The experience of mainstream inclusion for autistic children primarily educated in special schools

by

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July 2011

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Introduction to the portfolio

This portfolio contains a selection of work completed during the Doctorate of Psychology (PsychD) clinical training course. This volume contains the three dossiers: Academic, Clinical and Research.

The work presented in this portfolio includes academic essays and pieces of reflective writing as well as the research work undertaken. The clinical work presented reflects the range of client groups, presenting problems and psychological approaches covered during the course. Within each dossier, the work is presented in the order in which it was completed to illustrate the development of academic, clinical and research skills during the period of training.

Please note that all Identifying details have been changed or removed in this portfolio in order to maintain client confidentiality and anonymity.

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ACADEMIC DOSSIER

The Academic Dossier consisting of two essays, two problem-based learning accounts and two personal and professional discussion group process account summaries.
Edition 20 (5) of the Psychologist had a picture on its front cover of DSM IV burning. What issues might this raise for service users, psychiatrists, clinical psychologists and you?

Introduction

The fact that the Journal of the British Psychological Society has a picture of DSM IV burning raises a number of questions, foremost being what is so controversial about this manual that makes burning it seem a rational action, secondly what might conceivably take its place and finally, what implications would this have for all those touched by DSM IV?

I had been aware of the problems surrounding the diagnosis of Bipolar Disorder and Schizophrenia from my friendship with a service user, but this uncertainty of diagnosis had always been presented to me by my friend as something that went with the territory of mental illness and was something that he was personally resigned to. This contrasted with my reading of Richard Bentall’s book, ‘Madness Explained’ (Bentall 2003) where the issues relating to diagnosis, the medical model of mental distress and DSM IV are explored. I therefore chose to write this essay to enable me to develop my thoughts in this area. I also drew on my experiences as a research scientist working on the molecular aspects of viral vaccine design and my time as a programme manager for the Medical Research Council’s Neurosciences Board, experiences I found I could not ignore.
What is DSM IV and why is it so controversial?

DSM IV is a diagnostic manual of mental disorders produced by the American Psychiatric Association (American Psychiatric Association 2000). It purports to systematically divide mental disorders into categories in much the same way as, for example, viral diseases are by the ICTVdB (International Committee on Taxonomy of Viruses 2002). From the medical perspective this is an entirely reasonable and hitherto highly successful strategy. A brief perusal of the viral diagnostic codes will reveal a system where viruses can be placed into their family trees in much the same way as species of living organisms and their interrelations understood. Furthermore, this categorisation has enabled a greater understanding of viruses, how they cause disease at a molecular level and therefore the best strategies to use to combat them. For someone accustomed to the ordered world of the viral diagnostic system, where the diagnosis can clearly be made on the basis of, for example, the presence of antibodies against the virus, DSM IV is a very uncertain place.

DSM IV covers ‘disorders’¹ ranging from the dementias such as Creuztfeld Jacob’s disease, through Major Depressive Disorder to Academic Problems. Hence it covers human problems ranging from clearly biologically engendered diseases to human experiences which appear largely societal in origin. This in itself might not be a problem however, implicit in the way that DSM IV is used by much of the psychiatric profession, is the assumption that these discrete categories can all be explained by a biological model akin to the model used for viral diseases.

When the diagnostic criteria themselves are investigated, they appear to be purely descriptive, with no underlying rational for separating the various disorders. Indeed, clients present with conditions which cannot easily be fitted into any of the

¹ The use of language surrounding the description of mental health problems is complex, so for simplicity I have used the phrase ‘mental disorder’ throughout. I have used the specific terms ‘diagnosis’ where the procedures explained in DSM IV have been undertaken and used terms such as ‘schizophrenia’ again where the criteria in DSM IV have been applied.
categories available (Nease et al., 2005). Furthermore the difficulties described do not represent conditions discrete from normal human functioning, and can more accurately be explained as a continuum of normal human experience (Boyle, 2007; Bentall 2003). This, together with the breadth of human experiences that the DSM IV attempts to cover and the comparatively disorganised way in which these categories are arranged in DSM IV suggests that the basic concepts behind the diagnostic criteria need to be reassessed. This is not to say that a framework for the understanding of mental disorder is not needed, some form of labelling and ordering is necessary to enable communication between mental health workers and service users and also to provide a framework for research. However, this framework needs to be coherent and to have an underlying basis in theory.

Richard Bentall explores these issues in great depth in his book ‘Madness Explained’ with relation to the diagnosis of schizophrenia and suggests alternative avenues which could be explored which would provide a more useful approach to working with those with mental distress. However, this is not a new idea. In 1974 Torrey wrote a book entitled ‘The Death of Psychiatry’ (Torrey, 1974) in which he sets out much the same arguments, fully expecting there to be an imminent revolution in the field. Engle proposed his Biopsychosocial model in 1977 (Engle, 1977) providing a framework in which psychological and social factors could be incorporated into the predominating medical model. Yet nothing has changed. For me, this is the major issue raised by the symbolic burning of DSM IV: given the obvious problems it exhibits and the amount if criticism it has attracted, why does DSM VI still prevail?

The biomedical model

At the root of the issue seems to be the conflict between the biomedical model of mental disorder and more psychologically based perspectives. The medical model favoured by psychiatry and heavily supported by the pharmaceutical industry is that the disorders described in DSM IV are caused by problems in brain chemistry at the synaptic and neurotransmitter level and furthermore that these disorders can be
traced back to the genetic characteristics of the individuals concerned. This may be true for some problems but the over generalisation of the concept has lead the field down a very long, expensive and counterproductive blind alley for many disorders.

One of the problems with the medical model as presented is that it over simplifies what is known and therefore makes what is known seem more certain. It also makes it seem more comprehensible and controllable. The classic story is that mental disorders arise due to problems in brain biochemistry focused on biochemical events at synapses. It is assumed that neurones interact with each other using neurotransmitters via synapses, that different classes of neurones use different neurotransmitters and that these neurotransmitters can be blocked by drugs designed for the purpose thus rebalancing the system and curing the disease. Diagrams of neurones are usually as seen in Figure 1 and the whole system is presented as neat and tidy.

The reality, however, is rather different (see Figure 2). For example, there are thought to be at least 5 different dopamine receptor subtypes in the CNS grouped into two different classes. These two classes have opposing effects on the cell’s biochemistry when dopamine binds to them which directly affect whether a signal will be propagated. In addition 3 of the different receptor types are not found at synapses, but at sites on the shaft of the dendrite, or in the peri-synaptic space. Furthermore, many dopamine synapses interact directly with neurones from the glutamatergic pathways and vice versa, meaning that drugs aimed the dopamine pathway will inevitably have an effect on the glutamatergic pathway (Seamans 2007). The complexity and intricacy of this system means that focusing on events at synapses
and molecules that will block specific receptors may not be the most appropriate level at which to tackle mental distress.

The other main building block of the medical model for mental disorder is genetics. This is an emotive subject which frequently elicits strong reactions both from the geneticists studying the area and from those working with individuals diagnosed with particular disorders. There is strong and uncontested evidence for a direct genetic link for disorders such as Huntingdon’s Chorea (Harper, 2001) and Autism (Rutter, 2006 p67-68). However problems arise where the evidence for a genetic component for the disorder is present, but its contribution to the aetiology is in dispute, for example in ADHD (Timimi et al., 2004; Shastry, 2004). Here both sides of the argument are vociferous in defence of their viewpoint, and work to understand how both the genetic and the environmental aspects can work together seems lacking. These problems appear to arise due to an over simplistic interpretation of the mode of action of genes and the way in which they can influence the development of a disorder (Rutter, 2006 p221-225)

One of the major factors overlooked in this debate is the difference between the possession of a gene and its expression. All our cells (apart from one or two specialised ones) carry the entire genome and yet our eyes do not suddenly produce fingers and our neurones do not suddenly start producing haemoglobin, indeed, many of the genes we possess are never expressed (Diamond and Amos 2008). Understanding how and when genes are expressed is just as important as
knowing which ones we possess. Understanding, for example, how those genes associated with a diagnosis of schizophrenia are relevant to people’s experience is vitally important to bringing the biological and psychological viewpoints together. Work with rats has shown mechanisms by which behaviour can have long term influences on gene expression. Meany (2001) has demonstrated that maternal behaviour in rats influences the stress related behaviour of their offspring through mechanisms that alter gene expression. Moreover, these effects continue into adult life. Meany has shown that it is the early behaviour of the mother (not her genetic makeup), which causes long term activation of genes present in the pups that cause these effects.

This work has direct links to human development where infants who receive less touch show larger reactions to stress, grow more slowly, are more likely to have problems with cognitive functioning and are more prone to depression than infants who receive more touch (Lupien et al 2000). It has also been shown that neonatal massage lowers stress levels and increases weight gain and that these affects are seen cross culturally and that the cognitive affects are still evident a year later (Field 2004).

This work therefore demonstrates that it is gene expression rather than gene possession that influences psychological processes related to mental disorder and that therefore genetics is a fruitful area of investigation for those seeking a better understanding of mental disorder.

Work on the various components of the medical model has been extensive but progress has been slow, possibly because the biomedical model focuses on such a small part of the processes involved with mental disorder, i.e. the possession of genes and events at synapses. Indeed you could liken trying to understand mental disorder by understanding synapses as trying to work out how to get from London to Glasgow by studying traffic lights.
**Alternatives to the medical model**

Criticism of the medical model has been vocal, robust and long lived. It is epitomised by the writings of the Critical Psychiatry Network (Double, 2002). Moncrieff suggests, for example, that there is no evidence that antidepressants work directly on an abnormal brain state that gives rise to depression (Moncrieff, 2007), but instead, can be accounted for by non-specific pharmacologic and psychological interactions. Given the complexities of the neurotransmitter systems described above, this does not seem an unreasonable position. However, Moncrieff’s whole argument appears to revolve around criticising the methodology and interpretation of existing studies, rather than providing positive evidence for an alternative viewpoint.

This tendency is further exhibited in the criticism of the genetic contribution for ADHD (Timimi et al., 2004). Here the evidence for the existence of a group of genes associated with the diagnosis of ADHD in children is discounted on the grounds that the same constellation of genes is also found at raised levels in individuals with Conduct Disorder, without alluding to the fact that ADHD is a risk factor for Conduct Disorder and therefore that the same populations will be involved with both (Hinshaw, 1994). There are some very real issues surrounding the diagnosis of both ADHD and Conduct Disorder which are also aired in this paper, but the tendency for the anti-psychiatry movement to be as selective in their interpretation of information as the psychiatrists are themselves is less than helpful.

Engle’s Biopsychosocial model is frequently cited as an attempt to broaden the understanding of mental illness and it has lead to a greater acceptance that behaviour and the environment can affect health outcomes and are contributors to mental disorder (Kinderman, 2005) However, Engel’s original focus was on the whole of medicine, not just mental illness (Borrell-Carrio, 2004). He was reacting against the wholly biomedical model of medicine in the 1970’s and introducing the concepts of social and psychological factors in to the aetiology of disease in general.
(Engle, 1977; 1980). It is therefore not surprising that the Bio element of the biopsychosocial model has come to dominate thinking. Engel’s message was that psychosocial influences needed to be included when considering disease states, but did not formulate his ideas as a fully formed model of mental disorder (McClaren, 2002). It has therefore been easy for vested interests within the psychiatric and pharmaceutical industry to develop it towards their own ends, hence the admission of the Chairman of the APA that the Biopsychosocial model has now become the ‘Bio-bio-bio model’ (Read et al., 2006).

The problem with the Bio-bio-bio model is that it fails to adequately address those mental disorders that are not predominately biological in origin and provides little or no direction to non medical interventions for those that are. So again, there is a lack of a coherent model that can describe the experience of all mental disorder in such a way as to lead to a greater understanding and promote further research.

**A Psychological model of mental disorder**

When I first read Kinderman’s Psychological Model of Mental Disorder (Kinderman, 2005), I was both hugely encouraged that here at last was a coherent, alternative approach to the understanding of mental disorder, and dismayed that it took until 2005 for such a model to be proposed. Kinderman suggests that mental disorder arises from a combination of biological, social and circumstantial factors, but that each of these is mediated by disturbed psychological processes. (Figures 3),

![Diagram of Kinderman's Psychological Model of Mental Disorder](Image)

**Figure 3.** Kinderman’s psychological model of mental disorder. (Kinderman, 2005)
This, on the surface may not seem radically different to the Biopsychosocial model; however, the positioning of disturbed psychological functioning as the site of action of the biological, social and circumstantial factors focuses attention on the psychological mediators of mental disorder. It ensures that for any proposed model of a particular mental disorder, the psychological genesis is explicitly considered.

The model also introduces the concept of circumstantial factors which distinguishes between life events and the personal meaning of these events for clients. This therefore increases the importance of formulation in any consideration of mental disorder. Kinderman’s model incorporates those factors fundamental to the understanding of an individual’s experience which therefore means that service user perspectives are essential to a full understanding of mental disorder.

The positioning of disturbed psychological factors as an essential precursor to mental disorder opens the door to a wider understanding, not just as a biological phenomenon, or a psychosocial one, but one in which the brain is viewed as a complex system, interacting with the outside world at the physical, social and emotional levels and with its own inner processes which integrate current situations with previous experience. To fully realise this aim is a difficult task. The historical division between psychology and psychiatry, between the psychosocial and biological viewpoints of mental disorder, has meant that much effort has been spent with each discipline defending its own position against the other, in trying to prove that its own view is right and the other wrong (Rutter, 2006 p224). A somewhat more productive approach would be to try and understand how both are true and to illuminate the systems that enable them to interact. For me, this is a central issue.

Work by Johnson (Johnson et. al., 2008) Duff and Kinderman (2006) and Bentall (Bentall et. al., 2005) demonstrate how psychological processes contribute directly to mental disorder and how understanding the cognitive processes can lead to a deeper understanding of the disorder. Johnson et al. (2008) explore the cognitive
precursors to suicidal behaviour, particularly in those with a diagnosis of schizophrenia. Surprisingly this has been an under researched area (Ellis, 2006 cited in Johnson et. al., 2008) with most work focusing on risk factors for suicide, rather than cognitive precursors which could then lead to preventative treatment protocols. Johnson describes a testable model for suicidal behaviour in those with a diagnosis of schizophrenia comprising three interacting elements: negative information processing biases, negative suicide schema that are cued by an ever increasing range of thoughts and negative appraisal processes regarding situation, self, personal agency, future and external agency.

Duff and Kinderman (2006) have attempted an alternative formulation of personality disorders to see if psychological processes can satisfactorily explain these disorders. The current DSM IV categories for personality disorder are far from useful, providing only a description of the phenomena, without any theoretical framework linking them together, or to other mental disorders to which they may appear related. Personality disorders are also notoriously difficult to treat and for many a diagnosis of personality disorder leads to the withdrawal of other services (Horne, Johnstone & Brooke, 2007). However, if the personality disorders can be satisfactorily explained by considering the psychological processes involved, this could provide a framework for treatment and research into personality disorders. Duff and Kinderman use an integrative subsystems model of a distributed architecture for human cognition. This borrows heavily from information processing theory and may seem a very abstract interpretation of personality disorders. However, such abstract frameworks can provide a fresh perspective for complex problems and present new and testable solutions.

Hence Kinderman’s model is deceptively powerful; it enables information from a wide range of sources to be integrated into a single framework that has the potential to unify the diverse content of DSM IV. Hence the answer to the question in the first paragraph: ‘What would take the place of DSM IV?’ may possibly be a system of understanding mental disorder based on Kinderman’s model.
Implications for service users, psychiatrists and psychologists

The last question posed in the introduction was ‘What would this mean to those touched by DSM IV?’. Kinderman has explored his vision of a world where a psychological model of mental disorder predominates (Kinderman, 2008), and has also considered the implications for clinical psychologists (Kinderman & Tai, 2007).

Service users:

How changes in the predominating model affects service users will depend on the nature and severity of their mental disorder. For those with disorders already well served by the biomedical model, such as autistic spectrum disorders, the change may not be very large. Here diagnosis may often be welcome, especially in the case of children where a diagnosis of autism is often actively sought by parents trying to access the most appropriate care and intervention for their children (Randall & Parker, 1999). This is also an area where much research had been done into the psychological aspects of the disorder and there is a large and skilled workforce based in the education system able to put these ideas into practice. For one teenager known to me who has recently been diagnosed with Asperger’s syndrome, the news was greeted with great delight: it was a diagnosis that made sense of his life, which gave him strategies for improving his interactions with others and introduced him to a network of likeminded people with whom he could form friendships.

However, for many the diagnosis of mental disorder is not so positive. For those with a diagnosis of borderline personality disorder the world becomes a difficult place (Horne, Johnstone & Brooke, 2007). Moreover, the diagnosis does not seem to add to an understanding of their situation, but appears to be a label of convenience and one that may lead to the withdrawal of services. According to
Horne et al. (2007), the diagnosis is only seen as positive when it leads to support and without this was experienced as rejecting and isolating.

Similar difficulties are experienced by those with a diagnosis of schizophrenia, especially when given in bio medically oriented settings. There is increasing evidence that the nature and extent of psychotic experiences is frequently related to early trauma, but that this element is often missed by health professionals seeking to prescribe drugs to alleviate symptoms (Morrison et. al., 2005). Boyle points out that distress and behavioural problems; even the most bizarre are frequently understandable responses to highly adverse situations (Boyle, 2005). Furthermore, there is ample evidence (Read et. al., 2006), that associating schizophrenia with biological and genetic causations has lead to harsher reactions to those with the diagnosis, with studies from Germany, Russia and Mongolia indicating that viewing psychiatric symptoms as understandable psychological or emotional reactions to life events reduces discrimination.

For both those diagnosed with schizophrenia and BPD, a new framework understanding mental disorder focussing on the disturbed psychological process as described by Morrison et al. (2005) or Duff and Kinderman (2006) are likely to lead to a more humane and meaningful interaction with mental health services and are thus more likely to lead to recovery.

My experience as a facilitator for a service user group for those with a diagnosis of depression left me in do doubt that the current service models do not meet their needs. They had little difficulty in accessing medication aimed at depression, but found that in order to obtain psychological services most had to pay for them. For this group, the current focus on anti-depressants did not address the causes of their depression, and gave them little hope for the future. Moving to a psychologically based model of mental illness would be unlikely to change their understanding of depression, but may change the service model in which they find themselves.
Would a change in the dominant model for understanding mental health have implications for different ethnic groups? Cinnirella and Loewenthal (1996) investigated ethnic and religious influences on lay beliefs surrounding depression and schizophrenia and found that many members of the Muslim community found any association with mental illness was likely to be stigmatising and this belief precluded them from seeking help. Bowl (2007) found that for those South Asian service users already involved with the system, the most important factors were the degree of cultural sensitivity shown by staff and in the organisation of mental health services. Hence it may be that moving away from a biomedical model to a more psychologically based one would not have any greater implications for ethnic groups than for the rest of the population.

**Psychiatrists**

Kinderman’s model places the biological factors involved at a distance from mental disorder and in doing so changes the relationship between psychiatry and psychology. Kinderman (2008) recognises the potential for this altered relationship to change the way in which mental health services are delivered but does not address the difficulty that psychiatrists might have in accepting these new ways of working.

Kandal (1998) provides a long and detailed account of the biology of psychiatry and presents few links to psychological processes, he moves straight from biological mechanisms to psychiatric outcomes. He concludes that the route to a greater understanding of psychiatry and also the route to improving psychiatry’s standing in the medical profession, is a greater understanding of the biology of the brain at the molecular and cellular level. This may in part be due to his background in psychoanalysis in which he trained in the 1960’s and which he saw lacking in the ability to be self critical. It may also reflect the different traditions of American and British psychology. However it is also an indication of how far attitudes may have to
move, certainly in America, before any fundamental changes in the conceptualisation of mental disorders are possible amongst the psychiatric community.

In removing the direct link between biological factors and mental illness and therefore removing the need to find a ‘cure’ for mental disorders Kinderman’s model removes the main focus of the pharmaceutical industry in relation to mental health. It is unlikely that the pharmaceutical industry will be happy that the primacy of psychiatry within the mental health community may be eroding. The International Consensus Statement on ADHD (Barkley et. al., 2002) has been suggested by some (Timimi et. al., 2004) to be a reaction by the pharmaceutical industry to growing disquiet at the increasing numbers of young children diagnosed as having ADHD and therefore being prescribed stimulant drugs.

The current role of psychiatry in this country is also being challenged by successive government Guidelines, initiatives and acts of parliament, all of which are giving greater roles to psychology and other mental health professionals. Hence the Improving Access to Psychological Therapies is a major initiative that emphasises the methods used by psychology, the numerous National Institute for Clinical Excellence (NICE) guidelines in the area of mental health increase the emphasis on psychological approaches and the Mental Health Act (2007) also diminishes the primacy of psychiatry in the treatment of mental disorders. It would not therefore be surprising if psychiatrists started to become defensive and indeed, there is anecdotal evidence from members of our cohort that issues around the changing relationship between psychiatry and psychology are being openly raised by psychiatrists.

Psychologists

Writing this essay has radically altered the way I think about clinical psychology, through it I have realised that it is not only DSM IV that is lacking a coherent view of mental distress, but clinical psychology too. Kinderman’s model is a good starting
point, but the model needs to be fully populated if it is to become useful to mental health professionals and service users alike. In other words, we need to understand which psychological processes are vulnerable to the biological, social and circumstantial factors in an individual’s life and how disturbances in these may in turn lead to mental disorder. Furthermore, we need to have a good grasp of the therapeutic responses likely to be beneficial in any given set of circumstances. We have a good understanding of psychological processes in some areas of mental disorder, such as depression and autism, but in other areas, such as the personality disorders (Duff and Kinderman 2006) and a cognitive understanding of suicide (Johnson et al 2008), attempts to understand the psychological processes involved appear to be at an early stage.

Psychologist in general and clinical psychologists in particular need to undertake research to populate Kinderman’s model. This will necessitate some innovative and creative thinking and some genuine collaborative partnerships between researchers in differing fields. Clinical psychologists do not seem to have a good track record in this respect (Cheshire & Pilgrim, 2004 p 38). A brief perusal of the grants currently funded by both the MRC and the ESRC produces few projects which could be useful in increasing our understanding of this area. One genuine problem is that clinical psychologists have a heavy clinical workload and their employers (usually the NHS) may not be sympathetic to time spent developing a grant proposal. In addition preparing a grant application and jumping through all the hoops that the Research Councils put in place is indeed daunting, and experience is required to be successful. However, most psychology departments have researchers who are successful in this regard with whom rewarding collaborations could be made.

One possible way forward would be to increase awareness of the importance of research to the future of clinical psychology during training. Current training (from my very limited experience) suggests that as clinical psychologists workload is directed towards NHS priorities, clinical psychologists can expect their research skills to be used solely for service evaluation. Training (so far) is focused on the nuts
and bolts of the therapeutic process; it would be useful to know about current areas of research in the field and the research interests of the course team or visiting lecturers. It might also be useful to orient trainees to the skills of the department in which they are embedded, and to suggest that collaboration with these researchers may enable clinical psychologists to combine forward thinking research with a clinical career. Without this, it is likely that trainees will complete their courses with the idea that innovative research is not for them.

Conclusion

DSM IV is not fit for purpose; even manuals written for psychiatrists by psychiatrists on how to implement DMS IV allude to the difficulties presented in fitting the people they see into the categories in the manual (Fauman, 2002 p vii). There appear to be two factors which maintain this state of affairs, (i) the vested interests of the psychiatric and pharmaceutical communities and (ii) the lack of any coherent alternative. Responsibility for the lack of a coherent alternative must rest in part with psychology. Clinical psychology in particular appears to have an uneasy relationship with research (Cheshire & Pilgrim, 2004) with some sections of the profession being philosophically opposed to the kind of work needed to provide the evidence to counter DSM IV. There is currently a movement towards psychological thinking within mental health services given momentum by the IAPT agenda and NICE Guidelines for mental disorders. These developments have been made possible by the extensive research undertaken by psychologists working with Cognitive Behavioural Therapy and similar approaches. Thus demonstrating that in a world where research evidence is so highly prized, efforts directed towards research are well rewarded. If clinical psychology can focus its efforts towards understanding the psychological processes that are disturbed in mental disorders and also integrate this with their biological, social and circumstantial precursors, we may eventually have enough evidence to provide a coherent alternative to DSM IV.
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Academic Essays

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Academic Essays

Blackwell
Professional Issues Essay

What and where is the evidence that clinical psychologists make good leaders? Are there lessons that can be learned from other disciplines within the public and commercial sectors to inform the development of the evidence base?

Introduction

The fact that it was Lord Layard – an economist - who instigated major innovations in government policy regarding the way that psychological therapies are to be provided within the NHS and that these innovations have largely bypassed the British Psychological Society, as the established representative professional body in this country, would seem to be ample evidence that clinical psychologists have not made good leaders, at least in the recent past. Dig a little deeper and you find that not only have psychologists not instigated these changes, but that psychologists are not intended to be the major providers of increased psychological services and that newly trained clinical psychologists will not be deemed competent to provide such services without extra training. In short, psychology appears to be scampering to keep up with changes in the zeitgeist and Government policy, rather than being master of its own destiny. There appear to be few at the head of the profession who have a sufficient grasp of politics or the intricacies and subtleties of government to guide us through difficult times and even fewer who have a vision of
what the profession of clinical psychology could become and, more importantly, how to get there.

This does not seem to be a purely British phenomenon, the frustrations regarding the lack of leadership of clinical psychology evident in the opening paragraph of this essay are also evident in papers written by psychologists in the US and Australia (Farhall, 2001; Carmona, 2007; Kettlewell, 2004; Baker, 2009).

To understand why psychologists apparently (and surprisingly) have not made good leaders, we need an understanding of leadership and also of the origins and leadership narratives of clinical psychology.

What is leadership?

Over the last century or so, the understanding of leadership has gone through a number of recognisable phases (Van Wart, 2003). These started pre 1900, with the ‘Great Man’ theories which focused on leaders who have a significant effect on society and moved on to the trait theories which dominated from the 1900s to the late 1940s. These emphasised the personal qualities and skills of the individual and were focused on the measurement of traits and which of these were beneficial to leadership. Contingency theories were then developed which explored the situational variables of leadership and how these impacted on both leaders and followers. These studies were influenced by the behavioural and motivational theories that were prevalent at the time and also by the development of small group experimental designs. The concept of Servant Leadership appeared in the 1970’s largely out of the social changes which took place in the 1960s and early 1970s. These theories emphasise the ethical responsibilities leaders have to their followers and the wider community. At the same time Burns (1977) was developing his ideas of transformational leadership where the vision of the leader is transmitted to followers by appealing to their own beliefs and motivations, and contrasting this with more traditional, managerial transactional leadership styles.
which are characterised by a focus on clear roles and task requirements with the prospect of rewards if task requirements are met.

It needs to be remembered that most of the literature on leadership is written from a western cultural perspective and good leadership may well differ between cultures, hence a good leader in, for example, an Asian culture may look very different to a good leader in a western one (Walumbwa, et al. 2007).

Each of the phases described above has brought new insights to the concept of leadership, but none has proven entirely satisfactory. Hence ideas of **multifaceted leadership** in which the major theories are integrated have come to dominate current thinking and research. Keeping track of all these ideas and synthesising them into a coherent understanding has become something of a challenge. Winston and Patterson (2006), writing from the Servant Leadership perspective, have recently analysed the literature in the area and developed an Integrated Definition of Leadership which identifies over 90 variables. The reason for this complexity they suggest is that researchers have sought to understand leadership by understanding the parts, rather than the whole. They therefore present a definition of leadership which describes the whole; however, as this definition runs to some 5 paragraphs and approximately 500 words, it is not possible to reproduce it in full here. However, a brief summary of the main points are as follows:

- A leader achieves influence by conveying a vision of the future in a way that resonates with the followers’ beliefs and values.

- A leader takes into account the diversity and needs of their followers and adapts the message and means of conveying it in such a way as to include and motivate each person.
• A leader enables followers to be innovative and self-directed within the aims of the organisation by building credibility and trust through interaction and feedback and by building the follower’s sense of self-worth and self-efficacy.

• A leader recognises the importance of audiences outside the organisation and presents the organisation to the outside world so that its purpose and goals can be clearly seen.

Given the training of clinical psychologists, it would be expected that all should have skills in at least the first three of these points, the question is, are they implementing these skills in leadership contexts?

What is a good leader?

This seems to be such a simple question; however, as detailed above, a simple, comprehensive definition has been difficult to agree. This appears to be because good leadership is different at different times and places and in different situations and with different people (Schmid, 2006). Hence the kind of leadership needed in a small team is different to that needed to lead an organisation and is different again between private and public sectors and between simple, monolithic organisations such as schools and complex multifaceted ones such as the health service (Milward & Bryan, 2005). Different forms of leadership are also needed at different times, hence the leadership needed to turn around a failing organisation is different to that needed to maintain a good one and different to that needed to steer an organisation through difficult external pressures. Successful leaders are able to identify these different situations and different needs and to change their approach accordingly. Indeed, a Chief Executive in the process of turning round a struggling private hospital described a situation to me where she was using a transactional leadership style in the morning to shift the practices of some of the more senior members of staff and a transformational style in the afternoon to energise and motivate the exhausted and demoralised junior staff.
Hence the question ‘What and where is the evidence that clinical psychologists make good leaders?’ is rather a large one. Perhaps we first need to ask ‘What leadership roles are psychologists currently undertaking?’ and perhaps ‘Do psychologists show an aptitude for a particular style or form of leadership?’ Other interesting questions might be ‘Do clinical psychologists expect to be leaders?’ and even, ‘Do clinical psychologists want to be leaders?’ I had expected to find some answers to the first two questions within the literature; however, the required studies do not seem to have been done. Hence the evidence base on whether clinical psychologists make good leaders is founded on inference and opinion. It is for this reason that lessons need to be learnt from other sectors as to how to develop a useful and reliable evidence base which can actively be used to help develop clinical psychologists as leaders.

What can we learn from other professions?

Other areas are ahead of psychologists in both undertaking and training for leadership and in the development of evidence bases. Different professions seem to have understood and developed the concepts of leadership at different times and are therefore at different stages in the understanding, application and measurement of leadership. In this section the evidence base for leadership in three representative areas is examined to see what lessons clinical psychologists can learn. These areas are the commercial sector which has a long history of leadership research and upon which most of leadership theory is based, the teaching profession, in which leadership has been an important factor for some time and the nursing profession, where the explicit development of leadership is relatively new.

Leadership in the commercial sector

The commercial sector has long understood the importance of leadership and much of our understanding of leadership (detailed above) comes from research done in the business community. It is from places like the Harvard business School that
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careers such as the differing and somewhat opposing functions of leadership and management first emerged (Knotter, 1990). Management schools within the UK such as the Ashridge Business School have separate faculties dedicated to leadership research and work in partnership with major (and minor) companies to develop the understanding of leadership within the business world. This level of expertise is now being sought by the public sector and in response Ashridge has developed a Public Leadership Research Centre which works closely with government departments and local government alike. Hence the lessons learnt from the private sector are already being usefully transferred to the public sector and many of the difficulties of transferring between the two environments are being addressed.

How do you make a good leader?

Knotter (1990), in writing about the private sector, points out that successful businesses have specific programmes to identify those with leadership potential and to actively nurture their development in this area, as well as other, perhaps more technical aspects of their roles. As a profession we need to know that we are developing leadership skills, not just talking about developing them. A key factor in developing leaders is in the selection of candidates for posts which may lead to a leadership role (Garman & Lesowitz, 2006). There is clear evidence from the selection process for the PsychD course at the University of Surrey that this aspect of generating leaders within the field is being acted upon, as questions regarding leadership form a part of the formal selection interview. Themes of leadership are also emphasised in various aspects of the course, for example, two of the eight titles for the Professional Issues Essay featured leadership issues and leadership experiences are now explicitly planned for and assessed on placement.

Other important aspects of developing leaders cited by Knotter (1990) is exposing them to career experiences that will develop their leadership skills and to place
aspiring leaders with existing leaders who can act as mentors. This may be problematic within clinical psychology as the New Ways of Working for Applied Psychologists in Health and Social Care; ‘The End of The Beginning’ (BPS, 2007 a) makes clear, there are not enough suitable candidates for senior leadership positions, and therefore not enough good leaders in senior positions able to act as mentors for those that show potential as leaders.

Within the commercial sector it is recognised that not all people make good leaders, someone might be highly talented in technical aspects of their role, but not able to lead a team effectively. So how do we go about measuring the potential for leadership, the existence of leadership practices, and the effects these have on an organisation or team?

**Measuring leadership**

There are a number of approaches to measuring and researching leadership, ranging from small group experimental, or observational studies (Simmonds & Paul, 1997), through quantitative measures (Kouzes & Posner, 1995; Bobbio & Manganelli, 2009, Barrett et al. 2005; Zorn & Violenti, 1993) to qualitative research which explores the experiences of individuals and organisations and their responses and approaches to management (Barker, 2001; Webb, 2005). All these methodologies are familiar to clinical psychologists, so adapting them to measure leadership within the profession should not be technically challenging.

Leadership can be measured at a number of different levels, from the organisational level, through group level to the individual. When the leadership of individuals is measured it is common to use ‘360°’ measures in which the views of an individual’s line manager and the people that the individual leads are canvassed and the results used to obtain a rounded picture of how the individual operates in an organisation. In addition the same measures that are used to help individuals develop their leadership skills can also be used in research regarding the development of groups of individuals as leaders and of the efficacy of training
programmes. Some of these measures are exceptionally well researched and developed, for example, the Leadership Practices Inventory (LPI) (Kouzes & Posner, 1995), was originally devised from a survey of 1,100 managers, with qualitative interviews of a further 38. The 30 item instrument developed from this work was then normed on a sample of 2,876 managers from private and public sector companies. Chronbach’s alpha for this measure is reported to be .97. Furthermore, a step wise regression analysis indicated that the LPI was a good predictor of a manager’s effectiveness as a leader. The original analysis of the instrument has now been repeated on a database of 60,000 individuals and the same structure factors found as in the original (Kouzes & Posner, 1995) (see section on Leadership in Nursing for more details).

Hence, there is no shortage of high quality, accessible measures and methodologies available with which to develop an evidence base for the effectiveness of clinical psychologists as leaders.

**Leadership in teaching**

Leadership in teaching has been a focus for government backed initiatives for some time because the nature, ethos and success of a school (however it might be measured) is clearly dependant on the quality of the leadership provided by the Head teacher (Barker, 2001). Further leadership in schools is also provided by the Governors who are recruited from the local community and have varied life and leadership experiences. Ofsted therefore explicitly makes inspection judgments of the management and leadership of a school and has it set ways of doing this (Ofsted, 2009), explicitly separating leadership from management and looking at the development of leadership skills amongst the senior leadership team as well as the working relationship between Governors and Headteacher. There is therefore a rich evidence base regarding leadership in schools which is accessible to all via the Ofsted website. This has also lead to the development of a number of leadership training courses in which a teacher can participate from early on in their career:
from the aptly titled ‘Leading from the Middle’, to the National Professional Qualification for Headship’ (aimed at aspiring Head Teachers) to the Leadership Programme for Serving Heads.

Each of these leadership courses has been assessed and their impact on the leadership qualities of their participants investigated (Simkins et al, 2009). Furthermore, research is now looking at the best types of leadership for schools (Arrowsmith, 2007) and how this might differ between different types of school (Webb, 2005). The long history of leadership in schools and the more recent focus of Ofsted on leadership have meant that the teaching profession has integrated leadership into its professional identity.

However, it has to be acknowledged that head teachers are in a very different position to most psychologists. They are clearly the head of the school and have acknowledged leadership tasks. A school is also a relatively simple place, with one main professional body and a clear structure (although Governors have a slightly idiosyncratic role). In contrast, most psychologists find themselves in teams, or interacting with other teams with disparate professional memberships. Each of these will have different expectations of their own and other’s positions as leaders and the interactions between team members and the wider organisation is likely to be more complex. This being said, important lessons can be learnt from the approach the teaching profession takes to leadership, in that it is something that they approach right from the beginning of their career and on which they expect to be assessed.

**Leadership in Nursing**

Although nurses have only recently taken on the concept of leadership *per se*, there is a strong historical narrative of the nurse as a leader, starting with Florence Nightingale. This was continued though to the modern era, with the original post of
Matron being a powerful voice in the running of a hospital and ward sisters being the clear leaders of a team of nurses on a ward. Hospitals now have Directors of Nursing and it is not unusual for the Chief Executive of both NHS and private hospitals to have come from a nursing background.

Nurses have taken on board modern ideas of leadership, indeed, the Macmillan Nurses website has direct links to Ashridge leadership courses and there are numerous courses, similar to those available to the teaching profession that are aimed at nurses at different stages in their career. Hence ward sisters can undertake the ‘Ward Manager Development Programme’ to develop their skills as ward leaders and then ‘Leading an Empowered Organisation’ to prepare them for greater leadership responsibility. Furthermore, nurses assume that leadership training is a natural part of their role, with several of the CPNs on my last placement taking part in a University led mentoring course which provided a recognised qualification; the assumption being that the mentoring of newly qualified staff was the first rung of the leadership ladder.

There is also a large body of research evidence regarding nurses as leaders (e.g. Bondas, 2006; Kanste et al., 2007; Cummings et al., 2008; Endacott et al., 2008) which cover both the ways in which nurses lead, leadership styles that are most effective for nurses in complex health environments and the measures which are most appropriate to measure leadership in nurses.

So, how do concepts of leadership developed in business transfer to the very different environment of a health care system? There are some indications that some aspects of leadership that are important in the commercial sector are not so well suited to the complex, multi-professional environments found in healthcare systems. Tourangeau and McGilton (2004) examined the suitability of, the Leadership Practices Inventory (LPI) (Kouzes & Posner, 1995)(see above) for use with nurses, both to develop nurses understanding of their own leadership style and also as a research tool. They found that the five original leadership practices of
the LPI which had been reliably demonstrated over a number of years in different business environments (Challenging the process, Inspiring a shared vision, Enabling others to act, Modelling the way and Encouraging the heart), were not optimal in their factor analysis of the measure when used with nurses in the Canadian healthcare system. They instead found three factors (Cognitive, Behavioural and Supportive) which better fitted responses from nurses. One of the reasons that Tourangeau and McGilton suggests for this difference was that their sample was relatively homogenous, being 98.5% female and that the differences on factor structure may reflect differences in leadership styles between their sample and the more mixed samples used to generate the original data. Given the current dominance of women in clinical psychology, such issues need to be considered in the choice of measures used not only to develop the database, but also to train clinical psychologists in leadership skills.

Psychologists as leaders

Psychologists do not share the historical narrative of leadership evident in the commercial, teaching or nursing professions, indeed, during the formative period of the profession’s development (Eysenck, 1949, cited in Cheshire & Pilgrim, 2004), they were seen as a supportive profession to psychiatrists, undertaking psychological and personality assessments. Eysenck later modified his views and advocated the inclusion of psychological therapies as a legitimate focus for clinical psychologists. However, clinical psychology failed to develop a firm consensus as to its core role (Cheshire & Pilgrim, 2004), something, that I would argue, remains a feature of the profession today. This lack of leadership narrative means that those coming into the profession do not expect, and often do not want to become leaders. Even within current cohorts of clinical psychology trainees, the prospect of leadership is not viewed with any enthusiasm. However, there is growing recognition that leadership is important at all levels of the profession and there is
clear evidence that there are moves from both within the profession and from those that employ psychologists to promote leadership skills (BPS 2007a; BPS 2007b; Kiemle & Golding, 2008).

Using the same database searches that yielded countless papers on the evidence base for leadership in the commercial sector, teaching and nursing, NO papers on the evidence base for leadership in clinical psychology were found. That is, no papers using specific measures of leadership, no papers looking systematically at the kinds of leadership roles clinical psychologists undertake or their motives for doing so or papers using more qualitative methodologies to understand the experience of leading as a psychologist. Given the involvement of psychologists in developing the understanding of leadership this is a striking omission. So what can be found in the literature regarding psychologists as leaders?

Millward and Bryan (2005) make the case for the relevance of transformational leadership in healthcare settings and their description of transformational leaders as having good interpersonal and influencing skills and the ability to ‘motivate, inspire stimulate and facilitate others, irrespective of the circumstances’ would seem to describe many of the skills in which clinical psychologists are specifically trained. Indeed, it is possible to find a number of papers written by clinical psychologists in which the suitability of clinical psychology for leadership roles is asserted, for example King (2004), writing in the United States asserts that psychologists are well placed as leaders in health care because their training enables them to contribute to research, clinical practice and policy development. She also asserts that their knowledge of human behaviour, collaborative orientation and highly developed written and verbal communication skills equips them to be good leaders. However, she offers no evidence that this is indeed the case.

This pattern is repeated by Brown and Folen (2005) in their paper on psychologists as leaders in Multidisciplinary Pain Management teams as well as by Carr et al. (2007) in their paper on the integration of Behavioural and Social Sciences into the
Medical School curriculum. Indeed, Carr et al. go on to say that despite the clear value of psychological ideas to the health care setting and the benefits to be gained by integrating psychological and biological knowledge, little progress has been made in this area. They then imply that this lack of progress is due to a lack of leadership from the psychologists involved with curriculum development in US medical schools. Kettlewell (2004) takes this a step further and is more explicit in his criticism of psychologists as clinical leaders and in particular regarding their failure to promote, disseminate and implement evidence based treatments. He specifically admonishes the American Psychological Association (APA) for not doing enough to promote Evidence Based Therapies and suggests that this is because the APA does not want to alienate those practitioners that are sceptical about evidence based theories. He specifically calls for the APA to ‘show leadership on this issue’. Baker et al. (2009) develop this theme further and assert that the lack of clinical leadership shown by psychologists in the US is leading to the increased medicalisation of mental distress and to other professions adopting psychologically based therapies as part of their practice, hence further distancing psychologists.

Hong and Leventhal (2004) do provide concrete evidence that psychologists have become more prevalent in US medical schools. They suggest that this has been done thorough collaborating with others, by demonstrating that psychologists can be useful in a health care setting and by the leadership qualities of individual psychologists. They state that psychologists ‘can rise to leadership positions’ although they give no indication as to their success or otherwise. However, they specifically say that psychologists who have risen to leadership positions in medical schools have not promoted a psychology agenda per se. Hence it appears that in the US, psychologists have been making progress via leadership skills used at a local, small team level, rather than as a result of strong leadership from the APA or other professional representative organisation.

This lack of leadership at the organisation level has led those external to the profession of clinical psychology to call for greater clarity as to their role, for
example Carmona (2007) the Surgeon General of the United States in an article praising psychological intervention during times of crisis, specifically states that ‘The profession [of clinical psychology] needs to assert how it can best serve the country’.

Evidence that organisational leadership is lacking in the UK comes not just from the fact that IAPT was instigated by an Economist, but also from DoH publications such as ‘Organising and Delivering Psychological Therapies’ (DoH, 2004), which specifically calls for clear leadership in psychological therapies, ‘both professionally and managerially’ and suggests the formation of a new body in order to achieve this. The New Ways of Working for Applied Psychologists in Health and Social Care (NWWAPHSC)(BPS, 2007b) states that there is a need for psychologists to demonstrate the efficacy and cost effectiveness of their contribution when compared to other professions abilities to deliver psychological therapies. It also states that clarity is required regarding how applied psychologists can contribute to future services. That these needs have to be articulated in a ‘New Ways of Working’ document, suggests that organisational leadership has been lacking in clinical psychology and in particular those elements relating to vision and political awareness as well as an understanding of the wider environment in which psychologists are operating.

In a rare piece of direct evidence for the way in which psychologists are perceived as leaders, the NWW Leadership Project (BPS 2007b) lists both positive and negative ways in which psychologists in leadership positions are viewed by those with whom they work. These themes highlight the difficulty some psychologists seem to have in understanding and responding to the business and political environment in which they work, but also indicate that when psychologists do engage with these factors, they are able to effectively take the lead in areas such as service delivery. They also suggest that psychologists do not always work well in teams, often seeing themselves as separate to other team members and following their own agenda, whereas, when they were visible and accessible and proactively took the lead in their areas of expertise, their presence was appreciated. There
were also themes concerning psychologist’s inability to communicate their role to the rest of the team and in particular in being transparent and understandable; something that psychologists should be able to do well. Happily, the Leadership Project is able to say that psychologists’ contribution to leadership has been improving, with the number of positive experiences increasing over time.

Another positive development is documented in a special issue of the Clinical Psychology Forum (BPS 2008). This describes a leadership programme aimed at those aspiring to become consultant psychologists. Although welcome in itself, that fact that such a course should merit a whole issue in a professional journal is an indication of its rarity. In addition, the articles, although informative about some of the management tasks undertaken by those undergoing training, and their experiences of leadership; do not include any systematic attempts to evaluate the course. So there is no published information about the leadership skills of the participants when they joined the course and how these might have changed as a result of their experiences and no comprehensive qualitative work. However, one thing that is evident is the novelty of leadership for these psychologists and how unprepared many of them felt for the role.

**Developing an evidence base for Psychologists as leaders.**

As research for this essay has shown, the evidence base that clinical psychologists make good leaders is rather thin. This means that any future evidence base can be systematically planned, so that all aspects of leadership are covered, using a number of different approaches. Such a programme could include the following steps:

1. A comprehensive audit of the current leadership roles of clinical psychologists,

2. An audit of the training, if any, psychologists have had in leadership.
3. A study on the attitudes of clinical psychologists towards leadership, taking samples from all levels of the profession.

4. A study on the leadership attributes of clinical psychologists using both quantitative and qualitative measures, again, across all levels of the profession.

5. A study on the effectiveness of clinical psychologists as leaders in both small team and organisational roles using both quantitative and qualitative approaches.

Once this work is completed, we might indeed be in a position to demonstrate that psychologists can make good leaders, and from here would be able to develop the role of psychologists as leaders both within the profession and within multidisciplinary teams. Indeed, it is not unusual to come across clinical psychologists who are leading multidisciplinary teams, for example, in services for Looked After Children and in the field of learning disabilities. The profession needs to learn from these examples to enable it to spread good practice and to integrate the concept of leadership into our professional identity.

Conclusion

The evidence bases for leadership in the commercial, nursing and teaching sectors indicate that these professions assume leadership as part of their role, they prepare for it during training and continue to develop their skills via specific leadership training courses and are assessed on their leadership skills throughout their careers. Furthermore, each of these professions takes an active interest in leadership and has well developed research programmes to further their understanding. They also have robust organisational leadership, perhaps because those with leadership potential are able to be recognised early in their development via embedded systems and encouraged to take wider leadership roles.
Ultimately we will know that psychologists have learnt the skills of leadership, when psychologists work in partnership with all other professions in developing local services, psychological ideas make a major contribution to the underlying principles of publications such as DSM and ICD and it is psychologists (rather than economists) who are prompting major shifts in government policy related to mental health.
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Problem based Learning Reflective account (Year 1)

Introduction
We came together at the beginning of the course as 8 individuals who barely knew each other laden with the task of developing a presentation around the topic ‘The Relationship to Change’. We would remain as a group for the whole of our three years on the course and the intention of the task was to help us form the relationships necessary for the group to function effectively.

The knowledge that we were to form long-term relationships over the next three years gave an added edge to the first meeting, as did the title for the task. ‘The Relationship to Change’ was such a nebulous phrase, capable of being interpreted in many different ways, yet none of them entirely satisfactory. This uncertainty around the title and the prospect of being assessed on our presentation at the end of the Induction Block added to the air of anxiety in the room.

It seems helpful here to introduce the work of Tuckman (1965) and his seminal paper on the formation of groups which divides group development into four phases: Forming, Storming, Norming and Performing. Tuckman (1965, 2001) characterises Forming as a time of orienting to the task, testing the group structure and dependence: Storming as a period of resistance to group influence and task requirements: Norming as openness to other group members and: Performing as constructive action. Each of these stages were clearly visible in our own development as a group and I will therefore use them to help structure this account.

Forming
As is good practice in group learning exercises, we elected a Chair and a Scribe. This gave us a structure within to work which was certainly welcome at the beginning of the process. Having a Chair was a necessity with so many in the group and our Chair made an invaluable contribution, ensuring that we kept on task and organising the business of the meeting in a quiet, calm but highly effective way. Having a Scribe also freed the rest of us to focus on the content of the session instead of focusing on recording the details of the process.
Eight is a large number for a group of this nature, it takes longer to get to know and trust each other and the possibility of groups forming within the group is greater. We found discussing the details of our presentation challenging as a group of eight. It took time for everyone to present their point of view and over time the discussion had a tendency to lose focus. It also took time to recognise peoples’ different perspectives and for us to come together with a common view, or perhaps to be content with differences in opinion. However, throughout the task, all members of our group have been mutually supportive and sensitive to the needs and vulnerabilities of others. I felt safe within this group, even though I had known them for such a short time.

**Storming**

A key factor in the development of the group was our interaction with our facilitator. He appeared to have a rather paternalistic approach to facilitation and there was a tendency for him to impose his own direction, regardless of the preferences of the group. This evoked a complex mixture reactions in me; frustration and annoyance being uppermost at times. Frustration because we were not being allowed to follow our own instinct and interests, or to make our own mistakes and annoyance because I did not have the confidence to challenge our facilitator. There were advantages to this situation, the ‘storming’ phase of our group seemed to be directed outwards towards our facilitator, rather than inwards, amongst ourselves, with the result that the relationships between the members of the group were supportive and harmonious.

However difficult this experience was at the time, it was a useful reminder of how service users may sometimes feel within the mental health system. From my conversations with service users as the facilitator of a depression support group, I have found that people often feel that their voices have not been heard and that they are frequently coerced into accepting treatment or approaches that they do not really want. This seems directly relevant to my clinical practice as a number of my clients have multiple difficulties, for example, depression and Obsessive Compulsive Disorder (OCD). Although from a theoretical basis it is clear that depression should be treated first unless it is secondary to OCD (Wells 1997, Salvskovskis 1985) this may not always fit with the experience of clients, for whom OCD symptoms may be the dominant difficulty in their lives. In sharing formulations with my clients and developing goals at the beginning of therapy, I have
discussed these issues, but in each case, have come across the same response: that as I am the therapist, they will be guided by me. I did worry that this confidence in my abilities came more from an issue of power within the relationship rather than a genuine agreement from the client, although I do realise that this may also reflect my own lack of confidence in my abilities. I also realised that at the beginning of therapy the client may not know what to expect and to wish to be guided by someone who has gone through the process before. Therefore the direction that therapy takes needs to be checked with the client as the relationship between therapist and client develops and as the client’s understanding of therapy evolves. Above all, my experiences with our group’s facilitator have underlined the importance of listening carefully to what the client is saying and being mindful of imposing my own agenda

**Norming**

During those sessions where we worked without our facilitator, we began to gain confidence and a plan of action regarding our presentation emerged. We found that group members had different styles of working, some liked to discuss any topic completely before moving on, whilst others, myself included, had a more task oriented approach and wished for more structure to our discussions. One member of our group had a wonderful gift of recognising when we had covered most aspects of a topic and then drawing mind maps of our discussions. I realised that I tend to get involved in the detail of discussion, rather than seeing the wider context at the time. I tend to leave reflection of such complex discussions until I have a quiet moment on my own and really appreciated our other group member’s ability to do this in real time. As a visual learner I also appreciated the visual element of the mind maps as I find the lack of diagrams, graphs and pictures in the course in general something of a challenge. The purely language based teaching in many of our lectures omits my preferred route for assimilating information.

Much of our conversation at times was directed toward how we would justify our decisions to our facilitator and how we would defend our decisions if he disapproved. This process had a dual effect, firstly it ensured that we had thoroughly thought through each aspect of our presentation and had solid reasons for our decisions and secondly it increased group cohesion as we all had the common aim of ensuring that we would be able to continue with our task as planned.
The group’s final focus was on the Trainee Clinical Psychologist’s first meeting with a client and how the possibilities for change can be affected by the interaction between the two individuals. We looked at theoretical material from Chadwick (2006) and Bordin (1994) regarding client-therapist interactions to inform our discussions.

We decided to use a mixture of role-play and presentation as the most vivid way in which to put across the concepts of radical collaboration described by Chadwick. It also enabled us to incorporate information gained from our discussions with second year Clinical Psychology Trainees regarding their first experiences with clients. However, there were risks involved with this as we were unsure as to the extent to which humour would be accepted by those assessing our work.

Once we had decided on the format of the presentation and the main areas we wished to cover, we split into two groups of four. This was partly as a reaction to the difficulty in working as a group of eight but also because it was a logical way to divide the tasks, with one group working on the presentation and the other developing the role-play. I became a member of the role-play group and again, different learning styles emerged, some members of the group liking to talk things through thoroughly before committing themselves, whereas I preferred to get a rough idea of where we were heading, try it out and refine. I found that I reached a limit to my creativity when just talking about possible scenarios, but once we had rehearsed, new ideas flowed freely. This underlined the need to be mindful of others preferred styles of working, both with clients and within multidisciplinary teams.

**Performing**

Due to the format we had chosen, we needed to trust one another completely in order to perform our work well. As we had split into teams each group had needed to trust the ability and commitment of the other group to prepare work that was not only of the appropriate standard, but that would also tie in seamlessly with the others’ work. The session in which we put the two halves together tested our ability to act as a coherent group, as each had to make modifications in order for the performance to work. This was all done with great good humour, sensitivity and mutual support. The role play was semi-scripted, with variations possible within a framework, but with each person relying on
specific cues from the other members of the group. This needed a great deal of practice and trust in each other.

Working as two groups made us feel quite separate and I realised that I knew the members of the role-play group far better than those that had produced the presentation and there was an acknowledgement within the group as a whole that if we were to split in this way again, we would alter the grouping to enable us to understand other group members better.

The performance itself was very successful, the audience laughed at the appropriate times and we had a great sense of achievement that it had all gone so well. We received positive feedback, both from the formal assessment and from informal comments from the rest of the cohort. This was very important to us, not only because we had put so much effort into the performance, but also because we had taken a risk regarding the nature of the presentation and we were aware that it may not have been so positively received.

Sometime after the completion for the task out group reflected on the contributions we had each made. Some noted how they had purposely put themselves in certain roles, others noted that they had adopted a certain style of interaction at beginning of task that did not reflect their normal way of being but that it was now difficult to adopt a different role, as the group had formed to accommodate this original version.

What role did I play in the group? The answer is that I am not entirely sure. I have played many roles in my professional life having been at various times a team member, co-ordinator and leader as well as working in intense one to one relationships. I have also played many roles in my personal life, being a wife, mother, sister, friend and school governor. I found I drew on the skills learnt in all of these roles and at various times adopted different roles as the situation demanded.

In summary, the problem based learning task achieved its objective in helping us form as a coherent, functional group and I look forward to being part of it as we develop over the next three years.

References.


Problem Based learning reflective account (Year 2)

Introduction

Second and Third Year Clinical Psychology Trainees were gathered together at the beginning of the year and given the task of preparing a consultancy paper on how the effectiveness of IAPT (Increasing Access to Psychological Therapies) can be assessed. We were split into a number of groups each comprising 4 Second Year and 4 Third Year Trainees. We were to present our work some six weeks later to fellow trainees and course staff.

The Task

This group task felt very different from the original first year PBL exercise in which we participated. Although we worked together to complete the task in an efficient and constructive manner, the way we worked and formed relationships were very different. On reflection there were a number of reasons for this.

In the first year the purpose of the PBL exercise was to enable our PPLDG group to begin to form relationships that we knew would last for the three years of the course. In contrast, this PBL group was only conducted with a view to a single presentation. It therefore had far less significance, both practically and emotionally. Furthermore, two different groups, with prior relationships were brought together for this exercise; these being the second and third year clinical trainees. Hence the eight members of this PBL group naturally split into two groups of four, with the more experienced third years naturally having a greater influence in the early group stages.

In addition, the current PBL did not appear to be given the same priority by the course team as our first one. For the first year presentation on ‘The Relationship to Change’ we had timetabled slots and access to a facilitator. For this exercise, there were no timetabled slots and no facilitator. Furthermore it had not been made clear, prior to the meeting to explain the process, that we would need to find times to meet. Hence, where there were gaps in the timetable most members of our group had made arrangements to, for example,
conduct interviews for Major Research Projects, so finding times in which to prepare for the presentation was problematic.

I did wonder why things had been set up this way. The course team could clearly arrange group tasks that functioned well, given our experience during the first year. There was the possibility that that this task had been set up to be deliberately difficult, possibly to provoke more difficult group dynamics, or perhaps to underline the importance of organisation to the smooth running of any group activity. This would add an extra dimension to the learning experience, either by increasing our understanding of and ability to manage difficult group dynamics, or by making us more aware of the importance of good organisation to the smooth running of meetings. However, it was also possible that there was no alternative, that given to constraints of the timetable and the availability of potential facilitators, this was the only way a group task could be run. This is a situation frequently found in working environments as new tasks often appear that have to be fitted into already busy and complex workloads.

The Group

In looking for a theoretical structure to guide my thoughts regarding this PBL, I initially looked to Tuckman (1965, 2001) as I had done previously. However, Tuckman’s stages of Norming, Storming, Forming and Performing did not seem appropriate for this group as the relationships formed remained superficial throughout, with the focus being on the task rather than relationships. That having been said, a Storming phase could be identified, with the annoyance directed at the course team for not alerting us at a much earlier stage to the need to allot a significant amount of time to this task (Tuckman (2001) allows for the Storming phase to be directed outwards as well as within the group).

One theoretical model that did seem to be useful to describe how the group managed to produce a presentation is John’s 1973 model which identifies 4 phases, these being Immature, Fragmented, Sharing and Effective. The Immature phase for our group was characterised by relatively distant interactions between group members, especially between 2nd and 3rd years who had not previously met. The 3rd years initially took the lead, having had more experience of these exercises. This was in part a role they took for themselves, and in part one the second years looked to them to take. However, as we
gradually sorted through the issues related to the task, we became more comfortable in each other’s company and began to understand the strengths of individual group members. For example, the third years were clearly confident organising group processes, whilst some of the second years, myself included had had previous experience of work and management roles. We were therefore able to lead on the practicalities of evaluating a service and were also at times able to take a more strategic view and for example frame the appearance of IAPT as a response to a real need, rather than something that has been imposed on Psychology services for no reason.

We explored how IAPT could be evaluated and how we could approach this as a presentation and agreed to focus on how IAPT might be applied to CAMHS. We also decided that as meeting was so difficult and the task so low on our list of priorities, that the simple format of a presentation to a CAMHS Stake Holder Group would be most practical, with each person having responsibility for a certain role and to gather specific information. This naturally led to a Fragmented phase, where each person searched for the information relevant to their role in the presentation. Communication here was achieved by email and the group did not meet for some time.

Once this phase was complete and we did meet again the focus was on Sharing, albeit in a very rapid and superficial way, as we were at times constrained to gathering for half hour before 9.00 am meetings and lectures. However, there was much good will amongst group members, all recognising that this was a task that had to be undertaken and it would be accomplished more effectively if everyone played their part. It was during this phase that we began to feel more like a group, partly due to the simple fact that we had spent more time together and also due to the fact that we would have to form a co-operative group in order for the presentation to run smoothly. This perhaps represents our movement into the Effective phase in Jones’ model. In the event, each part of the jigsaw slotted together neatly and we accomplished our goal of giving a presentation on the theme of evaluating IAPT in CAMHS. There was, however, a feeling that it could have been done better, been clearer, more engaging and more original, but given the competing priorities and the challenges of meeting for a sufficient amount of time, our presentation went as well as could have been expected.
It was interesting to observe the changing interactions within the group and how an initial anxiety around how we could accomplish this task receded as we each negotiated roles within the group and the task. Having observed this and seen it in the context of the theory of group processes, I am now in a better position to aid these processes in future group tasks.

Having undertaken similar group tasks during my previous working life (as a research scientist, research manager and school governor), I had perhaps more confidence than most that the initial chaos and disorientation would eventually develop into a more coherent process. As this was not a real life task, the outcome would have fewer implications and was for that reason less stressful. However when the outcome of a group task is to be implemented and have implications for large parts of an organisation, the stakes are somewhat higher, stress levels greater and therefore working relationships more likely to be problematic. In addition, differences of opinion may well reflect the protection of, for example, organisational power bases, so finding common ground is likely to be considerably more challenging than experienced here.

**Practice links**

There are frequently times during the course of a busy and complex role such as those undertaken by clinical psychologists, when similar situations will arise. Disparate groups of people will be required to work together towards objectives that they may not value, with people they may never have met before. It is also important to understand how such situations can be improved and how, even under difficult circumstances progress towards a goal can be achieved and working relationships maintained or improved. Indeed, in difficult situations, the members of a multidisciplinary team may well look to a clinical psychologist to enable such processes to work more smoothly.

This has been a reminder of those factors that are important for ensuring the smooth running of group processes, which I would naturally address when organising such tasks in my clinical work. For example, when considering any long term group task sufficient planning needs to be put into place to enable others to incorporate the group meetings into their existing schedules. In addition, group members need to be carefully chosen to
ensure appropriate expertise and representation of stakeholders. The importance of the task also needs to be made clear so that group members do not resent their presence at meetings. This may not always be an easy task, previous experience has shown me that goals around service development may be resisted by many in a group as the aims of an organisation may run counter to the aims or values of those enlisted to make the changes. It is here that good leadership skills can enable difficult or unpopular changes to be made by, for example, explaining the importance of the task to the organisation in the current wider political context.

A good example of the consequences of not considering these issues has arisen in the Trust in which I am currently working, where a unit was given just 4 weeks’ notice that it was to close and operations moved a considerable distance to another hospital. None of the staff in the unit knew about this beforehand, none of the practical aspects have been addressed and the reasons for such a change not explained. Staff now have the task of organising and managing a complex move to which they are totally opposed, in a short amount of time, with low morale. It is therefore likely that the move will be badly organised and staff morale will suffer further. I suspect that this is not an unusual situation in the current climate and it is important that clinical psychologists develop the skills to navigate such situations.

Conclusion

Although undertaking the task of preparing a presentation on the evaluation of the IAPT process was difficult and frustrating for all the reasons outlined above, it did remind me of the nature of real life group processes where the commitment of individuals within the group, and indeed the group as a whole may not be complete. It also highlighted the importance of planning and ‘selling’ the purpose of a group task. As the task was an academic exercise, rather than a real life process, it enabled me to take a more reflective stance and observe the process as it unfolded and note my own reactions to it. Through this I realised the value of taking a step back and observing processes from a different position, even when I am involved in them myself. This is something that I will be able to take forward in my practice.
References.


Reflective Account 1

Summary

This reflective account follows the progress of our PPLDG Group through its first year. It addresses issues of group formation, power and leadership as well as group dynamics. These issues are explored within the group, clinical and professional contexts. Our group developed into a safe place to share difficult cases and raise sensitive professional issues. We formed a horizontal structure, with no clear leader emerging from amongst the trainees; this role being occupied by our facilitator. The PPLDG Group, and its supportive nature is contrasted with the group that most of our PPLDG Group joined during Psychoanalytic Week, where the dynamics were very different. The reasons for this difference are explored. My own realisation that my previous experience enables me to make a larger contribution to the PPLDG Group that I had originally thought I would be able is also examined.
Reflective Account 2

Summary

This reflective account follows the progress of our PPLDG Group through its second year. It explores the experience of having a new facilitator with a contrasting style to our first facilitator and the effect this had on group dynamics. It also explores the effect that different styles of interaction may have within the clinical setting. It describes the experience of sharing cultural genograms and the effect this had on my understanding of different group members. These themes are further explored in the context of clinical work.
CLINICAL DOSSIER

The Clinical Dossier containing summaries of the five placements, four case reports and the oral presentation of clinical activity.
Overview of Clinical Experience

Adult Mental Health

This placement was split between a Community Mental Health Team and a Specialist Psychology Service.

Clinical Work: I worked with males and female clients aged from 23 to 65 years old who were experiencing anxiety, depression, obsessive-compulsive disorder (including hoarding) and psychotic symptoms. I undertook extended cognitive assessments with two individuals. Risk assessment was an ongoing process with all clients. I used cognitive-behaviour therapy and psycho-education during the course of this placement.

Group Work: I co-facilitated two intensive cognitive behavioural groups for clients with Heterogeneous diagnoses which included anxiety, depression and low self esteem. I also led an anxiety management group.

Service Evaluation: I undertook a detailed evaluation of the outcome data for the Heterogeneous CBT group. This showed that the group was effective when compared against similar groups published in the literature.

Teaching and Presentations: I gave a presentation on Mindfulness, and fed back the results of the service evaluation. I also presented the Service Evaluation at the CPD meeting held at the University of Surrey.

Older Adults Mental Health

This placement was based with an older adults psychology service of a Primary Care Trust.

Individual Clinical work: I worked with clients aged 77 to 93 years old, experiencing anxiety and depression as well as a variety of health difficulties such as Parkinsons Disease. My therapeutic work drew on REBT (Rational Emotive Behavioural Therapy) I also undertook a number of cognitive assessments including dementia assessments
Reflective Accounts

and post stroke assessments. Much of my work involved liaising with ward staff, helping them understand the cognitive effects of stroke on their patients.

**Group Clinical Work:** I led a reminiscence group at an Alzheimer’s society day centre, alongside one of the centre’s staff.

**Consultancy work:** I developed and led a work shop on Bereavement for the staff on a local older adults ward and. Arising from this helped develop guidance on bereavement for future use on the ward

**Presentation and teaching:** I made a presentation to the local special interest group for Older Adults regarding bereavement and to the South East Area Special Interest Group for Older Adults regarding the Consultancy work. This work was also published in the SIG news letter.

**Learning Disabilities**

This placement was based within a multidisciplinary Community Learning Disabilities Team.

**Clinical Work:** I worked with clients between the ages of 19 and 65 who were experiencing difficulties such as challenging behaviour, anxiety, depression, memory problems and inter-personal difficulties. Therapeutic work took place in a range of settings, including the clients home, supported living, residential care homes and daycentres. I carried out a number of cognitive assessments including Dementia assessments with clients who had Down’s syndrome. Much of the work on this placement involved working with staff and carers,

**Group Work:** I co-facilitated a group on Managing Difficult Emotions’ for people with learning disabilities at a day centre.

**Teaching and Presentations:** I gave a feedback session to the staff of a group home regarding the nature of the work with my client and the future implications of this for staff.

**Child and Adolescent Mental Health**

This placement was based within a multidisciplinary Primary mental health team for children
Reflective Accounts

**Clinical Work:** I worked with young people between 8 and 16 years of age, with a range of emotional and behavioural difficulties including challenging behaviour, anxiety, and depression. I completed a number of behavioural observations and cognitive assessments. My therapeutic work drew on cognitive-behavioural and psychoanalytic models, and included some attachment focused work.

**Teaching and presentations:** I gave a talk to the Surrey CYPS psychology meeting on the neurobiology of attachment.

**Consultancy:** I developed a consultancy service alongside my supervisor to support the work of a local sure start centre.

**Specialist Child and Adolescent Mental Health**

This placement was based within a multidisciplinary Child and Adolescent Mental Health Team

**Clinical Work:** I worked with young people between the ages of 6 and 16, experiencing obsessive compulsive disorder depression, anxiety, low self esteem, school refusal and self-harm. Therapeutic work focused on cognitive behavioural models. I conducted a number of cognitive and behavioural cognitive assessments, worked indirectly with schools and carers and maintained ongoing risk assessments with all clients.
Case Report 1

Neurological Assessment of an Asian Man in his Mid Thirties Following a Stroke Located in the Basal Ganglia.

Summary

This gentleman had had an intra cerebral haemorrhage in 2003 which was located in the basal ganglia and had affected those parts of the brain distal to the middle cerebral artery. He therefore had problems with language, memory and some executive functions alongside hemiplegia. He had been working as a medical laboratory scientist prior to the intra cerebral haemorrhage and although he had returned to work, concern was being raised regarding his ability to undertake his duties. Our client was struggling to come to terms with his new circumstances and was finding it difficult to admit the extent of his difficulties. The report therefore describes a full assessment of his cognitive abilities and an assessment as to the extent of denial and lack of insight exhibited by the client. We found that many of our client’s executive functions were largely unaffected by his condition and he was able to understand complex and abstract concepts. However, he did have extensive problems with both expressive and receptive language, memory and speed of cognitive processing which affected his everyday life and his ability to follow his chosen profession. Both the process of assessment and the explanation of the results helped our client to begin to come to terms with his new circumstances.
Case Report 2

Cognitive behavioural therapy with a white British man in his late 30s with symptoms of depression, anxiety, obsessive compulsive disorder, self harm and alcohol misuse

Mr Jones was a white British gentleman was referred to the Community Mental Health Team by an Associate Specialist Psychiatrist with depression, anxiety, OCD, self harm and alcohol misuse. His alcohol misuse was successfully treated by the Drugs and Alcohol Service.

He was the youngest of 6 children who’s alcoholic father left when Mr Jones was 4 years old. Prior to this Mr Jones had been subjected to a violent and chaotic upbringing. His mother remarried and Mr Jones refers to his mother and his step father as his parents. Subsequent to this Mr Jones ‘ mother became ill and Mr Jones spent some time being brought up by his grandmother and older sister. Mr Jones has a stammer which did not resolve until his late twenties. In addition to this he was not encouraged to continue his education beyond 16 and has remained in employment that does not challenge him.

Two years ago his partner developed mental health problems, emotionally and physically abusing him. This lead to the onset of severe depression and the development of a range of OCD behaviours focused on keeping Mr Jones safe. These problems were addressed within a CBT framework. By the end of therapy, Mr Jones had stopped his alcohol misuse, markedly reduced his self harm and his depression was beginning to resolve, but his OCD remained a significant problem.
Case Report 3

Consultation regarding bereavement with the staff of a rehabilitation ward for older adults

The consultation described in this case report is part of a longer term project undertaken in response to a request for psychological support from a community rehabilitation ward. In addition to identifying a need amongst patients for intervention this initial suggested that staff might also welcome support from psychology in issues related to bereavement.

The consultee was the ward matron and the consultation was planned in close collaboration with her to ensure that the needs of staff and service were fully met. The consultancy comprised 2 workshops, facilitated by the trainee clinical psychologist. In the first of these, staff were invited to share their experiences of bereavement within the ward context and in the second these experiences were developed into guidelines that could then be used to guide practice on the ward.

The feedback available suggested that staff had valued the opportunity to share their experiences and that that discussing them together as a whole team had been particularly valuable. Further evaluation is needed to understand the longer term effects of this consultancy.

An important part of this consultation was the consideration of staff dynamics and how these needed to become integral to the planning of the consultancy to ensure its success.
Oral Case Report Summary

Psycho-educational work with a 50 year old woman with leaning difficulties and a diagnosis of autism.

This case report describes psycho educational work with a 50 year old woman with learning disabilities and a diagnosis of Autism who has lived in residential care since her late teens.

She lives in a fully staffed (8 residents to 4 staff), long term group home with 7 other women with a similar diagnosis. She has two sisters and a mother to whom she is very close and a brother that she no longer sees. She also had a step father to whom she frequently refers. The client has limited communication, using mainly one or two word utterances, supported with some Makaton signs. She has very concrete thinking and a diminished ability to generalise concepts. The group home in which she lives is part of a group of similar homes and she has access to a day centre on the same site. She is able to move independently between her home and the day centre. She is a relatively social person and has a good relationship with her key worker who she has known for over 10 years.

Maintaining good contact with her family is part of her relapse prevention plan. It was noted in her CPA meeting that now her mother has dementia there is a need to prepare the client for the time when her mother will no longer recognise her.

Existing psycho educational material originally designed for people with Down’s syndrome whose friends have dementia was modified for work with the client. The client’s learning disability meant that the materials needed to be simplified and the more complex concepts removed, with work focussing on normalising the aging process. The client’s concrete thinking, lack of ability to generalise and difficulty interpreting social information meant that the pictures in the original materials needed to be altered. For example the man in the pictures was altered to make him look like the client’s mother and only pictures which needed no social inference were used.

Work was undertaken over six short sessions, with work continued through the week by the key worker. Regular meetings with the key worker enabled materials to be further
developed in light of the client’s response to them. The intervention was successful and the client did realise that her mother might forget who she was.

This work formed part of a larger body of work planned to be undertaken with the home, the majority of which was in response to a CQC requirement that the home had more input from the MDT. Developing a good working relationship with staff was therefore particularly important for this piece of work.
Case report 5

Cognitive Behaviour Therapy with a 12 year old white British boy with symptoms of anxiety.

Bert was a 12 year old white British boy referred to the service by his GP due to problems with anxiety at school. He had difficulty staying in classes that he thought would be disruptive and had extensive anticipatory anxiety prior to these lessons.

Bert’s anxiety arose from a fear that others would think he was behaving badly and therefore think that he was not a good person. These fears originated from a family ethos that one should always be well behaved and a strong parental external locus of control that resulted in other people’s opinions of the family being highly valued. This was exacerbated by his mother’s own anxiety and tendency to shield Bert from difficult situations. This meant that Bert had never learnt that he could manage difficult situations by himself. In addition, Bert had an active imagination and a ruminative style of thinking.

Treatment consisted of CBT which focused on Bert’s tendency to catastrophise and mindfulness to reduce his rumination. In addition, his parents were involved in treatment to increase Bert’s independence and to reduce the number of times Bert’s mother intervened to reduce his anxiety.

Treatment was successful and by the end of therapy, Bert was able to stay in all maths lessons and had stopped largely stopped ruminating.
RESEARCH DOSSIER

The Research Dossier contains the research logbook, the service related research project completed in Year 1, an abstract of the qualitative research project completed in Year 2 and the major research project, completed in Year 3.
### Research Log

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<td>2</td>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
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<td>3</td>
<td>Critically reviewing relevant literature and evaluating research methods</td>
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<td>4</td>
<td>Formulating specific research questions</td>
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<td>5</td>
<td>Writing brief research proposals</td>
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<td>7</td>
<td>Considering issues related to ethical practice in research, including issues of diversity and structuring plans accordingly</td>
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Service Related Research Project

Evaluation of a CBT based group for clients with heterogeneous mental health problems referred to an adult out-patients service.

Abstract

Evaluation of a CBT based group for clients with heterogeneous problems referred to an adult out-patients service

Objective: To obtain a broad understanding of the benefits of CBT group therapy for clients with mixed diagnosis and to evaluate whether the group was of benefit to those with more severe difficulties.

Design: An effectiveness study using pre and post intervention measures.

Setting: An adult outpatient psychology service.

Participants: 112 clients who attended at least 5 of the 6 Heterogeneous Cognitive Behaviour Therapy Group sessions. Participants’ ages ranged from 22-70 years, with a mean age of 44 years, 62% were female.

Main outcome measures: statistical significance and effect sizes of any change observed on the Clinical Outcomes in Routine Evaluation (CORE), General Health Questionnaire (GHQ), the Rosenberg Self Esteem measure (RSE) and the Generalised Self Efficacy scale (GSE). Clinically relevant change and clinically significant change were also calculated for CORE scores.

Results: All measures showed a statistically significant improvement over the course of treatment. Effect sizes were comparable with other studies for the CORE and GHQ.
Preliminary studies suggest that those with anxiety did as well as those with depression. An interquartile analysis indicated that clients with more severe difficulties benefited more than those with less severe difficulties.

**Conclusions:** The HCBTG is effective in comparison to other mixed diagnosis groups and also to single diagnosis groups. Clients with severe difficulties do well in the group which suggests that it may be appropriate to develop it for use with a CMHT population.
Acknowledgements

There are many people who have helped with this project along the way. Firstly, I must thank Win Fleming, not only for the design and inception of this innovative group, but also for having the foresight to collect such extensive data. Thanks also go to Ruth Davies for the priority she gives data collection, without this the dataset would not be nearly so complete. I must also thank Naomi Hughes for her help in transferring data from the files into the database- a herculean task! Without her help I would have many more grey hairs. Finally I must thank Patsy Howe for patiently explaining how and where to find files and other more obscure pieces of information. From Surrey, I thank Nan Holmes who kept me grounded and read my draft with such a wonderfully critical eye and Linda Morison for statistical advice.
Introduction

The Heterogeneous Cognitive Behaviour Therapy group (HCBTG) was set up in the Specialist Psychology Service in 2004 in response to the 2-3 year waiting lists for therapy being experienced by the service at that time. It was known that group CBT was an effective treatment for anxiety and affective disorders when diagnosis specific groups were used (Morrison 2001) and evidence was growing that mixed diagnosis or heterogeneous groups were also effective (Hush and Fleming 2000). More recent work with heterogeneous groups has supported this view (McEvoy and Nathan 2007, Haby et al, 2005, Taylor and Clarke 2009). Barlow et al (2004) argue that the similarities across the disorders outweigh the differences and therefore that treatments may not need to be disorder specific. In addition co-morbidity is common within the current diagnostic framework so treatments that address common factors between disorders could be a more efficient and effective approach. Indeed, in their mixed diagnosis group, McEvoy and Nathan (2007) demonstrated a greater degree of improvement for those with co-morbid diagnoses than for those presenting with single disorders.

Heterogeneous groups also have the advantage within a clinical setting of being quicker and easier to set up as it is not necessary to wait for appropriate numbers of suitable clients with a specific diagnosis to accrue. It also means that individual clients do not need to attend more than one group to address co-morbid disorders; hence heterogeneous groups are more convenient for clients and more efficient in the use of therapist time. However, recently the service has joined a Trust whose mental health policy favours diagnosis specific pathways so it was of interest to evaluate how those with different initial difficulties progressed in the heterogeneous group programme.

The service is currently investigating the possibility of developing the HCBTG for work with clients of the Community Mental Health Team (CMHT). The clients served by CMHTs frequently have co-morbid disorders, so treatment designed for and tested on a heterogeneous population including those with co-morbid disorders may be suitable for this client group. CMHT clients also have more severe disorders than those attending the Specialist Psychology Service. DeRubeis et al (1999) showed that CBT was effective for
severe depression. However, in their meta-analysis of CBT Haby et al (2006) identified the inclusion of patients with severe mental health difficulties as reliably reducing treatment efficacy. It was therefore important to understand how clients with more severe difficulties within the Specialist Psychology Service population responded to the HCBTG programme.

In comparing this programme with other published studies it was important to take a number of factors into account; the design of the study (whether an efficacy or an effectiveness study); the measures used; and the client population studied. Most published studies are efficacy studies which are set up to demonstrate whether a treatment works and compare a study group against a control group (Barker et al, 2002). Such studies usually have stringent inclusion criteria. In contrast, effectiveness studies look at the performance of an intervention in a clinic setting and have less stringent controls and no control group (Barker et al, 2002). Most published studies for depression and anxiety use either the Beck Depression Inventory (BDI) or the Beck Anxiety Inventory (BAI) to follow progress. As neither of these had been used for the HCBTG due to its heterogeneous nature, comparison with other studies was difficult.

**Aims and Research questions**

The basic aim of the study was to gain a broad understanding of the effectiveness of the HCBTG for the Specialist Psychology Service client population and how this compared to other published group programmes. This would be done by evaluating the statistical significance of any change observed and also by calculating effect sizes, clinically relevant change and clinically significant change.

Specific aims were to evaluate whether:

1. different disorders benefited to a similar degree.

2. more severely affected clients benefited to the same extent as less severely affected clients.
Methods

Participants:
All clients referred to the Specialist Psychology Service were screened by Assistant Psychologists. Those who had a primary difficulty relating to depression, anxiety, health anxiety, panic attacks, self esteem, anger management or relationship difficulties were offered a place in the HCBTG. Any with psychosis or serious suicidal ideation, or a primary problem of drugs and/or alcohol abuse, Obsessive Compulsive Disorder or eating disorders were excluded. No cut-off scores on any of the measures taken at screening (GHQ, BDI, BAI, and the Clarke Beck Obsessive Compulsive Inventory) were used to decide on suitability for the group. A two hour Introductory Session was held for suitable candidates in which the aims and methods of the HCBTG were explained. Clients could then opt into the full programme. Data was collected over a period of three years from 112 clients who attended at least 5 of the 6 sessions (see below). Participants’ ages ranged from 22-70 years (mean 44.16, SD 11.23), 62% were female.

Measures:
Measures were chosen to be sensitive to change across a range of psychological difficulties; therefore disorder specific measures such as the BDI were not used.

General Health Questionnaire-28 (GHQ): This is an extensively used 28 item self-report measure of psychological wellbeing (Goldberg and the Institute of Psychiatry 1981).

The Clinical Outcomes in Routine Evaluation (CORE): This is a 34 item self report group designed to measure change during psychotherapy. It has a test-retest reliability of 0.95. The CORE has been extensively studied and information is available regarding its characteristics in clinical and non clinical populations as well as its correlations with other measures such as the GHQ and BDI. The clinical cut-off is 1.21 for women and 1.29 for men (Evans, Connell at al 2002, Mellor-Clarke et al 1999).

The Rosenberg Self Esteem Scale (RSE) and the Generalised Self Efficacy Questionnaire (GSE) are both 10 item self report measures with a test-retest reliabilities of 0.88 and 0.85 respectively (Rosenberg 1965, Schwartz and Jerusalem 1993, Scherbaum 2006). The GSE is reverse scored meaning increased scores represent improvement.
Procedure:

Treatment was composed of 6 sessions each lasting 5 hours with breaks for lunch and coffee. The HCBTG programme was based on Padesky’s approach to CBT (Greenberger and Padesky 1995). The first session focused on the experiences of participants and the information shared during this session used as a basis for discussion during the rest of the programme. Hence clients were given an understanding of the relationship between moods, thoughts, behaviours and physical symptoms and taught how to use thought records to challenge negative automatic thoughts. This was supplemented with work on core beliefs. In addition the group was taught methods of relaxation and introduced to mindfulness techniques.

A set format was followed for each session with supplementary handouts. The group comprised up to 8 participants and was run by two psychologists, at least one of whom was fully qualified.

Clients were asked to fill out all four of the questionnaires detailed above which were sent to them a week before they started the course and again during the last afternoon.

Ethics:

Ethics approval was not required for this study as it was a service evaluation.

Results

As this was an effectiveness study with few specific criteria for inclusion into the programme it was necessary to gain an initial understanding of the characteristics of the participants. Descriptive statistics using CORE showed that 24.5% of participants were below the clinical threshold on this measure when tested immediately pre-group. A group who tested above clinical threshold on the CORE (the Above Clinical Threshold group -ACT) were analysed separately from the whole sample (Table 1). Only those participants who completed pre and post measures were included in the analysis, hence between 8.7% and 12.1% of the sample were lost for each measure. Data for the measures reported were normally distributed, so parametric tests were able to be used.
Table 1 Descriptive Statistics for both the Whole Sample and the ACT group for all measures.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Whole sample</th>
<th>ACT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range (n)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>CORE</td>
<td>1.18-3.82 (102)</td>
<td>1.69 (0.71)</td>
</tr>
<tr>
<td>GHQ (total)</td>
<td>2.83 (100)</td>
<td>33.62 (16.2)</td>
</tr>
<tr>
<td>B (anxiety)</td>
<td>0-20 (100)</td>
<td>9.6 (4.5)</td>
</tr>
<tr>
<td>D (depression)</td>
<td>0-21 (100)</td>
<td>5.5 (4.7)</td>
</tr>
<tr>
<td>RSE</td>
<td>12-40 (97)</td>
<td>27.0 (6.0)</td>
</tr>
<tr>
<td>GSE</td>
<td>9-38 (96)</td>
<td>22.8 (6.0)</td>
</tr>
</tbody>
</table>

Results of paired two tailed t-tests showed significant differences for all t-tests between pre-treatment measures and post-treatment measures for the whole sample (Table 2) and also for the ACT (Table 3). Effect sizes (Cohen’s d) were also calculated to allow comparison with other studies.

Table 2 Whole sample: Pre and post-test scores, t-tests and Cohen’s d

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-test</th>
<th>Post-test</th>
<th>T statistic</th>
<th>significance</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (Std)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE (n=102)</td>
<td>1.69(0.71)</td>
<td>1.29(0.71)</td>
<td>7.08</td>
<td>p&lt;0.0001</td>
<td>0.67</td>
</tr>
<tr>
<td>GHQ (total)</td>
<td>33.62(6.2)</td>
<td>24.22(13.2)</td>
<td>4.3</td>
<td>p&lt;0.0001</td>
<td>0.69</td>
</tr>
<tr>
<td>B (anxiety)</td>
<td>9.53(4.6)</td>
<td>7.43(3.7)</td>
<td>4.93</td>
<td>p&lt;0.0001</td>
<td>0.50</td>
</tr>
<tr>
<td>D (depression)</td>
<td>5.36(4.7)</td>
<td>3.47(4.3)</td>
<td>5.05</td>
<td>p&lt;0.0001</td>
<td>0.49</td>
</tr>
<tr>
<td>RSE (n=97)</td>
<td>27.0(6.0)</td>
<td>24.9(5.7)</td>
<td>-6.7</td>
<td>p&lt;0.0001</td>
<td>0.45</td>
</tr>
<tr>
<td>GSE (n=96)</td>
<td>22.8(6.0)</td>
<td>26.1(5.7)</td>
<td>6.43</td>
<td>p&lt;0.0001</td>
<td>0.68</td>
</tr>
</tbody>
</table>
Table 3 Above Clinical Threshold group: Pre and post-test scores, t-tests and Cohen’s d

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-test Mean (Std)</th>
<th>Post-test Mean (SD)</th>
<th>T statistic</th>
<th>significance</th>
<th>Cohen’s D</th>
</tr>
</thead>
<tbody>
<tr>
<td>CORE (n=77)</td>
<td>2.02(0.48)</td>
<td>1.5(0.65)</td>
<td>7.69</td>
<td>p&lt;0.0001</td>
<td>0.86</td>
</tr>
<tr>
<td>GHQ (total)</td>
<td>37.5(14.1)</td>
<td>26.9(13.3)</td>
<td>6.98</td>
<td>p&lt;0.0001</td>
<td>0.78</td>
</tr>
<tr>
<td>B (anxiety)</td>
<td>11.04(4.1)</td>
<td>8.32(3.7)</td>
<td>5.02</td>
<td>p&lt;0.0001</td>
<td>0.61</td>
</tr>
<tr>
<td>D (depression)</td>
<td>6.47(4.46)</td>
<td>4.60(4.22)</td>
<td>4.60</td>
<td>p&lt;0.0001</td>
<td>0.59</td>
</tr>
<tr>
<td>(n=100)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RSE (n=74)</td>
<td>28.44(5.1)</td>
<td>26.54(5.2)</td>
<td>-3.79</td>
<td>p&lt;0.0001</td>
<td>0.46</td>
</tr>
<tr>
<td>GSE (n=76)</td>
<td>21.31(5.4)</td>
<td>24.8(5.5)</td>
<td>-5.9</td>
<td>p&lt;0.0001</td>
<td>0.67</td>
</tr>
</tbody>
</table>

Anxiety and depression

Due to the data collected pre-group, no specific measures for anxiety or depression are available. However, subscales B (anxiety) and D (severe depression) from the GHQ do enable an understanding of the levels of anxiety and depression within the HCBTG to be gained.

Independent two-tailed t-tests for GHQ B and GHQD indicate that both these show improvement, although the effect sizes are not as large as for CORE and Total GHQ (Tables 2 and 3).

Severity

The effectiveness of HCBTG for different levels of severity was investigated by dividing the whole dataset into quartiles based on the CORE scores; the first quartile being the most severe (Table 4). A one way between groups ANOVA was conducted and showed a significant effect for severity both for CORE and GHQ ($F_{(3,84)}=4.75$ p<0.01 and $F_{(3,84)}=4.67$ p<0.01 respectively), however, severity did not have a significant effect for either Self esteem or Self efficacy ($F_{(3,84)}=0.03$, $p>0.05$ and $F_{(3,84)}=1.07$, $p>0.05$ respectively). Cohen’s d was also calculated for the first three quartiles (Table 4) and indicates that effect sizes for

83
CORE and GHQ were highest in the first and second quartiles, although no pattern was discernable for RSE or GSE.
Table 4 Pre-Group Means, mean change scores and Cohen’s d for the Above Clinical Threshold group inter-quartile groups

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Group Mean (SD)</th>
<th>Mean Change Scores (SD)</th>
<th>Cohen’s d</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1&lt;sup&gt;st&lt;/sup&gt; Quartile (n=24, range for CORE Scores =2.21-4.0)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE</td>
<td>2.4 (0.47)</td>
<td>0.62 (0.53)</td>
<td>1.16</td>
</tr>
<tr>
<td>GHQ</td>
<td>45.7 (15.25)</td>
<td>12.17 (12.94)</td>
<td>0.94</td>
</tr>
<tr>
<td>RSE</td>
<td>32 (4.46)</td>
<td>2.17 (4.27)</td>
<td>0.50</td>
</tr>
<tr>
<td>GSE</td>
<td>19.3 (5.7)</td>
<td>-3.87 (4.65)</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>2&lt;sup&gt;nd&lt;/sup&gt; Quartile (n=26, range for CORE scores= 1.8-2.20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE</td>
<td>1.97 (0.17)</td>
<td>0.60 (0.56)</td>
<td>1.07</td>
</tr>
<tr>
<td>GHQ</td>
<td>36.9 (9.3)</td>
<td>14.47 (13.2)</td>
<td>1.09</td>
</tr>
<tr>
<td>RSE</td>
<td>28.7 (3.2)</td>
<td>2.4 (4.47)</td>
<td>0.50</td>
</tr>
<tr>
<td>GSE</td>
<td>22.0 (5.0)</td>
<td>-4.1 (3.48)</td>
<td>1.18</td>
</tr>
<tr>
<td></td>
<td>3&lt;sup&gt;rd&lt;/sup&gt; Quartile (n=23, range for CORE scores= 1.2-1.79)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CORE</td>
<td>1.55 (.12)</td>
<td>0.19 (0.57)</td>
<td>0.32</td>
</tr>
<tr>
<td>GHQ</td>
<td>33.9 (12.17)</td>
<td>8.27 (12.67)</td>
<td>0.65</td>
</tr>
<tr>
<td>RSE</td>
<td>25.3 (5.06)</td>
<td>1.33 (3.48)</td>
<td>0.38</td>
</tr>
<tr>
<td>GSE</td>
<td>22.9 (5.53)</td>
<td>-2.38 (5.04)</td>
<td>0.47</td>
</tr>
</tbody>
</table>

Effect sizes

Cohen’s d can also be used to compare against previously published studies, even where different measures have been used (Field, 2005). For Cohen’s d, effect sizes around 0.3 are
considered small, around 0.5 - medium and above 0.8 - large (Cohen 1992). Although the group only showed a medium effect when the whole sample was considered (Table 1), it improved for the GHQ and GHQ measures when the ACT group was considered (Table 2) but was at its most effective with the first and second quartiles. Care needs to be taken in interpreting this effect with the CORE scores as the sample was stratified using CORE. However, as the GHQ scores show a similar, though less marked pattern, the effect would seem to be robust. The HCBTG compares favourably both to other groups with mixed diagnoses and to studies which measure effectiveness for groups aimed at specific disorders. McEvoy and Nathan (2007) quote values for Cohen’s d for a mixed diagnosis efficacy study of 1.0 and for effectiveness studies for groups addressing specific disorders of between 0.5 and 1.1. For the first two quartiles, the HCBTG is at the upper end of this range for both CORE and GHQ. Using the work of Leach et al (2009) direct comparisons can be made between BDI and CORE scores. This indicates the first two quartiles are directly comparable to the participants in the McEnvoy and Nathan (2007) study and that the first quartile comprises clients with severe depression as measured by the BDI.

Clinically Significant Change and Clinically Reliable Change

Other measures of effectiveness are clinically significant change (CSC) where clinical populations move into the range of non clinical populations on a specific measure and clinically reliable change (RC) where the magnitude of change is greater than that which could be due to measurement error. Post-programme scores on CORE that were below the cut off expected of the normal population were attained by 39% of the ACT group, with 17% of the first quartile, 40% of the second quartile and 45% of the third quartile achieving this. The lower level of CSC in the first quartile was to be expected as they have to achieve a greater degree of improvement to move into the normal population.

RC for the CORE corresponded to a change score of 0.48 (Reliable Change Index >1.96). Fifty one percent of the ACT sample achieved RC on CORE, with the 1st and 2nd quartiles improving more (57% and 60%) than the 3rd quartile (31%). This is similar to that achieved by other published studies (McEnvoy and Nathan 2006).
Discussion

As this was an effectiveness study using data gathered from all participants in a routine service, it was necessary to understand the nature of the data before progressing further. This analysis showed that many participants had a total score on the CORE below that indicated to be clinically significant (Evans et al 2002). Given that all participants had been screened prior to inclusion in the HCBTG this was somewhat surprising. Further investigation revealed two groups within this sub-clinical set. The first consisted of those referred for specific problems such as a fear of contracting HIV or relationship difficulties. Although these problems had an impact on the individual client’s day to day life, they did not register on the CORE. The other group were those that had scored highly on screening but during the protracted time on the waiting list had reduced their scores; it may be useful to investigate this subset further to understand the reasons for this. It might also be worth considering an additional CORE assessment at the Introductory Session, especially when the waiting list is long to identify, in conjunction with other information, those who no longer need the service.

When exploring the effectiveness of the clinical group against other effectiveness studies the HCBTG appears in the mid to lower end of the range, although when compared against similar client groups to those in published studies (i.e. the first and second quartiles) the current study performs well (McEvoy and Nathan 2007). However, it has to be recognised that given the different measures used in this study compared to other studies that this is only an approximation.

Due to the nature of the referral and screening processes for the HCBTG and the measures used to assess clients pre-group, it is not possible to identify those with a single disorder of either anxiety or depression, although from the comparison between the depression and anxiety subscales on GHQ it appears that both kinds of problem show a similar degree of improvement. As it was not possible at the outset to distinguish between those who had a primary diagnosis of anxiety or depression or both, these comparisons include the scores from clients who do not present with these problems, this reduced the opportunity for change, increased the standard deviations and therefore depressed the Cohen’s d. A further analysis would therefore be useful to compare the progress of those who entered the HCBTG with high scores on GHQ B or GHQ D to understand this further. However, it has
to be noted that the GHQ D is a measure of severe depression which correlates most closely to the Risk subscale in CORE (Evans et al 2002) and may therefore not be a good measure of depression *per se*.

There are contradictions in the literature around the efficacy of CBT for severe depression, with some demonstrating efficacy compared to medication (Derubeis *et al* 1999) and others noting that inclusion of severe patients reduces efficacy (Haby *et al* 2006). However, these two positions are not mutually exclusive and it seems from the analysis presented above that the format of the programme (being held in six, weekly five hour sessions) and the focus on client’s life histories together with understanding core beliefs in addition to CBT may be particularly suited to more severely affected clients. The analysis, using both Cohen’s d and measures of clinically reliable change, certainly shows that the most severely affected quartile are not disadvantaged in the HCBTG, although it might be useful to further investigate the tenth percentile to see if this effect still remains. Overall, this study lends support to the proposal to develop the HCBTG for use with CMHT clients, although further work, perhaps with a focus group of the more severely affected clients may be useful to better understand the needs of this client group within the HCBTG setting.

Overall this group appears to perform well in comparison to similar groups and the inclusion of clients with different problems and/or co-morbid conditions does not seem to reduce the effectiveness of the group. This finding relates to a growing literature supporting mixed diagnosis groups which address the underlying psychological factors in both anxiety and depression (Dozois *et al*, 2009, Erickson *et al*, 2009, Taylor and Clark 2009, McEnvoy and Nathan 2007).

Given the results obtained here, it might be useful to alter the measures used to evaluate the group. For example, the GSE and RSE do not appear to add to the understanding of client progress and might be usefully replaced by specific measures for anxiety and depression so that these disorders can be specifically followed. This would enable greater clarity regarding the efficacy of the group to treat both those with different single disorders and also co-morbid disorders. It might also be useful to record further demographic details and whether clients are also taking medication to enable a greater understanding of the client group and a more accurate comparison to published studies.
Research Dossier.

The results of this evaluation were presented to the service on 14\textsuperscript{th} October 2009
References


Evidence of SRRP presentation

From: Win Fleming  
Sent: 17 June 2011 15:45  
To: Helen Stirk  
Subject: RE: Helen and David's SRRP presentations.

Dear Helen & David

Thank you for the presentation of your SRRP’s that you did for the Psychological Therapies meeting. It was very well received and very helpful.

Best wishes Win

Please note: When this work was undertaken, there was no requirement in the course handbook for the Evidence of SRRP Presentation to be signed by the supervisor.
Abstract of Qualitative Research Project.
Supervision is considered a central part of Clinical Psychology Doctorate training, yet there is a paucity of research exploring supervision structures and processes. This is especially so for research utilising qualitative methods, which arguably better capture experiences, perceptions and relative understandings. The aim of this project was to explore what is learnt through supervision and whether, and how, this learning is applied to future supervisory relationships. Method: Five semi-structured interviews were carried out, using an interview schedule. All participants were second-year trainee clinical psychologists. A thematic analysis was used to analyse the data. Results: Four core themes were identified as important in contributing to the quality of the first and second supervisory relationships; subthemes are given in brackets: trainee needs (practical and emotional); supervisor qualities (positive mentorship, challenges, communication); things gained from the first year supervisory relationship (knowledge and skills, reflective practice, understanding diversity, personal growth); and transition to the next supervisor (expectations, comparisons, adaption). Discussion: it was noted that those with a challenging first-year supervisory relationship were able to make better use of subsequent supervisory relationships. The authors reflected on how their own experiences and expectations were reflected in the findings. Limitations and assumptions inherent in this project were also discussed.
Major Research Project

‘The experience of mainstream inclusion for autistic children primarily educated in special schools’
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Abstract
The aim of this study was to explore how children with ASD predominately educated in special schools experience inclusion in mainstream schools.

Method: An Interpretative Phenomenological Analysis was used to explore interview data from four participants who were primarily educated in the boarding provision of a special school sixth form, but who spent some time each week included in mainstream settings.

Results: From the analysis of the data, seven super-ordinate themes were developed. These were: Independence, Belonging, Comparisons, Managing Self Presentation, Sense of Self, ‘Who Knows?’ and External Factors. The different school contexts highlighted different aspects of these themes and all appeared to be affected by the participants’ differing levels of social understanding.

Conclusion: The key findings were: 1) For most participants the move into a different setting appeared to result in an increased awareness of factors related to how they saw themselves and how others saw them; 2) The participant’s level of social understanding appeared to affect the extent to which the move into a new context prompted them to re-evaluate themselves and manage how others saw them; 3) Participants valued the independence that mainstream settings provided and did not report bullying. This was unexpected as evidence suggests that bullying is a significant problem for autistic pupils included in mainstream education; 4) Problems were experienced regarding who should know about the participant’s diagnosis of autism; 5) The generally positive experiences of these participants add to the debate regarding the inclusion of autistic children in mainstream settings.

Key words: Autistic Spectrum Disorder, School inclusion
Acknowledgements

I would like to thank my supervisor, Emma Williams, for her support and advice during the undertaking of this research. I would also like to thank the staff from each of the schools who took part and in particular to the SENCO and Sixth Form Co-ordinator of the special school who gave their time to make this study possible and last, but certainly not least, to the participants for entering into the interview process.

I would also like express my thanks to my family for their enormous support over the last two months; to my husband Paul, whose support was unwavering, to my daughter Kimberley, for her robust, funny and inspiring views and to my son Liam, for understanding beyond his years. Thanks should also go to my friends who gave such whole hearted support and sound advice.
1. Introduction

The question of how autistic\(^2\) children experience inclusion in mainstream schooling brings together a number of complex issues. The first of these is the inclusion agenda and the tension it generates between the human rights of those with disabilities and the challenges of providing truly inclusive education that is appropriate to both the learning and social needs of the individual. These tensions are stretched further where the education of autistic individuals is concerned as their problems encompass social interactions, thereby making the social environment of schools potentially distressing.

Moving between the relatively sheltered world of the special school to the intensely social, highly complex and challenging world of a mainstream secondary school would be problematic for any child. However, for the autistic child, these issues are further complicated by their difficulties engaging in the social world (Humphrey, 2008).

1.1 The inclusion agenda

The overarching purpose of the inclusion agenda in education is to *eliminate social exclusion that is a consequence of attitudes and responses to diversity in race, social class, ethnicity, religion, gender and ability* (Ainscow & Cesar, 2006, p. 231). It is an international movement that has its roots in the belief that education is a basic human right. In 1994 UNESCO endorsed the idea of inclusive education (UNESCO, 1994) arguing that the most effective means of combating discrimination and building an inclusive society is for mainstream schools to be fully inclusive. The sentiments and the reasoning behind this report is not contested, however, it is inevitably interpreted in different ways in different circumstances and cultures. Internationally it seeks to support education for all learners, for example to increase the number of girls around the world who have access to education. However, in western countries where few social groups are excluded from mainstream education, the focus has been on those with intellectual or physical disabilities.

---

\(^2\) Throughout this thesis, the term ‘autistic children’ is used rather than ‘children with autism’ as this is the preferred term of autistic community (Brownlow, Re-presenting autism: the construction of ‘NT syndrome’, 2010)
This has led to the assumption that all children should be educated in a mainstream school unless there is clear evidence that this would not be possible. The assumption is that children who have a Statement of Special Educational Needs (SEN) attend a mainstream school “unless it is incompatible with parental wishes or with the provision of efficient education for other children” (Department for Education and Skills (DfES), 2004). There is an argument that inclusion in its present form does not serve the interests of those with disabilities (Humphrey & Ainscow, 2006) and that for some, inclusion in mainstream school, whilst preserving their human right to the education received by others, may ignore their specific needs. This is true of both the deaf community (Freire & Cesar, 2003) and for those on the autistic spectrum who have the appropriate intellectual abilities to be educated in mainstream schools, but lack the social skills (Billington, 2006; Chamberlain, Kasari & Rotheram-Fuller, 2007; Frederickson, Jones & Lang, 2010).

1.2 Transitioning between special and mainstream schools

To counter some of these problems there is an increasing effort being put into enabling pupils in special schools to spend some time in mainstream schools for all or part of their days (Gibb, Tunbridge, Chua & Frederickson, 2007). This policy has had a mixed uptake and has met with varying degrees of success (Frederickson, Dunsmuir, Lang & Monsen, 2004). If not carefully implemented, it can lead to bullying and social exclusion thus decreasing the child’s self esteem (Nabuzoka, 2003).

There has been little work to understand the process of mainstream inclusion, but work looking at how typical children transition from mainstream primary to mainstream secondary can give some indication as to the factors involved. Humphrey and Ainscow (2006) looked at the psychological adjustment of underachieving primary school children as they transitioned to secondary school. They noted major differences between primary and secondary school that make such transitions difficult: increased size of the school (both in terms of physical structure and the number of pupils); differences in the curriculum; an emphasis on achievement and competition rather than on effort and improvement; more distant relationships with teachers; and a greater emphasis on rules and behaviour, with
less tolerance and understanding of misbehaviour. All these factors can be seen to apply to transitions between special schools and mainstream schools. The effect of these systemic transitions is often to increase anxiety and decrease self esteem (Harter, Whitesell & Kowalski, 1992; Wigfield, Eccles, Mac Iver & Midgely, 1991). Evidence suggests that they may also induce feelings such as fear, confusion and uncertainty (Shachar, Suss & Sharan, 2002).

1.3 How children in special schools see themselves

Being sent to a special school has been seen to be a ‘passport’ to a devalued lifestyle (Jupp, 1993). It entails being rejected from participation in mainstream education and also being socialised into a devalued social group. It is this notion of being devalued that has partly driven the sociological concerns regarding special education (Todd, 2000). However, many children embark on their special school careers before an awareness of stigma has emerged (Alonzo & Reynolds, 1995) and therefore this awareness may only develop when further transitions, between schools, or when leaving school brings these issues into focus.

Hence being in a special school is likely to have a significant influence on how an individual sees themselves. This may not be a negative influence. Cooney, Jahoda, Gumley, and Knott (2006) compared the experiences of children with intellectual disabilities who had attended either mainstream or special school and found that whereas both groups had experienced stigmatising treatment outside of school, those who went to a special school were protected from the highly stigmatising treatment evident within mainstream secondary schools. They note, however, that their participants made similar comparisons between themselves and either non disabled or more disabled people, irrespective of the school they attended and suggest that this is due to the influence of factors outside the school gates such as the extended family and social experiences within the children’s neighbourhoods. They took this to indicate that attending a special school had not protected the children from the stigmatising effects of the wider environment.

In contrast, Todd (2000) found that children attending a special school were protected to some extent from stigma. Todd points out that the way in which staff interact with pupils and the environment are crucial in shaping the social profile of those with intellectual
disability. When parents and staff act together to provide a ‘protective cocoon’ around those with learning disabilities, children are less aware of their stigmatised status. Todd also suggests that many children with learning disabilities are less able to interpret others’ actions as stigmatising and may not notice some of the more subtle ways in which stigma can be expressed. However, problems are likely to arise when leaving such a protected space as the existing, positive view of themselves is likely to be challenged.

An important process influencing how children see themselves is social comparison which was first formalised by Festinger (1954) over 50 years ago. He suggested that children in a classroom setting compare their abilities to others to gain some sense of their own abilities and their place in their social group. He suggested that most people compare with those similar to themselves, but who are slightly more able, thus giving themselves targets for self improvement. However, subsequent work has found a number of different motives for social comparisons these being: self evaluation, self improvement and self enhancement (Dijkstra et al., 2008). Children will compare themselves to those they think are more able (upward comparisons) if they wish to improve their performance, and to those they think are less able (downward comparisons) if their aim is self enhancement. The nature of social comparisons and their function changes as a child develops (Stipek & Mac Iver, 1989), hence children in infants school may watch their peers to gain information about competence, whilst it is not typically until the age of 8 that a child will use social comparisons for the purpose of self-evaluation (Ruble, Boggiano, Feldman & Loebel, 1980). At transition to secondary school, self-evaluation becomes more intense as new social groups are formed and the emphasis on performance increases. It develops further as children reach adolescence and issues of identity and social belonging increase in importance (Kuyper, 2004; cited in Dijkstra et al., 2008).

By the time a child reaches adolescence all the building blocks for social comparison should be in place. Indeed, adolescence has been seen as a time for the formation of these processes since Erikson identified the formation of identity as a critical task of this stage of life (Erikson, 1959). It is during this stage that individuals begin to gain independence and therefore to be able to choose the groups to which they belong. Steinberg and Morris (2001) note that teenagers may see themselves differently depending on where they are
and who they are with. This means that a child’s educational setting and their place within it is likely to affect how they see themselves in relation to others.

1.4 Autism and inclusion

In order to gain an understanding of how autistic pupils may experience mainstream school, it is necessary to have an understanding of autism. Autism is a pervasive developmental disorder that affects a person’s abilities in social communication (Rutter, 1968; Wing & Gould, 1979). It covers an enormous spectrum of difficulties, ranging from those for whom independent living is impossible to others who can only be described as high achievers.

There are a number of different theories which seek to describe the major deficits associated with autism, the main ones being Theory of Mind (Baron-Cohen, 2001), central coherence (Frith, 1989) and executive functioning (Dawson et al., 2008). However, none completely describe the experience of those with autism. For example, Frith focuses on the ‘weak central coherence’ of autistic people which describes their difficulties in seeing the context of a problem, rather than the detail (Frith, 1989) and Baron-Cohen on autistic individuals’ difficulties in perceiving what others might be thinking. Baron-Cohen has also conceptualised autism as an extreme form of the male brain (Baron-Cohen, 2003). Both Frith and Baron-Cohen emphasise that autism can be seen as an extension of normal human variation and this reflects the multifaceted genetic picture and the huge variation in experience expressed by people who describe themselves as autistic (contrast for example Temple Grandin (1996) and Wendy Lawson (2001)).

1.4.1 Wing’s Triad of Impairments

The most comprehensive description is Wing’s Triad of Impairments (Wing, 1981) and it is upon this that the Diagnostic and Statistical Manual of mental disorders 4th Edn. (DSM IVR) (American Psychiatric Association, 2000) and International Classification of Diseases 10 (IDC10) (World Health Organisation, 1993) definitions of autism are largely based. Wing
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outlines three areas of functioning found to be affected in autism. These are Social Interaction, Communication and Imagination. Wing’s recognition that autism is multifaceted is important as it emphasises that it is a complex condition and opens the way to understanding autistic people as highly individual.

1.4.1.1 Social Interaction

The problems with social interaction relate to an inability to comprehend the rules of social communication, or indeed their purpose. In her book ‘A Martian in the Playground’, Claire Sainsbury (2009), an autistic author, describes social interaction as ‘at best pointless and at its worst terrifying’ (p. 34). At its most extreme, this may result in a person not recognising other people as people; they are merely a class of object within their world. Part of this can be put down to an inability to read body language, facial expressions and social situations. However, this is not only a problem with reading and understanding the actions of others, but extends to the ability of those affected to produce socially informed and informative signals of their own. Hence even those with above average intelligence will frequently appear stiff or odd in their behaviour.

1.4.1.2 Communication

Communication is not just about the ability to speak, it encompasses the social meaning in communication (Baron-Cohen & Belmonte, 2005). It can range from those who do not speak, as they do not see the need for communication, or understand that this can have an effect on their world, to those who can speak fluently but lack the social understanding to do so effectively. People with autism may take language very literally, for example, if told to ‘pull your socks up’, that is exactly what they will do; completely missing the socially implied message that they need to improve their performance. They also have problems in taking turns in conversations and will dominate a conversation if on a topic that they find interesting. They do not see the point of a conversation if it is not to convey factual information; for them conversation lacks social meaning (Bagatell, 2007; Jackson, 2002).

1.4.1.3 Imagination
The final factor in Wing’s triad is that of imagination. This refers to problems in thinking flexibly and therefore finding change difficult and needing to keep rigidly to routines (Sainsbury, 2009). It also extends to problems with imagining what other people may be thinking. However, many people with autism describe the ability to develop complex imaginary worlds, or to imagine themselves within existing fictional contexts (Billington, 2006; Sainsbury, 2009).

1.4.2 Further aspects of autism

Wing’s Triad of Impairments describe many of the difficulties seen in autism, but do not fully explore all the facets of the experience. Simon Baron-Cohen has explored these observations of difficulties in social interaction with his work on Theory of Mind (Baron-Cohen & Belmonte, 2005) which seeks to explain the central deficit as an inability to recognise that others have thoughts that are different to one’s own. Hence someone with autism would not know that other people do not know what they know.

As mentioned above, autism is frequently referred to as a spectrum which ranges from those individuals who are profoundly disabled, to those who lead full and varied lives. However, this spectrum is multifaceted; for example, it is possible to consider each of Wing’s Triad of Impairments as a separate spectrum with each autistic person at a separate point on each spectrum. So, for example, it is possible for someone to be able to speak fluently, but have no social understanding, so their language is odd and conveys no social meaning. Conversely it is possible to have someone who does not speak, but has imagination and some social skills.

This heterogeneity has led to attempts to further categorise autism and labels such as Asperger’s syndrome and High Functioning Autism (HFA) are frequently given. However, there is a degree of unreliability regarding the diagnoses of both HFA and Asperger’s syndrome as the conditions appear to overlap (Fitzgerald & Corvin, 2001). There is also some evidence that a diagnosis of Asperger’s syndrome may be given in favour of one of High Functioning Autism as this is more socially acceptable (Shattuck & Grosse, 2007). Hence the label of Autistic Spectrum Disorder (ASD) is now the most frequently used amongst professionals. Irrespective of these academic arguments, the autistic community
has its own views on what they wish to be called and, for example, the term ‘Aspie’ has come to be adopted with pride by many people who have been given a diagnosis of Asperger’s syndrome (Bagatell, 2007; Brownlow & O’Dell, 2006).

1.4.3 How autistic people see themselves

The above theories focus on what autistic people cannot do and are rooted in the medical models of deficit and in comparing the processes in autistic people with those of neurotypically developing ones. However, there is a separate strand of investigation that gives voice to autistic people and reveals that for some understanding themselves is an ongoing and complex process of great importance (Bagatell, 2007). Bagatell’s work suggests autistic people, especially those with High Functioning Autism or Asperger’s syndrome may have the ability to see themselves in relation to others. She asserts that many are acutely aware of their differences to most of the people around them and welcome the possibility of belonging to a group of people similar to themselves. This is supported by Sainsbury who says that ‘Getting the right label was one of the best things that ever happened to me’ (Sainsbury 2009, p43) and Jackson who says ‘It’s good to know I’m in a group of people like myself’ (Jackson 2002, p23). Hence for many people with autism, having a diagnosis is a positive event as it gives them access to a group of similar people and a way of making sense of their experiences (Bagatell, 2007; Davidson & Henderson, 2010; Humphrey & Lewis, 2008).

There is a vocal group within the autistic community that has bypassed the difficulties inherent in social interaction by communicating largely on the internet (Brownlow & O’Dell, 2006). Here a new identity is being forged for those with autism that is exemplified by the move to describe those without autism as Neurologically Typical (NT) (Brownlow, 2010). This movement also eschews the tendency of NTs to use the term ‘people with autism’ and state that they would prefer to be called ‘autistic’. They argue that autism is an integral part of who they are, it is not an additional item and it makes them fundamentally different to the NT population. They see autism as a difference rather than a deficit.
1.4.4 Interacting with the social world

For some autistic people, interacting in the social world means continually having to ‘act normal’ (Bagatell, 2007, p. 416). Davidson and Henderson (2010) describe autistic adults ‘passing’ as normal and Carrington, Templeton and Papinczak (2003) have described a process of ‘masquerading’ in which autistic children hide their difficulties and distress at school and set around themselves a ‘cloak of normality’, but once in the safe confines of home may express acute distress. This becomes particularly acute in their teenage years as they become aware of the extent of their differences to those around them. It is notable that for some autistic people their difficulties interacting with the social world are clear to them and a source of distress, whilst for others, interacting with others holds no interest and social interactions are avoided because they seem unimportant, not because they are difficult (Sainsbury 2009; Williams 2004).

1.5 Mainstream inclusion for autistic children

Within a special school, especially one which caters solely for autistic children, there are few issues regarding labelling and there is less need to ‘masquerade’ as all children have similar problems. In addition, staff in special schools have been shown to place more emphasis on the individual child and on the child’s views and happiness (Frederickson, Osborne & Reed, 2004). They are also able to avoid those practices that autistic children find aversive (Ochs & Solomon, 2010) and can get to know each child individually, so that most encounters with others within a special school are positive and accepting of difference. Staff in special schools are also skilled at mediating interactions between their pupils and the wider community and can again help buffer the potentially negative experiences these children might otherwise encounter (Todd, 2000).

In contrast a mainstream school is a difficult place to be for many autistic children (Humphrey & Symes, 2010). Nationally, they are three times more likely to be bullied and twenty times more likely to be excluded than their normally developing peers, with 21% of pupils on the autistic spectrum being excluded at least once in their school career (Barnard, Prior & Potter, 2000). This is significantly more than other pupils with Special Educational
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Needs (SEN) and 20 times higher than pupils without SEN (Department of Education and Skills, 2006; Humphrey, 2008).

Part of the reason for this is that teachers in mainstream school report not having enough training and support to provide for autistic pupils and this feeds into the disaffection of both teachers and pupils (Frederickson, 2004). As a consequence, autistic children in mainstream schools are at a higher risk of developing mental health problems (Carrington & Graham, 2001). The children themselves report finding school to be a stressful and anxiety provoking place, particularly once they reach secondary school (Barnhill & Myles, 2001).

Formal means of support are often put in place for autistic children in mainstream schools to help mitigate these problems; unfortunately these measures can often create tensions. Humphrey and Lewis (2008) suggest that many autistic children are trying very hard to fit into the environment in which they find themselves and may require support to negotiate timetables and the curriculum. However, this support is usually highly visible in the form of a support worker and therefore underlines the differences and makes it harder for the child to merge into the social world of the school. This also leads to reluctance amongst many autistic children for their diagnosis to be widely known. They fear the stigma that may be attached to the label and the implications of this for their ability to fit in. However, for most autistic children it is not possible to hide their difference and they will find social acceptance difficult to achieve (Molloy & Vasil, 2004).

Humphrey and Lewis (2008) found a wide variety of responses to the label from autistic children in mainstream school. Some found it positive and saw their high academic abilities as arising from their autism; others see it in a totally negative light as the source of their troubles, whilst another group oscillated between the two. In Humphrey and Lewis’s sample, this seemed to be related to the attitudes prevalent in the mainstream school in which the child was included. They found that in schools where the staff and students had a good understanding of autism, and efforts were made to include children socially within their peer groups; autistic children had a more positive view of themselves.
Ochs, Kremer-Sadlik, Solomon and Sirota (2001) found that for those autistic children for whom mainstream provision had been successful, peer relations were more important than teacher relations and this was attributed to the social function peers play. When peers were educated as to the nature of autism and positive peer relationships actively fostered, inclusion was more successful. This appeared to be partly because a supportive peer network buffered the socially naive autistic child against the harsher elements of mainstream schooling.

However, as Molloy and Vasil (2004) point out, there are benefits from being in a mainstream school, especially for those with high academic ability. Few special schools can fully cater for the academic needs of brighter pupils and many autistic children will go on to have independent lives, with successful careers once they leave school; so being able to function in the wider world outside of the protected environment of a special school is a very important skill to learn (Molloy & Vasil, 2004).

Merely being in a different school with different rules will be challenging for many children, but for autistic children, their disability becomes visible. Within a special school, where all children have the same disability and staff are attuned to the needs of the pupils, the disability in essence ceases to exist. In a mainstream school this is not the case, and the difference and its consequences are unavoidable. In addition, the child will move from an environment in which they may be relatively competent, to one where everything has to be re-learnt. The process of inclusion into a mainstream setting for children in special schools has been considered from the point of view of the staff (Gibb, et al., 2007; Frederickson, Jones & Lang, 2010; Jones & Frederickson, 2010) but how the pupils experience this has not yet been explored. This study plans to address this issue by interviewing children who spend most of their time in special schools, but have some of their lessons in mainstream schools. Participants will be interviewed in both contexts to encourage comparison between their experiences in both settings.
2. Research question

1) How do children with ASD, educated in special schools, experience inclusion in mainstream schools?

3. Methodology

When considering the methodology to use to explore these issues, I found myself in an interesting epistemological position. Having had a career in science before entering clinical training, I had a rather different view of research to the one I found in quantitative psychology. The research I had been accustomed to was curiosity driven and research design almost entirely pragmatic: what is the best way to answer this question? Tempered with the inevitable: what resources do I have available? There was also an acknowledgement that research is a messy business, with research design rarely being optimal and with researchers’ preconceived ideas and theoretical orientations influencing the choice and design of experiment. In short, there was a tacit acknowledgement (at least in the fields in which I worked) that scientific research was far from objective. I would therefore argue that the same human tendencies to interpret what they perceive in the light of their own hopes, experience and influences are present in both qualitative and quantitative research.

I was also used to a field where whole careers were based upon ideographic work, for example around the investigation and greater understanding of the structure of a single protein at the atomic level, indeed several noble prizes have been awarded for such work (e.g. Walker for the structure of F1ATPase(Shirakihara et al., 1997)). Here the emphasis is on understanding how things are, rather than the causal explanations or predictions often associated with positivist research. I therefore saw an in depth study of a single person or a small group of people to be a valid and valuable activity.

So the basic assumptions of phenomenological qualitative research laid out by Barker et al. (2002) fitted well with my perception of research. These are that: 1) Understanding is regarded as the true aim of science and in the context of psychology this is focused on an
explanation of the person’s experiences in terms of intentions, purposes and meanings; 2) Perceived meaning is more important than objective reality, facts or events; 3) Multiple perspectives are equally valid and interesting; and 4) An individual’s perception of their world is based on implicit assumptions about that world and the purpose of research is to understand those assumptions.

My rationale for choosing a research method was influenced by the research question and contextual factors. The main factors I considered were as follows:

- The focus of the study on the individual’s perception of events and circumstances.
- The need to understand a social world and social interactions from the perspective of those with different social skills and abilities to neurotypical researchers.
- The importance of context in this study (special school versus mainstream school).
- The high degree of variability in social, communication and cognitive skills seen within the population of autistic individuals.
- The relatively small numbers of children, who primarily attend a special school, but spend some time in mainstream settings.
- The paucity of work on the experience of inclusion in to mainstream education of this group.

Within the available qualitative methodologies, Interpretative Phenomenological Analysis (IPA) stood out. Smith (Smith Flowers & Larkin, 2009) suggests that IPA is well suited for looking at issues of life transition as it addresses the ways in which people make sense of their experiences (Smith & Eatough, 2007).

In addition, IPA’s focus on attempting to understand experiences from the point of view of the participant is central to this study as this is an area where little work has been done previously. IPA represents a dynamic process, with the researcher acknowledged as being an active participant. This would be advantageous as interviewing autistic children may need a greater degree of prompting and perhaps scaffolding from the interviewer than
would be acceptable in other methodologies. IPA would allow for this eventuality, as long as its use was explicit and acknowledged in the analysis. A number of qualitative studies have been undertaken with autistic people using interviews. Some of these focus on identity (Bagatell, 2007; Davidson & Henderson, 2010; Molloy & Vasil, 2004) whilst others looked at friendship (Carrington et al., 2003) or the experiences of autistic children in mainstream schools (Ochs, Kremer-Sadlik, Solomon & Sirot, 2001; Humphrey & Lewis, 2008; Humphrey & Symes, 2010).

IPA assumes a connection between thinking, emotional states and talk, although it also acknowledges that this link is not straightforward. In this study, care would need to be taken in assuming these links, given the different perspectives and communication styles between the interviewer and those being interviewed as well as the difficulties autistic children have in making sense of the social world and expressing their thoughts. Some studies have addressed these issues by using alternatives to interviews to provide additional means of expression such as using drawings or diaries (Humphrey & Symes 2008). Others have analysed the extensive repertoire of written work produced by autistic authors (Williams, 2004).

I also wanted to give a voice to those people who seem to be spoken for rather than with. Many parents of autistic children are excellent advocates for their children and are frequently happy to participate in research. This has enabled research in to autism to move forward at a rapid pace. However, the efficacy of these parents as advocates, coupled with their children’s difficulty in social communication has meant that the views of autistic people have often not been heard.

4. Method

4.1 Participants

The 4 participants were all white Caucasian male and between the ages of 16 and 17 who all had a formal diagnosis of Asperger’s syndrome. Two of them also had a diagnosis of dyspraxia. None of the participants had learning difficulties. All participants were aware of and understood their diagnosis. Participants were all in the first year of the same special
school sixth form (St John's)\(^3\) and were weekly boarders there. The special school was situated in a rural location in the south of England and focussed its provision on more able pupils with a diagnosis of autistic spectrum disorder. They all attended local mainstream provision between 3 and 4 days per week. The mainstream schools involved were an academically oriented sixth form college that was organised in the same way as a mainstream secondary school (GC), and a more vocationally based college with a more person centred approach (LW). Two participants attended each mainstream location and at the time of interview had been attending for between 4 and 5 months. One of the participants (Peter) had spent some time in a mainstream primary school prior to his diagnosis of autism and one (Paul) had attended a different special school which catered for children with a wide range of difficulties. In previous years, all participants had attended one specially commissioned session a week in a mainstream school, in which pupils from St John's were the only participants.

4.2 Ethics

Approval was obtained from the University of Surrey Faculty of Arts and Human Sciences Ethics Committee (Appendix 1). Consent/assent was sought from participants and their parents, with separate information sheets and consent forms being prepared for each. The consent forms and information sheets were discussed with the staff team at the school prior to distribution in order to ensure that they would be understood by the pupils involved. Anonymity was assured, with the exception of any disclosures that might indicate serious risk to the participants or others. All participants were made aware that they had the right to withdraw before, during or after their interview.

4.3 Recruitment

Local special schools were contacted to enquire about their interest in the project and the number of pupils who met the criteria for recruitment. These were: being male, between the ages of 11 and 19, with a diagnosis of autism of which the pupil was aware and splitting their time between mainstream and special school provision. There are a number of special schools for autistic children in the area who have inclusion programmes for their pupils, however, due to the reorganisation of Local Education Consortia, those schools that were

\(^3\) All names of participants and schools as well as some of the subjects studied have been changed to ensure anonymity.
under local authority control were reorganising their provision of inclusive education at the time of recruitment and so did not feel able to participate. One of the independent schools did have an inclusion programme in place but as the programme was designed solely for the participation of pupils from the special school and did not involve integration with other mainstream pupils, or experiencing the mainstream curriculum, it was decided that this did not provide sufficient contact with the mainstream environment to satisfy the inclusion criteria. One independent school had recently introduced a comprehensive inclusion program for its sixth form students and was interested in participating.

Information packs were sent to all 14 sixth form students at the school. The information pack comprised parental and participant information sheets and consent/assent forms (see Appendices 2, 3, 4 and 5). Parents and students were invited to return the signed forms if they wished to participate. Once parental consent and participant consent/assent (dependent on age) had been obtained, the participant’s mainstream school was contacted to arrange the interviews. As only four participants were initially recruited, a further approach was made to the school once the initial interviews had been undertaken and the process understood by the school. However, no more participants were forthcoming.

The recommended numbers of participants for IPA studies range from a single in depth analysis (Lyons and Coyle, 2007, p39; Smith et al., 2009, p51) to 25 participants (Kuzel, 1992). For qualitative studies that aim for data saturation, Guest, Bunce & Johnson (2006) presented evidence that six interviews provided 94% of the codes seen in their sample of 60 interviews. Francis et al. (2010) reached similar conclusions in their study on data saturation in content analysis. Fewer interviews are needed for IPA studies in contrast to some other qualitative approaches as it is an ideographic approach with the aim being to understand the experience of each participant rather than to attain data saturation. This is the reasoning behind Lyons and Coyle’s (2007, p39) suggestion that a single in depth study can provide sufficient data for a meaningful IPA study and is also the reasoning behind Smith, Flowers and Larkin’s recommendation that between 4 and 10 participants is appropriate for this methodology (Smith et al., 2009, p52).

### 4.4 Interview schedule

Smith et al. (2009) suggest that as data collection in IPA aims to elicit detailed stories, thoughts and feelings from the participants, questions need to be abstract and to arrive at
the research question 'sideways'. However, given the known difficulties autistic people have with abstract thought and ideas, together with their difficulties accessing and describing thoughts and feelings (Carrington et al., 2003), I considered that a more detailed, guided interview, with the addition of a few concrete questions would be more appropriate and comfortable for the participants and more likely to provide the rich data IPA requires. The interview questions were based on those developed by Carrington et al. (2003) who consulted with a special needs teacher and two adults with Asperger’s syndrome to ensure the wording would be unambiguously understood by autistic pupils.

Each section began with an open ended question such as ‘Tell me about your friends’ which were followed up with more specific questions. As Carrington et al. (2003) describe, many autistic children find open ended questions such as ‘Tell me about your friends’ difficult to answer, so the secondary questions need more structure. Participants were interviewed using the same interview schedule in both their special school and mainstream schools. I decided to interview each participant twice using the same schedule, once in each educational setting they attended, as autistic children often have different behaviours and provide different answers in different settings, as well as having difficulties in remembering how they feel in other settings and at different times. The first interview was conducted at the special school and the second in the mainstream setting. Each interview focused on the experiences in the school in which the interview was held.

The interview schedule aimed to cover factors that have been previously noted to be important in the inclusion process such as friendships and experiences of bullying, as well as the extent to which the included pupils feel they are understood by staff (Carrington et al., 2003; Molloy & Vasil, 2004) (Appendix 6). It was also constructed in such a way as to allow participants the greatest opportunity to speak for themselves. Questions were open ended and sought information on those topics on which participants would be able to talk at length (e.g. personal interests) as well as those that might be more challenging (e.g. their views on how having ASD influenced how they saw themselves).

Questions were divided into four sections:

1. An initial section was used to gain an understanding of the participant and their experience of school. This started with deliberately easy, unthreatening questions to facilitate rapport building and to enable the
interviewer to gain some insight into participants’ social and linguistic abilities. Questions such as ‘What could be done to make you more happy?’ required an understanding of themselves and the impact that others’ behaviour has on them and are therefore indicative of the level of personal and social understanding of the participant. The question ‘What do you do at break time?’ further explores the theme of social ability and understanding and begins to explore the issue of how participants relate to different groups within the school. This section ends with a series of questions that probe the issue of bullying with questions such as ‘Are any of the children ever unkind to you?’

2. The second section focused on friends and relationships and asked questions specifically about self understanding such as ‘How are you like the other children here?’ and also about how participants presented themselves to others within the school, such as ‘Can you talk about the things you want to talk about when you are in this school?’. It also addresses issues of independence with questions such as ‘If there are any problems, how do you manage these?’ This section finishes with issues of friendship and a further exploration of participants’ perception of how others might understand them with questions like ‘What would you want your friends to know about you?’

3. The third section focused on participants’ thoughts regarding their diagnosis. It started with a question checking their understanding of ASD and then went on to ask about any problems or benefits participants associated with their condition. The question ‘Who do you tell about having ASD?’ looked at how they managed issues of disclosure in the mainstream environment. The question ‘Does ASD alter how you think about yourself’ addressed the issue of how having ASD influenced, if at all, how they saw themselves.
4. The final section was included in the second interview only. It asked the participants to compare the two schools that they attended and talk about the positive and less positive aspects of each.

4.5 Procedure

The schools’ advice was sought with regard to the appropriate setting for the interviews for each child. A balance needed to be made between the need for a confidential interview and the safety of the participant and the researcher. With these considerations in mind the interviews were conducted in private rooms provided by each setting. Participants also had a named person to whom they could go if they had been upset by the interview and this was checked with each participant before the interview began.

All interviews were recorded on a digital recorder and transcribed by the researcher.

4.6 Analytic Strategy

Transcripts were printed and read and reread before being analysed on a line by line basis. Analysis focused on personal meaning making and attempting to understand the participant’s point of view. Notes were added to the left hand margin on anything that was of interest (see Appendices 7 and 8 for examples) and were then used to develop themes which were recorded in the right hand margin. This was an iterative process with understanding developing and widening through successive readings of the interviews (Smith et al., 2009).

The richest pair of interviews was analysed first (i.e. both interviews from one individual) and a list of themes emerging from the transcripts drawn up. The development of these themes represented a synergistic process of description and interpretation which capture and reflect an understanding of the data (Smith et al., 2009). Once the analysis of the first interview pair was complete, subsequent interviews were analysed and patterns in the themes between the interviews were sought.

In looking for patterns, the most interesting and important themes were prioritised. This involved, for example, looking for relationships between themes which might usefully be brought together to form super ordinate themes, or noticing separate themes which when
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viewed across the whole dataset, might usefully be merged into a single theme. Strategies of contextualisation and numeration were used to develop and understand themes, with contextualisation involving attending to the temporal and cultural themes in an account whilst numeration looked to the frequency with which a theme was supported (Smith et al., 2009).

A structure was then developed which illustrated the relationships between the themes and enabled a richer understanding of the processes involved.

5. Evaluation

Assessing the validity of qualitative research is an important part of the process that needs to be ongoing throughout the process of the research. For this work the approach used by Yardley has been adopted (Yardley, 2008). Yardley (2000) proposed four principles for evaluating qualitative research irrespective of the theoretical orientation of the study. These principles are: Sensitivity to Context; Commitment and Rigor; Transparency and Coherence; and Impact and Importance. Smith et al. (2009) have taken these four criteria and clarified how these can be applied to IPA research.

5.1 Sensitivity to Context

Sensitivity to Context begins at the early stages of an IPA research project and encompasses, for example, sensitivity to the theoretical and empirical context in which the research sits as well as to the culture in which the participants are embedded and to the participants themselves. It is also demonstrated via an appreciation of the interactional nature of the interview process. This is taken further in the analysis during the process of making sense of how the participant is making sense of their experience.

This project was embedded in the school system and involved interviewing participants in three different schools. I therefore needed to be sensitive to the very different cultures in each and the interplay between them. Each school was concerned that they were doing the
best for the pupils in their care and were aware that a research project might highlight areas where they could do better, especially as this was the first year in which the special school pupils had been included in the mainstream schools. For the pupils I needed to be aware of their autism and their level of social understanding. This was an important part of the interview process and it was essential to enable each participant to tell their story in their own words, but as some of the participants found responding to open ended or abstract questions difficult, a greater level of scaffolding was needed. I had to be very careful to provide enough support to enable the participants to tell their story, without overly influencing the direction or content of the story.

The interplay between an autistic perspective and a Neurotypical perspective may also have influenced the way in which I made sense of the stories articulated by the participants.

**5.2 Commitment and Rigour**

Within IPA commitment can be demonstrated in the degree of attention given to the participant during the interview process. Here, my training as a clinical psychologist and my experience working closely with autistic children in a school setting provided me with the skills to undertake this aspect of the work at a high level.

Rigour is demonstrated by such elements as the appropriateness of the sample and the completeness of the analysis. Here, the sample was appropriate to the research question, although it has to be noted that as the participants were weekly boarders at St John’s, the experience of inclusion for the participants in this study may be different to other children taking part in inclusion. It may be the case that some experiences, especially those related to independence, might be different for those who attend special schools on a daily basis and further studies would be needed to understand these experiences.

The sample was as homogenous as possible given the small number of individuals in the target group. I would argue that the existence of the two different mainstream schools attended by the participants, although reducing the homogeneity of the sample, increased the richness of the data and in addition, the use of two interviews per participant in two different contexts increased the depth of the study.
Rigor and commitment are also demonstrated by the attention paid to the process of IPA, such that the interviews are interpreted not just on a superficial level, but by looking at the social and personal context of the transcripts and the meaning making of the individual. For example, one of the participants spoke about another pupil at the mainstream school he was attending. His words were interpreted in a variety of ways; the purpose of his words within the conversation were considered, his intention to position himself socially was noted as was his awareness of how others saw him (p36-37).

5.3 Transparency and Coherence

This relates to the clarity of the write up of the research process; is it possible for another researcher to follow the path taken by the author? The arguments need to be coherent and clearly grounded in the data. They also need to follow a logical path with ambiguities and contradictions appropriately addressed. It is also important that the methodology chosen should fit with the research question posed and this should be followed through in the research itself.

Care was taken to ensure that this study was both transparent and coherent, by close attention to following a logical path and by attending to ambiguities and contradictions as they arose. The study was also given to a number of co-workers to read to ensure that it was experienced as coherent by those who read it. In addition, the research process was carefully followed by my supervisor who ensured that the analysis and conclusions flowed from the data collected and that a step by step path could be followed, from the inception of the project to its conclusion.

Ideally, the analysis would have been discussed with the participants themselves to ensure that their contributions had been properly represented. However, given the time scale for this project this was not possible.

As discussed in the introduction, the methodology fits well with the questions asked and this methodology has been followed throughout the study, with frequent checks to make sure that the epistemology associated with IPA was guiding the process.

5.4 Impact and Importance
For research to be truly valid it needs to tell the audience something important and it needs to be disseminated to those who might wish to make use of it. As mentioned in the introduction, this study addresses an important current issue in regard to the inclusive education of autistic children. It is planned to visit the schools involved to give feedback and also to publish the study so that its findings can be more widely distributed and contribute to the body of knowledge in this area.

6. Reflection: Personal experiences that may affect my interpretation of the work.

It is recognised that my experience as a researcher in the fields of biophysics, virology and immunology and as a programme manager for the Medical Research Council may well have shaped my approach to research and influenced the way in which I interpreted the responses of the participants. I am also the mother of two teenage children and my experiences of guiding them through the education system may also have had a bearing on my thinking, together with my experience as a learning support assistant in a mainstream school gained while my children were young. However, the greatest influence on my interpretation is likely to have been my experience as a learning support assistant in a school for autistic children during which I accompanied some children during their inclusion in mainstream schools. The difficulties and opportunities that they experienced in these contexts were the inspiration for this project, and may well have coloured my interpretation of the data.

7. Analysis

There were 19 themes from the original interview (Appendix 9), however, after the analysis of all the data, this was reduced to 16 as two of the themes had been found to be specific to one individual and not related to other themes. Another regarding how participants managed problems in specific environments (Problems) appeared to be wholly driven by the interview schedule and was not an issue for the participants.
As the research question asked about the participants’ experiences in different contexts, the number of occurrences for each theme was recorded for each context in order to ensure that perceptions about the frequency of the themes in each context were valid. As analysis progressed, it became clear that both upward and downward comparisons were being made by the participants and it appeared that again these were different in the different contexts. The occurrence of comparisons was again recorded (see Appendix 10). It must be emphasised, that this data was not analysed, but rather used to ensure that perceptions of difference between the contexts was based on the data.

As the analysis progressed it was clear that some themes overlapped to a considerable degree and it was decided to merge these together. The 12 remaining themes were then examined to identify any connections between them and to develop super-ordinate themes. Five of the themes (Academic, Behaviours, Friendship, Social Competence and ASD) formed the super-ordinate theme of Comparisons, with the other themes remaining separate.

8. Results

The transcripts of the two interviews from each participant were analysed as a whole. However, it was noticeable that the second interviews were richer. Possible reasons for this are firstly that the participants may have been more comfortable with the interview process and therefore more forthcoming and secondly the interview questions may have been more resonant in the mainstream setting and therefore the participants had more to say.

The process of IPA described above led to the development of an understanding of how participants experienced inclusion into mainstream school and the factors which combined to influence how they saw themselves. Seven major themes were identified; Independence, Belonging, Comparisons, Managing Self Presentation, Sense of Self, ‘Who Knows?’ and External Factors. The relationships between these, together with their related sub-themes, are depicted in Figure 1. The different school contexts highlighted different aspects of each of these themes and all were affected by the participants’ differing levels of social understanding.
The different settings seemed to serve different functions for the participants. The special school, at which the participants boarded, appeared to serve the function of a family home, whilst the mainstream setting they attended was said to provide an opportunity for autonomy. Participants’ accounts suggested that moving from the relatively protected world of the special school into mainstream educational contexts challenged their sense of self by highlighting areas of difference in relation to the mainstream population. Pupils reported a sense of belonging in special school, and felt that they were understood by the staff there. In contrast they described having to use the staff in their special school to help them understand and negotiate situations in their mainstream setting.
The interview accounts suggested that these different settings affected participants’ perceptions of themselves via a series of comparisons made between themselves and their peers in each context. These comparisons focused on academic ability, behaviour, social competence, friendships and autism and appeared to be an important influence on how the participants saw themselves. The nature of the comparisons depended on the context in which they were being made and exactly what was being compared. For example, self-peer comparisons regarding ASD in the special school seemed to enhance participants’ sense of belonging, whilst in the mainstream school they appeared to be a source of difference. In contrast, comparisons based on academic ability served to improve or consolidate participants’ beliefs in their abilities as learners in both contexts as pupils had been carefully matched to their mainstream courses. The move into a mainstream setting and the understanding of difference that accompanied this prompted attempts by the pupils interviewed at managing their self-presentation to enable them to fit in and increase their sense of belonging.

Participants’ experiences appeared to have been moderated by influences outside school. For some these external effects, from family or previous school experiences, were powerful and seemed to have played a role in shaping how they saw themselves before the move to a mainstream setting.

8.1 Independence

For all participants, the interview data suggested that being in a mainstream setting enabled a greater sense of independence which appeared to be welcomed by all participants, although some were more enthusiastic than others:

Because sometimes I, it feels at St John’s that they’re always like there and they always like seeing, making sure you’re doing the right thing, but here it’s just like do whatever you want. And they don’t ever like moan at you like all the time if you are not at a certain place at break time, OK (Edward, Interview 2).

Yeah it’s good, it’s much more to yourself than at St John’s (Michael, Interview 2).

Yes I can talk to the staff, and tell them what I need to, they are usually helpful, but I prefer to do things myself, so I can learn and be independent (Paul, Interview 2).
For others, independence was not explicitly stated, but was clearly an important aspect of their time in mainstream:

*If we are down here the whole day we go to the landscape snack bar which is round by the equine horse centre and go in the bar down there and um, sometimes if we really have time there is a snack bar next to the main house called Ruby’s that we sometimes go to. So yeah there is a fair bit of variety of things to do and if it is not a time when we want to get something to eat we go to the library and read or something there, or go to the computer room (Peter, Interview 2).*

This reduced level of staff support and the participants’ ability to choose where they went within the mainstream setting appeared to increase their sense of independence and seemed to be important to the participants and enabled them to see themselves as competent and autonomous within this context.

### 8.2 Belonging

Pupils reported a sense of belonging in their special school; they experienced both the staff and other pupils as accepting and understanding which led to relationships being easier and more relaxed.

*I do get on with quite a few people here who, because, being a special needs school, people here understand a bit more about how the way I am ... so I know I can talk to people here without people thinking, without people thinking, you know, that I’m weird. Unlike some people would if I was in mainstream perhaps (Peter, Interview 1).*

The level of knowledge and experience held by the staff about autism in general and the needs of the individual pupils are valued by the participants. They feel that they are understood by the staff there who support them both socially and academically:

*At school it’s just um probably the fact that some staff can help you out even if they don’t know what’s going on, they can just help you out...... They understand the autism, there are therapists there who help me with stuff like that, yeah, they understand it much better, yeah (Paul, Interview 1).*
They like go over things more clearly. Like more clearly, more times over than what teachers do at mainstream school and college, yeah they um and they are more understanding of my problems than at mainstream (Edward, Interview 1).

In contrast, in mainstream participants describe needing to use staff from their special school to help them understand and negotiate situations:

Cos at St John’s, there’re like, the sixth form staff focus on just 15 or so people, here they have to focus on 800 people.......So we feel bit better if we need help, talk to the people at St John’s cos they have more time and they know how to help (Edward, Interview 2).

The two mainstream settings were very different in outlook and organisation and it was apparent from the interviews that this affected they way in which they were experienced by the participants. At GC, tutor groups and class sizes were larger than those as St John’s and the teachers were focussed on teaching subjects rather than individual pupils. The other pupils there were academically able and organised themselves into active social groups. Although the participants who attended GC were some of the most able academically at St John’s, they were not necessarily the most able socially. For one participant a decision had initially been made to provide him with one to one support but this had not been a positive experience as it made him feel different and the practice had been stopped.

And when everybody else doesn’t have someone with them because obviously they just go to mainstream by themselves, I think that,... I think that because I don’t have, because I have staff with me, it is harder for me to make friends at college than everyone else (Edward, Interview 2).

The participants reported difficulty in belonging in this setting, both in and out of the classroom:

Sometimes they want me to like work with other people when really I don’t really know some of the people in my class that well, so that’s quite hard cos most of the people that are in the class I just about know, the others know each other well and
can sit with whoever they feel most comfortable with, but I just sit wherever there is a seat. (Edward, Interview 2)

cos I can talk to people to talk to people in the lessons but I find it hard to talk to people out of the lessons (Michael, Interview 2)

This is in contrast to LW, where the participants were involved in vocational training and appeared to have found it easier to integrate after some initial difficulties.

I mean yeah like when I first started here obviously knowing people, I sort of, I feel the term friendly alienation which is sort of, they are very kind to you but you have the feeling that they are sort of separate from you. That’s how it started but it’s obviously got better now, got better now, obviously I was new here and I didn’t know any of them (Paul, Interview 2).

This suggests that it was easier for the participants to get to know people at LW. This may reflect the different organisation of the courses. At LW, pupils are with the same group of people for all their sessions and so the course members become the focus of social contact, whilst at GC, pupils are with a different group of people for each subject, so social contact remains with externally developed social groups.

I’m like just different because like everybody just like talks about stuff, but I can’t really do that cos I go to another school (Edward, Interview 2).

Um yes and no, because they normally go out a lot more than I will with groups of people from college, I haven’t, don’t do that yet (Michael, Interview 2).

8.3 Comparisons

Being in mainstream provision also prompted comparisons with a different set of people and a different set of expectations. These comparisons appeared to affect how they saw themselves. Their precise nature and effect on each participant’s view of themselves depended not only on the context, but also on the nature of that pupil’s autism. These comparisons related to academic ability, behaviour, social competence, friendships and autism.
The nature of the comparisons varied between the different themes, with comparisons between settings predominating in the ‘Academic’ theme and comparisons between peers predominating in the remaining themes.

The majority of the self-peer comparisons were in a lateral or downward direction in both special and mainstream settings, although some upward comparisons were seen in the mainstream settings (Appendix 10). This contrasts with the pattern of comparisons normally found where pupils tend to make lateral comparisons for the purposes of self evaluation or upward comparisons to their peers in such a way as to provide themselves with targets for improvement (Dijkstra et al., 2008). For the majority of children in educational settings, upward comparisons with peers predominate. Downward comparisons are usually made in an effort to enhance self esteem especially when children are under stress (Dijkstra et al., 2008).

8.3.1 The academic environment

All participants had a view as to how they fitted into the academic environment in which they found themselves, be it the special school or mainstream setting. Most of the pupils were well placed academically, so the move to a mainstream setting did not challenge their view of themselves as learners. This was the area where most upward comparisons were seen. For some, the academic environment of the special school was sufficiently challenging and the support they gained was appreciated:

> well, um this answer is if I’m honest based on the subjects I enjoyed during my original time here as part of my GCSEs and so on and so those particular subjects are art and Spanish that I enjoy.......I find hard things such as science or um or history because with science I often- kind of struggle to keep up with all the different um sections of it like physics, biology chemistry, I do kind of struggle to keep up with it because it just comes at it so suddenly sometimes I just don’t feel I have time to um absorb the first bit sometimes (Peter, Interview 1)

Whereas for others the special school seemed more limiting:

> Sometimes since there are people with worse difficulties here than there are in.... than me, then, then sometimes they have to like go over it for them over more than
I need and so they learn more slowly than I would in a mainstream school (Edward, Interview 1).

Well if I’d gone to a mainstream school, probably would have done, had a higher, have more choices for my subjects in GCSE (Michael, Interview 1).

For those at LW, their vocational courses fitted well with their interests and their motivation and enjoyment of these courses was evident:

Well obviously playing the sport, the whole part of it yeah, sport’s good, the lessons are well structured, the whole um course is good because there are no exams, it’s all assignments but, so that means I have more time, it’s a good course (Paul, Interview 2).

I did enjoy that we got to work with things like tractors, brush cutters and rotary cultivators and things like that, all very interesting stuff to do with horticulture and we actually got to learn about doing checks on things and maintenance and stuff I quite enjoy that. Um I think I liked driving the most to be quite honest because I found I was actually getting myself motivated really with that (Peter, Interview 2).

LW catered for pupils with a wide variety of abilities and many of the group had similar problems to those from the special school. This was helpful in developing a sense of belonging:

What gave me that impression when a few of us exchanged Christmas cards last year I got cards from a kid called Dan and one from a kid called Greg and their writing indicated that they must have been slightly dyspraxic, so yeah, I think it makes me feel a bit better that there are people here who are similar to me, that have learning difficulties, that sort of thing. {pause}............ It makes me feel a bit better to know that (Peter, Interview 2).

This suggests that Peter was actively looking for similarities with others on his course to help him feel he belonged and as a means of establishing his position within his peer group. He was also looking for similarities, other than those directly related to autism which suggested that he had a wider view of himself than just being autistic.
For those at GC the academic environment was welcomed and was the area of college life where they felt most comfortable. This was an opportunity for some participants to express pleasure in their achievements and to notice that they were more able than some of their peers:

*I can like learn, I just learn the same way as the other people here, so in lessons it’s like I’m OK. I’m better than other people, Its OK in the lessons (smiling and relaxing)*

[How does that feel?]

Feels good. (Edward, Interview 2).

*I can choose whatever subjects I like and um specialising in those subjects so that’s good. Um, I like um how the staff teach and um they are nice and the students are nice and we get on learning (Michael, Interview 2).*

This was also an area where the participants would be with people who were more skilled than they were in some aspects and therefore provided an opportunity for upward comparisons and goal setting. This is evident for one of the participants at LW:

*It’s 14 [golf handicap], it’s OK, but it’s not that good, some of the other boys on the course are better, they have a better handicap,*

[14 is good isn’t it?]

Yeah but I would still like to be better (Paul, Interview 2).

So for all the participants, the academic environment seemed to be a positive experience and consolidated their view of themselves as learners, and for some academic work was a real strength and was an area of respite in an otherwise challenging environment.

### 8.3.2 Behaviour

The interviewees were aware that others behaved differently to themselves and appeared to draw different messages from this, dependent on context. In the special school they noted that their own behaviour was better in comparison to their peers and put this into the context of the nature of their difficulties:
... he sometimes is quite annoying, he doesn’t like purposefully annoy me but he like, he like, I just find him irritating, the things that he does (Edward, Interview 1).

Here participants seemed to be following a narrative established within the special school, that when other pupils behaved badly, or upset one of the participants, this was not out of choice, but was a consequence of their difficulties.

Some participants also noticed that the younger children had similar difficulties to those that they had when they were younger and used this as evidence of their own progress.

Um normally we have the same difficulties or the younger kids have the same difficulties that I had when I was younger (Michael, Interview 1).

The behaviour of those in each of the mainstream settings was also different and often remarked on in the context of distracting teachers or being off task, with the behaviour of some of those at LW being challenging. This was sometimes seen as a negative aspect of the behaviour of those who are not autistic, because it was seen as intentional, rather than as a result of understandable difficulties:

Sometimes they perform in less than, in the sense that they don’t listen to the teacher, they speak over us (Paul, Interview 2).

... there are some other kids in our group that did tend to be a bit unpleasant sometimes, especially given that he once tried to throw a brick at me.

[Oh]

When he got rather annoyed. Um but since he was removed from the group no one has really been particularly spiteful to me, I think the only reason it was like it before was that it was encouraged by him really. If they won’t mind me saying this, he did come across to me as being a bit of a yob really, the way he behaved and things, he would just do anything to annoy you really (Peter, Interview 2).

Here Peter is making both behavioural and social comparisons and clearly has an understanding of social descriptions. He is also using this to position himself as socially better than the individual described. Furthermore, he is aware that others might think
badly of him for describing someone else in less than complimentary terms and sought to apologise for this; thereby managing how the interviewer might see him.

However, in general participants appreciated the behaviour of those around them in mainstream settings:

_The fact that I can study without people being too irritating (Peter, Interview 2)._ 

These differences in the behaviour of others in the different contexts led to a different understanding of the behaviour of those in special school and a repositioning of their view of their own behaviour. There was an acknowledgement that behaviours tolerated and managed in the special school, would not be tolerated in the mainstream setting

_Well, um in school they don’t take well, they still don’t take behaviour that well, bad behaviour in the sense that they are younger so they have to be appropriate to age with regard to what sanction to make, but here they are very strict cos we are all old enough to understand if you do something you would be sent out straight away (Paul, Interview 2)._ 

So participants saw their own behaviour as the same or better than those around them in both special and mainstream settings and this appeared to feed into their sense of themselves as good people.

8.3.3 Friendships

Participants were able to talk about their friendships but to differing degrees. For some friendships had been made to a level with which they were comfortable, but for others, issues of friendship and social belonging were a cause of distress as participants realised that in a mainstream school their social difficulties were a barrier to friendships that they desperately wanted. These differing experiences of friendships seemed to have implications for participant’s view of themselves. Their ability to talk about their friendships and social interactions also highlighted the differences in their levels of social understanding and therefore the effect that the different social environments had on their view of themselves.
In the special school, all had friendships, although the depth in which participants were able to talk about these varied. Some seemed to view all people that they talked to as friends, whereas others had specific friendship groups and talked of others in those groups as individuals:

[How do you get on with the other children?] Very well.

[Who do you like?] Anyone.

[Do you have any special friends amongst the boys?] I’m good friends with most of the boys (Michael, Interview 1).

I’m quite good friends with a guy called Max who I share a room with now we’re in the sixth form, I think in terms of being friends with people, I think I’m an ok friend with a guy called Josh and things with a guy called Leo aren’t as bad as they used to be. They are people I can talk to and laugh with, we are interested in similar things, like me and Liam are both into Top Gear and me and Max both like comedy like Michael Macintyre (Peter, Interview 1).

In the mainstream setting, friendships seemed less certain, especially at GC. This seemed to be a reflection of the nature of the difficulties of those that attended GC. For Michael, this lack of friends did not seem to be a cause of distress.

[Would you like to have someone to have a snack with?] I don’t mind too much, but I guess it would be nice (Michael, Interview 2).

In contrast, Edward found the social environment very difficult:

Yeah. It’s a bit awkward because like, everybody made their friends in the first week, so I didn’t make them then and it’s been like half a year already..... like at break times cos I’ve nothing really to do, Normally at break times I just go to the LRC and do my homework, so it’s a bit boring and I want to do something else most of the time but I just can’t really (Edward, Interview 2).

So although the two participants appeared to have a similar level of interaction with those around them, they saw the situation in very different ways and this appears to be related to the nature of their social understanding and their wish for social interaction. Michael
seemed content to spend time on his own and did not focus on, or engage with, the social
world around him, whilst Edward was acutely aware of his social environment and wished
to be more integrated within it. These contrasting levels of social understanding were
fundamental to the effect that being in a mainstream setting had on these two
participants, with Michael’s sense of self seemingly unaffected but Edward seeing himself
far more negatively as a consequence.

At LW, where a more person centred ethos prevails and social relationships were more
centred on course members, friendships appeared easier, but the extent to which they
were formed was again, variable:

There’s a few that I get on with and there’s Dan, Greg who I do have a bit of a joke
with every now and again, I get on OK with a guy called Robert and a guy called
Andrew, they’re all OK, the rest are all OK, but I don’t hang around with them
(Peter, Interview 2).

Um not really, I mean sometimes it’s just, since I have no idea who these people are
and I live miles away from any of them, it’s hard to sort of know who they are, but
yeah, it’s going on alright, at first it was a bit hard for me, obviously not knowing
them and stuff with socialising, yeah, it’s got better now and I know them fairly
well. They are all obviously different, they have different friendship groups and
stuff, but they are all cool (Paul, Interview 2).

Here again, the different levels of social understanding are evident, with Peter being able
to form friendships with people and see them as separate individuals, whilst Paul made
friendships at a more superficial level, but seemed equally happy with the associations that
he had formed. For both of these participants, friendships within the mainstream setting
had been a positive experience.

8.3.4 Social competence

Participants’ social competence varied and had an effect on the way in which they were
able to interact with those around them and also to understand the social situations in
which they found themselves. For some this did not seem to be a personal issue. When
asked how he would address a social problem Michael replied:
Um, talk to the staff and they will sort it out (Michael, Interview 1).

For Michael, social interactions did not appear to be important, in either the special school or the mainstream setting and his lack of social competence therefore did not appear to affect the way he saw himself or the way in which he experienced the social world. He responded to peers in both settings in a similar way.

This was not true for the other participants and all noticed some areas where their social competence was a problem. One participant saw the whole area of communication as problematic and looked to staff at the special school to teach him the skills that he perceived he lacked:

Probably like, I can’t communicate as well as people with, as well as people without any problems (Edward, Interview 2).

They can also teach me how to socialise with people at college and outside college and stuff, yeah (Edward, Interview 1).

For the others the difficulties were more subtle and it was the small misunderstandings that they noticed, sometimes this was about taking things people said literally, or not understanding colloquialisms:

And I just get the wrong end of the stick and it makes me feel quite an idiot really (Peter, Interview 2).

well, not always knowing when people are joking or being serious, and sometimes they say things and I don’t understand what they want me to do, because the words they use don’t make sense, but they don’t always know I haven’t understood, it make me feel a bit stupid sometimes (Paul, Interview 2).

At other times, it made it difficult for them to understand others’ intentions regarding the remarks they had made, for example, was someone joking or being serious? Were they being intentionally rude, or just socially inept?

Um well I do occasionally misinterpret things that people say like for instance, if we suddenly had a row and if someone says that reminds me, if they say it in a
particularly strange way, that would make me assume they are making fun of my family even if they are not necessarily (Peter, Interview 1).

I’m ok about them really, some people can say unkind things, but they don’t really mean it, sometimes I have trouble knowing if they are joking or not, some of them can, but other times they are serious and I don’t always, sometimes I can’t work out if they are serious or joking. But sometimes they do know [it is offensive] but say it anyway, some of them find that very difficult and some of them don’t make jokes, I find it hard to know if they are joking or not (Paul, Interview 1).

This higher level of social understanding seemed to cause more anxiety for the participants as they worried about whether others were being intentionally unkind and also how others would perceive them when they misinterpreted what was said to them in a mainstream setting. These issues fed into the way they perceived themselves.

8.3.5 ASD

Participants saw their ASD differently according to context. In the special school context, autism seemed to be a common thread that linked the pupils together and to the school, whereas in mainstream schools it was the focus of their difference and was reported by some as being the source of their difficulties:

Yeah, because, here, cos at St John’s there is always somebody to talk to and like people are like me there, but here nobody which I know is really like me, so I, mm, so it makes me feel a bit more negative about things (Edward, Interview 2).

However, there did seem to be a hierarchy of needs within the special school and some saw themselves as more able than others:

Well, we all have a diagnosis of autistic spectrum disorder, but it’s a spectrum and I’m at one end of it, right at the top end, and other people here have more difficulties (Paul, Interview 1).

This hierarchy seemed to enable the more able pupils to make downward comparisons and therefore increase their self esteem within the special school.
All had a view about the effect their autism had on their integration into their mainstream setting via social competence and communication difficulties, although their views on this varied greatly. For example, Edward said his autism made him different to the other pupils at his mainstream school and that this prevented him making friends there:

*I’d probably like be able to communicate better and would be able to communicate better with people at college and I’d probably have more friends at college (Edward, Interview 1).*

Paul, who had only learnt about his diagnosis recently, viewed his autism as separate from himself and thought that it had a minimal affect on his ability to integrate into his mainstream setting.

*I just I mean I just see myself as a normal guy having a laugh here and there, the only thing that autism may be a disadvantage to, is the understanding, that’s pretty much it. Physically I’m Ok, and academically I mean yeah, I get along with my work and stuff like that yeah (Paul, Interview 2).*

In the special school downward comparisons were made with others who were less academically able than themselves and also less socially able, as well as with those who had more behavioural problems. In the mainstream schools some participants noticed that they were better academically than many of those around them whilst others commented negatively on the behaviour of others. At these times participants seemed to be using comparisons to increase their self esteem, rather than to give themselves goals. For most participants upward comparisons were only seen in the mainstream setting. At the special school, the participants were some of the oldest and most able pupils and so it is possible that opportunities for upward comparisons may have been more limited, whereas in the mainstream settings, the participants were relatively new and they were more likely to come into contact with those that were more able than themselves.

### 8.4 Managing self presentation
The move into mainstream school, and the understanding of difference that accompanied this, appeared to prompt attempts by some of the pupils interviewed to manage how others saw them so as to enable them to fit in and increase their sense of belonging to the context they were in. This again was mediated by the extent of their social understanding, with Michael and Paul not seeing the point of managing how others saw them and therefore not using this as a strategy to belong, whilst Edward and Peter thought quite deeply about how they were perceived by others and how they wished to be perceived. So for Michael it wasn’t really something he had considered:

[Is there anything you don’t want your friends to know about you?] I haven’t really thought about that before (Michael, Interview 1).

For Paul it was, unusually, in the environment of the special school where he did not talk about his special interest as he realised that others would not be interested.

Yes, well, most of the time. I like to talk about sport and golf, and not all the other boys want to, some of them like talking about other things and I’m not always interested in what they want to talk about, some of them like talking about sport, but not all of them (Paul, on peers at special school, Interview 1).

However, in his mainstream placement, sport was an interest for everyone on his course which may explain to some extent why managing how others saw him was not so important for him in his mainstream setting. However, this could also have been due to his level of social understanding which did not lead him to form close friendships with the others on his course.

Sometimes I just talk general to them, obviously sport related cos I’m enthusiastic about sport (Paul, on peers at LW, Interview 2).

For Edward, managing how others saw him was important and he used it in his attempts to fit into a mainstream setting, but his lack of social understanding meant that he seemed to do this on a relatively superficial level.
cos I am different I like different things, I’d like to talk to them about my own things, but they might not like me or something. Yeah so they talk about what they want and I just talk about that subject (Edward, Interview 2).

This was in contrast to Peter, who had a good understanding of those areas where he was different to those around him and the things that he could say to them, he also differentiated between what he could talk to the staff about and those conversations he could have with his peers.

But um when it comes to people like my functional skills teacher, or my course team leader or people like that we sometimes have a decent little talk about things (Peter, on talking to staff, Interview 2)

I’m OK with telling them about my TV interests and things and what kind of sports I like watching and stuff. That’s kind of as far as it goes really, I don’t like telling them much about my musical tastes because my music taste is quite old fashioned, it’s all 60’s 70’s 80’s that sort of thing, whereas a lot of the people here just like modern day rap and drum and bass and stuff (Peter, on talking to peers, Interview 2).

8.5 Sense of Self

The experiences described above seemed to influence how the participants saw themselves. The move into a mainstream setting had consolidated their views of themselves as learners and had highlighted issues of friendship. For Peter and Paul this had seemed a relatively gentle process, with existing abilities being strengthened and their views of themselves as competent people enhanced. However, for Edward the process had been distressing, highlighting his social difficulties and leading to a sense of isolation which had had a negative impact on his self esteem. All had found their difficulties with social understanding problematic in their mainstream setting and this was frequently reported as causing participants to see themselves negatively. This contributed to their understanding of themselves as autistic people. All saw autism as causing them difficulties to some degree and was something that had to be addressed during their time in mainstream. All except Paul saw autism as an integral part of themselves and for Edward and Michael, it appeared to be the dominant feature of who they were. How all these factors affected the
participants’ view of themselves seemed to be mediated by their level of social understanding. Some expressed this in simple terms, with their autism as a central theme:

*I’m not normal (Edward, Interview 1).*

*[Um and does having Asperger’s alter how you think about yourself, is it an important part of how you think about yourself?]*

*I guess so, that’s who I am (Michael, Interview 1).*

Whilst others had more complex views of themselves and how they related to their autism for example, Paul saw himself as an ordinary person, with his autism as separate:

*I’m pretty easygoing really, Yeah I see myself as a fairly general person, understands things, um, has laughs here and there you know (Paul, Interview 2).*

*I suppose I was quite old when I found out, I’m just me, it’s separate from me, distant, far away, I’m me, and then there’s this ASD (Paul, Interview 1).*

In contrast Peter seemed to integrate his autism into his wider sense of self and expressed different aspects of himself at different times and in different places:

*Right so I just think I’m a football, fan, I’m a sensitive football fan, get me out of here! (Peter, Interview 2).*

*cos although I do get on with the people here, some people will also see me as a bit of a pushover, which I don’t really buy at all,(Peter, Interview 1).*

*I do have, because one of my tendencies having Asperger’s, is of course to occasionally talk to myself, I do have to keep myself very quiet, because I don’t want people hearing me and thinking I’m a big weirdo. Cos um cos to my knowledge not everybody here is like me, I think the majority are mainstream (Peter, Interview 2).*

How participants saw themselves was influenced by multiple, interacting factors which were moderated by their levels of social understanding.
8.6 External Factors

For Peter and Paul, external influences, such as family or previous school experiences, were powerful and appeared to have shaped how they saw themselves prior to the move to a mainstream setting. Paul had been to a special school previously which included children with a very wide range of disabilities and so his view of his own disabilities had been informed by this.

*Well there were some people like me but there were other people who had much more problems than me, they were in wheelchairs and had more problems than me (Paul, Interview 1).*

Peter had a profoundly disabled brother which seemed to have given him a different frame within which to view his own problems.

*Well he’s um somewhere in-between Downs and something else really, cos he can’t speak [……], cos the way his mind works, he’s 24, but it’s like his mind is telling him he is 4 or 5, so he is into really young stuff like spot the dog and the hungry caterpillar (Peter, Interview 2).*

8.7 ‘Who knows?’

Attending a mainstream setting raised unresolved issues regarding who should know about participants’ autism, whether others knowing was useful, or whether it underlined the differences and therefore reduced their sense of belonging.

For some participants, other people knowing was a positive thing as it would enable others to understand them. Peter and Paul took this further and saw telling others as a way of educating people about the problems related to autism.

*Um I suppose I wouldn’t mind if a few more people than usual could know cos I think it really would help to raise a bit more awareness of it really, even though there are um charities telling people. There is not an entire awareness really so*
I wouldn’t mind if people could know a bit more about it really, so they know about how they can deal with things (Peter, Interview 2).

There are different ways of how people would deal with it, different ways of how people would understand it so um no I’m, I’m ok with it. It’s their view and what they see, I can’t change that, it’s their choice. Um it’s I really wouldn’t mind, I would tell them, just say to see if they understood really to make them learn, yeah I’d be happy with them knowing. I don’t want to see autism as a disadvantage (Paul, Interview 2).

While Edward was more ambivalent and worried that others might think negatively about him if they knew:

Sort of, I want them to know about me, but I’m not sure if they did know about me, they would like me, don’t know if they would want to hang around me cos I am different (Edward, Interview 2).

Who should know about their autism in the mainstream setting did not appear to have been discussed with the participants before they went and some were still unsure as to who knew. For those participants for whom ASD was an important part of how they saw themselves, this lack of knowing who knew seemed to leave an uncomfortable feeling:

Mm, I haven’t told them, so unless somebody else told them, they don’t know (Edward, Interview 2).

I think they do know vaguely (Peter, Interview 2)

Whilst for Michael who knew did not seem to be important:

Um I don’t mind them knowing that I’m from a different 6th form um I’d not mind them knowing about me I guess, it’s not going to change much (Michael, Interview 2).

For Paul, this lack of openness over who knew was particularly important as his peers had been told of his autism without his knowledge. Although he believed that people
knowing was useful, his lack of involvement in the decision making process had left him feeling aggrieved.

Um ah, it’s hard to say, I mean at first I didn’t really want them to [know] but apparently my teacher said it to them, I asked her why she did that, cos I didn’t feel very comfortable at the time and she just explained to me cos ‘I only said that to say if there was a situation what happened’, or they wanted to know why I was doing something different that might be why (Paul, Interview 2).

The apparent lack of discussion of who should know about participants’ autism and the potential consequences of any disclosure seemed to be an important part of the experience of being included in mainstream education for these participants. For Edward and Paul it seemed to increase levels of anxiety and highlighted their difference further. For Paul, this had meant decisions about who should know being taken out of his hands and reducing his sense of agency and therefore his view of himself as a competent person, whilst for Edward, the uncertainty as to who knew and the apparent lack of discussion around the subject of disclosure meant that he was unsure about the response he would get from others.

9. Discussion

The aim of this study was to understand how children with ASD primarily educated in special schools experience inclusion in mainstream schools. The major themes identified in the analysis encapsulated the experience of mainstream education for the participants in this study and were: Independence, Belonging, Comparisons, Managing Self Presentation, Sense of Self, External Factors and ‘Who Knows?’. However, for each participant, these experiences appeared to be moderated by their levels of social understanding, their previous experiences and the nature of their mainstream setting.

The analysis yielded several key findings.

1) The move into a different setting did appear to result in an increased awareness of factors related to how participants saw themselves and how others saw them which were illuminated by the comparisons that participants made between themselves and their
peers. The majority of these comparisons seemed either to increase the participant’s sense of belonging in a setting or to be a means of self enhancement. However in the mainstream setting some upward comparisons were seen indicating that the participants were engaged in self improvement there.

2) The participants’ apparent level of social understanding (as suggested by the level of interest in others in their accounts) appeared to affect how they saw themselves and the extent to which the move into a new context prompted them to re-evaluate and manage their sense of self. This was not a theme voiced by the participants, but is evident when the responses from individuals are compared.

3) Participants valued the independence that going to a mainstream school gave them and did not report bullying in any form, even though this was explicitly asked in the interview. This is an unexpected finding as previous evidence suggests that bullying is a significant problem for autistic pupils included in mainstream education (Humphery & Symes, 2010). The value placed on independence and the absence of bullying may relate to the participants having been included in mainstream at a late stage in their school careers missing the most socially difficult phase of mainstream schooling (Slonje & Smith, 2008; Smith, Madsen & Moody, 1999).

4) Problems were experienced regarding disclosure and who did or should know about the participant’s diagnosis of autism. Whether disclosure was seen to be a positive move by the participants seemed to be affected by their existing view of themselves as autistic people and decisions around disclosure appeared to affect the development of their sense of self.

5) The generally positive experiences of these participants add to the debate regarding the inclusion of autistic children in mainstream schooling. Participants appeared to have missed the socially difficult years of mainstream education and been included at a time when both they and the other pupils in mainstream school were ready for the experience.

9.1 Context and Sense of Self
Changing context did appear to bring issues of how participants saw themselves into focus. This can be seen from the differing number and type of comparisons that arose in the two contexts, as well as from the detailed analysis of the content of those themes. This is unsurprising given that for most NT people, how people see themselves differs in different contexts and this in turn is influenced by changes in factors such as social position and health (Davidson & Henderson, 2010). This is suggested to be because changes in these areas highlight those things that are taken for granted in relation to the self (Galvin, 2005). This appears to have been part of the experience of inclusion for the participants in this study as they moved from an environment in which they felt they belonged and where their difference was supported to one where few of the people around them knew of their difference and fewer understood. They therefore moved from a position where their difference was accommodated and rendered largely invisible (Humphrey & Lewis, 2008; Ochs & Solomon, 2010) to one where their difference was clear and needed to be managed by the participants. These processes also seemed to be linked to the participants’ level of social understanding as judged by their interest in and awareness of others in their accounts, with the most able socially responding most to the new environment.

For two of the participants the experience of inclusion into a mainstream setting involved an element of isolation. For one participant, this was not problematic as he did not seek social contact; however, for the other the isolation was a significant problem which appeared to negatively affect the way in which he saw himself. This experience is similar to many autistic children in mainstream schooling and is thought to contribute to the increased incidence of depression seen in autistic children in mainstream school (Molloy & Vasil, 2004).

The environmental changes experienced by the participants were wide ranging, incorporating changes in the nature of social interactions amongst their peers, changes in the educational and behavioural expectations of the staff and changes in the organisational arrangements of the different settings. The participants also moved from a social position in which they were the most able academically to one where this was either not the case or where they were challenged socially compared to their peers. This change in environment appeared to prompt a series of comparisons in both the special school and mainstream settings. This is consistent with Galvin’s (2005) observation that changes in social position
prompt a reassessment of the sense of self. Many of these comparisons supported the participants’ existing view of themselves, for example, their view of themselves as learners was consolidated by their move into mainstream schooling due to the careful choice of mainstream placement for each participant. However, comparisons regarding friendships and social competence appeared to have a negative effect on the self esteem of one of the participants who was acutely aware that he had not been able to make friends and also aware that he lacked the social skills to develop friendships within the mainstream setting. In addition, more upward comparisons were made in the mainstream setting, possibly reflecting the greater opportunity for these in a context where participants did not outperform their peers socially and perhaps academically. As upward comparisons are known to be an integral part of target setting for individuals and hence for self improvement (Dijkstra et al., 2008), this potentially provides the participants with opportunities for growth which would not be available to them in their special school setting.

9.2 Social understanding

Bagatell (2007) and Davidson and Henderson (2010) suggest that for many autistic people, understanding how they see themselves and how others see them is an active and ongoing process. As autism seems to be best described as a multidimensional continuum, with individuals being placed at varying points along multiple dimensions, it is unlikely that all will have the same experience of others or of themselves. This is clearly seen with the participants in this study who vary from one that has multiple views of himself in different contexts and can begin to manage how he is perceived in different ways with different people to a participant who appeared to have a minimal understanding and interest in others and did not appear to have a strong sense of self or to see the need to manage how other people saw him.

It is possible that the autistic sense of self is different to that experienced by the NT population and may not involve situating the self in the social environment in the way usually observed. There are indications from the work of Rossetti, Ashby, Arndt, Chadwick and Kasahara (2008) that spoken language may not be needed for a sense of self. Their
work documents the unexpected sense of agency shown by autistic individuals who have little or no speech but type to communicate and could make their feelings about their interactions with others known. For example one individual typed 'I like others to not try to fix me' (p364). This suggests an awareness of a sense of self in relation to others.

9.3 Independence and belonging

The theme of independence appeared to originate from a combination of factors. The first of these was that unusually, the participants were weekly boarders in their special school which therefore held a more central role in their lives. This may have heightened feelings of independence as the school inevitably took on some of the role of a family home. It may also have increased the ‘cocoon’ like situation described by Todd (2000). The school had also spent time preparing the participants for the move into mainstream settings and part of the theme of independence came from a school narrative of preparing the participants for entry into the wider world. It is also possible that as the participants were older teenagers, they were beginning to value autonomy and the move to a mainstream setting provided an opportunity for this.

The experience of inclusion in mainstream schools for children on the autistic spectrum is frequently distressing with the most difficult time being during secondary school where the social environment is at its most complex and teachers have minimal contact with their pupils and so are not able to mediate relationships (Humphrey & Ainscow, 2006). In the current study, pupils did not appear to experience the overt bullying described in many other studies (Barnard, Prior & Potter, 2000; Nabuzoka, 2003; Humphrey & Lewis, 2008; Humphrey & Symes, 2010; Symes & Humphrey, 2010). This could be because participants were attending mainstream settings which only catered for post 16 year old students. The social environment in these settings is markedly different to a secondary school as much of the social manoeuvring, characteristic of the early teenage years has passed and students are more mature and more able to accept difference in those around them (Slonje & Smith, 2008). It is possible that the protective environment of the special school described by Todd (2000) has enabled the participants to develop a good level of self esteem. This is supported by the work of Harter and Renick (1989) who found that when children with
learning disabilities compared themselves to normally achieving children they had a lower view of their academic achievement than when they compared themselves to the other children in their resource room. As the majority of the comparisons available to the participants in their special school were with those of similar or lower ability than themselves, this is likely to have contributed to their view of themselves as competent learners. This relatively high level of self esteem was maintained for most participants by the relatively benign environment of their mainstream settings coupled with the support available from their special school.

9.4 Disclosure

The gradual process of acclimatisation to mainstream settings put in place by the special school and the careful choice of course and mainstream setting had made the process of inclusion a positive one for most participants. However, there remained some areas where the process was still difficult. One of the themes that came out of this analysis was control over the disclosure of the participants as autistic people. The participants had not been asked if they wanted people in the mainstream setting to know about their autism, and if they did, how this should be achieved. Instead decisions seemed to have been made for them and these decisions did not seem to have been communicated to the participants themselves; few of the participants were sure who knew, and if they did know, had not had control over what was said to whom. Interestingly, when asked, most participants said they were happy for others to know and some felt that telling others was important. In contrast many parents and teachers of young autistic people tend to hide the diagnosis, both from the young people themselves and from those around them when the evidence suggests that most young people want to know about their diagnosis as soon as possible (Davidson & Henderson, 2010; Jackson, 2002; Sainsbury, 2009). The reasons for this lack of openness appear to stem from a wish to protect children from labelling and the stigma associated with this (Punchon, Skirrow & Murphy, 2009; Ochs et al., 2001). However, the message from autistic authors is that this wish to avoid a specific label, results in unofficial labelling which is almost always more negative than a label of autism. Children are often labelled as ‘naughty’ or ‘weird’ or ‘retarded’. Giving a label of autism affords the child and their carers more control over how labelling occurs and provides the opportunities for education that the participants in this study cited as reasons for telling people that they were autistic.
Autistic authors have made the point that it is not the label that is the problem, but the stigma associated with it (Sainsbury, 2009; Jackson, 2002).

A number of authors have suggested that it is beneficial for the autistic child if those around them know of their diagnosis (Chamberlain et al., 2007; Rotheram-Fuller, Kasari, Chamberlain & Locke, 2010; Symes & Humphrey, 2010). Ochs et al. (2001), in their ethnographic study of 16 high functioning autistic children in mainstream education, came to the conclusion that when classmates had no understanding of autism the children's tendency to be marginalised increased. In contrast, where classmates were informed and given a brief description of autism and its characteristics, the autistic children encountered more tolerant peer interactions. In addition, where more extensive and personalised information was given, the inclusion experience was more positive and caring reactions to unusual behaviour were seen. Similar processes were seen in this study, especially at GC where the other pupils did not appear to have been told of the participants' difficulties and no attempts had reportedly been made to introduce them to individual members of their cohort. Here participants did appear marginalised, as outside the classroom, they had little or no interaction with peers and within the classroom, teachers appeared insensitive to their social needs. However, at LW, with its smaller class sizes and more person centred approach to education, the teachers took a closer interest in the needs of the individual pupils. Some classes at LW also had a high number of pupils with special educational needs and so help from adults was the norm within the class. As a result, help for difficulties related to autism became invisible amongst the general level of support provided for the class a whole. In contrast, for Paul who was on a higher level course, few of his peers had special educational needs so the teacher took the decision to explain his autism to the class to enable them to understand why his behaviour might at times be different to theirs. This appeared to have a positive outcome as Paul seemed to be integrated within the cohort.

Only one of the participants in the current study expressed concern regarding disclosure, the rest thought that disclosure was a positive move, either because they could not see that it might be problematic, or that they believed that the more people knew and understood their difference, the easier their life would be. These participants appear to be taking the first steps in joining a growing movement to educate NT society about the
realities of being autistic. This movement seeks to inform others of the abilities of autistic people and that being autistic does not necessarily mean having a learning disability and also informing them of the areas in which autistic people do have problems and the ways in which these might be mitigated (Shore, 2006).

**9.5 The inclusion of autistic children into mainstream schooling**

Humphrey (2008) reports that there is growing concern about the experiences of autistic children in mainstream schooling. Pupils with an autistic spectrum disorder are 20 times more likely to be excluded from school than those pupils without special needs and they are more likely to be bullied. Humphrey reports that although progress can be made with providing appropriate adult support for those with autism, the challenge is to increase awareness and acceptance of autism amongst other pupils (Humphrey & Symes, 2010). In addition Jones and Frederickson (2010) report that mainstream teachers emphasised compliance with school rules and expected work habits of included children and focused less on their social and emotional development, with these aspects being considered more important by professional support staff at secondary level. The most successful mainstream inclusion for children with ASD is reported to be found when the mainstream school also incorporated a specialist ASD centre (Frederickson et al., 2010). However, it is also possible to achieve similar results if close links are made between specialist centres and mainstream schools.

Many of the factors described above were observable in this study. Teachers at GC did not appear to be involved in promoting the social or emotional well being of the participants and this appeared to have an effect on the level of inclusion experienced in this setting which in turn appeared to result in lower self esteem for one participant. In contrast, at LW where the staff were involved in the social and emotional wellbeing of the participants, participants appeared to be more included. This supports the idea that the awareness by teachers of the importance of social and emotional wellbeing for autistic pupils, and their ability to act on such awareness, is central to the success of inclusion. In addition participants highly valued the expertise of the special school in helping them to negotiate problems they faced in mainstream which supports the findings of Frederickson et al.
(2010) that mainstream schools need close links with sources of expertise in ASD in order to make inclusion successful.

Perhaps the most important aspect of the inclusion process observed in this study was the timing of the inclusion and the extensive preparation involved. The participants had spent one session a week in a mainstream setting earlier in their school career on a course specifically designed for them and only for them. These participants had therefore been gradually acclimatised to the mainstream setting and had individual, expert support to manage the transition. As mentioned above, the age at which inclusion occurred and the participant’s experience in special school are also important factors in the participant’s experience of inclusion. Adolescence has been shown to be a particularly difficult time for autistic children due to the increasing social expectations at this time and the larger and more diverse student population with which they need to interact (Carrington et al., 2003). This is supported by the work of Molloy and Vasil (2004) who suggest that the specialist autistic school setting allows autistic children to develop their social skills in a more supportive environment and that ‘Aspie’ teenagers find it easier to make friends with other ‘Aspie’ teenagers rather than teenagers from the NT population. It is possible that a model such as this, where autistic teenagers spend their most vulnerable years within special education and then move into an appropriately supported mainstream setting could be a useful compromise for those autistic children for whom education in mainstream school appears to be detrimental.

9.8 Critique and Limitations of the Study

The aim of this study was to understand how children with ASD primarily educated in special schools experience inclusion in mainstream schools. I believe the study enabled an understanding of how the participants included in the study experienced inclusion in mainstream and adds to the existing literature by providing an example where bullying does not appear to be part of the experience of inclusion and raises new questions about who has control over the identity of autistic children during the inclusion process.

The study was limited by the small number of participants and educational establishments and so any conclusions cannot be generalised to the wider population of autistic pupils. In
addition, as a boarding school, St John’s was not typical of the special school provision experienced by autistic teenagers.

The participants were also those who agreed, along with their parents to participate in the study, and may therefore not be representative of the other pupils at St John’s who were invited, but decided not to participate. As only four of the 14 potential participants gave consent, it is possible that an important set of experiences has been missed. In particular it is possible that those who were not having a positive experience of inclusion declined to be interviewed. These and other factors were discussed with school staff at a feedback session conducted after the analysis was complete. Staff commented that the themes presented were compatible with their experiences of working with the participants and with the other pupils participating in the inclusion programme.

As this was an IPA study, the aim was to explore the experiences of the participants and to gain a deeper understanding of the meaning these experiences had for them. For this understanding of the participants to be developed into a wider understanding of the inclusion process for autistic pupils, additional studies would be needed. For example, a grounded theory study could be undertaken; using the findings of the present study as a starting point, alongside a more systematic survey to elucidate current disclosure practices in mainstream schools.

It is possible that there are elements of the experience of autistic people that are not accessible to NT researchers, so it would have been useful to undertake the analysis alongside an autistic person to understand some of the assumptions that I made, as a NT adult, regarding the thought processes of autistic teenagers. It is also possible, that the nature of the interview process itself meant that the participants were not able to fully express themselves and given the extent of the scaffolding needed for some participants (see Appendix 8), it is possible that their stories were not entirely their own. In addition, the nature of the interview schedule also may have had an influence on the results of the study as supplementary questions were more structured than is usual in an effort to ensure they were understood by the participants. For example, the question, ‘Are you happy here?’, although intended to focus the participants towards how they felt in each school, may have influenced the nature of their responses.
The design of this study meant that participants needed to be able to respond verbally in the social situation of an interview. This may have led to the participants being unable to fully express themselves. This could perhaps have been mitigated to some degree by the use of written media such as diaries as has been done in a number of studies, for example, (Humphrey & Lewis, 2008), although, this still requires the use of verbal understanding and expression. Humphrey and Lewis (2008) also used pictures effectively in their study of the experiences of autistic children in mainstream schools and it is possible that those who had difficulty expressing themselves verbally may have been able to do so using this medium. However the time available and the possible effects on recruitment of adding additional tasks precluded the pursuit of these avenues.

My previous experience with positivist research may have affected my initial approach to IPA. However, as described in the methodology, this experience focused on understanding how things are rather than finding causal explanations. This coupled with my commitment to giving a voice to autistic children influenced how I approached the analysis. As the analysis progressed, I came to appreciate the depth of interpretation that IPA allows and I hope this enabled me to gain an understanding of the experiences of the participants from their perspective.

9.9 Clinical Implications

For a clinical psychologist working with children about to embark on the process of inclusion, the experiences of these participants suggest that careful preparation is needed. The pupils in this study benefited from the long term and well planned process of inclusion, the careful consideration for the mainstream placement and the nature of their academic work there.

The participants in this study voiced their appreciation of the special school staff in facilitating their transition to mainstream; this is supported by the work of Frederickson, Jones and Lang (2010) who found that those autistic pupils in mainstream provision that had access to a specialist centre had better experiences of inclusion. This close, readily available personal support with a trusted and experienced adult would therefore seem to be an important ingredient of successful inclusion.
For the participants in this study who sought social interaction, the lack of friends within a mainstream setting was reported to be a cause of distress. In these circumstances, the current study suggests that clinical psychologists could encourage schools to identify accommodating social groups within the pupils’ peer group and to facilitate social interactions with this group. As part of this intervention, other pupils within the mainstream setting are likely to benefit from being informed about autism and efforts made to reduce the stigma attached to autism through psycho-education.

Finally, issues of disclosure need to be approached sensitively, but explicitly. For the participants in this study, this had not been discussed with them before the inclusion process began and the uncertainty about who knew of their autism and how they might react to it if they did know was a source of anxiety and confusion. Issues of disclosure appear to raise anxiety in both the pupils themselves and in the pupil’s wider network (Punchon, Skirrow & Murphy, 2009; Ochs et al., 2001). However, the benefits are well documented (Rotheram-Fuller et al., 2010; Symes & Humphrey, 2010). So prior to inclusion in mainstream education, an open discussion regarding disclosure needs to be had with the autistic pupil and their wishes and choices respected when introducing them to the mainstream setting. For many mainstream settings this process will be unfamiliar and it is likely that they will benefit from support from the special school setting to achieve this.

Although this study only involved a small number of participants and educational settings these factors are consistent with a number of previous studies in this area, as mentioned above and add to the growing consensus of the measures which can improve the experience of inclusion for autistic pupils in mainstream education.

**7.10 Remaining research questions**

The study suggests further work that could be undertaken so that the findings of this study can be applied with more confidence to the wider autistic population. For example, would discussing disclosure with autistic pupils and planning for this before inclusion improve the experience? Would introducing autistic children to accommodating social groups previously educated about autism improve the experience of inclusion for this age group? Does the age at which inclusion occurs influence its success with autistic children? Is the self esteem
and emotional wellbeing of autistic children educated in special schools different to those educated in mainstream settings?

One of the most intriguing questions raised by this work is the nature of autistic identity. There is evidence of identity here in the themes of Managing Self Presentation, Sense of Self and ‘Who knows?’ which echoes the work of other authors in this area (Bagatell, 2007; Davidson & Henderson, 2010; Molloy & Vasil, 2004). This sense of identity appears to be more closely linked to social understanding than linguistic ability and I believe further work on this topic preferably in collaboration with autistic researchers could enable a greater understanding of the experience of being autistic.
10. References


"http://web.ebscohost.com/ehost/viewarticle?data=dG1yM0MPP44rp2%2fdV0%2bnjlfk5le46bJJsKeU6lSk63nn5Kyl8e%2fhWK%2bnrUtqK5Jr5avUq6quEqyls5lpOrweezp33vy3%2zb2G59q7Ra%2bvtkuyprZrtKykhN%2fk5VXj5K84LPui%2ffeplz3btZzjzfhrurkivo69Qrqy3Ra6mtT7k5fCF3%2bq7fVPi6ozj7vIA&hid=21" \o "Theory of mind and autism: A review." *Theory of mind and autism: A review. International review of research in mental retardation: Autism, 23*, 169-184.


Research Dossier.


Research Dossier.


Appendix 1. Ethics committee approval letter.

Chair's Action

Ref: 482-PSY-10 (With Conditions)

Name of Student: HELEN STIRK

Title of Project: 'Understanding self identity in autism: the effect of inclusion in mainstream schooling'.

Supervisor: Dr Emma Williams

Date of submission: 26th July 2010

Date of re-submission:

The above Project has been submitted to the FAHS Ethics Committee.

Favourable ethical approval has now been granted.

Signed: [Signature]

Dated: 09th Aug 2010
Appendix 2. Parental consent form
Parental Consent Form

I, the undersigned, voluntarily agree for my child to take part in the study on 'Understanding self identity in autism: the effect of inclusion in mainstream schooling'.

- I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what my child will be expected to do. I have been advised about any possible ill-effects on my child’s well-being which may result. I understand that if there are any concerns regarding the wellbeing of my child that arise during, or as a result of this study, these will be referred to named individuals in the schools concerned in addition to myself. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

- I understand that all personal data relating to participants is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I understand that all data provided for this study will be retained under secure conditions for five years after the research report is produced in order to allow for the checking of any published data and to allow for the re-analysis of the data. I agree that I will not seek to restrict the use of the results of the study on the understanding that my child’s anonymity is preserved.

- I understand that my child is free to withdraw from the study at any time without needing to justify the decision and without prejudice.

- I confirm that I have read and understood the above and freely consent to my child participating in this study. I have been given adequate time to consider my child’s participation and agree to comply with the instructions and restrictions of the study.

Name of child (BLOCK CAPITALS) ........................................................................................................

Name of parent or carer ..............................................................................................................................

Signed/date ................................................................................................................................................

Phone number of carer (to enable phone call to be made after the interviews) ........................................

..................................................................................................................................................
Appendix 3. Participant consent form

Participant Consent Form

I agree to take part in the study on ‘Understanding self identity in autism: the effect of inclusion in mainstream schooling’

- I understand that Helen will interview me twice for 20-30 minutes each time. One interview will be at ___________ School and the other interview will be at my other school.

- I have been able to ask questions about the research.

- I understand that Helen will write about the things she finds out in the study, but will not tell anyone my name or which schools I go to.

- I know I do not have to take part if I don’t want to and that I can stop at any time.

Name of Participant (BLOCK CAPITALS) ..........................................................
Signed ..........................................................................................................
Date ..........................................................................................................

In the presence of (name of witness in BLOCK CAPITALS)
Signed ..........................................................................................................
Date ..........................................................................................................

Ethics Committee
Appendix 4. Parental information sheet

‘Understanding self identity in autism: the effect of inclusion in mainstream schooling’.

Information Sheet

I am inviting your child and their schools to take part in this research study. Please read the information below as you need to understand why the research is being done and what it would involve for your child. Once you have read the information you may find it helpful to talk to others about the study before you decide whether to take part.

Researcher: Helen Stirk (Trainee Clinical Psychologist)
Contact: H.Stirk@surrey.ac.uk Tel. 01483 689441

What’s the purpose of the study?
This research project is being conducted as part of a doctoral training programme in Clinical Psychology at the University of Surrey. The study investigates how people on the Autistic Spectrum see themselves and how this may be developed by inclusion in mainstream schooling. This is important because the experience a child has when they go to school affects how they see themselves and other people. If we can understand this better, we can help to make the experience of going to mainstream school and being with the children there more positive. Some research has already been done to look at this, but little is understood from the point of view of the children involved.

Why has my child been invited?

You have been contacted along with other people as your child has been diagnosed as being on the Autistic Spectrum, is normally placed in a special school, but also has periods of time included in a mainstream school or college.
Does my child have to take part?

It is your choice, in discussion with your child. You can use the information provided here to come to a decision and you are encouraged to read the ‘Information sheet for participants’ with your child to make sure that they understand what will happen and that they are happy to participate. I am happy to answer any further questions that you might have. You and your child are free to withdraw at any time, without giving a reason.

What will taking part involve for my child?

I will spend some time getting to know your child in their special school and will do 2 interviews, one in the special school and one in the mainstream school. This is because people on the Autistic Spectrum may give different answers in different environments. I will ask your child what they like most about their schools and what they like least. I will ask your child how they think about themselves and how they get on with other people. Each interview will take about 20-30 minutes to complete.

The interviews will be recorded and transcribed by me. The information is secure and I am the only person to have access to the recordings and the transcription. I am also the only person to know the names of the participants. Both recordings and transcriptions will be anonymised as far as possible. I will discuss aspects of the study with Dr Williams (Principle Investigator), but she will not know your child’s name.

I will phone you the day after an interview to answer any queries that may have arisen following the interview.

Are there possible disadvantages of taking part?

Most people who participate in this kind of study find talking about themselves and their experiences helpful. However, it is possible that talking about what they think about themselves and other people might raise issues that your child finds distressing. Before undertaking the interview, arrangements will be made for your child to talk to a familiar and trusted member of the school staff who is aware of the nature of the study should they find the process upsetting. You and the schools will also be informed if your child is upset.
What will happen if I don’t want to carry on with the study?

If you, your child or one of your child’s schools changes their mind about taking part in the study, they may do so at anytime, without giving a reason.

What if there is a problem?

If you want to make a complaint about anything to do with the study, please contact myself in the first instance. I will be happy to try to resolve any complaints you may have with the study. If you do not feel it appropriate to address your concerns with me directly then please contact Adrian Coyle, the Chair of the Ethics Committee of the Faculty of Arts and Human Sciences (A.Coyle@surrey.ac.uk) (Tel. 01483 686896) Any complaints will be taken seriously and any issues arising will be addressed.

What will happen to the results of the research study?

Upon completion of the study, the results will be written up by the researcher and submitted as part of the course requirements for the Doctorate in Clinical Psychology (your child will not be identified in any report or publication). The article will be submitted for publication with various academic journals. The results may be shared with local services and may also be presented at future conferences. Feedback on the overall results will be sent to you on completion of the study.

Who has reviewed the study?

This research has received a favourable ethical opinion from the Faculty of Arts and Human Sciences Ethics Committee at the University of Surrey to protect your safety, rights, wellbeing and dignity. It is carried out according to the code of conduct specified by The British Psychological Society www.bps.org.uk

Decision about taking part:

If you would like your child to take part, please sign the consent forms enclosed and return to the researcher in the envelope provided.

Thank you for your time.
Appendix 5. Participant information sheet

‘Understanding self identity in autism: the effect of inclusion in mainstream schooling’.

Information Sheet

I am inviting you to take part in this research study. Please read this information with your parent or carer to help you understand about the research and what you will be asked to do. You can then tell them if you want to take part or not.

Researcher: Helen Stirk (Trainee Clinical Psychologist)
Contact: H.Stirk@surrey.ac.uk Tel. 01483 689441

Why are we doing the study?

Research studies can help people find answers to important questions. I am trying to understand what children and teenagers with ASD think about going to two different schools. This is important as it might help people understand more about this so they can help children and teenagers with ASD more.

Why have I been invited?

You have been invited because you have been told you are on the Autistic Spectrum and normally go to St John’s School but sometimes go to a different school.

Do I have to take part?

You do not have to take part if you do not want to. It is up to you and your parents to decide to take part or not. You can ask me any questions you like about taking part. If you decide to take part, you can change your mind at any time and you do not need to tell me why.

What will I have to do?
I will come to see you at St John’s School and spend a little time getting to know you. I will ask you to answer some questions about school and your friends. Then I will come to your other school and talk to you some more when you are there. I will talk to you for about 20 to 30 minutes each time. I will record what we say and then type out the words so I can read them later. I will keep the information very safe. I won’t put your name in anything that I write or the names of your schools.

**What if there is a problem?**

Most people like talking about themselves but we might talk about things that make you upset. If this happens we can tell your teachers and your parents so that they can help you. If you do not like anything that happens, you can tell your parents or your teachers.

**What will happen when the study has finished?**

When I have finished talking to people, I will write about what I have found so that other people can learn about what it is like to spend some time in a mainstream school when you usually go to a special school.
Appendix 6. Interview schedule

Interview schedule.

Introduction
Introduce yourself. Welcome the student and thank him or her for coming. Explain what the session is about: “We will be talking about being at this school how this affects the way you think about yourself. I will be asking you about what happens at school and how you get on with the people here”

Explain that the identity of the students will be kept confidential and that the answers to the questions will be included in the results of the study, which will be used to help teachers and others understand how young people with ASD experience different kinds of schools. Tell the student to ask if he or she does not understand anything. Let the student know that he or she does not have to answer every question and that he or she can stop the session at any time.

Section 1. Gaining an understanding of the child and their experience of school.

Can you tell me about yourself: your age, what you like doing, what you don’t like doing?

Let’s talk about school . . .

Are you happy here?

What makes you happy/unhappy

What could be done to make you more happy?

What do you like doing best at school and why?

What do you find hard and why?

What does your teacher do that makes it easy for you to learn?
What does your teacher do that makes it difficult for you to learn?

What do you do at break times?

Are any of the children ever unkind to you?

In what way are they unkind?

Section 2 Friends and relationships

a) **Tell me about the other children here?**

   How do you get on with the other children here?
   
   How are you like the other children here?
   
   Do you think the other children in this school are like you?
   
   Can you talk about the things you want to talk about when you are in this school?
   
   If there are any problems, how do you manage these?
   
   How do you help yourself?
   
   Who do you like and why?
   
   Who do you not like and why?

b) **Tell me about your friends?**

   Do you have any particular friends here?
   
   How did they become your friend?
   
   Why are they a good friend?
   
   What would you want your friends to know about you?
   
   What things do they need to know about you?
   
   What things should not be told to your friends about you?
Section 3 Thoughts around diagnosis of ASD

What do you think ASD is?

I am going to ask you about the problems and benefits of having ASD.

Are there any problems with having ASD?

Are there any benefits of having ASD?

Who do you tell about having ASD?

Does having ASD alter how you think about yourself?

Section 4. Second interview only.

How do the two schools compare?

What is good in each school?

What is less good in each school?

How are the people different in each school?

Thank the student for participating and tell him or her that if he or she has any questions to please contact [previously agreed person]

Derived from Carrington et al. (2003) and Molloy and Vasil (2004)
### Appendix 7. Sample interview transcript Michael 2\textsuperscript{nd} interview\textsuperscript{4}

<table>
<thead>
<tr>
<th>Academic learning – likes increased ability to learn. Values learning.</th>
<th>Are you happy when you are here?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Um I like um how the staff teach and um they are nice and the student are nice and we get on learning</td>
<td></td>
</tr>
<tr>
<td>That sounds good. What is it about the way the staff teach that’s good?</td>
<td></td>
</tr>
<tr>
<td>I don’t know, they are just good at what they do</td>
<td></td>
</tr>
<tr>
<td><strong>Ok, so I’m wondering how what you are studying now is different from what you did at St John’s. So is it because you are more specialised here? What is good about what you do here?</strong></td>
<td></td>
</tr>
<tr>
<td>I can choose whatever subjects I like and um specialising in those subjects so that’s good</td>
<td></td>
</tr>
<tr>
<td>So is it that you don’t have to do subject that you don’t like</td>
<td></td>
</tr>
<tr>
<td>Yeah</td>
<td></td>
</tr>
<tr>
<td>Which are the ones you really don’t like</td>
<td></td>
</tr>
<tr>
<td>Er English (laughing)</td>
<td></td>
</tr>
<tr>
<td><strong>OK</strong></td>
<td></td>
</tr>
<tr>
<td>So I can see why giving up English could be good. Is there anything this school could do to make you happier, make your life easier?</td>
<td></td>
</tr>
<tr>
<td>Um mm, no I don’t think so</td>
<td></td>
</tr>
</tbody>
</table>

\textsuperscript{4} Please note that due to formatting change needed to include the transcripts in the portfolio and the need to type in comments originally handwritten, line numbers have been lost as they became meaningless.
About what like to have.

Working is best.
Academic.

Ability to choose — sense of what likes — what want to do.
Control.

Um ..what do you like doing best here?

Um.. working in my lessons

Any lessons in particular are good?

Um I like all my lessons because I chose them all,

So you don’t prefer the maths over the chemistry or anything like that

Nah

OK

Um what do you find hardest when you are here?

Probably the break times cos I can talk to people to talk to people in the lessons but I find it hard to talk to people out of the lessons

Break hardest — talk to people in lessons but not outside therefore does have problems with socialising which bothers him. ‘find hard’ — statement of fact -

What do you think that is about, why is it OK in the lesson and harder outside the lesson.

Um I don’t know mm

So when you are in a lesson what do you talk to people about

In lessons talk i.e. subjects and other outside stuff.

Um lots of things about the lesson and stuff that isn’t about the lesson
Style teaching not noticed or important...little awareness of own learning style.

Ok um do the teachers here do anything that makes it easy for you to learn?

Sorry?

Is there anything about the way the teachers teach here that you really like?

Um I haven’t really noticed to be quite honest

And is anything that they do that makes it harder for you?

Um no I don’t think so.

OK and what do you do at break time?

Er I do home work in the LRC or read a revision book or have a snack.

Break – solitary HW or snack.

All ‘I’ – no ‘we’.

College is about academic stuff – not about friendship or belonging – but not distressed by this.

So are there places here to go for snacks?

Yeah

Um when you go for a snack is there anyone that you go with? um no not particularly

Belonging.

No particular friends outside of lessons- no impulse to go with others outside lessons.

Ok and are nay o the other student here ever unkind to you?

Belonging.

Group identity.
No

*I guess they are all a bit older now aren’t they, so.. How do you get on with the other people here, the other students here?* Very well,

*And how are you like the other children here, how are you similar to them?*

Um well, in all my subjects we are all interested in that subject

*Mm and do you think the other children here are like you?*

Um yes and no, because they normally go out a lot more than I will with groups of people from college, I haven’t don’t that yes,

*OK, is that something you would like to do?*

Mm may be, but I don’t mind too much.

*Um can you talk about the things that you would like to talk about when you are here?*

What inside or outside the lesson?

*Outside the lesson I guess, or inside the lesson, do you think there is anything you are really interested in that if you talk to the people here they wouldn’t be interested in it?*

Um I can talk to them about pretty much anything,
Ok um if there are any problems when you are here, how would you manage those?

I haven’t had any problems, but I probably would talk to Terry or another member of staff, Coping with problems.

So there are people here that you could talk to?

Yeah,

Ok, um so of the people in you class are there any that you talk to more than others, who do you like and why? Um I talk to most of the people,

mm

Friendships.

So the people that you talk to more than the others, what is it about them that you like?

Um I probably do talk to some people more hat others but I like all the people here.

Behaviour of others.

Others friendly and fun.

Um they’re friendly um and they are quite fun some times,

Ok

Behaviour of others.

So when you’re having fun, what kinds of things are you doing with them?

Erm well just talking really,

Ok um so it’s an interesting talking that you r enjoying

Yes

Ok is there anyone in the class that you don’t like, that’s difficult to be around or irritating,
Friends – in same tutor – proximity. See more – no sense of common interests.

Can you tell me a little bit about the tutor system, cos I don’t understand how this college works?

Um every Monday and Tuesday they have a tutor time when the tutor registers every one and we either go and we have a work sheet or a video to watch about safety, like drug safety or a work sheet about how we are getting on, and

How many are in that tutor group?

Um maybe about 20

Ok and how many in paper classes?

Um maths and physics about 10-11 and chemistry about 16,

So quite small classes for a mainstream school, that’s quite good. Um what would you want your friends here to now about you?

Um I don’t mind them knowing that I’m from a different 6th form um I’d not mind them knowing about me I guess, not everything, yeah,

Happy if know from different 6th form – not mind knowing about ASD – but are some things would

Research Dossier.

Friendships.
keep quite – some sense of identity.

But no sense of managing his identity.

You don’t want everyone to know everything about you, I don’t think anyone wants that. Sometimes there are some things in particular that people want to keep to themselves, it doesn’t sound that there is anything really important that you like to keep quiet.

No

Is there anything your friends need to know about you that you think would help?

No I don’t think so

Um so, we talked last time a bit about having Asperger’s, how do you think that affects what you do here?

Um my longer lessons I sometimes have a hard time concentrating and I guess that might be why I can’t speak to people outside lessons but I can inside

I think quite often if it is a long lesson, most people find it hard concentrating the whole way though. So that might or might not be the Asperger’s, lots of people drift off, I wonder if you asked some of your friends if they drift off sometimes

Probably (laughing).

Um but you were saying that its why you might find it difficult to talk to people outside the
Is vague sense that talking to others would be good.

The attributions positive sense of self – not much affected by slight negative social side.

More that not talking to people about self than not wanting people to know.

ASD identity – not mind knowing – not issue for him.

Lessons

Yeah

Does that worry you?

No, not particularly

So is it something that you want to do – to talk to people more outside of lessons or is it just something that you have noticed?

I don’t mind too much but I guess it would be nice

Yeah

Um, is there any advantages her about having Asperger’s?

I guess it allows me to um keep going with my work without any thoughts of giving up,

So once you start something you are going to finish it.

Who do you tell about having Asperger’s

Well I didn’t tell anyone really

Is it just something you think people have found out, how do you think people know, or don’t they know?

Um no one has really asked, I don’t mind them knowing

Social competence.

Self identity.

ASD as positive.

Who knows about ASD managing identity.

Who knows.
Not think will change how they think about him or his experience of school.

Do you think it would be a good thing or a bad thing if they knew, I know you said you didn’t mind but..

Neither really, m, it’s not going to change much.

Managing identity.

Um so thinking about the two schools um, what is the best thing about each school, so what is the best thing about here and what is the best thing?

The best thing about here is being in a mainstream college and St John’s’s I guess it would be um I can’t think

Academic self identity.

So you said the good thing about being here is about being in a mainstream college. What good about being in a mainstream college?

Belonging – self identity.

Um well, I guess um it’s what most people go to, so there aren’t many special needs colleges,

No real thought about how it fits with him and his needs, likes etc.

Not that do A levels and things like that you mean, so is part of what is good about being here, the subjects you can study?

Yeah,

OK

What is the hardest thing here and the hardest thing at St John’s

Um hardest thing here is getting used to the timetables, cos you have really long gaps, like one really busy day and a really short day,

Academic.

Organisation – timetabling hard – no mention of social issues.
Also sees St. Johns mainly in terms of work, not social activity.

Yeah

And St Johns’ as um, I don’t have much time to do much work at St John’s so I’m just doing bits of work and not getting much at the moment

Is that that you do not get much time to yourself, or you don’t get much time to do things?

In the middle, when I m at school, I’m hardly ever there so I don’t get to do much.

Um and how are the people different in each school. How are the staff different in each school?

Um the staff at St Johns have to keep more people under control and more often, whereas here they are more worries about teaching I guess.

So the staff are worried about different things in the two schools

What about the of the pupils in the two schools? What are the main differences between them?

Um the sixth form students in St Johns?

Everyone is older in college obviously so they are much more independent, than all of the students in St Johns

And how do you feel about that independence

Yeah its good, it’s much more to yourself that at St Johns
So is that a good thing being independent and organising yourself or do you sometimes like a bit more help than you get here?

I guess it can be a good thing cos are becoming more independent

But it’s just um I’m trying to understand if you like being more independent or whether you prefer how it is at St Johns’

I guess I prefer being independent I probably need help with some things at some point

So it’s a question of having a bit of support to become independent.
Appendix 8. Sample interview transcript Peter 2\textsuperscript{nd} Interview

Has specific people that think of as friends – are people spends most of time with. \textit{It’s okay not to like everyone.}

There’s a few that I get on with and there’s Dan, Greg who I do have a bit of a joke with every now and again, I get on Ok a guy called Robert and a guy called Andrew, there all OK, there rest are all Ok, but I don’t hang around with them,

\textit{That’s the way it goes you never get on with everyone in a group and its um. So the people that you get one with here, what do they need to know about you?},

I’m sorry I didn’t quite get that,

\textit{It’s a difficult questions, they people that you are friends with here, what kinds of things do you like them to know about you?}

Well, , well i don’t like telling them where i live, or about I’m OK with telling them about my TV interests and things and what kind of sports I like watching and stuff and that’s about it. That’s kind of as far as it goes really, I don’t like telling them much about my musical tastes because my music taste is quite old fashioned, it’s all 60’s 70’s 80’s that sort of thing, whereas a lot of the people here just like modern day rap and drum and base and stuff, so but even then there are a few of those sorts of songs that I do like, um I just use those kinds of songs to sort of blend in really,

\textit{So what king of songs do you like?}
Research Dossier.

Well from the 60's I like things like Manfred Man and Freddy and the Dreamers OK, that sort of thing, 70's is usually things like Genesis, um er, there is someone else as well, Slade, that sort of thing.

Yeah,

80's is things like Bon Jovi, Aha, things like that,

So, which is quite different for what the lads are listening to.

I went to see a concert a while ago so I'm a bit more into that,

So musical tastes make things a bit different and you don't really talk to the lads about that. Is there anything you really don't want them to know about you?

We um one thing I wouldn't really want them to know about at the moment would be the fact that I do have a disabled brother,

Ok,

Cos um it was stuff i have occasionally heard them make they might make jokes, including stuff that is quite offensive to me,

Yeah

I don't want to like, I'd just be afraid to let them down, I don't want them to feel really
Research Dossier.

said the wrong thing. really bad about what they have said.

Sees self as good person.

Sensitive to others feelings. Sees self as good person. Sensitive to others feelings.

So is that you family would feel bad if you said it?

Well both really

Ok, is that your family would feel bad if you said it, or they would feel bad, because they have been making jokes about it? And your family might feel ad.

Well my family wont cos my brother’s like 24 now, so they are fairly used to his ways. Not to mention that all the new things that they have to get for him because he keeps blooming braking things

That’s quite difficult, What kind of disability does he have?

Well he’s um somewhere in-between downs and something else really, cos he can’t speak, but he doesn’t have the tongue thing, but he can’t speak properly, he can only indicate with groans (imitates different types of groan) means he’s not very happy for instance and he can’t walk entirely right, you can always see how bad is back is cos his back is always bent over slightly and his hips aren’t great and he can’t walk entirely properly which is one of the reasons why he has to have splints in his boots, so it’s a bit tricky really, cos the way his mind works, he’s 24 but it’s like his mind is telling him he is 4 or 5, so he is into really young stuff like spot the dog and the hungry caterpillar.
So how do you feel around him then?

Um not too bad, when I was younger I used to be a bit more nervous, cos the thing about people like that is that they are not always entire fans of younger children,

That's true actually,

Which I should know about from experience, but over the years I have become older, he has actually come to like me more and to like me as a brother really,

Yeah

Um yeah i feel a lot better about it now than I did before to be quite honest.

It could be a bit scary I guess when you were younger.

Yeah

OK Um, so we talked last time, about having Asperger's and what it was like at St Johns', how does that affect you here?

Um not too bad, um, I do have because one of my tendencies having Asperger's, is of course to occasionally talk to myself, I do have to keep myself very quiet, because I don't want people hearing me and thinking I'm a big weirdo. Cos um cos to my knowledge not everybody here is like me, I think the majority are mainstream.

Yeah
<table>
<thead>
<tr>
<th>Manages identity.</th>
<th>But um, but all the same I still don’t want other people to hear me talk to myself,</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upward comparison.</td>
<td></td>
</tr>
<tr>
<td><strong>Monitors self to help fit in.</strong></td>
<td><strong>So you are careful, you monitor what you do, is that so it’s easier to fit in, is that part of the reason for doing it (nods)</strong></td>
</tr>
<tr>
<td>Others vaguely know.</td>
<td><strong>Do the other people here know that you have Asperger’s?</strong></td>
</tr>
<tr>
<td>Aware of/sensitive to how others might see him.</td>
<td>I think they do know vaguely, so they are vaguely aware.</td>
</tr>
<tr>
<td></td>
<td>(Looked at the clock)</td>
</tr>
<tr>
<td>Becoming confident of identity as someone with ASD as would like to raise awareness – If more people knew –</td>
<td>Sorry I shouldn’t have done that, it looked a bit arrogant, No it didn’t, because I was doing exactly the same thing, when you have a time table to work to that is an important thing to do. That isn’t arrogant, that is managing your time properly. So that’s OK We were talking about other people sort of knowing that you have Asperger’s um, you were saying that they sort of know something is a bit different. Um are you happy with them sort of maybe knowing, Would you like people to know that you have Asperger’s? Um I suppose I wouldn’t mind if a few more people than usual could know cos I think it really would help to raise a bit more awareness of it really, even though there are um charities telling people. There is not an ASD identity</td>
</tr>
</tbody>
</table>


Research Dossier.

entire awareness really so I wouldn’t mind if people could know a bit more about it really, so they know things like how to, about how they can deal with things,

Would you think it might make it easier for you if people understood perhaps?

Mm, defiantly

Do you think all the staff here understand enough?

Yeah, I think they do pretty much know about it.

Ok and so they can help you with the things you find hard. OK um what do you think the Asperger’s, the difficulties when you are here?

Well reading is Ok, unless it is long distance, one of the things that I do find difficult is um is er getting the right end of the stick with what people say to me, cos having Asperger’s I do tend to misunderstand what people are saying to me which I do find quite annoying.

So is that when they are joking.

Um yes that sort of thing. I assume form the way they have said it that they are joking, but they might be you know..

And it’s actually joking on that’s quite hard

And I just get the wrong end of the stick and it makes me feel quite an idiot really

Yeah I can see it might feel that way if you have misunderstood something, I guess most people can misunderstand things at some things, but is sounds as if you might do it a bit more often.
Positive aspects of ASD.

Good – way brain retains info. Likes knowing a lot about subject.

Help with learning.

Positive aspects.

Likes countryside at St.Johns. Likes more free flowing environment at LW – learning at own pace. Independence at LW.

Likes both places – but is about to move to college in town to be with friend.

Will have to get used to busier environment.

And are there any advantages to having Asperger’s when you are here?

Well, my brain does retain information about certain subjects like Dr Who and things like that, it means, one thing that I do like is that I actually know a lot more about something’s, like I said Dr Who, or capital cities, or things like that.

Yeah, un so yeah, there is a bit of a bonus form that,

So that is that ability to store knowledge, so that could be quite useful, especially when it comes to learning things here.

OK, I think we are very nearly finished, um so thinking about the two schools that you go to, um they seem quite different, so what do you like about each one.

Well at St Johns I like the environment cos is all in the countryside and it’s not too busy around there, it can be quite peaceful and the thing i like about it here is that it’s a much more free flowing environment so, so that you can actually learn things at your own pace, that’s what I find. So each place has its own advantage, it sounds like it’s quite a good arrangement for you being in both.

Would you like to be in one place more than the other?

I think I’m OK being in both places really. But I’m probably going to have to make the most of this particular environment, co I don’t think I’m going to be in this part of the college net term, cos I’m looking more towards um course in catering for next term which is over in the stoke part campus in Guildford, so I’m going to have to get used to it being a lot more busy and a lot more hectic
Done specifically to increase interaction with friend.

I t will be quite different. OK what made you think about changing to catering?

Well I considered it before. It’s something that I still have an interest in and my friend Matt who does this course with me also has an interest so I thought I’d try and do something that would help us interact a bit better, even though we do interact a lot already. He is into the same music and comedies.

So its about being with your friend as much as anything else.
## Appendix 9. List of themes and their occurrence in the different settings.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Edward</th>
<th>Michael</th>
<th>Peter</th>
<th>Paul</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>a) b)</td>
<td>a) b)</td>
<td>a) b)</td>
<td>a) b)</td>
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<tr>
<td>1 Physical attributes*</td>
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<td>4 4 3 4</td>
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<td>0 0 0 0</td>
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<tr>
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<td>0 0 4 1</td>
<td>0 0 9 0</td>
<td>2 9 6 7</td>
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<tr>
<td>5 Skills of staff/being understood</td>
<td>0 0 2 2</td>
<td>0 0 4 1</td>
<td>0 0 9 0</td>
<td>2 9 6 7</td>
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<td>6 Coping with problems*</td>
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<td>2 1 1 1</td>
<td>2 1 1 1</td>
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<td>2 1 3 5</td>
<td>2 1 3 5</td>
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<tr>
<td>9 Vulnerability/insecurity*</td>
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<tr>
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<td>0 1 2 3</td>
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<tr>
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<td>0 4 2 2</td>
<td>0 4 2 2</td>
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<tr>
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<td>1 3 3 1</td>
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<td>1 3 3 1</td>
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<td>0 3 1 3</td>
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<td>5 7 7 5</td>
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<td>18 Social comparison</td>
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<td>4 5 6 11</td>
<td>4 5 6 11</td>
<td>4 5 6 11</td>
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</table>

a) first interview in special school setting

b) second interview in mainstream setting

* Omitted from next stage of analysis, or subsumed into other categories as only relevant to one person, or were comments in response to direct questions but were not issues for participants (i.e. problems).
Appendix 10. Occurrence of upward and downward comparisons in the different settings.

Comparisons

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<th>Participant</th>
<th>Special school</th>
<th>Mainstream setting</th>
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<td>lateral</td>
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<tr>
<td>Paul</td>
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