Integrated Care System
Nottingham & Nottinghamshire

Improving pathways to care for neurodevelopmental conditions in Nottingham(shire)

Nottingham Neurodiversity Network

Agenda

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9.00 Registration & refreshments

9.30 **Welcome**, introduction and NNN update - Dr Blandine French

9.45 **Research and local presentations**

- Hannah Wright and Kristy Angell - Optima clinical trial
- Dr Sarah Cassidy - Autism and suicide
- Shanine Fasasi - Diversity and inclusion

11.00 **Break & Refreshment**

11.15 **Presentations on National Initiatives**

- Emma Sharkey - Neurodiversity in prison
- Dawn Nicholls - Dimensions tool
- Janine Robinson - NHS England autism team national update

12.45 **Lunch**

13.30 **Networking Workshop**

NNN

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Who are we?

Nottingham Neurodiversity Network

NNN structure

- NNN-4
- Terms of reference
- RNN
- ADHD/autism taskforce

Steering group

ICB

Children: SPA: BEH Team (City), NBS (County)

Community Peadiatrics

Adults: NeSS

GPs

HIN

Researchers

Parents

Education

Charities: APTCOO (Bassetlaw)

ADHD adult group

Autistic Nottingham

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What do we do?

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Key Questions

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- What is the ideal pathway to care for neurodevelopmental conditions?
- What are the barriers in achieving this pathway?
- What do you think should be avoided in creating this pathway?
- How are we doing locally?
- What are the tangible solutions to these problems?
- Who are the key stakeholders who can make this happen?

Developing the ideal pathway to care for neurodiversities

Our network worked together to assess what the ideal pathway to care looks like

Support

Ongoing, throughout the journey and into adulthood. Flexibility, being able to dip in and out. One key person as point of contact. Waiting well.

Clarity

About the process, the pathway.

Knowledge and education

For parents and all other stakeholders.

Holistic approach

Less siloed thinking, not being passed around different services. Have a ND point of access. Need-led service rather than diagnosis led.

Nottingham Neurodiversity Network

The Nottingham Neurodiversity Network is a network of local charities, academics, commissioners, healthcare professionals and service users that aims to support access to care for neurodiversity.

www.nottsneurodiversitynetwork.org.uk

University of Nottingham
UK | CHINA | MALAYSIA

Nottingham and Nottinghamshire ADHD/Autism Assessment Pathways

Nottingham Neurodiversity Network

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	Children and Young People Pathway			Adult Pathway
1st step: Graduated Response	**Discuss your concerns/child's needs with your child's health visitor or education setting to agree a support plan that can be regularly reviewed and adapted. Also, speak to the Healthy Family Team or 0-19 Early Support Services for further help and advice. This process is often referred to as the graduated response. More information can be found here: Graduated Response**			**Not applicable**
2nd step: Referral (based on location of GP practice)	**Nottinghamshire County**	**Nottingham City**	**Bassetlaw**	**Any**
	Education, Health Professional/GP	**Self-referral, Education, Health Professional/GP**	**Education, Healthy Family Team**	**GP**
3rd step: Screening	**Neuro-developmental Support Team (NST)***	**Behavioural & Emotional Health Team (BEH)***	**General Developmental Assessment (GDA)***	↓
4th step: Specialist Assessment Services (subject to screening outcome)	**Community Paediatrics***	**AND /OR**	**other specialist services depending on needs***	**Neuro-development Specialist Service (NeSS)***

*While these pathways reflect the majority of referrals, some cases may be referred to other Nottingham(shire) based services. This is an overview of the pathway and does not include details of support services that are offered along the way. For more detailed information, please scan the QR code at the top of the page.

Pathways documents

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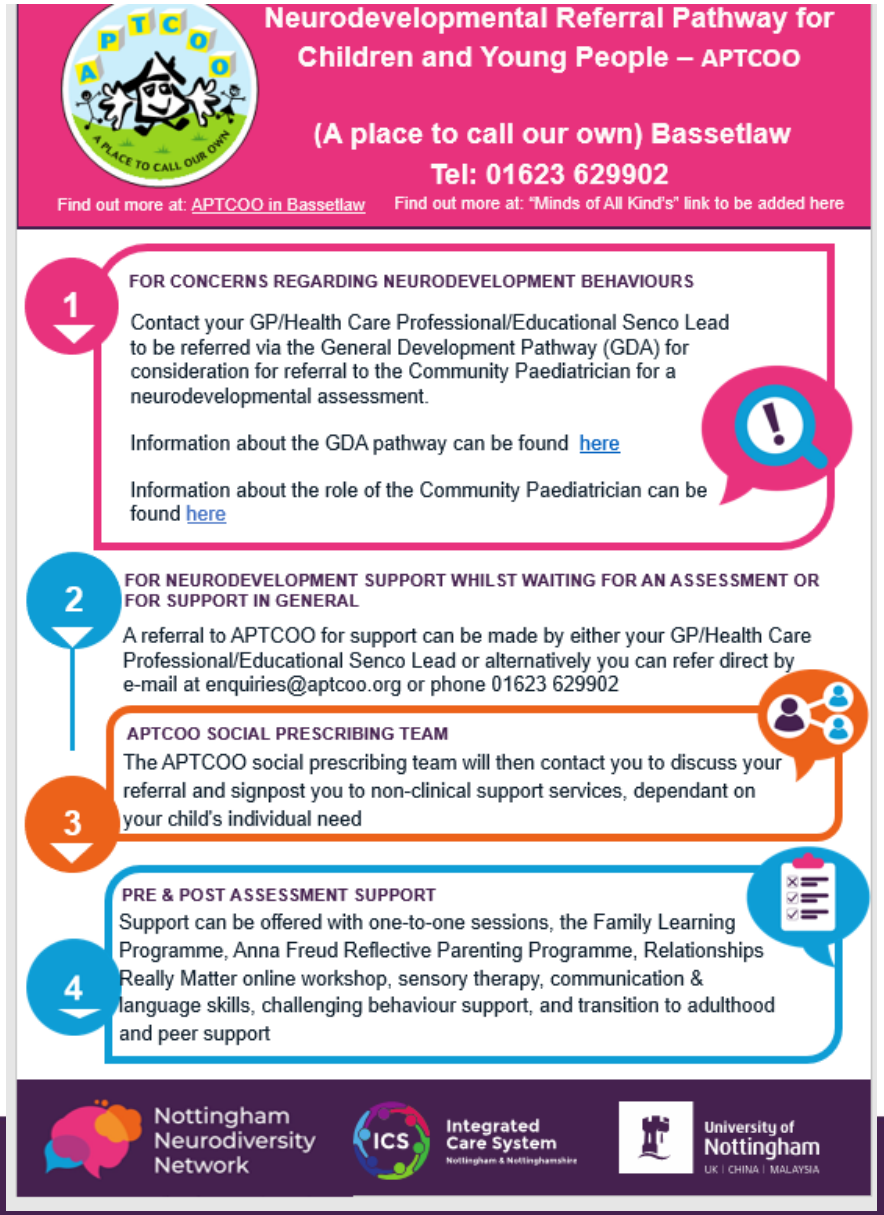

Neurodevelopmental Referral Pathway for Children and Young People – APTCOO

(A place to call our own) Bassetlaw
Tel: 01623 629902

Find out more at: APTCOO in Bassetlaw
Find out more at: "Minds of All Kind's" link to be added here

1 FOR CONCERNS REGARDING NEURODEVELOPMENT BEHAVIOURS

Contact your GP/Health Care Professional/Educational Senco Lead to be referred via the General Development Pathway (GDA) for consideration for referral to the Community Paediatrician for a neurodevelopmental assessment.

Information about the GDA pathway can be found here

Information about the role of the Community Paediatrician can be found here

2 FOR NEURODEVELOPMENT SUPPORT WHILST WAITING FOR AN ASSESSMENT OR FOR SUPPORT IN GENERAL

A referral to APTCOO for support can be made by either your GP/Health Care Professional/Educational Senco Lead or alternatively you can refer direct by e-mail at enquiries@aptcoo.org or phone 01623 629902

3 APTCOO SOCIAL PRESCRIBING TEAM

The APTCOO social prescribing team will then contact you to discuss your referral and signpost you to non-clinical support services, dependant on your child's individual need

4 PRE & POST ASSESSMENT SUPPORT

Support can be offered with one-to-one sessions, the Family Learning Programme, Anna Freud Reflective Parenting Programme, Relationships Really Matter online workshop, sensory therapy, communication & language skills, challenging behaviour support, and transition to adulthood and peer support

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Understanding The Different Roles Within The Neurodiversity Care Pathway

Nottingham Neurodiversity Network

The University of Nottingham | NHS

SCHOOL

PRIMARY SCHOOLS
No NURSERY = HUGE Difference!

Specific strands of diagnosis need their own interventions & Process

FURTHER EDUCATION
Information SHOULD be Shared from Secondary School —NOT ALWAYS THE CASE!—

16 to 19 Year olds generally have a longer wait time to be assessed

Work with external agencies = CAMHS & PAEDIATRICS

SECONDARY SCHOOLS
SHOULD receive information from Primary School prior to transition

Movement breaks in classrooms

FOCUS ON THE LEARNER NOT ON THE LABEL

Smaller classes to help students cope in classrooms

Eg-Vocational subjects

Learner profiles for all staff is IMPORTANT! due to range of conditions

GP

RESPONSIBILITY = To refer patients to SHARED CARE PATHWAY

We tend to be a 1st POINT OF CALL

We DO NOT diagnose ~ we collate information & Send on for referral

Once diagnosed, we can RE-REFER if needed

Once assessed - NHS will do further detailed assessments

CHALLENGES
WAIT LIST = knock-on-effect for families

Referrals can be REJECTED if there is not enough information

Patients could be moved to the back of the queue

MOST CONCERNED about mental & behavioural Patients Who can ESCALATE when waiting longer

10-15min APPOINTMENT TIME for Neurodiverse Patients IS NOT LONG ENOUGH!

Most Patients can give their own evidence to get referred Sooner

SINGLE POINT OF ACCESS

START — STARTING POINT for REFERRAL PROGRAMME

We support Parents/carers who's children have behaviours indicative of Autism/ADHD OR who already have a diagnosis of Autism/ADHD

WHEN TO REFER/CRITERIA

We provide support for PRE & POST DIAGNOSIS

We complete Neurodevelopmental Assessments — NON CLINICAL

Behaviour concern has been identified by a professional or parent/carer

We deliver programmes & Support groups to parents/carers

Providing tools, Strategies & Confidence to manage!

We PRIORITISE certain categories of children/young people

SPEECH & LANGUAGE 5yrs | UNDER 5's | 16+ | THOSE UNDER CHILD PROTECTION PLAN

— ALL GET A 12WEEK ACCELERATION —

Graduated response has been put in place & reviewed

TIER 1 Support has been completed

If child/young person is between 0-17yrs 9months

If child/young person is registered with a Nottinghamshire GP

Regular meetings with CAMHS Colleagues to work out best support

Doing all we can to REDUCE Wait & Assessment times

WE DO NOT...
- Work directly with children/Young people
- Provide diagnosis

WE ARE NOT...
- A crisis service
- A mental health service
- An education service

CHALLENGES
CAPACITY

FUNDING

UNDERSTANDING OF THE SERVICE/ROLES

GP's can not gather ALL the information we need!

MISCONCEPTION that a GP referral holds more weight = DELAY IN PROCESS

CHILDREN & ADOLESCENT MENTAL HEALTH SERVICE

CAMHS
We work with a range of Young People & Parents

We work with Speech & Language Specialists

Creating a BRIDGE between Mental Health & Neurodiversity to help practitioners

HOME VISITS help get a better understanding

Multi-agency work for the best process

DYNAMIC SUPPORT REGISTER Run by ICB for young people diagnosed with Neurodevelopmental disorders & who are at risk

Sensory check-list with Young People

We try to HELP SERVICES

CHALLENGES
When we get referrals for Autism, we are NOT commissioned for Assessments

Helping people to understand the difference between MENTAL HEALTH & AUTISM

COMMUNITY PAEDIATRICIAN

Most referrals come from GP's = long wait list

We do all sorts of Paediatrics

Picking up more RARE CONDITIONS & Supporting those

We see to complex Neurodisabilities as well as medical

ALL Patients are treated the Same no matter the Pathway

RED FLAG REFERRALS — When we have concerns about something else medical (eg neurodevelopmental regression)

Prioritise when we can

DIAGNOSIS may be given after a few assessments

IMPORTANT to examine child at 1st appointment as may be the only chance!

ALL get follow up appointment

THEN referred to Single Point of Access & other services to help families

KEY MESSAGE — Neurodevelopmental Assessments are only a part of what we do!

We try to look at medical reasons behind conditions

Statutory responsibilities of children in care

We are NOT a MENTAL HEALTH SERVICE

BUT we support where we can

We are NOT Behaviour Specialists

Number of referrals are INCREASING

BUT Funding & resources are NOT

CHALLENGES
NOT formally a Neurodevelopmental Disorder Service

We have no access to Educational Assessments

Struggling with Increasing number of patients requesting 2nd opinions

NATIONAL shortage of PAEDIATRICIANS — SHORTAGE

ADULT SERVICES

NESS

NOTTINGHAMSHIRE VERY FORTUNATE

A lot of places DO NOT have access to Adult Services

We are a MULTIDISCIPLINARY TEAM

We accept referrals for assessment & short term support for Autism/ADHD

We assess where there is diagnostic uncertainty &/or additional needs

CHALLENGES
Service originally commissioned to see 600 cases a year

BUT Demand is 10x HIGHER!

InkyThinking.com


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Resource repository

https://nottsneurodiversitynetwork.org.uk/news-and-resources/resources

Other outcomes

- Website – “Minds of All Kinds” to launch Summer 25.
- Working closely with providers to identify and implement “quick wins”

  - Videos
  - Resources
  - Guidelines
  - Transitions
  - Pilot of direct referral to Community Paediatrician.
  - SENCO training on ADHD

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Updates

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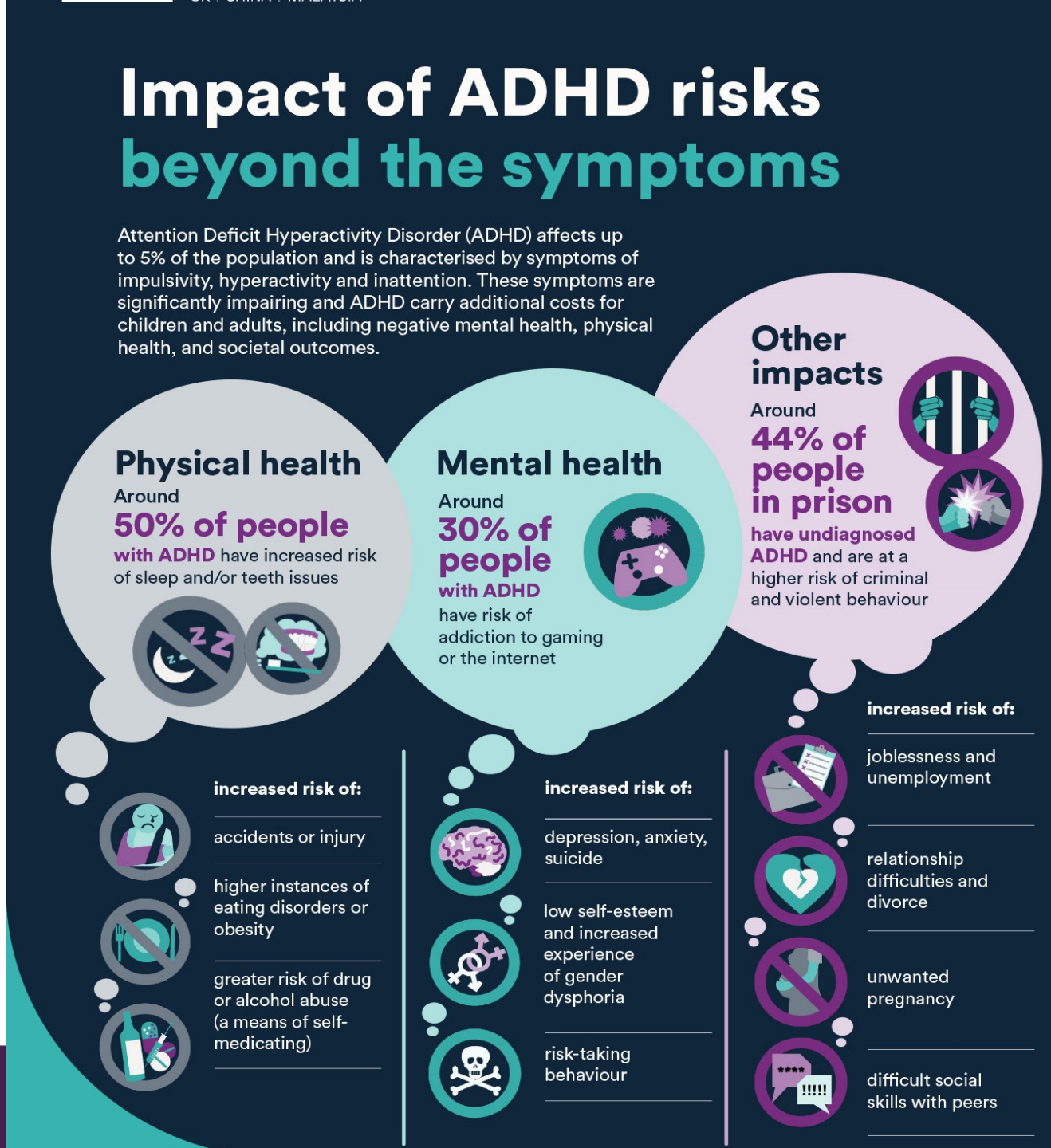
Research update

- Economic evaluation of undiagnosed ADHD/autism
- Waiting well projects
- Collaborations
  - UKAAN
  - ADHDUK
- National and international links
  - French institutions
  - International organisations
  - Uk Institutions

Research

ADHD review

French, B., Nalbant, G., Wright, H., Sayal, K., Daley, D., Groom, M. J.,& Hall, C. L. (2024). The impacts associated with having ADHD: an umbrella review. *Frontiers in psychiatry*, *15*, 1343314.



Autism review

Outcomes of autistic people

Autism is a common condition that affects both children and adults. Being autistic can come with many challenges, including increased risk of poor mental health, physical health and social outcomes.

Our umbrella review identified the most extensively researched outcomes in autistic people, summarising over 130 reviews and 1,000 studies.

Physical health

55% more gut and digestive system problems
compared to the general population

Higher rates of:

poor oral health

epilepsy (**12% compared to 1%** for general population)

asthma and diabetes

sleep issues

early death

Mental health

3x the odds of self-injurious behaviour and suicidality

Higher rates of:

mood disorders – depression, bipolar, schizophrenia, psychosis and paranoia

anxiety disorders – OCD, social anxiety

eating disorders particularly anorexia nervosa

Other impacts

Around **44% of autistic individuals experience victimisation** including bullying, interpersonal, and sexual

Higher rates of:

loneliness

challenges forming and maintaining friendships

lower quality of life outcomes

transgender or gender non-conforming identities

ADHD variation model

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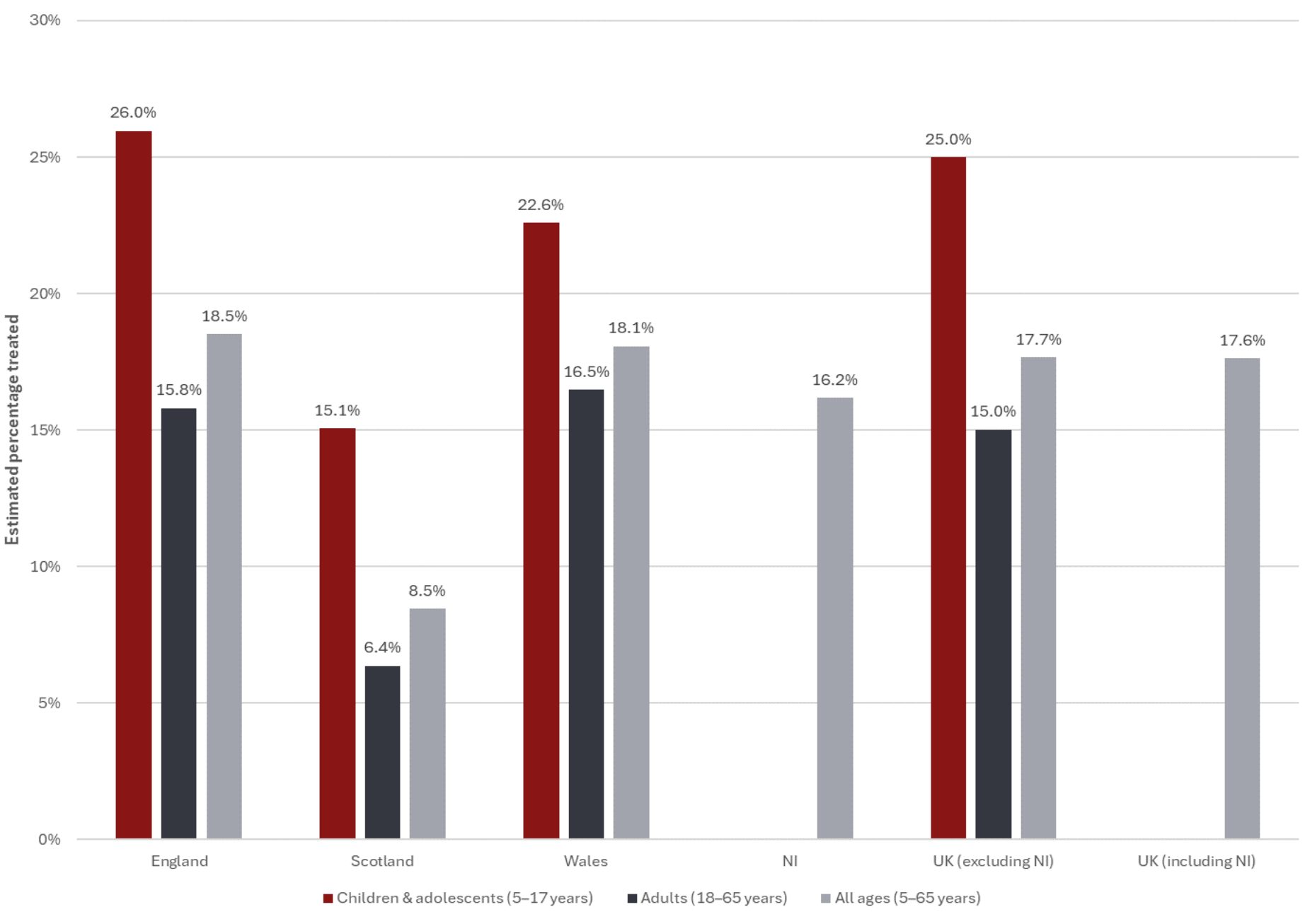
Country	Estimated ADHD population			Estimated number of treated patients		
	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)
England	442,692	1,209,739	1,652,431	114,958	191,135	306,094
Scotland	38,156	120,610	158,766	5,748	7,673	13,421
Wales	23,220	65,120	88,340	5,244	10,722	15,966
Northern Ireland	16,169	40,374	56,542	N/A*	N/A*	9,155
Great Britain	**504,068**	**1,395,469**	**1,899,537**	**125,950**	**209,531**	**335,481**
UK	**520,236**	**1,435,843**	**1,956,079**	**N/A†**	**N/A†**	**344,636**



Estimated percentage of patients treated with licenced ADHD medicines in the UK