South West Yorkshire Partnerships NHS Foundation Trust (SWYPFT) Autism Service for Adults

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Overview

- HISTORY AND OVERVIEW OF THE SWYPFT AUTISM & ADHD SERVICE
- WHAT IS AUTISM?
- THE LATEST DIAGNOSTIC CLASSIFICATION SYSTEMS FOR AUTISM (DSM-5 & ICD-11)
- RECOMMENDED APPROACH TO DIAGNOSTIC ASSESSMENTS (NHSE)
- THE SWYPFT AUTISM PATHWAY (ASSESSMENT METHODS AND TOOLS)
- SAMPLE CASES

SWYPFT Autism service - History

- ADHD service was established in 2009.
- The Autism service followed in 2014/15.
- Covers a large geographical area including Barnsley, Wakefield, Calderdale* and Kirklees.
- Population > 500,000
- Due to recognised success of the service, SWYPFT were also asked to work in partnership with Bradford District Care NHS Foundation trust to address waiting lists.

*One of several approved providers**

SWYPFT Autism service - Overview

- Multi-disciplinary team (MDT) of specialists including:

Medics, specialist nurses, occupational therapists, Psychologists and assistant psychologists, social workers and physician associates.

- All diagnostic decisions made within the MDT context.
- Anyone who receives a diagnosis will have been seen by at least 2 members of the MDT face to face.
- All assessments are face to face.
- Assessments generally conducted in outpatient clinics across our localities. Occasionally in other settings (inpatient, supported living, clients home).

What is Autism?

- A pervasive neurodevelopmental disorder which affects how people communicate and interact with others and the world around them.
- Accompanied by deficits in social cognition and theory of mind.
- With the presence of at least two of the following: Stereotypic, rigid, repetitive behaviour and circumscribed interests
- Symptoms beginning in childhood and persisting throughout the developmental course.
- A clinical disorder – must be significant functional impairment.
- We do not understand the cause. Research has suggested a role for anomalies in brain development (volumetric and connectivity differences; Levebvre et al. 2015).

Diagnostic Classification Systems for Autism

DSM-5

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity: Severity is based on social communication impairments and restricted repetitive patterns of behavior.

DSM – 5 cont.

- B. **Restricted, repetitive patterns of behavior, interests, or activities**, as manifested by **at least two of the following,** currently or by history
- Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- **Specify current severity:** Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

DSM -5 cont.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

ICD-11

- Atypical responses to sensory stimuli are included as part of the diagnostic requirements in ICD-11, in contrast to ICD-10, where unusual sensory processing was not yet considered a core (diagnostic) feature.
- In ICD-11 it is proposed that some individuals with Autism Spectrum Disorder start to experience distress, impairment and overt social challenges once societal demands increase (e.g., during adolescence or adulthood).
- Unlike DSM-5, ICD-11 does not emphasize the criteria related to Disorders of Intellectual Development (ID; such as flipping objects, strong attachment or preoccupation with unusual objects, excessive smelling or touching of objects, echolalia, stimming).

Over diagnosis

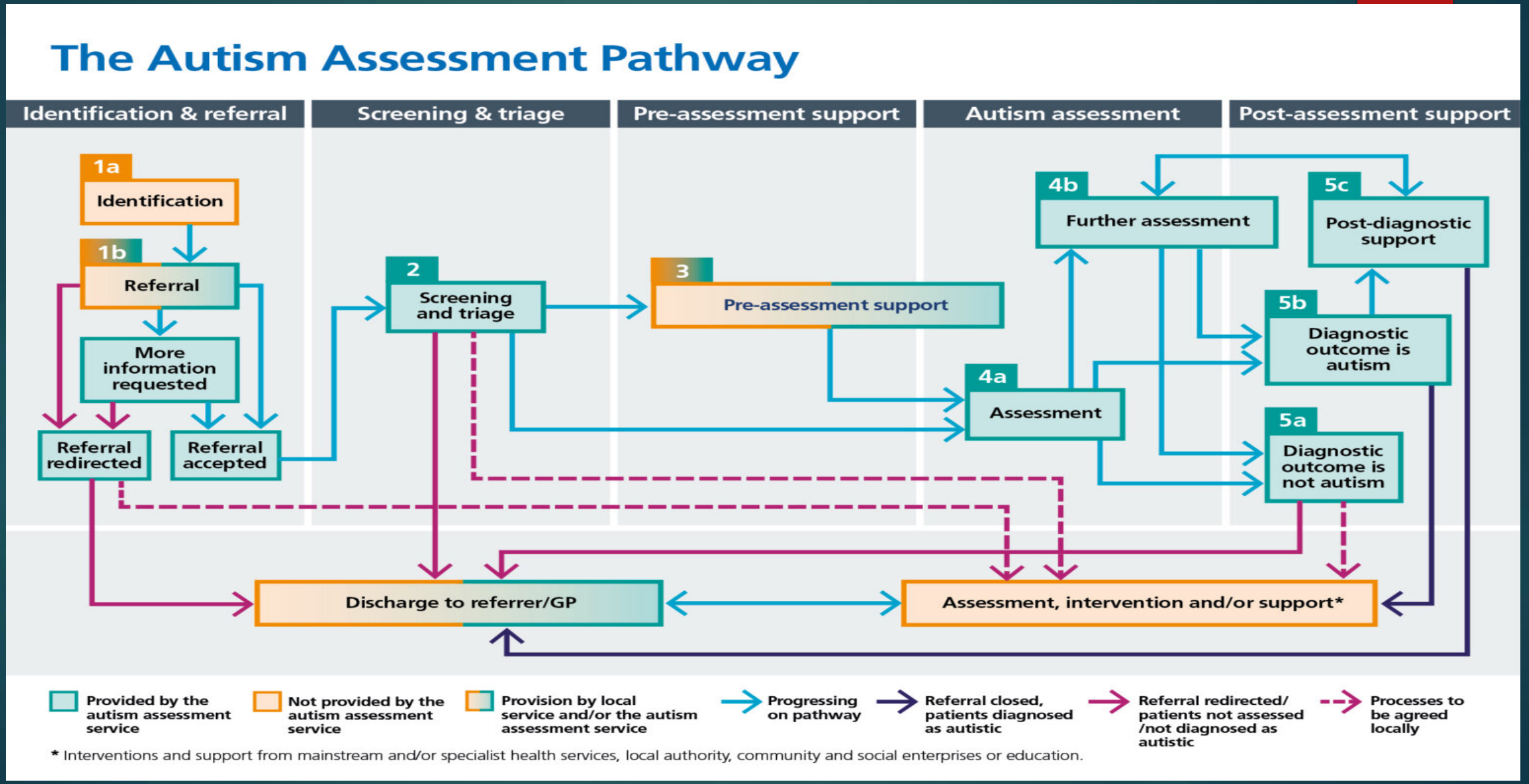
- Problem with overdiagnosis in childhood (O'Nions et al, 2023)
- According to national studies the estimated prevalence in adults with ASD is documented to be between 1.1-2% in the UK and 1% in children and young people. The proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1 [Nice, 202011].
- Locally a review in Sheffield highlighted that 1 in every 25 (4%) children and young people (CYP) has an ASD Diagnosis and 1 in every 32 (3%) has a diagnosis of ADHD.

A national framework to deliver improved outcomes in all-age autism assessment pathways (NHSE Guidance)

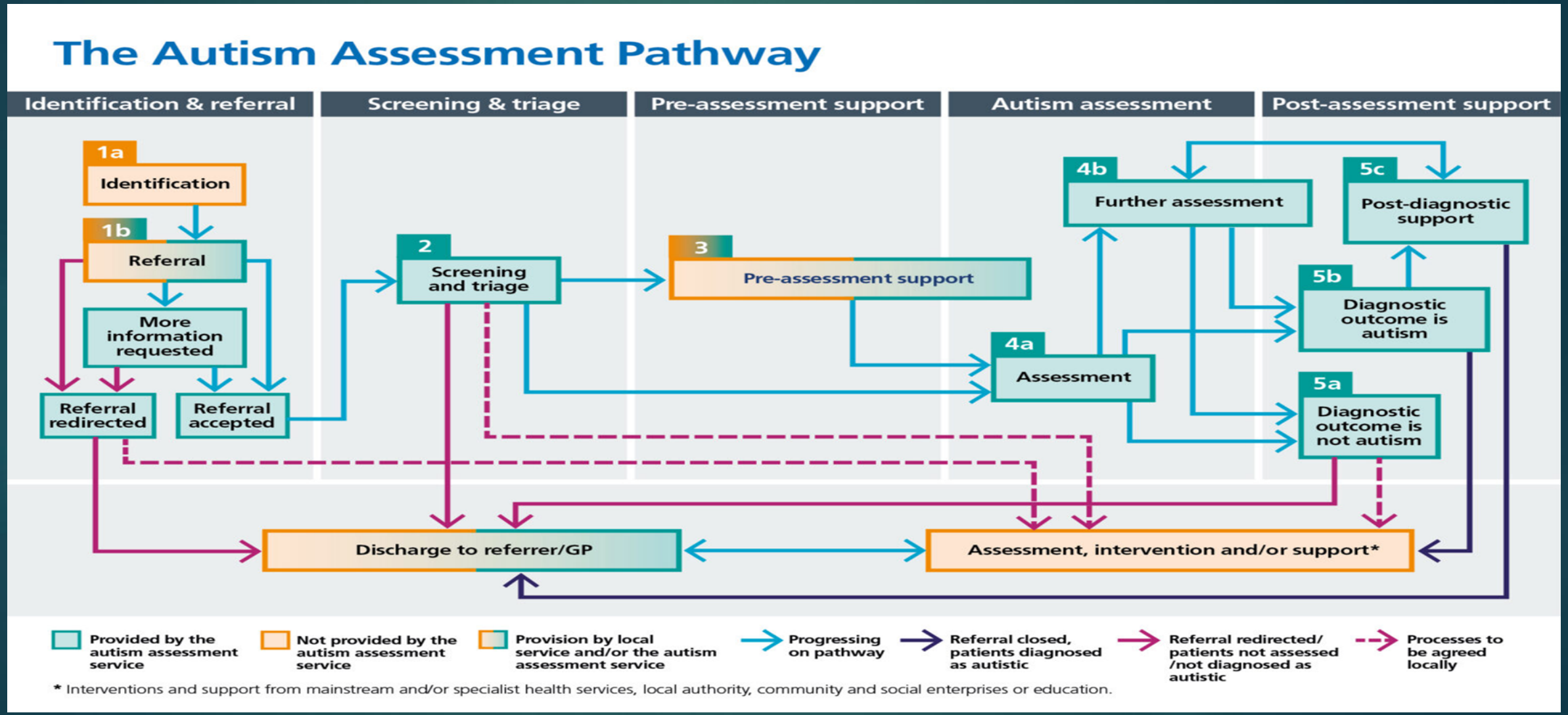
- *'Demand for autism assessments has risen rapidly over the past 20 years. Investment in autism assessment capacity has not kept pace with this growth; demand now far exceeds available capacity. Waiting lists for autism assessments across England have reached unsustainable levels. In July 2022, NHS Digital reported there were more than 125,000 people waiting for assessment by mental health services; an increase of 34% from October 2021 (1). These data show that most people wait longer, often much longer, than the three-months recommended in clinical guidelines for an autism assessment to begin (2) and the 18-week maximum waiting time for treatment to begin, as set out in the NHS Constitution (3). As demand continues to grow and capacity has remained stable or has dropped, the demand-capacity gap continues to widen'*

NHSE (2023)

NHSE Recommended Pathway



SWYPFT Autism Pathway



Referral management

- All referrals screened by a team of clinicians to identify clear and obvious reasons why a case should not be put forward for triage.
- Possible reasons include:

a) Consent is not indicated

b) A person had intended to refer for ADHD instead

c) It has been reported that the person has a Learning Disability/is awaiting a Learning Disability Assessment

d) Under 18

e) Already been assessed by our service

Triage

- Triage team consists of specialist autism practitioners from a range of professions (Clinical Psychology, Specialist Nurses, Occupational Therapists, Social Workers and Physician Associates).
- Depending on the commissioning agreements in each locality, a referral with either receive:
  - Paper based triage or
  - a face to face referral clinic appointment followed by a triage.

Paper based triage

- Service referral form is reviewed for information relevant to autism

(Social communication difficulties, social interaction difficulties and stereotypic rigid and repetitive behaviours).

- Presence of impairment is also considered.
- A comprehensive review of the electronic patient record and any other documents attached to the referral.
- A decision is made either a) not enough information to make a decision – invitation to re-refer with reference to our guidance b) information available does not indicate a person who requires an assessment – a letter explaining the outcome with sign posting information if appropriate and c0 invite for assessment

Triage with face to face appointment

- Patient's attend a face to face appointment with one of our clinical psychology assistant practitioners where information and observations relevant to autism are captured.
- This information is passed onto the triage panel for review, in additional to broader information available on the electronic patient record.
- Outcome: Offer an assessment or decline with advice/signposting.

Assessment

- **Stage 1:** A pack containing questionnaires (including the AAA) is sent for completion.
- **Stage 2**: Upon receipt a screening appointment is arranged. This face to face appointment can last up to 3 hours and is a structured assessment (core autism features, early developmental history where possible, behavioural problems, functioning at home, in education or in employment, past and current physical and mental disorders, other neurodevelopmental conditions.
- The screening assessment is structured around the CLASS system (structured interview based on the AAA).

Assessment 2

- **Stage 2:** outcome will be No Autism or MDT discussion followed by further assessment.

- **Stage 3:** Further assessment with ADOS-2 or ADIR

ADOS-2 (Autism Diagnostic Observation Schedule) is a structured observational tool based on the DSM criteria. Elicits behaviours/absence of behaviours indicative of ASD.

ADIR (Autism Diagnostic Interview, Revised) is a comprehensive semi-structured interview centred on a person's early development. Typically conducted with a parent, carer or a person who knew the patient well in childhood.

Assessment 3

- **Stage 4:** MDT discussion. Outcome either diagnosis of Autism awarded or further assessment necessary.

- **Stage 5:** 3rd appointment typically with a senior specialist. Might include additional observations in a different context, further in-depth interview or further information obtained from various sources.

Post diagnostic counselling

- Following diagnosis all patients are offered post diagnostic counselling with one of our specialist autism practitioners.
- A forum to talk about the diagnosis and what that means for the individual.
- An opportunity to ask any questions they might have.
- An opportunity to provide individuals with sign posting information for national and community resources.
- Typically 1-3 sessions.

Post diagnostic support

- Some individuals might benefit from additional time limited input.
- The service has capacity to offer up to 8 sessions of intervention.
- Examples include: cognitive assessments to further understand a person's formulation and support needs, a sensory profile, liaison with education and work settings, social skills groups/psychoeducation, occupational therapy assessment and input, and nursing/physical health interventions, social care referrals and liaison.

Sample Case - Triage

- Julie – 37 year old HR manager

Presenting issues: Has always felt different is wondering if this might be due to autism.

Social communication: No objective impairments described or observed. However she has learnt to mask well throughout her life. Has learnt how to use eye contact and respond in conversation through her interactions with others.

Social interaction: Can ***sometimes*** find it difficult to make small talk or to know how to respond in conversation.

Stereotypic, rigid and repetitive behaviours: Has an *intense interest* in hockey, going to the Gym, knitting and cooking. She engages in a range of stimming type behaviours ***when she in anxious*** (e.g., she will bite her nails, will be restless and will jiggle her knee).

Triage case – cont.

- Work and education: Never had any problems in either setting. On the contrary, popular and excelled (multiple promotions and commendations in work)
- Relationships: Married for 5 years, rich social network.
- Additional information: History of GAD for which she has taken medication.

Triage case - cont.

- Review of the electronic patient record indicates:

-A person who is communicative and able to interact with professionals.

-A person who is able to forge and maintain social relationships.

-A person who lacks routine and is flexible in their day-to-day life.

-Has a history of generalised anxiety which has been treated with propranolol but never with talking therapies.

Outcome

- Diagnostic assessment not deemed necessary as there was no evidence of the following when compared to the DSM-5 diagnostic criteria:
- A. Persistent deficits in social communication and social interaction across multiple contexts. If we acknowledge that the difficulties are there but were 'masked', still does not meet the current severity threshold.
- B. Restricted, repetitive patterns of behavior, interests, or activities. Broad range of hobbies and interests, situational specific behaviours which can be explained in the context of anxiety.
- C. D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. No evidence this is the case.

Sample case - Assessment

- 32 year old white British male, encouraged to get assessment due to his rigidity, lack of social skills or insight. Suggestion of trauma in childhood (CSA)?
- Scored the cut off for Autism on the CLASS (9). Further ax deemed necessary.
- ADOS was undertaken and scored at the cut off (2 for social communication and 9 for social interaction).
- Case reviewed in MDT, very little information on the electronic record to provide an alternative formulation. Presentation appears to be consistent with Autism but uncertainty remains around the input of trauma.

Sample case – Autism cont

- 3rd appointment offered with psychologist and the screening clinician to explore trauma.
- The context for trauma indicated a child with a lack of insight and awareness into peer relationships (vulnerable because of autism).
- Exploration of his personal history, interests and social interactional style in the 3rd appointment indicated a person with Autism.

Sample case – Autism cont.

- Outcome: Offered post diagnostic counselling and a place on a social skills group at his request.

Questions