Berkshire East -
Autism and attention deficit hyperactivity disorder project implementation.

Workshop pack and out puts
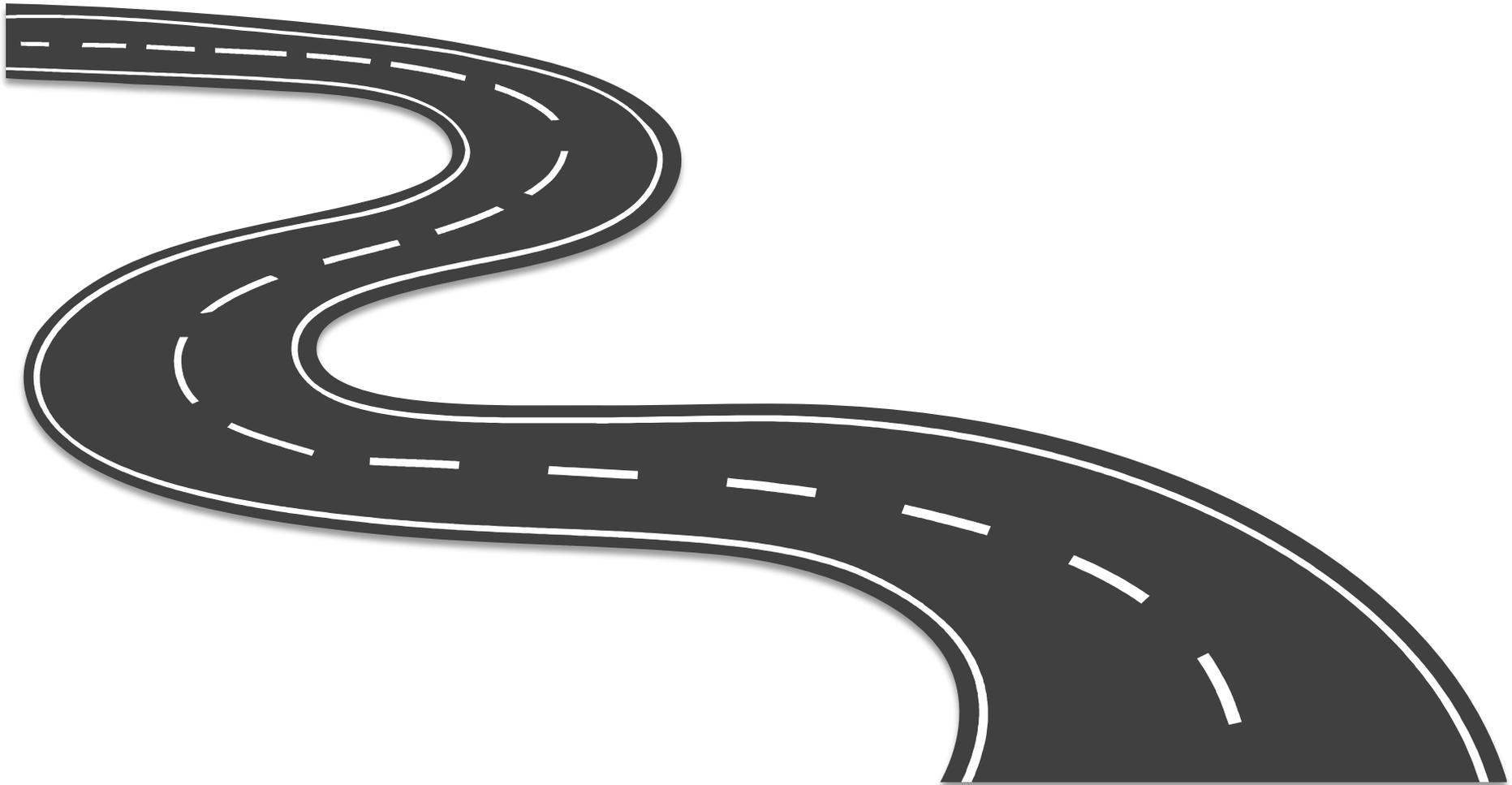
2-7%

3-4%

17,751

What is this session about?

Introduction and overview of work so far in phase 1:

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Workshop 1	Workshop 2

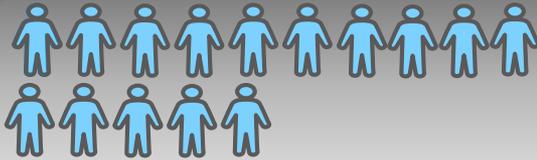| **1** What good looks like - defining service excellence	**2** Establishing the map of services	**3** Developing the blueprint	**4** Blueprint outline
• Consider positive and negatives associated with the current services • Establish what service excellence looks like • Identify opportunities for raising standards	• Establish an 'as is' map of current service provision • Clarification of identified areas • Identify any gaps/ areas that could be improved	• Start to develop a model of care blue print and some realistic service delivery options to be considered further	• Provide an overview of feedback from stakeholder involvement and engagement • Share the draft Berkshire East model of care blueprint and seek feedback

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Workshop overview

Workshop time table	15/10/19
Arrival and coffee	10.30 -10.40
Introduction and overview of work so far	10.40 – 10.45
What does the report tell us?	10.45 – 11.00
How far have we got?	11.00 – 11.05
Group/Table exercise	11.05 – 11.55
Short term service improvements progress – processes - BHFT	11.55 – 12.10
Short term service improvements progress – training audit- 3rd sector/CCG/Attain	12.10 – 12.25
Engaging and planning a new system progress – West Berkshire and Frimley Integrated Care System	12.25 – 12.30

What does the report tell us?

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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 diagnosis (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.

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**

Additional investment from health through waiting times initiatives has focused on children leaving **adults services under resourced**

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**

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**

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

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

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

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**.

Report headlines - Strengths of current provision : Bullet points

- Good examples of co-production : the Windsor and Maidenhead inclusion charter for CYP
- There are opportunities to develop child wellbeing practitioners across organisations
- Early support from the voluntary sector to support based on need has reduced waiting lists
- Training provided by parents with lived experience has really helped other parents
- Some councils have dedicated posts that signpost and supports parents through the process
- Committed workforce
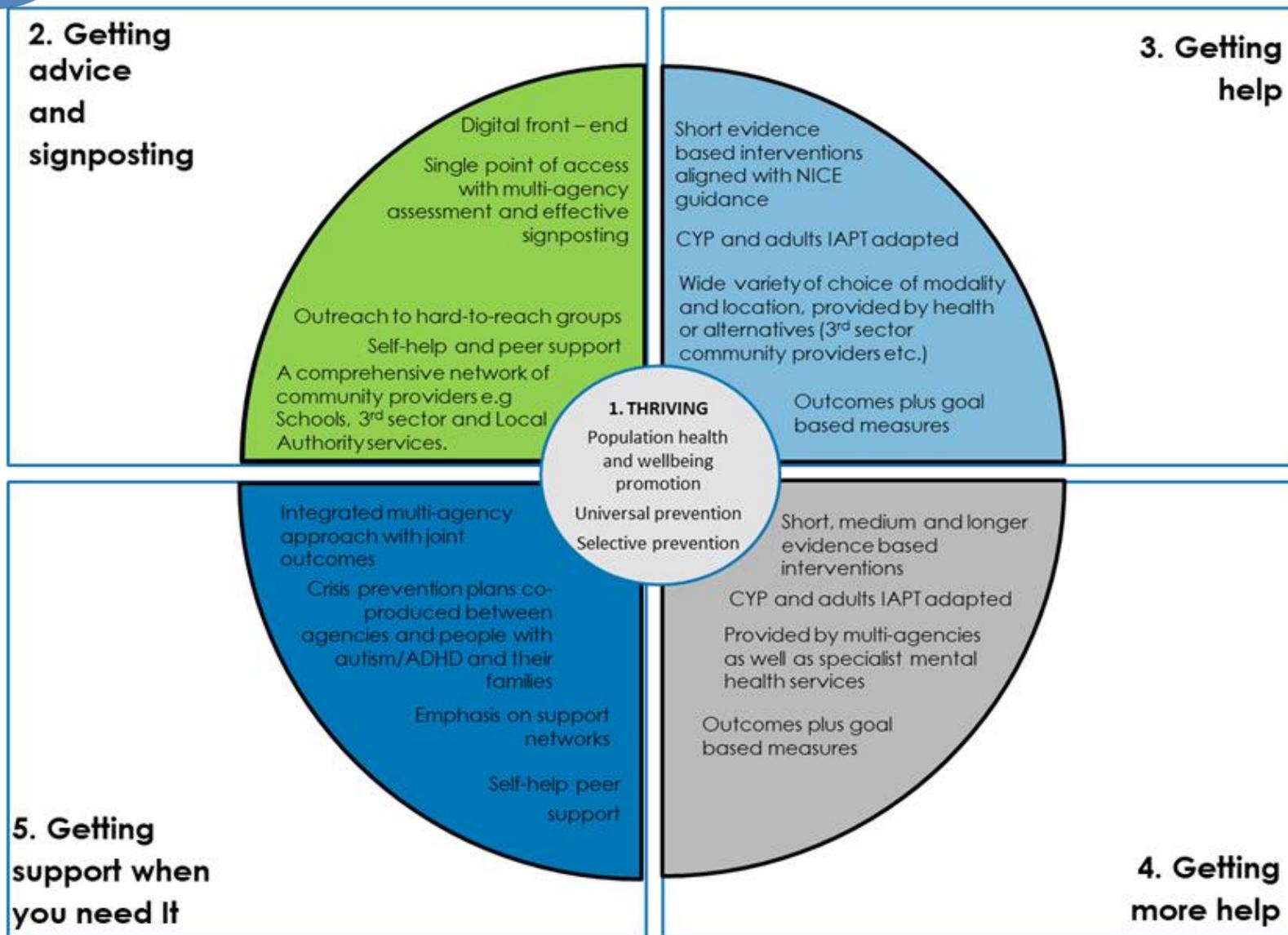- Use of technology such as SHaRON on line support for parents and carers

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.

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2. Getting advice and signposting

Digital front – end

Single point of access with multi-agency assessment and effective signposting

Outreach to hard-to-reach groups
Self-help and peer support
A comprehensive network of community providers e.g Schools, 3rd sector and Local Authority services.

3. Getting help

Short evidence based interventions aligned with NICE guidance

CYP and adults IAPT adapted

Wide variety of choice of modality and location, provided by health or alternatives (3rd sector community providers etc.)

Outcomes plus goal based measures

1. THRIVING
Population health and wellbeing promotion
Universal prevention
Selective prevention

5. Getting support when you need It

Integrated multi-agency approach with joint outcomes

Crisis prevention plans co-produced between agencies and people with autism/ADHD and their families

Emphasis on support networks

Self-help peer support

4. Getting more help

Short, medium and longer evidence based interventions

CYP and adults IAPT adapted

Provided by multi-agencies as well as specialist mental health services

Outcomes plus goal based measures

PERSON   PLACE
ENGAGE   INTEGRATE

Implementation framework

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

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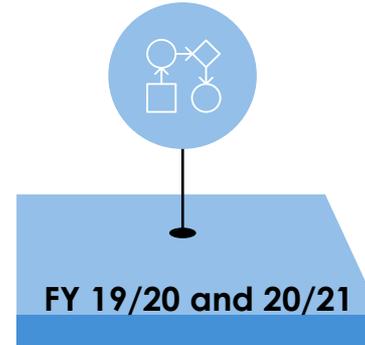**Clinical Commissioning Group**

June / July 2019
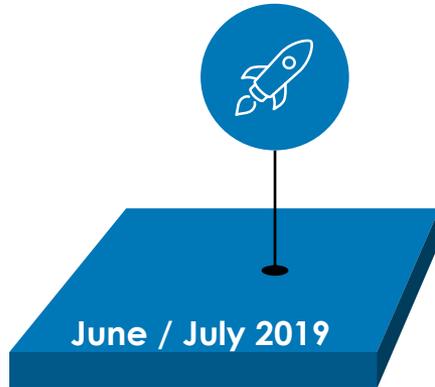
Phase 1:
- **Socialise the findings of the review** and intent to launch a programme to improve services and support
- **Mobilise project management** capability for East Berkshire

FY 19/20
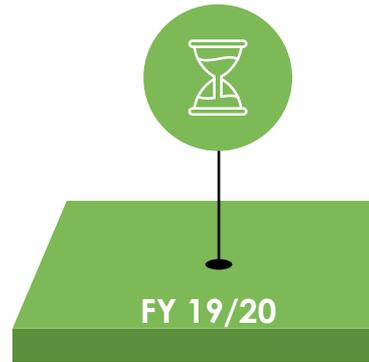
Phase 2:
- **Plan and deliver short-term improvements** to ADHD and autism services and support in East Berkshire

FY 19/20 and 20/21

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
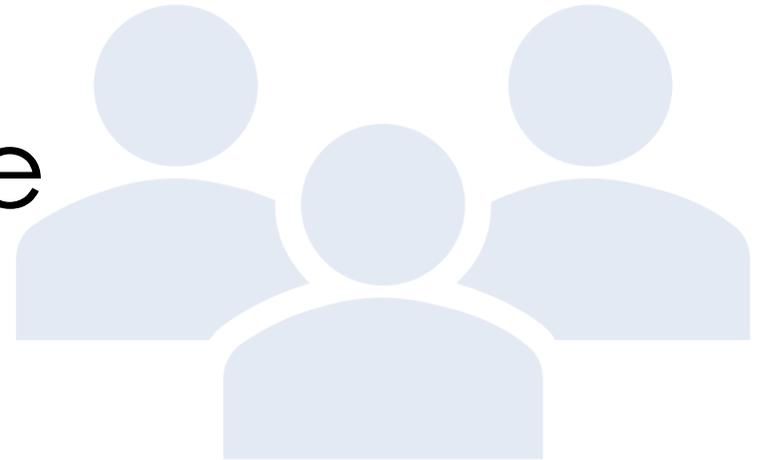
FY 20/21 onwards
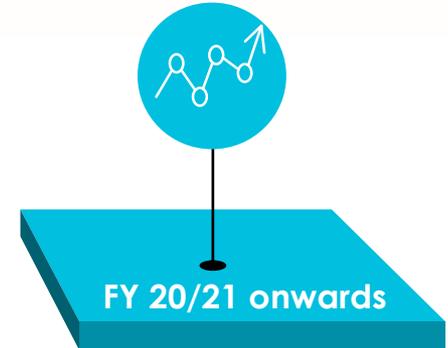
Phase 4:
- **Delivery of longer-term transformation** of ADHD and autism support and services across East Berkshire, the wider Frimley Health and Care ICS and West Berkshire
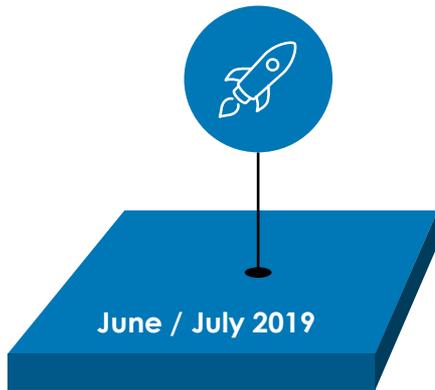
Coherent and aligned, and where possible, delivered in parallel

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How far have we got?

Phase 1: Socialising the review and intent to transform services – our progress

June / July 2019

Socialise the findings of the review and intent to launch a programme to improve services and support

Mobilise project management capability for East Berkshire and governance arrangements

What?	Who?	Output / outcome	When?
Identify clear and visible leadership to lead communication on findings of review and launch programme to transform services	Representatives from East Berkshire CCG, partners, service users parents and carers	Clear leaders and champions for change	End of Sept 2019
Engage with partners to agree next steps from the review including, implementation framework; priorities, resourcing and governance	Led by East Berkshire CCG as commissioners of the review, to include: - Frimley Health and Care ICS - Berkshire West CCG / ICS - Berkshire Healthcare - Local authorities - Third sector partners	Short-term Delivery Plan Roadmap for longer-term transformation	End of Aug 2019
Develop a **communication document** that summarises the findings of the review and next steps	East Berkshire communications team, with partners and with support from Attain	Communications document	End of Sept 2019
Mobilise project management support and governance arrangements to deliver short-term recommendations and represent and deliver East Berkshire transformation within wider ICS in the longer-term	East Berkshire CCG, with local partners	Project Manager in post Local governance agreed	Beginning of Sept 2019

In groups, assign a scribe and a person to feedback and discuss the following:

What elements of the model are already in place?

What elements of this model do you think we could implement quickly?

Are there any elements missing from the different stages in the model?

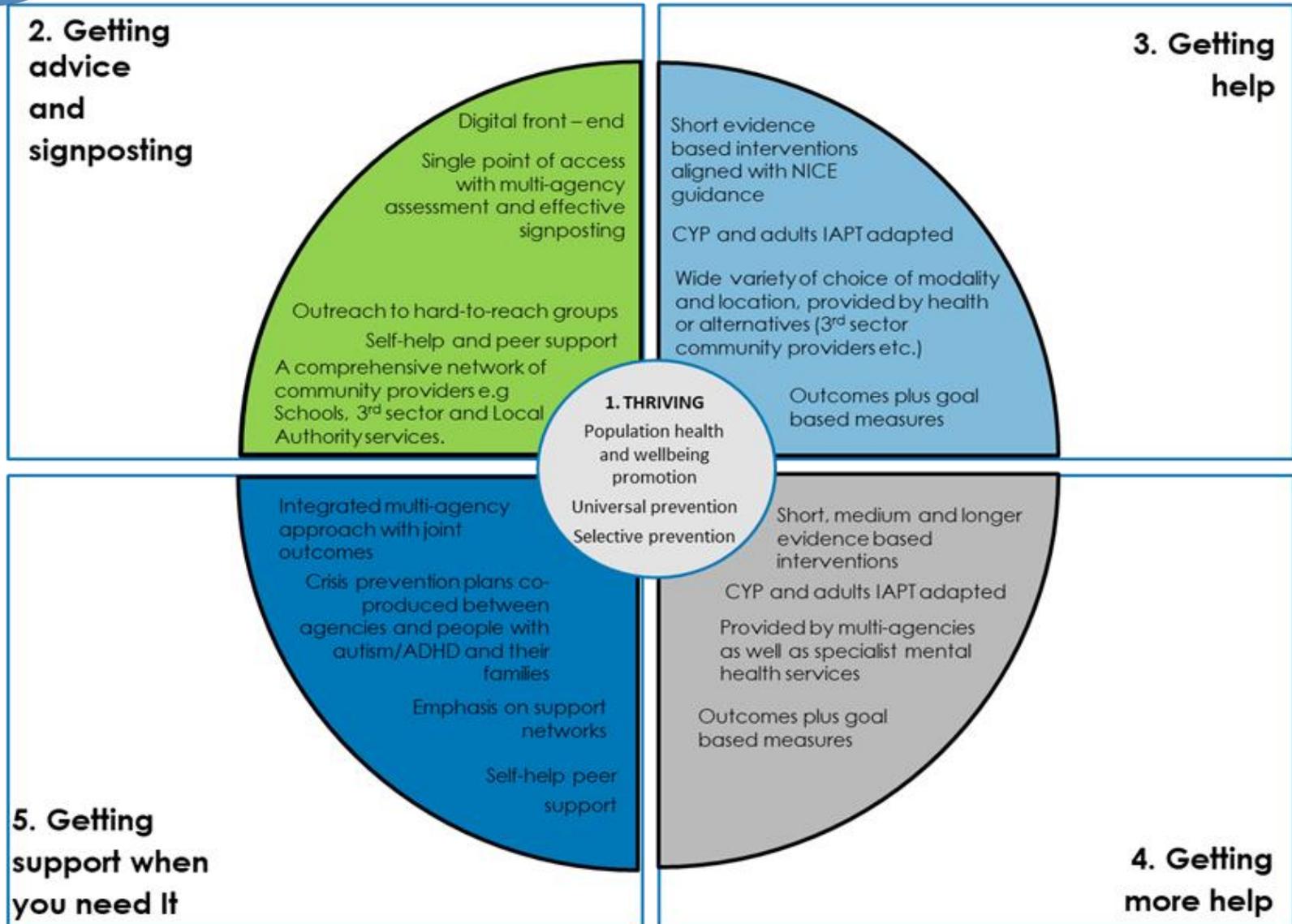25 mins plus 25 mins feedback/discussion

Adapted THRIVE framework in East Berkshire

2. Getting advice and signposting

Digital front – end

Single point of access with multi-agency assessment and effective signposting

Outreach to hard-to-reach groups

Self-help and peer support

A comprehensive network of community providers e.g Schools, 3rd sector and Local Authority services.

3. Getting help

Short evidence based interventions aligned with NICE guidance

CYP and adults IAPT adapted

Wide variety of choice of modality and location, provided by health or alternatives (3rd sector community providers etc.)

Outcomes plus goal based measures

1. THRIVING

Population health and wellbeing promotion

Universal prevention

Selective prevention

5. Getting support when you need It

Integrated multi-agency approach with joint outcomes

Crisis prevention plans co-produced between agencies and people with autism/ADHD and their families

Emphasis on support networks

Self-help peer support

4. Getting more help

Short, medium and longer evidence based interventions

CYP and adults IAPT adapted

Provided by multi-agencies as well as specialist mental health services

Outcomes plus goal based measures

Phase 2: Short-term service improvements

FY 19/20

Plan and deliver short-term improvements to ADHD and autism services and support in East Berkshire to improve the experience of our community through smoother access to support and services and building the awareness of ADHD and autism of those providing support and services

What?	Who?	Outputs / outcomes	When?
Building on the existing work in this area, **launch process review of 0-5, 6-18 and adults services**, to include a review of: - Referral processes and protocols - Waiting lists (ongoing) - Transition arrangements - Pre-assessment materials - Clinical governance - Shared care protocols - Support available to carers **Delivery of key recommendations**	Led by a project manager appointed across Berkshire Healthcare and East Berkshire CCG, engaging with local authority and third sector partners and schools (SEND) and primary care where required	**Output:** process improvements **Outcome:** improve the experience of service users and carers, including by reducing cumulative waiting lists	Sept to November 2019
Audit and review the provision of training available for parents, carers, service users and partner agencies. Source new training for any gaps identified (e.g. online). Disseminate awareness training materials to schools and GPs and wider partners	Project manager, with partners	**Output:** training provided to partner agencies **Outcome:** awareness raising and start of a cultural change	Sept to October 2019
Review and refresh Library of Services, ensure widely available to community and referrers	Project manager, with partners	Updated library of services, published to partner websites	On hold

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Short term improvement's our progress (2): Audit and review the provision of training available

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Service user journey review of autism and ADHD services all ages

What we have done:

• Carried out NICE guidelines baseline assessments for all services

• Service processes reviewed and areas for improvement identified

• Staffing level/resource identified

What will be different:

• Things should happen more quickly

• You should only have to tell your story once

• We will work more efficiently across our service teams

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Short term improvement's our progress (2): Audit and review the provision of training available

Service user journey review of autism and ADHD services all ages

What we have done:

- NICE Guidelines: Shared and refreshed our NICE guidelines baseline assessments

- Service processes for autism and ADHD teams are reviewed on an ongoing basis to see where/if these can be further refined/streamlined – and this has been shared in the project.

- Over 5 autism assessment processes and staffing resources have been mapped and reviewed in detail by BHFT and this has been shared during the project.

- Under 5 review of processes ongoing as part of the project – more complex as different models across Slough, WAM and Bracknell.

Short term improvement's our progress (2): Audit and review the provision of training available

Service user journey review of autism and ADHD services all ages

Next steps:

- We have a culture of continuous improvement in services and this will continue

- We have been working hard to ensure families receive support before, during and after assessment. This work will continue through the project as we explore models of service delivery

- We will continue working to make sure all families are aware of all of the services available to support their child and the family

- We are working on waiting list initiatives in East and West which includes work to offer the option of online autism assessments on an ongoing basis

- We will continue to offer joint autism and ADHD assessments where possible

- We are working across the autism and ADHD teams to streamline administrative and clinical processes to provide more joined up working and information gathering

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Short term improvement's our progress (2): Audit and review the provision of training available

Service user journey review of autism and ADHD services all ages

Support for families :

- Focus is on **needs led** support throughout the journey.

- Innovative support of children, young people and families before, during and after assessment, including information pack sent to parents.

  - **Helpline** – clinicians provide advice and signposting for families while child is waiting for assessment

  - **SHaRON online support** for parents/carers of children with autism/waiting for assessment. Plans to extend SHaRON to include parent/carers of children and young people with ADHD/waiting for assessment

  - Pioneering trial of **Trainee Children's Well-being Practitioner posts** to provide brief evidence based intervention for children with anxiety/low mood/ emotional regulation difficulties

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Short term improvement's our progress (2): Audit and review the provision of training available

Service user journey review of autism and ADHD services all ages

Other work: Innovative support of children, young people and families

- **Trainee parenting practitioners** to provide individual and group support for parents/carers of children with ADHD or waiting for assessment

- **PPEPcare** – Psychological perspectives in education and primary care – modules on a range of topics including autism awareness, autism and mental health and module on ADHD is being finalised

- Recently introduced **workshops for parent/carers of children with anxiety** who have autism and/or ADHD or who are waiting for either/both assessments

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Short term improvement's our progress (2): Audit and review the provision of training available

Service user journey review of autism and ADHD services all ages

What we have done:

- NICE Guidelines: Shared our initial NICE guidelines baseline assessments.

- Service processes for autism and ADHD teams are reviewed on an ongoing basis to see where these can be further refined/streamlined – and this has been shared in the project.

- Staffing levels shared with project led for ASD and ADHD services

- We have mapped our ADHD services and are working on improving transition between our child and adults services.

- We are liaising with the children's ASD service regarding access of post diagnostic services for 17 years plus

Short term improvement's our progress (2): Audit and review the provision of training available

Training/workshops for for parents, carers, service users, frontline and specialist staff -

What we have done:

- Collected all the training/workshops into once place to see just what is on offer

- Had meetings with key people leading on the training including vol sector, Educational Psychologist , parenting leads

- Identifying gaps in workshops/training (for example CYP workshops)

What we will do:

- Chunk together training so its into three levels universal, intermediate and specialist

- Recommission training/workshop for parents/professional/volunteers based on need (and gaps)

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Next steps

How to keep in touch:
Add in website address

Out puts by the end of the project

- By the end of October there will be a central repository of current autism and ADHD training available

- At the end of October there will be an outcomes based training specification for autism and ADHD. Training will be for service users, parents, carers and staff.

- By the end of November there will be a report describing the opportunities to improve service processes for autism and ADHD assessments for children and adults

- The report will contain a summary of future workforce requirements to meet the future demand

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Frimley Health and Care communities map

Handouts for exercises
to be printed

Report headlines - Strengths of current provision : Bullet points

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

Workshop outputs

Adapted THRIVE framework in East Berkshire

This framework is about providing timely support and should not be reliant on parents/carers driving the process

2. Getting advice and signposting

Access to information via information technology

Single point of access with multi-agency assessment and effective signposting

Training for ALL including staff providing universal services

Outreach to hard-to-reach groups

Self-help and peer support

A comprehensive network of community providers e.g Schools, 3rd sector and Local Authority services.

3. Getting help

Help and support based on best practice

CYP and adults talking therapies adapted to meet peoples needs

Wide variety of choice of locations, methods and providers e.g. local authorities, health or alternatives (3rd sector community providers etc.)

Achievements in small achievable steps

1. THRIVING

Population health and wellbeing promotion

Prevention initiatives to support all

5. Getting support when you need It

Integrated multi-agency approaches with joint outcomes

Crisis prevention plans jointly developed between agencies , people with autism/ADHD and their families
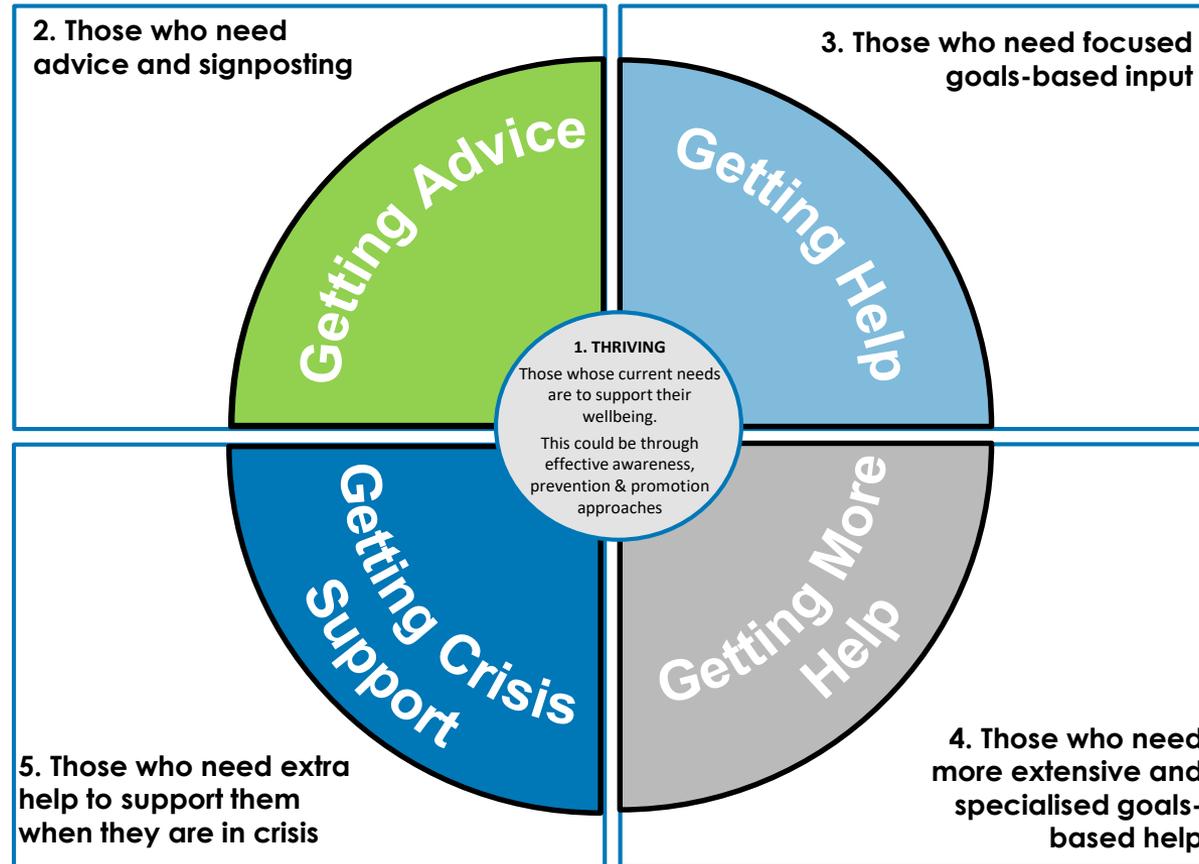
Emphasis on support networks

Self-help peer support

4. Getting more help

Short, medium and longer best practice interventions

CYP and adults talking therapies adapted to meet peoples needs

Support provided by multi-agencies as well as specialist mental health services

Outcomes plus goal based measures

Adapted THRIVE framework in East Berkshire

As a result of feedback from stakeholders, the high level view of the model has been simplified.

2. Those who need advice and signposting

3. Those who need focused goals-based input

Getting Advice

Getting Help

1. THRIVING
Those whose current needs are to support their wellbeing.
This could be through effective awareness, prevention & promotion approaches

Getting Crisis Support

Getting More Help

5. Those who need extra help to support them when they are in crisis

4. Those who need more extensive and specialised goals-based help

Based on the Tavistock and Portman NHS model.

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Thriving		
East Berkshire adapted THRIVE segment		
1. Thriving – Raising awareness and understanding		
Who	**What**	**Examples**
The THRIVE framework suggests that everyone, including those thriving in the community, should receive community initiatives that support mental wellness, emotional wellbeing and resilience of the whole population. Raising awareness and understanding in communities about autism and ADHD will enable people with autism and ADHD to be better supported within their local communities. Developing services together is central and means that people with autism/ADHD will help design and implement services.	This will mean providing access to universal services i.e.: leisure centres, cinemas, libraries etc. that are inclusive, where staff are trained to support people with autism and ADHD. Adequate training with targeted levels for professionals, parents, partners and people with autism/ADHD. Promoting understanding, self-awareness and self-management along the whole journey underpinned by robust safeguarding	• Supportive inclusive community resources, e.g. libraries, community centres, fitness centres, cinemas. Need to ensure the terminology used to access services is user friendly e.g. "relaxed performances" in cinemas – people need to understand what this means. • Mandatory training for universal service staff – routinely trained by people with lived experience to provide their services in a way that supports those with autism/ADHD. E.g. accessible video libraries with people with lived experience. • Engagement with education, primary care social care, housing and other universal services • Building knowledge and skills via developing autism/ADHD friendly communities, schools, hospital police, probation, employment, forensic & services ensuring there is awareness that people think differently • Blogs, skype and e-Learning and face to face training for people with autism/ADHD, parents/cares/partners and staff • Local publicity, youth and community workers. • Robust easily accessibly directory of services • Staff training to recognise needs and impact these are having • Awareness raising and training for parents, carers and partners including what is available • Awareness raising through third sector, local authorities, pharmacists, mental health providers and primary care including autism and sensory friendly environments • National campaigns, public health campaigns health /social care and VCS (community events/workshops/social media) • Mandatory training for mental health and frontline staff

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Getting advice and signposting		
East Berkshire adapted THRIVE segment		
2. Getting advice and signposting		
Who	**What**	**Examples**
Some people seek advice when adjusting to life circumstances. These people are choosing to manage their own lives.

Parents/partners/families, carers and care professionals seek advice on behalf of people who may or may not have autism and or ADHD. | This will mean providing access to early intervention and prevention through places of education, children's centres, health visitors, school nurses, GPs, helplines and websites for support.

We will provide early support to referrers such as health visitors and those in schools and general practice. | • Create a central place with all the information people, parents/carers need
• Through the use of community places and schools e.g. parents evenings, providing easy access for people and their families to information, advice, assistance, signposting and advocacy when needed including to hard to reach groups. Need to agree what elements of advice and support can be provided and the ways of accessing e.g. online, phone, face to face contact.
• Building system-wide leadership across East Berkshire to ensure 'getting advice' is embedded across our area and integrated into local services and processes through community networks
• Working with schools and education settings to ensure they get early help and that all staff are trained to support children with autism/ADHD.
• Support for school to develop a resource base for parents and children to access providing information on autism, ADHD and other diagnosis.
• Developing a 'no wrong front door' approach that signposts and navigates easy access to information, support and services – for example a single point of access. Clear/accessible pathway for route to diagnosis where needed
• Information advice and assistance (IASS), signposting for professionals
• Information advice and assistance (IASS) and sign posting for parents connecting them to local peer groups for support at the outset
• Sign-posting to local groups, neighbourhood networks, peer groups
• Access via community connectors word of mouth - people in the local community
• Advocacy and support, child wellbeing and parenting practitioners, youth workers
• Key worker/life coach to start as son as possible where identified and to follow through life |

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Getting help		
East Berkshire THRIVE segment		
3. Getting help		
Who	**What**	**Examples**
Children young people, those leaving care, adults, parents and partners sometimes need help during certain points in their life journey. This can be regardless of a diagnosis being made.	Support and services to people regardless of diagnosis and age will be provided through community support, hospices and bereavement services, counselling and mentoring in schools, education psychologists, education support centres, targeted youth support teams, family support, support to referrers and adapted IAPT services. N.B it is important staff in services are trained to be able to adapt their support to the needs of the person with autism and/or ADHD. Join up health and social care and 3rd sector on IT/shared documents/assessments/care plans	• Ensuring there is a clear route with choices as to how to access 'getting help' for children, young people, their families and referrers. The type of help needs to be identified and clearly defined • Providing care based on goals – that can be differentiated according to the needs of the person • Care plan from diagnosis – shared with parent/service user and to all services • Providing a wide variety of limited, goal focussed, 'talking therapies' which are evidenced based to be a positive element of support for people, for a range of needs (typically mild to moderate in nature) in a range of community based, school and health locations, and via remote access (e.g. Improving Access to Psychological Therapies for children and young people). • Access to on-line information, advice and support where appropriate. • Flexible access to information and advice and support according to the persons needs • Ensuring vulnerable groups are represented at the levels expected for the local population. • Developing support and training to schools including a named mental health link person. • Access to telephone advice for referrers. • Providing supervision across the services to support wider practitioners. • Assessment in multidisciplinary teams and development of a single care plan • Advocacy and support, child wellbeing and parenting practitioners, youth workers • Access for parents to 3rd sector support and training services and peer support groups • Support for parent/care/partner and person with autism/ADHD • Short term support for those who need it and follow up/referrals where needed • Understanding and manging behaviours • Planning for the future for both the carer and person with autism/ADHD • Help finding support groups with similar people

The pathway must be clear and publicised so people can access services which should not depend on diagnosis and an initial support plan should be drafted. Services to work in a joined up multi-disciplinary way accessing one single care plan. Multi-agency care plan needs to be developed.

Getting more help		
East Berkshire adapted THRIVE segment		
4. Getting more help		
Who	**What**	**Examples**
In addition to having autism and or ADHD some people have additional support needs such as mental health conditions (e.g. psychosis, eating disorders) substance misuse issues and challenging behaviour. These people may require extensive and short and/or long-term support from care professionals.	A system wide proactive response, support and services will be provided to people including multi-disciplinary/agency working in a community setting to meet more severe, complex needs. This includes eating disorder, substance misuse, self-harm behavioural support, mental health and manging challenging behaviour services. N.B. the care pathway must be clear so people know how to access support at a time when they need it.	• Making support simple and easy to navigate and focused on goals. • Ensure there is a clear route to 'getting more help' that is integrated with the other groupings, focusing on robust pathways that enable a flexible response to need including bespoke work for CYP as early as possible and access to mental health services. • Care coordination and advocacy, supporting a person and carer with a care plan that evolves along the journey (life coaching), providing goal focused evidence-based treatment for a range of more complex needs in a range of community based, school and health locations, and via remote access e.g. skype/online. This will include systemic interventions and pharmacological interventions, multi-agency care planning and management of risk, including intensive home-based support when required. • Locality teams working in the local community, to include educational psychology/CAMHS, social care and health multi-agency expertise). Mental health and general health support for the person with autism/ADHD and their carer through holistic MDT care planning supported by the autism/ADHD care -co-ordinator/life coach • Exploring co-location of staff to facilitate joint working and robust shared processes leading to integrated and multi-disciplinary care planning including end of life care planning for the care and the person with autism/ADHD (regular reviews) • Close working with the police and criminal justice agencies as part of the MDT care planning process ensuring place of safety is business as usual for those with autism/ADHD • Embedding talking therapies principles within the pathway with a focus on developing a culture of service user engagement and participation, consistent and embedded use of routine and goal-based outcome measures and the use of evidence-based interventions. • Aligning with crisis pathways where a person who is already 'getting more help' requires a response due to crisis. This should, wherever possible, be provided by the staff currently working with them and in line with national access and waiting time standards. • eLearning and continued training for ALL • Information, advice and assistance, signposting, and support for people with autism/ADHD and for parents/cares/partners when needed ensuring parents/carers understand the terminology that is sometimes used. • Meaningful living – use of universal services and ongoing support when needed • Autism/ADHD care-co-ordinator/life coach supporting person and carer through to end of life • Integrated and multi-disciplinary care planning including end of life care planning for the care and the person with autism/ADHD (regular reviews) • Use of assistive technology where possible • Specialist post diagnostic support when needed, CAMHS satellite clinics, adult services – access via hospital staff, CPNs, district nursing, social care staff • Support to remain in your own home for as long as possible – regular reviews of care plan which includes a persons environment

Getting risk support

East Berkshire adapted THRIVE segment

5. Getting support when you need it Crisis/risk management/challenging behaviours

Who	What	Examples
Some people find themselves unable to benefit from ongoing support but remain a significant risk or concern and can be supported by a multi-agency team. These people can go into crisis but are not able at the time to make use of the help offered or the help offered has not made a difference. These may be people with emerging personality disorders, on-going issues that have not yet responded to treatments or those that fail to attend appointments. People may also have not needed any support over a long period of time until a life event occurs such as a bereavement, loss of a job, failing to attain your degree in university or succeeding in college, retirement, marriage or relationship breakdown etc. and the person requires help as soon as possible. People with challenging behaviour may also need to access support when they needed	Support and services included here will include crisis care planning, specialised crisis support and day and inpatient units, where people with more severe autism and mental health problems can be assessed and treated. It will also include crisis support services, linked to national services that support people during times of crisis. Services that can provide training for those with challenging behaviour and their families are also included here.	• Developing robust integrated pathways across multiple agencies and that they that are embedded within the early help, safeguarding and social care frameworks, and include close working with education. Streamline across all areas e.g. social care local planning differs • Ensure better access to mental health support for those in crisis • Improved awareness for mental health/counselling/support for referral route for autism and ADHD • Adequate commissioned service support such as dieticians and occupational therapists for those with autism and ADHD • Using the care co-ordinator/life coach role, ensure that vulnerable people, those in care and care leavers have access to timely support and can influence the care they receive through joint care planning through to end of life. • Providing specialised risk support close to the person's home and where they can build local and personal support networks. Enabling people to live in their environment as long as possible (e.g. satellite clinics in the community) • Exploring co-location of staff to facilitate joint working and robust shared processes leading to integrated and multi-disciplinary care planning including end of life care planning for the care and the person with autism/ADHD (regular reviews) • Agreeing clear criteria for when a person would benefit from 'risk support'. • Providing consultation and indirect support to children's and adults services to enable informed decisions about the most appropriate THRIVE grouping for a person. • Endeavouring to work across partners to provide a 'team around the professional' approach that supports partners to support the young person/family and enables shared management of risk. • Working with colleagues across early help, education, social care and health to identify with people and their family who is best placed to be the person's key person. • Working with partners to develop a joint approach to person and family centred care planning. This should include care planning with the person/family to identify how best to keep themselves safe and what to do in a crisis. • Use of assistive technology where possible • Specialist post diagnostic support when needed, CAMHS satellite clinics, adult services – access via hospital staff, CPNs, district nursing, social care staff • Support to family and friends

Top 3 points following group discussion in relation to the new framework:

1. Thriving raising awareness

Scope who is eligible

Training - people/parents/professionals/partners

Specifics -

- Awareness of what the term means
- Autism friendly terminology
- Individualised services prioritised
- Case management

2. Getting advice and sign posting

Targeted advice and guidance 1:1 cross over with 1.

There is a lot of information out there – "I don't know what I don't know" need choice of accessing information, face to face, online etc. (Online can be powerful if it can be accessed).

Training for teachers shouldn't be optional.

Resources: Build on community centres (Schools, children's and learning centres)

Who is monitoring accountable? – shouldn't be the 3rd sector.

Adults need physical advice to supplement online or verbal advice.

Don't think ADHD and autism should be together

3. Getting help

Overlap with 2

Rephrase wording - more simple

Evidence-based/outcomes based interventions

Talking therapies difficult to access

Joining/accessing support groups difficult for this group

Choice of routes to get help

What adjustments do we need to make to help people access services?

4. Getting more help

Meeting obvious and not so obvious needs

'Food clinics' 'Anxiety clinics'

Access is the challenge

Service users more engaged/more training/more awareness – real improvements

Care plan after diagnosis – parents, teachers GPs etc. everyone contributing. Constantly adjusted to needs. Clear accountability.

Currently services and schools are too reactive not proactive – lack of resources

5. Getting support when you need it

Timely access is key. Improved referrals – more like LD before crisis

Autism awareness card – more awareness

Transition into adulthood

Sharing records between parts of the system

East Berkshire Thought Tree: Things that we need to address

PERSON
PLACE
ENGAGE
INTEGRATE

NHS
East Berkshire
Clinical Commissioning Group

Too long on the waiting list for every service. There is no booklet about benefits and allowance and where I need to go and nobody knows!!

Sensory integration assessments and support for everyone with and SLD, autism, ADHD, Dyspraxia, Dyslexia

We must use the right terminology Autism not ASD - disorder

Education of complex presentation of needs and multi service working across health, education and social care

Support for parents with children later diagnosed with behaviour issues – support groups

The adult diagnosis service for ASD ADHD and neurological for Berkshire is 1.5 FTE.

Disgraceful - CHANGE

More financial support for carers and family and people receiving support

AI services to have an understanding of parents frustrations and ability to empathise with parents

Equal life expectancy and quality of life

Too much talk not enough action.

Change of attitude from top down

What is happening for HEALTH AND SOCIAL CARE when does it start. No councillors here today

More emotional support for parents and children

Wider range of work placements on offer

Who is making the Health contribution to the current (5yr) review of the Autism Act (2009)

This is a distraction

We are still avoiding the "A" word.

Adding ADHD blurs the matter

We need services you are 10 year late – Act 2009

Diagnosis is a disgrace and the neglect continues for both children and adults. Why are we still talking about it?

More support for parents

What are the ASC incidence figures for East Berks

Children   Adults

    ?   ?

Not in the report that I see

When will we respect the individuals rather than classify them LD or MH. This is discrimination and clearly not working. CHANGE

Report started autism and ADHD changed to ADHD and autism – wrong

Separate conditions – that may over lap

Following user input better

Working together to deliver excellent and sustainable healthcare

East Berkshire Thought Tree: Training requirements

Multi-agency

Training for receptionists - Managing parents expectations and emotions

EARLY INTERVENTION AND HELP - Universal training for all early years staff to recognise and support needs of young children and their family. General awareness/practical/processes and procedures

Autism and ADHD training should be aimed at all practitioners/early years/teachers/parents. Training, workshops ad support should be more readily available to families

Training for shop staff/doctors etc. receptionists

Training for NHS, Las and parents/carers – when is it ADHD when is it trauma?

P.I.P Assessors/job centres/doctors/GPs/social housing (local authority)

Training for CAMHS and local authorities about working together – NICE guidelines

Training for professionals to update services and professionals that are current and in place

Training should include people who it affects such as the people they are intending to provide support to

Customer facing roles in local authorities e.g. housing customer service/GPs and reception staff

Training for police and front desk services in local authorities

Ongoing follow up training refreshers for staff

Understanding for professionals and families

Autism and ADHD training to all service providers to develop awareness and some generic strategies

Education

Better training for SENCOs to be able to tell the difference between ADHD–autism to improve quality of referral-quicker time to process

ADHD from service providers into schools

Autism awareness training for staff in schools is not good enough

Autism awareness training for staff in schools is not good enough

Training for teachers, Tas, lunchtime staff in understanding ADHD and autism

Should be a bigger part of teacher training and also training for early years practitioners

Professionals such as schools, CSC, family work around diagnosis and how to support families

Teachers + head teachers need training on how to support children with autism and ADHD on how to teach children/how to prevent bullying/support family

Training for teachers on subtleties of autism presentation especially in girls CAMHSAAT

Define training!! for school staff

Teachers need training in how to approach children during meltdowns and how to try to avoid them. Basic understanding of condition

East Berkshire Thought Tree: Training requirements

General

- Training strategies to support transition - Nursery to school/Year on year/Primary to secondary/Secondary to independence

- Training should be knowledge based. Parents/carers/siblings/class mates. Age appropriate. Focus to explore stereo type e.g. adolescent

- Mental health awareness especially self harm (training by mental health professionals)

- Target age group: Adolescents/social communication/social experiences

- Training needs to be varied and practical with follow-up afterwards

- Training based on input from the supported

- Training around process of referral and who to go through

- Better, quicker access to mental health social workers and social services support

- Everyone. Starting with health. Where is the autism team for health? Where is the autism team for social care? Education?

Health

- Patient focused service training – CAMHS admin staff

- All NHS staff – GPs, A+E, children's + adults, out patients and inpatients need training on autism and ADHD to understand behaviours, sensory needs different pain level and the needs to adjust care provision

- Basic autism training needed for:

  Patient transport service/patient appointments (Frimley Health)/Hospital admin

- NHS practitioners, physios, optician, midwives, health visitors etc. All need to understand the needs of patients with autism and ADHD

- GP training on autism and ADHD

Parents

- Understanding that safeguarding children requires an understanding of the whole families needs

- PROPER Applied behaviour analysis/positive behaviour support for parents and front line carers

- Training for parents coping with melt downs – particularly with young adults. Self harm

- Parents need information about autism and ADHD. If these one delivered as workshops, they will get mutual support

Social care

- Social workers need training on needs of children and families who are living with autism and or ADHD. They need to support families to help improve school attendance, attainment and family life

- Understanding that safeguarding children requires and understanding of the whole families needs.

Working together to deliver excellent and sustainable healthcare