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Demystifying the Autism Assessment
Demystifying the autism assessment

Dr Francesca Omisakin

Consultant Community Paediatrician
CONTENTS

- how can parents, school and other agencies support the referral process and assessment
- what to expect at the paediatric assessment
- challenges in the assessment
A little bit about me...

Community Paediatric Consultant Profiles

This is a consultant paediatrician-led community based service for children and young people with suspected disability, neuro-disability and development delay.

The Consultant Paediatricians also provide specialist medical opinion:

- in child abuse and neglect cases
- for statutory assessment and advice for Looked After Children
- for adoption processes for children and young people
- for those undergoing formal assessments for a statement of special educational needs

Edwin Lobo Child Development Centre
Luton
Neurodevelopmental disorders

*Disorders affecting development of the nervous system*

*Produce impairments of personal, social, academic or occupational functioning*

*Range of deficit vary from specific limitations of learning or control of executive function to global impairments of social skills or intelligence*
NEURODEVELOPMENTAL DIAGNOSES

• Learning disability (LD)

• Autism spectrum disorder (ASD)

• Attention deficit hyperactivity disorder (ADHD)

• Developmental coordination disorder (DCD)

• Speech and language disorders (SLD)
DIAGNOSTIC SYSTEMS

• ICD -10
• International Classification of Diseases and Mental Disorders, WHO 1993

• DSM-5
• Diagnostic and Statistical Manual of Mental Disorders, APA 2013

• ICD – 11 (2022)
Dsm-iv
PERVERSIVE
DEVELOPMENTAL DISORDERS

- Autism Spectrum Disorders
  - Autistic Disorder
  - PDD-NOS
  - Asperger Syndrome
- Rett's Disorder
- Childhood Disintegrative Disorder

The term Autism Spectrum Disorders is used synonymously with the term autism.
Introduced 2013

3 domains are now reduced to
2 core deficits

Social communication and interaction
(all criteria in this domain must be meet)

Restricted and repetitive patterns of
interests, behaviour or activities
(in which 2 out of 4 criteria must be met)
Autism Spectrum Disorder – DSM-5

• A. Deficits in social communication and interaction
  – across multiple contexts

• B. Restricted, repetitive patterns of behavior, interests or activities
  – currently or by history
Autism Spectrum Disorder – DSM-5

• C. Symptoms must be present in the early developmental period

  – but may not become fully manifest until social demands exceed limited capacities may be masked by learned strategies in later life
AUTISM SPECTRUM DISORDER – dsm-V

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

  – typically applies to pervasive/disabling difficulties within areas such as
    • work,
    • housing/home management
    • Relationships
    • education,
    • self-care
    • Employment

• Social communication severity level (1,2 or 3)

• Restricted Repetiive Behaviour Severity level (1,2 or 3)
Autism Spectrum Disorder – DSM-5

• E. These disturbances are not better explained by intellectual disability

• 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 than expected for general developmental level.
LEVELS OF SEVERITY

The Three Functional Levels of Autism

**ASD Level 1**
Requiring Support
- difficulty initiating social interactions
- organization and planning problems can hamper independence

**ASD Level 2**
Requiring Substantial Support
- social interactions limited to narrow special interests
- frequent restricted/repetitive behaviors

**ASD Level 3**
Requiring Very Substantial Support
- severe deficits in verbal and nonverbal social communication skills
- great distress/difficulty changing actions or focus

[Image source: verywell]
Social-emotional reciprocity

- abnormal social approach and failure of normal back-and-forth conversation;

- reduced sharing of interests, emotions, or affect

- failure to initiate or respond to social interactions.
NON-VERBAL COMMUNICATION

• poorly integrated verbal and nonverbal communication

• abnormalities in eye contact and body language

• deficits in understanding and use of gestures

• total lack of facial expressions and nonverbal communication.
DEVELOPING, MAINTAINING AND UNDERSTANDING RELATIONSHIPS

• difficulties adjusting behaviour to suit various social contexts

• difficulties in sharing imaginative play or in making friends

• absences of interest in peers.
REPETITIVE BEHAVIOURS OR LANGUAGE

• simple motor stereotypies

• lining up toys or flipping objects

• echolalia

• idiosyncratic phrases
ROUTINES, RITUALS AND RESISTANCE TO CHANGE

- extreme distress at small changes
- difficulties with transitions
- rigid thinking patterns
- greeting rituals
- need to take same route or eat same food everyday
RESTRICTED, FIXATED INTERESTS

• strong attachment to or preoccupation with unusual objects

• excessively circumscribed or preservative interest
Sensory issues

• apparent indifference to pain/temperature

• adverse response to specific sounds or textures

• excessive smelling or touching of objects

• visual fascination with lights or movement
Autism affects how people perceive the world interact with others

Autistic people see, hear and feel the world differently to other people
HOW TO SUPPORT THE REFERRAL PROCESS
I am worried about my child...

She’s still having tantrums

I think she might be autistic...

Why won’t he eat my food

He’s still not talking

He won’t play with his brother
WHO CAN I TALK TO?

- Health visitor
- Keyworker, class teacher, SENCO
- GP
SCHOOLS

• **Staff** are in contact with your child daily

• Staff provide vital information about functioning in classroom setting

• Working with the school should provide shared understanding of the child’s strengths and difficulties
GATHERING INFORMATION ABOUT YOUR CHILD

• Pre-school
  • Ages and Stages Questionnaire
  • M-CHAT

• School age
  • Social communication questionnaire
  • The Autism Spectrum Screening Questionnaire (ASSQ)
  • Autism Spectrum Quotient (AQ)
WHAT MAKES A GOOD REFERRAL?

- CLEAR QUESTION
- SAY WHAT YOU WANT
- COMPLETE INFORMATION
WHAT CAN I DO WHILE I AM WAITING FOR AN APPOINTMENT?

• Signposting to other services
  • Early Help
  • Parenting support groups
WHAT TO EXPECT AT THE PAEDIATRIC ASSESSMENT
Diagnosis guidance

• National Institute for Health and Care

Autism diagnosis in children and young people

Recognition, referral and diagnosis of children and young people on the autism spectrum

Issued: September 2011

NICE clinical guideline 128
guidance.nice.org.uk/cg128

* UPDATED December 2017
Who should be involved in the assessment?

Child/young person

- Speech and language therapist
- Paediatrician
- Educational psychologist
- Occupational therapist
- Clinical psychologist
- Child and adolescent psychiatrist
## WHAT ASSESSMENTS MIGHT BE NEEDED?

<table>
<thead>
<tr>
<th>Assessment Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual ability and learning style</td>
</tr>
<tr>
<td>Academic skills</td>
</tr>
<tr>
<td>Speech, language and communication</td>
</tr>
<tr>
<td>Fine and gross motor skills</td>
</tr>
<tr>
<td>Adaptive behaviour (incl. Self-help skills)</td>
</tr>
<tr>
<td>Mental and emotional health (incl. Self-esteem)</td>
</tr>
<tr>
<td>Physical health and nutrition</td>
</tr>
<tr>
<td>Sensory sensitivities</td>
</tr>
<tr>
<td>Socialisation skills</td>
</tr>
<tr>
<td>Behaviours likely to affect day-to-day functioning and social participation</td>
</tr>
</tbody>
</table>
We are building a profile

• What are your concerns about your child?
• What are the school/nursery worried about?
• How can we help you?
What do we need to know?

- **History**
  - Medical, social and family

- **Examination**
  - Growth, developmental and physical examination
  - Social and communication skills and behaviours
FAMILY HISTORY

Parents, carers, siblings

Neurodevelopmental disorders in other family members
Social history

• Family make-up

• Social networks

• Support accessed

• Housing situation
What we will assess

Growth

Hearing and visual ability

Examination

Language skills

Play/Social skills

Motor skills
OTHER ASSESSMENTS

Autism Diagnostic Observation Schedule (ADOS)

School observations
AUTISM DIAGNOSTIC OBSERVATION SCHEDULE (ADOS)

• Observational assessment tool

• Semi-structured tasks, activities, and discussion topics

• 5 different modules dependent on communication and language

• Designed to elicit the types of behaviors, interactions, and responses that we assess when considering an autism spectrum disorder (ASD) diagnosis
School observations

- Classroom and Playground
- Play and activities
- Initiation and response to peers
- Behaviours – following class rules etc
- Talk with teacher (and child/young person)
Investigations

- Developmental delay panel
- Genetic investigation

There isn't one!
What should we know at the end of this?

- **Diagnosis/differential diagnosis**
- Is there a need for **referral** to other services
- Is there a need for further **assessment**
- Are there any **investigations** that need completing
- What is the **follow-up**
Challenges in assessment
Why a diagnosis may not be made

• Not yet meeting diagnostic criteria

• Diagnostic overshadowing

• Information available
WHEN A DIAGNOSIS MAY BE DIFFICULT TO MAKE

• Autism in females

• Discrepancy in history and presentation

• Presence of co-morbid neurodevelopmental disorder

• Mental health difficulties

• Attachment difficulties
Autism in females

• Restrictive and repetitive behaviors

• Severity of symptoms

• Externalizing vs internalizing symptoms

• Social mimicry
Co-morbid neurodevelopmental disorders

• Intellectual disability

• Attention Deficit Hyperactivity Disorder

• Developmental Coordination Disorder

• Speech and language disorders
Mental health disorders

• Anxiety

• Depression/bipolar

• Psychosis
Attachment difficulties

• consistent pattern of inhibited, emotionally withdrawn behavior toward adult caregivers, manifested by both of the following:
  • persistent social or emotional disturbance
  • The child has experienced a pattern of extremes of insufficient care
creating a profile of strengths, needs and difficulties

Family & social background

Direct observations

Reliable informants/ various sources

comprehensive developmental history

rating scales
Child and family assessment professionals
Lucy Pedrick
Specialist CAMHS Clinician,
CAMHS Autism Liaison Team

Demystifying the Autism Assessment
Our aim

• To effectively contribute to the diagnostic process of children presenting with complex Autism Spectrum Conditions
• To ensure the child and family are at the forefront throughout the diagnostic pathway
• To inform and educate parents on ASC both pre and post diagnosis; aiming to develop understanding and the quality of support that they provide for their child
• To provide specialist mental health therapeutic support as required
• To work effectively in partnership with all stakeholders
• To plan and deliver care in line with best practice guidelines (NICE, 2017. Autism spectrum disorder in under 19’s: recognition, referral and diagnosis: CG128)
Our referrals..

• Children under the age of 13 who have a complex ASC presentation - complex case clinic to be held monthly and attended by CAMHS MDT

• Children under the age of 13 who have an identified mental health issue that require CAMHS interventions

• Joint consultation appointments held by CDC and attended by CAMHS and monthly complex case discussion at CDC attended by CAMHS
CAMHS ASD Liaison Service Pathway

Referral for ASD Ax

Accept referral
Screening tools
- Parents
- School
Screening tools reviewed & parents contacted for triage call
Further information required:
- Schools Observation
- Home Observation
- Supporting documentation
ASD Assessment appropriate?
No
Yes
Pre diagnostic Support meeting
ASD Assessment ADOS & 3Di
ASD Not indicated
Report sent to referring clinician
Discharge from CDC ASD Liaison

Refer for further Assessment

Confirmation of diagnosis
Report sent to referring clinician
ASD indicated

Is further support needed?

No
Yes

Parent
School consultation
Discharge from CDC ASD Liaison

Child
IAPT Assessment for therapeutic input
Discharge from CDC ASD Liaison

Signpost to relevant support agencies
Eg: EHA, Children & Disabilities Team

CDC Treatment
Group
Review
Outcomes
Additional support required?
Yes
No
Discharge & Signpost
Additional 1:1
Group
Review
Discharge from CDC

1:1
Review
Discharge from CDC ASD Liaison
Referral received by CAMHS Autism Liaison Team

Screening questionnaires sent to home and school

Parents invited for a pre-diagnostic meeting
Film sent to child to introduce CDC staff and environment

Child and parents invited to CDC for diagnostic testing

Diagnosis communicated in MDT meeting that parents are invited to attend at CDC

Post diagnostic workshops provided to parents on prevalent issues relating to ASC

Therapeutic work provided to child as required/ signposting

Child is discharged and referred to Autism Beds for ongoing support
Assessment and diagnosis of autism: what to expect
A quick guide for young people and their families

“I was so relieved when I got my diagnosis, it felt like recognition”
(Fran, a person with autism)
<table>
<thead>
<tr>
<th>Guidance</th>
<th>Yes</th>
<th>No</th>
<th>How?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arranging an Autism Assessment:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Keep you and your family informed throughout the</td>
<td>✔️</td>
<td></td>
<td>Telephone call at point of referral to provide contact details</td>
</tr>
<tr>
<td>process</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answer any questions that you may have</td>
<td>✔️</td>
<td></td>
<td>Ongoing contact encouraged</td>
</tr>
<tr>
<td>Provide you and/or your family with any relevant</td>
<td>✔️</td>
<td></td>
<td>Signposting Developing database</td>
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<tr>
<td>information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gather relevant information from a variety of</td>
<td>✔️</td>
<td></td>
<td>Home and school as a minimum</td>
</tr>
<tr>
<td>settings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss the need for sharing information</td>
<td>✔️</td>
<td></td>
<td>The importance of information sharing discussed and consent obtained</td>
</tr>
<tr>
<td>Guidance</td>
<td>Yes</td>
<td>No</td>
<td>How?</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
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<td>----</td>
<td>-------------------------------------------</td>
</tr>
<tr>
<td>Assessment should be completed in a variety of relevant settings:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strengths and weaknesses in all settings recognised</td>
<td>✔</td>
<td></td>
<td>School observations Home visits</td>
</tr>
<tr>
<td>Develop an awareness of any worries that you may have in certain environments</td>
<td>✔</td>
<td></td>
<td>Direct assessment with you, your family and teachers</td>
</tr>
<tr>
<td>How do you function in varying environments</td>
<td>✔</td>
<td></td>
<td>As above</td>
</tr>
<tr>
<td>Any issues with the relationships that you share with others?</td>
<td>✔</td>
<td></td>
<td>As above</td>
</tr>
<tr>
<td>Guidance</td>
<td>Yes</td>
<td>No</td>
<td>How?</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
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<td>-------------------------------------------</td>
</tr>
<tr>
<td>The Multi-disciplinary team should think about:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any physical health problems that you may have</td>
<td>✓</td>
<td></td>
<td>Joint working between CAMHS and CDC paedictrians</td>
</tr>
<tr>
<td>Any mental health problems that you may have</td>
<td>✓</td>
<td></td>
<td>IAPT support</td>
</tr>
<tr>
<td>Anything that may make things harder for you</td>
<td>✓</td>
<td></td>
<td>And what can we do to support this?</td>
</tr>
<tr>
<td>Complete any other relevant assessments</td>
<td>✓</td>
<td></td>
<td>Access to Psychiatrists and Psychologists at CAMHS</td>
</tr>
<tr>
<td>Guidance</td>
<td>Yes</td>
<td>No</td>
<td>How?</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
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<td>----</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td>After the Assessment process is complete:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome of diagnostic process discussed with you and your family</td>
<td>✓</td>
<td></td>
<td>Meeting held as soon as process concluded through discussion with all MDT members</td>
</tr>
<tr>
<td>Information about how this diagnosis may affect you now and in the future</td>
<td>✓</td>
<td></td>
<td>Reports provided Post diagnostic support begins</td>
</tr>
<tr>
<td>Provide you and your family with support as needed</td>
<td>✓</td>
<td></td>
<td>Post diagnostic support</td>
</tr>
<tr>
<td>Offer a follow up appointment</td>
<td>✓</td>
<td></td>
<td>Sessions</td>
</tr>
</tbody>
</table>
A child's journey through the CAMHS Autism Liaison Team from referral to diagnosis to treatment to discharge.

I have been referred to CAMHS Autism Liaison Team (CALT) by my teacher as I have been struggling with anxiety, social skills and making friends at school. My teacher thinks that I may have an Autism Spectrum Condition (ASC).

The team visit my school and talk about ways that I can be supported within this environment.

My parents/carers and my school complete a questionnaire about how I am in different environments like home and school.

My parents attend post-diagnostic workshops where they learn more about ASC and how they can support me if and when I need it. They are then referred to Autism Beds.

It is assessed that I need a bit of extra support with anxiety so I am offered 6 sessions of 1:1 therapeutic support with the team.

I make progress working 1:1 and it is thought that I would now benefit from some group work, so I start a group focusing on managing anxiety.

CALT speak to my parents to gather some further information and explain that to them that I have been accepted for an ASC assessment.

A diagnosis of ASC is made and my parents attend a meeting where this is explained to them. They also talk about ways that this diagnosis can be explained to me.

A video link is sent to me so that I know what the CDC looks like and who I will meet when I go there.

My parents are offered an appointment to meet with the team to discuss what happens during the diagnostic process.

My parents and I spend the day at the CDC where we complete all our tests.

It is assessed that I no longer need regular support from CALT. I am scheduled to attend a follow up appointment in six weeks time.

I am discharged from CALT.
Next steps....

• Focus group for children who have received an ASC diagnosis to inform pathway
• Focus group for parents of children diagnosed with ASC to inform pathway
• Develop post diagnostic resource pack
• Advertise the service to stakeholders and develop collaborative working processes
  – Develop post diagnostic sessions
CAMHS Autism Liaison Team

Lucy Pedrick
Specialist CAMHS Clinician

Kate Wilson
IAPT High Intensity Trainee

Sarah Kelly
IAPT High Intensity Trainee