#DRYMESTER

HELPING PARENTS-TO-BE GO ALCOHOL FREE

FASD CONSULTATION/SUPERVISION

GREATER MANCHESTER

Are you currently diagnosing children with FASD, or wondering if it is FASD? Do you have queries and questions? Arrange a consultation/ supervision session with a member of staff from the National Clinic to discuss your queries.

The consultation/supervision model is collaborative. The FASD specialist guides as to what information is required, and supports in the interpretation of the information and recommendations. The local clinician will remain the case holder, write up notes, make any diagnoses, and write up the report including care plan recommendations.

TYPES OF SITUATIONS APPROPRIATE TO BRING TO CONSULTATION/ SUPERVISION SESSION:

- Diagnostic queries
- Support around management and ongoing input
- General queries around impact of prenatal alcohol
- Other questions related to FASD

THE AIM OF AN FASD DIAGNOSTIC ASSESSMENT IS TO:

1) Help individuals or teams with FASD and their carers develop a better understanding of the profile of strengths and needs
2) Make recommendations for how best to support individuals which can also be used to inform local support plans

Part of Greater Manchester Integrated Care Partnership

NHS Greater Manchester Integrated Care

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INFORMATION PREFERRED FOR DIAGNOSTIC QUERIES:

- Documented evidence of why FASD is suspected, including history of alcohol and drug use before, during, and after pregnancy. If adopted, information may be in the Child Permanence Report
- Any reports or questionnaires from previous direct and indirect assessments that have been conducted already including: cognitive/psychometric, educational psychology, speech and language, Autistic Spectrum Disorder (ASD), and Attention Deficit Hyperactivity Disorder (ADHD)
- Complete essential information on the FASD assessment form, as well as other sections as far as possible (see Appendix 1; 'Assessment Form for FASD Consultation') including:
  - Patient demographics and consent for assessment
  - Presenting concerns and strengths
  - Birth history and 0–2-year growth charts from from the patient's Red Book if available
  - Developmental history (see form for details)
  - Mental health, self-regulation, and other behavioural issues
  - Medical/diagnostic history
  - Social care history and adverse postnatal experiences
  - Maternal alcohol and substance use – pre-pregnancy, pregnancy, and postnatal
  - Physical - growth, head circumference, sentinel facial features
  - Neurodevelopmental areas of assessment including ASD & ADHD (see Appendix 2; 'SIGN-156 Neurodevelopmental Areas of Assessment: Criteria for Severe Impairment')
- Results of genetic testing/confirmation that genetics testing is underway. Genetic testing is required for inclusion and exclusion of any genetic disorders alongside assessments (see Appendix 3 'Genetic Testing Information')

USEFUL QUESTIONNAIRES:

- Children's Communication Checklist – 2
- Behavioural Rating Inventory of Executive Function – 2 (BRIEF-2 Caregiver and Teacher)
- Vineland Adaptive Behaviour Questionnaire or Adaptive Behaviour Assessment Schedule
- Conners 3 (Caregiver and Teacher)
- Winnie Dunn Sensory Profile
- Strengths and Difficulties Questionnaire (Caregiver and Teacher)

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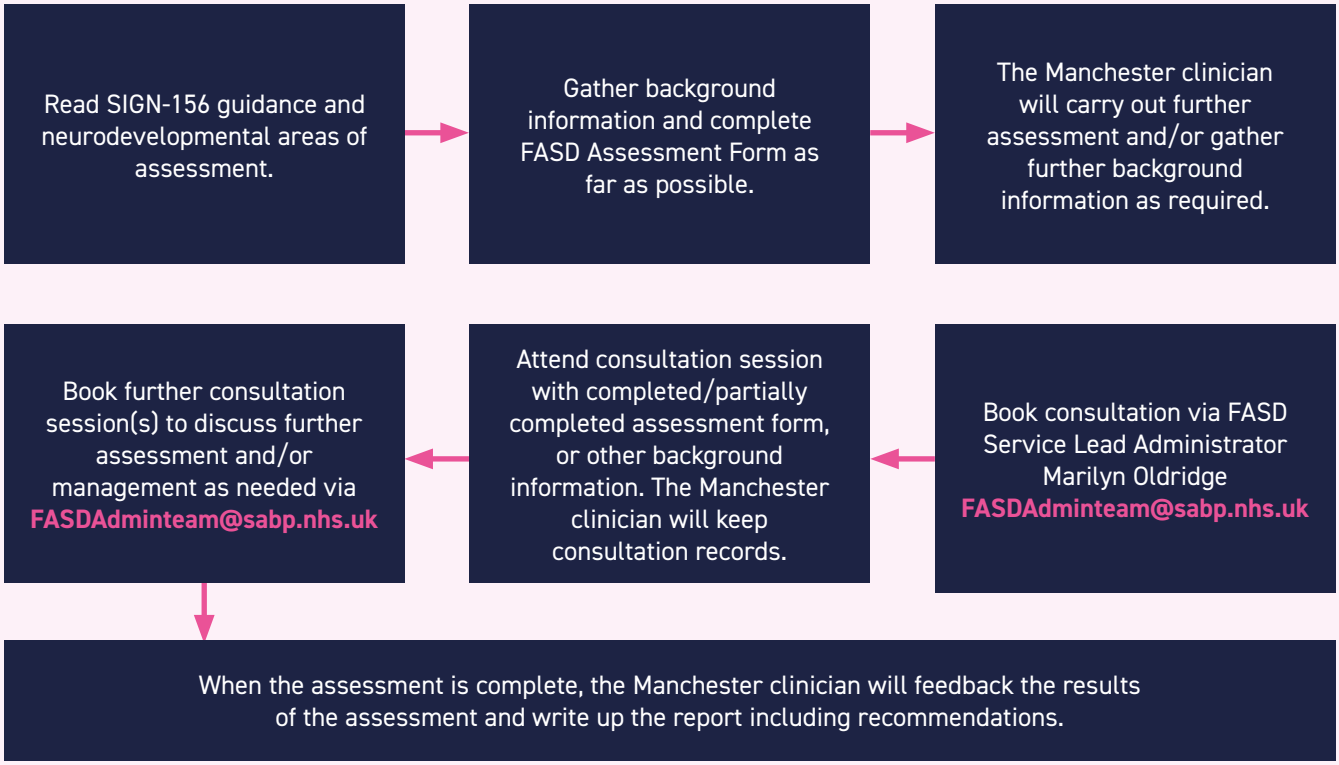
FASD CONSULTATION PROCESS MANCHESTER



BOOKING A CONSULTATION WITH MARILYN:

Clinic Contact details
FASD Service Lead Administrator:
Marilyn Oldridge
By Telephone: **01737 288813**
By Email: **FASDAdminteam@sabp.nhs.uk**

1. Contact FASD Admin to request a consultation. Specify number of cases to be discussed
2. FASD Admin to send out the FASD Assessment form if not already completed
3. Requestor to return the form prior to consultation, including essential information
4. FASD Admin will send a Teams meeting invite. Slots allocated according to availability

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APPENDICES

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Fetal Alcohol Spectrum Disorders Specialist Clinic

FASD Assessment Form for Consultation

Adapted from SIGN-156 guidelines: https://www.sign.ac.uk/sign-156-children-and-young-people-exposed-prenatally-to-alcohol

Prior to booking a consultation it is essential that consent for the discussion is established with the person with parental responsibility. The patient details section is essential information. Other sections are helpful but optional.

PATIENT DETAILS

NAME	
Sex	☐ Female ☐ Male ☐ Other
Date of birth (DD/MM/YYYY)	/ / Age at assessment:
Racial and ethnic background	
NHS number	
Person with parental responsibility (select 1 or more)	☐ Biological mother ☐ Biological father ☐ Foster carer ☐ Adoptive parent/s ☐ Other
Name of person with parental responsibility who has given consent	
Assessment form completed by	
Job title and employer	
Discussed in consultation with	FASD Specialist Clinician Surrey & Borders NHS Trust
Name	
Date(s) discussed (DD/MM/YYYY)	

HISTORY

Presenting concerns:

(Include concerns identified by referring doctor, parent, caregiver, teacher, such as behavioural regulation, memory and learning, social skills, and motor control concerns, as well as strengths and age-appropriate abilities)

Pregnancy and birth history:

(Include information known about antenatal care, number of weeks gestation at birth, birth weight, birth length, birth head circumference, type of birth, postnatal admission to special care baby unit, 0-2 years weight, height, and head circumference growth charts from Red Book)

Developmental history:

(Daily living skills including toileting, feeding, dressing, hygiene, domestic, independence; receptive and expressive language skills; social interaction with adults and peers; social play and imagination; visual-spatial skills; gross and fine motor skills; academic and conceptual skills including reading, writing, maths reasoning, knowledge, and memory; stereotyped repetitive behaviours; routines and resistance to change; response to sensory stimuli and sensory seeking profile; attention including selective, alternating, divided, and sustained; executive functioning including hyperactivity, impulse control, working memory, planning and problem solving, shifting and cognitive flexibility).

Developmental history (continued):

Mental health, self-regulation, and other behavioural issues:

(Affect regulation including anxiety and depression, sleep difficulties, behaviour affecting other people, awareness of danger, risk to self and others, confabulation, and awareness of fantasy vs reality)

Medical / diagnostic / formulation history:

Previous assessment, diagnoses and formulations, and interventions, medication, allergies, etc.

Social history: *(e.g., foster care / adoption, previous and current living arrangements, adverse childhood experiences)*

MATERNAL ALCOHOL USE

Evidence of maternal alcohol use in the three months prior to and during pregnancy should be assessed, including any special occasions when a large amount of alcohol may have been consumed. Standardised screening tools can be used (either AUDIT-C, T-ACE, or TWEAK).

The definition of a standard unit of alcohol should be explained prior to administering the AUDIT-C (Q1–3). Information on standard units and volume of alcohol can be found at www.drinkaware.co.uk/alcohol-facts/alcoholic-drinks-units/what-is-an-alcohol-unit

Alcohol use in early pregnancy (if available)

a.	Was the pregnancy planned or unplanned?	☐ Planned ☐ Unplanned ☐ Unknown
b.	At what gestation did the birth mother realise that she was pregnant?	____ (weeks) ☐ Unknown
c.	Did the birth mother drink alcohol before the pregnancy was confirmed?	☐ Yes ☐ No ☐ Unknown
d.	Did the birth mother modify her drinking behaviour on confirmation of pregnancy?	☐ Yes ☐ No ☐ Unknown
	If Yes please specify:	
e.	During which trimesters was alcohol consumed? (tick one or more)	☐ None ☐ 1st ☐ 2nd ☐ 3rd ☐ Unknown

AUDIT-C Reported alcohol use (if available)

1. How often did the birth mother have a drink containing alcohol during this pregnancy?

Unknown	Never *[skip Q2 + Q3]*	Monthly or less	2–4 times a month	2–3 times a week	4 or more times a week
☐	☐0	☐1	☐2	☐3	☐4

2. How many units of alcohol did the birth mother have on a typical day when she was drinking during this pregnancy?

Unknown	1 or 2	3 or 4	5 or 6	7 to 9	10 or more
☐	☐0	☐1	☐2	☐3	☐4

3. How often did the birth mother have 6 or more units of alcohol on one occasion during this pregnancy?

Unknown	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
☐	☐0	☐1	☐2	☐3	☐4

AUDIT-C score during this pregnancy: (Q1+Q2+Q3) =_____

Scores: 0=No exposure, 1–4= Confirmed exposure, 5+= Confirmed high-risk exposure

T-ACE (if available)

T **Tolerance**	How many drinks does it take to make you feel high (effects)? *0 to 2 drinks* *More than 2 drinks*	**Scores** **0** **2**	
		Yes	**No**
A **Annoyed**	Have people ever annoyed you by criticising your drinking?	**1**	**0**
C **Cut down**	Have you ever felt you ought to cut down on your drinking?	**1**	**0**
E **Eye opener**	Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hang-over?	**1**	**0**
	Scoring: A total of ≥2 represents potential risk	Add total _____	

TWEAK (if available)

T **Tolerance**	How many drinks does it take to make you feel high?				Score
	Less than 3	**0**	3 or more	**2**	
W **Worried**	Have close friends or relatives worried or complained about your drinking?				
	No	**0**	Yes	**2**	
E **Eye opener**	Do you sometimes have a drink in the morning when you first get up?				
	No	**0**	Yes	**1**	
A **Amnesia**	Has a friend or family member ever told you about things you said or did while you were drinking that you could not remember?				
	No	**0**	Yes	**1**	
K **K/Cut down**	Do you sometimes feel the need to cut down on your drinking?				
	No	**0**	Yes	**1**	
	Scoring: A total of ≥2 represents potential risk				**Total score** _____

Other evidence of exposure

Is there evidence that the birth mother has ever had a problem associated with alcohol misuse or dependency?
☐ No ☐ Yes (identify below, including source of information)

☐ Alcohol dependency (specify)
☐ Alcohol-related illness or hospitalisation (specify)
☐ Alcohol-related injury (specify)

☐ Alcohol-related offence (specify) ☐ Other (specify) Information from records: e.g., medical records, court reports, child protection records. Is there evidence that the birth mother's partner has ever had a problem associated with alcohol misuse or dependency? ☐ No ☐ Yes (identify below, including source of information)

Alcohol Exposure Summary

Source of reported information on alcohol use:	☐ Birth mother ☐ Other (specify)
In your judgement what is the reliability of the information on alcohol exposure?	☐ Unknown ☐ Low ☐ High
In your judgement was there high-risk consumption of alcohol during pregnancy?	☐ Unknown ☐ Yes ☐ No
Prenatal alcohol exposure:	☐ Unknown exposure ☐ No exposure ☐ Confirmed exposure ☐ Confirmed high-risk exposure

OTHER EXPOSURES

Assess evidence of adverse prenatal and postnatal exposures and events that need to be considered.

Prenatal

Other prenatal exposures identified: (if yes, specify and indicate source of information) ☐ Nicotine (eg cigarettes, inhalers, e-cigs and chewed tobacco) (specify) ☐ Marijuana (specify) ☐ Heroin (specify) ☐ Cocaine (specify) ☐ Amphetamines (specify) ☐ Other non-prescription drugs (specify) ☐ Anticonvulsants (specify) ☐ Other prescription drugs (specify) ☐ Don't know ☐ None
Specify other prenatal risk factors and assess risk: (eg pregnancy complications, congenital infection, trauma, exposure to known teratogens, including ionizing radiation, paternal or maternal intellectual impairment, maternal ill-health)

Other prenatal risk summary: ☐ No known risk ☐ Unknown risk ☐ Some risk ☐ High risk

Postnatal

Specify other physical or medical risk factors and assess risk based on your clinical judgement: (e.g., prematurity, history of abuse or neglect, serious head injury, meningitis or other medical conditions that could lead to brain damage, child substance abuse)
Specify other psychosocial risk factors and assess risk (e.g., emotional abuse, early life trauma, parental separation or incarceration, drug and alcohol use in the household; overcrowding, socioeconomic disadvantage):
Postnatal risk summary: ☐ No known risk ☐ Unknown risk ☐ Some risk ☐ High risk

GROWTH

Assess birth parameters and postnatal growth and determine if any deficit exists that is unexplained by genetic potential, environmental influences (e.g., nutritional deficiency) or other known conditions (e.g., chronic illness).

Birth	Gestation age	Birth length		Birth weight	
Date	weeks	cm	percentile	grams	percentile

Growth reference chart used: ☐ CDC ☐ WHO ☐ Other (specify)

Postnatal		Height		Weight	
Date	Age	cm	percentile	kg	percentile

Growth reference chart used: ☐ CDC ☐ WHO ☐ Other (specify)

Parental height (if available)

Mother's height (cm)	Father's height (cm)	Sex-specific target height (cm)	Sex-specific target height (percentile)

Specify factors that may explain growth parameters: (e.g., nutritional, environmental, neglect, genetic condition, prematurity, other drugs, nicotine)

Growth summary

Was an unexplained deficit in height or weight <3rd percentile identified at any time? ☐ Yes ☐ No If Yes: ☐ height or weight ≤10th and >3rd percentile ☐ height or weight ≤3rd percentile

SENTINEL FACIAL FEATURES

Assess for the 3 sentinel facial features of FASD: short palpebral fissure length (≥2 SD below the mean), smooth philtrum (rank 4 or 5 on the Lip-Philtrum guide), and thin upper lip (rank 4 or 5 on the Lip-Philtrum guide).

University of Washington Palpebral Fissure Length Z-score calculator: depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl

† University of Washington Lip-Philtrum Guides: depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm

Palpebral Fissure Length (PFL)			Right PFL		Left PFL		Mean PFL	
Date	Age	Assessment method	mm	Z score (SD)	mm	Z score	mm	Z score*
		☐ direct measure ☐ photo analysis						
		☐ direct measure ☐ photo analysis						
PFL reference chart used: ☐ Strömland (Scandinavian) ☐ Clarren (Canadian) ☐ Other								

Philtrum

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	

Upper Lip

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	
		☐ direct measure ☐ photo analysis	
Lip-Philtrum Guide† used: ☐ Guide 1: Caucasian ☐ Guide 2: African American			

Sentinel Facial Features Summary

Number of Sentinel Facial Features (PFL ≥2 SD below the mean, philtrum rank 4 or 5, upper lip rank 4 or 5):

☐ 0 ☐ 1 ☐ 2 ☐ 3

OTHER PHYSICAL FINDINGS

Dysmorphic Facial Features (please specify)

Other birth defects - major or minor (please specify)

Other medical conditions:

Hearing impairment: ☐ No ☐ Not tested ☐ Yes (specify)
Vision impairment: ☐ No ☐ Not tested ☐ Yes (specify)
Known syndrome or genetic disorder (please specify):
Other (please specify):

Investigations:

Chromosomal microarray:	☐ No	☐ Result pending	☐ Yes (specify result)
Fragile X testing:	☐ No	☐ Result pending	☐ Yes (specific result)
Other investigations as indicated: Full blood count, ferritin, metabolic screen, creatinine kinase, lead, and thyroid function (specify):			

NEURODEVELOPMENTAL AREAS OF ASSESSMENT

Assess evidence of significant CNS dysfunction due to underlying brain damage. Required evidence includes neurodevelopmental impairment (≥2 SD below the mean or <3rd percentile) in areas of brain function based on standardised assessment by a qualified professional.

1. BRAIN STRUCTURE/NEUROLOGY

BRAIN STRUCTURE

Occipitofrontal circumference (OFC)

Date	Age	OFC (cm)	Percentile*	Reference used
Birth:				

*correct for gestational age when <2 years old

If OFC <3rd percentile, is it explained by other aetiologies, e.g., infection, metabolic or other disease? ☐ No ☐ Yes (specify)

Imaging

CNS imaging performed: ☐ No ☐ Yes (specify image modality and date)

Specify any structural abnormalities:

If yes, are they explained by other aetiologies, e.g., injury, infection, or metabolic or other disease? ☐ No ☐ Yes (specify)

NEUROLOGY

Assess evidence of seizure disorders or other abnormal hard neurological signs.

Seizure disorder

Seizure disorder present: ☐ No ☐ Yes (specify)

If yes, are they explained by other aetiologies, e.g., injury, infection, or metabolic or other disease? ☐ No ☐ Yes (specify)

Other neurological diagnoses, e.g., CP, visual impairment, sensorineural hearing loss

Other abnormal neurological diagnoses present: ☐ No ☐ Yes (specify) If yes, are they explained by other aetiologies, e.g., injury, infection, or metabolic or other disease? ☐ No ☐ Yes (specify)

Brain structure/neurology area of assessment summary

Evidence of brain structure/neurology abnormalities of presumed prenatal origin that are unexplained by other causes? ☐ No ☐ Yes ☐ Not assessed

2. MOTOR SKILLS

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Motor Skills impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

3. COGNITION

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Cognition impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

4. LANGUAGE (expressive and receptive)

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Language impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

5. ACADEMIC ACHIEVEMENT

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Academic achievement impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

6. MEMORY

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				

Memory impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed

7. ATTENTION

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Attention impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

8. EXECUTIVE FUNCTION, INCLUDING IMPULSE CONTROL AND HYPERACTIVITY

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Executive function, including impulse control and hyperactivity impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

9. ADAPTIVE BEHAVIOUR, SOCIAL SKILLS, OR SOCIAL COMMUNICATION

Test/subtest name	Age/Date	Score	Percentile/ SD	Interpretation
Other information:				
Adaptive behaviour, social skills, or social communication impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

NEURODEVELOPMENTAL AREAS OF ASSESSMENT SUMMARY

Number of neurodevelopmental domains with evidence of severe impairment:
☐ None ☐ 1 ☐ 2 ☐ 3 or more (specify)_____

OTHER AREAS OF DIFFICULTY IDENTIFIED BY ASSESSMENT

Affect regulation (anxiety or low mood), sensory sensitivity, or sleep difficulties:

STRENGTHS

Unique abilities, favourite activities/hobbies, what other people like about the individual:

KEY RECOMMENDATIONS AND OPPORTUNITIES

Based on CNS deficits identified, what external accommodations are required? What can the individual do with support?:

Neurodevelopmental areas of assessment: criteria for severe impairment

1. Brain structure	**Definition**	**Brain structure** and **neurology** includes: • abnormal occipitofrontal head circumference • structural brain abnormalities • seizure disorder not due to known postnatal causes • significant neurological diagnoses otherwise unexplained.
	Direct/indirect assessment	**Severe impairment** is present when one or more of the following are identified: • **occipitofrontal head circumference** is <3rd percentile or ≤2 SD below the mean - For premature infants OFC should be corrected for gestational age until two years of age • **structural brain abnormalities** known to be associated with prenatal alcohol exposure are shown on brain imaging Examples include: - reduction in overall brain size - corpus callosum (agenesis, hypoplasia) - cerebral cortex (reduced gyrification or anterior cingulated cortex surface area) - reduction in volume in specific areas: cerebellum, hippocampus, basal ganglia-caudate • **seizure disorder** in which other aetiologies have been excluded • **significant neurological diagnoses** otherwise unexplained are identified, eg cerebral palsy, visual impairment, sensorineural hearing loss when other aetiologies have been excluded.
	Considerations	**Microcephaly** There are many other causes of microcephaly which should be excluded, including familial microcephaly, chromosomal abnormalities, intrauterine infection or exposure to teratogens other than alcohol. These causative factors may be identified in addition to PAE. When possible, parental head circumference should be measured. Investigate as clinically indicated. In some circumstances a child may have reliable past documentation of an OFC <3rd percentile, but at the time of assessment the OFC is >3rd percentile. In this situation, clinical judgement should be used to judge whether this discrepancy reflects persistent microcephaly or may reflect measurement error. **Neuroimaging** Brain imaging such as MRI is not required for a diagnosis of FASD, but is recommended when clinically indicated, eg by the presence of microcephaly or macrocephaly that is not familial; localising neurological signs; focal seizure disorder; or signs of neurodegenerative disorder.

2. Motor Skills	**Definition**	**Motor skills** include fine motor skills (manual dexterity, precision), gross motor skills (balance, strength, co-ordination, ball skills and agility), graphomotor skills (handwriting) and visuo-motor integration.
	Direct Assessment	Severe impairment in **motor skills** is present *when* on a validated test of motor skills: • a *composite score is below the clinical cut-off;* or • *1 or more major subdomain scores* (gross motor skills, fine motor skills, graphomotor skills and VMI) is/are *below the clinical cut-off* (eg gross motor and fine motor skills can be scored separately using the BOT-2). Examples of standardised tests: - Movement Assessment Battery for Children, 2nd Edition (Movement-ABC 2); 3 years–16 years 11 months - Beery-Buktenika Developmental Test of Visual-Motor Integration, 6th Edition; 3–7 years (short form) 7–100 years (full form) - Bruininks Oseretsky Test of Motor Proficiency, 2nd Edition (BOT-2); 4 years–21 years 11 months - Bayley Scales of Infant and Toddler Development, 3rd Edition (Bayley-III); 1–42 months - Griffiths Scales of Child Development, Third Edition; Birth–6 years.
	Indirect assessment	Clinical assessment may provide supporting evidence of severe impairment, eg report of problems with balance or co-ordination. Abnormal tone, reflexes, strength, soft neurological signs and other findings on the neurological examination may be considered in combination with direct assessment of motor skills using a standardised assessment tool. Clinical evidence of impairment in speech articulation or oromotor function may be considered in combination with direct assessment of motor skills. For motor skills, significant functional impairment may be evident in learning and play when motor skill levels are at 1 standard deviation below the mean (≤16th centile). If this is documented during assessment it is important to ensure adequate therapeutic supports are in place, even if criteria for severe impairment (≤2 SD or <3rd percentile) are not met. As therapeutic approaches differ significantly for different components of motor function (eg gross motor versus fine motor) it is preferential to use a motor assessment (eg BOT-2) which provides separate composite scores for gross and fine motor function to inform therapy. An overall motor composite score may hide an individual's relative strengths and weaknesses.

Motor Skills continues on page 3

2. Motor Skills continued	**Indirect assessment** continued	Musculoskeletal-based structural defects may also need to be considered for their impact on the motor skills area of assessment, eg lack of complete extension of one or more digits, decreased supination/pronation at the elbows, other joint contractures including inability to completely extend and/or contract at the hips, knees, and ankles. Examples of non-standardised assessment: - Child Development Scales (preschool).
3. Cognition	**Definition**	**Cognition** includes IQ, verbal and non-verbal reasoning skills, processing speed, and working memory.
	Direct assessment	Severe impairment is present when standardised tests of cognition or intelligence show: • a *composite score below the clinical cut-off* eg full scale IQ <70, or • a *major subdomain score below the clinical cut-off,* eg for the WISC this includes Verbal Comprehension, Visual Spatial, Fluid Reasoning, and Processing Speed, or • there is a *significant discrepancy* among major subdomain scores. Examples of standardised tests: **<6 years** - Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV); 2 years 6 months–7 years 7 months - Stanford-Binet Intelligence Scales (SB-5); 2–85 years - Differential Abilities Scales (DAS-II); 2 years 6 months–17 years 11 months - Wechsler Non-Verbal Scale of Ability-II (WNV-II); up to 21 years. **>6 years** - Wechsler Intelligence Scales for Children (WISC-V ANZ); 6 years–16 years 11 months - Stanford-Binet Intelligence Scales (SB-5); up to 85 years - Wechsler Adult Intelligence Scale (WAIS-IV); 16–90 years - Differential Abilities Scales (DAS-II); up to 17 years - Universal Nonverbal Intelligence Test (non-verbal test); 5 years–21 years 11 months - Wechsler Non-Verbal Scale of Ability (WNV); 4–21 years - Naglieri Nonverbal Ability Test – Second Edition (NNAT-2); 4–18 years.
	Indirect assessment	**N/A**

Cognition continues on page 4

3. Cognition continued	**Considerations**	Individuals who fulfil criteria for an intellectual disability, by definition, typically will have impairment in at least three neurodevelopmental areas of assessment (eg cognition, adaptive behaviour, language, motor skills). If working memory alone is severely impaired (below the clinical cut-off), this should be considered evidence of impairment in the executive functioning area of assessment rather than in the cognition area of assessment. A test that is independent of language and culture may be appropriate for certain populations.
4. Language	**Definition**	**Language** includes expressive and receptive language skills.
	Direct assessment	Severe impairment is present when: • a *composite score* assessing core language, receptive language, and/or expressive language is *below the clinical cut-off*, or • there is a *significant discrepancy* between receptive and expressive composite scores, or • there are *two or more scores below the clinical cut-off* on subtests assessing higher-level language skills (ie the integrative aspects of language such as narrative and complex comprehension abilities). Examples of standardised tests: - Clinical Evaluation of Language Fundamentals (CELF-4); 5 years–21 years 11 months - Pre-School Language Scales, 5th Ed (PLS-5); birth–7 years 11 months.
	Indirect assessment	Clinical judgment regarding severity of impairment is required if: • testing is not standardised • testing is not in an individual's first language • direct assessment is not possible.
	Considerations	This domain should be assessed as if it is a single entity. It is inappropriate to use scores on verbal IQ subtests as a measure of both language and cognition. When possible, testing should be done in the individual's first language. Problems with phonological awareness may impact on language and, if present, may contribute to impairment in this area of assessment.
5. Academic achievement	**Definition**	**Academic achievement** includes skills in reading, mathematics, and/or literacy (including written expression and spelling).

Academic achievement continues on page 5

5. Academic achievement continued	**Direct assessment**	Severe impairment is present when standardised measures of reading, mathematics, and/or literacy show: • a *composite score below the clinical cut-off*, or • a *significant discrepancy* between cognition and either reading, mathematics, and/or written expression. Examples of standardised tests: - Wechsler Individual Achievement Test (WIAT II); 4 years–adult - Woodcock–Johnson Achievement Test (WJAT-III); 4 years–adult.
	Indirect assessment	School reports with literacy and numeracy achievement levels can be used as supporting evidence for severe impairment.
	Considerations	The clinical team must determine whether the individual has had adequate access to and attendance at school or alternative instruction and/or remedial intervention before a deficit can be recorded. Consideration must also be given to the individual's educational placement, ie mainstream versus educational support class and opportunity, eg remote location, multilingual setting, new immigrant. Even if the Full Scale IQ is below 70 (indicating impairment of cognition), impairment can also be given in the area of assessment of academic achievement, as cognitive and academic skills do not necessarily directly correlate (eg some individuals with mild intellectual disability perform in the low average range academically). Both areas of assessment should be tested and considered separately. If an individual has a specific developmental disorder of scholastic skills according to ICD-10 they fulfil criteria for severe impairment in academic achievement, providing testing shows evidence of impairment at clinical cut-off of at or below 2SD. Problems with phonological awareness may impact on academic achievement and if present may contribute to impairment in this area of assessment.
6. Memory	**Definition**	**Memory** includes overall memory, verbal memory, and visual memory.
	Direct assessment	Severe impairment in memory is present when: • a *composite score* for overall memory and/or verbal memory, and/or visual memory score is *below the clinical cut-off,* or • there is a *significant discrepancy* between verbal and nonverbal memory. Examples of standardised tests: - Developmental Neuropsychological Assessment (NEPSY-II), Memory and Learning sub-tests; 3–16 years - Wide Range Assessment of Memory and Learning, 2nd Edition (WRAML-II); 5–90 years - Children's Memory Scale (CMS); 5–16 years.

Memory continues on page 6

6. Memory continued	**Indirect assessment**	N/A
	Considerations	A deficit in working memory should be considered in the executive function, including impulse control and hyperactivity area of assessment rather than the memory area of assessment.
7. Attention	**Definition**	**Attention** has several components: i) *selective* attention (ie focusing on a particular stimulus) ii) *divided* attention (ie attending to two or more stimuli at the same time) iii) *alternating* attention (ie switching focus from one stimulus to another) iv) *sustained* attention (ie attending for a long period of time and resistance to distractions). Attention deficits usually manifest as problems with concentration, task focus and work organisation. In many definitions and theories of brain function, attention overlaps with some of the executive functions. In order to distinguish these areas of assessment for diagnostic purposes in FASD, attention has been defined separately. Deficits in inhibition, impulse control or hyperactivity should be considered in the executive function, impulse control and hyperactivity area of assessment rather than the attention area of assessment.
	Direct assessment	Severe impairment in attention is present on *direct* assessment when *two or more subtest scores are below the clinical cut-off* on continuous performance tests or other neuropsychological measures of selective, divided, alternating or sustained attention. Examples of standardised tests: - Conner's Continuous Performance Test: 3rd Ed; 8–60+ years - Test of Everyday Attention for Children (Tea-CH); 6–16 years - Delis-Kaplan Executive Function System (DKEFS), ie Trail Making Test, Colour/Word Interference; 8–89 years - Developmental Neuropsychological Assessment (NEPSY-II), Attention subtests; 3–16 years - Children's Colour Trails Test; 8–16 years - Adult Colour Trails Test; 18–89 years.

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7. Attention continued	**Indirect assessment**	Severe impairment in attention by *indirect* assessment is present when *two or more assessments provide converging evidence of impairment*, eg: • clinical interview by different professionals • scores at or below the clinical cut-off on standardised observer rating scales, eg Connors 3 (parent, teacher or self report) • file review • direct clinical observation during neurodevelopmental testing. Examples of standardised rating scales: - Conners 3rd Edition (Conners 3); 6–18 years - Conners Adult ADHD Rating Scales (CAARS); 18–50+ years - Achenbach school-age scales - Child Behaviour Check List (CBCL), Teacher Report Form (TRF), Youth-Self Report (YSR); 6–18 years - Conners Comprehensive Behaviour Rating Scales (CBRS); 6 years–17 years 11 months.
	Considerations	A diagnosis of ADHD based on DSM-5 criteria (either inattentive or combined presentation) fulfils criteria for severe impairment in the attention area of assessment. Valid direct or indirect assessment methods and cut-offs should be used to make this diagnosis. ADHD hyperactive-impulsive presentation contributes to impairment in the executive function, including impulse control and hyperactivity area of assessment. Direct tests of attention which are part of testing in other domains (eg WISC, memory testing) can be used as evidence of impairment. When indirect and direct tests of attention do not concur, clinical judgment is required to determine whether severe impairment exists. Consideration that indirect assessment may better reflect attention deficits in real life situations (eg at work or in school) may be pertinent.
8. Executive function, including impulse control and hyperactivity	**Definition**	**Executive function** refers to a set of higher-level skills involved in organising and controlling one's own thoughts and behaviours in order to fulfil a goal with maximum efficiency. For the purposes of FASD assessment criteria, the executive function area of assessment includes impulse control and inhibition response, hyperactivity, working memory, planning and problem solving, shifting and cognitive flexibility. While in many definitions and theories of brain function attention overlaps with some of the executive functions, they have been defined separately for assessment purposes in FASD. **Impulse control** deficits are characterised by actions without forethought, which often have potential for harm to self or others. **Hyperactivity** is characterised by inappropriate and excessive levels of motor activity or speech.

Executive function, including impulse control and hyperactivity continues on page 8

8. Executive function, including impulse control and hyperactivity continued	**Direct assessment**	Severe impairment in executive function and/or impulse control by *direct* assessment is present when *at least two or more subtest scores below the clinical cut-off* are obtained on neuropsychological measures of executive function (which often assess impulse control). Examples of standardised assessment tools: - Behavioural Assessment of the Dysexecutive Syndrome in Children (BADS-C); 7–16 years - Developmental Neuropsychological Assessment (NEPSY-II) Executive Functioning sub-tests; from 3–16 years - Delis-Kaplan Executive Function System (DKEFS); from 8–89 years - Rey-Osterrieth Complex Figure (ROCF)
	Indirect assessment	Severe impairment in executive function and/or impulse control by *indirect* assessment is present when a *clinical assessment provides converging evidence of impairment from multiple sources,* including scores at or below the clinical cut-off on standardised rating scales and supporting evidence from clinical interview, file review and direct clinical observation during neurodevelopmental testing. Examples of standardised rating scales: - Behavior Rating Inventory of Executive Function (BRIEF-II); 5–18 years - Comprehensive Executive Function Inventory (CEFI); 5–18 years - Frontal Systems Behaviour Scale (FrsBe); 18–95 years. *Hyperactivity* is measured on rating scales which also measure attention problems, as listed for *indirect* assessment in the attention area of assessment (eg Conners 3).
	Considerations	Assessment may show a discrepancy between *direct* and *indirect* tests in this area of assessment due to the varying conceptualisations of executive function and related tests. In the situation where *indirect* tests show impaired scores but direct tests scores are normal, significant weight should be given to the *indirect* assessments, as they are a more valid measure of functional brain impairment in this area. Hence, if two or more standardised rating scales (eg observer and self report or two observers) are below the clinical cut-off, then the executive function, impulse control and hyperactivity area of assessment is considered severely impaired.

9. Affect regulation	**Definition**	**Affect regulation** includes mood and anxiety disorders.
	Direct assessment	Not possible
	Indirect assessment	Severe impairment in affect regulation by *indirect* assessment is present when an individual meets the ICD-10 criteria for any of the following: • recurrent depressive disorder • separation anxiety disorder, elective mutism, social phobia, panic disorder, agoraphobia, or generalised anxiety disorder • mixed anxiety disorders or mixed anxiety and depressive disorder • conduct disorder or oppositional defiant disorder. Clinicians should formally ascertain that the individual meets criteria rather than assign a diagnosis on the basis of clinical impression or data from rating scales alone. Standardised rating scales which may assist diagnosis include: - Spence Children's Anxiety Scales (SCAS); 8–15 years - Behaviour Assessment System for Children-III; 2–21 years - Beck Youth Inventories, 2nd Edition (BYI-II); 7–18 years - Children's Depression Inventory 2 (CDI-2); 7–17 years - Multidimensional Anxiety Scale for Children 2nd Edition (MASC 2).
	Considerations	Care should be taken to document longstanding dysregulation rather than a short-term response to unfavourable life events or environmental conditions (eg multiple foster placements).
10. Adaptive Behaviour, Social Skills, or Social Communication	**Definition**	**Adaptive behaviour** is defined as the life skills which enable an individual to live independently in a safe and socially responsible manner, and how well they cope with everyday tasks. These include: • *conceptual* skills – language, reading, writing, maths, reasoning, knowledge, and memory • *social* skills – empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships • *practical* skills – self-management in areas such as personal care and daily living skills, job responsibilities, money management, recreation, and organising school and work tasks. **Social communication** is a critical component of adaptive function but can be assessed separately.

Adaptive Behaviour, Social Skills, or Social Communication continues on page 10

10. Adaptive Behaviour, Social Skills, or Social Communication continued	**Direct assessment**	Severe impairment in social communication by *direct* assessment is present when a *composite score measuring social language, social communication skills or pragmatic language skills is below the clinical cut-off.* Examples of standardised assessment tools for individuals >6 years of age: - The Social Language Development Test – Elementary (SLDT-E); 6 years–11 years 11 months - The Social Language Development Test – Adolescent (SLDT-A); 12 years–17 years 11 months.
	Indirect assessment	Severe impairment in adaptive behaviour, social skills or social communication by *indirect* assessment is present when, according to a standardised interview or rating scale completed by a key informant a: • *composite score* is below the clinical cut-off, or • a *major subdomain score* is below the clinical cut-off. For children and most adolescents, standardised observer rating scales for adaptive function (typically for caregiver and/or teacher) should be used, although this may not be possible, eg for a child in detention. Examples include: - Vineland Adaptive Behaviour Scales, 2nd Edition (VABS-II); birth–90 years - Adaptive Behaviour Assessment System (ABAS-III); birth–89 years - Behaviour Assessment System for Children–3 (BASC-3); 2–21 years - The Pragmatics Profile of Everyday Communication Skills in Children; 0–10 years - Children's Communication Checklist, 2nd Edition; child and adult versions available. Observation by a speech and language therapist of the individual interacting with their peers in institutional, school or family settings may also provide supporting evidence of impairment.
	Considerations	Severe impairment in social skills and social communication is present when on *formal testing an individual meets the DSM-5 criteria* for: • autism spectrum disorder • social (pragmatic) communication disorder. When an individual meets DSM-5 or ICD-10 criteria for conduct disorder and/or severe oppositional defiant disorder, this provides supporting evidence for impairment in the adaptive behaviour, social skills or social communication area of assessment however the individual still needs to meet other criteria demonstrating severe impairments in multiple aspects of social, practical and conceptual function (eg on Vineland Rating Scales).

Adaptive Behaviour, Social Skills, or Social Communication continues on page 11

10. Adaptive Behaviour, Social Skills, or Social Communication continued	Considerations continued	**Older adolescents and adults** For older adolescents or adults, a standardised, indirect rating scale for adaptive behaviour is preferred wherever possible and may be required for eligibility for some services and financial support. Alternative assessment methods may be required for people living alone or in an institutional setting who have not had a consistent caregiver or partner within the last two years who can act as an informant. For example, assessment of *adaptive function* may involve structured interview, observation of self-care and living skills, or use of historical records. Severe impairment is based on clinical judgement that deficits are sufficiently severe to fall below clinical cut-off. This might include: • documented inability to function in key aspects on independent living (eg inability to manage money, maintain a household of reasonably safety and cleanliness, obtain/maintain a job, uphold personal hygiene, exhibit socialisation/coping strategies, care for children) • documented difficulty in social competence (eg being financially victimised or unintentionally involved in criminal behaviour due to social gullibility; chronic inability to participate successfully in group treatments and/or group home placements). For *social communication* assessment, a direct, age-appropriate measure should be used with the client, in combination with reports and historical information. Cultural and linguistic considerations should be applied if relevant, and testing and interpretation altered accordingly.

Information about Genetic Testing

Genetic testing is required to rule out other potential causes of the neurodevelopmental and behavioural presentation. In other words, prior to diagnosing FASD (where the cause of the neurodevelopmental and behavioural presentation would primarily be considered as prenatal alcohol exposure), genetic testing is typically advised, as genetic abnormalities could also account for many neurodevelopmental presentations.

Whilst the exact test completed and the sophistication of genetic assessment has changed with time, recent advice from Clinical Genetics colleagues advising the FASD clinic is to conduct a **CGH microarray.** This is the best level of test to undertake when looking for other possible explanations for the presentation. Genetic screening referrals should be made based on national testing guidance, criteria R377, which are the criteria recommended for unexplained autism or intellectual disability. There may be other genetic tests available in some localities (e.g., whole genome) which can also be used.

A GP can refer to a Clinical Geneticist asking for an assessment to review a possible genetic cause of the presenting neurodevelopmental difficulties (citing parental alcohol exposure and other possible known causes). GPs cannot refer directly for a CGH microarray test however direct referrals to the local Genetics hub can be made by Clinical Geneticist, Paediatrician, Neurologist, or Psychiatrist to rule out genetics as a potential cause. Local genetics services are centrally funded by the NHS. The national genomic testing service is delivered through a network of seven Genomic Laboratory Hubs (GLHs), each responsible for coordinating services for a particular part of the country. The seven GLHs are:

- Central and South Genomic Laboratory Hub led by Birmingham Women's and Children NHS Foundation Trust - West Midlands Regional Genetics Laboratory at Birmingham Women's Hospital | Birmingham Women's and Children's (bwc.nhs.uk)
- East Genomic Laboratory Hub led by Cambridge University Hospitals NHS Foundation Trust - Genomics Laboratory | CUH
- North West Genomic Laboratory Hub led by Manchester University NHS Foundation Trust - North West Genomic Laboratory Hub - Manchester University NHS Foundation Trust (mft.nhs.uk)
- North Thames Genomic Laboratory Hub led by Great Ormond Street Hospital for Children NHS Foundation Trust - About – North Thames Genomic Laboratory Hub (norththamesglh.nhs.uk)
- South East Genomic Laboratory Hub led by Guy's and St Thomas' NHS Foundation Trust https://southeastgenomics.nhs.uk/
- South West Genomic Laboratory Hub led by North Bristol NHS Trust - South West Genomic Laboratory Hub | North Bristol NHS Trust (nbt.nhs.uk)
- North East and Yorkshire Genomic Laboratory Hub led by The Newcastle upon Tyne Hospitals NHS Foundation Trust Genomic Laboratory Hub Services - NHS North East and Yorkshire Genomic Medicine Service (ney-genomics.org.uk)

In the case where genetics results are atypical, but the genetic variation is not associated with a neurodevelopmental and behavioural presentation similar to FASD, a referral may still be indicated and in this instance please contact the clinic with enquiries prior to referral. **Please note, genetic testing results are to be sent to the clinic once they are known.**