South West Yorkshire Partnership NHS Foundation Trust

Adult ADHD Services in Kirklees

Report for Kirklees Health and Social Care Scrutiny Panel – 4th April 2017

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CONTENTS

INTRODUCTION

This report was prepared at the request of the Kirklees Health and Social Care Scrutiny Panel to be presented at their meeting of the 4th April 2017.

The brief for this report included:

- An update on the waiting numbers and times for Adult ADHD for
- A detailed description of the pathway (It may also be helpful to include an example of a patients journey (story) that highlights the work of the service)

CONTEXT

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental condition characterised by inattention, hyperactivity and impulsivity, which present in at least two settings, interfering with functioning.

The mean worldwide prevalence of ADHD is between 5.29% and 7.1% in children and adolescents (< 18 years) and 4.4% in adults. It is now accepted that ADHD can persist into adulthood for the majority of individuals and as a result, adults experience pervasive impairment across multiple domains including academic, occupational, relational and self-concept.

It is also associated with psychiatric comorbidity, self-perceived stress and poor health outcomes. Furthermore, adults with ADHD have increased mortality rates, linked to psychosocial adversity and unnatural causes, including accidents.

NATIONAL GUIDANCE ON ASSESMENT AND TREATMENT OF ADHD

The NICE guideline CG72 produced in 2009 states that the diagnosis of ADHD should be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD, on the basis of:

- A full clinical and psychosocial assessment of the person; this should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life.
- A full developmental and psychiatric history.
- Observer reports and assessment of the person's mental state
- Use of Diagnostic Instruments such as Semi Structured Interviews and Rating Scales relevant for each profession.

The diagnosis of ADHD is not made solely on the basis of rating scales or observational data. However, it is recognised that rating scales/questionnaires are valuable adjuncts, and observations (for example, at work / during leisure time) are useful when there is doubt.

Locally in line with the evidence, members of the specialist service ADHD Team carries out a comprehensive assessment of adults with ADHD that includes their personal, educational, occupational and social functioning and the assessment of any co-morbidities, especially drug misuse and personality disorder. This is based on structured clinical interviews, rating scales and individualised personal assessment.

A comprehensive assessment procedure includes direct discussion with the service user and relevant carer/family members, contact with treating clinicians if appropriate and available, mental state examination, physical assessment including cardiac function, social and environmental circumstances. Service users must be given the opportunity to contribute information on their history and current situation. However, details must be verified and relevant and necessary information must be obtained from significant others.

Current ‘best clinical practice’ therefore relies on comprehensive clinical assessment based on clinical interviews, observations and use of questionnaires. To undertake the comprehensive assessment is often a lengthy and time consuming process.

Substandard care in ADHD has a number of adverse implications: ADHD is associated with work-related problems in adulthood such as poor job performance, lower occupational status, less job stability and increased absence days in comparison to adults without ADHD. The poor performance and work loss for adults with ADHD is likely to have profound economic implications. One study quantified this impact by estimating the excess costs (i.e. the difference between adult ADHD patients and matched controls) related to work loss. Indirect work loss costs were calculated based on employer payments for disability claims and imputed wages for medically-related work absence days (e.g. days in the hospital, physician visits). Another study estimated that adult ADHD was associated with a 4-5% reduction in work performance, 2.1 relative-odds of sickness absence, and a 2.0 relative-odds of workplace accidents-injuries. The excess costs were $1.20 billion for women with ADHD and $2.26 billion for men with ADHD in this US Study. However, after controlling for substance abuse, history of depression or anxiety, it was stimulant therapy during childhood that was the strongest predictor for being in work as adults and this was the item recognised to be not optimal during transition.

THE LOCAL SERVICE

A specialist service for Adults with ADHD has been commissioned and became operational in Kirklees since April 2009 and was originally commissioned to manage a caseload of 30 cases annually, based on prioritising cases transitioning from Children's services. The demand modelling based on intelligence from commissioners at the time estimated the demand in Kirklees to be for 30 transition cases per year, but this modelling did not take into account people previously diagnosed in childhood but not currently in receipt of services who might require assessment and treatment or adults never previously diagnosed requiring assessment and treatment.

Although never enacted as a formal contract variation as the service became embedded and following initial review the number of cases agreed annually with commissioners was increased in March 2012 to 50 as the maximum that the service could manage within the commissioned service capacity. However, there was no data for estimating the need of the local population for Adults who may be undiagnosed with ADHD or for adults who had been diagnosed with ADHD as a child but subsequently discharged from or disengaged with Children's services but who subsequently have further assessment or intervention needs as an adult.

The demand for services essentially falls into three categories:

- transitions from Children's services where a diagnosis is already confirmed and the person is in receipt of treatment within Children's services
- referrals for people who have had a diagnosis previously in childhood, but no longer in receipt of services who require further assessment or possible interventions as adults
- referrals for people who have never had a previous diagnosis but are suspected to have ADHD and require assessment, diagnosis and then treatment as necessary.

The service commissioned has essentially remained a transitional service prioritising cases that are in transition from children's services. The service has operated on the basis of managing 30 transitional cases per year. Where capacity facilitates, cases have then been prioritised for people who have had a diagnosis previously in childhood but are not currently in receipt of services. This cohort makes up the remaining 20 cases annually. In reality this has meant that

practically, the service has been able to see transitions and a small number of people with a previous diagnosis not currently in receipt of services. As a consequence two waiting lists developed for:

- People previously diagnosed in childhood but not currently in receipt of treatment (waiting list 1)
- People who had never had a diagnosis (waiting list 2).

Of these very few have actually been seen as these cases could not be taken up as a priority within the existing commissioned capacity.

The Service has consistently enjoyed excellent service user feedback and has been assessed as a place of good practice and innovation by the Care Quality Commission.

THE LOCAL PATHWAY

The Service is providing a nationally leading pathway for the people in line with NICE Guideline CG72 (SEE APPENDIX 2 for the pathway and specialist pathways). The Service provides full care coordination and management of adults with ADHD and the pathway follows the structure below:

Most commonly the **service user journey** starts from a referral from CAMHS informing the adult Service that the person is reaching the age of 18 and will need to be transferred to our service. This is discussed at our multidisciplinary team (MDT) meeting and a professional is allocated to meet with the family at the next CAMHS appointment. At that joint appointment which is the last appointment with CAMHS, the professional from our service will introduce themselves, the service, explain the process, be ready to answer any questions and leave an information pack with the service user.

At the first appointment with the adult service, the service user will meet with a doctor who will review their medication, their mental health needs and formulate the case. The doctor will then present the case to our MDT and a professional will be allocated to assess their other needs (holistic care) using a tool the Service has developed called ADHD Star®. This tool will create a care plan that identifies specific ADHD needs and then the professional will bring the plan back to the MDT for the best professional to be allocated to meet that person's needs ex. social worker, psychologist, occupational therapist or nurse. The person will receive interventions along their recovery journey as appropriate and discharged when appropriate.

This process has been recognised by the CQC as area of good practice and follows the NICE guideline NG43 published February 2016. It was commended by NICE in their document "a

review of the arrangements for child safeguarding and health care for looked after children in England" published in 2016.

REFERRALS

Expected Number of Referrals Based On NICE Guidance

In terms of capacity, the NICE Guideline (CG72) predicted a higher demand than was initially commissioned locally. That Guideline set out that "for an average general practice list size of 10,000, the average number of people requiring referral to a service for the diagnosis and management of ADHD in adults would be around 3 per year" which for the Kirklees population of 400,000 it equates to 120 patients a year.

Number of Referrals Per Year.

Table 1: Total Referrals by Year

	Kirklees
2009-10	**57**
2010-11	**57**
2011-12	**84**
2012-13	**90**
2013-14	**126**
2014-15	**162**
2015-16	**140**
2016-17 (April 16 - Feb 17)	**123**
Grand Total	**839**

NICE guidance predicted a higher level of demand than commissioned in Kirklees at 50 cases and this was confirmed from the first year of operations.

Number of people waiting for a first assessment

Table 2: Total people waiting in Kirklees

Pathway	No on W/L	Annual No Commissioned	Pathway Offer
Kirklees ADHD	**263**	**50**	**Diagnosis, Intervention & Social Care**

LOCAL FINDINGS

Further important findings are also observed locally from the people accessing the Service which were not expected when the Service was originally commissioned:

- Cases referred as transitions are more symptomatic than expected given that they are already in receipt of treatment and
- The level of disablement, almost as disabled as someone with Schizophrenia. This necessitated a greater amount of input by the Adult ADHD Service than expected both by the Service and Commissioner. This essentially means that the complexity of the cases referred and received are higher requiring more input and a longer duration of input from the specialist service which limits the capacity in terms of the number of cases that can be seen overall.

  The overall demand on the Adult ADHD Service is dependent on the complexity of cases as presented during the initial assessment. Due to well recognised system wide issues related to the service provision by Children's Services, the cases presented to the Adult ADHD Service bring significant clinical challenges and require heavier input to deliver successful clinical outcomes. It is expected that until those issues which are not within the direct control or at the sole discretion of SWYPFT are resolved, the Adult ADHD Service will continue to address the clinical needs through an appropriate pathway.

APPENDIX 1: SERVICE DEVELOPMENT JOURNEY

The overall aim of the service is to deliver a high quality, cost effective service whilst achieving efficiencies through the CIP AND QIPP, and meeting the challenges of the comprehensive spending review.

The primary focus for 2011/12 was to:

- Develop a new service offer to cover non transitional cases of Adults with ADHD
- Expand the service to provide an 'Out of Area' service
- Review the service operational and clinical management
- Produce a market plan to create and maintain a position of preferred provider
- Build strong partnerships with key stakeholders – commissioners, user/carers, workforce and other providers.
- Meet key performance indicators and develop a performance culture.

The primary focus for 2012/2013 was to:

- Review service specifications for commissioners, including the demand from other segments of the market for ADHD services.
- Explore opportunities for delivering an equitable Trust wide service for adults with ADHD.
- Ensure that services are delivered safely based on evidence based practice and meet national and local standards e.g. NICE guidance CQC standards and transition protocols.
- Develop a marketing plan that addresses areas for further development of the ADHD service.
- Explore possible clinic bases for improving the general accessibility of Kirklees service users.

- Explore strategies to ensure the service for adults with ADHD is accessible to all the local population, including those from minority ethnic communities
- To ensure the workforce maintains and develops skills/competencies as identified through CPD and development in service delivery.

The primary focus for 2013-2014 was to:

- Increase evidence base of Occupational Therapy Treatments for ADHD
- Develop OT Pathway for ASD Interventions
- Increase and consolidate partnerships with other agencies and organisations – also linking with a potential ASD offer.
- Manage the service offer expansion to Barnsley for both ADHD and ASD
- Develop the adult ADHD Recovery Star
- Improve ways we acquire feedback from Service Users
- Expand on the offer provided about medication and their management during the transition process
- Implement Action Plan from the Mock CQC Visit.
- Develop specialism of nursing in adult ADHD pathway

The primary focus for 2014-2016 was to:

- Continue to develop the expertise of staff and specialism of medical, nursing, occupational therapy; psychology and social work to best serve the ADHD Service Users.
- Continue to develop the expertise of staff and specialism of medical, nursing, occupational therapy; psychology and social work to best serve the ASD Service Users.
- Expand the ASD Service footprint and pathway offer in Wakefield, Kirklees, Barnsley and Calderdale areas: the aim is a single pathway for ASD for all areas across SWYPFT.

- Manage expansion into other geographical areas as they come ‘on-line’.
- Support the OOA offer.

Key Service Achievements in 2016

Recruitment of clinical and administrative staff to address waiting list demands (substantive and temporary posts)

Collaborative team work to support increased agile model of working

Increased options for providing appointment choice to services users in a community setting in their own locality (additional estate/room availability)

Positive outcome of Service reviews by Care Quality Commission and Care Excellence Award

Positive Service User feedback across pathways

Evidence based publications (ADHD Star/Checklist for Autism Friendly environments)

Academic and CPD achievements of staff in the development of specialist knowledge and skills including:

- Post Graduate Diploma in Autism and Asperger’s Modules
- MSc in Mental Health Practice
- Post Graduate Diploma Clinical Neuropsychology (1st Year)
- Sensory Integration – level 2/3
- NLP Master Practitioner Course
- Diagnosis and Treatment of Adults with ADHD (UKAAN)
- Pharmacological Treatment of ADHD (UKAAN)
- ADOS-2
- ADI-R

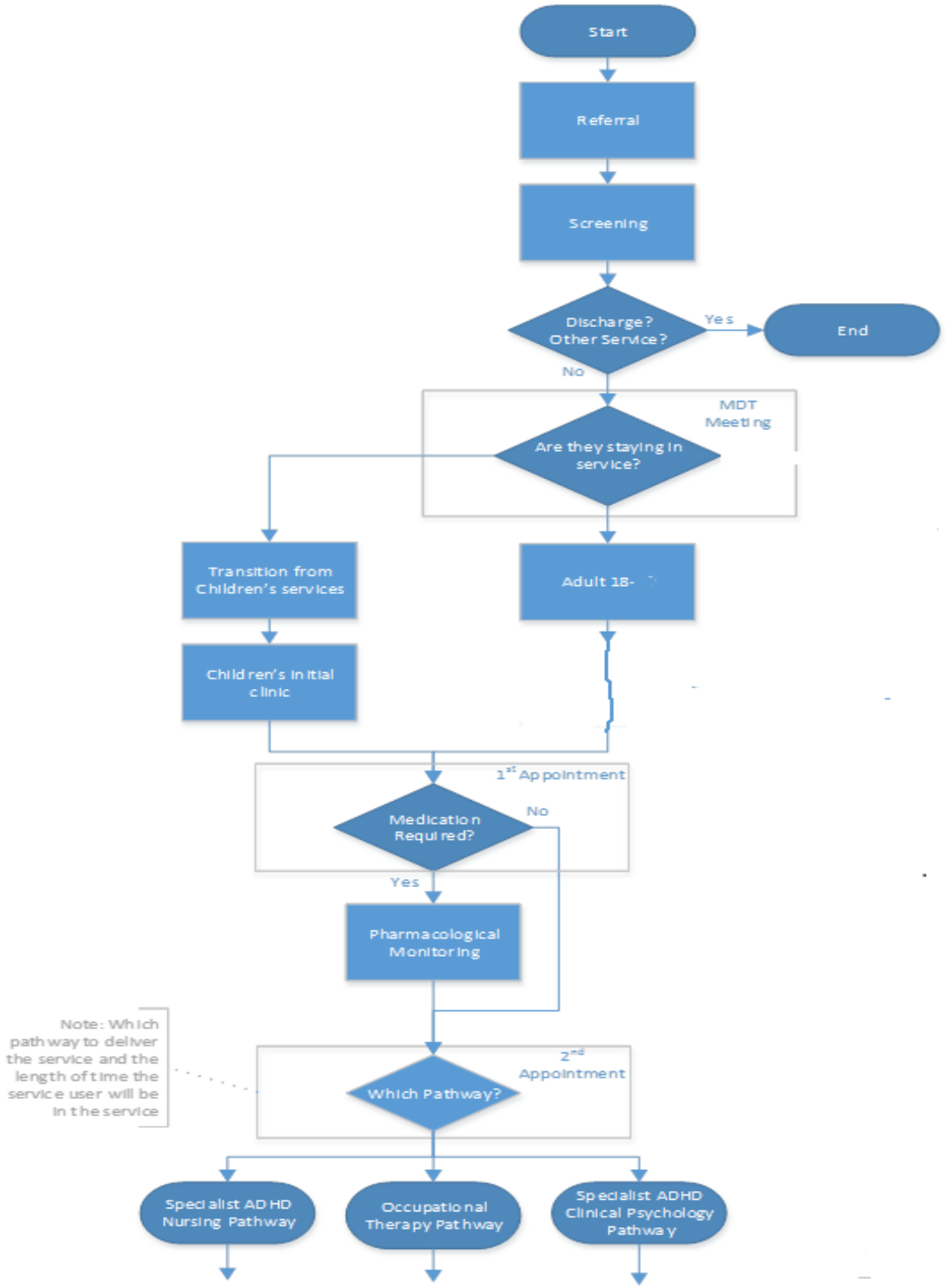
- Master class with Tony Attwood, adapting the diagnostic process for girls and women
- ASYE/Social Work Consolidation
- Prince2 – Project Management

The Primary Focus for 2017-2018 is:

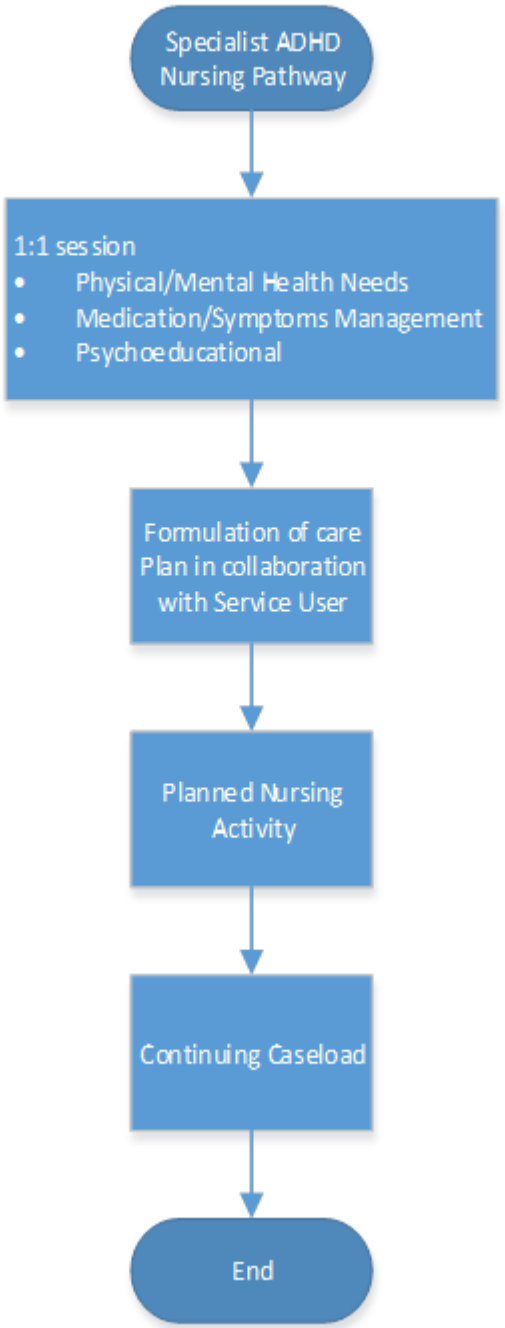
To contribute to the key areas of demand and capacity, quality, workforce, financial and sustainability planning identified in the Trust two year Operational Plan including:

1. Deliver outcomes to meet the expectations of Barnsley and Wakefield CCGs and SWYPFT investment in the ADHD Project to clear the waiting list backlog.
2. Deliver outcomes to meet the expectations of Barnsley, Calderdale CCGs and SWYPFT investment to clear the autism waiting list backlog.
3. Continue to deliver outcomes to meet the expectations of Wakefield, Kirklees & Barnsley CCGs investment in the sustainable (business as usual) ADHD Pathway.
4. Continue to develop the expertise of new and existing staff and specialism of medical, nursing, occupational therapy; psychology and social work to best serve the service users who access the ADHD pathway.
5. Continue to develop the expertise of new and existing staff and specialism of medical, nursing, occupational therapy; psychology, speech & language therapy and social work to best serve the service users who access the autism pathway.
6. Contribute to the evidence based literature in adult ADHD and Autism
7. Continue to expand the Service footprint and pathway offers in Wakefield, Kirklees, Barnsley and Calderdale areas: the aim is a single pathway for ADHD and autism for all areas across SWYPFT including adult social care.
8. Support the OOA offer through proactive marketing in collaboration with SWYPFT business and financial support Services.

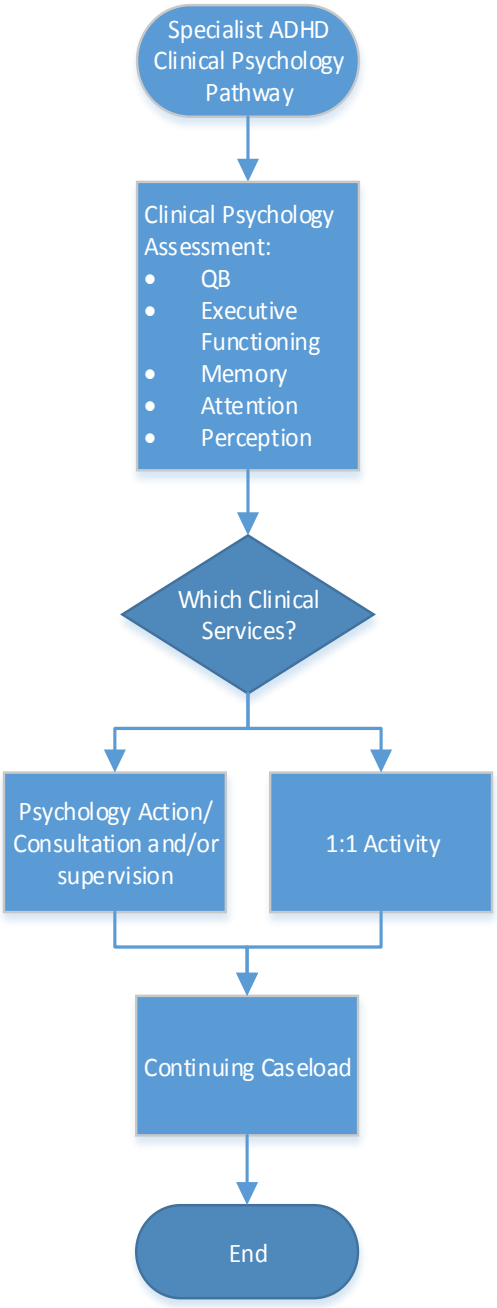
APPENDIX 2: SERVICE PATHWAYS



SPECIALIST ADHD NURSING PATHWAY



Specialist ADHD Clinical Psychology Pathway



OCCUPATIONAL THERAPY PATHWAY