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'Let's Talk Autism' -a school-based project for students to explore and share their experiences of being autistic

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Understanding what autism means on a personal level can be an important process for young people on the autistic spectrum, and being able to reflect on this and discuss with autistic peers can be particularly helpful. However, opportunities may be restricted by reluctance to talk about diagnosis and because of difficulties in communication inherent in autism. This article describes a therapeutic media project within an ASD school that attempted to support young people to reflect together about what autism meant for them and create resources to share with others. The process is described and main themes of discussions analysed using thematic analysis. Main themes emerged of making sense of diagnosis, experiences of difference and transition to adulthood. Various strategies to manage diagnosis and negotiate identity also emerged. Issues around informed consent and confidentiality and the therapeutic value of such groups are discussed.

***Key words*: ASD, understanding diagnosis, identity, difference.**

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Introduction and Aims

For some students, developing an understanding of autism can be pivotal in self acceptance and self esteem and also in being able to manage and cope with the differences that autism can present. This can be particularly important as students reach later childhood and adolescence and become more aware of their differences from others, and the impact their autism might have on their life choices.

Much literature now exists to support students to develop an understanding and awareness of autism. For instance, ‘I am Special’ by Vermeulen (2000), is a guided workbook to introduce children and young people to autism and what the diagnosis means for them, and Attwood’s ‘The Complete Guide to Asperger’s Syndrome (Autism Spectrum Disorder): Revised Edition’ (2008), is aimed at educating parents, professionals and young people themselves about what the diagnosis means. Furthermore, many social skills training packages exist in order to develop awareness of social communication difficulties linked to autism. For instance, a new package from the National Autistic Society ‘Socialeyes’ (2010) looks at eight key social communication difficulties that might be present for autistic adolescents and adults, builds an understanding of these for those people and suggests ways they can manage them. Such structured resources provide helpful ways to begin to explore and understand what an autism diagnosis means, and on the difficulties and differences that autism can create. However, the wider questions which adolescents face, of their changing identity, the path into adulthood, and where autism fits into this transition from adolescence into adulthood, are not so much a feature of these psycho-educative approaches and we would argue are important questions to help young people to answer.

Quite recently, three articles have been published where narrative therapy techniques have been used with young people with autism. Narrative therapy involves supporting people to individually construct their own meanings of the world, to:

> ‘examine and edit the stories the person tells himself or herself about the world to promote social adaptation while working on specific problems of living. These complex stories include those related to who they are as a person and their interpretation of events that signal to them where they fit into the world’ (A. Cashin, 2008).

Cashin’s article describes the successful use of the narrative technique of externalizing to work with an autistic adolescent who was referred for difficulties in controlling anger, (in this case the therapy entailed labelling anger management difficulties as ‘the bang,’ so making it something separate from the child and therefore able to be ‘spied on’ and ‘busted’ rather than inherent within the child and therefore harder to feel positive about changing). Cashin et al. present a further article where similar techniques were used successfully with ten young people (aged 10-16) in individual clinical sessions (2013).

A further article (Gilling, 2012) explores therapy from a social-constructionist perspective with an autistic teenager, in which the global ‘medical model’ of autism is challenged, to help the young person to construct a preferred identity through a narrative framework. She discusses how autism can become a ‘totalising identity’, becoming the only story about that young person, and the use of concealment to manage identity, with a concern that revealing autism can lead to negative attitudes. The author therefore attempted to listen to the young person’s ‘insider knowledge’ rather than a ‘professional discourse’ about autism, and to externalise the ‘autism’, thereby giving the opportunity to talk about his relationship with autism, and consider different, thicker stories of himself that went beyond his diagnosis. In all articles, the participants were stated to have made improvements in psychological wellbeing as a result of the process. Therefore, it potentially seems an additional helpful extension, from understanding what an autism diagnosis means, to also being able to find ways to reflect on what this means on a personal level. As Peeters (2002) states, for some people, autism is a part of identity. He quotes a lady in her 40s saying ‘Diagnosis is a pre-requisite … knowing about your own identity is a pre-requisite for everything else. Only then your personal integration starts,’ (Peeters, 2002), p.13.

In these articles, however, work was done on an individual basis, about clinical difficulties the participants were facing. Giving students the opportunity to engage together in this kind of reflection more widely, about what autism means to them, could therefore be potentially beneficial. The authors could find no articles that tried to create a shared, open forum within a school based setting to explore the meanings that autism held for the students and to share (safely) their own experiences of being autistic.

A variety of books written by people who themselves have an autism diagnosis e.g. (Grandin 2006) are now available to help develop an understanding of autism from this ‘insider perspective’. Furthermore, in recent years, the explosion of internet autism sites has made it more possible for teenagers and adults with autism to access shared information, networks and understanding previously hard to come by (Ward, 1999), and is particularly useful as it takes away the need for face-to-face social contact, which can be hard to navigate as an autistic person. Four online discussion groups were analysed by Brownlow (2010) using discourse analysis, who discovered that those for adults with autism were much more focused on autism as a ‘difference’ rather than a ‘deficit’, with a rejection of the goals to make people more ‘normal’ and ‘less autistic’ through therapy, and of the felt pressure to become more ‘neurotypical’, instead supporting individuals to embrace their autism and differences. The author discusses ‘the complex and sometimes competing representations that people with autism can draw upon when negotiating their own identity’ and the importance to not assume that ‘all people with autism or all professionals or parents will construct autism in an identical way.’ Similar themes emerge from other articles focussing on narratives of autism, specifically of culturally dominant metaphors of autism as ‘not normal’, or as disease, or deficit, and emerging counter-narratives of autism within neurodiversity. Most of these suggest that the framing of autism within a disease model comes from within non-autistic communities, and framing it as neurodiversity comes from mainly within the autistic community (Broderick 2008).

Qualitative research with autistic individuals also captures the dilemma of how to make sense of the differences autism might present. A study with parents, children and young people (9-16, mean age 11.7) using semi-structured interviews and framework analysis, focused on the utility and meaning of autism diagnosis for families. The diagnostic label was felt for young people to have little impact on understanding their own difficulties, often with an indifference from the children about the diagnosis, and for some, feelings of stigma – feeling they were different, or treated differently by others, with some worry about what others would think of them if they knew of their diagnosis. This was in contrast to parents, who could perceive more positive benefits of diagnosis (Calzada, 2012). Bagatell (2007) described in detail her ethnographic study with one young man with autism (aged 21), exploring the ‘ongoing, complex process of identity construction’ he goes through. Initially, of feeling ‘different’, of being encouraged to try to ‘fit in’, of finding it difficult to interact and feeling isolated, and that there was something ‘wrong’, of trying to ‘act normal’ (but finding this very stressful), and of adopting a ‘cure mentality’ – hoping for a way to eliminate autism. She then describes how the young man found the ‘aspie world’, in which his contact with others on the spectrum helped him to see that his experiences were ‘normal’ for people with autism, and to feel part of a group that shared experiences, and therefore to reframe who he was and construct a more positive identity. The final part discusses the difficulty of managing these multiple identities, managing the tension between the neurotypical and Aspie world. A further article by Hurlbutt and Chalmers (2002) interviewed three high-functioning autistic adults, and similar themes emerged of the importance of identifying with their own unique autistic culture (to be proud to have autism and accept themselves, to have no desire to be neurotypical, and in fact see most neurotypicals as narrow-minded), to use the support systems of families and church to develop feelings of self worth and esteem, and to have strong opinions about what could make a difference (community living, supported employment, respectful behaviour support, and support to develop social skills). They concluded that autistic adults want to be considered experts on autism, that they ‘need and want to be the ones to help spread the word about autism and increase awareness.’ It is interesting that across these articles there seems a very different perception of autism diagnosis at different ages, with an acceptance of autism emerging with age, and also a move toward the positive ‘neuro-different’ model, away from a more medical perspective.

These varied narratives suggest the importance for autistic young people to be able to reflect upon and develop their own construction of their identity, and to make sense of what their autism means to them. Whilst young people in other situations might typically turn to their peer groups at the age of adolescence in order to make sense of and understand their social world and identity, for young autistic people this is not always easy, especially about a complex topic such as what autism might mean to them. Difficulties linked to typical autistic presentation (e.g. in being able to express oneself, understand others’ perspectives, hold effective two way conversations, generalise from experiences) may limit the opportunities students may have of learning about and sharing experiences of autism with others. Specific difficulties around giving and understanding narratives may impact further. Research by Bang et al. (2013) explored how individuals with high functioning autism convey subjective experiences, and discovered that these individuals produced a smaller proportion of personal narratives and use of mental state terms within these narratives. Another research study by Goldman (2008) indicated that high functioning children with autism had more off-topic answers within narratives, focused less on people, and their narratives were generally less coherent, resulting in a string of unconnected experiences rather than a meaningful autobiographical story. They suggested that children with autism need more support to generate personal accounts, and to make them meaningful to a listener. Such difficulties might make it very hard not only to convey but also to understand autistic peers' experiences, with impact on their capacity to share stories and to learn from each other. Furthermore, especially for students who have additional learning needs such as dyslexia, finding ways to access on-line information and networks independently is a challenge.

This initiative arose from the realisation by some teachers, a clinical psychologist and certain students within an ASD school that, whilst they were able to talk about and learn about their autism individually, there was at the school a general 'quietness' in terms of talking more openly about autism. All agreed that finding ways to make it acceptable to talk about autism, and for this to become an ongoing project within the school, was key. This grew into an idea from one student of making a documentary with other students who wished to take part in the project and had a good enough linguistic level to do so – to share their own experiences and to also to produce media to help to raise awareness for others – both autistic and not. To our knowledge this has not been done before, and the purpose of this article is to share the process used and also, due to the richness of material, and therapeutic value of the project, to analyse the main themes that emerged from the project.

Methodology

The 'Let's Talk Autism' project had five main processes.

1. Two discussion groups were held, one Key stage 4 (three young men, one young woman), one sixth form (two young men, two young women) focusing on what ASD meant to them, facilitated by a clinical psychologist, the deputy head teacher, a facilitator and podcaster. The facilitator and podcaster were media professionals who had supported students in similar advocacy work previously. The discussions lasted around one hour, and were unstructured – following what the students wished to talk about. Making the discussions safe to participate in was important. All students prior to the discussions were aware of their diagnosis and had talked to either the teacher or the psychologist about this, and were invited individually to take part. At the beginning of the discussions, the students were told again that the discussion would focus on what ASD meant to them, and were informed that at any point they could leave the meeting,

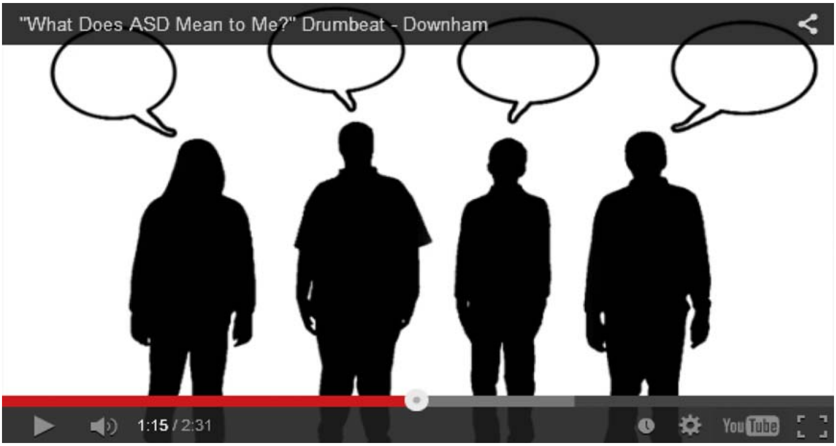

Figure 1. Screenshot of ‘What Does ASD Mean to Me?’

and did not have to talk if they did not want to. They were also informed that they could leave the project at any point and their input could be removed from ongoing media. All students chose to continue with the project throughout.

2. The discussions were made into short videos in which the main themes of the students’ discussions were pulled out and put to images developed by the podcaster. (See Figure 1.) Both student groups were consulted to check that the themes and images accurately reflected their experiences, and to record their narratives and images.
3. Three students (two young women, 15 and 19, and one young man, 18) led a series of podcast interviews – talking with key figures for them about their experiences of autism (a head teacher, a diagnosing paediatrician, a mother, and a young autistic man who was living independently). Again, the remit for interviews was relatively unstructured but entailed an initial discussion, where the students shared their thoughts about the topics that might come up with that week’s guest, the interview itself (led by the students), and a closing summary after the guest had gone, where the students reflected on what the interview had meant for them and their understanding. A further interview involved the deputy head and psychologist involved in the project, where all involved discussed the process and impact of the project.
4. An open evening at the school and special launch event (where students invited friends, family members and teaching staff) where the podcasts

and videos were shared and celebrated outside of the groups that had created them, and subsequently made available on the school website.

5. Finally, an interview took place at a borough conference, billed as a 'live podcast' where the students introduced the project and showed the videos to eighty delegates, then interviewed each other about the project on stage and took questions.

Throughout, the process and direction of the project was very much led by the students involved, in terms of the structure of the discussions and interviews, the form that media should take, and how we should share with others. At each stage of the process, consent was sought from parents and updated information given of the next stages of the project. All parents gave consent, and responses to the work were very positive.

The final stage of the project analysed the main themes and drew together some conclusions. This was done by the clinical psychologist and deputy teacher involved in the project. Thematic analysis of video content and podcasts followed guidelines suggested by Braun and Clarke (2006), namely:

1. transcribing all interviews verbatim
2. generating initial codes – features of the data that appeared interesting
3. pulling these initial codes together into themes and writing-up, with extracts from the data.

Thematic Analysis Results

In keeping with the initial question of 'what does ASD mean to me?' and the questions linked to this that were conceived and asked by the participants (with some help from facilitator and podcaster), the over-riding theme that emerged in the data was of making sense of autism and negotiating identity. These divided into three main areas, as shown in Table 1. Additionally, a separate theme of 'growing up with autism' emerged.

Theme 1: Making sense of autism and negotiating identity

The primary theme that emerged within the project linked up to students' questioning and understanding of their own autistic experience and how to make

Table 1. Thematic map of students' experiences of autism.

Theme 1: Making sense of autism and negotiating identity			
2a: Experiences of the diagnosis of autism	*2b: Experiences of Difference*	*2c: Strategies to manage*	*Theme 2: Growing up with autism*
● Getting the diagnosis ● Understanding the medical diagnosis ● Alternative understandings of autism ● Confusion and conflict in understandings	● Different or normal ● 'Invisible' disability and impact ● Difference as perceived by others and in how treated by them. ● 'Bubble' of special school	● Trying to act 'normal' or hoping it will go. ● Acceptance ● Learning to cope and have self belief ● Being an advocate or activist ● Taking advantage of 'special' opportunities ● Talking and sharing stories - thickening identities	● Wanting to become independent and have a 'normal' life. ● Fears about becoming independent and how to cope. ● Managing the transition.

sense of this. This focussed particularly on understanding what a diagnosis of autism meant for them, questioning whether this meant they were ‘different’, and also linked up to this experiences of being treated differently by others; finally the different strategies used to manage their autistic experience and construct their identity.

Theme 1a: Experiences of the diagnosis of autism

Getting the diagnosis

Experiences of getting the diagnosis came up in several interviews. Often, this was linked with something being wrong or not ‘normal’:

> ‘. . . I was born premature, three months, my brain wasn’t developed properly and then my mum realised that, when I was three I was then diagnosed with autism’ (student).
>
> ‘as they were growing up, they didn’t reach the normal milestones that children normally do. . . probably in your heart, as a mum, you know that something’s not quite right?’ (mother)
>
> ‘. . .you have a normal little baby and then things change’ (mother).

This was often accompanied by expressions of shock, upset or blame:

> ‘. . .you went to get diagnosed with autism, how did your mum cope?’ ‘Well, I’ll be honest with you, my mum was really shocked cos she didn’t know what autism was and she had to do some research on the internet. But then she got to understand me more’ (student).
>
> ‘When your son’s got diagnosed, did you know how to take it?’ ‘I was very upset, and also felt it was my fault, and you are sad because you want your child to have a perfect life, and you know that your child is going to be different and probably going to struggle a little bit more than most children? Erm but it doesn’t change the way you feel about your child, you absolutely love your child because they’re your child. . .. it was a shock to me because you don’t expect it’ (mother).
>
> ‘It’s always upsetting if there’s something wrong or different with your child, you know, even its, you know, parents always worry about their children, how

> it will affect them in the future, what does it mean, so it can be a worrying time for parents, and I that's I think why they sometimes get upset' (paediatrician).

Within these accounts, the emphasis on love and acceptance and researching to understand came out strongly as ways to cope with the initial diagnosis, and this also leads to wider themes of constructing a positive identity as discussed below.

Understanding the medical diagnosis

Often, the students would question each other and their interviewees about what they understood autism to be. Professionals would often give an account of symptoms or underlying causes from a medical/clinical perspective:

> 'So what I understand by autism is that people, and young people, have difficulties understanding the perspectives of others. I think that's how I would describe autism' (head teacher).

> 'Everyone with autism's got a perfectly normal size, normal looking brain. It just means that some of the connections inside it aren't working maybe quite as well as they could' (paediatrician).

> 'We just call it Autism Spectrum Disorder. Trying to mean that's still a range of difficulties that children have' (paediatrician).

This was summed up by one student in their statement: 'I get that it's a disorder.'

Students were also interested in the difference between mild and more severe autism, and what this meant for them:

> 'What does mild autism mean, cos I have that?' (student) 'Well, I think, we think of autism as a condition that can be very different in different people. So some people seem to be more affected than others. So I suppose people who are less affected, you might say they've got mild autism, and, in other words, they are not so affected in their lives as maybe some other people' (paediatrician).

Alternative Understandings of Autism

Alongside the desire to understand the medical diagnosis, the students also thought about their own personal meanings of autism, and this often moved away from the 'difficulties' of autism to the strengths or uniqueness that autism gave:

> 'Having autism can be good though, like I feel I look at the world in a different way . . . a bit like what an artist would look at it, or a film director, and it's a really interesting way like, to see it from my eyes' (student).

> 'I'm actually proud of what my autism makes me, huh? I believe it makes me a very unique person, I believe it makes me who I am' (young man).

However, the idea of autism 'making you who you are' was contradicted by another view point:

> 'I don't think autism makes the person, I think you make the person you're gonna be, not autism.'

The negative connotations of autism were also contradicted in different viewpoints:

> 'People who have autism, I just want them to realise you haven't got a disease, there's nothing really like, it's not the end of the world you know' (student).

> 'It shouldn't be that big of a deal. It's just special needs.' (student).

> 'Basically it's not something special, we've all got bits in us' (student).

Finally, there was in some opinions a mix of the negative and positive: 'Autism can have its difficult bits, but then it can also have its good bits.'

Confusion and conflict in understandings

Quite often in the interviews (especially when discussing causes of autism) there was a sense of confusion for the students:

> 'I don't get it. So now I'm thinking my brain is not developed properly. Does it mean my brain? The wires in my brain are not connected? That's what, I'm confused now.'

> 'So now it's a lot different but it's still new. No-one knows exactly how autism is affected, no-one knows how it affects you and no-one knows why it's given to you.'

> 'Lots of kids like me who have got it, don't know what it is, they tell you you've got it, but you don't know what it is.'

Understandably, this not quite knowing what was wrong, but being told that something was wrong, was difficult for students to accept. One student commented: 'It makes me feel like I'm retarded or something.'

For others, how the diagnosis fit with their own identity, and whether to feel positive or not was more complicated:

> 'Yes and no. Because for most people, we want to look at the good side of autism, we want people to think that we're happy with our diagnosis and not just like, I don't like it that we have autism and I'm not happy about it. We don't want them to think that we're unhappy with our conditions. We just, it's kind of like a conflicted situation, because at some moments it's sad, but we just want to be happy. You know what I mean?'

> 'It makes me think 'What am I then?' Am I Robert with special needs, am I Robert without special needs?' (Student name changed).

> 'Sometimes I'm proud to have special needs, sometimes I'm not.'

Theme 1b: Experiences of difference

The second part of making sense of autism, following on from the diagnostic label itself, was of the students perceptions and understanding of how autism made them different (or not); both internally and also in how others perceived and treated them.

Different or normal

Often within the interviews and group discussions, the students spoke about how they had realised that they were in some way 'different' from others:

> 'I realise that I was different to everyone else, like ask me anything about Dr Who and I know the answer.'
>
> 'With my autism I feel like I'm supposed to be different.'
>
> 'I always knew there was something there.'

For some students, this feeling of difference was often linked to a desire to be 'normal':

> 'You may seems a bit different, and I know sometimes it can be hard, you know, and sometimes you may look at people and think 'they're normal, I wish I was them.'
>
> 'I would say to myself I can't take it anymore, I want to change, to be normal.'

Sometimes, however, with continued discussion, there was a wider questioning of what it meant to be different that seemed to help the students construct a more positive perception:

> 'Keep in mind that everyone's different in their own way, and its nothing bad.'
>
> 'I realise now that every single person in the world is different. Normal is just a word and it's irrelevant to us.'
>
> 'I think it would be boring if everyone was the same.'
>
> 'If you can see that this person looks like you, does things like you, then he is like you.'

'Invisible' disability and impact

Linked up with experiences of different and normal was the at most times invisibility of the students' autism:

> 'And like most people in the street couldn't tell I had autism, because my type of autism is such an invisible disability? But when I'm kind of like upset, it can come to be a little bit more obvious that I do have some problems dealing with some forms of emotions' (young autistic adult).

> 'Sometimes when I get up and look in the mirror, sometimes I think I can't see it, in me.'

This invisibility was sometimes contrasted to young people with more severe forms of autism, both in the frequent references they made to their own 'mild' autism, and also in some of their discussions:

> 'Some people with autism look fine, other people look weird.'

Difference as perceived by others and in how treated by them

Often in the discussions and interviews students talked of experiences in mainstream settings, such as school or in the community, as negative. Often this was linked to feeling different or not being accepted:

> 'Well, when I went to mainstream secondary school I got bullied and I was very different compared to the other children.'

> 'When I think the children in mainstream school hear about autism they thinking 'a bit crazy, a bit loud, doesn't really, can't really read, can't really write.'

> 'Sometimes in life, sometimes people ain't always going to accept people with autism. Sometimes they will accept you, sometimes they won't. But sometimes I find it unfair.'

> 'You're in the street and you see a group a kids come and say loner.'

In one discussion, the importance of the 'first judgment' of hearing that someone was autistic was described:

> 'I think what it is, it's the first judgement. And the minute you hear autism you start thinking and you start thinking and unfortunately nothing can stop you thinking so.'

Sometimes, this was linked to a feeling of shock, because of the perceived invisibility of autism:

> '. . . sometimes when I tell people I got autism they're so shocked, and sometimes it makes me feel a bit angry when they're so shocked. Because when I tell them, it's like they weren't talking to me like they was before. Like they knew the girl who didn't have autism, but they found out the girl has autism, so they act a bit funny.'

The reasons behind why people might act in such ways also came up in several interviews, in terms of a lack of knowledge of autism below a surface level for some:

> 'When you say that people know about autism they may have heard about it, but they don't really know much about autism, and I think that's why you may get difficult looks and you may get the impression that they've never heard of people with special needs'(head teacher).

And linked to this, the perceived invisibility of autism, which confuses the other person:

> '. . . I think that's the thing, people who don't know people with autism struggle with, because I think they think you're going to look different, or there's going to be something they're going to be able to tell that you've got autism. And its probably until you start communicating that they don't, then they realise. . . Then they change how they interact with you and they don't need to' (mother).

Whilst for some students, being treated differently could be very hard to manage and lead to withdrawal:

> 'It's like when people judge me when I'm out. I think they take the mickey out of me sometimes. It's really upsetting for me. It makes me feel like I'm ashamed to go out on my own.'

For others, the reaction was one of anger:

> 'Who do you think you are? Don't judge me.'

Whether to ignore others had a mixed response:

> 'My sister makes me feel happy, when I tell her she says the people who take the mickey are idiots and I shouldn't listen to them.'

> 'People say just ignore it. It's not fair to ignore it, sometimes it doesn't work, it makes it worse. No teacher ever says 'it's ok to have special needs.'

In various interviews, there seemed an element of taboo in talking about autism:

> 'Even though I could talk about it any time I want, you just didn't and there was something telling you not to do it.'

This taboo perhaps linked to the difficult or anticipated negative reactions of others. As one student said simply:

> 'It can be scary to tell people sometimes.'

'Bubble' of special school

In contrast to the above feelings of difference, special schools were for the students generally seen as a place of acceptance:

> 'I can be myself, if that makes sense, because, when I come here, I can see that I'm not different, there's other people who I can talk to, who have autism and people who understand me . . . I don't feel alone.'

One student described this as 'a bit like the school is a bubble and the outside world is locked away.' This was further expanded by the head teacher:

> 'I think it is a bit of a bubble, but I think sometimes you've got to have a bit of a bubble, a bit of protection, a bit of security, in order to learn about the outside world and to learn to cope in the real world'.

Theme 1c: Strategies to manage

Throughout the interviews and discussions, students and their interviewees not only thought about what it meant to be autistic, and their own experiences of autism, but also talked about the ways that they had developed to manage their identity as autistic. This suggested very much that the students were not simply accepting a label, but actively constructing how to think about this and what it meant for them. The main strategies are outlined below.

Trying to act 'normal' or hoping it will go

On a few occasions, the students talked about trying to hide or minimise their autism:

> 'I research everything, I research to learn what I shouldn't do.'
>
> 'Sometimes I hide it, I don't tell people.'

For a few students, they had an ongoing question about whether their autism would stay for life:

> 'Can it go? I've been wondering for ages it it's a disorder that's for life. I wonder about it all the time. Autism, can it go?'
>
> 'Does it mean if my brain did develop, does it mean I wouldn't have autism at all?'

This element of hoping for a cure, for the autism 'to go' also came up in the interview with the mother: 'I think I thought he would go to the unit and then everything would be alright and he'd go to a normal school.'

Understanding and acceptance

In contrast to the above strategy of hiding or wishing autism away, the theme of accepting autism also came up for many students:

> 'I wouldn't want to change it, I'm perfect the way I am. I don't want to change who I am.'
>
> 'I used to say I wish I didn't have autism, I don't say it any more, I'm starting to accept it.'

Needing to understand and accept also came up for the mother, regarding some of her son's autistic behaviours:

> ‘My son has this thing about wearing certain clothes, having certain bedding, eating certain food. And as a parent I kept on thinking, if I keep on doing it, he’s going to change. He wasn’t going to change, I needed to change to be able to communicate with him. So to accept that some of the things that I think are completely abnormal are actually normal. … .. don’t try and change, just accept and go with it. Cos it don’t really make any difference does it? But as a mum you think, if I keep on doing it enough they’ll change; and they won’t.’

The need to understand in order to cope also came up in the interview with the head teacher: ‘My advice to young people with autism is to find out a little bit more about autism so that will give you an insight into how to cope with autism.’

Developing self belief

Linked to accepting autism was the strategy of developing self belief, and pride in oneself, and of the value they had, and that their autism or special needs gave them.

Part of this was in response to hearing a message from others that they could not achieve and retaliating:

> ‘I want to show people who said ‘oh, he can’t do it because he’s got autism’ I wanna show them that you can.’
>
> ‘We all know that people out there are saying that you can’t do this, and you can’t do that sort of thing. But I believe that you can. And if you believe that you can do it, you definitely can do it.’

Linked to this was the concept that having special needs made achievements even harder, and therefore even more amazing. This was particularly voiced by the mother:

> ‘As a parent to me what’s really special is everything you achieve, I know how hard it is and that makes it so much, so special for me. As a parent I just feel so blessed, I really do.’

For one student, this theme of acceptance and self belief went even further, into a desire or a felt duty to create greater acceptance and awareness of autism in society:

> ‘I think we have a duty and a job to change people with autism, change their awareness. Not just people with autism but people without autism. . .It’s very dark days with your autism to be honest with you. It’s always going to be like that until it gets acknowledged more.’

Taking advantage of ‘special’ opportunities

In several discussions, there was an idea that having autism created more opportunities than they would have otherwise got, such as going to a special school, or additional chances or support in the community that they only got because of their autism. Most students saw this as something positive:

> ‘Don’t be worried, don’t get embarrassed, someone’s going to help you, take advantage.’
>
> ‘So I think, you know, use the people that are around you to support you. And, you know, don’t be fearful to, don’t be frightened to get what you want in life.’
>
> ’Coming here to a special needs school has helped me and pushed me further.’
>
> For one student, however, it was important to not use or identify himself in terms of his autism, as evidenced in this statement:
>
> ‘I don’t want to be the person who says I’ve got special needs as an excuse.’

Talking and sharing stories - thickening identities

The final strategy to emerge strongly from the transcripts on this theme was of the importance of talking and sharing stories with other autistic young people. One of the outcomes of this was to take away the feeling of shame or taboo:

> ‘. . . just for people to talk about autism, and don’ be ashamed of it, It’s just your autism.’
>
> ‘People wanted to talk about autism and again, it’s giving people the opportunity and saying ‘it’s alright, we can do this.’ And the more we talk about it, the less of an issue it is to talk about it.’

For some students, being able to talk openly about autism helped to reduce a feeling of isolation:

> ‘Talking to him made me realise that I’m not the only person with autism. There are lots of people just like me.’
>
> ‘I felt that I was able to explain what autism felt like to me, and also I felt that I wasn’t alone, there was many people in my own school, I didn’t even know . . . had the same, very similar issues. It was as if they were copying me, they weren’t copying me though, and it was strange . . . but it sort of made me feel better that I weren’t the only one.’
>
> ‘There was someone else who feels how I feel. I’m not alone.’

Finally, talking openly was seen as positive in terms of being able to express feelings that had been kept hidden:

> ‘So it’s just best if you can talk about it, get it out your system, and then it will help you talking about it.’
>
> ‘And all the time I would look in the mirror and wish I didn’t have mild autism but when I founded out there was a podcast about it I go so excited because it’s like finally I could talk about it, I don’t have to keep it in no longer. And I could express how I feel.’

Theme 2: Growing up with autism

The theme of growing up came up only in the interview with a young man with autism who now had a job and lived independently. However, this was such a strong theme within this interview that it merited pulling out as an additional element.

Wanting to become independent and have a ‘normal’ life

One of the main themes that came out of this was of the desire to be independent and live a purposeful and ‘normal’ life. The students discussed their aspirations:

> 'I want to stand up for children with autism, I want people to know that 'okay, he's got autism, and he's famous'.

> 'I would like to be a nurse.'

They also discussed wanting to make others proud as a part of their future dreams:

> '. . .I want to make my parents proud, and I'd like to make other people proud. . .'

> 'Me too, I wanna impress my family.'

The students continued to talk about their hopes for independence and to have a 'normal' life:

> 'One day, I would like to have my own flat, have my own family, and be happy. . . I just want to be like everyone else.'

> 'I've always wanted to go to the cinema on my own. Or I want to go the shops and be able to confidently buy stuff.'

Fears about becoming independent and how to cope

However, whilst holding these aspirations, the students also expressed some anxieties about how they would manage in the adult world and make this transition:

> 'I can't lie, I am a bit nervous about going into the adult world. Sometimes I act like a kid. Sometimes I think about the things that I do. But I am really scared about going into the adult world.'

> 'Physically and mentally you don't prepare yourself, you don't know what's going to happen. No-one can see into the future.'

This was also reflected by the young man who had made the transition into living independently:

> ‘When you got your flat did it make you feel like, whoa, hold on a minute, like I’m invincible... did it put you on a high or...?’ ‘I believe it put me in quite a defensive position to be honest. Because I thought to myself ‘I can’t actually believe that this is happening. How am I going to cope doing all this, what if I don’t?’

> Being autistic was also for one student seen as potentially getting in the way of having adult relationships:

> ‘When you grow up you want to make friends, you want to get into relationships and you feel like autism is a ball and chain holding you back.’

Managing the transition

The final theme that emerged from this interview was of how to manage the transition, and this particularly focused on taking things gradually:

> ‘I think little steps, obviously, it’s a long, big stairway, and you have to take little steps before you get to the top.’

> ‘I manage living by myself, kind of taking it day by day, sort of thing, so kind of planning out what I need to do,’

accepting support:

> ‘... My main struggles were in my teenage years. My emotions popped up and all these strange feelings popped up. So these were obviously quite hard feelings to deal with, but I got through them with support,’

and the need to put in increased effort compared to others:

> ‘I believe it’s kind of proof that you can kind of like live on your own, it just takes a lot more hard work.’

Discussion

Overall, this project was successful in being able to create a safe, shared space for students to be able to talk about and develop understanding of the meaning of autism; this was reflected informally in feedback from students, their families and staff working with them. Throughout the project, the decisions of how and where to present ideas, of who to interview and what questions to ask came very much from the students, with some ideas and support provided by the team involved. This project therefore represents quite a novel approach to autism research, in which the students themselves led the focus and set priorities of what needed to be included. This fits well with recent research by Pellicano 2014, which highlights the needs for greater involvement of the autism community in priority setting and in research more broadly.

The level of student-led flexibility did create some difficulties in terms of ensuring informed consent for parents and the students themselves, which was particularly important as the work was shared on the internet and the students involved in interviews wished to use their own names. To make this as consensual and confidential as possible, the media produced was shared with families and students before wider release, silhouettes were used rather than actual images, and a series of information letters were sent to parents at the various stages of the project, making it clear that participation could be withdrawn and inviting ongoing discussion.

It is possible that the knowledge that discussions would be shared more widely, or that discussions took place in the school environment, may have limited what the students felt able to say. However, this did not appear to be the case as most expressed how helpful it had been to be able to talk together and how they felt the videos captured their thoughts well. The semi-structured, student-led nature of the interviews and discussions also meant that topics came up at times quite unexpectedly, some of which were quite emotionally powerful for the students to think about. It was therefore important that the project involved staff trained to support students emotionally, and that clear boundaries were in place in terms of not having to talk, to be respectful of each other and listen to each other, and to be able to opt out of the project at any point. Individual follow-up meetings were also offered to the students by the school psychologist, although none felt the need for this as a result of the project.

As the primary researchers were very involved within the school and knew the students well, it is unlikely that the analysis is objective, but this was not an aim of the project, and indeed it is hoped that the in-depth knowledge of the students' perspectives may have helped to most accurately understand and portray their experiences. However, the project may have been strengthened in this respect by adding perhaps a standardised pre and post measure (e.g. of self esteem) or structured questionnaire for student and family feedback. The fifth interview did however give the opportunity to reflect with the students who conducted the interviews about their perceptions of the process, and these reflections form a part of the thematic analysis. It was also reassuring that the themes that emerged from this research project resonated strongly with the existing literature base. For example, the students' discussions of difference or normality connected strongly with articles of narrative therapy, and also qualitative analysis from interviews and online sites.

One strand within these analyses was of the developing awareness of autism as a difference to be accepted, of the positive aspects of neurodiversity and a critique of the model of autism as deficit or 'not normal', with acceptance and the neurodiversity model seeming to be linked to older adolescence and adulthood. Again, within this project, it became apparent that as the students learned more and reflected more together, they began also to question a deficit model of autism, to think about the positives and negative for themselves in their diagnosis of autism, of how there is 'no such thing as normal'. It seems possible that this shared experience of talking and reflecting has made it easier for the students to begin this process of self acceptance than may have happened otherwise. Unique in this project was the expression of confusion students felt about how to make sense of the fact that no-one really understands the causes of autism, of what it meant for them that their brain was 'connected differently.' This suggests that those giving diagnosis must be prepared not only to be honest but to also be aware of the impact of giving such information on the young people receiving diagnosis.

The strategies to help with making sense of diagnosis also linked to previous literature, particularly those of acceptance, concealment, wishing it away, and wanting to educate or advocate for others. In particular, the helpfulness in being able to share experiences with others who were autistic came out very strongly as a supportive strategy, and suggests the importance of creating such opportunities for young autistic people. This might be even more important for autistic students in mainstream school settings. New strategies that came out of this project were in the importance of being able to understand what autism was as a way of coping with the challenges and differences it might present, and also the importance of developing self-belief, a concept that fits with a wider educational perspective of developing resilience.

Further, interesting and novel discussions from this project emerged in terms of the significance of segregation in special schools, the value of this in terms of developing skills to manage in the 'outside world', and being able to be accepted, but perhaps longer term feeling more separate and different from others. Again, it would be useful to be able to use a similar model to this for autistic young people in mainstream settings (or perhaps including both school populations) to be able to help develop a wider understanding of similarity and difference. Another key theme was of transition to adulthood which only arose in the interview with a young autistic man who was living independently and working, but in which the themes seemed so important as to need representation. Due to the importance of this theme, a further project was identified and is currently underway to explore this specific issue from the perspectives of young autistic adults.

The project was time- and staff-intensive, requiring specialist skills not easily accessible within most school settings. However, it is hoped that the resources produced within this project, freely available on the school website, may be helpful to those in other schools to facilitate discussions and reflection, and that similar work might be possible with the support perhaps of a school based counsellor or CAMHS worker. The clear importance and value of this work, in helping students to realise that they are not alone with a diagnosis of autism, of creating shared experiences and understanding, and in helping them to develop a positive identity and self acceptance, made the investment indisputably worthwhile.

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