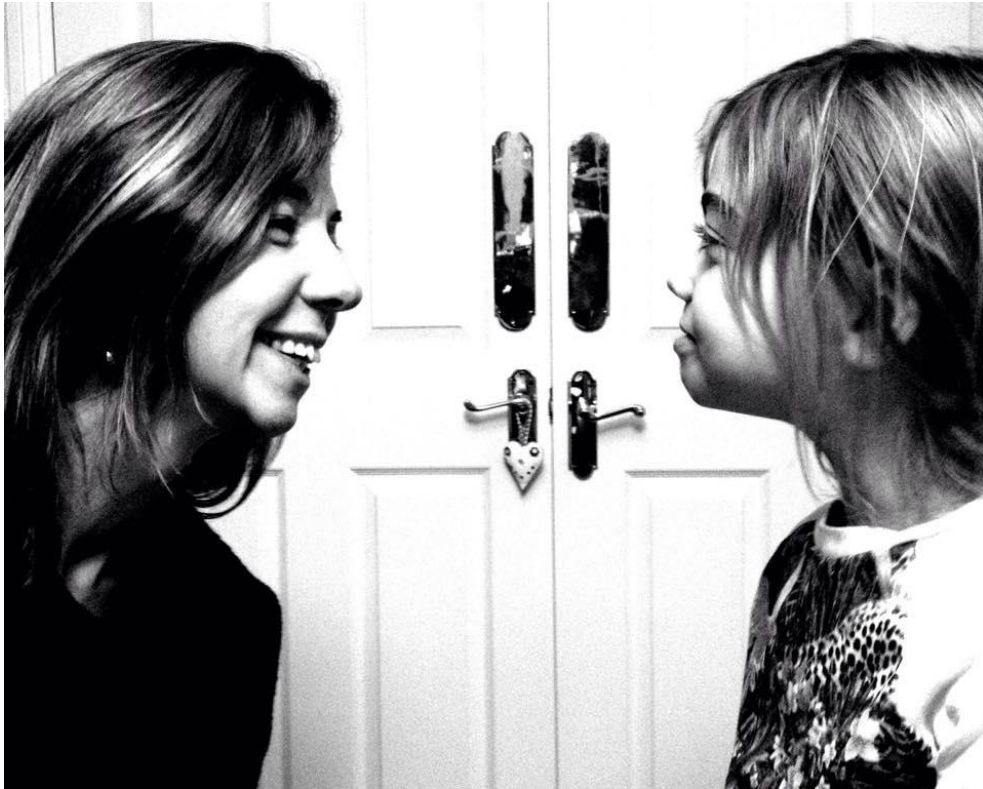# Rewriting the narrative: Lessons about inclusion from autistic adolescent girls who stop attending school

DR RUTH MOYSE

THE JOHN AND LORNA WING FOUNDATION
supporting autism research

University of
Reading

NDTi
National Development Team for Inclusion

Insider researcher

- Primary teacher

- Parent

- Trainer for PSC

- Visiting lecturer

- PhD

- #ActuallyAutistic

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Defining the issue

- How many autistic girls were missing from mainstream secondary schools? Was it a big problem?

- Why did some of them stop attending? What was the best way of finding out?

- How can this learning inform policy and practice?

Why language matters

What term do you use to describe a child or young person who does not attend school?

1. Truant
2. School Refuser
3. Emotionally Based School Avoider
4. Other (please write in chat bar)

- *Where does this locate the problem?*
- *Who does it imply has responsibility for creating change?*
- *What does this say about the child?*
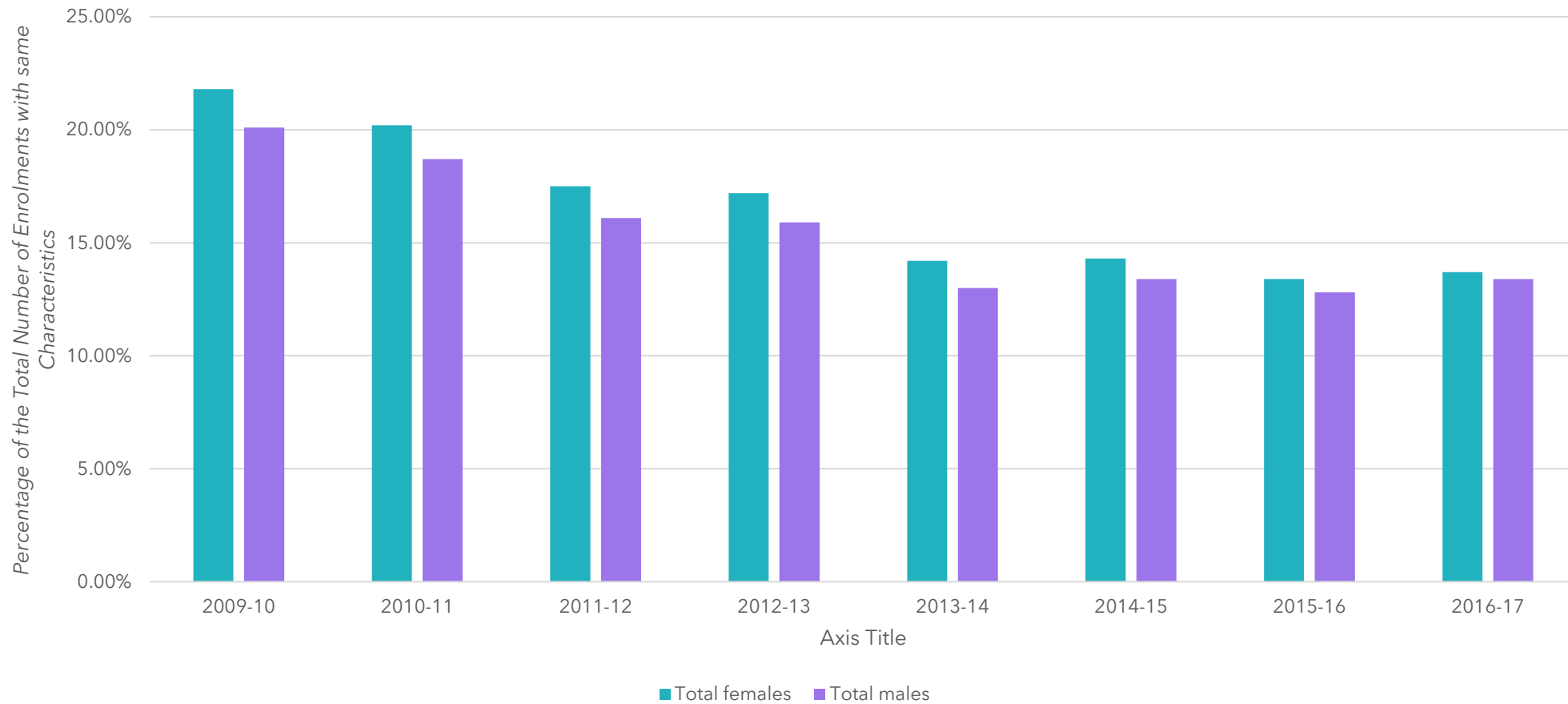
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Language matters

- "I defy anyone to pick her out in five minutes."

- "There is nothing. I see nothing."

- "I don't have to cope with anything."

- "We have children who have more needs."

- *Why might the term 'high functioning' be unhelpful to describe an autistic girl at a mainstream secondary school?*

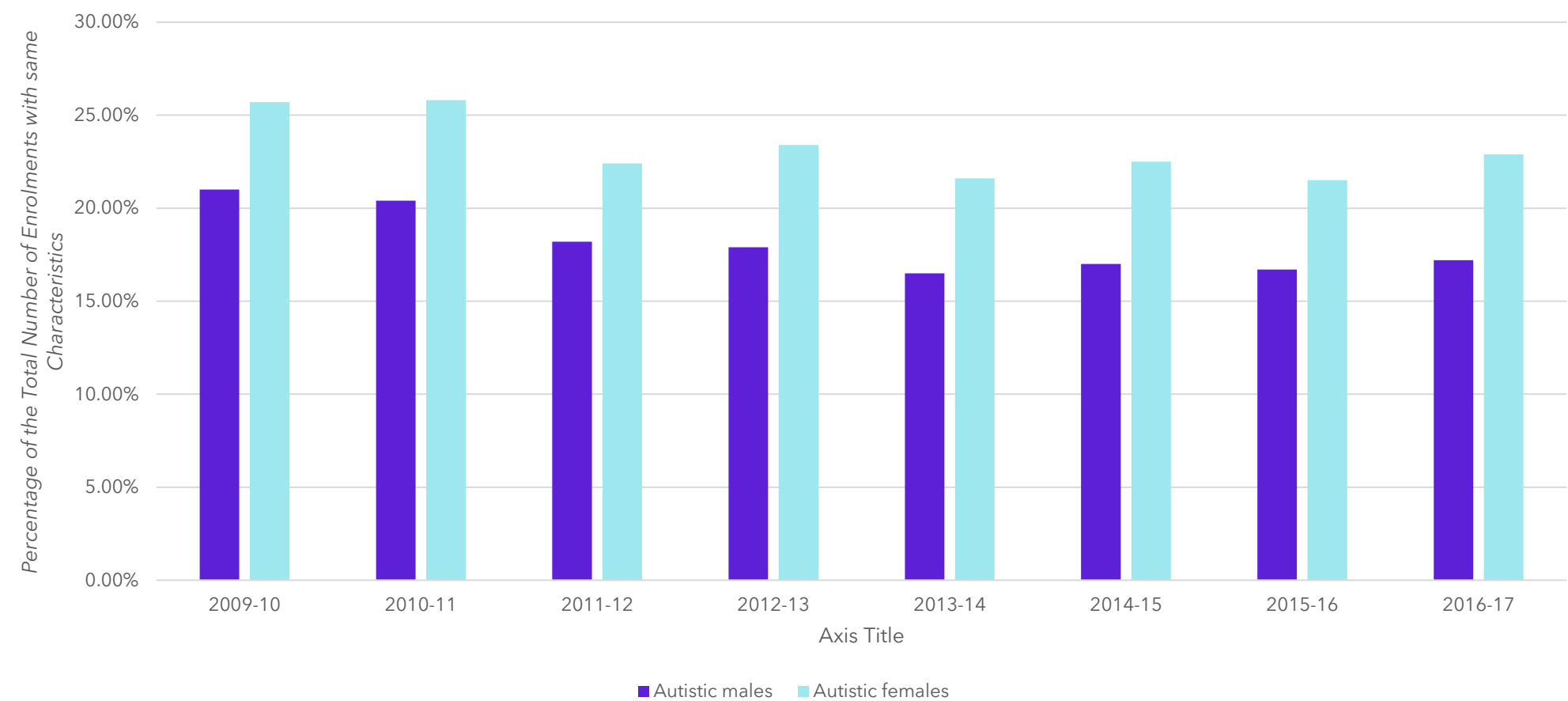- *Where do 'functioning' labels suggest value lies?*

Rights issue

- **'Children do not lose their human rights by virtue of passing through the school gates.'** (UN Committee on the Rights of the Child, 2001, para. 8)

- Local Authorities must provide sufficient schools 'in number, character and equipment to provide for **all** pupils the opportunity of appropriate education'. (Education Act 1996)

- Local Authorities '**must** have regard' to supporting the development of each child 'to help him or her achieve the best possible educational and other outcomes.' (Children and Families Act 2014)

- Schools must not discriminate against autistic girls in terms of their treatment or their access to learning and other services. (The Equality Act, Section 85, 5)

- Schools '**must** make reasonable adjustments' for them. (SEND Code of Practice, 2014)

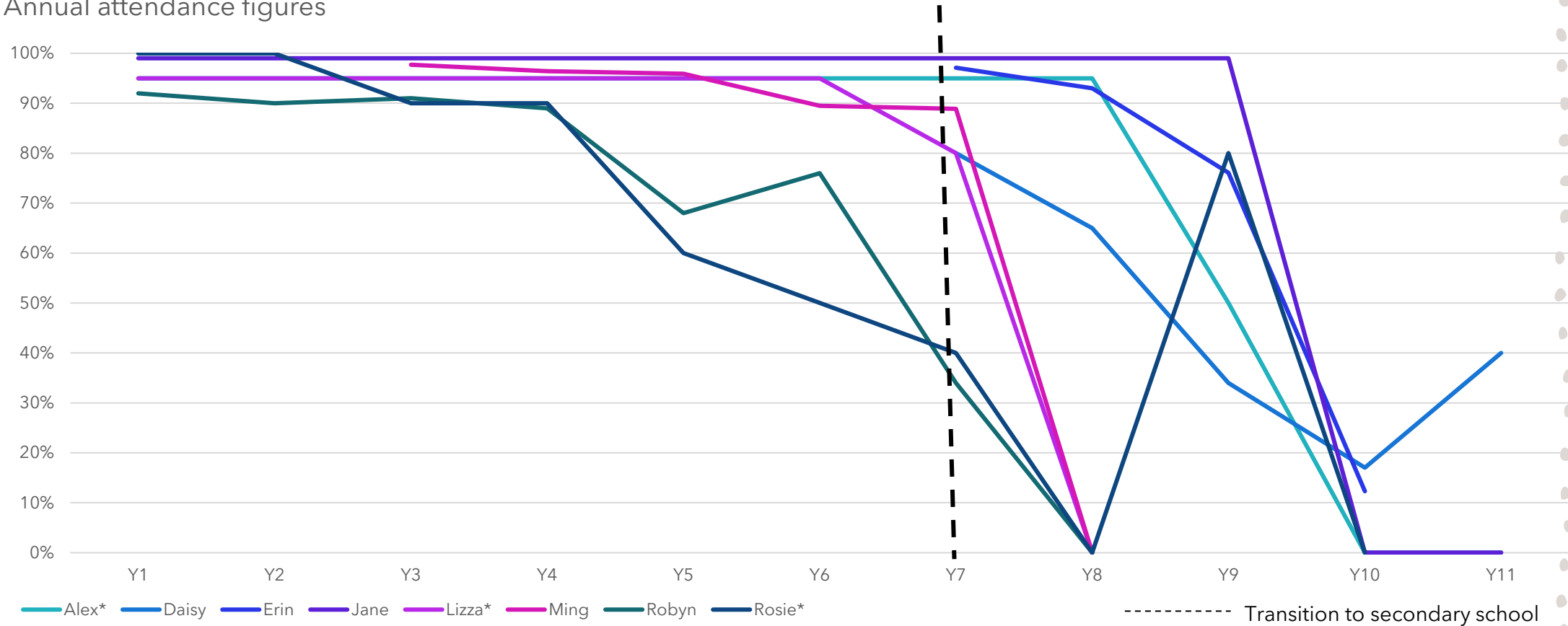# Persistent absentees: Secondary school

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A problem for secondary schools?

Annual attendance figures

Legend: Alex* · Daisy · Erin · Jane · Lizza* · Ming · Robyn · Rosie*

-------- Transition to secondary school

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Autistic girls as absent voices

'…right from the start, from the time someone came up with the word 'autism,' the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.'

(Donna Williams, 1996, p14)

All art work by I. Moyse

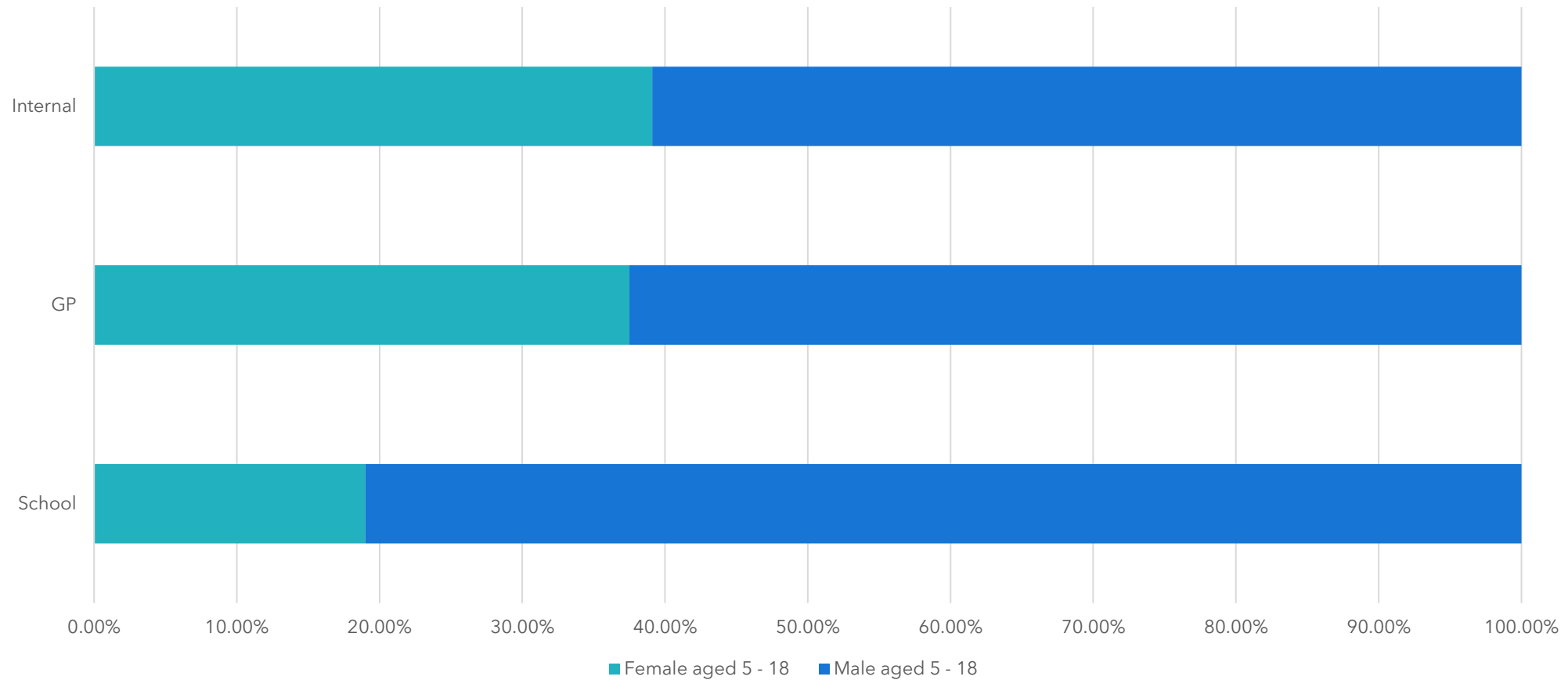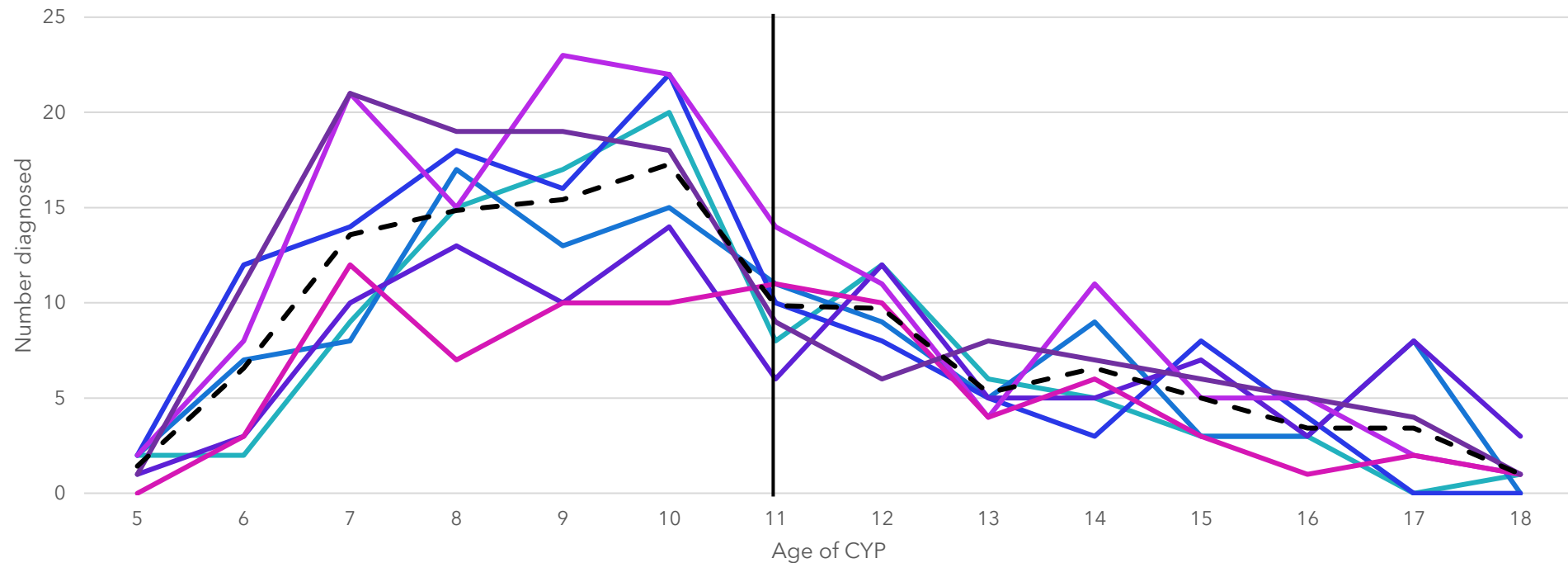JUST BECAUSE THEY CAN'T SEE IT DOESN'T MAKE IT ANY LESS REAL

Absences

- Half the girls reported wanting to stop attending school from the first day or within the first year, but persevered at school for 8-9 years before they finally stopped attending.

- Multiple examples of informal absences that do not show up in official statistics.

  - E.g. Being told not to participate in a lesson, being put in isolation, or removing themselves from class for respite.

  - In some cases, girls almost entirely absent from lessons, despite being recorded as present in school.

  - Lack of attendance did not always or initially correlate with obvious underachievement.

"When something starts to go wrong, you're meant to go, 'This thing has just started to go wrong, let's see what we can do to stop it, and see what we can do to make it go right again. You're not meant to just sit with it and let it go more and more wrong until it's completely fallen apart." Rosie
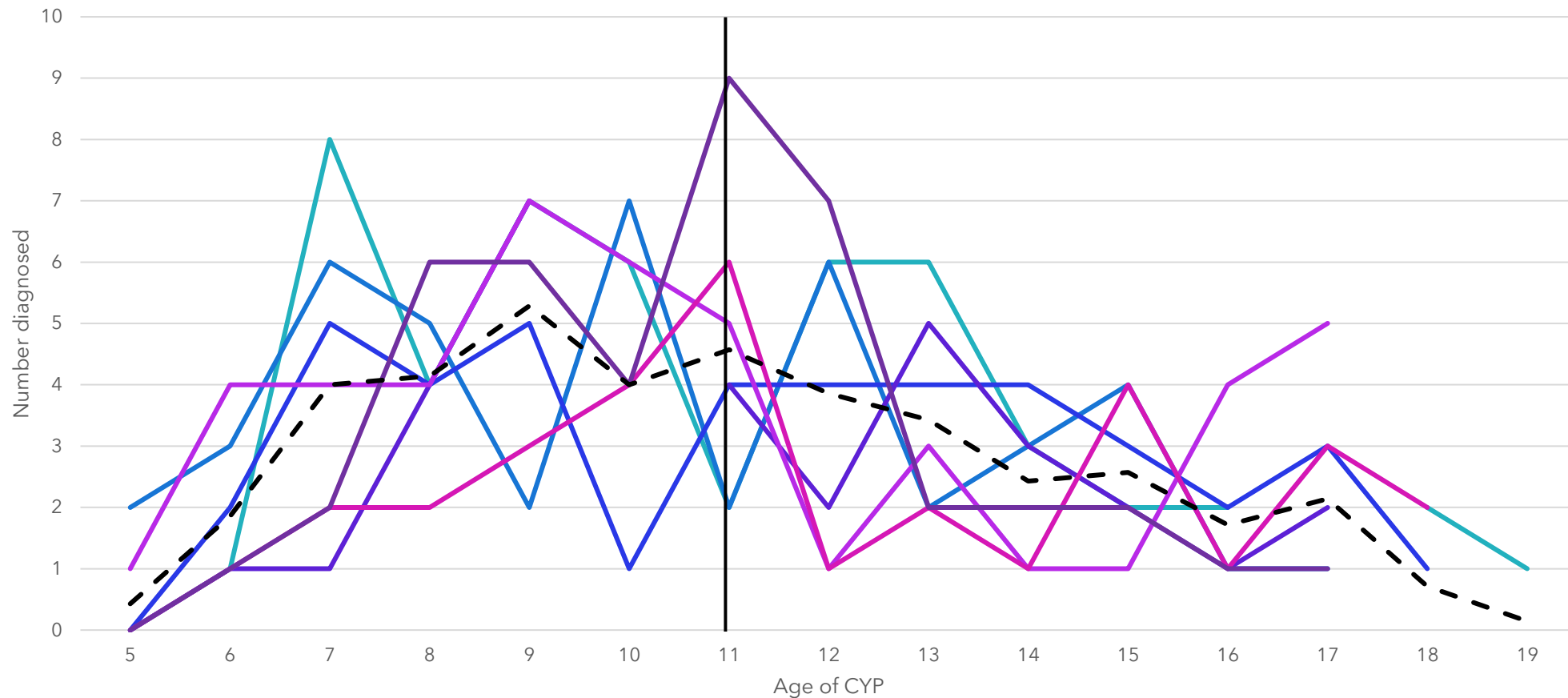
NHS Trust X: Main types of referrers

Chart legend: ■ Female aged 5 - 18 ■ Male aged 5 - 18

Categories: Internal, GP, School

X-axis: 0.00%, 10.00%, 20.00%, 30.00%, 40.00%, 50.00%, 60.00%, 70.00%, 80.00%, 90.00%, 100.00%

Males: Age at diagnosis in NHS Trust X

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Females: Age at diagnosis in NHS Trust X

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The referral process

Factor \ Case study pseudonym	Molly	Cayla	Lauren
Earliest evidence of concern	Pre-school	Pre-school	Infant School
Location of first concerns	Parent	Parent	Parent
Time between first concerns and first referral to autism pathway	6 years	9-10 years	3-6 years
Age diagnosed as autistic (yrs)	8	13	11
Requester of referral	Mum	SENCo	Head
Referrer	GP	School	GP
Previous referrals	Depression	Depression	Paediatrics, SaLT
Prior diagnoses	None	None	Reading & arithmetical disorders
Diagnosed after 1st or 2nd ADOS	1st	1st	1st
Family history of autism	Yes	Yes	Not known
Family history of other conditions	No	No	Genetic disorder

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Two broad types of descriptions
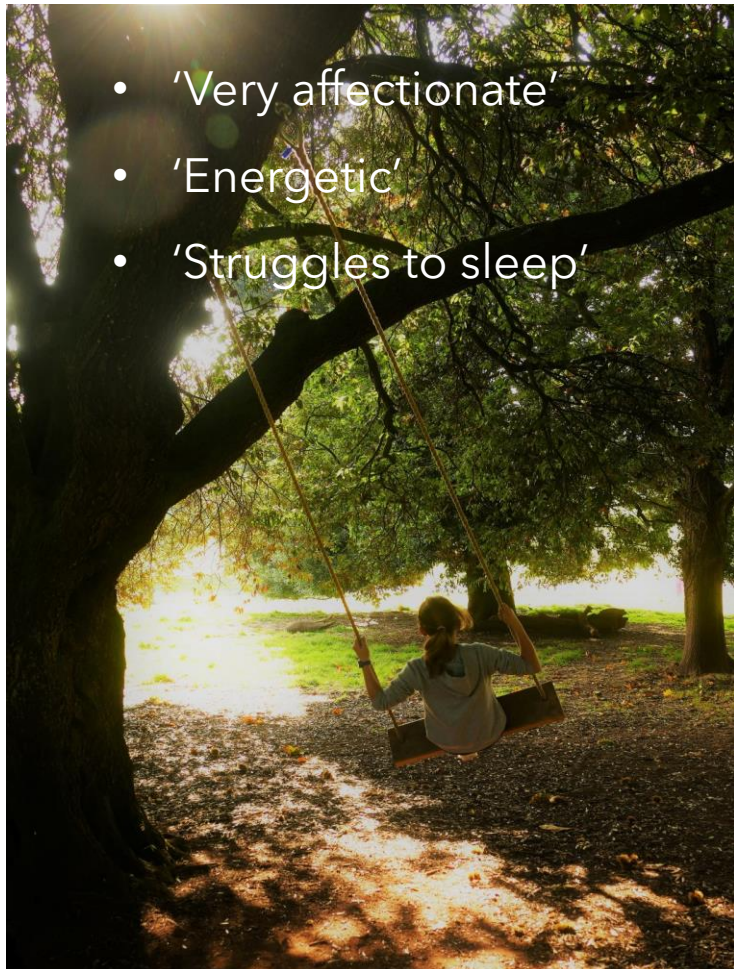
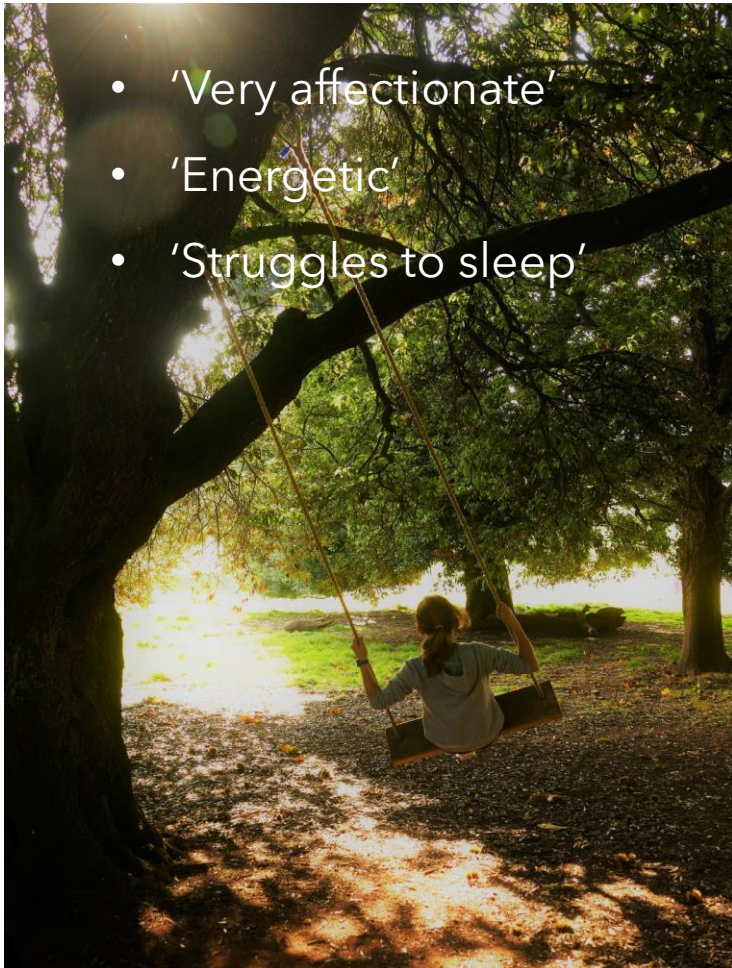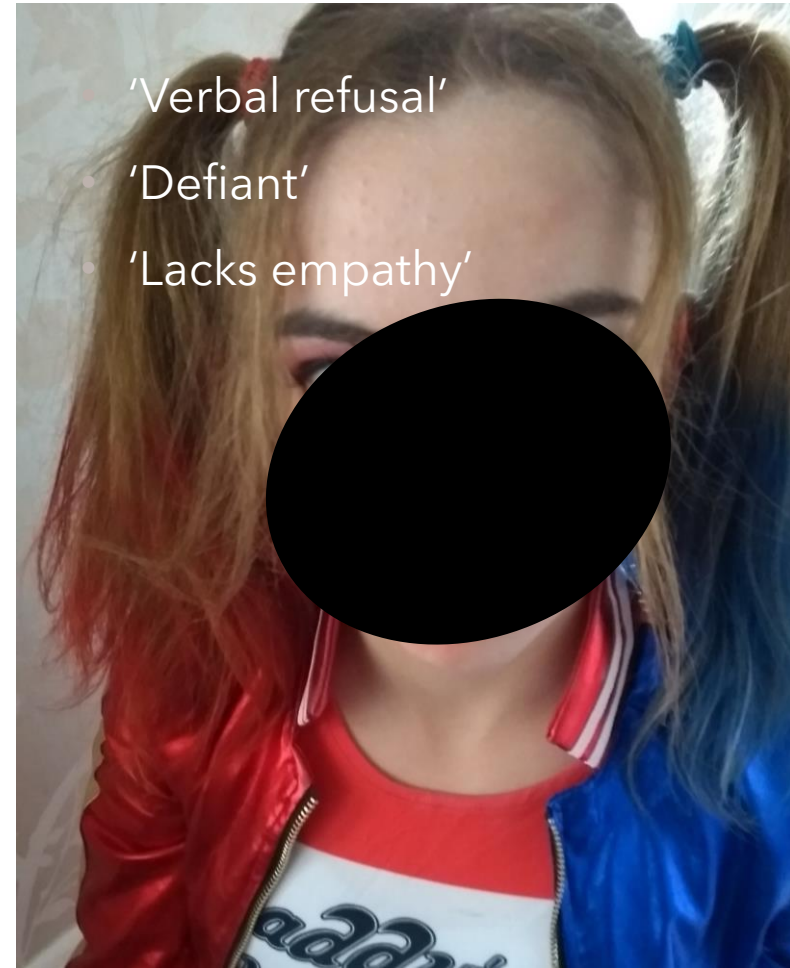- 'Very affectionate'
- 'Energetic'
- 'Struggles to sleep'
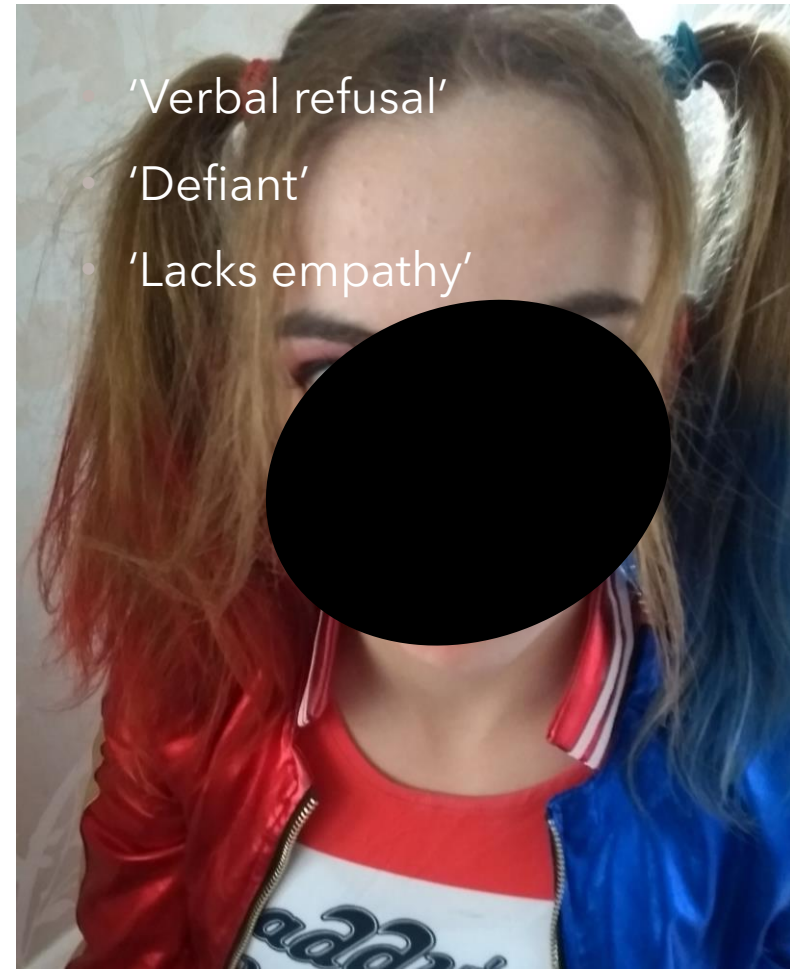
'Verbal refusal'

'Defiant'

'Lacks empathy'

Beth

- 'Very affectionate'
- 'Energetic'
- 'Struggles to sleep'

'Verbal refusal'

'Defiant'

'Lacks empathy'

Impact of language

FIRST TYPE OF DESCRIPTION

- 'Hides in cupboards' and 'tries to avoid/opt-out'. (Cayla)

- 'Works hard', 'anxious about failing with her work and in not being able to please'. (Emma)

- 'Very shy'; 'very submissive'; 'tries to fade into the background'. (Katie)

- 'Very compliant.' (Gina)

SECOND TYPE OF DESCRIPTION

- 'Partners think she's bossy.' (Molly)

- 'Resistant'; 'lacks empathy'; puts 'a great deal of burden on the class teacher and the class as a whole'. (Beth)

- 'Attention-seeker'; 'lashes out' and 'doesn't care about others if she has hurt them'; 'finds it hard to accept upsets and injustices'. (Lauren)

Whose perspective matters?

- Girls' voices absent until point of assessment

- Factors that impacted on the girls were overlooked or underestimated

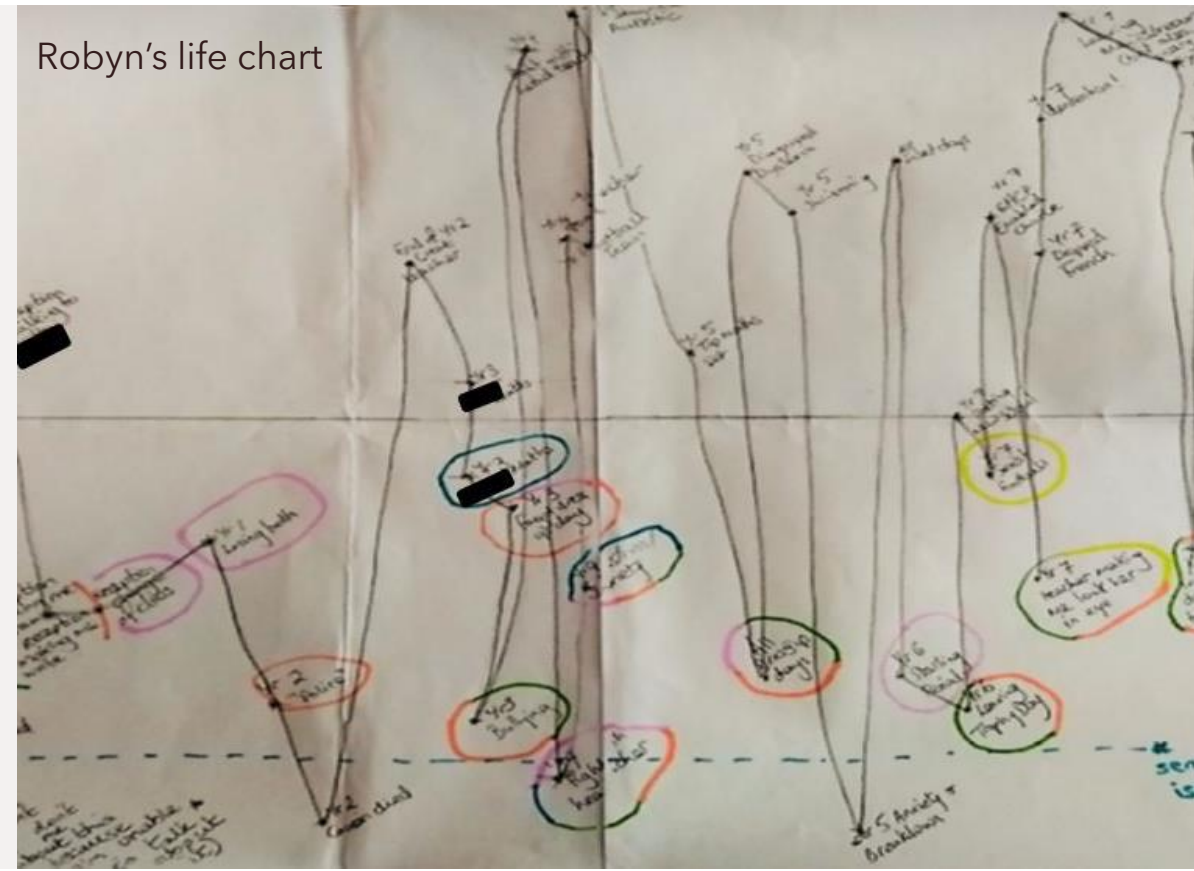- Some girls reached crisis point before access to autism assessment

How can you ensure the authentic voice of the child or young person is heard?

MUST. KEEP. SMILING.

Life histories

"*Not being in school was not fun. I wanted to learn. School put a lot of pressure on me about my attendance and this increased my inability to attend.*" Erin
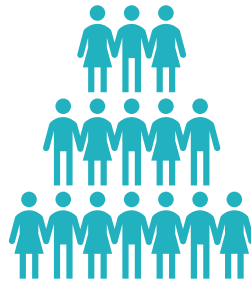

Robyn's life chart

The centrality of pupil voice

Non-ideal school: Biggest problem?

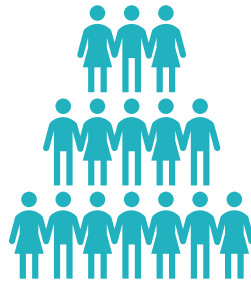a) the sensory environment?

b) the people?

c) the work?

Ideal school: Most important to get right?

Write your answer in the chat bar

a) the sensory environment?

b) the people?
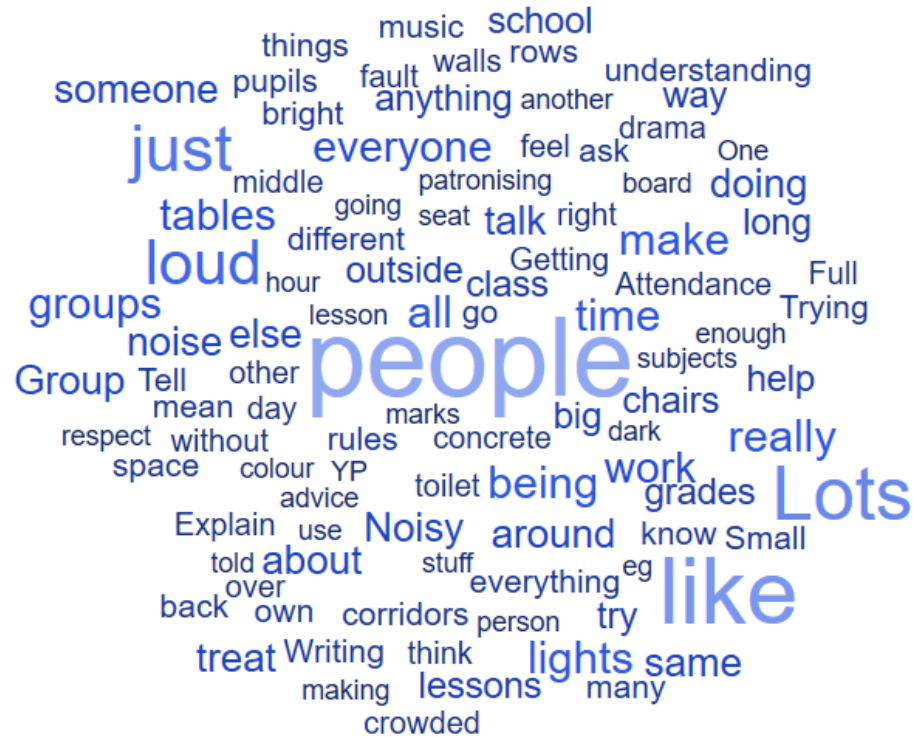
c) the work?

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The girls' responses

THE SORT OF SCHOOL THEY DID NOT WANT TO ATTEND

THEIR IDEAL SCHOOL

The ethos of the school

THE SORT OF SCHOOL THEY DID NOT WANT TO ATTEND

THEIR IDEAL SCHOOL

In my ideal school I would be...

'Safe'

'Accepted'

'Relaxed'

'Comfortable to be myself'

'Blending in – a part of it all'

'Learning!'

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Daisy

starting school
(2008)

was allowed
in Library (2009)

⑤

work was
read out in
assembly
(2011)

hS

⑤

moved school
(2011) NOV

moved class
(2008)
②

① trip to the
farm (2007)

excluded from
P.E (2008)
⑤

friend moved
(2009) ⑥

⑥
lunch times
alone (2011)

⑥
no-one
wanted to play
(2011)

② teacher left
(2007)

② not being invited
to birthday party
(2008)

bullying
(2008)

followed
home +
called names
(2011) ⑤

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Evidence of mental distress reported by the girls

Pseudonym	Breakdown	Eating disorder	PTSD	Self-harm	Suicidal thoughts	Suicide attempt(s)	Hospital admission
Alex				Y	Y	?	Y
Daisy		Y		Y	Y	Y	Y
Erin	Y	Y					Y
Jane	Y						
Lizza							
Ming							
Robyn	Y						
Rosie			Y	Y	Y	Y	Y

"Leaving school generally I would say, it's saved my life. I know that sounds a bit extreme, but if I'd stayed in school, I'd have carried on deteriorating." Daisy

Themes identified by the girls

- Described overwhelming environments, unmanageable group tasks and a lack of individualised support.

- Some teachers did not appear to listen to or believe them, were seemingly unresponsive to their needs or prevented them from accessing the personal adjustments they had developed to cope.

- Eight of the girls recalled (often multiple) incidences of bullying and abuse by teachers and peers, which were linked to them feeling unsafe, frightened, and anxious.

- Prioritising pupil wellbeing was the most important protective factor in being able to attend school. They needed to feel safe, cared about and understood; to be recognised and listened to, not overlooked.

Tensions and contradictions

Assumptions vs understanding

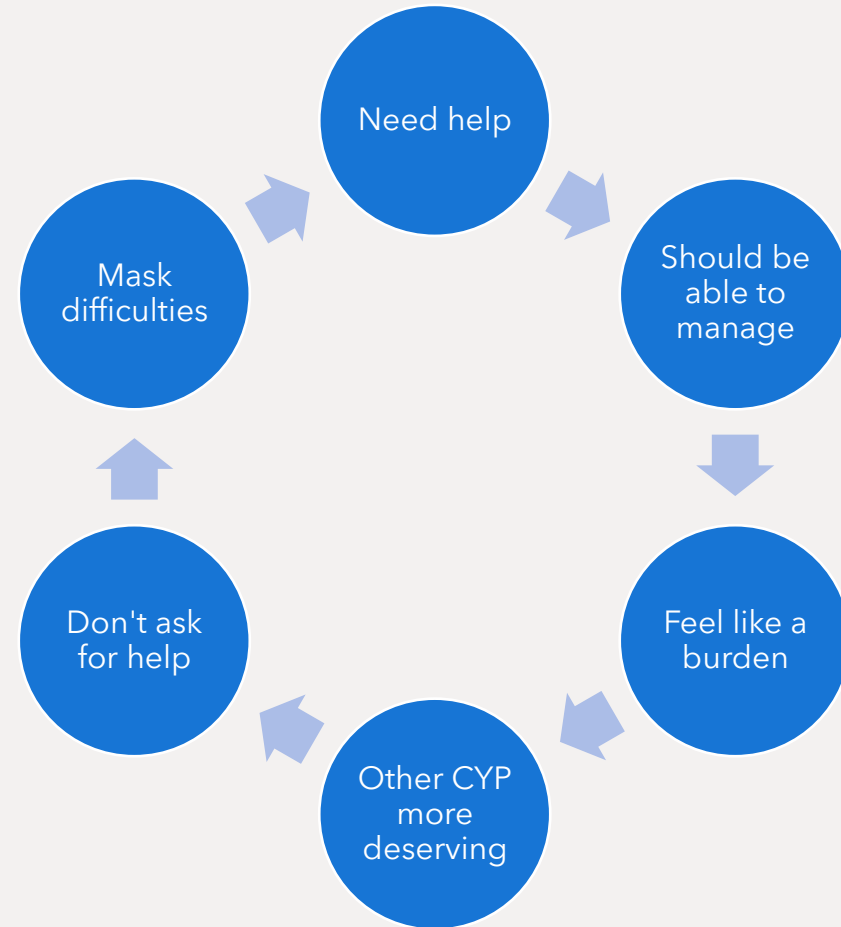Ethos and attitudes

Rights vs realities

Assumptions vs understanding 1

"If people didn't assume things about my needs and what they should do to help me, it would have made the whole experience so much easier. If they'd just asked, and then listened to the answer." (Rosie)

- Assessment of need:
  - ❖ Girls' voices not present in reports or records pre autism assessment
  - ❖ Standard assessment forms (eg SDQ) often unhelpful, lacking context
  - ❖ Teachers underestimated or did not recognise need to support autistic girls who were academically able
  - ❖ Difficulties with collaborative tasks experienced by all girls and their peers – but it was the autistic girls who were blamed, teased or marginalised
  - ❖ Support provided was often a general autism strategy, such as an exit pass, rather than individual provision based on what each girl said would help her
  - ❖ Use of positive events would have informed better support

Needing help

"[At secondary school] *I kind of thought I wasn't worth anybody's time. Felt a bit like worthless, like no one should really have to be my friend.*" Jane

Need help

Should be able to manage

Feel like a burden

Other CYP more deserving

Don't ask for help

Mask difficulties

Assumptions vs understanding 2

- Absence as a strategy used by school staff 👍
  - ❖ Supply of exit passes; exemption from lessons; part-time timetables
  - ❖ Loss of access to lessons and work
  - ❖ Short-term relief; didn't help return to class *in isolation*
  - ❖ Encouraged girls to feel didn't belong in class; problems wouldn't be solved in class; up to her to solve problems and then return

- Absence as a strategy used by the girls 👎
  - ❖ Support not always available in places allowed to withdraw to; not always safe places
  - ❖ Avoided certain spaces at school
  - ❖ Some staff objected to girls choosing absence: 'She said it was damaging my social skills'
  - ❖ Pressured to return
  - ❖ Leaving school positive for some, but a relief and a worry for most

Assumptions vs understanding 3

- Wrong red flags
  - ❖ What if academic targets met?
  - ❖ What if internal absences unrecorded?
  - ❖ What if they are the 'ideal pupil'?

Ethos and attitudes

Grades vs wellbeing

Relationships

Rights vs realities

- Action vs inaction

  ❖ *"The point at which someone is having issues is too late. You need to have fixed it beforehand, you need to have set things up to be there."* (Alex)

  ❖ *"I just didn't think they'd care enough."* (Jane)
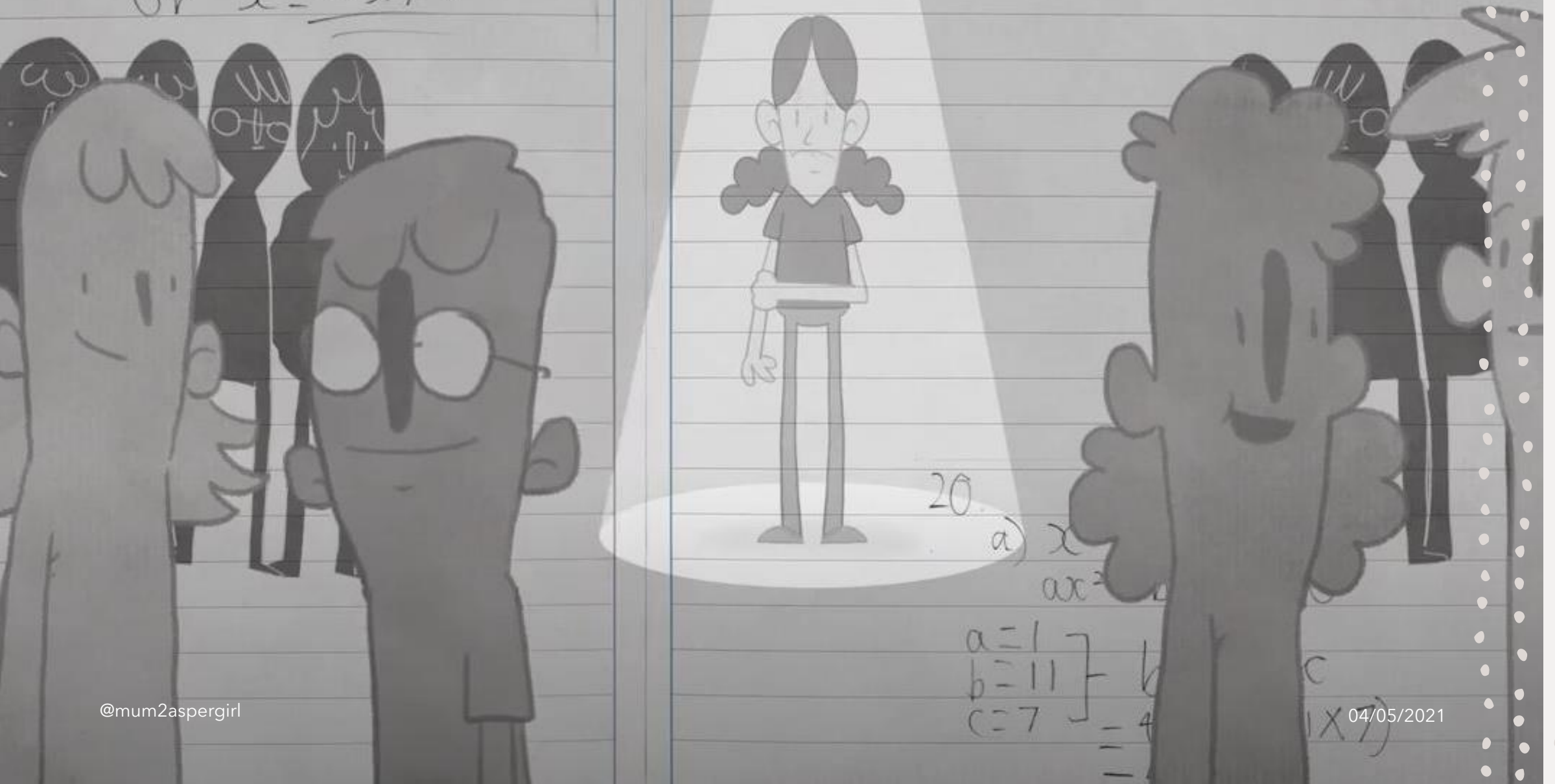
  ❖ *"Less empty reassurances from teachers. Actually <u>do</u> something."* (Ming)

'Even the most able children with autistic disorders may find mainstream school intolerable.'
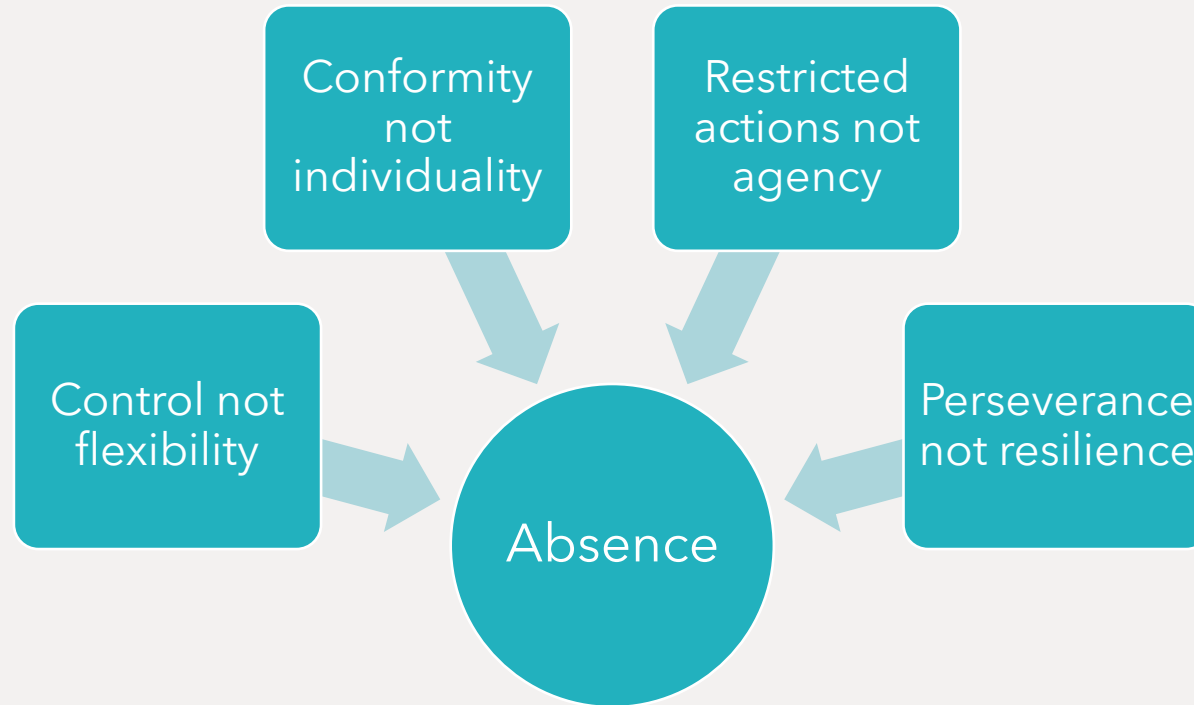
(Lorna Wing, 2007)

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Who is in charge?

Control not flexibility

Conformity not individuality

Restricted actions not agency

Perseverance not resilience

Absence

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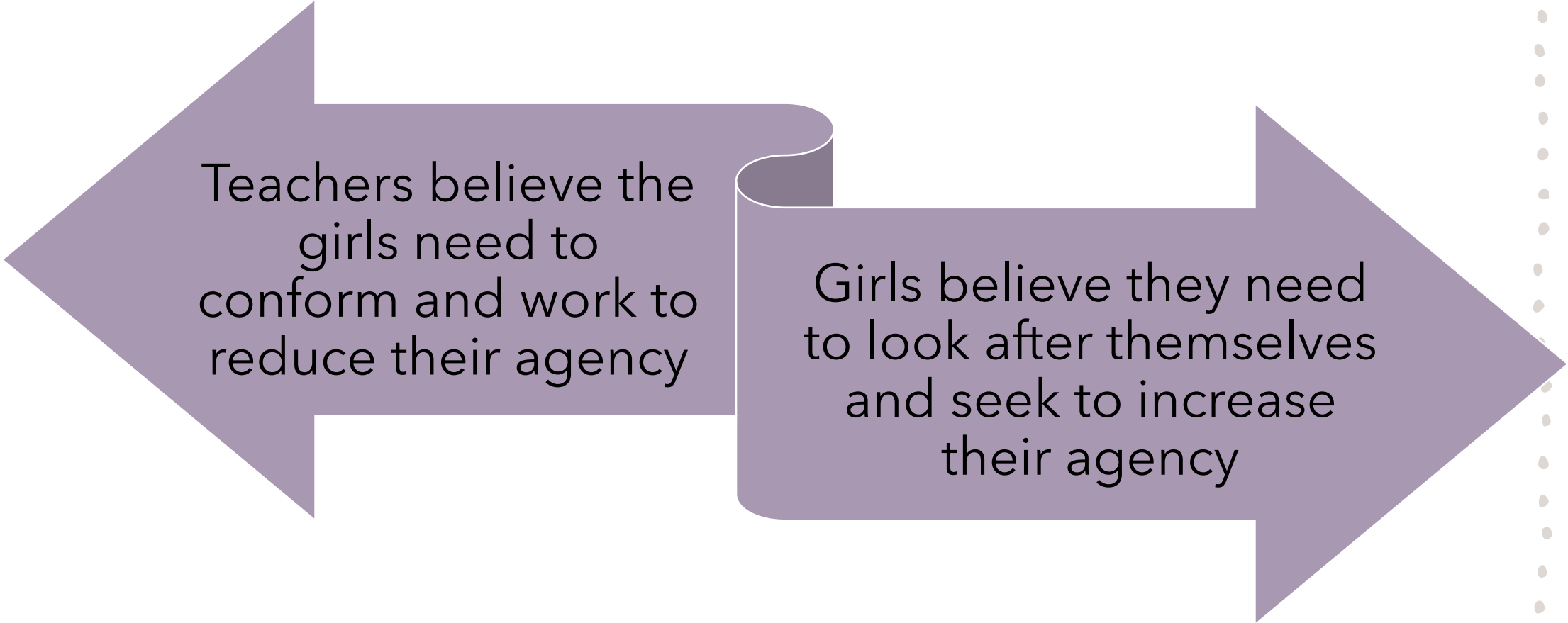
Importance of agency

Teachers believe the girls need to conform and work to reduce their agency

Girls believe they need to look after themselves and seek to increase their agency

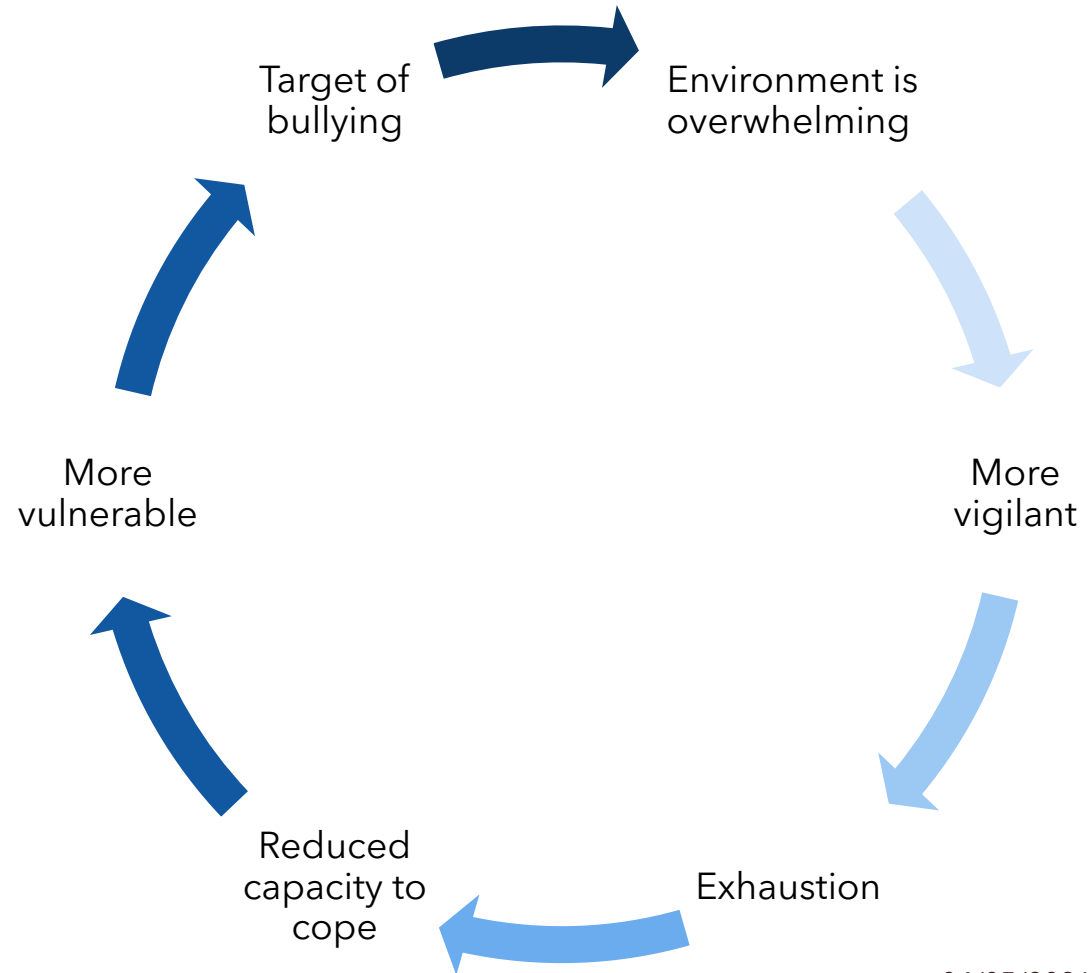# Factors influencing attendance

- External factors cause deterioration in mental health and exhaustion

- Reduced belief in own power to change things

Target of bullying → Environment is overwhelming → More vigilant → Exhaustion → Reduced capacity to cope → More vulnerable → (Target of bullying)

Conclusions

1. The autistic girls' voices were absent from reports and decisions about them

2. They were not rejecting learning, but an environment and ethos that were damaging their mental health

3. Attainment and absence statistics do not necessarily identify autistic girls who need support - alternative flags of concern are required

4. If you don't meet their needs, don't be surprised when they stop attending school!

Five recommendations

1. *"Just <u>listen</u>. It's not rocket science, just listen"* (Daisy)

2. *"Be curious"* (Robyn)

3. *"Prioritise pupil wellbeing"* (Erin)

4. *"Take action"* (Jane)

5. *"Be more informed about being autistic"* (Alex)

With special thanks to...

- The participants in the life history interviews: Alex, Daisy, Emily, Erin, Jane, Lizza, Ming, Robyn, Rosie and Sally (*all pseudonyms*)

- The girls who gave permission for their NHS records to be accessed: Beth, Cayla, Emma, Gina, Katie, Lauren, Molly and Sophia (*all pseudonyms*)

- The advisory group of autistic girls: Bronwen Hails, Izzie Moyse and Honey Parker

Any questions?

r.moyse@reading.ac.uk

Ruth Moyse | LinkedIn

@mum2aspergirl

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