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**School of Applied Social Studies,
University College Cork,
Ireland**

Aspergers Syndrome: An Insider's Perspective

Diarmuid Heffernan, Bachelor of Social Science Youth and Community

Abstract

Relatively little research exists on Asperger's Syndrome (AS), particularly from the perspective of people with AS. Recent medical research suggests that AS can potentially be detected in the womb, which may have enormous societal consequences. This research examines how people with AS articulate their experience of living with their condition. The people with AS who participated in this research showed that they are willing to learn and adapt to society because they have had to. The difficulties being 'different' has caused are obvious from their testimony with the word 'pain' being used on more than one occasion to describe their social interactions in the world.

Keywords, Aspergers Syndrome (AS), social model of disability, 'normal', empathy.

Introduction

The objective of this piece is to provide a sample group of people with AS the opportunity to discuss the condition from their perspective. One of the primary functions of this research is to provide society at large with an insight into the views of those with AS, taking the social model of disability as a guide. The often unique views of the world as expressed by those with AS should arguably be cherished and

valued for the independence of their construction, created by a lack of influence from mainstream society.

This research is also about the views of a group of human beings whose very right to existence is being questioned by modern medicine which is in the process of developing a test for autism in the womb. It is hoped that this research and the interviews in particular will give an insight into the humour, humanity, ability and diversity of a non homogenous group of people with an alternative perspective of the world.

Background to the Research

Introduction

My involvement in the area of AS is due to my position as an outreach worker in the community working with adults with Aspergers Syndrome. The participants in this research were users of the outreach service. Given the difficulties in accessing adults with AS I was in a position to explore the research issues with a willing group. The goodwill and trust built up between myself and the participants led to a level of access that may otherwise have been difficult to achieve. The names used for the participants in this text are pseudonyms to protect anonymity.

Aspergers Syndrome

‘One of the best ways of understanding what Aspergers Syndrome is like is to imagine yourself as a perpetual onlooker. Much of the time life is like a video, a moving film I can observe but cannot reach.’ (Lawson, W, 1998, pg 1). Although AS is classified as an Autistic Spectrum Disorder (ASD) it is diagnostically distinguished from classic autism due to the lack of language delay (Attwood, 2007). In its essence having Aspergers Syndrome for most people means having difficulty in communicating or interacting with people. Given that our society is very much structured around the ability to communicate and interact, this places many people with Aspergers Syndrome at a huge disadvantage (Carley, 2008). There are many examples of how this may manifest itself such as in job interviews, jobs themselves, college or school (Beardon, Edmonds, 2007). The sense of dislocation that this creates for many people with AS is disempowering, confusing and debilitating. AS is a non-curable condition and it affects different people in different ways. This means that

people with AS are an extremely diverse and heterogeneous group. (Holliday-Willey, 2007). People with AS tend to have a unique perspective of the world. This different perspective is usually accompanied by ‘special interests’. People with AS tend to become very passionate and fixed on specific subjects (Attwood, 2007, Gaus, 2008, Carley, 2008, Grandin, 2006, Howlin, 2007).

‘The problem of what causes autism is not yet solved’ (Heweston, 2002, pg 119) although many reasons have been put forward including genetics, MMR vaccine and environmental factors. In the case of AS there is even a theory that relates the condition to a neurological adaptation to the technological age we now live in (Baron-Cohen, 2001). It is clear that further research is needed around AS and ASDs (Europe Autism Action, 2010). There are varying estimates as to the number of people with ASDs ‘because ASD remains a diagnosis that is defined completely on the basis of behaviour, diagnostic assessment is both complex and expensive’ (Lord and Bishop, pg 1, 2010). Current estimates are that 1% of the population have ASDs (NAS, 2010. NCSE, 2009). Figures for those with AS are much more difficult to calculate as these tend to be subsumed into overall ASD figures, however estimates put the figure globally at one in every three hundred people (Ehlers and Gillberg, 1993)

Aspergers Syndrome-An Insider’s Perspective

Having sat around with ‘autistic’ people who have more empathy, curiosity imagination or ingenuity than most so called ‘normal’ people, I think it is time that the myths that hover over these people were not just uncovered but unravelled. (Williams, 1996, pg viii).

Donna Williams describes being on the autistic spectrum from the point of view of being part of a world that is structured in favour of the ‘neurotypicals’ i.e. people who are not on the autistic spectrum and who do could not have the same perspective on the condition. This is what she calls ‘the non-autistic world which can only view and describe them from the outside’ (Ibid, pg viii). One of the distinguishing characteristics of autism in the public consciousness is a sense that those with the condition are ‘odd’ or not ‘normal’. This idea has been perpetuated by a media influenced by the functionalist way of looking at society and ideas of ‘normalcy’. This led to people with autism being ostracised to an extent and also left society in general

‘with little ability to see how these people, who were so obviously ‘abnormal’, could be fitted into mainstream society and no reason why ‘normal’ people might want them to’ (Ibid, pg 9).

One interesting piece of research that has been done from the perspective of people with Aspergers Syndrome by Muller et al (2008) showed their: ‘pride in their autistic identity with one noting, ‘someday I hope people will realise what richness we have in our community’ . This study also defied much of the received wisdom on Asperger Syndrome which is very much from a Medical Model perspective by finding that: ‘The characterisation of individuals with ASDs as socially aloof, deliberately self isolating, affectively flat, and lacking consciousness of their social skills deficits’ (Muller et al, 2008, pg 187) did not correlate with the findings of the study.

In fact, writers with Aspergers Syndrome such as Kenneth Hall summed this view up by saying ‘...although I felt different I felt normal about being different, I thought I was the normal one and that it was the other people who were different, not me. Which is a perfectly feasible way of thinking’ (Hall, 2001, pg 14). The view of Aspergers Syndrome as discussed by Conrad (1992) places the person with the condition in a position of being disabled and not fitting in with the norms of society. Horowitz (2002) amongst others in fact argues that there are no known universal standards of ‘normal’ - particularly those that are independent of cultural or social contexts.

Theoretical perspective

Definition of Disability

There are many varied definitions of disability but in the Geographical context of this research it may be pertinent to look at the most recent Irish State definition which defines disability as:

a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the state or to participate in social or cultural life in the state by reason of an enduring physical, sensory, mental health or intellectual impairment. (Disability Act, 2005, pg 6)

The Social Model of Disability

The overarching theory used for this research was the Social Model of Disability which proposes to give a voice to those with ‘disabilities’. Although this model has been criticised for not taking into consideration issues of culture, gender, race or age (Priestly, 2003) and that it tries to diminish personal pain (Crow, 1996), it has provided a framework and a political and social medium to allow people individually and collectively to be heard in society. It also looks at the difficulties they face in society from the inside out perspective rather than the reverse, ‘the social model was received much more enthusiastically by disabled people because it made an immediate connection to their own experiences’ (Oliver, 1996, pg 31). This model was specifically chosen for this research because it proposes that society needs to change its views on disability and what is normal behaviour. This is key for those with AS given that some of the characteristic aspects of the condition such as difficulty interacting or repetitive behaviours are deemed to be abnormal, eccentric or errant by society at large. Inherent in the social model is the necessity for understanding by society of disability and for those with AS it is vital that society understands, accepts and embraces the differences inherent in the condition. Emancipatory disability research was also used as it fits in with qualitative data collection (Barnes, in Barnes et al, 2010) and in this research piece there was a direct input from the participants themselves. Given that all research is arguably subjective, implicit in emancipatory research is a political commitment to the empowerment of disabled people (Ibid, 2010). According to Oliver (1992) emancipatory research is located in the social model of disability and this research also adopts the social model of disability ethos in its view that society disables people. French and Swain (2000) believe that the social model acknowledges the social beginnings of disability in a society structured by and for non disabled people.

Methodology

The methodology used for this research piece was inductive using the principle of grounded theory. It used an interpretive approach beginning with a focus group which was formed from amongst the client group in order to allow all participants every opportunity to have an open and comfortable discussion in the company of their peers. It also creates the opportunity for themes to emerge which will be used to guide the focus of the research. These themes were then used to form the basis of semi

structured interviews which were tape recorded and transcribed. Semi structured interviews were chosen as: ‘the degree to which interviews are structured depends on the research topic and purpose’ (Sarantakos, 2005, pg 269) and in this case the flexibility of the semi structured interviews allowed for some set questions agreed with the interviewees and also some questions which occurred naturally during the interviews. The reason for choosing grounded theory is that it avoids a preconceived theoretical framework as theories emerge from the data, (Glaser and Strauss,1967).

Methods

This research began by having an informal pilot group/discussion with the service users which gave the interviewees an opportunity to discuss the issues they felt were most relevant for this research. Out of this discussion a series of questions emerged which were then used for a focus group. This method allowed ‘participants to bring to the fore issues in relation to a topic that they deem to be important and significant’ (Bryman, 2008, pg 475). In this way there was also an order to the interview which suited the client group who have an adherence to routines or rituals (Gaus, 2007, pg 14).

A big consideration in terms of the recording of the group was its size and bearing in mind Barbour and Kitzingers (1999) criteria about the nature of the group being interviewed-there were 4 members which is at the lower end of Morgans (1998) scale where he suggests 6-10 members. In this way there was room for extended discussion and the participants all had an opportunity to speak. For the individual interviews there were six participants and all were chosen randomly. Simple coding was used to establish themes after each interview and these themes were then used to inform each new interview. When all the interviews were completed themes were coded and used for the findings section.

Every aspect of the construction of the research process was informed by the nature of the participant group and the difficulties they faced with social interaction and the potential anxiety it creates. This included the location of the interview and the choosing of the participants in them. As interviews were completed and transcribed participants were interactively involved in the construction of the questions. The researcher analysed the data emerging from each interview using grounded theory.

Research Findings and Analysis

Introduction

‘[P]ersons with AS and high functioning autism are, have always been and always will be, invaluable citizens in our world of neurodiversity’ (Ortiz, 2008, pg 31). Michel Foucault (1977) suggests that society is organised and regulated according to what is deemed normal and the social sciences have played a part in that by studying people closely and hence defining normal and abnormal behaviour. It is not the intention of this piece of research to define the boundaries of what is ‘normal’ and what is ‘abnormal’, rather the intention is to look at a particular unique and diverse perspective on the world that has been seldom explored. People with Aspergers Syndrome do suffer many difficulties in a society that is structured to their disadvantage. There are many clichés and assumptions made about people with AS and indeed Autism generally, for example a lack of humour. Carley says of this: ‘we may simply find different things to be funny... However that is not to say our funny bone is completely foreign or alien’ (Carley, 2008, pg 19) and even a lack of emotion or empathy: ‘I have because of the kind of painful experiences I have gone through before I would say I have a lot of empathy’ (Thomas, interview C).

This research piece sets out to dispel some of these clichés and assumptions and use the social model of disability as a guide to explore the world of people with AS. The themes that have emerged from the interviews are categorised under the headings below and quotes from AS authors are weaved in with quotes from the interviewees:

- Difficulty Interacting and miscommunication
- There are a wide variety of symptoms and manifestations of Aspergers Syndrome
- People with Aspergers Syndrome would like society to have a better understanding of them
- The world can be fraught with difficulty for many with Aspergers Syndrome
- People with Aspergers and relationships

Difficulty Interacting and miscommunication

Sometimes reaching out and communicating isn't easy. (Prince-Hughes, 2004, pg 179)

[I]t is not surprising that communication is so high on the problem list, as it is one of the core traits caused by having Aspergers Syndrome. (Aston, 2003, pg 53).

Difficulty in communication and particularly in social interaction are primary traits that are commonly associated with Aspergers Syndrome (see Attwood, 2007, Gaus, 2008,). In this piece of research nine of the ten participants cited difficulty in communication and interaction. This manifested itself in different ways for the participants with for example one stating that: 'I don't want to be having to interact with people on an interpersonal level at every opportunity..because I don't feel like I ..have all the knowledge I would need in every given situation' (John, interview A) In John's experience not only is it difficult to actually talk to people its also difficult to read a given situation in order to assess what level of conversation is needed, whether it should be formal or informal or indeed what may be appropriate or inappropriate. This was a common theme for the participants and has knock on effects that go deeper than just being able to make appropriate conversation with people, for example:

I do misinterpret people sometimes I don't listen to what they are saying and I interrupt what they are saying and I misinterpret their intentions sometimes if I am depressed, I can be quite suggestible sometimes and if people give me advice I think its an order and I have to obey it. (Ralph, interview B)

In Ralph's case not only does he find it difficult to make conversation and misinterprets their intentions but he also sometimes finds himself doing things in a way that he feels he has to-which stems from his misinterpretation of a given situation.

There are a wide variety of symptoms and manifestations of Aspergers Syndrome

One of the best ways of understanding what autism is like is to imagine yourself as a perpetual onlooker, much of the time life is like a video, a

moving film I can observe but cannot reach. The world passes in front of me shielded by glass. (Lawson, 1998, pg 1)

Many of the participants felt that there was a general misconception about AS in that there are certain common aspects as explored in the previous section, but there is also a 'variety of symptoms or elements to it..everybody with Aspergers is different although they may have some similarities' (Ralph, interview B). The AS community is not a homogenous group and people are still individuals with a variety of cultural, social and political factors, as well as different personality traits which influence their experiences and manifestations of AS. This is reflected by Thomas in interview C:

'I suppose with the knowledge that's been put out there among neurotypical people anyway I mean there's actually much more variety of Asperger's people than people might expect, my eldest sibling thinks that I don't have it because my social skills are good and that from what she has read this does not apply to me at all'.

People with Aspergers Syndrome would like society to have a better understanding of them

Aspergers Syndrome 'is like looking at a bowl of fruit and becoming very interested in the bowl' (Gertrude, interview E). Hurtful words and attitudes

cause damage. Attitudes are unknowingly invalidating the very real experiences of the individual with AS. Even when we, the recipients of the diagnosis, are armed with the knowledge that such words are nonsense, the words still hurt...because they are words that may reflect the culture we've been raised in' (Carley, 2008, pg 49).

Of the participants 90% wished for society to have a better understanding of AS. Taking the social model of disability as a guide-it is society that disables people and it was very clear from this research that the participants felt that a greater understanding of AS from society generally would improve things for them immeasurably:

All I think of is for neurotypicals...for them to understand that it's just really a different way of thinking..rather than a disorder or whatever and for them to understand from that perspective that people are not necessarily that much

different either, it's just that they have a slightly different perspective (John, interview A).

The notion that having this different perspective on the world should be accepted by society is also reflected by Thomas who wishes that:

‘People have a much better understanding of the whole thing of what it is like to have the Aspergers, I mean if we were in a whole ideal world there would be no need for these type of diagnosis because everyone would just accept everyone else's way of thinking’ (Thomas, interview C)

The participants felt that there should be a greater understanding by the neurotypical world of Aspergers rather than vice versa: ‘the main thing is that people know what Aspergers Syndrome is and how to help and deal with people that have it as opposed to misinterpreting and hindering’ (Ralph, interview B)

The world can be fraught with difficulty for many with Aspergers Syndrome

‘I was very lonely, and was increasingly suffering from it-not from my actual solitude but more from comparing myself with others and wanting to be as normal right and ordinary as they were’ (Gerland, 1996, pg 139). Having Aspergers syndrome can cause many difficulties for people in many different ways. The lived experiences of the participants varied but there was commonality in terms of some of the difficulties they have- and continue to endure. For example Luke describes life with Aspergers Syndrome as: ‘I see a lot of life as a challenge, I feel like I am climbing a cliff with my bare fingers’, while Deborah describes living with Aspergers as: ‘I would just describe it as a painful experience...to not be integrated into society fully’ (Deborah, interview D). This has been exacerbated by bullying in School for fifty percent of the participants who had to contend with making sense of the world from an Aspergers perspective while also having to deal with being bullied by peers, for example Ger: ‘When I was bullied in school I didn't know what was wrong with me’ (Ger, focus group interview). In describing how he feels society sees him Luke reveals what is also a huge difficulty for many of the participants: ‘People look down on me because I can't socialise and take part in activities and contribute to the group’ (Luke, focus group interview).

For an individual to have Aspergers Syndrome certainly means trying to make sense of the world from a point of view that is at odds with how the world is structured ‘I see society as a massive game with its own rules which I cant quite understand but which looks very interesting’(Gertrude, interview E). The pain, anxiety and difficulty of trying to make sense of this has been added to for many of the participants in this study by being bullied and misunderstood.

Aspergers Syndrome and relationships

Having AS..can mean having great abilities, but it can also mean never leaving the home of one’s parent’s, never holding down a job for any extended period of time, and perhaps never enjoying a satisfying intimate relationship. Yet if these conditions were understood on a broad level, circumstances would enable most diagnoses to lead happy and productive lives (Carley, 2008, pg 12).

All of the participants in this piece of research said they would like to have a relationship but all expressed concerns over whether it was possible or if they could meet someone understanding enough: ‘I suppose somewhere down the line I would like to have a relationship, now I would need the person to understand my way of thinking and to show me their way of thinking’ (Thomas, interview C). Two of the ten said they had previous relationships: ‘I had a girlfriend for a while and that was a relationship, I just found it pretty normal, it was interesting and normal at the same time’ (Deborah, interview D) and seven said they had never had a relationship. The people with Aspergers Syndrome who participated in this research have the same hopes, desires and fears as the rest of society. The difficulties they have with social interaction combined with an associated lack of self esteem has led many to feel that while they would wish to have a relationship they could not see it happening. Some of them had given up hope that they would ever have a relationship:

‘When I was young I dreamed of getting married years ago but I’d say it’d never happen, especially when I was in my twenties ten years ago, you would fancy a woman but you’d be afraid with y’know the passing on of the genes..it wouldn’t happen and it’d end in divorce and it is’nt suitable..it’d make matters worse for partners and I, I actually said to myself I’m better off single and.. I was disappointed but I will have to live with it’

(Ger, focus group interview)

‘At the tender age of eighteen I’ve dismissed it and if first impressions are anything to go by its not really going to happen so you just learn to live with it’ (Mark, focus group interview).

It may be appropriate to finish this section on the optimistic and humorous thoughts of Gertrude on this topic:

‘It usually goes when I meet someone that I think I am going to like...and I get close to them and then discover they are a friend and I can’t make a move so that’s annoying...kind of hilarious but annoying, I like the idea of having someone – it’s definitely something to aim for and I would encourage everybody to!’ (Gertrude, Interview E).

Conclusion

People with AS have the same desires and needs as everyone else in society. There are more and more people being diagnosed with Aspergers Syndrome and the onus is on society in general to learn more about what AS is and more importantly how we can adapt to allow people with AS to flourish. It is vital that we as a society take on board the tenets of the Social Model of Disability and recognise that it is in fact us that create much of the difficulty that the AS community face, ‘what is needed is a move away from the medicalised view of autism and AS. Individuals with AS should be understood as people who process the social world differently rather than in a disordered fashion’ (Edmonds, 2008, pg 10).

‘All I think of is for neurotypicals to understand that it’s just really a different way of thinking rather than..a disorder or whatever and for them to understand from that perspective that people are not necessarily that much different either it’s just that they have a slightly different perspective’ (John, interview A)

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