

Rewriting the Narrative – Transcript of Webinar May 2021

Dr Ruth Moyse

So, welcome everybody. Thank you so much for coming along to this presentation. I know you've had the bank holiday weekend, but nevertheless, at the end of a working day, it's still a big commitment to come in and listen to somebody else talk for a couple of hours. So thank you. The presentation today is based on my doctoral research.

A couple of things from me before we carry on.

First of all, just to say right from the start that all of the participants in my research have got names, but the names that you see on the screen are pseudonyms, either chosen by me or by them. As we go through, I may share some of my own personal stories, please, if you are tweeting, please, don't tweet about those.

Thank you. This is a warning for some of the content. I will be referring to some serious issues around the decline of mental health as we go through the session. So please be aware that, that I will be mentioning those things. And as Jill has already said it, if you don't work in education yourself, or perhaps you're here through personal interest or as a parent or carer, as we go through the presentation, can I ask you to think about what it means for you and your own practice in your own environment or what it means for you as a parent or carer?

What can we take from the findings of this research to help you do things maybe a little differently in the future?

So a bit of background about me. I think it's always really important to understand where a researcher comes from and what I bring to my research and to how I interpret and understand the findings as well as how I chose the methods to do it in the first place. So the photograph that you see there is, is me a few years ago, and my daughter, so it's probably taken about 10 years ago, actually.

I always have a photograph of her in every single one of my presentations, because she reminds me why I do what I do because I trained initially as a primary teacher, I taught for about 10 years, became a parent. And we have my daughter who is now 15 and she was diagnosed as autistic about the age of five. She just turned five, actually just started school. I then became a trainer for a Berkshire charity parenting special children, and hello to Ruth Barlow, who I saw pop into the room a few moments ago. She also works in this area. Since doing my doctoral research, I have delivered lectures for different universities.

And fortunately in December, November, December, I pass my Viva and became a doctor. Along the way, I also got a diagnosis of autism. So I am actually autistic as well as my daughter. And that actually came about as a result of her going through the assessment and getting a diagnosis. So I bring all of these different experiences to the way that I work and to how I interpret things. And also how I want to share the findings from this research.

And I, I guess we're all set. What I'd like you to think about is what, what do you bring to your own practice or to your own parenting to, to your child?



So the things that I decided to research were very much based on the fact that my daughter was going to be starting secondary school. I'd had a conversation with a psychologist who'd said that a growing number of autistic girls appeared to be stopping attending school, but nobody seemed to understand why that was happening or what to do about it.

So these are the questions that I came up with and decided I wanted to investigate. As Jill has said, autistic girls, as you may well know, have historically been absent from stories about autism and exclusion. And of course, policy, government policy and resources for schools are very much based on data, so without the data there was, I felt there was a, we needed the data in order to try and effect some sort of change, but there was very little public data on the absence rates of autistic girls and referential research with autistic girls and their experiences of school specifically on absenteeism. Um, so Becca, can I ask you to put the second poll up, please?

So most people are calling it emotionally based school avoider. Very small handful of people have said truant.

Okay, fantastic.

You can see the results there on the screen. So most people, calling it emotionally based school avoider. And then almost a tie for school refuser, Persistent school non-attender.

Jill, could you tell me just a few of the other options that people talked about?

Yeah. So quite a few people Ruth saying it, an individual, some people talking about demand, avoidance, child missing education, Neat, not in education or training, not fitting in, school non-attender, school trauma.

Okay. Thanks very much, Jill.

And the reason that I went to run that poll was really to talk about the fact that what we call somebody matters, the language that we use matters. And the reason for that is it, it, where, what we, the tone we use can, I'm going to start that sentence again. So most of the terms up there on the screen tend to locate the problem of non-attendance within the child. So the child is refusing to go to school, the child is truanting (and we all know what the what sort of values we bring to that word there). I would even say actually for me, and that's me, this is me speaking as an autistic person, even emotionally based school avoidance, to me, locates that problem within the child.

And even though that may not be, I'm sure it's not the intention of the use of that term to do that. But for me, I read that, and I feel that I'm being blamed as an autistic person for being emotional about not wanting to go to school. So it is a very individual thing. But I think also it's really important that we, we do think about the language we're using and think about what that might imply for the child or the person that we're talking about.

Because of course, not only does that tell us where we're located the problem, but also who we think is responsible for creating change.



And talking about language there are some quotes at the top of your screen there, which come from some research that I did a few years ago. And these are quotes from SENCOS or teachers at primary schools.

And basically what they're saying here is that they were telling me that they couldn't actually pick out the autistic girl that they taught or who was in that school because there was nothing obvious, there was nothing visual for them to see. That can be problematic if you are autistic child who internalises difficulties in school, if you're relying for support on somebody spotting that you need it.

I put in the bottom, something to think about why you think the term high functioning might be unhelpful to describe an autistic girl at a mainstream secondary school. And again, if you want to please feel free to put a comment in the chat bar and also think about where functioning labels suggest our value lies.

So I have had a SENCO say to me in the past "Oh we just use functioning labels as shorthand because we all know what that means". I would suggest that actually we don't know what it means. If anything potentially high functioning can imply that you don't actually have any difficulties or you don't actually need any support, um, or that maybe you're not being believed that you are autistic, because if you were properly autistic, then you would need support that we'd be able to see.

It actually also is problematic. When you think of, if we're putting the term high in front of functioning, then also we're presumably going to be talking about the word low, low functioning. And then what does that imply about the children about whom we use that term? So that's problematic. But over and above all of that, it doesn't actually tell us what that child means, what they're like, what they need support with what their strengths are.

So to me, it's not really a very helpful term and can actually be very unhelpful.

Surely, you're all very well aware. That education is a right for all of the children and young people who go to school and I'm not going to spend a lot of time on this particular slide. It will be in the resource pack that you will receive after this presentation.

All I want to say really is that legislation is in place to protect the rights of children and to show that they must be provided with support. The question is, is it happening in reality?

The slide is data from the department for education. And I wanted to look at the numbers of, or the percentages of persistent absentees at secondary school. So on the vertical axis, you've got the percentage and along the horizontal axis, you've got those academic years from 2009, 10 up to 2016 to 17.

The teal colour is actually the total number of females and the purple colour, which is the one in the bar on the right, his total males. And you can see from this, that first of all, the number of persistent absentees has decreased over time, and DFE have actually used the same methodology to provide me with these statistics.

So it is a genuine decrease over time. And there is also very little variation between males and females. However, this is information from the, again, from the department



for education, that's not in the public domain, so it was a freedom of information request. And again, you have the percentages of on the left-hand side and you have the years along the horizontal axis.

What's interesting here is that. There isn't such a decline. The trend actually is pretty much, to stay similar sorts of numbers, similar sorts of percentages. And also there is a significant difference between the percentage of autistic males who are persistent absentees out of all the autistic males that go to secondary school and the percentage of autistic females out of all the autistic females that go to secondary school.

And that was interesting and surprising to me,

This graph here shows the official attendance statistics for the girls in my research. So for the interview stage of my research, I had 10 girls, eight of whom went on to do three interviews in total with me. And those eight girls provided me with their attendance statistics over the last, well from the, from the year they started school.

And you can see that each girl is shown in a different colour. The vertical dotted line shows year 7 which is when they would have transitioned to secondary school for most of them. And then you've got primary school, therefore, the years to the left of that line and the secondary school years to the right of that line.

And this would suggest that problems, with attendance become very pronounced in secondary school and that that's where the problem lies, but of course, Attendance is one of the performance indicators for schools that the government relies upon.

So Becca, can I have the next poll please?

That's fascinating. If you can see that most people think it's something other than a poor transition, the lessons or bullying. So, Jill, can I come to you now? Can you give me a flavour of some of the comments, please?

Certainly we've had brilliant engagement. So thanks for the comments. So a real mix, including change of key staff, anxiety and bullying, all of the above, all of the items that you've listed, exam pressure, not enough support, social anxiety, adolescence, change in staff. So quite a mix of responses.

Thanks very much. And what was interesting is that we will revisit absence and what it means for these particular eight girls as we go through the presentation.

Okay. So one of the things that that was important to me was to try and look at the differences between the data that we receive, that the statistics that we've just looked at that came from the department for education and whether that's told us anything about why these girls were absent.

So we knew that autistic girls, I found out that autistic girls, were more likely as a percentage of that group to be absentees, but we didn't know why, and statistics alone can't give you that information. So it was important to me to actually find out from those people who had experienced it, why it was happening, what it meant to them.



And for those of you, I know there'll be some, a lot of people in the audience who will be very familiar with, with this quote from Donald Williams and piece of artwork from my, from my own daughter, all of the artwork in my presentations is by her in my presentation today. And again, reminding us that actually, autism is not a look, you know, just because you can't see, it doesn't mean it's not there.

Okay. So, so the girls in my study actually reported. Half of them reported wanting to stop attending from their very first day or within the first year, but actually carried on going for eight to nine years before they finally stopped attending. And of course that information is not present in the official statistics.

And there were multiple examples of informal absences. So absences that aren't recorded by schools and that are requested by government statistics. And of course these are very, very difficult to capture aren't they - but not being able to participate in a lesson, being absent from lessons entirely though, of course being recorded is as present in school. and of course, lack of attendance did not always, or initially correlate with obvious under achievement. Um, Rosie actually, who was the quote is, is listed from there. She said that she was probably in 10% of her lessons, even when she was in school, 50% of the time. So statistics official statistics alone don't give us the whole picture about absences or explain what creates them.

So this graph here talks about types of referrals. So one part of my research, I actually went out and looked at some NHS autism assessment data from data from an autism assessment team from one NHS trust in the South of England. And I took all of the referral data. And so in this case, it's looking at the age in which males and females were referred.

And I looked at the database for males and females aged between 5 and 18. And the three main types of referrer were the school, GP or an internal referral. So that might be somebody within an NHS service already. So somebody that, had the child had already been referred to within the system effectively.

And what is interesting from this is that you can see that out of all the children that schools referred about just over 80% of them were males and just under 20% were females. And that was very different from the internal referral ratio and from the ratio referrals by GPs. So just have a think about why that might be and what effect that might have on the support for girls for autistic girls. Because of course they are autistic before they diagnosed as well as afterwards.

The next two graphs. We're looking at the age in which these people were diagnosed in the same trust. So the same group of children and young people, and this first slide looks at males.

So on the left-hand side. You've got the number of diagnosed at that age. And the horizontal axis has got the age of the child when they were diagnosed. Uh, again, those different colours refer to different regions within this same NHS trust. And you can see that there tends to be the follows a pattern here that the black dotted line is the average line.

And you can see that most regions follow more or less, that average line and most males are diagnosed at primary school.



When we look at females, however, it's a very different story. You can see here, massive regional variation, all of those different colours represented different region. And again, very little similarity with the average line, average diagnosis line.

The other interesting thing is that many of those girls are not being diagnosed until they get to secondary school, which has an impact on the preparations and support they're going to be put in place. They're going to miss out on the transitional arrangements to go from primary to secondary school as well, of course, as not having had that supporting primary school.

The third part of data collection. So just to reflect on this. So my first state of retrieval was a very large data set looking at when children were referred and diagnosed. And then I did a case study with eight different NHS records. So basically look through each girl's complete history on the NHS database, obviously with permission from the parents and from the girl herself.

This is a partial set of the data that I recorded. Just to give you an idea of some of the things I looked at when I was. Trying to unpack what was happening with the referral process and why those delays might have happened. And one of the key things for me was that concern was picked up by parents very, very early on.

So they were saying there's something, something different here, something that is not fitting quite well, I'm not quite sure what's happening. And they were all happening, either at preschool or infant school. And yet the time between those first concerns and actually getting a referral was anything in these three cases from three to 10 years, and they were all being diagnosed much later on one or two of them at secondary school.

The other thing that's interesting is that like, in this picture here, all eight of the case studies, all eight of those girls had got previous referrals to other services within the NHS.

So have a think about what might've caused those delays to those referrals was being made. It may be for example, diagnostic overshadowing. So it may be that other conditions may have been more obvious than autism, some cases it was because the clinicians thought that the typical development was typical for the age. Some people thought that it was actually down to pharmacy circumstances, so it might be, um, so in one case, Kayla's sister for example, was described as being very demanding by, by the SENCO. So it could have been that the sister took the focus in that particular family. Or, or indeed with regard to the school and Beth's father who was another girl I did a case study on had, was, notes in the record to say that he had significant alcohol problems. So again, potentially there a family circumstances, which meant that these referrals didn't happen because it was thought that there were other reasons for the concerns. And interestingly, even those with a family history of autism, didn't actually get a faster referral.

So when I looked through the records of these girls, there were records from clinicians, there were records from SENCOS and class teachers and parents. And there were two broad types of descriptions when it came to thinking and talking about the girls, on the left, you can see that some girls were described as very effectuate or energetic, or maybe had struggled to sleep at home.



And on the right side, you can stay, verbal refusal, defiant, lacks, empathy, so much more ... much harsher descriptions perhaps. What's interesting is that actually, in this example, they're both descriptions of the same girl. So a girl that I call Beth, and what that tells us is that actually different people have got different perspectives on the same child.

So it's really, really important when we, when we think about a child or young person that we actually remember to include everybody's perspectives and very, very importantly, that the child should be at a central of that giving her opinion. What was interesting to me was that, for most of the girls in the case studies, her voice was not present until the actual moment of the autism assessment itself.

So there was nothing in the records for many of them to actually, that recorded her voice or her views, or what was important to them leading up to that point.

To give you some other examples, sometimes practitioners at the same school had different opinions. So for example, in the case of Lauren, the school inclusion manager described her as an attention seeker who got angry very quickly. Whilst the play therapist said that she presented herself to be almost hidden.

They're also conflicting views between medical professionals. Of course, again, as we've mentioned, language does have an impact. So if we think about the first type of prescription, which, um, unsurprisingly, most of the girls in the research fell into, they tended to internalize their difficulties, but they also had words used around them such as being submissive and compliant as well as shy and hiding and avoiding.

And these are all words that suggest that we like the girls who are compliant. These girls would describe it as being a pleasure to teach being the ideal pupil, the second type of description. However not quite so, supportive that the words and the language used around these girls were, had a bit more, were a bit more judgmental. So Beth is described as resistant and lacking in empathy. She is a burden on the teacher and on the class. And I just want you to think about and reflect on how you would feel if somebody said those things about you and put it in writing as a judgment effectively, that would go down in your records.

Or if somebody said that about your own child, because this is simply one person's perspective on a child and yet is going to have a massive, a massive impact on her. It's interesting that actually the girls who got the earliest referrals were the girls who fitted the second type of description, the girls who are regarded as a burden and they tended to get the support as well.

And of course, what that means is that most of the autistic girls and most of the autistic girls in this study were the first type, were not getting the support and were not getting the referrals.

So whose perspective matters? It did appear from some of the records that I looked at that professionals felt that, or some of the professionals felt that their perspective was the most valid.

And yet we can see from some of this data that actually it is simply one perspective, and we need to collect those of the family as being as valid as those of a professional.



But most importantly, it's really important that we include the voice of the child. We must ask her about what's important to her.

So for example, the factors that impacted on some of the girls in, in the case studies were the environment, so their sensory environment, the way they, they experienced that. Most of them talked about lack of sleep. And also having high levels of anxiety. And in fact, three of the girls in the case studies, reportedly self-harmed and three had expressed suicidal ideation before they were diagnosed.

So talking a little bit more now about how I did the interviews and I use something called a life chart. So it's not very clear on this particular slide, but you'll see another one shortly. So I had a horizontal line, which goes across the middle of the page. And then I also had a vertical line down the left-hand side, which has just been cut off actually.

And I asked the girls, the girls in my study, to record, just to Mark on this chart, events and experiences that were significant to them. Either because they were positive or because they were negative. And just to try and do it in chronological order from left to right. And the higher above that, that horizontal line, they placed the chart then the more positive, the experience and the lower down the chart below that horizontal line there placed it the more negative experience.

I then asked them during the interviews to talk to me about these events and tell me a little bit more about them and what they meant to them. Tell me what helped with the positive events, what made them work so well and why the negative events didn't work, you know, what could the school have done better? What, what would it could have prevented or, made that experience better for them. And then from all of that data, the girls and I then made some recommendations.

Um, what was interesting to me was that actually I was kind of expecting that the, the line would all be, most of the events would be below that horizontal line, but in actual fact, most of them reflected the same sort of pattern is Robin's life chart that you can see on the screen.

So very much meandering above and below the line. So you can see, even for the girls and these girls were all girls that stopped attending school. Nevertheless, they all had positive experiences as well as negative experiences. And we can learn from those.

So, what I'd like to do now is stop talking from moment and let you listen to the voices of some of the girls, from the study. So they're not going to be, the words are going to be spoken by two of the girls in my advisory groups, I had a group of autistic girls who helped me plan the research and come up, check the questions and come up with things like, thinking about where to do the interviews, how to do them, how to make the girls feel comfortable and so on.

So, the girl on the left is, is my daughter Izzie, and the girl on the right is a girl called Bronwyn. So I'm just going to play those for you now. And they will speak the words of the girls from the research.

"Every time I got a friend, soon afterwards they would just not be my friend. Just start being mean. I don't know who it was hardest to get along with. Everyone. Just



everyone. All of them. When we had to go in groups, because like no-one picked me, and then when I was assigned to a group, no one would listen to me." (Ming)

"It was, you must talk, you must communicate with the world and these horrible teachers. They made me write a Mother's Day card. Yeah. I just remember crying. Thinking back, it's just like, yeah, I'm sure my mum would love a Mother's Day card that was made from me crying with sadness. Such logic." (Robyn)

"My TA turned out to have no experience with children, didn't know anything about autism. She stuck her fingers in my mouth when I yawned. She lied about me. She used to try to twist my words to make it look like I was lying about my pain. Because she couldn't see my pain, so she didn't believe it." (Rosie)

"I was eating my lunch in the toilet and then I stopped eating lunch, and Miss Smith was like, 'you know what? Just come and eat up here, you need to eat'. And then, the Safeguarding Lead person, she said it was damaging my social skills and I had to eat lunch outside with everyone else. Which, consequently, when she made me do that, I got my lunch thrown in the bin. The school told me that I was misperceiving the bullying because I was autistic, I wasn't understanding it. They were like, 'Oh you just need to be more resilient'. I can't be resilient. When I'm getting physically attacked." (Daisy)

"I tried to mask my difficulties for 4 years and broke in the process. My behaviour at school was perfect. I followed all the rules so I didn't stick out and I pretended to have friends by loitering near people. I was shut down and quiet. In contrast, at home I would either be happy and chatty, or recovering from school and a crying mess. In the space between year 7 and year 10 I had a mental breakdown and developed anorexia." (Erin)

"It's relieving to not be at school, but it's also created, it's created different stresses and worries. I feel let down that, you know, I've put so much into my education and yet...everywhere is either, is either gives you the support you need, but won't actually provide the thing, like all of the lessons you need, or they provide the lessons you need, but there's no support in place, and so neither of them are applicable for me." (Alex)

Sorry, there we go. Okay. So that, that gave you a bit of a flavour for some of the things that the girls were saying. So one of the exercises that I did was to ask the girls, there were 10 girls in this part of the study, to talk about what their ideal school would be like and what their non-ideal school would be like.

And this is to do with creating a personal construct of their school, their ideal school. And it was developed from an idea by a Williams and Hank who have a, an ideal school would exercise. So the educational psychologists in the room will, will be aware of that. So this has been adjusted slightly.

So I asked them, about nine different things, including the three that you see on the screen now and asked them about their non-ideal school, what they would be like in that school. And also about their ideal school, what they'd be like in that particular setting. And then I asked them to rank their responses.



So before we go any further, so looking at the non-ideal school, where did the girls in my study say the biggest problem would be in the sort of school they did not want to attend?

So Becca, can I have the next poll please?

So this is the school they did not want to attend.

okay. So we're gonna end with end of the polling there. So, so most people are saying the people, essentially environment, environment, also very, important there actually it was the people. Yes. Most of the girls said the people would be the biggest problem.

So, what did they say in their ideal school was the most important to get right?

And Becca can I have the next poll, please.

So more people this time said the people made the difference and that's absolutely what the girls in my research said as well. Um, but if, if you had the right people, if the people were the adults and the, the professional, the teachers and the teaching staff working in the school, work caring and supportive, then they would make sure that the work and the sensory environment were right, or adjustments would be made for them if the people had the right attitude and the right ethos.

So it gives me hope to know that actually it's not some expensive piece of equipment we need to get in different schools. It's just, we need to think about how we work as professionals when we're working with these young people. And probably most teachers and most school staff and most education professionals and indeed NHS staff feel they're doing the right thing and feel they are providing support.

But what the girls in my study showed, was that actually they may have thought that, but actually the support they were receiving was not what they needed. So it's about making sure those relationships are in place, that we can actually hear their voices and hear what they have to say and what's important to them as individuals.

So at the sort of school they said they did not want to attend people were the factor, the biggest factor. And again, they were the biggest factor at their ideal school.

And in terms of the ethos of the school, the sort of school they did not want to attend was one that focused on grades and results and their reputation.

They wanted to go to a school where the focus was on students, where it was kind and happy because all of the girls that were in the interview section of the research, all identified as academically able. So they were all students who are aspirational, who had talked about going on to further study, wanting to do well in their exams. However, for them being happy and being in a school that cared about them was far more important in order to facilitate the learning and the grades to come after that. And these are the sorts of things they said they would like to be. In their ideal school, they weren't actually rejecting learning. In actual fact, they were rejecting the environment and an ethos that were damaging to them.

And here's another example. This is for Daisy. You can see that on the left-hand side is a bit clearer there of the positive experiences above that horizontal line and the negative below and Daisy's life chart actually went on for five pages. So she was, she



was very thorough. What the girls did after they'd completed, it was send it back to me. And I would then basically build questions around them about round, what they wanted to talk about.

So her pet peeve was being treated like she was stupid. So she was forever being told a primary school to not worry about learning, just, just colour things in. She learned, played a few, the flute., well from year four she discovered music and that became a really intense interest for her and a really positive thing for her. But secondary school experiences were particularly negative. So she had to eat her lunch in the toilet. She had her head put through a wall. Um, she was told she couldn't do GCSE music because autistic people don't like noise. She self-harmed, and she made seven suicide attempts before she stopped attending school completely.

All of which is incredibly distressing for her to have experienced and for her family to have experienced what I will say is that this particular girl, um, I happened to be aware that she has gone on to university. So she is now at university and she's doing very well, which I'm really pleased to be able to share with you.

So what was, really upsetting. And obviously I will say that there are only eight girls in my interviews and there were only eight case study girls. So, you know, we can't generalize from these results by any means, but it is worth noting that three of the eight girls in the case studies, which were names picked out by the NHS staff for me, three of them had self-harmed and had suicidal ideation and in these eight girls, again, only a very small sample and we can't generalize, but these are the sorts of mental illnesses that were reported to me by the girls. And Daisy says, literally saving school had saved her life.

So we can't make the connection that school was what caused the mental health decline, but it is something that is really important that we consider.

Okay. At this point, please take a breather. I'm going to have another glass of water and try to stop shuffling my papers around and we will see you at half past four Thank you.

So welcome back everybody. So this next half of my presentation is going to really look at some of the things that were identified by the girls and some of the recommendations that they made as a result of their own experiences. So you won't be surprised to learn. I'm sure that most of them described overwhelming environments, group tasks that were particularly difficult and also a lack of individualized support.

Sometimes support was based on stereotypical understandings of what all autistic people should appreciate and find useful. And that's not actually, it wasn't actually the case for these girls. The girls in the study reported that they didn't feel believed or didn't feel that the staff were, were listening to them or were seemingly unresponsive to what they needed, or sometimes prevented them from accessing the adjustments that they had made.

So, Daisy, for example, who's life chart you saw before the break. She had taken to having her lunch in a classroom with her English teacher only to be told by the head of inclusion that she needed to go out onto the playground, which she had withdrawn from because she was being bullied and having her lunch thrown away.



She was told to go out on the playground because it was damaging her social skills to be inside in the classroom. So presumably that the inclusion manager had the girl's best interests at heart. However, because she hadn't actually tried to unpack why the girl was staying in the classroom. She didn't actually understand that the, the adjustment that needed to be made, which was not around going out.

It was around trying to stop her being bullied and to stop her lunch being thrown away and so on. Whereas the other teacher who had said you can't take your lunch in the toilet had shown, had unpacked and found out what was going on. So there are two different ways of two different attitudes or approaches on display there. and I should say again that I'm really conscious that the teachers don't go into teaching unless they want to do the best for the children.

So it may well be that these teachers felt they were doing the right thing and felt they were listening, but I'm reporting how these girls experienced it. Eight of them talked about multiple cases of bullying and abuse. Um, one of them reported about a TA putting her finger inside the girl's mouth every time she yawned, for example, to stop her from doing that. And they felt very unsafe, very frightened, very anxious. So they certainly were not in a place where they could be learning, and prioritizing well-being was the most important for them. They wanted to feel safe. They wanted to feel cared about, even though most of them internalize those difficulties and tried not to draw attention to themselves, nevertheless, they did want it to be seen. they want it to be recognized and listened to and not even looked.

So these were the, the three different areas that I looked at, um, based on their, on their findings, based on what they told me. So assumptions that schools were making versus the actual understanding that needed to be happening.

So the example I've given you already of Daisy about not being able to take music as a GCSE, because autistic people don't like music. Don't like it noise. And being told to go on the playground when she was avoiding the playground so she wouldn't get bullied. If, if questions had been asked of her and those things have been unpicked, then a better solution could have been found.

Schools didn't always take action to support or for example, to prevent or stop bullying, or they took action that removed the girl from the classroom, but without solving the problem as we're seeing the moment. So, so some schools and some teachers encourage the girls to be absent from the classroom, but then didn't resolve the reason why they needed to leave.

One of the things that came up from the case studies, the NHS case studies, was the use of standard assessment forms such as the SDQ or their strengths and difficulties questionnaire were often unhelpful because they lacked context. So to give you an example about that, one of the questions is, other people, my age, generally like me and one of the girls, Lisa responded to that item by ticking every box, meaning that that statement wasn't scored and said, I don't know, I'm not a mind reader, which is actually a very reasonable response.

How could she know whether other people, her age like?

They also queried the meaning of statements and struggled with a lack of context, with the self-awareness that their response would vary depending on the situation



and their skills. So, Alex, for example, who identified as a gender fluid gave particularly detailed explanations of their thought process for each statement and for the term, I'm helpful if someone is hurt, upset, or feeling ill, for example, they said, "I feel very empathetic for people. And like, if somebody is upset, I'll feel really bad for them. But at the same time, I have zero clue what to do about it. So I'll try, but I'm probably not that helpful." So they're saying that they are very empathetic, so that for them, it's about understanding what to do, not how to feel, because they said to me, we're feeling.

And the SDQ and other forms like that demonstrated the mutual understandings that can occur through that sort of imprecise language. And so we need, I think when we're gathering information, we need it. We need ways of collecting information that is more precise and provides context. So these girls can give an accurate and authentic, description of, of their experience.

Or as Alex said, "if they just spoke to me and asked me what things I think I'm dealing with, that would be better."

All of the girls that I spoke with needed help and found it very difficult to ask for help, partly because they weren't necessarily sure what the procedural process was. They didn't want to draw attention to themselves, but also, they felt that they should be able to manage, so a question to you would be, why did they get that feeling? Why did they feel they should be able to manage? And I would come back here to the functioning labels on the language that we use about somebody you're a bright girl, you should be able to manage. So then if they asked the question, they felt like a burden. They felt that other children and young people were more deserving of help.

So then they sometimes didn't ask for help. They mask their difficulties, and this became a circle that they never got out of. So they stopped at actually asking for help. And interestingly, there's some research recently has been done on autistic people and mental health. And one of the, one of the things that's most relevant is that feeling of being a burden and of not belonging that can lead some autistic people to feel suicidal, to feel that they shouldn't be here. So it's really important that, that we change that in schools and the children don't feel those things.

Another interesting thing that came out of the research was that when absence was used by school staff, that was okay. But as soon as absence was used as a strategy by the girls' schools objected. So for example, a very common, strategy is to give an autistic girl or boy, an exit path so they can leave a lesson if they're feeling overwhelmed.

That's an example of an absence. It only gives short-term relief. It doesn't actually resolve the difficulty. It doesn't resolve why that child needed to leave the class in the first place. Uh, and didn't help them to retain the class. What it did do is it encourages the girls to fail that they didn't belong, that the problem would not be solved in class. And it was up to her to solve them and then returned. She can come back when she's able to take part in the class.

But when the girl reused that same strategy of absence by avoiding certain spaces or, going to a timer, I know it's a timeout space, a space where they can use their timeout



card or when they chose not to go into school one day, because they were finding, going to school very difficult.

Then that was a problem for the school. So it's interesting to see the different ways in which absence was used, depending on how it was interpreted, depending on who was using it.

The way that schools are performance indicators for schools are used by this current government, are around attendance and grades, meeting certain standards of those aspects.

But the girls in the study suggested that these are the wrong flags, the wrong warning flags for them, because most of them are meeting their academic targets. Most of them had internal absences that were unrecorded, and some of them were described as the ideal pupil. And yet all of the girls and the interviews that I did, all of them stopped attending school.

And many of them had a mental health decline during their time at school. So perhaps we're looking for the wrong warning signs, the wrong red flags and in order to get a better picture, we need to include more voices. We need to centre to the voice of the child, and we need to include everybody's perspectives.

Before we talked a little bit about, the importance of wellbeing before grades and of developing strong relationships. And that's sometimes problematic in schools because, quite often the young person needs to choose their trusted adult. It clearly isn't always going to be the inclusion manager. It may be the English teacher. It may be the TA. It may be a dinner lady. The key thing for that young person though, is, to build relationships with adults who will make them feel safe and cared for and as though they belong.

And the girls also talked about that contrast between action and inaction. The girls wanted school to be proactive, to put support place before them stopping attending school showed that they needed it before their mental health declined. And as Alex says, "the point at which someone is having issues is too late, you need to fix it beforehand."

Jane wanted people to care, and Ming said, "you know, it's all very well saying, yes, we'll stop the bullying. Um, yes, we're an inclusive school. But if you don't actually do something to, to change something, to change the bullying, to stop the bullying, then nothing's going to, nothing's going to change." So Ming wanted teachers to do what they said they were going to do.

Now I'm going to show you a clip from, a short animation that I put together with the Donaldson trust and also, funded by the same people who funded my PhD research. The John and Lorna Wing Foundation, and this is just a small clip. But we will again put the, the clip in the resource pack so you can watch the whole animation, which is about 10 minutes long on YouTube.

It's based on, uh, the narrative of an autistic girl who stopped attending her secondary school. And you can hear me interviewing her as we, as we go through the animation.



For Erin, the girl whose voice you just heard from the animation. One of the things that was difficult for her was knowing that every day was going to be the same, that things were not going to change.

So this slide here refers to different people's responses to the absence. So school wanted to be in control, teachers wanting to be in control of the autistic girl. wanted the girl to conform to what was happening in school to the rules and regulations of the school. So it was very difficult for them to exercise any sort of flexibility or appreciate or accept any individuality.

So for example, if there's a very strict uniform policy, it's going to be very difficult then for that school or those teachers within the school, the individual teacher to say, "it's okay, you can, you can take your blazer off. I understand you; you have a sensory processing difference that interferes with the way that you might be able to learn So take your blazer off." If you're working in a school that reinforces conformity any difference, it's going to be very hard to meet. Of course, from the girl's perspective, they were trying to find their own solutions by going to the library at lunch time, or by eating their lunch in the toilet, for example.

But whenever they came, to quite often, when they, when I thought of a strategy like that, they were told that they couldn't do that. So they were back being forced into the conformity. Everybody has to do the same and. I don't think it's so much as resilience, but more perseverance that these girls were expressing by continuing to go to school for so long, they were persevering because they did actually value education and they did want to be in school, but they didn't want what they were experiencing either.

So the teachers believed the girls needed to conform and try to reduce their agency. Whereas the girls believed because they weren't getting any support from teachers that they needed to look after themselves and would therefore trying to increase their agency.

So some of the factors that were influencing their attendance or on this slide here, so they were the target of bullying. The environment was overwhelming. So maybe it's too bright or too noisy, or there were too many people. So there were being, um, corridors, for example, frequently came up in conversation.

So they became more vigilant about their time in school and watching out for different, things that might harm them, which created large amounts of exhaustion in them and reduce their capacity to cope, which made them more vulnerable. And, and so it went on and of course over time, this resulted in a deterioration in their mental health. It made them very tired. as you heard from Erin's piece, then also reduce their belief in their own power to change them.

So to conclude

One of the key things that I want you to take away is that the autistic girls' voices were absent. From the reports and their decisions about them, and that needs to change because their voices are what we need to hear first. We need to hear how they're experiencing things. we need to hear what they're learning from those positive experiences. What can we, what can we learn from that?



We need to understand why negative events were negative. What can we do differently?

And we can only truly understand that if we actually ask them, rather than making assumptions about, what would work. TAs is a good example. So some girls wanted a TA to help them and interpret instructions for them. Other girls did not want a TA with them at all. They felt that would be completely the wrong thing for them. And yet that's, a form of support that may be thought to be true for and needed for everybody. So these girls will not be rejecting learning, but an environment. And an ethos that we're damaging their mental health, the attainment and abstinence statistics do not necessarily identify autistic girls who need support.

So again, we need to be looking for alternative flags of concern. If they're saying, or their parents are saying that they're really struggling with the sensory environment, if they're struggling to sleep, if they're feeling very anxious, these are all issues that the girls in my study raise as problems, which had they been noted and acted upon earlier on would have brought support, which would have helped at a much earlier age.

And finally, of course, if you don't meet their needs, don't be surprised when they stopped coming.

Five recommendations

Daises was simply "just listen. It's not rocket science. Just listen."

Highlighting that the priority of the, of the voice of their voices that are clearly they felt were not being listened to or not being acted upon.

Robin asked you to be "more curious". So find out why they're behaving in a way they are, find out why they are in a classroom instead of on the playground.

Erin wanted you to remember to "prioritise their wellbeing" because unless they felt safe or cared for or nurtured, or like they belonged, like they belonged in school, then they wouldn't be able to learn. And that would have a knock-on effect on their mental health.

Jane, would you to "take action". So if they say that something they need something or that something is, so for example, if they say that they're being bullied, then act upon it. Don't ignore it.

and Alex said be "more informed about being autistic."

And that's about recognizing that, that actually what we know about autism has changed a lot over the last few years. And it's really important that when you learn about autism and what, what it means to be autistic and what it means for living, the world we live in as an autistic person, it's really important to speak to autistic people.

There are many trainers, some of whom are in the room with you tonight, who are autistic and, r trainers and, by incorporating or including autistic trainers in your development plans for staff training. Then you're going to learn far more.



So, I'll give you an example from my own work, I was invited to go into a primary school, and I was taken into a room, which they used for small group work with, autistic children and other children who required support in different areas. And as soon as I walked in, I put my hands over my ears because it was so noisy. They had all these little, other little groups going on with multiple TAs with multiple groups of two or three or one child.

And I just said, "it's so noisy. How can anybody concentrate in here?" And if this is something that SENCO, who is a brilliant SENCO and really cared about her children, had not even considered. And again, incorporating this being more informed about being autistic. Listen to the children. You know, if they're in your class, if they're in your school, if they are, within your, one of your patients, then ask them that should be the starting points.

So thanks. Go to all the participants in the life history interviews, and those who gave permission, for their NHS records access as well as my advisory group of girls. And we're going to end with a short survey before we come to the question-and-answer section of this session. Thank you.

Becca would like to share that survey, please?

I, yes, the link is being just placed in the chat and I will just, carry on putting it as people put messages in so that it is at the bottom.

My email address will be in the resource pack. So if I have gone through my, methodology at a bit too quick, a pace, and you want to know more about that then, and that is Nettie's comment. Then please do feel free to contact me and I'll be very happy to talk you through it.

Yeah, shall I give people a little moment to complete that form? I'll share some reflections, first of all, Ruth, and then I'll come to questions. Um, so thanks to everyone. We've had quite a lively, chat function, and, and a lot of comments, a lot of questions, a lot of agreement and support for your findings.

I'm just going to share some of the reflections that have come out. So quite strong agreement that the voice of the child, but also the parents, is often missing and that this often results in children missing out on support because they appear fine at school. Reflected that the engagement, uh, awareness and education of peoples is really important, as part of inclusion, another reflection that, some people would really benefit from more support with the social elements in school and the social demands of the next seed people's capacity to cope. And the previous coping strategies don't always work as people reach secondary school.

A lot of agreement and consensus that it's really important to ask people, uh, girls, what would be helpful for them? There was quiet, quite a discussion around, different school environments. Uh, so especially around specialist schools around, mainstream schools and home-schooling.

And linked to that Ruth, one question, which is was there any learning during lockdown? And I think your study finished before a lot of time, but I don't know if you have any, experience of, of how people manage with education during that time. And if generally, if people found it easier or more difficult.



Okay. Thank you, Jill.

Okay. So with regard to lockdown, I would say that my experience as a parent and also from working with parenting special children, is that some children actually found it really, really great. I'm not a child. I fell into that category. It was lovely to be able to work from home and not have to spend a lot of time interacting with lots of different people.

Some children actually really enjoyed that working from home. And have found it very difficult to transition back into the classroom. Other children didn't like it and again, it's one of those, I think it's very difficult. Some children and some of the girls in my study, didn't go back into a physical school.

They went into online learning and that suited them really, really well. They could sign up for subjects that they really enjoyed and that were real intense interests for them. And they were, they had much more control. They could be in their own environments at home. They could manage that really well. They could eat what they wanted, wear, what they want to drink, etc.

But there were also some girls that I know who, who actually missed that socializing that they got from being in school. So it's mixed.

Yeah. I was just going to come back to actually, if I can, I want to cut on those things that you've mentioned before.

So, um, with the voice of the parents, I, I think one of the things that if you are. Here as a professional today. I would, I would encourage you to do certainly in education. Is it makes sense for you to be the ones to invite the parents into school and to, it's really, the onus is on you to be collaborative because I think very, it's very easy to sort of say yes, come in for a parent's evening and they will tell you how your child is doing? Have you got anything to say to us, but that doesn't really encourage a great deal of collaboration? And I think the more that you encourage parents and carers into the school to collaborate with you, the better results are going to be for the child.

Um, in terms of the mainstream or special school, one of the things that came out quite strongly from the girls in my study was that I should, there was nowhere for them to be. That academically they should have been in a mainstream school. But actually that was it wasn't nurturing enough. And the schools that did provide that nurture didn't provide the academic learning that they needed, that they wanted.

So for them, they were saying, we need a school that suits our needs and there isn't one. And then the other thing went to pick up on it was the social elements. Um, but I think that's going to come out in one of the questions, so thanks.

Right. So we've, had some questions around, whether your research, has been published and also about a copy of the slides and recording of the presentation.

So just to confirm that the slides, the presentation and a booklet will be shared with, with everyone who's come and will be available online for other people as well. Ruth, did you want to reflect on whether your research is available?

Um, so my thesis is available. If those of you that, there are quite a lot of pictures in it as you'd probably expect to have to say my presentation. So it is available through the



University of Reading library. It's not published as yet. But I am hoping to publish, some of the findings. yeah. But yes, you can, if you want to, if you want to read the thesis, you can do so.

Okay, another question, do we know why boys get referred and assessed earlier? And there was quiet, there's quite a lot of theories shared in the chart, but to hear your reflections, Ruth?

Um, I think, I think partly some of it is historical in that, you know, there is still that mindset that girls don't get autism, not that you get it anyway. So, so I think people look out more for it in boys. Maybe that's they think of autism before they think of autism when it's girls. And I think also the way that, and of course autism is autism, whether you're a boy or a girl, I think the way that, a child behaves in class and how much of an impact they have on the classroom and on the teacher. And this is something I've picked up on in my master's research when I was looking at primary school children.

If you're not having an impact on the class because you're internalizing or distress, then you are less likely, and this is also seen through in this research, you're less likely to get that support. You're going to have to do, parents are gonna have to fight for it more and you're more likely potentially to, to actually stop attending as a result. So you're not going to be the child who's being excluded for throwing bricks around the classroom. For example, if you internalise it, so you're not having an impact on the teacher, therefore again, less likely to get referred other children have got more needs. And you know, and I have had teachers say that to me, you know, it's hierarchy of needs. Um, we've got children with more needs. The more visible you are perhaps the more chance you've got of getting an earlier referral.

Okay. You've touched on this, but I will, I will ask it as it was a question. How much of your learning and recommendations also can be applied to boys?

I would say most of it, if not all of it, actually it's, it's actually not agenda thing. The reason I studied girls, females is because there is certainly, they used to be a dearth of research into females.

Precisely because people thought that only boys could be autistic. So part of the way of redressing the balance is by doing research specifically with females. But certainly, you know, I, I personally know autistic boys the same age as my daughter who are also internalisers, and they've all flown under the radar and these, these findings are equally useful.

And in fact, the recommendations are the same, whether you externalize or internalize your distress, you know, the voice of the child asking and unpicking and being curious. These are all things we can apply for all children.

And do you have any data on the number of girls in your study who had an EHCP, an Education Health and Care plan? And do you think they are important in ensuring that the right support education is provided for autistic girls?

It's a really interesting question. Isn't it? Some of the girls in my study did have an EHCP, not all of them. I would answer it from a personal perspective if that's all right. So my daughter, actually, during the time of me studying this, my daughter stopped



attending school and my daughter is also academically able and she doesn't have an EHCP. And on multiple occasions I feel retrospectively I wish that I had applied for one, because she experienced lots of other issues as a result of not getting the right supporting school in a secondary school. However, I also know friends whose daughter has got an EHCP who also struggled to get the right support.

So I think from thinking about my own friendship with parents or my work with the charity, I think it's about the, one of the things that EHCP does that's really valuable. It gives you more choice of selecting which secondary school your child goes to. And possibly that's one of the things for me that would have been most useful because you can know what the support is, but if you don't put it in place, then even if it's written on the EHCP then. I don't know if that's answered the question.

Thank you. Yeah, I think it's, a really interesting reflection. So a question on, you mentioned, research about autism and mental health, and particularly around, people not wanting to be a burden or ask for help. We've had a request for a link for that. So perhaps we can share that with the resources.

Yeah. It's Sarah Cassidy is the name of the researcher, but I will, you tell it yes, unless I'm Sarah Parsons would like to pop it in, in the, in the chat for me or Hannah if you happen to have it to hand.

Some more questions coming up in the chat. Let me see. There's a lot of people with them.

Someone Posted something about not being believed, parents not being believed when their daughter has a meltdown at home. And I think that's really important then when we come back to your perspectives, quite often, if your child internalises distress at home at school, often as soon as they set foot outside the school gates, that was certainly the case with my daughter. Literally they could step over the threshold from school playground onto the pavement and they would have meltdown. As a teacher when you don't see that happening in school then it can be very difficult to appreciate that that's actually not a, is not a response to school, and instead of think it's a response to the parent and, and that's very problematic because, a number of levels, obviously it means that you're placing, you're ignoring all the reasons that's caused the distress. And it means those things are likely to happen again, like we saw in the video with Erin.

And it also means actually the parents are going to struggle to be heard and, and that they are going to be blamed. I know multiple parents who have been referred to other services as a result of their child having a meltdown is they release that stress because they can't hold it in anymore. To social services, for example. Yes, it is the Coke bottle effect. Exactly. So yes, yes. Yeah. Everybody everybody's told to go on a parenting course. And the, the joke in parenting special children is when one of our practitioners in the autism team are told to go and a parenting course, and we have to turn around and say, we run them.

So but it is unfortunate, but that's why we need to have the shared perspectives. And that's why we need to work collaboratively because everybody's trying to do their best. And as a teacher, you know, I know myself at primary school, you've got 30 kids, it might be easier. At secondary school. You might teach 200 kids in a week, but it



doesn't take very long to show a child that you care. It doesn't take very long. It takes far longer if you don't give them a little bit of time and it takes far more resource.

Ruth another question, just diagnosis, help these girls in terms of their own wellbeing and or understanding themselves.

Um, I think that's a really good question. And I, I would say that I think it depends very much on the age of the girl. If those girls who are diagnosed as teenagers, it can be really, really tricky because that's the time when teenagers are trying to find out who they are, that they're jostling for position in secondary school, and they're trying to work out their own identities and they're forming groups.

So it can be very difficult depending on how that diagnosis is presented and the language, again, clinicians use that goes around that about, and how that is they're managing school. Can be very alienating. You know, I do know some autistic girls who just don't want to accept it because they don't want to be different. They want to be part of the group. They want to be able to fit in and it can take a very long time to accept that actually, you know? So that whole thing about, please invite me to the party. Please invite me to the party and you get the invitation and then you spend the next week trying to work out how you can get out of going to the party because you know you to be, you want to be wanted and you want to be invited, but you don't want to go.

Uh, it's that contrast that it can be very tricky, particularly in teenage years, I think. But yes. Yeah, I think certainly for a late diagnosis, women such as myself. I find it incredibly liberating and, and helpful and, yeah, brilliant. But it's timing it's and it's the support that goes with it. And of course it's secondary school and it's around managing identity and acceptance of difference. And if you're in a school that doesn't accept difference, it's going to be very difficult.

Thanks Ruth. Another question. What are the next steps? If you believe a child, a child outside of an educational setting is autistic.

What are the next steps?

If you believe a child outside of an educational setting is autistic.

Not quite sure. I understand the question,

I guess. Yeah. I'm not entirely sure I do either, but it, I, how I'm interpreting it is if, if you're perhaps if you're working with a child perhaps in education or in a community setting, and if the child is autistic.

What would your next steps be to make sure they have the right support?

I think it's a difficult one because I would, maybe I would probably start again. It depends on the age of the child. I would probably start by talking with the parents. I, because, because again, some parents don't want their child to know that they're autistic personally I think that's wrong. I think a child deserves to know who they are and what their identity is, but there are, there are ways of dealing with that. Are there other ways of managing that and don't always need to use the word autism, you know, ultimately what we want for these young people is for them to be supported



and to feel safe and to feel loved and to feel cared for and to feel able to live their best life, to be able to thrive.

And we can talk about, preferences around interaction and the fact that, you know, for example, if I use myself as an example, you know, I'd love to see a friend for coffee, uh, in my garden, never in Costa. So, I don't need to tell her I'm autistic to give her that information or for that preference to be known. It's simply a preference. Yeah, it is because I'm autistic. Um, because I don't want to be, I can't, I can't filter noise out, so it's very difficult to concentrate if, if more than one person's talking. So, I can't talk in group situations very easily. But there are ways of thinking about information and challenges and support without necessarily using the word autism.

If you're being home educated, then I probably, then if the parents are in agreement, then go to the GP. I think you can start referring some places now. I'm not sure somebody will be able to say in the chat.

Great. So, I'm compiling a few questions that have come up parents one and, and the essence of it is how do we support schools to work in a more inclusive way?

I think we start by asking autistic people to come in and do an audit. So, in terms of the environment, as I mentioned about, you know, this teacher, the SENCO who thought she had an amazing room for, um, I won't use the word, I will use the word intervention. Don't use that word. For the support. She said, you know, and it was a, it was a lovely room, but it was very noisy. So, in order to even, even a school that thinks they're doing really well and lots of ways they were doing really well, there are small things that somebody who's not autistic simply won't pick up on. So, so there are those sorts of things you can do.

But I think genuinely it is about finding ways, particularly in schools that are under pressure, secondary schools, particularly to get grades, to get, you know, people wearing the right uniform and so on. How can you find ways to build those relationships with your pupils?

Because it's your attitudes that are going to make the difference to whether a child will come into school for your lesson or not. If you show an interest in them, if you listen to them and show that you've listened to them, by acting on what they've told you, if you share your care, then these are the things that make the difference.

Find out what's important to them, you know, It's very straight forward. With autistic people we tend to have particular interests and it just knowing one interest and be able to say, you know, for example, it might be using myself as an example, Line of Duty was an interest. So, you could just say at the beginning "how's Line of Duty last night?" you know, it doesn't take very long or when you see them in the corridor, it's about showing them that you've seen them and that you care.

Yep. So that would be really looking at your, your ethos and your attitudes and think, okay, these are the things that we expect of our pupils, but are we doing that ourselves? Or are we modelling that acceptance ourselves? How do we get around the, we want everybody to conform and wear the same and do the same because you know, nobody who is autistic is going to fit into that model. So we need to change that.



Thank you. I wanted to stand and applaud when you were talking about that Ruth. You're creating quite a manifesto here, Ruth. Thanks for everyone who's, commenting and putting, sharing links in the chat. That's, that's really good to say. I'm conscious that I'm likely to be missing some of the questions here, but, but just to reassure people that we, we will go through the chat and anything that we've missed.

So another question, how can we support anyone with gender identity confusion Ruth? Do you have any experience on, on this?

Okay. So, I think that's one of the questions that came up as a pre-question and I've got a few points. One of the young people in my research, Alex identified as gender fluid. Their parents. And they responded to my open invite to people to participate. My research was stated it would be about girls and Alex was born a girl. And therefore, I felt very happy to include them in the research. The national autistic society do say that there's some evidence that autistic people may be more likely to have gender dysphoria, but little is known about why, but transitioning itself is not an area of my expertise at all. So, I'm not going to say anything about that. What I will say in terms of gender as a social construct though, is to say that I think autistic girls may feel less obligation to dress and act in a, in a way that's traditionally female. As such, you know, stereotypically, female, they may not feel they have to, they may rebel against that and they may feel it's not important to them.

Um, just because society says they should. And also, I think autistic people tend to prefer clear explicit, functional conversation. Whereas a lot of girls and women tend to use a lot of fluffiness. A lot of kind of nurturing relationships through words that are irrelevant to me. Like, you know, where did you get your hair done? Your hair is lovely. What did you have for dinner?

And I'm not really interested. My preferred style of communication. I can do it. I can do some of some fluffiness, but my preference is for functional language. And. Therefore some autistic females may prefer the company of males because quite often that their language is more functional and less fluffy. That's just my thoughts.

And there was a question on transitions that I thought would be interesting to pick on. Because I know that, and again, there are, there are some papers that we can, we can put in the chat. Um, Sarah Parsons and Hannah being one of them whom I'm naming them because I saw them coming to the room and you're on. And I know they've happened to have written on transitions. So maybe they can very kindly put their own paper in the chat bar. I think one of the things with transitions is from my own perspective is, is that they tend to be quite brief. So, one or maybe three visits to a secondary school, which is, it seems to be about introducing the children to the environment.

And then the transition, once they've moved to secondary school can be very short. So, it might only be a week when they get somebody to help them find their way around the school, for example, and then there'll be no more transition. And as most of you will know autistic children and young people don't like uncertainty or unpredictability, or the unknown or not knowing when something's going to happen.

So, increasing familiarity is important, certainly. but you do need to find out what's important to the individuals. So not every autistic child is going to want to do three



special visits to the school because they don't want to be marked out as 'special'. For example, in their own words. Relationships are really important in transitions, but again, harder necessarily to get going before the child's moved because, you know, you need to be in the same environment. when you start building relationships and also because the young people tend to prefer to pick their own trusted adults. But I think the other thing I would add is that I think the period of transition at secondary school itself needs to be longer.

So, for some children, they might need a few months of transition, a few months of somebody checking in, you know, are you happy with the way you're organizing your lessons? You know, we, we, we send our children off to secondary school and expect them to be independent or schools expect them to be independent the very time they need the most support and on one week isn't going to cut it. So, I think if you're, if you're work in school, then, then be alert to that and think about how can I support this young person to transition to being independent in this new school setting and look at communication, look at interaction, look at organization and all these different aspects, uh, but over a longer period of time, Thanks, Sarah.

Excellent. Yeah, some, some, a flurry of links have been shared in the chat as well, which is great to see. Thank you for that. So a question from earlier, Ruth, someone requesting, a form or a template that might help people to be heard and help teams to understand and support, autistic girls.

Okay. So there are two things I would do here. One is the simple life chart that you saw in the presentation. So you literally have that vertical line and the horizontal line and just ask, you can, you know, if you want to look out over a period of time, that's a really simple timeline, task. That conversation can then develop from. So by giving the power back to the child, then you're allowing them to talk to decide what they want to talk about and, and them to decide what's important to them without having to be too focused on actually, when it happened in it, we, we're not interested, was it the 1st of October, it's roughly when it happened. What's the kind of chronology of that? And the other thing is, is to think about then think about, you know, asking them to unpack those events in a bit more detail. So, you know, what was great about that trip when you all went away, what did the school do that really helped make you feel that that worked for you and looking at the things they regard as negative?

Well, what went wrong there? What, what do think might have helped? So that, you know, actually. I think the most important thing is that you've given them a task to do, or it might be something as simple as a quadrant, you know, where you've got an activity that, helped or, you know, you mark on that, what helped and what didn't help, what it was positive and what wasn't positive?

But the key thing is, is to keep it really simple. So it's a very basic framework and you give the power to the young person to decide what's important and what they want to talk about.

\Some really helpful suggestions that offer time and place but still very much focused around the person, which is really helpful. So we had a question on around the gaps in the assessment process., so I think this was a reflection both on the diagnostic criteria that tends to have quite a male presentation focus but also questions about people who self-identify and also about waiting lists.



So, uh, what your kind of experience or reflections on the, on the diagnostic processes?

Oh my goodness. That's a very big conversation. So, first of all, in terms of self-identification, all the girls in my study had a clinical diagnosis and that was for ethical reasons. However, if you, you know, certainly in the autistic community, self-identity is valid.

And I'm part of the reason for that is why should you need somebody that meets you for two hours to tell you what your identity is? You know, in many ways that doesn't seem very logical does that it doesn't seem right. That a clinical professional could, could tell you who you are based on the amount of time when you've got a whole life of living it.

So there is that element of it. I know a lot of parents feel it's really important in terms of accessing help and support to get that diagnosis. And there are long waiting lists in many cases, which makes it very problematic, which is why I think it's important that we gather the voice of the young person as soon as first concerns are raised, whoever raises them, and we start looking at how to support them pre-diagnosis. So if you know that the child is having difficulties with the noise levels in the class, and you don't actually need somebody to come along in two years' time and tell you that you know that already. So therefore put supporting in place, and it's the same with all those different act actions. If the need is there, it shouldn't necessarily have to have a label or a term or diagnosis to tell you to meet that need, you see the need, meet it.

Excellent. Thanks, Ruth. So we do still have, have questions coming in. I'm conscious that we're coming to the end of the session. I'm going to ask one that that's, just come in the chat and then I can ask you for your final reflection truth. Um, so the last question for today, is there any research on long-term prospects for young people who are autistic, who aren't able to stay in school?

That's an interesting question. So my research is the first research that looks at autistic girls who stopped attending school as a result of persistent absenteeism. So they weren't excluded formally. They, they stopped attending through absence, uh, persistent absence. Um, I don't know whether there is any ongoing research that's long-term however, it's, it's something that's on my radar.

Ruth it's we are coming to time, if you've got any, any kind of final thoughts or reflections or anything else that you would like to share with people?

I think I probably hopefully covered most of what I wanted to say. And I say that if anybody's got any questions, please do feel free to email me.

I sometimes forget, but you don't all know what I know and that I might think I've said something and haven't, so if it's something that doesn't make sense or that you feel was a bit confused, please feel free to get in touch and I'll do my best to, to clarify things. If you want the template for the life chart again, very happy to include that in the, in the pack.



Thanks so much, Ruth it's, it's been an excellent session and there's been some, some really, warm and positive feedback and reflections from people, what they've taken away from the session.

I'm so grateful to you for the way that you did the research, but you know that your participatory reapproach and hearing and valuing, autistic voices and especially girls who tend to be missed.

So thanks so much, for how you've done it and what you've done and for sharing your learning with us. And we will gather this presentation and the supporting booklet and additional bits of information that will be useful to people in taking forward the learning and recommendations and, and supporting us to, to see change for more people.

So thank you so much for, um, for making that possible. Thanks everyone for attending. If you do have any anymore questions or reflections, you've got our contact details, so please feel free to get in touch and we'll share this hopefully early next week on the NDTi website and we will be sending out a link to people.

Thanks very much. Thanks.

