of going through teenage-hood and the way they saw the power relations between themselves and adults in their lives. While some young people seemed to accept that these power relations existed, others challenged them. They asserted agency in attempting to exercise control over their own activities. For some young people, feeling in control was not just important in terms of challenging adult control. Having control was also important in relation to particular feelings and experiences that they associated with their diagnosis. The various ways young people discussed these aspects of control in their lives are outlined below.

8.5.1 Being an adult: The importance of having control in one’s life

Central to how these young people managed physical and cognitive changes was a desire for agency and control within their lives. They discussed ‘being in control’ which seemed related to having control over one’s life, in contrast to their parents and other adults controlling them. Some of the young people explained that the changes they felt within themselves meant that they were beginning to feel more like adults. For example, Ian was beginning to feel that he could contribute to and have some influence on society:

... we’ve been considered children all our lives, but this is the point where we’re looking out and saying all of a sudden ‘I can be an adult, I can do certain things. I can get a job somewhere, I can earn a living. I can start making a difference in the world
... We’re no longer kids and we can start changing the world.

With the experience of change, most of the young people were making plans for, or at least considering, what they would be doing in their adult lives. They had expectations of gaining more
independence in the future. Some participants expected to gain employment related to their personal interests. Four participants stated a desire to get married and raise a family.

Despite the changes they were going through, most participants expressed the view that adults were still in a more powerful position than themselves. For example, Dylan explained how he understood the difference between teenagers and their parents as being within an unequal balance in power:

Lise: So is it different to be a teenager than to be an adult?
Lise: How is it different?
Dylan: Because … because when you’re adult you can then boss your children around.
Lise: OK.
Dylan: But when you’re a teenager you can’t boss your children around yet.

When young people felt their competence and sense of self-determination were undermined by adults, they typically referred to ‘feeling like a child’ or ‘feeling younger’. I mentioned in Section 8.3.1 that for Dylan, turning 13 had been the pivotal point in seeing himself as an adult. At the same time, Dylan gave several everyday examples of how he experienced restrictions and felt he was ‘being treated like a child’. Here he states how he sometimes resisted adult control when he did not agree with their decisions:

Lise: Is there anything in particular that makes you feel like you are a child?
Dylan: Well once when I was choosing a video on Youtube and like I didn’t have any head phones on, my dad told me to stop watching it. But I was pretty much watching it anyway.
Lise: Why did that make you feel like a child?
Dylan: Well cause like at 13 people should be able to watch MA19 by now even though it is for 15.

Dylan’s account shows how he resisted the way his parents sometimes used formal rules to enforce control. The account also suggests that adult-defined rules may not necessarily make sense to the young people they were designed to protect.

19 MA=Mature Audiences over 15 years of age, formal content classification in Australia (Australian Government, 2009b).
**The role of age and competency in having control**

Dylan recognised a difference in the way his parents enforced rules based on whether they saw him as sufficiently competent for the activity or not. While Dylan’s mother seemed accepting that he was able to deal with certain adult content in movies, Dylan explained that his father did not acknowledge how much he had changed. The example below shows how Dylan felt that he was treated as less competent by his father than by his mother:

*Dylan:* Well like my … my Mum lets me watch MA-rated stuff cause [sic] she knows I’m old enough for it even though I’m under 15. But my Dad keeps on thinking that I don’t know anything, everything about the rude stuff yet.

Ian expressed the view that children were often discriminated against by adults because of their age. Drawing on his own experiences, Ian explained how he understood adults to restrict children’s opportunities by failing to take account of their views:

*Well, I think that children – they do have a potential but that only goes so far, up until a certain point and then adults will probably stop listening to them because they’ll just think ‘oh they’re just kids imagining things’…*

In contrast, Ian explained that some adults changed their attitudes towards young people once they perceived them as being more competent. His own experiences of this change had significance for the way he understood himself:

*… once someone starts taking you seriously and saying ‘OK you’re an adult now, you’re equal with us’. So that’s, yeah, puts a whole new perspective on the whole thing and I think that, in a way, we don’t have more potential to do it. It’s just that we’ve been given the opportunities to do it more.*

**Struggles with adults for autonomy and control**

For some young people, their experiences of change led to struggles between themselves and adults around gaining autonomy and control in their lives. I observed in several families how access to and use of the internet gave rise to negotiation of terms between the young people and their parents. Typically adults explained how they set rules for the young people as a form of protection. They made decisions on when they could use the internet and what websites they could access. Some
young people resisted adult control in the area of computer technology, expressing that this form of communication was important for their generation. In the example below, Dylan’s father compares, in a light-hearted manner, his own childhood with Dylan’s generation. He states his annoyance with young people’s fascination with this technology and the time they spend on using it. In contrast, Dylan viewed his father as a bit ‘old fashioned’ but he did not take his father’s concerns too seriously:

Father: Oh, when we grew up, when we were kids we didn’t have computers ... that’s why we have pigeons out the back ... [Smiling]
Dylan: Computers are what we’ve got now ...
Father: Yeah I know, you’ve got all sorts of stuff. I think that’s bad in a way don’t you?
Dylan: Na...
Father: ... cause you are stuck in here playing computer or your game instead of going outside ...
Dylan: Oh well ...

Lucas felt that he probably knew more about computer technology than most adults. He expressed the view that some adults tended to place constraints on young people when they were unsure of their children’s engagement with modern technology. He felt it would be better if adults took an interest in, and tried to understand, the issues of importance to young people:

Lise: Is there anything you think adults, so to speak, should know about teenagers?
Lucas: Probably learn more about what is happening on the internet and sort of not getting involved in such a way that they control what their sons and daughters can do on the internet ... Because they had nothing like it when they were young or when they were at their prime of their life ... Yes probably to find out what is going on. Sort of they were teenagers once as well and they have been through the basics and the hardships but they don’t know what it is like being a teenager through these times and these sorts of events.

School as a context for feeling controlled
The school environment was one environment where these young people felt controlled by adults. When first asked about school, most of the young people rejected school as an important aspect of their lives. Anna was reluctant to talk about school because it was ‘boring’. Lucas stated that school was ‘... something that I just have to put up with ... it is pretty annoying but you know ...’. Typically
school was described as a place with too many rules and restrictions (Kim, Dylan). Other participants felt there was a lack of choices (Anna) and opportunities for individuality (Kim, Ian, Lucas).

Control in school was often discussed or displayed in relations between students and teachers. As described in Section 8.3.1, Kim understood the notion of ‘being a teenager’ as associated with the formal structures within the education system. She also described how the student/teacher power relations constrain young people’s individuality and their opportunities to make decisions. Kim explained that although certain structures were in place at her school to allow students to ‘have a say’, teachers did not necessarily take the students’ views into account:

*Kim:* They (teachers) tell you what has to be done. It’s a community.
*Lise:* As a community do you have meetings and representatives?
*Kim:* We have representatives but ... yeah. Teachers control everyone, everything pretty much so ... they say you have representatives but ... not really.

With Andrew, constraints and controls of the school environment were particularly obvious. On several occasions I observed how adults placed restrictions on what he could do in his free time or made assumptions about what he wanted to do in the classroom environment. Other more articulate students were given choices. I am not sure whether being given a choice was necessarily important to Andrew all the time; he mostly accepted that others took control and made decisions for him when at school. However, when having a choice was important to Andrew, he asserted – or made attempts to assert – his agency. For example, during one visit I observed how he resisted being controlled by a more verbally articulate student who was making decisions on his behalf. When allocated an activity he did not want to engage in, Andrew simply handed the materials back to the other student and took the materials he wanted. During another visit, a fundraising fete was held on the school grounds. This fete involved many visitors, including parents and children from other schools. My field notes describe an episode where Andrew was denied having his lunch on the park bench where he usually sat:
I ask him where he wants to sit to eat. He goes up to the shaded area where he usually eats at recess and lunch. I follow and sit with him for a little while as he gets ready to eat. It is nearly time for me to leave, so I tell Andrew that I am about to go and that I will tell his teacher where he is. He looks at me briefly without making any gestures while he continues to unpack his lunch. I walk a few metres to where Andrew’s teacher is standing and tell her where he is. ‘Oh, he can’t sit there today!’ she exclaims. I feel surprised. There were only a few people around that area, mostly staff and the area is not used for the fete.

The teacher walks to where Andrew is sitting and tells him he has to sit where the other students are sitting – on the circular benches. She puts his food in a plastic bag so he can move. Andrew does not look happy. The teacher coaxes him back to the benches. Andrew stops a few metres before they get to the circular benches. ‘No’ he shakes his head. He doesn’t want to sit on the benches. Andrew usually eats his lunch alone and the benches are crowded with people. ‘Come on Andrew, you have to sit here’ the teacher urges. ‘No, no, no’ Andrew shakes his head several times and now his face looks very unhappy and upset. He throws his bag on the ground. The teacher picks it up and coaxes Andrew with his bag onto the circular bench seats among the other 11/12 students, their parents and some of the students from other classes.

I say goodbye to Andrew. He just looks at me, still with an unhappy expression on his face. I ask him whether I can come back on Friday. ‘NO’ he shakes his head. [At the time I was not sure whether Andrew was upset with me as well as the teacher, or whether he said no because that was his only option for agency. However he appeared happy to see me on the Friday].

In this extract, Andrew clearly shows how the teacher’s request upset him. The teacher did not negotiate with Andrew. She expected that he would do what she asked of him without considering the reason for his resistance. In that situation, Andrew’s usual habit of sitting alone to eat his lunch was ignored. His competence to carry out an everyday task was negated on the basis of the teacher’s responsibility to constantly monitor his whereabouts during the fete.

There was a general expectation by participants that they would have more control when they left school. While most participants saw school as an important context for achievements towards future opportunities, they expressed a desire to finish school and get on with their lives in ‘the real world’. For example, Lucas stated that ‘just generally trying to get through school’ was one of the single most important things in life at that time. Being in her final year at high school, Kim expressed that there was ‘a light at the end of the tunnel’. In the example below, Kim and her mother describe how
Kim expected her life after school to be more ‘self-determined’ in contrast to the restrictions she was experiencing at school:

**Kim:** ... Being able to make my own decisions and sort of having my own space to think. Sort of I don’t have to ... I can say ‘no more’ ... and say I am going to move on from this now because I don’t want to do it anymore. But at school you have time limits on an assignment and stuff like that ....

**Mum:** A bit more self-determined. You can pick and choose what you feel you can cope with and what you can’t cope with.

**Kim:** Yeah ... You don’t have to stick to it. You can say ‘no this isn’t me’ ... Yeah you have your options.

**Mum:** Whereas at school it ... sort of the expectation is there all the time to cope with it, you know to keep going.

**Kim:** Yeah.

Kim explained that she understood being an adult to involve having different ways of thinking and making decisions in life views, which were limited within the context of school:

**Lise:** So when you are not at school, what is it that makes you feel more like an adult?

**Kim:** I guess it is that I think like an adult more.

**Lise:** So the way you make decisions or ...?

**Kim:** Yep.

**Lise:** Are you very independent in the way you make decisions now?

**Kim:** Yep. Would you say so? (to mother)

**Mother:** That would be a big difference with school too because you’ve got ... you are formed in your mind what you think you should do ... but you’ve got teachers telling you otherwise ... in that respect, is it?

**Kim:** Mmm ... yes.

### 8.5.2 Negotiating impairments: Taking control of oneself

Some participants discussed one aspect of control related to autism and having impairments. The young people talked about having personal ‘faults’, ‘flaws’ or ‘limitations’. These individual ‘limitations’ were discussed as tasks or situations that were difficult for them or what Thomas (1999) refers to as ‘effects of impairment’. For example, Kim suggested that she could be ‘quite unfocused’ at school, so she sometimes found concentrating on, and completing, school work difficult. Other examples included having trouble finding the ‘right’ words in conversations (Kim, Ian), having difficulty seeing other people’s point of view (Lucas) or having difficulty understanding meanings in
different social contexts (Anna). Anna and Ian gave examples of how they experienced the effects of impairments in social situations:

Anna: If they [my friends] say something mean, I take it personally. Like if they say something that is mean ... like a joke ... I take it personally.
Lise: So do you feel like you don’t get the jokes people tell you?
Anna: Yeah ...

...

Ian: I’ve got some of my faults ... I guess um the friendship thing it has always been a big sort of problem for me ... I go too far in some jokes, sort of thing. Sort of – I don’t understand that there’s a certain boundary that you don’t cross when you’re speaking to people ... And I reckon that sometimes I just cross that line and it drives people away from me, – and not a nice thing. And I can do that unintentionally, just not even knowing I’m doing it.

The participants expressed the view that the effects of impairment sometimes promoted a feeling of losing control of self:

Ian: ... I really lose it ... or something, so I can get angry quite a bit ... um ... just snapping at people over nothing ...

Anna: The fact about ... it’s not normal ... I get angry at Mum, and when she asks a question I sometimes yell the answer at her ... I don’t know but it just comes out ... I can’t control it ...

The participants indicated that losing control of self was related to their diagnosis. Losing control implied a lack of competence. Anna explained that she wished away her diagnosis when she felt her friends were judging or discrediting her. In the following example, she talks about the experience of being stared at for her emotional reactions:

Lise: When is it that you wish that [you didn’t have Asperger’s syndrome]?
Anna: When I get angry at school ... like when people look at me when I get angry ... in particular at school most of the time ... people look at me and think ‘it’s not that bad’...

In Kim’s case, feelings of losing control as related to diagnosis and impairment were associated with particular social contexts. After changing schools, Kim began to feel the effects of the new
environment and the demands that followed. For her, this experience led to feeling that she was losing control and meant that she had to make a decision to confront her differences:

Kim:  ... I went to boarding school then that’s when we had to sort of open up and discover about it because of problems being with the stress issues and stuff like that ... I can be quite unfocused. And that was hard to begin with cause [sic] I didn’t really want to. But then sort of had to. I had to make that decision.

Mother: The environment at boarding school was such that it was such a high level of stress all the time. Kim started saying things like ‘I feel like I’m becoming autistic again’ or ‘I feel like I’m not controlling it anymore’. ‘It throws me ... I used to be able to control it, now I can’t’ ... Would that be right?

Kim: Yeah.

In her example Kim describes how the context of the new school environment meant that she felt pressured to acknowledge her diagnosis and see it as the key contributor to her problems. However, while disabling attitudes within the environment were perhaps the main contributor to Kim’s feelings of incompetence, she still attributed her loss of control to having autism.

The participants described how they made conscious efforts to gain some control over their limitations and abilities. Ian expressed the understanding that being able to maintain control over his own actions and emotions would make his life easier:

... if I could just sort of control that a bit ... and yeah, just not lashing out at other people when I’m angry and stuff. If I could control the anger, turn it into a bit of a minimum and also just sort of reel in the jokes a bit, but I reckon if I can get those things under control well – yeah – I’d have an ideal life that I wouldn’t have to worry about.

Lucas explained how he had already made a conscious effort over time to acquire certain skills to overcome his perceived social limitations:

Lucas:  ... you know how people with autism generally have really bad social skills ... I’ve tried to teach myself good social skills ... Over 12 years I have taught myself through trial-and-error, thinking and learning from people to gain social skills ...

As noted earlier, Lucas’ preferred mode of social interaction was communicating online. In the extract below, he explains that one reason for this preference was that using the internet provided a sense of control in terms of feeling comfortable and secure:
Lucas: I think speaking over the internet is a lot more easier [sic] for me.
Lise: What makes it easier?
Lucas: Well because you are not, probably because it’s say if you are really uncomfortable speaking outside your house or something and but when you have people at your house you really like to talk to them probably because your house is sort of like a comfort zone or someplace you really like to stay in or you know it just feels it’s yours and you know. You feel happy there. That is probably what it is like with the internet.

For Kim, gaining control meant overcoming or concealing her unwanted differences:

Mother: It was very much about ‘if I work hard to fix what is wrong with me then maybe I will become normal’.
Kim: Yes.

Kim explained that ‘being normal’ included being able to fit in to any given social group and being able to ‘behave like everyone else’. Kim and her mother described how she had become proficient at executing social strategies that allowed her to adapt to various social contexts:

Mother: She is very good at slipping into character anyway, aren’t you?
Kim: Yeah.
Lise: OK. So do you want to tell me about that?
Kim: You describe [to Mother].
Mother: I describe. Ok. Kim has told me that because she spent so much time observing what she calls NT’s behaviour and working out how people tick that she’s worked out that there is certain characteristics of people. Like she has studied it so much that she can pick how … what someone is like … the way they behave sort of describes to her what they’re like as a person. And then she is able to sort of put on like a mask, she puts on a mask that allows her to fit with that person’s character so she can relate to them … or at least fit … is that right? …
Kim: Yes.
Mother: Without feeling um …
Kim: Uncomfortable … Yep.
Mother: Uncomfortable … So she is quite often in character when she is talking to people depending on who they are …

The extract above shows how Kim saw herself as different from people in her everyday social groups, to whom she referred as ‘NTs’. Kim explained that, for her, fitting in with NTs was important and involved a conscious and well-researched process. She made efforts to understand people within a particular context in order to change aspects of her own behaviour that would allow her to

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20 NT=Neuro-typical: A description people diagnosed with autism use about non-diagnosed people within autism advocacy forums (see for example Brownlow & O’Dell, 2006)
act and be like them. At the same time, Kim explained that ‘slipping into character’ did not change her personality or sense of self:

Kim: But it is not necessarily fake either, like ... I still am who I am, still have the same opinions and that ...
Mother: You don’t change who you are ... just ...
Kim: Change to a special context of behaviour.

Ian and Kim both explained that maintaining control in their everyday lives required ongoing planning and effort:

Ian: It takes a lot of time and effort and just um, just thinking ahead before you do something to keep everything ... to actually keep things under control ...

Kim: Years ahead. Yeah plan every single day ... everything would go like ... not consciously, but pretty much the next hour, to the next, to the next. I will just do a plan to the week, to the month to the year ...

Issues of control were not explored in detail with Andrew. However, I observed how having routines at home and school was important for him. Insisting that others allow him to maintain these routines helped Andrew to gain control within these contexts. Other participants also indicated that a sense of control was gained by maintaining routines. Withdrawing from stressful situations also helped them to gain control by spending time alone or engaging in preferred activities including computer games (Lucas, Dylan), watching TV or movies (Ian, Kim, Andrew), sport (Anna) or performing arts such as drama and singing (Kim, Anna).

The findings in Sections 8.5.1 and 8.5.2 show how these young people actively negotiated two different aspects of control in their lives. One aspect related to generational relations. The other aspect about which they negotiated related to their impairments, disability and differences.

In terms of generational relations, the data suggest that for these young people teenage-hood was a social structure within which they were acted on by socio-cultural norms and rules, but in which they were also active agents themselves who negotiated some control over their lives. The young people
discussed the implications of social context for their feelings of competence and control including
the family, the school and their social relations with friends. Within the school and sometimes the
family, the young people felt that adults undermined their social competence as persons because of
their age. Within the family, parental control often related to issues of protection and guidance.
Within the school young people expressed feelings of being denied individuality. This finding is
illuminated in the argument put forward by Hutchby and Moran-Ellis (1998) who argue that
competence cannot be understood as separate from the ‘structural context in which it is displayed
or negotiated’ (p. 16). For example within the school context, control is associated with the
enforcement of normative behaviour and the promotion of competency-related goals and
achievements that are typically dissociated with existence outside of the school (Hutchby & Moran-
Ellis, 1998).

The other aspect of control that the young people negotiated related to the ways in which they
understood their impairments and diagnosis to be the basis for social difficulties. One effect of
having autism was described as feelings of losing control. This loss of control was often associated
with feelings of being inferior or less competent in ways that were consistent with the medical
sciences definition of autism. An example of this internalisation of social problems was given by Kim.
When faced with the need to negotiate a stressful boarding school environment she stated: ‘I feel
that I am becoming autistic again’, ‘I can’t control it’. These findings suggest that the young people
had internalised a medical understanding of autism as they typically related social difficulties to their
diagnosis and the personal characteristics they saw as their ‘flaws’, rather than disabling attitudes,
such as being excluded, teased or what Reeve refers to as being ‘gazed’ at (Reeve, 2004 drawing on
Foucauldian themes). Nevertheless they challenged this understanding by taking control of
themselves in various ways. These included planning ahead, learning skills that would conceal or
diminish differences, or by emphasising characteristics they identified with.
These findings illustrate complex interrelations between the effects of impairment and effects of 
disablism as discussed by Thomas (1999) and Reeve (2002). The findings also highlight that that the 
young people were struggling with control in relation to being seen as incompetent in terms of both 
being young and having a diagnosis. The young people demonstrated agency in negotiation control 
with adults as well as in the experiences they felt related to their diagnosis. However, the effects of 
disablism seemed significant for whether young people accepted or resisted their diagnosis and how 
they constructed their social identity.

8.6 ‘I just want to be me’ and to be accepted as me

These data suggest that the young people were trying to construct their changing selves in the 
context of their experiences of autism and the labelling of this condition through diagnosis. While 
mostly seeing themselves as ordinary young people, the participants acknowledged that in some 
ways they were different from others because of their diagnosis. However, the extent to which they 
felt that others should know about this diagnosis differed. Hesitations to disclose a diagnosis or 
publicly identify with autism seemed related to the common assumptions the participants felt 
were associated with the diagnosis. These views are outlined in the next sub-sections.

8.6.1 Who am I? Accepting difference, resisting disclosure

Some participants understood autism to define them as being different from others, as noted in 
previous sections. As the examples below show, these participants suggested that because of their 
diagnosis they had different views, interests and preferences from others generally:

Anna: I see the world different to other people ...

Kim: I just relate to everything differently. I have a different view of everything.

Lucas: I feel different as I can enjoy myself without others, I don’t need one group of friends 
and that I can just drop out at any time.
Ian: Most of my friends are quite different from myself, but there are a few who share similar interests to me. I would probably consider myself a very unique type of person...

Despite the acknowledgement of difference within themselves, the notion of disclosing their diagnosis was a contentious issue for some young people. For example, sometimes there seemed to be some struggle around which aspect of difference to identify with and when:

Lise: ... so you do feel somewhat different from your peers? All the time or just sometimes?
Kim: Mmmm ... I guess it is like I acknowledge it sometimes but don’t acknowledge it some of the time. Yeah.

While some individuals expressed a desire to be understood by others and accepted for their differences, they were not necessarily prepared to tell those others about their diagnosis. The differing feelings about disclosure appeared to be associated with their perception of whether their diagnosis was understood as primarily positive or negative.

Kim and Anna were reluctant to disclose their diagnosis. Both participants expressed a struggle between wanting understanding from others and needing to conceal their diagnosis. As explained below, both participants had a desire for others to appreciate their perceptions of ‘the world’. They wanted others to understand why they sometimes reacted differently in certain situations:

Anna: I wish they would understand ... like ... why I do something that they are not doing ...
Lise: Do your friends know [about your diagnosis]?
Anna: Nooo I don’t tell them.
Lise: Do you think it would make life easier for you if they knew ... sometimes?
Anna: Yeah.
Lise: But at the same time you don’t really want them to.
Anna: No.
Lise: Why don’t you want them to know?
Anna: I just want them to think about me the way they think about me now.
Lise: Do you think they would think about you differently if they knew?
Anna: Yeah.
Lise: Do any of your friends know about the diagnosis?
Kim: I didn’t want to tell them at first because I wanted them to have their own opinion before they find out something that could ... you know, let them treat me differently ... I didn’t want to be perceived as different.

Anna expressed her concern that disclosure may lead to ‘special’ treatment, although she thought that telling others about her diagnosis might in fact help them to understand her. Kim’s reluctance was also based on the assumption that disclosure would taint the way others perceived her, especially if they learned about her diagnosis before they got to know her. For both Anna and Kim, concealing their diagnosis and hiding their differences were important strategies for projecting normalcy and competency. In contrast to Anna, however, Kim found it necessary to let her close friends know about her diagnosis. Kim was very selective about who she told about her diagnosis. She carefully chose the information she gave to her friends:

Kim: I formed the idea to people three times ... now most people know in my grade ... in my grade at the boarding residence. Hardly anyone knows at school and I choose that because I don’t want to be questioned about it.

The male participants seemed less concerned about being seen as different, ‘fitting in’ and being understood as ‘normal’, as long as these aspects did not define them in a negative way. Lucas and Ian did not express that they would intentionally disclose their diagnosis to others. They did not seem to mind that others probably perceived them as being different.

Kim perceived a diagnosis of autism as implying incompetence. For her disclosing in order to gain special consideration at school was undesirable. Such a disclosure portrayed her as less able. Although her diagnosis had been disclosed to the school in order to attain and arrange support, Kim stated that she did not like using the diagnosis with a teacher as a justification to make things easier. Nevertheless, Kim understood the diagnosis to be important in terms of accessing support even if accepting the need for assistance was hard. When she really needed assistance, her diagnosis legitimised difficulties:
Kim: I guess it’s like a set thing … so accepting I have difficulties … in areas at least I can pull out the diagnosis and say here it is. Please support me, I suppose make use of a doctor’s certificate for something that really means exemptions. Yeah … but I try not to use Autism as an excuse.

These young people’s perspectives illustrate the complexity of dealing with a diagnosis in terms of identity and the significance of the label for sense of self as a competent person. Along with other participants, Kim felt that too much focus in society was placed on the negative connotations attached to the diagnosis. This focus may compound the emotional implications of having a diagnosis and the reluctance to disclose. I now turn to report on how the young people viewed attitudes and stereotypes which they felt were commonly associated with a diagnosis of autism.

8.6.2 We are all different: Resisting negative attitudes and stereotypes

Four of the participants were conscious of the stigma and negative connotations that existed around the diagnosis of autism in society. These negativities were aspects of the diagnosis that the participants resisted as part of their identity. They discussed how feeling different was sometimes emphasised by the negative attitudes from other people. Although participants were reluctant to discuss experiences of poor treatment by others, they described times when they felt angry, frustrated or upset at being the target of ridicule, being misunderstood or being excluded by others, as illustrated in the example below:

Anna: I wish they would understand … like … why I do something that they are not doing …
Lise: Do you feel that sometimes people don’t really understand you?
Anna: Yeah.
Lise: How does that make you feel?
Anna: Yeah … sometimes I get a bit angry at them …

Other participants expressed the view that society in general lacked understanding of autism and those living with the diagnosis. Three participants felt that there were many misconceptions around autism. They discussed how people attached negative stereotypes to the diagnosis. This aspect is illustrated below by Lucas:
Lucas: Really I think a more in-depth awareness that there is no definite diagnosis for any case of borderline autism, autism, Asperger’s, ADD/ADHD, and that we are all different, and not all anti-social, aggressive and arrogant ... and that Autism is not a form of mental retardation. ... Also the stereotype of an autistic or borderline autistic, and even Asperger’s as people who are anti-social, can’t handle relationships (Sexual and otherwise) and know a lot about trains.

Kim agreed with Lucas on the negative stereotypes that are often attached to autism. Her brief statement below is a response to a question about misconceptions associated with the diagnosis.

Kim’s answer is marked by her own experiences with intervention:

Kim: Well, that we are not stupid. That we can think for ourselves ... so think past the early intervention stage ...

Ian had noticed the significance of context in the interpretation of the diagnosis, having recently completed high school and being engaged more in life outside of school. He mentions this aspect in the extract from an email interview below. He also indicates that the way others perceive autism and related disorders is influenced by the context within which they experience the people with this diagnosis.

Ian: The whole ‘concept’ of AS definitely varies from each individual who perceives it ...

I strongly believe that nobody is necessarily ‘right’ or ‘wrong’ in their opinion, but every viewpoint is affected by one thing only – the ‘context’ from which their opinion originates ...

Ian stressed that, to him, the diagnosis signified difference rather than deficit. He acknowledged that this distinction had significance for the way children and young people with the diagnosis are approached, educated and treated by others:

Ian: All that I would like to say about the whole ‘condition’ of AS is that to me it is not the fact that people are disadvantaged by it, but just a bit different.

... we aren’t worthless, just different and therefore no better or worse off than anybody else ... it’s just the method of teaching, interpretation or communication which has to differ ... (Extracts from email)

21 Participant’s bracket – email interview
In challenging the negative attitudes towards autism, all participants emphasised the heterogeneity among diagnosed people: as Lucas stated, ‘we are all different’. Although they resisted the negative connotations attached with the diagnosis, these participants still indicated (using ‘we’) that they felt some connection with others so labelled. Yet they did not always want to publically identify as being autistic. Mostly the young people just wanted to be accepted and liked for who they were without having to explain their diagnosis.

Sections 8.6.1 and 8.6.2 show that between them, the young people described a range of different experiences that were associated with autism. They differed in the ways they experienced impairment and felt different from others. The meanings they placed on having autism and the extent to which they identified with the diagnosis also differed. The findings indicate that these young people had common views and experiences that were associated with the way others responded to the diagnosis. They described how negative attitudes and stereotypes are often attached to autism. In discussing these disabling aspects of a diagnosis these young people saw a connection between themselves and others labelled with autism. In this way their experiences of impairment differed significantly from their experiences of disability.

The reluctance to disclose their diagnosis to others appeared to be linked with these negative attitudes. For some the reluctance was due to the assumptions that others’ view of and responses towards them would change upon realising their diagnosis. Active non-disclosure is one method that young people can use to negotiate their identity; this method may allow them to ‘pass as normal’ (Reeve, 2002; Thomas, 1999). Thomas (1999) refers to this aspect of ‘disablism’ as a psycho-emotional dimension of concealment (p. 55). Again these dimensions may have significant implications for young people’s sense of self-worth and the way they structure their identity.

Finally, it is important to note that those participants who reflected on their past expressed the view that all their individual social experiences, including (but not exclusively) those of living with a diagnosis, were significant for the way they understood themselves. While having a diagnosis was
significant for understanding self as different from others, the changes experienced, imposed and anticipated as part of the structure of teenage-hood also had implications for the way they structured their identities. This view was stated explicitly by Ian:

... in having these differences, I probably have grown up differently from most other teenagers. I do believe that I have been changed by my experiences with these illnesses, but it has been far more than just them that have managed to shape who I am today.

8.7 Summary

The findings reported in this chapter illustrate the diverse lives and experiences of six young people diagnosed with autism. The findings show how these young people understood themselves and negotiated their identity in terms of the changes associated with being a teenager, through social relations with others and in having a diagnosis of autism.

These participants understood themselves as young people in a phase of change between being a child and an adult. Their individual experiences of teenage-hood involved a range of embodied and social changes as well as an increasing desire to have more control over their lives. These changes led to negations of control and conflict with adults in their lives. Within the school and sometimes the family, the young people felt that adults undermined their social competence as persons because of their age. Within the family, parental control often related to issues of protection and guidance. Within the context of school, these young people also expressed feelings of being denied individuality. Other contexts that intersected with school included the young people’s social relations with friends or peers and the labelling process resulting in their diagnosis of autism.

For five of the six young people, a diagnosis of autism was significant for the way they saw themselves as different from others. However, having a diagnosis of autism did not mean that they identified as autistic. The participants also did not describe themselves as disabled. They expressed views and experiences that related to concepts of difference, impairments and disability. These young people either accepted or resisted their diagnosis and label of being different, depending on
whether their experiences were positive or negative. Feelings of being different could be
detrimental to their sense of self when associated with lack of social competence. While the young
people typically resisted the negative stereotypes, some were uncomfortable with the connotation
of incompetence around autism that seems to persist in society.

These young people were active in upholding their sense of control in relation to social competence.
Some concealed or minimised their differences. Others focused on their strengths or created
identities that defined them as unusual but funny or mysterious persons. For most participants,
engaging in their personal interests, making plans or having routines and time for themselves were
important dimensions of feeling a sense of control in their everyday lives.

The findings show how these young people developed their own understanding of autism within the
context of their lives. While acknowledging impairments and personal limitations, most participants
resisted or challenged the negative stereotypes associated with autism. Few participants understood
autism as the most important aspect of identity. Clearly identity was not a fixed or static entity, but
influenced by fluid and complex processes that these young people negotiated at different times and
within a range of social contexts. Nevertheless, having a diagnosis had implications for young
people’s sense of self and the way they constructed their identity during a time also marked by
changes associated with teenage-hood.

In Chapter 9, I discuss the significance of the findings produced from this research. The discussion
will relate to the young people’s views and experiences as reported in this chapter, as well as the
practical processes that allowed me to engage with the participants.
PART FOUR: DISCUSSION AND CONCLUSION
Chapter 9: Discussion and conclusion
9.1 Introduction

In this final chapter, I draw this study to completion. First I reflect on the research purpose and outline the way in which the aims were met. After a brief summary of the research approach and process, I discuss the findings and new knowledge produced. I draw conclusions from the findings and consider the implications these may have for theory, social policy, practice, education and further research. I also discuss the limitations of the study. Finally I reflect on my own journey through the research.

9.2 Understanding the lives and experiences of young people diagnosed with autism using an alternative approach to knowledge

The main aim of this study was to learn about the lives of young people diagnosed with autism from their own experiences. A secondary aim was to implement an approach that included the views of the participants in a meaningful and respectful way. This study was successful in that it provided a forum through which young people diagnosed with autism could contribute their knowledges on being young and living with a label that defined them as different from the norm.

The findings add to extant literature focusing on children’s views on, and experiences with, impairment and disability, as well as their views on teenage- hood and being labelled with autism. The study responds to calls for research that includes ‘insiders’ accounts’ by children diagnosed with autism (Billington, 2006). Further, the approach I have implemented has provided knowledge about the inclusion in research of young people diagnosed with autism and with different abilities and preferences for communication. In this way my thesis has produced knowledge about the lives of a group of young people diagnosed with autism and about engaging with them in research. The theoretical framework and methodological approach were significant in being inclusive of the young people’s views. Therefore I discuss these aspects of the research first.
9.2.1 The value of theory in hearing young people

A theoretical framework informed by childhood sociology and disability studies was inclusive of the voices of young people. As discussed in Chapter 4, the ‘new’ sociology of childhood takes children’s views seriously. The key principles in childhood sociology value young people as active social agents with views of their own, who play a part in shaping their own lives (James, Jenks, & Prout, 1998; Prout & James, 1990). These principles challenge traditional views of children as passive and immature (Piaget, 1968). The social model of disability enables us to understand the disabling effects of material, social and attitudinal barriers on disabled people’s lives as separate from individual experiences of physical, cognitive or sensory impairments (Morris, 2001b; Oliver, 1996). The views of children and young people diagnosed with autism have been explored in other studies, as discussed in Chapter 3. However, while sociological interpretation was a goal in some of these studies, concepts significant to childhood and disability theories were not always apparent. Typically these studies used a traditional framework focusing on understanding children’s perceptions of specific topics selected by adults. These studies often present findings that focus on defining deficits; highlighting characteristics and impairment associated with autism. Priestly (1998) suggests that such approaches to research deny disabled young people’s rights as children and individuals.

Combining theoretical insights from childhood and disability was significant for the analysis of my data. These methods produced knowledge about the lives of teenagers diagnosed with autism. This knowledge differed from research using an etic approach with a medical sciences perspective. In other research, connecting these concepts and principles has also been useful for further understanding the lives of disabled children more generally (Cocks, 2006; Connors & Stalker, 2007; Kelly, 2005, 2007; Morris, 2003). Using these theories allowed me to look more broadly at the lives of young people diagnosed with autism. The broader focus has contributed further understanding of the diverse lives of young people diagnosed with autism by opening a space to talk about the issues that are important to them. For example, the meanings these young people attribute to being teenagers, the importance of negotiating control in their lives and their experiences of being
diagnosed and living with a label are issues rarely discussed in research with or about children diagnosed with autism. By using a theoretical framework informed by both the ‘new’ sociology of childhood and the social model of disability I have been able to focus the research on the individual experiences and opinions of young people both when engaging with young people and in analysing the data. As such the theoretical framework formed the basis for the inclusive research approach.

9.2.2 The importance of using an inclusive research approach

The collaborative participatory research approach used in this study responded to methodological challenges reported in previous studies involving children and young people diagnosed with autism. The approach differed from the way research typically involves these children and has been important for facilitating the views of the young people involved. Implementing this collaborative participatory approach placed the young people at the centre of the research. They were involved in directing the research process, selecting the methods and strategies by which they engaged. This research approach along with the theoretical framework enabled me to engage the young people as social actors and co-constructors of knowledge (John, 1993).

My choice to not use a traditional research approach is congruent with contemporary research in both childhood sociology and disability studies. Researchers spanning both fields challenge the hierarchy in traditional research similarly to the way they challenge the inherent power relations between adults and children, and the power of the medical model in defining disability (for example Connors & Stalker, 2002; Connors & Stalker, 2007; Davis, 1998, 2000; Kelly, 2005, 2007; Morris, 2003; Priestly, 1998). However, while the approach focused on young people’s views, implementing the research required time, resources and flexibility. Four factors helped achieve success in this study.

Firstly, consultation with young people early in the research process allowed me to be inclusive of their views. Consulting young people encouraged their active contribution to the research and enabled me to appropriately approach and respond to individual participants during interviews and
observations. Consulting young people prior to the formal data collection phase has been emphasised in other studies involving disabled children (Connors & Stalker, 2002; Kelly, 2007; Kelly, McColgan, & Scally, 2000; Morris, 1998, 2003). Children and young people diagnosed with autism are assumed to present with particular social and communicative impairments. These impairments and the diversity of ways in which these affect diagnosed young people have challenged researchers for years. Consideration of those challenges was useful in the preparation for this research. Challenges such as participant reluctance to engage during data collection visits were resolved or circumvented by approaching participants as individuals. The consultations allowed for time to develop rapport and select appropriate methods for engagement as favoured by the young people.

Secondly, it was important that preconceived ideas about autism did not get in the way of listening and hearing the voices of young people. Being aware of common issues and impairments associated with a diagnosis of autism was useful when preparing for interviews. However, the research process and the methods used were not directed by the label. Using a flexible and eclectic research approach enabled me to engage young people as individual persons and engage with them according to their individual preferences and requirements. With this group of young people it was appropriate to use a number of research methods and communication strategies. This feature of the research process is important. Previous research including young people diagnosed with autism has reported difficulties in using one single method with all participants (Beresford, Tozer, Rabiee, & Sloper, 2004; Preece, 2002).

My research reinforces the value of using concepts from the social model of disability to implement inclusive research. Focusing on the way young people communicate is more useful than focusing on the way their impairment affects their ability to use speech for communication. This point has been emphasised by researchers such as Morris (1998) and Davis and colleagues (2000). It links with the next point which emphasises the willingness of the researcher to step outside of traditional research
in order to be inclusive of participants with a broader range of communication abilities and preferences for interaction.

The third point highlights the importance of the researcher’s role and attitudes in being inclusive of young people. The importance of the researcher’s role has been discussed extensively in contemporary childhood research (for example Christensen & Prout, 2002; Christensen, 2004; Davis, 1998; Davis, Watson, & Cunningham-Burley, 2000; Mandell, 1991; Mason & Urquhart, 2001; Mayall, 2000), including studies focusing on disabled children (Cocks, 2006; Davis, et al., 2000; Davis & Watson, 2000; Kelly, 2007; Morris, 2003). However, few studies focusing on children diagnosed with autism report much on the significance of the researcher’s role in facilitating the views of children. An exception is the study by Beresford and colleagues (2004) which found that researchers needed to be prepared to accommodate the needs and abilities of participants. My approach extended these findings by involving the young people in selecting the methods they were comfortable with and by learning from them how they could best communicate their views. This approach may be viewed as a ‘making it up as you go along’ approach. However, Beresford and colleagues (2004) also noted that ‘there is a balance to strike between “methodological rigour” and facilitating the direct participation of the participants in question’ (p. 32). While my eclectic use of methods challenges traditional research approaches, I suggest that the ‘methodological rigour’ lies within the way researchers strive towards facilitating the views of the children involved.

Fourthly, involving the parents as partners in the early stages of the research process added both positive and negative dimensions to the research. Parent involvement was important in terms of providing access to young people and sometimes facilitating their children’s views to be heard. The involvement of parents in the early stages also provided knowledge about their motivation for wanting to involve their children in this research. The latter aspect is rarely discussed in research involving children. Typically, researchers highlight how parents may act as gate keepers in order to protect children: a role that sometimes excludes young people (Alderson, 2004; Christensen & Prout,
This challenge has also been reported in research including disabled children (Kelly, 2007; Morris, 2003). In previous research involving children diagnosed with autism, some parents were happy to participate themselves. Some parents excluded their children from direct involvement as they assumed research participation would be meaningless for their child (Beresford, et al., 2004).

The findings from my study suggest that parents may facilitate access to their children if they agree with the foci and methods of the research. These parents emphasised advocacy and empowerment of young people as reasons for participating. Most of these parents themselves were struggling to be heard within the context of their everyday lives. As noted previously, in light of the slow recruitment process, it is likely that the parents who volunteered for this study were particularly proactive. It seemed that parents saw it as important for their children to contribute their views and experiences. Other parents may have different priorities. I suggest that because children’s lives are not static, different aspects of research may become relevant to parents and children at different times in their lives.

The findings also illustrated how shared meaning making between parents and children may produce deeper knowledge. At other times, involving parents had the effect of limiting the extent to which some young people’s voices were heard. Other researchers have suggested that involving both parents (or other carers) and children in research may enrich knowledge about the lives and experiences of children and young people diagnosed with autism (Beresford, Tozer, Rabiee, & Sloper, 2007; Preece, 2002). However, as Mayall (2000) has emphasised, when involving children it is important for researchers to be responsive to generational tensions that may impact on research relations. There is a need to ensure that the views of the young people are included and taken seriously during the research process. In this research it was evident that some young people did not want to talk about particular aspects of their lives with their parents present. This aspect was most marked with Anna who only agreed to participate when she was assured that the interviews could be conducted in private. With Andrew, the opportunity to learn his reasons for not talking was lost.
when his father disrupted the interview activity. Thus involving both parents and children in the research process may sometimes require that the researcher negotiates with all participants, adults and children, how research engagement will occur.

Sections 9.2.1 and 9.2.2 have discussed how the theoretical framework and the methodological approach were important for my research. These aspects of the research determined how the young people were included and heard, counting those with more complex cognitive and communication impairments. This research process was time consuming, resource intensive and rather messy at times. However, similar issues have been reported by researchers conducting participatory research with children and young people generally (Australian Research Alliance for Children and Youth & New South Wales Commission for Children and Young People, 2008). Part of the problem is perhaps that while participatory research with children and young people is considered best practice, it is still not the norm – especially when it comes to being inclusive of children such as those diagnosed with autism. Thus it is important that researchers become more skilled in participatory research. They need to hear the views of children and young people and learn ways to include those with different requirements and preferences for interaction and communication.

### 9.3 Young people define teenage-hood and autism

The research focused on the young people’s individual views. Similarities and differences in their experiences were identified. The knowledge contributed by the young people included their experiences as teenagers, issues that were important in their lives and their views about having a label of autism. By focusing on the issues of importance to them as well as my own research questions, a broader set of findings was produced than those in research focusing explicitly on autism.

The findings reported in Chapter 8 indicate that these young people had dual experiences as teenagers and individuals diagnosed with autism. While these experiences are interrelated, some young people clearly articulated the aspects that they associated with being a teenager and those
they associated with having autism. These findings provide some understanding of how some young people experience and define teenage-hood and autism, and the way they relate these concepts to their lives. In the next two sub-sections, I discuss key findings reported in Chapter 8: firstly views and experiences relating to being a teenager, then those focusing more specifically on autism.

9.3.1 Same but different: Young people first

The findings highlighted the importance of seeing young people who are diagnosed with autism as young people first. Three aspects of this finding raise considerations for policy and practice. Firstly, the findings highlighted that the participants identified themselves as teenagers or young people, rather than persons with autism or as ‘autistics’. For most participants, autism was not the most important aspect of their lives even when the issues they associated with autism sometimes had significant implications for their everyday lives. Only one participant brought up the topic of autism before I asked about it. At the same time, however, some participants suggested that they were probably growing up differently to other young people because of the particular experiences associated with having a diagnosis of autism.

Five participants also stated that they felt different from other young people or felt treated differently from other young people on the basis of their diagnosis. In relation to sameness and difference, Ian suggested that feeling different was associated with social context and the responses from others. Kim stated that while she understood herself as ‘very different’ from others, there were times when she did not want to acknowledge this difference. Other research suggests that disabled children generally see themselves as being the same and different to other young people, but they do not necessarily want to emphasise the differences (Connors & Stalker, 2007; Kelly, 2005). Connors and Stalker (2007) found that their participants focused on the way in which they were the same as other children despite apparent physical differences. Kelly’s (2005) findings showed that some children resist the way adults tend to focus on their differences or ‘special needs’ and ignore other important aspects of their lives.
Secondly, and further to the findings discussed above, the concerns raised in the interviews were the same as those of other young people. For example, the importance of feeling secure, having a positive sense of self and being valued and respected as an individual have also been found important in recent research about children’s views on wellbeing (NSW Commission for Children & Young people, 2007). Some young people had distinct aspirations for the future. Others were more concerned with here and now issues, such as developing social relations outside of the family context and developing romantic relationships. Contrary to popular metaphors portraying the ‘non-humanness’ (Waltz, 2006, p. 2) of children diagnosed with autism, as discussed in Chapter 2, several of these young people had distinct concerns for others. They described complex perspectives of social injustice and moral responsibility, which they acted on within the context of their lives. Some participants indicated desires to carry their interests in social issues into future studies and careers. The finding about concerns for social justice is again in line with findings from research on children and young people (NSW Commission for Children & Young people, 2007).

Thirdly, these young people contributed knowledge about being teenagers. The ways in which they expressed their understandings on teenage-hood and experiences of becoming ‘an adult’ were not embedded in notions about autism. At one level, being a teenager was described as a transitional time involving experiences of biological changes. At another level, being a teenager was described as a structure for socialisation in which young people were being prepared for adulthood. Some of the participants were beginning to identify as adults because their bodies and views were changing. At the same time they felt they were being inappropriately treated as children by adults. They were resisting adults' imposition on them of socio-culturally established norms dictating young people’s competence on the basis of their age (as in their challenging of restrictions on the viewing of movies and use of the internet).

In summarising these findings the young people were describing teenage-hood as resolving tensions posed both by biological changes and by the way adult–child relations are structured in relation to
power and control. For some young people diagnosed with autism these issues become further complicated as they may be more protected and more closely observed than other teenagers. Not all teenagers have the same abilities and opportunities to negotiate control with adults. As was particularly evident with Andrew, adults tend to further protect a young person who is understood to have significant cognitive impairments, regardless of their age. Priestly (1998) highlights the way such protection may have the effect of restricting young people’s opportunities for agency, independence and developing social relations, thereby elongating their childhood.

What is important to draw from these findings is that young people are young people first regardless of their labels, appearances, abilities or actions. Children diagnosed with autism are typically portrayed as being significantly different from other young people, while their experiences tend to be generalised. Once a label is applied there is an inclination to view young people exclusively through the lens of the diagnosis, forging an understanding that difference is reflected in all their experiences. It is imperative that teachers, researchers and service providers who are involved with young people diagnosed with autism acknowledge the experiences and concerns that are important in young people’s lives and understand that not all revolve around impairment or diagnosis. This notion brings me to the discussion about the significance for young people of the label of autism itself.

9.3.2 Autism as a context for understanding self as different

The findings provided knowledge about the role of a diagnosis of autism in the lives of these young people. The diverse experiences of being labelled or learning about having a label meant that the significance of the label varied for individuals. However, while the significance varied, it seemed to have two major effects. Firstly, some young people were unaware that they, or aspects of their personality, were seen as unusual and different by others. For these individuals, receiving a label of autism had the effect of discovering aspects of themselves in a new light, which through the lens of the diagnosis they came to understand as different and sometimes problematic. This discovery had
quite powerful implications for their sense of self. This finding reflects recent research by Huws and Jones (2008) who referred to such unawareness as an ‘absent present’ of autism in young people’s lives.

Secondly, for young people who had always felt somewhat different from others, a diagnosis of autism had the effect of confirming and explaining these feelings, but also legitimised experienced difficulties as ‘real’. This finding corroborates with personal accounts by adults who recollect feeling different from other children through their childhood and youth (for example Grandin & Scariano, 1986; Lawson, 1998; Williams, 1992). Huws and Jones (2008) speculate that adults who receive a diagnosis later may have had longer to retrospectively examine their childhoods in light of their diagnosis and do so with years of other experiences on board. Thus the recollected experiences of adults may reflect new knowledge and hindsight. The varied experiences of the young people in my study do not support or refute this argument. Rather they signify the importance of finding out from children themselves about the effects of a diagnosis on their understanding of themselves.

The findings illustrated how most of the young people resisted autism as a social/public identity. While a diagnosis was sometimes helpful for young people in understanding themselves, few young people were willing to publically disclose their diagnosis. Only one person took distinct pride in being different. He structured his identity around the positive traits and strengths that he associated with autism. The resistance to disclose a diagnosis was particularly strong in relation to peers. Resistance to disclosure was also stated more explicitly by female than male participants. With such a small sample, however, it is difficult to know whether non-disclosure and the desire to ‘pass as normal’ are associated with gender roles.

The young people discussed two reasons for not wanting to disclose their diagnosis. The first reason for rejecting the label of autism reflects other studies including children diagnosed with autism: that young people do not want to be seen and treated as different (Carrington & Graham, 2001; Carrington, Papinczak, & Templeton, 2003; Humphrey & Lewis, 2008). Humphrey and Lewis (2008)
described how some young people felt forced to adapt themselves in order to appear ‘normal’ and fit in with peer groups (Humphrey & Lewis, 2008). Carrington and Graham (2001) used the term ‘masquerading’ to describe the strategy their participants used to blend in. The sophisticated efforts to learn the interests and behaviours of particular peer groups described by one participant in my study also reflect the findings in the two previous studies. These findings are important on two levels. Firstly, they challenge the common understanding that those diagnosed with autism have a weak ‘theory of mind’ (Baron-Cohen, 2001) in relation to non-diagnosed children, as discussed in Chapter 2. Secondly, there is a need to find ways to develop a more inclusive peer culture in schools. The efforts described by young people diagnosed with autism to understand other people, and to establish rapport with and be included in peer groups, should be reciprocated by peers.

The second reason that the young people resisted the diagnosis as part of their identity involved the way they felt challenged by negative stereotypes associated with the label of autism in society. Diagnostic labels tend to have a homogenising effect. A label suggests that all who share it are the same and thereby overrides individuality (Ho, 2004; Low, 1996). At one level this effect may be oppressive to the individual carrying the label, especially when particular negative stereotypes are associated with the diagnosis. At another level the homogenising effect may confuse others. For example, teachers and service providers may assume certain impairment needs and abilities on the basis of the diagnosis and focus on these rather than the issues that are important for the individual.

Deliberate concealment of impairment or diagnosis has been discussed widely in the disability literature (Goode, 2007; Joachim & Acorn, 2000; Low, 1996; Reeve, 2002; Shakespeare, 1996; Thomas, 1999). For some people the goal of concealment is to fit in, while for others it relates to feelings of competence. Either way, the concern here is that the individual in question may then live in fear of being ‘caught out’, which carries the risk of being rejected or treated as different and having to negotiate how to respond to others. Thomas (1999) refers to this fear as the psycho-emotional effects of concealment. The significance of considering the psycho-emotional effects of
both impairment and disablism (Thomas, 1999) that may be associated with having a diagnosis is an approach rarely taken in research focusing on children with autism. Authors in the disability studies literature have suggested that such effects may have far-reaching implications for self-worth and self-identity (Priestley, 1999; Reeve, 2002; Shakespeare, 1996; Watson, 2002).

The findings show the importance of understanding whether difficulties encountered by those diagnosed with autism are an effect of their individual impairments or of social barriers in their environment. The way young people defined autism for themselves and internalised the problems associated with a diagnosis was consistent with the medical model. These participants defined autism in terms of a range of effects of impairments that needed to be ‘normalised’ or remediated. They also described personal characteristics that they saw as being different from others. However, the way the young people discussed the experiences associated with autism involved disabling attitudes within particular contexts such as being treated differently by peers and teachers. Participants who discussed such experiences sometimes expressed emotional effects of disabling attitudes (Thomas, 1999) in terms of feelings of anger, sadness or frustration when not fitting in with peer groups, or being teased or feeling stigmatised because of the way they acted in certain situations.

The experiences young people described of losing control seemed to integrate effects of both disability and impairment. Feeling powerless or incompetent in a particular context was described by some as losing control. These findings illustrate the usefulness of considering how the psycho-emotional dimensions of disabling environments or attitudes may lead to what Thomas (1999) refers to as ‘barriers to being’ and ‘barriers to doing’. For three participants such experiences sometimes led to having difficulty controlling emotions and actions causing anger outbursts. For two participants these experiences almost had a paralysing effect which inhibited their ability to communicate verbally. Similar experiences were discussed by teenage author Luke Jackson (2002). In his book, Jackson talks about the way life often seems out of control for him and the security in
escaping into a part of life that he can control – electronic games. Some participants in my study described similar strategies of engaging in favoured activities to gain control of themselves. These strategies allowed them to remain in control of their lives in response to stressful everyday demands. Others expressed a desire to find ways of controlling situations that promoted such emotions and actions. These findings raise important considerations for parents and those working with children diagnosed with autism. In terms of the effects of autism, the findings challenge the common idea that those diagnosed with autism have a reduced emotional register. Rather they highlight the importance of considering a sensitive emotional register. Further, ‘focused interests’ have been discussed in other research with children diagnosed with autism as a characteristic or an impairment associated with the diagnosis (Carrington, et al., 2003). However, few studies have explored the meanings these may have for the individual or their significance for maintaining control. Secondly, distinctions between experiences of impairment and disability are significant dimensions of disability research and such findings reflect research with disabled children more generally (Connors & Stalker, 2007; Davis, et al., 2000; Davis & Watson, 2002; Kelly, 2005). However, distinctions between experiences of impairment versus disability are rarely examined in research focusing on children diagnosed with autism as these studies tend to frame their research on a medical model. The traditional focus on the ‘deficits’ of the children diagnosed with autism needs to be considered in relation to the way in which many problems faced by these children are contextual and often created by society.

In summary, some of my findings reflect research involving young people generally and emphasise the need to view children diagnosed with autism as young people first. As my findings also showed, children and young people come to associate differences and difficulties with their diagnosis due to the way the medical approach to autism promotes normalisation through intensive intervention. My findings resonate with research involving other disabled children in that the extent to which individuals feel different is associated with responses from others. The diagnosis itself becomes a context for experiences of difference with implications for the way young people structure their self-
identity. At the same time these young people developed their own understanding of and attitude towards autism within the context of their lives. These findings are important because they show how experiences of impairment interrelate with and may be distinguished from those of disability in the way young people experience ‘having autism’.

The way these participants define autism for themselves has both confirmed and challenged previous understandings of children and young people so labelled. Some of the findings challenge common stereotypes about children and young people diagnosed with autism. Other findings support existing literature about children and young people diagnosed with autism, but present these from the views and experiences of young people themselves. Taken together with findings in other studies, my findings indicate that the extent to which young people feel the same or different is typically experienced through the success and failure of achieving within ascribed social norms. While these findings are perhaps not surprising they have implications for policy writers and educators responding to children diagnosed with autism. Such findings also raise considerations about the further need to increase awareness of impairment and diversity in society.

9.4 Implications for policy, research and practice

This research has produced findings about the lives of a small group of young people diagnosed with autism and ways of including their views using a collaborative participatory research approach. In the next sections I consider the implications of these findings for social policy relevant to children and young people diagnosed with autism, as well as for researchers and practitioners involved with this population.

9.4.1 Implications for policy

Research about children and young people should, Mayall states (1999), ‘increase knowledge about children’s experiences, knowledge and views; these data can then contribute to policy-oriented work towards improving the social condition of childhood’ (p. 13). The knowledge contributed by this small group of young people has raised important considerations for developing inclusive social
policy relating to children diagnosed with autism. This knowledge also has implications for those researching and working with these children and young people. Thus in contributing the knowledge produced from this research, I highlight considerations for social policy relevant to the lives of children and young people diagnosed with autism. I make the following recommendations accordingly.

**The significance of labelling young people for social policy**

Policies and services that promote the early identification and diagnosis of children with autism for the purposes of service funding need to recognise positive and negative implications of labelling for a child’s self-identity.

Within current Australian social policy (Australian Government, 2008a) children and young people diagnosed with autism are defined as a social problem because their expected biological development milestones, actions and preferences often differ from valued social norms. Often their abilities do not fit neatly into the Australian education system. In developing social policy relating to children diagnosed with autism, these children’s differences are emphasised as deficits in need of early identification, labelling and intervention in accord with the medical model.

McDonald (2008) suggests that social policy developed for and about children has a significant role in creating and promoting identities of those who are its object. She argues that the identities created by social policy may or may not reflect those that children themselves take up or agree with (McDonald, 2008). My findings support this argument. The label of autism may become a negative identity for the child through the process of socialisation as the diagnosis or the impairments/differences associated with it become the sole focus of analysis. A diagnosis may become the rationale for failure to achieve academically, while societal issues such as inclusion and acceptance are converted to personal woes (Shakespeare, 1996). As illustrated in Kim’s story, the diagnosis may have ongoing implications for the young person’s sense of self and the way they structure their identity. Several participants in my study were also concerned about the negative
connotations and stereotypes associated with autism in society. Consequently some participants feared that others would see and treat them differently on the basis of the diagnosis.

The labelling predicament discussed in this research is reflected in the tension that exists between international policies such as the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) and national social support policies, such as the ‘Helping children with autism’ policy (Australian Government, 2008a). The CRPD, which is based on a social model of disability, promotes enabling processes for people with disabilities (equality) and celebrates achievement and progress. The focus of the principles of the CRPD is on capability, inclusion and mainstreaming. In contrast, the ‘Helping children with autism’ policy, which is based on research grounded in a medical or individual model of disability principles, focuses on impairment, exclusion and segregation in that individuals have to prove their impairments to qualify for services and education which are increasingly specialised for children diagnosed with autism. The way the medical model dominates this social policy has the effect of reinforcing the notion of deficits and thereby emphasises difference. The dilemma lies in how policy makers can respond to those individuals who are diagnosed with autism and facilitate them receiving services while limiting the extent to which they are labelled and the impact of these labels on them.

I suggest that it is important for policy makers to recognise children diagnosed with autism as young people first and promote this understanding to the wider community. My findings suggest that autism was not necessarily the most important aspect of the young people’s lives. However, these participants expressed the view that the diagnosis was significant for the way they saw themselves as different from others. Therefore it is important that policy makers acknowledge that labelling can result in negative attitudes towards disabled young people including those diagnosed with autism. It is important that policies promote rights as well as needs, cater for capability over inability and facilitate participation and inclusion rather than segregation. More specifically, policy makers should consider the stereotypes that may be created through diagnosis-specific policies and the
implications that the application of labels have for young people’s sense of self. There is a need to think beyond early intervention and to consider the individuality of those diagnosed with autism. While young people’s needs and circumstances differ and change over time, understandings of self as different and less competent may remain.

**Developing a multilayered approach to social policy in education**

Policy makers should develop a more holistic approach to educational inclusion and the way disability issues are managed in schools.

It seems necessary that social policy integrates social and medical models when responding to children and young people diagnosed with autism. The findings illustrated that for these young people being teenagers and ‘having autism’ involved complex experiences that integrated biological development and socio-cultural structures with negative emotional dimensions of both impairment and disability. In terms of policy these experiences mean that, at one level, individual intervention is important in terms of building strengths and helping young people to be the best they can be. At another level, intervention needs to effectively address environmental barriers and societal attitudes. Thus individually neither the medical model nor the social model of disability provide a strong or adequate basis for social policy as also argued by Davis, Watson, Corker and Shakespeare (2003) in relation to social policy that responds to disabled children more broadly.

In dealing with educational inclusion, Davis, Watson, Corker and Shakespeare (2003) proposed a ‘multilayered approach to social policy’. This approach was to work closely with children, parents and practitioners in bringing forth their own local solutions, and to include the peer group in the solution. This collaboration would enable children, parents and practitioners to engage in more meaningful discussion around inclusion with consideration for the variability of disabled children’s lives. Davis and colleagues (2003) suggested that more resources are allocated to resolve technical rational issues that create barriers to inclusion. They also highlighted that there is a need to change
the structures of societal and educational settings by addressing the cultures of discrimination within them.

**Developing disability and diversity awareness programs as part of the school curriculum**

It is important that policy makers find positive ways to address awareness and acceptance of difference in education and the wider community. There is a need to develop and implement disability and diversity education programs that foster more open-minded and positive attitudes in the general population about disability and diversity.

My research suggests that there is a need to address persistent negative stereotypes attached to ‘having autism’. Findings from other research with disabled children and young people seem to support this indication (Connors & Stalker, 2007; Islam, 2008; Kelly, 2005; Madriaga, 2007; Morris, 2001b). While some young people may develop skills to negotiate problems affecting their everyday lives, others experience lasting emotional effects of misconceptions and negative stereotypes associated with autism.

Negative attitudes towards disabled people typically result from lack of knowledge and uncertainty about how to interact and communicate. However, addressing social attitudes has often been deemed more complicated than focusing on the individual because these attitudes are embedded in social structures and cultural beliefs (King, Rosenbaum, Armstrong, & Milner, 1989; Lau & Cheung, 1999). Peer education programs are often delivered at an individual level. These programs are typically reactive when a young person has decided to disclose their diagnosis to peers because of problems encountered. I argue that such programs function as band-aids and that they are not sufficient to change societal attitudes. Education about impairment and disability needs to become a priority within social policy and should be implemented proactively. Efforts to increase public awareness of disability issues and acceptance of diversity need to be addressed consistently and on a national level.
I suggest that for education about impairment and disability to be effective, the topics need to be included as a substantial subject within primary and secondary school curricula. Recent experimental research found that implementing a disability awareness program increased knowledge about disability issues and enhanced attitudes towards disabled people in the workforce (Hunt & Hunt, 2004), as well as among secondary school students (Rilotta & Nettelbeck, 2007) and primary school students (Jacon, et al., 2010). Policy makers need to consider making such programs obligatory and including ongoing subjects within the school curriculum that address the negative stereotypes that persist towards disabled children.

The significance of hearing young people’s views in social policy research

It is important that policy makers are respectful of children and young people diagnosed with autism and take account of research that is inclusive of their views when developing policy relevant to the diagnosis, funding, services and education.

This study has shown that young people diagnosed with autism are capable of contributing to research and have something to say about their lives. McDonald (2008) argued that policy makers should acknowledge children as informed agents with knowledges about their lives, experiences and future. While researchers are beginning to consult and engage with Australian children on issues relevant to their lives (Australian Research Alliance for Children and Youth & New South Wales Commission for Children and Young People, 2008), this progress is much slower with disabled children.

Currently, research that focuses on the views and experiences of children and young people diagnosed with autism is sparse. Typically only very small samples are included. Further research is needed to understand the lives and experiences of children and young people diagnosed with autism. The scarcity of research including the views of children and young people diagnosed with autism leaves open a broad scope for research in the future. With the focus on early diagnosis and intervention of children, it is imperative for policy makers and researchers to consider the meaning
of autism in the context of children’s lives. Thus it is important to follow through from my research
and extend it to larger populations within Australia and in other countries where policies are
developed specifically for people labelled with autism. Similarly, it will be important to identify
opportunities for collaborative work across countries. Australian research culture would particularly
benefit from partnerships with researchers in European countries where children’s views are more
often included in research and policy development.

9.4.2 Implications for practice

It is important that professionals become instrumental in changing negative attitudes and
stereotypes towards disability and the stereotypes associated with autism.

My findings suggest that professionals can be influential in promoting or limiting negative attitudes
associated with autism. While the young people in my study had developed their own understanding
of the diagnosis, medical definitions, as well as their experiences with teachers and health
professionals, were significant in the way they defined autism for themselves. The implied need for
normalisation and experienced provisions of special educational allowances meant that the young
people internalised problems in a manner congruent with the medical model.

Intervention programs need to adopt a more holistic model that moves beyond diagnosis and
impairment, and includes advocacy and education. It is important that in this move, diagnosis and
impairment are not necessarily promoted as an identifying aspect of disability. Efforts to discuss
autism with children should not promote the view that impairment determines who they are in
relation to disability more generally (Watson, 2002). Thus professionals need to consider alternative
ways of talking about the diagnosis of autism that does not simply focus on impairment.
Professionals need to examine and discuss the significance of context for experiences of difference
and difficulty.
Professionals need to engage in reflexive practice that promotes the important roles of children in making decisions as active service users.

The findings highlight the importance of ensuring that intervention is relevant to individual children’s own understandings of their challenges and the things they want to change in their lives. This idea has also been emphasised by Hodge (2005). Professional practitioners and educators sometimes overlook informing children and young people of their options and including them in decision making about intervention (Davis, et al., 2003), especially children with cognitive and communication impairments. However, educators and services providers are in a prime position to help create a space for the active participation of children who use varied communication styles.

To involve children as active service users, professionals need to encourage and facilitate reciprocal communication with children and young people. They need to consider how they ask questions and the methods of communication that are most suitable for individual children’s participation (Kelly, 2005; Morris, 1998). Practitioners also need to understand the issues that are important for young people as priorities for intervention. As raised in this research, having a sense of control was important for young people: for some within the intervention setting and for most within their lives more generally.

Professionals also need to be considerate of power relations between adults and children (Morris, 1998). They need to work with parents to promote children’s participation in decision making. They should encourage parents of newly diagnosed children to recognise their child’s abilities and educate them about their child’s right to become an active participant. Where possible, professionals should take time to consult with children with, and without, the presence of other adults (Kelly, 2005). Professionals also need to be reflexive in the way they as adults interact with individual children, who as recipients of service are influenced by their approach and attitude.
Further to these recommendations, it is necessary that professionals develop an approach to practice that considers the implications for the child beyond early intervention, which typically denotes practice for children less than five years of age. The findings suggest that diagnosis and early intervention experiences can have lasting implications for children’s sense of self-worth. A diagnosis should not be given lightly. Practitioners who diagnose need to consider the diagnosis of autism in the context of individual children’s lives and how it may affect them in the future. Similar considerations should be made in terms of intervention. Jones (1998) argues that while early intervention can be seen as enabling for some children, policy and practice ‘needs to take account of the wider context within which a child “grows up with disability”’ (p.47).

**9.4.3 Implications for researchers**

Researchers seeking the views of children and young people diagnosed with autism need to implement research approaches that facilitate collaborative participation and communication with individuals with diverse abilities.

My findings suggest that the overall research approach is fundamental to what we learn about children diagnosed with autism. Using a child-centred approach that integrated principles from contemporary disability research was beneficial in including the young people in decision-making process and facilitating their views during data collection. As also emphasised by Kelly (2005, 2007), this approach underlines children’s competencies as active contributors to the research process.

In attempting to be inclusive, I found that it was important to ensure that the research approach was sensitive to individual children’s abilities and preferences for participation. However, more work is needed to develop effective approaches to facilitate the views of individuals who use no formal methods of communication. I suggest that researchers need to focus specifically on including such participants. I also found that it was important to be flexible in the use of method types. Thus researchers need to be prepared to change methods during the course of the process if necessary or appropriate. When including parents and young people at the same time, it was important for me to
consider child–adult power relations, even when engaging with older children and teenagers. This finding is congruent with arguments by Mayall (2000). Researchers who involve parents to help facilitate or contribute to young people’s views need to focus on hearing young people’s voices and take their experiences and opinions seriously. Mason and Hood (2010) argue that children’s subjectivities are easily subsumed by adult research agendas. This point was also illustrated in the literature review in Chapter 3. Therefore, researchers should endeavour to also engage with the young person without other adults present.

In the future researchers need to ensure that adequate time, skills and resources are available for inclusive research. In following a child-centred approach, I see it as imperative to support young people diagnosed with autism in setting their own agendas and conducting research about their lives, if they are able and willing to do so. These aspects present challenges in terms of funding while confronting dominant approaches to research with children diagnosed with autism. However, it is clear from my research, and that of others, that children and young people diagnosed with autism have important knowledge to contribute to the development of research approaches and appropriate social policies.

9.5 Research limitations

Within traditional research approaches it is good practice to address the limitations that may have constrained the study and identify ways of overcoming them in future research. I consider that most of such limitations were discussed in Chapter 7 within the context of the findings pertaining to the research methodology. However, I will briefly reiterate five aspects of the research that pose considerations for future research.

Firstly, the recruitment restraints were discussed in Chapter 7. As noted, it is difficult to know the exact reasons for the low number of inquiries related to this research. However, it is important to consider that a large group of participants was not deemed appropriate for this research. Additionally, my research was designed to be considerate of children and their families so that they
would not feel coerced to participate. These aspects of the research were successful. For future research, it is necessary to consider recruitment methods effective in reaching larger population groups to extend knowledge about the lives of children and young people who are diagnosed with autism.

Secondly, researching with a small sample of research participants limits the extent to which sociological variables were apparent within the data. Within this group of participants there was little opportunity to explore socio-economic, gender and multicultural aspects of teenage-hood and autism. In hindsight I consider that calling for participants in written English may have excluded some families: for example where English is a second language and where literacy is problematic. Ideally researchers should consider methods of reaching such participants. Their experiences are likely to add different knowledge to the experiences of living with diagnosis, impairment and disability.

Thirdly, and as mentioned earlier, the diverse abilities and preferences for communication among the young people meant that the data collected varied. As with the general population, some young people were simply more talkative and interactive than others, producing longer and more detailed accounts. This meant that the depth of knowledge provided by individuals varied, adding complexity to the analysis process and producing broad and varied findings. However, this complexity is not unusual within qualitative research; other researchers have discussed the messiness of qualitative research (Sandelowski & Barroso, 2002). I suggest that when working outside of the frames of traditional research, and in order to be inclusive of a diverse range of children and young people, it is necessary to expect different types of data. Researchers should recognise all knowledge contributed by young people as valuable to the research findings and process and become comfortable with the messiness and irregularity of alternative research approaches.

Fourthly, through consultation with the young people I was able to facilitate their being able to make decisions about whether to participate in the research, how to withdraw from it at any time if
they wished to do so, and to make choices about the ways in which they wanted to participate and contribute their knowledge. However, involving the young people in the data interpretation and dissemination of findings was not within the scope of this study as would have been ideologically consistent with the research approach. Two participants provided feedback on the research process and four participants commented on their own contributions. Otherwise few of the participants were interested in being involved in the research beyond being interviewed. I am hoping to provide a second opportunity for young people to view and comment on the research and findings at the completion of this study. In case of particular requests for amendments by participants, these will be adjusted for further dissemination of the findings. While full involvement of children and young people in the research process is the goal of collaborative participatory research, it is necessary to recognise that this is practically difficult when involving participants with cognitive impairments or individuals using no formal methods of speech for communication. Full involvement is also not always desired by the participants in question.

Finally, as a researcher, I have to consider myself as a possible limitation to this study. Meanings are shared between people through social interactions (Crotty, 1998). Thus it is inevitable that my personal views and contribution have had some influence in the findings produced through the interviews and observations. It is also likely that young people may have shared or left out particular information because they knew I was a mother and a carer of children diagnosed with autism. Because of the way knowledge is collected and shared, it is doubtful that other researchers would produce the exact same findings even when using the same research approach and question topics. This notion brings me to reflecting on my experiences of the research journey.

9.6 My reflections on the research journey

A doctoral degree is often described as a journey. Being a runner, I have come to compare my PhD to ‘running a marathon’. The process has been a long and intense event. It involved thorough preparation which was imperative for success. In order to succeed, mental application was just as
important as physical and technical efforts. There was a distinct excitement when starting the journey. Changes of scenery and people encountered along the way carried me through the middle stages. In the final stages, persistence and mustering up energy have been important in order to keep going. When additional challenges have arisen outside of my control, there has been a need to negotiate ‘the wall’ – whether to stop or to keep going. However, when crossing the finish line there was an indescribable sense of achievement with a mixed bag of memories of enjoyable and challenging phases of the journey. On reflection, it is likely that alternative ways of completing the journey will become evident as there is always more than one way of doing things.

In terms of the research journey, I have no regrets about the study, topic and approach I have chosen despite some of the challenges along the way. I have enjoyed engaging with a group of delightful young people and their families. When challenges mounted I had fantastic support from my supervisors, family and friends. Below I reflect on four aspects of the journey that have been important to me and which have contributed significantly to my learning.

Firstly, I found engaging with young people an enriching experience. For me, the most enjoyable part of this journey was the months of field work where I had frequent contact with the young people and their families. Admittedly, I had reservations during the preparation phase as to whether I would be able to communicate meaningfully with each of the young people and whether they would communicate with me. These concerns were largely unfounded. With all participants I met an unexpected openness and willingness to engage with me, although there were challenges along the way as described in Chapter 7.

Secondly, as noted in Chapter 1, the research journey involved a steep but valuable learning curve due to the complexity of spanning different research paradigms. The shift from studying and working within the medical model to engaging with theoretical frameworks such as the ‘new’ sociology of childhood and the social model of disability was a significant leap. However, this leap from working within a medical model as a practitioner to researching within a social model as a researcher has
both challenged and broadened my own understanding of disability issues, as well as of children and young people. Further, working with supervisors with perspectives from the sociology of childhood and medical sciences respectively added a unique aspect to the journey. This aspect was sometimes challenging. Nevertheless the experiences raised interesting questions along the way which have taught me to see things from different angles. Within the context of spanning different paradigms, this study is not about either/or, the medical versus the sociological perspectives. Rather, I feel that one of the strengths of this research lies within the way that it intersects with medical sciences perspectives and sociological perspectives in learning about the lives of young people diagnosed with autism. Being able to understand and work with both these perspectives will be of value to my future research and in engaging with children and young people professionally. As an occupational therapist, I now have the advantage of understanding the significance that different models may have within the context of children’s lives. My role will include promoting children’s inclusion and participation to colleagues within my field as well as implementing in practice the understandings of impairment and disability from a social model perspective.

Thirdly, in conducting research such as this, which involves engaging directly with the young people, I believe that there is value in one’s own life experiences in being aware and observant. My role as a mother of children diagnosed with autism and my grounding as an occupational therapist have contributed a unique set of experiences, knowledge and skills to this research. Certainly my position as a parent seemed to facilitate trust and rapport with the participating parents. Through collaborative participation, every effort was made to maximise the young people’s opportunity to contribute their views and opinions. Through this process I feel that the young people were mostly comfortable and forthcoming in sharing their experiences. In reflecting on my fieldwork experiences I also feel confident that the young people would not hesitate to tell me if I had got the wrong impression, as several were comfortable enough to tell me when they did not want to answer particular questions. Despite my efforts to balance the power relations and maximise opportunities for communication in the research process, however, I am not a teenager or a person diagnosed
with autism. One can only speculate how the process and findings would have differed if conducted by someone with more direct experiences of ‘growing up’ with impairment or having a diagnosis.

Finally, the journey has taught me the importance of reflexivity when research resonates with one’s own life. The final two years of conducting this research has seen the project edge very close to my personal life as I have supported my two children in their transition from primary school to high school. In the process I have experienced from a parent’s perspective many of the issues raised by both parents and young people participating in the project. It was very difficult for me not to give more space to the parents’ views in the thesis, but that would have defeated its purpose. These personal experiences, together with my professional background, have made it even more important for me to be reflexive. I have had to question how my own views and experiences have influenced the final analysis and writing up of the thesis. At the same time, I feel that conducting the research has been helpful for me in understanding and negotiating everyday complexities with my own children. This may sound indulgent, but it gives me hope that I may be able to share the views and experiences contributed by the young people in this study with a broader population through dissemination of findings and engagement as a practitioner and researcher in the field in the future.

9.7 Concluding words

The young people involved in this study have contributed to research by providing knowledge that enriches current understandings related to autism, childhood and disability, but also by contributing their views and opinions about the research process. Thus at the end of the research process it is difficult to understand the thinking that children and young people, including those with impairments, are not competent to contribute actively to the research process.

This research has emphasised that applying a research approach that facilitates communication and is sensitive to individuality can be inclusive of young people diagnosed with a diverse range of abilities and preferences for interaction. The young people had different knowledge and awareness of their diagnosis. Therefore some participants were able to talk about autism in more detail than
others. The young people’s individual contribution did not seem age, gender or diagnosis specific, although the contributions by participants with limited communication was more limited than the contributions of others. However, as the findings have shown, this limitation was not simply a consequence of interpersonal communication barriers but related to particular events and contextual circumstances.

This research has emphasised the importance of viewing and approaching young people diagnosed with autism as young people. They described similar concerns and desires as other young people. At the same time, these young people described having a diagnosis of autism as a significant defining factor which made them feel different and be seen and treated as different. However, while feeling challenges and lacking control in terms of both being young and having autism, they were active in negotiating control within various contexts of their lives.

A diagnosis of autism did not mean that young people identified as autistic. The findings also show that the diagnosis did not reduce these young people to one single identity. Therefore to understand diagnosed children and young people purely as if they had a singular identity would be to deny them the expression of equally important aspects of their lives and experiences that define their individuality. At the same time, these young people had views and experiences in common that related to stereotypes of autism and disability which had significance for the way they felt about having a diagnosis. These experiences were somewhat different to young people more generally. To deny these differences would be to ignore a considerable and powerful factor in their marginalisation (Shakespeare, 1996). In light of this research, and as the medical labelling of children is on the increase, it is important to continue to critically examine how children and young people experience the application of labels such as autism and how they contextualise such labels within their lives.
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University of Western Sydney (UWS). (2005). *Towards the highest standards: Research code of practice.* Sydney: UWS.


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: Identity and disability. *Disability & Society*, 17(5), 509–527.


**Resources:**

PCS for Boardmaker
DynaVox Mayer-Johnson, 2100 Wharton Street, Suite 400, Pittsburgh, PA 15203
Phone: 1 (800) 588-4548, Fax: 1 (866) 585-6260
Email: mayer-johnson.usa@dynavoxtech.com
Web site: www.mayer-johnson.com
Are you the parent of a teenager diagnosed with Autism?

If you are, this is an opportunity for you and your son or daughter to participate in research about the lives of teenagers with autism spectrum disorders (ASD).

What is the project about?

- The aim of this project is to find out what it means to be a teenager with ASD and learn about individual teenagers’ everyday experiences and the things that are important to them.
- This project is also about finding different methods of communication that will let more teenagers be involved in research. Including those who do not like to talk, cannot use words or have difficulty finding the right words when there are things they want to let others know about.
- This project is collaborative. While research methods have been prepared, parents and teenagers will be asked to help finding the best ways for individuals to participate in the project.

What is involved?

- There are two parts to this project, these are described briefly below.
- Participants can withdraw from the project at any time they wish to do so without judgement.

**Part 1: Family meeting/interview (1-2 hrs)**

- This meeting can take place at a time and location that suits you.
- The purpose of this meeting is to provide information about participation in research and give you and your son/daughter the opportunity to
  - meet the researcher, and
  - ask questions about the research before a decision to participate further is made.
  - Express your views, suggestions or concerns related to research participation
- If you and your son/daughter agree to participate in the second part, the researcher will
  - consult you and your family about the best ways to communicate with the teenager and involving them in Part Two of the project.

**Part 2: Individual meetings with teenagers (up to 3 meetings x 1-1.5 hrs)**

- Up to three meetings between teenagers and the researcher will be arranged, ideally in at least two different settings of participants’ choice (for example at home and school).
- These meetings include observations, and interactions based on the individual teenager’s communication needs and preference.

**Who is doing the research?**

My name is Lise Mogensen. I am an occupational therapist and a parent of two children with ASD. I am conducting this project under the supervision of Professor Jan Mason & Dr Annie McCluskey to meet the requirements of a PhD through the Social Justice and Social Change Research Centre, at the University of Western Sydney.

If you are interested or would like more information about the project, you can contact me by Email: l.mogensen@uws.edu.au

Phone: 02-4620 3149 or Mobile: 0409441685

The project has been approved by the Human Research Ethics Committee at the University of Western Sydney, and Autism Spectrum Australia (ASPECT) Ethics Committee.
Research Project Information for parents

Project title
Learning about the lives of teenagers with autism spectrum disorders (ASD)

What is the project about?
- This project aims to increase understanding of the everyday lives and experiences of teenagers diagnosed with ASD.
- The overall purpose is to find out about individual teenagers’ personal experiences, perspectives and aspirations.
- The researcher will collaborate with parents like you, to develop effective ways of communicating and consulting with teenagers, in a manner that is respectful to them.

Why is this research being conducted?
- Children and young people with ASD rarely have the opportunity to express their views, experiences, and self-perceived needs. Many have difficulties being understood by others.
- We hope that developing better methods to obtain the views of teenagers with ASD will enable more of these young people to participate in decision making about issues concerning them.
- We also hope that the personal views of teenagers diagnosed with ASD will provide a significant contribution to the planning and development of education and services as well as the policies impacting on their lives and futures.

Who is invited to participate?
- Parents of teenagers (age 13 to 19 years) diagnosed with ASD are invited to participate in the first two of three studies (see below).
- Teenagers diagnosed with ASD are invited to participate in the second and third studies.
- Teenagers with a range of different cognitive and communication abilities are welcome to take part.

Who is conducting this project?
- My name is Lise Mogensen. I am the investigator on this project, an occupational therapist and a mother of two children with ASD.
- The project is designed to meet the requirements of a PhD which I am studying through the Social Justice and Social Change Research Centre, at the University of Western Sydney under the supervision of Professor Jan Mason & Dr Annie McCluskey.

What is involved?
The project includes two studies. Parents are invited to participate in the first study. Teenagers are invited to participate in both studies. Participants can withdraw from either study at anytime they wish to do so.
Appendix B

Study 1 - Family meeting/interview (1-2 hrs)

- This meeting will allow your son/daughter and other family members to meet the investigator (Lise) before a decision is made to participate further in the project.
- The aims of this meeting are to:
  - Provide you and your son or daughter with further information about the third study and the investigator.
  - Make adequate preparations for your son or daughter to participate in the third study, which will consist of individual meetings/interviews with teenagers.
- To develop suitable research strategies, information about your son or daughter’s communication requirements, skills and abilities will be useful.
- The investigator may also make observations and ask some questions of individual family members. Your input may be used in the preparation for the second study in this project.
- You may also have suggestions that may be useful to ensure your son/daughter’s participation will be meaningful and enjoyable.
- Your son/daughter will be asked for their consent to participate. Together we will find the most suitable methods of determining their willingness to participate.
- If your son or daughter is willing to participate in the third study the investigator may ask you and other family members for permission to take photos for use in the third study.

Study 2 - Individual meetings with teenagers (up to 3 meetings x 1-2 hrs)

- This study will be developed based on the first two studies.
- Up to three meetings are currently planned between the teenager and the researcher.
- Ideally these meetings will occur in at least two different settings (for example at home and school). However, you and your son/daughter will help decide the places and times that would be best to meet so that risk, anguish and discomfort is minimised.
- Before and after each meeting, your child will be asked if he/she wishes to take part again. Individual techniques will be developed for declining/ending participation or asking for a break. These techniques will be practised with individuals at the beginning of each meeting, so that they have the opportunity to decline or accept on the day.
- It is likely that this study will involve observations, natural interaction and unstructured ‘interviews’ while engaging in activities of interest to the individual teenager. Alternatively teenagers can communicate with the investigator via email/internet if we agree that this method is more appropriate.
- Your son/daughter will receive a $20 gift card for their participation as a small token of our appreciation.

Will we have to participate in both studies?

- No. You as a parent are invited to participate in the first study.
- Teenagers are being invited to participate in both studies. If they wish, teenagers can participate in study 1 only and not study 2.
- All participants can withdraw from the project at any time they wish without prejudice and without providing an explanation.
- If they would like, teenagers can have their parents present during meetings in study three.
- As previously stated, teenage participants will be asked if they want to take part before and after each meeting.
Appendix B

Can I or my son/daughter be identified as a research participant?
• Participants cannot be identified through the research. The information collected from teenagers and their families will be confidential. The information collected from teenagers cannot be accessed by or disclosed to parents, school staff, respite carers or other third parties.
• The only exception will be if a teenager reveals they are at risk of abuse or neglect, have recently been abused or neglected, are currently being harmed or are at risk of harming themselves or someone else. In these situations the investigator is required by law to make a report to the Department of Community Services (DoCS). Should such action be necessary, the intention to report to DoCS would be discussed with the young person.
• No participant names will appear in research reports or articles produced from this project.

What will happen to the information collected?
• Tapes, interviews notes and consent forms will be kept in locked storage at the University of Western Sydney for five years after the completion of the project. Only the investigator will have access to this information. After five years the material will be destroyed.
• The summarised findings will be published in professional journals and presented at conferences with all identifying information removed.
• Transcripts (typed text) from focus groups and family meetings will be provided to the participants to ensure credibility and authenticity of information collected.
• Feedback to participating teenagers will occur in a format that suits the individual’s abilities and communication requirements.

If you agree to participate
• You should complete the consent form attached to this letter and return it to me (Lise) at your earliest convenience. I will then contact you to talk more about the project.

Contact details: Lise Mogensen
University of Western Sydney,
Campbelltown Campus, Building 26
Locked Bag 1797, Penrith South DC NSW 1797
02 - 4620 3149 OR l.mogensen@uws.edu.au

Alternatively contact Professor Jan Mason - jan.mason@uws.edu.au

NOTE: The ethical aspects of this study have been approved by Autism Spectrum Australia (Aspect) and the University of Western Sydney Human Research Ethics Committee. The Approval Numbers are HREC 06/159 and HREC 07/119. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the Director, Education and Research at Aspect or the University of Western Sydney Ethics Committee through the Research Ethics Officers (tel: 02 4736 0883 or 4736 0884). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Research project information for teenagers

**Project title:** Learning about the lives of teenagers with autism spectrum disorders

**What is this paper about?**
This paper will help you decide whether you want to be a part of a research project about teenagers with autism spectrum disorders (ASD).

**Who is doing the project?**
My name is Lise Mogensen. I am a research student from the University of Western Sydney. I am also a Mum to two boys with ASD.

**What is the project about?**
My project is about teenagers who are diagnosed with ASD such as Asperger’s Syndrome or Autism. I am trying to find out what it means to you to be a teenager.

For example,
- What are the most important things, people, and places in your life?
- Do you think about the future?
- Are there things you would like to change?

This project is also about finding different methods that will let more teenagers be involved in research. Not everyone likes to talk. Some teenagers can not use words or have difficulty finding the right words when there are things they want to let others know about.
Why is this project important?
Many people do a lot of guessing to find out what teenagers with ASD need. Adults often forget what it is like to be a teenager. Sometimes people forget to listen to or have difficulty understanding what is important for teenagers, what they want or what they like. If adults don’t ask teenagers about the things that are important to them, they may not really understand what it is that teenagers need.

Why should I participate?
You are a teenager, so I would like your help with finding out what may be important for teenagers. I would especially like to find out what being a teenager means to you. For example, things you like or do not like, things you would like to change or what you dream will happen in the future. There may also be other things you think are important for me to know about.

What will I have to do if I agree to take part?
I will meet with you first so that we can get to know each other a little bit.
- During the visit I may ask you some questions about you.
- You can also tell me or show me things you would like me to know about.
- While I visit I will write down some notes about what I see.
- I may ask you if it is ok that I use a tape recorder or a video camera to help me remember.
- If you have photos of things you like, you can show them to me so we can talk about them. I will only record or take photos, if you agree. I will make sure that no one else hears the tapes or sees the photos, unless there is someone you want to show.
- You can choose if you want your parents to be there (if first visit is a group visit, all participants must to agree for parents to be present).
After the first visit there are different ways you can participate. You can let me know how you prefer to tell me about your life.

For example:

If you prefer to talk, I can phone you and we can talk about some of the things that are important to you.

If you like to use email, I may ask you some questions using email and you can answer when you have thought about the question.

You can also email me if you think about something else you would like me to know.

If you like to write, but do not have email, we can organise envelopes for you to post letters or other small items that may help express your views (for example photos, pictures or poems that you may like me to see).

Do I have to take part?

- You may not want to be a part of the study – it is ok to say no.
- If you want to take part in the study, that would be great. I would like to spend some time finding out about you and your life.
- Remember, if you say yes, it is still OK to change your mind later.
- You can also ask to have a break at any time.
- If you become upset and want to stop taking part, that is OK too.
If you want to find me!

There are 4 ways you can contact me:

1. Phone me on **4620 3149**

2. Phone or text message me on **0409 441 685**

3. Email me at **l.mogensen@uws.edu.au**

4. Post me a letter: Lise Mogensen,
   University of Western Sydney,
   Campbelltown Campus - bldg 26,
   Locked Bag 1797
   Penrith South DC NSW 1797

**NOTE:** The ethical aspects of this study have been approved by Autism Spectrum Australia (Aspect) Ethics Committee and the University of Western Sydney Human Research Ethics Committee. The Approval Numbers are HREC 06/159 and HREC 07/119. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Aspect Committee through the Director, Education and Research or the University of Western Sydney Ethics Committee through the Research Ethics Officers (tel: 02 4736 0883 or 4736 0884). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Consent form for Family interview
(Parents)

Project title
Learning about the lives of teenagers with autism spectrum disorders (ASD)

Please complete this page if you consent to a family interview between you, the researcher and your son/daughter with ASD.

I ____________________________________ (please print your name) agree to participate and give consent for ____________________________ (please print your son/daughter’s name) to take part in family interviews as a part of the above mentioned project. I understand that the researcher will contact me to organise the family interview and will be visiting at a time and location that is suitable for the family. I also understand that all family members will be asked to sign separate consent forms if they would like to take part in the family interview.

I have read the information about the project and understand what is involved. I understand that my son or daughter may be asked to participate in a study based on information collected from this interview and that it is ___________________’s (please print your teenager’s name) choice to agree or disagree to continue participation in this project. I also understand that he/she may withdraw from this project at anytime without providing an explanation for doing so. I understand that the researcher, Lise Mogensen, will provide information to my son/daughter about the study, and that declining/ending participation will be practiced at each meeting. I have provided a contact phone number or other contact details so the researcher can contact me.

Name: __________________________________________________________________

Signature: _____________________________________________ Date: ____________

Phone number: __________________________________________________________________

Other contact details: __________________________________________________________________

The best time to contact me is: ______________________________________________

Researcher name: _____________________ Signature: ___________________________
Consent form for teenagers to participate in research

**Project title:** Learning about the lives of teenagers with autism spectrum disorders

I ________________________________ (please print name) agree to take part in a project about the experiences of teenagers with autism spectrum disorders.

**I understand that:**

- A researcher called Lise wants to find out what it means to me to be a teenager
- Lise has shown me different ways, I can choose to tell her about myself
- I can ask questions anytime there is something I don’t understand
- It is OK for me to stop being part of the project whenever I want to
- If I feel upset 😞, I can have a break or stop participating
- Lise will not tell anyone else that I was part of the project
Appendix E

- Lise will only tell someone else if she is worried:
  - That I might be hurt by someone
  - That I might hurt myself or someone else
  - That I am not cared for properly

I will be given a gift card for $20.00 as a thank you for participating.
I will be given the gift card even if I don’t want to answer some questions, if I want to stop the visit or if I don’t want to take part anymore

I get a copy of this form. If I have any questions, I can phone Lise, the researcher on 02-4620 3149 or 0409441685 or I can email Lise on l.mogensen@uws.edu.au

Name of participant: _____________________________________________________

Signature of participant ____________________________________________________

Indicate if consent was verbal □ signed □ indicated by use of communication aid □

Other □ - specify__________________________________________________________

Name of Researcher: ______________________________________________________

Signature of researcher: _____________________________________ Date: ________________

NOTE: The ethical aspects of this study have been approved by Autism Spectrum Australia (Aspect) and the University of Western Sydney Human Research Ethics Committee. The Approval Numbers are HREC 06/159 and HREC 07/119. If you have any complaints or reservations about the ethical conduct of this research, you may contact the University of Western Sydney Ethics Committee through the Research Ethics Officers (tel: 02 4736 0883 or 4736 0884). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Lise visits Andrew at Home

This is Lise

Mum spoke to Lise on the phone.

Lise is coming to see Andrew and Mum on Wednesday after school.

She will come to the house in her car - it is silver.

Lise will ask Andrew some questions.

Lise will ask Mum some questions.

Andrew and Mum can ask Lise questions too.

Lise will bring a ‘Stop’ card with her.

Andrew can hold Stop card to stop or have a break.

Lise will be at Andrew’s house for about one hour. Then she will go and it will be dinner time.

It will be OK to meet Lise.
Appendix G

Questions

Start with open questions; use more specific questions if required

Tell me about yourself
  - How would you describe yourself
  - Tell me about something you are good at doing or not so good at doing
  - Tell me about some things you like or dislike
  - What is your most favourite place, person, pet, item?
    - What do you like most about it?
  - What is your most important achievement?
  - Do you have a favourite family story?

Tell me about being a teenager/young person
  - How do you think about yourself at this point in time/
    - Child, teenager, young person, adult, young adult
  - Tell me what it means to you to be a teenager/young person
  - What do you think is the hardest thing for teenagers?
  - Are teenagers better at certain things
  - What is the role of teenagers?

What aspects of being a teenager are significant to you?
  - What is the most important thing to you at the moment?
  - Is there anything in your life that you would like to change? Or stay the same?
  - Do you think about the future?
    - Is there something that you are really looking forward to or that you would really like to do?
    - How do you imagine yourself in the future?

Tell me about autism
  - What do you know about it?
  - How long have you known about the diagnosis?
  - How did you find out about it?
  - Does it make you different or feel different in any way?
Introduction:
Greet participant – restate who I am (the researcher) and what I am there to do
Determine willingness to participate using the agreed method
Determine if audio and/or video recording of data collection is ok using agreed method.

Guide:
The topics below will be explored through different strategies depending on the individuals’ ability and preference.

- Teenagers using speech for communication may be talking about the topic areas as they relate to them. Questions are to be used as openers and prompts for conversation. All topics will be attempted. However, wording will be modified to suit individual participants.

- Some participants may require or like to use photos, pictures, prompt cards or symbols to help with understanding topic and expressing their views.

- Visual activities to assist with interviewing such as using life maps, taking photos, making posters, drawing and writing may be preferred or required by some participants.

- Participant observations will occur with all participants. For some participants, observing them and spending time with them, in different environments, may be how they best participate or choose to participate. If that is the case, the researcher will make extensive field notes which include description of person/interaction/environment.

Resources:

- Pen, participant folder, exercise book
- Box of activities
  - Paper, textas, coloured pencils
  - Communication cards
  - Deep speak cards
  - Stones with feelings
  - Talking mats
  - Velcro, sticky tape, blue tac
  - Disposable camera
  - Handheld tape recorder
- A3 card board
- Digital voice recorder or tape recorder
- Video camera
Appendix H

Topic 1 - What are the perceptions of self of teenagers with ASD?

Main
• Tell me something about yourself
• Draw pictures/write words/take photos that describe the type of person you are?

Prompts
• What do you think are your strengths? Or weaknesses
• Is there something about you that you would like other people to notice?
• Tell me about something you are good at doing?
• What is your most important achievement?
• What makes you feel good about yourself?
• What makes you laugh?
• Would one of these (pictures) help you to talk about yourself?

Topic 2 - What aspects of being a teenager are significant to young people diagnosed with ASD?

Example questions

Main
• Do you describe yourself as a teenager? (or you described yourself as a teenager)
• Tell me about being a teenager. (or tell me about being...)
• Tell me what it means to you to be a teenager.

Prompts
• Are you different now from when you were younger? How?
• Are there things teenagers can do better than other people?
• Is anything easier/harder for teenagers? For you?
• What do you think is the hardest thing for teenagers? For you?
• If you were me, what question would you like to ask teenagers?
• What do you think is the role of being a teenager? What is your role?(Explore individual teenagers’ self-determined role)
Appendix H

Topic 3 - What aspects of their lives do teenagers like and value?
Example questions

Main
- Tell about some things in your life you like/are happy about/value?

Prompts
- What people/places/things make you feel happy/good
- Tell me about your Friends/family/pets/interest/hobby/school
- Tell me about being a brother/sister, being the oldest/youngest
- Do you have a favourite family story?
- What is your most precious/valued/special possession?
- What are some of your favourite activities/things to do?
- Where do you do this? At home/school/community?
- What is your most favourite place? What do you like most about it?
- What is the most important thing to you at the moment?

Topic 4 - Do teenagers think about the future, and if so do they have specific aspirations?
Example questions

Main
- Do you think about the future?
- What do you think about, when thinking of the future?

Prompts
- Is there something that you are really looking forward to or that you would really like to do?
- How do you imagine yourself in the future?
- Are there anything in your life that you would like to change
- If you had a magic wand and 3 wishes, what would you wish for?
- Would you change something about yourself/the world?
Appendix H

Topic 5 - What are teenagers’ perceptions of having autism?
First, ask parents whether diagnosis has been disclosed to teenager and if so, when.
If so, talk to teenager about ASD
  o What does the diagnosis autism/Asperger’s syndrome mean to you?
  o Does a diagnosis have a meaning/ function for you?
  o What does a diagnosis mean to the way you see yourself?
  o Has the diagnosis influenced/affected/changed the way you see/think about yourself?

If not, do not ask directly, but observe
  • Does participant talk about experiencing being diagnosed [or different]?
  • What do any answers, actions, responses, treatment by others indicate?