



Championing the voice of autistic women

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1. Introductions

2. Research overview

The diagnostic bias against girls and women on the autism spectrum

Autistic girls and women are less likely to receive an autism assessment...

(Loomes et al., 2017)

...or if they do receive it they receive this later on average than equivalent males.

(Giarelli et al., 2009)

The diagnostic bias against girls and women on the autism spectrum

And even when females do receive an assessment *they are less likely to meet current diagnostic criteria*, compared to males with equivalent levels of autistic traits.

(Dworzynski et al. 2012; Russell et al., 2011)

Why is there a diagnostic bias against autistic females?



DIAGNOSTIC AND STATISTICAL
MANUAL OF
MENTAL DISORDERS

FIFTH EDITION

DSM-5

AMERICAN PSYCHIATRIC ASSOCIATION

DSM-5 account of ASD

*“Girls without intellectual
impairment or language delay
may go unrecognized,
perhaps because of subtler
manifestation of social and
communication difficulties”*

(p.57)

The female autism phenotype | **Social motivation**



On average, autistic girls and women
are more interested in the social
world



Hiller et al., 2014; Head et al., 2014

The female autism phenotype | **Special interests**

$$\begin{aligned} &= 2\pi \int_0^{\sqrt{3}} x \sqrt{1 + (2x)^2} dx \\ &= \frac{2\pi}{8} \int_0^{\sqrt{2}} (1 + 4x^2)^{1/2} (8x) \\ &\pi [(1 + 4x^2)^{3/2}]^{\sqrt{2}} \end{aligned}$$



The female autism phenotype | **co-occurring emotional & behavioural difficulties**



Mandy et al., 2012; Westwood et al., 2017; Huke et al., 2013

Some questions

What is the female autism phenotype from the point of view of autistic women?

How does it impact on the chances of receiving a diagnosis?

Are there costs of a late diagnosis?
What are they?

3. Study of Late Diagnosed Autistic Women

**University College London researchers
want to learn more about women's
experiences of the Autism Spectrum**

Can you help?

- ▼ Are you a woman on the Autism Spectrum aged 18 - 30?
- ▼ Are you interested in taking part in paid research?

Who are we looking for?

Young women aged between 18 to 30 years, who received a diagnosis of Autism Spectrum Disorder (ASD, including high-functioning autism and Asperger Syndrome) after January 2004.

What would happen if I took part in the study?

You would be asked some questions by a female researcher on your general health and ASD in a safe and confidential space at UCL. Your answers will be made anonymous.

How much will I get paid?

You will get £15 in cash to thank you for your time.

The benefits of taking part in the study could include:

Finding out more about yourself and how your ASD has influenced who you are.
Contributing to scientists' knowledge of female ASD and how women are diagnosed in the future.

To take part or to find out more:

Please contact Sarah Bargiela: sarah.bargiela.12@ucl.ac.uk
or visit <http://bit.ly/1jpPIPO> for more information.

The principal researcher for this study is Dr Will Mandy at UCL. This study has been approved by the UCL Ethics Committee Project ID: 5339/001.

INTERESTS

What are your main interests at the moment?

- What do you like about this area of interest?
- How has having this interest helped you?
- How has having this interest caused you problems?

Do you think any of your interests are particularly 'female' and why?

(It might help to think about any male friends with autism that you know who might have special interests and how your interests might compare)



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The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype

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CAMOUFLAGE

The Hidden Lives of Autistic Women

DR SARAH BARGIELA

Art by Sophie Standing



YOU'RE TOO POOR
AT MATHS TO BE
AUTISTIC

YOU'RE
JUST A
SHY GIRL

THE FIRST HEADLINE IS

YOUR'E NOT AUTISTIC

LOTS OF THE WOMEN TOLD ME THEY THOUGHT THEY HAD
AUTISM BUT WHEN THEY SUGGESTED IT TO FAMILY, FRIENDS
OR THEIR TEACHERS, IT WAS DISMISSED. WHEN THEY WENT
TO THEIR DOCTOR THEY WERE EITHER GIVEN THE WRONG
DIAGNOSIS OR TOLD THERE WAS NOTHING WRONG.

YOU ARE
ANXIOUS
NOT AUTISTIC!

PRETENDING TO BE NORMAL



A SOCIAL IDENTITY BASED ON INTERESTS

IT SHOWS HOW MANY WOMEN
BASE THEIR IDENTITIES ON
THEIR SPECIAL INTERESTS,
EMBRACING THEIR DIAGNOSIS
AND FINDING A COMMUNITY
OF FRIENDS LIKE THEM...



FROM PASSIVE TO ASSERTIVE

MANY WOMEN TALKED ABOUT HOW THEIR IDENTITIES WERE BASED ON THEIR SPECIAL INTERESTS AND HOW THEY CAME TO EMBRACE THEIR DIAGNOSIS THROUGH FINDING A COMMUNITY OF FEMALES JUST LIKE THEM.

BEING SOCIALLY ISOLATED MEANT MANY WOMEN DIDN'T HAVE FEMALE FRIENDS AS TEENAGERS, WHERE INFORMAL RULES OF 'STAYING SAFE' WERE LEARNT. THIS MEANT THAT AUTISTIC WOMEN WERE ESPECIALLY VULNERABLE IN INTIMATE RELATIONSHIPS AND MANY WERE VICTIMS OF SEXUAL ABUSE. LATER THEY ALSO SHARED THEIR STORIES OF HOW THEY HAD LEARNT TO ASSERT THEMSELVES.



4. 'You're not autistic'

Co-occurring mental health difficulties

“Four to five years of depression and anxiety treatment.

Five different antidepressants taking to maximum dose and back down again with no effect...years of talking therapy...and not once did anyone suggest I had anything other than depression”. (P05)

Preconceptions of professionals

Teachers

“I’ll always remember my special needs teacher saying I’m too poor at maths to be autistic”.

Healthcare professionals

“When I mentioned the possibility to my psychiatric nurse she actually laughed at me...I asked my mum, who was a GP at the time...if she thought I was autistic. She said, ‘Of course not’. At the time, a good 10 years ago now, there just wasn't much information about how girls presented, and from what she knew, I was nothing of the sort”.

Regrets

“The reward for trying hard to be normal was to be ignored because you were acting normal and I look at stories online of kids who were going off the rails and I think, I should have just burnt more cars”. (P09)

“Had I known about Asperger’s, I think I’d have known that I’m more suggestible... I might not have ended up in the situations that I did”. (P14)

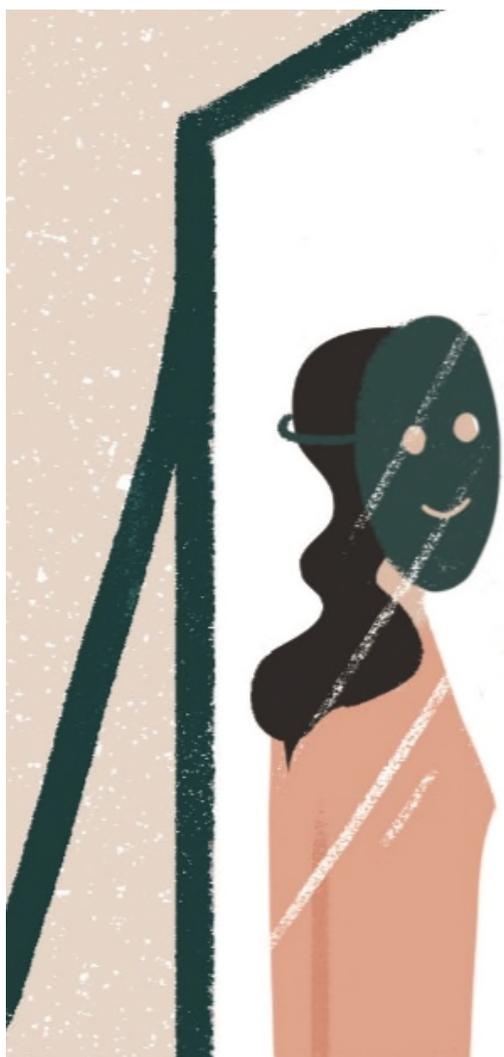
5. Pretending to be normal

An illustration of a bedroom. A person with blonde hair is lying in bed, covered with a dark green blanket, looking towards the right. To their left is a white nightstand with a small potted plant, a blue water bottle, and a black circular object with a smiley face. On the wall is a red circular clock. To the right is a window with red and white striped blinds. The room has a warm, orange-toned floor and walls.

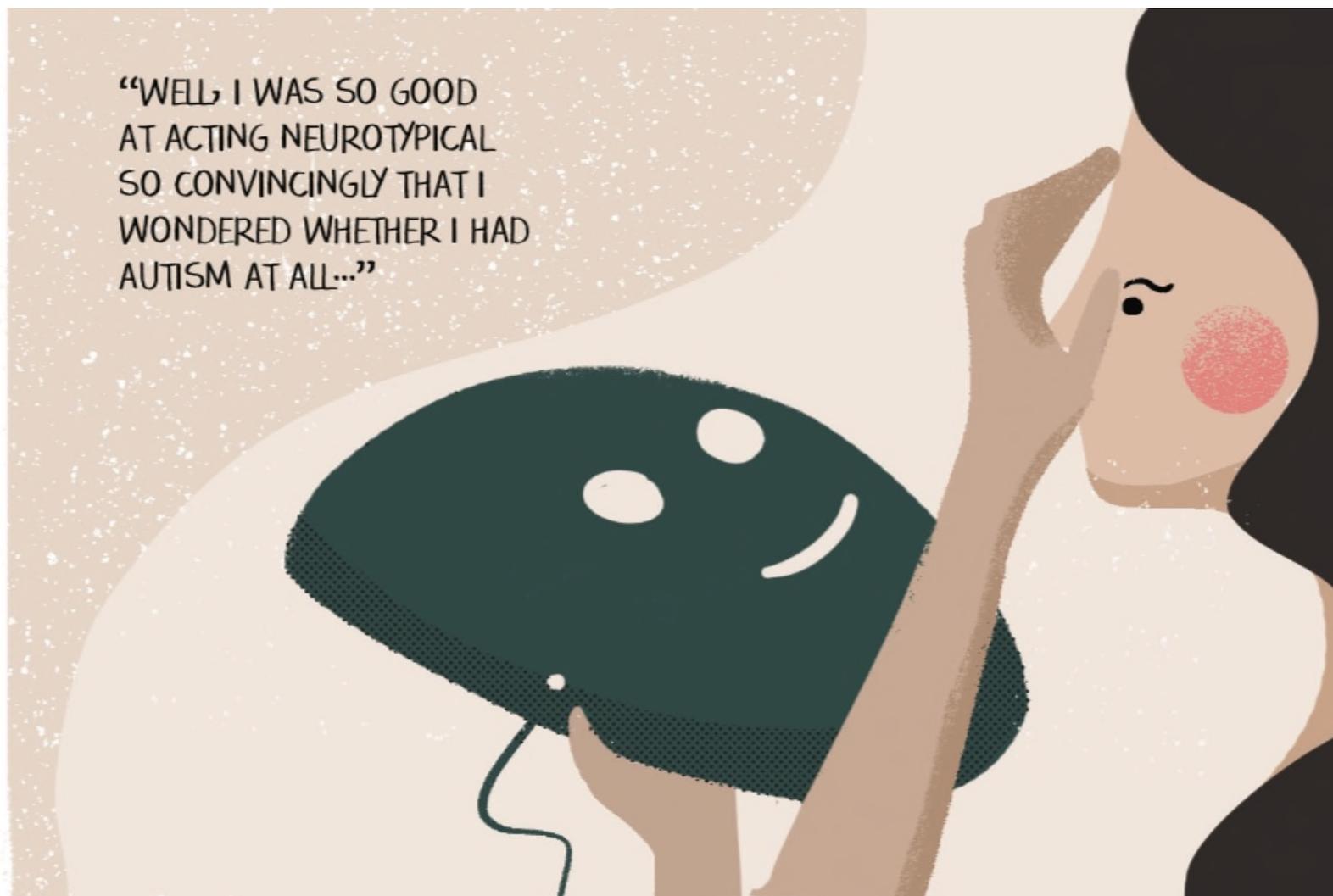
“THAT’S FUNNY, I WAS MORE CONSCIOUS OF TRYING TO ‘FIT IN’. I HONED SOMETHING OF A PERSONA WHICH WAS BUBBLY AND MAYBE A BIT DIM, BECAUSE I HAD NOTHING TO TALK ABOUT AT PARTIES, OTHER THAN CREATIVE WRITING. SO, I CULTIVATED AN IMAGE THAT I BROUGHT OUT TO SOCIAL SITUATIONS THAT WAS NOT ‘ME’. AFTERWARDS, I WAS EXHAUSTED, IT’S A MASSIVE EFFORT HAVING TO PLAY SOMEONE ELSE. I HAD TO GO AND LIE DOWN IN A ROOM ALONE TO RECOVER.”

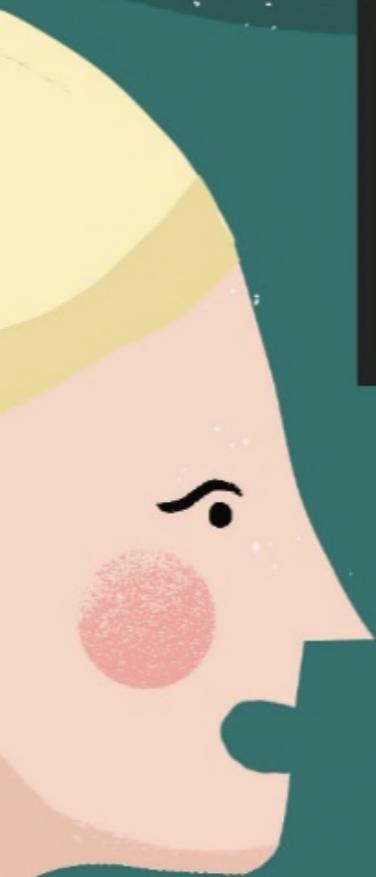


“FOR ME, IT WAS AUTOMATIC, I’LL MIMIC WHAT OTHER PEOPLE ARE DOING OR SAYING OR THEIR ACCENTS WITHOUT NOTICING. I USED TO GO CAMPING WITH GIRL GUIDES AND COME BACK WITH STRONG ACCENTS. ONE TIME I CAME BACK WITH AN IRISH ACCENT AND IT TOOK A WEEK TO GET RID OF IT...”



“WELL, I WAS SO GOOD
AT ACTING NEUROTYPICAL
SO CONVINCINGLY THAT I
WONDERED WHETHER I HAD
AUTISM AT ALL...”





```
@conversation
```

```
// command: listen to other person  
//: wait until they finish  
// command: [smile] talk back
```

```
// display: open body language  
// command: ask questions  
// := friendship
```

“IT’S VERY DRAINING TRYING TO FIGURE OUT EVERYTHING ALL THE TIME, EVERYTHING IS MORE LIKE ON A MANUAL, YOU’VE GOT TO USE ONE OF THOSE COMPUTERS WHERE YOU HAVE TO TYPE EVERY COMMAND IN.”

6. Social identity through interests



“SOMETHING THAT I REALLY APPRECIATE ABOUT HAVING A DIAGNOSIS IS ACTUALLY BEING IN THIS CLUB NOW WHERE PEOPLE TALK ABOUT THEIR EXPERIENCES THAT HAVE SO MANY ECHOES OF MY OWN.”

“ALSO, JUST USING A COMPUTER TO COMMUNICATE RELIEVES LOAD OF PRESSURE AROUND SOCIAL COMMUNICATION. YOU DON'T HAVE TO THINK ABOUT BODY LANGUAGE OR FACIAL EXPRESSIONS OR RESPONDING STRAIGHT AWAY. ALL YOU HAVE IS THE TEXT YOU ARE TYPING FOR EACH OTHER AND IT FEELS COMPLETELY EQUAL. ALSO, IT'S MUCH EASIER TO TALK ABOUT YOUR EMOTIONS WHEN TYPING!”



“WITH MY ASPERGER’S THERE’S ALWAYS A MILLION THINGS IN MY HEAD, BUT WHEN I’M IN A BOAT I CAN JUST FOCUS ON BEING IN A BOAT. IT’S THE ONLY PLACE I EVER GET THE SENSATION OF FEELING CALM... ASPERGER’S IS TIRING BECAUSE IT’S ALMOST LIKE YOU’RE ON HIGH ALERT ALL THE TIME, SO TO BE AT PEACE AND NOT CONSTANTLY FEEL ON THE EDGE OF A MELTDOWN IS GREAT.”



“BEING A RESEARCHER IN A SPECIALIST AREA OF ARCHAEOLOGY IS VERY GOOD FOR MY SELF-BELIEF, TO SEE THAT I CAN DO SOMETHING THAT’S RECOGNISED BY OTHER PEOPLE AS BENEFICIAL AND PRODUCTIVE.”



7. From passive to assertive

Sexual abuse

8. Conclusions and Recommendations

Staying safe

Why you might need a diagnosis

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