

# Autism

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# Why me?

- Who am I? – formerly lead clinician with an NHS Adult Autism Diagnostic Service
- Why do I do what I do?- Because I found so many women with AS which had never been suspected
- What is my involvement with women with AS?- previously carried out a doctoral study into women with AS: What they had found their main life challenges and what would have helped.
- What do I do now? – run a peer mentoring group for women with AS

# My thoughts on ASD in women

## Diagnosis

- Is it the right word? –too medical?
- Is it the right concept?- implies deficit rather than difference?
- Might be necessary in order to access services/support

## Recognition

- Seems more useful :
- Helps people and their families to understand them/selves,
- Plan their lives
- Gives them permission to be themselves
- and to appreciate this!

# Some women with Asperger Syndrome



# Background

## **Tony Attwood**

- In over 1000 diagnostic assessments in children found 4:1 males to females
- In adults with AS 2:1 males to females
- These are women who have sought diagnosis

## **Chris Gillberg**

- Found male to female ratio 4:1 but wondered if it might be lower

## Local Service findings

- In our Service we found the overall numbers over 12 years to be 3:1 males to females
- Some months it was down to 2:1
- Sometimes even numbers

CAVEAT-this could be because I did a lot of talks and presentations regarding females on the spectrum so possibly had more direct referrals for that reason

# Why are women with ASD missed?

- Because boys' behaviour may draw attention to them at an early age?
- Because it doesn't occur to clinicians to think of ASD in girls?
- Because quiet, well behaved girls who enjoy study and reading are not seen as problems- can be seen as being very good?
- Because women are seen as having a "personality disorder", Eating Disorder etc – people don't seem to look for the underlying potential cause?
- Diagnosticians look for what they know about. If they don't know about ASD in females they wont see it!

# My Study

- Women were asked what their main life challenges were and what would have helped.
- Responses were thematically analysed and the challenges and suggestions noted.
- ***Diagnosis*** was noted as a challenge but-
- One key suggestion for “What would have helped” was-
- ***Early diagnosis.***



Having AS	Other people and places	Suggestions for overcoming these challenges
a) <u>Diagnosis</u>	a) Feeling excluded	a) <u>Early diagnosis</u>
a) Being a woman with AS	a) Feeling bullied	b) Information
a) Feeling different	a) School; the people, the place, the teaching	c) Mentors
a) Coping with change	a) Relationships	d) Others
a) The search for rules		
a) Perfectionism		

# Diagnosis

Being diagnosed with AS itself is a challenge –

- *“a bit sort of; **oh crap**, kind of thing [laughs] excuse the language, because obviously it's not... it's a diagnosis but it's obviously not an illness as such. Just the way I am, but it's obviously... it's **not something that can be cured** of either obviously, a lot of people just consider it part of personality really. But it has... over the years obviously I've suffered from recurrent depression, anxiety and that kind of thing and it obviously meant that that's going to continue probably throughout my whole life, there's... **depending, if I get stability...**” (Diana)*

However early diagnosis was strongly recommended as being of major benefit:

# Diagnosis

- It was good to have a diagnosis in that I think it **made a little bit more sense** of a lot of my life, especially my teenager years which were really the hardest to cope with. (Diana)
- That's another reason that things have probably gone... got so **better since the diagnosis**, because I've been made to feel that nothing, you know, what's right and what's wrong in life, you know, there's no such thing as normal. (Audrey)

- I now know why I do things. I'm not scared to go up and talk to people now. I don't wear black all the time any more. **I don't try and hide.** I am a person. I am here. You know, I didn't want people to see me, I wanted to hide away all the time. (Beata)
- I was relieved, **extremely relieved**, because it answered a lot of questions that I had unanswered, and it made me feel a bit more happy about myself, and that I wasn't so strange . (Fiona)

Diagnosis/formal recognition was recommended not only for the benefit of the individuals themselves but also for their **parents** **sakes**:

- *My mum could have done so much with the right information, and she'd been saying to doctors since the day I was born, "There's something wrong with her, you know, help me, there's something wrong with her," and they just kept saying, you know, "Don't be ridiculous." (Christine)*

## The value of diagnosis at **school** :

- *Maybe, just being given more space, like, school wise, you know, the situation I was in in school was not good for me. If I'd not been taken out, because that's pretty humiliating as well, but if it's recognised earlier that you need to go to a smaller school where you can, you know, act differently then, that might have helped. (Emma)*
- *I think they need to have a professional in the schools, .....somebody that can counsel and help with the issues. (Audrey)*

Harriet had had specialist schooling that did address her specific needs and she found aspects of it very helpful within the classroom:

- *The teachers were nice, we had speech and language therapists in every classroom that we went into, like each class had a speech and language therapist with them. So they would help you describe like, some people like myself had problems understanding the work so they would help you describe the work and what the challenge was meant to be so it was good and made a lot more new friends and the teachers understood you more (Harriet)*



- *Probably having like a support worker at the time in class when I was at college. Just somebody to help me like, translate the questions or, you know, saying “This is what you are going to do, do you understand the work. Would you like me to read it to you, would you like me to translate it for you, do you understand the teacher is saying?”, things like that, but I didn’t have any of that I was just completely on my own.(Susan)*

# So what are the questions?

- For parents
- For educators
- For clinicians
- For the girls and women themselves

# Parents

- Could it be Autism?
- What should I do?
- How should I go about things re my daughter, my family, the school etc
- How can I best support my daughter whether or not she has a formal diagnosis?

# Educators

- Could it be Autism?
- What should I do?
- How should I go about things?
- How can I best support my pupil? (Check the “Autism Toolbox”)

# Clinicians

- Could it be Autism? (don't forget to think about ASD as a possibility)
- What should I do? (find out how to carry out a diagnostic assessment for ASD if you don't already know)
- How should I go about things? (carry out this assessment or find a service who will, not forgetting to find out earliest possible developmental history from parents(Mum))
- How can I best support my "client/patient/person"? (be familiar with the "Menu of Interventions and the NES Training Framework)

# Girls and women

- Could it be Autism?
- Do I want this to be formally clarified?
- If so by whom and how?
- If I get the diagnosis what next?
- Who can help me to organise my life to take my ASD into consideration?

PS- Hooray I'm not mad! Its not just me! I'm not alone!

# Some last words

- You get your little obsessions with Asperger's Syndrome, your little things that you focus on completely and there's nothing else, and then you get this little person in your life who's just absolutely everything, you know, they take up your entire life and they take over any of your other obsessions and they become your obsession and you do it right, you learn everything. (Christine)
- *I think being given help to cultivate what you're good at, I mean, I know that could apply to anybody in the world, but I think that, from what I know of people with Asperger's, it's almost like an untapped resource of people who are able to love something so, so much that they will just do it so brilliantly and it's not used. (Emma)*
- Yeah I feel like I'm just an original person really (Harriet)

The End ?