Greater Manchester Youth Combined Authority Meeting Briefing Thursday 9th/June 2022

## How can schools better support neurodivergent young people?

A summary of neurodivergent young people's views from across Greater Manchester

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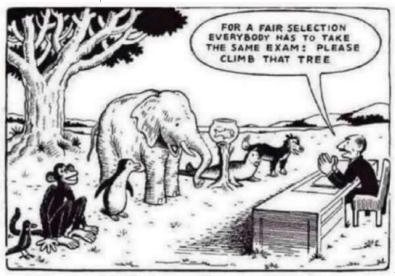
Created by: Thomas Gasseling (young person) Bill Morris (young person) Andy Smith (Spectrum Gaming) Jen Hughes (Spectrum Gaming)

## What is neurodiversity?

People have different skin colours, hair colours, eye colours and more. This is part of diversity.

We have differences in the ways our brains function too. This is part of neurodiversity.

Whilst everyone's brains are different, around 20% of people are neurodivergent. This means that our brains work in ways that are very different to societal standards of 'normal'. Examples of neurodivergence include: autism, ADHD, dyspraxia and Tourette's Syndrome.



**Our Education System** 

"Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid."

#### - Albert Einstein

Diversity is important for society, as different perspectives is vital for creativity and innovation. If we were all the same, the world would be much less interesting, and so being different is a beautiful way to be! Being different or neurodivergent compared to others can mean that you can find some things difficult, but if you get support for your difficulties, then your strengths and unique thinking are a true credit to the world.

But, since people can't see that our brains work differently, neurodivergent people are often misunderstood. Not only this, but the world is set up in a way that works for the majority, and this can have a detrimental impact on neurodivergent young people.

One of the biggest examples of this is the difficulties neurodivergent young people experience in school. This is a topic that comes into conversation regularly in our community. As a result, by combining both our own and our peers' experiences, we are able to share the main reasons why neurodivergent young people can struggle in school.

## What are the main reasons we struggle in school?

### Schools prioritising grades over wellbeing

When young people are struggling in school, rather than focusing on gaps in knowledge and grades, we believe schools should focus on a young person's overall wellbeing as a starting point. When a young person is feeling well, they are able to achieve more!

"When I am at school my anxiety is so high that I don't take anything in" - anonymous Spectrum Gaming member

#### The foundations of educational achievement

Meaningful friendships Peer acceptance Hope for the future Hope for the future Hope for the future Hope for the

Resources such as the NHS Five Ways to Wellbeing are a great way to categorise what every young person should have for positive wellbeing in order to have a solid foundation for learning. In addition, here are some of the key priorities that are often mentioned by neurodivergent young people:

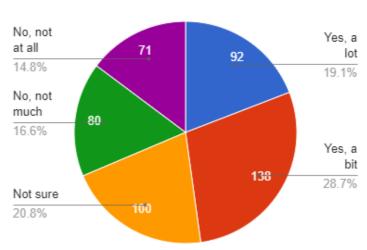
#### Having meaningful friendships

A huge number of neurodivergent young people say they feel alone, and there are two key reasons why:

- Not having access to social opportunities where they can meet others who understand them (e.g. a meetup for young people with ADHD only)
- Not having access to social opportunities based around their interests

Often young people say:

- There is a lack of provision available to help them connect with like-minded young people
- Whilst there are sometimes social opportunities available based on their interests, the events are often not very inclusive, making them inaccessible for neurodivergent young people.



#### l feel alone

NW SEND Young People's priorities survey, December 2020

#### Having opportunities to understand ourselves

When young people are diagnosed with a neurodivergent condition, often their parents are told about this but the young people themselves are not. This means that young people often do not understand why they are struggling or what support they need in order to thrive, which can be confusing and overwhelming. In addition, they are often denied the opportunity to identify and take pride in their strengths as a result of their neurodivergence. Unfortunately as a result of this, a lot of neurodivergent young people are ashamed of, or reject their diagnoses

"When I was diagnosed as autistic I thought that it was a problem. Because I was diagnosed when I was struggling at school I felt singled out and like I was the problem" - anonymous Spectrum Gaming member

"When I was in year 4, I couldn't tell anyone I was autistic, as I learned that people thought autistic people were brainless and were bad for society" - anonymous Spectrum Gaming member

"At the beginning I felt so lonely and thought no one will ever like me then me and my mum did some research and luckily we found Spectrum Gaming which changed that" anonymous Spectrum Gaming member

#### Peer acceptance (not just anti-bullying)

A huge number of neurodivergent young people are bullied because of their differences. It is one of the main reasons mentioned as to why young people struggle to access school, or find it a negative experience. Often schools say they focus on anti-bullying schemes, but we believe they should go one step further and focus on acceptance. It is vital for the long term wellbeing of neurodivergent young people that their differences are accepted.

"Through school I learned that who I am is not ok. I still haven't recovered from this as an adult" anonymous Spectrum Gaming member

"Let's forget about the pupils and without them school was ok. Now add the pupils and school is hell." anonymous Spectrum Gaming member

*"I felt anxious and worried about the other students every day" - anonymous Spectrum Gaming member* 

"Not everyone understands sensory overloads or self stimulatory behaviours." - anonymous Spectrum Gaming member "I FEEL LIKE PEOPLE ARE ALWAYS TELLING ME THE THINGS I NEED TO DO TO FIT IN WITH OTHER KIDS, BUT NO ONE TELLS THE OTHER KIDS THE THINGS THEY CAN DO TO MAKE ME FEEL LIKE I BELONG."

#### I CAN MENTEE (AGE 13)

Source: I can Network

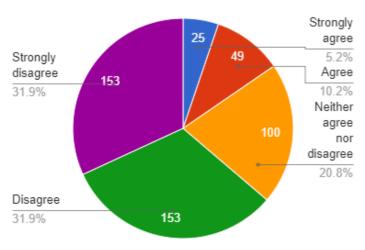
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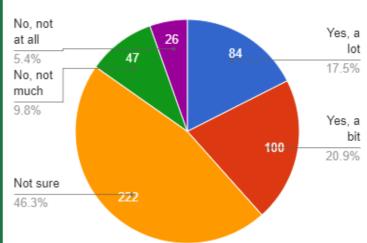
#### Hope for the future

A lot of neurodivergent young people have faced huge struggles/challenges. As a result, they may not feel hopeful for the future, resulting in a lack of motivation to succeed in school and do other things to improve their wellbeing. What can be done to address this?

I know what support is available for me when I finish education



#### I will reach my goals



NW SEND Young People's priorities survey, December 2020

## **Staff Understanding**

Neurodivergent young people across Greater Manchester feel that school staff do not understand them and their needs well enough.

"They would push and push for me to get back into class when it was not possible for me. After teachers were given instructions to sit me at the back of class many ignored this and put me at the front thinking they could help me when they should have listened to me and the pastoral team." - anonymous Spectrum Gaming member

"they promised things and I trusted them but it never happens (multiple times) they didn't listen to me or what I have to say or what i would like to do they thought I looked ok on the out side but on the inside I was having a mental breakdown" - anonymous Spectrum Gaming member

"Stimming teacher asked me to calm down and stop making a face and I couldn't help it." anonymous Spectrum Gaming member

"They say they don't see my anxiety or I'm doing well well I don't feel like that they don't understand I mask and I don't want too it's very tiring " - anonymous Spectrum Gaming member

"I was shouted at a lot and told to stop crying or to calm down which obviously if I'm having a meltdown isn't very helpful. I was put in a separate building which was the same building where the excluded kids went and that made me feel like I was being punished" - anonymous Spectrum Gaming member

"Teachers used to get annoyed with me when I didn't make eye contact. They also denied me leaving the class and I was really overwhelmed so I just walked out of class and I got detention." - anonymous Spectrum Gaming member

"There have been countless times staff have not only misunderstood but blatantly ignored. I have needed space and time, expressed this, but I have been forced back into classes panicking. I have ran out of school before due to it being the only way to escape the expectations." anonymous Spectrum Gaming member "It would be easier to list the times someone actually helped me than didn't, because there are probably less than 5 occasions over 8 years. The rest of the time I was completely overwhelmed and at the point of meltdown because schools didn't understand/care and assumed I was being defiant." - anonymous Spectrum Gaming member

"My junior school said I was definitely not autistic and I was fine in school once I had been dragging in crying.. I wasn't fine at all, I was breaking inside all the time. I got diagnosed autistic aged 13 by then I had suffered a lot of unnecessary trauma and developed extreme anxiety, I struggle to go to school at all." - anonymous Spectrum Gaming member

Young people are often accused of being naughty, lazy, defiant and more when they are struggling to engage in school or displaying stress related behaviours. It is important to know that all neurodivergent young people want to thrive in education, but often have barriers to this. As long as professionals focus on controlling behaviour rather than understanding and addressing underlying reasons for difficulties, the needs of neurodivergent young people will continue to be unmet.

## **Restraint and exclusion**

Many young people have reported being unnecessarily restrained or excluded from school, and the damaging impact this has had.

"Normally people restrain me to get control and contain me. I would be locked in rooms and treated like an animal.

Then when I was excluded from school, it made me feel worthless and unvalued.

When you are treated like you are worthless or like you are an animal, you become one. I already struggled with controlling my emotions, but this made me even more angry and full of rage. Professionals never understood the impact that restraining and excluding me had.

If I was treated differently, I wouldn't be the hateful, angry person I am now" - anonymous Spectrum Gaming member



When young people are struggling in school, we are often told that better support 'costs too much money'. But we don't agree! Most of what is important to us costs nothing or very little... Here are some of the things we would like to see:

## Not just staff training, the RIGHT staff training

Schools often have training that shares what neurodiversity is, and some classroom support strategies. This is a great introduction, but every neurodivergent young person is different, so this one size fits all approach is often ineffective.



What is missing

What may work better is a different approach, which is focused on listening to young people, working in partnership and understanding lived experience. Often for us, feeling valued and listened to is much more important than having all of their needs met:

"Due to lack of understanding from staff our son was constantly in fight or flight mode. Everything became an issue and his level of coping skills reduced. He was tipped over the edge for the smallest of issues and staff not following advice from his passport. Situations escalated and he became angry all the time.

It was terrible dark time for our son and for us as a family. He was referred to Healthy Young Minds numerous times due to self-harm and suicide ideation.

We felt that as a family we were at breaking point as we were worried about his emotional health. He was so angry and anxious all the time which caused his behaviour to become very challenging at home as well.

Fast forward a little and our son is in a new school, where he is thriving. He now has lots of friends and he is a popular member of the class.

Our son is getting his confidence and self esteem back, he attends clubs and after school activities on a regular basis. He is happy in himself and although he is now a teenager we don't have any of the challenging behaviour as previously experienced when he was on high alert/anxiety mode.

He happily goes to school and comes home relaxed. No concerns re his mental health and he no longer has thoughts of self harm. However he is scarred from his previous experience of school. For this I can't forgive, but have to let it go for the sake of my own mental health. We still have bumps along the way but the difference is that staff listen and as a result have an understanding of his challenges and needs. I am so grateful to his new school because I have my boy back." - anonymous parent of autistic young person

Key Question:

<u>Can training be developed alongside neurodivergent</u> <u>young people to ensure it is truly reflective of their priorities</u> <u>and needs?</u>



Source: Dr Ross Greene, https://livesinthebalance.org/

As mentioned earlier, no young person ever wants to struggle, but still schools and services can put the onus on a child to change their behaviour, rather than identifying the underlying reasons behind difficulties.

"I don't need a reward chart. I am motivated to learn. If I am struggling to engage in lessons it means you need to do something differently, not me. I am trying my best." - Anonymous Spectrum Gaming member

Key Questions:

- Can we create a system that focuses less on behaviour and more on understanding the reasons behind why young people struggle and what can help them to thrive?
- <u>Can we problem solve and create solutions together,</u> <u>rather than being punished, restrained, and excluded?</u>

## Create neuroharmony

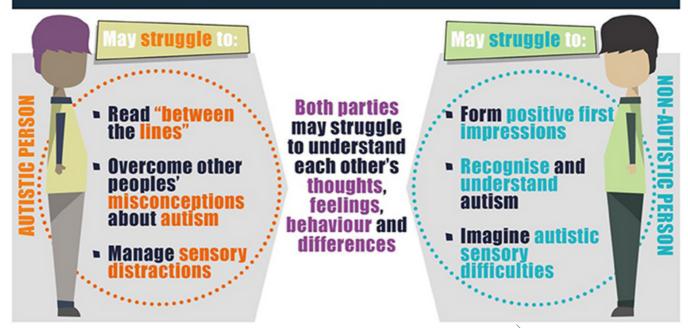
Spectrum Gaming is a community for autistic young people. In this unique community, autistic young people (and neurodivergent adult volunteers) collaborate and connect on a daily basis, creating a shared space in which the young people can be themselves and thrive.

In reflection, when comparing our community to spaces in which neurodivergent individuals are the minority, we have deduced that many of the issues we encounter in daily life stem from communication barriers we have with others who are not autistic.

This is not a one-way problem, but two way!

While neurodiversity is beautiful for society, it means there are barriers in understanding each other.

### THE DOUBLE EMPATHY PROBLEM



Source: Crompton, DeBrabander, Heasman, Milton and Sasson: https://kids.frontiersin.org/articles/10.3389/frym.2021.554875

We believe in creating an environment that works in neuroharmony. This is where an environment has the right level of compromise to make it work for all brain types, so everyone can focus on their strengths, and have support for their difficulties. This requires a lot of proactive education, understanding and collaboration, but the effects can be incredibly positive when we have a truly accepting space.

Key Questions:

- <u>Can we create a culture of neurodiversity acceptance</u>, and start open conversations so everyone can be <u>understood</u>, accepted and receive the right support?
- <u>Can everyone be educated about neurodiversity in the</u>
  <u>right way?</u>

## Focus not just on educational needs, but overall wellbeing

When we are being supported, can our wider wellbeing be a focus too?

- Can we be signposted to activities/groups we may enjoy, and be supported to access these?
- If after working with us you notice there is a gap in services or support, can you advocate on our behalf in the Local Authority? If there is not a feedback mechanism at the LA, can one be created?



Source: NHS Five Ways to Wellbeing

DIVERSITY IS HAVING A SEAT AT THE TABLE, INCLUSION IS HAVING A VOICE, AND BELONGING IS HAVING THAT VOICE BE HEARD. Source: Liz Fosslien https://www.fosslien.com/

Key Questions:

- Can wellbeing and coproduction be everyone's business?
- How can we make sure/it becomes everyone's business?

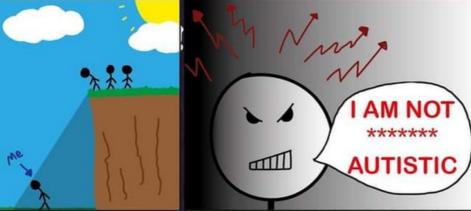


This briefing has been written using neurodivergent young people's views that have been gathered over the past 2 years. Here are the key pieces of consultation that were used:

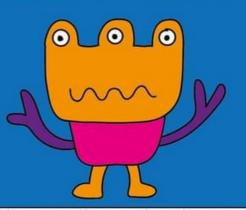
Spectrum Gaming's 'School is Difficult' project (2021): Spectrum Gaming ran a project on why neurodivergent young people struggle at school and what can help. 107 young people and 118 neurodivergent adults contributed to this through surveys, small focus groups and 1:1 interviews.

North West SEND Young People's Priorities Survey (December 2020): This survey aimed to capture quantitative data on the priorities of SEND young people across the North West. The results of this survey are not public, but were presented to the North West SEND Young People's Coproduction Steering Group. 482 young people contributed to this.

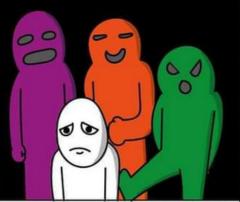
The writing of the briefing was led by Andy Smith (Founder of Spectrum Gaming). It was co-designed alongside 8 autistic young people and edited by Jen Hughes (Spectrum Gaming volunteer). Everyone who has worked on this briefing is neurodivergent.



It is important to remember that we don't have always the same starting point as everyone else. I received my diagnoses when I was struggling, so I related my diagnoses with hate, guilt or shame, rather than simply seeing them as differences.



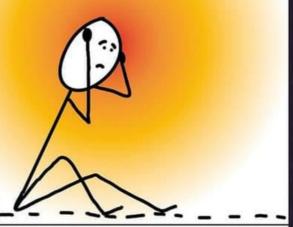
If you aren't diagnosed, you know you are different but don't have a reason why, which can leave you feel frustrated and lonely. We lose either way.



We are often misunderstood and seen as 'naughty', 'rude' and more. Not just by other pupils who may pick on or bully us, but staff too.



We never mean to act out, have meltdowns or get upset, this is a response to high levels of stress. WE DO WELL IF WE CAN.



If I am struggling, then either some of my needs aren't being met, I don't have the skills I need to deal with the situation, or I am completely overwhelmed!

There are some really simple things you can do to help us feel safe and happy, wherever we are:

Spectrum

Gaming



Talk openly about difference. Maybe if people understood why I am struggling, they will judge me less or even try to help



Help me understand my strengths and needs. Then when there is a problem or a barrier, we can try and problem solve together.



There is always a reason behind it, even if you do not understand it just yet. Try and see the situation from my point of view.



Please let me know you take my voice seriously, even if you get things wrong. Mutual trust and respect are more important than anything else.

Graphic created by Spectrum Gaming members on autsim and inclusion January 2021

# Thank you for reading

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Spectrum Gaming



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