

NHS Rotherham Clinical Commissioning Governing Body

Title: Commissioning an All Age Rotherham Neurodevelopmental Pathway in Rotherham.

GP Members Committee: 24th April 2019

Strategic Clinical Executive - 20th February 2019

Operational Executive - 8th February 2019

Governing Body - 1st May 2019

Lead Executive:	Ian Atkinson Rotherham CCG Deputy Chief Officer
Lead Officers:	Garry Parvin - Joint Head of Learning Disability, Autism and Transitions Commissioning (Joint Commissioning CCG/RMBC) Kate Tufnell - Head of Adult Mental Health Commissioning, Complex Needs & Housing Related Support (Commissioning (Joint Commissioning CCG/RMBC)
Lead GPs:	Dr Russell Brynes, SCE Clinical Lead mental Health and Learning Disability

Purpose:

This paper provides the Governing Body Members Committee with a proposal to commission an all age Neurodevelopmental Pathway, covering the diagnostic and post diagnostic provision of ADHD and Autism in Rotherham, to allow this our focus needs to be on enhancing adult provision.

This proposal has been supported by the CCG Operational Executive (08/02/19) and the Strategic Clinical Executive (20/02/19).

It is proposed that a direct award of contract (following the publication of a VEAT notice) would be made to RDaSH to allow integration of the adult offer with the Children and Young People Pathway delivered by RDaSH CAMHS, supported by the third sector.

A VEAT notice has been published on OJEU and it is expected to close on Midnight, Tuesday 7th May 2019. At the time of writing this report, there has been no other expressions of interest.

Background

The purpose of this report is to set out a proposal to commission an all age local, Rotherham Place pathway that will provide Autism Diagnosis, ADHD diagnosis and develop a strength based post diagnostic offer across the Rotherham Borough.

A strength based approach means tapping into the knowledge and skills of children, young people and adults with autism ; understanding the value of relationships between families, friends and informal (neighbours and community) networks; and recognising the importance of local community and voluntary groups

There is already an established Rotherham Place Pathway for Children and Young People.

Therefore the focus of activity (and this paper) will be to develop a local adult diagnostic pathway and service, aligning and therefore integrating to the current RDaSH provision in relation to:

- Children and young people Autism and ADHD diagnostic and Post diagnostic support provided through the neurodevelopmental pathway.
- Adult learning disability community health provision.

This proposal addresses the following national and local policy drivers:

National Policy:

Nationally, The Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy (DOH 2015) states the NHS should:

- Provide access to services that can diagnose autism, and it's frequently associated medical and mental health conditions.
- Designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway
- This development will also support our commitment to improving transition within our SEND development.

NICE Guidelines:

CG142 recommends:

In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists
- support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

Local Policy:

Rotherham's emerging Health and Wellbeing Strategy (2018 – 25) identifies the transformation of the offer made to people with autism and / or ADHD as a key priority to ensure children and adults with autism and / or ADHD get:

- the best start in life and go on to achieve their potential and have a healthy adolescence and early adulthood.
- the best possible mental health and wellbeing and have a good quality of life.
- live well and live longer.

Rotherham CCG Commissioning Plan (2018 – 20) gives a commitment to ensure; all children, young people and adults with autism in Rotherham are able to:

- Live fulfilling and rewarding lives within a community that accepts and understands them
- Receive a diagnosis and access support if they need it
- Depend on mainstream public and third sector services to treat them fairly as individuals to get the right information and help them make the most of their talents

Rotherham's Autism Partnership Board in its delivery plan for 2018 – 19 identified diagnosis and post diagnosis support as a key priority.

What is Autism?

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over – or under – sensitivity to sounds, touch, tastes, smells, vision and movement.

Although autism is a lifelong condition, it is important to recognise that with the right support, people with autism can live full and active lives in their community.

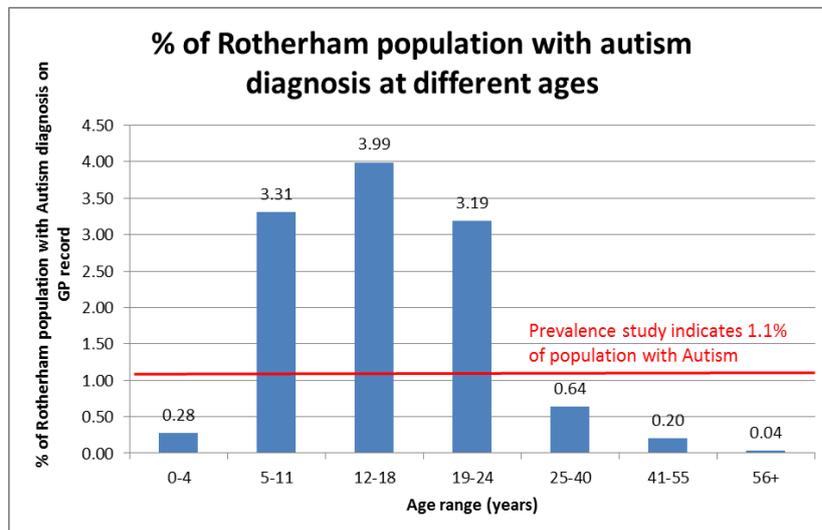
What is Attention Deficit Hyperactivity Disorder (ADHD)?

NICE (2018) define ADHD as a condition that affects people’s behaviour. It can make them seem restless or hyperactive, have trouble remembering things and focusing on tasks, and they may often act on impulse without stopping to think. It is usually spotted in childhood but some people are not diagnosed until they are adults. It can affect people throughout their lives, disrupting relationships and making everyday life difficult. Symptoms of ADHD can be mistaken for other conditions or overlooked altogether – for example, it is sometimes missed in girls and women.

Prevalence:

(Taken from Draft Rotherham All Age Autism Strategy):

- According to modelled predictions, there is greater diagnosis of autism in Rotherham children and young people than expected, but also much lower diagnosis rates in older people. This could be due to changes in awareness and acceptance of ASD, and the potential perceived benefit of diagnosis for a younger person with respect to educational support. See table below:



- If diagnosis continues at a similar pattern and rate to current, then over time Rotherham will see a total increase in ASD as patients diagnosed as children become older adults. This has the potential to add significant burden on support services for adults with ASD.
- There is greater diagnosis amongst males than females, though more females are diagnosed locally than predicted by the prevalence estimates.
- Approximately half of patients with autism may have learning disabilities, and up to a third of people with learning disabilities may have ASD.
- Additional work with South Yorkshire Integrated Care System partners will be undertaken to

establish if the rates of diagnosis as reported by Rotherham are seen in other areas.

There are links between ASD and other medical conditions, such as mental health problems, risk of suicide and epilepsy. Autism is often diagnosed alongside other conditions. It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs arising from autism are distinct. It is important to acknowledge these comorbidities when considering health service planning and medical pathways of care.

Current commissioned activity to support diagnosis and post diagnosis support for children, young people and adults :

a. Children and Young People:

RCCG commissions the following services for children and young people with Autism:

- Child Developmental Centre (TRFT): Provides assessment for children under 5 who are having difficulties in more than one area of their development
- Neurodevelopmental pathway (RDaSH)- this pathway covers both autism and ADHD. Autism Family Support Team (AFST) from RMBC: - who provide post diagnostic support.
- Parent Carers Forum for their Peer Support Service and the majority of cases they deal with are families with C&YP with autism or suspected autism. Similarly, the Healthwatch advocacy service (£20k) deals with a lot of autism related activity.

b. Adults:

Provision for the diagnostic assessment of adults for autism (without a learning disability) is currently commissioned from Sheffield Health and Social Care (SHC) Foundation Trust at the Sheffield Adult Autism and Neurodevelopment Service (SAANS) meaning that people registered with a Rotherham GP currently travel to Sheffield for a diagnostic assessment.

The service can be directly referred to by services in Rotherham in primary and secondary care. The service is not widely advertised or accessed, recognising that the commissioned level of activity is low in relation to potential prevalence in the borough.

Commissioned activity with SHCFT for 2017/18 was as follows:

Category	Commissioned activity (2017 -18)	Commissioned activity (2018 -19) – April – Aug
New / first assessments	55	15
Follow-up appointments / sessions	55	18
Counselling sessions	100	29

Provision for the diagnostic assessment of adults for autism (with learning disability) is currently commissioned from RDaSH through the Community Learning Disability Team (CLDT). The team provides post diagnosis support and meets the NICE recommended skill mix. Currently activity relating to numbers of learning disabled people diagnosed with autism has not been collected.

Adults with ADHD:

The support for adults (18 plus) with ADHD is commissioned as part of the block contract with RDaSH. In 2017/18 the service provided 7 people with a diagnosis of ADHD.

Analysis of key issues and of risks

Rotherham's Current Performance in delivering NICE Guidelines: Adults

A review into the provision of adult autism diagnosis and post diagnosis provision in Rotherham (NB without a learning disability) was conducted in March 2018. The review, examined current adult autism diagnosis and post-diagnostic support in the borough to assess compliance with national guidelines (NICE), identify any gaps in service and to make recommendations on this basis.

The review highlighted the following themes in relation to RCCG's and partners current performance against NICE guidelines:

Table 1

Key theme	Assessment	Comment
Identification of assessment	Partially met	<ul style="list-style-type: none"> Evidence that appropriate referral for diagnosis is taking place Low-levels of activity in comparison to potential demand No clear pathway or criteria in place / documented for reference
Comprehensive (diagnostic, needs and risks) assessment of suspected autism	Partially met	<ul style="list-style-type: none"> Specialist diagnostic assessment available using comprehensive assessment process and tools People feedback positive on process, involvement and engagement of family / carers and tailored to the individual Feedback at assessment and report provided Feedback indicated most people were not provided with care plan Feedback indicated not all service users were offered a follow-up appointment
Post-diagnostic intervention Psychosocial interventions for core symptoms of autism and specific or adjusted interventions for life skills	Not Met	<ul style="list-style-type: none"> No provision available to provide psychosocial interventions for the core symptoms of autism (either individual or group based) No provision of psychosocial interventions based on life-skills including leisure activities, anger management interventions, anti-victimisation and supported employment interventions which are adjusted to meet the needs of people with autism
Post-diagnostic intervention Psychosocial interventions for coexisting mental disorder	Further assessment required	<ul style="list-style-type: none"> People with coexisting mental disorders are accessing services for treatment of these disorders Clear some professionals have good training and awareness of autism to make reasonable adjustments e.g. clinical psychologists. Wide range of RDaSH staff have had basic autism training A fuller assessment of the reasonable adjustment of services to meet the needs of people with autism is required
Assessment and interventions for families, partners and	Further assessment	<ul style="list-style-type: none"> No specific pathway in place other than via Care Act assessment if offered

carers	required	<ul style="list-style-type: none"> Rotherham Parent and Carers Forum commissioned via the CCG but focused on CAMHS / for the parents and carers of children and young people Engagement work has focused on service users and should be expanded to include carers' views
Developing local care pathways	Not met	<ul style="list-style-type: none"> Local care pathways not in place to promote implementation of good principles of care outlined in the guidance and to offer evidence based interventions at each stage of the pathway Autism strategy group established but does not yet have the prescribed role in developing, managing and evaluating local care pathways No health lead professional in place responsible for the local autism care pathway

The Autism and ADHD Pathways:

Taking together recent reviews and looking at current commissioned activity it appears that Rotherham's current Autism pathway is fragmented and has created lots of 'hand off's' which can cause delays. This is reflected from feedback given at recent engagement events with people with autism, their families have flagged the following issues:

- The lack of support groups post diagnosis.
- there is a gap in the pathway for young people moving into adulthood between Children and Adult services
- Difficulty accessing allied health professional assessments (Speech and Language Therapists, Occupational Therapy – in particular access to special assessments in relation to Sensory Integration¹ (SI)
- There is an urgent issue of sustainability for the adult ADHD service raised by RDaSH

Overall, the following can be concluded:

- There is a need to develop a local pathway for diagnosis and post diagnosis support in Rotherham for adults with autism without a learning disability
- The need to develop a post diagnostic offer in Rotherham to enable access to psychosocial interventions, peer support, support with employment, education and benefits.
- People with autism are traveling to Sheffield which can be a barrier.
- However, this option would not address the gaps identified in the March 2018 of the adult autism pathway review and nor is there any additional capacity in the adult ADHD pathway.
- Pathways remain separate in scope and therefore do not address the need for meeting the needs of young people in the preparing for adulthood cohort.

Proposal to commission an all age Neurodevelopmental Pathway in Rotherham through RDaSH:

The all age neurodevelopmental pathway would be commissioned on existing RDaSH pathways (see appendix 1). The all age pathway would see the opportunity to:

¹ Sensory integration is about how our brain receives and processes sensory information so that we can do the things we need to do in our everyday life.

- Develop a local Rotherham based diagnostic service as per NICE guidance.
- Create a single Neurodevelopmental pathway encompass the diagnosis and post diagnosis support of both autism and ADHD in children's and adults
- Align activity for adult diagnosis and post diagnosis support for autism.
- Develop an enhanced therapy offer using current commissioned services in RDaSH
- Sustain the adult ADHD pathway (see appendix 2)

Key elements of new activity:

Autism:

Appendix 1 sets out the pathway and model of provision. To deliver the neurodevelopmental pathway there is the need to commission key elements to support adult diagnosis (without a learning disability). The model sees the creation of a post to be located in third sector to provide specialist advice and support and liaise across a wide range of stakeholders in Rotherham, to ensure these services are made more accessible.

The pathway set in appendix 1 is a proposed pathway only and further work with RDaSH and partners (including primary care) would be required to ensure its 'fit for purpose' in Rotherham. The pathway will have clear Key Performance Indicators (KPI's) to ensure evidence of delivery is collated. These will be based on (a) outputs (for example):

1. Numbers of children, young people and adults diagnosed within NICE timeline guidelines.
2. Numbers of people referred and diagnosed with sensory issues
3. Numbers of people referred to post diagnostic service

As well as outcomes:

1. The number of young people or adults remaining or going into employment.
2. Level of satisfaction with the pathway.

The above metrics are proposed Key Performance Indicators (KPI's).

ADHD:

RDaSH is in the process of developing its ADHD Service in order to increase its scope of support to the Rotherham Community. The service establishment has increased to include a Full Time Equivalent Non-Medical Prescriber who will be commencing in 2019. This role will be to support the CAMHS transitions and to work alongside the RDaSH Leadership Team to develop the service model in order to meet the current capacity and demand for this service.

Both pathway elements (autism and ADHD) will be incorporated into a single neurodevelopmental pathway linked to the children and young people's neurodevelopmental pathway.

Patient, Public and Stakeholder Involvement:

The development of this proposal has been (and will) incorporate the values of **coproduction to ensure the co-design of the proposed service model**. This has included:

- The Rotherham All Age Autism Partnership Board has identified the development of a clear diagnostic and post diagnosis pathway as a priority.
- Healthwatch.
- Active engagement with **Autism Speak Up** who have articulated the need for a local autism pathway.

- Active engagement with Rotherham Parent Carers Forum, Genuine Partnerships and Voices to shape the design.

The ethos of co-design will continue into shaping the neurodevelopmental pathway itself.

Equality Impact:

The following Equality Impact Assessment has been completed and it concluded:

Extensive patient and public engagement with a variety of sources alongside national and international research, and local data.

All impacts are positive; therefore no further action needs to be taken in relation to the EIA



Autism Diagnostics
EIA.docx

Financial Implications:

RCCG commissions a number of providers to provide diagnosis for adults with autism and / or ADHD

- ADHD: RDaSH under its current commissioned block activity fund a consultant psychiatrist. (ADHD adults only): £11,595 in 2017/18 on the 7 adult ADHD assessments.
- Sheffield Adult Autism and Neurodevelopment Service (Sheffield Health and Social Care (SHC) Foundation Trust: £94,759.88k

Adult neurological Diagnostic pathway:

The proposal to support the pathway (individually set out in both appendix 1 and 2) would potentially involve funding of:

- 1 wte- 8b psychology post
- 1 wte assistant psychology (band 7)
- 1 wte Occupational therapy post (band 7)
- 1 wte Non-Medical Prescriber (band 7)

Post Diagnostic Service:

3 wte peer support posts will work in north, central and south Rotherham localities. These posts will deliver support for people recently diagnosed with ADHD and /or autism. As this will be procured management overhead costs will need to be added.

The estimated cost implications for developing the adult neurological pathway:

	Band	WTE			Total cost	
			Mid point	Top of scale	Mid point	Top of scale
1 wte- 8b psychology post	8b	1.00	£69,158	£76,030	£69,158	£76,030
1 wte assistant psychology (band 7)	7	1.00	£48,044	£54,338	£48,044	£54,338
1 wte Occupational therapy post (band 7)	7	1.00	£48,044	£54,338	£48,044	£54,338
1 wte Non-Medical Prescriber (band 7)	7	1.00	£48,044	£54,338	£48,044	£54,338
3 wte peer support posts	3	3.00	£23,673	£25,378	£71,019	£76,134
Management support costs and overheads					£56,862	£63,036
Total costs					£341,171	£378,214

Additional funding to the level of £378K has been identified within the 19/20 RCCG plan on a recurrent basis. The Sheffield Health and Social Care contract will need to be re-negotiated to reflect the change in local pathway an element of the £95k currently in the contract. If this was realised we would review use of this funding accordingly.

RDash have affirmed that they feel confident that they would deliver the skilled workforce to support the adult diagnostic elements of the pathway.

Human Resource Implications:

No HR implications for RCGG have been identified.

Procurement:

To allow for the full integration of this pathway across C&YP and Adults it is proposed to make a direct award of contract to RDASH. There is a risk of challenge associated with this approach and therefore to mitigate this it is proposed that a VEAT notice is issued for 30 days prior to making the final award of contract to RDASH:

. The rationale for the direct awards is that:

- The full integration of this pathway can only be achieved by bringing C&YP and Adults services together; the CCG has identified transition as a key area for improvement. It is judged by the CCG as being in the patient's best interest to make the direct award.
- RDash have the local infrastructure to support and sustain the pathway.

Approval history:

Not applicable at this stage

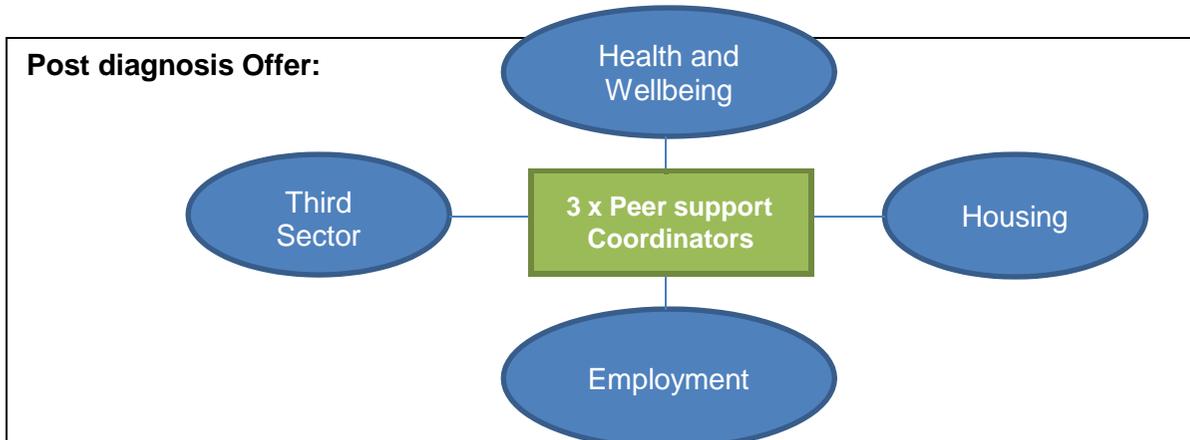
Recommendations:

Governing Body Members are asked to note and approve:

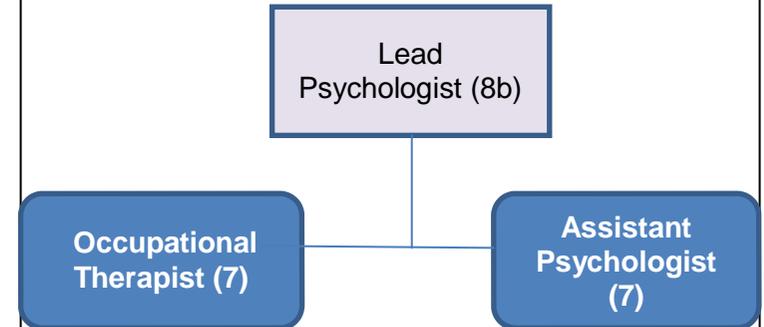
- 1. The creation of a local all age neurodevelopmental pathway to ensure that Rotherham aligns with NICE guidance.**
- 2. An additional resource of £378k for the 19/20 plan to support the development of the all age neurological pathway.**
- 3. The direct award of contract following an unchallenged VEAT notice to RDASH.**

Appendix 1: Adult Autism Diagnosis (without a learning disability) and Post Diagnosis Support Offer:

 Screening Process and Assessment Process 'Assessing Well'	 Interventions 'Treating Well'	 Discharge 'Living Well'
<p>Determine urgency and priority - Immediate, 24 hours, 2 weeks; or commissioner agreed targets, assessed via screening process.</p> <ul style="list-style-type: none"> • Symptoms suggestive of ASD for people 18 plus • One or more of the following: <ul style="list-style-type: none"> • Persistent difficulties in social interaction • Persistent difficulties in social communication • Stereotypic (rigid and repetitive) behaviours • Resistant to change or restricted interests • One or more of the following: <ul style="list-style-type: none"> • Problems in obtaining or sustaining employment or education • Difficulties in initiating or sustaining social relationships • Previous or current contact with mental health or learning disability services • A history of a neurodevelopmental condition (including learning disabilities and attention deficit hyperactivity disorder) or a mental disorder. <p>Use of a recognised and validated tool</p> <ul style="list-style-type: none"> • Core autism signs and symptoms that have been presenting since childhood and continuing into adulthood. Carry out direct observations of core autism signs and symptoms, especially in social situations • Behavioural problems. <p>Commissioner specific guidance</p> <ul style="list-style-type: none"> • Full Needs Assessment; dependent upon commissioned service provision to include any neurodevelopmental disorders, including hyper and hypo sensitivities • Physical health and wellbeing assessment • Functional Analysis of Care Environment Risk Assessment (FACE) • Diagnostic formulation / review; Multi-Disciplinary Discussion as appropriate. <p>Team based assessment drawing on a range of professions and skills with family, significant others, involvement to provide information regarding past behaviour and early development.</p> <p>Carry out direct observation or core autism signs and symptoms especially in social situations.</p>	<ul style="list-style-type: none"> • Diagnostic confirmation. • Post diagnostic psychoeducation, advice and support. • Carers advice and support. • Risk management where required. • Co-morbid mental health, substance misuse or physical health needs identified signpost to appropriate service provision. • Risk assessment to eliminate substance misuse and drug diversion further risk assessment; FACE Risk Assessment as clinically indicated. 	<p>Referral to appropriate services e.g. Local Authority, Local Support Group.</p> <p>Letter to service user and significant other and GP confirming assessment information, diagnosis and plan.</p> <p>Where physical health and wellbeing needs are identified signpost for support, advice and intervention.</p> <p>Handover to primary / third sector care services as appropriate.</p> <p>Social prescribing and or signposting to other support services available in the local area.</p>



Proposed Structure – Autism Diagnosis:



Key Elements:

Assess and diagnose:

Support colleagues in mental health services to assess and diagnose.
 Social and sensory support assessments to people who have been diagnosed.

Advice and Support:

Support groups on mindfulness, managing anxiety, social cognition and interaction, as well as an opportunity to book one to one sessions.

Support colleagues in primary care

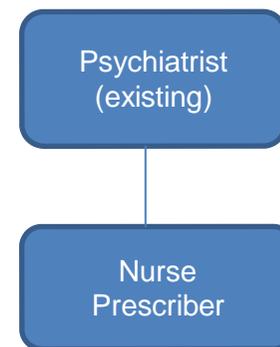
Post Diagnosis Support: - psycho-education, coping strategies, employment support and signposting

Training: Support the RMBC training programme.

Appendix 2: ADHD Adult Diagnosis and Post Diagnosis Offer

 Screening Process and Assessment Process 'Assessing Well'	 Interventions 'Treating Well'	 Discharge 'Living Well'
<p>Determine urgency and priority - immediate; 24 hours; 2 weeks; assessed via screening process.</p> <p>New diagnostic assessments/ screening of people aged 18 or over, carried out considering the environment and ease of access.</p> <p>Diagnosis or symptoms suggestive of ADHD for people aged 18 plus:</p> <ul style="list-style-type: none"> Evidence of typical manifestations of ADHD that began during childhood and persisted throughout life, resulting in moderate or severe psychological/ social/ education or occupational impairment that are not better explained by other psychiatric diagnosis Express wish to access treatment . <p>Transition from 18 years of age with confirmed ADHD diagnosis from Child and Adolescent Mental Health Services. (Referral made at 17½ years of age).</p> <p>Assessment</p> <p>Full Needs Assessment to include: clinical and psychosocial assessment, behaviour and symptoms in different domains, including social, occupational and educational.</p> <p>Full Needs Assessment dependent upon local commissioning agreement to include full developmental and psychiatric history.</p> <p>Assessment via a validated recognised and evidence based tool to provide supporting evidence to meet diagnostic criteria (International Classification of Diseases (ICD)-10).</p> <p>Observer reports provided from self, significant other and childhood; consider behaviour at school.</p> <p>Physical Health Screen Assessment tool and baseline physical observations for adults with ADHD, via the physical health and wellbeing tool. To exclude cardiovascular symptoms, heart rate, blood pressure, weight and family history of cardiac disease.</p> <p>Referral for necessary physical health investigations, for example Electrocardiogram, blood tests.</p> <p>Risk assessment to eliminate substance misuse and drug diversion further risk assessment.</p> <p>Functional Analysis of Care Environment Risk assessment as clinically indicated (FACE).</p>	<p>Psychological Wellbeing Interventions (may be individualised / group).</p> <ul style="list-style-type: none"> Post diagnostic advice and support including self-management advice; e.g. balanced diet, good nutrition and regular exercise Cognitive Behavioural Therapy interventions for persistent /functional / residual impairment <p>Consider non-pharmacological treatment as indicated in line with National Institute for Health and Care Excellence Guidelines (NICE)</p> <ul style="list-style-type: none"> Structured supportive psychological intervention focused on ADHD Regular follow-up, either in person or by phone Treatment may involve elements of a full course of Cognitive Behaviour Therapy (CBT). <p>Pharmacological Treatment</p> <p>Medicines reconciliation.</p> <p>Medication is standardly prescribed in line with British National Formulary and Maudsley guidance. On occasion individual prescribing decisions are made relating to dose or indication outside of these but must be made at consultant level, have recorded justification and relevant monitoring arrangements.</p> <p>Monitor for side effects, efficacy</p> <p>Medication management:</p> <ul style="list-style-type: none"> Reviewed until dose optimised Consider modified release Yearly standard symptom rating scale. Minimum six monthly review of heart rate, blood pressure and weight, efficacy and co-existing conditions. <p>Shared care options with GPs are recommended.</p>	<p>Criteria for discharge.</p> <p>Following adequate response, drug treatment should be continued as long as it is clinically effective.</p> <p>Discharge would be considered only at the service user's request if they no longer wish to access ADHD services/ medication – this may be by non-attendance.</p> <p>Annual health check: review of heart rate, blood pressure, efficacy, weight and co-existing conditions.</p> <p>Letter to service user, significant other and GP confirming assessment information, diagnosis and plan.</p>

Proposed Structure – ADHD Diagnosis:



Key Elements:
Assess and diagnose:
Advice and Support:
 Support groups on mindfulness, managing anxiety, social cognition and interaction, Support colleagues in primary care
Post Diagnosis Support: -
 To link into roles created in autism service.
Training

