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2015-08-31
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"Too different to be accepted, too different to fit in":

Adolescent girls' perceptions of living with ASD, as presented on YouTube

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A research report submitted in partial fulfilment of the requirements for the degree of Master of Education (Educational Psychology) in the faculty of Humanities, University of the Witwatersrand, Johannesburg, 2013.

"A central issue in any research that examines the lived experiences of individuals who have had some kind of diagnostic label applied to them is their understanding of and engagement with the label itself" (Humphrey & Lewis, 2008, p. 30).

DECLARATION

I, Naomi Anna Feist, hereby declare that this dissertation is my own unaided work. It is submitted for the Degree of Master of Education (Educational Psychology) at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



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Naomi Anna Feist

_____24 February, 2014_____

Date

ACKNOWLEDGEMENTS

There are a number of individuals who I would like to extend thanks to for helping me complete this research report:

Firstly, my supervisor, Dr Gillian Mooney, for her patience, enthusiasm and guidance throughout the process.

My husband, Anthony, whose love and support has been my strength and my inspiration.

My brother, Chris, for his time and patience in proof-reading this report, and for his words of encouragement, which lifted me up and kept me going.

My parents who have, through their continued support, laid the foundation for me to achieve my highest potential.

Finally, and very importantly, the individuals in this study who had the courage and passion to enlighten the world about their condition. May I do justice to your cause.

ABSTRACT

It is well known that those with autism spectrum disorders (ASDs) have difficulties with social interactions and the forming of meaningful relationships. This difficulty becomes even more pronounced during adolescence when peer relationships and friendships become extremely important for the formation of identity. The way in which these individuals experience these difficulties and make sense of the disorder may be influenced by the views society has regarding their diagnosis and their behavioural differences. This research focused on girls with ASD. Females on the spectrum may present with different symptomology to males, which may further influence their experiences. Sixteen videos of three girls with ASD, who are at the stage of adolescence or emerging adulthood, were selected for the sample. These videos were analysed with regard to how these girls construct this condition on YouTube and experience their differences within Western culture. It was, therefore, a unique study in that it involved the analysis of YouTube videos, which allowed access to these adolescents' unsolicited opinions. An Interpretative Phenomenological Analysis (IPA) approach to data collection and analysis was adopted to gain an in-depth understanding of their experiences. This approach is applied within a social constructionist paradigm, which provided the epistemological framework for this research. The study focused primarily on views of ASD as a difference (identifying flaws and strengths in ASD), and as a disability (viewing it only in terms of the difficulties associated with it). The results revealed that the way ASD is perceived by individuals with the condition may have an impact on their identity formation and acceptance of the diagnosis during the adolescent and emerging adulthood phase of development. Based on the literature in the field, several hypotheses were developed to explain the findings, which may be of interest for further research. Furthermore, several recommendations are provided to inform therapeutic intervention.

KEY WORDS

Autism spectrum disorder, Asperger's syndrome, adolescence, perceptions, diagnosis, identity, YouTube, Interpretative Phenomenological Analysis.

ABBREVIATIONS

AAC – Augmentative and Alternative Communication System

APA – American Psychiatric Association

ARI – Autism Research Institute

ASA – American Sociological Association

ASD – Autism Spectrum Disorder

AS – Asperger's Syndrome

CDC – Centers for Disease Control and Prevention

DLA – Disability Living Allowance

DSM – Diagnostic and Statistical Manual of Mental Disorders

GCSE – General Certificate of Secondary Education

HFA – High Functioning Autism

IPA – Interpretative Phenomenological Analysis

IQ – Intelligence Quotient

OCD – Obsessive Compulsive Disorder

REB – Research Ethics Board

TCPS – Tri-Council Policy Statement

USA – United States of America

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1. INTRODUCTION

1.1 Aim of the Study

This study used interpretative phenomenological analysis (IPA) to analyse the first-hand accounts of girls in adolescence and emerging adulthood speaking about their experiences of autism spectrum disorder (ASD) on YouTube, the most widely used online video website.

These videos were analysed through the lens of social constructionism to explore how individuals with ASD frame their diagnosis. That is, I[1] aimed to determine how they construct and make sense of their disorder, and whether notions of it as a difference or disability have influenced their perceptions.

1.2 Research Problem

This research aimed to address the following research problem:
What perceptions of ASD do adolescent females living with this disorder present on YouTube?

The research will aim to address the following questions:
1) How do adolescents with ASD construct their diagnosis on YouTube?
2) What are their experiences of their impairments in socio-emotional functioning?

1.3 Background and Rationale for the Study

Autism spectrum disorders (ASDs) are a group of developmental disabilities that fall along a continuum ranging from severe to milder expressions of autism. People with ASDs share common symptoms. However, there are differences with regard to when the symptoms start, how severe they are and their exact nature (Centers for Disease Control and Prevention, CDC, 2012a). The level of severity of ASD is determined by how much support is needed with regard to the individual's difficulties with social communication and restricted interests and repetitive behaviours (Autism Research Institute, ARI, 2013).

[1] This research report is written in the first person as the researcher occupies a central position within IPA studies. The interpretations of the analysis are those of the researcher and are, therefore, reflexive. This is discussed further in Section 3.4.5.

According to the Fifth Edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Asperger's syndrome[2] has now been folded into the autism spectrum and is now referred to as ASD (Happé, 2011). The characteristics that marked ASD in the DSM-IV-TR included impairments in communication and social interaction, and a narrow, repetitive pattern of activities (American Psychiatric Association, APA, 2000). The new edition requires more symptoms to meet the criteria for a diagnosis for ASD than the DSM-IV-TR within the area of fixated interests and repetitive behaviours. Furthermore, in the DSM-5, the communication and social interaction domains will be combined into one, titled "Social/Communication Deficits" (ARI, 2013).

As is evident from the above diagnostic criteria for ASD, those with the disorder experience marked difficulties in their social understanding and ability to empathise with others, which can affect their ability to form meaningful relationships (Attwood, 2007). During adolescence this can be of particular concern as the role that peer relationships play in the formation of identity is highly significant at this stage of development (Gouws, Kruger, & Burger, 2000; Tarrant, Mackenzie, & Hewitt, 2006).

There is limited research regarding how adolescents and young adults experience these difficulties associated with ASD, and there have been various recommendations that in-depth, qualitative research be conducted in this regard (e.g. Barrett, 2006; Molloy & Vasil, 2004; Rydzewska, 2012). There is also a lack of research on their perceptions of the diagnosis and how this influences their developing identity (Bagatell, 2007; Billington, 2006; Huws & Jones, 2008; O'Neil, 2008; MacLeod, Lewis, & Robertson, 2013). In particular, there appear to be no published qualitative studies focusing on girls' experiences and perceptions of ASD.

How young people with ASD perceive their condition may be influenced by various factors. For instance, the changing nature of the diagnosis (from Asperger's syndrome to mild autism spectrum disorder) may influence how they perceive it, particularly if they identified strongly with a previous diagnosis. Some may also take issue with the diagnosis in general because they do not believe that their behavioural differences are symptoms of a disorder or disability

[2] The adolescents in the YouTube videos I analysed referred to themselves as having Asperger's syndrome (AS). Therefore, in order to remain true to their perceptions and accounts of the diagnosis, where these adolescents refer to AS in the 'Results and Discussion' section (Section 5), I have also referred to it as such. In the remainder of this thesis, however, it will be referred to as ASD, in accordance with the DSM-5 diagnostic category.

(Bagatell, 2007; Humphrey & Lewis, 2008). Some may instead consider such differences in behaviour as manifestations of a difference in cognitive style (Bagatell, 2007). Furthermore, many girls with ASD receive a late diagnosis, possibly because their symptoms are less obvious than boys' symptoms (McKnight & Culotta, 2012). The stage at which they attain a diagnosis may further influence their perceptions of the condition.

This research aims to analyse how young females with ASD experience these difficulties, as well as the various ways in which they construct and make sense of their diagnosis. Though this is a small-scale in-depth qualitative analysis and the results will, therefore, not be generalisable, it is hoped that it might contribute to the body of knowledge in this area and help to give voice to those living with the disorder. We cannot run successful support systems for people with ASD if we exclude their views in the process of establishing and evaluating these systems, as certain needs will be overlooked and inadequate support provided (Griffith, Totsika, Nash, & Hastings, 2011).

In order to gain a better understanding of how these young people with ASD construct their disorder on YouTube, I have adopted a social constructionist stance to this research. This view holds that society has constructed this disorder in order to marginalise these individuals' behavioural and neurobiological differences (Molloy & Vasil, 2002). For the purposes of this research, I attempted to remain actively aware of my own views regarding ASD, and how these might affect the analysis. At the same time, I sought to remain open to the multiple ways these adolescents understand this disorder. I focussed specifically on their perceptions of it as a disability or difference.

YouTube videos have been ideal for analysing the perceptions of these adolescents. This online video forum was founded in 2005 and not much research has been done using this medium, despite it providing access to naturally occurring data that can be relevant to understanding people's perspectives. Millions of people have now taken to producing and sharing user-generated video, known as video blogs or "vlogs". Vlogs are a form of online publishing and can also serve as personal online diaries. Anyone with simple video production tools (e.g. a webcam or cellphone) can share their videos online. YouTube is an obvious choice for sourcing such videos as it is currently the most popular online video website (Molyneaux, O'Donnell, Gibson, & Singer, 2008).

There are several other reasons why I have chosen YouTube videos as the focus of my research. Firstly, as Humphrey and Lewis (2008) explain, it is very difficult to conduct interviews with people with ASD because they struggle with conversational skills. They may have difficulty understanding complex questions and instructions (Attwood, 2007). This said, they do have the capacity to describe eloquently how they perceive the world and their relationship to it (Griffith et al., 2011). The use of YouTube prevents the difficulties associated with trying to understand my questions or intentions, which may hinder their ability to adequately express themselves. Secondly, in an interview situation I would be a stranger to them and this may inhibit their ability to open up about personal matters. Thirdly, analysing YouTube videos allows me to access adolescents and young people with ASD's unframed, unsolicited accounts of their experiences of living with ASD. Without direction from the researcher, they are given the space to express what they deem important about living with this condition. There has been no previously published research on autism spectrum disorders that looks to YouTube for personal accounts; thus, this research is unique and adds new insight into their perceptions and experiences.

The videos will be analysed using IPA. Smith (2004) explains that many IPA studies are focused around life-transforming or life-threatening events, conditions or decisions. This is relevant to the present study as having a diagnosis of ASD, particularly during adolescence and emerging adulthood, when so many changes are already taking place in one's life, *is* life-transforming. Another key organising principles that emerges in this approach is *identity* (Smith, 2004). Identity formation is significant to this stage of life. How these adolescents with ASD make sense of themselves and their personal world in relation to the disorder is central to this research.

Here has been provided a brief background and rationale for this study. I highlighted the importance of capturing the voices of young females diagnosed with ASD in order to better understand their experiences of living with this disorder. I also discussed the potential benefits of using YouTube in this endeavour. A more in-depth overview of the literature will now be provided in order to establish a deeper level of understanding of ASD, and how society's constructions of it might influence these young people's perceptions of their condition and identity formation.

2. LITERATURE REVIEW

The review of literature relevant to this research will begin with a brief overview of the changes to criteria for a diagnosis of ASD, according to the DSM-5. Following this, I will briefly address the difficulties with socio-emotional functioning that are experienced by individuals with ASD, as well as the gender differences in presentation of symptomology. Once a better understanding of ASD has been provided, I will address the diagnosis from a social-constructionist position, showing how it is largely a Western phenomenon. I will then look at the various psychobiological theories postulating ASD as a disability or difference, which may influence people's perceptions of their diagnosis. This will be followed by a review of qualitative research on individuals' experiences of living with the condition. Finally, I will look at an identity theory, which may guide understanding of the effect of having a chronic disability on identity progression, as well as the collective identity of individuals with ASD.

2.1 The Formation of the Diagnosis

The development of ASD evolved originally from separate discoveries made by Hans Asperger and Leo Kanner in the 1940's. Asperger identified a pattern of abnormal behaviour, which he referred to as autistic psychopathy (Khouzam, El-Gabalawi, Pirwani, & Priest, 2004). The term psychopathy was used in the technical sense to mean an abnormality in personality (Wing, 1981). Not long before Asperger presented his original paper on this condition, Kanner published his account on infantile autism (Khouzam et al., 2004).

It was only in 1979 that Judith Gould and Lorna Wing proposed the concept of an "autistic spectrum disorder" to describe a specific group of children that displayed symptoms of autistic disorder, but did not quite meet this classification. And in 1981, Wing first coined the phrase 'Asperger's syndrome' to describe individuals that had symptoms similar to those described by Hans Asperger. This is when the term began to be more widely used in the English-speaking world, but it only entered the DSM-IV as an official diagnosis in 1994. This was revised by the APA in 2000 with the DSM-IV-TR (Khouzam et al., 2004).

Since then, there has been a significant rise in the number of children diagnosed with ASD (CDC, 2012b; Rivet & Matson, 2011), and current estimates indicate that about 1 in 88

children now has an autism spectrum disorder (CDC, 2012b). In recent years, it has been the goal to develop a better understanding of ASDs and gain insight into why there has been such a dramatic increase in cases, as well as to determine better ways to support individuals on the spectrum. However, researchers have struggled to identify any significant differences between AS and mild ASD, which was previously referred to as high functioning autism (HFA), and it is believed that the formation of subtypes, such as AS and pervasive developmental disorders, has hindered research into the epidemiology of ASDs (Grzadzinski, Huerta, & Lord, 2013). In the DSM-IV-TR, the major difference identified was that those with AS did not have a history of language impairment unlike those with HFA (APA, 2000). However, recent research has shown that a delay in or complete lack of development in expressive language is neither specific, nor universal, to individuals with ASD (Hartley & Sikora, 2010; Lord, Storoschuk, Rutter, & Pickles, 1993) and, consequently, this criterion has been removed from the DSM-5 (Grzadzinski et al., 2013).

In accordance with this, Shea (2005) discusses the 'lumpers' and 'splitters' of AS and ASD in the professional community who either consider HFA and AS to be separate diagnoses (the splitters), or who consider AS to be on the autistic spectrum (the lumpers). Shea (2005) suggests we should be splitters when we consider the individuality in experiences and presentation of this disorder, but lumpers when it comes to providing support and funding for those with ASD. Grzadzinski et al. (2013) discuss how the latest diagnostic criteria for the DSM-5 will support future efforts at categorising individuals on the autistic spectrum into more easily definable subtypes which may aid treatment and support.

The new criteria for the DSM-5 calls for recognition of the non-ASD symptoms that individuals with the condition may also be affected by, such as cognitive ability, expressive language ability, onset patterns, and comorbid psychopathology. These distinctions may provide an additional means by which to identify subtypes within ASD (Grzadzinski et al., 2013). While there is still uncertainty about the subtypes of ASD, the core characteristics of the condition have remained the same in the DSM-5, such that those previously diagnosed with AS need not seek a re-diagnosis (Hyman, 2013). However, the quality and quantity of these characteristics across the spectrum are variable (Grzadzinski et al., 2013).

These characteristics are divided into two domains: social/communication deficits, and fixated interests/repetitive behaviours. Two of the four criteria for the fixated interests/repetitive interests/behaviours domain need to be present. These include:

> "Stereotyped or repetitive speech, motor movements or use of objects; excessive adherence to routines, ritualized patterns of verbal or nonverbal behaviour, or excessive resistance to change; highly restricted interests that are abnormal in intensity or focus; hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment. According to the DSM-5, these symptoms must cause functional impairment" (Hyman, 2013, para. 6).

Individuals need to meet all criteria for the domain of social-communication deficits. These include:

> "Problems reciprocating social or emotional interaction, including difficulty establishing or maintaining back-and-forth conversations and interactions, inability to initiate an interaction, and problems with shared attention or sharing of emotions and interests with others; severe problems maintaining relationships – ranges from lack of interest in other people to difficulties in pretend play and engaging in age-appropriate social activities, and problems adjusting to different social expectations; nonverbal communication problems such as abnormal eye contact, posture, facial expressions, tone of voice and gestures, as well as an inability to understand these" (Hyman, 2013, para. 5).

The difficulty with social communication is considered to be the one clear and unchanging characteristic of ASD, which emerges in childhood (Sigman, Dijamco, Gratier, & Rozga, 2004; Whitehouse, Durkin, Jaquet, & Ziatas, 2008). Consequently, understanding the nature and impact of problems with interacting with others in a social world may be the key to understanding this "pathology". The difficulties that these individuals experience with regard social communication deficits will now be discussed in more detail.

2.2 The Socio-Emotional Functioning of Adolescents with ASD

Adolescents with ASD may struggle to establish meaningful relationships because of their difficulties with social understanding and empathising with others (Attwood, 2007). They struggle to identify subtle social nuances, such as different facial expressions, changes in tone of voice or seemingly simple expressive gestures. This can make it difficult for them to read

people's intentions and feelings (Attwood, 2007; Bauminger, Solomon, & Rogers, 2010; Frith, Happé, & Siddons, 1994). Furthermore, individuals with Asperger's syndrome have a tendency to focus on one particular interest often to the exclusion of all else, which may bore their peers (Attwood, 2007; Barnhill, 2001). Their 'odd' behaviour and 'strange' manner of speaking may also alienate them from others and make them vulnerable to rejection from the peer group (Camarena & Sarigiani, 2009; Carrington, Papinczak, & Templeton, 2003).

This is problematic for the individual with ASD as peer acceptance has multiple benefits and is crucial for healthy social and emotional development during adolescence and emerging adulthood (Bauminger et al., 2008; Tantam, 1991). It provides the person the opportunity to establish an identity, form meaningful friendships, learn about and approach members of the opposite sex, and gain valuable social skills that will later be of value in the working world (Gouws et al., 2000).

Those with ASD may not only face peer rejection, but may also be at risk for becoming victims of bullying and teasing (Billington, 2006; Carrington et al., 2003; Humphrey & Lewis, 2008). This can lead to the development of clinically diagnosable depression (Barnhill & Myles, 2001; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Wilkinson, 2005), anxiety (Ghaziuddin et al., 1998; Safran, 2002; Wing, 1981) and conduct disorders (Myles & Simpson, 1998; Tantam, 2000) in this group of people. They may also experience loneliness as they struggle to make friends (Bauminger & Kasari, 2000; Whitehouse et al., 2008). Some people develop social anxiety because of their difficulties, which may further hinder their ability to form meaningful social relations (Bauminger et al., 2010).

For a while it was believed that individuals with ASD prefer isolation (Kanner, 1943); however, this is not always the case and many with ASD have a strong desire for friendship (Church, Alisanski, & Amanullah, 2000; Locke, Ishijima, & Kasari, 2010; Molloy & Vasil, 2004; Portway & Johnson, 2003). Individuals with good verbal and cognitive abilities may be at an advantage when attempting to form friendships (Daniel & Billingsley, 2010), and they may be able to learn social skills that come naturally to others, which is referred to as masquerading (Carrington et al., 2003).

Various social communication difficulties, experienced by young people with a diagnosis of ASD, were raised here. It was discussed how these difficulties can impact on peer

relationships. This can be particularly harmful for young people as it can result in psychological and emotional problems. The gender of people diagnosed with ASD may also influence the severity with which they experience these social problems. These gender differences in the symptomology of ASD will now be broached.

2.3 Gender Differences in ASD Symptomology and Diagnosis

Here I will explain how autistic traits in ASD may present differently in girls than boys. It will be discussed how this may affect their social-emotional functioning and their attainment of a diagnosis.

For years, autism was seen as primarily a male disorder, with a significantly higher number of boys diagnosed with ASD than girls (Fombonne, 2009; Giarelli et al., 2009; McKnight & Culotta, 2012; Sarris, 2013; Volkmar, Szatmari, & Sparrow, 1993). However, it is suspected that many girls with ASD are simply being underdiagnosed (McKnight & Culotta, 2012; Sarris, 2013).

In Dworzynski, Ronald, Bolton, and Happé's (2012) study, which aimed to explore how sex differences in autistic traits affect the diagnosis of girls with ASD, it was found that girls who met the diagnostic criteria for autism were more likely than boys with ASD to have additional learning and/or behavioural problems (Dworzynski et al., 2012). They suggested that girls with high levels of autistic traits without behaviour or learning problems may go unidentified by the Childhood Autism Spectrum Test, which is used to diagnose ASD. This may be a result of gender bias in diagnosis or because girls may be able to adapt better to their condition than boys (Dworzynski et al., 2012). Thus, when they do not present with such learning and/or behavioural problems, their symptoms go unrecognised. What is becoming increasingly acknowledged is that tools used to assess ASD need to be developed which take gender into account (Constantino & Charman, 2012).

The reason behind the possible lack of recognition of girls' difficulties may relate to their symptom presentation. For instance, Kasari, Locke, Gulsrud and Rotheram-Fuller (2011) suggest that gender influences the social organization of children with ASD. While social-communication difficulties are reported as similar across genders (May et al., 2012), research suggests that boys have more difficulties with social communication as children, while girls

experience more social difficulties as they enter their teenage years and beyond (Rivet & Matson, 2011). Young girls with ASD may blend into the social group more easily in childhood because they may be "mothered" by other girls (Attwood, 2006). However, certain characteristics of ASD may be less tolerated in adolescent girls than in adolescent boys. For instance, some of the dominant features in female bonding conflict with autistic characteristics, such as engaging in reciprocal conversations about thoughts and feelings, as well as using self-disclosure to intensify relationships (Maccoby, 2002), which is a challenge for many adolescent females with ASD. Furthermore, girls may use silences, shared glances, and direct but polite requests to socialise with one another, which may be difficult for the girl with ASD to understand (Dean, Adams, & Kasari, 2013).

Many girls with ASD may also be at increased risk for rejection from their typical peers because of their high potential for making social blunders (Dean et al., 2013). Once they have been rejected, it may be difficult for them to form new friendships because of the nature of secret-keeping characteristic of many stable female friendships – girls will not easily share their secrets with other girls and, therefore, will not easily accept new girls into their friendship circle (Crick & Dodge, 1996). According to Donvan (2008, p. 2), girls with ASD are "literally disabled when it comes to surviving the more sophisticated social complex of teenage female society".

Girls with ASD may also be more likely than boys with ASD to avoid demands placed on them, to be careless with their appearance and dress, and to interact mostly with younger children (Kopp & Gillberg, 2011). They also show earlier proficiency in language ability (Burman, Bitan, & Booth, 2008) and may be more passive, anxious and depressed, while boys tend to be more active, busy or angry. Boys with ASD may also be more likely than girls with ASD to lack a best friend, speak with a monotone voice (whereas girls with ASD are more likely to speak in a high-pitched, childish or hoarse voice) (Kopp & Gillberg, 2011), and have higher levels of repetitive and stereotyped behaviours than females. All such differences may prevent a girl's symptoms of ASD from being recognised. As a consequence, many girls with ASD may not receive a timely diagnosis, or a diagnosis at all (Krahn & Fenton, 2012).

Such gender differences in symptomology of ASD still need to be accurately determined, and there is no agreement about the nature and causes of gender differences in ASD. May,

Cornish and Rinehart (2012) suggest that there is no consistent evidence for gender differences in severity of symptoms of ASD in the existing research literature, which may be a result of small sample sizes in research, heterogeneous study methodology, and possible changes in symptoms across development; or there may simply be no clear differences. McKnight and Culotta (2012) also challenge the idea that girls present with a more benign expression of ASD than boys. However, some scientists believe that ASD phenotypes do indeed express differently in girls than in boys (Thompson, Caruso, & Ellerbeck, 2003).

While there is debate around whether there are gender differences in ASD, it is apparent that females are still negatively affected by symptoms (McKnight & Culotta, 2012), and there is concern that a late diagnosis may result in painful identity issues (Krahn & Fenton, 2012). Assessment tools that fail to recognise gender differences in symptomology, thus leaving females undiagnosed or misdiagnosed, as well as limited research on females with ASD (May et al., 2012; Rivet & Matson, 2011; Thompson et al., 2003), may also result in many girls being excluded from the prospective benefits of research. That is, they may not receive the therapeutic and educational interventions designed to respond to their specific needs and interests (Krahn & Fenton, 2012; Nyd*é*n, Hjelmquist, & Gillberg, 2000; Thompson et al., 2003; Wilkinson, 2008).

As a psychologist, I recognise the importance of such interventions in helping people with ASD, and I value the role the diagnosis plays in ensuring the suitability and adequacy of these interventions. However, I also believe that these difficulties are largely a Western phenomenon, and that such differences in people have been constructed into disabilities by this culture. I will now go on to explain this position by addressing ASD from a social constructionist position, which will form the epistemological framework for this study.

2.4 Social Constructionism

The social constructionist approach suggests that ASD is a disorder constructed by Western society, which marginalises people with these neurological and behavioural differences (Molloy & Vasil, 2004). Whilst this approach recognises that there are differences and impairments amongst people, it refers to these without adding value judgments such as ‘normality’ (Molloy & Vasil, 2004, p. 9). According to this approach, what is considered 'normal' behaviour is relative to the society in which one finds herself.

For instance, in China it is considered polite for a child not to look one in the eyes or use an index finger to point; yet these behaviours are weighted as strong indicators of ASD according to the Autism Diagnostic Observation Schedule – one of the most reputable instruments for research diagnosis of ASD in Western North American and European societies (Norbury & Sparks, 2013). From a Western perspective, these behaviours of the Chinese would be considered a difference; yet when they are characteristics of individuals in Western society, and are associated with ASD, they are perceived as a disability (Norbury & Sparks, 2013).

Many theories surrounding ASD focus on the importance of attending to the eye region of the face for learning about the internal states of other people. These theories suggest that individuals with ASD may struggle in their social development as a result of their inability to engage in prolonged eye contact with another person (Klin, Jones, Schultz, & Volkmar, 2003). However, in South Korea, it is considered 'normal' amongst young people to not look someone in the eyes. Furthermore, in this country's schools, focus is more on academic achievement than social interaction, which would suit the preferences of a child with ASD. This may explain why South Korea has the highest known rates of ASD in a total population sample of school children living in South Korea (1 in 38 children), yet 60% of those identified as having ASD, that were sampled from mainstream settings, had no reported history of educational concern or referral for psychological assessment. In such a setting these behavioural 'symptoms' seem to go unnoticed and people with ASD fit in (Norbury & Sparks, 2013).

It can be seen that the manner in which developmental differences are experienced and perceived may depend largely on the culture the individual with the disorder finds herself in. For instance, certain cultural values, such as an emphasis on family togetherness and mutual co-operation, found in African American, Latino and Native American communities, may allow for more acceptance of differences and disabilities in children (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Furthermore, cultures that base human worth on holistic and spiritual values, rather than physical or cognitive ability, may also be less concerned about developmental differences in people (Cappiello & Gahagan, 2009).

These examples suggest that the perception of certain ASD behaviours as disabilities is at least partly a cultural construction. How such behaviours are viewed by the adolescents in

this study is fundamental to this research. The YouTube users' perceptions may be influenced by the theories and understanding of ASD as developed in Western culture, which they have easy access to through the World Wide Web. Some of these theories will now be explained in order to exemplify further the manner in which ASD behaviours may be shaped as a disability.

2.5 Psychobiological Theories of ASD as a Disability or Difference

In Western society, conceptions of ASD are based largely within the framework of the medical model (Molloy & Vasil, 2004; Norbury & Sparks, 2013). It is assumed that since YouTube is a Western phenomenon, the young people in the videos I will be analysing will have an understanding of the disorder based on this model. Therefore, it is necessary to have a background of the various theories underlying this model, which may influence their perceptions of ASD.

When applying the medical deficit model to an individual, any type of difference or disability is singled out and the origin of the difference is looked for within the person in terms of their behaviour, mental health or biological makeup (Dowd, Sewell, & Truesdell, 2007). Some of the psychological theories, such as theory of mind and mindblindness, follow this medical deficit framework as they seek to explain ASD in terms of impairments in cognitive functioning or the way in which individuals with ASD think about and see the world.

Theory of mind explains the capacity to reason about another person's mental states. This ability enables one to explain and predict another's behaviour based on what one presumes his or her thoughts and feelings to be. Those with ASD have what Frith (2001) refers to as mindblindness – the inability to attribute mental states to self and others. In other words, they have a problem with imagining the others' thoughts and feelings, and thus have difficulty understanding their behaviour (Frith, 2001). People with ASD's problems with theory of mind and mindblindness explain their social and communication difficulties and problems with imagining others' minds (i.e. empathising) (Baron-Cohen, 2004).

Frith (1989, as cited in Boucher, 2009) argued that mindblindness results from weak central coherence. The essential argument in this theory is that individuals typically integrate information holistically at a global level and that those with ASD lack this drive. They focus

rather on local detail, resulting in a fragmented perception and cognitive experience of the world (Happé & Frith, 2006).

It is not within the scope of this research report to explain all the cognitive theories; nevertheless, these theories exemplify how Western professionals are seeking to understand the cognitive styles of people with ASD in order to locate the area of their impairment. This may serve an important function in helping to determine effective interventions for people with ASD. However, following a social constructionist paradigm, it is my belief that the source of the difficulties that individuals with ASD experience does not lie entirely in the individual, but society may also be a source of the problem.

The medical deficit model focuses on problems within the individual. As a consequence, people with ASD who view their condition according to these theories will have to come to terms with the fact they are perceived as having a personal pathology and may be viewed as a 'patient' or 'case' in need of treatment, therapy or rehabilitation (Molloy & Vasil, 2004, p. 19). As the focus is placed on the person's deficits or impairments, she may develop the belief that there is something wrong with her.

While many of these theories follow a disability perspective with regard ASD, one such theory that does not follow this view will now be discussed. This is the extreme male brain theory (Baron-Cohen, 2004), which places emphasis on ASD as simply a different way of thinking about and experiencing the world – in other words, a difference in cognitive style – and focuses less on ASD as a disability.

According to this theory, ASD involves a difference in cognitive style that is neither better nor worse than the cognitive style of those without ASD (Baron-Cohen, 2004). Baron-Cohen (2004) explains it in terms of two different modes of thinking: "systemising" and "empathising". Systemising refers to understanding systems or how things work. Empathising refers to thinking about and understanding people. It is believed that most people possess both modes of thinking; however, according to the theory, females are often stronger at empathising and males at systemising. One of the characteristics of autism is a difficulty with empathising. On the other hand, those with autism have what Baron-Cohen (2004, p. 77) describes as the "triad of strengths" of autism: "a good attention to detail, deep, narrow interests and islets of ability". In other words, the individual with autism may be

stronger at systemising and, therefore, have a cognitive style similar to an extreme version of the male brain (Lai et al., 2013).

Another way of describing this difference in those with ASD is that they are immersed in a world of 'things' rather than 'people' (Baron-Cohen, 2002, p. 187). Baron-Cohen (2002) lists the characteristic behaviours that set those with ASD apart from those without ASD, and which define the former group's preference for a focus on objects. Below, I have divided these up into those characteristics that mark a difference in preference, rather than a disability, and those that can be considered valuable to the individuals with ASD themselves as well as society. (Baron-Cohen, 2002, points out that these are based on DSM-IV diagnostic criteria, except where alternative citations are given.)

Those characteristics listed by Baron-Cohen (2002) that can be considered a difference in preference are: individuals with ASD communicate less than others do; they do not show much interest in what social groups are doing, or in being involved in them (Bowler, 1992; Lord, 1984, as cited in Baron-Cohen, 2002); what they view as relevant and important may not coincide with others' views (Frith, 1989, as cited in Baron-Cohen, 2002); they may be fascinated by material with patterns, such as shapes, dates, timetables, license plates and lists of cars or songs; and they prefer experiences that are controllable rather than unpredictable (Baron-Cohen, 2002). Again, these characteristics do not necessarily result in a problem for these individuals or indicate a disability.

Those characteristics that may be considered useful to their future careers and functioning in society are: individuals with ASD spend more time involved with objects and physical systems than with people (Swettenham et al., 1998, as cited in Baron-Cohen, 2002); they generally prefer to follow their own desires and beliefs rather than paying attention to or being influenced by others' desires and beliefs (Baron-Cohen, Leslie, & Frith, 1985, as cited in Baron-Cohen, 2002); they have strong, persistent interests; they are good at accurately perceiving the details of information (Plaisted, O'Riordan, & Baron-Cohen, 1998a, 1998b, as cited in Baron-Cohen, 2002); they notice and recall things that other people may miss (Frith, 1989, as cited in Baron-Cohen, 2002); they can show fascination with systems, whether simple (e.g. water taps), complex (e.g. weather fronts) or abstract (e.g. mathematics); they may be driven to collect categories of objects (e.g. train maps) or categories of information (e.g. types of rock) (Baron-Cohen, 2002).

As mentioned, these characteristics could help individuals with ASD to be more successful in their careers. What needs to be noted here, however, is that what characteristics a society deems beneficial and acceptable will be based on the culture and expectations of that society. Baron-Cohen (2000) argues that if society were more tolerant of people who prefer to systemise, then life would be easier for people on the autism spectrum. ASD is a disability in so far as we live in "a world where individuals are all expected to be social" (Baron-Cohen, 2000, p. 499).

The questions then arise: Has Western culture set a defined norm of social behaviour into which people should fit? If people do not behave according to Western cultural norms – as those with ASD do not – are they to be considered outsiders or 'others' in need of help to 'correct' the behaviour and fit them back into what is considered 'normal' and acceptable in this society? Would it be more appropriate to view ASD as a 'natural human variation' and should those with this diagnosis rather be viewed as a 'separate minority culture', rather than as having a disability (Norbury & Sparks, 2013, p. 46)? And if those with ASD held such perceptions, how would this influence their experience of living with this disorder in Western society?

The medical model may aim to determine the source of people's problems in order to provide help to them. However, these disability theories, which focus on the impairment within the individual, may feed a Western culture that seeks to marginalise people with differences rather than respect diversity in people. Nevertheless, it was determined here that not all such theories focus on ASD as a disability; the male brain theory identifies strengths in people with ASD. With further reflection on how such understandings influence the perspectives of individuals with ASD, the following section will examine research that has given voice to individuals living with this condition.

2.6 How Those with ASD Perceive Their Diagnosis

In several studies, participants diagnosed with ASD had mixed views regarding their diagnosis, with some viewing it in a positive light and others viewing it negatively (Camarena & Sarigiani, 2009; Humphrey & Lewis, 2008; Jones, Zahl, & Huws, 2001; MacLeod et al., 2013; Molloy & Vasil, 2004; Punshon, Skirrow, & Murphy, 2009). The

researchers of these studies lay down possible reasons for these divergent views, which will now be explained.

Some individuals appreciate the diagnosis as it provides a framework for them to understand their difficulties (Punshon et al., 2009). They may perceive it as a means for them to gain support and relate to others who share a similar diagnosis (Bagatell, 2007; MacLeod et al., 2013; Punshon et al., 2009). Several participants in Huws and Jones' (2008) study, an IPA study that addressed the experiences of ASD of nine young people, perceived it positively as it provided a means for them to gain educational accommodations and opportunities for attending college. While Humphrey and Lewis (2008) – who carried out a qualitative study that analysed the views and experiences of secondary school learners with ASD – suggest that some individuals may be more able to accept themselves and their ASD because of the friendships they have formed despite their differences.

Many people with ASD, however, show dissatisfaction with the diagnosis. They do not want others to see them as being different or as having a 'disability'. For instance, a participant in Camarena and Sarigiani's (2009) study, which analysed the post-secondary educational aspirations of students with ASD, explained: "I'm good academically but not so good socially. I'm on the edge of being normal". This participant then went on to question whether it was right to label adolescents with these kinds of disorders as having a "disability" (Camarena & Sarigiani, 2009, p. 119). This individual was able to identify his strengths and abilities related to his condition and, therefore, did not really believe it was correct to view ASD as a "disability".

Part of the concern with ASD being seen as a disability, by those diagnosed with the disorder, may be related to fears of becoming stigmatised as a result of the label (Humphrey & Lewis, 2008; Huws & Jones, 2008; Molloy & Vasil, 2004; Punshon et al., 2009), which has the potential to harm people's self-concepts. As Humphrey and Lewis (2008) suggest, when referring to the participants in their study who held negative views of ASD, people may construct their view of themselves and their diagnosis based on the feedback they receive from others. Camarena and Sarigiani (2009) support this by suggesting that some adolescents with ASD struggle with self-acceptance possibly because they have not been provided a more positive framework for "the nature of their exceptionality" (p.126).

MacLeod et al. (2013), in their study, which explored the views of six higher education students with autism/Asperger's syndrome, found that some young people with ASD struggled to accept their diagnosis because they received unsatisfactory information regarding the disorder when they were first diagnosed. This made it difficult for them to relate the symptoms of ASD to their own personal experiences. Some participants in this study also felt that the meaning behind the label was "fragile and inconsistent", and as such felt they would rather distance themselves from it (MacLeod et al., 2013, p. 41).

What emerges from the current research is that how individuals with ASD perceive the label is largely determined by the views others (for example, peers and teachers) have towards it. The ability to relate to others who share the diagnosis, and the individual with ASD's ability to form meaningful relations with others, may also play an important role in how easily the diagnosis is accepted. Such perceptions of their diagnosis may impact on their identity development as they come to terms with having a label applied to them, while at the same time having to cope with the difficulties they face as a consequence of the condition. The manner in which having a chronic disability impacts on their identity development will be explored in relation to the literature on identity formation.

2.7 Identity Development

In order to understand how perceptions of ASD as a disability may influence young people's identity, it is necessary to have a conceptual basis for comprehending the process of identity development. This will be addressed in terms of Luyckx, Goossens, Soenens and Beyers' (2006) process-oriented approach to identity formation. Following a discussion of this theory, I will discuss the collective identity of ASD, or 'autism identity' (MacLeod et al., 2013), which will take into consideration the collective approach that some people with ASD take to reconstructing the meaning behind the label.

2.7.1 The process of identity formation.

While there are numerous theories on identity development, I have elected to explain Luyckx et al.'s (2006) process-oriented approach to identity formation and evaluation, which is one of the most prominent among the identity status-based models (Schwartz, Luyckx, & Crocetti, 2013). It focuses on both the development and evaluation of adolescents' and young

adults' identities, and helps to determine more and less adaptive personality strategies. It is beneficial to this research as it can be applied in our understanding of how people integrate aspects of their selves (e.g. a chronic disability) into their identity.

This theory of identity formation is primarily inspired by Marcia's (1966) identity status paradigm. Marcia's (1966) theory was an expansion on Erikson's (1968) theory, which posited that identity development is the most fundamental developmental task of adolescence. Erikson (1968) held that identity is a multidimensional construct that forms in relation to the moral, cultural, social and cognitive aspects of one's life (Luyckx, Schwartz, Goossens, Beyers, & Missotten, 2011). According to Erikson (1968), identity refers primarily to "a subjective feeling of sameness and continuity across time and across contexts, and it is best represented by a single bipolar dimension ranging from identity synthesis to identity confusion" (Luyckx et al., 2011, p. 78). Identity synthesis involves translating childhood identifications into a more clearly set of self-defined goals, values and ideals (Luyckx, et al., 2011), or integrating an aspect of self (e.g. a sense of self as a person with ASD) with other aspects of the self (e.g. a sense of self as a person with ASD who is also religious, who enjoys football, who is an adolescent etc.) (Vignoles, Schwartz, & Luyckx, 2011). Identity confusion, on the other hand, results from an inability to establish a set of realistic and desirable goals and commitments on which to base an adult identity (Schwartz, 2001). This may be a consequence of having an aspect of self that one is not yet prepared to accept. This inability to accept this part of self may lead to anxiety, bewilderment and emotional tension (Luyckx et al., 2008).

Marcia (1966) built on this theory by highlighting key identity processes, described by Erikson (1968), which could be used to guide empirical research. He determined identity statuses by looking at the point of intersection of two dimensions of identity development: exploration (i.e. the consideration of multiple identity alternatives) and commitment (i.e. making a choice to adhere to one or more of the alternatives considered). The statuses he developed were achievement, foreclosure, moratorium and diffusion (Luyckx et al., 2011). These four identity statuses inspired an abundance of theoretical and empirical work. However, his theory was criticised for altering Erikson's (1968) dynamic and changing self-system into a static set of categories (Schwartz, Zamboanga, Meca, & Ritchie, 2012). Furthermore, Erikson (1968) had posited that identity involved interaction between an individual and his or her social and cultural context, whereas Marcia's (1966) theory was

based almost solely on the individual with minimal attention to the external factors that may influence identity development (van Hoof, 1999).

Schwartz et al. (2012) propose that Luyckx et al. (2006) have managed to expand on these models. They have provided a dynamic approach, which is guided by Erikson's (1968) assumption of identity development as a continuous psychosocial task, which may further our understanding of identity development (Schwartz et al., 2012). Furthermore, Luyckx et al. (2006) have provided sufficient evidence to support their theory of identity formation (Schwartz et al., 2013).

Through the use of confirmatory factor analysis, Luyckx et al. (2006) were able to validate a four-dimensional model, which includes processes of commitment formation and commitment evaluation. The two dimensions involved in commitment formation include exploration in breadth and commitment making. Exploration in breadth refers to the gathering of information on various identity alternatives. Commitment making refers to taking on strong choices in different identity domains, which may be as a result of exploration in breadth.

Commitment evaluation involves the other two dimensions, in which young people continuously evaluate their identity commitments. These dimensions are referred to as exploration in depth and identification with commitment (Luyckx et al., 2006). Exploration in depth involves evaluating the commitments already made. Identification with commitment refers to the level of security and certainty provided by one's current commitments, and how successfully these commitments satisfy one's own standards and values (Bosma, 1985, as cited in Luyckx et al., 2011). Findings suggest that commitment formation and evaluation begin to take place most prevalently during the adolescent phase (Luyckx et al., 2011).

Luyckx et al. (2011) suggest that this model provides insight into what ascribed identities (i.e. those personal characteristics that one has no personal control over, such as ethnicity, being male or female, or having ASD) mean to the individual. For instance, having ASD may carry different meanings for different people and these meanings may be *explored* (e.g. "I think actively about the different ways ASD might affect my life and what life decisions I might make as a result"), *committed to* (e.g. "I have decided that this is how I will view ASD and I will make decisions for my life based on this view"), *identified with* ("The way I have chosen

to view ASD allows me to make decisions in my life that match my true interests and values"), or *re-evaluated* ("I am not sure that the way I view ASD is the best way to view it as I do not feel satisfied in my current state, and I am going to explore my diagnosis further so I can find a greater sense of fulfilment living with it"). These four identity dimensions characterise identity development (Luyckx et al., 2011).

Luyckx, Goossens and Soenens (2006) drew from previous models (e.g. Marcia, 1993; Josselson, 1996; Côté & Levine, 2002; Helson & Srivastava, 2001) and combined these four identity dimensions to develop various empirically identified typologies of identity formation in adolescence and adulthood (these are: pathmakers, searchers, guardians and consolidators). However, in the present study, I did not draw on these typologies as most research on these stems from longitudinal data on subjects, and it was felt that there would not be sufficient data to categorise these YouTube users according to these typologies. It was also felt that it did not adhere to the socio-constructionist nature of this research to apply more labels to these individuals and fit them into yet another box. Therefore, I decided to determine their state of identity development simply through the aforementioned four-dimensional model of identity formation.

Through research on this identity development theory, Luyckx, Seiffge-Krenke et al. (2008, as cited in Luckx et al., 2011) found that achieving a secure sense of identity appeared to facilitate one's ability to cope with diabetes and with a daily diabetes regime, as well as to facilitate integrating the illness into one's sense of self. Furthermore, a recent study of over 400 adolescents with congenital heart disease confirmed the importance of having a strong sense of identity in coping with and adjusting to chronic medical illness (Luyckx, Goossens, Van Damme, & Moons, 2010, as cited in Luyckx et al., 2011). From these studies, it seems that a strong identity represents a fundamental 'internal resource' that may help to determine how individuals cope with (chronic) illness-related stressors (Luyckx et al., 2011).

While I recognise that these conditions are health-related, it seems that this process of integrating these conditions into one's sense of self may apply to adolescents and young people involved in the process of accepting their chronic 'disability' of ASD into their sense of self. Just as people may be involved in a process of accepting that they have congenital heart disease and what this condition means for them, so too must young people with ASD come to terms with their diagnosis and what this will mean with respect to their lives.

This process is important as studies have revealed that the sense of identity that one forms in adolescence and emerging adulthood may help predict one's success in fulfilling important developmental tasks in adulthood (Luyckx et al., 2011). Research has shown that many adults with ASD struggle in their professional, social and private lives (Roy, Dillo, Emrich, & Ohlmeier, 2009) despite having the potential to function adequately in these life domains (Berney, 2004). This may be as a result of their experiencing difficulties with their psychosocial adjustment, possibly related to identity confusion in their adolescent and emerging adulthood years. Perhaps deeper reflection on the process of identity development in adolescence may help to prevent current adolescents with ASD experiencing these difficulties when they reach adulthood.

While identity synthesis may aid one in coping with the difficulties related to having a chronic disability, an additional concern arises when people experience stigmatisation from others as a result of their diagnosis. In response to the negative views people may have toward ASD, many individuals on the autism spectrum appear to have developed a collective identity (or autism identity) as a means to stand together against such negative reactions. The manner in which this has been achieved and the value it provides individuals that take part in it, may increase understanding of the significance and meaning the diagnosis may hold for those so labelled.

2.7.2 Collective identity development.

The collective identity of ASD refers to the collective of individuals with ASD who together form an identity related specifically to their diagnosis. With regard the notion of this collective identity, I will discuss how society treats people who belong to this collective and how this might influence the individual's identity. I will also address how the collective has responded to negative treatment by society and has tried to alter people's beliefs about ASD.

As suggested the process of identity development in adolescents with ASD needs to be considered in light of how the diagnosis is constructed by society and what it means for the individual. The various views or meanings of ASD that they explore and commit to, as explained in Luyckx et al.'s (2006) theory, are likely the socially constructed views provided by the society they are in. For instance, individuals with the diagnosis that are in the medical deficit camp will view ASD as disability or neurological impairment. In contrast, those who

agree with the social model propose that the construct of ASD as disability is an issue of social injustice as those who are categorised as having physical, mental or cognitive difficulties receive unequal treatment by members of society (Chaskes, 2010). Such views may drive many people to disassociate themselves from the label because it connotes a negative sense of "disability" (Baines, 2012; Davidson & Henderson, 2010) and, as discussed, this may result in identity confusion.

The label may make one lose their individual sense of identity. For instance, the behaviour of individuals with ASD may be constantly scrutinised in terms of its consistency with the label. This can influence people with ASD's identities as their every action is foreshadowed by their "disability" as opposed to their personality preferences. Exemplifying this point, Martine Levine, an individual with a learning difficulty, said: "If someone else whispers a lot during the play people might ignore it or get angry. If we whisper it is because we are retarded. It's like we have to be more normal than normal people" (cited in Goodley, 2001, p. 215). While one's individual identity is compromised, it may be particularly damaging to one's self esteem when there is a stigma attached to her diagnosis.

Many members of society still have negative views of people with ASD (Huws & Jones, 2001; Shtayermman, 2009; Tidmarsh & Volkmar, 2003). In response to this concern, self-advocacy and disability rights movements are trying to renegotiate the label and create more public awareness of the harmful ways in which society views and treats those with difficulties (Goodley, 2001). Through the self-advocacy movement, people present their stories in ways that emphasise their resilience in the face of the adversity they have encountered as a result of their differences. In this respect they become empowered by actively reshaping their identities and 're-authoring' their stories (Gillman, Swain, & Hayman, 1997, p. 689). Self-advocacy allows them to establish their own identity as well as reconstruct the collective autism identity.

The internet has provided an ideal means for this to happen. Many people on the autism spectrum connect through the internet, on websites such as YouTube, Facebook, and online autism chat rooms (Davidson, 2008). It appears that many people with ASD prefer the interaction created by the online community rather than face-to-face interaction. As one author suggests, "The impact of the internet on autistics may one day be compared to the spread of sign language among the deaf" (Singer 1999, p. 67). This captures the significance

of the internet for many with ASD who have found a space where they no longer have to be limited by the 'alien' communication style of the Western world. An online Asperger's/autism culture has been formed, which enables individuals with ASD to more easily find support and learn about their condition from others who share the diagnosis. This further provides an opportunity for people with a diagnosis of ASD to construct a shared, collective identity (MacLeod et al., 2013).

2.8 Conclusion

What has been determined from a review of the literature is that multiple viewpoints may impact on and shape an individual's perception of the diagnosis and herself. In and amongst the various constructions of ASD is the person with the condition that daily has to cope with her differences in order to function adequately in society. How adolescents and young adults, who are at a pivotal point of identity development, makes sense of their diagnosis, and what societal voices they internalise, will be explored in the YouTube videos in this study.

I chose social constructionism as the epistemological framework for answering my research question, as it allows for deeper reflection on how these adolescents make sense of and assign meaning to their experiences of this phenomenon in light of society's views of ASD (Terre Blanche & Kelly, 2002). In the following section, I will explain how this approach will frame this study, and how IPA is ideally suited for this endeavour.

3. METHODOLOGY

In this section, I will provide a detailed description of the process of data collection and analysis that was conducted, and how quality and trustworthiness were ensured. The methodology was guided by the IPA approach, which, as will be shown, complements social constructionism. This approach is founded on three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography. These will now be explained in order to elucidate the design of this research; a more detailed description of how social constructionism was applied will be discussed in the analysis section.

3.1 Interpretative Phenomenological Analysis

IPA is a qualitative research approach that is concerned with exploring how people make sense of their lived experiences. In particular, it reflects on aspects of lived reality that take on significant meaning for people (Smith, 2004). In this respect, IPA is phenomenological as it is focused on the 'phenomena' people consciously encounter as they engage in lived reality (Willig, 2001). This area of philosophy is based on the work of theorists such as Husserl, Heidegger, Merleau-Ponty and Sartre, which enables one to see that the concept of experience involves "an unfurling of perspectives and meanings, which are unique to the person's embodied and situated relationship to the world" (Smith, Flowers, & Larkin, 2009, p. 21).

The IPA approach involves an analysis of the sense individuals make of these experiences in their lives, and in this manner it draws on the theory of interpretation, or hermeneutics. It suggests that the accounts people provide regarding lived events reflect their attempts at determining the meaning behind the experience. This involves researchers' interpretation as they attempt to access and understand the individual's experience from his or her own account of it. Therefore, the IPA researcher is involved in a double hermeneutic in which he or she must try to make sense of the subject making sense of his or her experience. Consequently, IPA researchers must remain self-conscious and systematic in their sense-making and ensure that it remains second-order to the participant's own sense-making of the phenomenon (Smith et al., 2009).

IPA is an idiographic approach in that it seeks to attain the minutiae of the subjects' sense-making of the experience. The aim is to reveal something of the subjects' experience and as such it requires a detailed exploration of the similarities and differences between the different subjects' accounts. While the nomothetic approach, adopted by more traditional, positivist and post-positivist psychological research, aims to apply its findings to a wider population, the idiographic approach refers rather to a focus on a particular case, from which generalisations are cautiously developed (Smith et al., 2009). Moreover, Smith et al. (2009) suggest that with 'theoretical generalisability', the reader may be able to utilise their existing professional and experiential knowledge in assessing the material. Thus, in the present study, I make no claims regarding generalisation, but rather hope that the findings may form part of a growing corpus of similar IPA studies, which together might yield greater theoretical transferability with regard to how young females with ASD perceive and make sense of their condition.

With an understanding of these three tenets of the IPA approach, it can be seen how it provides the opportunity for a detailed analysis into how adolescents with ASD make sense of their condition on YouTube. It enables their views to be heard with a depth and quality that other methods may not be able to provide (Lander & Sheldrake, 2010).

There is no prescriptive methodology for IPA. Researchers are expected to adapt the methodology to their personal way of working; as Smith and Osborn (2003) state "qualitative analysis is inevitably a personal process". Nevertheless, throughout the process, the aims of this research have guided the organisation and interpretation of the data. That is, in this study, my interest was in developing a greater understanding of adolescent girls' experiences of living with ASD as presented on YouTube. The aim was to reflect on the constructs and beliefs the adolescents held with regard ASD through analysis of their talk on YouTube. Such talk, as well as other data gained from an analysis of the users'[3] profile page, is believed to reveal portions of the users' identities, which will help to develop an understanding of the self they present on YouTube.

[3] The terms 'YouTube users' and 'vloggers' will be used interchangeably throughout this paper to describe the girls in the YouTube 'channels' on AS.

3.2 Data Collection

Whilst the vast majority of studies using IPA have utilised semi-structured interviews as the method of data collection, Smith (2004) points out that it is possible to acquire rich verbal accounts from other means, such as diaries. In this respect, the YouTube videos could also be considered rich verbal accounts as they involve individuals sharing their personal experiences.

3.2.1 Sampling videos.

This research involved purposive sampling, which is appropriate for gaining in-depth understanding of a phenomenon. It requires selecting information-rich cases that hold data relevant to the purpose of the research (Patton, 2002). The sample consisted of sixteen YouTube videos made by three girls in the adolescent and emerging adulthood phase of development who reported having ASD[4]. The use of small samples facilitates the IPA analysis as it allows researchers to recall individual accounts, which may reduce the loss of any subtle similarities or differences between them (Smith, Michie, Stephenson, & Quarral, 2002).

Sandelowski (1995) suggests that the judgment of how many subjects to use in a sample should largely be based on previous research, but as there has been little qualitative research on YouTube videos, it was difficult to judge how many videos I should have included in the sample. In order to prevent inadequate data being retrieved, which would undermine the credibility of my findings, I employed the concept of theoretical saturation when determining how many YouTube videos to include in my analysis. Theoretical saturation refers to the point reached during analysis where no new dimensions, properties or relationships emerge from the data (Strauss & Corbin, 1998). Therefore, I used my judgement when collecting data and, through theoretical saturation, was open to expanding the sample until I reached a sense that I had enough data to answer the research questions.

When selecting the videos, I typed in the tag "Asperger Teenager" into the YouTube interface. This brought up every video with this tag in the title. I then selected the first ten

[4] The veracity of the subjects' diagnosis is not within the scope of this study. Rather, the aim was to analyse the perceptions of those who *believe* themselves to have ASD.

videos where an adolescent or emerging adult was speaking about his or her experience of having AS or ASD. At this point, I decided to focus on those adolescents that had YouTube 'channels' (more than one video addressed at an audience) focused on AS. The reason for this was to gain more context and in-depth, rich data from the videos. I decided to select three YouTube users that had channels on AS, as I believed this would allow me to identify sufficient themes for comparison. Furthermore, Smith et al. (2009) recommend that at a Master's level the sample should consist of three participants for an IPA study. Therefore, from the ten YouTube users I had already been through, I chose three by determining which ones met the following criteria:

- In the video, an adolescent or emerging adult must be addressing the YouTube viewer.
- The individual must have several videos about their experiences of living with ASD.
- The selected videos must have the highest number of views (as determined by the view count below the video on the YouTube interface).
- The video must be between five and fifteen minutes long. (A counter appears on the YouTube interface.)
- The video must be of a decent technical quality (both audio and visual).

At this stage I decided to focus on three female users for the following reasons:

1) They have more in-depth, rich data and speak more about their experiences and perceptions of ASD than the other people in the videos I had viewed; thus, they met my research question and sampling criteria.
2) There has been limited research done on females with ASD and I was interested in gaining an understanding of how these girls perceived ASD in light of the apparent differences in the way it presents itself in boys and girls.

After I had selected three YouTube users' videos, I went through each video of each user, developing a thorough understanding of the user's profile and what sorts of videos she had posted. During the process, I developed criteria for what videos I would transcribe and analyse. These criteria were based around the research question and the previous criteria for selecting videos. They included the following:

- It must be a vlog (i.e. a video blog)

- Three-quarters of the video must be on the adolescents' perceptions of ASD and/or their experiences of living with ASD, particularly how it has affected their socio-emotional functioning (i.e. what is their understanding of AS/ASD in light of its effect on their relationships with others)

Sarah[5] had 242 videos divided into several playlists. I noted the genre of each playlist (see "Table of Categories of Videos" in Appendix A). While there were many more videos about AS in her playlists, in the interest of saving time, I decided to only consider those videos in the playlist she titled "Serious Asperger's videos", as these seemed to cover sufficient, detailed and relevant data for my research purposes. I then went through all the videos in this playlist and highlighted several videos that were particularly relevant to the research question and met the sampling criteria. Seven of her videos were selected for the sample. (See "Table of Videos Related to ASD" in Appendix B for a list of all the users' videos related to AS and those that were selected for the purposes of this study.)

I then went through Johanna's videos, of which there were a total of 63 and seven of these were related to AS. I selected the headings that appeared most relevant to the research topic. Of these, I selected four, which met the sampling criteria above. Following this I viewed Jessica's videos. She had made a total of 25 videos and seventeen were related to AS. I viewed those videos with headings most relevant to the research topic. Of these, five were selected to be a part of the sample. In total, the sample consisted of sixteen of these videos. I then began the process of transcribing them.

3.2.2 Transcribing videos.

For IPA, the level of transcription is generally at the semantic level. In line with this approach, I tried to identify all the words spoken including false starts, significant pauses, laughs and other features which were considered worth recording. However, for IPA, one does not need the more detailed transcription of prosodic features of speech, which are required in conversation analysis (Smith & Osborn, 2003).

[5] Pseudonyms are used for all three vloggers in this study (refer to 'Anonymity and Confidentiality' in Section 4.2).

3.3 Data Analysis

IPA subscribes to the social constructionist epistemology (Eatough & Smith, 2004) in that the various constructions of a phenomenon are determined by "an interpretation of the meaning for a particular person in a particular context" (Smith et al., 2009, p. 195). That is, in this study, the various constructions of ASD have been determined through interpreting the current meaning it holds for adolescents with ASD in the context of Western culture.

When I analysed the videos, I adhered to Burr's (1995) fundamentals of the social constructionist position. I did this by firstly adopting a critical stance towards the various constructions or meanings of ASD as presented by these young people, not taking anything for granted. Secondly, I remained aware that the ways in which we make sense of the world depends on the historical and cultural context in which we find ourselves (for example, I was cognisant of how the Western culture might influence the perceptions of adolescents and young people on YouTube). Thirdly, I remained aware that knowledge is created and maintained through social interaction (Burr, 1995). For instance, language plays an important role in the construction of knowledge (Gergen, 1985); from this understanding, I analysed the language these girls used in the videos to describe and construct their ASD (e.g. paying attention to the underlying meanings in the words they used) I also considered how their social interactions, including interactions through YouTube, may also have played a role in such constructions. Fourthly, Burr (1995) suggests that knowledge and understanding impact on social action. In this regard, I considered how the constructions of ASD influence society's treatment of such individuals.

While adhering to these fundamentals, the aim was to analyse the content and complexity of meanings rather than measure their frequency, as may be expected of other approaches, such as content analysis. In this respect, I engaged in an interpretative relationship with the transcript such that meanings could be obtained through sustained engagement with the text (Smith & Osborn, 2003).

3.3.1 Looking for themes.

This step involved an initial read-through and jotting down of notes in order to gain a preliminary sense of each user and her perspective. After I had done this, I then went back to

the first user (Sarah) and analysed her accounts more closely, paying attention to her use of language and the self she was portraying. As I read and reread through each transcript of the first user I continued making notes on the printed text. These notes aimed to capture "the essential quality" of that which emerged from the text (Smith & Osborn, 2003, p. 68).

These were then converted into comments, using Microsoft Word 2010, in the right hand margin of the saved document. These comments consisted of notes on similarities and differences, echoes, amplifications and contradictions in what the user was saying. After having reread it to the point where I was satisfied that my notes embraced the text, I printed off the comments. I then read through these with the text and drew up a list of emerging themes (Smith & Osborn, 2003).

As initial notes were transformed into themes through the whole transcript, similar themes emerged and where this happened the same theme title was repeated. As the "New Comment" function in Microsoft Word 2010 highlights the area that has been commented on, I could see which portions of the data had not been analysed. The entire transcript was treated as data and there was no attempt to select passages for special attention or omit others. However, there was also no requirement for every piece of data to generate themes (Smith & Osborn, 2003).

3.3.2 Connecting the themes.

The list of themes was placed on a separate sheet of paper in the order with which they emerged from the material. These were then analysed for connections between them. After this, the themes were ordered according to these connections. Some of the themes clustered together and some emerged as superordinate concepts, which helped me to make more sense of the other themes (Smith & Osborn, 2003).

3.3.3 Comparing themes to the transcript.

These clusters of themes were checked back against the transcript to make sure the connections satisfied the primary source material. This is an iterative form of analysis that involves a close interaction between reader and text. It was important that I regularly checked my interpretations against what the person actually said. My supervisor also cross-checked

my themes against the transcript in order to ensure that I was accurately capturing the essential quality of the data.

The clustering of themes and comparing them to what was in the transcript helped me to ascertain Sarah's most apparent perceptions on this topic. Once these clusters had been organised into categories, each was given its title and came to represent the final superordinate themes (Smith & Osborn, 2003).

3.3.4 Continuing the analysis with other users.

The superordinate list from Sarah's account was used to inform the analysis of the other users' transcripts. I was then able to identify what was new and different in the subsequent transcripts in comparison to the first user, as well as data that were related to the extant themes that could illuminate them further. For students with a small number of cases, Smith and Osborn (2003) recommend that this method should be used as opposed to treating the analysis of each case as though it were the first.

When all the transcripts were analysed through this interpretative process, a final table of superordinate themes was constructed. This enabled me to prioritise the data and begin to reduce them. Data were selected according to the richness of particular passages that highlighted certain themes, and how these themes brought to the fore other significant aspects of the account (Smith & Osborn, 2003).

3.3.5 Table of themes.

All the themes were placed in a table and ordered coherently so that the relevant sub-themes corresponded with the superordinate themes. An identifier was also placed with these themes so that the original source could be found more easily. This identifier helped me to identify where in the transcript this instance of the theme could be found by providing key words from the particular extract and the comment number of the transcript. At this stage, certain themes that neither fitted well in the emerging structure, nor were rich in evidence within the transcript, were omitted. (See "Table of Themes" in Appendix C for an example of the themes and identifiers used for this study.)

The table came in useful for helping me determine whether I had reached data saturation or if there was more data I needed to collect. At this stage, I was aware that I had reached data saturation and had sufficient data for my research purposes.

3.4 Validity and Quality

Smith et al. (2009) propose that in order to determine the validity and quality of IPA research, Yardley's (2000) four basic principles for assessing quality in qualitative research should be adhered to. These principles – sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance – will briefly be described in order to explain how I attempted to ensure quality and validity throughout the research process.

3.4.1 Sensitivity to context.

Sensitivity to context should begin in the early stages of the research process, and can be demonstrated in multiple ways; for example, one may show sensitivity to socio-cultural milieu, existing literature or subjects' material, which are all relevant to the study (Yardley, 2000). As I was conducting research online, and thus did not have interaction with the adolescents in the study, I had to remain sensitive to how they might feel when speaking on the internet and how this might affect their accounts. I also had to consider if they intended their vlogs to be analysed for psychological research and how this might affect them. I tried to remain sensitive to the various reasons for why they were choosing to speak to strangers over the internet about the difficulties they were facing. I drew on the existing literature in the area to better understand this and incorporated this into my analysis.

The most important context to remain sensitive to is the data (Yardley, 2000). I ensured I remained sensitive to this by grounding any interpretative claims I made in the data I had obtained. As mentioned, my supervisor checked my interpretations against the text to ensure I had achieved this. I tried to provide a sufficient number of verbatim extracts from the subjects' material to remain sensitive to their voice and enable the reader to check the interpretations being made. I also sought to present my interpretations as possible meanings, and made more general claims with caution (Yardley, 2000).

3.4.2 Commitment and rigour.

Commitment involves the care and attentiveness given to the manner in which data analysis is carried out, and rigour refers to the thoroughness of the study (Smith et al., 2009). I provided commitment and rigour with regard the care I took in selecting a sample that was appropriate for the research question. I used tables to carefully keep track of the potential subjects and constantly referred back to the proposed criteria I had developed in determining the sample. During the analysis phase, the constant reading and rereading allowed me to have a thorough engagement with the material. The table of themes enabled me to gain a firm grasp on the themes that emerged from the users' accounts. Finally, I engaged in an ideographic process in the analysis and writing up of the results, focussing on and presenting the details that emerged from the texts, and constantly reminding myself to make sure that the research questions and aims were being addressed. I worked at moving the analysis beyond a merely descriptive approach; and in my interpretative endeavour, I sought to reveal something meaningful about the subjects and the themes that emerged from their accounts.

3.4.3 Transparency and coherence.

In accordance with Yardley (2000), I tried to remain transparent by carefully describing the stages of the research process that were carried out, and the manner in which the sample was selected. In terms of maintaining coherence throughout, this could only be achieved by placing myself in the reader's position when reading drafts, and determining how clearly and concisely the process and argument were relayed. My supervisor also helped me in this respect by pointing out to me parts of my argument that did not flow and focussing on areas that required more thought. Coherence could only be achieved by remaining true to the IPA principles throughout the process.

3.4.4 Impact and importance.

Yardley (2000) suggests that the real validity of a piece of research is determined by whether what the researcher has to say is important, interesting or useful. It is hoped that this research will fulfil all three suggestions and all four of the above principles.

3.4.5 Reflexivity.

In order to remain truly faithful to the principles of IPA, I needed to maintain reflexivity throughout the research process. This concept develops from the understanding that complete objectivity cannot be achieved in the qualitative research process and pure subjectivity of the research undermines the credibility of the findings. In this respect, researchers should aim to understand and depict the world with authenticity while remaining self-aware, politically aware and conscious of their own perspectives at every step of the research process (Patton, 2002). That is, researchers need to maintain reflexivity in the process.

In order to achieve this, I reflected back to my beliefs and presuppositions about ASD throughout the research in order to remain aware of how they might influence the process and the findings. I did this by keeping fieldwork notes and in these I recorded any thoughts and feelings I had in response to the research process and/or the subjects under study (Haynes, 2012).

Themes that emerged through analysis were checked back against the transcripts to ensure they were supported by the data (Smith, 2004). In order to ensure the trustworthiness of these themes, the process involved my supervisor being consulted at each stage of the analysis to audit the emergent superordinate and sub-themes, and ensure they represent the subjects' views shown through the transcripts (Smith, Jarman, & Osborn, 1999).

4. ETHICAL CONSIDERATIONS

This research was given ethical clearance by the Human Research Ethics Committee (School of Human & Community Development) of the University of the Witwatersrand, Johannesburg. The ethical clearance certificate can be found in Appendix D.

4.1 Research in the Public Domain

As the sample was taken from YouTube which is in the public domain (Berger, 2012). there is no need for ethical review when analysing these videos, according to the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2, 2010, Article 2.3; p. 18). Research ethics board (REB) review is not required for research involving observation[6] of people in public places.

4.2 Anonymity and Confidentiality

All the information gathered for this research is in the public domain and, therefore, there is no need for concern about confidentiality (*American Sociological Association Code of Ethics, ASA*, 1999, point 11.2). However, I felt it would be right to ensure that data from the research is not linked with these YouTube account holders so to preserve their online reputation. I, therefore, ensured these individuals' anonymity and privacy by using new pseudonyms (i.e. not the ones they use for their YouTube accounts) and omitting any personal information (i.e. names, email addresses, places of residence etc.) that they have provided through their videos.

4.3 Informed Consent

Another ethical concern significant to this research was the issue of informed consent. Typically in research involving a vulnerable population, such as adolescents with ASD, it is necessary to get parental consent. However, according to Gaiser and Shreiner (2009), deciding on whether parental consent is required may depend on whether the space used by

[6] Observation, in this Article, refers to observational research that is used to study acts or behaviour in a natural environment and can be undertaken in publicly accessible spaces such as virtual spaces (e.g. internet chatrooms or YouTube) (TCPS2; 2010).

the young person is considered public or private. Once again, there is no doubt that YouTube is considered a public space.

By uploading a video to YouTube, one is providing all users of YouTube with "a worldwide, non-exclusive, royalty-free licence to access [one's] Content through the Service, and to use, reproduce, distribute, prepare derivative works of, display and perform such content to the extent permitted by the functionality of the Service and under these Terms" (YouTube Terms Of Service, par. 8). One gives their informed consent when uploading videos to this site.

4.4 Further Considerations

As mentioned earlier, these individuals expect their videos to be watched by strangers many times. The site is interactive and strangers can pass comments and criticism on the video to the user that uploaded the content. In this respect, these individuals have already willingly exposed themselves to critical analysis when uploading their videos to this site.

My intentions when analysing these videos was to benefit this group of people by providing deeper insight into their experiences of ASD. The information that was analysed is information they have publicly shared; it is information they want everyone to know. Therefore, the objectives of this research adhere to their intentions and will not harm them.

5. RESULTS AND DISCUSSION

This chapter will present an interpretative account of the analysis that commenced in order to answer the research question: *What perceptions of ASD do adolescent females living with this disorder present on YouTube?* Using the qualitative technique of IPA, several relevant superordinate and sub-themes have been identified within the data and are presented here. These themes will be "explained, illustrated and nuanced" (Smith & Osborn, 2003, p. 76), such that the meanings inherent in the subjects' accounts will become more apparent. The discussion of these themes will be interspersed with verbatim extracts from the transcripts to support the case, as well as linked to relevant literature and theory within the field of study. This is in keeping with the IPA recommendations for writing up results (Smith & Osborn, 2003). Before a discussion of the results commences, however, it is necessary to provide a brief background of the users in order to contextualise the analysis.

5.1 Background Information

Langdridge (2007) recommends that a mini-profile of each subject is provided which will enable the reader to determine the homogeneity of the subjects as well as provide further background information pertaining to the experiences of each individual. Here, I will provide a general overview of Sarah, Johanna and Jessica's background information, which they have provided on YouTube.

Sarah

Seven of the sixteen videos included in this study were created by Sarah, who lives in England. In her videos, she explains that she was only diagnosed with ASD when she was seventeen years old. She dropped out of high school because of the difficulties she was encountering with being bullied, and she only completed her General Certificate of Secondary Education (GCSE) and A-levels at a later stage. Currently she is living on the disability Living Allowance (DLA).

In her description about her YouTube profile page, she explains that she makes videos about AS, which she tries to get out every Wednesday night, and also generally does a more light-hearted video over weekends. She states here that she is a writer and she also runs this page, her vlog and a forum for people with AS as her 'job' (on her webpage is a link to this forum).

The quotation included in her YouTube profile site is: “I may not fit into the real world, but I fit into the internet”; this is stated again in one of her videos I analysed and is included in the discussion.

In her videos that I selected, which span from 2009 to 2013, her age ranged from seventeen to twenty years. She has made over 200 videos. Twenty-seven of these videos are included in the playlist, “Serious Asperger’s videos”, five are in the playlist, “Answering Your Questions”, which are about ASD, and sixty-nine videos are in the playlist “Video Blog”, and also cover her experiences of ASD. Thirty-eight videos are included in the playlist “Me and Tom” (Tom is her boyfriend/fiancée). She also includes videos on music, singing, her holidays, and graphic design.

As was gathered from her videos, Sarah’s parents are divorced, but she appears to have a good relationship with both her parents. She describes how her mother understands her difficulties and describes ways in which she supports her, such as helping Sarah in the kitchen. With regard her father, she found that her AS was something to bond over with him because he experienced similar problems to her when he was young. Sarah’s younger brother also had AS. After she was diagnosed with AS, she encouraged her boyfriend, Tom, to get an assessment; he was then also diagnosed with AS.

Johanna

Johanna is an American girl who was diagnosed with ASD when she was fifteen years old. She was at college studying a major in music at the time these videos were made, and was eighteen years of age. She has made a total of sixty-three videos, seven of which are related to ASD and the rest are videos of music; in several of these videos she is playing music with fellow musicians. In her descriptions about herself on this site, she says: “I'm a musician before I'm autistic, but it's my Asperger's that lets me be a musician”. The significance of this comment will be extrapolated in the discussion. I have included four of her videos in this study, which she made at the end of 2011, when she was eighteen years old. She also has a blog, which is titled “The Artistic Spectrum: Perspectives of an autistic mind”, which includes articles written about autism and herself. I did not include data from this site in my research as, due to time limitations, I chose only to focus on video blogs. It is assumed that Johanna does not have a boyfriend as there is no mention of one. She also does not mention

her family in these videos, except that she was going to spend thanksgiving with them and seemed to be looking forward to this. It appears that she is in boarding at college.

Jessica

Five of Jessica's YouTube videos were included in this study. In these videos, her age ranged from fifteen to sixteen years old. She is, therefore, the youngest of the three subjects in the study and, unlike Johanna and Sarah, she is still in school. Jessica was diagnosed with AS before she reached high school.

Not included in the videos that were selected for the study, but are worth mentioning, were videos about her mother who died of cancer a few years ago (she does not mention how old she was when this happened). Also of relevance is a video where she threatens to run away or commit suicide because she is struggling to cope with the peer rejection she is facing at school. This video did not meet the criteria for this study, as three-quarters of it was not related to her speaking directly about ASD, but rather just her emotional difficulties that may be a consequence of her ASD.

In total, Jessica made 25 videos for YouTube, of which nineteen are related to her experiences of AS. In her descriptions about herself and the site, she says: "Autism RULES!!! Being weird is totally normal!" The enthusiasm she expresses with regard autism in this statement conflicts with some of the statements she makes in her videos where she appears less positive about being 'weird' and having autism, which will be discussed under the sub-theme 'Identity'.

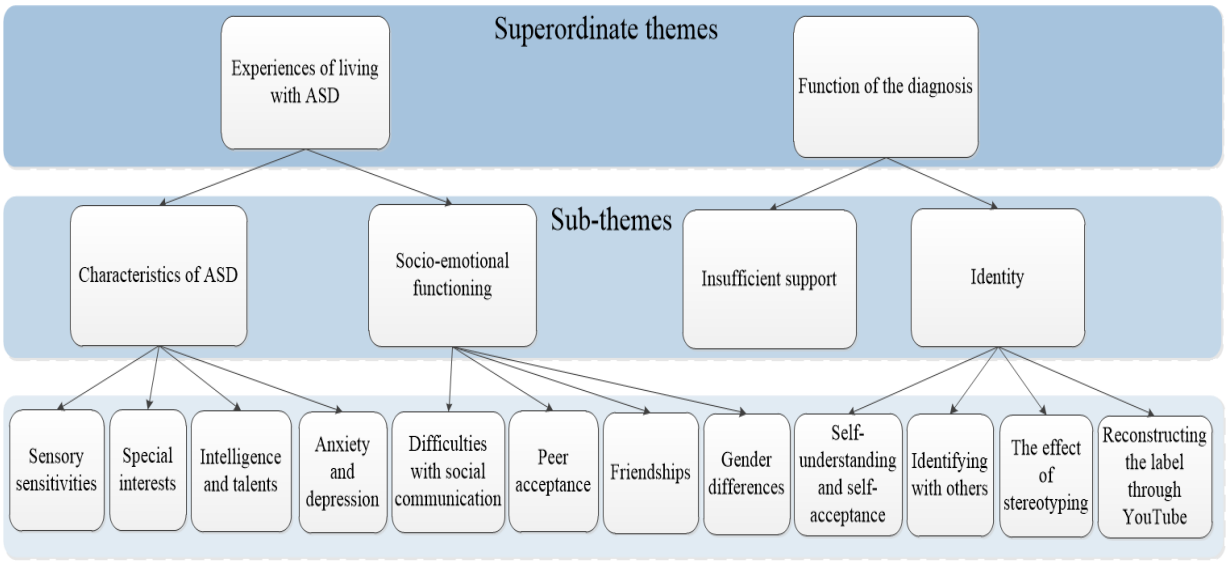
She has a younger sister of whom she is very fond, and her father has remarried. She appears to have a good relationship with her stepmother as she says she misses her in one of the videos and she also speaks positively about her when she informs the audience that her father remarried. She does not have a boyfriend, but mentions in one video that she has invited someone to a dance, which she was very excited about.

5.2 Interpretative Account and Discussion of the Analysis

From an analysis of the transcripts of these users' videos, the following superordinate themes emerged: 'Experiences of living with ASD' and 'Function of the Diagnosis'. The theme,

'Experience of living with ASD', delves into these girls' perceptions of the symptoms and characteristics of ASD at present, in terms of disability or difference descriptions. The second theme, 'Function of the Diagnosis', addresses how the diagnosis/label is viewed by them, whether hindering or helpful. Figure 1 represents the sub-themes derived from each transcript, which contribute to the superordinate themes.

Figure 1: Thematic map depicting superordinate and sub-themes



Before the results of these themes are presented, it must be noted that in this study a view of ASD as a disability is defined as a focus that is solely on one's flaws or disabilities, whereas a view of ASD as a difference is defined as a recognition of both strengths and difficulties related to this condition. Thus, throughout this discussion, mention of perceptions of ASD as a disability or difference will be understood according to the above explanations. This understanding of 'disability' and 'difference' developed through the process of analysis. An understanding of these girls' views of ASD as a disability or difference will be fundamental to our understanding of how such perceptions influence their identity formation.

5.3 Experiences of Living with ASD.

In Punshon et al.'s (2009) study, it was suggested that participants' perceptions of their diagnosis may have been influenced not only by their view of the ASD construct as either disability, difference or advantage, but also by their previous experiences related to their symptoms. In order to gain a clearer understanding of these adolescents' perceptions of ASD,

it seems necessary to first reflect on their own experiences of the symptoms and characteristics of ASD. What will be made apparent here is that the characteristics and symptoms of ASD, as viewed by these three adolescents, involve those characteristics that have caused considerable difficulty for them, and in some instances have impaired their daily functioning, as well as those that are perceived as positive and beneficial to them. Thus, it will be seen how their view of these characteristics and symptoms may influence the value (difference or disability) they place on ASD.

This first superordinate theme, 'Experiences of Living with ASD', is divided into two sub-themes, 'Characteristics of ASD' and 'Socio-emotional Functioning'. It is felt that, as difficulty with socio-emotional functioning is a core characteristic of ASD, this topic warrants a separate discussion under an alternate sub-theme.

5.3.1 Characteristics of ASD.

5.3.1.1 Sensory sensitivities.

The first characteristic broached is sensory sensitivities, which was mentioned by all three vloggers**.** From a medical model perspective, sensory sensitivities may be viewed as impairments as they can be overwhelming and disabling for the individuals who experience them. However, it has not been clearly established what causes them (Rogers & Ozonoff, 2005) and, while frequently noted in individuals with ASD, they are not an essential characteristic of the disorder (Minshew & Hobson, 2008; Talay-Ongan & Wood, 2000). It has been suggested that unusual sensory sensitivities are likely to influence cognitive-linguistic and socio-emotional development (Talay-Ongan & Wood, 2000); however, these three vloggers do not seem to perceive these sensitivities as having a profound influence in this regard.

The discussion will begin with Johanna who actually describes her sensitivity as an advantage. While she mentions several sensitivities, such as sensitivity to taste and light, she does not describe these as posing a problem for her. The sensitivity that she speaks about most is her auditory sensitivity, which she acknowledges as synaesthesia, and describes as enhancing her musical ability:

> "It comes with a lot of good things too. I wouldn't trade Asperger's for anything in the world. Like I probably wouldn't be so musical if it weren't for my Asperger's" [Johanna].
>
> "Um, it affects my sense of pitch, because, like I said, um, my sense of sound is more acute, more acute, so um, I'm able to pick out, uh, smaller differences in sound than most people would. So I have perfect pitch, um, and I have synaesthesia which is the connection between my eyes and my ears, so I see music" [Johanna].

Then there is the neutral stance that Jessica takes toward these sensitivities. She mentions that individuals with ASD have sensitivities, but she neither describes these in positive nor negative terms. For instance, her dislike of the feel of wool merely comes across as something that may be of interest to other people, or something that sets her apart from most people – in other words, a difference. She says:

> "Um, here's some things we're probably going to cover in future videos: sensory issues, like taste, smell and especially touch, um the feel of things, uh, one thing about this is I hate the feel of wool, so we'll learn about how sensory, how autism can actually affect your senses; that's going to be pretty interesting" [Jessica].

Sarah, on the other hand, describes how her sensitivities (specifically tactile and auditory sensitivities) have negatively affected her. She mentions that she cannot bear the feeling of a number of materials and explains how this sensitivity as actually affecting her school performance. She also mentions how her tactile sensitivity affected her relationship with her boyfriend:

> "I used to have issues with clothes and different materials, but because of school uniform, so now that I can wear what I want 24/7, it's, uh, I don't really have a problem. Certain materials still freak me out, but I don't buy them so…" [Sarah].
>
> "I'm hypersensitive to touch and noise, and the touch thing can affect our relationship. But I'm getting a lot better. And my sensitivity to touch is mostly with people I don't know, which isn't a bad thing. It's just like, walking in a crowd and being jostled, and that kind of thing. An unexpected touch is really what bothers me" [Sarah].

While these sensitivities may at times pose an inconvenience to Sarah, it seems that she has learnt to manage them and they no longer affect her as severely. Sarah's auditory sensitivities, however, can pose a problem for her. She says:

> "With noise usually I just get very annoyed with really quiet things that other people can't really hear. But if they persist, it just becomes deafening for me" [Sarah].

Her description of it becoming "deafening" may indicate that it drowns out all other sounds. Her sensitivities to sound, therefore, appear to be a particular challenge for Sarah, possibly even affecting her concentration. In this respect it is an area of difficulty for her.

From this, we see that these three vloggers' sensitivities at times pose a hindrance for them (for instance, Sarah's sensitivity to sounds), but at other times a strength (such as Johanna's synaesthesia). Another characteristic that has the potential to be experienced as either harmful or an advantage by individuals on the mild end of the autistic spectrum is that of obsessive interests. This will now be reflected on with regard to how these girls position this characteristic in relation to their views of ASD.

5.3.1.2 Special interests.

Special/obsessive interests fall within the restricted, repetitive behaviours and interests domain in the DSM-5 and are defined as "fixated or excessively circumscribed interests" (Lord & Jones, 2012). What marks these interests as clinically significant in comparison to hobbies is the degree of abnormality in intensity and focus of the interests (Attwood, 2007).

Jessica's account bears no mention of this characteristic, perhaps because she does not have any special interests or because her special interest is researching ASD. Johanna and Sarah, on the other hand, briefly touch upon their special interests. They both describe their obsessive interests, by and large, in positive terms. For instance, Sarah's obsessive interests used to occupy a lot of her time, but now she is using them to build her career:

> "I used to have crazy obsessions, which ate up all of my time. But they don't seem so all-consuming any more. Or at least, I can compartmentalise them and fold them away when I need to. Now it's really just graphic design, painting, writing, photography, singing and making videos which, they all combine and go towards the website which I'm launching anyway, which will hopefully become my job; so it's not like they're wasting my time anymore" [Sarah].

The use of the terms "crazy" and "ate up all my time" suggest that Sarah recognises that she had no control over her obsessions, and they devoured and took away something from her. She feels she can now "fold them away", which suggests that she has gained control over them. They are no longer "wasting her time", suggesting that she has found meaning in them. This finding corresponds with other studies which reveal that many individuals with ASD find purpose in and may even base their career plans on their special interests (Attwood, 2007; Grandin & Duffy, 2008; Molloy & Vasil, 2004).

Johanna holds that such obsessions can turn into talents, which she believes is the case with regard her musical ability:

> "The main problems that come with it are social problems, hypersensitivities, and obsessions which turn into talents and I guess you could watch any of my music videos on my channel" [Johanna].

Here, Johanna reveals her self-confidence and recognition of her abilities as she invites the viewers to watch her playing music. As can be seen, both Johanna and Sarah seem to have found their obsessive interests beneficial.

It seems at times that Johanna has a need to play music:

> "Um, so then I started Luvox, which is an OCD medicine, um, and I noticed it [anti-depressant medication] made my anxiety less, but it also affected my sense of pitch… That's just too valuable to me, so I stopped taking medicine altogether… And you know, I realise that the best treatment really is music… And I think I'm gonna go do that now, before I um, before I explode" [Johanna].

The use of the verb *explode* is evocative of an involuntary release of intense pressure and this seems to illustrate her attempt to control her emotions, very likely her feelings of anxiety that she described prior to this statement. It seems from this that her obsessive interest provides this form of release for Johanna. It has been suggested that obsessive interests are often accompanied by euphoria for many people with ASD, and may help to bring structure to a world that at times may seem chaotic (Fischer-Terworth & Probst, 2009). This perhaps accounts for Johanna's use of music to control her difficult emotions.

While society may view such obsessive interests as 'odd' or a 'symptom' of a disability, it seems that they can be considered advantageous by some who experience them. Johanna and Sarah have both found benefit in these interests and are using them to their advantage.

Another characteristic of mild ASD, which is considered by all three girls to be a strength, and which can make them feel more advanced than most other people, is intelligence.

5.3.1.3 Intelligence and talents.

All three girls speak about their intelligence, but Johanna and Sarah speak about it more than Jessica does. Furthermore, Johanna and Sarah speak about their talents, but Jessica does not mention any of her talents in these videos, possibly because she is not yet aware of them.

It seems that focussing on intelligence helps to improve these individuals' sense of self-worth, as can be seen in Jessica's comment:

> "It can be like really fun to have it because, well, in school, like academically you do great. And my IQ was like 130, I don't know. I don't know what it is but it was high. It was at a college level when I was 12" [Jessica].

Jessica's remark here is confusing, as IQ scores are not indicative of the age level of one's cognitive functioning. She perhaps has a misunderstanding of what IQ scores represent, or alternatively she is attempting to bolster her intelligence and highlight how much more advanced intellectually she is than her peers. Nevertheless, this characteristic stood out as one that enabled Jessica to appreciate her ASD. Similarly, it allowed Sarah to make sense of, and perhaps more easily accept, her difficulties:

> "And when I found myself with no friends, other people started reacting to that, you know like bullying me for being on my own, and then as they grew up, they realised I was actually more mature than them intellectually, but I didn't share any interests with them" [Sarah].
>
> "I may not be able to go out on my own but I have special talents like painting and singing and, and you know, I wouldn't have those without AS and creativeness is my thing. And with like learning at school, it never seemed like I had to try very hard. And things just sort of stuck in my head. And even though I didn't realize it at the time, the knowledge would always be there for me to retrieve later, which I think that's down to AS" [Sarah].

Sarah suggests that creativeness is "[her] thing" and she associates this with ASD, which reveals how she owns the positive attributes of ASD; she seems to recognise that her talents are a part of her. As mentioned previously, Johanna also ascribes her musical talent to AS. In this manner, AS signifies certain strengths for Sarah, Johanna and Jessica.

While high levels of cognitive functioning are not a prerequisite for mild ASD, and many individuals with this form of ASD are actually in the average range of intelligence (Lord & Jones, 2012), some may focus on scholastic performance and the development of talents as a means of compensating for deficits in social functioning and developing self-worth (Camarena & Sarigiani, 2009). Johanna and Sarah recognise that the benefits of having these talents seem to outweigh the negative attributes of the disorder, suggesting that they are focussing on these attributes possibly as means to compensate for their deficits:

> "That's just too valuable to me, so I stopped taking medicine all together. Um, so I agree with you that it [medication] affects music. That's just not worth it. It's not worth anything" [Johanna].
>
> "I don't think AS is a disability because with everything that I can't do because of it there's something else which I can do because of it. I may not be able to go out on my own, but I have special talents like painting and singing and, and you know, I wouldn't have those without AS…" [Sarah]

Sarah and Johanna seem to have recognised both the difficulties and strengths that result from her ASD, and feels that there is a balance in these. However, while Jessica views her intelligence as a strength of ASD, she goes on to say that, as a teenager, she is no longer as intelligent as she used to be. Though others tell her she has talents, she at times feels she has more flaws:

> "And my IQ was like 130… But I think it's decreased since then 'cause you know I'm a teenager and apparently you get dumber when you're a teenager" [Jessica].

It appears from her idea that she has become "dumber" as a teenager, that she no longer recognises this positive attribute of intelligence in herself. This same sense of imbalance in her positive and negative attributes of self, which are associated with ASD, is identified when she says:

> "So, here's my poem called 'Too different': Too different to be accepted, too different to fit in, there's no hope for me, so there's no way I will win. I long to be without my disabilities. I want to have a normal life, but I guess I'm just here for the sadness, pain and strife. Everyday I cry because I am so odd. I am told I have talents, but I am afraid I have more flaws" [Jessica].

It is possibly this feeling of having so many flaws that makes her feel helpless and defeated, with "no hope" and "no way [she] will win". Her focus on flaws makes her feel "different" from others, as though these differences make her abnormal. As she is unable to identify her

strengths, it seems she is less able to accept her ASD. For Sarah and Johanna, on the other hand, talents and intelligence provide a means for them to accept ASD as part of themselves and develop their sense of self-worth.

While the characteristics that have been analysed thus far have been expressed by these individuals in terms that can be described as signifying a difference (in other words, not simply an impairment or disability), anxiety and depression are symptoms they all associate with ASD, which they describe in more crippling terms. These will now be discussed.

5.3.1.4 Anxiety and depression.

While anxiety and depression are not listed as criteria for a diagnosis of ASD in the DSM-5, many individuals with ASD report experiencing depression (Barnhill & Myles, 2001; Ghaziuddin et al., 1998; Wing, 1981) and anxiety (Ghaziuddin et al., 1998; Farrugia & Hudson, 2006; Wing, 1981). These symptoms are particularly debilitating for these three girls, and are generally described by them in relation to their ASD.

Sarah and Jessica have both experienced depression, which may or may not be related to their symptoms of ASD. Jessica believes that her emotional struggles are related to ASD:

> "I'm just very sad, very lonely, very… This is the life of an aspie kid, guys… And I'm just angry, and sad and negative all the way" [Jessica].

It seems that she also has had suicidal thoughts, which she sometimes expresses when she speaks about ASD:

> "I've done all I can do. I have my whole life just fine. I must get rid of this pain and go to cloud nine above" [Jessica].

Again, Jessica expresses defeat, as though there is nothing more she can do. She appears here to lack the resources to cope. What she is trying to cope with is the experience of rejection from her peers. In these videos, all her comments about sadness arise in relation to this. This is in line with other findings that many individuals with ASD experience depression as a result of difficulties with social interaction (Barnhill & Myles, 2001; Ghaziuddin et al., 1998; Wilkinson, 2005).

Sarah has also experienced depression:

> "I have been given antidepressants before, but I decided not to take them. I sometimes get myself into a really bad place and yea, it would probably be easier or quicker to get myself out of that with pills, but I'd rather drag myself out of it and then at least I know it's real" [Sarah].

The sense that she "drags" herself out of her depression indicates that, while it is a burden and a struggle, she manages to find the resources to cope. Sarah seeks to recognise feelings that are "real" or related to genuine difficulties and not simply her hormones. It appears that she also associates her depression with her difficulties related to ASD:

> "So professionals didn't really think anything was wrong with me. They just said I wasn't very social, and anything else, like depression or anxiety, they said was just due to hormones… But after taking a shot at secondary school and the same thing happening in a much less amount of time, I knew it was something more than just hormones" [Sarah].

In this manner, Sarah, as with Jessica, associates her depression to her difficulties with social communication. Johanna, on the other hand, does not make any reference to depression.

Sarah also experiences anxiety, which is another characteristic that commonly occurs in individuals with ASD that may be associated with social communication difficulties (Bellini, 2004; Cath, Ran, Smit, van Balkom, & Comijs, 2008). Sarah explains on several occasions how panic attacks have caused her significant problems:

> "… I just have panic attacks when it was time to leave the house" [Sarah].
>
> "It becomes almost immobilising. You can't, you can't just move past something like if you're having a panic attack or if you're anxious. You just stop functioning, and you can't put that into words for them" [Sarah].

The use of the term "immobilising" highlights how severely this anxiety can affect her functioning.

Farrugia and Hudson (2006) suggest that some individuals with ASD not only experience higher levels of anxiety than typically developing teenagers, but experience anxiety at equivalent levels to adolescents with anxiety disorder. This is evident in Johanna as she was first diagnosed with generalised anxiety disorder and obsessive compulsive disorder before arriving at a diagnosis of ASD. She says:

> "… but the fact that my entire routine was just blown out of proportion and everything was so different in high school, just because of that, I totally melted

> down. I was having panic attacks every night. Um, they lasted like two or three hours. I wasn't getting any work done. I was handing stuff in months late. Um, it was really just horrible. Really terrible. Um, and at that point, I started seeing a psychiatrist and a psychologist. Um, I was diagnosed with OCD and panic disorder, and generalised anxiety disorder, I guess. Um, and we thought it was an anxiety disorder for the longest time" [Johanna].

In this respect, her symptoms caused her significant concern as she describes the anxiety as affecting her school performance. This anxiety seems to have arisen out of an inability to adjust to the changes of routine she experienced at school. This is a common concern among adolescents with ASD (Attwood, 2007) and, in Johanna's case, resulted in her feeling like she "melted down" or simply could not maintain control of herself. While Sarah's and Johanna's anxiety results from different experiences of ASD, in either case, they both perceive the anxiety as related to challenges with meeting societal expectations. They experience their anxiety in relation to the expectation that they must adjust and cope in a world that appears too volatile and chaotic for them.

As can be seen from an analysis of the results, the characteristics these vloggers describe comprise areas of strength, as well as areas of difficulty. Some of the difficulties that were raised include sensory sensitivities, problems with adjusting to change, anxiety and depression, while strengths were spoken about in terms of their talents, intelligence and interests. It seems that these girls have generally developed strategies to cope with their difficulties. However, experiences of anxiety and depression are particularly difficult for these three girls to manage, and appear to arise largely as a consequence of difficulties with social functioning. Socio-emotional functioning is categorised, in this study, as a separate subtheme as these vloggers, particularly Jessica and Sarah, describe it as the characteristic that causes them the most significant impairment in daily functioning. This area will be explored in more detail.

5.3.2 Socio-emotional functioning.

One area of difficulty that is consistent across the autistic spectrum is that of social functioning. So significant is this difficulty that the DSM-5 stipulates that all criteria related to persistent deficits in social communication/interaction must be met for a diagnosis of ASD (Hyman, 2013). In the videos under analysis, Sarah and Jessica speak more about this

problem than any other. Here I will discuss this difficulty in terms of their experiences of social communication deficits, and how they perceive these as having affected their relationships with peers.

5.3.2.1 Experiences of difficulties with social communication.

There are similarities in the manner in which these girls portray the difficulties they experience with social communication. Many of the ways in which they describe them highlight an experience of a deficit. This will now be discussed in relation to their descriptions of this area of difficulty.

Johanna explains that she struggles to identify how others perceive her and if she is acting appropriately in a given situation. It is difficult for her to imagine what others think of her and to determine whether she is annoying someone:

> "It's really hard to tell what somebody thinks of me or if uh I'm annoying them at any point in time. Um, you know things like that are just like really tough to figure out" [Johanna].

This concerted effort to 'figure out' what another person is thinking about her seems to be suggestive of a problem of mindblindness (Baron-Cohen, 2004; Frith, 2001), which Jessica also alludes to when she says:

> "It's, it's wondering what people think of you and not ever knowing, and not understanding anything that comes your way" [Jessica].

Jessica cannot make sense of the difficult and confusing social scenarios that she encounters. Sarah feels that she is "just blind to other people". It seems that by this she means she has difficulty recognising and understanding others' gestures and social nuances and, therefore, she cannot always *see* what others are communicating. This may also be indicative of weak central coherence, or the inability to see the holistic sense or meaning behind one's multiple expressions (Happé & Frith, 2006). The metaphor of being 'blind' suggests that she views this as an impairment or deficit.

One gains a sense from these accounts that these adolescents' experiences of such difficulties amount to feelings of being lost and lonely, and unable to make sense of the social environment around them. Further indicating an impairment and sense of being lost, Johanna

describes this difficulty in terms of concepts that come naturally to others, but are 'foreign' to her, and people are just a 'mystery' to her:

> "'cause I never think just to ask somebody to hang out. It's a sort of foreign concept... and, um, people just are a mystery uh to you" [Johanna].

Jessica suggests that she feels as though she is "from a different planet" or she is "a different species of human", and on four occasions in the video, 'My life with Aspergers', suggests that she is just "too different". Similarly, Sarah and Johanna both speak about a set of guiding social rules, which is embedded in the minds of most people but not in theirs:

> "So when you have AS, you're sort of not born with the social guidebook that everybody else is born with…" [Johanna]
>
> "I always say that it feels like everyone had a copy of the social rules since early childhood. Um, but I never got my copy" [Sarah].

What these descriptions seem to suggest is that these girls perceive themselves as having been born with something important that is missing; in other words, having a deficit.

It appears that these vloggers experience a lack of understanding of others that can be difficult and perhaps even anxiety-provoking for them. As they experience people responding to them in ways they cannot always decipher, it can, according to Jessica, become difficult for them to determine whether what they have done is right or wrong:

> "A kid that's autistic isn't born with the social part of their brain. Well, they are, but it's not working properly, there's something wrong, there's something missing. There's a piece that's disconnected in their brain that doesn't tell them what's right and what's wrong, like what's right and what's wrong in a social situation; even what's right and what's wrong in the case of like, for example, stealing" [Jessica].

It is not common for people with ASD to steal, and many individuals with the condition have good moral standards (Attwood, 2007); what Jessica is alluding to here, therefore, might be the taking of something without realising that it is socially unacceptable to take.

In Western culture, it seems these girls feel they are missing out on an important function (the social function) that most other people seem to possess naturally. We see that Jessica describes this in terms of the functioning of brains of people with ASD, suggesting that there is a piece 'missing from their brains', or something is not working properly; she perceives it in terms of a deficit in the brain. Johanna also describes it in terms of the functioning of the brain:

> "Asperger's does mess with the brain, that's what it does. Um, there are two sides of the brain (*holds up fists).* There's this side and this side. Uh, for most people they're connected in one way, but for us they're connected in a different way and it makes certain parts of the brain work better than people who don't have Asperger's" [Johanna].
>
> "Our brains are just wired differently" [Johanna].

The description of it 'messing' with the brain indicates that something does not function as it should. However, Johanna then explains it as "different" and that it has to work harder in processing some things, but is much better at processing other things. This corresponds with Baron-Cohen's (2002) suggestion that a difference in the brain of someone with ASD does not imply that it functions better or worse than most people's brains. Again, while Johanna recognises her difficulties, she also recognises strengths in other areas; therefore, she describes ASD more in terms of a difference.

The impairment in social interaction is considered to be the core symptom of ASD (Whitehouse et al., 2008), and Farrell (2004) suggests that individuals with ASD may require support because of such deficits. Nevertheless, some individuals with ASD manage to learn these social 'rules' (Carrington & Graham, 2001; Carrington et al., 2003). These three girls perceive themselves as managing in certain social situations as they have also learnt certain rules to guide them. Sarah says:

> "I observed what everyone else did and tried to copy that on a daily basis" [Sarah].
>
> "I'm not social. I can put on a front and sort of just act in a temporary social environment" [Sarah].

In this manner, Sarah learnt the social rules through observation and re-enactment, which is referred to as masquerading (Carrington et al., 2003; Grandin & Barron, 2005). This way she attempted to blend in with others in her environment. While Jessica recognises she still struggles socially, she does not believe others will recognise she has AS because she does not act like she has difficulties:

> "If I had never told anyone I had AS they never would have guessed. I knew and that's what really bothered me, but no one knew I had AS because I, I behaved like an AS child when I was little but when I got older I didn't act like it. But the social part of my brain still is kind of weird. It doesn't work very well. Like I can't socialise with people to save my life" [Jessica].

Johanna also feels she copes in social situations:

> "So you can meet some people who have Asperger's who just can't function in a social setting and then, I guess I do pretty well in social settings" [Johanna].

Therefore, it seems that these three girls have learnt certain techniques for managing aspects of the social terrain.

It appears that all three vloggers view their difficulties with social communication as a deficit which makes it harder for them to interact with and understand other people. These girls, however, suggest that they have found ways to manage these difficulties; yet, their experiences reveal that they may still benefit from social skills training. I will now look at the extent to which such difficulties influence their relations with peers and how peer support, acceptance and friendships can influence their sense of well-being and self-acceptance.

5.3.2.2 Peer acceptance.

The problem that adolescents with ASD have with social understanding makes it difficult for them to form social relationships with peers (Attwood, 2006; Carrington & Graham, 2001; Bauminger et al., 2010). While Johanna does not speak in great detail about her relationships (the reason for which will be discussed later), Sarah and Jessica describe how their social difficulties have affected their acceptance by their peers.

Jessica explains with much sadness that for four days prior to her video, 'Rough Day… true fellings [sic]"**,** she had eaten lunch alone:

> "I've eaten lunch alone for the past entire four days and my first four days have not exactly been the best. I don't like to be by myself unless I want to be by myself. Unless I say I want to be by myself for now. I never like being alone. But I… I've been really sad today and I cried in my room because I was feeling really sad and down" [Jessica].

She explains how she tries to put on a front of being positive and happy in front of her age-mates so that others may not recognise the difficulties she is experiencing:

> "And I know I said I was going to be positive [Jessica], and I know I said I was going to be happy, and I know I'm supposed to be happy, but do you have any idea how frickin' hard it is to be happy when you're me, okay" [Jessica].

She expresses hurt as she explains that others do not like her and that she does not fit in with her peers at school because she is too different from them.

> "I must get rid of this pain and go to cloud nine above. All I wanted was to be happy. All I wanted was to be loved" [Jessica].
>
> "For me it feels like I don't belong here, like I feel like I, I don't know, like I'm from a different planet or something, like I'm a different species of human and there's only one of me, one person that will ever like me is me, you know. And so, it feels like no one really likes me because they don't have the same interests as me. And I know that people are supposed to differ and be different, and it's good to be different, but there is such a thing as being too different, I think" [Jessica].

In the above remark, Jessica uses the term "different" five times, which she relates to why people do not like her. It seems that she has come to understand that her being "too different" results in her being rejected by her peers.

While Jessica's responses may be related to typical teenage angst, it is clear that the source of her emotional difficulties is related to her differences, which she associates with ASD. Therefore, the emotionality in her response may be typical for a teenager, but what she is responding to (peer rejection as a result of her differences) is an atypical adolescent experience, related to specific difficulties with ASD (Attwood, 2007; Barnhill & Myles, 2001; Humphrey & Symes, 2010). Her peers' responses to her have affected her ability to accept her ASD.

Not only does Jessica experience rejection by her peers, but she also experiences teasing and bullying:

> "And people always would ask me, have you been bullied and I'd say yea, and they would say why, and I would say, I don't know. But I did know why. I knew that I was different. I knew that I was more likely to be teased than most kids because of my problems" [Jessica].

This sense of loneliness and pain does not really dissipate throughout the videos, even though there is a decrease in her experience of teasing; she believes this is because people are simply getting used to her differences:

> "My days are getting better, probably because people are getting used to me being a weirdo" [Jessica].

While she says she is coping better because this situation has improved, there is a sense of helplessness in this remark, as though she cannot move herself out of the cast-out role her peers have positioned her in. Sarah also experienced bullying, which she explains resulted in

her dropping out of two high schools because emotionally she could not cope with it and she fell behind academically as a result:

> "…and the bullying started so I did leave that school and I went to another school, but unfortunately the year that I was there the same thing happened and I had to leave that school as well" [Sarah].

Here we see that, as a result of their social difficulties, Sarah and Jessica experience peer rejection and bullying that leaves them feeling isolated and alone. Many individuals with ASD become more aware of their differences as they reach adolescence (Shtayermman, 2007). The peer rejection and bullying, which they are at increased risk of experiencing, exposes their differences and forms them into vulnerabilities that can result in feelings of low self-esteem and affect their adjustment (Schäfer et al., 2004; Stoddart, 1999). Research has also shown that difficulties with social functioning may be related to experiences of anxiety and depression (Bellini, 2004; Safran, 2002; Whitehouse et al., 2008; Wilkinson, 2005), which may account for such experiences in Sarah and Jessica.

The anxiety caused by these difficulties can be debilitating, often resulting in isolation, fear, substance abuse, depression and suicidal ideation, as well as other forms of psychopathology (Tantam, 2000). This anxiety can be seen in Sarah as she explains how her days revolve around her list of chores and her waiting for her boyfriend to come home:

> "My life is structured to the extent that my boyfriend leaves for work and then comes back home again… And when he doesn't come home at lunch, I usually completely forget to eat… I do have a timetable of chores for work that needs to be done and on which day it needs to be done on. And I have things in bold which are essential because usually I end up wasting a lot of time on the internet and forget to do the important things... I used to nap until lunchtime and now I don't nap at all. So stage one complete" [Sarah].

This could be the life of one who is incapacitated – she is so afraid to leave the house that she is left alone and waiting for people to arrive. Her remark, "[s]o stage one complete", relates to what she said earlier about dragging herself out of her depression, struggling even to get out of bed in the morning. This depression appears to be caused by her anxiety related to leaving the house. The only people she perceives as accepting her are people who are very similar to her, or her family who she believes just excuse her differences:

> "I'm just blind to other people, unless they're just like me, or unless they know me very well, like my family. But then they just excuse any weirdness on my part" [Sarah].

It seems that she feels that very few people accept her and the rest of the world does not. Later this notion is reiterated when she says:

> "My life is basically my fiancé and the internet and I haven't the foggiest idea how the world views me. Probably badly" [Sarah].

This experience of a societal rejection may stem from earlier experiences in her adolescence. She explains how she did not get on with girls at her school because she felt very different from them.

> "When it got to the point, well, you know, when I got to the age where girls start to get bitchy as their hormones kick in, I just sort of stayed the same, like child-like. And they started falling out with me because I wasn't learning fast enough the new, the new way they were acting. It was natural for them to be ever changing, but not for me because I like my routine and my stability… but I didn't share any interests with them" [Sarah].

While I will go on to discuss gender differences in ASD in Section 5.3.2.4, it is necessary to point out here how Sarah's remark highlights the struggles that adolescent females experience with learning the complicated social behaviour of their peers (Maccoby, 2002; Rivet & Matson, 2011). While Sarah may have attempted to masquerade amongst her peers, she was unable to keep up with their complicated social behaviour, which resulted in the exposure of her differences. Similar to Jessica, it seems that Sarah just felt too different from her peers and did not share similar interests with them, which affected her ability to feel accepted.

Johanna describes a different experience of peer relations at school to Jessica and Sarah. While she appears to have been very focused on her academic performance at school, she does indicate that she had some positive peer relations:

> "'cause what I thought was a friend was somebody who I talked to during class. I only saw them in class. Um or if I passed them in the hallway and they talked to me, I considered them to be a friend" [Johanna].

Here we see that Johanna converses with her peers in a friendly manner, which suggests that she possibly felt some form of acceptance from her peers at school. Furthermore, an analysis of her videos reveals that she spends much of her time playing musical instruments, but in several of these videos she is playing instruments with other people, which may suggest that

she experiences a sense of peer support and acceptance derived from a shared interest in music. The only time she mentions bullying in her videos is when she refers to boys with AS and how they are less likely to be accepted by their peers than girls:

> "Um, I think they're more likely to accept a girl who has AS into their group of friends than boys are" [Johanna].

Thus, it may be assumed that Johanna has not experienced much peer rejection and bullying, which may be a consequence of her confidence in herself and the respect she has elicited from her peers as a result of her musical talent and intelligence.

On the other hand, it is also possible that Johanna does not speak about her difficulties with peer relations because she is more guarded in this respect than Jessica and Sarah. There are times when it seems she struggles to admit to or accept these social problems, as may be interpreted in the hesitant manner with which she describes them:

> "I'm glad somebody brought that up. Um, because, uh, that's one of the main problems in AS. Not only does that affect most, it affects everybody with AS. If you don't have social problems you don't have AS. Um, there, I said it" [Johanna].

This last piece where she says "there, I said it" may reveal the reluctance she feels at saying 'it' or admitting to her difficulties. This may indicate that she struggles with exposing this vulnerable part of herself in the public domain and may explain why she does not really speak in depth about her feelings regarding friendships and peers. Nevertheless, it seems she does not present this as the major area of difficulty for her, but rather speaks about her challenges with adjusting to the demands of high school as her main area of concern that led her to seek the diagnosis. These 'demands' appear to be related more to changes in routine than problems with social interaction.

From these accounts, it may be determined that the major consequence of the apparent social communication difficulties, experienced by some adolescents with ASD, is their peers' reaction to it (Humphrey & Symes, 2010; Schäfer et al., 2004). Where Johanna's peers respond positively to her despite her difficulties, she experiences less concern over her difficulties; whereas Sarah's and Jessica's peers negative response to their difficulties results in more severe consequences such as depression and anxiety. Thus, we see the influence that peer relationships can have over these girls' experiences of their ASD.

Humphrey and Lewis (2008, p. 41) suggest that where 'diversity becomes the norm' individuals with differences are more able to embrace the challenges and opportunities of the mainstream school environment. It is possible, in this case, that Johanna perceives her peer relations more positively than Sarah and Jessica because she is simply in an environment where individuals are more accepting of differences in people. Or it may be that she has developed a talent that she is able to share in common with her peers and thus feels more accepted by them. Either way, it appears she experiences a sense of fitting into her environment.

Sarah has also now found a space where she feels accepted by others and has been able to establish meaningful relationships. This space is the internet:

> "But I don't really go out into the real world very often and I don't work in it either. My life is basically my fiancé and the internet" [Sarah].

Much of Sarah's socialising occurs through cyberspace, which is how she met her fiancée:

> "And I had known him for five years or so, um, already, over the internet through a mutual friend" [Sarah].

She later explains:

> "I don't suppose that I fit into the world, uh, but I fit into the internet… it's easier to navigate" [Sarah].

At the time of making these videos, Johanna and Jessica also appeared to do most of their socialising on the internet as neither of them had any friends. The nature of the internet may make socialising easier for these girls because they are not expected to read gestures, tones of voice and facial expressions, but rather another's message in the form of words written on a screen. This gives them time to decipher the meaning behind those typed words and respond appropriately. In this respect, the internet serves as an augmentative and alternative communication system (AAC), which is a device that supports social communication (Carson, Moosa, Theurer, & Cardy, 2012). It acts as a social filter, providing a form of communication that is easier for individuals with ASD to decipher. To repeat the earlier quotation from Singer (1999, p. 67): "The impact of the internet on autistics may one day be compared to the spread of sign language among the deaf". This emphasises how, for many individuals with ASD, the internet helps cater to their differences in communication style (Davidson, 2008).

It is evident that difficulties in social communication have resulted in experiences of peer rejection, bullying and teasing for Sarah and Jessica. In contrast, though Johanna recognises difficulties in this area, she seems to feel accepted by her peers despite them. I will now look at how these vloggers' experiences of friendships may also be affected by their difficulties with social communication.

5.3.2.3 Friendships.

While the internet can be beneficial with respect to youth with ASD's peer relations, it is questionable whether it can help with the formation of meaningful friendships for these individuals. The distance inherent in cyberspace may not be in keeping with the required interpersonal closeness considered necessary for intimate friendships during the adolescent and early adulthood phase (Newcomb & Bagwell, 1995). This may explain Jessica's struggle to cope with her difficulties even while she may have found more acceptance through the internet. However, a meaningful friendship, in the traditional sense, may not always be necessary for one with ASD to find contentment within one's self (Church et al., 2000), as will be discussed in relation to Johanna's ability to cope without meaningful friendships. Here, the views regarding these three girls' friendships will be reflected upon based on the satisfaction they seem to derive from them, and the extent to which their difficulties with social interaction have impacted on their forming of these fundamental relations with others.

Johanna admits that she has difficulties with the concept of friendship:

> "… I struggled for a really long time with the definition of friends. 'cause what I thought was a friend was somebody who talked to me during class. I only saw them in class" [Johanna].

She then goes on to explain how she only really spends time with someone when she has a reason to do so:

> "I didn't really understand that people actually got together outside of school. Um, I'm still having problems with that now. Um, I will never really make plans with anybody I know because it never really occurs to me do that. Usually if I hang out with somebody it's, it's because we have some reason to do it, it's never really just to do it. 'cause I never think just to ask somebody to hang out" [Johanna].

This would suggest that Johanna's view of a friend is someone she talks to in class, or someone she is doing some form of work with. It appears that she is content with this notion

of friendship, finding satisfaction in the social relations she has with peers on an academic level.

While Johanna seems somewhat unconcerned about the nature of her friendships, Jessica is deeply troubled that she has so few real friends:

> "… it's even more painful for kids with disabilities and it's harder because they don't have as many friends as some kids do" [Jessica].

Her understanding of a friend is someone who likes her and who shares similar interests with her:

> "And so, it feels like no one really likes me because they don't have the same interests as me" [Jessica].

She feels a friend is someone who will help her when she is experiencing difficulty:

> "I need help or a friend who will lift me up" [Jessica].

She believes it is someone who accepts her for who she is:

> "And so, if you can't accept me for who I am, then don't be my friend" [Jessica].

Jessica's discourse on friendship seems to be in accordance with a more traditional view of friendship than that of Johanna. It is perhaps because she has this view of friendship that she is aware of how few friends she actually has and how difficult it is for her to find friends that match these criteria:

> "I love making friends, but I feel every attempt I've made to make a friend has always gone downhill. And so I'm just going to let them come to me from now on" [Jessica].

This strong desire for friendship is not being satisfied in Jessica's case, which may explain her deep sadness and occasional expressions of hatred toward ASD.

Sarah explains that she struggles to keep a friend:

> "… relationships as far as friendships go, I've always been not very good at that. I can't really keep a friend. It's very difficult for me to concentrate on more than one friend because I find it easy to focus my attention on one, do everything with them, go everywhere with them, and that's fine, because it's just one person. It's simple" [Sarah].

Here we see that Sarah prefers to have one friend because she feels she cannot concentrate on more than one friend, perhaps because it is easier to read the social communication of one person rather than a group people (Attwood, 2007). Sarah considers a friend someone she

goes everywhere and does everything with. In one video, she says that her only friend is her boyfriend. She describes how dependent she is on him in that she will not leave the house without him:

> "When I go places, I'm always with my boyfriend now, so that's okay" [Sarah].

She relies on him financially:

> "I don't really handle money, my partner… he usually tops up my purse with change and the odd note. And we have joint bank accounts which I have cards for. But I don't spend without him saying how much I can, like to start with" [Sarah].

She explains that she is happy to just spend all her time with her fiancée:

> "We're so similar it's untrue. So it's a really easy relationship. Aside from work we spend all of our time together and I love it that way, I wouldn't have it any other way" [Sarah].

This reveals just how much her life revolves around this relationship. Though this is more than just a friendship, it still constitutes the only friendship that Sarah has in life, and yet it seems to satisfy her. For her, it is "simple" and "easy":

> "It simplifies things to an extent…. Plus I don't have to keep track of a gazillion different friendships, it's just me and my partner, which is easy" [Sarah].

This sense that having only one friend is "easy" may not only be related to a dislike of group social situations (Attwood, 2007), but also a concern for sameness and resistance to change that has been identified in many individuals with ASD (Baron-Cohen, 2002; Lord & Jones, 2012).

These accounts suggest that these three vloggers generally have different perceptions of friendship. Johanna's understanding of friendship is more in line with the common view that adolescents with ASD have a poorer quality of friendship (Carrington et al., 2003; Whitehouse et al., 2008) and less intrinsic motivation to engage in friendships (Bauminger & Kasari, 2000; Whitehouse et al., 2008). Nevertheless, she seems satisfied with the relationships she has formed with her peers. Sarah's concept of friendship involves a focus on one individual who she spends vast amounts of time with. She has found such a friendship in her boyfriend with whom she shares much in common and who she feels understands her difficulties and accepts her in spite of them. Jessica has a more traditional view of friendship; however, her strong desire for a friend has not been met, which has resulted in feelings of depression, low self-esteem and difficulties with accepting her disorder.

Friendships hold increasing importance for identity formation and emotional well-being in adolescent and early adulthood years (Collins & Laursen, 2004; Howard, Cohn, & Orsmond, 2006). It is possible that had Jessica even one friend this might provide a buffer against the painful rejection she experiences from her peers (Humphrey & Lewis, 2008). Many individuals with ASD can and do make friendships when they share common interests with another (Carrington et al., 2003; Church et al., 2000; Howard et al., 2006). Perhaps because Jessica has not found a particular interest or strength (which may be assumed from her lack of mention of any such interests or talents in these videos), she has had less opportunity to form such friendships. As Sarah explains, when she was in school she did not share similar interests with her adolescent peers, which made it 'impossible' for her to make friends with them. On the other hand, Johanna is in college and is able to participate daily in a shared interest with her peers.

It is possibly because she feels accepted by her peers that Johanna seems less concerned about her lack of friendships. Sarah and Jessica, however, faced peer rejection and had no friends at school. It was only when Sarah formed a meaningful relationship at a later stage that she was better able to accept herself and her disorder. This finding correlates with Humphrey and Lewis's (2008) study (as described in Section 2.6) where participants that had formed meaningful friendships were more able to successfully integrate AS into their identity.

This issue of identity formation will be discussed under the next superordinate theme, 'Function of the diagnosis'; however, before this theme is broached, it seems necessary to discuss Sarah and Johanna's view that the nature of girls' friendships can mask symptoms of ASD up until adolescence. This may shed light on the reason these girls' became more aware of their differences at this period of their lives, which will aid our understanding of why they sought the diagnosis and what function it plays in their lives.

5.3.2.4 Gender differences.

During their adolescent years, Johanna and Sarah became more aware of their differences, and both girls took it upon themselves to determine what was 'wrong' with them. However, they both experienced difficulty in the process of arriving at the diagnosis of ASD. This may be as a result of gender differences in the way ASD symptomology presents itself

(Dworzynski et al., 2012; May et al., 2012), which has resulted in many girls with significant ASD symptoms experiencing misdiagnosis, delayed diagnosis and even a lack of a diagnosis (Rivet & Matson, 2011).

Sarah and Johanna suggest that boys' symptoms are more noticeable than girls' symptoms because of the nature of their friendships. Sarah holds that it is more difficult for boys with AS than girls to form friendships:

> "Um, I think it must be easier to spot it with boys because they don't really hide their weirdness as much, and they don't have, you know, an emotionally strong group, or a strong network of friends that they can blend in with. Um, because that's just not how guys are. Within a group of girls there's always gonna be like a mother hen that will put a certain amount of time in to take care of the girl with AS and so it just goes unnoticed to everybody" [Sarah].

She suggests that girls with AS are taken into the group by a 'mother hen' figure who takes care of the girl with AS such that her difficulties with social communication may go unnoticed. Johanna echoes this, saying that girls are more likely to accept children with AS into their group because it is their nature to be more sympathetic and caring:

> "They're, I, I think more accepting than boys are, they're more keen on their emotional, um, emotional metre. Um, I think they're more likely to accept a girl who has AS into their group of friends than boys are. 'cause a lot of the time what happens is that boys will be bullied by other boys. Um 'cause boys are, I have found, not, um, not as accepting of differences" [Johanna].

Their hypotheses are in accordance with Attwood's (2006) theory that suggests that girls with ASD are more likely to be guided and protected by same sex peers. He also suggests that they have more gender appropriate special interests that enable them to blend in better with their peers than boys. They may also have fewer special interests and better superficial social skills (Gillberg & Coleman, 2000). As discussed previously, all three girls in this study suggest that they cope adequately in certain social settings. Their ability to masquerade made their symptoms less noticeable such that their teachers and parents did not realise they were experiencing problems.

While Sarah and Johanna seem to find the symptoms of ASD less noticeable in girls than boys, they do not believe this makes ASD easier to manage. On the contrary, Sarah suggests

that the problems she experienced that were related to a late diagnosis were as a result of her symptoms being masked by a protective group of female friends. Even when she had no friends and expressed her difficulties to her family, they did not take her concerns seriously and rather believed it was due to hormonal changes:

> "I think that it helped them because I have been going through a really rough time for the previous four years and they didn't really know what was wrong with me or they didn't really think anything was wrong with me, that it was just hormones" [Sarah].

Johanna and Sarah believe that boys are more likely to get a diagnosis, or at least an earlier diagnosis, than girls are. In this respect, Sarah believes they have a greater opportunity to receive earlier support, to help them cope with their differences and the demands of adolescence, than girls do. Johanna and Sarah struggled throughout their adolescent years not fully understanding why they were experiencing such difficulties. While these individuals recognise gender differences in the way ASD presents itself, it seems they perceive it as being equally difficult to manage, regardless of whether experienced by males or females:

> "I think it's actually pretty even, but girls are so good at hiding their symptoms…" [Johanna]

Perhaps their experiences of ASD may have been even more challenging initially because they did not have a diagnosis as a point of reference to locate their difficulties.

These gender differences in ASD have raised serious concerns as many girls with ASD are being overlooked, and as a result are not receiving the academic support and services they require (McKnight & Culotta, 2012). Wilkinson (2008) suggests that the consequences of a missed or late diagnosis may include lowered grades, peer rejection, social isolation, and increased risk for mental health, such as anxiety and depression for individuals with ASD. While Sarah and Johanna describe experiencing some of these consequences, so does Jessica who actually did receive a diagnosis before adolescence. This gives rise to the question of what function the diagnosis actually serves these girls and if it can actually help in preventing these negative consequences. Their perceptions of the function of the diagnosis will now be explored in more detail.

5.4 The Function of the Diagnosis

Thus far the discussion has centred on these vloggers' perceptions of the difficulties and strengths they experience in relation to the characteristics of ASD. Now the focus will shift to the meaning found in receiving a diagnosis as described by these three adolescents. Such meaning is to be determined through a reflection on their view of the support the diagnosis has provided them, as well as the impact the diagnosis has had on their developing sense of identity. This analysis will further address the disability versus difference argument – that is, it will reflect on the values these vloggers have attached to ASD and how these may have influenced their acceptance of the diagnosis, as well as their self-acceptance.

5.4.1 Insufficient support.

This sub-theme takes into consideration the lack of support services provided for these vloggers in their countries, and the level of perceived support offered to them by their families. While many learners with ASD are now being educated in mainstream settings (Dybvik 2004), research in various countries has shown that accommodations in schools for those with ASD are currently insufficient (Hay & Winn, 2008; Humphrey & Symes, 2013; Leblanc, Richardson, & Burns, 2009; Osler & Osler, 2002; Pisula & Łukowska, 2011). Furthermore, difficulties with recognising ASD in individuals may result in their receiving inadequate support and understanding from teachers and their families (Neihart, 2000; Portway & Johnson, 2003).

As discussed earlier, Johanna expressed that her greatest difficulties arose when she entered high school, in the United States of America (USA). However, when she received a diagnosis it seems that she was able to manage her symptoms better. In this respect, the diagnosis seems to have helped Johanna gain the support and understanding she required. However, Johanna's late diagnosis may be indicative of inadequate awareness of ASD by her teachers, which may have been related to gender differences in the way ASD presents itself (Rivet & Matson, 2011) and/or stereotypical views people have regarding ASD (Singer, 1999). It is possible that had her teachers a better understanding of ASD, they may have been able to identify these difficulties in her earlier and recommend that she have an assessment.

For Jessica, also in the USA, the diagnosis provided her the means to gain educational accommodations at school and the opportunity to receive scholarships when she went to college. She feels her accommodations have provided her a degree of relief at school as she has struggled to cope academically in the past. For her, these accommodations are one of the major benefits of having the diagnosis. Nevertheless, the diagnosis has not been beneficial to her in terms of her emotional well-being, which has been affected as a consequence of her rejection from peers. When she disclosed her diagnosis to her peers it did not have the desired effect of helping them to understand her better. She says:

> "But here's the problem, after some kids knew I had it, they still teased me anyway. Maybe not on purpose, but they kind of used it to their advantage and didn't help me in any way. They would kind of tease me, make fun of me about it and it still hurt. And deep down I wish I had never told anyone" [Jessica].

She had wanted them to know that she knew she was different. The diagnosis became a way for her to explain her behaviour to others and to elicit empathy; however, her peers teased her even more after she informed them about it. In this respect, it failed to frame her behaviours in a more acceptable way for her peers.

Sarah, in England, also found that the diagnosis did not provide her access to the support she required when she was seventeen years old:

> "It was a little bit of a let-down because when I was diagnosed I was 17 and the services which are in place to help with people with Asperger's, there is kind of a children's half and an adult half and the children's services stopped at 16 and the adult services started at 18. So because when I got my diagnosis I was 17, nothing could be put in place. So that kind of like a year that I didn't have any help and by the time I got to 18 I didn't really feel like I needed much help" [Sarah].
>
> "I've never had any medical stuff for my AS. As soon as I got the diagnosis, that was that and I dealt with it on my own" [Sarah].

While Sarah required support to help her cope with her panic attacks and difficulties with peer relations when she was younger, at the age of eighteen she felt she no longer needed support and could manage her symptoms on her own. This was possibly because she had already dropped out of school at this stage and, therefore, no longer had to confront that which may have been aggravating her symptoms: the bullying and lack of understanding from others.

Sarah describes how one of her teachers at school revealed a lack of awareness and understanding of ASD. She says:

> "And I explained that I had AS and that part of that diagnosis included being hypersensitive like to certain textures and that kind of thing. But she just wasn't having any of it. It didn't matter what I said. She just couldn't understand why that would be a problem" [Sarah].

Here, Sarah describes how she attempted to explain her difficulties to her school teacher, but the teacher did not seem to understand the difficulties associated with ASD and, as a result, told Sarah to wear a jersey that she could not tolerate the sensation of. The teacher told her that if she did not wear it, she would have to go home, which is what Sarah eventually decided to do. She explains that when she got home she experienced a panic attack because of the stress this incident caused her. The school teacher failed to recognise her difficulties, which led Sarah to feel misunderstood. With regard the jersey, she says:

> "I couldn't deal with it, I don't know why. I can't explain why other than I just couldn't… she didn't get it, and you might not get it. It's complicated and there's no reason for it other than AS" [Sarah].

It is difficult for her to explain her symptoms to others and her attempts to use her diagnosis for this purpose are at times unsuccessful because it seems that she experiences many people lacking awareness of what ASD is.

While Sarah feels that there is not much support for those with AS in England, she does believe the diagnosis helped her to be accepted back into school two years below her age level, after she had dropped out as a result of her difficulties. She also says that the school put 'some things in place' to help her with her AS. This enabled her to complete her GCSE's and her A-levels.

> "Honestly, having a diagnosis, it doesn't really seem to do that much. It didn't do a lot for me in terms of actually getting help and support and everything because it doesn't seem that there is much help and support to be had. But at the same time the clarification and like the understanding that came with the diagnosis just for me personally was just really what I was looking for. I wasn't looking for help and support so yea" [Sarah].

Here she admits that she did not really seek a diagnosis so to receive support, but rather to better understand the nature of her difficulties. The diagnosis did help her in this respect.

Sarah also believes that the diagnosis helped her to receive understanding and support from her family:

> "And so to finally get a diagnosis, I think it made them think 'oh right, there was something, maybe we shouldn't have been so harsh'. Uh, I dunno, having been something they can research and put the symptoms together with things I have done in the past helps I think" [Sarah].

It seems that the diagnosis, in this respect, enables her family to "research" ASD, which helps them understand her behaviour. Thus, they are less "harsh" and possibly more forgiving, which seems to have made it easier for Sarah to accept and be more forgiving of herself: "And that not necessarily wasn't it my fault, I just didn't understand myself at the time." [Sarah].

The users often draw from the literature in their explanations of AS. For instance, Jessica says:

> "… well, if you have AS you're going to have symptoms of other diseases as well…
> I'm going to make another video after I do a bit of research on something" [Jessica].

Johanna says: "And with girls, um, if you look at statistics…", which suggests she has done her own research on the disorder. This reveals the function of the diagnosis as a point of reference for them to learn more about their difficulties, as well as for their families and friends to gain a better understanding of them.

These accounts highlight the different experiences of support provided by these girls' schools and governmental services in their countries. In accordance with Humphrey and Lewis's (2008) study into adolescents' perceptions of support in schools, all three of the users in this study expressed a need for more support, particularly in their high school years. While it seems the diagnosis has provided access to academic support for these girls, they all feel there is a need for greater awareness of ASD. As pointed out earlier, it seems that there is a particular need for more recognition of gender differences in the way ASD presents itself, which may have prevented Sarah and Johanna from receiving support and accommodations earlier. While Sarah and Jessica did not feel the diagnosis provided them adequate understanding from others, particularly their peers, as they might have desired, it is possible that it has provided them a degree of self-understanding. This will now be reflected on in more detail.

5.4.2 Identity.

The concept of 'identity' will now be explored and will be considered with respect to the level of self-understanding provided by the diagnosis, the benefits these vloggers derive from identifying with others with ASD, as well as reflection on their experiences of being stereotyped as a result of their label, and finally, how they are reframing and constructing their diagnosis on YouTube. By gaining deeper insight into the effect the label has on their developing identity, it may give us a better understanding of the value they assign to their diagnosis (Humphrey & Lewis, 2008).

Luyckx et al.'s (2006) theory will be applied to our understanding of these vloggers' identity development. However, a definition of identity provided by Baines (2012, p. 549) seems appropriate to the psychosocial underpinnings of Luyckx et al.'s (2006) theory; that is, the self will be viewed as "constructed and enacted through continuous participation across diverse contexts, shaped by how individuals are positioned by themselves and others". What is fundamental in this definition is that identity is not static, but is constantly in the process of becoming as the individual interacts with and is influenced by those in his or her world. This idea of a dynamic identity becomes increasingly important when we consider the position that the diagnosis plays in one's identity formation and how the perception of it as a disability or difference can shape one's identity to the point of self-acceptance or self-loathing. This idea will now be explained further in light of the experiences of these vloggers.

5.4.2.1 Self-understanding and self-acceptance.

Some individuals with ASD experience the diagnosis as providing them increase self-understanding and self-acceptance (Camarena & Sarigiani, 2009; Humphrey & Lewis, 2008; Punshon et al., 2009). I will now look at the extent to which the diagnosis has provided this for these YouTube users, and how it has affected the integration of ASD into their identity.

Johanna sought meaning and understanding in her diagnosis, which can be seen through her effort at finding it:

> "And I started exploring other options. Um, and I came across AS and I brought it up with my therapist and she agreed that it was, it's AS" [Johanna].

> "I think it's actually pretty even, but girls are so good at hiding their symptoms that um, that it's not really noticeable, until something very disastrous happens and then you go to all the doctors, and then they tell you you have AS, surprise" [Johanna].

Johanna points out that her search for a diagnosis occurred after something "disastrous happened". The negative event in her life led her to seek a diagnosis to make sense of or find the meaning behind her difficulties. Johanna had read up on AS and found that this diagnosis seemed to fit her symptomology better than other disorders she had previously been given (for example, obsessive compulsive disorder). Although she needed confirmation from her therapist on the matter, it seems she essentially diagnosed herself with AS. One can then assume the diagnosis of AS was acceptable to her.

If we refer back to Luyckx et al.'s (2006) four-dimensional model of identity (as described in the "Literature Review" in Section 2.7.1), it may be seen that Johanna explored the different identity alternatives, or ways of perceiving her differences and difficulties. Through this exploration, she committed to and identified with a diagnosis of ASD as it brought meaning and understanding to her differences, and it corresponded with her true aspirations in life (for instance, her talent for music, as well as her apparent lack of concern with regard to forming intimate friendships) (Luyckx et al., 2011).

Sarah has also committed to a diagnosis of AS as it was easier to accept than some of the other diagnoses she had previously received. She says:

> "'cause during the process of getting diagnosed they kind of wanted to rule out a lot of mental health conditions first which upset me 'cause I went from thinking I was fine to thinking I was mentally ill. It wasn't very nice and I thought that I had maybe done something wrong or that there was something wrong with me. I dunno, it was just a horrible feeling. When they finally came and said Asperger's I just felt a lot more comfortable with that diagnosis because it definitely felt like that one fit a hundred percent compared to some of the other things they had thrown around like borderline personality disorder" [Sarah].

For Sarah, as with Johanna, the diagnosis of ASD is acceptable and enables her to feel that it fits her. In this respect, the diagnosis allows these girls to make sense of their difficulties. Though they do not feel they fit into the frame of what constitutes 'normal', they do fit somewhere and into some group, or category of people, which allows them to accept themselves more easily.

The concept of the diagnosis fitting or suiting them, described by Johanna and Sarah, suggests that it has given shape and meaning to what they were experiencing. They finally had an excuse for their behaviours and a name for their difficulties. Sarah says:

> "But at the same time the clarification and like the understanding that came with the diagnosis just for me personally was just really what I was looking for" [Sarah].

The diagnosis enabled Sarah to gain an understanding and acceptance of herself and allowed her to relinquish responsibility for some of the things she had done:

> "So it just gave me more of an understanding about myself and I felt like whilst I don't like to use it as an excuse for the things I have done wrong, it felt like with a few things I understood why I had done certain things. And that not necessarily wasn't it my fault [sic], I just didn't understand myself at the time so I couldn't control certain aspects of my life and now I can" [Sarah].

Here we also see how the nature of this self-understanding that the diagnosis provided her enabled her to take control of certain aspects of her life. For instance, she developed systems and routines to guide her through her daily activities, she went back to school to complete her GCSE's and her A-levels, she later strives to bring her skills together to begin a job that is more realistic for her in light of her difficulties (starting up a website), she begins to accept her fit into the virtual world of the internet, and she gets together with her boyfriend (to whom she eventually becomes engaged). In this respect, Sarah has successfully *identified with* the diagnosis as it has allowed her to accept her behaviours and differences, and has also provided her enhanced self-understanding so that she is able to make decisions that match her true interests (Luyckx et al., 2011).

For Jessica, the diagnosis has become a means for her to contain her differences and difficulties, and it has provided meaning and an explanation for them. For instance, she says:

> "…doctors are trying to help you and tell you what's going on, so you can understand like why you're doing the things you're doing" [Jessica].

As it enables her to become more aware of her behaviours, the diagnosis helps her to gain a better understanding of herself. However, it is not always perceived in such a positive light by Jessica.

In Humphrey and Lewis's (2008) study, some adolescents described themselves and their diagnosis in negative terms, others seemed to accept their AS, while others seemed to

struggle to come to terms with the role AS played in their lives. Jessica seems to meet the latter description, as she has a similar difficulty with locating AS in her life. In one video, Jessica seems to recognise and accept that AS is something she will have for the rest of her life, as she refers to her videos as the "Autistic for life video series". She finishes off this same video saying: "And I'm Jessica and I'm autistic", showing the extent to which the diagnosis has come to form a part of her identity. However, in a later video, she also expresses a desire to be 'autism-free':

> "I need to change myself, but change is not enough. I want to be autism-free, but unfortunately I cannot" [Jessica].

In this respect, there appears to be a constant flux of association with and dissociation from her diagnosis. At times she would describe her diagnosis as being something separate from herself – a disability she has been cursed with – and at other times as something that forms a part of her essential self:

> "I just don't understand why He [God] has to give me these disabilities. I mean, I understand that He has to give us these so we will get stronger. But it's killing me, you guys. It's hurting me so bad because I don't… I'm just angry with Him. Because I don't understand like how He could do this to me. I mean, I'm His baby girl and I just don't get it… like why He wants to torture me with this crap that I'm going through" [Jessica].
>
> "Like if you're just teasing saying you're weird, that's fine I can handle that. It hurts. But if you tell me, if you make fun of my disabilities, well, that's like making fun of somebody because they have Down syndrome or something. That's like making fun of somebody because they have cancer. That's like making fun of somebody because of who they are" [Jessica].

While Jessica perceives the diagnosis as containing her disability and vulnerability, she at times seems to recognise it as forming a part of who she is, albeit the 'disabled' part of herself. When she identifies too much with the diagnosis, she is sensitive to others denigrating this part of her, and does not appear to have the resources to cope with it; therefore, it seems she tries to limit her identification with it.

According to Luyckx et al.'s (2006) integrated model of identity development, Jessica may be in a state of exploring the different meanings and views associated with ASD and evaluating how well her current views correspond with her true interests and values (i.e. her

true sense of self). In other words, she may be thinking actively about the different ways ASD might be affecting her life and what views of it she might adopt, but she has not been able to successfully commit to or identify with any of these alternative views of ASD. As a consequence, she may be experiencing high levels of distress, ambivalence and self-doubt (Luyckx et al., 2011). This can be identified in Jessica when she says: "… I just don't get it… like why He wants to torture me with this crap that I'm going through". It appears that she has not yet successfully negotiated the meaning of her disorder.

Sarah, on the other hand, identifies strongly with the diagnosis, and says, "…it's not what I got, it's who I am". The diagnosis stands for something that is inherent in her, and if that something was taken away from her she would no longer be who she is:

> "So I really don't think it would be a good idea to take it away from any person with it. I mean I know… if you take it away, yes, you won't get the phobias, the anxiety and the panic attacks and all of the rest of it, but you also wouldn't be, you'd be empty. It would be horrible" [Sarah].

Therefore, she does not require a cure for it; she would not like to be autism-free as Jessica would. It plays such a significant role in her life that it comes to define her:

> "I think, it's obvious to me at least, that AS defines who I am because it is who I am. It's not something I have, it's something I am" [Sarah].

Unlike Jessica, she does not perceive her diagnosis simply as a disability, but a source of her good qualities as well. This perhaps makes it easier for her to accept her diagnosis.

Similar research has also found that some participants with ASD successfully integrate AS into their identities as Sarah has done (Humphrey & Lewis, 2008; MacLeod et al., 2013). Humphrey and Lewis (2008) suggest that this acceptance of one's self and one's diagnosis may be related to the positive impact of friendships in one's life. Though Sarah expresses that she did not have friends at school, her relationship with her boyfriend may be having a similar effect on her, enabling her to be more accepting of her difficulties because he accepts them in her too:

> "Um, and in September I'm attending sixth form doing my A levels just like everybody else, except I'm a few years behind. And what's really great is that my boyfriend is going to take them with me" [Sarah].
>
> "When I go places, I'm always with my boyfriend now, so that's okay" [Sarah].

> "And obviously I've got my boyfriend now and we've been together almost a year so, and that's really good because he has AS as well. I guess we're both quite subtle with our AS, em, but we both have similar problems so it's nice to share that with somebody" [Sarah].

In contrast, Jessica's sensitivity to her diagnosis may arise in response to the peer rejection she faces, which is expressed in her desire to be 'normal' and 'fit in':

> "And I just wanna… I just wanna be a normal kid (*cries*)" [Jessica].

Again it can be seen that, while it may have formed a part of her identity, Jessica's diagnosis can at certain times be something she is ashamed of.

Jessica's diagnosis makes her feel different from her peers and she may feel that she does not meet their standards. Côté and Levine (2002) explain how some people may be driven by unrealistically high standards for functioning, which can undermine their capacity to form steady commitments (i.e. commit to an identity). As such, they may be locked in what may be referred to as a 'ruminative cycle' (Luyckx et al., 2011, p. 90) because of their unrealistically high expectations. Jessica's standards for herself may be too high because she is comparing herself to a standard of 'normal' set by her peers. That is, she sees how others succeed socially, yet she constantly struggles with this and appears to feel inferior as a result.

In a study by Kelly and Norwich (2004) – which examined learners with ASDs' views of their experiences of mainstream and special schools – it was found that children with mild learning difficulties had better self-perceptions if they were placed in a special needs setting than if they were placed in a mainstream setting, despite equal exposure to negative attitudes towards them in both settings. These researchers suggested that this may be explained by way of the social comparison theory (Festinger, 1954), which assumes that comparisons with those of similar abilities will result in positive self-perceptions, while comparisons with those of higher abilities will lead to less positive self-perceptions. In light of this, Johanna and Sarah may be better able to accept themselves because they are aware of their strengths and talents, which build their self-confidence. In contrast, Jessica may be caught in a ruminative cycle, unable to fully accept herself and her diagnosis, because she cannot recognise her strengths and abilities and can only see how she does not meet the standard set by her peers.

Jessica has been unable to commit to a view of ASD, not yet having found one that allows her to feel satisfied in her current state. Her failure to accept this aspect of herself has led to ambivalence and emotional distress (Luyckx et al., 2011). Johanna and Sarah, on the other hand, seem to have found a view of the diagnosis that has provided them a sense of self-understanding and self-acceptance. As the perspective of ASD they have committed to satisfies their true sense of self, and allows for recognition of talents and strengths, they are more able to successfully integrate it into their identity (Luyckx et al., 2011). As will now be reflected on, it seems they are also able to identify strength in their diagnosis through identifying with others with ASD who have succeeded in spite of or because of their differences.

5.4.2.2 Identifying with others.

According to MacLeod et al. (2013), another possible strategy for helping individuals with ASD to accept their diagnosis is by identifying with role models on the autism spectrum. Johanna explains how she sought the diagnosis as a means of identifying with others who share a similar diagnosis. For instance, she initially thought she had obsessive compulsive disorder (OCD) because she identified with a character in a television show that has OCD:

> "Um, I actually, I brought OCD to my doctors, because I had been watching [the television show] – now you know where my username comes from – um, I was actually, I think I was in eighth grade when I made this account and you can see how much, how much I loved [this character]. Um, it's a show about, um, an obsessive compulsive detective. I just watched and I was I, I am [this character]. I identified so much with him" [Johanna].

However, when she watched a documentary on OCD, she found that she did not relate to any of the individuals in this show:

> "I can't, I can't connect with these people at all; I don't know what they're experiencing. Whatever it is, it's not what I'm experiencing" [Johanna].

Nevertheless, she could recognise traits of AS in herself, and identified with others with this disorder. Therefore, the diagnosis could only fit her if she was able to identify with others who share the same diagnosis. Her taking on of the character's username before she received a diagnosis, highlights her need to have someone to identify with to provide a means for her to understand and accept her difficulties. For Johanna, the diagnosis of AS seems to have

taken over the role that the television character played in her life, providing her with a more comprehensive understanding of her symptoms.

Johanna also seems to perceive the diagnosis as something that brings together people with similar traits. In one video, Johanna responds to a comment from a child with AS by saying: "... it is people like you and me who have picky taste when it comes to food"; there is someone who understands her experience and she is able to share this with them. Similarly, one participant in MacLeod et al.'s (2013) study said: "Seeing somebody else I may be able to see similarities with myself*"* (p.43). It seems that being able to share their experiences and learn from others with AS may help some people to more effectively incorporate AS into their identity.

The diagnosis also becomes a means for Johanna to differentiate herself from those that do not have AS. She points out that the light on the desk that is bothering her would probably not bother those who do not have AS. She is differentiating herself from the out-group (those who are 'normal' or 'neurotypical') in this regard. She points out that these sensitivities, which she attributes to AS, make her sense of sound more acute which enhances her musical ability. She seems to imply that others who have AS also have such sensitivities which enable them to be more talented in specific areas than those without AS:

> "… though somebody who didn't have Asperger's probably wouldn't be fazed by it. Um, it affects my sense of pitch… I'm able to pick out, uh, smaller differences in sound than most people would" [Johanna].

For Sarah, AS defines a group of people that are more advanced than those without AS:

> "I do think AS is the next stage of evolution… It's stupid to want rid of something you don't understand. Those people are clearly just ignorant and won't last long when Aspies take over" [Sarah].

In this portion of her speech there seems to be a hostility toward those who want to find a cure for or get rid of AS. As discussed earlier, Sarah feels that without her AS she would "be empty". Therefore, she may view those that wish to get rid of AS, or cure it, as not accepting the way she is, which she may feel is an attack on herself. Following the above comment, there is an immediate identification with others who have AS who are perceived well in society:

> "People who think AS needs to be eradicated clearly don't want any more awesome tech developing from Silicon Valley because most of those guys are Aspies" [Sarah].

She finishes off here saying: "My name is [Sarah] and I'm proud to have AS…" [Sarah]. The diagnosis becomes a means for her to identify with others with the disorder, to accept who she is and maintain or enhance her self-esteem.

The discussion in the previous sub-section, 'Self-understanding and self-acceptance', revealed how Sarah and Johanna have found the diagnosis beneficial in helping them gain a deeper level of self-understanding, as well as a more forgiving and accepting view of themselves. It has given meaning to their behaviours and has helped them to establish more control in their lives. In this sub-section, it can be seen that the diagnosis has also provided a means for them to identify with others who they are similar to, who help to provide a positive reflection of their potential to function in the world.

It seems that these role models on the autism spectrum have provided identity alternatives for Sarah and Johanna, enabling them to explore various meanings of ASD outside the 'disability' perspective (Luyckx et al., 2011). Jessica, on the other hand, does not seem to have found an alternative view of ASD that she is willing to commit to. It appears that she has not found role models on the spectrum that can help her better accept herself. Instead of having someone she looks up to on the autism spectrum, who can mirror her potential capability in the world, she is provided a negative depiction of her diagnosis through the socially constructed stereotypes of the disorder that have been presented by her peers. These stereotypes will now be discussed in relation to Jessica's desire to be seen as different from others on the autism spectrum, as well as the need expressed by all three girls to maintain a sense of their own personal identity outside of their diagnosis.

5.4.2.3 The effect of stereotyping on identity development.

> "Because what they will do is this, when you say the word autism, what do you think of? Just think of it in your head. Just think of what do I think of when I hear the word autism. You probably think weird, you probably think speech problems, you probably think smart too. You probably think they're weird or strange behaviours or special needs. Those are all stereotypes" [Jessica].

Here Jessica is speaking about her experiences of disclosing her diagnosis to peers and how she regretted it. For her, the diagnosis did not have the desired effect of helping others to understand her symptoms and why she behaves a certain way. Instead, what she experienced was others teasing her because of the stereotypes associated with AS. She feels she is not understood and that her diagnosis, which forms a significant part of her life, becomes the object of others' mockery of her:

> "Like before kids were just like 'You're weird', but now they're like pointing and laughing and laughing at me" [Jessica].

She states that it may have been better for her to have kept the diagnosis to herself because it was easier when her peers just thought she was "weird". She explains how having people relate her to others with AS was harmful to her self-esteem because she was stereotyped, and in this respect she lost her uniqueness and individuality.

It is perhaps for this reason that Jessica at times tries to disassociate herself from her ASD – identifying with the disorder may be equivalent to viewing herself in the negative manner her peers view her. This may be why she struggles to recognise her strengths and focuses so much on her flaws: "I am told I have talents, but I am afraid I have more flaws" [Jessica]. Many individuals with ASD have described feelings of fear, alienation and depression at how others perceive them (Baines, 2012; Grandin, 1992; Jones et al., 2001). The way people react to the label and treat the individual it is applied to can become incorporated into his or her self-concept (Murray, 2006). Such individuals may become defined by their diagnosis and, as seems to be the case with Jessica, lose their individuality in the process.

Sarah and Johanna may be better able to maintain an individual identity because of their interests and talents. Johanna's music, for instance, seems to significantly influence her identity, as may be gathered from the number of musical videos she posts on her YouTube profile. Sarah's creative talents, such as singing, photography and graphic design, also form a significant part of who she is. When referring back to the definition of identity given earlier, which suggests that the self is "constructed and enacted through continuous participation across diverse contexts…" (Baines, 2012, p. 549), we see the significant function that talents and interests play in the development of secure identities. Participation in multiple activities and contexts provides a means for one to explore and be exposed to more positive aspects of one's self.

In Jessica's case, she is in an environment where she is not provided an opportunity to recognise her strengths, and where interactions with her peers only heightens her awareness of her differences and "flaws". As she is prevented from identifying and focussing on her strengths, she is unable to adequately explore and negotiate the alternative meanings of her ASD. Therefore, she may have greater difficulty accepting herself and integrating her ASD into her identity. However, if she is provided more opportunities to identify and develop her strengths, and is exposed to diverse contexts which allow for more positive experiences of self to be explored, it is possible that she may be able to find her fit in society and be more accepting of herself and her diagnosis.

Johanna and Sarah, while they desire that people recognise their strengths, also need people to understand the difficulties they face as a result of their ASD:

> "And this really isn't making sense right now. But I'm filming it anyway and I'm posting it anyway. Because I want you to see what Asperger's is like and this is what it's like. Not one of my finest moments right now, but that's okay" [Johanna].
>
> "First of all I will just talk about some of the day to day difficulties that I have" [Sarah].

It is not always possible for these girls to explain their difficulties because of the misunderstandings people have regarding the diagnosis. For instance, some people have a propensity to attach stigma and stereotypes to diagnostic labels (MacLeod et al., 2013). Singer (1999, p. 63) points out that those on the autism spectrum are often "associated in the public mind with images of rocking, emotionally cut-off, intellectually impaired children and 'Rainman'-like savants'". In line with this, Sarah says:

> "People think I have autism even though they're very different things realistically which is why they probably arrive at giving me a funny look [when she tells them she has AS]" [Sarah].

She feels that people have a preconceived idea of what AS is and she does not match their preconception. She says:

> "It's a widely misused term or at least the definition that people have or that people give is mismatched" [Sarah].

She believes that this is why some people fail to trust her diagnosis, because they cannot see that someone with high levels of intelligence, such as herself, can have this kind of 'disability'. She says:

> "Sometimes people are ridiculously clever with AS, I mean really clever, and it's probably because the one thing that they're really good at happens to be maths or English, or something you know that's, um, that looks intelligent… it doesn't mean that the people that are clever don't have AS just because of their intelligence. It just annoys me" [Sarah].

This description that it "just annoys" her, reveals the frustration she experiences at people not believing she has ASD and, consequently, failing to understand her difficulties.

According to MacLeod et al. (2013), "[a]utism is a hidden disability with no physical signifiers" (p. 43). It cannot be seen like being "in a wheelchair" [Sarah] and, for this reason, Sarah does not always receive the understanding from others she desires:

> "But when it isn't obvious like with AS, people are just harsh and it's not very nice…" [Sarah].

In this respect, the diagnosis does not always prove to others that she has specific difficulties, and does not always help her to receive the sympathy and support she desires. As many people seem to hold a certain perception of ASD that those with milder forms of ASD do not meet, Wing, Gould and Gillberg (2011, p. 771) suggest that it may be more appropriate to refer to 'the autisms' in plural to respect the diversity of those on the autism spectrum. This becomes even more important for girls with ASD because, as discussed previously, their symptoms often manifest differently to and are less obvious than their male counterparts.

While there are similarities between those with ASD, they experience their symptoms in unique ways. Many people in the general public fail to understand this and have negative perceptions of ASD, and those with the diagnosis, as a result (Chambres, Auxiette, Vansingle, & Gil, 2008; Gray, 2002; Huws & Jones, 2001). As a consequence, the diagnosis may become invalidated as people match the individual that has ASD to their incorrect perception of what ASD actually is, as in Sarah's instance. In this manner, while the group/collective identity can at times be beneficial to people on the autism spectrum, at other times it can devalue their unique experience of ASD as others fail to accept their diagnosis, or mock them because of it.

It seems there needs to be greater recognition that the autism identity is a social construction with the potential to constrain and degrade (MacLeod et al., 2013). In this respect, professionals made need to change their discourse, avoiding interventions that seek to

normalise people with ASD, and preventing perceptions of the label that associate it with deficit rather than difference (Brownlow, 2010). Furthermore, in line with the 'splitters' view (Shea, 2005), as mentioned in Section 2.1, they may need to draw awareness to and respect the individuality of people on the autism spectrum. While the "lumpers" perspective is useful in helping these individuals receive adequate support (Shea, 2005), according to MacLeod et al. (2013, p. 47), "[i]n identity terminology, individuals need to be enabled to identify with a group that is perceived as constructive and empowering rather than detrimental and limiting". In light of this, it is possible that these vloggers take to sharing their experiences of ASD in an attempt to reconstruct the meaning behind the diagnosis. Through emphasising their strengths, intelligence and the uniqueness of their experience, they may be striving to empower those who share the autism identity.

5.4.2.4 Reconstructing the label through YouTube.

As discussed previously (see Section 2.7.2), the collective of individuals with ASD respond to negative views of the label held by society by attempting to alter society's beliefs about the label. In this section, it will be explained how YouTube plays a significant role in helping these individuals to achieve this.

> "Because I want you to see what Asperger's is like and this is what it's like" [Johanna].
>
> "My name is Jessica and, um, what I'm going to be doing is videotaping a bunch of short videos about what it's like to be autistic" [Jessica].
>
> "Um, my friend said I should do one about girls and AS, and it's a really difficult thing to try and approach, because it's really hard for me to explain AS, because it's just me, it's just how I am" [Sarah].

What we see from these comments is these girls' desire to explain their experiences of what it is like to have ASD. What came across strongly in their accounts is a desire to be understood. As explained, it seems that they experience many people misperceiving what ASD is – that is, they recognise it only for the disability aspect associated with it and fail to see that people with a diagnosis of ASD are individuals who possess talents and abilities along with their difficulties. The internet – YouTube, in this instance – has become a powerful tool for these young people to voice their concerns and raise awareness of what ASD is like for those living with it.

This is where contentions arise with the medical deficit model, as Sarah and Johanna express that they do not desire a cure for their ASD, as it is simply a part of who they are: "I wouldn't trade Asperger's for anything in the world" [Johanna]. This remark of Johanna's echoes her earlier sentiment about her musical ability and how curing her anxiety was not worth her losing her talent, that risk "is not worth anything" [Johanna]. This reveals how invaluable ASD is to her.

> "And people always ask me, if there's a cure would you want it, and I don't think I would. Well, I know I wouldn't. Because they say cure as if it was something that I caught, which I didn't, I was born with it" [Sarah].
>
> "And if you took it away what would be left... you'd be empty. It would be horrible" [Sarah].

Similar to Johanna, this notion that Sarah feels she would be "empty" without ASD indicates how much it is worth to her and how much it fills and satisfies her.

While they both admit that they required a diagnosis to help them through their difficulties, they both seem to be on the side of those that advocate for ASD as a difference rather than a disability (e.g. Baron-Cohen, 2002; Davidson, 2008; Norbury & Sparks, 2013; Molloy & Vasil, 2002). Throughout these videos Johanna and Sarah speak about their difficulties with ASD, but they also speak about the benefits of having it:

> "Like I probably wouldn't be so musical if it weren't for my Asperger's" [Johanna].
>
> "I may not be able to go out on my own but I have special talents like painting and singing and, and you know, I wouldn't have those without AS and creativeness is my thing" [Sarah].

They speak about their pride of ASD, in this manner standing against those that pathologise it and address it merely in terms of deficits.

YouTube has become a means for them to interact with others online, both with and without ASD, and discuss, debate and develop understanding of what ASD is:

> "So, like leave a comment. If you're a girl and you've got AS, leave a comment to say what it was like…" [Sarah].
>
> "And if you guys want to, ask me questions. Go right ahead, ask me anything you want" [Jessica].

In this way they are using their personal agency to construct the group 'autism identity' as well as their own personal identity. Bagatell (2007, p. 414) suggests that a "more positive

identity with disability may also be constructed as individuals resist the dominant discourse and locate themselves as part of a larger disability community". An online autistic community may provide just that for these three vloggers, helping them not only to develop others' understanding of ASD, but also providing a space where they can freely be themselves, reconstructing their personal identities and 'coming out' as people with autism (Davidson & Henderson, 2010, p. 155).

5.5 Conclusion

In this section, I discussed the various superordinate and sub-themes that emerged from the analysis of these young people's accounts. Firstly, I discussed their experiences of living with ASD by reflecting on their perceptions of their symptoms and their difficulties with social communication. It was found that Johanna and Sarah associate both strengths and difficulties with their ASD, whereas Jessica associates mostly her difficult experiences, particularly her difficulties with social communication, with ASD. Therefore, Jessica appears to have a more negative perception of ASD than Johanna and Sarah, and views it more in terms of a disability.

Following this, I analysed and discussed these girls' perceptions regarding the function of the diagnosis. This was addressed in terms of how they view the support they have received as a result of having a diagnosis, as well as how having the diagnosis has affected their identity development. From this analysis, it was determined that these girls have received some support as a result of having the diagnosis; however, they all feel that they require more understanding from others regarding ASD, and Johanna and Sarah felt they would have benefitted from an earlier diagnosis.

In terms of their identity development, it was also found that having a diagnosis of ASD in some ways helped Joanna and Sarah feel as though they fit somewhere and it helped them make sense of their difficulties. Through identifying with positive role models on the autistic spectrum, they were better able to accept themselves and their diagnosis. All three girls seemed to feel that the diagnosis provided an explanation for their behaviours, thus it promoted self-understanding and self-acceptance. However, Sarah and Jessica were stereotyped and stigmatised as a result of the label, which they felt jeopardised their individual identity.

While Sarah and Johanna, for reasons that will be discussed in more detail in the following section, seem to have accepted themselves and their diagnosis, Jessica still seems to be searching for a meaning of ASD that will satisfy her; that is, she has not committed to a view of ASD that fits her identity and, as a consequence, is in a state of identity confusion. Finally, in this section I discussed how these girls used YouTube to raise public awareness of ASD and change others' negative perceptions of it, and possibly develop their own individual identities.

These findings, whilst not generalisable, may shed light on how some individuals with ASD cope with their symptoms and develop a positive attitude towards themselves and their diagnosis. This may provide insight into how one can successfully integrate ASD into her identity. I will explore this further by reflecting on the main findings of this study and what implications they may have for clinical intervention with regard adolescents and young people with ASD.

6. MAIN FINDINGS, IMPLICATIONS AND LIMITATIONS

In this section, I will discuss the main findings and what implications these may have for clinical practice. Following this, I will reflect on the areas of this research that may be considered limitations and those areas that were deemed successful and beneficial. Drawing from this, I will then provide suggestions for future similar research.

6.1 Main Findings and Implications for Clinical Practice

The present study has explored what values the three adolescents in these videos have associated with ASD (with ASD representing their experiences of the symptoms, as well as the meaning found in the diagnosis). Similar to previous studies (e.g. Camarena & Sarigiani, 2009; Humphrey & Lewis, 2008; Huws & Jones, 2008; MacLeod et al., 2013; Punshon et al., 2009), it has been found that the way society responds to the label has an influence on how successfully these vloggers have been able to integrate their ASD into their identity, and consequently accept themselves and their diagnosis.

We see from Jessica's account that when her peers use the label to highlight her flaws, so stigmatising her, she becomes ashamed of her ASD and herself. This may be the risk of adopting a medical deficit perspective of ASD, pathologising the individual that bears the label. It appears that it can be detrimental if there is too much identification with the 'disability' aspect of the diagnosis; and this is where the understanding of the 'difference' value seems to be important. If the individual is perceived as being different, it is recognised that there are areas with which they may struggle; however, it is also recognised that there are areas where they have strengths. If the perception of the diagnosis is weighted on the 'difference' value then society, and the particular individual living with the diagnosis, may be able to respect the person for her differences because of her strengths.

It is perhaps as a result of Sarah and Johanna being able to weight their diagnosis on the 'difference' value, and recognise their capabilities, that they have been able to develop self-respect and feel a certain pride towards their ASD. They have a balanced perception of their difficulties and their strengths. On the other hand, Jessica who feels "[t]oo different to be accepted; too different to fit in" becomes so focused on the ways in which she is different, and here it is different in the negative sense such as having a disability or 'flaws', that she

cannot see her strengths. As a result of her differences no one accepts her and she cannot accept herself.

From an analysis of her account, it appears that Jessica struggles emotionally as a result of her peers rejecting her. On account of her differences, it seems she is unable to meet the standard of 'normal' that her peers have set. As such she is left wishing she were "normal", "autism-free" and that she was not "tortured" by her ASD. At other times, however, she values her ASD as it provides her opportunities to go to college, and she feels a certain pride towards it, as could be seen in her comment on her profile page: "Autism RULES!!! Being weird is totally normal!" This reveals the conflict she experiences in negotiating the meaning behind her diagnosis. On the basis of this, it was hypothesised that Jessica is in the process of exploring her identity alternatives without having yet committed to a view of ASD that fits. As mentioned, this can be emotionally distressing for her; however, as Luyckx et al. (2011) suggest, this can also be a path to self-discovery. Whether it leads to distress or self-discovery depends on how well the process is managed. For this reason, Luyckx et al. (2011) recommend that people that are in a ruminative cycle receive counselling to guide them through the process and support them emotionally while they explore their identity alternatives.

It may be beneficial to help individuals with ASD, such as Jessica, find strengths and talents that foster self-acceptance, as well as the potential for acceptance from peers. Psychologists can play an important role in helping individuals with ASD recognise and develop these talents and interests and, in this way, guide them in exploring more positive views of themselves and their ASD. This will not only boost these young people's self-esteem, but may also help them to find others who share similar talents and interests to them. This in turn may help some individuals with ASD find a space where they feel they fit in, or feel there is a view of ASD to which they are willing to commit, as well as help them to form meaningful friendships.

The importance of friendships in helping adolescents with ASD to recognise their strengths and feel more content within themselves, is an important finding of this study, and is in line with other research (Bauminger et al., 2008; Howard et al., 2006; Whitehouse et al., 2008). It seems that Sarah was able to accept herself and her diagnosis largely because her boyfriend respects and accepts her. In contrast, Jessica's lack of friendship makes it more of a challenge

for her to accept and love herself; there is no one to "lift her up" and make her feel good about herself and frame her differences in a more positive way. Therefore, the psychologist should strive to work with young people with ASD, and with their families, to encourage the formation of friendships (Howard et al., 2006). This may involve helping them find common interests with others, as well as help them manage their differences in the Western culture with greater ease through social skills training (Farrell, 2004). Individuals such as Jessica may also benefit from support groups, where they can share experiences and develop acceptance and understanding from those with similar experiences to them (Weidle, Bolme, & Hoeyland, 2006).

It is perhaps this strong desire to be understood, and to share their experiences, which has drawn so many individuals with ASD to the internet. They have formed an online culture where they are able to support one another as well as give voice to those with the condition (Davidson, 2008). Certainly, these three girls' reasons for speaking on YouTube seem to be multi-layered. At times, it seems they have a need to explain their experiences and raise awareness of ASD, answering questions that some might have about the disorder. It has also formed a means for them to relate to and share experiences with other individuals who are similar to them. In Jessica's case, it has provided a means for her to express her pain and frustration, possibly in order to elicit more support and understanding from others. However, from beneath their discourse on ASD seems to surface their own individual identities – their unique facets that make them who they are in spite of their condition. Perhaps part of the reason why these girls use YouTube is to reveal to others that they are 'normal' people with a life outside their diagnosis. It appears they have a desire for people to see this side of them so they will no longer appear 'too different'.

While the internet may have become a place where many individuals with ASD feel that they 'fit' – and certainly this can be an important tool in developing their self-esteem and well-being – it is apparent that more effort needs to be made in helping these individuals fit into the 'real world', so that they can function optimally in it and experience the value of intimate relationships with others. Psychologists can play a significant role not only in providing these individuals the tools to find their fit in society, by helping them explore and commit to more positive identity alternatives, but also by helping them to create more awareness in society of what ASD actually is and what it is like to live with this condition. This can only be achieved

through listening to and being guided by the accounts of people living with ASD (Griffith et al., 2011; MacLeod et al., 2013).

6.2 Limitations and Strengths

This research does not address the broader context of these individuals' lives, but rather it focuses on the experiences of ASD that they have presented on YouTube. As a result of a need to interact with the audience and portray a particular perception of ASD on YouTube, it may be assumed that their accounts of their experiences of living with ASD may not be entirely accurate. A one-on-one interview situation may have been more conducive to their opening up about the parts of their lives they would not feel comfortable sharing on YouTube. Therefore, the use of research using this medium is limited. While it does provide a deeper insight into some experiences these girls have shared, it may be more worthwhile in identifying the perception of ASD they *wanted* to present on the internet, and the reasons behind their choosing to construct the disorder in this manner. Nonetheless, for reasons discussed in the 'Background and Rationale for the Study' (see Section 1.3), the use of YouTube was well-suited for the purposes of this research.

The heterogeneity of the sample may have been a limitation of this study. The girls were from different countries, which may impact on the relevance of the findings with regard the support they received. Furthermore, Jessica was still at school in these videos, whereas Johanna and Sarah had left school. While all three girls spoke about their high school experiences, Johanna and Sarah were recalling past events, while Jessica was in the midst of the school experience. This 'being at school' may have had a significant influence on Jessica's ability to accept her diagnosis in relation to Johanna and Sarah; as they are at the stage of emerging adulthood in these videos, they are likely addressing different difficulties to Jessica, and are possibly at a different point in their identity formation. Nevertheless, it was worthwhile to identify the similarities and differences in each of their accounts of living with ASD, as well as relate their responses to current research in this area. It is felt that these divergences and convergences have highlighted important points for consideration in understanding the general needs of young females with ASD.

Another consideration was that I based my understanding of these individuals' perceptions of ASD on a limited number of videos. While I feel I reached data saturation, I also recognise

that I would have gained richer information if I had analysed more of their videos, analysed their responses to comments on their sites, as well as looked in more detail at their other blogs they have created. In this respect, it may have been worthwhile to do a case study of one or two of these girls, which may have yielded a more in-depth understanding of the individual and her perceptions. Nevertheless, I felt that I had gathered sufficient data to form some illuminating interpretations from these accounts.

It was also questionable whether I could accurately identify these individuals' state of identity development from a limited number of videos. Again, more in-depth information and a longitudinal study may have yielded clearer results with regard their identity status. In this respect, the findings on their state of identity need to be taken with caution.

Despite certain limitations, it is felt that this study provides a contribution to an understanding of the phenomenon of identity development in adolescents with ASD through reflections on the constructions of the disorder on YouTube. It appears to be the first study of this sort to have been conducted (searches of the literature showed there have been no published IPA studies using YouTube conducted on this topic previously). Therefore, it is believed that the findings provide a contribution to the increasing corpus of knowledge on girls with ASDs' experiences and perceptions of living with ASD and, as will now be shown, provide implications for future studies.

6.3 Implications and Recommendations for Future Research

YouTube provides a beneficial source for attaining insider accounts from individuals with ASD. It is thus recommended that it be utilised more frequently in future to build professional understanding of the needs of individuals with this condition. Further recommendations for improving or elaborating on the current study are as follows:

- As previously suggested, a more in-depth analysis may have involved a reflection on the comments, as well as the forums and blogs these individuals included in their YouTube profile page. It is recommended that when analysing such videos in future, these sources also be analysed in order to provide more background information and richer data. This might also provide deeper insight into why these individuals use YouTube and who their audience is.

- Future similar studies might also focus on girls who are going through a similar stage of adolescence. Comparing and contrasting such studies might add insight on how differences across stages of adolescence and emerging adulthood impact on girls' ability to cope with their symptoms and accept their diagnosis. This might inform more appropriate means for disclosing the diagnosis to adolescents with ASD, and potentially their peers, as well as how to guide them through their identity transition.
- The nature of YouTube permits that longitudinal studies on individuals can be more easily carried out. It may be enlightening to refer back to these YouTube users' sites in several years' time, should they still have a YouTube account, and conduct similar research to determine their progress in identity formation over time.
- One might also conduct a more in-depth study that focuses on why adolescents with ASD use YouTube to voice their opinions of their disorder.
- It would be particularly important to analyse these adolescents' views on the DSM-5 changes to the disorder, from AS to ASD, and how this might affect their autism/Asperger's identity.
- It is recommended that more qualitative research be conducted to provide "insider" views from young people with ASD. They are the experts on their condition and it is through their accounts that psychologists can determine more suitable means for meeting their needs.

7. CONCLUSION

This IPA study aimed to explore how adolescents with ASD construct their diagnosis on YouTube and describe their experiences of living with this disorder. In so doing, it was able to answer the research questions and aims. Two superordinate themes were identified: 'Experiences of living with ASD', which was divided into 'Characteristics of ASD' and 'Socio-emotional Functioning', and the 'Function of the Diagnosis', which was divided into 'Insufficient Support' and 'Identity'.

The results of the interpretative analysis indicate that Jessica viewed ASD more in terms of a disability. As a result, she appeared to have greater difficulty with developing an identity that successfully integrates ASD into her identity, and tended to over-identify with the disability aspect of herself. On the other hand, Johanna and Sarah seemed to view ASD in terms of a difference, a balanced focus on difficulties and strengths attained as a result of their ASD. As such, they were more able to accept their diagnosis as well as establish their own personal identity outside of their disorder. Their ability to achieve a positive perspective of their ASD appears to be largely dependent on their ability to recognise their strengths and talents, identify with role models on the autism spectrum, as well as to feel accepted by peers and friends.

This could have implications for clinical practice in that it reveals the harm of constructing ASD through a medical model perspective, which focuses only on the difficulties that these individuals face. It appears that such a medical-deficit perception of ASD has filtered into society's view of the diagnosis, resulting in many individuals being stigmatised and stereotyped as a result of their diagnosis. The manner in which society frames this condition can have a tremendous influence on how these individuals view their condition, which in turn can have a profound effect on their developing identities. As such, instead of a focus on difficulties, psychologists can help adolescents with ASD explore more positive identity alternatives. This may be critical during the adolescent period when identity formation is at its peak.

While society forms an important part in shaping the meaning of their diagnosis, these vloggers have also taken a stance in constructing their own autism identity through speaking out about their condition on YouTube. They are taking an active role in reconstructing the

meaning of the diagnosis and providing a voice for others who have similar difficulties. It appears they use YouTube in an attempt to raise awareness and at the same time make sense of their ASD. Through such pursuits, it is likely they gain support and acceptance from other people on the autistic spectrum who can aid them in finding their fit in society. While they form part of an online autistic culture, which has clearly become a part of who they are, they also seek to position their own personal identity in and amongst this discourse so that they can better understand themselves as individuals independent of their diagnosis. This appears to be fundamental for their acceptance of themselves and their diagnosis.

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APPENDIX A

TABLE OF CATEGORIES OF VIDEOS			
YouTube User	**Category**	**Content**	**Number of videos**
Sarah	Relevant to AS	About AS	97
	Interviews/Press	About her art and poetry	7
	Me and Tom	Miscellaneous	35
	Announcements/Thank You's	Announcements about new website, thank you for support	19
	Randoms	Miscellaneous	19
	Answering your questions	Answers questions on Aspergers	5
	Music	Concerts she has been to	5
	Serious Aspergers Videos	Perceptions and experiences of AS	27
	Holiday Videos	Festive holiday videos	11
	Video Blog	Personal experiences	65
	Singing	Her singing	49
		Total:	242
Johanna	Relevant to AS	About AS	7
	Musical	Her playing music	56
		Total:	63
Jessica	Relevant to AS	About AS	19
	Mother	Tribute to mother that died	2
	Post operation	After scoliosis operation	3
	Other	Miscellaneous	1
		Total:	25

APPENDIX B

TABLE OF VIDEOS RELATED TO ASD			
User	**Title**[7]	**Date of video**	**Length of video**
Sarah	Sarah - Eye Contact, Panic Attacks and Meltdowns	23/08/2009	07:22
Sarah	Sarah - Post Panic Attack	24/08/2009	04:48
Sarah	Asperger's Syndrome	29/08/2009	02:42
Sarah	Sarah - Blog 21 - Asperger's and Girls*	30/08/2009	05:19
Sarah	Sarah - If There Was A Cure? *	3/09/2009	03:10
Sarah	Shopping Center Escapades	6/9/2009	06:21
Sarah	Still Didn't Get Into School...	14/09/2009	02:07
Sarah	Aspie Girl Makeup Tutorial	6/03/2010	08:21
Sarah	Sarah- Aspergers Conference Video - Part One *	20/06/2010	09:44
Sarah	Sarah - Aspergers Conference Video - Part Two	20/6/2010	05:35
Sarah	Sarah - People's Perception of Asperger's Syndrome *	29/11/2011	04:14
Sarah	Sarah On Aspergers Syndrome *	15/11/2012	13:49
Sarah	Obtaining a diagnosis of Aspergers Syndrome	20/11/2012	11:13
Sarah	Aspergers/Dissociative Identity Disorder Similarities	24/01/2013	04:24
Sarah	Aspergers Children Caught In A Marriage Breakdown	24/01/2013	02:35
Sarah	Sarah - How Did A Diagnosis of Aspergers Help*	25/01/2013	06:15
Sarah	Aspergers - People Not Understanding Our Viewpoint *	31/01/2013	05:13
Sarah	Aspergers Syndrome vs Borderline Personality Disorder	31/01/2013	05:57
Sarah	Aspergers vs Schizophrenia	31/01/2013	04:12
Sarah	Aspergers Syndrome - Traits in Girls - Part One	1/02/2013	07:14
Sarah	Aspergers Syndrome/Autism - Sensory Overload	6/02 2013	02:34
Sarah	Aspergers Syndrome - Traits in Girls - Part Two	5/03/2013	08:36
Sarah	Aspergers Syndrome - Traits in Girls - Part Three	20/03/2013	11:10
Sarah	Aspergers Syndrome - Traits in Girls - Part Four	27/03/2013	07:30
Johanna	Aspervlog #2: Autism vs. Asperger's	19/09/2011	07:21
Johanna	Aspervlog #3: What is Asperger's? *	22/09/2011	06:06

[7] I am aware that by providing the title names of these videos I am jeopardising the anonymity of these users. Nevertheless, it is felt that the titles provide substance for my argument for sampling, and provide important information with regard the users. As these videos are already in the public domain, it is not an ethical concern.

Johanna	Aspervlog #1: Introduction *	11/09/2011	04:58
Johanna	Aspervlog #4: Social Difficulties *	2/12/2011	07:08
Johanna	Aspervlog #4.1: Diagnosis and Frustration *	3/12/2011	06:45
Johanna	Aspervlog #5: Meltdowns	9/12/2011	08:22
Johanna	Aspervlog #6: Hidden Disorder	5/01/2012	08:09
Jessica	My life with Asperger's *	12/01/2012	03:17
Jessica	My Life with Asperger's II	12/01/2012	04:27
Jessica	Motives of people (in my personal opinion)	13/01/2013	09:41
Jessica	My life with Asperger's III	16/01/2012	10:09
Jessica	My life with Asperger's – part 4 (sensory issues)	16/01/2012	11:19
Jessica	My Life with Asperger's / Autism – part 5 (bullying)	20/01/2012	09:03
Jessica	My Life with Asperger's (& now scoliosis)	1/02/2012	01:42
Jessica	Relationship Advice for Autistic or Aspergers Boys	3/07/2012	08:57
Jessica	Jessica- Update on Me	23/08/2012	08:22
Jessica	My Life With Aspergers (Self hate)	23/08/2012	09:26
Jessica	Relationship Advice for Autistic and Aspergers girls	3/09/2012	08:57
Jessica	Depression & Asperger's? What a combo!	6/09/2012	09:29
Jessica	Rough day…true fellings *	7/09/2012	08:05
Jessica	last video*	18/09/2012	06:24
Jessica	stronger ;)	18/09/2012	08:36
Jessica	Why Do People Do Suicide?	8/10/2012	10:39
Jessica	Clarifying something here*	2/11/2012	05:06
Jessica	Changing definitions	14/12/2012	08:29

***Videos selected for this study**

APPENDIX C

TABLE OF THEMES

Superordinate theme: Experiences of Living with ASD

Sub-theme: Characteristics of ASD

Sensory Sensitivities	Special interests	Intelligence and Talents	Anxiety and Depression
Sarah C40because I've learnt what clothes I can and can't wear, C94,95,96 but the older I get the more used to it I become C116,120 … I'm hypersensitive to touch and noise, and the touch thing can affect our relationship. **Johanna** C.18: symptoms into two categories… social problems and sensitivities C21when I'm talking about sensitivities I mean we have sensitivities to um you know the common five senses C45,46 Asperger's does mess with the brain, that's what it does C49,50,51,52 things that you hear, things you smell, things that you see. C56,57,58,59 brain work harder to process information. So it over-processes even simple information C68 you're born with AS. Um, it is an alteration in your brain **Jessica** C13 sensory issues…emotional struggles	**Sarah** C18, obsessive interests C115, 122 I used to have crazy obsessions, which ate up all of my time. **Johanna** C.8 Social problems, hypersensitivities, and obsessions C9: my music videos… you can decide if it's a talent C14: I probably wouldn't be so musical if it weren't for my Asperger's C47, certain parts of the brain work better than people who don't have Asperger's.	**Sarah** C8 I was also quite intelligent at school C97 I wouldn't have those without AS and creativeness is my thing. And with like learning at school, it never seemed like I had to try very hard. C121 I'm super creative really, which is a nice plus. I learn new things relatively quickly. Plus I don't have to keep track of a gazillion different friendships, it's just me and my partner which is easy. **Johanna** C114 Um, so I agree with you that it affects music. That's just not worth it. It's not worth anything **Jessica** C51 I am told I have talents, but I am afraid I have more flaws C86. It can be like really fun to have it because well in school C104 you can actually get scholarships and stuff like that for having special needs	**Sarah** C39 panic attacks when it was time to leave the house. C113,114 My life is structured to the extent that my boyfriend leaves for work and then comes back home again C42,43,44,45, everything's just done for me. Just because it's safer that way… I can't leave the house on my own. **Johanna** C106,107 generalised anxiety disorder C103,104 anxiety… that's how I got diagnosed **Jessica** C31,32 symptoms of many other mental conditions C56 I must get rid of this pain and go to Cloud 9 above. C64 I'm just angry. And sad and negative all the way C13 sensory issues…emotional struggles

Socio-emotional Functioning		
Difficulties with Social Communication **Sarah** (C.7)I observed what everyone else did and tried to copy that on a daily basis" (C.10Girls ever changing' and this conflicted with her need for stability and routine (C.101).just blind to other people" "copy of the social rules since early childhood", but she never got her copy (C.101) (C.101).I'm not social. I can put on a front and sort of just act in a temporary social environment" C111 My life is basically my fiancé and the internet (C. 102And I had known him for five years or so, um, already, over the internet through a mutual friend" C14 I was monumentally different from them C16 my weirdness **Johanna** "(C.23)pretty well in social settings" C72 If you don't have social problems you don't have AS C. 75).people just are a mystery uh to you" C. 97: person living inside my head who makes perfect sense C72 If you don't have social problems you don't have AS C77 of not born with the social guidebook that everybody else is born with and um people just are a mystery uh to you. **Jessica** C40 It's, it's wondering what people think of you and not ever knowing, and not understanding anything that comes your way" C88) C.56 C92if you can't accept me for who I am then don't be my friend C8 makes it difficult for some to react to and communicate with other people." C17 it's hard to deal C10 A kid that's autistic isn't born with the social part of their brain… There's a piece that's disconnected in their brain C16 it feels like I don't belong here…, like I'm from a different planet or something, like I'm a different species of human C49 Too different	**Peer acceptance** **Sarah** C9 when I got to the age where girls start to get bitchy C10 It was natural for them to be ever changing, **Johanna** C 77 'cause I never think just to ask somebody to hang out **Jessica** C40 I've eaten lunch alone for the past entire four days C41 I know I said I was going to be positive [Jessica] C49 Too different to be accepted, too different to fit in C50 Everyday I cry because I am so odd C52 And I'm feeling too different. C63 I'm just not having a very good day today C91 I'm actually doing pretty well now… probably because people are getting used to me being a weirdo C78 "And people always would ask me, have you been bullied 91 being a weirdo C59 I deal with this crap every single day. And it's kinda coming out a little bit C78 I knew that I was more likely to be teased C56 All I wanted was to be loved C89 Like I can't socialise with people to save my life. C64 this is the life of an aspie kid guys	**Friendships** **Sarah** C82, 83 we both have similar problems so it's nice to share that with somebody C61 what's really great is that my boyfriends going to take them with me. C12 but I didn't share any interests with them. C21 I think it must be easier to spot it with boys C6 You know, they got into a group of female friends C10, 11 And when I found myself with no friends So for me to socialise with them was impossible C52 I never had many friends, C53 I had absolutely no friends C63 so nobody thought that having no friends was a problem C74 I can't really keep a friend. C80 because we didn't share similar interests. C99 I dislike situations so much that I'd rather not have friends. 121 it's just me and my partner which is easy. C. 50 I did have a major problems throughout school, secondary school, um bullying. **Johanna** C85 boys…They're more likely to pick on somebody who's different C.12: harder to tell… anything wrong with us C79 I think what makes it seem like I don't have problems is the fact that I am a girl – C81,82,83,84 they say that four times as many boys I struggled for a really long time with the definition of friends. **Jessica** C16one person that will ever like me is me C54 . I need help or a friend who will lift me up. C71… they don't have as many friends as some kids do C93 if you can't accept me for who I am then don't be my friend

C55 I want to be autism-free, C65 like why He wants to torture me with this crap C76 “You just want to be who you are” C105 “It’s like a person in a wheelchair” C43 I didn’t feel I fit in very well with many people		

The Function of the diagnosis

Insufficient Support

Sarah

C163,164,165,166,167 she didn’t get it, and you might not get it… she really frustrated me because she just wouldn’t listen… I think it’s hard to explain AS related things to people without AS just in general.
C170,171 They don’t understand why it would be a problem…. And you cannot make them understand that it’s harder… Because how are you supposed to make them understand
C148 by the time I got to 18 I didn’t really feel like I needed much help
C149,150,151,152 So that kind of like a year that I didn’t have any help
C157 It didn’t do a lot for me in terms of actually getting help and
C17 They just said I wasn’t very social
C169 And you cannot make them understand that it’s harder, hence why you’ve been diagnosed

Johanna

C72 If you don’t have social problems you don’t have AS
C62 hope you like spending your time, spending time with your families and whatever you do.
C111 and I brought it up with my therapist and she agreed that it was
C43,44 diagnosed until I was, um, until I was fifteen, so it’s good that you’re learning about this so early

Jessica

C72 . It’s about like the time I told people I had AS
C98 doctors are trying to help you and tell you what’s going on,
C103 if I don’t fall under that category, I lose my accommodations.
C87 just share your disability with someone you trust

Identity

Self-understanding/self-acceptance	Identifying with others	Differences amongst those with ASD	Reconstructing the label through YouTube
Sarah C4 it’s just me, it’s just how I am C89 It’s not something I have, it's something I am. C31 but I think sometimes just accepting what they have and working around it is the best thing for them. **Johanna** C83 it’s not really noticeable, until something very disastrous happens C.13 I wouldn’t trade Asperger’s for anything in	**Sarah** C133 Those people are clearly just ignorant and won’t last long when Aspies take over. C155,156 like “Right so that’s why I thought you were normal and why I couldn’t understand that you had something wrong with you”, ‘cause he had it too	**Sarah** C5 It’s like asking you to explain why you’re normal. 86, 87, 88 To me, Aspergers means people giving me a funny look 136, 137 sometimes people say that because I wear makeup I don’t have AS… it’s just silly that people view it like that’ 139 Because it’s a disability you have to look disabled, you	**Sarah** C23 you’re a girl and you’ve got AS, leave a comment to C24 that was my really, really bad attempt at explaining so I’m gonna go now. C34 that’s just my view on it anyway 4 it’s really hard for me to explain AS 131 It’s stupid to want rid of something you don’t understand. 160,161 but I think I answered your questions at least I hope I did 37 I’m doing this video for a conference 28 Because they say cure as if it was something that I 33 AS isn’t a disease, **Johanna**

the world. **Jessica** C34 if you're speaking from a medical perspective C7 Online Dictionary says about autism 68 but more recently I saw a psychologist and he did actually diagnose me with AS and attention deficit disorder C7: You might be jealous that you can't catch AS 29 it wouldn't be him any more and he would just be somebody else. C84 I am kind of proud that I have it C49 I want to have a normal life C58 I just wanna be a normal kid C76 I wanted an explanation for my behaviour, C80 if you look at statistics C98 doctors are trying to help you and tell you what's going on, C30 I might make another video to back this up with some good information	**Johanna** C107,108,109,110 I was I, I am [character from a television show]	have to be stupid. That's how people seem to think. 141 but it doesn't mean that the people that are clever don't have AS just because of their intelligence. It just annoys me 105 . I do think that the second I say I have AS I become vulnerable to some extent **Johanna** C22,23 it affects everybody differently, C 39 different from some of them who have Asperger's too, **Jessica** C4 it's different for every person C110 they have problems organising – well, stereotypically they do. C88 when you say the word autism, what do you think of?	C:3: "you're never going to understand until you meet me…" C.5: I'm going to make a video series every week C15: for the people who do know me…don't know how AS affects me C.16: know me…don't know how AS affects me C24,25 on the condition that this becomes an interactive thing C31 the show where I answer your questions about Asperger's syndrome C62 leave a comment with a question. C95: I hate being misunderstood. That happens a lot C. 98: I want you to see what AS is like…this is what it's like. **Jessica** C3 about what it's like to be autistic C6 those of you who don't know what Autism is C95 I really would like to find out more about myself and my disability…I bet you would too. C19 I will be posting this on Facebook and maybe YouTube, I don't know. I'll be posting as much as I can and when I can. C74 speak for kids like me

APPENDIX D

Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (SCHOOL OF HUMAN & COMMUNITY DEVELOPMENT

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MEDP/13/006 IH**
PROJECT TITLE:	Adolescents' perceptions of living with ASD
INVESTIGATORS **DEPARTMENT**	Feist Naomi Psychology
DATE CONSIDERED	19/03/13
DECISION OF COMMITTEE*	Approved

This ethical clearance is valid for 2 years and may be renewed upon application

DATE: 16 May 2013

CHAIRPERSON
(Professor A. Thatcher)

cc Supervisor: Dr G. Mooney
Psychology

DECLARATION OF INVESTIGATOR (S)

To be completed in duplicate and **one copy** returned to the Secretary, Room 100015, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure, as approved, I/we undertake to submit a revised protocol to the Committee.

This ethical clearance will expire on 31 December 2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES