

**“DETERMINED TO SUCCEED”:**

**PERCEPTIONS OF SUCCESS FROM AUTISTIC ADULTS**

**by**

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## **ABSTRACT**

This qualitative study employed a participatory approach to consult with sixteen autistic students on their experiences of success. Participants were students at five different UK higher education institutions. Using Interpretative Phenomenological Analysis, the research explored how they defined their successes and made sense of them in relation to their autism diagnoses.

A flexible, multi-staged interview process was used. Evaluations indicated that the methodology enabled participation on both practical and theoretical levels. Participants became co-analysts of their data and demonstrated commitment to the project.

The students described a wide range of successes, from the academic to the deeply personal, providing powerful counter-narratives to the dominant deficit-based interpretation of autism. The encouragement of one key individual (professional, family member or friend) had often been greatly influential to their achievements. Findings indicated the need for participants to both resist essentialist discourses regarding autism and to make themselves 'extra-visible' as an autistic person in order to assert their rights, with the autism diagnosis perceived as both an aid to self-understanding and a cause of additional barriers. In raising awareness of their own needs, participants contributed to broader understandings of autism, becoming educators and role models. The research demonstrates the importance of insights from autistic individuals, in particular showing how making sense of the autism label relates to perceptions of success. Implications for post-diagnostic support are discussed.

## DEDICATION

This is for you, Mum, “the star I steer by” – with love x

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## CHAPTER 1

### INTRODUCTION

#### 1.1 Personal context for the research

In May of 1989 I drove 1200 miles to attend the tenth annual TEACCH conference, where I learned that autistic people can't drive. (Sinclair, cited in Howlin, 2004, p. 335)

This thesis is concerned with the phenomenon of success and personal achievement, as experienced by autistic adults. I introduce my thesis with the words of Jim Sinclair, an autistic man from the US, as it has been the single most influential quotation to my professional and academic career. In these few lines Sinclair highlights at once his personal achievement, its contradiction of accepted 'autism fact' and the way in which this in turn impacts on him as he is asked to 'learn' something about autistic people that he knows to be untrue.

I became involved in the support of adults diagnosed with Asperger syndrome in the early 1990s. As a new practitioner I was keen to read psychological and educational theory written by professionals in the field and did so with interest. However, most of the literature and research focused on children rather than adults and on those with more apparent communicative impairments. Although this literature was helpful to a point, it often did not capture the complexity of experience described by those individuals with whom I was coming into contact, who were largely outside of educational and statutory services.

At this time there was a small number of autobiographies by autistic individuals (Grandin and Scanario, 1986; Williams, 1992; Lawson, 1998). In reading these and in listening to the stories of the individuals I met in the course of my work, I gained some insights into the very particular life experiences of autistic adults, which greatly influenced my approach as a non-autistic practitioner. For example, our group changed from a 'social skills' group to a 'peer support group', reflecting the desire of members to learn from one another's experiences, rather than be taught the norms of social behaviour. I became convinced that an exploration of the 'lived experience' of those diagnosed on the autism spectrum had much to offer in deepening our understanding of the full continuum as represented by people at different levels of ability and stages of life. I also developed great respect for many of the autistic people that I grew to know and who taught me an enormous amount about the way that they experienced the world, often challenging and contradicting my 'non-autistic' interpretation of their behaviour, or the behaviours of other autistic people. Reading Patricia Howlin's textbook on autistic adults, I came across the quote from Jim Sinclair that opens this thesis. It was a revelation to me, as Sinclair was telling a story I recognised, both in the stories I was hearing and the literature I was reading. Howlin (2004) wrote:

Sinclair warns how the progress of people with autism may be severely restricted by the mistaken expectations, assumptions and prejudices of others – assumptions that often prove extremely difficult to shift. Thus, whilst it is important to avoid excessive demands or to have unrealistic expectations of what individuals are able to achieve, undervaluing their potential ability may do even more damage. (p. 335)

This caution about the damage that can be done by making presumptions based on diagnosis or observed behaviour, resonated strongly with me, reflecting as it did many of the experiences described by autistic adults and their families.

## 1.2 The neglect of success

A number of autistic individuals are achieving relative success in various areas of their lives, but this is not apparent from the available research. Success and achievement of personal goals is often described within autobiographies, blogs and savant accounts, but rarely explored within autism research. The predominant literature takes a deficit approach, focusing on areas of difficulty. Autistic individuals are often reported as being a disadvantaged and struggling group (Eaves and Ho, 2008). Whilst this may well be true, I argue it gives an incomplete and distorted reflection of the reality for many people, neglecting the achievements and successes that can also form part of the autistic experience. Moreover, there is good evidence that autistic individuals do best when they tap into their strengths (Grandin, 2009; Plaisted Grant and Davis, 2009) and this is an area meriting further attention. An exploration of these voices of success could offer new insights about how best to make opportunities for achievement available to all autistic individuals. My thesis is premised on this belief; that there is a sub-set of autistic individuals who are currently not well represented within the literature, but whose insights, experiences and self-perceptions would provide an important additional dimension to our current understanding of autism. Through this research, I have explored individuals' own perceptions of

their successes and how they did or did not relate these to their diagnosed condition. By following a 'differences' rather than 'deficit' model and focusing on individuals' achievements (as defined by them), a different type of data has emerged that expands our understanding of the autistic experience and adds another dimension to the existing autistic vocabulary.

### 1.3 Higher education as a measure of success

...there is much solidarity among us, and we are more alike than we are different. I don't think that a diagnosis of high-functioning autism, Asperger autism or any other type of autism is separated according to our difficulties as much as it is in the minds of other people who don't know us. (Lawson, 2006, p. 200)

Participants for this study were recruited from the population of autistic individuals currently studying within higher education. This is not to imply that those characterised as 'higher-functioning' have greater insights to offer. Presumptions with regard to level of functioning are problematic and contentious. I subscribe to the view that existing sub-categories are insufficient to describe the many ways in which the autism spectrum is manifest, and these sub-categories can reflect false assumptions regarding level of cognitive functioning. Accounts from verbal and relatively autonomous autistic adults often describe childhoods featuring developmental delay, detachment from the social world and difficult behaviours more generally associated with the category 'low-functioning'. (Williams, 1992; Lawson, 1998; Andrews, 2006). Dawson, an autistic researcher, cites evidence that IQ of some individuals on

the autism spectrum can change dramatically over time and questions the validity of current diagnostic distinctions such as high/low functioning (Dawson, Mottron and Gernsbacher, 2008).

My reasons for focusing on higher education students as research participants were more pragmatic. Firstly, in seeking to access the perceptions of those most likely to have experienced 'success' according to the predominant culture's objective measurements, those individuals who have attained sufficient educational and life skills to enter higher education form a convenient natural category. As a group, these individuals are likely to have relatively good communication skills, some insight into their situation and hopefully the confidence to be candid in giving their personal views. In consideration of the ethical issues that may arise in consulting with potentially vulnerable individuals, it seemed pertinent to identify a group of individuals located within institutions that could offer appropriate support to them if needed. By contacting individuals via the gatekeepers of student support services, I was able to ensure as a researcher that I had a clear protocol to follow up on any issues arising for individual participants.

Therefore, whilst I acknowledge that students within higher education are a distinct group and in many ways a non-representative sample that come with a number of caveats relating both to methodology and applicability, for qualitative research of this nature endeavouring to capture a 'snapshot', the sample is legitimate.

#### 1.4 Success as a step towards equality

By getting people involved and organized around various issues a leader can help individuals transform themselves from passive recipients of discrimination into dedicated and involved agents of change. (Foster-Fischman et al., 2007, p. 342)

I have described largely pragmatic reasons for recruiting participants from within higher education. However, considering the experience of autistic adults from a disability rights perspective, higher education does have a particular relevance. Within our society, young people have been encouraged to regard higher education as the most desired route to employment. Earning opportunities are closely correlated to level of education, with “the average graduate...expected to earn comfortably in excess of £100,000 more over their working life compared to someone with only 2 or more A-Levels” (Department for Business, Innovation and Skills, 2015, p. 19).

Disabled students continue to be an under-represented group within higher education (Higher Education Statistics Agency, 2014). However, since the 1990s, changes in legislation and policy have contributed to a growth in the number of disabled students entering higher education. Following the duties placed on providers by the Disability Discrimination Act Part 4 (Disability Rights Commission, 1995) the Equality Act (UK Stationery Office, 2010) (following the former Disability Equality Duty) directed institutions to be proactive in their efforts to promote equality of opportunity and participation for disabled people. Terminology employed within these policy documents refers to anticipatory adjustments, conveying a clear message that responsibility for adjustments is



now seen to lie with the institutions and not with disabled individuals. Thus, in theory at least, higher education has the imperative to identify and remove barriers to achievement for its autistic students and, through its focus on areas of specialism, to play to their strengths.

If autistic voices are to be heard within academic debates and discussions, education has a key role to play. Academic education offers two important opportunities: firstly, it teaches the language of academia, enabling autistic people to communicate with the dominant autism communities in a way that they understand and cannot ignore. Secondly, if autistic people have the tools to communicate their experiences to others, they also have greater opportunity to become role models and leaders, thus potentially transforming not only their own lives, but those of others. Thus, a greater understanding of the experiences and perspectives of autistic adults currently studying in higher education informs us of who the future leaders of the autism communities might be, and what they might want to say.

### 1.5 What we don't know about autism

If we're honest, the foundational observation we might make, the 'central fact' about autism with which we should probably start, is that we don't know very much about it at all. (Murray, 2008, p. 3)

If Murray's caution gives pause for thought about autism generally, then its application to our knowledge of autistic adults must be given even greater weight, considering the relative neglect of this group. The vast majority of

autism literature and research focuses on children, despite the recognition of autism as a lifelong condition. Outcome studies in relation to autistic adults are few and the majority of studies rely on data received from parents and caregivers (Howlin et al., 2004; Eaves and Ho, 2008). Largely absent from these reports are the perceptions of the individuals themselves and their own insights into their situations. Those that do include this perspective can reveal findings that are at odds with the predominant literature. For instance, Robledo and Donnellan (2008) interviewed a group of autistic higher education students. Some interviewees said they preferred to be supported by people who knew little about autism because of bad experiences of supporters who had made assumptions about them based on stereotypes, rather than taking the time to get to know them as individuals. There is much emphasis placed on the need for support staff to have training in autism (Jones et al., 2009; National Audit Office, 2009) and this 'insider' view adds to our understanding of what this should entail, in highlighting the need for staff to be given opportunities to develop not just their knowledge about the different ways in which autism can be manifest, but also their skills in applying their learning to the individual they are supporting in ways that are sensitive and appropriate. It would appear, from the perspective of some autistic individuals at least, that a little knowledge can be worse than none at all.

Hacking (2009a) also reminds us that autism as a recognised, diagnosable condition has a relatively recent history. Until a quarter of a century ago, representations from people diagnosed with the condition did not exist. (The first published work by a known autistic author was in 1985: David Eastham's *Understand; Fifty Memowriter Poems* (Eastham, 1985), closely followed by

Temple Grandin's co-authored *Emergence: Labelled Autistic* in 1986 (Grandin and Scanario, 1986); Canadian and US authors respectively).

## 1.6 A note about terminology

The participants of this study have been diagnosed with either Asperger syndrome specifically or an autism spectrum condition. Boundaries between sub-categories of the autism spectrum, such as between Asperger syndrome (AS) and high functioning autism (HFA), are recognised as problematic (see Wing, Gould and Gillberg, 2011 for a fuller consideration of the issues). Within this paper, autism and Asperger syndrome are used interchangeably and on the whole, I refer to 'autistic adults' in recognition of the fact that this tends to be the preferred term for those thus diagnosed (Kenny et al., 2015). However, different terms inevitably appear in relation to particular citations and research studies. Likewise, although as outlined above, I personally do not subscribe to simplistic definitions of functioning or IQ, current research is dominated by such categorisations. Like the writer Orwell (1946), I believe that language is "...an instrument which we shape for our own purposes." (p. 102), and although I have tried throughout to be conscious of the terminology I have employed and its broader implications, inevitably there were times when, in order to interrogate certain aspects of the literature, I overlooked others and reverted to definitions that offered convenient categorisation. Like him, I have in this thesis "...committed the very faults I am protesting against" (p. 116) and in my defence, I can only say that I have done so self-critically.

## 1.7 Research questions

Having briefly considered the background and rationale for undertaking a study of the phenomenon of success, as experienced by autistic adults, I outline below the research questions:

1. How do autistic adults, defined by some objective measure as successful, define their own successes?
2. How do they make sense of these successes in relation to the 'Asperger/autism' identifier?
3. In what ways does a participatory approach help or hinder our understanding of autistic and non-autistic interpretations, to achieve a shared understanding of a given phenomenon?

## 1.8 Outline of the thesis

In the next chapter I review the literature most pertinent to this topic, in order to fully establish my rationale within context and consider the current debates and contentions within this area. In chapter three I outline my reasons for choosing an interpretative phenomenological analysis (IPA) approach and combining this with a participatory methodology, demonstrating why the former is naturally compatible with the latter, and how both are well suited to my research aims. Chapter four describes in detail the methodological and analytical processes. In chapter five, I present my findings with detailed thematic analysis, following the principles of IPA and illustrating themes with representative samples of data. Chapter six extends this analysis, drawing on the theoretical perspectives of Foucault and Hacking to discuss the means by which participants sought to

most successfully navigate, and indeed take control of, their situations. Finally, in chapter seven I consider both the limitations of this study, and the ways in which its findings may inform practice and research in the field more generally.

## **CHAPTER TWO**

### **THE AUTISTIC EXPERIENCE: REVIEW OF THE LITERATURE**

#### 2.1 Introduction

This study sought to explore the lived experiences of autistic adults in relation to the phenomenon of success. Although the intention was to access ‘insider interpretations’ both of how successes were defined and interpreted, it was necessary to identify an objective measure of success in order to recruit a relatively homogenous sample. Gaining entrance to higher education seemed to offer such a measure. Entrance to higher education is considered to be a good outcome for any young person, and, alongside the academic requirements, necessitates a range of communication and social skills.

In this chapter, I will consider the literature relating to both outcome (including success) and higher education, in order to build a picture of the current situation for autistic adults generally, and the implications for my sample in particular. Since the diagnostic label of autism is a key aspect of this exploration, I will also consider how this is represented within the literature, historically and currently, and set it within the broader context of disability studies. Finally, I will consider how autism has been represented within recent research, both by non-autistic and autistic academics.

## 2.2 Outcomes for autistic adults

### *2.2.1 Overview of outcome research*

Despite the rising numbers of adults diagnosed with autism (Fombonne, 2009), and the fact that autism is widely recognised as a lifelong disability, there remains relatively little research that specifically considers adults. In their review of international research relating to the education of autistic individuals, which included post-secondary educational interventions for adults, Parsons et al. (2008) found that research articles with an adult focus accounted for only 8% of total references. A more recent study of autism research within the UK (Pellicano, Dinsmore and Charman, 2013) found that less than 30% of research included individuals who were eighteen-plus, and less than 15% focused exclusively on adults. These reports highlight the need for more research in this area and, in particular, on the impact of interventions and services. A range of studies do consider the notion of 'outcome', associating better outcomes with greater equality and inclusion. In this section I will briefly consider the available evidence, both for mixed cohorts and for groups with IQ of 70+ in order to explore the current evidence base regarding outcomes for autistic adults.

### *2.2.2 Outcome studies with mixed cohorts*

Outcome studies that focus on autistic adults indicate that even in comparison to other disabled groups, autistic individuals tend to fare worse and experience greater disadvantage. For example, an international review of twenty-three research studies which had been published between 1967 and 2011 (Howlin

and Moss, 2012) found disadvantage in terms of employment, relationships, health and quality of life. The authors highlighted that studies tended to focus on participants under the age of forty, thus they do not add to the knowledge base regarding middle-aged and older adults. A more recent study sought to address this gap by again conducting a meta-analysis of research, focusing on quality of life across the lifespan, but including their own separate study looking at elderly adults (Van Heijst and Geurts, 2015). They found a lower quality of life overall regardless of IQ. It was noted that the majority of ratings were based on parental or staff report, and that third-hand reports tended to give lower ratings than self-reports. In the case of one paper (Tavernor et al., 2013), when parents were asked to respond as their child, the correlation improved, and some parents noted that their child did prefer to be alone. If autism involves a qualitatively different experience (Sinclair, 1993; Lawson, 2011), then it is not surprising that self-report and third-person report might not agree. The lack of first-person perspectives in much of this research can therefore be viewed as problematic for the validity of findings.

Consultations funded through government via, for example, the National Audit Office or the Autism Education Trust, have likewise identified relatively poor outcomes for autistic adults. The National Audit Office (2009) conducted an extensive consultation with key stakeholders in England, including directly with autistic adults. They recommended that better support to “adults with high-functioning autism” (p.7) would not only improve outcomes, but also potentially lead to significant savings for the public purse, due to reduced benefits and need for services. This consultation used the National Autistic Society’s database as its route to contact families. Wittemeyer et al. (2011) conducted an



extensive piece of research investigating educational provision and outcomes for autistic children, and their consultation also included autistic adults. Parsons (2014) reported specifically on the consultation, which took the form of an online survey of fifty-five autistic adults within the UK, most of whom had received late diagnosis and attended mainstream schools. Respondents reported low satisfaction with school experiences and support. Parsons concluded that “experiences at school really matter: there was a positive correlation between ratings about experiences at school and current ratings of life satisfaction...” (p. 21). The author called for approaches that “more closely resemble *their* aspirations rather than the assumptions that others may make about them.” (p. 22)

Studies in the US have revealed similar trends. In a review of research focusing on transition to adulthood for young people with autism, Hendricks and Wehman (2009) called for a greater focus on research that could empower individuals “to become active change agents in their lives.” (p.83) Despite recognising limitations in their data, the authors go on to make some overgeneralised statements, for example:

...despite reports highlighting improvements in core behavioural characteristics in adolescence and adulthood, functioning seldom leads to normal ability and significant deficits continue for most. (p. 77)

Using the pejorative language of ‘normality’ and ‘deficit’, this is an example of authors employing insufficient data to reach unsubstantiated and potentially damaging conclusions.

### *2.2.3 Outcome studies limited to IQ 70+ cohorts*

A number of studies have focused on the so-called 'higher-functioning', in recognition of the fact that outcome studies to date have tended to neglect this group, as they were less likely to have been known to clinical services in early childhood (Howlin, 2000). Howlin reviewed existing research on outcome, for children diagnosed with Asperger syndrome or high-functioning autism (2000). She highlighted that, since these were follow-up studies, the adults would have been diagnosed in childhood rather than later, with implications for the profile of the participants. Howlin cited here that in 1997, she and Moore found the average age of diagnosis for Asperger syndrome to be over eleven. Therefore, although the focus was on 'high-functioning' individuals, only children with autistic symptoms sufficient to warrant diagnosis in early childhood would have been included in this review. Within the review, Howlin found some evidence that IQ was related to better outcome, but this was not consistent and overall, outcome was found to be variable.

In a more recent study, Howlin et al. (2004) focused exclusively on individuals with an IQ over fifty, interviewing sixty-eight families in the UK. The authors found that most remained dependent on their families or support services. Average age at first assessment was seven, and so again the findings need to be viewed with consideration to this. Participants were originally referrals to the Maudsley Hospital in London, and had been first seen between 1950 and 1979. The authors acknowledged that during this period, the sample would have been reflective of more serious impairments. The assessments were generally based on parental reports, including information that may be subjective such as friendship ratings. Only ten had been educated in predominantly mainstream

schools. Outcomes tended to be better with those who had an IQ 70+, but overall IQ was not found to be a reliable indicator. Those adults with the highest IQ scores were still found to be experiencing significant problems as adults. The authors concluded that "...the ability to function adequately in adulthood may depend as much on the degree of support offered (by families, employment and social services) as on basic intelligence..." (p. 226).

In a Belgian study, Renty and Roeyers (2006) used self-report to determine how disability and support characteristics each affected quality of life in adults with high-functioning autism (HFA). The authors highlighted that many outcome studies have limited themselves to unidimensional domains, whereas "Internationally, there is a broad consensus about the fact that the term 'quality of life' refers to a set of factors comprising personal wellbeing." (p. 512).

Participants were recruited via an autism advocacy group and contacts from previous research studies. Just over 24% of the sample had attended college or university, and almost 28% were in mainstream employment. Disability characteristics were not found to be significant to quality of life, whereas support was, and notably, individuals' perceptions of the informal support they received was more important than the support they actually received. These findings are supported by other studies (Billstedt, Gillberg and Gillberg, 2011) and give an indication of the need to consider support holistically.

In Japan, Kamio, Inada and Koyama (2012) conducted a nationwide survey on quality of life for 'high-functioning' autistic adults. 154 participants were recruited through support services, and all had used at least one support service over the survey period as part of the eligibility criteria. Self-report was

used to assess subjective quality of life, supplemented with parental/staff report and demographic information. 88.3% of the samples had completed mainstream education and higher education. Subjective quality of life was compared with a matched neurotypical sample and the autistic samples' ratings were significantly lower overall. This study was novel in finding early diagnosis associated with better psychological quality of life in adulthood. In this case, a minority were diagnosed early, whereas a majority had reported developmental concerns early and not received diagnosis. This finding possibly therefore says more about misdiagnosis/failure to diagnose and the long-term impact of this on the individual. The authors again emphasised the importance of environmental factors.

#### *2.2.4 Mental health and anxiety*

Many studies have noted extreme levels of anxiety, depression and/or psychological disorder in autistic individuals, particularly in adolescents and those considered to be most 'high-functioning' (Ghaziuddin, Weidmer-Mikhail and Ghaziuddin, 1998; Green et al., 2000; Ghaziuddin, Ghaziuddin and Greden, 2002; Williamson, Craig and Slinger, 2008; Hebron and Humphrey, 2014). In a discussion paper, Tantam (2001) noted that secondary psychological disorders were more common than had been previously appreciated, and could be overlooked if they manifested in untypical ways. In the US, Bellini (2004) investigated social and anxiety disorders in adolescents aged twelve to eighteen, using self-report and parental report. They found that the sample experienced much higher levels of social anxiety, that there was a

negative correlation between “assertive social skills and social anxiety” (p. 83) and that higher empathy scores were associated with higher anxiety levels. In our report on a support group for adults with Asperger syndrome (MacLeod and Johnston, 2007), I noted with shock Johnston’s revelation that she had felt like killing herself after receiving the diagnosis she herself had initiated:

When I got home and thought it over I felt like killing myself. The diagnosis, together with the IQ test results confirmed my suspicions, That I had a really good mind, which was trying to function through a physical organ (my brain) which doesn’t work properly. The consequences of this are that I can do virtually nothing with these abilities. (p. 85)

The implications of these extreme levels of anxiety, particularly for those individuals with greater self-awareness, are only gradually being recognised, but as the small body of empirical research grows, the seriousness of the issue becomes more evident. In a recent landmark study by Cassidy et al. (2014), 374 adults diagnosed with Asperger syndrome during the study period completed a self-report questionnaire, recording lifetime experience of depression, suicide ideation and autistic traits. 66% of participants reported ideas of suicide and 35% reported attempts or plans to commit suicide. This was a relatively large study, based on self-report, and offers important empirical evidence to an area that has otherwise been largely anecdotal. The authors noted that the sample were all diagnosed in adulthood and called for greater awareness of the risk of suicide, particularly for those with late diagnosis. Putting this into a practical context, Walsh and Hall (2012) considered the impact of the Autism Strategy and highlighted that although the need for post-

diagnostic support was acknowledged, there was insufficient emphasis on specialist health services, including mental health.

#### *2.2.5 Optimal outcome (OO)*

The notion of 'optimal outcome' has received attention recently, such as in the US study by Fein et al. (2013) which compared thirty-four individuals (aged eighteen to twenty-one) who had been assessed as having lost all autism symptoms (having been diagnosed with autism in their early years) with a group who were diagnosed with high-functioning autism and a neurotypical group. The authors cited other studies which identified a minority of participants who no longer met the criteria for autism at follow-up (eg. Rutter, 1970; Sigman et al., 1999; Helt et al., 2008). However, even when autism symptoms were no longer evident, individuals remained more vulnerable to depression and anxiety. Studies addressing the possibility of initial misdiagnosis have tended to conclude that at least for some of these children, initial diagnosis was valid and 'optimal outcome' was therefore accurate. The OO group had higher than average IQs, and the authors hypothesised that individuals with above average cognition may be more able to cognitively compensate for their difficulties, although in this small sample, it could also reflect a sampling bias. Likewise, a review of outcome studies by Helt et al. (2008) concluded that 3-25% seemed to lose the diagnosis over time. In consideration of the fact that they tended to remain prone to anxiety, depression and attention, the authors questioned whether this was due to co-morbidity, or could suggest that anxiety and attention difficulties should be considered to be core characteristics of autism.

### *2.2.6 Autistic success*

The specific topic of success has not featured greatly in autism research to date. Some theoretical papers have considered the uneven pattern of skills and abilities often observed in autistic individuals, leading to sophisticated skills in certain areas (Happé, 1999; Baron-Cohen, 2000; Baron-Cohen, Burtenshaw and Hobson, 2007; Baron-Cohen et al., 2009; Bennett and Heaton, 2012) and others have considered how practitioners might maximise the potential of those they support (Frea, 2010; Grenier and Yeaton, 2011).

A notable exception is the study undertaken by Beresford et al. (Beresford et al., 2004; Beresford et al., 2007). In a study which explicitly attempted to address the lack of autistic voice within research, they consulted directly with autistic children and adolescents (as well as parents and practitioners). Employing a deliberate strategy to focus on positives and aspects of their lives that they valued, their data focused on desired outcomes rather than difficulties. Although the authors described the direct consultation as challenging and limited, all children did describe experiences of success and achievement, with aspirations similar to the general population.

The tendency to view success within autism as an exceptional offshoot of core autistic characteristics is perhaps most clearly reflected in a group of papers published following a Royal Society discussion meeting focusing on 'Autism and talent' (2009). Although the papers do include discussions problematizing how autism is currently presented (eg. Draaisma, 2009; Hacking, 2009b) and celebrating autistic achievement (Cardinal, 2009; Grandin, 2009), the dominant theme is well described by Happé and Frith's introduction "The beautiful

otherness of the autistic mind” (2009, p. 1343) whereby the “otherness” of the autistic experience is emphasised above all else. It has largely fallen to autistic autobiography to celebrate a more inclusive notion of autistic achievement (eg. Santomauro, 2011; Grandin, 2012).

### *2.2.7 Concluding comments on the literature relating to outcomes*

From the available literature to date, the evidence indicates that outcomes for autistic adults, although variable, are generally poorer than for others, and that higher IQ is not a predictor for better outcome, although support networks may be. Even in the case of those adults classed as achieving ‘optimal outcome’, the effects of disadvantage in childhood are associated with higher levels of anxiety and mental health needs in adulthood, so that individuals continue to face challenges and disadvantage, but may lose entitlement to specialist support.

However, one potential problem with many of these studies is that they provide us with a picture of how life is now for adults who were diagnosed as children between ten and twenty years ago. The landscape has changed dramatically within that time, both in terms of education and provision for disabled individuals generally, and in terms of how autism is recognised and treated. This data in a sense tells us what we have been doing, rather than what we should be doing next. Nevertheless, some useful points arise, not least the need for us to more meaningfully take account of the perspective of individuals and their families.



Related to this is a limitation arising from how data for these studies was gathered - mainly not through self-report from individuals with autism, but via third hand reports from carers and relatives. It has been argued that, if autism is a qualitatively different life experience, quality of life instruments that are formulated, tested and used by non-autistic individuals lack validity (Renty and Roeyers, 2006). Where individuals with autism were questioned directly, their responses were generally not examined separately, so we do not know what differences or difficulties there may have been with their use of the instruments, although one study did note a difference between parental and self-report (Tavernor et al., 2013).

In relative terms, these data are also small, often dealing with relatively small, sometimes biased, samples. In comparison to what is available with regard to children with autism, especially young children, this constitutes a narrow evidence base and the authors repeatedly highlight this limitation and call for more research that focuses on adolescents and adults.

In addition, there is often overlap in terms of where research participants are being recruited from. Within the UK, the National Autistic Society (NAS) database is a common route of recruitment, and this potentially could mean that many of the same families are responding to multiple consultations, giving the same data to different researchers. We can make some assumptions that NAS members, and those on its database, will tend to be actively interested in autism (i.e. not ambivalent or hostile about it as a construct or personal diagnosis) and crucially, feeling in need of some form of support.

Those individuals (and their families) who are coping well within more generic or mainstream environments may be less motivated to be involved with a specialist charity, and thus remain under the research radar. In effect, much of the existing research is skewed towards those individuals with the worst experiences, and largely discounting those with the best. Success is a hugely neglected area within current research, and where it does feature, it tends to focus on savant skills and abilities that can be related directly to core characteristics of autism, thus limiting its scope even further.

Certain types of individuals, including some of those most likely to be successful, may therefore be excluded from research data for a number of reasons: firstly, they are largely absent from follow-up studies as they are less likely to have been identified as young children; secondly, they are largely absent from services as they are less likely to meet criteria for formal support services and therefore be known to agencies; and thirdly, their voice is largely absent from research as direct consultation is either omitted or a secondary aspect of the methodology.

## 2.3 Autistic students within higher education

### *2.3.1 Overview of disabled students within higher education*

Improving educational opportunities and achievements is key to improving outcomes for any young person (Riddell, Tinklin and Wilson, 2005). In recent years, both in the UK and more widely, the emerging widening participation agenda has led to changes in policy to address the needs of 'non-traditional'

students (Adams and Brown, 2006). This focus has included disabled students, although arguably they have been given relatively low priority compared to other disadvantaged groups (Barer, 2007). However, since it was not until 2001 that disability discrimination against students in higher education became illegal in the UK, there remains the potential for greater discrimination within higher education than other sectors. Moreover, in 2006/7, only 6.8% of students in higher education disclosed a disability, compared with a national average of 12% of 20-35 year olds who are disabled, so even accounting for a proportion of students who may opt not to disclose, disabled students are still under-represented within higher education (Hopkins, 2011). Non-disclosure is itself an issue that needs to be recognised (Barer, 2007), particularly given the evidence that students may seek to adopt a more positive identity in joining higher education, and thus attempt to conceal disabilities (Goode, 2007). In their report on support for students with mental health difficulties, Riddell, Tinklin and Wilson (2005) discussed the impact of increasing student numbers, pressure to prioritise research above teaching, and modularisation of the curriculum, as factors that have impacted on the student experience to the detriment of more vulnerable students. These are the additional, and growing, pressures to be negotiated by students entering higher education.

### *2.3.2 The experiences of disabled students*

A number of studies have investigated directly the experiences of disabled students entering higher education, examining both individual perspectives and the institutional implications arising from the findings. Students in these studies

have generally reported receiving an individualised response to their needs, rather than the institution either acting in an anticipatory way, as required to do by the Equality Act (UK Stationery Office Ltd, 2010) or working towards offering an inclusive environment (Goode, 2007; Madriaga, 2007). Instead, the onus has been on the individual student to make others aware of their needs (Fuller, 2008; Vickerman and Blundell, 2010). Goode (2007) identified students whose needs were ignored, and who were in a sense invisible, having to become “extra-visible” (p.41). She discussed the ways in which adjustments can lead to extra-visibility, whether the student likes it or not, noting that the responsibility for an inclusive environment can be subverted by the notion of personal responsibility, a stance often taken by higher educational establishments. Similarly, in his study on the experiences of dyslexic students, Madriaga (2007) highlighted that for *all* disabled students, there is a concern that their impairments will not be ‘seen’ by those that need to provide adjustments. Students described being forced to confront lecturers about their teaching methods, and therefore make disclosure a public matter. The author asserted that “...tutors, not educational institutions, were held responsible for perpetuating disablism.” (p. 402).

A potentially positive effect of this situation was that in some cases, students seemed to be “actively ‘managing’ their disabilities in a number of important ways.” (Goode, 2007, p. 40) Some students who had experienced discrimination had a wish to take on an ‘activist’ role. In his study, Hopkins (2011) concluded that disabled students were therefore acting as pioneers and role models within their environments, albeit with the accompanying pressure to be assertive in the face of practice that is not inclusive.

Considering the implications for the institutions themselves, Hopkins (2011) found that the students' decisions tended to be influenced by the need to minimise the barriers they had to negotiate. For example, they reported opting for a particular university due to its accessibility. Lang (2015) conducted a Swedish study on student experiences and perceptions, looking at where responsibility was located and the potential impact on identities. The author highlighted the lack of support provided to professionals within the institution, and the need for students therefore to raise awareness directly:

Students bear a large responsibility for the skills enhancement of professionals who have not yet encountered diversity in their professional life. (p. 140)

This finding, that it tends to be individuals (both students and staff), rather than systems, that take on the responsibility of adjustments, was echoed elsewhere (Hewitt and Wheeler, 2004; Madriaga, 2007; Fuller, 2008). Holloway (2001) reflected further on the need for greater clarity in agreeing how higher education should respond to the needs of its students, underlining that within current structures, institutions must be motivated to do so, and thus identify potential advantages for themselves, either economic or moral, in increasing the numbers of disabled students.

### *2.3.3 Autistic students within UK higher education*

Autistic students represent a small but fast-increasing proportion of the disabled student community:

Over the five years 2003-2008, the number of accepted applicants to higher education with declared autism in the UK has risen by 408 per cent, from 139 to 706. This is a higher rate of growth than for any other disability... (National Audit Office, 2009, p. 30)

In light of this, a growing body of research has investigated the autistic student experience specifically and the ways in which the higher education landscape is, or is not, adapting to its population of autistic students. In a relatively early study, Taylor (2005) investigated the type of adjustments that might be appropriate for autistic students, through a two-year case study within one institution. This was very small-scale, focusing on just three students. Nevertheless, some useful recommendations for practice were raised, many of which are now commonly recognised, such as the need for greater communication with parents than might usually be the case, and the need to prompt and remind students about appointments and deadlines. In some ways, the paper is a useful indicator of how understandings and expectations have changed within the last ten years. For instance, the author suggested that pastoral support be kept to a minimum to avoid embarrassment for the student. The potential effects of anxiety and depression are not considered at all. Both the importance of pastoral support and the right for disabled students to access the range of opportunities afforded to the main student population are now well recognised (Goode, 2007; Fuller, 2008; Lang, 2015), as is the impact of anxiety and/or depression on autistic adults (Cassidy et al., 2014).

In contrast, Taylor [not same author as above] and Knott (2007) reported on the provision of one university's provision, and highlighted that often, the social needs of autistic students were under-estimated, leading to emotional isolation

and difficulties. They highlighted the extreme anxieties that some students developed in relation to deadlines, and reflected that within their institution, supporting the academic and practical needs of students was generally more straightforward than supporting their social/emotional needs. The authors recommended a closely co-ordinated approach, involving both academics and support staff. This team was unusual in that they offered a diagnostic service, and they found the provision of diagnosis, plus acknowledging the diagnostic label, to be important for outcomes. Arguably, they had a biased view, given their vested interest, and this article is a discussion paper, lacking in formal data collection. However, it is a point worthy of consideration, and given the fact that funding relies on formal diagnosis within higher education, as it does within statutory education, it bears relevance.

Their finding is lent credence by the ASPECT report, which consulted directly with 238 autistic adults via questionnaires and a focus group (Beardon and Edmonds, 2007; Beardon, Martin and Woolsey, 2009). This consultation was notable in its relatively large scale, and the fact that it was co-led by an autistic adult. Its focus was on the needs of adults (with Asperger syndrome) and it therefore included further and higher education. The majority of respondents cited no or insufficient post-diagnostic support. The authors also suggested that diagnosis should not be a necessary gateway to support, arguing that in its “othering” (p. 36) of individuals so labelled, it can cause additional anxiety and a greater sense of exclusion.

In a study comparing student and staff perspectives, Knott and Taylor (2014) conducted separate focus groups with staff members and with autistic students. This study was particularly useful in identifying the discrepancies between staff

and student perspectives, as well as the common points they raised. Both groups commented on problems with time management, and anxiety/depression, as key areas. However, whilst students described extreme anxiety about day-to-day tasks, staff tended not to be aware of these lower-level stressors, and described instead incidences of severe depression. The authors reasonably concluded that, by not recognising the impact of initial anxieties, staff may have overlooked opportunities to intervene before serious depression developed. Within this study, staff suggested that social mentoring could be helpful, whilst students disagreed and perceived it to be potentially humiliating. Whilst this was a small-scale project, and findings need to be treated with caution, this discrepancy reinforces the need to check student views rather than rely on academic or parental perceptions.

In another small-scale case study MacLeod [this author] and Green (2009) also noted the need for staff to be aware of the unexpected ways in which anxieties may manifest themselves, and for individualised pastoral support. We also highlighted the fact that higher education may be the best, and to some extent, only option, for some of these young people leaving school, in a climate where employment opportunities are highly dependent upon qualifications, and eligibility for statutory support otherwise is unlikely.

In a longitudinal study of students' transition into a number of higher education institutions across the UK, Madriaga and Goodley (2009) examined inclusive educational practice and the ways in which educators responded to diversity and difference. They noted the tendency to pathologise difference and focus on practitioner rather than student experience. Student experiences were often at odds with prevailing notions of Asperger syndrome. The authors called for a



move beyond baseline measures, toward best practice, and a move away from deficit-focused approaches. Arising from the same research, Madriaga (2010) reported specifically on the students' use of university spaces and sensory impact. The author asserted that the barriers present effectively led to a shrinking of their worlds. However, findings were somewhat inconclusive on this point. For instance, respondents did highlight attendance at 'Fresher's' events as a problem. However, most did attend, and some went on to join societies which they then attended throughout the year. Half the respondents could not socialise in pubs; whilst the other half enjoyed doing so. In this sense, the study highlighted above all the diversity of profile and need that exists within the autistic student population. The author concluded with a constructive plea that "...instead of emphasising incidents of bad practice, future work could also highlight examples of good practice – where students with Asperger syndrome have social alternatives to offset the effects of isolation and depression." (p. 48).

#### *2.3.4 Autistic students in higher education outside the UK*

Given the parallels between the development of higher education within the UK and elsewhere, it is worthwhile considering studies that have taken place in comparable contexts, some of which have utilised larger-scale approaches.

In the US, VanBergeijk, Klin and Volkmar (2008) reported on the (then new) Higher Education Opportunities Act, which provided specific financial support, and considered the type of support available. They highlighted the need for support that went beyond standard academic input, noting that:

...the failure to provide supports in the social realms for students with ASDs would exclude these students from being successful in academic achievement, which is a major life activity and the primary focus of universities. (p. 1362)

Also in the US, Camarena and Sarigiani (2009) conducted semi-structured interviews with twenty-one adolescents and their parents, to assess their aspirations of postsecondary education. Interestingly, 68% of the young people in this study were either unaware of their diagnosis or chose not to share it when prompted, whilst those with greater awareness seemed also more able to articulate what this meant for their learning. All rated college as an important aspiration, and likewise all raised concerns about disability awareness on campus. The authors noted that these children may be the first diagnosed autistic students in their college and therefore need to be able to self-advocate in order to survive.

In an international review of articles related to autism and further/higher education, Gelber, Smith and Reichow (2014) reviewed a total of twenty articles relating to sixty-nine individuals. This in itself highlights the relative scarcity of research in this area, and therefore our current evidence base. The authors favoured 'gold-standard' experimental approaches and critiqued the research for being primarily small scale/case studies. They concluded that findings indicated "anxiety, loneliness, and depression and the need for academic and non-academic support." (p. 2599) Some of the same authors undertook an online survey of current and former students (Gelbar, Shefycyk and Reichow, 2015). Although the authors are not specific on this point, the survey seems to have been disseminated regionally rather than within one institution. However,

only thirty-five students were recruited, making this a small-scale study for the methodology employed. Key findings were the need for non-academic adjustments, including social and emotional support and the paradox of adjustments such as provision of quiet spaces, that can increase isolation as reported elsewhere. They found some evidence of depression and bullying, but anxiety was a more significant factor, with over half respondents stating they could not cope with anxiety. Whilst most received study support, input from ancillary staff (e.g. Careers Advisers) was lacking, and the authors noted the need for more effective transition out of higher education. The participants of this study did not fulfil common autism stereotypes, tending to be recruited from liberal arts rather than STEM (Science, Technology, Engineering and Mathematics) subjects, and were also recruited from autism self-advocacy groups, so potentially a non-typical sample.

In another large scale, US-based survey, Shattuck et al. (2012) used national data to examine the prevalence and correlates of post-secondary education (PSE) and employment in young people with autism. Interviewing 500 families, they found a high risk for young people to find themselves in neither, especially within the first two years after high school (more than 50%). Although the data came from a nationally representative survey of parents, guardians and young adults, the sample focused on young people who had used special educational services, so data potentially had a negative bias. Nevertheless, PSE and employment rates were lower for these participants than for other categories of disability, revealing a continuing trend for autistic adults to experience greater inequality than other disadvantaged groups. The authors call for better transition planning from school into postsecondary.

Going beyond the US, two Swedish studies from the same author focused on the experiences of students. Firstly, Simmeborn Fleischer (2012a) investigated the perspectives of relatives and coordinators of three students entering higher education, using a case study methodology. The results revealed that relatives lacked information and opportunities to engage in collaboration, despite the fact that the relatives of autistic students played a central role in supporting them and in understanding their impairment. In a related study, the same author used a semi-structured narrative approach to investigate the first-hand experience of three students, looking specifically at whether support acted as a facilitator or a barrier (Simmeborn Fleischer, 2012b). The students expressed wanting to fit in at school and concealing their difference, whilst at the same time feeling different. All viewed diagnosis as stigmatizing. They cited the additional effort required for simple daily tasks or study tasks, as compared to other students, and the exhaustion and anxiety caused by this, as upsetting the balance between daily life and studies. In these studies, support was generic, depended on the student initiating it, and ultimately did not work for the students. Alienation and struggle were constant narratives, described by the author thus:

The respondents have a need to be alone, but at the same time they long for friends and fellowship with other students. (p. 191)

Another (pilot) study questioned thirty-four students with autism, motor disabilities or hearing impairment, with the aim firstly of piloting the research tool, and secondly, of comparing the perceptions of the different groups (Simmeborn Fleischer, Adolfsson and Granlund, 2013). The three groups described similar patterns of difficulties, both in their academic studies and more generally, but the underlying reasons for these were variable. All groups

were found to need support in academic and non-academic aspects of their lives, and there was no clear link between impairment and the restrictions experienced. The authors suggested that, when using such data collection tools, open-ended questions are important to identify more exactly the nature of the issues. They also highlighted the need for collaboration between relevant services to ensure appropriate and individualised adjustments can be provided.

In Belgium, Van Hees, Moyson and Roeyers (2015) used semi-structured interviews to explore the experiences of twenty-three students. They used grounded theory to analyse the data, and reported findings within the three domains of education, student life and daily living. In this study, the authors also highlighted the efforts made by students and their successes, such as the development of personal strategies and using shared interests to forge new friendships with peers. Once again, a personalised approach to support was advocated, as well as the importance of listening to the student experience in order to “contribute to a better, more accessible and inclusive education.” (p. 1686)

Finally, an Australian study explored the existing international literature, making recommendations from a mental health nurse perspective (Mulder and Cashin, 2014), thus also raising the question of where support for autistic students should sit within a university. The paper reviewed a range of studies, but did not specify selection criteria or strategy. The authors reflected upon the Australian system, considered the potential benefits of higher education for autistic students, and asserted that mental health nurses are well placed to support autistic students within this context, due to their person-centred focus. Whilst this may be true, it is not a conclusion derived from analysis of the literature

and may well be disputed by Disability Support Practitioners, so this finding arises from a weak evidence base. However, the question of where the needs of autistic students are best met, in relation to disability/mental health departments, is a live debate and one that merits further consideration.

### *2.3.5 Concluding comments on the literature relating to autistic students within higher education*

In summary then, the literature identified that within higher education, as Outhred (2012) succinctly put it:

...the contemporary moment is defined by momentous shifts across the global and national higher education landscape. (p. 881)

This is not least demonstrated by the ways in which the sector is being called upon to be more inclusive, both in its strategies and its processes. The number of disabled students entering higher education, whilst still disproportionately low, is growing fast. Autistic students make up an increasingly significant proportion of this number. However the sector is 'playing catch-up', being a relative latecomer in terms of legislative imperatives.

The implications for individual students entering higher education have been enormous, as they have been pioneers, and consequently cornered into being role models and educators on disability rights, on top of the existing pressures of studying. A recurring theme in student accounts was the fact that they, as individuals, bore personal responsibility to educate tutors about their disability, and in these ways were forced to publically disclose, and to become 'extra-

visible'. Their rights were thus compromised. Additionally, the tendency for individual tutors to be held accountable, rather than institutions, was highlighted. The lack of strategic or joined-up thinking was apparent in much of the research. Institutions tended to be responding to individual need, rather than pro-actively adapting processes to be more inclusive, and in this way were more closely aligned to an individualised model of disability that overlooked structural and cultural barriers.

However, this also highlights the abundance of contradictions within the literature, with key messages being expounded and then immediately undermined in the face of the diversity they seek to represent. For instance, as above, students ought to be encouraged to live away from home, yet this almost certainly will present additional challenges that could compromise their capacity to cope with their studies. Students ought not to be segregated yet in some cases, autistic students may actively opt for this, in order to have an environment free of sensory distraction. In fact, even the simple notion that students ought to be consulted can become problematic if decision-making is a cause of anxiety. Tensions can be identified in several areas of the literature, for instance between the need to offer support that is individualised for the student, but does not amount to the student bearing individual responsibility for their disability; and the importance of collaboration, which may need to include parents, without compromising the rights of adult students, who have the right to make their own decisions, even against their best interests. This is not to say that any of the above is incorrect, but neither is it straightforward, and it can almost never be presented as general fact.

The final consideration is of the very lack of research focusing on this sector. This is true of autism in particular and disability in general, and the lack of available data limits the extent to which issues can even be identified, never mind analysed, challenged and resolved. Nevertheless, there are some important themes emerging which are consistently reported and pertinent to this study. Perhaps the most critical of these is the issue of post-diagnostic support. Autistic students differ from some other groups in that they are more likely to receive a diagnosis in later childhood or adulthood (Fombonne, 2005), and so more likely to still be coming to terms with diagnosis during their higher education studies. Related to this are two other strong findings; firstly, that anxiety and depression are common but may not present typically; and secondly, that students will almost certainly be required to self-advocate, and make themselves visible, or even 'extra-visible', in order to educate staff within their institutions about their needs. These findings, reported consistently and on a global scale within the research, serve to underscore both the weight of additional pressures to be negotiated by autistic students, and the roles they are taking on, by choice or necessity, as role models and advocates of the autistic experience.

#### 2.4 Representations of autism

Autism has traditionally been represented as a disability, albeit one that sits uncomfortably within and between categories such as 'less visible disability' (including for instance, dyslexia and mental health) and 'learning disability' (Howlin, 2004) and so it is pertinent to contextualise this section by considering



the ways in which disability has been understood over recent years. Firstly considering this in a generic context, I will then move on to consider how these ideas have been applied to less visible disabilities, before finally considering autism as a specific case.

#### *2.4.1 The place of autism within disability studies*

Within the last forty years, the field of disability studies has emerged as a means of critiquing the ways in which the systems of post-industrial society have operated to exclude disabled people from work and society, medicalising difference (Shakespeare, 2006) and subjecting individuals to “the professional gaze” (Beauchamp-Pryor, 2011, p.8). Through the efforts of disabled political activists, a social model of disability was conceived in the UK as an alternative interpretation. This articulated a distinction between disability and impairment, attributing the former to social oppression:

Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976, P. 3)

The social model of disability has since become hugely influential and has now been adopted by much of the social care sector, albeit with differing degrees of effectiveness (Oliver and Barnes, 2012). However, its very influence has become controversial, with Shakespeare and Watson (2002) noting that it had become something of “a sacred cow” (p. 5), almost beyond critique. Some

disability studies authors have attempted to do so, for example in noting its tendency to be exclusive in focusing mainly on people with physical and sensory disabilities. Ferri (2015) noted the multiple discourses that make up the experience of one individual (beyond disability to include race, gender, etc.) and the need for all of these to be taken into account. Rhodes et al. (2008) offered a similar critique, suggesting that “the (British) social model assumes a single, unifying and essential identity as disabled.” (p. 388) In their consideration of the experience of epilepsy, they discussed the interaction of multiple factors that can influence how a person does or does not identify as disabled. They also noted that theoretical models such as the social model may not be viewed as relevant to disabled individuals outside of academia, struggling with their day-to-day lives. Shakespeare and Watson (2002) likewise called for the disability movement to go beyond its original impairment/disability dualism and instead consider “an embodied ontology” that acknowledges the potentially debilitating effects that impairment can have, regardless of environment (p.2).

Beauchamp-Pryor (2011) articulated this need for acknowledgement of impairment thus:

Whilst disabled people are not their impairments, their impairments are likely to influence who they are, in the same way as does being black or white, gay or straight, young or old, male or female. (p. 11).

She also considered where the experience of being ‘cured’ fits into the model, using her own personal experience of receiving corrective surgery for visual impairment. She noted that the inequality and exclusion she had experienced

throughout her life continued to impact on her, imposing psychological restrictions which arguably continued to disable her, a consideration with relevance to the literature noted above. Autistic individuals defined as 'optimal outcome' likewise continue to live with the psychological impacts of their childhood experiences, as previously noted (Fein et al., 2013).

This domination of the disability movement by people with physical/mobility impairments has led to a perceived hierarchy and a focus on physical barriers (Beauchamp-Pryor, 2011). Additionally, since some impairments are less visible than others (autism being one), certain individuals can potentially opt (or at least try) to 'pass' and identify as non-disabled (Goffman, 1963). This has been a contentious issue within the disability movement, with some activists asserting that this is "internalised oppression or false consciousness" (Shakespeare and Watson, 2002, p. 20) whilst others contend that it can in fact be a positive act of self-determination (Olney and Brockelman, 2003; Rhodes et al., 2008).

#### *2.4.2 Less visible disabilities*

In relation to the hierarchy of impairments noted above, Goodley (2001) described how people with learning difficulties have experienced discrimination by the disability movement itself, which continued to apply a medicalised model and view them as "personal tragedies of their unchangeable 'organic impairments'." (p. 211) Boxall, Carson and Docherty (2004) considered the ways in which people with learning difficulties contributed to courses within higher education. They noted the discrepancy between social model theorizing

generally (dominated by disabled theorists) and theorizing in relation to learning difficulties (dominated by non-disabled theorists). The authors noted that this imbalance has contributed to the continuance of a deficit perspective, and the need for people with learning difficulties to have access to higher education in order to gain credibility and confidence as “producers of knowledge.” (p. 107)

Gillman, Heyman and Swain (2000) noted that individuals in learning disabled groups tended to favour person-first terminology, in contrast to other disabled groups, because “...the fight against the colonisers of learning difficulty is of a different order and is a fight against the denial of humanity itself.” (p. 405)

Rhodes et al. (2008) talked of individuals with epilepsy being viewed with suspicion by both disabled and non-disabled groups, and noted that it is often those whose impairments are less visible but stigmatised who choose not to identify as disabled.

Thus the literature indicates that those individuals with less visible disabilities may bring very different experiences to their understanding of disability, and indeed, reach different conclusions about where they fit or how they should be represented. The case of autism emerges from this context, particularly for those classified as ‘higher-functioning’, who are less likely to receive early diagnosis (Mandell, Novak and Zubritsky, 2005) and may be more able to mask their difficulties in their efforts to conform (Hebron and Humphrey, 2014).

### *2.4.3 A brief history of autism*

At this point, it is useful to briefly consider how ideas about autism have evolved, since much has happened over a relatively short period, which in itself carries implications for current interpretations. A term first coined by a Swiss psychiatrist (Bleuler, 1913) to describe a particular symptom of some schizophrenic patients (Eyal et al., 2010), autism first became known as a childhood disorder through the case study descriptions of Kanner (1943) and Asperger (1944), working in clinical and educational settings respectively. Introduced at a time when psychoanalytic theories dominated, autism was theorised as a product of “emotional refrigerator” families (Kanner, 1949, cited in Eyal et al., 2010, p.137) and autistic children and their families received invasive treatments such as those expounded by Bettelheim (1967), designed to reverse the effects of faulty parenting. Although Bettelheim’s theories have now been largely discredited, autism interventions have continued to be contentious, often invasive and imposed without consent (Silverman, 2008). This is perhaps most clearly exemplified by the most popularised and profitable intervention, the Lovaas approach (Lovaas, 1987), opinion of which divides autism communities. Characterised as having the strongest evidence base of all autism interventions (Eyal et al., 2010; Keenen et al., 2015), it is generally condemned by autistic writers (Dawson, 2004; Milton, 2012) who argue it is a cruel approach which seeks to extinguish by force behaviours that do not conform to a non-autistic norm. The Lovaas approach began in the 1960s, whilst autistic writers emerged much later, so that it and others like it became established without reference to the experience of the subjects involved.

The latter half of the twentieth century was characterised by the re-framing of autism as a 'continuum' disorder (Wing and Gould, 1979) and the identification of Asperger syndrome as a distinct and separate category (Wing, 1981), to be included in the DSM-III-R as such in 1987 (APA, 1987). Alongside these developments, a number of key clinicians developed cognitive theories based on the notion of a theory of mind deficit (Baron-Cohen, 1989), weak central coherence (Frith, 1989), and executive dysfunction (Ozonoff, Pennington and Rogers, 1991). More recently, an autistic researcher (Lawson, 2011) has developed a theory of single attention and associated cognition in autism (SAACA), moving away from deficit interpretations, developed from his work with Murray and Lesser on monotropism (Murray, Lesser and Lawson, 2005).

However, none of these developments have proved conclusive in our understandings of autism (Rajendran and Mitchell, 2007). There is still no evidence for any one cause or genetic base for autism, and researchers have called for us to move away from this kind of theorising, and by implication, to move away from the notion of a single intervention (Happé, Ronald and Plomin, 2006; Lord and Jones, 2012).

The distinction between autism and Asperger syndrome in particular has always been vague, with evidence that diagnosis depended more on geography than individual presentation, termed by Eyal et al. as "classificatory chaos" (2010, page 195). Partly for this reason, the latest iteration of DSM-5 (APA, 2013) has reverted to 'autistic spectrum disorder', and it is supposed that some children who would previously have received a diagnosis of Asperger syndrome will not meet the new criteria for autism (Smith, Reichow and Volkmar, 2015). Thus, as in Goodley's (2001) allusion to the removal of

borderline retardation from the 1973 Manual of Terminology of the American Association on Mental Deficiency, a Foucauldian re-ordering of subjects has taken place and a group (or sub-group) of people are “cured overnight” (p.214).

The purpose of this very brief potted history is above all else to illustrate that autism is very much “a moving target” (Hacking, 1999, p. 105) and as Murray summarises, “...the condition occupies contested ground in an arena in which it appears as if little is agreed upon.” (2008, p.6).

What can be said with some assurance is that autism has traditionally been framed using a deficit model, and autistic voices have not featured in our understandings, and in fact, have been largely absent from discussions within disability studies (Murray, 2008). In the following sections, I will consider how dominant narratives have begun to be challenged, by both non-autistic and autistic authors.

#### *2.4.4 Representations of autism from non-autistic writers*

A number of non-autistic academics have critiqued dominant autism narratives and the ways that systems can work in their own best interests rather than those of the autistic individual. Arguing that the deficit interpretation is an inaccurate representation of autism, O’Neil (2008) critiqued the data on which dominant theories rely and, drawing on a range of literature and research, illustrated the ways in which behaviours perceived as maladaptive in one context could be regarded as strengths in another. The author concluded by calling for the voice of autistic people to be heeded by clinicians and

researchers, in order to achieve “a genuine understanding” (p. 795) of autism, a call supported by others (Solomon and Bagatell, 2010; Waltz, 2012). Silverman (2008) noted how autistic self-advocates have disputed autism theories and taken issue with their underlying assumptions. She cautioned against an essentializing discourse, which risks viewing autistic people “as members of a distinct species of human to which our obligations and responsibilities might be different.” (p. 333).

Also considering the societal response, Hodge (2005) talked of the risk of the diagnostic label becoming more significant than the nature of the child, and the ways in which presumed access to specialist services can put pressure on parents, so that they “report that they feel ‘blackmailed’ into diagnosis.” (p. 346) Hodge expressed the hope that, if services are able to take better account of the child’s individuality and life experiences, an inclusive society would not need labels. In the US, Connor (2013) took what he described as a disability studies in education framework to consider the problems of definitions, considering the ways in which Asperger syndrome is both socially constructed, and challenged, by autistic self-advocates. He called for more use of first-person accounts to “provide alternative renderings that cast themselves in three-dimensional terms” (p. 124).

Molloy and Vasil (2002) also highlighted the socio-cultural influences that surround diagnosis, beyond the best interests of the child:

The common rhetoric of the child's needs conflates with a range of different needs: the need of the school to maintain order and to function smoothly; the needs of the parents to make sense of their



child's behaviour; the needs of the speech therapist and occupational therapist to have a common methodology and concomitant professional language to support their practice. (p. 666)

The authors asserted that autism is thus pathologised, with the child regarded as a “sufferer” (p. 667) rather than merely naughty or eccentric. The authors framed this as a disadvantage since it reduces the range of behaviours that would count as 'normal'. However, this argument seems to neglect the views asserted by some autistic individuals that they prefer to have their behaviours understood in autism terms than to be seen as eccentric, naughty or rude, which can lead to a different, but not necessarily less damaging, range of interventions (Sainsbury, 2000).

Considering the impact of autism stereotypes on lay understandings of the condition, Draaisma (2009) cited on the one hand the best-selling text *The Curious Incident of the Dog in the Night-time* (Haddon, 2004) as an example of a fictional account which may eclipse more factual, but less entertaining, representations. On the other, he offered the Tammet autobiography (2006) as an example of the positive image that can be projected of an individual surpassing expectations, influencing parents to expect more from, and give more to, their own children, thereby potentially transforming their situations.

Orsini and Davidson (2013) noted the impact that diagnosis and labelling can have on how one interprets oneself:

...this politics of naming – whether autism is a spectrum, a difference, or a disorder – has implications for how individuals who exhibit some

of these characteristics or behaviors view themselves and interact with the world. (p.3)

Ortega (2013) noted that “The psychiatric label of autism or Asperger syndrome affects the persons so labelled and/or their families and caregivers, and potentially changes their behaviour and hence the meaning of the label itself.” (p. 75)

Ortega related this phenomenon to what Hacking has described as “making up people” (Hacking, 1986, p. 221) and by Foucault as externally imposed “technologies of the self” (Foucault, 1988, p. 16). Hacking’s work on representations of autism has been influential and is worth considering here in more detail. Drawing on the work of Gestalt psychologist Wolfgang Köhler, he considered the autistic experience (2009b). According to what he called Köhler’s phenomena, there are a range of phenomena through which individuals see (from behaviour) rather than infer (from what a person is doing). Through this, a “common property and practice of mankind” (Hacking, 2009b, p. 1471) is acquired. Autistic individuals do not share this non-autistic “common property and practice”. There is a partial symmetry in this: autistic people do not understand the thoughts and feelings of non-autistic people from their outward behaviour. Equally, non-autistic people are unable to understand the thoughts and feelings of autistic people from their behaviour. Non-autistic people have tended to conclude from this that individuals on the autism spectrum are ‘thin’ or “...lacking a thick emotional life” (p. 1471) and Hacking hypothesised that autistic self-narratives thus have a critical role in conveying the true ‘thickness’ of the subjective autistic experience. He illustrated this with the example of hand-flapping, perceived by non-autistic people as a meaningless behaviour

until autistic authors described the feelings of release and satisfaction incurred by the activity. Such explanations made meaning for non-autistic caregivers and teachers for whom these accounts were a revelation, but moreover, they validated and re-defined the behaviour for autistic people. In doing so, self-narratives have begun to create a language to describe experiences that are not represented in the “common property and practice” of non-autistic people, because they are not part of their experience:

They are creating the language in which to describe the experience of autism, and hence helping to forge the concepts in which to think autism. (Hacking, 2009b, p. 1467)

In this way they are compensating for the lack of Köhler’s phenomena within the interactions that take place between autistic and non-autistic people (McGeer, 2009). Autistic people have always been exposed to examples of what it is to be non-autistic; this is the predominant language of our culture. Self-narratives for the first time offered explicit examples of what it is to be autistic. By sharing this alternate ‘common property and practice’ such narratives influence the interactions between autistic and non-autistic people and also influence the ways in which autistic people think about themselves, thus creating a “looping effect” (Hacking, 1999, p.34). If autism is framed as a disability in which existing impairments are compounded by disabling barriers that are socially constructed (Shakespeare and Watson, 2002), then narratives that reveal alternative interpretations can help to alter the social constructions. In doing so, they can give rise to more positive social responses for people on the spectrum and consequently improve the quality of their lives. Self-narratives

thus not only inform, but have the potential to transform, for both author and audience:

If autistic self-narratives have the power to change those conditions for the better, then autistic self-narratives have the power to transform what it is to be autistic. (McGeer, 2009, p. 528)

Lest we forget that diagnostic classifications are not fixed but rather, in a constant state of flux, Hacking (2007) proposed we focus on dynamics, not semantics:

How do people make themselves up, as they act in ways that conform to, or stay away from, powerful classifications? (p. 123)

Draaisma (2009) considered the evolution of this phenomenon, and discussed the case of Temple Grandin, who he viewed as a bridging figure for the “looping effect” (Hacking, 1999, page 105), in that she presented as a typically autistic child and developed into an independent and indisputably successful adult, thus:

...she stretched the autism prototype, making room on the spectrum for others who may not have shown such classic autistic traits as children but identified with her circumscribed interests, visual thinking, or particular sensory experience of the world. (p. 228)

According to Draaisma, such accounts “tie the “high-functioning” person to the “low-functioning” one, not only discursively, but within common forms of life.” (p. 231). Articulating one of the greatest dilemmas, particularly for those who find themselves having to choose whether or not to disclose their diagnosis, Ortega

(2013) questioned “How can autistic people struggle against oppression based on the category of autism without using the very same category and organizing themselves around it?” (p. 88).

By thus asserting their rights, autistic individuals make themselves visible and potentially stigmatized. He goes on to argue that criticism must not only challenge the deficit narratives, but also “examine the emancipatory discourses and practices sustained by autistic people themselves.” (p.89). In the same vein, Brownlow and O’Dell (2013) consider Foucault’s notion of biopower and whether “the identification of “neurobiological citizens” can offer the potential for autistic individuals to construct alternative understandings of autism, ones that are not dominated by a deficit-model focus.” (p. 98). Considering the two competing interpretations of autism, the authors observe that in reality, autistic individuals draw on both interchangeably, depending upon the situation and their own needs. This brings us back from theoretical discussion to the lived realities of individuals so diagnosed, and how they navigate their situations.

The plurality of perspectives and experiences is apparent even in the use of autism terminology. Kenny et al. (2015) consulted with over three thousand UK residents using an online survey, including autistic people, their families, researchers and practitioners. Their study revealed evidence of deeply held differences of opinion, with support practitioners more likely to use ‘person-first’ terminology as is dominant within the learning disability communities, whilst autistic people in particular objected to this implied separation of autism from their identity, viewing it as perpetuating “the notion that autism is an inherently ‘wrong’ way of being.” (p.16)

#### *2.4.5 Representations of autism from autistic writers*

Above we have seen some of the ways in which autistic writers and activists have influenced non-autistic thinking about autism, introducing new perspectives and challenging accepted truisms. I wanted to consider their contributions separately here, in order to present the 'insider' perspective on its own terms. One of the earliest autistic activists, Sinclair (1993), wrote a seminal piece addressed to parents of autistic children, calling for them not to mourn for their lost expectations as if they were mourning a lost child. In the paper, Sinclair characterised autism as a fundamental aspect of the individual: "Autism is not a way of being. It is not possible to separate the person from the autism." (1993, page unknown) and declared that the tragedy is not to be found in autism, but rather, in what autistic children are subjected to as a consequence. Ne'eman (2010) was more reserved in his consideration that "while it does not represent the totality of what makes us who we are, it is indeed a significant part of us." (page unknown) Comparing the dominant metaphor of autism as disease with the counter-narrative of autism as neurodiversity, Broderick and Ne'eman (2008) noted that in pushing a 'cure' agenda, the dominant narrative focused on parental suffering, rather than the experiences of autistic individuals. Describing autism as a "popular cultural obsession" (p. 462), the authors called for a Foucauldian counter-narrative "to advance a positive image of the autism spectrum, as well as to resist and transgress the negative one." (p. 472).

Another important consideration is that pursuing a diagnosis of autism can be a choice made in adulthood. Diagnosis is increasingly sought by adults who self-identify and were not diagnosed in childhood. Singer (1999), the autistic author

credited with coining the term 'neurodiversity' and also parent to an autistic child, described reading the autobiography of Donna Williams (1992) and recognising an experience of autism to which she could relate. However, the decision to seek diagnosis involved a weighing up of "the benefits of a clear identity against the potential of being stigmatized." (p.64) She articulated the position of many autistic adults who self-identify before being formally recognised:

Whereas the traditional image of 'diagnosis' is of something reluctantly sought, dreaded, resisted and imposed from outside, people with 'marginal' neurological differences clamour at the gates, self-diagnosed, and demanding to be let in. (p. 65)

Autism is thus both an imposed diagnosis with which a developing child and their family must come to terms, and a potentially less stigmatizing identity than the undiagnosed one, but one which must be fought for.

Such debates have tended to focus on those regarded as 'higher-functioning'. However, assumptions about capacity have increasingly been called into question. Although there is an associated co-morbidity with learning disability (Fombonne, 2003), autistic researchers in particular have questioned the validity of data. Dawson, Mottron and Gernsbacher (2008), for example, explored learning in autism. They noted the enormous variability in assessing "mental retardation" (p. 761) within the current evidence and called for savants and non-savants to be considered as one group.

Finally, a phenomena that has developed alongside the rising prevalence of autism is that of the world-wide web and the opportunities for global

communication that it has opened up. As far back as 1999, Singer identified its impact on autistic individuals, proclaiming that “It has begun to do what was thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society.” (p. 67).

Almost ten years later, in his consideration of autism advocacy, Ne’eman (2010) identified the ways in which it had enabled collective action for a group that otherwise consisted of geographically and socially isolated individuals. Sinclair (2005) recalled the founding of Autism Network International (ANI), an autistic self-advocacy organisation which was developed in the US by autistic adults. This voice and collective action is identified by autistic authors as contrasting starkly with the traditionally dominant autism communities of clinicians, practitioners and parents. In his description of the history of ANI, Sinclair (2005) described the hostility they had experienced from some parents and professionals and how, in their efforts at self-advocacy, they were perceived as an overt threat, and the authenticity of their experience (diagnosis of autism) was called into question. However, he also highlighted that some parents were drawn to their group as a more constructive alternative to the ‘deficit and tragedy’ narratives, indicating both the potential for, and the benefits of, collaboration that exists between autistic people and other autism-related groups. Broderick and Ne’eman (2008) later noted that the autistic and autism communities share many of the same goals, such as better quality of life for autistic people, and argued that the counter-narratives of autism can play an important role “in the process of cultural critique and resistance to ideological hegemony.” (p. 474).



Considering the ontological status of autism, Milton (2012) described a 'double empathy problem', highlighting the reciprocity of the communication barrier (similar to that described by Hacking). He concluded that in light of this, practitioners should not presume (but do) that they understand what constitutes 'good autism practice.' In a later paper, Milton (2014) reflected further on the production of knowledge in autism studies, and the fact that it is largely based on interpretations from non-autistic researchers. He suggested that as this has involved a lack of "interactional expertise" (p.800), it has led to mutual distrust between non-autistic researchers and autistic people. However, in a separate study reporting on nine autistic adults undertaking an online action research project (Milton and Moon, 2012), the second (autistic) author commented on the course being 'owned' by the first (autistic) author and her feeling 'fish-bowled' by the research element of the project. This provides one illustration of the tensions that exist between, but also within, autistic communities. Just as being a disabled researcher does not automatically lead to being inclusive in one's research approach (Kitchin, 2000), being an autistic researcher does not necessarily enable one to understand what constitutes 'good autism practice' by another's interpretation.

Autistic counter-narratives are thus much more than an individual assertion of worth; they are an essential element of the ongoing debates regarding how autism should be represented, and provide new dialogues, not just to the autism self-advocacy communities but to parents, and crucially, through them, to children receiving diagnosis (or having diagnosis imposed upon them).

#### *2.4.6 Representations of autism within research studies*

To conclude this section with some empirical data, I will summarise the key findings arising from the small number of studies which have drawn directly on the autistic experience and explored how autistic participants made sense of their diagnostic label.

In a US study, Hurlbutt and Chalmers (2002) undertook a small-scale, qualitative study of the life experiences of three adults over a nine month period. A major theme was that participants wanted to be considered experts and be consulted on issues that affected their lives. Diagnosis was perceived as a positive explanation for difficulties and the discovery of a group they 'fitted'. The support systems they had, mainly from family, were found to contribute to their sense of self-worth.

Two studies have focused on existing Internet accounts written by people with Asperger syndrome/high functioning autism (Jones and Meldal, 2001; Jones, Zahl and Huws, 2001). The authors highlighted that autism literature usually points to an absence or lack of emotion in autism, which contrasts with their studies, in which participants expressed the importance of emotional issues in their lives. However, their studies carried some limitations. Samples were biased, with participants being Internet users by default, and accounts were pre-existing, rather than produced for the purpose of the research, so participants did not have the opportunity to validate or comment on findings.

In a Canadian study, Davidson (2010) examined forty-five autobiographical texts, considering barriers described in relation to socio-spatial inclusion. Although this study carried some of the same limitations as those above, the

author developed some original and worthwhile points, in particular noting the capacity for autistic individuals to develop their own coping mechanisms, so that in many cases, it is not so much that adjustments need to be *made*, but rather, that autistic people need to be *allowed* to use the strategies they have. This is a shocking observation, that not only are we not making necessary and simple accommodations, but that we are refusing individuals the entitlement to make their own, because we associate them with behaviours that do not fit our expectations.

Barrett (2006) presented a case study, whereby autobiographical accounts were used within a teacher training setting. In his session, the autistic trainer, Kenneth, described “my Aspergers” (p. 102), leading teachers to hypothesise on autism as a core part of self-image. The author repeatedly described the teachers as identifying with the experiences described by Kenneth, enabling them to “hear the voices and see the faces” (p. 106) of the children they supported. Barrett concluded that “...it provided an opportunity to explore the nuances, paradoxes and complexities involved in attaching labels to constructed profiles of human difference.” (p. 107). Bagatell (2010) explored the emergence of a US autistic community as a participant-observer and expressed surprise at the social nature of the group, noting that group members socialised in ways that would not be recognised as such by non-autistic observers. Participants described autism as a fundamental aspect of themselves and responded positively to the researcher, having previously experienced researchers as looking for deficits rather than listening to their stories. MacLeod [this author], Lewis and Robertson (2013) undertook a qualitative study of six autistic students using social identity theory. Accounts indicated the lack of “a

clear place” (p. 45) for autism within concepts of disability, with the literature being viewed as largely alienating rather than reassuring. Participants projected strong self-images, but we cautioned that distance from autistic identity could equate to distance from an empowering collective identity.

There are a number of studies worthy of consideration, which do not focus exclusively on the autistic experience, but include it within their investigations. For example, Brownlow (2010) explored the role of therapeutic intervention and constructions of autism, analysing four discussion lists over a three month period. Two of these were autistic groups, one was a parent group and one a professional group. She noted the dominance of the deficit model, as demonstrated on the professional board and its implications for the autistic identity. Langan (2011) used a study of parental accounts to consider the evolving discourses underway. He described the recent shift in parent activism towards autistic diversity, and asserted that the declining influence of the biomedical model has resulted in greater collaboration between parents and professionals, and between parents and autistic people. Since the decline of the biomedical model must be attributed directly to influential autistic writers such as Sinclair (1993) and Singer (1999), this is testament to the constructive, and growing, influence of autistic writers and researchers.

A Korean researcher based in the US compared the context of autism within Canada, Nicaragua and Korea, using interviews and observations with professionals and families (Kim, 2012). She observed that in Nicaragua, where little is known about autism, a teacher would want more knowledge merely in order to help their child - not because she regarded him/her as a problem, but

because "...she saw a person with needs, not a disability that incidentally had swallowed up a child." (p. 542).

The author acknowledged the limitations of her research, being very small in scale and informal in approach. However, the study was useful in highlighting the need for autism to be viewed "through the sociocultural model, which emphasizes the social contexts in which autism is understood and viewed..." (p. 544) and the author concluded that "...what is more needed than any autism prevalence data are the acceptance of and desire to understand individual differences in this diverse twenty-first century." (p. 535)

In a study using a lifeworld approach, Hodge (2008) explored the experience of parents of autistic children. He described the parents' view of their children's disability as "relational" (p. 30), in that they saw the children's need to make the most of their capabilities, but also felt that structures etc. should meet them half way. Hodge described the conflicting experience of diagnosis for parents, whereby they were being "retrained" to view their child not as a source of enjoyment, but as in some way "deviant" (p. 35).

Considering the ethics of autism research, Pellicano (2014) drew on findings from a larger study, consulting with 1700 autistic individuals, families/carers, practitioners and researchers. She noted the expansion of autism research in the last decade; more than in comparable fields. Pellicano highlighted that as the autistic community remains largely uninvolved in decision-making processes around research, priorities are decided by funders and academics. Autistic adults and families within the consultation felt that they were used as providers of data, without either their "experiential expertise" (p. 203) being

acknowledged or findings being reported to them, leading to a distrust of researchers. From the same study, Pellicano, Dinsmore and Charman (2013) considered what UK autism research should focus upon. In addition to findings already noted, they highlighted that within autism communities, although researchers and autistic adults tended to agree on overall priorities, autistic adults differed in not supporting a normalising approach. In contrast, parents tended to want their children to develop skills and manage their environment.

#### *2.4.7 Concluding comments on representations of autism*

Autism sits somewhat uncomfortably within and between a number of other categories such as disability, learning disability and mental health. As a less visible disability, there is a notional choice for the individual and their family regarding whether it is preferable to pursue formal diagnosis and risk the stigma and re-interpretations of the individual that tend to follow.

Autistic voices have joined the debates relatively recently, but have been hugely influential, both for autistic communities and for non-autistic academics. These direct perspectives have challenged existing stereotypes and articulated the existence of, on the one hand, commonalities between people seemingly at opposite ends of the autism spectrum, and on the other, huge differences between autistic people who are on the face of it very similar.

The majority of empirical studies have been small-scale and qualitative in their approach, thus limiting the extent to which findings can be generalised. However, their findings have largely endorsed both the lived experiences

articulated by autistic writers, and the theoretical discussions developed by autistic and non-autistic academics. By drawing out the complexities of the autism phenomenon, exposing the damaging effects of certain representations of autism, and critiquing the current evidence base, these three strands of analysis push us to new, hopefully more authentic, understandings and interpretations.

## 2.5 The autistic voice within research

Autistic academics have recently added their voices to the discussion on how autism research should be conducted, and autistic people meaningfully included. Unsurprisingly, they take as their starting point the frustrations at the current research landscape, in which autistic participants are passive participants and still “...are frequently frozen out of the processes of knowledge production.” (Milton and Moon, 2012, p. 794). This seems to reflect the position of autism within the disability movement, somewhat “left behind by the progress that much of the rest of the disability community has enjoyed.” (Ne’eman, 2010, page unknown).

It has also been highlighted that autistic adults in particular (in comparison to children) and their lived experiences have been a neglected group within research (Milton and Bracher, 2013; Milton, 2014; McWade, Milton and Beresford, 2015). Even in relation to consultation with autistic stakeholders, the body of research consulting with autistic children is more established than that relating to adults (Beresford et al., 2004; Kelly, 2005; Lewis, 2007; Humphrey and Lewis, 2008; Parsons et al., 2009; Moyse and Porter, 2015), providing

useful lessons that can be adapted for use in adult contexts. For example, in their Australian-based research on the experiences of autistic children in mainstream school, Harrington et al. (2014) found that assumptions about autistic behaviour or capacity could be restrictive and undermine the research process. This is a useful caution for researchers, which chimes with the arguments made by autistic researchers that research which makes assumptions about the autistic experience can wrongly presume shared understandings, leading to misinterpretations and flawed research findings (Nicolaidis et al., 2011; Milton and Bracher, 2013). The authors also found that, by employing a flexible approach and using multiple interviews to give their participants time and space to feel comfortable, the participation of the young people involved was much greater than either they or the parents/teachers had anticipated. Given an approach that took account of their individual styles, participants surpassed expectations and the research provided valuable findings, not least on ways to successfully consult with autistic individuals. Similar findings were described by Beresford et al. (2004) in their participatory study with autistic children. Authors also highlighted the extra time, resources and flexible approach required to enable meaningful participation to take place (Harrington et al., 2014). Beresford et al. (2004) reflected that the fieldwork seemed to end before its potential had been fully realized. These are important considerations in an under-funded, pressurised research climate which often demands short deadlines and quick outputs.

Within the US, a collaborative research partnership formed of autistic people, family members, academics and practitioners has been successful in undertaking community-based participatory research. Nicolaidis et al. (2011)



employed a methodology specifically geared to the needs of autistic participants. This was an Internet-based study, and amongst its benefits was the unexpected finding that, in employing a mode of communication that some non-autistic researchers found challenging, the balance of power was in certain ways upset. On the one hand, autistic researchers were required to support non-autistic researchers in developing appropriate skills; on the other, non-autistic researchers felt more empathy with the experience of communication in a non-preferred mode. McWade, Milton and Beresford (2015) talked of the need for autistic (termed in this paper as neurodiverse) people to affirm a positive identity, reclaiming 'impairment' in the same way that 'disability' has been reclaimed by disabled activists. The study noted above by Nicolaidis et al. (2011) is one example of how participatory approaches can enable this to happen.

Within the dialogue about autistic people as active participants and indeed activists and self-advocates, it is notable that the Internet features heavily. Singer first alluded to its potential power in her seminal article on neurodiversity (1999) and Sinclair and Ne'eman described its influence over the development of Autism Network International (Sinclair, 2005; Ne'eman, 2010). The study by Nicolaidis et al. (2011) used the Internet to conduct an international study, and indeed the research team themselves were geographically dispersed, thus the research study relied on the Internet in the most fundamental ways. The authors liken its influence to that of sign language for the deaf communities, noting that it can "equalize communication." (p. 147) Milton and Moon's (2012) autistic-led study in the UK also described an Internet learning group.

### *2.5.1 Concluding comments on the voice of research participants*

Within both the UK and the US, research led by autistic people is characterised by the fact that it is dominated by the few, attempting to represent the whole. They are predominantly the voices of a certain sub-set, from a specific class and educational background, as noted by Nicolaidis et al. (2013) in relation to their study of healthcare experiences of autistic adults. That it not to say that these voices have no validity; indeed they do and have an important role to play in bringing some balance to academic debates around the autistic experience. However, they also highlight the need to bring more voices to the debate, representing a greater range of autistic people, and the responsibility of academia in helping this to happen.

### 2.6 Summary of the literature in relation to the thesis

Considering the literature in relation to my thesis, some key points emerge. The first, and perhaps most important of these, is the place of autism and autistic individuals within larger debates about disability and difference. Across the literature, with regard to outcome generally, it is noted that the situation for autistic individuals is generally poorer than for other, similar groups, and IQ measurements are not a reliable indicator of outcome in this respect. This disadvantage is compounded by the higher education context itself, which lags behind other sectors in relation to disability awareness, and tends to place the onus for seeking and offering adjustments onto individual students and staff rather than onto the institution itself. Autistic students within higher education are commonly pioneers, educating those around them about their own needs

and about autism. Due to the later age of diagnosis associated with Asperger syndrome (AS) and high-functioning autism (HFA), they may be more likely to be doing this alongside coming to terms with their diagnosis. Thus, autistic students are liable to experience significant pressures in addition to those directly linked to their studies, which they must withstand if they are to succeed within higher education.

The other key point arising here is the need to recognise what we still do not know. Autism itself is a relatively recent, and ever-changing, diagnostic category. The current evidence base has largely depended on non-autistic interpretations of autistic behaviours, which have been increasingly brought into question by a growing body of evidence from 'insider' accounts. The volume of research that focuses upon autistic adults remains relatively slight, often based on samples with a negative bias, and depending on third-hand reports. Exploration of success is an aspect of the autistic experience that has been almost entirely neglected.

This study seeks to address an important gap in our understandings, by exploring how autistic individuals define and understand their successes, using their own interpretations and incorporating their own analysis. It is useful to re-state the research questions here:

1. How do autistic adults, defined by some objective measure as successful, define their own successes?
2. How do they make sense of these successes in relation to the 'Asperger/autism' identifier?

3. In what ways does a participatory approach help or hinder our understanding of autistic and non-autistic interpretations, to achieve a shared understanding of a given phenomena?

In the next chapter, I will consider in detail how I attempted to address these questions.

## **CHAPTER 3**

### **THE CASE FOR INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS (IPA) AND A PARTICIPATORY APPROACH**

#### **3.1 Introduction**

This research sought to explore the ways in which autistic adults made sense of their achievements in the context of the label they have been given. As noted in chapter two, this is in contrast to the autism research agenda in the UK, which continues to be dominated by research into children with autism, largely taking a traditional positivist and cognitive approach, whereby research participants are passive subjects and the research agenda is led by non-autistic theorists (Pellicano, Dinsmore and Charman, 2013; Parsons, 2014). Autistic researchers, in common with other disabled groups, have taken issue with this stance and the limitations imposed by it (Dawson, 2004; Milton, 2014). In this chapter I will discuss in detail my rationale for choosing Interpretative Phenomenological Analysis (IPA) as my research approach, combined with participatory methods, illustrating with reference to relevant literature how these combine to best suit my research aims.

#### **3.2 The autistic experience**

As we have already considered in chapter two, there are powerful arguments in favour of ensuring that the autistic voice and perspective have a greater prominence within research which seeks to represent autism. A qualitative

methodology was deemed most appropriate to meet this study's aim to explore the experiences of autistic individuals as directly and authentically as possible, recognising the synergy of person and society as co-constructors of their reality (Darlaston-Jones, 2007). Since autistic individuals can experience multiple social challenges, the person/society dynamic may often seem more antagonistic than synergic and all the more need, therefore, to explore and seek to understand when and how synergy is achieved. In my aim of undertaking an in-depth exploration of the phenomenon of success, in which participants would be viewed as the experts of their own experiences, I regarded interpretative phenomenological analysis (IPA) to be the most well-suited approach (Smith, 2004).

### 3.3 "*Back to the things themselves!*": Making the Case for an IPA Stance

(Husserl, cited in Smith, Flowers and Larkin, 2009, p. 12)

Interpretative Phenomenological Analysis (IPA) as an approach is still in its relative infancy. It was first articulated by Smith in the 1990s as a means of offering a qualitative approach that was focused on personal experience and firmly embedded within psychology (Smith, 1996). Smith "argued for an approach to psychology which was able to capture the experiential and qualitative, and which could still dialogue with mainstream psychology." (Smith, Flowers and Larkin, 2009, p. 4). IPA is influenced by symbolic interactionism and is concerned with the ways that meanings are constructed both socially and personally (Smith and Osborn, 2008).

Early work tended to focus on health psychology, reflecting the interests of its pioneers. The approach is idiographic, concerned with the particular and thus focusing in-depth on a small number of cases, or even a single case. Smith, Flowers and Larkin (2009) argued against nomothetic approaches, which typically deal with large samples and seek to identify generalised trueisms, at the expense of the individual experience. In contrast, idiographic approaches, by undertaking a more indepth exploration of a phenomenon at an individual level, can reveal new insights and identify flaws in existing theory:

Thus in some ways the details of the individual also brings us closer to significant aspects of the general. (p.32)

Therefore a successful IPA study, through a detailed exploration of the specific, may identify universals that are novel and bring new knowledge and understandings to the field.

Phenomenology, developed by Husserl, concerns itself with retaining focus on the phenomenon in question, based on the notion of 'intentionality'; that humans impose meaning on all they experience, whether they consciously intend to or not. Heidegger interrogated this further, questioning whether we simply perceive a thing or in fact reflect upon the act of perceiving as we do so: 'this is me perceiving a thing'. Heidegger (1962) proposed that the human experience was unavoidably situated in context. The human being's experience is of its time and place. It is temporal, relative and interpretative (Smith, Flowers and Larkin, 2009), and this intersubjectivity refers not only to the situating of the individual's experience, but also acknowledges the role played by the

researcher in interpreting through their own experience, past and present (influenced by the current researcher/participant interaction).

Heidegger's approach (following the work of Husserl but diverging from it in some aspects) followed a hermeneutic principle, concerned with bringing out meanings which may be hidden. The researcher, as well as the research participants, are viewed as active agents in this process. Not only is the research participant interpreting their experience as they describe it, influenced by many factors as they do so, but the researcher then makes their own interpretation, which is in turn coloured by *their* influences. Here, Heidegger departed from Husserl, who proposed a conscious attempt towards objectivity, or in practice, a process of bracketing one's knowledge and presuppositions. For Heidegger, this was never fully achievable, and instead the preconceptions of the researcher should be acknowledged and transparent as a valuable part of the process. Indeed, this is arguably merely a more authentic and transparent version of what all researchers bring to their work.

Smith, Flowers and Larkin (2009) talked of a hermeneutic circle, whereby the researcher attends closely to the participant and their words during the research phase, and in this way is a "return to the thing themselves" (Smith and Osborn, 2008, p. 11) as Husserl counselled, investigating the ways in which the individual is constructing meaning from their experience of the phenomenon in question. Smith (1996) acknowledged the limitations inherent in trying to fully understand the inner world of another, since the researcher's conceptions both colour and complicate the "process of interpretative activity." (p. 264) Nevertheless, with this caveat, the researcher aims initially to "get as 'close' to



the participant's views as is possible" (Larkin, Watts and Clifton, 2006, p. 104), and re-introduces their own ideas and reflections later in the reflexive process. In this way, IPA employs a 'double hermeneutic' (Smith and Osborn, 2008), as the participant actively interprets their experience through their account of it, and the researcher in turn interprets through their analysis. This aspect of IPA, heavily influenced by Heidegger, moves the researcher away from *bracketing* to a more reflexive position, in which potential biases are acknowledged.

The research process is therefore an active and dynamic interaction, and may lead to the revelation of hidden meanings. Smith and Osborn (2008) described this as:

Is something leaking out here that wasn't intended? (p. 53)

This question highlights the imperative for IPA to go beyond the merely descriptive, and in keeping with its debt to symbolic interaction, engage in a level of interpretative analysis that considers the language used by participants at a more conceptual level. Heidegger viewed language as "the house of Being", the instrument through which our experiences are shaped, limited and enabled, both consciously and unconsciously (Smith, Flowers and Larkin, 2009, p. 194). Moreover, the authors proposed that IPA offers a combined hermeneutics of empathy with a hermeneutics of questioning, whereby the researcher attempts both to understand the 'insider' perspective and illuminate it from an external position, through making connections with the extant literature. This return to the mainstream literature and theory is a critical part of

the IPA process, in order to both connect and deconstruct, according to the data that presents itself (Smith, 2011a):

IPA's concern with the links between talk, thought and experience (or behaviour) mean that there is a focus on the 'wholeness' of the individuals' experiences as opposed to focusing on the separate parts of the phenomenon under investigation. (Dickson, Knussen and Flowers, 2008, p. 461)

This holistic approach, focusing on the integrated self, seems appropriate in exploring the experience of individuals labelled with autism, whereby sense-making may require accommodating (or rejecting) an externally-imposed identity or aspect thereof. The IPA approach encourages exploration not just of the individual experience, but also how this is contextualised by history, society, and dominant cultural forces (Lopez and Willis, 2004). Larkin, Watts and Clifton (2006) suggested that:

The analyst in IPA is doing more than this [descriptive account]; he or she is also offering an interpretative account of what it *means* for the participant to have such concerns, within their particular context. (p. 113)

This would seem very relevant to the context of autistic individuals, whose impairments are in some senses defined by their social context and their lifeworld. Crucially, the impact of this is largely assessed and measured from the outside, in terms of the ways in which behaviours influence the environment, rather than from the inside, in terms of the ways in which the environment affects the individual. Access to 'insider interpretations' of this

phenomenon are currently lacking within the research, and IPA has the potential to expose these, and in doing so, bring forth new understandings.

### 3.4 Participatory and emancipatory paradigms

Having considered above in earlier chapters the potential weaknesses of a research landscape that does not incorporate the autistic perspective, I hope I have established the case for employing a participatory approach in this study. In this section, I will first offer a brief critique of participatory and emancipatory approaches and their use generally within disability studies research, before considering how they have been used to date within autism research.

Participatory, and in particular emancipatory approaches, have been developed with the intention of equalising the balance of power between disabled and non-disabled people, whereby disability research is viewed as “...part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives.” (Oliver, 1992, p. 102).

It has been a response to research that has traditionally objectified disabled participants, leading them to view it as a personal violation and irrelevance (Oliver, 1992). In contrast, participatory approaches and emancipatory approaches have been regarded as a transformative experience (Danieli and Woodhams, 2005; Nind, 2011). Kitchin (2000) interviewed disabled people about their experience of research, and found concerns that research was both unrepresentative and misrepresentative. However, he questioned whether an emancipatory model necessarily addressed this, since “...not all disabled

academics adopt a critical, emancipatory position or all disabled people agree with disabled academics.” (p. 39). Danieli and Woodhams (2005) further critiqued the demand for all disability research to be emancipatory, arguing that it runs the risk of carrying its own bias, whereby results are sought that support a social model approach, and participants who do not subscribe to such views are marginalised.

There is some evidence that disabled participants, whilst wanting an active role in research that is relevant to their lives, do not necessarily want to invest the time and energy required by emancipatory approaches (or have it available). Only a minority of Kitchin’s sample (2000) felt they had the time to be research partners and some welcomed non-disabled researchers, feeling they may be more impartial. Bourke (2009), reflecting on participatory research, cited case studies in which participants did not take up all the options available to be active within the research processes. She questioned whether the participatory elements reflected the priorities of the participants or the researchers, highlighting that “...participants did not always advocate the principle ‘the more participatory the better’.” (p. 466)

In consideration of adults with learning difficulties, Walmsley (2001) highlighted their need for supportive allies, and also their diversity as a group (which of course applies equally to disabled people in general and to autistic people), concluding that “...who should undertake research is a question which needs a more complex answer than ‘disabled people’.” (p. 199). Also reflecting on how participatory approaches have been used with people with learning difficulties, Chappell (2000) highlighted that as this group remained excluded from

academia, participatory research was in effect the only option available to them if they were to be involved at all.

In their discussion on the role of non-disabled researchers within disability research, Stone and Priestley (1996) noted that for disability studies to be taken seriously, the academic demands need to be met alongside the emancipatory goals. However, Danieli and Woodhams (2005) have cautioned that emancipatory research should not be seen as obligatory, or it risks becoming in itself “an exercise of power” (p. 293), and restricted to its own advocates, thus “a self-fulfilling prophecy” (p. 292) in which non-conforming research is circulated only to non-disabled communities, thus excluding disabled groups from the bulk of research findings.

Participatory research thus tends to be viewed as a pragmatic compromise (Chappell, 2000), following a more pluralist approach that is able to heed the complexities of the experience of disability, and intersectionalities inherent within it (Danieli and Woodhams, 2005). Participatory approaches nevertheless require time, not just from participants, but also from researchers, in making participation accessible and processes meaningful (Kitchin, 2000; Bourke, 2009; Nind, 2011). They also require acknowledgement of the ethical implications, such as the impact of entering someone’s life for the period of the research, potentially “reinforcing inequality by passing through and passing on.” (Porter, Parsons and Robertson, 2006, p. 14).

A survey of disabled people’s organisations found that there was a continuing need for researchers to have a greater knowledge of disability equality issues, and called for greater collaboration between researchers and “civil actors” to

shape research agendas (Priestley, Waddington and Bessozi, 2010, p. 732), whilst Castrodale and Crooks (2010) found that community dissemination was given low priority, reflecting the different priorities of institutions and funding bodies. Findings such as these have been echoed in the autism field, for example by Milton, Mills and Pellicano (2014), who critiqued care guidelines reported in a leading international autism journal (Post et al., 2013). Purportedly developed to inform ethical and social issues in relation to autistic people, their families and professionals, the US-based guidelines followed a deficit interpretation and did not incorporate autistic perspectives, indicating that despite the growth of self-advocacy and the efforts of autistic activists, traditional approaches following a medicalised model and excluding autistic stakeholders were still deemed worthy of space within research publications. Evidently there remains a mismatch between the presumed intention of disability research, to improve the lives of disabled people, and their access to its processes and findings.

### 3.5 The use of IPA with autistic participants

IPA was initially developed for use within the health sciences. However, the approach has increasingly been used more broadly, including within education and disability studies. IPA's conscious intention to foreground participant experience clearly makes it eminently suitable for research which seeks to employ a participatory approach, and here I will consider the ways in which it has been used with autistic adults in particular.

A database search, cross-checked with google scholar, revealed a total of nine articles in which IPA had been used with autistic adults or adolescents as participants. Of these, seven were UK-based, one from the Netherlands and one from Australia. Sample sizes tended to be larger in the UK studies, using between nine and twelve participants, and three articles related to the same study (Huws and Jones, 2008; Jones, Huws and Beck, 2013; Huws and Jones, 2015). The Netherlands study used a more typical sample with just three case studies, combined with an extensive review of the literature.

In the Huws and Jones studies, students at a specialist college (aged sixteen to twenty-one) were interviewed about the ways in which they made sense of their diagnosis of autism. There were three simple questions:

1. What is autism?
2. What does autism mean to you?
3. If you were asked to explain your autism to someone else who has never heard of it, what would you say?

Interviews were conducted individually and the authors described several ways in which they sought to accommodate potential needs. In addition to the usual information and consent processes, the authors provided participants with a written outline of questions in advance of the meeting. They asked each participant to identify a trusted person within the college who could be contacted in case the interview caused distress, and they were de-briefed following the interview. In one case (Jones, Huws and Beck, 2013) an older autistic adult was involved in the analytic process. He highlighted that certain

interpretations could be attributed to the developmental stage of the participants, just moving out of adolescence, rather than the experience of autism per se. The authors regarded this additional analysis to be of such value that the contributor became third author, and they recommended that future studies should involve a panel of autistic contributors at all stages of the research. In the other two studies, interpretations were checked with participants during data collection but not afterwards. The authors did not cite any difficulties either with the processes or with the data collected, in relation to social or communication difficulties associated with autism. No-one withdrew from the study and no reports of distress were conveyed to the researcher.

Punshon et al. (2009) interviewed ten individuals on their reactions to receiving a diagnosis of autism as adults. The authors highlighted the significance of receiving this diagnosis in adulthood, in that on the one hand, they may for the first time have had insight into difficulties that had been lifelong, whilst on the other, they needed to come to terms with a diagnosis for which there was currently no 'cure' or 'prognosis'. In tackling the experience of adult diagnosis, they touched upon an area with very little research. Of eleven individuals asked to participate, ten agreed and none withdrew. All were currently in receipt of some form of support. Themes were checked with participants and research methods followed the standard format recommended in IPA studies. The experiences described by participants were in line with other studies, although novel data included the experience of some that autism had been suspected in childhood, but had either been resisted by the individual's family, or the clinician involved at the time had not felt qualified to give a diagnosis. The experience of



misdiagnosis, or general lack of understanding from support services, was common. There was also evidence of individuals internalizing negative messages about themselves, in the absence of another explanation of their difficulties:

I thought of myself as weird and strange and...just odd...I used to beat myself up a lot about the things that...I failed to do. (p. 276)

In light of this, the authors described formal diagnosis as 'exonerating' individuals, and in some cases, enabling them to identify positive aspects of their condition. The authors found that this study largely supported the small amount of existing research in this area, but also, that in consideration of their mixed (positive as well as negative) reactions to diagnosis, bereavement or trauma models were inappropriate for supporting them in coming to terms with their condition. They also highlighted the finding that awareness of difference impacted hugely on participants through their development to adulthood, concluding:

...one of the strong messages from this research is that diagnosis, for the individual with Asperger syndrome at least, should be considered not as a single event but as a process that may span months, if not years. (p. 281)

The authors did not highlight any difficulties for the participants in contributing to the research, and presented rich and full data to support their assertions. The research contributes to our understandings of a crucial area and makes some very practical recommendations for practice.

Griffith et al.'s (2011) study on the support experiences and needs of autistic adults was unusual in its focus upon adults on the autism spectrum in middle adulthood; aged over thirty-five. Four main themes emerged from the data: living with Asperger syndrome; employment issues; experiences with mainstream support; and future steps towards supporting adults with Asperger syndrome. These themes in themselves are not surprising given the research focus, but the research did identify some novel and useful points.

Firstly, and in common with other qualitative accounts of this type, although participants described disadvantage that they experienced and attributed to autism, they also highlighted positive aspects; in particular, a freedom from social expectations or limitations:

I've never had a box, I don't even know what a box is, I've always thought outside the box. (p. 538)

A critical finding in relation to the support offered to adults was the experience by some that failure to diagnose earlier became a justification for not diagnosing now. Participants also described frustration at their own powerlessness in the dominant autism discourses. Eleven adults were interviewed for this study, and were given the choice of face-to-face or telephone interview (five chose to have a telephone interview). Participants were provided with a general outline of topics to be covered within the

interview, but otherwise the authors did not describe any particular accommodations, or issues arising from the research process.

Two studies focused on adolescent participants. Humphrey and Lewis (2008) consulted with twenty secondary aged (11-17) children using interviews, diaries and drawings, in order to explore how the students made sense of their educational experiences as students with autism. The authors described a “*transformative framework*” (p. 26) aiming to confront inequities, in which participants were active consultants from the outset and at every stage, including validating the researchers’ interpretations. The analysis was formulated into a network of six themes, and revealed the way that difference was perceived by students, often negatively and as a result of the label, rather than arising from any recognised difference as such. However, more positive accounts also surfaced, as for some students, autism was an accepted, even celebrated aspect of themselves. Some students described experiences of both, highlighting the ambiguity of their position. In these accounts, the role of peers was seen to be more influential than the role of teachers, a key finding for future research and practice developments regarding inclusion, which often focus on the teacher:student interaction. The students in this study articulated an experience of feeling different, whilst also the same, as their peers, and continuously trying to adapt accordingly. The authors concluded:

What has become known as the 'dilemma of difference' is neatly summarised by Dyson: 'The more educational responses emphasize what learners have in common, the more they tend to overlook what

separates them; the more they emphasize what separates them and distinguishes each learner, the more they tend to overlook what learners have in common. (p. 41)

The authors suggest that the general differences position proposed by Norwich and Lewis (2005) provides a useful conceptual framework for taking account of the needs common to all; specific to the group (eg. autism); and unique to the individual. In this way, specific needs can be recognised and addressed without undermining those that the group share, or indeed those that are specific to each individual.

The Petalas et al. (2015) study involved twelve adolescents on the autism spectrum, aged 12-15 years, and focused on their experience of sibling relationships. This research was unique in focusing entirely on the perspective of the autistic sibling. Two major themes emerged, namely the seemingly typical sibling interactions and the interactions influenced by autism. Participant accounts described more typical sibling relationships than other research in this area which has focused on the non-autistic sibling and/or parent perspective. Interviews were conducted by telephone and participants were encouraged to give feedback at the end about the process. All were positive and no-one withdrew or terminated the interview. Authors noted that in describing the (mainly negative) effects of autism, participants were responding to prompts, so possibly these prompts served to remind or reinforce feelings of difference. The authors argued for a move away from absolute dichotomies towards a more

nuanced and balanced perspective, and also away from interventions that focus on difference:

This new understanding of the experiences of adolescents with an ASD calls for a different value system, opposing the prominence placed on diagnosis or handicap, which may be inadvertently denying adolescents access to typical experiences. (p.48)

This study provided a crucial new interpretation of the experiences of families; one in which sibling relations were not necessarily disrupted by one family member having autism, and one in which the sibling with autism was an active and positive family member.

Two papers employing an IPA approach were less successful in their aims. Newman et al.'s (2010) Australian paper did not specify an IPA approach but was notable, in that it considered ways in which a hermeneutic, phenomenological approach might be adapted for use with autistic participants. The authors referred to IPA and studies using this approach, without engaging with it in any depth. They considered some of the dominant theories associated with autism and framed their discussion around generalisations based on these. For instance, they stated that:

Individuals with autism have an inability to form a unified centrally coherent base of knowledge about the world through constructionist learning... (p. 266)

The most striking assumption made was that individuals with autism respond best to visual information. Although this would seem to be true of some people, there is now evidence from first-hand accounts that it is not the case for all (Williams, 2006) and the authors based their research approach on generalised presumptions such as this. However, they did not report on the research itself, how the approach worked in practice and there have been no further publications arising from this work. Overall, the paper is problematic in its tendency to cherry-pick from the autism literature in a way that seems to be selective. They claimed that:

Individuals with autism will be less able to express through language their interpretation of an experience, as this would require a level of abstraction ability. (p. 269)

This statement would seem to be at odds with a core principle of hermeneutic phenomenology, that the individual's lived experience, and their own interpretation of that experience, is 'the thing itself'. Discussion of an "abstraction ability" suggests a level of attempted objectivity that is not relevant in this case. Moreover, there is increasing evidence, both within the literature and online in forums and blogs, that people with autism are often able to articulate their experience, and indeed interpret it for the benefit of a neurotypical audience. Many of the studies cited above offer such evidence. Therefore, even if this consideration were valid to the philosophy of IPA, it would not be valid, in the simplistic and universal way it has been expressed, to

“individuals with autism”. Whilst it is undoubtedly true that individuals with autism share the common experience of processing some information differently, and in some cases therefore benefit from adaptations, what remains unproven is the case for any single method, or indeed generalisation, applying to all, which seemed to be argued in this paper.

Williams (2009) offered a different type of study in that the author analysed existing data using ten published autobiographies. Four themes concerned with human interactions were presented: distance between self and others; inaccessibility of social/emotional cues; coping strategies and limited success of coping strategies. This was a very different methodology in that participants were not active in the process, did not give their consent, and were not provided with the opportunity for a dialogue with the researcher. Moreover, the researcher seemed to come to the research with a fixed notion of her focus, and in all senses, the data was more ‘fixed’ than would usually be the case for an IPA study. These last two papers departed from the core philosophies of IPA as an approach which recognises both the dynamic, mutual influence of the researcher: participant relationship and the ‘situatedness’ of the participant account. They were therefore less successful in their efforts to offer new insights to the field.

In contrast, the other studies revealed much that is novel, often venturing into areas that have been neglected by other research studies, perhaps because these topics do not lend themselves to the more traditional, positivist paradigms that are dominant within the field (Smith, 1996). What these accounts had in

common was their uncovering of a more complex, nuanced account of the autistic experience. The insider perspective here moved away from the traditional deficit interpretations, highlighting the positive aspects that some individuals experienced, whilst still recognising the social disadvantage they faced. The insecurity of the autism identity was exposed. In their findings, they reflected on their data in the light of broader theoretical understandings as well as the wider context, making well-grounded recommendations for practice and highlighting the need for greater user involvement within autism research, through both their data and the efficacy of their methods.

### 3.6 IPA and sample size

As described above, IPA foregrounds the individual experience and therefore involves very in-depth analysis of the data at the level of the phenomenon itself, abstraction to the level of theme, and also incorporating a level of linguistic analysis in order to interrogate the symbolic level. A small sample size of around six has generally been favoured, and in fact Smith has encouraged consideration of a single sample (Smith, Flowers and Larkin, 2009).

Within the context of IPA, this study utilises a relatively large sample of sixteen participants, for several reasons outlined briefly below. Since the study relies entirely on interview data, it was crucial that enough data be collected, of sufficient depth and quality, to enable a rigorous analysis to be undertaken. In any research project, a level of dropout is to be anticipated (Robson, 2002). Given the relatively intense participation demanded by this research, recruitment was planned to accommodate some dropout, without compromising



the final sample. In fact, not one participant withdrew following the initial consent stage, and all of the data were sufficiently rich to contribute to the final sample. It was therefore deemed most appropriate to work with the complete dataset of sixteen in order to do justice to the contributions.

There are some potential benefits of a larger sample, identified through the process described here. Firstly, in foregrounding the participant experience, it is necessary to provide many illustrative quotes. A larger sample provides a greater wealth of examples so that analysis and data are closely linked without need for repetition. Secondly, although small-scale research such as this is not generalizable and not intended to be so, it is hoped that through focusing on the particular, common threads can be identified that establish something novel about the phenomena in question (Smith, Flowers and Larkin, 2009). In the case of this research, the combination of a narrow focus regarding the phenomena under investigation (the experience of success for autistic individuals) with a relatively large qualitative sample has enabled the emergence of commonalities with a more robust evidence base than would otherwise have been possible.

Smith (2011b) critically reviewed all IPA papers published between 1996-2008 in order to assess the ways in which the approach was being used and identify some broad guidelines for good practice. There were 293 papers in all, the majority of which originated in the UK, where IPA was first developed. In his review, Smith suggested that a sample of over eight participants is a large sample for IPA research. Giving seven examples of large IPA studies that he considered to be strong (with sample sizes of between nine and fourteen

participants), he considered in detail how larger samples best did justice to the data, and concluded that in order to ground the analysis sufficiently in the data, each theme should be represented by a minimum of three participants, or at least half the sample. Prevalence of each theme should also be transparent to the reader. Smith highlighted the importance of retaining a clear focus throughout and ensuring that the analysis is sufficiently nuanced to capture more than a purely descriptive account. In my research I have attempted to follow these guidelines, as I will describe in more detail in the next chapter.

### 3.7 Summary of the research approach

Within IPA analysis there is an emphasis on the language used and the meanings, conscious and subconscious, that it may hold for the individual. It may therefore seem a surprising choice of approach to use with individuals who are, by definition, categorised as experiencing *'impairments'* in their social communication. Nevertheless, the studies above have demonstrated that the approach has been successful in obtaining rich and eloquent data from autistic participants. IPA's exploration of the hermeneutics of empathy may also seem contentious, if autistic and non-autistic perceptions are qualitatively different. Through a dialogic approach, I have aimed to give attention to this in order to identify and directly address differences in perceptions and interpretations.

In its emphasis on the individual and 'insider' perspective and how this is situated, politically and socially, it seems a suitable approach for research that aims to understand both the internal experience of autistic individuals and the

ways that this may be influenced by their interactions and environment, and is a natural fit with participatory methodologies. IPA is a research approach that has emerged within the last twenty years, and as such, it continues to develop. IPA researchers have proposed that as part of its maturity, it may be valuable for the personal experience to be more explicitly situated within its socio-cultural context (Smith, 2011b; Todorova, 2011). This would seem to be all the more relevant in the case of a focus such as autism, which is in many ways a socially constructed and culturally determined disability.

The studies described here made some practical accommodations in order to facilitate participation for autistic adults, but were limited in their consideration of this aspect within the articles. This was probably due to constraints of space and the fact that in all cases, autistic participants remained engaged in the research process, with no procedural issues apparent. Nevertheless, given the social anxieties that can pervade the autistic experience, further exploration of procedural aspects would seem worthwhile. The next chapter will consider in detail the ways in which I sought to make the research process accessible on a practical level, as well as endeavouring to interpret and represent participant data in the most authentic way possible.

## **CHAPTER FOUR**

### **METHODOLOGY**

#### 4.1 Introduction

This chapter will describe how the research design endeavoured to be faithful to the philosophies of both interpretative phenomenological analysis (IPA) and participatory research; firstly by ensuring the primacy of the participant's interpretation of their experience (Smith, 1996); secondly by recognising them as an active stakeholder in the production of knowledge through research (Chappell, 2000); and thirdly by holding myself accountable and open to scrutiny as researcher (Stone and Priestley, 1996) in all stages of the process.

##### *4.2.1 Research aims*

This research study aimed to explore the ways in which autistic adults made sense of their achievements. It sought to identify individuals outwardly deemed to be 'successful' by one particular measure, that of formal education, explore their own perspectives of their successes and identify in which ways (if any) they associated these with autism. Data collection tools were entitled: 'Perceptions of Successful Adults Diagnosed on the Autism Spectrum' in a conscious effort to instil in participants' minds that they were objectively deemed to be successful and that this was the focus of the research. In this way, I deliberately attempted to influence the emphasis of the interview data.

At a pragmatic level, the decision to involve students within higher education as participants related to the difficulty recruiting novel research participants, i.e. in my quest to recruit individuals who do not currently have a 'voice' within the autism community. Within the autistic population there are communities who, for a variety of reasons, have heightened awareness of themselves as autistic. This may be because they live in specialist accommodation and are supported by staff who view themselves as specialists. In these contexts the 'autistic-friendly' culture of the organisation will pervade, and both staff and residents are likely to have contact with autism networks of various kinds. Individuals may be active within the autistic communities that exist through online forums, the autistic conference *Autreat*, or the newsletter *Asperger United*. Through these networks and by virtue of being 'in the system' (of formal support), these individuals are the most accessible within the autistic population and therefore the most likely to be involved in research. The same is sometimes true of those individuals receiving informal support from parents and family members. Due to the struggles faced by informal carers and the current role of the voluntary sector within the UK, these families may well be tapping into similar/overlapping support networks. It remains very difficult to make contact with autistic adults outside of these networks, since data are not yet consistently collected through statutory bodies (National Audit Office, 2009). Higher education is one sector where data are kept on those students who disclose autism, and 'autistic spectrum disorder' has been a distinct category on the Universities and Colleges Admissions Service (UCAS) form since 2004 (MacLeod and Green, 2009). By approaching participants via their involvement in higher education

rather than their associations with the 'autism world', it was hoped that I would access, in part at least, some novel voices that would not otherwise be heard.

As I have already demonstrated, accessing 'user voice' is not simply an ethically desirable activity; it furthers research with important knowledge and insight that non-disabled 'professional intellectuals' (such as myself in this case) do not otherwise have (Dyson, 1998). It also develops users' understanding of the underlying processes and aims of research, potentially aiding them to 'crossover' into academia (Chappell, 2000). The methodology sought to render the research transparent and meaningful to participants and enable them to retain agency throughout the process.

#### 4.2.2 *Pilot work*

The current study follows on from a pilot project undertaken in 2008. This was a participatory project to develop an online portal (*the AS Portal*) for autistic students within one higher education institution. The project included face-to-face interviews with six autistic undergraduate and postgraduate students (see MacLeod, 2010, for a full account of this project). The pilot work indicated the need to further access a broader 'autistic voice' than is currently available via existing communication networks. The research design was also informed by feedback from this pilot phase, which aimed to identify and address accessibility issues specific to autistic individuals. Potential barriers to participation were identified as: anxieties concerning certain modes of communication (for instance face-to-face interviews); anxieties concerning the unpredictability of the interview process; time-management difficulties, affecting participants' ability to

remember appointments etc.; and social communication difficulties, causing participants to misinterpret questions or be misinterpreted by the researcher.

During the pilot phase it had become apparent that for these participants, there might be many reasons for non-response or non-attendance other than not wanting to be involved. For example, one pilot-participant reported that he found it difficult to manage his inbox and emails simply got lost. These circumstances could arise for any individual participating in research. However, for autistic respondents, there may be a higher likelihood of difficulties arising from the need to multi-task and self-organise (Martin et al., 2008). It might be expected that those individuals who succeed in accessing higher education will have fewer difficulties with these aspects of their lives and/or will have developed successful strategies for dealing with them. However, the literature indicates that this remains a significant problem for many (Madriaga and Goodley, 2009) so was regarded as an area worthy of attention.

In order to ensure such difficulties did not become barriers to participation, it was important to be rigorous in alerting participants to meetings and communications, to ensure that as far as possible, non-participation occurred through choice rather than circumstance. Developing from the pilot and feedback from its participants, several strategies were implemented, firstly to adapt the research approach in order to accommodate potential difficulties, and secondly to monitor the effectiveness of these adaptations. At every stage of communication there was a system of reminders. If any participant did not respond within a set time frame, eg. one week, then they would receive a reminder with their own name in the email subject heading:

'CHARLIE: PLEASE RESPOND!'

A total of three reminders was given, where needed, at each stage. At the end of the research, participants were asked whether they had found these reminders helpful. Such techniques could potentially be viewed as an intrusion or unwelcome pressure. However, participants reported that this had been helpful, since all were keen to see the project through but either became distracted or lost emails within the large amount of 'spam' they received.

#### *4.2.3 Means of participation*

As has been described, the autism spectrum describes a set of common characteristics but this is represented within individuals in vastly different ways (Happé, Ronald and Plomin, 2006). For this research, the intention was to avoid making generalised presumptions but rather to engage with individual preferences as far as possible. Three options for interview participation were offered: face-to-face; telephone; or synchronous ('real-time') online-interview, so that participants had a choice of format that hopefully included their preferred means of interaction. All have been used successfully within IPA research, with alternatives to face-to-face interview commonly being offered to respond to participant's needs (Murray and Rhodes, 2005; Reynolds and Lim, 2007). A synchronous online chat system was used, rather than (asynchronous) email, so that all formats used real time and in that sense, offered a similar interview dynamic. For face-to-face and telephone formats, interviews were digitally audiotaped and transcribed. The software saved a copy of the online chat automatically.



#### *4.2.4 Use of the 'Critical Incident Technique' (CIT)*

In keeping with IPA's intention to "elicit detailed stories, thoughts and feelings from the participant" (Smith, Flowers and Larkin, 2009, p.57) a semi-structured interview format was deemed most suitable for the research. A tool was developed, encompassing some set questions but also allowing space for the course of the interview to follow individual responses (see Appendix I). At this point, consideration was given to the particular needs that autistic participants may have in an interview situation. It is well documented that autistic individuals can experience extreme levels of anxiety particularly in novel situations (Lawson, 2001; Howlin, 2004), and I wanted to make the initial interview questions as clear and straightforward as possible. Flanagan's (1954) Critical Incident Technique (CIT) seemed to offer a useful template for this. His technique was first employed in aviation research as a means of collecting and recording data that was specific to a set criteria. It has since been found to be useful within health-related research (Schluter, Seaton and Chaboyer, 2008) as a tool to facilitate responses by triggering particular recollections, and is compatible with an inductive analytic process. Schluter, Seaton and Chaboyer (2008), in their description of its use within the field of nursing, propose that its usefulness is threefold:

First, participants' complete and rich descriptions of the situation or event to be explored; secondly, the specific actions of the person/s involved in the event to aid understanding of why certain decisions

were made; thirdly, the outcome of the event, to ascertain the effectiveness of the behaviour. (p. 107)

This seemed to offer a useful framework to initially trigger memories that were specific and factual, but also allow space for reflection and more in-depth description of context. Schluter, Seaton and Chaboyer (2008) suggest that in health research, the term 'significant event' may provide a more appropriate emphasis than 'critical incident' and this terminology was used for this research. To enable participants to prepare for the interview, a prompt sheet was sent out in advance (see Appendix II for full prompt sheet), providing a brief definition of what was intended by 'significant' and 'event' in this context. This opportunity for advance preparation has proved effective in other IPA studies with autistic participants, as highlighted above (Huws and Jones, 2008; Griffith et al., 2011). Participants were asked to think of four 'significant events'; ideally two academic and two non-academic, and provided with some broad examples. In this way, individuals were given a common frame of reference, had the opportunity to predict what would be expected of them during the interview and to prepare their initial responses. It was hoped that this would offer an accessible way of beginning the dialogues, which could then develop naturally from these starting points.

#### *4.2.5 Interview process*

The interview process was divided into two phases:

Phase One: Initial interview

Shortly after the prompt sheet was sent out, the initial interview took place in whichever format was preferred by the participant. Interview questions were framed around:

1. Initial 'settling-in' questions based on general information relating to higher education context; background of diagnosis; previous involvement in research.
2. Discussion of the participant's perception of their major successes and achievements.
3. How did these come about? What personal characteristics contributed to them?
4. What other factors contributed to them? People (champions)?

See Appendix I for interview template. Following this first interview, I undertook an initial analysis of the data and annotated the transcript. Participants were then sent a copy of their annotated interview transcript and a personalised email containing the following set information:

*'Please mark any notes that you either would like more clarification on, were particularly struck by, or disagreed with. We can discuss these in more depth when we next chat.*

*When we next chat, it would be good if we could discuss:*

- *Whether the transcript seems to you to reflect our discussion (and if not, in what ways);*
- *Anything you were particularly struck by, either in our discussion or in my notes;*
- *Anything you disagree with, would like clarification on or are unhappy about.*

*In the notes section I have also indicated with numbered points some questions arising from this initial analysis. I would like us to arrange a 2<sup>nd</sup> interview to discuss these points, which should be a bit shorter than last time.'*

The intention here was to offer explicit guidance on the feedback wanted, including an overt invitation to disagree or take issue with some aspects of the analysis. By making this explicit I hoped to encourage an open dialogue and minimise the risk of participants simply acquiescing and seeking to give the 'correct' or 'best' answers to questions. This has been identified as a general risk in research, and potentially a greater risk with autistic participants (Podsakoff et al., 2003; Lewis, 2007).

Numbered questions were included so that this second interview also had a kind of framework, albeit much less structured. Although it was hoped that participants would give feedback beyond the questions set by me, they had this structure to follow if they wished.

#### Phase Two: Follow-up interview

The purpose of the second interview was to discuss emerging themes with participants and compare notes on my analysis of the interview and their own. The intention was both to validate the analysis, and to explore areas of disagreement or misinterpretation. Additionally, it was hoped that in this phase, participants would identify whether there was data that I had neglected but that they perceived to be highly significant. This opportunity for a reflective dialogue would bring me back to their 'lifeworld' and protect the analysis from becoming wholly my own interpretation of the encounters.

Following the second interview, the same process of analysis and annotation took place, and an annotated transcript was once again sent to the participant for cross-checking. Participants were sent a personalised version of the email below:

*'As before, in the right hand column you will find notes indicating my initial analysis. I would be grateful if you could read the transcript and notes and let me know of anything that you either:*

- *would like more clarification on*
- *were particularly struck by*
- *agreed with*
- *disagreed with.*

*Regarding the research generally, I would be interested to know:*

- *any general comments you have about the experience of being involved*
- *whether you have been happy with the amount of contact.*

*What happens next?*

1. *Please send me your response and let me know if you would like to discuss this in more detail. (We don't need to do this unless there is something in particular that concerns you).*
2. *Once I have your response (and we have had a discussion if needed), your participation will be complete. I will then send you my theory doc so that you can read about the aims of the research if you wish. I would also value your perspective on how well the research method seemed to you to meet the stated aims, and on the general relevance of the stated aims.*
3. *I would like to report on this work in academic journals and I will send you drafts to comment on so that you are fully aware of the reports and can opt to receive named credit.*

*Once again, thank you very much for being involved in this research.'*

Participants therefore had another opportunity to feed into the analytic process and were also further encouraged to reflect on the research process as a whole and on their experience of it.

#### *4.2.6 Evaluation of the research process*

Following each interview, participants were asked to complete a brief evaluation form (Appendix III). It was made clear that the purpose of this was to evaluate the process itself. Participants were encouraged to be honest and critical. In order to keep this as simple as possible (Robson, 2002), questions were multiple-choice, using a four-point Likert scale of agreement: 'definitely'; 'yes'; 'no'; 'definitely not' (Thomas, 2009). Each question allowed space for further information to be provided, with a directed open question, eg. 'If you answered no, why not?'. The aim here was to elicit specific information in relation to negative experiences. Participants were asked to rate the clarity of questions set; interview environment and format; aspects of the process that were most and least liked; and further reflections now that the process was over.

On receipt of feedback from the second (final) interview, participants were sent a document detailing the underlying theory of the research. (Participants had been provided with brief initial information on this at the recruitment stage). They were advised that they need not read all or any of the document, but that the researcher welcomed comments. Participants therefore had the opportunity to engage with the research on a deeper theoretical level, and another opportunity to identify potential inconsistencies between the researcher's interpretations and their own, furthering their input into the analytical stage of the research. Identification of potential differences in interpretation between non-autistic researcher and autistic participants was central to the research and the researcher undertook to acknowledge and report all such differences. Subsequently, academic papers have been published on aspects of the research (MacLeod, Lewis and Robertson, 2013; MacLeod, Lewis and

Robertson, 2014) and drafts sent to participants for comment. To ensure the continued representation of participants' voices, comments have been incorporated into final published drafts, and participants invited to receive named credit if they would prefer this to anonymity. (Although participants did or did not give consent for named credit at the outset, this has been revisited with every publication and acknowledgements adapted accordingly).

#### *4.2.7 Recruitment*

Participants were selected who met the following criteria:

- Higher education student aged over eighteen
- Known to have received a formal diagnosis of Asperger syndrome or autism (Student Support Services request evidence of diagnosis as a matter of course)
- Willing to be involved in qualitative research and be interviewed on two separate occasions.

This criteria offered a purposive, rather than representative, sample in keeping with the IPA stance, whereby participants “represent’ a perspective, rather than a population.” (Smith, Flowers and Larkin, 2009, p. 49). Participants were self-selecting, recruited through Student Support departments at six higher education institutions. These departments acted as gatekeepers, sending information sheets (Appendix IV) out to all registered students who had disclosed autism. Potential candidates therefore remained unknown to me until they volunteered to participate. When I was contacted directly by a potential

participant, I then sent out the prompt sheet (Appendix II) and arranged the initial interview according to their preference.

#### *4.2.8 Ethical considerations*

Ethical approval was formally sought and gained via the University's committee. The research intended to focus on the individuals' perceptions of their achievements, in order to further our understanding of the different paths towards these achievements. It was recognised that, in relating the circumstances of particular achievements, data might also emerge regarding childhood and adolescent experiences. Moreover, focusing on success within the context of a qualitative interview does not preclude the possibility of negative experiences being described, and I was aware that there could be damaging consequences of the interview that I had not foreseen. By contacting individuals via the gatekeepers of Student Support departments, I sought to ensure that I had a clear protocol, and contact point, to follow up in the case of any concerns arising for individual participants. Potential participants who were current students on the autism taught programmes of study at the School of Education were automatically excluded from the research, to avoid any conflict of interest regarding my teaching responsibilities.

Informed written consent was obtained from all students involved, with the option to withdraw consent made explicit (Appendix V). The negotiation of consent was also treated as an ongoing process, rather than one event (Usher and Arthur, 1998; Lewis and Porter, 2004). Autistic individuals can have widely differing learning preferences (Lawson, 2001) and by reiterating participant



rights and my responsibilities at every contact, I hoped to allow adequate time for this information to be processed and meaningfully understood. Participants thus had multiple opportunities to raise questions or concerns - or indeed to withdraw - as a relationship of trust and familiarity with me as the researcher developed.

As will be apparent from the description so far, the process of participation was very time-consuming, a necessity but also a challenge if active participation is to be truly meaningful (Bourke, 2009; Nind, 2011). This in itself was recognised as a potential ethical issue, particularly in consideration of the fact that participants were primarily young adults studying full-time, already under considerable pressure from coursework deadlines, and some also living away from home for the first time. It was therefore all the more important to revisit the fact that participation was entirely voluntary and unrelated to their studies. In addition, the estimated time commitment was detailed within the initial information sheet and this aspect will be considered more fully in the following chapters.

#### *4.2.9 Analytical process and theoretical influences*

In keeping with the IPA philosophy, an idiographic approach to analysis was taken. A conscious effort was made to enter each participant's world during the interview period (Smith, Flowers and Larkin, 2009). Since the process of participation was relatively lengthy, recruitment was staggered, with the intention that each interview set would be completed within a three-week timeframe. In this way, it was hoped that participants would remain engaged

with the process, and I as researcher would be able to focus on each interview set individually.

Immediately following each interview, initial thoughts and impressions were noted in a reflective diary. These were referred to during subsequent stages of analysis as part of the reflexive process, which I will consider further in my findings. Each interview was then fully transcribed and read alongside the original recording. The intention here was to remain as close to the original interview as possible, in recognition of the fact that even a detailed transcription is a form of interpretation, as it necessarily excludes some aspects of the event (Smith, Flowers and Larkin, 2009). The same is true of the recording itself, but to a lesser extent, and so it was deemed helpful to initially read and listen, in order to be immersed in the data.

Having read and listened to the interview in full, a process of “free textual analysis” was followed (Smith and Osborn, 2008, p. 67). At this point, this was interpreted literally, in that the original focus of the research was disregarded in order to accurately represent the interests of the participant (with the caveat that the interview followed a loose structure prescribed by me rather than the participant). The transcription template in this case had two margins, one for initial hand-written notes and one for emerging themes (see Appendix VI for sample transcript).

Having completed initial annotation, the transcript was read once again and emerging themes identified. In these early stages, attention was also paid to the use of language. Where accounts were particularly vivid, or otherwise notable in their articulation of the phenomenon described, these were highlighted in

yellow. A limited amount of conceptual coding also took place at this stage, although this more interpretive and reflective stage occurred to a greater extent once all interviews and initial analysis were completed and the data sample was considered as a whole.

A copy of the annotated transcript was then sent to the participant. Each participant was asked to read their transcript, consider my analysis, and add their own notes. A second interview was arranged in order to discuss and reflect on the points raised. The participant was asked to specify where they disagreed or particularly agreed with the researcher analysis, or further clarify anything they wished. In some cases, further clarification of a point was sought, for instance if a point seemed ambiguous or I wanted to confirm the validity of my own analysis. Participants were also asked to evaluate this stage of the process. This second interview was then transcribed and annotated in the same way, and sent out again for comment. Initial analysis was thus intended to be a structured and transparent dialogue between researcher and participant.

Table 1 below gives an example of how this dialogue worked in practice, indicating the original analysis in the first interview, and Debbie's response to it in the follow-up.

Table 1: Example of Progression of Analysis Between First and Second Interview.

<b>Initial interview</b>		
	<p><i>Researcher: were there other people who were supportive in the process?/</i></p> <p>Debbie: <b>It seemed like we had to fight everyone, things didn't change until I got diagnosed but it was still a struggle to get them to understand what my needs where as we felt they didn't know the disorder well enough as they seemed to take it as a personal attack on their teaching</b> e.g. at parents evening mom asked if it would be ok for me to sit at the back of the room by the door as the room had no windows, was blacked out, and made me feel like I couldn't get out <b>so I couldn't concentrate which had an effect on my work but the teacher got very defensive/</b></p>	<p><i>Mother as sole support. Very much 'we' not 'I'; Debbie is not alone, it is her and her mother against the world.</i></p>

<b>Follow-up interview</b>		
	<p><b>Researcher:</b> Great. When you read through the transcript and my notes, what did you think of it? Did it seem to reflect our discussion? (sometimes it's different to read what you've said or what someone else has said and it can be surprising)/</p> <p><b>Debbie:</b> I thought it was accurate your notes, it did make me laugh when you said Debbie is not alone, it is her and her mother against the world because I get a lot of people saying that to me/</p>	<p><i>Agreement on transcript &amp; analysis- seems accurate</i></p> <p><i>Sense of others' perceptions of Debbie and her mother as a team.</i></p>
	<p><b>Researcher:</b> do you agree with it?/</p> <p><b>Debbie:</b> yes I do that's how I feel about me and my mom/</p>	<p><i>Debbie's agreement</i></p>

The intention was that at every stage of research production, analysis and publication, participants should have the opportunity to have an influential voice within the research. However, this voice was not without boundaries – the research design was influenced, but not led, by the user group. Participatory analysis was interpreted here as “a process of ‘dialogue’” rather than “handing over control of something.” (Nind, 2011, p. 358).

Once each interview set was complete, a short one-page summary of each individual dataset was completed (a dataset being the first and second interview compiled, plus evaluations and reflective notes). In this way, I hoped to reflect further on the essence of what the participant had shared and have a record of this alongside the emerging tables of themes. Since the sample, at sixteen participants, was relatively large for an in-depth IPA study, it was hoped that the use of summaries alongside the full tabulated data would protect the individuality of each participant's contribution. For the same reason, these individual summaries are presented in the next chapter before the findings are considered as a whole.

Having thus coded each transcript individually, I then re-read the data and began to organise it into over-arching themes. This again was an iterative process. At this stage, NVivo was used to facilitate the coding process and enable better identification of repetition or overlap. As I worked on each new set of analysis, I not only revisited the original data relating to each theme, but also previous datasets, in order to bring consistency to the coding and maintain a sense of the whole (see Appendix VII for data theme table and Appendix VIII for analysis checking summary).

Having worked through the entire dataset in this way, I repeated the process once more, focusing this time on cross-checking themes between later and earlier datasets, in order to identify patterns across cases and ensure that relevant themes had not been missed. For instance, in some cases, points were implied rather than stated explicitly, so that text needed to be scrutinised anew in the light of themes that emerged from other datasets. This involved returning

to some of the complete transcripts and was a lengthy process, with continuous movement between datasets.

Following Smith's (2011b) review of high quality IPA studies using large samples, codes represented by fewer than 50% of the participants were discounted. It is recognised that in some circumstances, a minority of participants may highlight something of such significance that it ought to be included, and so text within these codes was carefully considered in the light of the research focus and the other codes. In some cases, text was re-coded at this point. Consequently four codes were removed on the basis that they were represented elsewhere. Throughout this process, I made use of my two supervisors as 'critical friends' who conducted "mini audits" (Smith, Flowers and Larkin, 2009, p. 184) by reading all annotated transcripts and commenting on the analysis. In this way, the validity of my interpretations were continuously reviewed as the analysis evolved, and in dialogue with my supervisors, I was reminded to critique my stance at every stage as a reflexive researcher, a stance critical to qualitative research (Finlay, 2002).

In the following chapter, I have presented an analysis of the data according to the processes described above, and have discussed in detail the themes emerging from my analysis. I have then gone on in chapter six to develop this discussion and consider the implications of my findings. In keeping with my commitment to a critical disabilities approach, I have explored the different ways in which participants navigated the labels they had been given, the ways in which it influenced (or did not) their own sense of identity, and whether these activities were relevant to their successes. I have utilised here the work of two key theorists: firstly, Foucault, to examine participants' activities, and then

Hacking, a philosopher directly influenced by the work of Foucault, who has focused on the phenomenon of autism within his work as I have earlier described.

Foucault (1982) used historical investigation (regarding this more as an archaeological investigation than a historical description) to study the relationships between power and knowledge. He stressed that his ideas “represent neither a theory nor a methodology” but rather are intended: “to create a history of the different modes by which, in our culture, human beings are made into subjects.” (p. 777) His focus however, was not on the production of historical accounts, but on the analysis of historical practices (Foucault, 1985). Crucially, he did not view the power games that take place within societies as necessarily detrimental, and indeed asserted that societies need these power relations. Rather, he proposed the key to be the acquisition of these rules by all players, so that they could be played with “as little domination as possible” (1998, p. 299). Although Foucault did not consider disability specifically in his work, its relevance is apparent, and his ideas have been taken up and used by disability theorists (Barnes, Oliver and Barton, 2002). Many of his ideas are therefore relevant to the practices described within this study.

Foucault has been described as a post-phenomenologist and his works could be regarded to be incompatible with an IPA approach. However, I would argue that Foucault’s approach can be seen, not at odds with the work of Heidegger which underpins IPA, but rather offering an extension of it. As Nealon (2008) describes, Foucault talked of “the irreducible importance not of subjective “experience” or “meaning” but of conceptual relation and its irrevocable ties to



practices and processes that lie far “outside” the subject”. (p. 16) This links to the way that IPA authors have suggested that the approach be developed, acknowledging the ways in which external structures influence the individual experience (Larkin, Watts and Clifton, 2006; Shaw, 2011; Todorova, 2011). “From start to finish, you have to go where the power leads you, and Foucault’s own research on the genealogy of power led Foucault directly to the “private” subject.” (Nealon, 2008, p. 91) The personal experience is of value, since, viewed through the lens of ‘biopower’ (Foucault’s term for the ways in which people are ‘managed’ by the regulatory bodies surrounding them), we can appreciate the ways in which it contextualises the structures surrounding it, reflecting the importance of our relation, both to the self and the forces upon it. The contentions around Foucault’s position are perhaps best summarised by Hacking’s (2004) observation that “Foucault was a major figure in the destruction of phenomenology. And yet it is precisely the care of the self that is at the heart of Foucault’s last work.” (p. 288) I hope I have demonstrated here how the theoretical ideas of Foucault and Hacking are complimentary to one another and to the overall research aims.

#### 4.3 Summary of the methodology

In summary, in order to participate fully in the research, participants were required to provide consent; prepare topics for interview; commit time for two interviews; comment on annotated transcripts; and evaluate their experience of the process. The research approach therefore required a significant commitment of time and effort from its participants.

From a researcher perspective, it was also a daunting process. Annotating data so that participants could understand and engage with it presented a considerable challenge. Every note had to be carefully considered to ensure that it would be clear to another reader. Points with negative connotations needed to be presented with sensitivity, given that potentially vulnerable participants would be reading them 'uncut'. I had to be ready and willing to accept criticism; my analysis may have been deemed inaccurate or irrelevant and I needed to be prepared for how this might influence my approach. This raised the question of how researcher/participant disagreement was to be addressed and reported so that both sides were adequately represented. For this project, it was stated explicitly that where differences arose, both would be reported. In fact, early acknowledgement of this potentially thorny issue was very useful, in light of the fact that this exploration of differing interpretations was a central aim of the study. Indeed, it was a further tool to encourage my reflexive position and mindfulness that I needed to apply "...the same refusal to take things for granted..." (Kamler and Thomson, 2006, p. 75) to my own work as I would to that of others.

Through the methods described above, I sought to create an accessible and transparent partnership cycle, in which it would be impossible to misrepresent participant data. I hoped to be true to the principles of both IPA and participatory research, and to produce a strong qualitative study that demonstrated Yardley's (2000) four criteria of: sensitivity to context; commitment and rigour; transparency and coherence and impact and importance.

## **CHAPTER 5**

### **RESEARCH FINDINGS**

#### 5.1 Introduction

In this chapter, I present and discuss the initial research findings. In an effort to retain the individuality of each participant, summary information pertaining to each participant has been provided first. I then consider modes of participation and results of the evaluations, before moving on to indepth thematic analysis of the data, using representative data samples to illustrate how they have been interpreted, and integrating an analysis of how language has been employed by participants.

#### 5.2 Summary of participants

In this study, twenty-three participants responded to the initial recruitment calls. Of those, three did not respond to follow-up communications, one decided not to proceed due to personal reasons and three responded too late to be included. A total of sixteen participants, ten males and six females, from five universities, went on to give consent and participate in the research. Their profiles are offered below (in alphabetical order, according to pseudonym) in Table 2.

Table 2: Summary of participants

[N/A = information not available]

Name	Gender	Age	Type of Degree	Part-time(P/T) Full-time (F/T)	Route into HE	Interview Format
Aimee	F	19	Media & Comms UG Yr 1	F/T	'A' levels	Face to face
Ben	M	23	Medicine UG Yr 1	F/T	'A' levels	Online chat
Bridget	F	23	Physics UG Yr 2	F/T	'A' levels	Face to face
Christian	M	20	Media, Comms & Drama UG Yr 1	F/T	'A' levels	Face to face
Debbie	F	22	English and Drama UG Yr 2	F/T	'A' levels	Online chat
Elliot	M	20	Physics UG Yr 2	F/T	'A' levels	Face to face
Greg	M	20	Drama & Creative Writing UG Yr 1	F/T	'A' levels	Face to face

Name	Gender	Age	Type of Degree	Part-time(P/T) Full-time (F/T)	Route into HE	Interview Format
Hannah	F	21	Biomedical Science UG Yr 2	F/T	'A' levels	Online chat
Josh	M	24	Archaeology UG Yr 2	F/T	Access Course	Face to face
Lewis	M	37	MA Drama & Theatre Education UG Yr 1	F/T	Access course	Face to face
Lila	F	18	Psychology UG Yr 1	F/T	European Baccalaureate	Face to face
Rob	M	37	PhD Autism Yr 1 P/T	P/T	'A' levels	Telephone
Rosie	F	19	Sociology UG Yr 1	F/T	'A' levels	Online chat
Sandy	M	21	MPhil(B) in Egyptology	F/T	'A' levels	Face to face
Thomas	M	23	Geology UG Yr 3	F/T	'A' levels	Face to face
Warren	M	24	Politics with Int. Relations UG Yr 3	F/T	'A' levels	Online chat

Of the sixteen participants, only three had previously volunteered to participate in autism research. Eight had volunteered to share their autism experiences in other ways, through writing, speaking or performing about autism. Two had done both. It is worth noting the discrepancy between the few individuals who had chosen to volunteer for autism research and the greater proportion who had chosen to share their experiences informally, in the course of their daily lives. This may have been simply because they had never been contacted and asked to do become involved in research. However, it could also suggest that they had not perceived autism research as relevant to them, whilst in contrast they did feel they could impact their community positively by sharing their knowledge. The profile of participants was fairly typical overall: primarily undergraduate students (n=13) under the age of twenty-five (n=14), who had reached higher education through a standard secondary school pathway (n=14). The male:female ratio of 10:6 reflected a higher proportion of females than the reported male:female ratio of 4-5:1 (Lai et al., 2015) and the sample is unusual in this respect.

### *5.2.1 Participants and their successes*

As part of my endeavour to remain close to each individual's experience during the early stages of analysis, I created a profile of each participant immediately following the data collection stage, detailing their chosen successes along with my reflections on their narrative and the developing analysis. These are copied below to offer a sense of each individual before I move on to consider the corpus as a whole:

## AIMEE

Successes	
1	Coming to terms with diagnosis
2	Passing GCSEs
3	Achieving good 'A' Level grades
4	Getting into university

Aimee conveyed a clear sense of who she was and a positive, optimistic interpretation of her experiences. She described a determination to succeed and moreover, to surpass and confound the expectations of those who had under-estimated her. Throughout her account, Aimee referred to her parents and brother as caring and supportive. There were also teachers who had motivated and encouraged her, and she alluded to specific friends as 'heroes'. A key motivation for Aimee was to recognise the support she had received by achieving success and proving to others that they had been right to have faith in her.

Whilst comfortably accepting the autism diagnosis, at the same time Aimee saw herself as a 'rare breed', unwilling to be categorised in simple terms. She described autism as a flaw, but also an essential part of who she was, and did not regard it as changeable. She described this in very matter-of-fact terms. However she did describe frustrations at being judged as an autistic child, and was keen not to allow herself to be limited. In her descriptions of discussions with others regarding her diagnosis, she framed herself as 'atypical' and 'the

polar opposite' from others she had met. Aimee seemed to accept her autism diagnosis without relating to an 'autism identity'.

Aimee's account was a success story, so much so that she described having too many successes from which to choose. These tended to be framed as situations where Aimee had surpassed her own or others' expectations. Through her passion (drama) she had created a dramatic piece using chains, tight and then gradually loosening, as a metaphor for her autism. In this, there was the sense of her gaining increasing control and understanding as she matured.

Aimee gave an overtly social account and described no social or communication difficulties at all. Where she did allude to points that could be interpreted as autism associations (being a 'nerd' and 'blowing off' a friend), Aimee was clear that she did not interpret these as related to autism or its effects.



## BEN

Successes	
1	GCSE Results
2	Getting into Medical School (post Engineering degree)
3	Being employed as a senior steward
4	None offered

Ben actively pursued diagnosis, learning about the condition and recognising himself in the official descriptions. He viewed his successes as at least partly stemming from disadvantages related to autism, in that social isolation had encouraged him to focus on academia. His successes were academically-based rather than social. All three were hard won, sometimes following initial failure; indicators of Ben's determination to realise his potential and prove it to himself and/or others.

Ben was very clear that his diagnosis was a positive turning point. However, this was not because of better support or understanding from others, but because it enabled him to understand himself better and develop more effective coping strategies. Coming to terms with diagnosis was a cause of confusion and anxiety, with Ben worrying that he had somehow 'created' it, a reflection perhaps of the intangible nature of the condition. He perceived autism as a 'mixed bag', providing him with some academic advantage and social challenges. For Ben, the academic successes outweighed the social stumbling blocks. Ben's account conveyed a series of turning points, such as when he

decided to write neatly - to him, this seemed to lead to a greater engagement with, and motivation for, education.

Although Ben acknowledged the support he had received from his parents, he viewed himself as very, and in fact fiercely, independent of them. He described the importance of allies who understood him and were willing to give him opportunities. Others, such as twins he had met, seemed to be hugely influential for reasons that Ben was not able to explain. There was a sense that it was the decisions he made, and not the reasons behind them, that mattered.

Ben's account was full of reflection, both of himself and his situation, and of the interview dialogue itself. He noted that the opportunity for reflection was a helpful one. Within the interview dialogue, there was some disagreement with researcher interpretation. Ben viewed himself largely as a passive individual, whose successes had been mainly due to luck. However, there was some evidence (from the researcher's perspective) that his actions, and resilience in the face of setbacks, had in fact been instrumental in leading to his key successes. He agreed with the interpretation that he had confidence in his own abilities and a determination to prove these to others.

## BRIDGET

Successes	
1	Being given the Headteacher's prize
2	Achieving grade 8 piano
3	Getting grades to get into first choice university
4	Making a friend with Asperger Syndrome

Bridget had been treated for a serious, disabling and disfiguring cancer towards the end of her time at school, and so unsurprisingly, some of her successes were contextualised by this experience. She described the period without any self-pity, although she did recognise its seriousness. What came across was a great resilience. Bridget did not seem to take an analytical approach to important events in her life, but rather met each challenge unquestioningly.

In her description of achieving grade 8 piano, she described a long gap without lessons due to her illness, without losing any skills. This could be attributed to memory, natural ability, or passion for the subject. However, Bridget offered no theorising or apparent curiosity about the reason for this. She did, however, recognise and highlight it is an unusual achievement.

Bridget did not offer, but did agree, that her strategy was simply to do her best at everything she tackled. She described in different ways that she 'simply gets on with it', suggesting an unquestioning approach and an unwavering determination. Although she accepted support and acknowledged when this had been helpful, she did not count external support as significant to her

achievements. In describing her evidently close relationship with her mother, what was apparent was the mutuality of support.

Bridget's final success was somewhat different in that it described making a connection with another autistic student. She described an instant recognition of this person as being like her, and the importance of this social support link was evident. Although she did not offer details of how this relationship developed, she was clear about her reasons for wanting it to. The impression given was that Bridget actively sought to foster a relationship because of the empathy she felt towards this other student. Whereas her other successes appeared to be about tackling whatever she was faced with, albeit with a determination to do her best, here she appeared to have taken control of a situation more actively and influenced the outcome.

## CHRISTIAN

Successes	
1	Winning school award (nominated by teacher)
2	Winning school awards three years in row in Key Stage 3
3	Achieving brown belt in karate
4	Achievements in drama

Christian gave a very positive account in his transcript. Whilst he recounted that it had caused him some difficulties, particularly in terms of social anxieties, he viewed this as an additional incentive to achievement. He also described an awareness of benefits in terms of ability to focus and be successful in areas of interest. In his discussion of autism and Asperger syndrome, he referenced dominant literature and related himself to this. He attributed his successes to 'overcoming' and 'getting over' aspects of autism, linked with a personal determination to succeed, further nurtured by his achievements and others' recognition of these.

In his account he charted his own development in terms of a growing maturity linked with a lessening of the negative effects of autism. He described two major breakthroughs in this regard: firstly, in his conscious or unconscious decision to 'start trying' and take notice of his environment, leading to greater academic success. Secondly, in his use of his performance abilities to form social links with peers and develop social self-esteem.

Christian described a clear division between things in which he had a natural interest and those in which he did not, and indicated that he was making a

determined effort to persist in those latter areas, recognising that he needed to do this in order to succeed. He also showed an attitude of resilience in facing potential failure, seeing this as a necessity which could also be '50% of the fun' and describing practical strategies to deal with these. He acknowledged a number of people who had supported him, including family members and teachers, and this support plus the formal recognition of his personal successes, were important motivating factors for him.

His use of language was often striking, as he articulated his outlook very succinctly, showing considerable insight into himself and his context. On paper this was even more apparent than it was during the interview.

## DEBBIE

Successes:	
1	Passing GSCEs post diagnosis
2	Drama
3	Writing about autism for a training event
4	Passing driving test

Debbie's account indicated an ongoing negotiation between her inner world, the 'real' Debbie, and the social world, which she wanted to be part of and understood by. A sense of conflict pervaded: Debbie accepted the autism diagnosis but at the same time, maintained a conscious distance from it. This was not because she did not relate to it; in fact she related closely to the fictionalised account in 'The Curious Incident of the Dog in the Night-time' book. It seemed more a matter of protecting herself, both from individual difficulties which might be exacerbated by recognising them as part of a disabling condition, and from barriers caused by the reaction of others to the label. She felt clearly that her sense of self was unchanged by the autism diagnosis; she was 'still Debbie'.

Debbie described a number of experiences where either her diagnosis, or a lack of understanding from others, had caused hurdles that had made her life more difficult as she sought to overcome them. Autism for her was primarily a series of extra challenges that she had to face. In this, she recognised and valued the support of important people in her life, including her family and support worker. This support spurred her on to achieve more.

Success for Debbie was finding ways to forge links with the external world, to be recognised as ‘the real Debbie’ and to be understood. There was a sense that, by relating more closely to autism, she felt more disconnected from her non-autistic peers. Despite this, she was clear that she wanted to increase understanding for others with her condition, demonstrating here a sense of shared experience with, and responsibility for, other young autistic people. Debbie’s account indicated resilience in the face of these challenges and a very conscious determination to succeed.



## ELLIOT

Successes	
1	Getting good grades in GCSEs and 'A' Levels
2	Participating in the shooting range with the Cadet Force
3	Designing walkthroughs on the internet
4	Creating YouTube videos

Elliot reflected on his successes in a very positive way. He described his personal effort as being largely linked to his motivation and interest, attributing certain interests to Asperger syndrome, in accordance with the general literature. However this was not always the case and he also described putting effort into areas that he perceived as personal weaknesses, presenting an outlook that was overtly positive: 'you might as well have a go'. He also described that there were things that he felt he might be able to do if he really tried.

Diagnosis was comfortably accepted and Elliot presented a strong sense of self that was not compromised by this diagnosis. He described learning about it through his mother and their shared reading of the literature seemed to be a joint journey. Diagnosis was a 'name' rather than a major event. One of Elliot's successes involved presenting himself as 'a user with Asperger syndrome' and he described being motivated to promote this in a positive way and help others.

Elliot was balanced in his consideration of his successes in relation to Asperger syndrome. He described, as above, instances where it may have proved an advantage. He also described instances where it proved a disadvantage, very

much due to others not understanding his learning style and needs. In re-telling this, he showed insight into how things may have turned out differently for him – the suggestion was there that his positive outlook was due at least in part to his positive experiences. He had an awareness of his abilities and it was important that his achievements were able to confirm these, and even surpass expectations, rather than suggest a lower level of ability. He described having had a set of expectations of what he would achieve, no doubt influenced by culture, class and education, and these coloured what he aimed for. In describing this, he referenced key people whose support had been important: his mother, his SENCO, and a teacher who had ignited his passion for maths.

Elliot's narrative seemed to reflect a clear awareness of who he was, where his strengths and weaknesses lay and what factors needed to be in place for him to best learn and succeed. Although fairly determined, he also seemed to not be afraid of failure in his willingness to 'have a go'. Elliot described finding it difficult to appreciate others, describing this as an 'empathy issue', yet in his description he showed great appreciation of those who had helped him. Perhaps here he was being influenced negatively by the autism literature? He was quite specific and clear in his descriptions and corrected a term used by the interviewer (milestone) as not being quite accurate.

## GREG

Successes	
1	Talking about Asperger syndrome in school assembly
2	Leadership role in school production and winning trophy
3	Learning a lesson about relationships and self-control
4	None offered

Greg did not select achievements that were directly academic, but rather related to his academic environment, and focused on successes within the 'social' world. Each of the things he described related to how he interacted with his social environment and the responses that he triggered.

In his first account, Greg spontaneously spoke in assembly about his experience of having autism. There was the sense that, in this, he was doing something he had wanted and needed to do for some time; to 'clear something up' and take some action so that others would understand him. He also acknowledged the support of his mentor and the need for her to be recognised by his student peers. In common with some other accounts, Greg described the importance of an achievement which also reflected doing something he enjoyed.

His autism was described as a barrier and a challenge that he did not yet fully understand, and its effects for him were always described in negative terms, representing lack of control and social misunderstandings. At times during the interviews, Greg found it difficult to articulate what he wanted to say and was unhappy with what he had expressed, possibly reflecting ongoing difficulties in

making sense of his condition. The issue of 'control' or lack of it pervaded his account. Greg described the importance of having self-control and he associated a lack of self-control directly with autism.

Successes were described as significant turning points for Greg, leading to greater confidence, popularity and/or self-awareness. They were not formally validated successes such as qualifications, but informal successes indicating evidence of his social development and acceptance by peers.

## HANNAH

Successes	
1	'A' Level results
2	Getting a 1st in first year at university
3	Attending university ball
4	Coping alone at home

Reading through Hannah's transcript, self-deprecating comments and indications of low self-esteem pervaded. This was somewhat in contrast to what I would describe as her bravery in meeting challenges head-on and facing her fears and the possibility of failure. She described feeling proud in achieving what she had in the face of some challenges, and specifically when she felt that doing badly would have been 'justified'. Here and throughout there was a sense of resilience and personal determination; Hannah found the motivation to achieve what she aimed for, either through interests (such as the Science festival) or connected with broader goals such as adult independence. She described a wide network of external support including family, friends, teachers and lecturers, and attributed much of her success to the support she had from them. Through the understanding that Hannah received from those around her, barriers associated with anxiety and/or autism had been, at least to an extent, broken down or overcome.

She was unwilling to distinguish aspects of autism from aspects of herself or other genetic predispositions (such as mental health difficulties), and was very clear that diagnosis was a good thing and had been a positive in her life,

leading to better understanding from others and a definition for 'the way she is'. Hannah attributed many of her past difficulties to being undiagnosed. The associated pros of autism were described in the context of the negatives; social barriers, leading to poor social life, made it easier to study. Nevertheless she had proved to herself that she could continue to succeed with a social life; here there was a possible contradiction, or evidence of development. She made an interesting and useful distinction between diagnosis and recognition, viewing the latter as of paramount importance.

Hannah indicated that through her achievements she had developed self-awareness of the fact that her abilities may exceed her expectations, thereby making it easier for her to face new challenges. However she offered the caveat that this may not be the case with completely new challenges – again, this was perhaps in contradiction to her description of facing several challenges that would have been largely outside of her experience, eg. staying at home by herself.

It almost seemed as if she found some safety in maintaining her own fears, whilst simultaneously making positive efforts to face them and/or overcome them. Hannah conveyed a strong sense of self; she seemed to be clear in her convictions. She also showed insight into the breadth of her achievements in terms of developing independent living skills alongside academic skills alongside social skills: here there was evidence of self-analysis, and she described these achievements very much in the context of autism as the cause of the challenge.

## JOSH

Successes	
1	Passing GCSE Maths
2	Getting into university
3	Passing driving test
4	Learning to ride a bike

Josh's successes were mainly framed as achievements in areas that did not come naturally to him. (His entrance to university was the exception, being more straightforward in encompassing personal determination and hard work). He made the point that, in valuing successes that were hard-won, he positioned himself within the general population, hypothesising that in this, he was typical. He attributed successes generally to the desire to achieve each thing, personal effort, and the support from parents and friends. This effort to straddle and comprehend the middle ground, between 'autism as difference' and 'typical but with autism' pervaded his account. Whilst accepting his diagnosis, Josh perceived himself as untypical. Moreover, whilst recognising difficulties associated with his autism, he was at pains not to exploit these aspects or over-interpret his individual strengths or weaknesses as being due to autism.

There was some contradiction in Josh's view that he had grown out of autism, whilst recognising some continuing social difficulties. He reflected on experiencing some social awkwardness previously attributed to the age difference between himself and fellow undergraduates, which he now suspected may be autism-related. This reflection illustrates his conscious

efforts to distinguish/navigate between autism and 'the norm', including the tricky no-man's-land in between.

His outlook indicated a determination to succeed and a resilience in the face of failures. His bad experiences, of being judged and misjudged, seemed to have been re-framed as constructive experiences, leaving him keen not to judge others, to prove himself, and to make a difference to the wider world.



## LEWIS

Successes	
1	Campaigning to have a school rule changed
2	Succeeding at work placement
3	Achieving a degree
4	Discovering skills at teaching English

Lewis's account was bittersweet and revealed a sense of conflict in coming to terms with diagnosis. Lewis felt he experienced lack of understanding prior to diagnosis that may have disadvantaged him. At the same time, he distanced himself from others with the condition, and there was a sense that he needed to protect himself from the possibility of being 'dragged down' by others more severely affected than him.

In his earlier reflections, Lewis' account was of a passive and powerless experience, in which he was subjected to interventions without understanding their purpose. Diagnosis was something initially in the hands of his parents and this information was not shared with him. Lewis was clear that an earlier diagnosis, or awareness of diagnosis, would have been helpful to him and aided his self-understanding. He described his diagnosis as a relief, and this despite the fact that, in practical terms, things became worse, not better, following diagnosis.

In contrast to some other accounts, Lewis's successes sometimes ended unsuccessfully. Nevertheless he took the positives that he could from them, indicating a determination to make the best of his experiences and move

forwards. In his accounts, Lewis seemed at times to be struggling to gain a full understanding of what had happened. Control, or lack of it, seemed to be an important theme.

Lewis described a journey of self-discovery and understanding, and a process of gradually overcoming problems. He described a realisation that over time the gap had narrowed between his aspirations and the possibilities available to him. Drama, a goal he had his heart set on, had become attainable. He attributed this to his maturity; the development of practical skills and self-control. With this, there was a sense of the need to maintain control in order not to lose ground.

He described drama as being useful in enabling him to rehearse social situations, and thereby perhaps take control and affect the outcome of interactions. The relevance of autism here was only helpful in the need for a good memory. A potential turning point had been the awareness that he possessed a natural (and appreciated by others) skill at teaching English. He was very enthusiastic about the good feeling gained from affecting others in this positive way and the experience had been very influential, so much so that he was considering changing his career trajectory as a result. Using his skills in this way was much preferable to him than becoming a role model for the autistic community.

## LILA

Successes	
1	Recognition from teacher of academic ability
2	Passing chemistry test with friend's help
3	Presentation in class
4	Confirmation

Lila's successes had the common combination of an academic *and* social element. She talked about her intellect as very important to her, and external recognition of this and of her as a person were at least as important. There was a sense of absolute faith in her own abilities, frustrated firstly by the lack of recognition from others, and the boundaries imposed upon her by the predominant autism narratives.

Diagnosis of autism seemed to have been an extremely traumatic and distressing experience for Lila, from which she still bore the scars. She found the initial 'deficit' messages so negative that she resisted diagnosis for some years, and the whole process was described as something from which she had been excluded and regarded as almost an incidental player. Lila as insignificant and peripheral was conveyed also in the context of her classroom, where the successes were significant in creating 'rare' experiences of acceptance and recognition. In her line that perhaps she had been silent for too long, Lila described a need to 'release' in some way and make herself visible to her peers. This was of great importance to her.

Lila related neither to the academic literature nor to the autobiographical accounts celebrating autism, so there was a strong sense of her not only being literally alienated by her non-autistic peers, but also feeling alienated from autistic communities. She resented the sensationalising of autism at the expense of factual accuracy. Nevertheless, she did indicate that she had used forums for people with autism, and moreover, that she had related to some of the views expressed there.

Lila's descriptions of those closest to her often indicated lack of support rather than support. There was a sense of great pressure coming from both parents, rather than acceptance. Nevertheless she did recognise the importance of support from others in her successes, and the importance of others' reactions to her, as above, in defining those successes.

## ROB

Successes	
1	Teaching
2	Achieving distinction for Master's degree
3	Parenting his autistic son
4	Winning a handicapped (handicap as in golf) tennis tournament

Rob, a mature student, asserted himself as a strong-minded individual who was not easily influenced by others. For him, diagnosis was welcomed and actively sought. It provided an explanation for previous difficulties and bad experiences.

Rob counted his teaching as a major achievement and valued the impact that he had upon his students, despite the fact that this had ended in redundancy, leaving him scarred and with a sense of injustice. Nevertheless he held onto the positives and viewed the negatives as reflecting the ignorance of his former colleagues and the barriers they imposed. Rob's second success in achieving a Masters distinction indicated his appreciation of his own individuality. What mattered in this instance was his proof to himself and others that he could achieve as a result of his own efforts. The value was threefold: achieving the status of a distinction; satisfying himself that he had worked hard and earned the success; and impacting others through the product; his writing.

By far his most powerful account was his description of fatherhood and desire to be a good father to his autistic son. He described an approach of unconditional acceptance and indeed celebration of his son just as he was, with no pressure or desire for him to change. He related closely to his son and also

recognised a line of family members with similar traits. His son was his soulmate and in helping and supporting him, Rob felt a great achievement and sense of satisfaction.

Rob was a student of Sociology and well able to articulate his experiences in terms of the social barriers he had encountered. He described the transactional nature of the social difficulties associated with autism and conversely, the importance of 'right people, right subject, right time' in achieving success.

## ROSIE

Successes	
1	Passing GCSE Maths
2	Getting into first choice university
3	Bowling
4	-

Rosie couldn't think of a specific fourth success to share. In describing her successes, she conveyed a strong sense of conscious determination to aim as high as she could to overcome challenges associated with her autism. Her diagnosis was something she had grown up with and come to accept over time. She accepted and valued the support she was offered from educators and family, and attributed her successes to the combination of her personal determination, hard work and external support. As a result she had surpassed her own expectations in her achievements, and also perhaps those of others.

## SANDY

Successes	
1	Getting a first in undergraduate degree
2	Volunteering in Equador
3	Starring role in school play
4	Representing University Challenge team

Sandy described a mix of academic and non-academic successes. He attributed his successes to memory, a natural ability to write clearly and process information quickly. He was adamant that hard work had not played a part in his successes, although this was seemingly in contradiction with his interest in reading a wide range of books and in learning new things. In his description of his determination to master a new language, it was apparent that he had persevered, committed time and effort, and communicated his aims to those who could help him. Sandy expressed strongly that his successes were not motivated by competition with peers, but rather his own interest/enjoyment in the field and desire to achieve his personal best. He 'likes to know stuff'.

Sandy felt that support from his peers had contributed to his successes and again, considered himself lucky to have had good friends who shared his academic interests. In contrast to some of the dominant autism literature, he emphasised the importance of social learning and learning through dialogue with peers, from his own experience.

Sandy simultaneously queried his diagnosis and accepted it uncomplainingly. He described no negative views or experiences resulting from it and



acknowledged aspects of himself that fitted with the criteria. He reflected on the distinction/lack of distinction between 'self' and 'autism' and he expressed frustration that disclosing diagnosis could alter the perceptions of others, leading them to interpret all behaviours as autism-related.

## THOMAS

Successes	
1	Getting a place at university
2	Graduating from university
3	Getting a job in Finland
4	Finding Wing Chung school

Thomas's successes reflected a balance of academic and non-academic achievements. Pervading his account was a sense of his personal development and growing awareness of his environment and self as a social being. He described making conscious changes to his behaviour in order to move towards his goals. He also recalled receiving criticism for not taking pride in his work and related this to his tendency to be happy in his inner world, oblivious to his environment and external expectations.

Thomas talked about his diagnosis as a process that had been driven by his parents and in which he had not been actively involved. He indicated that he did relate in some ways to the autism diagnosis and generally did not describe this in pejorative terms. He also described his autism as developmental, less personally relevant to him now that he was more engaged with the social world. He talked of autism as something that could be viewed by others as no more than a 'personal idiosyncrasy', highlighting its ambiguity. He also postulated that most autistic people do need other people and are social beings, suggesting that he did not view his social self as at odds with the 'autism identity'. In this, arguably, Thomas was struggling to make sense of the

predominant stereotype of autism as anti-social or a-social, and the fact that he both reflected and contradicted this stereotype in his self-description.

There was a sense that the diagnosis was not a barrier to Thomas, in part perhaps due to supportive people within his environment who understood, helped and motivated him. Each success was framed by supportive people who provided motivation and encouragement. Thomas talked of needing others, and moreover of a growing consciousness of this fact, and throughout his account there was much reflection on his own learning processes and evidence of a considered approach to life, with clear outcomes in mind. In fact, in providing feedback on the first transcript, he commented that he had planned what he wanted to say and felt that he had said it, so there had been no surprises when reading it back.

Thomas' account articulated a clear determination to achieve his goals, to the extent that he applied to only one university and focused on this. He talked of the need for passion and was passionate in his descriptions of each of his successes. He was willing to experience failure in order to achieve his ultimate goals. He reflected on his own learning style in relation to his autism, in terms of the advantage of passion, versus the disadvantage of not being able to persevere with topics that failed to ignite his interest. Thomas also described the growing desire for independence and to 'contribute' to society.

## WARREN

Successes	
1	Getting close to getting a girlfriend
2	Attending summer school in Germany
3	Starting first year of University
4	'A' Level results

Warren didn't come prepared with four successes and thought of the last one during the interview. Warren's preoccupation with finding a girlfriend pervaded the interview. Almost achieving this was his first, and possibly most valued, success and he was open about his ongoing frustrations, and also the comparisons he made between himself and non-autistic peers. He struggled with loneliness and depression and perhaps perceived that a girlfriend would alleviate some of these struggles. Warren did not talk of supportive others in his life, other than one female friend. In fact, he described advice from family members as contradictory and unhelpful.

Warren described a series of ups and downs in his life and although he discussed these in matter-of-fact ways, he described some very difficult times. In this context, his appreciation of his current university experience as being worthwhile regardless of educational outcome was all the more striking. It was university life, and not just his university course, that suited him. He perceived himself as naturally clever, rather than clever due to hard work on his part.

Warren described a route to diagnosis that involved a struggle to obtain it, after numerous attempts. Whilst the diagnosis was good news, Warren was clear

that it did not lead to an improvement in his feelings or his circumstances. He did not make contact with others on the spectrum and in fact, was 'freaked' out by meeting people who were negative, rather than positive, role models for him. This arguably distilled the benefits of diagnosis into one aspect only: an explanation for the difficulties he was experiencing.

There was a sense of resilience and determination in Warren's account. His successes were sometimes within or beside experiences that could be construed as failures; nevertheless he was clearly seizing every opportunity given to him and persisting in his efforts, despite the challenges. His recent successes at university and abroad suggest that these efforts were paying off for him.

### *5.2.2 Modes of participation*

The majority of participants opted for face-to-face interviews, with ten choosing this format outright and a further two specifying that they would have preferred face-to-face, but their circumstances precluded it. (One was a full-time dad and one was studying abroad). This is perhaps a surprising finding, given the literature that suggests autistic individuals may find online communication preferable to direct contact (Jones et al., 2001). The fact that participants opted primarily for face-to-face contact is an indicator that they, in common with other young people, were selective in their use of ICT/social networking, using it alongside, rather than in preference to, direct contact. This apparent preference must however be viewed in the context of the sample size; a larger sample may have indicated different preferences.

There were some practical factors arising from the different interview modes used. There was a significant difference in how long interviews lasted. Whereas the time for face-to-face interviews ranged from 52 to 137 minutes (total for both interviews), for online-interviews the time ranged between 119 and 198 minutes. Data must be treated with caution given the small samples, but the disparity seems significant. The shortest online-interview set was over twice as long as the shortest face-to-face interview set. This represents a considerably greater time commitment required by participants being interviewed online, reflecting the additional time it takes to write, rather than speak, responses. From a researcher perspective, the online format offered an advantage in that data was automatically transcribed. In effect, the 'workload' of transcription was thus transferred from myself on to my participants, potentially raising ethical and practical questions for the methodology.

However, no participant objected to the time commitment required and no-one dropped out midway through the process, which suggests that they were happy to contribute, and that they perceived the research to be relevant to them.

### *5.2.3 Participant evaluations*

Before considering participant data in more detail, I will report briefly on the evaluation findings. As described above, participants were asked to complete a short evaluation immediately after each interview (see Appendix III for evaluation template) and the vast majority did so. Appendix IX provides a summary of the evaluation data itself. For the purposes of the study, it is sufficient to report that responses were overwhelmingly positive. All participants found the environment and format suited their needs and the interview questions were sufficiently clear. The majority reported specific positive aspects of the experience; primarily being able to reflect on positive experiences and feeling that their voice was being heard. No participant reported a negative reaction to the interview, although when asked how they were feeling now the interview was over, two participants reported feeling confused or negative as a consequence of re-living certain experiences. In all cases however, participants were more positive following the second interview, so this two-part process may have been helpful in giving participants time and space to work through these feelings. Six participants used the 'Additional Comments' box to add further thanks and appreciation for the process. Overall, the evaluations did not signal any particular problems with the process and gave a strong indication that it had been successful in suiting their preferences.

### 5.3 Summary of themes

The interview data will now be reported and analysed, within three superordinate themes of 'The autistic experience'; 'Elements of success' and 'Identity and autism' (see Appendix X for superordinate theme summary, indicating all clustered sub-themes).

'The autistic experience' is the shortest theme, considering the data pertaining to the experience of participating in the research, and points arising from the research process. It is presented as two sub-themes:

- *"That's my own perception and I can see how based on this conversation you might see it differently"* considers the ways in which participants and researcher either agreed or differed in their interpretations of the dialogue that was taking place;
- *"Sometimes I don't really want to relive bad moments. And reading it wasn't the hard part, the hard part was more like understanding that it happened"* explores the ways in which participants reflected, during and between interviews, both on their experiences and on their own meaning-making as the process evolved.

'Elements of success'. In this section, participants' accounts articulated factors that they felt had contributed to their successes. Featuring heavily were personal characteristics and motivations. Participants also recognised direct support, or a sense of impetus, that they had received from key people in their lives. Overcoming prejudice or changing perceptions was also described as a significant element of many experiences. There are three sub-themes:



- *“Weebles wobble but they don’t fall down”*: representing the different ways in which success was articulated as arising from challenges presented, or from the determination of individuals;
- *“You’re a social animal”*, the largest sub-theme, encompasses the ways in which the social world was perceived as contributing to success (or not), through the influence of others or individual motivation derived from social aspects;
- *“I really wanted to go to university to sort of get away and start anew”* considers the ways in which the context of higher education was deemed important to participants.

‘Identity and autism’ likewise has three sub-themes:

- *“What I have always felt, like I was on the outside looking in”* encompasses the ways in which participants described feeling ‘different’;
- *“I feel that having the diagnosis put this barrier there as they looked at the label instead of me”* articulates the different ways in which participants made sense of the ‘label’ of autism and its implications;
- *“And that’s what drives you forward. It’s like ‘I will show you’ and that’s what it’s all about really”* articulates the ways in which participants perceived aspects of the autism diagnosis as contributing to their achievements.

NB. In relation to the terminology employed in the following sections, I recognise that all language is culturally loaded and every term employed carries its own connotations. Navigating this can be problematic when seeking

to engage closely with textual data derived from a number of participants. For instance, several participants made use of the term 'normal' in their accounts, which I would consider to be an effectively meaningless and culturally loaded concept. Whilst in places I have used this to refer to quotes from participants, where possible, I have replaced it with the term 'typical' or 'non-autistic', which, though still imperfect, better capture the distinction between diagnosed and non-diagnosed. Likewise, in referring to an 'autistic identity', I do so in the knowledge that this is a gross generalisation, but serves a shorthand purpose in this context. The complex and multiple ways in which different identities have been made use of by participants is more fully explored in the discussion chapter, as is the notion of the 'autistic identity' itself. The researcher's words are presented in italics.

#### 5.4 Theme one: The autistic experience

##### *5.4.1 "That's my own perception and I can see how based on this conversation you might see it differently"*

One of the stated goals of this research was to explore the space between autistic and non-autistic interpretations. If the autistic experience is qualitatively different, then the way in which autistic individuals construct meaning from events within their lives would presumably reflect this difference. Likewise, if non-autistic individuals are largely ignorant of how these qualitative differences are experienced, their assumptions of how events are interpreted may be very flawed.

The process of transcribing and analysing the data, then returning to the participant for a further dialogue to explore themes arising and the ways in which these had been interpreted, aimed to expose these differences and either navigate commonalities or explicitly identify divergences. The following excerpts have therefore been taken from the follow-on interviews, where participants and I reflected together on key points from the initial interview and how we had each interpreted them. In fact, there was far more evidence of shared meaning-making than of difference, and the process enabled some closer exploration of this.

For example, Ben and Warren offered specific comments and gave evidence that they had closely read both the transcripts and my analytical notes:

Ben: It was an interesting read! Everything was accurate though... definitely, and it's probably the first time I've been able to reflect properly on the events.

Warren: "Girlfriend as ultimate goal" That's completely true. "Mutuality of relationship important": well that's obviously important, since if the feeling weren't mutual there's no chance of them going out with me.

Debbie indicated that my interpretation echoed observations made by others who knew her:

I thought it was accurate your notes, it did make me laugh when you said Debbie is not alone, it is her and her mother against the world because I get a lot of people saying that to me.

*Do you agree with it?*

Yes I do, that's how I feel about me and my mom.

In certain circumstances, I made a point of elaborating on my notes in order to check understanding, as in the case of Greg's account of spontaneously standing up in school to talk about Asperger syndrome:

*What really struck me about that was that there were a lot of really positive effects coming from this one experience, which I thought was really powerful and very significant. And I wanted to check that you agreed with that, that this is a fair interpretation of what you're telling me?*

Uh-huh. An exact interpretation.

There was also evidence that participants were themselves striving to make the most accurate possible analysis, as in the case of Sandy:

*One of the things that came across was that you are quite ambivalent to autism literature, the diagnosis, I really got a sense of that – not in a bad way – but just you know 'it's there but I'm not bothered by it'. I just wanted to check that that was fair, the way that I put that.*

Yeah, more or less. I'm definitely ambivalent towards autism literature. Hmm. Not entirely ambivalent. Well, I suppose ambivalent. Indifferent. [pause] Yeah I'm probably ambivalent. ...Ambivalent I suppose is the word for that really, I'm happy to talk about it if it comes up, it just doesn't ever really come up.

Here the process of analysis was an ongoing one and a shared one between researcher and participant. What is striking is that this indicates the participants were not simply 'going along' with me, but interrogating the assumptions made and language used. This is also apparent in the instances of disagreement.

Participants were very clear about the aspects with which they disagreed and happy to articulate these.

Ben and Hannah took issue with my interpretation of their characters as, respectively, persistent and brave. Ben rejected my interpretation, whilst acknowledging how it could have arisen:

*You don't strike me as the kind of person who gives up easily (or at all?).*

I would disagree. I'm quite passive actually.

*So in these situations where success seems to have come on the back of apparent failure (ie. not getting in first time) would you put that down to luck/circumstance more than your own persistence?*

Personally I would put it down to chance - e.g. the steward breaking a leg meaning a job opened up, the students not getting their grades so there were more places at med school...but that's my own perception and I can see how based on this conversation you might see it differently.

Hannah rejected the notion that she was brave, but in her explanation, seemed to resist the compliment as uncomfortable for her, rather than disagreeing with the interpretation per se:

I'm not sure I agree. I don't think of these things as brave, and am often a bit strange when others compliment me. I know some people find it patronising when people say it was brave of them to do something and I'm not like that. I don't know really what I think!

*Ok I'm trying to get it straight in my head...it feels uncomfortable to be told you are*

*brave as you don't think it is accurate, or would you say that what is difficult is that it's a compliment, and you don't feel comfortable being complimented?*

I think it's more the latter. I have called people brave for doing things despite anxiety, so it can't be the first as that would contradict my own thoughts.

Through this dialogue, Hannah seemed to be working out 'what she thinks' and acknowledging her own contradiction in judging herself more harshly than she would another person. Lila offers further explanation of her dislike of autism texts, in response to my initial analysis:

It is not that all texts I have read about Asperger's syndrome are inaccurate. The books about Asperger's syndrome (except 'The Curious Incident', of course) do contain facts that are correct, but the accuracy of the facts cannot dissemble the sensationalist bias of some of the works (especially 'The Complete Guide').

Within this exploration of disagreements, there also arose some key points in relation to participants' sense of an 'autism identity' and how this could colour and distort interpretations. Josh articulated this in his reminder to me that an experience is not 'autistic' simply because it is experienced by an autistic person:

Oh right, do I value something more because it was difficult to achieve so it gives it more value? Yeah, I'd say so. But you'd probably find that with most people to be honest...I think we all value things that have been hard won, you know?...it's something I'm always wary of. Would somebody classed as normal do the same thing, do you know? You've got to be so careful of creating difference where there isn't any difference as such.

Rob interrogated the language used in order to be very clear about his intended meaning in relation to the support his mother gives him:

You say “external motivation’ from informal support rather than formal support”.  
[pause] Motivation, I’m not sure is the right word there. I think practical support and kind of finding common ground like I’ve been saying, is more important because I was so impractical – in many ways the way my mother has helped me out the most is doing practical things for me...instead of just saying ‘grow up, buy your own clothes’ she just accepts me as I am and occasionally clothes appear. Do you see what I mean? And that support is not exactly motivation, it just keeps me going in being myself.

It is easy to presume that ‘enabling’ support is of primary importance, and as a former practitioner, this is where my own bias led me. In fact, Rob was talking about something far more fundamental; straightforward acceptance of Rob as he was, and practical help. He is not ‘motivated’ (the implication being ‘changed’; but rather, allowed to continue as himself). Likewise, Sandy provided further reflections on a point relating to diagnosis:

The other thing, probably more important, is that I don't entirely agree with this:  
**[analytical note in first interview]** *"Frustration with diagnosis – Generalisations render it meaningless, it becomes an unhelpful concept."*

I think it's not so much the diagnosis I'm frustrated with, it's the response. People hear autism and start to see every action through a haze of autism. I think the biggest irritation is that it becomes easy to marginalise something that can be classified away.

This is an important additional comment, articulating as it does the distinction between the autism diagnosis itself, and the response that it triggers, which leaves the person diagnosed being forced to react to these responses, and potentially being marginalised by them. Whether ‘a haze of autism’ is different or similar to the notion of ‘generalisations’ is open for discussion, but Sandy’s use of language here was most powerful, evoking the invasive, yet obscuring effect that the label can bring.

It is apparent that participants were fully engaged in the subject, and active in their efforts to achieve shared understandings of their accounts and thorough, complete interpretations. I would assert that their willingness to take issue with my analysis lends weight to the validity of the analysis as a whole. Moreover, the follow-on interviews enabled both parties, through the reflective process, to identify the most salient elements of the first interviews and explore those points more fully.

*5.4.2 “Sometimes I don’t really want to relive bad moments. And reading it wasn’t the hard part, the hard part was more like understanding that it happened.”*

Within the follow-on interviews, there was evidence that participants were reflecting on their experiences and continuing the process of interpretation and meaning-making through the process of interview and review. Several participants were explicit about this. For instance, Ben highlighted how the interview process had enabled him to consider the events himself through his discussion of them:



It's probably the first time I've been able to reflect properly on the events.

For Greg, this seemed to go further, in that through his reading of the transcript, he seemed to be accepting these events as real:

Sometimes I don't really want to relive bad moments. And reading it wasn't the hard part, the hard part was more like understanding that it happened.

For Sandy, Lila and Debbie, the analytical notes enabled them to recognise or reinforce particular aspects of themselves. Sandy noticed for the first time his tendency to make light of his achievements:

Yeah, I never really noticed, most of the things you put on the side about playing down things and saying it's easy, I didn't know I did that.

*And do you think that's fair comment?*

I think that's fair enough, yeah...I never sort of considered it really. It always sounds like boasting when I say it but it's not really when you look at it. It doesn't sound like boasting when I read it through again.

Through reading his words in transcript form, and seeing my interpretation, Sandy accepted a new and very different interpretation to his approach. Lila had a similar experience in seeing her spoken words written down:

When I read through the manuscript, I must say that I was a bit shocked because I realised that I had been using rather grandiloquent, purple and quite cumbersome language. Verbal infelicities abound...Regardless, everything you wrote down perfectly reflects our discussion, I have no cavil. It is, indeed, very surprising to read a spoken discussion you conducted, because you become aware of the mistakes

that can occur when you are having an impromptu discussion. This is very elucidatory.

Debbie was glad to see my interpretation reinforce her own:

*Was there anything else that struck you as you were reading through the transcript?*

I think the way you wrote about my sense of self not being altered by the diagnosis was something I felt happy with because that is really important to me.

There was evidence in all of these accounts that participants were taking something useful from the process and from their own participation. Each individual was active in the process of co-analysing their transcript and through doing so, engaging in a dynamic process of reflective meaning-making.

## 5.5 Theme two: Elements of success

### 5.5.1 *"Weebles wobble but they don't fall down"*

One of the predominant stereotypes in autism is that of the 'autistic savant' which is extended to encompass the idea that all autistic people have the potential to excel at something. Whilst arguably this may be true, in as much as all people generally may have the potential to excel at something, there is also a danger that unrealistic role models provide impossible aspirations for an average young autistic person who seems not to possess a 'special skill'. Participants' accounts described a range of factors related to their internal characteristics, or ways of responding to challenges, that contributed to their achievements. In these accounts, participants described their successes arising

very clearly from their efforts, and in some cases, struggles. For most, successes were hard-won and much sought-after, rather than easily come by.

For Ben, success followed a sudden, conscious decision to change a minor aspect of his approach to studying, which seemed to trigger a great progression:

But on the first day of year ten I decided to turn a new leaf and have really neat exercise books and handwriting (I know it sounds weird!)...but with that came working harder and out of nowhere in 2003 I got nine 'A\*' and two 'A' grades which was a massive massive surprise. That seemed to set me up on a path to doing really well academically.

For Josh, there was a clear sense of his target university being a goal he was aiming for, and for which he was willing to work:

I really had to pull the stops out to do that and I worked very hard in the last two or three months to get enough work done to get the credits so when I got the sixty credits which meant I was accepted to come here that was quite a good day and I was quite pleased with myself because, you know I did work pretty hard for that.

Rosie described her academic effort as a means in itself of demonstrating her potential, with the results surprising herself and others:

Yeah I did surprise myself, I would say that people did spot my potential by how hard I worked, and by how I'd done in practice essays etc., although I would also say that they were surprised as well.

Debbie also focused on self and in her description of the need to push herself to learn, she gave an account of effort that was constant and iterative, almost

like 'groundhog day' in the pressure, and also willingness, to face old challenges which incurred the same feelings of stress that new ones would provoke:

I think pushing myself and learning from repeated experiences, it has helped me develop life skills but each time I revisit anything it still causes the same amount of stress as the first time I did it.

In contrast, for Hannah the effort required was not towards the academic, but the social. Here there was evidence of the same stress and need to push herself, but for the purpose of participating in a student social event that for others would have been a source of relaxation and fun:

I rarely go out in the evenings. I did not go to my school prom or sixth form leaver's ball. So I'd never done anything like this before, so I'm proud I managed to do it - it's a step forward in my social skills and stuff.

For Lewis, the effort involved controlling his impulses to relive bad experiences and focus on his current goals:

Often I'll think if I allow my mind to go down that track again, I'll bugger up my grades, because the first time it really got me, it was at school.

This need to take and maintain control of self was also expressed by Thomas:

What matters is you take the best control you can, you do something about it and you know, you do the best you can, you make it as damn good as you can. If a man does his best what else is there?

Thomas was emphatic in his language of control, effort and striving for personal best, whatever that may be. Likewise, Bridget was very matter of fact and definite in her response that what mattered was the personal effort to do one's best:

*Do you have a goal in mind or do you just take the attitude that you're going to do the best that you can?*

[pause] the best

Rob highlighted the need to count on himself in his efforts:

A lot of self-determination...I didn't get much supervision, not much help, the guy was hardly there and tended to waffle in ways I didn't quite understand, so I did most of the work for it blindly, in a sense, and for it to have worked meant it was good to have basically done it myself.

In these accounts, the potential of self was of primary importance. All shared a determination to strive to the limits of personal ability, take control of aspects of self that may act as a barrier to progress, and to do this in spite, or even because, of barriers associated with autism.

Participants also reflected on their own learning styles and the ways in which these had influenced their successes. Josh related his liking for detail to the autistic savant artist Stephen Wiltshire:

I like detail. I think this is probably why I like archaeology because you have, there is such a lot of detail in it...Cos, doing art at school, I was quite good at art and I think that's a lot to do with perception being able to sort of like, I suppose, being able to photograph a shape you know - a picture in my mind and then be able to go

back and sort of reproduce it, you know...I wouldn't be surprised if it is a very similar skill to – what's that lad who can draw cityscapes from his memory in pencil?

Elliot and Christian also related their learning approaches to autism characteristics. Elliot considered his strengths in maths and science:

Well one of the most common things with Asperger's is to have an area of special interest...mine are mainly maths and physics and games, then almost anything to do with games is interesting to me.

Christian described his high standards as stemming from autism:

And me being OCD [obsessive compulsive disorder] because of my autism, one of my things is perfection, I am a perfectionist, I will try and get everything done as perfectly as I possibly can as well, which means that my work is of a high standard.

Others described characteristics that are often associated with autism, but did not offer an explicit link in their accounts. Sandy described having a good memory:

Memory is the thing I've got that I think helps. I've got a very good memory, I can remember stuff and it means that I don't bother with lectures very often.

Rob described his ability to focus on one area for long periods:

I have an intense way of working where I either don't do anything or if I'm interested in something I can work for hours on end without much of a break and can get a lot done very quickly. It's the kind of thing – once I know what I'm doing I'm like a freight train in a sense...and the older I've got it seems the more tutors appreciate me than not, so I think I'm calming down in a sense and they're seeing more what I'm about I

think, because I think I've learnt their way of doing things a lot better so I can express to them my kind of way of doing things better in their terms...But it's been an awful lot of effort for me [laughs] to do all this.

In contrast, Aimee highlighted the fact that her learning strengths contradicted the dominant notion of autistic strengths:

Well, I think what I've always found with autistic people is that there's always something that they're really good at and really bad at. And usually it's quite funny because I know from past people I've met, they're always really good at sums or something like that and not very good with like creative writing. I'm like the polar opposite, like making creative ideas off the top of my head. Maths though, I'm completely useless.

Some participants described having particularly strong memories and the ability to retain information of interest to them, and related this ability to autism:

Debbie: My AS I feel helps me learn my lines, I can learn scripts quickly.

Rob: Everyone always commented on how well I knew the subject, so any question a student had, I'd have an instant answer for off the top of my head and could remember dates when things were published – and students were always kind of a bit agog by this memory thing I had...I've always had a very good memory for things I'm interested in.

This facility for memorising information was perceived very simply as helpful, relevant to their achievements and a skill that came easily to them. This was in contrast to the efforts that participants described forcing themselves to make, in order to keep learning from their experiences. Greg highlighted that, for him,

there was no 'easy way' to learn:

That was when I needed to learn that I need to slow down and take a breath from these things. I kept on being reminded about this lesson when I was younger but I just didn't accept it. I guess that's the thing about...that's actually the number one reason about life, I can't learn any easy way, other than the hard way.

There was considerable contrast in these accounts, with some participants describing how their natural skills enabled them to master certain topics, apparently with ease. In other cases, the challenge was enormous and did not become easier with familiarity or repetition. To an extent, these two experiences could be divided into those that were primarily academic and those that were primarily social. However, such distinctions are never so neat. Social challenges are an essential part of the academic experience. Moreover, in some cases, the academic achievements described (eg. drama) were overtly social.

Participants spoke a great deal about their determination to succeed in particular goals, whether this was in order to achieve academic success or to participate more fully in the adult social world. After transferring to a different degree course, Ben described committing himself to his new choice:

Since being here I've got into the mindset of a future doctor and I'm willing to dedicate my life to it.

He also described taking the initiative in pushing for a role he really wanted:

*You must've been on their reserve list for them to give you a go so quickly?*

Actually now you mention it, I was pretty persistent on insisting on being put on a



reserve list and I gave them a phone call to ask if anything had opened up...

The language here was of 'persistence' and 'insistence', indicative of a tenacity and focus on the end goal. Josh described his determination to ride a bicycle, partly to overcome teasing and partly to achieve a recognised 'rite of passage':

I was still on stabilisers and there were some older boys picking on me saying like you know, stabilisers – I can't remember what they said but basically they were being very derogatory. I thought to myself 'I have got to get rid of these stabilisers – I have got to learn to ride this bike', you know... yeah, it's probably the same as passing your driving test or buying your first house or getting married – it's one of those sort of periods of your life where, whereby gaining the skill changes your life forever, if that makes any sense.

This was a determination driven by social pressure. Josh went on to explain this further in relation to difference:

I think when you've been judged– I think it makes you more determined to make a difference and to find a way of publicising the idea that 'ok. I might be a bit 'odd' in inverted commas, but I can do this'.

Here Josh's language about 'publicising the idea' seemed to move beyond a focus on individual achievement. It was about changing perceptions on a bigger scale; a 'public' scale. For Debbie, Asperger syndrome itself was a potential barrier, and the determination she needed was in not allowing it to be so:

But I think I have proved to myself that I don't allow Asperger syndrome to stop me doing things, but I think it's important not to stop.

For Debbie, what was important was proving to herself that she would not be

held back by this barrier – it was her *self* that needed to be convinced of this, and in using the past tense, she described this as a goal achieved. She *had* proved that she would not be limited by autism. Hannah's determination was linked to her passion for the subject; the goal in sight was worth the challenge involved in reaching it:

I was determined because I really wanted to go to the science festival! Also, term hadn't started yet, so I was a bit less stressed. I suppose I was quite determined to manage, I try to be.

There is emphasis here in the repetition of 'determined' underlined by the additional indication of effort that is conscious and continuous: 'I try to be'.

Rob regarded his determination as a core and lifelong character trait:

I think that's one of my character traits, stubbornness and determination, not kind of...My mum relates it to one of my childhood toys. I used to collect weebles when I was a kid, and the advert used to be 'weebles wobble but they don't fall down.'

*You're a weeble.*

Yeah and that kind of determination and stubborn streak in me, I kind of keep going, no matter what's in front of me. I think that's partly related to the autism.

Using his mother's analogy, Rob described this characteristic as central to himself - it is within the physical nature of a weeble that it cannot be knocked over, and likewise, Rob's determination to carry on in the face of challenges seemed a fundamental aspect of himself.

Bridget went through traumatic and disabling treatment for cancer as a child,

and in her description of resilience, she too conveyed this 'weebleness' of facing unquestionably the challenges in front of her:

Because you get some people saying 'why me?' Well, why anyone?

*I think a lot of people when it happens to them would find it difficult to think 'why anyone?' They would be more inclined to think 'why me?' Did you find it was OK to think 'why anyone?'*

I didn't think that. I was just coping.

Thomas talked about having only one university choice and no back-up plan:

I didn't have a second backup option at all, every other single person in my school year did and my friend even told me I was an idiot for doing it [laughs]! But like no - it was what I felt like doing so...I didn't feel like I wanted to, you know, why have a back-up that I don't feel keen on cos, if you want to do something you should be really, you should be all about it, you know, you want, you're really passionate, you want to do this thing.

Determination and passion were here inextricably linked and uncompromising. Thomas took an 'all or nothing' approach and he was counting on his personal drive and passion to take him to his ultimate goal - his first choice university. In contrast, Christian seemed ready to embrace failure and be philosophical about the experience:

You cannot achieve success if you are scared of failure. If you're not afraid to fail your chances of succeeding increase mentally but you're never going to get there unless you risk it all away. I risk failure and was proud of what I do. Sometimes 50% of the fun can actually be failing. Learning from your mistakes. Waking up the next

morning and saying 'ok here I come again'.

In many of these accounts, there was a theme of repetition. A weeble is a small toy that is perpetually in motion, always on the verge of, but never actually, falling over. Others cite the need 'not to stop' but to keep repeatedly striving, even if the hundredth attempt is every bit as stressful as the first. The experience of failure becomes an important aspect of the learning - even, in Christian's case, a positive aspect.

Lila described the impact of experiencing success as a result of such determination:

When you yourself manage to master the strength, the mettle to live, to survive actually such a situation, when you thought that everything was lost, that nothing would ever pull you out of this quagmire - if you then manage to end up with such a brilliant and fortifying remark, this does leave an indelible stamp on your...this is an indelible experience.

Lila's description was a rollercoaster of emotion, moving from the depths of despair to celebration, and importantly, describing an experience that was 'indelible'. This word signifies more than permanence, it conveys the sense that no person or experience could ever undo the good that was done; this positive experience had left its mark on Lila and could never be taken from her.

Rosie was very clear in her interpretation of her success:

*What would you attribute your success here to?*

Lots of hard work and determination, some help from my teachers.

Again and again in these accounts, participants described successes that had arisen from a conscious determination on the part of the participants: to achieve valued goals, and in doing so, be willing to risk failure; to prove to self and others that they possessed the potential for success. Linked to this was the desire to demonstrate that internal or external barriers could be overcome. Participants often framed their narratives of success within the context of obstacles to be surmounted, which they made sense of either as personal (internal) barriers, or (external) barriers associated with their autism diagnosis.

For Josh, passing his GCSE maths exam was about overcoming an area of academic weakness, one which was necessary for him to progress into higher education:

One that always sticks in my mind was when I passed my GCSE maths. Now I have always been poor at maths, I shouldn't be but I am...So, I had one chance so I re-took the core in the next year and I passed it. I got a 'C' for GCSE maths and I remember getting the piece of paper and reading it, like, and I sort of whooped with joy, skipped off down the corridor.

Josh seemed to be trying to make sense of his problem with maths in relation to his autism diagnosis – he 'shouldn't be' poor at this subject because in doing so, he was going against type. The elated response he described after finally passing is childlike in its abandon – a literal whooping and skipping. Debbie described her success in drama as originating from the desire to overcome social hurdles and develop strategies for social coping:

I have always been interested in drama from primary school. I was always in performances and I used it as a way of overcoming hurdles in the outside world. I

have watched my mom in situations before, even if its answering 'what time is it?' from a stranger as I use this as a way of trying to get through the difficult situations and speak up for myself.

What Debbie was describing here seemed to be the use of drama to create a 'social bridge' between herself and the world. Her repetition of the word 'use' suggests a purposeful employment of the tools at her disposal to overcome social difficulties. Hannah described a challenging time at school, with which she was almost unable to cope, and she took personal pride in not just coping, but excelling:

I hoped for 'A' grades in Biology and Chemistry but I was really scared I would do badly in Physics and not get the 'B' I needed to get into [uni]. Also, sixth form was really difficult for me and I considered dropping out, so I'm proud that I did well when it was difficult to just stay studying! I could have easily justified getting bad results.

There was an awareness here that in her circumstances, failure would have been an acceptable outcome. She 'could have justified it' – presumably to teachers, parents, significant others – but her motivation to get to university was strong enough to keep her on track. Her description of being 'really scared' that she would not achieve the necessary grades indicates the significance that this end goal held for her. For Lewis, the concept of success was in itself a difficult one:

*You thought of four [successes], which is great, did you have any trouble thinking of four?*

Only trouble in that I have had my bright periods, my success periods. I'm not

saying I haven't had happiness of other sorts in between them, but often the way they've ended was sad...I've chosen four that have got lasting significance or lasting legacy.

Lewis opted to define success as anything of 'lasting significance or lasting legacy' in his life. Successes for him tended to be temporal; phases of success which impacted on his life but did not necessarily end as successes per se. This reframing is interesting as it suggests that Lewis was keen to learn, and take something constructive, from every experience. Whilst not ignoring the negative, he was able to view it within the context of the positive, and this enabled him to reflect on a broad range of successes within his life. The terminology of happiness, sadness and success being used together is interesting here.

Likewise, Rob couched a success as surviving in a difficult job, from which he was eventually made redundant, seemingly for personal rather than professional reasons:

I disliked authority or power figures in my life misjudging what I was doing. I've never got on with authority very well, but I think by surviving five years in it and helping the students in the way I did, that was a success for me.

Rob described his success in terms of his own personal 'survival' and his ability to help others (his students). Again here there was a sense of tenacity, and a focus on the positive amidst the negative. For Aimee, the hurdles to be overcome were the (low) expectations that others had of her:

Well, I remember every single little meeting – you know when they have these meetings about how they think you're going to do in the future? – I remember every single time it was like 'she's doing better than we expected' and I was like 'well what did you expect?'

Aimee was very precise in her memory of 'every single little meeting' and her repetition of 'every single time' emphasises the impact of the responses she received from adults in authority, whose expectations were consistently out of step with her actual progress. Success for her was the confounding of those low expectations. Thomas reflected on developing, with his growing maturity, the will to change in order to achieve:

And I got to the thought that if someone does have a tendency to be very introverted and only focused on certain topics, if they want to change or if they want to be able to overcome that at times when they need to, I think it is possible to do that if you reckon that's right, 'I ought to change'. I think it is actually possible, definitely, to do that.

Here, Thomas described traits associated with autism: to be introverted and have a narrow focus. He hypothesised (based on his experience) that the desire to change could lead to actual change. His language conveyed a narrative of personal control and autonomy; it was not just about change, but also about identifying 'times when [he] need[s] to', suggesting that individuals could, and may choose to, retain those aspects of themselves at other times.

Elliot described re-sitting an exam once adjustments had been put in place for him, and moving from a fail grade to an 'A' grade:

Obviously a sense of achievement that I felt that I had a grade that was obviously a lot more representative of my ability...because since 'D' was a result of a particular



difficulty not as a result of not being able to do it...Well, if I had got the 'D' and then hadn't been given the opportunity to do it again and have it explained then obviously I think I would have felt a bit hard done by...But, em very happy that I obviously got the support and had the chance to try it again.

In this case, the hurdle to be overcome was a lack of understanding from his teachers. Success stemmed directly from appropriate adjustments being put in place, and in Elliot's case, the difference this made was extreme. In Elliot's comment that he would have 'felt a bit hard done by' if he had not had this support and second opportunity, there was a strong message. Although understated, it was rendered emphatic by Elliot's repetition of the word 'obviously'. Where for Elliot, this account was presented as an experience of success and self-affirmation (in his understanding that the barrier was connected with autism and not his abilities per se), for others without this second chance, it would have become an experience of failure, leaving a sense of injustice and potentially limiting educational opportunities.

Christian received school awards, and perceived those as recognition that for him, autism was not a barrier to success:

*In terms of winning those awards do you think there were other factors that might have contributed, that we haven't spoken about?*

Probably the fact that I wasn't going to let my autism get in the way and that I was saying to myself 'I'm going to do stuff to show to everyone that just because I'm autistic, doesn't mean I can't be successful'.

Again here, the language speaks of control and self-control. Christian was not

going to 'let' autism be a barrier and the repetition of 'I' here is active and purposeful. Christian's description of giving himself a pep-talk suggests an inner strength and faith in self; evidence of self-determination. Lila spoke of autism as a very personal burden:

When you have AS and when you are burdened with the debilitating knowledge that an innate, immutable condition will forever stifle your social or athletic prowess, you will want to make even harder endeavours to hone your intellectual nimbleness to the utmost. Accordingly, the dismalness of my every academic failure or flawed reasoning that I discover is hugely amplified by my excruciating quest for logical, mental and academic brilliance.

The language used here of debilitation and being stifled was vividly emotive. For Lila, academic success was crucial as a means of balancing these 'stifling' effects, and consequently, minor failures were not just amplified but 'hugely' so. It is easy then to understand why, for Lila, this situation was 'excruciating', involving as it must, extreme highs and lows. This is the language of physical pain, suggesting an intense, all-consuming experience.

Despite these narratives reflecting complex interpretations of successes as couched within ultimately unsuccessful experiences, or arising from additional challenges, nevertheless what each one revealed was a belief in the potential of the self, and a determination to hold onto that belief. For some participants, successes were inextricably linked, or directly stemming from, negative aspects of their experiences. Ben viewed his academic success as arising at least in part from limited social distractions, in turn a consequence of autism:

Socially if I didn't have AS I would have had more friends, and would have been able to

go out more...the reason I was at the far away school was because of bullying at my local schools...but having no distractions from a social life was probably instrumental in me doing well academically.

*Ok, is there anything else you'd like to say about that or shall we move on to the second event?*

Only that probably I wouldn't be where I am today without those results so that's why I see it as important, sure it was difficult socially but the positive outweighs it.

For Ben, the benefits of academic success outweighed the negative social experiences, which he associated with autism. Hannah took a similar perspective:

*Sounds like you had some good people around you. Do you regard your AS as being a factor in this event, positive or negative?*

In a way, it's both positive and negative. Having AS made school difficult, and was a big factor in making my mental health rubbish, so in that way it's very negative. But also, I didn't have much of a social life, so it was much easier to study!

Here again, the social limitations imposed by autism were linked directly to academic success. Inactive social lives offered space for a single and sustained focus on study. Greg described having to learn lessons the hard way, through difficult experiences:

And I was so convinced I was a goddamned fuck-up at what I was doing, I needed to shape-up myself more or less. It was then and there that I had to learn a lot more about patience...to be honest I'd already had the lesson thrown in my face, just not that hard.

This was part of his learning process about himself, and his growing acceptance of this aspect of himself. Aimee described what seemed to be almost a conscious personal decision to actively transform the negative of the situation into a positive:

Usually some people when they've got a problem they think 'oh yeah, I'll turn this to my advantage, I won't do any work, I'll be a troublemaker' whereas me I saw it as a positive, basically to put a middle finger up at everybody saying that I couldn't do it, saying 'yeah, well look what I just did'.

The importance of disproving others' low expectations and demonstrating her own worth and value is clear here. Barriers imposed by others' perceptions were to be broken down rather than accepted, and this in fact provided additional impetus for achievement. Lila went further, suggesting that she may have benefited from the stress associated with a challenging situation:

My hunger for words is, indeed, a positive feature of Asperger's syndrome, but it is not the only ingredient in the spectrum of abilities that make up my gift for languages, if you will excuse my immodesty...It is a good idea to point out that I might have scored so brilliantly at this vexing test not despite, but because of my hopelessness. Stress enhances memory, as demonstrated by the long-term consequences of traumatic events on patients. There is a good chance that the stress I felt during that evening actually boosted my ability to remember so much complex information within so short a period...That occasion on which I delivered an extemporaneous yet perfectly fluent speech about a specific topic was, indeed, imputable to the memory enhancement that is generally associated with Asperger's syndrome. This was one of the very rare occasions on which a disorder actually paid off.

Lila was clear that she regarded Asperger's syndrome as a disorder and a personal burden, but nevertheless, embraced and enjoyed the memory skills with which she associated it, suggesting a complex and unresolved response to her diagnosis and what it ought to mean for her. Participants here viewed successes within their broader contexts. They often presented an overview of their situation, reflecting upon experiences dispassionately, almost objectively. They were thereby able to perceive positives within outwardly difficult experiences.

Not surprisingly, participants also described ways in which they had learnt to cope with, or compensate for, difficulties, often over time as they matured and better understood their social environment and its demands upon them. Ben described his efforts to document those aspects of the social world that he could not understand:

I used to keep a book of things that had happened that I didn't understand. So if someone said something, or ignored me or pulled a face and I didn't get the reason, I'd add it to the book and cross it out later if I understood it.

*That sounds like a good strategy, was it helpful?*

It was nice to compartmentalise, almost like a brain dump or that pensieve thing in Harry Potter when you can put some thoughts in a bowl somewhere so they don't bother you.

*Did you find that more things got crossed out in time or were left uncrossed?*

Most things never got crossed out. But that was okay because I knew why and I was able to put the actual event out of my mind - otherwise I would have dwelled on it.

It seemed that for Ben, this was more of a coping mechanism than a learning tool. Although he may not have developed his understanding of the situations he recorded, by making a note of them, he was more able to set them aside, at least temporarily. Debbie described employing a persona which enabled her to cope with social situations:

Outside my immediate family I feel people don't always listen and talk over you, like they don't care what you're saying, so I don't feel as confident talking to people, but I become someone people think is quite loud as I see people doing this and are heard...

Debbie 'became' someone who was visible to others, unlike her true self, and this distinction was underlined by her description that 'people thought' she was loud, emphasising that the real, quieter Debbie was still there, but masked by this persona, which allowed her to be 'heard' rather than ignored. In contrast, Hannah relied on friends as a support and safety net, and it is the knowledge of this that enabled her to face new challenges:

I suppose I was quite determined to manage, I try to be. I did have friends in the area who I could contact if I needed to, and I could have gone home if I couldn't manage. The latter thing is again that it's easier to do things sometimes if I know it's okay if I fail, it reduces the anxiety which is sort of the main problem I have.

For Hannah, allowing herself to see the possibility of failure as acceptable was paramount. Nevertheless, her determination *not* to fail came across effectively, with repeated use of 'I', emphasising her role as the central actor. Lewis described his maturity over time contributing to achievements, and his conscious efforts to maintain control over his anxieties:

*And what do you think has contributed to where you've got to?*

I think the seventeen years in between, I think I learnt a lot and developed a lot of skills. Not just socially but emotionally and spiritually as well...I learnt how to manage [my worries] and rein them in and focus on what I'm supposed to be doing...Often I'll think if I allow my mind to go down that track again, I'll bugger up my grades, because the first time it really got me, it was at school.

In his language, there was the sense of a struggle to control his mind, which wanted to follow a potentially damaging track. This was reflected in his terminology of 'managing' and 'reining in'; the language of control and discipline. Like Lewis, Rob also expressed a development alongside his maturity:

...and the older I've got it seems the more tutors appreciate me than not so I think I'm calming down in a sense and they're seeing more what I'm about I think, because I think I've learnt their way of doing things a lot better so I can express to them my kind of way of doing things better in their terms...But it's been an awful lot of effort for me [laughs] to do all this.

Here there was a sense that Rob had over time learnt, not to change himself, but to change the way he presented himself to others. In doing so, he had been able to achieve shared understandings with others, and through this gained respect and acknowledgement for abilities that had previously been overlooked or misunderstood. Christian described using humour to cope with challenges:

I look on life with a sense of humour basically. I think that's what's helped me cope in life, looking at it with a sense of humour, you know? And the fact that if something fails you just accept reality and move on. Say if I was to fail at uni for example, I already have a fall-back plan for that...it's just that anyone who would not try and move on from

failing at uni or anything major, would live in denial for the rest of their lives.

Christian was ready and willing to fail in his efforts, and had even planned for this, so that it became less of a potential failure, and more of a potential alternative route to success.

Narratives here described a range of ways that participants had learnt to manoeuvre and manipulate themselves and/or others, in order to achieve their goals and overcome barriers. Often, these strategies hinged upon their evolving understanding of their own internal barriers, of barriers imposed by their environment, and of the relationship between the two.

#### *5.5.2 “You’re a social animal, you just need it and I’m no exception to that”*

Not surprisingly, parents featured highly as a means of support, providing practical help such as arranging extra tuition or a change of school (often due to bullying). In many cases they were also important allies and advocates, offering unconditional acceptance and belief to the individual. Rob described support from his mother as fundamental to his wellbeing:

As usual, my mother’s probably the one who helped me most in life – very supportive...in many ways the way my mother has helped me out the most is doing practical things for me...instead of just saying ‘grow up, buy your own clothes’ she just accepts me as I am and occasionally clothes appear. Do you see what I mean? And that support is not exactly motivation, it just keeps me going in being myself.

Acceptance and practical support were central here and in this example, inextricably connected. By quietly accepting Rob’s practical needs and meeting



them, his mother enabled him to 'keep going' as himself. Aimee described her initial, negative reaction to her diagnosis as a child:

Because I basically thought I was a freak, at first, a little bit. You know that first reaction you kind of think, you're just thinking...and then I think I remember my mum saying 'you're not different, you're not a freak, you've just got something that no-one else has and unfortunately you can't be undone, you know. Well, everybody might be ahead a little bit of you, but if you try your hardest you'll catch up', so that kind of convinced me. My mum's probably my biggest hero if anything.

Aimee's mother 'convinced' her to believe in herself and not be held back by her diagnosis, and in doing so, became her biggest hero. Christian likewise:

*It sounds like they've been very supportive, your parents*

Yeah. Most particularly my mom. She's the kind of person who has encouraged me to hone my creative talents you know and never let obstacles get in the way. She's always been supportive and whenever I've had a panic attack because of my autism, she's always there to ensure that I'm ok.

Through focusing on his strengths and being a reliable, supportive presence ('always there') at times of anxiety, Christian's mother offered both encouragement and a safety net. Thomas described his parents as important motivators:

...some credit must go to my parents, to my mum and dad for egging me on and going 'nah, there's good stuff out there for you, you've got to keep looking'; you know I might be lazy sometimes and play computer games instead...my parents did force me to study – [laughs] I'm being careful to choose the words correctly – they did force me to

study quite a lot for the 11+ and I passed the entrance exams to all the grammar schools.

It is interesting to note that in 'choosing his words correctly', he described them as 'forcing' him to study for the 11+ exam. In his description, Thomas seemed to appreciate this extra pressure, rather than resent it, possibly due to the positive outcome. Generally, participants highlighted ways in which their achievements had been motivated by the encouragement they received from their parents and in particular, acceptance of their difference and the determination that their children should not regard those differences as barriers to achievement.

Participants also described how they had been influenced and supported by teachers and mentors, who often spotted potential and went on to actively nurture it, providing motivation and encouragement which was instrumental to their progression. Ben described the motivation that he gained from having a supportive lecturer:

*Do you feel there have been others who have seen your potential and given their support?*

Yes there is a CEF (Clinical Education Fellow) at [name of institution] who has taken me under his wing...he gives private tuition in biology which isn't really taught here because it's assumed everyone already knows it...He told me he can see a brilliant doctor in me, if only there were a way to download all the required knowledge into my mind...It was really nice of him to say it and very motivating.

The CEF recognised the potential within Ben and offered him the additional

support he needed to fulfil it. The language used here that he had 'taken me under his wing' suggested a mothering, nurturing role. Likewise, Warren described the help that he received from his university mentor:

*And do you think this has been helpful or unhelpful?*

Yes. Though not in the sense of actually helping resolve anything.

*Yes helpful? How?*

By giving me somebody to go around in circles with and vent my obsessive thoughts to.

The university had 'given him somebody'; a description that carries more weight in the context of the social isolation often experienced by individuals on the autism spectrum. The role of a close friend often includes tolerating repeated moans and worries, or to be the recipient of 'venting'. For Ben, there either may not have been a friend close enough to rely on for this, or his close friendships may have been rare and precious commodities that he dare not put at risk by revealing vulnerabilities. Either way, the role of the mentor was seen to be a helpful one, albeit not quite in the way intended. Hannah made the distinction between some teachers and others:

My physics teachers were really great; they supported and encouraged me and didn't get angry with me like the other teachers.

For Hannah, these teachers seemed to be the exception in the patience they displayed, whilst other teachers got angry, and in doing so, created additional problems for her. Likewise, for Rob a good teacher was a rare experience, but a highly influential one:

The sociology teacher was one of the rare good teachers that I've ever had – he still writes references for me today [laughs] occasionally – and he was really good and got me going in the first sociology seminar...So good teaching and having those kind of tangible things to myself internally – 'I'm getting somewhere for myself, whatever the marks are – and other people are recognising that I'm good at something'. So that was the motivation I guess, that I've got something to say and someone's starting to listen and I'm finding a way, finally, of expressing what my ideas are about.

The importance of shared understandings was important here, and the recognition of value coming from another person. The fact that Rob's teacher listened and saw value in his work was a great motivation for him on what was to become a very successful academic path. Aimee's account also highlighted the enormous influence and motivation that the right teacher can provide:

*So this drama teacher has really been a very important mentor and influence then?*

Yeah sometimes I don't think he realises how much impact he's made...yeah he, after my family, were one of the main things that motivated me.

Likewise, Christian described a turning point in his academic path, when his natural talent in drama was spotted by a teacher:

*How did you get into drama and doing impressions?*

When I was younger really. One time I was doing comedy impressions in the playground, the music teacher spotted me and said 'I want you to come with me' and she took me to the drama department and put me in the drama club.

Once again, there was a clear connection made between the influence of an understanding teacher and the motivation to follow a particular path, associated with subsequent success. Elliot reflects upon the role of his SENCO (Special

Educational Needs Co-ordinator) in ensuring that his learning needs were met, which ultimately led to him gaining results in line with his abilities:

Hmm...It is entirely possible that if she had not been the SENCO it would have still been alright but I wouldn't be surprised if it was helpful and...yeah. I mean it's hard for me to actually specifically appreciate it and that's I think partly an empathy issue, that's the thing, that it's hard for me to actually properly feel certain things but then I don't think enough people appreciate the value of a good teacher.

It is striking to note how often one teacher, in identifying potential and actively nurturing it, provided the motivation for participants to pursue or persist on certain paths. Doubtless this is the case for many children with and without autism. What may be different in these cases, as highlighted by Hannah's example of a teacher 'who didn't get angry like the other teachers', is the potential influence of the autism condition on the teacher: pupil interaction. Autistic children are more likely to be socially isolated, socially anxious and unpopular (Howlin, 2004). They often have an uneven pattern of development and skills (Jordan and Powell, 1995). These factors can cause them to be misunderstood within a busy school environment, and their potential overlooked. We know that exclusion and outcome rates are higher for autistic children than for other groups (Batten et al., 2006). The narratives above reflect the experiences of high-achieving young autistic adults, yet more often than not, they cited only a minority of teachers who identified or sought to develop their potential, amidst a majority who misunderstood or overlooked them.

In contrast to much of the dominant autism literature which focuses on the social isolation and exclusion of autistic individuals, participants often cited the

support of peers as being instrumental to their success. Josh described the support he received from one classmate in particular:

*You said you worked very hard, were there any things you think helped you do that then? People, or..?*

Funnily enough I did have a, one thing I did have going for me on the Access course, two of the girls, well they were women, I mean like they were like sort of my age, a bit older but, we did gel together as a group and, my one friend Penny in particular, I mean, she did help me a lot with sort of study skills and sort of, not so much you know writing it for me but sort of like saying, you need to get this done and you need to look at this and you need to look at that and sort of you know sort of basically essay structure and things like that because again, this was before I was diagnosed with dyslexia, so I didn't know what problems were, you know, so she gave me a little bit of guidance so it was really more of a conduit, sort of narrowed down what I needed to do, you know, sort of like a study buddy if you like.

Josh's classmate was a 'conduit', helping to channel his focus, and a 'study buddy'. Hannah described a strong and close peer network at university, through a Christian student group:

My friends were helpful, too, because they helped me to revise and helped me cheer up when I was fed up of work.

There was formal dress, and food, and an area with music and disco lighting. I did not panic much, despite the large amounts of people. I danced, which in most situations I would be far too shy to do, as I can't really do it properly but I knew most of the people there and knew they wouldn't mock me and didn't care.

Hannah's network helped with both the academic achievement and her personal – arguably more challenging – achievement of attending the university ball. Again here, shared understandings were highlighted. Hannah's trust that she was amongst friends who would not mock her removed some barriers that would otherwise have excluded her from this situation. Her description that she 'knew they wouldn't mock [her]' was very definite and confident. There was no doubt or hesitation here; her trust was total. As a result, she was able to tolerate the sensory challenges of the environment and participate in the accepted rituals of the ball. Sandy attributed his academic accomplishments in large part to having made the right friends at university:

I mean all the way through...the friends I made in the first year are the friends I've stuck with, the people on my course. I'm living with two of them now. But they all got firsts or high 2:1s...so I think I was just lucky ending up with the people who were good at it to start with...and they read through my things and I read through theirs...also just people there to talk about stuff because that's much more helpful I think than not doing that.

These relationships were clearly mutually supportive and had been sustained successfully over several years, although Sandy described his situation as 'lucky', somewhat dismissing his own part in maintaining the friendships. Similarly, Aimee described a number of valued, close friends:

Because I have very different forms of best friends. I've got probably my oldest friend, [A] – who I've known since I was three – so she's known me my whole life and I know I am going to have that friend for life if you get what I mean. She's kind of a hero because she's been with me from the start. I've got my best guy friend, [L] – and he's just someone, pretty much like a brother from another mother if you get what I mean.

And then there's [C] who's kind of like the fun, hang-out type of friend...She's somebody from school. I met her in Year 7.

Thomas described the importance of friends, from an academic and non-academic perspective. At university, developing friendships was for him an important part of the experience and an aspect that protected him from dropping out:

And there was no question ever of dropping out for me...but overall I had lots of good lecturers and met lots of nice people on the course you know, made a bunch of friends as well while I was at university, particularly in the second half of it.

*Was that an important part of the experience do you think?*

Yeah, I think it is. There is a very tiny minority of people who do not need contact with other people and they can entirely do everything on their own and they will feel nothing and that's fair enough. I think the vast majority of people cannot do that. I think you need to have friends, you need to have a group, a family, a team or whatever, you're a social animal, you just need it and I'm no exception to that, but there's no problem there. I got on well with everyone on the course.

Lila described being aided in an academic challenge by a friend who helped her to pass an important test, when she was struggling to understand the topic:

Because it is obviously a meritorious achievement if, firstly a friend...well this is not an achievement, this is serendipity when a friend comes to succour you in such a hopeless situation.

In her description, his help gave her the strength and determination needed to persevere and she went on to describe how this experience left 'an indelible



stamp'. Lila's choice of words is powerful in illustrating how positive experiences such as this one leave a permanent mark upon the individual.

In these accounts, the role of peers was central to their achievements and much valued. Peer relationships took different forms, but commonly the support offered was twofold: practically offering informal academic support, but also offering emotional support, sometimes long-term over a period of years. These narratives do not replace the notion of autistic individuals as socially excluded - these individuals offer such narratives alongside – rather they add an important additional dimension.

Successes were often defined as such when they exemplified experiences of making connections with others, or in other ways gaining acceptance within a particular community. For example, Greg described a spontaneous decision to stand up in assembly and share his experience of having Asperger syndrome:

I just felt like I wanted to speak up and say something...Next thing you know I got a letter from one of the girl's classes that everybody's signed and it said 'thank you for being so brave'...Conquered my stage fright for quite some time.

*So what would you say were the repercussions from you having done that?*

Well, I was well-known and popular throughout the school there. I wasn't actually complaining about that.

In his account, the positive repercussions of this were transformational, making him immediately 'well known and popular'. For Lewis, success was reflected in the response he received from colleagues during a work placement:

I left after fifteen months and I'd gained a lot of respect from people and when they

discovered on the day I was leaving that I was leaving, they raised this big petition that people had signed – and my boss had signed it three times.

There was recognition and support here from both colleagues and his boss. Lewis had ‘gained respect’, suggesting active effort, and indeed success, on his part. Rob had a son who also had a diagnosis of autism, and this relationship was for him the most valuable in his life:

To be able to help him and give him that space where he’s happy and he knows his needs are going to be met and he has a lot of freedom and things to do his own thing with me as well I think. I don’t try and change his behaviours and things. If he wants to flap or inspect a hair for half an hour, that’s up to him in a way. But I think he’s very content in his existence and I think I’ve helped provide that in a way. I think it’s by far and away the biggest achievement in my life is helping him.

*It sounds like a fantastic relationship, it sounds like he’s a very lucky boy.*

Well I’m lucky too. To have him in my life, because I get on with him easier than probably anyone else because we are so similar. So it’s done me a lot of good in a way, to have that role and that relationship.

This was a relationship that was very clearly of mutual benefit. The sense that they shared a common outlook seemed to be a significant part of this. Rob’s sense of achievement in enabling his son to be a happy child, partly through his natural acceptance of his difference, was underlined by his reflection of this as ‘by far and away the biggest achievement in [his] life’: nothing else could remotely compete.

Elliot was very clear of his motivation in designing gaming walkthroughs:

With the walkthroughs it's very much the satisfaction of doing something that might help other people.

His walkthroughs were openly available online and users could post feedback, so that Elliot received recognition for his gift and through this work became a valued, visible and useful member of these communities, which was 'very satisfying' for him. Bridget described making a friend on her course who she recognised as also being autistic:

*So how has it been significant then, meeting him?*

Well, I've got a friend. Someone to compare my answers to the questions with, before I hand them in, just to check [laughs]

This was important firstly, because she had a friend: for her, a rare and exciting accomplishment. Secondly, she had a peer on her course and recognised immediately the potential benefits for her learning. Her description suggests that up to this point, Bridget had experienced not just social isolation, but also academic disadvantage. Thomas described a turning-point in his life; a sudden realisation of the social world around him and how he did, or did not, fit into it:

Before I was completely not reality-based, I would just daydream and I would absolutely not care about reality and just be in total fantasy but I think further on in secondary school, in the sixth form I kind of realised, I began enjoying things in the real world more, I began opening my eyes to them more and I began to realise, you know, I live here and I ought to make the most of it. And also as a teenager, you crave independence, don't you? And then you realise 'right, I'm going to have to do some kind of work'...I do crave human society I actually realise I depend so much on other people, I depended on my parents, I depended on society and all the infrastructures around me

that I really hadn't contributed anything to up until that point but then I'd always been independent, I wanted to be independent, I was always aloof and I realised – this was some sort of irony because I wanted to be all cool and on my own and depending on myself and yet I'm depending on all these people around me, who I haven't really contributed anything to. And that kind of became a thought I had.

Thomas began to develop a consciousness of himself within the context of others; of his dependence and need to contribute if he wanted to participate. His statement 'I do crave human society' was emphatic and also appeared to be carefully considered. The use of the term 'human society' was almost scientific - dispassionate language for what he is describing - his need of relationships with other people. This was perhaps indicative of the contradictory outlook which he identified within himself: his desire to be aloof and independent whilst at the same time being dependent and in need of relationships.

Christian also described a transformational experience, when he started to entertain his peers by doing impressions in the playground:

I did Vicki Pollard from Little Britain and I thought 'oh good, I've made some people laugh', I felt good about myself and then I didn't think about it again until I came back the next day and it turns out they'd told the whole of year 9 what I was good at.

*That sounds like a major shift then?*

Yeah. And it cured my phobia. I used to hang around the playground by myself and then other people who knew me, and were nice to me asked if I wanted to come and hang with them. And as I became popular it cured my phobia, I was able to talk to people more and as you can see now, I'm able to speak proper and fluent English.

The positive recognition he received from this experience had a huge effect, enabling him to develop friendship and more - 'become popular' and overcome phobias. Lila described an occasion when she delivered a project based on her knowledge of the pop singer Madonna:

And I disappointed nobody; not my teacher, not myself, and certainly not my students...I delivered abnormally detailed facts about Madonna's life in painstaking minutiae and a suave fluency which made my audience gasp with amazement. The one minute that I had went by rather quickly, as you can guess...everything came out of my mind very easily and I had only read about Madonna...well, Madonna was a topic that I had studied with some passion but...this time I really was the centre of positive attention. I still see the radiant smiles of my audience...The room reverberated with laughter which was free of any poisonous tinge. This was one of the very rare occasions on which I felt integrated into an atmosphere of warmth and serenity, a situation I had hardly ever encountered at school before.

Once again here, there was a description of transformation from 'bizarre outsider' to 'the centre of positive attention', and for Lila, this feeling of inclusion and acceptance was entirely novel, and an opportunity to reveal aspects of herself that she felt had hitherto been ignored or overlooked by peers and teachers. In these narratives, what was often described was a personal transformation from invisible to visible: through particular experiences or opportunities seized, participants were able to exert an influence on those around them, and this experience, often rare, was greatly valued and sometimes life-changing.

Participants shared specific experiences of achieving recognition, formal and informal, and the ways in which these influenced their further achievements.

Debbie described using her skills at drama to make an impact on others:

My psychologist questioned why I would choose to take drama as it's not the easiest subject to take having Asperger Syndrome, but as I really enjoyed it I found my confidence grew and people finally knew who Debbie was, because they then knew me as the one who's really good at drama, when before they thought of me as the shy girl who didn't say very much...so now I'm continuing to do drama at university and I'm getting the same reaction and this makes me happy that people know me because of something I'm good at.

Her skills allowed her to re-invent herself to others as having a specific talent. Her use of 'finally' suggests a frustrating wait to be recognised in a positive way and in a way that she felt reflected her true self. Hannah described the impact that supportive teachers had on her:

I think their kinder attitude towards me was important because it relieved me of some of my anxiety and therefore helped me not give up and also not to be so anxious I couldn't function properly...I also wanted to do well to sort of thank them for their encouragement if that makes any sense. I wanted to do well to show that they were right to support me and that it helped. I suppose that sort of links with what you said earlier about feeling good that I proved to people who believed in me they were right. I understand a bit more what you were saying now, I think.

In addition to the direct benefits of a supportive teaching approach, the input of these teachers served to enable Hannah to cope with anxieties that may otherwise have caused her to give up. Moreover, there was additional

motivation for her to do well in order to validate their faith in her. Here there is a sense of mutuality and value in the personal relationship as well as the teacher: pupil contract. Aimee described getting her GCSEs:

Because that, at that point, was a way to sort of prove to people that I could do it, could get good grades...And the 'B' was in Drama so I think through that I managed to find my passion, in Drama. I went on to do an 'A' Level and BTec in Theatre Studies, so that was a big highlight for me.

Again, this success was twofold; firstly, she proved her abilities to others and secondly, through achieving a good grade in Drama she 'managed to find her passion'. The external recognition of a formal grading seemed to be helpful in showing Aimee where her skills lay, and 'through that' she found her passion. Christian also described external recognition from both peers and teachers:

Yeah, so it's pretty cool because a lot of people tend to respect me because of what I've accomplished. Whether or not they like me or don't like me, they all respect me because of what I've overcome in my life and what I've accomplished thus far and they're thinking 'oh he's someone who never let what he's got wrong with him get in the way of his life' and that he's going to go on to do something great.

*And do you feel that those prizes were a real recognition of that then?*

Yeah. Because it just made me work harder, made me more determined as well and I think it made my parents back me up even more because they were even more impressed 'oh he can do it you know, and he'll get better over the years'...and my intelligence has got better over the years. I've got more knowledge of the stuff I'm interested in and became more hard working.

Recognition here was tied in with respect, and the formal accolades of being awarded prizes were valuable both to promote the message to parents and peers that 'he can do it you know', and to foster greater determination within Christian. However, Lila gave a very different example and perspective:

My teacher said to my mother that I already had the academic level of some of those students who were in the last year of secondary school, and hence studying for their school leaving examinations...I found the overall course so extremely easy to process that I regarded that teacher's remark as an almost superfluous corroboration of my unspoken instincts. Now, however, I consider more vividly that I was not even twelve at the time, so that the mere recollection of that remark now suffuses me with unalloyed elation.

An accolade which did not seem to Lila to be greatly valued by her at the time, nevertheless retained and in fact increased its significance to her over time. Within these narratives, what comes out very clearly is the importance of this formal, external recognition, through both grades and prizes, in consolidating participants' sense of their own abilities. In some cases, it seemed that grades were important in signposting individuals to their areas of strength, leading them to pursue those areas with greater focus and enthusiasm.

Participants were often explicit in linking success to the act of proving their potential to others, although the ways in which this was experienced by individuals varied greatly. For Debbie, being required to demonstrate her potential to learn to drive, before being allowed to do so (as this was called into question due to her diagnosis) had the effect of tainting the experience of success for her:



I'm very determined, but I think a lot of the things like my driving that I achieved is not as much of a success when you have to prove you can then drive.

Rosie gave a similar message:

*And do you feel Asperger syndrome was relevant in any way to this?"*

I guess it made me even more determined to succeed, that I could get good grades, despite the difficulties.

Within these narratives, participants described a determination to succeed which, at least in part, was fuelled by other's questioning of their potential. Although they expressed frustration and injustice at their abilities being put into question, their sense of purpose appeared to remain intact, even strengthened by the conflict.

Successes were often defined as the links achieved with others through shared interests, or a natural talent being recognised. Debbie had used her drama to present a different aspect of herself to others:

So now I'm continuing to do drama at University and I'm getting the same reaction and this makes me happy that people know me because of something I'm good at.

The idea that other people, perhaps for the first time, associated her with a talent 'made [her] happy', reflecting both her need for this external validation and her appreciation of it. For Rob, using his natural interests to enthuse his students and his personal experiences to empathise with them, led him to have a fulfilling role as a teacher:

*So in what way was it significant to you, the teaching?*

Well, I felt successful because I was helping others and I was getting very positive feedback every year and students went on and some have got firsts and 2:1s in their degrees and have sent me letters thanking me for my input and for getting them started on their paths. I think I had quite a big impact on some because I related to a lot of access students who hadn't done so well first time round in education, because I had a terrible time at school and things like that, so I think I had some understanding of where they were and compassion for it...That did me a lot of good, that I could help people. That's what I wanted to do, to teach about my special interests as they say and infuse that.

In this instance, Rob measured his success by the feedback he received and the impact he had on his students. He identified a common experience between himself and his students and in his use of language - 'relating', 'understanding' and 'compassion' - there are indicators of him actively reaching out for shared understandings, and directly benefiting from helping others. Christian described his discovery that he could entertain peers with his impressions:

And they laughed their heads off because they absolutely loved it because I did Vicki Pollard from Little Britain and I thought 'oh good, I've made some people laugh', I felt good about myself...Because I like to joke with people, I like to make jokes about really strong things, do you know what I mean. And people are OK with that and people can relate to me on that and I think that's why a lot of people like me, because I'm funny to them and I use my sense of humour to get through life.

Again, the positive impact he was able to have on others influenced how he felt about himself, raising his self-esteem and confidence, and leading to the breaking down of some internal barriers; in his case, extreme anxiety and social

phobias. The discovery, not of the talent per se but the way it could influence others, was significant here as a survival strategy – ‘he ‘used [his] sense of humour to get through life’. These narratives revealed ways in which the sense of self was directly influenced by the reactions of others. Participants were bolstered, enthused and motivated by the positive reactions they were able to trigger in others through exploitation of their natural talents.

In some cases, diagnosis of autism was felt to be instrumental in the achievement of success, through the support that followed. Debbie described the support she received post-diagnosis as making the difference between passing and failing her GCSEs:

After getting the diagnosis mom called for another meeting to arrange support as she didn't want me to fail, so she explained all of my stresses and managed to get me a room on my own with a key to go to the toilet if I needed to, as the toilet is also a big issue for me...after doing my GCSEs in a room I then passed them which proved it was the environment rather than my learning skills which my mom knew.

These relatively small adjustments validated Debbie’s experience of having the potential to achieve, but being unable to do so because her support needs had not been recognised. Likewise for Elliot, the support he received raised his grade from a ‘D’ to an ‘A’, evidencing his need to have his learning style fully understood:

Well, if I had got the ‘D’ and then hadn’t been given the opportunity to do it again and have it explained then obviously I think I would have felt a bit hard done by...but, em very happy that I obviously got the support and had the chance to try it again.

Elliot's comment that, had he not had the support and opportunity to re-take, he would have 'felt a bit hard done by' resonates all the more, reflecting as it does the experience of many other young people like him. His words reflect his awareness that he narrowly avoided this experience of unjust failure. These examples share the story of a 'near miss'. These two individuals did succeed and went on to be successful within higher education. However, they each narrowly missed failing in their exams, which would have undoubtedly affected their confidence and future opportunities, and both were absolutely clear that the difference between success and failure rested on recognition of, and support for, their autistic condition.

### *5.5.3 "I really wanted to go to university to sort of get away and start anew"*

Participants described their efforts to reach university, articulating a strong sense of purpose towards the end goal. Ben described a great sense of achievement:

*In what ways was it significant to you, getting into med. school?*

It was a turning point like, after everything in education, all those difficult times, I'd made it (and a very difficult group interview! Not very autism-friendly way to select future doctors).

For Ben, it was 'a turning point' and in the use of his words 'I'd made it' after numerous challenges, there was the sense of reaching a summit: the end goal. Likewise, for Warren, the whole experience was important and positive:

Everything was much better, even with the issues about girls still. I was in such a bad

way in those two years I would consider the last three years of uni worth borrowing all that money even if there wasn't a degree at the end.

Again here, the university experience was better than the school one, and in itself enormously valuable, even without the academic qualification. Hannah articulated the transition to university as an opportunity for re-invention:

*It is doubly amazing that you got the results that you did then. And by the sound of things it was important for you to get into [name of institution]?*

I really wanted to go to university to sort of get away and start new. I only needed 'BBB' to get into [name of institution], and I was happy I exceeded this.

In contrast, Thomas was focused solely on the academic aspects:

The sort of things that matter the most to me was the academic basically, for me that's all about my education in university really so I was going to be getting into [name of institution] in the first place is obviously the only university that I applied to and sort of I really wanted to get in and for me it felt like everything rested on me getting in.

Thomas employed the high risk strategy of aiming for just one university, with therefore 'everything resting on it'. Participants' accounts were striking in their focus at aiming for their desired university. Higher education in these narratives was more than a 'next step'; it was a hugely significant goal, in some cases promising much more than an academic opportunity. Through the university experience, participants hoped to achieve a positive 'new start', and from these accounts, it would seem that they were often successful in doing so.

Accounts also described ways in which the higher education experience seemed to have a very direct influence upon personal development. Greg

reflected on his maturing self:

I'm definitely a whole lot more mature than I used to be though I'm still changing. Uni actually does that to you.

In his use of the words 'Uni actually does that to you' there was a sense of university being the active player, manipulating the individual. Aimee employed a similar description:

So I think that's a high, university is getting me more mature.

Thomas described his development differently:

But what I really feel I'm getting from it, it's the qualification but it's not just the experience of it. It's the experience of all the work that I've done, all the field work and the write-ups and the people I've met, the people on my course, friends I've made and the time that I've been there - I've developed more as a person as well.

Thomas was 'getting' an entire holistic experience which was developing him as a person. He was the active player in this, 'getting' benefits from the university rather than having them conferred, and he emphasised the social as well as the academic development. The experience of higher education in these accounts is very much a holistic one; participants reflected on their personal development and maturity and the fact that university itself was a catalyst for this.

## 5.6 Theme three: Identity and autism

'Success' can stem from a subjective judgement or from some external measure such as a prize or a qualification, and participants provided examples of both in their accounts. This research was concerned with how participants perceived their successes, both in terms of how they identified what these were, and in what ways, if any, they related them to their diagnosis of autism.

One of the salient features of autism is that it is largely a 'hidden disability', bearing no physical or visible indicators. Additionally, there is to date no biological test to diagnose the condition. Diagnosis is based on observable behaviours that meet set criteria (Boucher, 2009). As such, this carries an element of subjectivity, and the recent updates to DSM criteria stemmed in part from the unreliability of distinctions between sub-categories such as Asperger syndrome and high-functioning autism (Wing, Gould and Gillberg, 2011).

Autism is a condition in which many of the difficulties are connected with social interaction. However, social and communication difficulties can be experienced internally as well as a result of social exchanges. For instance, an individual can be aware that they do not comprehend a particular kind of communication that is clear to others, without others being aware that they do not comprehend. Both of these types of experiences were present in participants' accounts.

### 5.6.1 *"What I have always felt, like I was on the outside looking in"*

Participants described ways in which they perceived that they were different: for some, there had been a persistent sense of being different, interpreted via both

the reactions they received from peers and their own observations of the ways in which peers behaved and interacted with one another. For Ben, his autism diagnosis was welcomed as an explanation for long-standing difficulties. Nevertheless, this was not without its anxieties and uncertainties, both in terms of the authenticity of the 'autism identity' and his own conscious or sub-conscious reaction to it:

*So how did you feel about getting the diagnosis?*

Pleased! Because it seems to explain so much about the issues I've had all my life...

Likewise, Rosie reflects on how things would be if she did not have autism:

Yeah, I just feel frustrated by certain things that I can't do or don't understand, and sometimes wonder what it would be like if I didn't have AS...Well for instance in certain social situations when I don't understand what someone has said.

In these accounts, participants imagined *themselves* but without autism - autism was considered to be something potentially removeable rather than an intrinsic part of the self. Some participants described the difference between their perception of themselves as being 'alright' and the reactions they received from others, which signalled to them in different ways that perhaps they were not. Josh recalled:

I have always, my parents, well obviously, you never look at yourself do you? You are always feeling 'well I'm alright', you know, but people obviously, people look at you, third parties look at you and sort of think, that I was always, people always thought I was somehow different, in a nice way but it was just like some people called me a bit nerdy and a friend of mine used to call me an anorak and things like this you know, and



then, I always had problems with time management and never understanding jokes.

Whereas Josh had an awareness of aspects of life with which he seemed to struggle, alongside the reactions he perceived from others, Lewis did not, and his perception of being different stemmed entirely from the different treatment he received:

I know I was suspected of having some sort of autism in my early years. It didn't occur to me that 'you're a bit different because you keep getting taken to Great Ormond Street and you see three therapists'...and it never occurred to me 'oh. Why can't I be with all the other kids in school instead?' That didn't occur to me until I was about eight or nine. But even then I thought well, I'm overcoming my problems...But anyway, it wasn't until about a year after I left school that I realised my problems weren't going away.

Lewis's repetition of the phrase 'didn't occur to me' conveyed a sense of insistence. Even in the face of signs to the contrary, Lewis did not recognise his difference, and again and again did not do so. There was a sense here that for Lewis, difference was for some time being rejected and denied by him. Difference was often experienced through reflections on personal struggles to understand and respond appropriately to social demands, as in Warren's experience:

I can't do what [E] does, and look at somebody's face and tell what they think of me, or figure out if they want to be touched etc. without anyone saying anything. I also don't like getting too drunk (though do sometimes) and don't binge drink (ie. don't drink with intent of getting drunk) and don't think being drunk really relaxes me. I think it interferes with the conscious effort I have to put into socialising (much of which is presumably subconscious for NTs even when drunk) which makes me not like most of the students I

meet.

In this account, Warren hypothesised on both the social skills and the cultural habits of his peers, and compared himself to them, identifying his difference through these comparisons. Although Warren did relate this to autism and the effort required to be social, it was also in part his personal choice. Difference here was therefore recounted as individuality as well as autistic difference. Greg observed his peers interacting as a group and, like an anthropologist, tried to make sense of their cultural norms:

Basically I'm still going through some, shall we say, phases, like understanding I've made a change for myself, I don't have to say something, like I'm still trying to understand sarcasm without pissing someone off. Of course that's still in progress. And so far, just understanding how different people work and sometimes...that every action can mean something completely different...that and still understanding how people react to one another.

For Debbie, reading a work of fiction which featured an autistic character was an unwelcome experience, triggering recognition of links between herself and the character, and in doing so, the gap between herself and her peers:

I did have to read 'The Curious Incident of the Dog in the Night-Time' for my fiction class and I found it very difficult to get through because a lot of the things that were written I related with and when everyone was discussing the book I felt the difference between me and everyone in that room.

Debbie's description of 'feeling the difference' was a powerful one. The novel's narrator describes events from his own perspective. Due to his limited

awareness of wider social context, he is an 'unreliable narrator', and it is this aspect that serves to provide much of the dramatic tension in the narrative, as key information is revealed piecemeal, and left for the reader to assemble. The contrast between Debbie relating to the book's narrator, and her peers analysing him as essentially a literary device, served to compound her awareness of difference in a form most unwelcome to her. Her internal experience was here represented more accurately by a fictionalised character than by her closest peers. In contrast, Bridget described recognising a shared difference with another student on her course, leading to the development of a friendship:

There was only one space left and I went round and asked the boy who was sitting next to the space if there was anyone sitting here and he said no and then he asked if I could keep to my space and not touch him. I knew then he had Asperger's [laughs]...that happened and we're friends now, I've got friends.

Here there was again a recognition of shared difference, but in this instance, it was welcome and served to provide mutual support in the form of a most valued (and rare) 'friend'. Bridget's emphasis here: 'we're friends now, I've got friends' highlighted the significance of this experience to her life, an experience that arose directly from her identifying as an autistic person and relating to an autistic peer.

Some participants described few or no overtly social problems, but reflected upon inner or 'hidden' differences that they had observed, but felt others had not, such as in the cases of Thomas and Sandy:

Thomas: I don't know if you pick up any sort of difference when you speak to me

compared to when you speak with other people?...If I'm trying to get something across, particularly something complicated, I try to assemble it all in my mind as quickly as I can before coming out with it...Yeah OK, so you might not think I have Asperger's Syndrome if you didn't know and you'd just met me a few times. But yeah, like I said, I think in terms of thought process and in fact the general way I think and see the world.

Sandy: I don't do all of the other things that I hear about as being part of it. I don't do most of the things anyway. And generally speaking I talk to people quite well, I think. And they seem to be the salient things about having it, so I don't necessarily think particularly I've got it. But, that said, there are things I do. I do occasionally think 'oh. That's a weird thing to do'.

Thomas and Sandy did not particularly identify with their respective diagnoses of autism, questioning whether they fitted the criteria, although both did identify characteristics within themselves associated with autism. For them, these characteristics were largely internal: 'the way I think and see the world' rather than apparent to others. In a similar vein, Lila described the intensity of her inner thoughts, which in her case, could cause behaviours that drew negative reactions from others:

I tend to mouth words when I am overcome by so intensive thoughts that I can't control the movements of my mouth and I have to utter them, but since there is no-one to whom I can verbalise these thoughts I tend to inadvertently voice them to myself. And that, of course, triggers bullying.

Awareness of difference here was multi-faceted. For some, difference was perceived largely as internal, in terms of cognitive processes or outlook; for others, it was recognised only from the reactions of others and the experience of being treated differently. Participants reflected on their non-autistic peers and hypothesised about how their experiences – and abilities - compared. Autistic peers could be the source of mutual support and friendship, but likewise, relating to an ‘autistic identity’ could serve to alienate further, or provide a template that still did not quite fit. Frustration and confusion were repeated expressions in the accounts of trying to fathom cultural and social norms, but there was also, throughout these accounts, a purposefulness in the efforts that participants were making to understand their social environments, and in doing so, better thrive within them.

Participants described ways in which they perceived that individual differences and/or impairments had impacted on their achievements. Ben described difficulties that he related directly to autism:

Again (story of my life) I had social issues at University and it was a very tough time for me, and ultimately I had to drop out in my fourth year due to depression. This meant I was awarded a Bachelor’s degree instead of the Master’s I should have got.

*...would you see your confusion about feelings towards others as related to your AS?*

Yes a direct consequence in my view. I may be wrong.

Warren described communication difficulties and the barrier they posed to making social contact, contrasting his perceived limitations in this area to the skills, apparently displayed instinctively, by his ‘neurotypical’ friend:

It is the main reason I can't meet strangers in clubs I'm certain. I can't reliably communicate with somebody if I can't talk to them. And clubs are too noisy and busy. Even in bars I can't approach strangers, I've only managed that in 'safe'-feeling environments like school, uni or work. I can't do what [E] does, and look at somebody's face and tell what they think of me, or figure out if they want to be touched etc. without anyone saying anything.

Hannah described the achievement of attending her university ball:

I do not go to clubs, or very many parties (never parties with a load of loud music and people and lights). I rarely go out in the evenings. I did not go to my school prom or sixth form leaver's ball. So I'd never done anything like this before, so I'm proud I managed to do it - it's a step forward in my social skills and stuff. There was formal dress, and food, and an area with music and disco lighting. I did not panic much, despite the large amounts of people. I danced, which in most situations I would be far too shy to do, as I can't really do it properly but I knew most of the people there and knew they wouldn't mock me and didn't care. I also danced with other people - I am even more reluctant to do this as I feel I am a nuisance to them and I have problems with touching.

Both of these accounts described the additional challenges experienced because of sensory differences. In the context of the university culture, access to social opportunities is often synonymous with loud music and parties, which can be problematic for certain types of student, including those on the autism spectrum (Madriaga, 2010).

Debbie described her motivation for writing about autism and sharing her experiences:

Having AS I wasn't able to let people know how I felt and things I felt difficult, the only person I would tell is my mom, but as I get old I feel it's important to let people know as other people who have been diagnosed may feel the same and not be able to let people know.

For Debbie, the communication barrier extended to her being unable to articulate her personal struggle, but with adult maturity seemed to come an awareness of the benefits of doing so, not just for her own sake but also for others in a similar position. Greg reflected on the complex interactions between social groups and his own confusion in determining what was genuine and what was play-acting:

Like say if I was watching two people having a conversation, I couldn't tell if they were being sarcastic or being meaningful. Then say, there was a group of people, just trying to take the piss out of one another - that it was a little difficult for me to understand. There was one group I know that actually revolved their friendship with a complete circle of hatred. Which was really really confusing for me, I mean insults turning to friendship.

Interactions in such circumstances are informal and fluid, often with much posturing and bravado, as young people endeavour to impress their peers. Compared to the workplace or more formal settings, there are few clear conventions, or in some cases, the breeching of convention is what is expected. For Greg, these apparent contradictions were upsetting and confusing and his choice of words 'circle of hatred' gives an indication of the strong emotions he perceived in these interactions, and was trying to understand.

This articulation of wondering how life would be without autism was repeated by others. Lewis recounted a growing awareness of problems that were not going away, and which were preventing him from getting on at work:

Again I thought you know, I've had problems in the past but I'd overcome them. But you know it was noticeable that when stress, when stressful things happened in my life, you know, like moving up to secondary...Anyway, I got to the point when I was about nineteen or twenty – I realised that whatever problems I had remaining were affecting my ability to carry out and understand instructions in the workplace.

Rob likewise described ways in which his communication style interfered with him being able to do what was expected from him at work:

I didn't like being in the office, so I would avoid being there and avoid my manager because I didn't want to interact with her and things. And when there is a personality clash, I tend to withdraw or avoid, which isn't always the best thing to do.

Thomas reflected on his childhood and the fact that his lack of interest in sport was in fact a social fear:

I loved to play in the garden and I loved to do all that stuff - what prevented me from playing in the street or the park or playing team sports was more the social thing. I had lots of energy and I loved spending it but I think it was more the social thing because if I remember my Asperger's was much more pronounced when I was younger when I was a kid...and if I'm like that with other people they might go 'oh, this guy's strange' and their acceptance may go lower and that will make my like and trust of them become lower and then that will make their acceptance of me go lower and I'll think 'ah, these guys are not my friends' and then it'll go even lower.



In this description there was a repeated downward spiral, as firstly the (potentially) negative reaction of his peer, and then his own in response, reduced the interaction to a mutual rejection. Thomas seemed to be describing a situation with which he was very familiar, and which he had taken time to analyse.

Christian described his earlier paranoia about being bullied:

Because every now and then I tend to be paranoid about something going wrong – I hold my hands up about that – but back then it was really worse, much worse than what it is now, I was much more paranoid.

In these accounts, participants gave an awareness of ways in which their experiences and opportunities were, or had been, limited by social or sensory barriers. There was in each account evidence of considerable analysis and reflection, both of self and of contexts, in an attempt to develop understanding and find ways of overcoming the barriers described. What stands out is the intermingling of ‘socially’ and ‘individually’ derived differences. Boundaries between the two were not clear and interrogation of a description of the latter at times revealed the former.

Participants articulated ways in which they felt on the outside of ‘what life is like for everyone else’ and described their efforts to find ways or places in which to belong. For example, Josh articulated ‘being on the outside looking in’ and for him, this had been a disadvantage to overcome:

So, if somebody who is on the outside looking in which is what I have always felt, like I was on the outside looking in, sometimes by choice, other times it is because I’d like to

be involved but I am not.

Nevertheless, Josh acknowledged that his outsider role was sometimes adopted by choice, rather than imposed. Debbie described her motivation for studying drama:

I think I may be good at it because of using acting as a way of getting through life as the only time people see the real me is when I'm in the house with my mom, brother and sister. This then would change if anyone visited.

For Debbie, drama was a natural choice as she has regarded her real-life interactions as drama performances, taking on the role she perceived as most acceptable rather than revealing her true self. Here, the outsider was concealed, visible only to her closest family. Hannah described joining a Christian community, despite being an atheist:

Ironically, it's the first time I've ever felt part of a community...Ironically because the first place I have really fit in is somewhere where I am obviously different to everyone else - they are all Christian, and I'm not. So that would logically be somewhere I fit in even less.

Hannah's description of being 'obviously different' was interesting here. Perhaps being an 'official' outsider in this situation was more comfortable than being expected to conform. Whilst Debbie felt obliged to "pass" (Goffman, 1963, p.92), Hannah was more free in this group to just be different on her own terms. Likewise, in discussing the job he had secured, Thomas talked of belonging in an environment which on the face of it, was alien and strange for him:

Cities are alright but I think, you know in a lot of places I feel like I do not really belong whereas I think that if I go up in Finland and, you know, work with these nice people on this Husky Farm and I think I'll get on with them very well, I think very similar, I will feel I belong a lot more.

What was common to these accounts was the effort to 'belong', whether by adjusting behaviour or by finding the right environment. Striking also, was the nature of the environment that might be 'right'. Individuals were not necessarily seeking places that suited their interests or beliefs, but rather seeking acceptance and the feeling of belonging. Thomas reinforced this with his memory of childhood, when he was less socially aware:

Everyone needs acceptance right but when I was younger, even when I was more of a little kid and more into myself, in my own world, even then I wanted to be accepted and liked.

Lila described having the opportunity to impress her classmates with a project:

I had always suffered from my ignominious position as the bizarre outsider who was the ideal target for bullying and who was misunderstood by her teachers in the bargain and when you go through such hardships you can more easily sense when an opportunity is imminent to present a positive and more shining side to your personality and your abilities.

This was a rare opportunity to reveal herself to her peers and gain their understanding, and in her description, the intensity of the experience is evident:

And in retrospect I'm really nonplussed by my candour and my loquacity, because usually I'm very reticent and coy and not at all talkative...Maybe I had remained a silent person for too long a time.

Lila expressed here a need to communicate something of herself to her peers and move from being 'a silent person' to someone actively presenting her abilities and indeed, her *self*. Her closing comment 'Maybe I had remained a silent person for too long a time' suggested a repression of feelings and expressions that needed an outlet. These accounts talked of the search for acceptance, and actions taken to find it. Individuals perceived themselves as outsiders, but they were also agents of their own destinies, open to new opportunities and seizing them when they arose.

#### *5.6.2 "I feel that having the diagnosis put this barrier there as they looked at the label instead of me"*

Participants talked of the ways in which autism, either through the 'label' or through the associated difficulties, had acted as a barrier for them. Josh described the ways in which educational and social structures worked against his learning style and needs:

Yeah I think you are at a disadvantage in an education system, particularly in a, this type of education system where a lot of onus is put on group work and things like that...you do lose out socially as well, definitely, I mean I happen to have experienced my education, I've missed out on a lot over the years you know, various things like, you know, going round to somebody's house for a party and school trips and things like that.

Debbie talked of the diagnosis itself as a barrier:

I feel that having the diagnosis put this barrier there as they looked at the label instead of me and this is why I don't tell many people that I have a disability...it knocks your confidence as it feels like you have to be searched just because you have a disability, and I understand why they do this, but it isn't very nice to be on the receiving end.

For Debbie, her own identity had been replaced by the label of autism, and so she preferred to hide the label. Hannah perceived her successes in the light of the barriers resulting from autism, so that it was the overcoming of these barriers that defined the successes:

It's the autism that makes this difficult, which makes overcoming it significant.

Lila made a similar point:

But even if someone does achieve meritorious things in a particular area, I do not believe that these high achievements are connected or caused by Asperger's syndrome. I believe that those people who have Asperger's syndrome and who have become, who have enjoyed above average success, I believe that they are successful despite having Asperger's syndrome, not because of it.

For her, even the greatest achievements of an autistic person should be perceived as arising in spite of, and not due to, the autism. Thomas, in describing being included in sport, suggested that others need to take the initiative to invite their autistic peers, who may be unable to initiate such opportunities themselves:

If there's someone on the AS spectrum and they want to come out a bit more, they want to communicate more with people, maybe they want to change, be necessarily more

open, sometimes it's easier for other people to make the push to them than it may be for them to make that.

Thomas made the point here that barriers can be removed through quite simple actions, as was the case with him. In his description, Thomas repeatedly referred to the 'need' for social acceptance according to the cultural norms of the context. In his reflection on his school years, he relayed that for him, this was the case even when his outward behaviour seemed to be conveying the opposite. He was a child happy in his own world, but, in his adult reflections at least, this belied the fact that he did nevertheless want acceptance from his peers.

In these accounts, the autistic experience was one of facing barriers, both those imposed by the condition, and those imposed by a society that relies heavily on the internalising of social conventions. Individuals had to find ways of overcoming these barriers in order to achieve success, and in some cases, it was this additional challenge that defined the success.

Participants often couched the 'autistic identity' in contrast to the 'neurotypical identity'. Autism is often regarded as being on a continuum, meeting 'typical' at a certain, but non-specified point on the continuum. It is perhaps unsurprising then, that participants considered the typical/autistic boundaries in relation to themselves. Ben articulated perfectly this non-specificity, in describing how his sense of himself as an autistic person could change according to mood or circumstance:

On a good day it's just barely there, just something in the background but on a bad day when you're sat on your own (or reading Facebook and seeing what life is like for everyone else) it is tempting to imagine how things might have been different.

It is interesting that for Ben, being alone may have been the trigger to make autism a problem – it was the non-social time that seemed to highlight the social gaps in his life. In this example, Facebook seemed to compound the problem rather than alleviating it. This may seem surprising, since social media has been held up as offering great potential for autistic users. However, as it is a social medium that often mirrors real social groupings, it can also, as here, serve to remind users of a social world from which they are excluded.

In contrast, Josh considered how the same trait could be viewed as autistic or typical, depending on who was doing the viewing:

Would somebody classed as normal do the same thing, do you know? You've got to be so careful of creating difference where there isn't any difference as such...Is my anxiety AS or is my anxiety that a normal person would have. Getting anxious over my driving test for example. Plenty of people get anxious over a driving test.

In his caution about 'creating difference where there isn't any difference as such', Josh articulated a key dilemma. Participants described awareness of difference, both in their approach to the world and the response of others to them. However, they were still very much in-the-world, and these differences were not all-encompassing. Josh's words caution that the label can in fact have a de-humanising effect; the dominance of 'difference' over commonality in the 'autism identity'. Likewise, Sandy, who was unsure if he agreed with his autism

diagnosis, reflected on the complexity of defining associated characteristics within himself:

It's at least very difficult and probably impossible to say – 'well it's not' or 'yes it is'. Regardless of what you say it's going to be part of you because it's intimately linked. Or not intimately linked but I don't know what the difference is. And nor do they...after a while people start saying everything is to do with it. And then what's the point of saying it?

Again here, the lack of clarity regarding such distinctions was raised with evident frustration. The efforts to identify boundaries between 'typical'/'autistic' and indeed, between 'autism'/'self' were so complex, subjective and ultimately elusive that they became futile: 'then what's the point of saying it?'

Hannah considered her social success in achieving, through considerable effort and courage, what a 'normal' [her words] person would manage with relative ease:

It's the autism that made it a success, really. Normal people without autism or anxiety issues just do these things. It's a success 'cause I managed to do it despite the autism making it difficult.

Lewis described a 'no-man's land' of autism:

Either you're mentally handicapped and you can't do anything about it or you're normal and you can do things about yourself, but it didn't occur to me that there was maybe a problem in-between, where you sort of have the pre-disposition to do those things and you need telling but it doesn't come to you naturally.



For him, this was an 'in-between' problem, neither one thing nor the other. Rob expressed what was on the face of it a more 'us and them' position:

I think if other people are more like me and blunter and things, it's a preferable way of interacting with me...A lot of the time they'd prefer me to be more like them, when I find that almost impossible and [pause] it seems with their social skills and acting skills they'd be more able to, I dunno, just say it like it is once in a while...I think empathy is a strange thing, this theory of mind thing, because I think empathy is a two-way process.

Here there was also a sense of frustration and injustice that the 'typical' group, ostensibly with the greater skill-set, did not seem able or willing to adapt their own style. Thomas talked about his personal development since childhood, questioning whether his progress had rendered the diagnosis irrelevant:

I was diagnosed with Asperger's syndrome at that time and I was quite different at that time, it was, it would actually, you could, you know, you could see that I had Asperger's syndrome I think at the time because some of my tendencies. Whereas now I think, it's not obvious, personally now I am not sure how relevant that diagnosis is.

Christian likewise described his autism as 'getting better':

Yeah and it shows that my autism has got better over the years. Now as you can see I have a mild form of it. Most people wouldn't even notice I have it – [pause] I'm just a regular person.

Christian's use of the term 'mild' was interesting. This term remains politically loaded. Historically it was used to describe individuals who were 'higher-functioning' but was discredited by individuals and parents as a term that overlooked the pervasive nature of difficulties and the ways in which they

compromised quality of life and opportunity. The 'mild' descriptor was deemed inappropriate to apply to individuals who, by any standard measure, remained excluded and disadvantaged within their communities. However, this argument did not take account of the individual's self-perception and how this may be influenced by terminology. For some individuals, the notion of being only 'mildly' affected was a protection, meaning that they were on the edge of the 'autism identity' with its associated stigma, and perhaps had potential to escape completely. Moreover, as long as the literature on outcomes for autistic adults gives such a negative prognosis, it may be more constructive not to identify with that group. By distancing from it, individuals are more free to engage with 'typical' outcomes and harbour these as realistic goals.

In these accounts, 'autism identities' were fluid, varying across different contexts and situations, but also over time, becoming less of a noticeable feature and instead, something that was 'in the background'. It was also an identity that was hard to pin down, falling in between different categories and without definitive boundaries, so that it seemed to become a pointless social construction.

Participants gave accounts of the ways in which they had recognised themselves within the autism literature they had read, often at point of diagnosis. Ben's account reflected a common reaction of instantly relating to the descriptions:

I met someone last summer who told me he had autism and before then I didn't know much about it, so when I got home I did a bit of research on it (as we do! special interest and all that)...everything I read sounded just like me.

For Josh, the prompt came from a friend, but 'sowed the seed' for Josh to recognise the 'match':

He said, 'Have you ever heard of Asperger's?' and I said 'No, never heard of it in my life' and he said 'Oh, it's a form of autism'. And we got talking and he said to me, he said, 'It shines out of you', how did he put it? 'It shines out of you like a lighthouse'... That sort of sowed the seed in my head and of course I got talking to my parents about it and I thought to myself, you know, read about it and realised that I did match the criteria in far too many ways for it just to be one of those things.

Elliot likewise recognised himself instantly within the characteristics of autism described in the literature:

It had basically a checklist of common characteristics and we just went through that with a 'Yes', 'Yes', 'Yes'.

However, Rob described relating more to autobiographical accounts:

And it wasn't the formal way of viewing it, it was more reading autobiographical accounts and stories from actual people which I started relating to...It was more relating to other people on the spectrum.

Debbie articulated the challenge of engaging with autism literature, and in her case, the decision not to:

I didn't read about anything because, I know it may sound silly, but I didn't want them to give me ideas of other things to worry about or other things that could happen to me.

In the same vein, Ben did choose to read the literature but felt anxious about its potential effect on him:

It seems to explain so much about the issues I've had all my life...at the same time I was a bit concerned that I'd got it just because I'd described text book symptoms/signs - having read the text book.

Autism literature here was problematic. On the one hand, it served to inform and enlighten. Individuals did tend to relate to what they read and it formed for them a path to greater self-understanding. Yet there was in these last two accounts the fear that learning about autism might lead them to take on new traits or worries. These participants articulated the dangers of identifying too strongly with the 'autism identity' as expressed in the literature; its own boundaries may become theirs.

*5.6.3 "And that's what drives you forward. It's like 'I will show you' and that's what it's all about really."*

Often, successes exceeded either participants' own expectations, or those of the people around them. Ben described a trigger point for turning over a new leaf, leading to an unexpected leap academically:

Well, despite being above average intelligence, my grades at (secondary) school were only average at best. But on the first day of year ten I decided to turn a new leaf and have really neat exercise books and handwriting (I know it sounds weird!)...but with that came working harder and out of nowhere in 2003 I got nine 'A\*' and two 'A' grades which was a massive massive surprise. That seemed to set me up on a path to doing really well academically.

In Josh's case, achievement was important in order to prove wrong those authority figures who had written him off during his school years:

Because I've got a lot of bad memories of people in education who basically said to my mum 'Josh will not achieve anything in his life'. And that's what drives you forward. It's like 'I will show you' and that's what it's all about really.

Some participants highlighted the importance of formal adjustments. For Debbie, adjustments to the environment were critical:

After doing my GCSEs in a room I then passed them which proved it was the environment rather than my learning skills which my mom knew.

The accounts above each revealed a determination to achieve, and suggested an awareness of their own potential, even in the face of external barriers. In contrast, other participants surprised themselves, such as Warren:

Yeah, I was amazed when I found I could speak German with people, never thought I'd be able to.

Hannah was surprised by her achievements, despite the fact that they had been predicted by her parents and teachers:

...because I really didn't expect to do that well. You asked if anyone expected me to do so well in my 'A' levels; my mother said she wondered if I'd get an 'A'. Physics teachers had believed I could get an 'A' (I never thought I could and still don't know how I managed to!).

*Wow, that's fascinating! So there were a few people in the background who really saw your potential?*

Why is it fascinating? I don't really see it like that, because I really don't understand how I did so well and I think of a lot of it as luck. But I can understand why you see it like

that.

It is notable that Hannah attributed her success to luck rather than ability or effort. For Sandy, only gradually, through comparisons with peers, did he come to realise the scale of his achievements:

The academic one was probably getting a first in my degree. That was quite good...I didn't realise until a long time afterwards, until the summer. When I went back home and nobody at home had got a First either – I sort of knew that not many people here would get one, but some people I knew got them, and only five or six people in each course gets one - but I got home and nobody at home had got one. I didn't realise quite how rare they were.

Many of these accounts talked of exceeding expectations, but in quite different ways. For some, their differences growing up had led them to be judged and under-estimated. Worryingly, these judgements came from educators who were instrumental in either affording, or withholding, opportunities. Their potential to succeed was therefore very directly affected by the way in which they were perceived by the adults surrounding them. In other cases, participants under-estimated themselves, but in each case, they nevertheless worked to the best of their abilities, and in doing so, surpassed their own expectations.

Participants described a sense of self that remained strong and consistent through, or in spite of, the process of coming to terms with an autism diagnosis. In some cases, diagnosis served to strengthen sense of self, in providing an explanation for some past difficulties that had undermined self-esteem. Elliot described diagnosis as useful for clarifying and defining difference, but not influencing his sense of self further than this:

Yeah. It wasn't exactly a big change it was just like 'hm – that puts a name to it'...yeah.

I'm one of these people who doesn't see a diagnosis as a bad thing.

However, whilst Sandy described no pejorative aspects in his self-perception related to autism, he became frustrated by how the label came to be used by others:

If autism is meant to be an aspect of me, then good memory is surely an aspect of both. Or the other way round. But I doubt the other way round because the other way round doesn't sound sensible. I don't know how far you could reasonably separate them...Because if autism is still an aspect of me then by extension it is an aspect of me. And if I am an aspect of autism, which is probably not true or if the two are so intimately linked that you can't really tell them apart, there's no way to distinguish which is an aspect of which thing...Well to be honest, the only negative feeling about autism that I've ever had is that I tend not to tell people because as soon as you tell people they think 'oh, that's to do with that then ' and they start distinguishing between what is to do with me being great and what's to do with autism being annoying. Or vice versa...And when you tell people you've got it, people start distinguishing between them, people start going 'oh, well you're autistic' or 'oh yeah, that's good'. And it's not even a particularly annoying thing it's just a thing you can't say 'yeah'...there's no useful thing you can say back to it. I wouldn't be annoyed about it, I'm not annoyed about it, it's not an annoying thing to say, it's just a thing that I can never think of anything to say back to it. I can just say 'Yeah. Very good.'

The autism diagnosis could be helpful in 'putting a name' to differences and validating negative experiences as being due to a disabling condition, and as such, did not undermine personal self of identity. However, others could

perceive it in pejorative ways, and participants had to contend with the reactions of others on top of their own. In Sandy's case, it was this aspect that brought the 'negative'. Nevertheless, in these accounts diagnosis was generally welcomed as an explanation for difficulties and bad experiences, and a means of revisiting these more positively, with new understanding:

Ben: [2<sup>nd</sup> interview]

*... I was interested in how you feel that diagnosis has helped?*

I think it's mainly helped me to accept that there are things that I won't understand and there is an explanation for why I'm different, which of course is something I haven't personally had growing up. So I've always known I'm different to other people but I'd never known why.

For Josh, diagnosis was a reassurance that the difference he had identified in himself was identifiable as a distinct and meaningful difference:

You always compare yourself with your peers, like friends, and you observe your friends interacting with your other friends or the opposite sex or whatever and you sort of compare yourself and you think 'well, I'm not like that', in your mind's eye, so you've always got this sort of, these wonderings around...and people do treat you differently sometimes as well. So when somebody comes along and says to you 'oh, did you know... it shines out of you like a lighthouse', you suddenly start linking it all together and thinking 'oh, right ok. So perhaps I'm not going mad after all'. It's that type of thing really.

His allusion to 'not going mad' suggests that prior to diagnosis, he had experienced the sense of chaos and loss of control commonly experienced with



a mental illness. Warren and Hannah described the ways in which an autism diagnosis provided an explanation for difficulties in their respective histories:

Warren:

*Sounds like it was important to you for a long time.*

Yes. As an explanation for my problems with socialising, etc, and inability to find a girlfriend yet.

Hannah:

*What I mean is, was it important to you to get the diagnosis?*

Yeah it was. I think my life's improved since, because I know I'm not just making a fuss over nothing, and I have a word for the way I am, and I can therefore get appropriate help/understanding.

Like Josh, Hannah's description of 'having a word for the way I am' suggested relief and reassurance in having a specific diagnosis. Lewis looked back on his adolescence; his 'black patch' and wished he could have been diagnosed then:

We should have been following the Asperger's lead because around sixteen I hit a black patch and boy, would a diagnosis have helped. I'd kind of come out of it by the time I was twenty-one and got diagnosed but when I did get diagnosed it's like over time I came to understand more and more that this was what it was.

'Boy, would a diagnosis have helped' is unequivocal – for Lewis, it was indisputable that an earlier diagnosis would have benefited him. Rob contrasted the function of the formal diagnosis with his own need to consider himself in

light of it:

I would say formal diagnosis wasn't internally important to me. It's an important social label I guess in how others may use it positively or negatively [laughs] as the case may be. It was understanding what people have said about it, and kind of self-awareness that was much more important, I'd say.

Some participants described very little personal impact from diagnosis, although in these cases, the reaction tended to be more ambivalent than negative:

Christian [2<sup>nd</sup> interview]:

*When you were talking about Asperger's Syndrome and it came across, it seemed as though you knew a lot about the topic...So I was just wondering if you could tell me a little bit more about what reading you have done on that?*

I used Wikipedia – I'm sure you've heard of that, the free encyclopaedia – and I looked up Asperger's Syndrome, just out of interest, just to see what aspects of the disorder I had, and I took one look at it and I was mesmerised by it because one of the key features that I have is obsessions for certain things that I like.

*So when you were looking at that information you related to it quite well?*

I did. And I actually understood it.

## 5.7 Summary

This chapter has reported and considered the most dominant themes from the data in relation to the research aims; namely *The autistic experience* (in relation

to their participation); *Elements of success* (in relation to their descriptions and interpretations of success) and *Identity and autism* (in relation to the ways in which they made sense of their autism diagnosis). Responses were very individual as would be expected, reflecting a diverse group of participants with different life experiences and perspectives. The sheer volume of data was striking – indicative of participants who were keen to reflect on these experiences, and willing to be honest and open in doing so. The depth and eloquence of these accounts suggested the expression of ideas and opinions that had been formed and contemplated over a period of time. In many cases, the research seemed to offer the opportunity for participants to voice long-held thoughts on their own situations. The next chapter will consider the implications of these findings in greater depth.

## CHAPTER SIX

### DISCUSSION: 'WORKING' ON SUCCESS

#### 6.1 Introduction

This research sought to explore the perceptions of autistic adults in relation to the successes they had experienced, and in doing so, made a conscious departure from dominant approaches to autism, which tend to focus on deficits associated with the condition. In their accounts, participants spoke a great deal about their own interpretations of the diagnosis they had been given, how they made sense of it and their activities to both work within, and work against, limitations they either experienced internally or felt imposed upon them.

Within the environment of higher education, additional support is contingent on disclosure of diagnosis, but for autistic students, like others with less visible disabilities, disclosure is also a choice (Riddell, Tinklin and Wilson, 2005). Decision to disclose will be influenced by, among other things, the ways in which individuals identify (or not) with the diagnoses they have been given. Holt (2012) acknowledged that "identity" is problematic and contentious but that it "matters to the way young people imagine themselves in education and into their futures." (p. 930) The case of epilepsy was considered by Rhodes et al. (2008), which, like autism, is something of an anomaly. Both are less visible disabilities, not clearly located within common definitions of what constitutes 'disability'. The authors discussed notions of identity as multiple and temporal. Individuals may subscribe to different identities (eg. disabled, non-disabled)

depending on time, context and, to some extent at least, personal choice. Such notions lead us to sociologist Zygmunt Bauman's assertion that identity in our post-modern society is fluid rather than fixed (2000). Bauman considered how cultural shifts have removed the barriers of class and status, to replace them with infinite possibilities available at an individual level, at least on the face of it. However these infinite possibilities come with the price of insecurity and anxiety about the choices made and the choices that need to be made next: the responsibility lies entirely with the individual, or so it feels. This post-modern interpretation of identity most closely reflects my own position and, I will argue, most accurately reflects the different ways in which participants of this study navigated their own terrain.

In this chapter, I consider in more detail the implications of my analysis. I explore the different ways in which participants navigated the labels they had been given, the ways in which it influenced (or did not) their own sense of identity, and whether these activities were relevant to their successes. I will utilise here the work of two key (and related) philosophers: firstly, Foucault, to examine participants' activities, and then Hacking, a philosopher directly influenced by the work of Foucault, who has focused on the phenomenon of autism within his work, and in particular has explored the influence of autistic narratives.

### 6.2.1 Foucault and the self

Foucault studies practices, agents doing things, plain and simple (and recall it's actually agency that he studies, in that it's the actions that make the agents, rather than vice versa). (Nealon, 2008, p. 101)

Yates (2015), in her critique of neoliberalism, suggested that a Foucauldian analysis might usefully cause those in positions of power over disabled people to "...find their actions problematic in new ways, find previously easy gestures and practices difficult and...those who are the subjects of power find new ways to articulate resistance and push against constraining limits." (p. 103). Such an approach may therefore enable us to view a familiar topic in new ways, with the possibility of both problematizing accepted practices and empowering those disadvantaged by those practices.

Foucault (1988) defined four technologies active within our social systems: of production, of signs (language), of power, and the last of these, the technologies of the self, which:

...[permits] individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (p. 18)

Thus Foucault's approach enables us to focus on the individuals at the centre of this study and examine both their practices as agents and the way in which these are influenced by the systems that surround them. This investigation of

both subjectification and the ways in which individuals respond to the forces upon them, would seem to fit very well with a critical disability analysis which considers the mechanisms by which different types of individuals are constrained by their environments, rather than by impairments per se.

Considering these practices of the self, Allan (2010) emphasised the conceptual transfer of power and control that this can engender for individuals encouraging them to “see themselves as the main source of transformation, rather than as passive subjects waiting for a more substantial structural or material change.” (p. 284) Within this study, participants were very evidently active in their efforts to work on themselves, both in the ways that they defined themselves - going beyond the limits of what the literature offered and insisting on employing their own criteria - and also in the ways that they presented this to the world.

We can see these acts of transformation on the self, in the accounts which describe focused effort to attain a set goal, such as Ben deciding to write neatly, Thomas deciding to become more social, or Hannah deciding to become more independent. Through these decisive, reflective and ultimately successful activities, individuals created for themselves significant turning points in their lives, consciously striving to adapt themselves into a desired self, another type of person from what they had been, or seemingly been capable of. They acted through identification of a desired goal and a desire to reach it, and on a very practical level, this highlights the importance of meaningful goals, combined with a belief in the potential of personal agency to provide the motivation to act, even in the face of barriers.

In the practices described, there is repeated indication of control and discipline

through the language used by participants. Lewis talked of the need to 'rein in' [impulses he associated with autism]; Rob of 'calming down' as he has matured, whilst Thomas asserted that 'what matters is you take the best control you can'. In order to achieve their goals, participants thus identified internal barriers, often associated with autism, and sought to overcome them through conscious repression of impulses or fears. 'Effort' too is a repeated theme across accounts, and this is clearly conscious, reflective and continuous. Debbie's description of making repeated efforts towards her goal, despite the fact that it is just as difficult each time as the first time, is powerful in its communication of an exhausting, endless but ultimately worthwhile endeavour. There is a sense of fearlessness here too, in participants being ready to face challenges that were terrifying to them, over and over again if necessary. Christian perhaps puts this most succinctly in his description of 'Waking up the next morning and saying 'ok here I come again'.'

### *6.2.2 Becoming extra-visible*

In her discussion of the experiences of children with special educational needs (SEN) within mainstream education, Allan (1996) talked of the "constant surveillance" (p. 222) experienced by disabled people. This was also described by disabled students within higher education, who were forced to make themselves 'extra-visible' to peers and staff in order to have their needs met (Goode, 2007; Madriaga, 2007), which in some cases was construed as positive action to improve the situation. Likewise, participants in this study often responded to the negative experiences in their lives by wanting to



improve understanding of autism and the situation for autistic people more generally. In this way, they connected themselves not just with the autistic/disabled communities, but with the community as a whole, which stands to benefit from this increased awareness, and importantly, found a constructive way to navigate a challenging situation and create a positive outcome.

Moreover, in their school careers, these participants had often chosen to make themselves 'extra-visible', foregrounding their 'autistic self' in order to share their personal experiences with peers or educators. There were examples of this even in cases where the participant had described ambivalence about the part autism played within their sense of identity, as in the case of Aimee depicting her autism through a drama piece (of her escaping chains). They often saw themselves as agents for change and were pro-active in their efforts - writing, speaking and performing in order to share their experiences with others.

Foucault (1988) contended that in the Greek and Roman tradition, care of self would necessarily imply care of others, in that care of the self equates to knowledge of what you are and should be, including roles and responsibilities. For Foucault then, proper care of the self was inseparable from care of others, and in their activities, these participants demonstrated awareness beyond their direct experiences, in their desire to improve understanding and awareness, not just for themselves but for the benefit of others with similar situations.

This notion of becoming extra-visible was evident in other ways. Debbie described consciously becoming 'someone people think is quite loud' because

she had observed that those kinds of people were heard. In this case, she was willing to overlay her authentic (invisible) self with a persona that would achieve her desired goal of being heard. Similarly, Lila gave an emotional account of becoming visible for the first time in her class, and reflected that she had 'perhaps been silent for too long.' Becoming visible here was in every sense transformational.

However, in becoming extra-visible, participants were also being forced to declare themselves autistic, "taking up a victim position" (Shakespeare, 2006, p. 79) and to some extent, conceding an essentialist interpretation of autism. In Foucauldian terms, they were compelled to speak one particular truth about themselves (Nealon, 2008) at the expense of "being ordinary, not different..." (Shakespeare, 2006, p.79). Ironically, in order to be successful, they had to demonstrate their vulnerability.

### *6.2.3 Autism as a 'form-of-life'*

Participants had very different reactions to the 'autism' identifier, from resistance and denial (eg. Lila, Lewis) through ambivalence (eg. Sandy, Bridget), to seeking and welcoming the diagnosis (eg Rob, Hannah). Within each account, there were descriptions of ways in which participants related some aspects of themselves, both positives and negatives, to autism. Even those who resisted their diagnosis spoke of their sense of difference from non-autistic peers, as in the poignant example of Debbie, whose sense of difference was magnified by the reading of 'The Curious Incident of the Dog in the Night-time'. Others wondered how their lives might have been different if 'they did not

have autism' (Rosie, Ben) and Josh and Sandy perhaps articulated the dilemma best, in their reflections on the inadequate nature of the 'normal'/'autistic' and 'autistic self'/'self' constructions.

In Smith's (2015) consideration of Foucault's work on ethics and subjectivity, he took account of Italian philosopher Agamben's development of the topic, and in particular his concept of a 'form-of-life'. He proposed that:

Rather than starting with the idea of an "authentic" identity which is then more or less effectively expressed in a work, we should consider the way in which the process of the work can, in turn, have a significant effect on the one doing the work. (p. 146)

Thus, the artist works on his creation, but in doing so, is in turn influenced by its making, and in some way, is determined by it. In certain instances, the work undertaken becomes so fundamental to the self that it is indistinguishable from it:

In a form-of-life, by contrast, the life cannot be conceived apart from the form it takes. (2015, p. 147)

In the accounts given within this study, descriptions of aspects related to autism incorporated both positive and negative aspects. Participants were often working to suppress behaviours associated with autism, but at other times they were working to protect them, or even to nurture them, as in the case of attitudes towards memory and focus, both of which are associated with both autism and success in a chosen goal. Thus, although participants described different kinds of identities and asserted themselves as not-to-be-defined-by

autism, they at the same time articulated this 'form-of-life', in which aspects they associated with autism could not be separated from aspects they associated with themselves. Smith (2015) asked the question:

...is someone who practices Foucault's aesthetics of existence not also constructing a form-of-life, but this time in a positive sense? (p. 148)

In section 6.3, Hacking's consideration of autism enables further exploration in relation to the research findings.

#### *6.2.4 Action and resistance*

In his consideration of the opposition that has taken place in recent history (for example, to the power of men over women, or of psychiatry over the mentally ill), Foucault (1982) asserted that:

Finally, all these present struggles revolve around the question: Who are we? They are a refusal of these abstractions, of economic and ideological state violence, which ignore who we are individually, and also a refusal of a scientific or administrative inquisition which determines who one is. (p. 781)

Participants of this study were largely consistent in their efforts to resist external determinations of 'who they were' and indicated ways in which they maintained their own sense of self, outside of accepted definitions of autism. In this working on the self, there was apparent a continuous effort to gauge not only what needed to be adapted, but also what needed to be protected. In Thomas'

description about his efforts to change in order to integrate more effectively with his peers, he talked not just about change, but also about identifying ‘times when [I] need to’, suggesting that at certain points, he might consider, *and reject as unnecessary*, an external pressure to adapt his practice. Thus participants indicated ways in which they had to negotiate the pressure to conform alongside their desire to protect and retain their sense of self.

### *6.3.1 Hacking and the ‘making up’ of autism*

Hacking (1986) talked of the “making up people” (p. 222), a concept most clearly illustrated in his consideration of the ‘game’ of the DSM manual and its contentious revisions (Hacking, 2013), around which a lucrative industry revolves:

And trying to get it right, in revision after revision, perpetuates the long-standing idea that, in our present state of knowledge, the recognised varieties of mental illness should neatly sort themselves into tidy blocks, in the way that plants and animals do. (p. 8)

On the one hand, this can be evidence of power in the hands of certain people at the expense of others, as they put forward certain ‘knowledge’ and ‘truths’ as interpreted by themselves. It speaks of an essentialist approach and Hacking found it wholly inappropriate in trying to understand neurological differences within humanity. However, he also identified another, more positive aspect of “making up people”, proposing that:

Social change creates new categories of people, but the counting is no mere report of developments. It elaborately, often philanthropically, creates new ways for people to be. (1986, p. 223)

Within the accounts in this study, we can observe both of these phenomena. Participants questioned the descriptions they found in much of the literature, which depicted autism as an apparently fixed category with clear boundaries in which they ought to neatly fit. They articulated an experience of 'autism' that was much messier, where they did not conform to a 'type' but rather, identified some common experiences of difference and disadvantage. Nevertheless, having a name for the experience of difference was by and large perceived as positive, and preferable to being considered mad (eg. Josh) or bad (eg. Hannah).

In this light, we need the category as it helps to make meaning. We can see this in the way individuals and collectives play with, and take ownership of, the language. In some cases, this has involved a rejection of the 'people first' terminology which separates the individual from the label (Sinclair, 1999), with a recent study indicating that adults diagnosed with the condition preferred to be called 'autistic' whilst practitioners tended to favour 'people first' terminology (Kenny et al., 2015). One of the consequences of this is arguably that researchers and practitioners in the autism field have been unsettled in their own confidence in choosing the 'correct' terminology to employ. Traditionally, those in the positions of power got to do the naming; creating the 'knowledge' as Foucault would have put it. Here, their accepted terms are being questioned and debated by those thus diagnosed. The still-problematic issue of 'disorder', which continues to feature within the diagnostic criteria, is often completely

rejected (Broderick and Ne'eman, 2008). Yet for every autistic person who rejects 'disorder' and identifies with an autistic identity, there may be another who views it as an unwanted, disabling appendage (Blackburn, 2000). In this way, discussions and debates about autism terminology mirror the landscape of autism itself: enormously variable, and impossible to neatly categorise.

Hacking (2009b) proposed that:

There is a partial symmetry between the autistic and the non-autistic. Neither can see what the other is doing. The symmetry is only partial because we have an age-old language for describing what the non-autistic are feeling, thinking and so on, but are only creating one for the autistic. (p. 1471)

This 'partial symmetry' can be expressed differently: the non-autistic, able-bodied voice is *the* dominant narrative within our culture. The lack of an autistic voice renders the autistic person invisible, voiceless and powerless. The development of an autistic voice creates then, not just a new way of being, but a new knowledge, a knowledge that is sometimes at odds with that which already exists, is sometimes in direct contradiction to it, but one that, if accepted, potentially enriches it and gives it greater credibility as 'Knowledge'. Lila's description of her presentation to her peers indicates, not merely a change in others' perceptions of her, but through her actions, a change in her perception of herself. Thus the work of autistic people, both in terms of their self-work, and their willingness to describe their experiences, can change what *is*, and create new possibilities of *being*.

Hacking (2009a) and Draaisma (2009) highlighted the influence of Haddon's (2004) fiction, *The Curious Incident of the Dog in the Night-time*, and its use within teacher training as a tool to consider children with special educational needs:

Hence classroom teachers' notions of their charges are molded [sic] by what began as just a lively and well-written novel. (Hacking, 2009a, p. 501)

Or, to put it another way, teachers who will be imminently working with autistic children develop their notion of autism via a fictional account, conceived for entertainment purposes by a non-autistic author. Moreover, as illustrated by Debbie's account, autistic children and their peers may then go on to learn about their own condition via the same means. Whilst Haddon's fiction is a good one, and Debbie does indeed relate to some aspects of the central character's experience, it is nevertheless a dramatic conceit, and in that sense offers a very shaky foundation on which to build knowledge. Moreover, as a fiction, it offers no real possibility of connecting with the protagonist. Whereas the reader may follow Grandin's story, empathising with her struggles, aspiring to her successes, and ultimately recognising her as a real autistic person, Chris remains a fictional character.



### 6.3.2 Hacking's 'Looping Effect'

Ortega (2013) described Hacking's 'looping effect' thus:

The psychiatric label of autism or Asperger syndrome affects the persons so labelled and/or their families and caregivers, and potentially changes their behaviour and hence the meaning of the label itself. (p.75)

The creation of 'Asperger syndrome' without doubt created a new way for people to be. We can observe Hacking's 'looping effect' in the way that individuals recognised themselves in descriptions of Asperger syndrome, went on to be formally diagnosed, and both consolidated and altered the sub-category of Asperger syndrome and indeed, the main category of autism. Over time, sub-categories such as 'mild' and 'high-functioning' and their validity have been brought into question by those diagnosed (Lawson, 2006; Dawson, Mottron and Gernsbacher, 2008). Classification here is important. Within DSM-5, Asperger syndrome has ceased to exist as a distinct category. The majority of individuals previously diagnosed with Asperger syndrome will now be simply autistic, regarded as being on the same continuum as those with severe learning disabilities. It is more difficult to assert lack of common experience in a group with a common diagnosis. This surely should add weight to the relevance of the autistic perspective, as currently articulated in all its forms. Whilst an individual may not be able to speak for the majority, they can be, as Hacking (2009b) suggested: "...creating ways in which to express experiences." (p. 1472) First-hand accounts may not properly give a voice to the voiceless,

but by their actions, these authors raise the possibility that others too could and should *have* a voice.

Essentialist approaches to autism ultimately do a great disservice to those whose profile puts them at the boundaries; those formerly categorised as ‘Asperger syndrome/high-functioning autism’. Rather than prioritising their experience of difference and disadvantage, and addressing associated inequalities, attention is given to the authenticity of the diagnosis and how a person should be categorised. There is concern that with the most recent iteration of the DSM criteria, some individuals who would formerly have been categorised as autistic will now not be (Smith et al., 2015). This matters because the diagnosis does serve to validate the experience for many individuals, especially those undiagnosed in childhood, and we can see its value in the accounts of many participants in this study. Dumit described “illnesses you have to fight to get” (cited in Ortega, 2013, p. 77) and several participants described fighting for their diagnosis, or feeling that it had been in some way been denied to them (eg. Ben, Greg, Hannah, Rob). Hacking (2007) considered the work of John Stuart Mill and ‘real kinds’ or ‘natural kinds’ of phenomena, which can share many features whilst still being very different. Hacking suggested that this gets to the dilemma of “autism as no mere characteristic” (p. 314) but something inseparable from the person, or, returning to Foucault, a ‘form-of-life’. If we take this to be the experience of many autistic people, it is all the more harmful if this integral part of them is brought into question, and they should be forced to defend their position.

#### *6.4.1 Voices within the debate*

I will now contextualise my findings within current debates around disability.

Goodley (2013) characterised critical disability studies thus:

If late-twentieth-century disability studies was associated with establishing the factors that led to the structural, economic and cultural exclusion of people with sensory, physical and cognitive impairments, then disability studies in the current century might be seen as a time of developing nuanced theoretical responses to these factors. The politicization of disabled people is at the heart of these developments. (p. 631)

This politicization is inevitable if dominant voices are to be challenged, but arguably, it need not be as overt and conscious as suggested above. Indeed, ensuring that disabled people have a central role in debates, whether politicized or not, is the key to marrying theoretical ideas with the daily realities that disabled people experience. Foucault (1980) made much the same proposition, in considering who should have power:

The intellectual no longer has to play the role of an advisor. The project, tactics and goals to be adopted are a matter for those who do the fighting. (p. 62)

Foucault made the distinction between “the intellectual” and “those who do the fighting”. He was writing at a different time and not in specific consideration of disabled people, and so perhaps we can attribute his presumption that these are two separate groups to the context. Nevertheless his words are useful in

reminding us that having the voices of disabled academics included within debates, though significant, does not by itself achieve representation of disabled people – as Vernon & Swain (2002) attested:

...disabled people will not judge disability theory by its contribution to academic or research discourses, but ultimately by its role in social change, in the emancipation of disabled people. (p. 92)

Thus the lived experiences of unpoliticized, non-academics must be better understood and viewed as equally significant contributions to the field.

In their consideration of critical autism studies specifically, Orsini and Davidson (2013) suggested that it ought to challenge deficit models and distinctions of functioning, but that this is not the same as either celebrating autism, or denying that it can be disabling. They proposed that an essential role should be to acknowledge and explore what Hacking called the ‘thickness’ of the experience and move away from polarised perspectives which, in Vernon and Swain’s (2002) terms, serve to “cast one group against another” (p. 93) . The authors observed that within the various autism stakeholder groups, diversity is often perceived as threatening rather than celebrated. Those able to articulate their experience can at some times be perceived as threatening to those who cannot, in that the former are seen to undermine the experience of the latter (assumed to be qualitatively worse) – as articulated by parents and professionals. This in-fighting serves to distract the different communities from what could otherwise be important opportunities to learn from one another, and create a new knowledge founded on this learning.

#### *6.4.2 The foundations of success*

In interviewing individuals who had gained entry to higher education and were successfully studying there, I expected my findings to indicate relatively good school experiences, and that narratives would describe effective support within education. To some extent this was true, but not to the extent, or in the ways, expected. Predominantly, these (mainly young) people articulated experiences of feeling and being misunderstood, and a lack of support and understanding that had often presented barriers to them in their educational endeavours and beyond. Often, successes were attributed to a single event. For Aimee and Christian, a teacher spotted and nurtured their potential. Lewis and Lila discovered a natural ability they had not been aware of and nurtured this themselves. Thomas, Ben and Rob described developing a new self-awareness at a key point in their development. The influence of key figures on the lives of these young people was also striking, and in the narratives given, tutors, teachers and parents were not only seen to remove barriers to access through provision of adjustments - as in the case of the SENCO helping Elliot to understand underlying meanings within exam questions. Most significantly, they were often able to remove, or at least minimise the impact of, impairments intrinsic to the individual. For example, in the case of Christian, a teacher's recognition of his natural skill in mimicry, and encouragement to develop it, was pivotal in enabling him to overcome his social anxiety with peers. For Rob, his mother's acceptance of him and non-judgemental support in practical matters that on the face of it were well within his capabilities, gave him the confidence to 'keep going and be himself', no small matter for an anxious young person who has already experienced numerous challenges and rejections. Notably, the

majority also described instances where peers were influential in aiding their achievements. Other studies have highlighted the importance of support, but again, not in the structured ways that might have been expected (Eaves and Ho, 2008; Van Heijst and Geurts, 2015). In these studies too, formal support was far less important than the kind of support that came from people close to them, who spotted potential and encouraged it, in whatever way.

Within the 'autism industry', much is made of specific interventions, many of which are marketed to families at their own personal cost. Without engaging in debates upon their relative merits (for which the evidence base is in any case low, see Parsons et al., 2008), the greater danger is that this brings us to what Foucault (1998) termed "games of truths" (p. 296), whereby the condition of autism is homogenised, and the individual subjectified, in order to justify the chosen intervention. In the accounts here, a readiness to know and nurture the individual was what counted, rather than any 'specialist' approach. Although I do not take this to mean that there is no value in seeking to develop a broad understanding of autism, I would suggest that a greater acknowledgement of what can be achieved without it, potentially moves us away from the powerplay that can take place within the 'autism industry' and back to the individual in question.

Within this study, reflections on success revealed experiences framed by awareness of disability. There were descriptions of personal barriers, sometimes related to social anxiety or ambivalence (eg. Thomas, Hannah, Greg) but more often, related to the assumptions and limitations imposed by others. In order to succeed, participants had been forced to become agents of resistance. Voices of resistance were apparent throughout the accounts;

articulating in very different ways participants' determination to reach their goals, with or without support – for them, the glass ceiling was there to be smashed. Many of these narratives referred to negative experiences at school, and in contrast, participants often described their university experiences as positively transformative, describing experiences of acceptance (eg. Thomas); achievement (eg. Sandy); finding their 'place' (eg. Hannah); and not only academic, but also social success (eg. Ben). Madriaga (2009) found that students welcomed the opportunity to re-invent themselves at university, and this often seems to have been the case in these accounts, albeit with continuing challenges.

Boxall et al. (2004) suggested that:

When we apply the social model of disability to children's education, it prompts us to ask what is 'wrong' with the education system and the learning environment, rather than what is 'wrong' with the child?  
(p. 105)

This research has revealed considerable challenges faced by young autistic students within the compulsory education system. These young people had the potential to succeed, as evidenced by their transitions into higher education. However, within their narratives, they presented more as 'lucky escapees' than products of an effective and inclusive school system. Were these participants successful because of the environmental supports available or in spite of them? Mainly in spite of them. Adjustments often came later, following initial resistance from educators, and they depended upon a minority of isolated champions or the serendipity of good fortune (for instance, in a random discovery of talent),

rather than a network of supportive professionals. Parents often had a pivotal role in raising self-esteem and offering acceptance, to bolster fragile identities, although in some cases (eg. Lila and Warren) they served to undermine, so that separation from parents could bring its own freedoms. Accounts were less critical of the higher education system, perhaps due to its ability to offer opportunities for transformation, reinvention and escape, or perhaps, as found in other studies, simply because the experience of higher education was not as bad as what had gone before (Hopkins, 2011).

Nevertheless, within the accounts is evidence of supportive people who had pivotal roles in enabling and encouraging their achievements, and this is not insignificant. In Madriaga's (2007) study, he suggested that individual tutors who imposed barriers be viewed not as the core problem for disabled students, but rather as examples of the wider societal problem. Conversely, the individual pedagogues, peers and parents in this study who, in countless small and often simple ways, removed barriers, opened up possibilities, and influenced the futures of participants for the better, should be viewed as examples of what is possible within our current societal structures.

#### *6.4.3 Negotiating the diagnosis*

All participants in this study had a formal diagnosis of autism, although not all agreed with it. Whilst some had pursued diagnosis for themselves (eg. Josh), others had it imposed upon them in childhood, causing a traumatic period of coming to terms with its implications (eg. Aimee, Lewis). Still others reacted with an ambivalence that suggested unproblematic acceptance (eg. Sandy, Elliot). In



short, responses and experiences were hugely varied even in this fairly small sample. Diagnostic labelling is a problematic practice. Its stated intention is to support the child and ensure they receive better provision and opportunities. As Allan (1996) has suggested, "...in a climate of resource constraints, distance from the norm has become valued" (p. 223) and this is particularly apparent in the case of autism, where specific implications for therapies and interventions are attached to a diagnosis. However, although this may be an accepted truth generally, often Asperger syndrome/high-functioning autism is the exception. This diagnosis, in particular for adults, may not carry any resource implications beyond the cost of the diagnosis itself. It is still the case that within UK statutory services, it falls between the categories of Learning Disability and Mental Health, often denied by both (Singh et al., 2010).

Other studies looking at higher education students have indicated that diagnostic labels were useful in enabling practitioners to be more aware and ensure that adjustments were put in place (Madriaga and Goodley, 2009; Molloy and Vasil, 2002) More often, the key difference was better self-awareness and crucially, less self-blame. Diagnosis removes, or at least reduces, the barrier of feeling personal responsibility for disabling experiences. The environment may become no more accessible, but at least the individuals affected now know that it should be. This was certainly the case for the participants of the current study, who tended to express a similar viewpoint to Sainsbury (2000), an autistic author and the first to publish a compilation of first-hand experiences from autistic adults:

Frankly, I prefer the official label. It's the stigma that's attached to being different which is the problem, not the label. (p. 31)

There has recently been some discussion on 'best outcome' for individuals with autism. Some research has considered the proportion of children who no longer meet the criteria as adults, and how their profile has changed over time. These debates miss the point somewhat: the research tends to state, somewhat matter-of-factly, that individuals do retain certain characteristics such as extreme anxiety or depression (Helt et al., 2008; Fein et al., 2013). They therefore do not lose much of the practical disadvantage of the autism diagnosis. Instead of debating whether 'loss of diagnosis' is more attributable to in-person characteristics or changes to criteria - discussions endlessly theoretical in nature - time would be better spent looking at these adults and the needs they continue to have if they are to be offered equality of opportunity. We can observe this in the revision of the DSM criteria, whereby human and material resources were focused on replacing one set of imperfect diagnostic criteria with another. This was ostensibly to get close to the 'truth' of what autism 'is'. In reality, debates continue to abound and Hacking's looping theory seems the most relevant 'truth.'

Nevertheless, those unhelpful sub-categories do persist and can still be found in many research accounts and literature on the condition. Perhaps one of the most important roles of participatory research is to continue to push the debate about who represents whom, and most of all, who can represent those autistic individuals who are unable to represent themselves effectively. Autistic advocates are aligning themselves with these individuals, and as imperfect as this might be, it does enable people to draw relevant parallels between their experiences. Hacking (2007) suggested there is no general story, and each one

should be accepted as different, but a useful framework to apply might consist of two vectors:

One is a vector of labelling from above, from a community of experts who create a “reality” that some people make their own. Different from this is the vector of autonomous behaviour of the person so labelled, which presses from below, creating a reality every expert must face. (p. 235)

Participants here described vivid realities, many of which eluded a straightforward interpretation of one thing or another. For example, whilst Lila was aware of some difference from her peers and felt like an outsider, the diagnosis added something else, which she perceived as specifically limiting. Even for those who welcomed diagnosis, the tone was not celebratory, but more bittersweet, bringing its own challenges: Debbie and Ben were fearful that they may change (and by implication, regress) to conform to the diagnosis. Sandy accepted his diagnosis only because it brought with it resources in the form of study equipment, whilst for others it offered a route to greater self-understanding, but nothing more concrete. This is arguably the problem with diagnosis and how it is currently used – it is primarily a language of categorisation, rather than a force for change.

The way that autism is constructed and presented assumes a truth, albeit one that is constantly shifting through the re-categorisation of diagnostic criteria (see Hacking, 2013). Whilst undermining the notion of ‘one truth’ by doing so, this shifting also imposes a change to what is accepted as ‘true’. The question, it seems to me, is not whether we should have these categories, as this feels

unavoidable, but rather, how we make them serve the individuals they apply to, rather than restrain them.

Allan (1996) proposed that Foucault offers the possibility of looking at the official discourses and those actually operating within settings, suggesting that children with SEN (special educational needs) could be seen to be constructed through the disciplinary techniques that surround them; “the medical gaze” (p.220). We can observe similar practice in the way that autistic people who have spoken out in recent years, have often been silenced within academic discourses using threats to their authenticity. Debates rage most strongly around those diagnosed with Asperger syndrome or high-functioning autism. Hacking (2009b) described Alison Singer, of *Autism Speaks*, who had been vocal in resisting the validity of autistic advocates being qualified to speak for her severely autistic daughter. Autistic activists Sinclair (2005) and Ne’eman (2010) have both described the hostility they experienced from some parental factions, who regarded their experiences as irrelevant to those of their severely autistic children, and in some cases, questioned the validity of their autism diagnosis. (It should be noted that both highlighted they also had support from some parents, who found their insights helpful). The argument here is that, for those individuals at the so-called ‘higher’ end of the spectrum, there is a better quality of life and better outcomes. What is generally overlooked is that the ‘better’ is in comparison to the most severely disabled and disadvantaged, who are also amongst the most disadvantaged within the disabled population as a whole (Eaves and Ho, 2008; Billstedt, Gillberg and Gillberg, 2011). This is a skewed way to judge what quality of life and opportunity an individual should expect - when this group of ‘high-functioning’ autistic people are compared to the

general population, their outcomes are found to be poor and their disadvantage still greater than other disabled groups. This is despite the fact that these individuals, viewed objectively with regards to their levels of functioning, have the potential to thrive within the mainstream. The inequalities experienced by the autistic population as a whole ought to be most easily addressed for this sub-group, yet they are doubly failed – failed by the systems that surround them, and failed too by the autistic communities that suggest they have no right to complain, precisely because they have the skills to do so.

And yet, if we consider that autistic people have some characteristics in common, there could be valuable lessons learnt which could be applied elsewhere. Autistic individuals who can articulate their experience can help to break down some of the barriers experienced by others and remind us of the need to listen, not just to those voices most readily accessed, but to all. Of course, as Allan (1996) cautioned, there is a danger that one dominant discourse may simply replace another. This is true within autism as within disability more broadly. Listening to autistic people needs to take account of the plurality of perspectives, but by making constant efforts to do so, we can at least move towards accessing and understanding this plurality, rather than fearing it.

## 6.5 Summary of discussion

Participants in this study were active in their efforts at self-work, consciously seeking to control aspects of themselves that they perceived to be barriers to their ambitions. They showed readiness to make themselves 'extra-visible', and in doing so, sought not only to improve their own situations, but the situations of

their unknown peers. In becoming 'extra-visible', they were forced to declare themselves to be autistic, accepting what this would cost them personally. However, at the same time they resisted presumptions associated with the label, and articulated instead the complexity of autism as an identifier, and indeed its inadequacy in representing their experience. Foucault's notion of a 'form-of-life' reflects the position often described by participants, that characteristics of autism were so closely bound with their sense of self as to make distinctions between the two meaningless, and at times, frustrating. Through their activities, they also took ownership of 'what it means to be autistic' and sought to change this in positive ways, contributing to Hacking's 'looping effect'. This challenging of dominant ideas potentially helps to bring autism studies in line with some other areas of disability studies, in which debates are influenced more equally by stakeholders who experience disability and those who do not. They contribute forcefully to discussions surrounding diagnostic labelling practices, highlighting the additional barriers, internal and external, that these processes can impose upon the individual, as well as the benefits that they could and should confer. Moreover, if we agree that by definition, success involves a taking of power, then these participants in their activities are successful examples of this phenomenon in practice.

## CHAPTER 7

### CONCLUSIONS

#### 7.1 Introduction

Within this thesis, there were three central aims, which I re-state below:

1. How do autistic adults, defined by some objective measure as successful, define their own successes?
2. How do they make sense of these successes in relation to the 'Asperger/autism' identifier?
3. In what ways does a participatory approach help or hinder our understanding of autistic and non-autistic interpretations, to achieve a shared understanding of a given phenomena?

I will conclude this thesis by firstly considering the limitations of this study and aspects that would merit further investigation. I will then reflect on how the research has informed each of the three main research aims in reverse order and, before finally considering the implications for future research and practice.

#### 7.2 Limitations and caveats

In choosing to focus in-depth on the experiences of a relatively small number of participants, my findings are inevitably constrained by sample size, and caution must therefore be exercised in generalising results. It is acknowledged that IPA research cannot be used to generate nomothetic claims, although key emergent themes can be of use in moving understanding forward on a more

general level (Smith, Flowers and Larkin, 2009). Within this research, however, I have problematized an 'essentialist' approach to autism and critiqued the current over-use of nomothetic claims within the field. Whilst the small-scale, idiographic nature of the research approach may in a certain sense be a limitation, it also arguably serves to redress the balance within existing research by moving from the general to the specific.

Perhaps of more significance is the fact that participants had a very specific profile, in that they were all students within higher education and had all attended mainstream education. They were therefore well able to reflect upon their life experiences and articulate their responses. However, the autism spectrum is a messy construction and as I have already considered, whilst it describes an extremely diverse population, distinctions in terms of functioning are problematic. We know that some individuals termed 'high-functioning' both exhibit behaviours, and relate to the behaviours, of other individuals termed 'low-functioning'. What is more difficult to ascertain is the perspective of those individuals with whom we cannot so easily communicate. The views of these individuals remain poorly represented within the literature, and it must be acknowledged, absent within this thesis. I hope that some of the findings may be applied or adapted to have a broader relevance, but this cannot be presumed to be the case. Here indeed there is a caution: the danger being that the dominant autistic voices are presumed to speak for all, and thus those who are silent remain silent, and merely (mis?)represented by a different group of advocates:



The person who has the capacity to formulate truths also has a power, the power of being able to speak the truth and to express it in the way he wants. (Foucault, 1998, p. 298)

Also, as Miles and Huberman (1994) suggested, there is a tendency for qualitative research methodologies to exhibit an 'elite bias'. Research participants are often the most articulate and accessible members of a given group, thus calling into question the extent to which findings can be seen as representative. As higher education students, these participants may have had relatively privileged backgrounds, which arguably mediates the penalising effects of autism to some extent (Vernon and Swain, 2002). It may therefore have been useful to collect further demographic information in order to more broadly contextualise these participants. I decided not to do this as I was concerned that, in collecting too much 'peripheral' information, I might increase anxiety levels amongst the participants and make it more likely that some would withdraw. Moreover, due to the phenomenological nature of the study and small sample size, the collection of this kind of data did not seem of central importance. In my efforts to keep the research process accessible and relevant to its participants, I elected not to collect certain data that was less centrally relevant to the research aims. As it was, participants were required to give a great deal of their time to the study.

This decision arguably moved my research to a more essentialist position, where important intersections were suppressed by my focus on the "single issue politics" of autism (Vernon and Swain, 2002, p. 88). Within my research, multiple identities were partially addressed through discourses around mental health and depression. Other intersections were not revealed, and this may

have been particularly significant in terms of gender. There is a growing body of evidence to indicate that autistic women present differently to autistic men (Gould and Ashton-Smith, 2011; Rivet and Matson, 2011) and the intersection between gender and autism is in need of further investigation.

A useful progression of this research might consider some of the intersectionalities neglected here. In particular, the influences of gender, race and mental health on the life experiences of autistic individuals would be worthy of exploration. Finally, in focusing on adults within higher education, this study favoured younger adults at the beginning of their academic/professional careers. A logical next step would be to interview autistic adults who are established within their careers.

### 7.3 The research approach

This research was novel in several respects. In its subject matter of the exploration of success, it ventured into relatively uncharted territory. It employed several techniques to improve accessibility. The Critical Incident Technique and Interpretative Phenomenological Analysis were combined to provide a research process that enabled participants to prepare in advance, choose a preferred means of communication, and enter into a reflective dialogue with the researcher. All participants who consented to participate, remained committed to the study, providing a good indication that, where the topic is meaningful to the respondents, and the processes accessible, autistic participants are not only willing to engage, but are prepared to offer a high level of commitment to research studies, actively participating in ways that inform not

only the topic, but also inform methodologies seeking to follow participatory principles.

The double hermeneutic of IPA acknowledges the active role that the researcher plays in the interpretation of data. Given the wealth of data provided in this study, it must be acknowledged that another researcher may have focused on different aspects of the findings and interpreted them differently. However, I would argue that this does not render the interpretations presented here any less valid, but merely highlights the plurality of interpretations available. Conscious efforts were made throughout to validate interpretations by checking back with participants, and these give further evidence that interpretations were authentic in representing participants' experiences.

Kamler and Thomson (2006) suggested that:

...a reflexive scholar is one who applies to their own work the same critical stance, the same interrogative questions, and the same refusal to take things for granted as they do with their research data.

(p. 66)

In my research approach, and in keeping with the philosophy of IPA, I have tried to take stock in this way at every stage of the research, and this has led me to some reflections of interest, and potentially broader relevance. For example, it has been striking to me throughout this study, how articulate the accounts within the transcripts were. Often, the transcript gave me a much clearer, more comprehensive account than I had been aware of during the interview. That is to say, the verbal or social style of the participant, and my own responses, seemed to have in some way undermined my ability to process

what I was actually being told in very clear terms. Some participants also talked of making sure their account was planned in their own mind before they began, so that for them, the account was not being constructed as they went along, but was a coherent whole from the start. Returning to Heidegger's position that language is central to the human experience and how it is interpreted, this aspect takes on even more significance. In this instance, the research approach enabled these accounts to be released from the social context that potentially compromised the value of their content. Participants were enabled to convey their experiences very much on their own terms, and in doing so, brought forth vivid, eloquent and enlightening accounts.

For these reasons I am hopeful that this study will have benefits beyond the immediate impacts on its participants, by offering an example of a participatory study that is flexible enough to incorporate different communication styles and that develops an interactive, in-depth dialogue with participants. There is already some evidence of impact. Firstly, two articles based on this research have been published and cited subsequently elsewhere (MacLeod, Lewis and Robertson, 2013; MacLeod, Lewis and Robertson, 2014) and a poster was presented at the 2013 Autism Europe conference in Budapest [see Appendix XI for details of outputs and citations). Secondly, an adapted version of the methodology is being used in a current project. In this project, autistic students are being employed as Project Assistants to consult with the wider population of autistic students at this university, in order to make recommendations for educational enhancement. Both the interviewees and the Project Assistants have indicated that they found it beneficial to have questions provided in advance, and for there to be a choice of participation modes. Project Assistants

have also valued having the direct feedback provided by participant evaluations. This methodology may therefore have potential in making not only the participant role more accessible, but also that of the researcher.

Autistic and non-autistic researchers have identified both the need for, and benefits of, collaborative approaches to autism research. Research commissioners and academics alike need to take this call seriously, if research findings are to be properly meaningful to those they feature, and make a difference to real lives. It should be viewed not as rhetoric but as imperative, and although I do not subscribe to the view that stakeholders should take an active role in all research pertaining to them, a research landscape in which the default expectation is that researchers must justify *not* involving stakeholders in their research would be a much healthier one.

### 7.3 Autistic and non-autistic interpretations

One of the aims of this research was to capture the perspective of those individuals who, whilst diagnosed with autism, were ambivalent about its meaning for them, choosing not to engage with autism networks, and therefore invisible to the research communities. A significant majority of participants did meet these criteria, and in explaining the various reasons for their ambivalence - or even hostility - to the construct of autism, they offered valuable new insights.

Thirteen of the sixteen participants had never previously been involved in autism research, and so in this sense the research was successful in obtaining

a largely unheard perspective. Whether they had been uninterested, or had not been contacted due to being outside the usual networks is not known and this is an area meriting further exploration. What was apparent was that these individuals were enthusiastic about sharing their experiences, and actively wished to increase understanding of autism within their own communities. The research gives a clear indication, albeit on a small scale, that, even individuals who strongly self-identify and want to take an active role in the development of knowledge around autism, often do not align themselves with mainstream research communities. They therefore risk being excluded from current debates - and autism communities of all kinds (autistic and non-autistic) risk remaining ignorant of their perspectives and potential contributions.

This speaks of the need to recognise that awareness and understanding of autism may not be sufficient to remove the barriers termed by autistic academic Milton (2012) as “the double empathy problem” (p. 883). Just as the most sensitive person may find it difficult to ignore the stump of an amputee on a first meeting, many social responses are sub-conscious and instantaneous, operating differently from those that are more planned and deliberate. With regard to my own surprise at how articulate the respondents were within the transcripts, in comparison with my recollection of the interviews, the social aspects had proved a distraction and, to some extent, a hindrance to my understanding. My analysis does not suggest that I badly misconstrued what people were saying to me, but I certainly missed some key points in the initial meetings, or failed to absorb at the time all that was being shared. Through the analytical dialogue that followed, participants were able to help me fill in these gaps, which enriched the data. Personally I am left with an even deeper

impression of the potential significance that written accounts have to offer “thick” descriptions of the autistic experience, and to overcome some of the existing barriers to meaningful communication.

Another consideration here is to ascertain whose viewpoint is valid, when these differ within a dialogue. As with any reflective account of historical events, these narratives could be contradictory, often indicating an evolving appreciation of the events being described, with new understandings emerging through the dialogue itself. There is validity to this as it reflects the individual perception at the time. Nevertheless, in seeking to give participants a voice, was I at times undermining my own voice and my own interpretations? Within the text there was evidence of my (admittedly gentle) disagreement or contention with participants. These dialogues were generally constructive, ending in a mutual understanding, if not explicit agreement. Whether we changed one another’s mind is not clear, and indeed was not necessary. It is clear that we appreciated one another’s viewpoint, and in those ways, I hope that we each increased our understanding of the phenomenon in question.

Foucault (1998) contended that power relations are an inevitable part of society, and rather than wanting to be rid of them, we should focus our energies on ensuring our games of power can be played “with as little domination as possible” (p. 298). Voices of resistance and dissent therefore need to be welcomed in order to move towards a balance of power. This methodology, complex and protracted as it was, did seem to provide participants with an effective space to describe, interpret and disagree freely, in a relatively un-dominated space.

Whether autism is viewed as a disability or neurological difference, what we can say for certain is that autistic people experience disadvantage, not only in relation to the general population, but also in relation to other minority groups. This inequality is reflected within the academy, where the voice of autistic activists, though growing, is generally less apparent than in other discourses of disability. Reflecting on the development of his ideas and their impact on his personal perspective, Foucault (1985) observed that:

Perhaps at most they made it possible to go back through what I was already thinking, to think it differently, and to see what I had done from a new vantage point and in a clearer light. Sure of having travelled far, one finds that one is looking down on oneself from above. (p. 11)

I recognise this within my own research: I have made efforts throughout to be reflexive in my approach, and to explore this topic thoroughly and critically, but in some ways it has compounded for me what I already believed. The current practice of diagnosis renders the diagnosed as passive subjects, and maintains a position where knowledge and power are situated with certain groups of professionals and presented as 'truths'. This is a harmful practice, erecting further barriers that those diagnosed then need to overcome. Furthermore, whilst some individuals in this study took issue with the ways in which autism was described and the generalisations employed, they also recognised that some aspects associated with it were aspects they associated with themselves. Indeed, they considered these aspects to be a fundamental part of themselves, so that distinctions between 'autism' and 'self' were disingenuous. This captures the tension between an essentialist position of attempting to describe



the core of what autism *is* and the pluralism reflected within its heterogeneity. Like my participants, I too have found myself navigating between essentialist and pluralist positions within this thesis, sometimes clumsily, in my attempts to consider both the accepted and contended ‘knowledge’ regarding autism.

Happé, Ronald and Plomin’s (2006) proposal, that we stop talking about a single spectrum and start to acknowledge autisms as plural, is in this context all the more useful. By doing so, we can remind ourselves of the fact that the language we use reflects the social constructions we create, which ought to serve the interests of the individuals so labelled, rather than the various autism industries surrounding them. Returning to Foucault’s notion of biopower, Brownlow and O’Dell (2013) suggested that:

Biological citizenship can be claimed on the basis of two competing representations of autism: as a “neurodiverse spectrum” (drawing on a medical, health discourse) or as “neurological difference” (drawing on a discourse of rights and political separatism)...it may be politically expedient to conceptualise autism in terms of dualisms rather than as a spectrum on which everyone rests. (p. 111)

Indeed, they recognise that autistic individuals currently draw strategically on both discourses, contingent on context, which may be the most appropriate course of action in the current time. Rather than debating the ‘true’ ontology of autism, energies are better spent focusing on the common disadvantages and inequalities experienced by those so labelled. Within this study, participants took pragmatic decisions about their identifications. Just as disability research moves us to question distinctions between people as disabled and able-bodied,

autism research moves us to question distinctions between people as neurotypical and atypical, “forcing a broader consideration of what it means to be social and how sociality is expressed.” (Bagatell, 2010, p. 51) In his consideration of autism stereotypes, Draaisma (2009) reminded us of Asperger’s original approach to the cases he observed:

Each human being, Asperger argued, must be understood as an alloy of traits, as a unique blend of capacities and inclinations. (p. 1475)

The definition of autism has been in a state of constant flux since first identified. Those individuals categorised with high functioning autism and Asperger syndrome have arguably suffered from this the most, generally viewed as falling outside of learning disability services, but not within mental health, and so literally abandoned in a ‘no-man’s land’. The recent changes to DSM, which may not be paralleled within ICD, might address this confusion for diagnostic purposes, but it is far from clear how this will translate into improvement to access of services for those affected. The imperative then, to go beyond diagnostic labels and shorthand understandings, is greater than ever. Perhaps this is what we can most usefully do, not to dismiss autism as a social construction, but to ensure that in our responses and interventions, the diagnosis of autism is seen as an additional complexity within an already complex individual, rather than a simplifier.

Pellicano (2014) highlighted that as autistic communities are not involved in decision-making processes about research, priorities are “set almost exclusively by funders and academics in specialist fields.” (p. 203), and called

for research agendas that are more relevant to autistic stakeholders. It is of note that the researchers she consulted felt neither that community members should be co-producers, nor that there was a need for user-controlled research. Autism research seems persistently to fall behind other areas of disability in being more wedded to a medicalised view of autism and more resistant to the notion of user involvement and co-production. Ironically, this suggests that the autism research community is itself disconnected from the wider cultural sphere of disability studies. This may be because of the dominance of cognitive psychology in its roots, but nevertheless seems bizarre, all the more so given the high incidence of co-morbidity in autism, which might be expected to result in close links with, and influence from, other sectors. There is now a pressing need for autism researchers to foster greater connections with related fields and learn from the work that has gone before, in order to retain relevance and credibility in the face of contesting viewpoints being articulated by increasingly knowledgeable (and frustrated) stakeholders.

#### 7.4 Enabling success

Participants in this study gave vivid accounts illustrating the enormous additional efforts and determination required by them, to attain similar goals to their peers. They also indicated a willingness to become 'extra-visible' in order not just to help themselves, but to engender positive change for others who might be in similar situations. This sense of a collective identity and willingness to create a language to describe their experiences (Hacking, 2009b) is all the more significant in that it was apparent in different ways, in different individuals.

It was not a politicised activity but an individual sense of injustice, being transformed by those individuals into something constructive and positive. It gives an indication of the potential that autistic individuals have to be a force for positive change, and ought to be a call to arms for practitioners and academics within the autism field to harness this potential and acknowledge the contribution it offers. These first-hand accounts are also critical in achieving a balance in Hacking's 'looping effect'. Without insider descriptions and the new language they give, the discourse around autism risks remaining "thin" (Hacking, 2009b, p. 1471) and one-dimensional. All of the participants within this study had experienced successes within their lives. These were not limited to academic successes; however, by entering higher education, they had each achieved one of their life aspirations, and were working towards others. They demonstrated that they were resisting limitations imposed by a deficit model of autism, or by narrow, two-dimensional definitions. I hope that their voices in this research can add positively to the 'looping effect', articulating both new possibilities for young autistic people, and for autistic research and their role within it.

Higher education plays an increasing role in the lives of young people, as more are steered towards undergraduate and postgraduate study as the pathways most desired by employers. However, in its efforts to meet the needs of disabled students, the higher education sector is playing 'catch-up', lagging behind other areas and imposing systems that are counter-productive to their intended goals. In the very act of seeking adjustments, students are faced with further hurdles to negotiate, requiring their time and effort, and potentially causing stress – an additional challenge that non-disabled students do not

face. Institutions, and the staff within them, need to take note and seek to minimise the stress caused by their own systems. The pressurised higher education environment has already been linked to an increase in students with mental health needs (Callender et al., 2011).

Participants were on the whole positive about their experiences within higher education. However, there were within this study (and echoed in the wider literature) many descriptions of social alienation, being misunderstood by figures of authority, and social/ economic disadvantage. Sadly, they too often experienced this from those in positions of power and authority, whose role might suggest a knowledge of diverse learning needs. An essentialist approach to autism tends to marginalise those who do not exemplify the definition – even in the language we use, where ‘Kanner’s autism’ is also known as ‘classic autism’, we imply a hierarchy, in which other embodiments of autism are ‘less so.’

An important finding for educators is that, in many cases, the accommodations that made the difference between success and failure for these participants were very minor: for instance, access to toilet facilities (Debbie); discussion of the implied meanings of exam questions (Elliot); or simply highlighting a talent and encouraging it (Aimee and Christian). In an educational environment that properly values individuality above conformity, such adjustments would happen naturally, without the need for a diagnostic label. Just as many autistic adults will never have a formal diagnosis, many autistic adults *with* a formal diagnosis will never access specialist services. A recognition of the impact made by simple adjustments is therefore of huge value to autistic adults and practitioners

alike - in illustrating inclusivity as an achievable aim, rather than a complicated ambition.

That is not to suggest that it is necessarily preferable not to diagnose, but its purpose needs to be addressed, to ensure it is to the benefit of the individual. Currently, a diagnosis of autism is life-changing, carrying with it as it does mainly negative implications for the life trajectory of the person concerned. A few isolated practitioners are doing what they can to offer constructive post-diagnostic support, and from the evidence here, a useful part of that could be the emphasis that current outcome data is limited at best – based on small samples, possibly biased through recruitment methods, and in many cases, now out of date.

Whether we agree with it or not, within our current society, there is considerable emphasis on employment and economic productivity as expectations of adulthood. Moreover, inclusion within the adult sphere to a large extent depends upon it, and so the effectiveness of education in harnessing the potential of its students becomes all the more important. As Christian described, some autistic children have been anecdotally described as 'little Professors' because of their desire for learning. In a world which values learning so highly, this potential ought to be welcomed as a gift to educators. This study focused on students within higher education, but in their accounts, they talked frequently about school experiences. Unfortunately, schools did not come out well. They were often characterised as largely hostile environments, where staff tended to resist changing their practice to accommodate the needs of their students, and students were often isolated by both staff and peers. Despite this, the influence of those few pedagogues who spotted potential and

nurtured it was strong within the narratives. Often, the person concerned changed the course of the participant's life, and in these accounts, there is a sense not of enormous effort on the part of the adult, but of everyday positive practice, to the extent that they may not even have been aware of the influence they had. Encouraging success for these participants was not about implementing a specific intervention, so much as tapping into their skills and interests and offering encouragement and support. This might seem straightforward, but within an educational context, autistic children are often the least popular, not only with peers but also pedagogues, as participants here often indicated. This speaks of the complexity of autism, where the breaching of subtle social norms may be unavoidable for one of the social partners, and unforgivable for the other. Understanding and addressing this form of social barrier may be an important step forward, if it can be recognised.

### 7.5 Concluding thoughts

As many disabled commentators recognize, disabled people will not judge disability theory by its contribution to academic or research discourses, but ultimately by its role in social change, in the emancipation of disabled people. (Vernon and Swain, 2002, p. 92)

This research has been described (by my supervisor) as 'knocking at an open door', because of the enthusiastic and committed response from participants. This did seem to be the case, both in their appreciation of the methodology and in relation to the subject. In considering their experiences of success, participants did talk about the challenges they faced, but rather than

approaching this from a deficit perspective, they were framed by the successes they had achieved, and in their evaluations, they emphasised how novel it was for them to be asked to reflect on these. This in itself is a shocking finding, revealing the extent to which the deficit model currently poisons the experiences of autistic people. This is all the more serious in the context of the lack of post-diagnostic support, by which I mean specifically, support to understand the diagnosis itself. The diagnosis of autism is often imposed upon individuals without their choosing it (Shakespeare, 2006), and there needs to be recognition that to apply a label that is likely to influence that person for the rest of their life, whether or not they have chosen it themselves, is not a neutral action which carries no further responsibility. Rather, it is a radical action, carrying significant potential for damage. Within the sphere of higher education (and indeed, employment), it becomes a different type of issue. The Equality Act (2010) confers a range of rights and adjustments for disabled people, but these are entirely dependent upon individual disclosure, and disclosure is in turn dependent on the individual having some acceptance, and ideally ownership, of their diagnosis.

Within this study, efforts were made to develop “interactional expertise” (Milton, 2014, p. 795) and to respect the expertise of the autistic experience, moving beyond a deficit model to explore the phenomenon of success. The autistic experience was presumed to be diverse, encompassing a range of perspectives, reflecting not only the heterogeneity of the spectrum, but also the need for individuals to ‘work’ on their own identities, in order to navigate their situations in any given context. Only by doing so could they resist externally imposed limitations. In revising this thesis, I have read the contributions of my



participants many times over. Each time, I am struck anew at their resilience in the face of challenges. It has felt exhausting just to read of their repeated efforts - their willingness to fail and to confront their fears in order to meet their goals. As a practitioner, I will forever be mindful of this effort and the cost it represented for the individuals concerned. I hope that in exploring, with my participants, their experiences of success, the activities they have undertaken in order to be successful, and the barriers they have overcome, I have demonstrated how their experiences are relevant to current discourses. This research has shown the challenges faced by even the most successful autistic adults. It has also demonstrated, through its methodology, that autistic and non-autistic researchers can reach shared understandings, and this occurred more often and more naturally than I anticipated, emphasising our commonalities above our differences. I hope that their insights serve to demonstrate the importance and value of the autistic voice within research, and the need for the research agenda to be meaningfully informed and influenced by priorities identified by those diagnosed with autism.

The more negative finding is that what we are doing in schools is too often not working. Even those who achieve well educationally, thereby giving themselves the best chance of success as adults, report as much difficulty with educational systems and staff as they do with peers. They do not conform to the expectations of the educational system, and their achievements are too often in spite, rather than because, of the support available to them.

Nevertheless, they *are* achieving, and in these narratives are stories of developing insights with regard to the social world, and of individuals who navigate their environments and find a comfortable place within it, sometimes

by teaching those around them how best to meet them halfway. They are changing themselves, at great cost, but they are also seeking to change their environments, and in the process, increasing understanding of the many different facets of the autistic condition. They are certainly social agents, with positive social relationships and valued social roles, albeit at times hard-won and a long time in the making. We all need to work on ourselves to become what we aspire to be, but for most of us, this is not prescribed, and we tend to work more on areas of strength than weakness. Discussing the relationship between 'truth' and 'power', Foucault (1980) characterises it as "...a battle about the status of truth and the economic and political role it plays..." (p. 132).

Perhaps to be noted above all, these participants indicated their readiness to work, not just on themselves, but on their contexts, becoming pioneers and role models in their direct environments (and sometimes beyond). In doing so, participants re-imagined the 'truths' associated with autism and asserted their own status as valid representatives. This study has indicated strongly the ways in which autistic people work to manage their identities, including managing and effectively training those around them. In doing so, they are teaching their educators, and the community at large, about the individuality of autism. Moreover, they are teaching that attention to individuality is more important than specialist knowledge. Much is made of the need for specialist autism knowledge. This is not to suggest that such knowledge is unnecessary. Undoubtedly, understanding of autism can be beneficial in encouraging practitioners to look beyond observed behaviour. However, an over-emphasis on specialism can backfire, to the detriment of those it is intended to help. Firstly, as noted in an earlier study, there is a danger that practitioners with

limited experiential knowledge resort to stereotypes (Robledo and Donellan, 2008). Secondly, those without specialist knowledge can feel unqualified, leading them to offer nothing, for fear of offering something inappropriate. The experiences of the participants in this study perhaps offers a more productive way forward, in their informal efforts at self-advocacy. Through their activities, they have influenced those around them and worked to send positive messages, not just about what they can achieve personally, but what can be achieved by autistic people. This message is all the more important in consideration of the fact that most autistic adults do not reside in specialist institutions, surrounded by specialist support. Rather, they are living in ordinary communities and, as often observed by participants within this study, their potential for success depends upon employers, educators, peers and carers with no specialist knowledge of autism.

It seems pertinent to end on the insightful reflection of Hannah, as she unpicks my notes on her first transcript. In explaining what, from her personal experience, has been the difference between formal diagnosis and actual recognition of need, she summarises the dilemma faced by the participants of this study and many others:

...on the transcript you've written 'diagnosed' rather than 'recognised' - I think there is an important difference. I don't think having a diagnosis when I was at primary school would have made much difference because they were fairly useless when someone had a diagnosis of ASD...Some teachers at secondary school seemed to recognise that I struggle with some things, so there it wasn't actually needed to have a diagnosis to provide a word for it, because they seemed to 'get it' anyway...

Diagnosis of autism, without recognition of what this means for the individual so diagnosed, is at best worthless, at worst, a scarring experience. Autistic adults who are able to, are working endlessly to help those around them 'get' this crucial, but neglected autism fact, and in taking a stand, to succeed.

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**“DETERMINED TO SUCCEED”:**

**PERCEPTIONS OF SUCCESS FROM AUTISTIC ADULTS**

**by**

**ANDREA GEORGIA MACLEOD**

A thesis submitted to the University of Birmingham for the degree of DOCTOR  
OF PHILOSOPHY

**VOLUME II**

Department of Disability, Inclusion and Special Needs

School of Education

College of Social Sciences

University of Birmingham

March 2016

## APPENDIX I

### Interview Schedule

#### **1) Introductory Information:**

Introduce myself & research.

Have you read the information sheet?

Are you happy for this to be recorded?

Can I make a few notes if necessary?

Explain how interview process will work, purpose of evaluation form at end. Length of process – should be maximum one hour each time. Any questions?

Any particular thing I should bear in mind? (speak slowly, supply visual aids, is participant feeling ok today? Might you need time out and if so, how will I know?)

Check participant is happy to sign consent form and get them to do so. Explain where toilets are!

**Feel free to interrupt & ask questions if anything unclear - you can end interview at any time if you need to, or choose not to answer specific questions.**

#### **2) Basic Information for Context:**

Name, Age, Gender, Course, Year (first time or re-take/change?), Living Situation.

Are you:

Campus undergraduate

Campus postgraduate

Full time

Part time

Distance Education or Web

Qualifications on entry to institution.

Have you been involved in research before? When and what?

#### **3) Non-academic interests:**

What do you like to spend your time doing when not studying?

Ask for details of what is involved, who with, etc.

#### **4) Information on diagnosis**

What was diagnosis, when given and where. What information was provided at the time?

How do you feel about diagnosis?

**5) Significant events: Ideally 2 academic, 2 non-academic. Was it ok thinking of 4, did you have too many/too few?**

**What are the 4 events you'd like to discuss?**

Can you please describe your first significant event to me.

Prompt for details: when, how, who else was involved?

	1	2	3	4
<b>What?</b> exactly was the event and its context? What happened?				
<b>When and Where?</b> did it take place?				
<b>How?</b> did it come about and what factors contributed to it?				
<b>Who?</b> was involved and who was helpful or unhelpful in the process?				
<b>Why?</b> was it significant to you and was it significant to anyone else?				
<b>Autism</b> - a factor in the event, helpful or unhelpful?				
<b>Is there</b> anything else you'd like to say about that?				

**This is the end of the interview, do you have anything you want to ask me?**

**Summarise follow-up:**

1. Please complete and return evaluation (SAE needed?).
2. I will transcribe and briefly analyse transcript – will send to you with notes.
3. In meantime, note down any significant events that occur during the interim. We will discuss these when we next talk.
4. I will be in touch to arrange another (shorter) interview/discussion.

## APPENDIX II: Interview Prompt Sheet

### RESEARCH STUDY: 'Perceptions of Successful Adults Diagnosed on the Autism Spectrum'

**Thank you very much for agreeing to be interviewed.** In preparation for the interview, it would be helpful if you could think of **4 significant events** when you have experienced success. Ideally this would be **2** events that are academic-related and **2** that are non-academic (related to your personal or social life).

By significant, I mean an event that you found important at the time, or consider to be important in retrospect.

By event, I mean anything that has happened, which could be a specific occurrence or a time when you realised that you have achieved or become successful at a particular aspect of your life.

Below I give some examples of experiencing success or achievement, but these are just examples to help you in case you have difficulty thinking of things. Think of a time when you:

- *Passed an important test, exam or audition*
- *Won a prize or accolade*
- *Overcame an obstacle to achieve something*
- *Produced or did something that makes you feel proud*
- *Did something that you consider a personal achievement*
- *Were given a valued role or responsibility*
- *Received praise for something you did*
- *Received gratitude from others for something*
- *Did something that made you feel you'd made a difference or had an influence*
- *Did or achieved something that made you feel good, important or valued*
- *Experienced success or achievement at school*
- *Experienced success or achievement since entering higher education.*

I will be asking you about your significant events in the following ways:

**What?** exactly was the event and its context?

**When and Where?** did it take place?

**How?** did it come about and what factors contributed to it?

**Who?** was involved and who was helpful or unhelpful in the process?

**Why?** was it significant to you and was it significant to anyone else?

It would be great if you could think of 4 significant events. Don't worry if you can't, I can help with this during the interview. If you can think of more, please choose the most important 4 to share with me.

**Thank you!**

APPENDIX III

**BRIEF EVALUATION OF INTERVIEW**

**This should take just a couple of minutes to complete. The purpose is to let me know what was good and bad about the interview process. It would be very useful for us to have this information but you can choose not to complete it.**

1. Were the meanings of the questions clear to you?

definitely	yes	no	definitely not

If you answered no, which were not?

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2. Did the interview environment suit your needs?

definitely	yes	no	definitely not

If you answered no, why not?

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3. Did the interview format suit your needs?

definitely	yes	no	definitely not

If you answered no, why not?

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4. Did any aspect make you feel pleased or particularly positive?

definitely	yes	no	definitely not



If you answered yes, what and how?

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5. Did any aspect make you feel upset or particularly negative?

definitely	yes	no	definitely not

If you answered yes, what and how?

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6. Now that the interview is complete, how do you feel?

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7. Additional Comments – this might be further comments on what you liked, didn't like, or suggestions for next time.

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***Thank you very much for taking the time to help with this.***

## APPENDIX IV: PARTICIPANT INFORMATION SHEET

# UNIVERSITY OF BIRMINGHAM

### **Title of Research Study:**

'Perceptions of Successful Adults Diagnosed on the Autism Spectrum'

I am a lecturer in Autism Studies at the University of Birmingham and as part of my PhD I am researching the perspectives of successful adults who have received a diagnosis on the autism spectrum. I want to talk to individuals about their experiences of success and achievement. I am hoping that you will agree to let me talk to you.

### ***What do I have to do?***

The research would involve an initial interview which would either be conducted via email, telephone or face to face, depending on what you would prefer. I will send you some brief questions to consider in advance of the interview so that you can feel prepared, and also some guidance on the interview process itself, depending on the format you choose. The interview is likely to take between 40 minutes and 1 hour.

With your permission, telephone and face to face interviews will be digitally recorded and transcribed. Following the initial interview I will send you a full transcript with main points highlighted and plan a shorter follow-up interview, during which I will share my initial analysis of our discussion and ask for your feedback. In doing this, I hope to ensure that my analysis incorporates your ideas and reflections on what you have told me. **All information received will be treated confidentially.**

### ***What is the purpose of the study?***

This study intends to explore experiences of success amongst adults diagnosed on the autism spectrum from their own perspective. The purpose is to gain a better understanding of the area of success, which is a neglected area within the literature. Your experiences may be useful and informative for other young people who are learning about their own diagnosis of autism or Asperger syndrome.

### ***What will I get out of it?***

In discussing your experiences with me, I hope that you will benefit from reflecting upon your achievements. You will receive a copy of the interview transcript and have the option to receive and comment on my analysis of the interview and any documents (eg. publications) arising. I will also provide copies of relevant literature relating to adults with autism if you would find this useful.

*Continued overleaf...*

***How will the results of the study be used?***

Results of the study will be included within my doctoral thesis and may be published in academic and/or practitioner journals. Data will be presented so that individual participants can not be identified, although you can opt to receive named credit as a contributor if you wish. (If you do so, your name will not be identifiable with specific data). As a contributor, you will receive copies of all reports and publications arising from the research.

***What if I agree to take part and then change my mind?***

If you decide to let me interview you, you can change your mind and withdraw at any time. You do not have to give a reason. If you decide you want to withdraw, all data relating to you will be erased or destroyed and will not be used in the analysis or reports.

***I am happy to agree for you to interview me. What do I do next?***

Contact me directly as soon as you can and let me know whether you would like to answer questions:

- Via email
- Over the telephone
- In a face-to-face meeting.

Let me have your name, email address and a contact phone number. I will then contact you to arrange an interview in the next few weeks and send you a consent form so that you can formally give consent to be interviewed. ***If you have some questions you would like to ask before deciding whether to participate, please get in touch.***

***Contact me at:***

- [redacted] or on [redacted]

***Andrea MacLeod (Researcher – ACER Team)***

***Autism Centre for Education & Research***

***School of Education***

***University of Birmingham***

**APPENDIX V: CONSENT FORM**

**UNIVERSITY OF  
BIRMINGHAM**

**PARTICIPANT CONSENT FORM AND RIGHT TO WITHDRAW**

**Title of Research Study:**

'Perceptions of Successful Adults Diagnosed on the Autism Spectrum'

**Ref:** \_\_\_\_\_

**Date:** \_\_\_\_\_

Thank you for agreeing to participate in this research study. Please tick the boxes below to indicate that you are clear about the study and if you are not clear about any aspect, ask me.

I confirm that I have read and understood the information sheet

I confirm that I understand my participation is voluntary, that I can withdraw at any time without giving a reason and have my data removed from the study

I confirm that I understand all data will be confidential and personal details will not be included in reports or publications

I agree to participate in the research study

I agree to interviews being recorded and transcribed and understand these will be kept secure and confidential

I agree to anonymised material being used within the researcher's doctoral thesis and other publications

If you are in any way unsure of what you are agreeing to, please say so.

If you agree to participate please complete the following:

Participant

Name\_\_\_\_\_

Signature\_\_\_\_\_

Email address\_\_\_\_\_

2<sup>nd</sup> email address\_\_\_\_\_

Permanent postal address (if you would like me to post docs to you):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

POSTCODE:\_\_\_\_\_

Date\_\_\_\_\_

If you would like to receive named credit in publications (your name would not be related to any specific data) please tick the box below:

Researcher

Name\_\_\_\_\_

Signature\_\_\_\_\_

Date\_\_\_\_\_

**Researcher Contact Details:**

*Andrea MacLeod*

*Researcher – ACER Team*

*School of Education*

Email: 

Tel: 

## APPENDIX VI: SAMPLE TRANSCRIPT

### INTERVIEW TRANSCRIPT

**Interview Participant Code:** T1-Hannah

**Transcript Code:**

**Date of Interview:** 29<sup>th</sup> November 2010

**Length of Interview:** 112 minutes/ 3787 words

**Format of Interview:** MSN Messenger

**Transcript Conventions:**

[ ]	= non speech and notes, eg. inaudible speech
[p]	= pause
/	= overlapping or interrupting speech
[L]	= laughter
[N]	= name
<u>Underlined</u>	= stress or emphasis
Light font	= section not fully transcribed



**INTERVIEW 1**

<b>TIME &amp; EMERGENT THEMES</b>	<b>INTERVIEWER</b>	<b>INTERVIEWEE</b>	<b>EXPLORATORY NOTES</b>
	Hi Hannah	hello	
	<p>How are you#</p> <p>Did you find it quite straightforward to set up MSN messenger? I find it very intuitive.</p>	is this working correctly?	
	I received that ok, are you getting my replies?	<p>no</p> <p>That's why I asked</p>	
	you got that last message though?	<p>I have received 'hi ' and nothing more</p> <p>Well, other than the last 2 messages which I</p>	

		have replied to	
	ok, perhaps it had a delayed start but it seems to be working now. How are you?	Ok how are you?	
	other than that little glitch was it ok getting on to MSN?	yeah	
	I'm good thanks, thankfully in a warm office!  Are you ok to start the interview now?	yes	
	It can be difficult to pace online chats and I don't want to cut you off before you've finished, so I suggest we both use '...' to indicate we have more to say, and '/' to indicate we have finished speaking. Does that make sense?/	So I put '/' at the end of each message?/	

	<p>exactly - or if you want to send a partial message then carry on writing...</p> <p>use the dots/</p>	Ok./	
	<p>Great. Have you had the chance to read the information I sent through and does it all make sense to you?/</p>	<p>I read through the stuff in the email about thinking of 4 successes and I have just filled in the consent form/</p>	
	<p>Good - just email that back to me. As we go along, feel free to interrupt &amp; ask questions if anything is unclear and bear in mind you can end interview at any time if you need to without giving me a reason, or choose not to answer specific questions./</p>	Okay thank you/	
	<p>Right, first of all, could you tell me whether you have been involved with any autism related research before?/</p>	<p>No, i have not/</p> <p>Oh no wait..</p>	<p>One prior involvement in research</p> <p>1. How did this come about?</p>

		<p>Sorry!..</p> <p>I filled in a thing about mental health on the National Autistic Society website/</p>	
	<p>ah ok - thanks. I know it's easy for these things to slip your mind. Do you use the NAS website quite a bit?/</p>	<p>I've looked at it quite a lot I suppose/</p>	<p>Has been pro-active in seeking autism info</p>
	<p>I find it a good site - a good source of quick information...</p> <p>Ok, thank you for that. I would next like to ask you what you like to spend your time doing when not studying?/</p>	<p>I am a member of a Christian society here at my university, despite being an atheist (Odd, I know!), and so I meet with them every Sunday evening, and often go into the Chaplaincy here and hang around with members of that society. I like listening to music. I probably spend a lot of time looking up things on the internet - just questions about anything that have come into my head (eg. yesterday I looked up how Padong women put those rings around their neck). I also like learning sign language. i can't think of anything else; I don't know where most my time goes</p> <p>/</p>	

	<p>that sounds like a lot! Do you mind if I ask why you're a member of a Christian society if you're an atheist?/</p>	<p>Okay! no, that's fine, most people do ask! Quite a few years ago I used to be friends with a girl called J [redacted]. I then lost contact with her. When I got into [uni], a mutual friend informed me [J] was going there too. I got into contact with her again. At the first weekend here, we texted each other to say we should meet up. She said she would be at this Christian society ([J] is Christian), and I should meet her there. At first I was very nervous of this, and asked the other members if it was okay for me to be there. They said it was, and they were nearly all really nice people, so I kept going! Ironically, it's the first time I've ever felt part of a community...</p> <p>Sorry if that's too much detail/</p>	<p>H feels part of this community: a significant first.</p> <p>2. Why ironically?</p>
	<p>That is not too much detail and very interesting - do you find you are</p>	<p>No, if anything I am more strongly atheist since</p>	<p>H not influenced by community beliefs; maintains</p>

	becoming tempted by Christianity or is it easy for you to keep that aspect at arms length?/	coming here./	personal convictions
	You sound firm in your own beliefs. And your interest in sign language, does that stem from anything in particular?/	I think it's partly to do with Lee's BSL Songs on YouTube - a guy called Lee translates popular songs into British Sign Language. Also, the school I went to had a hearing impaired unit so there were many deaf people at my school (but they spoke rather than signed). My friend [N] was friend with one of the deaf girls [A], and [A] knew some sign language which she taught [N], and [N] taught me.  /	
	I didn't know about the youtube thing, I'll have to check that out. OK, thank you for that, can we move now onto the circumstances of you getting your diagnosis? Ie. What, where and when?/	Very recently - I was diagnosed in February this year. I suspected I had AS already and had tried to get a diagnosis through the NHS but that all went wrong. When I came to uni I contacted the disability services telling them I had mental health problems and 'traits of Asperger's Syndrome'. They offered to refer me to a private clinical psychologist who	Recent diagnosis, instigated by H.

		specialised in adults with AS and could say if I actually had it or not. So I went there, and was diagnosed./	
	I know that [name] Uni is really hot on support for students on the autism spectrum...  so you pursued diagnosis yourself, how did you feel to get the formal verification?/	I'm not sure I understand that sorry/	
	that's fine - what I mean is, was it important to you to get the diagnosis?/	Yeah it was. I think my life's improved since because I know I'm not just making a fuss over nothing, and I have a word for the way I am, and I can therefore get appropriate help/understanding./	Diagnosis a significant positive. Improved life by bringing help and better understanding, both from others and herself
	That's good to hear. What information did they give you when they gave you the diagnosis?...  eg books, weblinks, leaflets?/	They didn't give me any of those (but I knew quite a bit about it already)/	No info at point of diagnosis

	Sounds like it was just as well! Ok shall we move on to your significant events? What would you like to start with?/	Erm, I got 3 As at A-level. That was a significant event. What do you want to ask about that? Just what you sent in the email?/	
	well, it may seem an obvious question with such an achievement but I'd like to know why it was significant for you?/	Partly because I really didn't expect to do that well. I hoped for A grades in Biology and Chemistry but I was really scared I would do badly in Physics and not get the B i needed to get into [uni]. Also, sixth form was really difficult for me and I considered dropping out, so I'm proud that I did well when it was difficult to just stay studying! I could have easily justified getting bad results./	Surpassed own expectations.  3. Do you think there were people who were expecting you to do so well?  Definite personal pride in achievement
	It's an excellent result, you are right to be proud. Why was 6th form difficult if you don't mind me asking?/	Thank you...  I don't mind you asking. I have always had problems with school very probably due to having undiagnosed AS; I always got into trouble. In sixth form, I had a lot of trouble with my mental health and was quite ill so it was quite difficult to get through a school day	Problems attributed to undiagnosed AS. School unsupportive, a challenge just to stay in school.  4. Do you attribute your mental health



		and the school were not very sympathetic towards this! Again, I was always in trouble, and they threatened many times to throw me out./	problems to undiagnosed AS and has diagnosis helped?
	It is doubly amazing that you got the results that you did then. And by the sound of things is was important for you to get into [uni]?/	Yes, yes it was. I really wanted to go to university to sort of get away and start new. I only needed BBB to get into [uni], and I was happy I exceeded this./	Uni as an opportunity to again; escape and reinvent
	And were there particular people who were supportive in the process?/	My physics teachers were really great; they supported and encouraged me and didn't get angry with me like the other teachers. My parents are very nice and helped me to stay in sixth form./	Support of one teacher and parents  5. How was this important?
	Sounds like you had some good people around you. Do you regard your AS as being a factor in this event, positive or negative?/	In a way, it's both positive and negative. Having AS made school difficult, and was a big factor in making my mental health rubbish, so in that way it's very negative. But also, I didn't have much of a social life, so it was much easier to study!./	

	That makes sense - and in terms of the negatives, do you feel diagnosis has improved things?/	Yes./	Diagnosis beneficial
	Very definite! good. Is there anything else you'd like to say about that or are you ready to move onto the second event?/	no, that's all i want to say about it...  Does it matter which event I chose next?/	
	no entirely up to you/	If it's not too similar to the last one, I could talk about getting a 1st in my first year at [uni]./	
	wow, congratulations! No that is not too similar, please tell me about it/	Okay. Again I didn't expect to do that well! It counts for 10% of my degree which is really nice as a lot of the time people's first year counts for nothing towards their degree, so even though it's really tiny, I feel I've got a bit of my degree done (and done well). It shows I can still do well at the next stage up, because they always say people who do well in school might not do so well at uni because it's	Again surpassed expectations.

		<p>different and they're with a load of people at their ability level and have to do well against them. Also, I did this while learning to live far more independently (I think that's harder for me than for a lot of others), and coping with new problems that started at uni. I also have a social life at uni so this shows I can still do well academically without being alone all the time with nothing better to do than study!</p> <p>...</p> <p>the head of undergraduate studies for the department supported me throughout the year, and he was very happy about my result. My friends were helpful, too, because they helped me to revise and helped me cheer up when I was fed up of work. My parents helped again just by talking to me about my work which helped me to remember I am very interested in it even if I feel a bit fed up with it...</p> <p>... Part of the reason I did well was taking a psychology module for extra credit. I knew quite a bit about psychology already, so it was nice to see that pay off as I sometimes feel</p>	<p>Importance of gaining other skills: independent living, and being able to succeed AND have social life</p>
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		when I learn a lot about something other than biology that I'm wasting my time with the wrong thing/	A network of supports: Dept head, Uni friends and parents – parents helpful at maintaining motivation
	When you talk about your helpful friends, it sounds like these are all the new friends that you made at [uni]?/	Yes /	
	It makes such a difference to have supportive people around you doesn't it? And it sounds like you keep being surprised by your own abilities?! /	Yes, it does. It's very different from school where most people were really unhelpful! And yes, I do seem to always manage much better than I think I will! /	Contrast of uni from school: much more positive experience.  Also awareness that H does cope better than she expects to  6. Do you think this recognition affects your ability to take on new challenges?
	Perhaps in time all these achievements will help you to see how successful you really are! Are you ready to move on to the next thing?/	I'll just add to the last thing that there was no one at uni who was unhelpful really, as that was mentioned in the email questions, and it's a huge contrast to the last success at A level./	No-one unhelpful

	Thanks, that is quite a massive compliment to the Uni/	Yeah, it's great here/	
	It really does sound it /	Shall I move on to the non-academic achievements now?/	
	yes please/	<p>Okay. In June of this year, I went to the Chaplaincy Ball; an event by the Christian society I am part of. They run one every year. I do not go to clubs, or very many parties (never parties with a load of loud music and people and lights). I rarely go out in the evenings. I did not go to my school prom or sixth form leaver's ball. <b>So I'd never done anything like this before, so I'm proud I managed to do it - it's a step forward in my social skills and stuff.</b> There was formal dress, and food, and an area with music and disco lighting. I did not panic much, despite the large amounts of people. <b>I danced, which in most situations I would be far too shy to do, as I can't really do it properly but I knew most</b></p>	<p>Facing new social challenges, awareness of and pride in achievement</p>

		<p>the people there and knew they wouldn't mock me and didn't care. I also danced with other people - I am even more reluctant to do this as I feel I am a nuisance to them and I have problems with touching. I stayed for the whole of the evening. I admittedly did go outside at one point, and away from most the people at another point, both times because I had begun to panic. But I calmed down again, and overall really enjoyed myself.</p> <p>...</p> <p>again it's the friends at uni who helped. It helped being part of the Christian society community. The former president of the society used to suffer very badly from panic attacks, so she was able to tell me it would be okay and I could go somewhere quiet and calm down if I got freaked out during it. She persuaded me to go, really, because she knew what it's like to be scared of these things...</p> <p>actually I think that's all I have to say/</p>	<p>Confidence through feeling supported and safe within the group</p> <p>Conscious efforts to control anxious instincts and stick with it – overcoming panic and enjoying the event.</p> <p>7. It sounds like it was</p>
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			important that she was able to empathise with you: would you agree?
	<p>You sound like a very brave person, to face all those challenges at once. What do you think made you feel able to do it?/</p>	<p>I felt I could just leave if I couldn't cope, so there was no pressure. Also, I could go outside and calm down if I got panicky. But it was mainly my friends, and the community here that made me feel able to do it. They mostly understand how I am, so it's far less of a problem. Also, I am not brave! As I've kind of mentioned already, stuff's always a lot worse in my own head and so I surprise myself with what I'm able to do./</p>	<p>Personal strategies for dealing with panic/anxiety, in effect removing pressure.</p> <p>Understanding from others making new challenges possible.</p> <p>H prefers not to regard these achievements as brave</p> <p>8. Would you agree with this?</p>
	<p>What is it they say, bravery is not doing stuff and not being afraid, it's being afraid and still doing it...</p> <p>I was just about to say it sounds like you feel that your friends really understand you...</p>	<p>It's the autism that made it a success, really. Normal people without autism or anxiety issues just do these things. It's a success cause I managed to do it despite the autism making it difficult./</p>	<p>Success stemming from overcoming problems caused by autism</p>

	<p>you beat me to it!...</p> <p>do you feel that your autism was a factor in this at all?/</p>		
	<p>That's a good way of putting it...</p> <p>Are you ok to move onto the last thing?/</p>	<p>Yes. The last thing was in September of this year. I had just moved into my accommodation for the year with one of my housemates. Less than week later, she had to go back home to help her mother with stuff. There were many problems with the house, which I had to continually communicate with the property manager about. I managed to stay in the house for 5 days by myself and report faults. The main reason I stayed was that the British Science Festival was on in [redacted] so I stayed here to be able to go to it. So I did that during the day, as well as talking with the property manager and my housemates (none of whom were in the house) about fixing the problems with the house. I even managed when I frightened the life out of myself by setting off the smoke alarm and the front door lock broke as i was getting out of the house. I am very anxious and tend to think I can't cope with adult life</p>	<p>Taking responsibility and being independent: a new challenge motivated by a specific event</p>



		<p>and this is more independent than I have ever been: I lived in halls last year, where I never had to report problems and there were always other people about, and there were places I could go in the middle of the night if I was to frightened to be in the house. Managing makes me feel like I can manage adult life maybe. I hope this is not all too vague, but basically I survived independently for 5 days and communicated effectively about problems with the house I'd just moved into./</p>	<p>Tendency to expect that she cannot cope</p> <p>Experience providing H with more confidence/awareness of her potential</p>
	<p>Took on a lot of responsibility. Again, were there specific things that helped you to feel you could manage this or do you think you are just generally a determined person who rises to the</p>	<p>Yes, responsibility. I hadn't thought of it that way.</p> <p>I was determined because I really wanted to go to the science festival! Also, term hadn't started yet, so I was a bit less stressed. I</p>	<p>Determination to succeed, motivated by festival but also desire to be able to manage.</p>

	<p>challenges you are presented with? things or people/</p>	<p>suppose I was quite determined to manage, I try to be. I did have friends in the area who I could contact if I needed to, and I could have gone home if I couldn't manage. The latter thing is again that it's easier to do things sometimes if I know it's okay if I fail, it reduces the anxiety which is sort of the main problem I have. The property manager was nice and was helpful about the fault reporting. If she'd been annoyed and not helped perhaps I'd have given up and gone home rather than living in a house with a broken cooker and a dodgy front door lock etc. My friend [C] was with me for most of the last day (the same day I set off the smoke alarm!) and slept over here that evening and it helped to have someone with me. /</p> <p>(Just to clarify 'home' in that paragraph refers to my parents house in [L])</p>	<p>Importance of knowing that it's ok to fail; this making it easier to try.</p>
	<p>It sounds like you have developed lots of strategies to help you succeed in these circumstances - persevering even when things do go wrong (like the smoke alarm and lock, which</p>	<p>Sorry I forget you keep asking that! Er, I think it's the same as the last thing partly: it's the autism that makes this difficult, which makes overcoming it significant. I don't know if being autistic makes me more determined to do this</p>	<p>Difficulty of judging where 'H ends' and</p>

	<p>would make most people anxious) if very admirable...</p> <p>Sorry to be repeating myself but do you think autism was significant in any way?/</p> <p>is not if! (above) /</p>	<p>so I can go to the British Science Festival. It's difficult to know, particularly with things like being fascinated by science, where autism ends and my personality begins./</p>	<p>'autism begins</p>
	<p>fair point and a very good one...</p> <p>Thank you very much for giving up so much of your time, [H], I have found your insights really valuable and interesting and you've been a pleasure to interview, most of the time you've done my job for me!...</p> <p>For me, this is the end of this interview. Before I explain about the next stages, is there anything you'd like to ask?/</p>	<p>Will I be sent the results of the study?</p> <p>/</p>	

	<p>Yes, you will be kept informed at all stages, I will explain now...</p> <p>Next, I will put this interview into a transcript format (so it's easier to read) and briefly analyse it with some notes...</p> <p>Then (in the next few weeks) I will then send these to you to read, and ideally have a follow-up online interview with you to get your feedback on my analysis...</p> <p>the idea being that I ensure I'm reflecting your views accurately, and if your analysis disagrees with mine, I report both fairly...</p> <p>The next interview should be quite a bit shorter though, you'll be relieved to know!...</p> <p>I will also run any subsequent analysis/reports by you so that you know what I'm saying and have the chance to respond (this is why I ask</p>	<p>Yes, thank you for explaining /</p>	
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	<p>for multiple addresses, as some of this will take some time)...</p> <p>After our 2nd interview I would be happy to send you the theory behind what I'm doing, if you would be interested in reading it...</p> <p>But for now, does that all sound ok?/</p>		
	<p>Great - and shortly I would like to send you a brief evaluation so that you can give me feedback on how this process has been for you (I'm researching that aspect as well as the actual content of interviews)...</p> <p>so I'd appreciate it if you complete that and email it back to me/</p>	<p>Okay/</p>	
	<p>Thank you for bearing with me over the date confusion, and for signing up to MSN messenger...</p> <p>It's been a real pleasure to 'meet' you</p>	<p>That's fine. MSN is very easy to use. Nice to meet you, too. /</p>	

	online /		
	Thanks - and I hope you have a good week and are not too inconvenienced by the snow we're due/	You too./	
	Thanks. Bye then, I'll be in touch soon/	Bye! /	

**Interview Evaluation (from participant)**

1. Was the meaning of the questions clear to you? If you answered no, why not?	yes
2. Did the interview environment suit your needs? If you answered no, why not?	definitely
3. Did the interview format suit your needs? If you answered no, why not?	definitely
4. Did any aspect make you feel pleased or particularly positive? If you answered yes, what and how?	Yes  Just because I was talking about times I had been successful it made me remember stuff that made me feel good about myself.
5. Did any aspect make you feel upset or particularly negative? If you answered yes, what and how?	no
6. Now that the interview is complete, how do you feel?	okay
7. Additional Comments	

## APPENDIX VII: DATA THEME TABLE

	EL	HA	DE	DE	LE	AI	RO	ROS	WA	LI	JO	BR	BE	TH	GR	SA	TOTAL
<b>DIAGNOSIS</b>																	
validation		x			x		x		x		x		x				6
positive		x			x	x	x		x			x	x				7
Undiagnosed autism as barrier		x	x		x		x		x								5
Distance from process			x	x	x			x		x		x		x	x	x	9
Route to self-understanding **	x	x	x		x		x	x	x	x	x		x				10
Positive for self rather than practical benefits **					x		x		x				x				4
Route to support	x	x		x		x		x		x		x		x		x	9
Social definition							x				x						2
Actively sought		x			x		x		x	x	x		x				7
Seeking appreciation of potential (IQ)	x	x			x					x							4



negative				x		x				x	x							4
Worried 'self-created'									x					x				2
Questioning validity										x				x	x	x		4
Struggling to understand						x				x					x			3
ambivalence			x														x	2
unhelpful concept										x							x	2
		EL	HA	DE	DE	LE	AI	RO	ROS	WA	LI	JO	BR	BE	TH	GR	SA	TOTAL
<b>IDENTITY</b>																		
Consistency thru diagnosis (not defined by autism)	x	x	x	x	x	x	x	x		x		x	x		x		x	12
Independent thinker	x	x						x							x			4
Outsider vs. insider 'belonging'		x	x	x	x			x	x	x	x	x		x	x	x		12
Autism vs self		x		x			x	x			x	x			x		x	8
Autism not a good fit							x			x	x	x			x		x	6
awareness of difference	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	16
<b>SMOD</b>																		
Making sense of failure as laHa of understanding **	x	x		x			x	x				x			x			7
Potential vs. barriers	x	x	x	x				x	x	x	x	x		x				10
Recognition of difference thru reactions of others			x	x	x		x	x	x	x	x	x		x	x	x		12
Turning down adjustments										x								1
Adult environment more tolerant								x				x			x			3

	EL	HA	DE	DE	LE	AI	RO	ROS	WA	LI	JO	BR	BE	TH	GR	SA	TOTAL
<b>SUCCESS</b>																	
Reliant on personal interest	x	x	x			x	x							x		x	7
Passion for topic	x		x	x		x	x			x				x		x	8
Exceeding expectations	x	x	x	x	x	x		x	x	x	x	x	x			x	13
Importance of feedback	x			x			x			x					x		5
Resilience & determination		x	x	x		x	x	x		x	x	x	x	x	x	x	13
Success from overcoming barriers/failures	x	x	x	x	x	x	x	x	x	x	x	x	x		x		14
Courage: facing fears		x	x	x					x			x	x				6
Success as luck		x	x									x	x			x	5
Motivation to succeed to repay others		x		x		x				x							4
achievement for its own sake	x											x	x			x	4
Helping others as achievement	x			x	x		x					x					5
Interest vs. motivation	x	x	x				x						x	x		x	7
Willing to risk failure		x	x											x			3
Life-changing event			x				x			x	x		x		x		6
Using natural interests to connect	x		x	x	x		x			x		x		x		x	9
Success through effort	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	16
Proving potential to others	x	x	x	x	x	x		x		x	x						9
Success as increasing understanding of autism	x		x	x		x									x		5
'Making a difference'	x			x	x		x					x		x			6

'snowballing' of successes							X						X						3
Success as relationships with others/inclusion	X	X	X	X			X		X	X		X		X					10
Success as natural ability	X								X	X	X	X	X		X	X			8
External recognition	X	X	X	X	X	X	X			X	X	X	X		X	X			13
Developing strategies	X	X	X	X	X		X				X		X	X	X				10
	EL	HA	DE	DE	LE	AI	RO	ROS	WA	LI	JO	BR	BE	TH	GR	SA	TOTAL		
<b>AUTISM</b>																			
Advantage from passion	X		X			X	X			X			X	X		X		8	
Different thinker	X						X			X	X				X			5	
Interests/obsessions	X				X		X			X	X		X	X		X		8	
Innovator & role model	X																	1	
Positives arising from negatives		X				X	X	X		X	X	X	X		X			9	
Autism as barrier		X	X	X	X		X	X	X	X	X		X	X	X	X		12	
'normal' vs autism		X	X		X	X	X	X	X		X	X	X	X	X	X	X	13	
anxiety		X	X	X	X					X	X		X	X				8	
Authoritative voice	X		X		X	X	X		X	X	X		X	X		X		11	
Not engaging where not interested			X											X				2	
Sudden social developmental leap			X										X	X				3	
Development & 'growing out' of autism			X		X	X	X	X			X			X	X			8	
Relating to literature			X	X	X		X		X	X	X	X	X	X	X	X		12	
Sharing peROsonal experiences	X		X	X		X									X			5	
Escape from autism				X														1	
Memory				X	X	X	X			X	X	X		X		X		9	
Autistic empathy	X			X			X					X						4	
Misunderstanding others								X	X				X		X			4	



	EL	HA	DE	DE	LE	AI	RO	ROS	WA	LI	JO	BR	BE	TH	GR	SA	TOTAL
<b>SUPPORT</b>																	
Teachers	X	x	x			x	X	x	x	x	x	X	X	x	x	x	14
Parents	x	x	x	x	x	x	x	x		x	x	X	x	x	x	x	15
Peers		x				x	X		x	x	x	X	x	x	x	x	11
Understanding managers					x						x						2
Understanding/acceptance from others as removal of barriers	x	x	x				x	x					x	x	x		8
Supportive people/environment as key to success	x	x	x	x	x	x	x	x		x	x		x	x	x	x	14
gratitude	x	x	x	x		x	x	x		x							8
Being a supporter/mutuality	x				x	x	x					x	X				6
Supporter as means of release									x								1
Autistic peers	x			X			x					x					4
Needing social relationships		x			x	x	x		x	X				x	x	x	9
Lack of support		x		x	x	x	x		x	x	x	x	X				10
<b>METACOGNITION</b>																	
Reflecting on learning style	x	x	x	x	x	x	x			x	x		X	x	x	x	13
awareness of internal	x	x	x	x	x	X	X	x	x	x	x		X	x	x		14

barriers																			
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These themes were revised in the third iteration of coding, which significantly changed and strengthened them in terms of representation from participants. This resulted in more themes with higher representation. Therefore, in this version, those themes representing 8, or 50%, of participants have been excluded. These are listed separately below in case some or all become relevant in the next stage of analysis.

Number of Participants	Theme	
16	awareness of difference	
16	Agreement with researcher	
16	Success through effort	
15	Support from parents	
14	Support from teachers	
14	Supportive people/environment as key	
14	awareness of internal barriers	
14	External recognition	
14	Success from overcoming barriers/failures	
13	Exceeding expectations	
13	Resilience and determination	
13	Reflecting on learning style	
13	'Normal' vs autism	
12	HE as precious goal	
12	Identifying with autism literature	
12	Autism as a barrier	
12	Consistency of identity through diagnosis	
12	Outsider vs insider	
12	Recognition of difference through reactions of others	
11	Support from peers	
11	Reflection/development of thinking through process	
11	Authoritative voice	
10	Route to self-understanding	
10	Potential vs. barriers	

10	Developing strategies	
10	Success as relationships with others/inclusion	
10	Lack of support	
9	Proving potential to others	
9	Disagreement with researcher	
9	HE as transformative	
9	Positives arising from negatives	
9	Autism & memory	
9	Using natural interests to connect	
9	Diagnosis as route to self-understanding	
9	Diagnosis as route to support	
9	Needing social relationships	

8	Autism not a good 'fit'	
8	Success as passion for topic	
8	Autism as advantage of passion	
8	Interests/obsessions	
8	Anxiety	
8	Development and 'growing out' of autism	
8	HE: holistic benefits	
8	Success as natural ability	
8	Understanding/acceptance from others as removal of barriers	
8	Gratitude	



## APPENDIX VIII: ANALYSIS CHECKING DOCUMENT

Presentation of data:

First, I checked each theme and noted how many quotes it was represented by overall. In this way I ensured that themes were well represented, and at this point I also identified participants who were not represented by a particular theme. I wished to ensure a reasonable balance of accounts, or at least identify any potential bias I may have introduced at this stage. Next, I created a section for each participant and copied and pasted all quotations into their section, divided by theme. This gave me an overview of the quotations used for each participation and enabled me to identify repetition. Finally, I counted how many participants represented each sub-theme. This stage was helpful in once again bringing me back to the raw data and considering again its meaning, both at an individual and a collective level.

Having completed this process, I then re-read the entire analysis in order to get a sense of it 'as a whole', to draw out over-arching themes and identify commonalities. I highlighted points that I felt to be of particular significance, in order to ensure that these parts were not lost in the subsequent editing process, when I aimed to minimise repetition and balance representation of themes as much as possible.

Following this was a final edit, where repetition was minimised, contributions counted to get a sense of balance, and any repetition that was deemed necessary was highlighted so that I could reflect further on whether and how this was justified.

### **28/04/15 14,000 words of quotations**

#### From The Autistic Experience

Quotes per theme:

Ben, Warren, Debbie, Greg, Sandy, Hannah, Lila, Josh, Rob, Elliot, Christian, Aimee = 12

Missing: Bridget, Thomas, Rosie, Lewis

Sub-themes:

**"That's my own perception and I can see how based on this conversation you might see it differently"**

Ben, Warren, Debbie, Greg, Sandy, Hannah, Lila, Josh, Rob = 9

**"Sometimes I don't really want to relive bad moments. And reading it wasn't the hard part, the hard part was more like understanding that it happened."**

Ben, Greg, Sandy, Lila, Debbie, Josh, Elliot, Christian, Aimee, Rob = 10

**\*More than half for each sub-theme.**

#### From Elements of Success

Quotes per theme:

Ben, Josh, Rosie, Debbie, Hannah, Greg, Lewis, Thomas, Lila, Rob, Aimee, Bridget, Christian, Elliot, Sandy, Warren = 16

Missing: none

Sub-themes:

**“Weebles wobble but they don’t fall down”**

Rob, Josh, Ben, Rosie, Debbie, Hannah, Greg, Lewis, Thomas, Lila, Aimee, Bridget, Christian, Elliot = 14

**“You’re a social animal, you just need it and I’m no exception to that”**

Debbie, Rob, Aimee, Christian, Thomas, Ben, Warren, Hannah, Elliot, Josh, Sandy, Lila, Greg, Lewis, Bridget, Rosie = 16

**“I really wanted to go to university to sort of get away and start anew”**

Ben, Warren, Hannah, Thomas, Josh, Greg, Aimee = 7

**\*Fewer than half for last sub-theme\***

From Identity and Autism

Quotes per theme:

Ben, Rosie, Josh, Lewis, Warren, Greg, Debbie, Bridget, Thomas, Sandy, Lila, Hannah, Rob, Christian, Aimee, Elliot = 16

Missing: none

Sub-themes:

**“What I have always felt, like I was on the outside looking in”**

Ben, Rosie, Josh, Lewis, Warren, Greg, Debbie, Bridget, Thomas, Sandy, Lila, Hannah, Rob, Christian = 14

**“I feel that having the diagnosis put this barrier there as they looked at the label instead of me”**

Josh, Debbie, Hannah, Lila, Thomas, Ben, Sandy, Lewis, Rob, Christian, Elliot = 11

**“I saw it as a positive, basically to put a middle finger up at everybody saying that I couldn’t do it, saying ‘yeah, well look what I just did’”**

Ben, Josh, Aimee, Elliot, Debbie, Warren, Hannah, Sandy, Rob, Lewis, Christian, Thomas, Lila = 13.

**\*More than half for each sub-theme.**

## APPENDIX IX: INTERVIEW EVALUATIONS

### Question 1: Was the meaning of the questions clear to you?

All answered affirmative to this on both occasions.

### Question 2: Did the interview environment suit your needs?

Participant	Definitely	Yes	No	Definitely
ROB				
BRIDGET				
ELLIOT				
DEBBIE				
AIMEE				
WARREN				
THOMAS				
SANDY				
GREG				
CHRISTIAN				
LEWIS				
JOSH				
BEN				
ROSIE				
HANNAH				
LILA				

Table 3: Did the interview format suit your needs?

Participant	Definitely	Yes	No	Definitely
ROB				
BRIDGET				
ELLIOT				
DEBBIE				
AIMEE				
WARREN				
THOMAS				
SANDY				
GREG				
CHRISTIAN				
LEWIS				
JOSH				
BEN				

ROSIE				
HANNAH				
LILA				

**Question 4: Did any aspect make you feel pleased or particularly positive? If you answered yes, what and how?**

Interview 1 Evaluations	
Participant	
ROB	<i>It was good to relay experiences and think about my achievements in life in this way</i>
BRIDGET	<i>yes</i>
ELLIOT	<i>yes</i>
DEBBIE	<i>Being able to share things that I'm proud to say I've achieved and someone wanting to know and be interested</i>
AIMEE	<i>Yes Getting my story heard and trying to make things positive.</i>
WARREN	<i>No</i>
THOMAS	<i>Yes Talking about/remembering some good times.</i>
SANDY	<i>yes Remembering the thing about being on plates. I'd forgotten it completely</i>
GREG	<i>Definitely The environment of the office was pleasant and it was a good idea to offer refreshments.</i>
CHRISTIAN	<i>Definitely The fact that I've accomplished a lot of things in life because it shows I am a determined individual.</i>
LEWIS	<i>Definitely Speaker didn't talk down to me. It's nice to be talked to like you're normal.</i>
JOSH	<i>Yes Reflecting past events that are positive increases confidence in your abilities in the present.</i>
BEN	<i>n/r</i>
ROSIE	<i>yes It was positive to discuss my experiences.</i>
HANNAH	<i>Yes Just because I was talking about times I had been successful it made me remember stuff that made me feel good about myself.</i>
LILA	<i>Definitely You were so deeply impressed by my English skills that you felt compelled to praise them.</i>

Interview 2 Evaluations
-------------------------

ROB	<i>Being able to clarify points made</i>
BRIDGET	<i>No</i>
ELLIOT	<i>Yes. Informal, friendly atmosphere is always a positive thing</i>
DEBBIE	<i>Definitely It's nice to look back on things I have achieved and how I have overcome many difficulties</i>
AIMEE	<i>Yea Because I feel that people can understand autism a little better</i>
WARREN	<i>No</i>
THOMAS	<i>Yes Good chat, pushes me towards some thoughts/ideas I might not get otherwise</i>
SANDY	<i>no</i>
GREG	<i>Definitely She brought refreshments and always addressed herself in a calm manner</i>
CHRISTIAN	<i>Definitely Maybe just having a positive recap on my comments from the previous interview. It's just double checking.</i>
LEWIS	<i>Definitely Being listened to and understood on that last question. Thank you.</i>
JOSH	<i>yes</i>
BEN	<i>no</i>
ROSIE	<i>Yes It was good to share my experiences and to get feedback from the first interview.</i>
HANNAH	<i>no</i>
LILA	<i>Definitely I rejoiced at your praise of my English skills; like other people with Asperger's syndrome, I love being commended for intellectual achievement, as we have already discussed.</i>

**Question 5: Did any aspect make you feel upset or particularly negative? If you answered yes, what and how?**

Participant	
<b>Interview 1 Evaluations</b>	
ROB	<i>No No problems</i>
BRIDGET	<i>No</i>
ELLIOT	<i>Definitely not</i>
DEBBIE	<i>Definitely not</i>
AIMEE	<i>No</i>
WARREN	<i>No</i>
THOMAS	<i>Definitely not</i>
SANDY	<i>Definitely not</i>
GREG	<i>Definitely not</i>
CHRISTIAN	<i>Definitely not</i>
LEWIS	<i>No</i>

JOSH	<i>no</i>
BEN	<i>n/r</i>
ROSIE	<i>no</i>
HANNAH	<i>no</i>
LILA	<i>Definitely not</i>
<b>Interview 2 Evaluations</b>	
ROB	<i>No</i>
BRIDGET	<i>No</i>
ELLIOT	<i>Definitely not</i>
DEBBIE	<i>Definitely not</i>
WARREN	<i>No</i>
AIMEE	<i>nope</i>
THOMAS	<i>Definitely not</i>
SANDY	<i>Definitely not</i>
GREG	<i>Definitely not</i>
CHRISTIAN	<i>Definitely not</i>
LEWIS	<i>No</i> <i>Glad to have been of service</i>
JOSH	<i>No</i>
BEN	<i>no</i>
ROSIE	<i>no</i>
HANNAH	<i>no</i>
LILA	<i>Definitely not</i>

**Question 6: Now that the interview is complete, how do you feel?**

<b>Interview 1 Evaluations</b>	
Participant	
ROB	<i>It was good to share my experiences</i>
BRIDGET	<i>fine</i>
ELLIOT	<i>Hard to pin down a positive feeling, but a distinct lack of any sort of negative feeling. I suppose sort of neutral to good.</i>
DEBBIE	<i>I feel positive, as the information I gave may be able to help people with Autism or Asperger Syndrome</i>
AIMEE	<i>I feel refreshed somehow and kinda depressed cause now I have to go and revise.</i>
WARREN	<i>OK, though I feel a bit negative when I think too much about social problems, and talking/thinking about Ela too much can still sometimes be problematic</i>
THOMAS	<i>Mutual benefit I think – always good to discuss some of the matters in your life, maybe get some new perspectives.</i>
SANDY	<i>Like I'm about to be rained on.</i>
GREG	<i>Very confident in myself, both from the interview and from my journey here.</i>
CHRISTIAN	<i>Really good about myself and my accomplishments</i>
LEWIS	<i>Like I've used my condition to help people.</i>

JOSH	<i>Just as confused as ever!</i>
BEN	<i>n/r</i>
ROSIE	<i>I think that it was very interesting, and look forward to what happens next.</i>
HANNAH	<i>Okay</i>
LILA	<i>I feel very uplifted and gratified, there are no alternatives!</i>
<b>Interview 2 Evaluations</b>	
ROB	<i>Like I rambled a bit, but hopefully explained things well</i>
BRIDGET	<i>The same as when I came in</i>
ELLIOT	<i>See previous response [first interview] for this question</i>
DEBBIE	<i>Happy, because I know what I have said has been understood</i>
AIMEE	<i>I feel pretty good! I was a little surprised that I had to do a second interview but hey-ho I'm rather pleased with it</i>
WARREN	<i>I feel OK, not as bad as last time. Glad I could help.</i>
THOMAS	<i>Good</i>
SANDY	<i>Like I've got a very annoying cough.</i>
GREG	<i>More confident in myself.</i>
CHRISTIAN	<i>Really great.</i>
LEWIS	<i>Like I've used my condition to help people.</i>
JOSH	<i>That knowing what I know now would probably of made life easier! However, the person you are today is shaped by events of the past therefore you have to ask yourself the question if the decisions made by the people who were responsible for me when I was a child would have been different if they had known about learning difficulties then possibly I might not have been the person I am today and may not have been as successful. Sometimes life has to be difficult for you to appreciate it when things are easier, and to give yourself a sense of achievement. Hope that makes sense!</i>
BEN	<i>It was particularly interesting to hear another person's perspective on the events!</i>
ROSIE	<i>It has been a great experience and I have found it very interesting to take part in the research and I look forward to further analysis!</i>
HANNAH	<i>Fine</i>
LILA	<i>I feel much better than before, because the opportunity to give somebody an interview about my condition gave me a feeling of usefulness, maybe even of being accepted. The realisation that I can use my experiences and viewpoints to assist other people was very uplifting. Moreover, I very much enjoyed being listened to. So far it has only rarely happened that somebody took note of my thoughts and feelings.</i>

### Question 7: Additional Comments

Interview 1 Evaluations	
Participant	
ROB	<i>Thanks – I enjoyed taking part.</i>
BRIDGET	<i>n/r</i>
ELLIOT	<i>Way interview is conducted is very good when considering the potential issues that could arise for interviewees with more significant ASD.</i>
DEBBIE	<i>n/r</i>
AIMEE	<i>n/r</i>
WARREN	<i>n/r</i>
THOMAS	<i>n/r</i>
SANDY	<i>n/r</i>
GREG	<i>n/r</i>
CHRISTIAN	<i>Any more information on accomplishments is something I can give any time.</i>
LEWIS	<i>n/r</i>
JOSH	<i>n/r</i>
BEN	<i>n/r</i>
ROSIE	<i>n/r</i>
HANNAH	<i>n/r</i>
LILA	<i>n/r</i>
Interview 2 Evaluations	
ROB	<i>n/r</i>
BRIDGET	<i>n/r</i>
ELLIOT	<i>n/r</i>
DEBBIE	<i>It's nice to look back on things I have achieved and how I have overcome many difficulties</i>
AIMEE	<i>I can't think of any...</i>
WARREN	<i>n/r</i>
THOMAS	<i>n/r</i>
SANDY	<i>n/r</i>
GREG	<i>n/r</i>
CHRISTIAN	<i>I like the idea of being credited on paper.</i>
LEWIS	<i>n/r</i>
JOSH	<i>n/r</i>
BEN	<i>n/r</i>
ROSIE	<i>n/r</i>
HANNAH	<i>Thank you for reminding me I can say I don't want to answer questions or stop taking part; I forget things easily! Doing the interview over msn is very good as it's easier for me than face-to-face conversation. The use of '...' and '/' was also helpful.</i>
LILA	<i>Thank you for not having treated me like an "outlandish pariah" that people often see in me. Objectivity is a very important ingredient of effective professional research.</i>



## APPENDIX X: SUPERORDINATE THEME SUMMARY

The three superordinate themes were 'The Autistic Experience', 'Elements of Success' and 'Identity and Autism'.

The autistic experience is the shortest theme, considering the data pertaining to the experience of participating in the research, and points arising from the research process. It is presented as two sub-themes:

*"That's my own perception and I can see how based on this conversation you might see it differently"* considers the ways in which participants and researcher either agreed or differed in their interpretations of the dialogue that was taking place:

- Agreement with researcher
- Disagreement with researcher.

*"Sometimes I don't really want to relive bad moments. And reading it wasn't the hard part, the hard part was more like understanding that it happened."* explores the ways in which participants reflected, during and between interviews, both on their experiences and on their own meaning-making as the process evolved:

- Reflection/development of thinking during the process.

### Elements of Success

This theme includes three sub-themes: "Weebles wobble but they don't fall down" representing the different ways in which success was articulated as arising from challenges presented, or from the determination of individuals:

- Success through effort
- Resilience and determination
- Success from overcoming barriers (inc. exceeding expectations, potential versus barriers, positives arising from negatives)
  - Developing strategies
  - Autism and memory
  - Reflecting on learning style.

The second and largest subtheme "You're a social animal" encompasses the ways in which the social world was perceived as contributing to success (or

not), through the influence of others or individual motivation derived from social aspects.

- Supportive people or environment as key to success (inc. support from parents, teachers and peers)
  - Success as relationships with others or inclusion
  - External recognition
  - Proving potential to others
  - Using natural interests to connect
  - Diagnosis as a route to support
  - Needing social relationships.

The third, smaller theme “I really wanted to go to university to sort of get away and start anew” considers the ways in which the context of Higher Education was deemed important to participants:

- Higher education as a precious goal
- Higher education as transformative.

### Identity and Autism

The first subtheme “What I have always felt, like I was on the outside looking in” encompasses the ways in which participants described feeling ‘different’:

- Awareness of difference
- Awareness of internal barriers
- Outsider versus insider
- Recognition of difference through reactions of others

The second subtheme “I feel that having the diagnosis put this barrier there as they looked at the label instead of me” articulates the different ways in which participants made sense of the ‘label’ of autism and its implications:

- Autism as a barrier
- ‘Normal’ versus autism
- Identifying with autism literature.

The third subtheme: “And that’s what drives you forward. It’s like ‘I will show you’ and that’s what it’s all about really” articulates the ways in which participants perceived aspects of the autism diagnosis as contributing to their achievements:

- Exceeding expectations
- Consistency of identity through diagnosis

- Diagnosis as a route to self-understanding
- Authoritative voice.

## APPENDIX XI: EVIDENCE OF IMPACT

### Direct Outputs

MacLeod, A., Lewis, A., and Robertson, C. (2013). 'Why should I be like bloody Rainman?' Navigating the autistic identity. *British Journal of Special Education*, 40(1), 41-49.

MacLeod, A. G., Lewis, A. and Robertson, C. (2014) 'CHARLIE: PLEASE RESPOND! Using a participatory methodology with individuals on the autism spectrum', *International Journal of Research and Method in Education*, 37(4), pp. 407-420.

MacLeod, A. (2013) "Bit different from being asked for a brain scan": Reflections on using a participatory methodology with individuals on the autistic spectrum'. Unpublished poster presentation at: Autism Europe conference, 26-28 September, 2013. Budapest, Hungary.

### Citations within peer-reviewed journals

De Bruin, C. L. (2015) 'Conceptualizing effectiveness in disability research', *International Journal of Research & Method in Education*, pp. 1-24.

DePape, A. M. and Lindsay, S. (2015) 'Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder A Qualitative Meta-Synthesis', *Focus on Autism and Other Developmental Disabilities*, 25(4), pp. 569-583.

Gelbar, N. W., Smith, I. and Reichow, B. (2014) 'Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs', *Journal of Autism and Developmental Disorders*, 44(10), pp. 2593-2601.

Haas, K., Costley, D., Falkmer, M., Richdale, A., Sofronoff, K. and Falkmer, T. (2016) 'Factors Influencing the Research Participation of Adults with Autism Spectrum Disorders', *Journal of Autism and Developmental Disorders*, 1-13, doi:10.1007/s10803-016-2708-6.

Kubiak, J. (2015) 'Researching Inclusively with College Students with Intellectual Disabilities', *International Journal of Learner Diversity and Identities*, 22, (3), pp. 37 – 50.

Parsloe, S. M. and Babrow, A. S. (2016) 'Removal of Asperger's syndrome from the DSM V: community response to uncertainty', *Health Communication*, 31(4), pp. 485-494.

Parsons, S., Guldborg, K., Porayska-Pomsta, K. and Lee, R. (2015) 'Digital stories as a method for evidence-based practice and knowledge co-creation in technology-enhanced learning for children with autism', *International Journal of Research & Method in Education*, 38(3), pp. 247-271.

Seale, J., Nind, M. and Parsons, S. (2014) 'Inclusive research in education: contributions to method and debate', *International Journal of Research & Method in Education*, 37(4), pp. 347-356.

Seale, J., Nind, M., Tilley, L. and Chapman, R. (2015) 'Negotiating a third space for participatory research with people with learning disabilities: an examination of boundaries and spatial practices', *Innovation: The European Journal of Social Science Research*, 28(4), pp. 483-497.