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Abstract

The aim of this study was to explore the relationship between being diagnosed with a developmental disorder and whether growing up this can affect individual environmental experiences and ideas of self-identity. This was achieved by exploring whether knowledge and awareness of diagnosis at contrasting ages produces differentiating results.

Focusing on Adults diagnosed on the Autistic Spectrum Disorder, this study intends to explore social assumptions of positives and negatives associated with having a diagnosis and how this may have affected participant's well-being.

50 participants took part in a qualitative survey designed specifically for adults with a diagnosis of ASD, two groups were subsequently formed which comprised of those diagnosed in childhood and those diagnosed in later life (18+). Using thematic analysis, questions featured in survey directly contributed to the discovery of five important themes, these were: Difference between peers, difference in treatment, positives of diagnosis, negatives of diagnosis and informing/withholding diagnostic information.

Key findings suggest that the most common code within these themes came under multifaceted versions of stigma, this manifested both positively and negative and consequently there is evidence suggesting that stigma experienced from others regardless of awareness of diagnosis can lead to self-stigma which contributes to a lesser state of positive well-being. Furthermore the presence of Introversion was discovered using the Myers Briggs Personality Test, which suggests a platform of ASD being considered as a difference rather than a disorder, which could help alleviate associated stigma.

However due to a found lack of previous research surrounding this area, this study is not enough to produce an influential and concrete theory surrounding this subject, but does however provide reasoning for future studies to follow a similar path.

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Introduction

Autism Spectrum Disorder (ASD) is a developmental mental health disorder, diagnosis for autism in modern western society is achieved either by the Diagnostics and Statistical Manual of Mental Disorders (DSM) (American Psychiatric association, 2013) or using the International Classification of diseases (ICD) (World Health Organisation, 1992). However the majority of research surrounding autism and mental health is critiqued using the DSM criteria, as such that is what this report will be focusing on. Signs and symptoms of ASD diagnosis in the DSM-5 includes "Persistent deficits in social communication and social interaction across multiple contexts" and "Restricted, repetitive patterns of behaviour, interests, or activities" (Black and Grant, pg 41, 2014). In 2000 the prevalence of Autism worldwide was reported to be 1-150 and by 2010 it climbed to 1-68 and it is still growing with 1.1% of the population of Britain said to be diagnosed with Autism (Centers for Disease Control and Prevention, 2015). This displays an alarming and persistent increase in the diagnosis of ASD, which due to its developmental nature, generally consists of children and adolescents. This high prevalence rate has bought with it a significant amount research on the subject of Autism, issues on biological etiology versus cognitive, behavioural and environmental theories are still being explored and will be examined within this report.

The main purpose of this study is to explore the effect of diagnosis surrounding autism with a focus on a perceived social influence. To achieve this, research surrounding the beneficial and detrimental effects of diagnosis on individual well-being and self-concept will be highlighted and related to ASD where available.

Cases of Autism are said to have been prevalent since the 1800's, it is often assumed due to

Causes & Theories

the nature of the disorder that Autism as a different mind-set has most likely been around long before this time (Davis, White and Ollendick, 2014). Despite this possible presence in antiquity, the term Autism was not founded until 1911 by a doctor called Eugen Bleleur, who adapted the Greek word autos, meaning self, into a mode of thinking which was later explored and expanded by Leo Kanner, who was the first to show cases of patients who all had the same autistic type symptoms in 1941(Bernier and Gerdts, 2010).

Autism as a specific diagnosis was not included in the DSM until the DSM lll (1980) (Volkmar, Bregman, Cohen and Cicchetti, 1988), this in essence means ASD is considered a modern disorder. Varying perspectives are given for the cause of autism which highlight that ASD could have biological roots, henceforth the exploration to uncovering causes of ASD has received significant support both financially and supportively.

Recent studies examining brain scans are said to have revealed noticeable differences in structure of people with ASD, as such (Amaral, Schumann and Nordahl, 2008) compiled a review on multitudinous research surrounding this. Some of the main trends within their review highlighted that difference in size of brain in young children could be associated with autism, however it is the presence of matter within these enlarged brains which are said to be more indicative. They suggested that MRI scans are popularly used and have shown difference in grey and white matter, although this matter diversity is not specifically a predictor of autistic symptoms, it does show plausible difference in social structure (Amaral et al, 2008), these findings generally suggest that whilst difference is noticeable, more research is needed to definitively predict biological cause.

As ASD is often said to be one of the most common heritable disorders, Genomic studies tend to back up biological research and there is numerous research supporting this (Hallmayer, Cleveland, Torres, Phillips, Cohen, Torigoe, Miller, Fedele, Collins, Smith, Lotspeich, Croen, Ozonoff, Lajonchere, 2011). The preferred way of examining genetic trends, tends to be through Twin studies, one study conducted on 192 pairs of twins explored this by examining pairs where only one of them was diagnosed with autism, although their research did signify a moderate genetic concurrence among twins (31-77%), it was said that the largest influence on presence of ASD seemed to be the environmental factors associated with the participants (Hallmayer et al, 2011) similar research produced concurrent results (Anderson, 2012).

Due to non-causal results in biological theory the focus on environmental and cognitive

factors are becoming increasingly explored. For example Grabrucker (2012) reviewed a variety of research and suggests that findings elude to the idea that people are not born with autism, but are pre-dispositioned to it, triggers later on in life, usually during childhood are said to then set this condition off. Conversely (London, 2000) argues that the possibility of environmental factors in pregnancy could be off interest when regarding environmental etiology. Cognitive impact has been examined more in explaining symptoms of ASD, rather than identifying cause. One popularized theory is that autism in itself is not simply a mental health disorder but an absence of being able to see and understand the world from other people's perspective's, which is described as Theory of Mind, suggesting that it is this impeded theory of mind which mainly contributes too noticeable autistic traits (Baron-Cohen, Leslie and Frith, 1985).

They conducted a study on reality and perception relating participant's with autism to those with no disorder and participants with Down Syndrome, finding that autistic children showed symptoms of a deficit which could not be related to mental retardation. Furthermore stating that whilst autistic children seemed to be centred in reality, other aspects of the task set showed they lacked the ability to understand or predict another's behaviour (Baron-Cohen, Leslie, Frith, 1985).

Simon baron Cohen (2009) expanded this creating the Empathizing-Systematic Theory of ASD which explains that empathy, which is the ability to see the world from another perspective, should be considered in conjunction with literal/systematic thinking, although this can cause problems in social situations, it also suggests a higher aptitude for certain areas of cognition.

When regarding health, it is a general consensus that biological research provides the most concrete evidence for credibility of etiology, contrarily most mental health conditions have not been definitively explained by biological roots and despite its research popularity and prevalence, autism is not an exception to this, when studied findings suggested that 15% of cases are explained by biology and only 1% of said statistic was generalizable (Abrahams and Geschwind, 2010), this poses the question of why diagnosis is climbing so rapidly.

Advances in technology and changes in Diagnostic Criteria are said to have had a influential impact on the increase of ASD (Hansen, Schendel and Parner, 2015), however it could be examined that prevalence of disorders such as ASD could be heavily influenced by societal views on causes and normality.

This can be seen through the changing views in society on ASD causes (Weintraub, 2011) suggested that previous societal thoughts of bad or cold mothering being a direct cause for autism, could have attributed to the low diagnosis at the time. In contrast modern societal consensus is that autism is biological and cannot be prevented or cured, possibly contributing to the heightened rate of diagnosis (Pellicano and Stears, 2011). Commenting on a more interactionist based social belief, Osmond, Krauss and Seltzer (2004) found that although children diagnosed with ASD showed significantly lower peer relationships, there openness to socializing was no different, which manifest's that rather than lacking in motivation to socialize, people with ASD experience lesser interaction from the environment around them, leading to a diagnosis based on abnormal socialising.

Conversely a research team based in America has published a series of papers examining the rise and has found numerous social reasoning behind the increase, by examining clusters of specific areas they found that children living in close proximity to a child diagnosed with autism were significantly more likely (47%) to receive a diagnosis themselves, including instances where such children were born outside the cluster (Mazumdar, Winter, Liu and Bearman, 2013). They postulate that this could be down to the parents of diagnosed children sharing information with others, which contributes to diagnosis seeking behaviour from other care givers (Liu, king and Bearman, 2010). Whilst this research lacked generalizability, due to both studies being conducted in the same area, the high rate of influence suggests that environmental based social reasoning for the causes of ASD should not be ruled out. Evaluation of whether mental illness is a product of disordered thinking or whether it is a direct comment on fear of abnormality in society, has been of previous concern surrounding mental health. One example of a socially created diagnosis would be the addition of homosexuality which featured in past DSM manuals, however the changing views of society, which now largely believe that homosexuality is not a disorder, meant this was taken out (Garnets and Kimmel 2003). These types of worries has caused contention on whether we are creating new disorders based on unknown or unaccepted behaviour in society as homosexuality once was. With this in mind and with autism's criteria mainly expounding the presence of abnormal social behaviour, there is arguably a cause for exploration.

The idea of mental illness being a social construct is not a recent idea, for example ideas

from past theorists such as Thomas Szasz (1920) who famously explored "the myth of mental illness" under the category of anti-psychiatry (Szasz, 1974), suggested that society is largely responsible for creating mental health issues. Tew (2005) has explored that in modern context this is seemingly manifesting as a focus on biological predictors leading to a heightened rate of diagnosis, which can in turn negatively affect society and those diagnosed in a variety of ways. In comment to past anti-psychiatral views, Jutel (2011) has reviewed modern research surrounding this and suggests that it wasn't until 1995 where the idea of social construct in diagnosis started to become re-researched and despite this resurgence, sociological aspect of diagnosis are still largely being ignored, postulating that lack of knowledge and evidence into these ideas has led to possible over diagnosis, which may have implications on economy, society and those directly diagnosed.

As they stand societal views on diagnosis of autism are seemingly undeterred by these types of worries, with research generally suggesting that autism should be diagnosed as early as possible due to the idea that early diagnosis and treatment is integral to the development of the individual (Matson, Wilkins and Gonzales, 2008) (Valicenti-McDermott, Hottinger, Seijo, Shulman, 2012). In contrast some argue that whilst autism is undoubtedly a disorder, which can have varying negative symptoms, the majority of research tends to focus too much on these, commenting that highlighting the positive attributes associated with ASD instead of focusing on the negatives, could prove beneficial to the individual (Mottron, 2011) Furthermore suggestion of reclassifying autism as a condition rather than a disorder, could help fight stigmatic implications (Russell and Norwich, 2012).

A key concept by Simon baron Cohen (2002) is his popularized idea of The Extreme Male Brain Theory of Autism, this comment's on his theories of empathizing and systemizing thinking into categories of gender differences, simply put he maintains that males natural way of thinking is systematic, compared to females which is said to be more empathizing, furthermore he suggests that those with autism are on the extreme end of a male brain pattern, leading to over systemizing thinking (Baron-Cohen, 2002).

This is important to note as it is generally found that more males are diagnosed with autism (Baron-Cohen, Lombardo, Auyeung, Ashwin, Chakrabarti, Knickmeyer, 2011). This type of thinking led to him expanding theories based in positive regard to attributes often seen from systematic brain patters, in which he advocated that many people on the spectrum have a mind which is built for science and mathematics (Baron-Cohen, Wheelwright,

Skinner, Martin, Clubley, 2001).

Ioan James (2003) broadened this view by suggesting that some of the world's most influential scientists could have been on the Autistic Spectrum had diagnosis been available at the time. His reasoning for this research was to advocate positive models with ASD, in the hope that these types of statements could reduce negative future thoughts and treatment of individuals with ASD (James, 2003).

If more research like this focused on ASD as a positive difference, perhaps diagnosis would not be rising so rapidly, consequently to aid these types of worries, we could attribute some symptoms of disorders like ASD merely to personality difference rather than an abnormality which requires the segregation of diagnosis.

Elizabeth Austin (2005) examined Autism Spectrum Quotient (AQ) diagnosis scores and personality measures, finding in general that those scoring highly on the AQ test tended to be low on extraversion and high on neuroticism scales. These findings in essence contribute to the idea that personality is a key factor in noticeable differences, however the terms used are still generally associated with negative implications, possibly showing that being introverted and neurotic are considered negative and a less common personality trait which are reminiscent of perceived disorder's.

Whether research indicates a constant need for diagnosis or suggests that over diagnosis may be occurring due to unfavourable reasons, diagnosis in itself, poses various impact on those on the receiving end. When considering diagnosis of mental health in development, which ASD largely applies too, it is important to highlight not only the positives of receiving a diagnosis, but also possible negatives which could be attributed to well-being.

Positives of diagnosis

Positives of early diagnosis in developmental disorders are well established. The main outcomes all gear towards the ultimate goal of diagnosis, which is described as a process which starts by identify the issue as early as possible so developmental problems can be addressed and hopefully improved by accessing support and treatment, which is said can provide symptom reduction and relief throughout childhood and in later life (Volkmar, Paul, Klin and Cohen, 2005).

Other gains which are attributed to a wider context of positives are sometimes present economically and politically, with regards to education, children diagnosed with a disorder are often not accountable when considering overall grade count, thus funding for schools based on performance will not be affected, consequently often the choice of whether children with ASD can attend mainstream or specialized school's is limited (Batten, Corbett, Rosenblatt, Withers and Yuille, 2006). Despite this academically driven concept, segregation of those diagnosed is considered not only helpful economically but also critical in the individuals learning development (Rones and Hoagwood, 2000). Extending this idea, some key positives for the diagnosed individual in education are financial gain, support for the family and understanding from school officials, these types of support are said to be the key to those with autism not being left behind within education (Marianna, 2010).

Although education is said to be a critical part of a child's development, the main positives with regards to symptomatic relief, are said to be gained through family and community support. (Gillis and Beights, 2012). This can be seen through explored treatment plans for ASD, as treatment is often achieved through therapeutic interventions which tend to be largely behavioural and longitudinal, a focus on family involvement proves beneficial both economically and in well-being associated with the family (Boyd, McDonough, Rupp, Khan and Bodfish, 2011). In accordance Hoagwood (2005) explores extensive previous research from 1980-2005 commending that diagnosis leads to this elevated interaction from the family on treatment and interventions, which is said can directly lead to family empowerment, in turn creating better outcomes for those diagnosed.

Research such as this is vast however it tends to ignore wellbeing from the child's perspective, this could be due to the fairly recent rise of ASD diagnosis as it is commonly assumed that the majority of people diagnosed tend to be considered too young to measure their own well-being, meaning treatment outcomes are usually focused from a parent's perspective (DePape and Lindsay, 2015). In consequence research from the individual's point of view is limited, furthermore the research that is available tends to point to a conflicting symptom reduction in adults.

One study testing the longitudinal value of diagnosis in adults who were diagnosed as children, found improvement in behavioural symptoms, however also found that social issues tended to maintain themselves from childhood (Billsted and Gillberg, 2007). Exploring variables which could influence adult prognosis, another conducted an in-depth

review of 68 adults diagnosed with autism as children, key findings suggested that those who grew up in an environment specifically designed for those with mental health issues (ie. Non mainstream schools) tended to have a negative adaptive social outcome and were less independent than those with limited knowledge of their diagnosis, who grew up in mainstream education (Howlin, Goode, Hutton and Rutter, 2004).

Critically examined, the ratio of this study was unbalanced as the majority of participants were those who did not grow up in mainstream education, leading to higher probability of lower social outcome, however this research does indicate a possible lack of impact on diagnosis and interventions for reducing symptom severity in later life, meaning that an exploration of the negatives of diagnosis might prove beneficial in exploring why this seems to be the case.

Negatives of diagnosis

Research surrounding the negatives of specifically diagnosing ASD in modern day is fairly limited, therefore when regarding the negatives of diagnosis most research focuses on differentiating mental health issues. One of the most well explored negative's, is the issue of stigmatization both by society and by the individual themselves (Hinshaw, 2007).

Mental health stigma is not a new constraint, it could be argued that throughout history mental health has been misunderstood and present through antiquity, such as the Greek's abandonment of the mentally ill, up to the extreme persecution of those who were perceived as possessed in the middle ages, although we no longer persecute in such tortuous ways, mental health stigma is still very much a modern concern (Hinshaw, 2007) .

Goffman famously describes stigma as a dehumanizing mark of shame, which leads to discriminating practices and thoughts manifesting in an idea that those stigmatized are abnormal and inferior to others, furthermore he implies that society tends to assume behaviour is a direct result of this abnormality, or as result of bad upbringing, theorizing that this is what gives society justification for treating stigmatized individuals inhumanely. (Hinshaw, 2007).

The majority of later research surrounding stigma, tends to adopt Goffman's theories, Link and Phelan (2001) have produced various papers examining the role of discriminative stigma and adapted an up to date popularized version of Goffman's process.

Social labelling is said to come first, this leads to the role of perceiving that someone is

different from yourself, which is then said to lead to stereotyping, "us and them" thinking and disadvantage as a consequential result. As we have grown as a society, it is proposed that often modern day stigma is not necessarily intended for harm, Corrigan, Markowitz and Watson (2004) highlight a structure for this kind of stigma, which comes under intentional discrimination and unintentional. Intentional is said to be related to societal policies, such as laws prohibiting those considered disordered from achieving the same life goals as an able person might. An example of this found within the UK and American law, says that people suffering from mental illness cannot be held accountable to the same community standard. This type of stigma said to achieve positive and negative effects, for example this intentional stigma can harm an individual's idea of abilities, but at the same time it can highlight necessary limitations, which can lead to necessary support for the individual (Corrigan, Markowitz and Watson, 2004).

In cases of ASD most individuals diagnosed with autism, would not be exempt from lawful policies, due to the idea that autism is not usually assessed as a severe mental disorder (Haskins and Silva, 2006), despite this, the term unable and incompetent is still used by the general public to describe those on the spectrum (Campbell, 2006).

This would come under Corrigan et al's (2004) subsequent category of unintentional stigmatization, suggesting that stigma comes from observation, such as representations in the news and how society has adopted intentionally discriminative policies. For example, those diagnosed with mental illness may have more trouble with receiving mortgages, insurance or financially stable job opportunities, Link and Phelan (2001) would describe this as the disadvantage part of the stigma model.

With regards to children and adolescents stigma which seems to have the biggest damaging effect is generally associated with discriminative interactions with peers.

Highlighting Link and Phelan's (2001) "us and them" thinking, research found that children and adolescents were substantially likely to avoid contact with peers who have mental health issues, remarking that this was down to fear of assumed negative or dangerous behaviour attributed to their illness (Martin, Pescosolido, Olafsdottir and Mcleod, 2007). Receiving stigma from outside sources such as peer discrimination, is also said to lead to self-stigmatization, however there are other diagnostic factors which can contribute to this manifestation. Moses (2010) found that participants who believed they could not control

their disorder, due to perceived causal understanding and awareness of symptoms, were much less likely to improve on symptoms, furthermore they correlated that those who's disorder's suggested social interactions were challenging, were less likely to engage in social behaviours due to anxiety surrounding their ability to do so.

Similarly Pasman (2010) found that being included under any DSM diagnosis tends to lead a lower self-concept, which resulted in less attempts to adapt, or to cope with symptoms, this demonstrates the idea that knowledge of symptoms and prognosis surrounding diagnosis can lead to a self-fulfilling prophecy.

Although this concept is rarely examined surrounding ASD, one study did find a correlation which found that self-awareness of symptoms provided relief in early life, but stated that longitudinal effects of this led to lower daily functioning and higher psychological issues in adult life (Seltzer, Krauss, Shattuck, Orsmand, Swe, Lord, 2003).

An example of adult psychological issues associated with these varying stigmatic processes and experiences are said to lead to a state of isolation and hopelessness among those diagnosed with mental health issues (World Health Organization, 2010).

With regards to this Carroll, Pantelis and Harvey (2009) found that hopelessness, usually surrounding thoughts about the future, was directly related to the knowledge of symptoms and prognosis of having a debilitating mental disorder, presenting that higher understanding of limitations led to dejected thoughts about the future. Correspondingly Connell, Cathain and Brazier (2014) explored that awareness of symptoms led to a state of helplessness as-well as hopelessness, expounding that depending on the chronicity of disorder, those diagnosed tended to display a longing to be independent, but due to awareness of outcomes had also displayed feelings of hopelessness surrounding their ability to do so based on their knowledge of limitations. This led to elevated helplessness, in which they perceived they required significant support in their everyday lives, within the study they also found that social interaction tended to lead to a lesser state of hopelessness (Connell, Cathain and Brazier, 2014).

ASD is not commented on within this research, and on closer examination of the literature there is a scarcity of research surrounding these types of issues which do feature ASD. Since it is largely known as a long term disorder with no cure and symptoms which are

largely affiliated with social issues, an exploration to associated hopelessness/helplessness to ASD diagnosis could prove vital when researching the well-being of such individuals.

Present Study

Research on diagnosis's varying positive and negatives effects is vast and has been applied to a wide range of mental health issues, however autism often seems to be excluded. This could be due down to the highlighted etiology debate which, as explored, has been at the forefront of autism research, however with the idea that diagnosis can have significantly damaging effects on the individual, a concern surrounding the high prevalence of diagnosis of ASD in children and adolescent's should be explored with regards to negative impact, especially with the found absence of finite etiology.

Most of the research in this review has focused on perceived well-being from outside perspectives and has ignored individual's experiences and own self perspectives of how diagnosis has affected them and on exploration, research from this point of view could not be found, hypothesizing that it is extremely limited.

As such the research we aim to explore has the intention of filling this void, by conducting qualitative investigation into psychological implications of those diagnosed on the Autistic Spectrum. Comparing the positives and negatives of diagnosis and the impact on the individual's well-being and sense of self.

Research Question:

A qualitative investigation into psychological implications of those diagnosed on the Autistic Spectrum. Exploring social issues and the impact of diagnosis on the individual's well-being and sense of self.

Design (purpose of study)

Due to the high prevalence of diagnosis there is a wealth of research exploring Autism Spectrum Disorder (ASD). Presently the most well researched factors are based on causation despite correspondence that research has failed to discover a finite etiology.

It has been found that despite this lack of causal understanding, diagnosis is continuing to rise for ASD at what could be considered an alarming rate. In response to this, previous research has explored the implications diagnostic labelling can have, including positive and negative effects on economy and the individual themselves.

Although there is a vast amount of research studying the impact of diagnosis with regards to other mental health issues, impact of ASD diagnosis is limited, when found, research typically focused on parental perception of their children's well-being (DePape and Lindsay, 2015) with limited studies found which examine implications of diagnosis from the individual's point of view. Bertsen & Rubin, 2006 suggest that increased knowledge of a disorder can alter the individual's self-identity and possibly adjust their personalities, in

consequence this study aims to fill the void of this type of research surrounding ASD by exploring self-perception of what it means to have diagnosis of ASD and how this has affected the individual diagnosed.

Due to the symptoms of ASD being described in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) as largely socially based, this study will also test experiences of these symptoms in childhood and in adulthood, with the explored idea that mental health diagnosis is at an all-time high due to a "pathologizing normality" (Bolton, 2013) theory that suggest a socially constructed view of disorders.

With regards to previous research, relating this to ASD has proved scarcely explored, however due to the cognitive associations of ASD, with reference to male brain theory (Baron-Cohen, 2002) and theory of mind (Baron-Cohen, 1985), personality traits such as Introversion/Extraversion were explored to accentuate a plausible social difference rather than disorder relating to ASD.

To explore self-perception in-depth, this study focused on a qualitative design approach, qualitative data is said to lead to in-depth results which is attributed as important specifically in the field of social sciences (Ritchie, Lewis, Nicholls, Ormston, 2014).

This research method is appropriate for the study in a variety of ways, first and foremost, data gathering in-depth responses tends to produce more personal results from the participants, (Shank, 1994) which was of vitality to the exploration of self-perception in this study.

Qualitative research is also described as based in experience rather than theory, although general theories underpin parts of this study, the overall concept was not based with a concrete hypothesis in mind, the exploration into the participants experience was of main evaluation, as such qualitative research methods allowed this to take place (Polkinghorne, 2005). Furthermore this approach is useful in aiding the perception based methods by grounding it in practice of diagnosis. Leerman and Sandelowski (2012) explored that qualitative research can address this using the following categories "causal mechanisms, approaches to adaptation, how-to guidance, unanticipated effects, and relevant contextual factors" on reflection the proposed study to did to some extent feature these categories, due to the practice based elements of mental health diagnosis.

Due to social issues associated with ASD (American Psychiatric Association, 2013) and the preference for systematic approaches (Baron-Cohen, 2009), a Survey/Questionnaire was

used in place of interviews, on the basis that an increasing response rate and length may be gained compared to using face to face interaction (Eyesenbach and Wyatt, 2002). Questionnaires are also useful in gathering a capacious amount of responses, having a wealth of responses can be beneficial to the legitimacy of results and also help in ensuring differentiating data, useful for comparison (Jansen, 2010) which is constituent for the study.

Participants

50 Participants took part in this study and were all adults of or over eighteen years of age, for the purpose of comparison, participants were segregated into categories of Diagnosed as a child (15) and diagnosed as an adult (35). In order to gain as many responses as possible the only constituency for participating in this research was having an official diagnosis of ASD, It was found that the sampled participants often presented themselves with a diagnosis of Asperger's, however due to the recent changes to diagnosis of ASD in the DSM-5 (American Psychiatric Association, 2013) such participants were included into the ASD diagnosis bracket and were informed of this prior to taking part in the survey. Gender, location and any other variables were not included as sampling criteria.

Materials

The Survey was produced on an online website (E-Surv, 2015), designed using mainly open-ended questions in order to encourage lengthy responses from participants (Denscombe, 2008), three closed questions were included to establish gender, current age and age of diagnosis. Gender was included in order to comment on previous theories which suggest a higher level of males diagnosed with ASD (Cheslack-Postavaa, Jordan-Young, 2012), age of diagnosis was included in order to establish two separate groups, which manifested as those diagnosed as children (DAC) and those diagnosed as an adult (DAA), this allowed for

comparison regarding the effect of diagnosis at different ages. Due to the nature of the research, the questions designed were largely open to interpretation to the participant, this was in keeping with the exploration side of qualitative data, allowing participants to talk freely and broadly on the questions asked (Descombe, 2008).

A degree of motive based questioning was included to establish responses relatable to the research in question, specifically on experiences from society and perceived positives and negatives of diagnosis, response bias was avoided as much as possible by using personal pro-nouns encouraging their own perception of what the question was exploring (Rohleder, P. Lyons, A. 2015).

To gain personality results, the Myers Briggs personality test, based on Carl Jung's theory of psychological types (1971) (Humanmetrics Inc, 1998) was included in a link at the bottom of the survey.

Procedure

The produced Survey was posted on selected forums specific to ASD, Selectivity was based on websites which did not discourage researcher involvement. Emails to the administrators of various websites were sent out requesting permission to post the research and questionnaires were only posted on websites where and when electronic confirmation was received, two websites responded back, these were AspiesCentral (2015) and WrongPlanet (2015).

Issues of confidentiality and ethical clearance were featured in a note both on the forum's and on the questionnaire's web page. It is said that receiving in-depth responses is influenced by feelings of trust and acceptance from the participants to the researcher which is often elevated by the qualitative social interaction approach (Marshall and Rossman, 2011). Although face to face contact was not conducted, the researcher interacted on forums explaining the nature of the research and addressing any questions received both before and during data collection. Social interaction of this sort was also used in order to alleviate participant's possible feelings of dehumanization, this in turn is said to lead to higher response rate (Marshall and Rossman, 2011). Personal association however was kept as minimal as possible in order to reduce the probability of demand characteristics experienced by participants (McCambridge, Bruin and Witton, 2012). Survey included the

Myers Briggs Personality Test (Humanmetrics, 2015) reasoning for the application of this test was first gained due to found preference and familiarity to the participants involved (Wrong Planet, 2012). Though research signified contention over the MBTI's validity and reliability (Capraro and Capraro, 2002) this test was chosen due to the reliability and test-retest value of the Introversion/Extraversion scale (Sipps and Alexander, 1987) (Capraro and Capraro 2002), as such this was the only result highlighted in report.

Results were collected electronically and stored both on a password protected website and hard drive for back up, accessibility to these results was only available to the researcher. Web based data was downloaded onto Microsoft Word in order to achieve structured line numbering for data analysis.

Data Analysis

The first process of analysis came from identifying participants from two different categories, those diagnosed with ASD as a child and those diagnosed as an adult, these were identified using responses given in the "Age of Diagnosis" question.

Once separated a process of Thematic Analysis was applied, this allowed for a flexible but valid analysis of data by identifying important themes (Braun and Clarke, 2006), each theme produced reflected the questions featured in the survey, which were gained by examining previous research and highlighting common attributes with the research in question, allowing for contextual final themes, these were;

1. **Difference Between Peers**

This related to participants views on perceived social and behavioral differences between themselves and others in childhood and adolescence.

2. **Treatment**

This referred to any experienced difference of treatment participants had perceived, relating to how they were treated, who by and how it differed from others.

3. **Positives of Diagnosis**

This theme highlighted participant's views of varying positive aspects gained by receiving a diagnosis of ASD.

4. **Negatives of Diagnosis**

This theme highlighted participant's views of varying negative aspects gained by receiving a diagnosis of ASD.
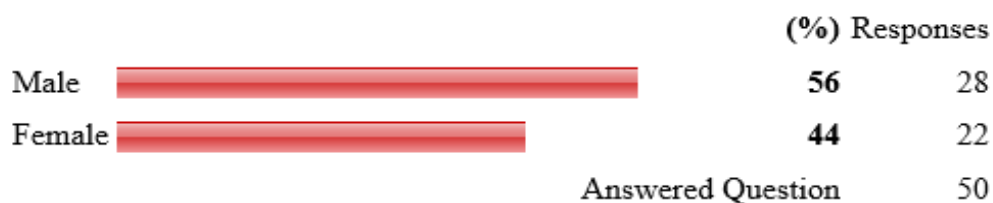
5. Informing Others

This refers to reasoning behind participant's decision to inform or not inform others of their diagnosis of ASD.

Due to the multiversal nature of these themes, final coding came from identifying common and relative sections within these themes, useful for consequent results and discussion. These were then utilized in a Grounded Theory (GT). Grounded theory allowed for comparison of unexplored findings meaning results were not based emotively, but still focused on social comparison. Using GT allowed for results to be transcribed clearly under a systematic basis this in turn allows for hypothesis to be gained and for future studies to be able to review and test-rete **Results and Discussion** ar terrain (Smith, 2008).

	(%)	Responses
Male	56	28
Female	44	22
Answered Question		50

B: Age of Diagnosis subgroup

	(%)	Responses
Adult	70	35
Child	30	15
Answered Question		50

 A: Gender Prevalence

The main bulk of results are presented in four identified themes: Difference between peers, Treatment, positives of diagnosis, negatives of diagnosis and Informing/Withholding. *(Extended explanation of themes in methodology)* These themes were present and relevant throughout both categories of participants who were diagnosed as children (DAC) and those

who were diagnosed as an adult (DAA).

Participant number = P.

Line number = L.

C: Theme - Difference between peers

The main bulk of self-perceived differences were closely relatable to diagnostic symptoms featured in the DSM-5 (APA, 2013). 20% of participants mentioned difference in interests and 12% of participants mentioned Pragmatic communication issues. Decreased Socialising were the most common across both categories (30%) which coincides with the DSM criteria of "Persistent deficits in social communication" (APA,2013).

The way in which these deficits manifested however came from two different perspectives which varied between the DAC and DAA groups. Participants out of the DAC group stated social interaction as a significant difference with phrases as follows. *"My own lack of need to socialise"(P.41-L.550)* and *"No-one wanted to play with me"(P.45-L.566).*

These answers display two possible perceptions on social interaction; we have described one as A-social, which defines the choice to not take part in social interaction and the other defined by feelings of segregation from others. Whilst these two perceptions are displayed as equal in the DAC group, the majority of participants who mentioned socialising in phrasing within the DAA group, fell under the category of Asocial (80%) with phrases such as: *"Not at all concerned with what was popular or what other kids thought of me"(P.7-L-85:86)"I preferred to be alone"(P.39-L.56:57).* As the DAA group seemed more comfortable in an Asocial role, one possible suggestion is that having a diagnosis in the DAC group led to more self-stigma with regards to socialising in childhood. Other ways in which this is presented is through found perceptions of Superiority; *"They were boring, shallow and very immature"(P.26-L.14)"I thought I was ok, but everyone else delusional"(P.22-L.25) "I was a more mature child so I saw other kids as slow"(P.2-L.70)*

15% of participants used superiority phrases in the DAA group compared with 6% within the DAC group. The presence of apathy came up in 20% of participants from both groups; the use of pronouns within such phrases between the groups also displayed this stigmatic difference. Common phrasing among the DAC group included: *"They always understood*

things that I didn't"(P.45-L.545)"They always seemed to know what everyone was thinking"(P.30-L.556). Common phrasing among the DAA group presented as: *"Other people did not seem to be interested in the most interesting things in life"(P.4-L.73) "I was often frustrated with their apparent superficiality"(P.7-L-88:89)*

Although responses were similar between the two categories, the way in which they were presented differs, the use of "they" within the DAC group displays known segregation with the hint that the DAC participants grew up perceiving others as correct and that lack of understanding was down to them as an individual, whereas apathy in the DAA group tended to oppose to this view. These responses are reminiscent of Link and Phelan's (2001) "us and them" thinking, the variance between the two displays that the DAC participants saw "us and them" as a negative association with "them" being superior, whereas the DAA group perceived that in childhood, the "us" was processed as a positive difference where they view their own abilities and processing as superior compared to "them". Whether this difference came specifically from having a diagnosis in childhood is unknown, however the difference in frequency between the two groups could suggest this as a possibility.

D: Treatment

Treatment presented itself negatively in responses from the majority of the participants from both sub groups (62%) which is equally split between the two. Presented under themes of experiences, the two most prevalent of these are bullying (26%): *"Verbally and physically abused"(P.49-L.146), "laughed at me some even teased me"(P.33-L.589)* and stigma (24%): *"being treated with an odd sort of caution"(P.7-L.202).*

Bullying as treatment was only accounted in 13% of participants from DAC compared to 34% in the DAA group, possibly suggesting that diagnosis in childhood led to less bullying from peers. Furthermore bullying responses presented themselves as treatment in the past rather than treatment in the present. In response present negatives usually manifested themselves through stigma, whilst stigma on an individual basis was highlighted throughout, the main course of stigma in adulthood seemingly came from others who were aware of participant's diagnosis, *"I can tell when I'm being patronized or handled with care in relation to my autism"(P.17-L.595)"When others are aware of diagnosis; they treat me as If I were younger or less intelligent than I am"(P.20-L.231:232).*

Bullying is not a surprising find within this research, as it has been highlighted that

discrimination from children and adolescent's is common with those who have a mental illness (Martin et al, 2007). Furthermore it seems that although bullying is less prevalent in adulthood, unintentional stigma (Corrigan et al, 2004) still surrounds ASD, possibly brought on by policies which regard those diagnosed as disadvantaged (Link and Phelan, 2001) therefore leading to the found feelings of being patronized or thought of as less intelligent.

E: Positives of Diagnosis

Reflective views on the positives of diagnosis between both categories displayed the largest wealth of information, postulating that diagnosis seemingly is regarded as a positive influence throughout the majority of participant's experiences. The biggest attribute of this was found in Self-Acceptance with 58% of all participants stating this as a gained positive:

"that I'm not broken; I can let go of trying to fix problems that aren't fixable"(P.42-L.296)"I have an explanation – I don't just think I'm a failure"(P.27-L.634).

Managing of symptoms also came up frequently and prevalence was found equally between the two groups. Presented through different aspects, one participant referred to symptoms as sensory issues and one other mentioned accessing therapy as part of this category, the rest manifested under social integration and adaption: *"things I can do to appear more "normal""(P.39-L.292) "I now understood why certain situations made me uncomfortable and was now able to avoid them"(P.33-L.622:623) "I've learned when to keep my nose out of other people's business, and I've become more conscious about the things they tell me in secret"(P.45-L.610:611)* This demonstrates that learning to adapt, avoid or cope with social scenarios they find challenging seems to be highest on their list of symptom management,

which reiterates that the one of the largest issues associated with ASD is that of relating or appearing normal to society.

Conversely social aspects surrounding positives was also presented by participant's gaining social interaction by means of a found diagnostic community: *"Feeling that there are others who exist in a similar reality"(P.22-L.265) "It was the first time I really felt part of something"(P.15-L.344:345).* Alongside community, the feeling of being part of something also manifested as pride of having a label from receiving diagnosis: *"A great sense of pride for being an aspie, as I've found from joining an online Asperger's forum that aspies are a wonderful gifted group"(P.7-L.321:322).* This finding somewhat contradicts the previous preference of A-Social, demonstrating that openness to socializing (Osmond, Krauss and Seltzer, 2004) is present, but is seemingly impeded with regards to people outside of the ASD bracket. This postulates that the gained positive of social interaction is specifically related to interaction with a community of people diagnosed specifically with ASD, who therefore likely have a similar way of processing information (Baron-cohen, 2002) and theory of mind (Baron-Cohen, Leslie and frith, 1985).

C:4 Negatives of diagnosis

Words which feature frequently throughout this theme reflect that having knowledge and a label received from diagnosis contributes to negative implications and thoughts *"The knowledge that you are different on such a substantial level kills your confidence"(P.45-L.645)* This highlights Pasmans (2010) theory of DSM diagnosis leading to a lower self-concept. as well as being treated as different from society, which seemed to have a direct relation to society's perspectives and knowledge of autism:

"People are idiots and think we are mass murderers because of the large amount of misdiagnosed psychopaths who get presented as aspies"(P.1-L.423:424)

Re-highlighting Link and Phelans (2001) "us and them" thinking this lowered self-concept seemed to emerge self-stigmatic thoughts which matched those experienced from stigma in society, with frequent use of similar segregating phrases such as *"I sometimes feel like a mutant freak"(P.48-L.433)* and *"the continued idea that I'm 'disordered'"(P.21-L.386).*

Moses (2010) found that causal understanding of a disorder affected the progress made in managing symptoms, in accordance to this views of causation about participants awareness of their diagnosis are present throughout: *"the basis of my alienation from most people is not some personality quirk but something basic in the fibres of my being"(P.48-L-433:434)*

and were often demonstrated through the belief that now they have received a diagnosis they are aware that there symptoms *"Can't be cured"(P.29-L.368).*

Carrol et al (2009) presented that this perceived understanding of etiology led to dejected thoughts about the future, this was a theme present in both categories highlighting a common state of hopelessness found in 24% of all participants *"I no longer have any hope that i will be acceptable for myself someday and wish for my life to end"(P.32-L.362:363).*

Conell et al (2014) directly related this hopelessness to increased helplessness, which was less common but still found among participants responses: *"Before my diagnosis i went on holiday by myself to another continent. After my diagnosis i feel i need help going to the doctor, which i did by myself since a teen"(P.2-L.429:430:431*). Other negatives include loss of identity, within the DAC group this was only shown in one participant, compared to the DAA group where loss of identity was displayed more often (17%) *"It was uncomfortable to suddenly have to change my view of myself"(P.29-L.468:469).* Loss of identity was also present due to experienced change in behaviour from the people around them *"My family went through a phase of querying me to no end about what it feels like to be me and how I experienced the world. Since they've known me all my life, it was a bit isolating to feel like id become a curiosity"(P.49-L.441:442:443:444).* With previous research suggesting that family involvement and interaction is a key positive in relieving symptoms of ASD (Hoagwood, 2005) this response apposes this by highlighting that instead of receiving relief, they ended up feeling isolated, this could be down to the found theory that most research surrounding this type was predominately focused from the families perspective (DePape and Lindsay, 2015) which highlights reasoning for exploring this concept from an individual's perspective.

D: Informing/Not informing

	(%)	Responses
Informs	38	19
Withholds	62	31
Answered question		*50*

The amount of participants who choose to inform others of their diagnosis was significantly lower compared to participants that withheld the information, in response, reasoning for informing others echoed previous examples of social stigma, with 47% relating reasons for informing to receiving understanding *"i am worried people will think im lazy and stupid rather than autistic"(P.13-L.530:531) "so they realise why i may seem a little different"(P.36-L.508)* Dispelling stigma accounted for 26% of reasons for informing *"i attempt to spread awareness of the condition and its symptoms in an effort to elicit more empathy"(P.20-L.540:541)* Coping with symptoms and issues of ASD only came up in 3 out of the 19(16%) participants. Stigma was also the most commonly attributed theme in the withholding group, although most participants did not expand on their reasons for withholding, all of the participants who did (7-31) mentioned avoiding stigma as reasoning for not informing others of their diagnosis; *"I worry that people will see it as a weakness and an excuse to manipulate me"(P.39-L.503:504)* With a strong essence of disgruntled feelings about how informing others shouldn't be issue *"If they are polite and mannerly, my diagnosis doesn't matter. My needs fall well within the range of common courtesy"(P.26-L.487:488)* One

participant also comments on this by almost directly displaying concerns surrounding Goffman's societal dehumanizing description of stigma (Hinshaw, 2007) *"Because it gives people justification for treating you like shit. It's dehumanizing"(P.43-L.506)*.

E: MBTI Results

The Myers Briggs Personality results (Humanmetrics, 2015) revealed that 100% of participants fell under the category of Introversion. Although all other segments of the MBTI were variant, introversion/extroversion is the only highlighted category *(Reasoning featured in methodology)*. Although simplistic, this does in essence show how a disorder could be attributed to a personality difference and rather than associating ASD Introversion to neuroticism (Austin, 2005), the MBTI provides a neutral difference with less reference to disorder and heightened reference to personality, this could account for the preference found from the ASD community for this over other personality test's (Wrong Planet, 2012).
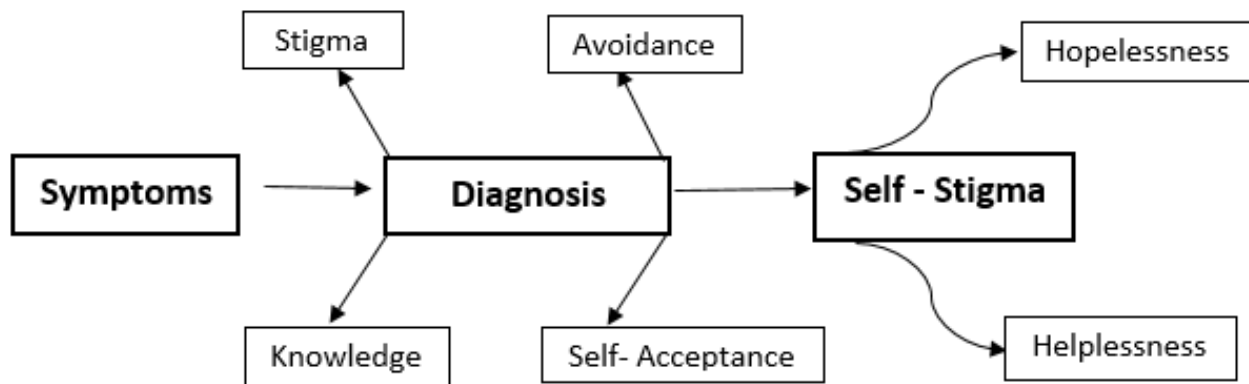
Conclusion

The main purpose of this study was to address a gap in research surrounding ASD, as previously explored a lack of perspective studies from individuals diagnosed with ASD was found when researching this subject area. As such, with the combined use of participant selection and qualitative questionnaires, in-depth and perspective individual responses were observably gained. Themes C and D provided generic results, simply highlighting the already well established social differences between those with ASD (American Psychiatric Association, 2013) and others around them, as well as the consequent avoidance and maltreatment that mental illness is often associated with (Martin, Pescosolido, Olafsdottir, Mcleod, 2007)(Hinshaw, 2007).

Possibly the most substantial finding, first presented in section D and then consistently highlighted throughout, is the multifaceted role of stigma in these participant's lives. As highlighted, stigma and mental illness is not a new phenomenon (Hinshaw, 2007), but the way in which stigma manifest's within this study is a much lesser explored concept. Research surrounding stigma associated with ASD is now largely historical, differing policies, diagnosis criteria and social beliefs of it as un-curable, has exploratively led to an overwhelming belief that it is a developmental disorder, which undoubtedly should be diagnosed and addressed early in order to obtain symptom reduction in later life ((Weintraub, 2011)(Matzen et al, 2012). These types of beliefs and general stigma

associated with mental health, have seemingly led to a new concept of self- stigma, directly related to those with a diagnosis, presented in a grounded theory as follows;

F: Grounded Theory displaying association of diagnosis to stigmatic thought

From the obtained results a link between all aspects of themes was discovered, this theory demonstrates that by means of receiving a diagnosis of ASD, symptoms must have been present in both categories regardless of age.

This diagnosis was associated with positive and negative implications, a neutral component of diagnosis led to increased knowledge of symptoms and information about ASD, the main associated positive was self-acceptance and the main negatives were avoidance and maltreatment in childhood, later demonstrated by means of stigma from society.

The conflict of whether the positives outweighed the negatives was not the found but generally all attributed effects of diagnosis led to a heightened self-stigma among participants. For example knowledge and self-acceptance possibly related to the found etiological belief of incurability among participants *"The basis of my alienation from most peoples is not some personality quirk but something basic in the fibres of my being"(P.48-l.433:434).* Avoidance and stigma led to lower self-concept and a belief of abnormality among them, all contributing to the umbrella category of self-stigma.

Which then in turn presented participants with hopeless and dejected thoughts about ASD *"I hate this disease, I hate myself"(P.32-L.362)* and their future prospects *"The main negative is that the part of you that you thought you could change will never change"(P.15-L.471*), as well as a learned helplessness in everyday life *"Maybe it gives me an excuse to avoid self-improvement"(P.27-L.679).* Although theoretical and specifically designed to this

study, research gathered could suggest a generalizability for this model, which could be associated to many mental health issues including ASD. The awareness shown by participants within this study is of interest, since the majority of studies do not examine adults with ASD, this study clearly demonstrates an ability to subjectively analyse their own diagnosis and their emotions towards it. With some seeing there diagnosis as means to advocate ASD as a difference rather than a disorder *"In much the same way the gay rights movements moved forward by people coming out, I believe that autism will one day be accepted as a difference rather than a disorder, I believe by telling people I am autistic, I am helping to dispel the myths and ideas that groups like autism speaks promotes"(P.21-L.496:497:498:499).* With this in mind the MBTI results showing that all participants were introverted suggests a platform for this type of difference demonstrating that this different "theory of mind" could manifest under a personality difference rather than a disorder.

Limitations

This study was limited in a variety of ways, although the sample size was vast and correlations were found, the majority of participant's presented with differentiating personal experiences make demonstrating links complicated and inherently theoretical. Sample size also faltered in the separation of the two groups, as the majority of participants fell under the DAA category, this meant comparing these answers with the DAC could be considered bias and inconsequential. The way in which the research addressed lack of participants diagnosed as children, was to include the question based on all participants view of themselves during childhood, however as this study featured self-reported measures, re-call bias could not be avoided, suggesting that as adults, answers may not reflect the true nature of their experiences growing up.

Measures used to collect data did prove effective, using a survey, with the reasoning that those with ASD struggle with social interactions, observably seemed to facilitate long and honest responses, this could be considered of importance when conducting future research of this nature.

However due to the limitations of using survey limitations, there is a number of key questions that came out of the data which would have been useful to include in the original document, such as their beliefs and understanding of etiology of ASD, key information about upbringing (whether they grew up in mainstream education) and what treatments they

have received, if any, would have been useful additions to the research, which may have been easier to include had interviews taken place. The longitudinal value of this paper is limited, a hint of demand characteristics may have been of influence due to researcher interaction with participants prior and during process, however participants were not aware of the specific approach the research was taking, so whilst unavoidable, this was generally kept at a minimum. Perception based research also is very limited to how participants were feeling at the time, if the study was to be re-done, results and opinions would most likely differ.

Despite these limitations the presence of stigma surrounding the majority of responses, could be considered an important finding, perhaps the best platform for these results is to motivate more research based on the socially constructed idea of diagnosis, especially when ASD diagnosis is rising, the negatives highlighted in this research could be explored in future studies to highlight a found prevalence of "Pathologizing normality"(Bolton,2013)
with regards to diagnosis, which, as demonstrated within the study, concurrent findings between over-diagnosis of mental health issues, with no finite causal understanding and the relation of this to ASD perhaps requires more research, as seemingly there is scarcity available at this present moment.

Furthermore because of the found hopelessness associated with diagnosis and the advocating stance of hope that ASD will someday be a difference rather than a disorder an exploration into personality or research focusing on positive differences would be useful to explore in the future surrounding this topic.

Thomas Szatz famously stated that "*no further evidence is needed to show that "mental illness" is not the name of a biological condition whose nature awaits to be elucidated, but the name of a concept whose purpose is to obscure the obvious".*

This study is very reminiscent of this idea, however, as positives of diagnosis is explored and was demonstrated by the participants, further and a vast amount of research is needed in this area. However with regards to diminishing stigmatic implications, future research could

utilize this idea, which could help in the shifting of ASD into a difference and possibly address the over-diagnosis problem society seems to be gaining.

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Research Project Ethical Approval Form

1. Research Details

Student Name: Amy Bayes	**Supervisor:** Caroline Keech
Programme Title: BA (Hons) Human Behaviour Studies	**Module Title:** Dissertation

2. Signatures

6.c College Ethics Board Approval

We agree that this project has been:

☐ approved at the College Ethics Board and research may continue

☐ declined at the College Ethics Board. Review of methodology recommended.

☑ approved at the College Ethics Board and the research may continue subject to

- *Supervisor to view questions prior to testing*

Signed:_____ Ethics Board Chair or nominee

Date of Panel: Wednesday 26th November 2014