"How Can We Better Educate People About Autism and Asperger's?"
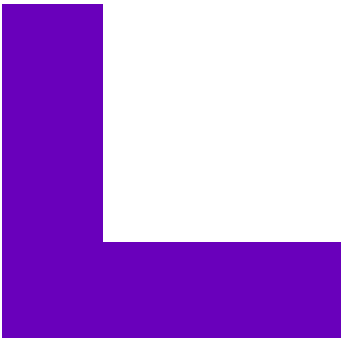
Charlie Abbott – Insights Report

Contents

Framing the Question

This project will be framed around educating people about autism and Asperger's. I have chosen this topic as I have a personal investment as an autistic person. There is an opportunity to use this project to better explain how we see the world to the people around us and give them an insight into the world of autism that they may not have considered before. We can also challenge some common inaccurate views and combat some negative perceptions. A big problem with autism is communication and people assuming there is a lack of communication when they are just speaking a different language.

In my personal experience, I have seen that not many people know much about autism and the surrounding disorders. Autism is a lot more common than people think, with just over one in 100 people in the UK with one form of autism alone (The NHS Information Centre, Community and Mental Health Team, 2012). There are many misconceptions that have been seen related to autism, mostly due to the lack of common knowledge, and the aim is to solve this issue with this project.

Aims and Objectives

Aim: Find out current perceptions of autistic people from a non-autistic perspective

Objective: I will investigate general perceptions and attitudes towards autistic people via a survey. The survey shall be used to gain insights quickly and objectively. To reach the aim, questions will be asked to find out what people know of autism and Asperger's, and if they are aware of any stigmas around the disorders. This survey may also be supported with interviews for more in-depth, personal insights from people who have completed the survey.

Aim: Conduct research into existing materials on autism and Asperger's

Objective: I will review the current literature on autism and Asperger's from trusted sources. The objective is to analyse the quality of information and the ease of accessing this information. The information I find may be useful to help reach the other aims for the project.

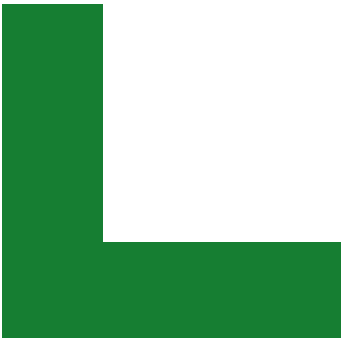Aim: Find out perceptions of how people are treated from an autistic viewpoint

Objective: I will conduct interviews with autistic people to gain an in-depth personal insight into how they feel people with autism and Asperger's are treated. These interviews will be supplemented by additional research, such as studies and articles, to help inform the next stage of my project.

Methodology

For the project, I made sure to use both primary and secondary research. For personal insights, primary research is much more useful whereas, for factual research, secondary research is more effective and helps to save time. So, by utilizing these methods, research was completed in the timeframe given.

I carried out research into current literature on autism and diagnostic materials. This was to strengthen my own knowledge and to find any information about autism and Asperger's that I did not know. Trustworthy sources, such as the National Autistic Society, were used to find studies, articles and educational material.

This research is purely factual, rather than the other research which is about personal insights and perspectives.

An online survey was conducted to gain information about general perceptions of autistic people from the general public. The survey was up for a few weeks and on several forms of social media to reach a wider audience. An online survey rather than a paper survey was used for ease of comparing results. As part of the survey, people were asked about what they knew of autism and Asperger's and about any characteristics they associated with the disorders. The aim was to find any trends and prevalent themes among the answers that were received from the survey.

Methodology

Interviews were conducted alongside the survey to get an in-depth, personal insight into perceptions from both an autistic point of view and a non-autistic point of view. Two interviews were conducted, one from someone who had worked alongside people of the spectrum and assisted with their education whilst at school. The other interview was with the mother of a young autistic adult. He was unable to contact me directly so to aide with communication and for his well-being, I spoke with his mother about his experiences and how his autism affected his day-to-day life.

These interviews were very informal, with the interviewee leading the conversation and questions were changed depending on what was discussed. The informal nature of the interview also helped to ensure the interviewee felt comfortable to answer my questions, which was necessary due to the nature of this project.

Discussion

I went to the National Autistic Society to find current literature on the definitions of autism and Asperger's. There were many resources on what autism is and various other support groups. A few people were noted as ambassadors, such as Chris Packham and Alan Gardner. Chris Packham has a good quote in one of the resources:

This was in an understanding autism printout, which was very helpful for newly diagnosed people.

"The greatest discomfort for autistic people can be the social one. For me, it led to constant self-persecution because I was failing to manage the interactions. I was confused about why people behaved the way they did."

Discussion

There was an insightful study on the language that autistic people prefer on the website. The National Autistic Society study (2015) found out that most autistic people dislike the terms 'low-functioning' and 'Kanner's autism'. Stating that someone is 'low-functioning' implies that people with more severe autism are lesser, and that those who are 'high-functioning' are more normal. When in actuality, those with more severe autism simply have more issues with communication and find it harder to mask, and 'high-functioning' autistic people find it easier to communicate and mask any issues they may have.

The same basic problems apply to both ends of the spectrum and they should not be treated any lesser regardless of what part of the spectrum they fall on.
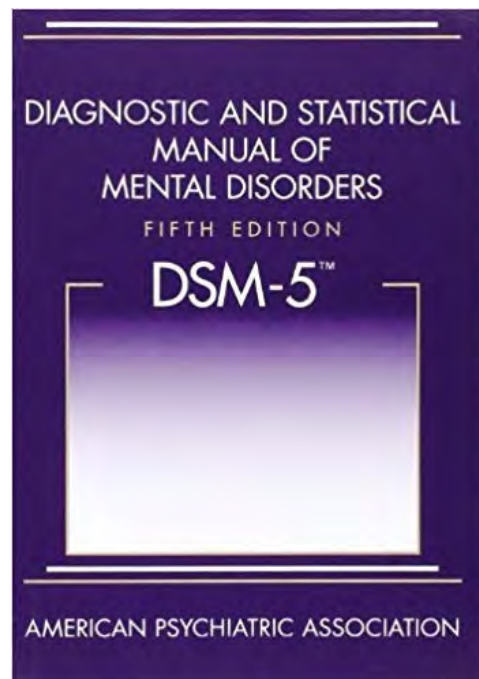
On a more positive note, autism first language has become more popular in recent years. Saying 'autistic person' helps a lot of people become more comfortable with their diagnosis rather than 'person with autism'. 'Aspie' is also a popular term, but mostly among autistic adults, rather than autistic families. This may be as 'Aspie' is more of a fun term, and some families may feel it takes the disorder less seriously.
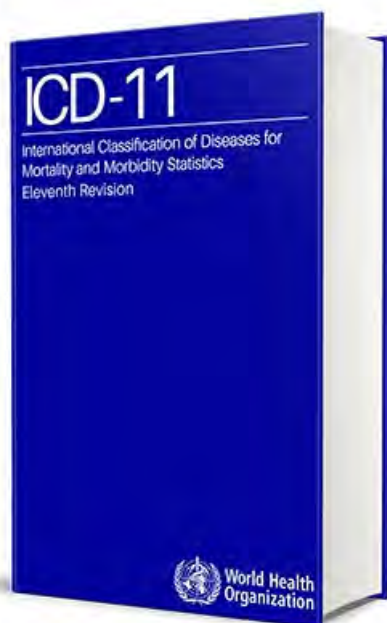
Discussion

The most up-to-date diagnostic material is the Diagnostic and Statistical Manual, fifth edition. With the changes in the DSM-5 criteria as of 2018, Asperger's, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and other developmental disorders related to autism have all been replaced by the collective term of Autism Spectrum Disorder (ASD). These changes have been made due to the criteria becoming clearer and simpler to aide with diagnosis (National Autistic Society, 2018).

This is information that not many people are aware of and a few people I questioned thought that autism and Asperger's were two completely unrelated disorders, rather than just two terms for different strengths of autism spectrum disorder. Asperger's is simply a different form of autism.

Discussion

The International Classification of Diseases, tenth edition is the most commonly used version in the UK. Recently, the eleventh edition became available and was updated to be more in line with the DSM-5 criteria. In the ICD-11, autism is classified in sub-types based on ability to use functional language and whether or not there is impairment of intellectual development (Research Autism, 2019).
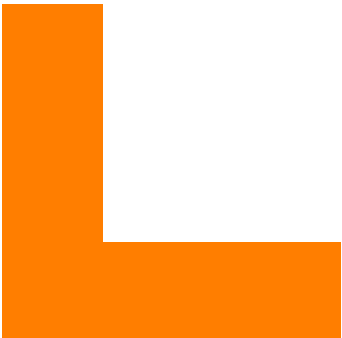
The ICD-11 does not mention any other disorders on the autistic spectrum by name, it only mentions sub-types so we could assume that Asperger's has been classed under autism spectrum disorder like in the DSM-5, but without reading the full classification it is hard to tell. I was unable to access the full criteria of the eleventh version as it has yet to be fully published. The tenth version does mention Asperger's and other disorders on the autism spectrum. This version, published in 2016, does however used some language and terms that are outdated and politically incorrect, so it is best to use the more up-to-date version or the DSM-5.

Discussion

Survey

I conducted an online survey to find general insights into what people know about autism and Asperger's, and also what characteristics they associated with the disorders. The survey results were very informative. When asked about what they knew of the learning disorders, most people knew very little. One person stated that autistic people could be prone to violent outbursts and found it difficult to deal with everyday situations. This was interesting as when I asked about the stigmas autistic people faced, they said that as people do not understand the disorders, autistic people are labelled as violent and awkward.

Those who did know a little about autism and Asperger's mentioned sensory issues and problems with communication and socialising.

The triad of impairment was mentioned by a respondent who I later interviewed. The triad of impairments is a set of characteristics common in people with autism spectrum disorder. These characteristics are grouped into three main themes: Social communication, social understanding and social imagination. Every autistic person is different but most people with autism will have issues in each of these three areas (Aspire 2020).

Discussion

Social understanding issues are categorised as:

•   Difficulty in group situations
•   Small talk and chatting are difficult
•   Problems understanding double meanings, this can result in not knowing when people are teasing you
•   Not choosing appropriate conversation topics
•   Taking things very literally

Social communication issues are categorised as:

•   Difficulty understanding gestures, body language and facial expressions
•   Unaware of what is socially appropriate, leading to difficulty choosing speaking topics
•   Difficulty making friends
•   Difficulty making eye contact
•   Repetitive speech
•   Difficulties expressing themselves especially when involving emotions
•   Anxiety in social situations and nervous tics that occur because of this

Social imagination issues are categorised as:

•   Difficulty imagining alternative outcomes and finding it hard to predict what happens next
•   Obsession with social routines
•   Severe distress if routines are disrupted
•   Problems with making plans for the future
•   Difficulty organising your life
•   Problems with sequencing tasks, so planning for a night out is difficult as you cannot remember what you need

Discussion

The triad of impairments was developed in the 1970s by Wing and Gould and is still used in some manner to diagnose people today. I thought it was interesting that someone in my survey was aware of this as it is medical knowledge and reasonably unheard of unless you are in the medical field. I later interviewed this person and discovered that this person had an autistic child, so it made sense that she was aware of this once I had some background knowledge.

Following this, those who took the survey were asked about characteristics they knew where associated with autism and Asperger's.

This question received much more thorough responses than the previous question.

Sensory issues and communications were mentioned from most respondents again. Hyper fixation was also mentioned quite often, although only a few people actually knew the correct terms for these symptoms. Agitation due to being overwhelmed was mentioned by a few respondents, with the reasons being both strong stimuli and unfamiliar situations. These are all common characteristics that seem to be well known; it was interesting to see that people knew these things.

Discussion

A few of the respondents who mentioned that they knew little about autism for the first question mentioned a few stereotypes, such as substituting social skills for the ability to hyper focus on certain topics, quietness and the need for special education. Whilst, special education is needed for some people on the autistic spectrum, it is not a necessity for all autistic people, and it can be harmful for people to assume otherwise.

One respondent noted that 'higher functioning' autistic people can be incredibly intelligent, a common stereotype potentially caused by the way the media depicts some autistic people. A good example of this is Stephen Wiltshire, the autistic artist known for his ability to draw a landscape after seeing it once. Whilst many savants do have autism, they are not a good example of autistic people as a whole. However, as the media tends to focus on these select few people, this can be the only representation people have of autistic people. This is inaccurate and can be potentially damaging to autistic people who feel they have to fill societies high expectations of them.

Discussion

When asked if there was a stigma around autism and Asperger's, everyone but one person said yes. The one respondent did not say why they thought this. All of the other respondents noted that certain behaviours that were seen as odd and abnormal even though these behaviours are used to help self-regulate in stressful situations. Such behaviours, like stimming, can be used to express emotion. For example, in my own case as someone with autism, when excitable I flap my hands and wiggle. When stressed, I sometimes rock or I may flex my hands. Stimming is a way to help release energy and/or stress caused by a heightened state of emotion and is highly beneficial.

Stimming is not only a physical behaviour. It can also manifest as echolalia – repetition of phrases, vocalisations and repetitive movement of objects (Bennie M, 2019). Visual stims – watching repetitive movements such as a moving fan - is a less noticeable stim compared to others but is just as helpful. More recently, videos involving cutting up soap, playing with slime or other repetitive movements have become a popular way without disturbing people around us. Tactile stimming is also very common where people with autism find textures that are comforting, and use said texture to calm them down. Soft fabrics are popular for this, and fidget cubes and fidget spinners are also a good way to discretely stim in a public situation.

Discussion

A good quote from one of the respondents was "If anything is different and breaks social norms, it will have a stigma". This was thought provoking and also what I feel to be a very accurate insight. Things that break the status quo are seen as different and weird. This can make people feel out of place, especially if it is due to things they cannot control – such as stimming and other behaviours due to mental illness.

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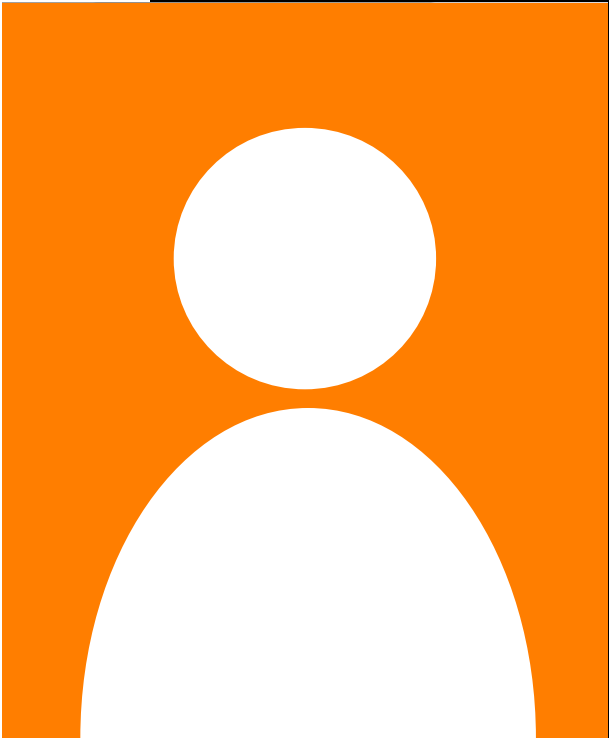
Discussion

Interviews

Interviews were conducted to gain additional insights into how autism is perceived by others. I have personal experience as an autistic person, but the interviews give a different perspective that I may not have considered before.

I interviewed Jordan, a student at USW who had a lot of experience interacting with autistic people. He was a tutor for an autistic student during year 5/6. This student knew him beforehand, so it was much easier to communicate with Jordan rather than a new person entirely. He mentioned that this student also had a teaching assistant that helped him throughout his studies as well. This teaching assistant did not change during his time at the school which was also beneficial. When I asked about any issues this student faced, Jordan mentioned that he had difficulty socialising, especially with new people. He would not go up to people willingly. Stims were mentioned. This student would rub his hands together and occasionally giggle, which would cause funny looks in class. It was noted that this student did not always fully understand things, so would need an additional explanation. I asked Jordan if he knew if he had struggled with finding a diagnosis and support, so I know this is an issue many people face. As this student was diagnosed fairly early on, he was able to find the support he needed.

I then asked about Jordan's experience with his friend in comprehensive, who was diagnosed much later on in year 11. He mentioned that his friend found it difficult to get a diagnosis as it was noticed so late on in his school journey and he had been coping with it unassisted for many years. Jordan noted that his friend was picked on quite a lot in school as he showed many signs of Asperger's but as he was not yet diagnosed, people were unaware of why he acted the way he did. His friend had 'childish' interests, such as Pokémon and Star Wars and would bring toys into school – which he would get teased about later on. As he was picked on quite a lot, Jordan mentioned that he had developed attachment issues. Once he made a friend, he would not want to leave them. This is something I feel is quite common among autistic young people, especially if undiagnosed. Certain behaviours that are out of your control can turn people away and as socialising is difficult, it can be even harder to make friends.
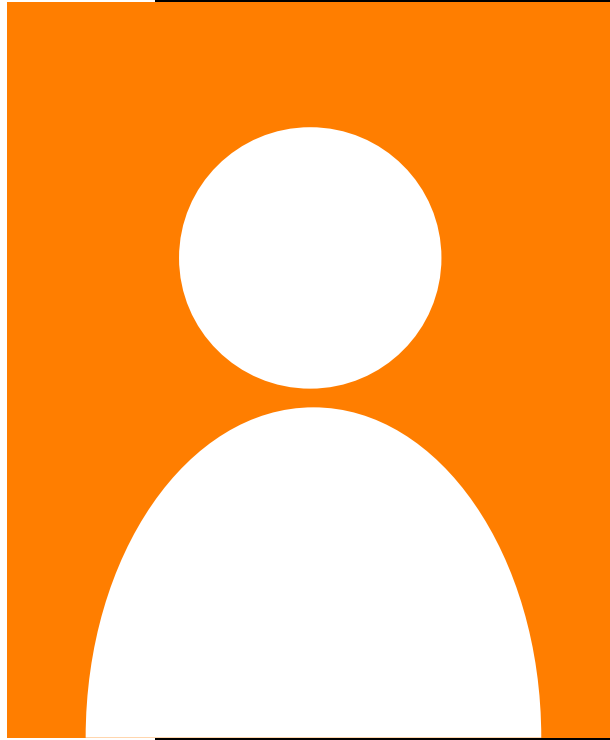
Discussion

Next, I interviewed one of the respondents from my survey. She asked that I keep her and her son's name anonymous, so I am complying with her wishes to respect her privacy.

In this interview, we talked about the issues her son has faced with his autism and how it affects his day-to-day life. She mentioned how difficult it was to find a diagnosis for her son, despite him showing many symptoms of autism. She knew from a young age that there were issues and many people found him difficult to deal with in nursery and school. She noted how at the age of 5, she would find him rocking under the table covering his ears. They now know this is due to extreme sensory issues, but at the time school officials said he had anger management issues and refused to offer help. Her son was diagnosed in 2009 after they lobbied and sought help from a local MP as the waiting list was so long. After receiving a diagnosis and moving schools, her son was able to get some of the help he needed – although there were still struggles. She noted how her son struggled with auditory sensory issues and sensory processing (touch and smell). These issues could result in sensory overload, where he would become overwhelmed and quite volatile until he had a chance to calm down. Due to these issues, many parents and children at the school avoided her and her son. Him as he struggled with socialising, which would cause conflict during after school activities and he would not be invited to parties. She mentioned that as her son had these conflicts, many saw him as a bad child and due to this, her as a bad mother.

She did say that things improved once her son started secondary school although there are still problems as he struggled considerably with homework and the division between home and school. The fact that things could change without prior warning for example, seating arrangements, could cause him distress. Her son is now 19 and is now more emotionally able to deal with the troubles he may face. He still faces issues with social impairment and rigidity of thinking, but it is less of a concern than it was previously.

Discussion

A brief interview was conducted with Alice, a student working a placement at a special needs school. She asked that I not name the school or her full name for privacy, so I have complied. In this brief interview, we discussed what she knew of autism and what she had learned at her time on the placement. She mentioned that there were different levels of autism – as it is a spectrum – and that some students with more severe autism would require special considerations to assist with communication and some subjects. Special interests were brought up as well, with Alice noting a few noticeable special interests that students had. One was interested in trains and another was highly into medicine. She said that occasionally this got in the way of school, but for the most part the students were allowed to freely express their interests as long as schoolwork was completed as well. After discussing this, stimming was mentioned. Echolalia was vaguely noted, but the terms was not known until I explained it a little further. Some students were known to hum, and one whistled. Stimming was a topic mostly discussed when I asked about any issues the students face. Some of the students had stims that were potentially harmful, such as head banging and scratching, so measures were being taken to stop those stims and redirect them into less harmful ones. Whilst on this topic, Alice spoke about some meltdowns that students had gone through. As some of the students have quite severe autism, these meltdowns could be harmful and seem to come out of nowhere. Most of the meltdowns had been caused by students being overwhelmed by sensory issues, such as there being too many people or the room being too loud or too bright. When these meltdowns occur, they would take the student out of the situation into a dark, quiet room with a weighted blanket for the student to calm down and compose themselves.

After I had asked my questions, we had a small discussion about well-known autistic people in the media. Greta Thunberg and the autistic gardener, Alan Gardner were names mentioned. Whilst I am aware of Greta Thunberg, I was not aware of Alan Gardner before this. Alan Gardner has a tv show – the Autistic Gardener – where he recruits people on the autistic spectrum with a passion for gardening to fix gardens of members of the public. This tv show is a very good representation of autism and Asperger's in the media as it is showing real life people on the autistic spectrum and showing how they deal with challenges within the show. This is a much better show compared to shows like the Undateables, which can seem tactless to people who have the disorders and disabilities shown of the tv show.

Discussion

I found a table from this study:

From Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis. This table includes quotes from autistic people rather than people who are not directly affected by autism. It is an insight into how autistic people felt at the time of the studies.

This study compiled the results of many studies on how autism affects people from a first-person perspective. The table shows key quotations from these studies and has grouped them into four key themes:

1.   Perception of self

2.   Interaction with others

3.   Experiences at school

4.   Factors related to employment

Table 2. Representative Quotations From Themes.

Theme	Quotation
Perception of self	"I'm not that interested [in the meaning of the diagnosis]" (Calzada, Pistrang, & Mandy, 2011, p. 235).
	"I lack self confidence, I don't like myself, I always look in the mirror and think I'm not good looking enough or too short . . . I'm always looking at other people wishing I was them . . . I feel different" (Portway & Johnson, 2005, p. 80).
	"I know that I can do things they [neuro-typical people] can't . . . I could actually read the building spec, go through the plans, and then put it together in my head, and I'd find faults and problem" (Griffith, Totsika, Nash, & Hastings, 2011, p. 538).
	"I started using alcohol to mask the illness" (Punshon, Skirrow, & Murphy, 2009, p. 275).
Interaction with others	"I remember feeling quite uncomfortable around people, straight away. I realised I was not right. It was just a sort of vague uncomfortable feeling that grew and grew" (Portway & Johnson, 2005, p. 80).
	"One thing that I like is that if we have the same interests" (Daniel & Billingsley, 2010, p. 226).
	"at the bottom of a remote abyss, removed from everything, and not developing the normal peer relationships I perceived everybody else as experiencing" (Müller, Schuler, & Yates, 2008, p. 179).
	"I think if you're going to get support . . . unless you're talking to somebody who is a real expert with Asperger's, you're going to end up doing more damage than not speaking to somebody" (Griffith et al., 2011, p. 541).
Experiences at school	"I get on with the majority of my teachers" (Humphrey & Symes, 2010, p. 87).
	"It's hell. It would help if teachers realize a lot of sensory and social aspects of high school can directly impact the work in school. Very negatively in some cases, at least mine" (Penney, 2013, p. 86).
	"If they were following me then the other students know that there's something different about me and I don't like it at all" (Humphrey & Lewis, 2008, p. 38).
	"Everything was so busy at school, everyone else seemed to know what they were doing, but not me. I was always out of sync, always in the wrong place, late for lessons" (Portway & Johnson, 2005, p. 77).
Factors related to employment	"The years roll by, and I stumble from one job situation to another, and nothing consummated into a promotion or career type move" (Müller, Schuler, Burton, & Yates, 2003, p. 166).
	"I worked for 13 years at the post office. The relationships with people are straightforward and the tasks are well defined. . . . Everything followed a routine, and the expectations of everyone were clear" (Krieger, Kinebanian, Prodinger, & Heigl, 2012, p. 150).
	"It's interacting . . . they come up to you and start asking you questions about your problems . . . I may make a comment, I may do something inappropriate and it builds up and then the employer . . . usually it leads to a reason for dismissal" (Griffith et al., 2011, p. 539).
	"I am not ashamed to talk about being an Asperger. But as long as the word 'autistic' is used as an insult, I don't believe in progress after disclosure" (Krieger et al., 2012, p. 151).

Discussion

These quotes show key trends in areas that autistic people are affected in. People mention within interaction with others issues of communication, such as discomfort and seeing a disconnect with interacting with people compared to how they interact with each other.

Experiences at school was a highly insightful key theme with people stating issues within education. One study (Humphrey & Lewis, 2008, p. 38) mentioned that there were many sensory and social aspects in high school that directly affected education negatively.

Another mentioned that everything was busy which made it hard to concentrate, whereas other people around them seemed to find it easy (Portway and Johnson, 2005, p. 77).

Identity was mentioned within the study, with some people stating that autism was a key part of their identity such as cited in Hughes' 2012 study, and with others mentioning that they felt "devastated and helpless" as the disorder is lifelong (Haetrl et al, 2013).
This study has some very good insights that will useful for my project, especially as the study is focused on a first person perspective.

Summary

From my research, I have discovered many common trends within general perceptions of autism. Many people know of basic characteristics of autism and Asperger's, but these characteristics are often misunderstood and can cause conflict between people with autism and those without. Misunderstandings and a lack of communication can be potentially harmful and cause distress to those on the autistic spectrum.

I assumed that most people would know very little about autism and so was pleasantly surprised that people knew more than I thought. There are still some misconceptions that need to be combatted however, so I will do so in this project.

Due to the research I have collected, the original question will be reframed. Rather than "How will we better educate people about autism and Asperger's?", a better framed question is: "How can we combat the stigma around autism spectrum disorders?" The question has been changed slightly to combat stigma rather than focusing purely on education. A solution to this question may well be to educate people about autism in order to combat the stigma around autism.

My question has changed as the research I have collected is less focused on current forms of educational resources and more focused on current perceptions of autism spectrum disorder. Therefore, I feel it would be better to try to combat these perceptions within the final project.

Reference list

1)   The NHS Information Centre, Community and Mental Health Team (2012), Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Available at: https://files.digital.nhs.uk/publicationimport/pub05xxx/pub05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf (Accessed 12/02/2020)

2)   National Autistic Society (2015), The language we use to describe autism.
Available at: https://www.autism.org.uk/about/what-is/describing.aspx (Accessed 17/02/2020)

3)   National Autistic Society (2016), Profiles and criteria – National Autistic Society. Available at: https://www.autism.org.uk/about/diagnosis/criteria-changes.aspx (Accessed 08/02/2020)

4)   Research Autism (2019), Autism Spectrum Disorder – Diagnostic Criteria. Available at: http://www.researchautism.net/conditions/7/autism-(autism-spectrum-disorder)/Diagnosis (Accessed 15/02/2020)

5)   WHO – World Health Organisation (2016), International Classification of Diseases – 11th Revision. Available at: https://icd.who.int/browse10/2019/en#/V (Accessed 10/02/2020)

Reference list

6)   Aspire Ireland, Asperger Syndrome Association of Ireland (2020), Describing the triad of impairments. Available at: https://www.aspireireland.ie/cmsWP/whatisaspergersyndrome/adult-diagnosis/describing-the-triad-of-impairments/ (Accessed 15/02/2020)

7)   Wing, L. & Gould, J. (1979). 'Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification'. Journal of Autism & Developmental Disorders, 9, pp. 11-29. Available from the NAS Information Centre

8)   Bennie, M (2019), 'Understanding Stimming and Autism: The Good and Bad Side of Anxious Behaviours', Autism Awareness Centre, 15 May. Available at: https://autismawarenesscentre.com/stimming-the-good-and-bad-of-anxious-behaviours/ (Accessed 18/02/2020)

9)   Admin of experia USA (2019), 'Understanding the Different Types of Stimming', experia usa – multisensory for everyone, 22 November. Available at: https://www.experia-usa.com/blog/understanding-different-types-stimming/ (Accessed 18/02/2020)

Reference list

10)   DePape, A and Lindsay, S (2015), 'Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis', Focus on Autism and Other Developmental Disabilities, 31(1), Sage Journals. Table. 2

11)   DePape, A and Lindsay, S (2015), 'Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis', Focus on Autism and Other Developmental Disabilities, 31(1), Sage Journals. Available at: https://doi.org/10.1177/1088357615587504 (Accessed 05/02/2020)

12)   *Image of Chris Packham,* Available at: https://www.dfmanagement.tv/wp-content/uploads/2018/10/Chris-Packham-8-845x562.jpg (Accessed 21/02/2020)