VRU Difference Matters Report

Resources For Autism August 2024

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1. Executive Summary

This report summarises insights from a consultation with 78 neurodivergent children and young people and their parents about their experiences of mainstream secondary school in London.

It was commissioned to inform the development of <u>London Violence Reduction Unit's</u> (VRU) <u>Difference Matters</u> programme, funded by the Mayor of London. Difference Matters seeks to improve the experiences of neurodivergent young people in school by making schools more neuroinclusive. It aims to reduce persistent absence, suspensions and exclusions as part of preventing young people from being affected by violence.

This report summarises the findings of our research and makes key recommendations for the attention of school leaders in London's mainstream secondary schools. It accompanies a companion report, written by research consultant ECORYS, which shares the findings from their research with professionals supporting neurodivergent young people.

We found that:

- 56% of respondents have 2 days or less per week that they would consider to be good days at school.
- 57% of the survey respondents reported that they missed most (34%) or a few days (23%) at school.
- 51% of children and young people said that they did not feel safe at school for some of the time, rarely or never.
- 28% reported some form of exclusion, both fixed term internal fixed term external, and permanent.
- 49% of the survey respondents reported that they didn't have any friends at school.
- 47% reported not having a quiet or sensory space available at school for them to use.
- 60% find lunchtimes, transitioning between lessons, break times, the start and end of the school day overwhelming.

Our recommendations are for schools to:

- 1. **SPACES:** Provide social hubs and safe spaces for neurodivergent young people to be when needed
- 2. VOICE: Ensure there are opportunities for neurodivergent young people to advocate for their needs, e.g. through school councils or youth voice groups
- 3. **POLICIES:** Review policies to ensure these are neuroinclusive and that adaptations and adjustments can be accommodated
- 4. **PASSPORTS**: Work with young people to create pupil passports that help staff understand young people's strengths and needs
- 5. **PEOPLE:** Identify key staff who will support neurodivergent young people
- 6. **TRAINING:** Provide quality opportunities for adults and peers to learn about neurodiversity



2. Introduction

Resources for Autism (RFA) is a registered charity founded in 1997, operating in London and the West Midlands. Our vision is a world where autistic people can live fulfilling lives, with equal chances to those of their non-autistic peers.

RFA provides practical services for autistic people of all ages and level of needs, and for those who love and care for them in. Those services include, but are not limited to, social opportunities, mentoring, support to families and training for professionals.

Our research

Resources For Autism's research focussed on the lived experiences of neurodivergent children, young people and their families who attend mainstream secondary schools. Our research took place over 6 months from April to July 2024, and comprised of three strands:

- an online survey
- focus groups for children and young people
- qualitative interviews for children, young people and parents and carers.

78 children and young people aged 11 to 23 and 4 parents fed directly into the research via focus groups and qualitative interviews, amounting to over 30 hours of interview time.

We collected responses from 13 London Boroughs via the survey.



Key Findings

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3. Findings

Reported anxiety rates for neurodivergent students

When we surveyed children and young people and asked the question, how many good days at school do you have on average a staggering **56% of respondents have 2 days or less per week that they would consider to be good days at school.**

If you couple the number of school days that "could be considered to be good" and the related question about missing school due to feeling anxious you start to build a picture of neurodivergent children and young people who are not thriving at school.

57% of the survey respondents reported that they missed most (34%) or a few days (23%) at school, compared to 41% who stated that they didn't miss any days of school due to being anxious.

"Because of my sensory issues, I couldn't cope with overcrowded classes, busy hallways, not enough assistance provided during lessons or lunch time. After endless meetings between the school and LA, I was excluded from school and stayed home for a long time. Having such hard times at school, I developed anxiety and depression, so barely left the house."

Survey respondent

Perception of safety at school for neurodivergent students

51% of children and young people said that they did not feel safe at school for some of the time, rarely or never.

In focus groups and qualitative interviews, the young people said that they feel unsafe at school due to bullying, feeling isolated and not knowing who they could speak to about feeling unsafe.

"I spent my free time at school...sometimes on my own in the playground, sometimes playing football but finding the social/physical side of that difficult."

Survey respondent

Exclusion rates for neurodivergent students

28% reported some form of exclusion, both fixed term internal fixed term external, and permanent. The disruption to their education that these can have on a child or young person who has additional needs cannot be underestimated.

"My child was so miserable during their second year at their secondary school. They seemed to fade before my eyes as they were often in detention, more than 2 per week for relatively small infractions like forgetting equipment. They were anxious all the time, and often very dysregulated in the morning."

Parent respondent

Heyne *et al.* (2019) proposed an updated definition of three dominant ways of conceptualising school attendance problems - truancy, school refusal, and school withdrawal, and they add school exclusion as a fourth concept (which is significant as it now acknowledges that school-based actions can create and influence attendance problems).

"It was much more difficult to get my son into a new secondary school after he was permanently excluded from his first secondary school at the end of year 7, as it was perceived that he was a "problem child" rather than a child with unmet additional needs."

Parent in interview

School exclusion is defined by Heyne *et al* (2019) as an absence from school or from specific school activities. This absence is caused by the school: employing disciplinary measures in an inappropriate manner; 'being unable or unwilling to accommodate the physical, social-emotional, behavioural, or academic needs of the young person'; or 'discouraging the young person from attending, beyond the realm of legally acceptable school policy'.

Differentiation Between School Attendance Problems: Why and How? Heyne et al (2019)

Making friends at school for neurodivergent students

49% of the survey respondents reported that they didn't have any friends at school.

Belonging to a community is part of being in the wider world. Many neurodivergent children and young people find it more difficult to make friends, and at secondary school

that is compounded by dealing with anxiety, overwhelming spaces, and a myriad of sensory based difficulties.

"My son was not bullied but socially struggled to find and make new friends, lack of support and understanding of his ASC, lessons were too long (double lessons) with short breaks in between meant he could not focus, strictness of teachers and threat of detention for homework etc led to constant anxiety, lack of understanding of sensory needs etc- all adding up to overwhelm and stress throughout a school day."

Parent survey respondent

During the Focus Groups and Qualitative Interviews, young people were able to talk about friendships at school; they overwhelmingly shared that they had made their friend(s) in the quiet spaces (libraries or the SENCo spaces) that are set up. Many self-reported that it was easier to make friends in these spaces as they are more likely to be people who understand them, and that they felt that they could be themselves.

"The library is a place we go to at break or lunchtime, we can play D&D and card games. I found it difficult to find friends in Year 7, but I found some friends through shared interests and using the library as a safe place."

Interview respondent

Neurodivergent students and unstructured time at school

We asked about the areas of the school that are overwhelming and the times of the school day that are overwhelming. The results are concerning.

"I mostly (spent my time) in the learning support room. I made one friend, also with autism and other needs, but we were frequently split up as we were seen as a bad influence on each other."

Survey respondent

We would expect to see that moving around school between lessons would be overwhelming, and other transition points such as arriving to school as these are areas of the day when many people are moving around a finite space such as the entrances and corridors.

It is more concerning to see that lunchtimes and breaktimes are also overwhelming, with many neurodivergent children and young people feeling isolated and unable to interact with their peers.

"Absolutely zero positive experiences, I hated everything and because school is such a hierarchical environment- I hated most of my friends too. I made one amazing friend, which maybe was a positive experience(?) but we bonded over our struggles, and she was later diagnosed with autism too and hospitalised for mental health struggles. As sad as it sounds, I think our most positive experiences were hiding under the staircase together."

Survey respondent

60% find lunchtimes, transitioning between lessons, break times, the start and end of the school day overwhelming.

58% find corridors and hallways overwhelming,

53% find playgrounds, play areas and playing fields overwhelming and not a place that they want to spend their time at lunch or break.

49% reported finding specific classroom overwhelming and 40% find the gym and sports hall overwhelming.

35% find the toilet facilities as being overwhelming.

School is in general a very stressful experience for many neurodivergent students, even when we are only factoring in the school environment.

The sensory environment at school

53% of respondents didn't feel that the school environment is supportive of their sensory needs.

The reasons for not feeling supported in school on a sensory level were reported as: Not having accommodations such as a Breakout card applied consistently across the school, which in turn adds to the anxiety of being at school.

Some young people mentioned in the interviews that they felt that they had to mask or camouflage their self-stimulating behaviours (known as stims or stimming) and their need to use fidget toys such as spinners due to an inconsistent application of accommodations across the school.

When we factor in the respondents who spoke about whether staff at school understand their sensory needs, **54% felt unsupported by school staff** for most of their time in school.

The reasons behind the challenges relating to sensory support were raised by some of the parents and carers: that staff were not following the Pupil Profiles that had been made and disseminated at school, accommodations were not applied consistently, and any Behaviour Support Plans that were in place were also not being applied consistently. This can lead to problems in school, feeling of not being understood, and a raised risk of some form of exclusion.

"Having an open SEN room at lunch and breaks for young people, just a fully open-door policy with support, the chance to get lunch early and take it there. My cousin is at a different school and spends lunchtime in the toilet hiding like I did as a teen."

Survey respondent

47% reported not having a quiet or sensory space available at school for them to use.

25% stated that they used the spaces that were available when they are made available, with 15% using these designated spaces often.

"The system needs to change, if they keep focusing on supporting only students with special needs- then what about the kids that aren't diagnosed? The only reason a diagnosis was necessary for me was because I was disabled within the school environment. I'm not innately disabled, but the way that things were run was incredibly disabling."

Survey respondent

Recommendations from neurodivergent young people and their families



6. Training for staff & peers



Recommendation 1: Safe spaces & social hubs



Provide safe spaces or Hubs for neurodivergent & additional needs students.

These Safe spaces or Social Hubs for neurodivergent students should include being used throughout the day, including as a Breakout space and for schoolwork when they are overwhelmed.

Additionally, we need to consider spaces for students who may need a more active space and equipment such as a trampoline that can be used to help self and co-regulate.

Recommendation 2: Spaces on student councils or forums



Many young people who were asked about being able to take part in a school council with other young people from school felt that it would be a good idea, however, they did not want to be made to feel "othered" or "singled out" for their neurodivergence as being the main reason for being on the school council.

There is also the issue of ensuring that all young people can have the opportunity to be on a school council, not just the young people who are more confident about having a voice, such as those young people who might have limited speech, and other additional needs.

Schools would need to ensure that all materials and paperwork for school council meetings are produced to be as accessible as possible.

Recommendation 3: Review of school policies



Schools need to be aware that school policies are not usually neurodivergent friendly.

In particular, the policies for behaviour, uniform, homework, were singled out as creating confusion, discomfort and higher anxiety levels.

These could be co-produced within the school councils and alternative student groups so that they better reflect the needs and experiences of neurodivergent students.

Recommendation 4: Pupil passports



Many young people and parents felt that not enough school staff had read the pertinent information for the neurodivergent individual. We spoke about having a Pupil Passport, and it was felt by those interviewed that this should be a Strengths based document, starting on what the young person can do, and their interests, and then moving into strategies to be used at times of dysregulation, as well as making sure that the accommodations are clearly stated so that they can be applied consistently across the school. It is also important that this is co-produced with the young person and a trusted adult in school.

Recommendation 5: Identified staff



Identified staff (allies) who can be the person that the young people can turn to if they are having difficulties during the day.

These should be staff who have had additional training and are able to act as a mentor to neurodivergent young people.

It was also felt that other young people could also act as these mentors or allies if they had specific training.

Recommendation 6: Training for staff and peers

Staff training and understanding of neurodivergence was an issue that came up often in the discussions and interviews.

It is felt that more and better training is needed across the board for all staff, so that they can better teach and work with neurodivergent children and young people.

This training should be done with an accredited organisation that includes lived experience trainers.

Additionally, many young people spoke about wanting their peers to have better understanding of neurodivergence and additional needs, but that this should be placed within a school cohesion programme rather than focussing on the differences of the neurodivergent students, as this can lead to an increase in bullying. It is felt that using an *"Everyone is different"* approach rather than singling out what makes someone different specifically might alleviate the isolation and bullying of neurodivergent students.

5. Conclusion

"I'm filling this in for my daughter who did not receive her autism diagnosis until after she had left school. Despite my flagging my concerns around her anxiety and difficulties I was dismissed and ignored because my daughter is very high functioning and academically gifted, exacerbated by undiagnosed selective mutism which meant she could not ask for help. Her problems were swept under the carpet, and they didn't refer her until it started affecting her academic achievement right at the end of her school career. This means she didn't get any support at university and nearly died as a result."

Parent survey respondent

The grim reality is that for many neurodivergent young people in secondary mainstream schools is that these are not environments where they can thrive and develop into young adults in the same way that neurotypical young people may be able to.

The levels of anxiety around school contribute to emotionally based school avoidance (EBSA), lower academic outcomes and potentially a loss of opportunity for their future.

Missing school, and the social disenfranchisement that this can lead to, can also make neurodivergent young people more vulnerable, and can open them up to several personal safety factors such as being involved in crime, families in crisis, self-harm, suicide ideation, social isolation.

This doesn't mean that all is lost. Implementing the 6 recommendations within mainstream secondary schools will go some way to helping to make sure that school does work for everyone.

Teachers and school leaders, particularly those working in mainstream secondary schools, should review the report and recommendations from young people. They should take the time to plan the changes they can make in their schools to improve the experiences of neurodivergent young people. It is also important that schools remember to look beyond those young people that have a diagnosis, so they also support the wider cohort of neurodivergent young people in their community.

Organisations such as the VRU, through programmes like Difference Matters, can highlight the recommendations, and create opportunities for young people and school leaders and teachers to collaborate to bring about real change for neurodivergent members of their communities. Organisations such as Resources for Autism can offer training and support to schools.

Statistics



The other range included answers that reflected the complexity of this issue – many revealing that they no longer attend school at all and others that they had missed whole terms.



Do you feel safe at school?



Do you have what you consider to be good friends at school?

Where do you spend your break & lunchtimes?





Do you feel that the school environment is supportive of your sensory needs?

Do you feel that school staff are supportive of your sensory needs?

