Children & Young People's 5-17 years Autism & ADHD **DRAFT** Care Pathway

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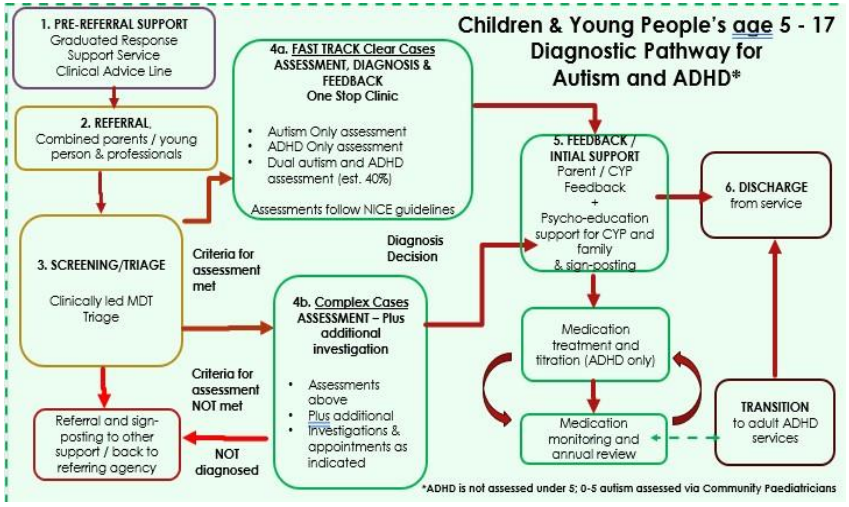
Herefordshire and Worcestershire Integrated Care System

NHS Herefordshire and Worcestershire

Cover …

NICE
guideline
Autism spectrum disorder in under 19s: recognition, referral and diagnosis
Clinical guideline
Published: 28 September 2011
Last updated: 20 December 2017
NICE
guideline
Attention deficit hyperactivity disorder: diagnosis and management
NICE guideline
Published: 14 March 2018


Children & Young People's age 5 - 17
Diagnostic Pathway for
Autism and ADHD*
1. PRE-REFERRAL SUPPORT
Graduated Response
Support Service
Clinical Advice Line
2. REFERRAL
Combined parents / young person & professionals
3. SCREENING/TRIAGE
Clinically led MDT
Triage
Criteria for assessment met
Criteria for assessment NOT met
Referral and sign-posting to other support / back to referring agency
NOT diagnosed
4a. FAST TRACK Clear Cases
ASSESSMENT, DIAGNOSIS & FEEDBACK
One Stop Clinic
Autism Only assessment
ADHD Only assessment
Dual autism and ADHD assessment (est. 40%)
Assessments follow NICE guidelines
4b. Complex Cases
ASSESSMENT – Plus additional investigation
Assessments above
Plus additional
Investigations & appointments as indicated
Diagnosis Decision
5. FEEDBACK / INTIAL SUPPORT
Parent / CYP Feedback
+
Psycho-education support for CYP and family
& sign-posting
Medication treatment and titration (ADHD only)
Medication monitoring and annual review
6. DISCHARGE
from service
TRANSITION
to adult ADHD services
*ADHD is not assessed under 5; 0-5 autism assessed via Community Paediatricians

OLD WAY
NEW WAY

Your involvement ….

- Questions
- Q&A Sheet
- Member of Herefordshire Parent Carer Voice
  - design & information about the services
  - referral materials
  - while you waits materials

Background & Development

Why have we got long waiting lists?

- Demand v's Capacity
- Diagnostic assessments embedded in Community Paediatrics/CAMHS - competing caseloads
- Front-line support patchy

What are we doing about it?

Reduce waiting times

Extra capacity In-sourcing Services

Family Psychologists 16+

Quality Assure Right to Choose

Improving Information & Communication

Local Offer

While Wait Materials

Workshops for Parents & Young People

Autism West Midlands

ADHD Foundation Trust

New Services

Combined diagnostic service for Autism & ADHD

Support Service

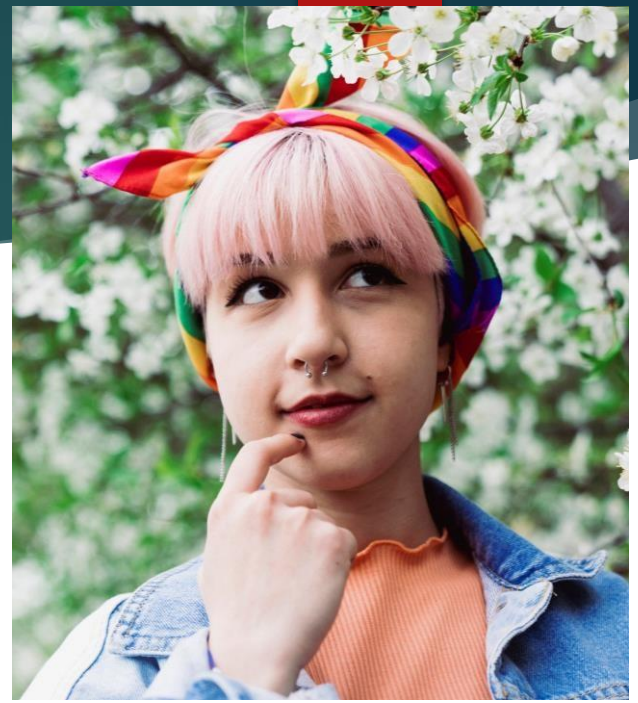
Mental Health Early Intervention Service

Workforce Development

Improve understanding of neurodivergence & support

Across Education/Social Care/ Health

Views – Parents/Carers and Young People



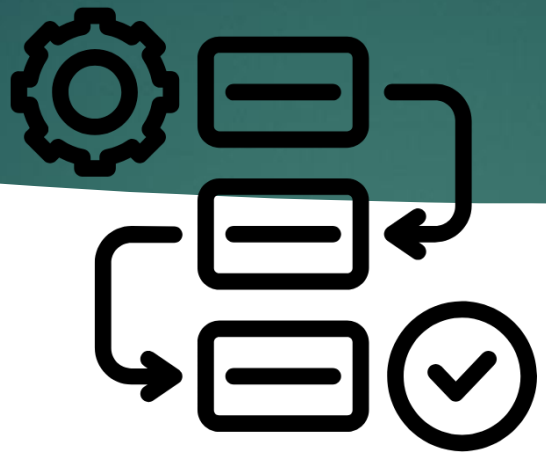
- Co-production Workshop
- Herefordshire SEND Summit
- 2 x Neurodivergence Zone Local Offer Parent/Carer Workshops
- 6 x Focus Groups Parent/Carer Focus Groups – Autism Strategy
- Feedback from parents attending Autism West Midlands training
- 1:1 conversations with parents

Feedback young people

- 1:1 on-line meetings with young people
- Case studies
- Autism Strategy Survey

What parents & young people told us…

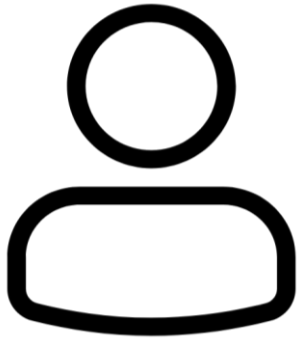
Parent/ carers should refer … they know their children best & support is lacking / parenting courses feel 'blaming'



Clear process and communication

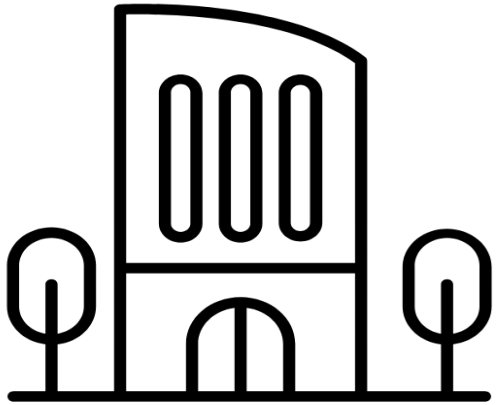
Digital referral system

Information Gathering Front-load

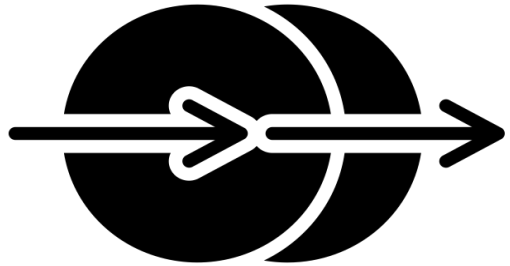


Key Point of Contact

Mental Health Support



Waits too long One Stop



Robust Transition

Development – Learning from Professionals & other NHS Services

- Autism & ADHD combined

- Coventry & Warwickshire
- St Helen's
- Birmingham
- Bath, NE Somerset, Swindon & Wiltshire
- Derby & Derbyshire
- Dudley
- Northamptonshire
- Shropshire

- Investment diagnostic process not enough
- Early intervention & needs-led approach
- Investment digital technology
- Support services – essential & highly valued by families
- Review Guidance National Institute for Health & Care Excellence – Gold Standard Evidence & Safety

H&W Children & Young People's age 5 – 17 Diagnostic Pathway for Autism and ADHD*

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0-25s Neurodivergence Support Service

What?

- Advice & Guidance
- Sign-posting and support to access existing provision & tools
- Develop NEW provision to fill gaps – training, peer support
- A space to work out how to manage their situation
- Support with the assessment process, before and after a diagnosis
- Training for parents and individuals
- Sign-posting to housing, employment & finance support

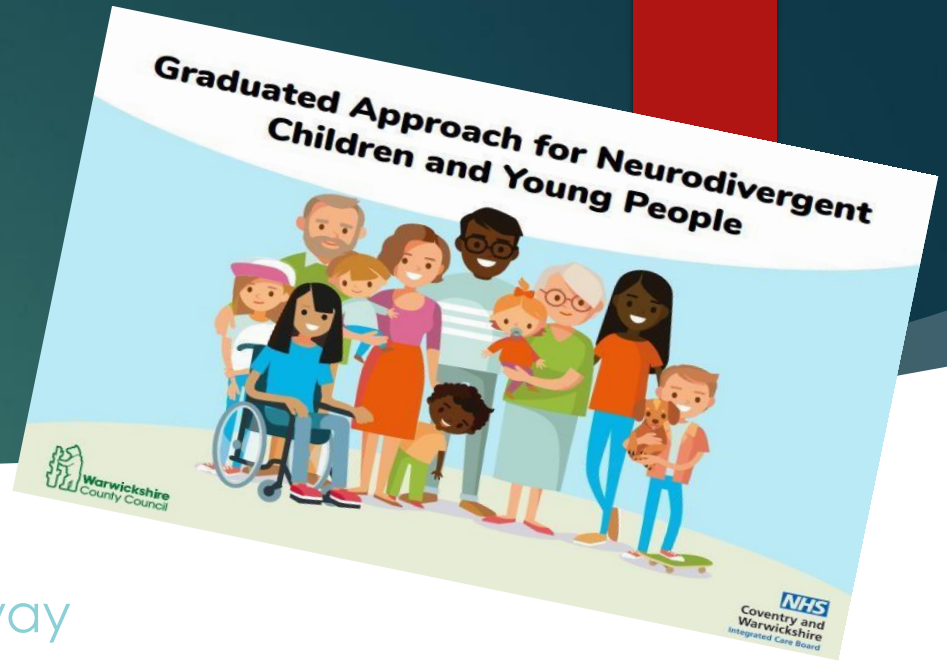
How?

- Hubs in community settings
- Drop-ins
- 1:1, group sessions, peer support –young people, families & directly to families neurodivergent
- Accessed – with or without a diagnosis
- Linked to diagnostic service

- Being out & about
- Communication & interaction
- Education, work & play
- Sensory Processing
- Sleeping / Eating / Toileting
- Managing behaviours that challenge / distress
- Becoming independent

Stages of the Pathway

1. Pre-referral Support



NICE GUIDANCE

- a period of watchful waiting of up to 10 weeks)(ADHD)
- offering parents or carers a referral to group-based ADHD-focused support (this should not wait for a formal diagnosis of ADHD)(ADHD)
- consulting a member of the autism team who can provide advice to help you decide if a referral to the autism team is necessary (Autism)

Pathway

- Graduated Response - Menu of support already available (also forms part of referral information)
- Children and Young People's Preventative and Early Intervention Emotional Well-Being and Mental Health Service (0-25 years)
- Autism & ADHD Team Clinical advice line
- Support service

2. Referral

NICE GUIDANCE

Symptoms are persistent and create difficulty in more than one setting e.g. at home, in school, social settings * (ADHD)

Both criteria refer to causing significant difficulty in daily life this includes: social skills, problem-solving, self-control, active listening, dealing with and expressing feelings

ADHD - Showing core symptoms of inattention, hyperactivity or impulsivity for at least 6 months

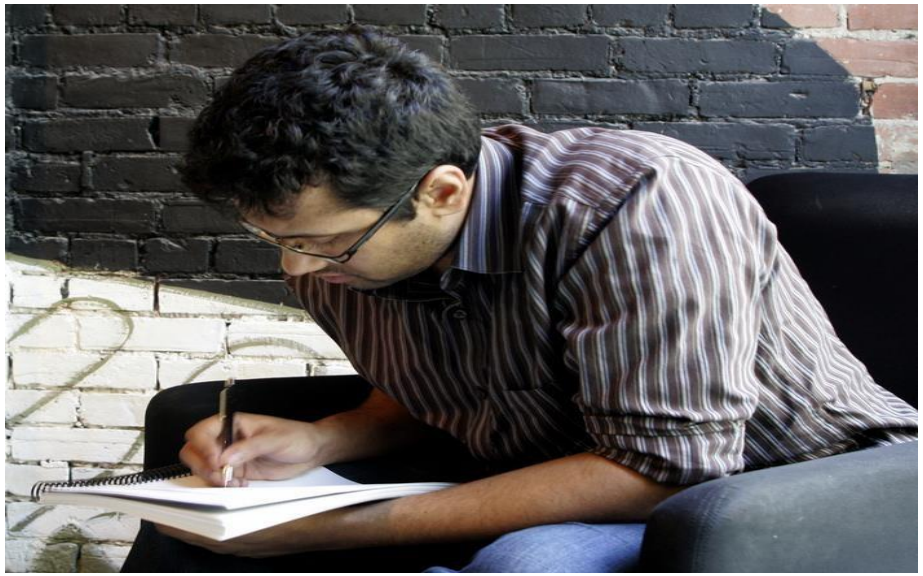
Pathway

- Combined Referral – parent/carers and appropriate professional – nursery, school, GP, school nurse, health visitor, CAMHS.
- Supporting information education or other setting
- Front-loaded information gathering – enable quicker assessments
- Digital portal – easier transfer of information & analysis of results
- Age-Appropriate Mental Health questionnaire

3. Screening/Triage

NICE GUIDANCE

- A case coordinator in the autism team should be identified for every child or young person who is to have an autism diagnostic assessment. [Autism]



Pathway

- Information reviewed – Senior Clinician + members of the Diagnostic Team
- Decision on type of assessment – combined Autism/ADHD or single
- Key Worker allocated:
- Consistent point of contact
- Co-ordinate the referral – arrange additional assessments
- Provides 'Wating Well Information'
- Continue to Diagnostic Appointment OR
- Criteria Unmet – refer back to refer for support and / or to alternative service

4. Diagnostic Assessment & Feedback

- **Option 1 - Classic Presentation - FAST TRACK**
  - One Stop Clinic – face to face appointment
- Communication of outcome with parent/ professionals – email / messaging
- **Option 2 – Complex Presentation - FURTHER INVESTIGATION REQUIRED**
- Additional assessments: observations, Speech and Language therapy assessment, Educational Psychology assessment
- Other conditions – medical, emotional /mental health / other neurodevelopmental
- Inconclusive
- Appointments: initial face to face and on-line as needed

NICE GUIDANCE

Waiting Times

- First appointment – within 12 weeks of referral
- Start the autism diagnostic assessment within [Autism, 2021]
- Diagnosis – Clinically led MDT diagnostic decision

- **Support Service:**

- Tailored Psycho-Education
- Understanding the diagnosis
- Strategies, therapies' & treatments
- Mental Health
- Sign-posting to tools / services

ADHD Medication Titration & Follow-up Appointments

- Series of appointments (NICE guidelines):
- Pre-medication checks
- Regular checks during testing (titration) of medication until stable

- Review every 3 months in children 10 years and under
- Review at 3 and 6 months after starting treatment in children over 10 years
- Every 6 months thereafter
- CYP will continue to be monitored by the CYP ND Team until decide to come off medication or transition to Adult ADHD service

Next Steps & Timescales

- Quality Assure Right to Choose Providers – November 2024
- Agree funding for new diagnostic & support services September – end December 2024
- Set-up & transition process for new service – December – June 2025
- Implementation – Earliest June 2025