Nottinghamshire Health & Wellbeing Board

Joint Strategic Needs Assessment: Autism in Nottingham and Nottinghamshire

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Introduction: Autism

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Autistic people have a range of strengths and challenges, and every autistic person will have their own unique experiences of being autistic.

Autism can affect how people communicate and interact with world, this can include:

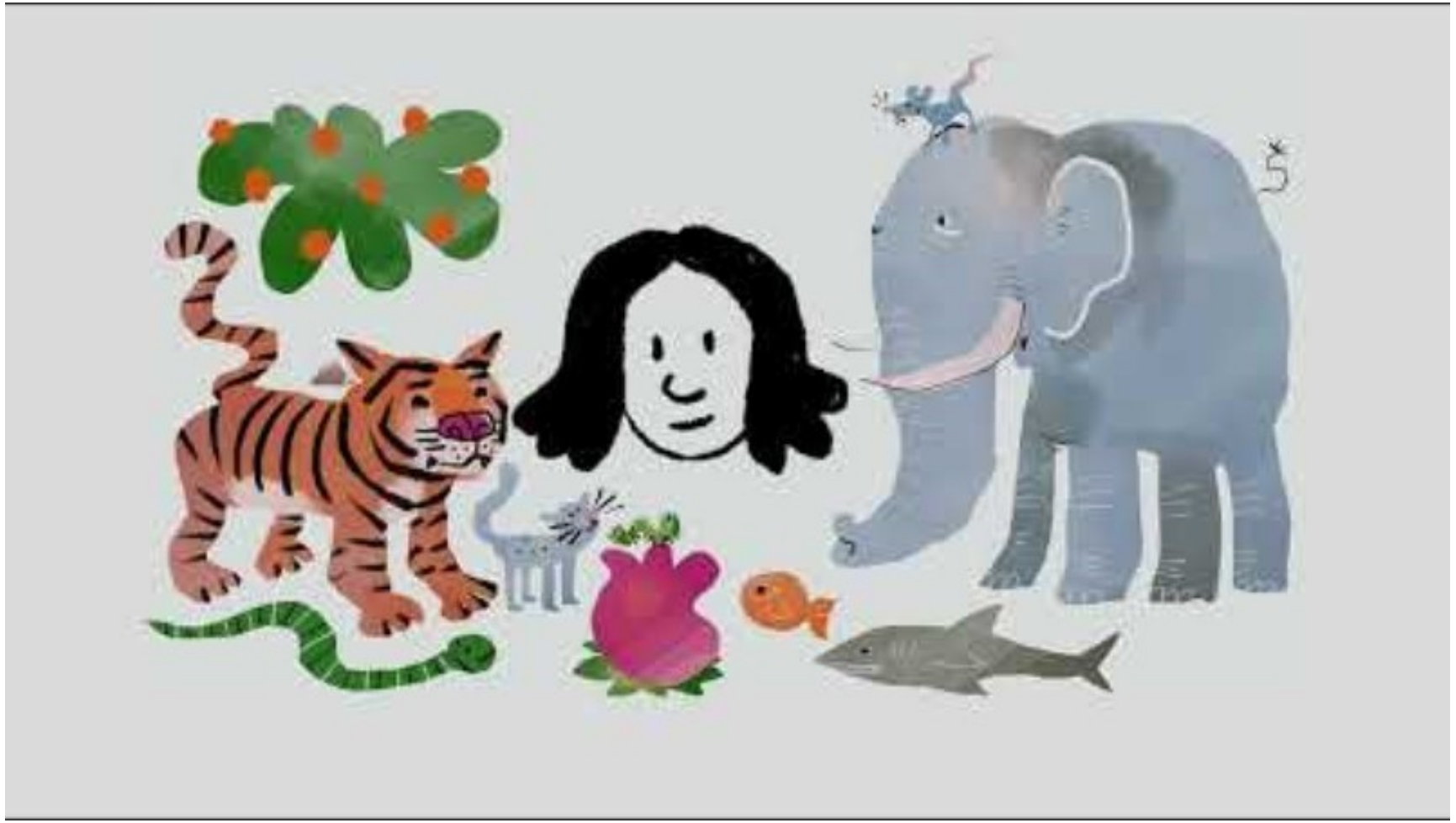
- Differences in processing, understanding and interpreting social communication and interactions
- Preference for routines
- Repetitive behaviour which serve a variety of purposes known as “stimming”
- Differences in sensory processing
- Highly focused interests

These differences can offer many benefits but for some autistic people it can be challenging to adapt to a world that is too often centred around neurotypical people’s needs

Some autistic people may have little or no need for additional support to live their lives, and other autistic people may have co-occurring conditions and require a higher level of support. Having the right adjustments or support to live well can be essential.

National Autism Trainer Programme (NATP) animation

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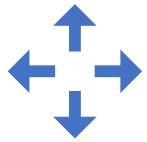


Neuro-affirmative practice

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Neuro-affirmative practice is the philosophy and social movement, recognising the need to work towards ‘neurotype’ rather that disorder.

Sometimes autistic people both consciously and unconsciously try to mask their differences which is exhausting and can have a negative impact on their health and wellbeing.



The Equality Act 2010 sets out the legal obligation to make reasonable adjustments for people with disabilities.

There are many ways that communities and services can adapt, adjust and personalise their approach to be more inclusive to every autistic student, patient, and person.



There has been a focus on building awareness of autism however there is a need to move into a phase of **acceptance**. where services that support autistic people make adjustments and adaptations and seek to eliminate stigma, embracing the strengths of autistic people in order to r educe inequalities and support autistic people to thrive.

Governance and Working Together

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Nottingham and Nottinghamshire have established a Learning Disability and Autism Executive Board.

The Board is made up of a range of representatives including Experts by Experience and representatives from Nottingham and Nottinghamshire Integrated Care Board, Nottinghamshire County Council and Nottingham City Council and representatives from Nottinghamshire NHS Healthcare Foundation Trust.

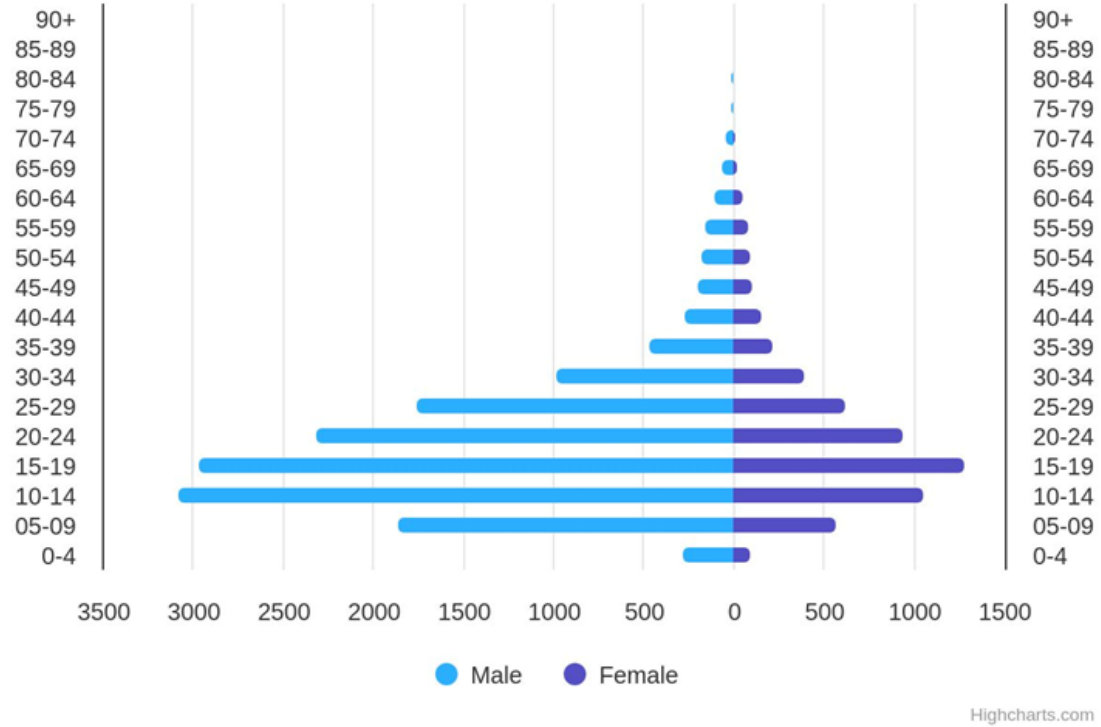
There is an opportunity to improve the governance and oversight across this structure to ensure that broader concerns for autistic people and their families are prioritised.



There are important groups and communities working together to hold system partners to account. This includes the Autism Alliance which offers a protected space for autistic individuals and allies to challenge existing structures where necessary.

Population

Number of people with diagnosis across Nottingham and Nottinghamshire according to gender and age.



Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care Board. May 2024

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It is broadly estimated 1% of the population are autistic however in Nottinghamshire prevalence is higher at 2% of the population.

Evidence shows that rates of diagnosis is much higher in children than it is in adults and many autistic adults have reached adulthood without a diagnosis.

Research also highlighted under and misdiagnosis in females.

Autism and Gender

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The table below shows the number of autistic children, young people and adults in Nottingham & Nottinghamshire with a confirmed diagnosis by gender as of September 2024.

	Children and Young People		Adults	
	Female	**Male**	**Female**	**Male**
Nottingham City	860	2,501	963	2,010
Nottinghamshire County	2,345	5,865	2,006	4,715
Total	3,205	8,366	2,969	6,725

Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care System (September 2024)

Autistic women and girls face serious health inequalities. Autistic women with a learning disability are among those at highest risk of early death in the autistic community.
Autistic women are also markedly more likely to die by suicide than non-autistic women, and report lower quality of life than their male peers.
Initial evidence suggests that autistic women are at greater risk of abuse.

Autism and Ethnicity

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There is an ethnically diverse white non-British population in Nottingham and Nottinghamshire with 9% of the general population identifying as non-white non-British, including 6.1% in Nottingham City.

Category	Number of people assessed as autistic where ethnicity is recorded	Percentage of Estimated Population of each Ethnicity category (2021 Census Data)
White Ethnic Group	17390	1.8%
Mixed Ethnic Group	985	3.3%
Asian Ethnic Group	755	1.1%
Black Ethnic Group	545	1.4%
Other Ethnic Group	195	1.5%
White Gypsy or Irish Traveller ethnicity group	15	Data not available

Source: E-Healthscope Nottingham and Nottinghamshire Integrated Care Board. May 2024

The National Autistic Society report "Diverse Perspectives" published in 2014 found that some communities lacked an understanding of autism which could lead to stigma and shame around someone being autistic which resulted in families not seeking support and social isolation.

In addition to this there was a lack of confidence in and mistrust of professionals and other barriers in terms of accessing services.

Assessment

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There is no definitive test for autism. Assessments are based on the range of features evaluated by a combination of specialists who work together.

Many autistic people face long waits for their assessment – and do not always receive support that is tailored to their needs at an early enough stage.

Receiving a confirmed assessment has a number of benefits:

- enabling access to services, support and adjustments
- validating for the person and help foster a positive autistic identity
- facilitate connection within the autistic community.

Demand for assessments locally has nearly doubled and investment has been made locally to increase capacity for assessments.

Children and Young People

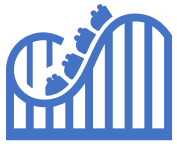
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National prevalence of autism in children and young people has increased from 1% to 2.78% . Many children and young people may not have a formal diagnosis or may be waiting for an assessment.

Nottingham and Nottinghamshire Integrated Care System have reviewed the diagnostic pathway for children and young people and published their report in April 2024. Delays to assessments were noted as a concern but families felt communication and support whilst waiting was an opportunity for improvement.



National Autistic Society have undertaken research 73% of autistic children and young people attend mainstream schools and 3 out of 4 of the families of these autistic children felt the schools were not able to meet the needs of the young person. The research found that schools were not routinely putting in place adjustments to reduce sensory overload, improved training was needed for teachers.



The transition between childhood and adulthood is often a time of enormous change. Different legal frameworks are applied in health and care settings and very often there are different services available, with different pathways. This can give children, young people and their families the impression that becoming an adult is a “cliff edge”.

Work and Wellbeing

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Autistic people are more likely to experience loneliness and feel socially isolated than non-autistic people which can lead to a deterioration in mental health. Ensuring there are local opportunities for autistic people to socialise and that networks are adapted to meet the needs of autistic people is necessary to reduce social isolation.

The benefits of employment are well documented which include the development of social networks and friendships, improved independence, economic mobility and social status. Autistic adults have a wide range of skills, interests, and experience, in which the different approaches to cognition and communication can be key strengths, and generate new ideas.

In 2022-2023 30.6% of autistic people were in employment. There are a range of potential barriers to employment for autistic people, including inaccessible recruitment practices. Maintaining long-term employment can also be a challenge for autistic people. Many do not receive the necessary support or adjustments to enable them to fulfil their role.

Access to Care

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The majority of autistic people will access generic healthcare services. There is the need to make health and social care services more accessible to autistic people.

- For planned appointments, services should try to identify a person's needs before the visit or where this isn't possible, try to be flexible.
- Allowing autistic people more time to process questions, providing clear explanations and avoiding metaphorical language may be helpful.
- Where possible, services should provide information in advance about what to expect during or before a medical appointment. Uncertainty is a known cause for anxiety amongst autistic people and can exacerbate sensory difficulties.
- Providing information and pictures in advance can help autistic people prepare themselves for challenging physical environments and social interactions.
- Giving patients a choice about how they make an appointment (e.g. online instead of over the phone) and when that appointment could be (e.g. at a quieter time of day or during a specific time in a routine).

Health Inequalities

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Autistica's Happier, Healthier, Longer Lives report indicates that autistic people die on average 16 years earlier than the general population. Important factors include:

- Approximately 1 in 5 women with an eating disorder were autistic. Anorexia has the highest mortality rate of any mental illness.
- A disproportionate number of people who die by suicide are autistic. Ongoing research suggests up to 11% of people who die by suicide have autism. Autistic women are significantly more likely to due by suicide than neurotypical women.
- Between 15% and 40% of people with epilepsy are autistic. Epilepsy is the leading cause of death for autistic people with a learning disability.

The national LeDeR programme began reviewing the deaths of autistic adults without a learning disability in 2022 and found the most common causes of death were suicide, drug and alcohol related deaths and accidental deaths, such as falls.

Ethnicity was strongly associated with age at death, and that people from an ethnic minority background (black, black British, Caribbean or African and Asian British) were more likely to die younger than those who were white.

Mental Health

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- 7 in 10 children with autism have a mental health condition and 8 in 10 adults with autism have a mental health condition.
- Up to 10% of adults in mental health inpatient settings are autistic.
- 11% of people who die by suicide are autistic and that NICE recognise that autistic people are among those who are at highest risk of suicide.

Factors driving the prevalence of co-occurring mental health include:

- Autistic people can experience social isolation, which can contribute to feelings of loneliness, anxiety, and depression.
- Sensory sensitivities common in autism can also lead to heightened stress and anxiety, particularly in overwhelming environments.
- Higher rates of bullying and social discrimination faced by autistic people can also exacerbate mental health issues.
- Mental health conditions in autistic people are sometimes overlooked or misdiagnosed, particularly reported in children and young people experiencing mental health issues.

Government figures show that since March 2015 the number of autistic people in mental health settings has increased by 23% and 53% of autistic people stay in Hospital for over 2 years.

Recommendations

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Children and Young People

- ✓ Implement recommendations from the review of neurodevelopmental pathway for children and young people and Special Educational Needs and Disabilities Improvement Plan.
- ✓ Review the experiences of autistic children and young people transitioning into adult services.

Strategic Planning & Governance

- ✓ Refresh Autism Strategy and action plan with people with lived experience.
- ✓ Strengthen co-production and governance structures.
- ✓ Improved data and reporting.

Health and Wellbeing

- ✓ Review local suicide prevention plans.
- ✓ Review the experiences of autistic people accessing local mental health services.
- ✓ Co-produced implementation plans for needs led adjustments to autistic people accessing mental health services.
- ✓ Consider the need for a strategy in relation to employment for autistic people.
- ✓ Co-produce a needs-led toolkit for implementing adjustments for autistic people across Health, Social Care, Education and Employment services to reduce inequalities across all services.
- ✓ Continue to support training across Health and Social Care beyond awareness to embed needs led practice.

Example of Recommendations

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*"Current **mental health services often fail to meet the needs of autistic individuals**, lacking both **understanding and accountability.** Healthcare professionals frequently lack awareness and training in autism, leading to **discrimination and inadequate support**. The slow-paced nature of the healthcare system makes it **difficult for autistic individuals to access timely help, contributing to higher rates of suicide.** Moreover, those **awaiting a diagnosis** often struggle to regulate their emotions and behaviours without proper guidance or support. The services provided **post-diagnosis are often insufficient**, leaving individuals feeling underserved and marginalized. It's disheartening to feel dehumanized and invalidated by a system that should prioritize our well-being. While training on autism exists, it's **often not effectively applied**, highlighting the need for a filter system to ensure only competent professionals are entrusted with the care of others. Overall, there's a pressing need for comprehensive and inclusive mental health services that prioritize the needs of autistic individuals and hold healthcare professionals accountable for providing appropriate support and understanding."*

AUTISTIC NOTTINGHAM

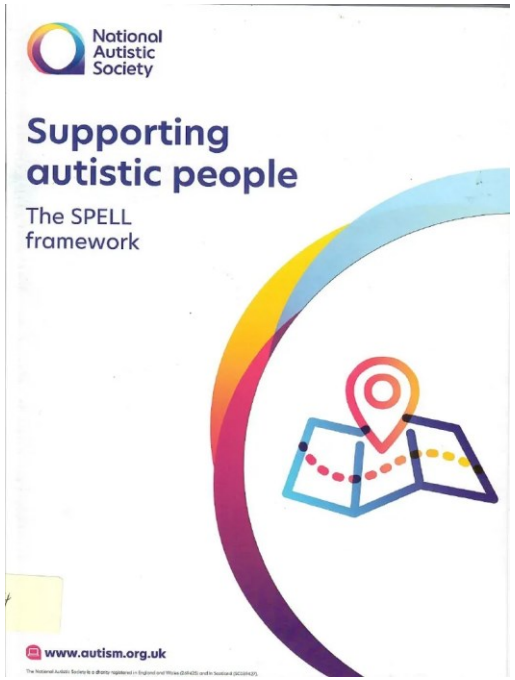
Examples of Recommendations

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Example of Recommendations

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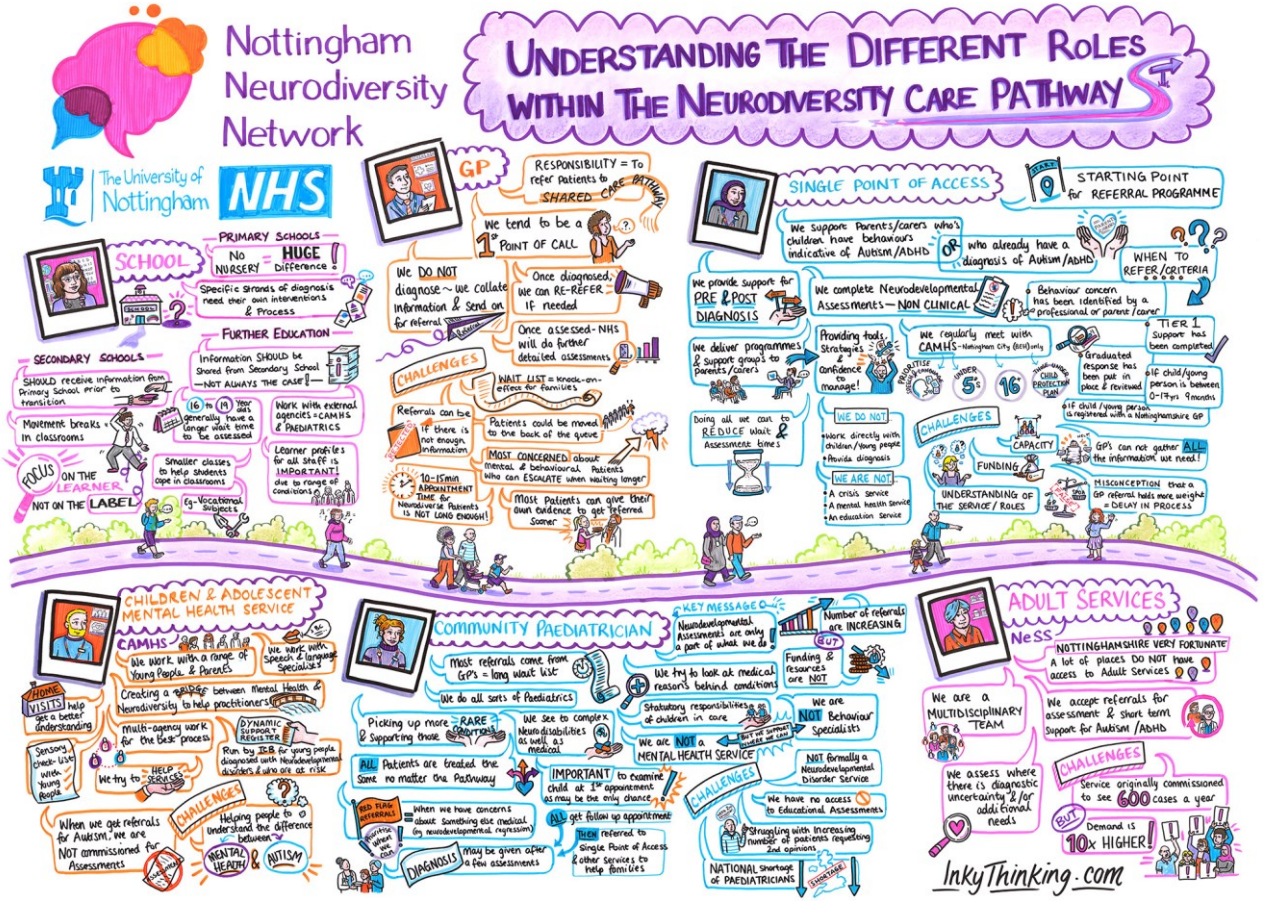






Example of Recommendations: Notts Neurodiversity Network

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Any Questions?



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