

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

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## Discussion points

1. The impact of language
2. The referral process
3. Same child, different perspectives
4. Absences & missing voices
5. Task-based insights
6. Assumptions vs understanding
7. Importance of agency
8. Warning flags
9. Recommendations

## Absent autistic girls

The absence of autistic girls from mainstream secondary schools is a growing issue. Research findings presented here are primarily drawn from interviews with ten autistic girls. These are supported by the analysis of attendance data from the Department for Education (DfE), data from the autism assessment team of one National Health Service (NHS) Trust, and case studies of the NHS-held records of eight autistic girls.

This booklet encourages the reader to see the issue of non-attendance from the perspective of the autistic girls who participated in the study. Recommendations to support good practice are made throughout. This learning can be applied across all environments and might be useful and of interest to any individuals or services working with autistic young people.

## 1. The impact of language

- 'Truant'
- 'School refuser'
- 'Emotionally-based Non-attendance'

The words we use to describe a child who stops attending school says a lot about **where** we think the problem lies, and **whose** responsibility it is to 'fix' it.

Terms that locate the problem within the child imply that there is something wrong with them, and that they are the one who needs to change.

Using a neutral term, such as **non-attendance**, is more helpful in finding solutions together and without blame.



## 2. The referral process

In the NHS Trust examined, fewer girls aged 5-18 years were referred for assessment or diagnosed than males, as expected.

However, there were wide variations **between areas** served by this Trust in the number of these girls who were referred to the autism assessment team.

Three main types of people referred children and young people for assessment: GPs, school staff and staff within other CAMHS teams. Teachers referred far fewer girls than the other two main types of referrer.

Eight case studies of girls who had been diagnosed **all** showed delays in the referral process, with implications for the provision of suitable support and the quality of educational outcomes.

## 3. Same child; different perspectives



*The words we use hold value, so it is important to choose them carefully. Share and value the perspectives of others.*

An examination of the records identified multiple occasions when the same girl was **perceived differently** by people involved in her care. Often the picture described by the school was in contrast to that of the girl's parent. In addition, sometimes practitioners at the same school held differing opinions, or there were conflicts in the views of clinicians.

### Assessing impact

Some language used by teachers to describe a girl was unexpectedly judgemental, such as the use of words like **'burden.'** Other girls were reported to be 'a pleasure to teach'. Both types had implications for the way the girls were supported. Those described as the second type were referred earlier and received most support in school, perhaps because they had a greater impact on the class or teacher.

#### FIRST TYPE OF DESCRIPTION

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

## 4. Absences

Statistics obtained from the Department for Education show that autistic girls are more likely to be **persistent absentees** at secondary school, as a percentage of their group, compared to autistic boys, non-autistic boys or non-autistic girls.

The official attendance figures of the girls in this study also declined significantly once they began secondary school. However, half the girls reported wanting to stop attending school from the first day or within the first year of primary education, but persevered at school for 8-9 years before they finally stopped attending.

However, the girls also revealed multiple examples of informal absences that did not show up in official statistics, such as:

- Being told not to participate in a lesson
- Being put in isolation
- Removing themselves from class for respite

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

*"It's difficult because I did really want to go there and I really wanted it to work out. And I was trying my hardest." Lizza*

Strategies involving absence sometimes appeared to benefit the staff or other pupils more than the girls. Absence from the classroom meant lessons were missed and relevant work typically not provided, which penalised girls for not being able to endure intensely challenging situations. Absence, when used by the girls as a coping strategy, was not approved of by some staff who prioritised compliance over understanding. On one occasion in particular this led to an autistic girl being returned to a place she felt unsafe.

*"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*

## Missing voices

The voices of the girls in the case studies were not present in their NHS records until the point of their autism assessment.

*When the girls felt in control and listened to, they were able to provide explanations for their concerns and suggest simple solutions.*

The participants in the life history interviews stated that their views were not sought in school, or they were not acted upon.

Individual teachers had the most impact when they showed an interest in why the girls struggled and helped them find solutions.

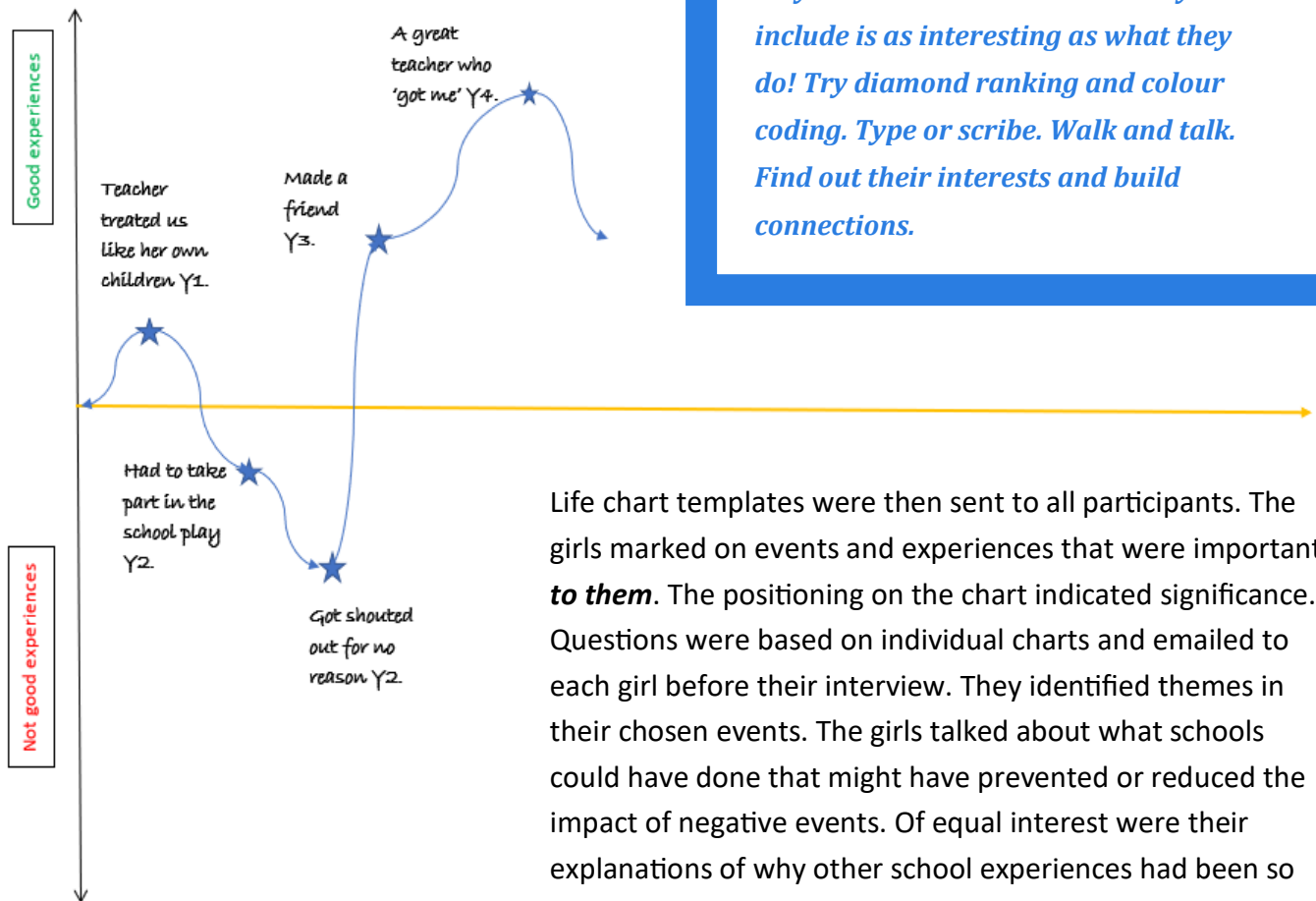
## Conclusion

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

Incorporate views of young people from the start. Be proactive in inviting parent/carers to share their knowledge and collaborate. Don't assume. Share perspectives. Use respectful language.

## 5. Task-based insights

This research first used a personal construct exercise about each girl's ideal school and the sort of school they did not want to attend. The girls were asked to say or draw three things about nine themes. They then used diamond ranking to prioritise their responses about their ideal school.



### 'I can't get them to talk'

*Talking is not the only way to communicate. Use visual methods and activities to engage interest and take the pressure off interacting. Ask children to draw, make collages, create timelines or take photographs of things they like—or don't like. What they don't include is as interesting as what they do! Try diamond ranking and colour coding. Type or scribe. Walk and talk. Find out their interests and build connections.*

Life chart templates were then sent to all participants. The girls marked on events and experiences that were important **to them**. The positioning on the chart indicated significance. Questions were based on individual charts and emailed to each girl before their interview. They identified themes in their chosen events. The girls talked about what schools could have done that might have prevented or reduced the impact of negative events. Of equal interest were their explanations of why other school experiences had been so positive, as these revealed what helped each individual most.



a) the sensory environment?



b) the people?



c) the work?

The adults in school were regarded by the girls as the most important factor in their ideal school. The girls said that the **right approach by school staff** would mean the adjustments they needed would be understood and accepted. This did not mean that getting the sensory environment right was unimportant, but a recognition that a personal plan would not be actioned unless staff agreed with it.



## Ethos

All the participants in the life history interviews described themselves as academically able. They were aspirational with most hoping to attend University, and achieving good grades was important to them.

However, they wanted to attend a school that cared primarily for their **wellbeing**, not one focused on grades or reputation. They wanted to feel safe, accepted cared for and **seen** in school, and believed that achievement would follow.

*Don't assume. Show you care.  
Build trust. See the child.*

## 6. Assumptions vs understanding

### Assessment of need

The girls identified lack of understanding by school staff as a key theme in their experiences, despite their autism diagnosis. This sometimes led to their needs (and strengths) being incorrectly assessed. In some cases their academic ability overshadowed the adjustments they required to **thrive** or, conversely, it was not recognised. Assumptions

*"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." (Rosie)*

made by adults sometimes meant support was not provided or the strategies offered were inappropriate for the individual. Some girls felt their differences were pathologised and regarded as deficits.

Standardised assessment forms used imprecise language or lacked essential context which did not enable the girls to convey their thoughts. This highlights the need for unambiguous tools to avoid mutual misunderstandings, and which start with the voice of the young person.

### Relationships

All these girls required some form of support, yet getting **help** was difficult. Some were told they asked too many questions, that others were more

*"I just didn't think they'd care enough." (Jane)*

deserving, or that they needed to be more resilient. Some described feeling worthless, or a **burden**, and felt they ought to be able to manage alone. The result for some girls was that they stopped asking for help and tried to find their own strategies to manage or to resolve difficulties alone.

Having an adult at school they **trusted** made the difference for some girls between being able to attend or not. These were often librarians, offering quiet, safe spaces, or a favourite teacher.

# Mental health

The qualitative aspects of this study required small numbers of participants and case studies. Findings can not be generalised. However, some of the findings relating to mental health merit reporting. Three of the girls out of the eight in the case studies and the same number in the interviews had self-harmed and expressed suicidal ideation. At least two of the girls had made suicide attempts, with one making multiple attempts. Four of the eight girls interviewed had been admitted to hospital due to mental illness. Seven believed that a decline in their mental health was due at least partially to their experiences in school.

*"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." Erin*

Education is a right, and yet some of these girls felt they had to sacrifice their education in order to protect their health.

## Conclusion

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

Focus first on pupil wellbeing. Find out what they need to feel safe, and take action. Engage an autistic adult to do a sensory audit of the environment. Model acceptance.



*Small actions can have a big impact. Be proactive about establishing support before problems grow. Make them feel seen and that they belong. Provide a nurturing environment.*

## Time

Staff are under pressure to teach a packed curriculum and achieve high grades for their pupils. They may feel there simply isn't time to remove barriers to the inclusion of these girls. However, the girls in this study didn't need a lot of time. **Small gestures** that made these girls **feel seen** and **accepted** had a big impact. Being allowed to eat lunch in a quiet classroom, go to the library or have a talent recognised were all appreciated.

The possible implications for mental health of unmet needs mean that time must be found.

## 7. The importance of agency

The evidence from the research showed that conformity was a requirement in school. It was seen in the words used by teachers to describe some of the girls in the case studies. Some of the girls who participated in the life history interviews reported the use of restraint, abuse and assault in school. Some said they felt blamed and unfairly punished, whilst others felt forced into doing things that made them extremely uncomfortable.

*“It was, you must, you must talk, you must communicate with the world and these horrible teachers.” Robyn*

This insistence on conformity was problematic. Meeting individual needs and accepting difference is made more difficult in a rigid system. However, a legislative framework protects the right of autistic girls to an education meaning ‘reasonable adjustments’ must be made.

*“I would be smiling and acting like I was fine. I would be getting on with my work and doing everything I could to fit in. Inside I would be worried and upset and anxious.” Rosie*

Without the right support, most of the girls in this study tried to find ways to look after themselves. However, staff who prioritised conformity prevented this, such as by stopping access to the library. This could also lead to punishment, for example for not wearing mandated school uniform despite sensory overwhelm.

These autistic girls knew what they needed. Increasing their agency could reduce demands on teachers and their time.

## Conclusion

**Attainment and absence statistics do not necessarily identify autistic girls who need support.**

Listen to the young person. Find out what is having the most impact on them. Accept that they may have different priorities to you. Consider mental health and wellbeing, the environment and sleep patterns. Seek to understand the cause of absences from class and other spaces. Take action to stop bullying.

## 8. Warning flags

Some girls reported hitting academic targets even when persistently absent from school. It is important to consider alternative warning flags. Earlier indicators of unmet needs in this study included bullying, sleep problems and in-school absences. Persevering in school was exhausting.



*“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*

## 9. Recommendations

### 1. “Just listen. It’s not rocket science.”

(Daisy)

The autistic girls in this research said the best way to find out what would have helped them stay in school was to ask them, and then pay attention to their responses. Their **voices** and views should form part of all plans and assessments about them, in school and in referral documentation for assessment.

### 2. “Be curious.” (Robyn)

The girls wanted school staff to query **why** they were absent from the classroom, playground or canteen. The use of a short-term relief strategy - such as an exit pass - should be followed up. The reason for leaving must be understood and action taken to provide a solution in class. Otherwise absence will continue to be necessary.

### 3. “Prioritise pupil wellbeing.” (Erin)

These girls wanted to be in school learning and achieving. Being happy, feeling safe and that they belonged in their school were prerequisites. This



## Conclusion

### This is a 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.

requires staff who acknowledge them, who build relationships based on interest and respect, who avoid unnecessary pressure, and who give them time. Provide academically appropriate education in a nurturing environment.

### 4. “Take action.” (Jane)

Most of the girls had experienced significant bullying yet, when they told staff, nothing was done. The girls wanted “less empty reassurances from teachers” (Ming).

*“When something goes 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.’” Rosie*

### 5. “Be more informed.” (Alex)

Training for **all** school staff is necessary to combat myths and misunderstandings. It is a recommendation of the study that training be autistic-led. Schools may find they have experts in their midst, and can benefit from input from autistic staff, parents and pupils.

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