Caxton Youth Organisation

CHANGEMAKERS

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Who We Are

We are a group of young people from Caxton Youth Organisation who have connected through shared lived experience and a passion to make change.

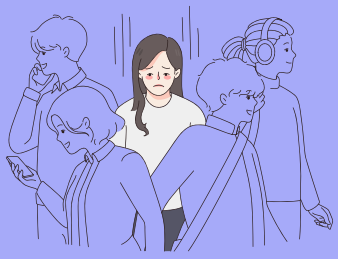
As a group, we want to make a difference through changing perceptions, raising awareness, and dismantling barriers in our ableist society.

We want to see the government and organisations create meaningful change, involving neurodivergent young people in these decisions and creating a more inclusive society for disabled people.

mental health, wellbeing and neurodivergence

Autism is NOT a mental health disorder, but autistic people are disproportunately more likely to experience poor mental health such as depression, anxiety, eating disorders, self-harm and suicidal thoughts.

Communication differences can lead to us being misunderstood and socially excluded; this creates isolation, loneliness and a sense of not belonging.



A lack of safe spaces to socialise and unmask can leave us without community or social connections.

On average, autistic people die **6 years** earlier than the general population.
For autistic people who also have a learning disability, this can be up to **15 years** earlier.

Our needs not being met means we are forced to push through without the correct support or accommodations in place. This can cause burnout, anxiety and depression.

Negative representation creates shame, stigma and a lack of understanding.

School environments are dysregulating and **not neuro-inclusive.** We have an **increased chance of being bullied.**

Environments that cause sensory and emotional dysregulation contribute to high levels of stress and anxiety.

There is a lack of funding for accessible therapies in many parts of the country.

women, girls and neurodivergence

Girls are more likely to be diagnosed at a later stage in life.

This can be due to several factors:

Literature and the diagnostic criteria have historically been centered around males.

Girls often find ways to blend in. This is called masking. It involves imitating others to camouflage.

Girls are more likely to be misdiagnosed with anxiety, borderline personality disorder and other mental health conditions.

Why is late diagnosis dangerous?

Prolonged masking can lead to burnout and emotional distress. People may have difficulties with friendships, a sense of not belonging, and might be labelled as antisocial.

Often, people will reach a breaking point. Autistic women are 13 times more likely to die due to suicide compared to those who are not autistic.

Girls often struggle through their schooling and often cannot reach their full potential due to their needs being unmet.

A late diagnosis often leads to years of confusion and feeling “wrong” or “broken”. Early diagnosis helps girls understand themselves and develop self-advocacy skills.

race, ethnicity and neurodivergence

Neurodivergent people of colour face additional barriers when it comes to receiving diagnosis and accessing support.

Underrepresented in research=doesn't fit diagnostic criteria

Systemic Bias: racial bias in healthcare and education mean that autistic traits in Black individuals are often misidentified as "rudeness" or "aggression," contributing to higher rates of school exclusion and police interaction.

Studies show that black autistic people are less safe stimming in public.

Racial bias views these behaviours when done by people of colour as dangerous, threatening or non-compliant.

Autistic people of colour are more likely to experience forceful restraint if stopped by the police.

Risks can be even greater for those that are non-speaking or minimally verbal.

employment and neurodivergence

A significant majority of autistic adults (79%) on out of work benefits want to work.

Around 22% of autistic adults are in employment, compared to 81% of non disabled people.

The employment rate for people with autism is considerably lower than both the general population (81%) and all disabled people (52%), as reported by the Office for National Statistics.

- Bias and stigma
- Work environments that cause sensory dysregulation
- Burnout from having to mask
- Comlicated hiring processes
- Social exclusion
- Lack of reasonable adjustments
- Lack of understanding within workplace

43% of autistic adults reported leaving or losing a job because of their condition.

There can be anxiety around disclosing a diagnosis which can make it harder to access support.

Fear of being treated differently or misunderstood if you do disclose

Being unsure if you can ask for adjustments, and not knowing what they might be

46% of adults say revealing a diagnosis receives a negative reaction

It is important that people's value is not limited only to what they can offer as workers.

Not everyone is able to work and those that do might experiences fluctuations in their capacity and ability to work for periods of time.

There needs to be support in place for those who cannot work, as well as to help those that can stay in or return to work.

Narratives that focus on autistic and disabled people as economic burdens increases stigma and misunderstanding.

Everyone deserves to be paid for work they do - autistic and disabled people should not be expected to only be offered volunteering or low paid roles.

education and neurodivergence

Neurodivergent people can experience additional struggles throughout their education:

Autistic students face higher chances of being bullied: This means that for many school is not experienced as a safe space.

Anxiety and stress caused by the environment: Schools are busy, noisy places. This can lead to sensory overload and dysregulation.

Rigid timetables: Many neurodivergent people experience fatigue from social situations or masking and this can worsen it, potentially leading to meltdowns, shutdowns or burnout.

Difficulty with transitions throughout the day: A school day requires many changes such as between classes and teachers. These can create anxiety and can add to sensory dysregulation.

These issues contribute to school absenteeism being a major issue for neurodivergent children.

Often schools respond by penalising families or trying to force children to increase attendence without addressing the causes.

This can lead to greater isolation and feelings of being misunderstood and punished for the challenges you experience.

Autistic students are much more likely to consider dropping out of university with 56% considering this.

This is 10 times higher than the general drop out rate.

Students who report being supported by knowledgable disability advisors are more likely to complete their courses: this is inconsistent and depends on the funding, training and expertise available at individual universities.

Studies have shown that less than **40%** of autistic students complete their degree.

Only **45%** of students who apply for reasonable adjustments report that their universities approve all adjustments.

what needs to change

1. **Better funding for all services that neurodivergent people will interact with:** this includes schools, universities, youth clubs and the NHS. This funding can ensure higher quality services delivered in suitable environments by experienced staff.

2. **More funding for youth clubs and social spaces for neurodivergent adults, enabling access to:** support groups, friendships, role models and mentors. These spaces should be designed with inclusion needs as the priority and not as an after thought.

3. A **focus on holistic care**: access to neuroinclusive therapies and better collaboration between teams e.g teachers, families, individuals and medical professionals. Medical professionals such as therapists should be trained to understand how neurodivergence can impact mental health.

4. **Better representation**: in both culture and workplaces we need representation that acknowledges the diversity of neurodivergence and centres our voices, especially those that have been most marginalised. Our voices, which are informed by lived experience, should be included and inform decision making at all levels.

5. **Training that is delivered and/or designed by neurodivergent people, and which recognises intersectionality**: this would help raise awareness of things that are still misunderstood such as autistic burnout, the cost of masking, recognition of how autism may present in different groups such as women and girls and the impact of racial bias on black and ethnic minority neurodivergent people

6. **Earlier and more accurate diagnosis:** current diagnostic tools often miss women and people who mask or camouflage leading to late or misdiagnosis. This should also be accompanied by more research into underrepresented groups such as women and shorter waiting times for diagnosis.

7. **Supportive schools and education settings:** support with transitions, flexibility (such as reduced timetables), sensory spaces, mentoring, mental health support and access to study advisors. Investing in TA's who can offer 1:1 support when it is needed. Student advisors who can give feedback on inclusion and make suggestions for change.

8. **Workplaces that value neurodivergent staff and easier pathways into work:** clear communication around what workplace adjustments are available, easier recruitment processes that support the skills of the individual (such as access to interview questions in advance or a practical task/ trial rather than an interview).

9. **Government backed campaigns to help raise awareness, understanding and inclusion:** posters on the TFL and national transport networks that encourage better understanding of things such as stimming or meltdowns would be a step towards making public spaces safer for neurodivergent people. More knowledge and empathy from the general public makes shared spaces easier to navigate.

10. **More support post-diagnosis:** continued support after diagnosis for individuals and families which ensures the needs of the person diagnosed are being met and that appropriate support systems are put in place. These should help develop tools to navigate challenges in different areas of life, build connections and support the development of self confidence.

Do you want to help drive this manifesto forward? Contact Sarah, the lead youth worker on Changemakers through her email address: sarah@caxtonyouth.org.

Caxton Youth
Organisation

Caxton Youth is a youth club for learning disabled and autistic young people in Westminster aged 11-25.

You can find out more about what we do on our website:
www.caxtonyouth.org

And contact us on:

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