



East Berkshire Autism and Attention Deficit Disorder (ADHD) Analysis Project Final Report Short Summary

Produced for East Berkshire CCG

it is strongly recommended that people read the main report and
accompanying appendices.

August 2nd 2019
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Executive summary

Introduction

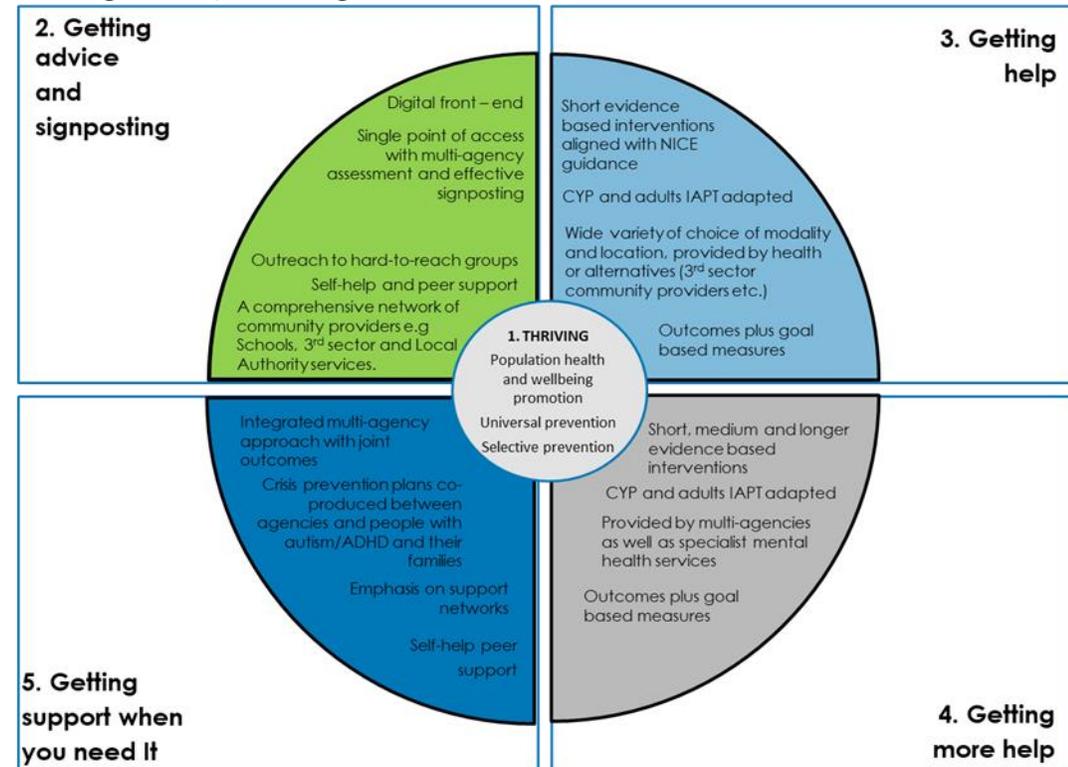
Earlier this year East Berkshire CCG commissioned an independent review by Attain of autism and attention deficit disorder services (ADHD) for both children and adults in East Berkshire. Over the years, the services have been commissioned by the CCG and local authorities in an ad hoc way which has resulted in a patchwork provision of services across the area. East Berkshire has been experiencing a series of challenges, particularly that service users are affected by long waits for assessment and diagnosis and that staff are experiencing high numbers of referrals. There is also limited post-diagnosis support available for people with autism and/or ADHD. The CCG commissioned this review with the aim of identifying the challenges impacting the service, within the context of the wider system, and to propose solutions.

Our recommendations

Following an intensive and thorough review of the overall services for children and adults living with autism and ADHD, involving substantial input from parents, people with autism and/or ADHD and provider staff, the report developed set out a **'Blueprint'** that illustrates a future state and strategy for the delivery of support and services. The principles of this 'Blueprint' are early help, collaboration, system navigation, communication and environment.

The report covers national and local challenges and sets out an **Implementation Framework** that supports East Berkshire CCG and partners to prioritise their immediate steps in respect of this report, but also start to plan their engagement with partners across Frimley Health & Care ICS and West Berkshire.

N.B. It is strongly recommended that people read the main report and accompanying appendices.

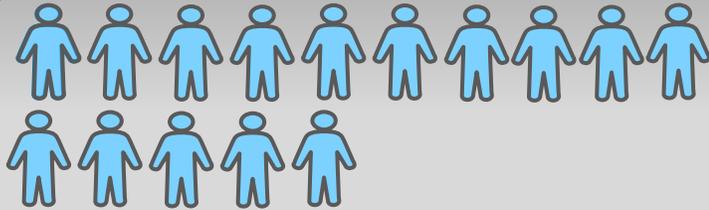


Working together to deliver excellent and sustainable healthcare

The Blueprint



Report headlines – the national challenges



Around 66% of children and 92% of adults living with ADHD and 60% of adults living with autism are undiagnosed (aged 40+).

Undiagnosed ADHD: Currently about a **third of children** are diagnosed, while for **adults** it is about **7-8%**, of expected prevalent population.

Autism is much **more common than many people think**. There are around **700,000** people on the autism spectrum in the **UK** – that's more than **1 in 100**.

About **2 to 5%** of school age children can suffer from **ADHD**.

70% of children and **80%** adults with **autism** will have at least one mental health problem (incl **ADHD**).

4 times as many boys as girls are diagnosed with **autism**.
3 times as many boys as girls are diagnosed with **ADHD**.

Around **66% of children** and **92% of adults** living with **ADHD** and **60% of adults** living with **autism** are **undiagnosed** (aged 40+).

ADHD tends to get diagnosed from age 6, **autism** from age 3 to 4 with a median age of diagnosis around aged 7.

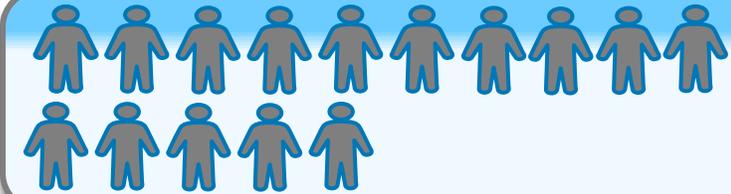
Early diagnosis will impact on life costs, **preventing moving into MH/LD/substance misuse/criminal justice system**.

For every autism/ADHD patients **3 more people** are affected surrounding the person.

Section 3 of the review report provides a summary to the approach taken with the review, a summary of current/future demand and prevalence and highlights the strengths of the current provision. For sourcing, see appendix 1 of the report, pages 4 – 6.



Report headlines – the local challenges



Waiting times for diagnosis vary between 12 and 24 months for Children and Adults. This represents a considerable short term unmet need, lack of support risking escalation of peoples behaviour, exclusion, ending up in mental health or LD services, and criminal justice system.

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|---|---|---|
| <p>The main focus across the system to date has been on autism and yet the number of people with ADHD is far greater than those with autism</p> | <p>Additional investment from health through waiting times initiatives has focused on children leaving adults services under resourced</p> | <p>Prevalence figures for autism vary between 1/100 and 1/68 (1 to 1.5%) by 2039 there will be 6,677 people in East Berkshire living with Autism</p> |
| <p>ADHD prevalence estimates in school aged children between 2% and 7%, in adults 3% to 4% by 2039 there will be 17,751 people living in East Berkshire with ADHD</p> | <p>Total number on waiting lists at March 2018/19: (Number of people) Autism under 5's - 126 Autism over 5's - 512 ADHD over 5's - 208 Autism adults – 135 ADHD adults – 136 Total waiting: 1,117</p> | <p>Total number on 2018/19 waiting list expected to be diagnosed:(Number of people) Autism under 5's - 97 Autism over 5's - 379 ADHD over 5's - 138 Autism adults - 99 ADHD adults – 88 Total expected to be diagnosed: 801</p> |
| <p>In 2017 2,924 children and YP had an EHCP statement. 45% Slough, 30% RBWM, and 35% Bracknell respectively. 1/3 have a primary need for autism support.</p> | | |
| <p>Current services are not joined up which means they do not meet NICE guidelines – the challenge is - how do the organisations in East Berkshire jointly commission autism and ADHD services.</p> | | |



Report headlines - Strengths of current provision

NHS

East Berkshire

Clinical Commissioning Group



Strategy

- All local authorities have an adult autism strategy (Slough refreshing theirs)
- Universal commitment to delivering high quality services to those with ADHD and autism
- Good examples of co-production, including the Windsor and Maidenhead inclusion charter for children and young people
- Good relationships in early years services are enabling a more joined up service offer
- Effective communication and working between multi-agency groups for under 5's is resulting in a high level of nursery/school involvement
- There are opportunities to develop child wellbeing practitioners across organisations
- Many Hands service in Bracknell means children who are requiring services from a number of professions, e.g. physio, SALT, CDC are invited to the group and can be seen by all services



Services

- Introduction of early support from the voluntary sector to support based on need has reduced waiting lists
- Providing support regardless of diagnosis greatly helps families
- Training provided by parents with lived experience has really helped other parents
- Providing home visits where needed really helps the child and their families
- 0-5 multi-agency assessment groups work well providing a seamless service
- Some councils have dedicated posts that signpost and supports parents through the process
- SALT drop in sessions at children's centres are easily accessible
- A nominated person within CMHT enables a more holistic support for adults
- Dedicated autism social care staff in adults aids transition
- CAMHS has a very accessible website that is easy to navigate



Enablers

- Committed workforce
- Use of technology such as SHaRON on line support for parents and carers
- Accessible children and young people families website (BHFT) website
- Supportive delivery teams
- Multi-agency working to deliver services to those presenting with ADHD and autism
- Some recent evidence of improved working with schools
- Implementation of shared care with primary care
- Willingness of service leads to work with commissioners to improve services

Working together to deliver excellent and sustainable healthcare

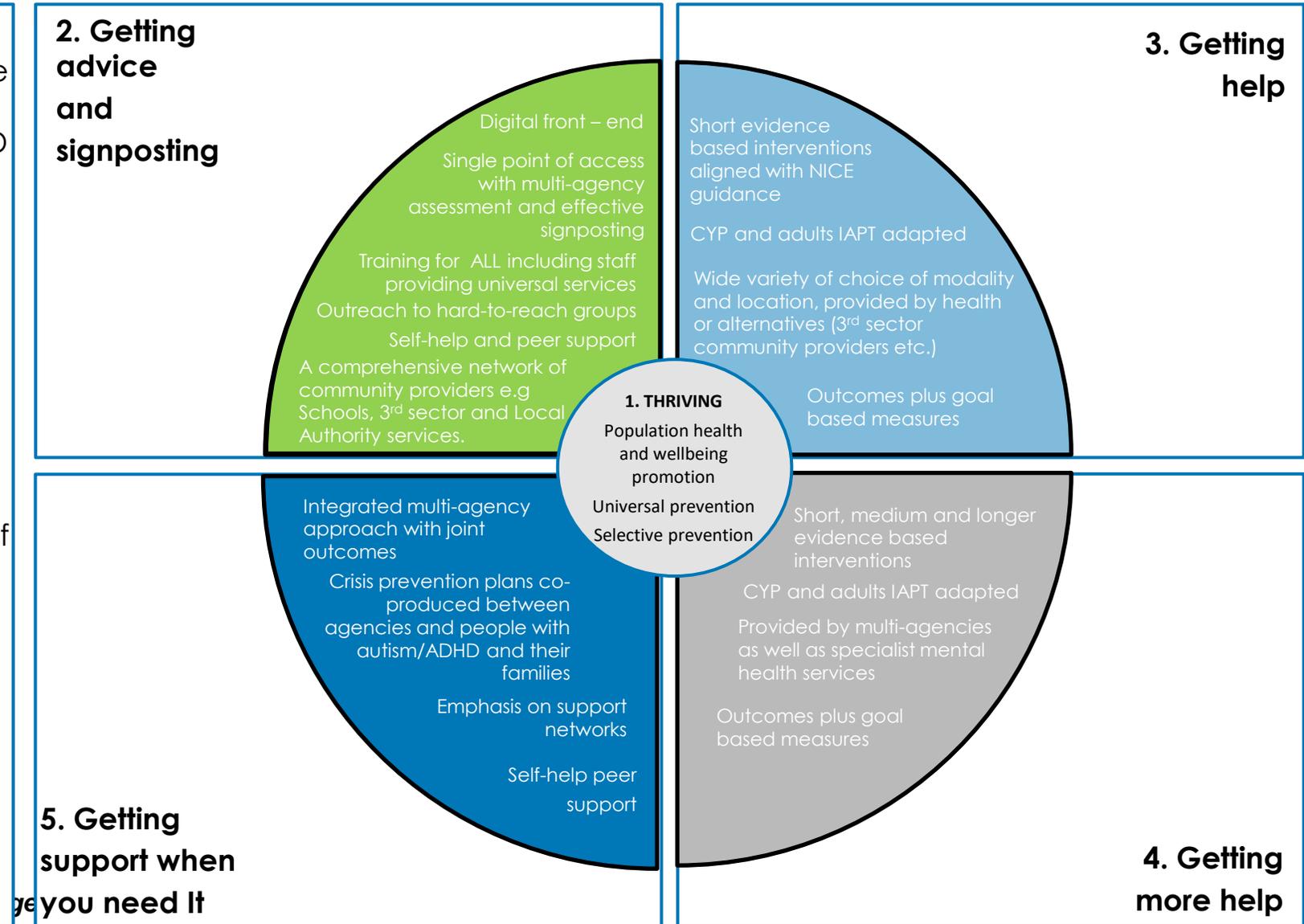


Adapted THRIVE framework in East Berkshire

Section 4 of the main report outlines a proposed model of care framework for the further development of autism and ADHD services.

There are many models upon which we could base our proposed blueprint for Berkshire, however, long-term, quantifiable evidence is limited in this area. Having considered the models that are available, the evidence about where they have been used successfully and the needs of our community, the review report proposes to base the model of care on the THRIVE framework.

The elements included in each section have been developed through a series of stakeholder engagement sessions and workshops held during March – May 2019.

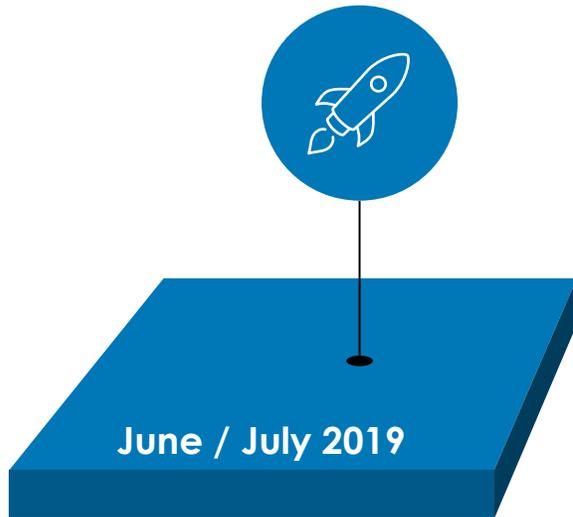




Implementation framework

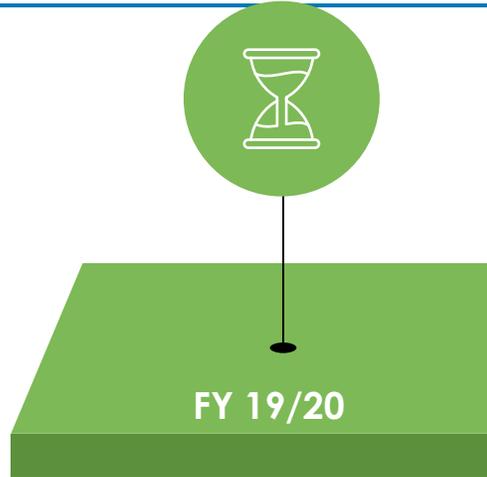
Section 5 in the review report outlines the phases for transformation:

Coherent and aligned, and where possible, delivered in parallel



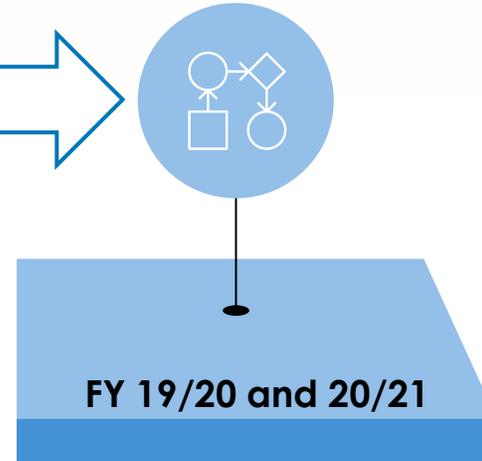
Phase 1:

- **Socialise the findings of the review** and intent to launch a programme to improve services and support
- **Mobilise project management** capability for East Berkshire



Phase 2:

- **Plan and deliver short-term improvements** to ADHD and autism services and support in East Berkshire



Phase 3:

- **Engagement and planning with partners to design system transformation** of ADHD and autism support and services across East Berkshire, the wider Frimley Health and Care ICS and West Berkshire



Phase 4:

- **Delivery of longer-term transformation** of ADHD and autism support and services across East Berkshire, the wider Frimley Health and Care ICS and West Berkshire

The principles of the implementation framework are:

- Do a smaller number of things well, rather than start lots of things
- Prioritise activities that will have an impact on the most amount of our community
- Be realistic on timescales, particularly as much of this requires system working
- Actively engage service users and carers in the design of short-term and longer-term transformation
- Don't wait for system work to begin the transformation of services in East Berkshire
- Co-design across partner agencies will harness collective skills and knowledge
- Work with system partners to drive regional change



For further information contact:

NHS EAST BERKSHIRE CCG

www.eastberkshireccg.nhs.uk/our-work/adhd-autism/