Australian Guide to the diagnosis of FASD

Updated February 2020

Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)

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Contents

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Foreword

In 1973, the term *Fetal Alcohol Syndrome* (FAS) was used by Jones and Smith to describe a group of children born to 'alcoholic' mothers, who had characteristic facial anomalies and poor prenatal and/or postnatal growth and who later exhibited problems with development and learning. (1) Some had microcephaly and some had other structural birth defects. (1)

By 2000 it was recognised that alcohol exposure in utero may result in neurodevelopmental problems in the absence of facial and other physical features and the term *Fetal Alcohol Spectrum Disorder* (FASD) was coined. (2) Rather than a diagnosis, FASD was used as an 'umbrella' term to encompass the diagnostic categories of Fetal Alcohol Syndrome, partial Fetal Alcohol Syndrome, Alcohol-Related Neurodevelopmental Disorder and Alcohol-Related Birth Defects. (2) Over the years several guidelines have been produced internationally to assist clinicians in making a diagnosis of FASD. (3-7) Although they have many similarities, there is inconsistent use of diagnostic criteria, diagnostic terminology, methods of documenting prenatal alcohol exposure and cut-off points to determine impairment in growth and neurodevelopment.

Alcohol readily crosses the placenta and is teratogenic and no level of maternal consumption has been deemed 'safe' for the developing embryo and fetus. Furthermore, 'risk' is difficult to predict in the individual pregnancy, being modified by a number of maternal and fetal factors. (8, 9) In light of these facts, the *National Health and Medical Research Council of Australia* (NHMRC) advises that the safest option for women who are pregnant or planning a pregnancy is to avoid drinking alcohol. (10) **FASD is preventable**.

FASD occurs in all parts of Australian society where alcohol is consumed. It has lifelong consequences, is extremely costly to our health, education, disability and justice systems and the personal costs to families living with FASD are enormous. (11) Early recognition and early therapy will minimise the adverse outcomes often seen.

In Australia FASD is under-recognised and often goes undiagnosed, such that it is described as a 'hidden harm.' (12) Health professionals are often unaware of the diagnostic criteria, of how to diagnose FASD and where to refer for diagnosis or treatment. Many have not read the NHMRC national guidelines to reduce health risks from drinking alcohol and few routinely ask pregnant women about alcohol use in pregnancy. Some are concerned about stigmatising families through making a FASD diagnosis. (13, 14) Limited training opportunities for health professionals, the lack of a nationally adopted diagnostic instrument, confusion about diagnostic criteria and perceived lack of evidence-based treatments are persisting barriers to early diagnosis and appropriate management and prevention of FASD.

In 2010 we successfully tendered for funding from the (then) Australian Department of Health and Ageing to develop a FASD diagnostic instrument for Australia and a guide to its use. These were developed following a systematic literature review and evaluation of existing diagnostic guidelines, a consultative process with experts in the field and

consultation with community and advocacy groups. Three diagnostic categories were recommended: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (PFAS) and Neurodevelopmental Disorder-Alcohol Exposed (ND-AE). (15) During 2015, the instrument was trialled in clinical practices around Australia and deemed to be informative, useful and flexible.

However, just as the Australian instrument was finalised, a revised Canadian guide on the diagnosis of FASD was published (16), and so the Australian FASD Diagnostic Instrument was reviewed and modifications made. Specifically, we have adopted the concept that **Fetal Alcohol Spectrum Disorder** be used a diagnostic term. For a diagnosis of FASD, an individual must have prenatal alcohol exposure and severe neurodevelopmental impairment in at least three of ten specified domains of central nervous system structure or function. The overarching **diagnostic term of FASD** simplifies the terminology and emphasises the primary importance of the severe neurodevelopmental impairment that results from an acquired brain injury caused by alcohol exposure before birth. Within FASD are two sub-categories: **FASD with three sentinel facial features** (similar to the previous diagnostic category of Fetal Alcohol Syndrome); **and FASD with less than 3 sentinel facial features** (which encompasses the previous diagnostic categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed).

The Australian Diagnostic Instrument and the Guide to its use will give clinicians the confidence to consider a diagnosis of FASD, the knowledge to make the diagnosis and the information they need to manage or refer an individual and family and to take steps to prevent FASD.

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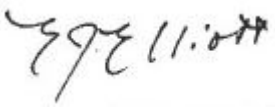

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Purpose

The Australian Guide to the Diagnosis of FASD was produced to assist clinicians in the diagnosis, referral and management of Fetal Alcohol Spectrum Disorder. It contains the ***Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Instrument*** and information about how to use the instrument. The instrument was developed to facilitate and standardise the diagnosis of FASD in Australia. It provides clinicians with diagnostic criteria for FASD, which were agreed following review of existing guidelines and consultation with clinical experts. The recommended Australian criteria are similar to criteria in recently published Canadian guidelines (16) and use clinical aids developed at the University of Washington to assess facial dysmorphology. (3)

The diagnosis of FASD is complex, and ideally requires a multidisciplinary team of clinicians to evaluate individuals for prenatal alcohol exposure, neurodevelopmental problems and facial abnormalities in the context of a general physical and developmental assessment. Alternative diagnoses must be considered, including genetic diagnoses and exposure to other teratogens. FASD may co-exist with these and other conditions. The impact on neurodevelopment of both physical and psychosocial postnatal exposures such as early life trauma must also be considered.

Diagnostic categories and criteria for FASD

A diagnosis of FASD requires evidence of prenatal alcohol exposure and severe impairment in three or more domains of central nervous system structure or function.

A diagnosis of FASD can be divided into one of two sub-categories:

i. FASD with three sentinel facial features

ii. FASD with less than three sentinel facial features

The diagnostic criteria are summarised in Table 1.

FASD with three sentinel facial features replaces the diagnosis of Fetal Alcohol Syndrome, but without a requirement for growth impairment. FASD with less than three sentinel facial features encompasses the previous categories of Partial Fetal Alcohol Syndrome and Neurodevelopmental Disorder-Alcohol Exposed). (15)

The aetiological role of alcohol is most clearly established in the presence of all three characteristic facial abnormalities. In this situation a diagnosis of FASD with three sentinel facial features can be made even when prenatal alcohol exposure is unknown(3), provided there is also severe neurodevelopmental impairment.

Table 1 Diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder (FASD)

FETAL ALCOHOL SPECTRUM DISORDER		
Diagnostic criteria	**Diagnostic categories**	
	FASD with 3 Sentinel Facial Features	FASD with < 3 Sentinel Facial Features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains - Brain structure/Neurology - Motor skills - Cognition - Language - Academic Achievement - Memory - Attention - Executive Function, including impulse control and hyperactivity - Affect Regulation - Adaptive Behaviour, Social Skills or Social Communication	Severe impairment in at least 3 neurodevelopmental domains	Severe impairment in at least 3 neurodevelopmental domains
Sentinel facial features - Short palpebral fissure - Smooth philtrum - Thin upper lip	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

Key components of the FASD diagnostic assessment include documentation of:

- History – presenting concerns, obstetric, developmental, medical, mental health, behavioural, social
- Birth defects – dysmorphic facial features, other major and minor birth defects;
- Adverse prenatal and postnatal exposures, including alcohol
- Known medical conditions – including genetic syndromes and other disorders
- Growth

Infants and young children under 6 years of age and older adolescents and adults warrant special consideration during the FASD diagnostic assessment process. (16) There are also circumstances where an individual may be considered to be 'at risk' of FASD. These special clinical considerations are discussed in detail in Section B: Neurodevelopmental Impairment.

Figure 1: Diagnostic algorithm for Fetal Alcohol Spectrum Disorder (FASD)

[a] Assessment fully completed and other diagnoses have been considered. Currency of assessment is also assumed. For infants and children under 6 years of age, *severe* Global Developmental Delay meets criteria for neurodevelopmental impairment (in 3 or more domains) if it is confirmed on a standardised assessment tool (e.g. Bayley or Griffiths).

[b] In the presence of confirmed PAE, reassessment of neurodevelopmental domains can be considered as clinically indicated (e.g. if there is a decline in an individual's functional skills or adaptive behaviour over time).

[c] In infants and young children under 6 years of age with *microcephaly and all 3 sentinel facial features*, a diagnosis of FASD with 3 Sentinel Facial Features can be made, *whether PAE is confirmed or unknown,* even without evidence of severe neurodevelopmental impairment in 3 domains based on standardised assessment. Nonetheless, in these children, concerns about neurodevelopmental impairment are likely to be present and should be documented.

Modified from Cook Fig 1. (16) (with permission from the publisher)

Diagnostic assessment

To assess an individual with prenatal alcohol exposure and/or suspected FASD, the following *essential* criteria must be considered:

1. **Maternal alcohol use and other exposures (see Section A)**
2. **Neurodevelopmental impairment (see Section B)**
3. **Facial and other physical features (see Section C)**

Alternative diagnoses that might explain neurodevelopmental impairment must be excluded, including genetic diagnoses, exposure to other teratogens and both physical and psychosocial postnatal exposures such as early life trauma. FASD may, however, co-exist with other conditions.

The multidisciplinary diagnostic team

Ideally, the diagnostic assessment for FASD is conducted by a multidisciplinary team to enable accurate assessment of the range of outcomes that may be associated with prenatal alcohol exposure. (17) A small number of specialist FASD clinics are currently operating in Australia and have a multidisciplinary team conducting the diagnostic assessment. https://www.fasdhub.org.au/services/.However these clinics are few in number and where multidisciplinary teams are not available, assessments may be conducted across a range of clinical settings over a period of time.

Clinicians participating in a diagnostic assessment may include, but are not limited to: a paediatrician, psychologist, speech and language pathologist and an occupational therapist. This will depend on a range of factors including the patient's age, the availability of qualified clinicians in the geographical location and the nature of the suspected disabilities. The assessment process may be confronting and the individual, their caregiver and family, should receive appropriate practical and psychological support.

The Australian FASD Diagnostic Instrument contains:

- Australian FASD Diagnostic Assessment Form (Appendix A1)

  A form to assist in conducting an assessment and recording the information required to diagnose FASD according to the Australian diagnostic criteria. Use of this form is recommended during the assessment of individuals for FASD. A coordinating clinician may collate the information onto the form from the multidisciplinary assessments.

- Australian FASD Diagnostic Assessment Summary Form (Appendix A2)

  A form to summarise the essential information required for diagnosis.

- Australian FASD Management Plan Form (Appendix A3)

  A form on which to record parent, caregiver and patient goals, referrals and intervention and support strategies.

The FASD Diagnostic Assessment Form, Summary Form and Management Plan Form can be downloaded and completed in hard-copy or electronically (Adobe Acrobat). https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/

- Information on FASD diagnostic assessment for individuals and caregivers (Appendix A4)

  Information about the diagnostic assessment process for individuals and caregivers prior to the diagnostic assessment.

- Australian FASD Diagnostic Assessment Consent Form (Appendix A5)

  It is recommended that clinicians seek informed consent prior to conducting a diagnostic assessment.

- Information for clinicians (Appendix A6)

  Includes issues that individuals and their caregivers may experience during the FASD diagnostic assessment and of which clinicians should be aware.

- Information for individuals and caregivers after a diagnostic assessment (Appendix A7)

  Provides information and resources for individuals and caregivers after a diagnostic assessment, including formulation of the management plan and referrals to therapy and other support services.

- Information for clinicians after a diagnostic assessment (Appendix A8)

  Provides information and resources for clinicians to support individuals and their caregivers after a diagnostic assessment.

- Referral and screening guidelines for FASD (Appendix A9)

Section A: Assessing maternal alcohol use

The timing, frequency and quantity of prenatal alcohol exposure (PAE) are linked to the pattern and severity of fetal outcomes, but may not be available or reliable. (4, 18-21) In addition, both maternal and fetal characteristics are associated with variability in alcohol-related outcomes. Brain growth and development occur throughout pregnancy hence **adverse cognitive, behavioural and neurodevelopmental outcomes may result from exposure *at any time during pregnancy* and may occur in the absence of facial anomalies or structural central nervous system abnormalities**. (22)

It is likely that multiple mechanisms are involved in damage to the brain from PAE and **no 'safe' threshold for alcohol consumption during pregnancy has been established**. (23) Although there is limited evidence associating low levels of prenatal alcohol exposure with risks to human fetal development, (24) the Australian Guide to Reduce Health Risks for Drinking Alcohol(10) states that maternal alcohol consumption can harm the developing

fetus and recommends that *for women who are pregnant or planning a pregnancy, not drinking is the safest option.* (10)

The level of risk to the fetus from prenatal alcohol exposure is highest when there is high, frequent maternal alcohol intake. The level of risk for the fetus is likely to be low if a woman has consumed only small amounts of alcohol (such as one or two drinks per week) before she knew she was pregnant or during pregnancy. (10)

A diagnosis of FASD is not appropriate where there is *confirmed absence* of prenatal alcohol exposure, but a diagnosis of FASD with three sentinel facial features can be made when prenatal alcohol exposure is unknown (see Table 1). (3)

Assessment of prenatal alcohol exposure requires clinical judgement and careful evaluation of a range of information that may provide confirmation of maternal alcohol use and allow quantification of intake.

Evidence of confirmed prenatal alcohol exposure may include:

- Information reported by the birth mother about her alcohol consumption during the index pregnancy, ideally using a validated tool;
- Reports by others, including a relative, partner, household or community member who had direct observation of drinking during the index pregnancy; or
- Documentation in child protection, medical, legal or other records of maternal alcohol consumption, alcohol-related disorders, and problems directly related to drinking during the index pregnancy, including alcohol-related injury and intoxication.

Assessing the reliability of evidence:

- If recalled information from different informants is in direct conflict (confirmed absence and confirmed presence) and reliable information on exposure is not available, alcohol exposure should be recorded as unknown. (4)
- The reliability of information on prenatal alcohol exposure may reflect the timing of pregnancy awareness.
- A history of alcohol dependence *without evidence of consumption during the index pregnancy is not sufficient to indicate confirmed exposure* but should raise suspicion of risk. (3, 4)

Alcohol Use Disorders Identification Test - Consumption (AUDIT-C)

When detailed information on maternal alcohol use is available, consumption during pregnancy should be assessed using the AUDIT-C questions(25) as included on the *Australian FASD Diagnostic Assessment Form* (Appendix A1) and reproduced in Table 2.

The AUDIT-C questions provide a standardised method for the assessment of maternal alcohol use and are based on a validated sex-specific version of the instrument.(26, 27) The use of a sex-specific threshold of *5 or more drinks on one occasion for question 3 of the AUDIT-C* reflects known levels of maternal alcohol consumption associated with increased risk of FASD and other harms.(10, 28, 29) Five or more drinks on an occasion (consumption of 50+ g of alcohol) is sometimes referred to as a binge.(29)

Derivation of the AUDIT-C score, although not essential for diagnosis, allows the clinician to categorise the **level of fetal risk associated with maternal drinking**.

Information on the definition of a standard drink for different types of alcoholic drinks should be provided prior to using the AUDIT-C. Appendix B shows standard drink sizes for commonly consumed drinks. A complete guide is available at: https://beta.health.gov.au/health-topics/alcohol/about-alcohol/standard-drinks-guide

Some guiding principles for taking an alcohol history in pregnancy:

A non-judgemental approach is important when taking a history of alcohol consumption in pregnancy.

Some factors to consider:

- A pregnancy may be unplanned and not confirmed for some time, during which time alcohol may have been consumed.
- A woman may have made lifestyle changes once the pregnancy was confirmed, including reducing or stopping alcohol consumption.
- A woman may be unaware that not drinking during pregnancy is the 'safest' option and may have been given incorrect advice by other health professionals.
- Women may be more likely to drink if their partner and household members also drink and this may be explored.

Some questions to begin history taking:

- Was the pregnancy planned or unplanned?
- When did the birth mother realise that she was pregnant?
- Did the birth mother modify her drinking behaviour on confirmation of pregnancy?
- Were there any special occasions (e.g. a wedding) during pregnancy when alcohol was consumed at a high level?

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. The definition of a standard drink should be explained prior to administering the AUDIT-C (Q1-3), using the Standard Drinks Guide (Appendix B).

Table 2 Reported alcohol use, including AUDIT-C Questions

Alcohol use in early pregnancy (if available)

Was the pregnancy planned or unplanned? ☐ Planned ☐ Unplanned ☐ Unknown

When did the birth mother realise that she was pregnant? _____ (weeks) ☐ Unknown

Did the birth mother drink alcohol before the pregnancy was confirmed? ☐ Yes ☐ No ☐ Unknown

Did the birth mother modify her drinking behaviour on confirmation of pregnancy? ☐ Yes ☐ No ☐ Unknown
If Yes please specify:

During which trimesters was alcohol consumed? (tick one or more) ☐ None ☐ 1st ☐ 2nd ☐ 3rd ☐ Unknown

AUDIT-C questions

Source of reported information on alcohol use: ☐ Birth mother ☐ Other (please specify)

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 standard drinks 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 5 or more standard drinks 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 this pregnancy: (Q1+Q2+Q3)=_____ Scores= 0=no exposure 1-4= confirmed exposure 5+= confirmed high-risk exposure

Assessing prenatal alcohol exposure: Summary

Assessment of prenatal alcohol exposure requires clinical judgement and careful evaluation of a range of information that may provide confirmation of maternal alcohol use and quantification of intake.

Evidence of exposure can be evaluated to estimate the overall level of risk using the following broad risk categories:

i. **No exposure** (confirmed absence), no risk of FASD;
ii. **Unknown exposure** (alcohol use is unknown);
iii. **Confirmed exposure** (AUDIT-C score =1-4; or confirmed use, but exposure less than high risk level for FASD; or confirmed use, but not known if exposed at a high risk level for FASD); and
iv. **Confirmed-high risk exposure** (AUDIT-C score = 5+; confirmed use, exposure at high risk level for FASD).

Confirmed high risk exposures for FASD can be considered to include, at any time during pregnancy:

i. An AUDIT-C score of **5 or more**
ii. Reported consumption of **5 or more standard drinks on one occasion** (e.g. AUDIT-C question 3)
iii. Other reliable evidence of high consumption

Other prenatal and post-natal exposures

Neurodevelopment impairment observed among individuals being assessed for FASD may be associated with exposures other than alcohol. It is important to determine whether any observed impairments can be explained by other causes or events (e.g. prenatal complications, genetic factors including chromosomal abnormalities, head injuries, early life trauma (including social and emotional abuse), problems with vision or hearing, or substance abuse by the patient).

All relevant prenatal and postnatal exposures or events, including prenatal exposure to prescription and non-prescription drugs, should be documented during the diagnostic assessment, and evaluated based on their likely influence. Other exposures should be considered when determining the appropriate diagnosis and management plan.

There may not be a single explanation for the observed neurodevelopmental impairment, and it is important that the diagnostic assessment process considers the effects of other adverse prenatal and postnatal exposures. (3)

In addition to vision and hearing testing, other clinically indicated investigations may include chromosome microarray analysis and Fragile X testing, and other tests such as full blood count, ferritin, vitamin B_{12}, metabolic screen, creatinine kinase, lead, and thyroid function.

Section B: Assessing neurodevelopmental impairment

Introduction

Exposure of the fetal brain to alcohol can cause a range of structural brain abnormalities, neurological problems and functional neurodevelopmental deficits. These can result from prenatal alcohol exposure (PAE) at *any* time during the pregnancy and may be present in the absence of facial dysmorphology, which is associated with first trimester exposure.

Domains of neurodevelopment (16)

In FASD, ten domains of neurodevelopment have been identified that reflect areas of brain function known to be affected by PAE, based on evidence from human and animal research and clinical experience. These are as follows and should be assessed as part of the diagnostic evaluation for FASD:

1. Brain Structure/Neurology
2. Motor skills
3. Cognition
4. Language
5. Academic Achievement
6. Memory
7. Attention
8. Executive Function, including impulse control and hyperactivity
9. Affect Regulation
10. Adaptive behaviour, Social Skills or Social Communication

A FASD diagnosis requires objective evidence of *severe impairment* of brain function in *at least 3* of these 10 specified neurodevelopmental domains. The rationale for this is that PAE may cause widespread fetal brain injury and result in pervasive brain dysfunction.

Patterns of neurodevelopmental impairment in individuals with PAE are complex and diverse. There is no typical pattern of impairment in FASD, most likely due to differences in the timing and level of PAE and genetic and environmental factors that influence maternal blood alcohol level and brain development.

Evidence of severe impairment in 3 or more domains should be attributed to prenatal alcohol exposure only when other possible aetiological factors have been considered.

Criteria for severe impairment in neurodevelopmental domains:

*The **'clinical cut-off'** for **severe impairment*** is defined either as a *global score or a major subdomain* score on a standardised validated neurodevelopmental scale that is 2 or more standard deviations below the mean (≤2 SD) *or* less than the 3rd percentile (<3rd PC). The

specific criteria for impairment in each domain and examples of standardised tests that may be used in assessments are shown in Table 3.

Assessment process

Assessment of neurodevelopmental domains includes:

- Measurement of occipitofrontal head circumference (OFC)
- Neurological examination
- Developmental assessment, typically by a multidisciplinary team involving:
    - Clinical history taking which includes interviewing caregivers to identify the reasons for presentation, individual's strengths and weaknesses, and developmental, family, psychosocial and medical history
    - Review of maternal, birth, child medical and other e.g. child protection records
    - Clinical observation
    - Use of standardised rating scales and psychometric assessment tools and application of diagnostic criteria (Australian Diagnostic Criteria for FASD)
- Review results of relevant investigations – e.g. Brain MRI or genetic screening

Testing typically involves *direct* and *indirect* assessment

- **Direct assessment** uses standardised tests that *directly* measure brain structure or neurodevelopmental skills (e.g. verbal reasoning on cognitive assessment, expressive language skills on standardised language assessment). When available, standardised assessment tools should be used that are appropriate for the age, developmental or educational level of the child, and their cultural and linguistic background.
- **Indirect assessment** uses a combination of clinical observation or examination, and evidence from multiple sources and/or standardised observer or self-report rating scales to measure the *functional manifestations* of neurodevelopmental impairment (e.g. parent and teacher rating scales to measure inattention or adaptive behaviour, and observation to assess quality of social communication during play).
- Direct assessment is preferred; however, in assessing some domains (e.g. Attention) a combination of *direct* and *indirect* assessment can be used. Use of *indirect* assessment alone is indicated when standardised tests are not available (e.g. when using DSM-5 (30) diagnostic criteria to document depression and anxiety for the *Affect regulation* domain)
- The clinician should combine all available evidence, from both direct and indirect assessments, to determine whether or not an individual meets severe impairment for a specific domain. For example a low score on the Beery VMI (31) (direct assessment) and the Vineland motor scale (32) (indirect assessment of motor skills obtained during assessment of adaptive function) provide converging evidence for impairment in the domain of *Motor skills.*

Other considerations regarding FASD assessment

Ideally assessment is performed by a multidisciplinary team that includes a paediatrician or adolescent physician and psychologist with any combination of speech pathologist, occupational therapist, social worker and physiotherapist depending on availability of trained professionals. Referral to a psychiatrist, clinical geneticist or neurologist may be required if clinically indicated.

Few specialised diagnostic clinics for FASD exist in Australia and most children are diagnosed in child development clinics or by individual developmental, general and community paediatricians. Clinicians without access to a multi-disciplinary team play an important role in history taking, physical examination, and referral for allied health and psychological assessments, and in collating results, applying diagnostic criteria and coordinating ongoing care.

The diagnosis of FASD does *not* necessarily require assessment of all domains. Assessment should be prioritised according to the individual's functional difficulties, age and capacity for testing, given local resources. We recommend that adaptive function is assessed in all individuals (*Adaptive Behaviour, Social Skills or Social Communication* domain)*. (16)* Even when three domains are found to be impaired, testing of other domains is encouraged when there are clinical concerns. This will assist clinicians to fully identify the individual's strengths and needs and to develop appropriate recommendations for management, referral and intervention.

The assessment describes an individual profile of current neurodevelopmental function and thus ideally most domains should be assessed concurrently. However, according to the psychometric properties of each standardised assessment tool, *previous* assessments may be valid for inclusion and may not require repetition. For example, most measures of intellectual functioning such as the Wechsler scales (33-35) have valid test-retest reliability for a period of up to 2 years and should not be re-administered within this time frame due to the influence of the "learning effect" on subject responses and scores. As a general rule, any direct or indirect assessment including clinical diagnoses can be considered "current'' if it has been made *within the last 2 years* (depending on test properties). Clinical judgement is required to ensure that past assessments or diagnoses are valid and meet criteria for impairment.

Apart from PAE, a range of prenatal or postnatal exposures and existing genetic, medical or mental health conditions may contribute to neurodevelopmental impairment and should always be considered in the diagnostic formulation. These include intrauterine infection, extreme prematurity (prenatal), hearing or visual impairment, head injury, early life trauma and CNS infection (postnatal).

FASD may be associated with a wide range of co-morbidities. (36) These include:

- Developmental and behavioural conditions e.g. Language disorders, ADHD, anxiety disorders, Autism Spectrum Disorder
- Genetic (chromosomal) abnormalities
- Congenital malformations

These factors may co-exist with FASD, thus FASD is not necessarily a diagnosis of exclusion. From a clinical perspective, pre-existing diagnoses such as ADHD should be reviewed and documented as part of the FASD diagnostic assessment as they may contribute to impairment. This includes obtaining *current* observations, reports and information from rating scales.

Cultural and linguistic considerations

Assessment of neurodevelopmental impairment must take into consideration the *linguistic and cultural background* of the child, adolescent or adult being assessed, as well as their educational experience within the schooling system. This includes ensuring *cultural safety* in the assessment process and a process of seeking *informed consent* that is culturally and linguistically appropriate. This may be achieved using verbal or written communication and may require an interpreter or cultural consultant or liaison officer. The process and implications of the assessment, the regard for confidentiality and restricted access to the results, and the way results will be used should be discussed with families. This is critical for all individuals undergoing assessment for FASD, but requires additional consideration when patients have diverse cultural or linguistic backgrounds.

Ideally, clinicians will have had *cultural awareness* training and have achieved a level of *competency* relevant to the family's background prior to the FASD assessment process. This will help maximise rapport and ensure awareness of relevant *familial, historical, social and legal factors* that may affect individual and family engagement with and performance during the assessment. This is particularly important for Australians who identify as Aboriginal and Torres Strait Islander because their current or prior experience with health care practitioners and researchers may impact on their willingness to engage in FASD assessment. Furthermore, intergenerational and current trauma, high rates of chronic stress, mental health disorders, social disadvantage and marginalisation and contact with legal system or incarceration affect many Indigenous communities. These factors may impact on both neurodevelopment and interaction with the healthcare system. Clinicians should also be aware of ways in which their own cultural and linguistic backgrounds, beliefs and experiences may influence how they engage with individuals and families and conduct assessments.

Assessment strategies for people of diverse linguistic or cultural backgrounds might include use of:

- Appropriately trained interpreters during direct assessments to enable use of the individual's first or preferred language if possible.
- Psychometric tests that are untimed, non-verbal, do not rely on acquired knowledge, involve spatial processing and are not influenced by culture, particularly if they provide a practical context (e.g. use pictures). One example is the Universal Non-Verbal Intelligence Test (UNIT). (37)
- Observer reports or rating scales that are contextualised within the cultural or learning environment of both the patient and the observer.

- Specific professional guidelines regarding cross-cultural assessment, e.g. The Australian Psychological Society's *Guidelines for the provision of psychological services for Aboriginal and Torres Strait Islander people of Australia* (2003). (38)

Key definitions:

*The **'clinical cut-off'** for **severe impairment*** is defined either as a *global score or a major subdomain* score on a standardised validated neurodevelopmental scale that is*:*

- **2 or more standard deviations below the mean (≤2 SD) *or***
- **less than 3rd percentile (< 3rd PC)**

Considerations

- There should be appropriate allowance for test error.
- The 2 standard deviations cut-off is the usual standard for defining a severe level of impairment. For example, using DSM-5 (30) a diagnosis of Intellectual Disability requires scores of ≤ 2SD on tests of intelligence and adaptive functioning such as the Wechsler Intelligence Scale for Children-5th edition (WISC-V A&NZ) (35) and Vineland Adaptive Behaviour Scales - 2nd Edition (Vineland-2) (32) respectively.
- Some tests e.g. the Bruininks-Oseretsky Test of Motor Proficiency (BOT-2) (39), which is used for assessing motor skills, consider a score of less than1 standard deviation from the mean to be indicative of *clinically significant* impairment, though this would not qualify as a child as having *severe* impairment in this domain. In such situations, where significant functional impairment is evident although FASD criteria for severe impairment (≤2SD or <3rd PC) are not met, *it is critical to ensure adequate therapeutic supports are in place.*

Significant discrepancy

In some domains, severe impairment may be considered when there is a ***large discrepancy between subdomain scores,*** even if the global (overall) score is within 2 standard deviations of the mean. In this situation the clinical cut-off for severe impairment is defined by:

1. A ***statistically significant discrepancy between subdomain scores*** (i.e. a discrepancy seen in less than 3% of the population). This is calculated by the relevant clinician using scoring software provided with standardised neurodevelopmental tools.
2. The lower of the two discrepant scores is ***at least one standard deviation below the mean*.**

Note - This assumes that a discrepancy is both *clinically* and *statistically* significant according to the particular standardised scales being used. Each has their own cut-offs for what is considered a significant difference between scale scores (e.g. For WISC IV this is an Index score difference of 23). (38)

Clinical judgement

Clinical judgment should be used to determine whether severe impairment is present in the following situations:

a. When test data is inconsistent within a domain.
b. When a global score or major subdomain score is in the borderline range and/or within the standard error of measurement for cut-off.
c. When there is discrepancy between indirect and direct assessment measures or between observers (e.g. two clinicians, parents and teachers).

In these situations, the decision should be supported by clinical observation and history, preferably evidenced from two or more sources.

- A domain should not be considered impaired on the basis of a *single subtest score* from one assessment measure.
- Domains should be assessed as though they were *separate entities* and clinicians should not use a single test score as evidence of deficits in two domains, even when those domains are theoretically related (e.g. Verbal IQ cannot be used as evidence of impairment in domains of both language and cognition).

Inconclusive assessment

In some circumstances, a clinician may identify individuals who, despite having undergone assessment, fail to fulfil criteria for diagnosis for FASD at the current time, but may nevertheless potentially have FASD. Some example situations include:

- Neurodevelopmental assessment is incomplete or inconclusive.
- Despite confirmed PAE, neurodevelopmental impairment is present in fewer than three domains.
- Neurodevelopmental impairment is present in three or more domains, but impairment is not sufficiently severe to meet criteria.
- Comprehensive, age-appropriate neurodevelopmental assessment is impossible or unavailable e.g. in infants and young children.

These individuals may be considered ***'at risk of FASD'*** and ***require follow-up and reassessment***. In the diagnostic formulation the clinician should explain why the child is considered at risk but indicate that they do not currently meet diagnostic criteria.

Special considerations

Infants and Children under 6 years of age

Infants and children under 6 years of age represent a special group when being assessed for FASD. This is because:

- The developing brain has the capacity for change, related to brain plasticity and ongoing development of neural connections, in response to environmental and other factors (e.g. an adverse or stable caring environment).

- Assessment is more difficult and limited in scope compared to that available for older children e.g. assessment of executive function.
- Some functional manifestations of FASD may not become apparent until later in childhood e.g. problems with academic achievement or developmentally inappropriate behaviours that become progressively problematic in the school setting.

A diagnosis of FASD can be made in an infant or young child under the age of 6 years using the diagnostic algorithm (Figure 1) with the following considerations:

Neurodevelopmental Assessment

- Assessment of neurodevelopment should be made using age-appropriate standardised assessment tools, not just clinical assessment or observation. This will enable confirmation that neurodevelopmental skills are severely impaired at clinical cut-off level (≤2 SD or < 3rd pc).
- By definition, Global Developmental Delay constitutes impairment in 3 or more domains of neurodevelopment. For a FASD diagnosis, Global Developmental Delay must be *severe* as indicated on a standardised assessment (e.g. Bayley Scale of Infant and Toddler Development Third Ed (Bayley III) (40) or Griffiths Mental Development Scales – Extended Revised (GMDS-ER) (41).

Microcephaly

- In an infant or young child *with microcephaly and all 3 sentinel facial features, a diagnosis of FASD with 3 sentinel facial features can be made, whether* PAE is confirmed or unknown, even without evidence of severe neurodevelopmental impairment in 3 domains based on standardized assessment (42, 43). Nonetheless, in these children, concerns about neurodevelopmental impairment are likely to be present and should be documented accordingly. Children with microcephaly are at high risk of subsequent neurodevelopmental disorder: they should be monitored, and genetic testing should be considered.
- Infants and children under 6 years of age *without microcephaly* and with all three sentinel facial features who do not meet criteria for neurodevelopmental impairment are considered *'at risk of FASD',* whether PAE is confirmed or unknown. These children do not fulfil FASD diagnostic criteria and require follow-up and reassessment.

Older adolescents and adults

Special considerations in the assessment for FASD in adolescents and adults include:

- Changes in physical characteristics occur with age e.g. facial features.
- Obtaining information about the pregnancy (including prenatal alcohol exposure) and early childhood may be difficult.
- Adolescents/adults may require different types of assessment than children.

- Functional manifestations of FASD may differ in adolescents/adults e.g. problems with sexual behaviour, psychological and mental health, substance misuse, vocational training and employment, risk taking behaviour, independent living, and contact with the legal system.
- Social and family situation such e.g. living independently, in supervised residential care or detention, may impact on validity of testing using observer reports.

Evaluation of general and sexual health, substance use, protective factors and risk taking behaviour is important to assess the individual's overall health and wellbeing, and may provide supporting indirect evidence for impairment in FASD domains. For example, poor judgement and limited experiential learning may suggest impairment in executive functioning.

There are also some specific considerations when assessing the domain of *Adaptive behaviour, social skills or social communication* in older adolescents and adults. Please refer to Table 3.

Table 3: Neurodevelopmental domains: criteria for severe impairment

1. Brain Structure / neurology	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 PC or ≤2 SD o For premature infants OFC should be corrected for gestational age until 2 years of age ▪ **Structural brain abnormalities** known to be associated with prenatal alcohol exposure are shown on brain imaging[i] Examples include: o Reduction in overall brain size o Corpus callosum (agenesis, hypoplasia) o Cerebral cortex (reduced gyrification or anterior cingulated cortex surface area) o 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 e.g. 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 e.g. 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 (VMI). (44, 45)
	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 visuo-motor integration) *is/are below the clinical cut-off* (e.g. gross motor and fine motor skills can be scored separately using the BOT-2). (39) Examples of standardised tests: ○ Bruininks-Oseretsky Test of Motor Proficiency (BOT-2); (40) (gross motor and fine motor); 4y-6y. ○ Berry-Buktenica Development Test of Visual-Motor Integration (VMI); (32) (visual motor integration); 2y - adult. ○ BOT-2 (40) (gross motor and fine motor); 6y- 21y. ○ Movement Assessment Battery for Children 2nd Ed (Movement-ABC 2) (45) 3y- 16y 11m
	Indirect assessment	Clinical assessment may provide supporting evidence of severe impairment: e.g. report of problems with balance, coordination. Abnormal tone, reflexes, strength, soft neurological signs (46) 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 oral-motor function may be considered in combination with direct assessment of motor skills.

	Considerations	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 (≤2SD or <3rd PC) are not met. As therapeutic approaches differ significantly for different components of the motor domain (e.g. gross motor versus fine motor) it is preferential to use a motor assessment (e.g. BOT-2) (39) 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. Musculoskeletal based structural defects may also need to be considered for their impact on the motor domain e.g. 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. (47)
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* - e.g. full scale IQ <70; *or* ▪ a *major subdomain score below the clinical cut-off* e.g. for the WISC (34) 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) (34); 2y 6m - 7y 7m ○ Stanford-Binet Intelligence Scales (SB-5); (48) 2y - 85 y ○ Differential Abilities Scales (DAS-II) (49); 2y 6m - 17y 11m ○ Wechsler Non-Verbal Scale of Ability-II (WNV-II); (50) up to 21 y ▪ > 6 years ○ Wechsler Intelligence Scales for Children (WISC-V ANZ)(35); 6y - 16y 11m ○ Stanford-Binet Intelligence Scales (SB-5); (48); up to 85 y ○ Wechsler Adult Intelligence Scale (WAIS-IV) (35); 16 - 90 y ○ Differential Abilities Scales (DAS-II); (49); up to 17 y

		○ Universal Nonverbal Intelligence Test (non-verbal test) (37); 5 - 21y 11m ○ Wechsler Non-Verbal Scale of Ability (WNV); (50) 4 -21y ○ Naglieri Nonverbal Ability Test - Second Edition (NNAT-2) (51) 4 - 18 y
	Considerations	Individuals who fulfil criteria for an Intellectual Disability, by definition, typically will have impairment in 3 domains of neurodevelopment as defined for FASD criteria (e.g. 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* domain rather than in the *Cognition* domain. A test that is independent of language and culture may be appropriate for certain populations (see Cultural and Linguistic Considerations, Section B).
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 *2 or more scores below the clinical cut-off* on subtests assessing higher-level language skills (i.e. the integrative aspects of language such as narrative and complex comprehension abilities) Examples of standardised tests: ○ Clinical evaluation of language fundamentals (CELF-4);(52) 5y - 21y 11m ○ Pre-School Language Scales, 5th Ed (PLS-5); (53) birth - 7y 11m
	Considerations	This domain should be assessed as if it is a single entity.. It is inappropriate to use scores on verbal IQ sub-tests as a measure of *both* language and cognition. When possible, testing should be done in the individual's first language. Specific tests may be available e.g. for some Indigenous languages. 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.

		Problems with phonological awareness may impact on language and if present may contribute to impairment in this domain.
5. Academic Achievement	Definition	***Academic achievement*** includes skills in reading, mathematics, and/or literacy (including written expression and spelling).
	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) (54) 4y- adult ○ Woodcock–Johnson Achievement Test (WJAT-III) (55) 4y- adult
	Indirect assessment	The following information can be used as supporting evidence for severe impairment: ▪ The National Assessment Program Literacy and Numeracy (NAPLAN) test results (54) ▪ School semester reports with achievement levels
	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 i.e. mainstream versus educational support class and opportunity e.g. remote location, multi-lingual setting, new immigrant. Even if the Full Scale IQ is below 70 (indicating impairment of *Cognition)*, impairment can also be given in the domain of *Academic Achievement* as cognitive and academic skills do not necessarily directly correlate (e.g. some individuals with mild intellectual disability perform in the low average range academically). Both domains should be tested and considered separately. If an individual has a Specific Learning Disorder according to DSM-5 (30) 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 domain.

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) (55), Memory and Learning sub-tests; 3 - 16 years ○ Wide Range Assessment of Memory and Learning, 2nd Edition (WRAML-II); (56) 5 - 90 years ○ Children's Memory Scale (CMS), (57) 5 - 16 years
	Considerations	A deficit in *working memory* should be considered in the *Executive Function, including impulse control and hyperactivity* rather than *Memory* domain.
7. Attention	Definition	**Attention** has several components: i) *selective* attention (i.e. focusing on a particular stimuli) ii) *divided* attention (i.e. attending to 2 or more stimuli at the same time) iii) *alternating* attention (i.e. switching focus from one stimuli to another) iv) *sustained* attention (i.e. 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 domains for diagnostic purposes in FASD, attention has been defined separately. Deficits in inhibition, impulse control or hyperactivity should be considered in the domain of *Executive function, Impulse control and Hyperactivity* rather than *Attention*.
	Direct assessment	Severe impairment in attention is present on *direct* assessment when t*wo 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 (58); 8 - 60+ y ○ Test of Everyday Attention for Children (Tea-CH) (59); 6 - 16 y ○ Delis-Kaplan Executive Function System (DKEFS) (60) i.e. Trail Making Test, Colour/Word Interference; 8 - 89 y ○ Developmental Neuropsychological Assessment (NEPSY-II)(55), Attention sub-tests; 3 - 16 y ○ Children's Colour Trails Test (61) ; 8 - 16 y ○ Adult Colour Trails Test; (62) 18 - 89 y
	Indirect assessment	Severe impairment in attention by *indirect* assessment is present when *two or more assessments provide converging evidence of impairment* e.g.: ▪ clinical interview by different professionals ▪ scores at or below the clinical cut-off on standardised observer rating scales e.g. Conners 3 (parent, teacher or self-report) (58) ▪ file review ▪ direct clinical observation during neurodevelopmental testing Examples of standardised rating scales: ○ Conners 3rd Edition (Conners 3) (58); 6 - 18y ○ Conners Adult ADHD Rating Scales (CAARS) (63); 18 - 50+ y ○ Achenbach school-age scales - Child Behaviour Check List (CBCL), Teacher Report Form (TRF), Youth-Self Report (YSR) (64); 6-18y ○ Conners Comprehensive Behaviour Rating Scales (CBRS) (65); 6 - 17y 11m
	Considerations	A diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) based on DSM-5 criteria (30) – either *inattentive* or *combined* presentation - fulfils criteria for severe impairment in the domain of *Attention.* 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* domain. Direct tests of attention which are part of testing in other domains (e.g. 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 (e.g. 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 diagnostic criteria, the domain of *Executive Function* 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 diagnostic 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.
	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: ○ Developmental Neuropsychological Assessment (NEPSY-II) (55) Executive Functioning sub-tests – from 3 - 16 y ○ Delis-Kaplan Executive Function System (DKEFS) (60) – from 8 - 89 y ○ Rey-Osterrieth Complex Figure (ROCF) (66)
	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) (67); 5 – 18y ○ Comprehensive Executive Function Inventory (CEFI) (68); 5 - 18y

		○ Frontal Systems Behaviour Scale (FrsBe) (69);18 - 95 y *Hyperactivity* is measured on rating scales which also measure attention problems, as listed for *indirect assessment* in the *Attention* domain (e.g. Conners 3) (58).
	Considerations	A diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) – either combined or hyperactive-impulsive presentation - based on DSM-5 criteria (30), does <u>not</u> fulfil criteria for severe impairment in the domain of *Executive function, including impulse Control and hyperactivity Domain*. Additional evidence is required from other indirect and direct assessments to fulfil criteria for severe impairment. Assessment may show a discrepancy between *direct* and *indirect* tests in this domain 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 domain. Hence, if two or more standardised rating scales (e.g. observer and self-report or two observers) are below clinical cut-off, then the *Executive Function, Impulse Control and Hyperactivity* domain 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 DSM-5 (30) criteria for:* ▪ Major Depressive Disorder (with recurrent episodes) ▪ Persistent Depressive Disorder ▪ Disruptive Mood Dysregulation Disorder (DMDD) ▪ Separation Anxiety Disorder Selective Mutism, Social Anxiety Disorder, Panic Disorder, Agoraphobia, or Generalised Anxiety 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); (70) 8-15y ○ Behaviour Assessment System for Children-III (71); 2 - 21y ○ Beck Youth Inventories, 2nd Edition (BYI-II) (72)

		○ Children's Depression Inventory 2 (CDI-2), (73)7 – 17y ○ Multidimensional Anxiety Scale for Children 2nd Edition (MASC 2) (74)
	Considerations	Care should be taken to document longstanding dysregulation rather than a short-term response to unfavourable life events or environmental conditions (e.g. multiple foster placements). For the purpose of FASD diagnoses, children who meet criteria A to F for the Disruptive Mood Dysregulation Disorder may be considered to have impairment in this domain. This diagnosis cannot be formally made until children are >6 and <18 years of age and the onset of symptoms must occur before the age of 10 years.
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: (30) ▪ *Conceptual* skills - language, reading, writing, math, 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.
	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) (75); 6y - 11y11m ○ The Social Language Development Test – Adolescent (SLDT-A) (76); 12y - 17y11m
	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 e.g. for a child in detention. Examples include: ○ Vineland Adaptive Behaviour Scales, 2nd Ed (32) (VABS-II); birth - 90 y ○ Adaptive Behaviour Assessment System (ABAS-III); (77) birth - 89y ○ Behaviour Assessment System for Children – 3 (BASC-3) (77); 2 - 21 y ○ Pragmatic Language Observation Scale (PLOS) (78); 8 – 17y 11m ○ Children's Communication Checklist, 2nd Edition (79); child and adult versions available. ○ Clinical Evaluation of Language Fundamentals (CELF-4 Australian) (52) Pragmatics Profile; 5 - 21y 11m Observation by a speech pathologist of the individual interacting with their peers in institutional, school or family settings may also provide supporting evidence of impairment.
	Special considerations	Severe impairment in social skills and social communication is present when *on formal testing an individual meets the DSM-5 (30) criteria* for: ▪ Autism Spectrum Disorder ▪ Social (Pragmatic) Communication Disorder When individuals individual meet DSM-5 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* domain however the individual still needs to meet other criteria demonstrating severe impairments in multiple aspects of social, practical and conceptual function (e.g. on Vineland Rating Scales). In some older adolescents and adults, indirect assessment can be complicated and additional considerations apply (see below). **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 (e.g. 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 (e.g. 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. (see Cultural and Linguistic Considerations in Section B).

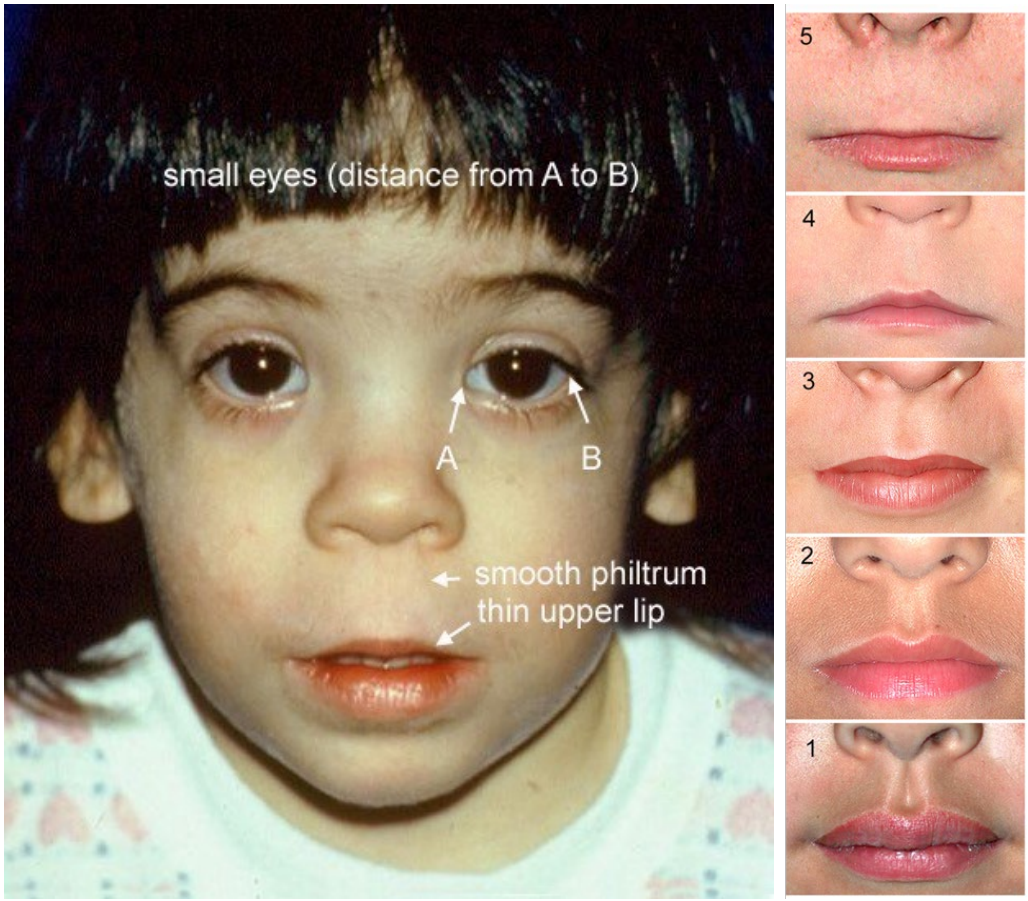
Section C: Assessing Sentinel Facial Features

Fetal exposure to alcohol during the first trimester affects development of facial features. The areas most affected are the orbital region (eyes) and mid-face. The effect of prenatal alcohol exposure on fetal brain growth is also thought to affect the size and shape of the face. A range of facial anomalies can occur as result of prenatal alcohol exposure.

There are three features which commonly occur across age, gender and ethnic groups:

- **Small palpebral fissures:** short horizontal length of the eye opening, defined as the distance from the *endocanthion* to the *exocanthion* (points A and B on photo below)
- **Smooth philtrum**: diminished or absent ridges between the upper lip and nose
- **Thin upper lip:** with small volume

These features are shown in the photo below.



(Photo reproduced with permission from Susan Astley, University of Washington)

Although these facial features may also occur independently as normal variations in the general population (unrelated to prenatal alcohol exposure), when seen ***in combination***, these facial features are **pathognomonic of and highly specific to prenatal alcohol exposure. *They are termed the 'sentinel' facial features of FASD***.

Facial anomalies are one of the three diagnostic criteria for FASD, together with prenatal alcohol exposure and neurodevelopmental impairment. A diagnosis of FASD may be made with or without facial features.

- A diagnosis of **FASD with three sentinel facial features** means that the individual has all 3 of the characteristic (or 'sentinel') facial features that have been associated with prenatal alcohol exposure.
- A diagnosis of **FASD with less than 3 sentinel facial features** means that the individual may have 0, 1 or 2 of the characteristic facial features

The University of Washington FAS Prevention and Diagnostic Network has developed criteria for FASD sentinel facial features:

- **Short palpebral fissure length** (PFL) 2 or more standard deviations below the population mean (or <3rd percentile). This equates to a z-score of -2 or more.
- **Smooth philtrum** – Rank 4 or 5 on the University of Washington Lip-Philtrum Guide
- **Thin upper lip** – Rank 4 or 5 on the University of Washington Lip-Philtrum Guide

Assessment can be using direct measurement and clinical examination and/or computerised analysis of a digital facial photograph (as described by Astley and Clarren (80, 81). Facial features may alter with age. Diagnosis should be based on the point in time when the features were most clearly expressed.

Further details regarding how to assess sentinel facial features are found in Appendix C.

Considerations regarding assessment of sentinel facial features

Palpebral fissure length (PFL)

PFL growth charts have been developed for populations overseas. In the absence of Australian reference data, we recommend using:

- **Scandinavian (Stromland) charts if a child is under 6 years of age**
- **Canadian (Clarren) charts if a child, adolescent or adult is over 6 years**

The Canadian charts are based on a multi-racial population considered to be a better representation of Australian children, although this has not been qualified by research. As the charts start at 6 years of age, Scandinavian charts need to be used in children under 6 years of age.

For infants and children under 2 years of age, the *corrected age of an ex-premature* child should be used if they are under 2 years of age (similar to other growth parameters such as head circumference, height and weight).

For older adolescent and adults, since PFL matures by 16 years without further changes, PFL norms and z scores for 16 year olds can be used for individuals over 16 years of age (from the Clarren charts).

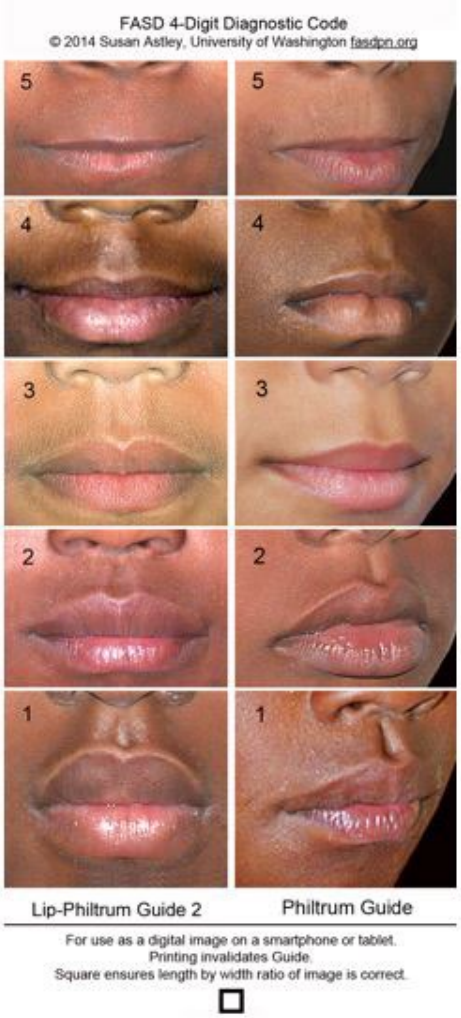
Upper Lip Thinness and Philtrum Smoothness

Upper lip thinness and philtrum smoothness should be assessed using the University of Washington (UW) Lip-Philtrum Guides, which comprise photographs according to a **5 rank scale**, which the range of **lip thickness** and **philtrum depth** seen in a population (i.e. the normal distribution).

- ***Ranks 1, 2 and 3*** are not associated with prenatal alcohol exposure, and are **below diagnostic threshold for FASD**
- ***Ranks 4 and 5* are also caused by and characteristic of prenatal alcohol exposure and FASD** but are also seen in a small proportion of the general population.

The University of Washington has developed guides for two ethnic populations: Caucasian (Guide 1) and African American (Guide 2) – see Appendix C. They recommend:

- Lip-Philtrum Guide 1 should be used for Caucasians and all races (or combinations of races) with lips like Caucasians.
- Lip-Philtrum Guide 2 should be used for African Americans and all races (or combinations of races) with thicker lips like African Americans.



Guides specific to Australian populations have not yet been developed, although research has commenced. In the absence of Australian lip-philtrum guides, the clinician should use charts which best fit the ***lip thickness*** of the individual they are assessing, *while also considering the ethnic background/s* of the individual.

Nonetheless, Lip-Philtrum Guides specific to every racial group may not to be required due to the lack of a homogenous phenotype for many races, the frequency of multiracial ancestry, and the small magnitude of differences involved.(18) In addition, small palpebral fissure length is the most consistent finding in 2D and 3D studies of facial features of FASD in different ethnic populations and ages, suggesting it is particularly sensitive to prenatal alcohol exposure. Smooth philtrum and thin upper lip are also consistent findings across populations. Recent studies indicate there are racial differences in other PAE related facial features (82, 83).

Other dysmorphic features

Other dysmorphic features have been observed in FASD but are not specific to FASD. These should be documented during assessment and include:

- *Facial features:* Flat nasal bridge, midface hypoplasia (flat midface), epicanthic folds, differences in craniofacial width, ear length and facial depth, widened intercanthal distance, anteverted nares (short upturned nose), micrognathia. (47, 84)
- *Other minor congenital anomalies*: clinodactyly (abnormal curving of the fifth finger toward the fourth finger), "Hockey stick" configuration of the upper palmar crease, other palmar crease abnormalities, “railroad track” ears, ptosis, strabismus, decreased elbow pronation/supination, incomplete extension of one or more digits, camptodactyly (permanent flexion of one or both finger interphalangeal joints, most commonly fifth and fourth fingers), shortened fifth digits. (47)
- Major birth defects of the cardiac, renal, ocular, auditory and skeletal systems such as optic nerve hypoplasia and septal defects. (4, 85, 86)

Individual dysmorphic features can occur in multiple syndromes and examination for features that differentiate alternate or co-existing syndromes and other disorders during the diagnostic assessment is essential. Differential diagnosis should include consideration of conditions that have a clinical presentation that is similar to FASD.(85)

If a genetic disorder is suspected, or any uncertainty regarding differential diagnosis exists, review by a clinical geneticist is indicated.

See Appendix D for Syndromes with constellations of features which overlap with FASD. (4)

Section D: Growth assessment

Growth assessment is an important aspect of any paediatric examination and impairment may reflect a teratogenic insult, genetic or other prenatal or postnatal factors.

Growth (weight and height) should be assessed and plotted on locally appropriate sex-specific growth reference charts by gestational age (at birth) or age to identify percentile ranks. (87) Correction for prematurity should be used until 2 years of age. (88)

In some study populations, children exposed to prenatal alcohol exposure have growth deficiency which is relatively consistent over time (3) and correlates with severity of neurodevelopmental impairment. (43)

However, *growth impairment is no longer considered diagnostic of FASD* due to the range of factors which can influence growth in an individual in combination with prenatal alcohol exposure (16). Recent evidence and clinical experience suggest that growth impairment is neither sensitive nor sufficiently specific to indicate a FASD diagnosis.

Examples of growth charts include:

Centers for Disease Control and Prevention:
http://www.cdc.gov/growthcharts/clinical_charts.htm

World Health Organisation:
http://www.who.int/childgrowth/standards/en/

Fenton Preterm Growth Chart provides equivalent information for pre-term babies.
http://www.ucalgary.ca/fenton/2013chart

Section E: Formulating a diagnosis

Information collected during the diagnostic assessment should be reviewed, ideally in a multi-disciplinary team context, to evaluate the strength of evidence to:

- Support a diagnosis of FASD with 3 sentinel facial features or a diagnosis of FASD with <3 sentinel facial features (Refer Table 1); or
- Consider whether the individual is at risk of FASD, requiring reassessment and/or further investigation; or
- Exclude other causes or conditions; and/or
- Assess the potential influence of other exposures and events.

The yellow shaded sections on the FASD Diagnostic Assessment Form (Appendix A1) and the Summary Form (Appendix A2) summarise the clinical findings required to make a diagnosis of FASD.

Section F: Discussing the diagnosis and developing a management plan

After completing the diagnostic assessment, irrespective of the diagnosis, it is recommended that the health professional/s coordinating the diagnostic process:

- Discuss with individual/parents/caregivers the outcome of the medical assessment and any reports from other health professionals involved in the assessment.
- Discuss the diagnosis, as applicable, and develop a Management Plan, incorporating parent/caregiver and patient goals, referrals, management strategies and review dates (Appendix A3).
- Provide the individual/parents/caregivers with a written report.
- Discuss how this information may be important to share with relevant service providers and school staff. Parents/caregivers will need to provide consent for any reports to be sent directly to others; however, the parent/caregiver may take their copy of the reports to the school or other organisations, to develop an appropriate plan and access services, for example through the education system or the National Disability Insurance Scheme.
- Provide contact details for follow-up communication with the clinic, if required.
- If FASD has been diagnosed, provide written information about FASD and contact details for the National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia https://www.nofasd.org.au/ or phone 1800 860 613, and/or Russell Family Fetal Alcohol Disorders Association http://rffada.org/ or phone 0412 550 540.

- For information and resources for individuals/parents /caregivers after a diagnostic assessment, including formulation of the management plan and referrals to therapy and other support services: see Appendix A7.
- Consider the need for referral for individuals or family members with alcohol use disorders, as appropriate.
- For information and resources for clinicians to support patients and their families after a diagnostic assessment: see Appendix A8.

Section G: Reporting a FASD diagnosis

Please note that FASD is a notifiable birth defect in some states (South Australia, Western Australia).

Western Australian Register of Developmental Anomalies

https://ww2.health.wa.gov.au/Articles/U_Z/Western-Australian-Register-of-Developmental-Anomalies-WARDA

South Australian Birth Defects Registry

http://www.wch.sa.gov.au/services/az/other/phru/birthdefect.html

Australian Paediatric Surveillance Unit (APSU)

The APSU monitors rare childhood conditions that include congenital/genetic disorders, infectious/vaccine preventable conditions, mental health and other injuries. FASD is one of the studies on the APSU Report Card.

Many Australian Paediatricians are currently reporting cases of FASD to the APSU.

Any clinician who wants to be included in the surveillance program can contact the APSU for information on the reporting process.

APSU Contact: 02 9845 3005 or email schn-apsu@health.nsw.gov.au

Online Case Report Form: FASD https://redcap.sydney.edu.au/surveys/?s=NXJ3J37PNW

Printable Case Report Form: FASD http://apsu.org.au/assets/current-studies/APSU-FASD-CRF-V5-16.09.19.pdf

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List of Appendices

Appendix A: Australian Fetal Alcohol Spectrum Disorder (FASD) Diagnostic Instrument

Appendix A1: Australian FASD Diagnostic Assessment Form

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT FORM

PATIENT DETAILS

NAME	
Sex	☐ Female ☐ Male ☐ Other
Date of birth (DD/MM/YYYY)	/ / Age at assessment:
Racial/ ethnic background	
Preferred language	
Hospital number (if applicable)	
Referral source, date, provider number and contact details	
Name of person(s) accompanying patient	
Relationship (s) to the patient	
Patient's primary carer (select 1 or more)	☐ Birth mother ☐ Birth father ☐ Foster carer ☐ Adoptive parent/s ☐ Other
Birth mother's name	
Birth father's name	
Patient in care of	☐ Department of Child Protection ☐ Juvenile justice ☐ Not applicable
Consent form for assessment completed	☐ No ☐ Yes
Assessment Form completed by	
Place of assessment	
Completion of this form (DD/MM/YYYY)	/ /

History

Presenting concerns:

(Include concerns identified by referring doctor, parent, caregiver, teacher; strengths and needs; age-appropriate abilities e.g. behavioural regulation, memory and learning, social skills and motor control)

Obstetric history:

Developmental history:

Mental health and other behavioural problems:

Patient's medical history:

Social history: e.g. foster care, living arrangements.

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. The definition of a standard drink should be explained prior to administering the AUDIT-C (Q1-3). A Standard Drinks Guide can be downloaded.
http://www.health.gov.au/internet/alcohol/publishing.nsf/Content/drinksguide-cnt

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 standard drinks 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 5 or more standard drinks 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

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 (e.g. cigarettes, inhalers, e-cigs and chewed tobacco) (specify)

☐ Marijuana (specify)

☐ Heroin (specify)

☐ Cocaine (specify)

☐ Amphetamines (specify)

☐ Other non-prescription drugs (specify)

☐ Anti-convulsants (specify)

☐ Other prescription drugs (specify)

☐ Don't know

☐ None

Specify other prenatal risk factors and assess risk: (e.g. 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 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, socio-economic 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	Gestational 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 or 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 Fetal Alcohol Spectrum Disorder: short palpebral fissure length (2 SD or more 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).

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: ☐ Stromland ☐ Clarren ☐ 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 or more 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):

*University of Washington Palpebral Fissure Length Z-score calculator: http://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl
†University of Washington Lip-Philtrum Guides: http://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm

NEURODEVELOPMENTAL DOMAINS

1 BRAIN STRUCTURE / NEUROLOGY DOMAIN

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. cerebral palsy, 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 domain summary

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

FUNCTIONAL NEURODEVELOPMENTAL DOMAIN SUMMARIES

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

2. MOTOR SKILLS

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

3. COGNITION

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

4. LANGUAGE

(Expressive and Receptive)

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

5. ACADEMIC ACHIEVEMENT

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

6. MEMORY

Test/subtest name	Age /Date	Score	%ile/SD	Interpretation
Other information:				
Memory impairment ☐ None ☐ Some ☐ Severe ☐ Not assessed				

7. ATTENTION

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

9. AFFECT REGULATION

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Affect regulation impairment: ☐ None ☐ Some ☐ Severe ☐ Not assessed				

10. ADAPTIVE BEHAVIOUR, SOCIAL SKILLS, OR SOCIAL COMMUNICATION

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

NEURODEVELOPMENTAL DOMAINS SUMMARY

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

DIAGNOSIS:

For derivation of the Australian FASD diagnostic categories, please refer to the Australian FASD Diagnostic Criteria and FASD Diagnostic Pathway Algorithm below (also see Table 1 and Figure 1 in the Guide). Record the diagnosis below.

Indicate as applicable:

☐ FASD with 3 sentinel facial features
☐ FASD with < 3 sentinel facial features
☐ At risk of FASD
☐ Incomplete assessment e.g. further investigation/information needed
☐ Other diagnoses (with or without FASD)

Clinical notes:

Appendix A2: Australian FASD Diagnostic Assessment Summary Form

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT SUMMARY FORM

PATIENT DETAILS

NAME	
Sex	☐ Female ☐ Male ☐ Other
Date of birth (DD/MM/YYYY)	/ / Age at assessment:
Racial/ethnic background	
Hospital number (if applicable)	

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

SENTINEL FACIAL FEATURES SUMMARY

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

☐ 0 ☐ 1 ☐ 2 ☐ 3

NEURODEVELOPMENTAL DOMAINS SUMMARY

Neurodevelopmental Domain	Impairment			
1 Brain structure/Neurology	☐ No	☐ Yes	☐ Not assessed	
2 Motor Skills	☐ None	☐ Some	☐ Severe	☐ Not assessed
3 Cognition	☐ None	☐ Some	☐ Severe	☐ Not assessed
4 Language	☐ None	☐ Some	☐ Severe	☐ Not assessed
5 Academic achievement	☐ None	☐ Some	☐ Severe	☐ Not assessed
6 Memory impairment	☐ None	☐ Some	☐ Severe	☐ Not assessed
7 Attention	☐ None	☐ Some	☐ Severe	☐ Not assessed
8 Executive function, including impulse control and hyperactivity	☐ None	☐ Some	☐ Severe	☐ Not assessed
9 Affect regulation	☐ None	☐ Some	☐ Severe	☐ Not assessed
10 Adaptive behavior, Social Skills, or Social Communication	☐ None	☐ Some	☐ Severe	☐ Not assessed

Number of neurodevelopmental domains with evidence of severe impairment

☐ None ☐ 1 ☐ 2 ☐ 3 or more (specify) _____

Other Prenatal or Post-natal risk/exposure

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

Growth summary

Was an unexplained deficit in height or weight < 3rd percentile identified at any time? ☐ Yes ☐ No

DIAGNOSIS:

For derivation of the Australian FASD diagnostic categories, please refer to the Australian FASD Criteria and the FASD Diagnostic Pathway Algorithm below (also see Table 1 and Figure 1 in the Guide). Record the diagnosis below.

Indicate as applicable:

- ☐ FASD with 3 sentinel facial features
- ☐ FASD with < 3 sentinel facial features
- ☐ At risk of FASD
- ☐ Incomplete assessment e.g. further investigation/information needed
- ☐ Other diagnoses (with or without FASD)

Clinical notes:

Appendix A3: Australian FASD Management Plan Form

AUSTRALIAN FASD MANAGEMENT PLAN FORM

PATIENT NAME: DOB: / / Date of assessment: / / Diagnoses (FASD and other):				
Patient/Caregiver goals:				
Domain assessment: (as applicable)	Problem / Issue:	Recommendations:	Responsibility:	Timeframe:
1 Brain Structure/ Neurology				
2 Motor skills				
3 Cognition				
4 Language				
5 Academic achievement				
6 Memory				
7 Attention				
8 Executive Function, including Impulse Control and Hyperactivity				
9 Affect regulation				
10 Adaptive behaviour, Social Skills, or Social Communication				

Other Problem/Issue: e.g. medical, safety, sleep	Recommendations:	Responsibility:	Timeframe:

Caregiver/Family Support:

☐ *NOFASD Australia* contact details: 1300 306 238 www.nofasd.org.au

☐ *Raising Children Network* details: http://raisingchildren.net.au/
(information about other disabilities, comorbidities and general parenting information)

Problem/Issue/Goal:	Recommendations:	Responsibility:	Timeframe:

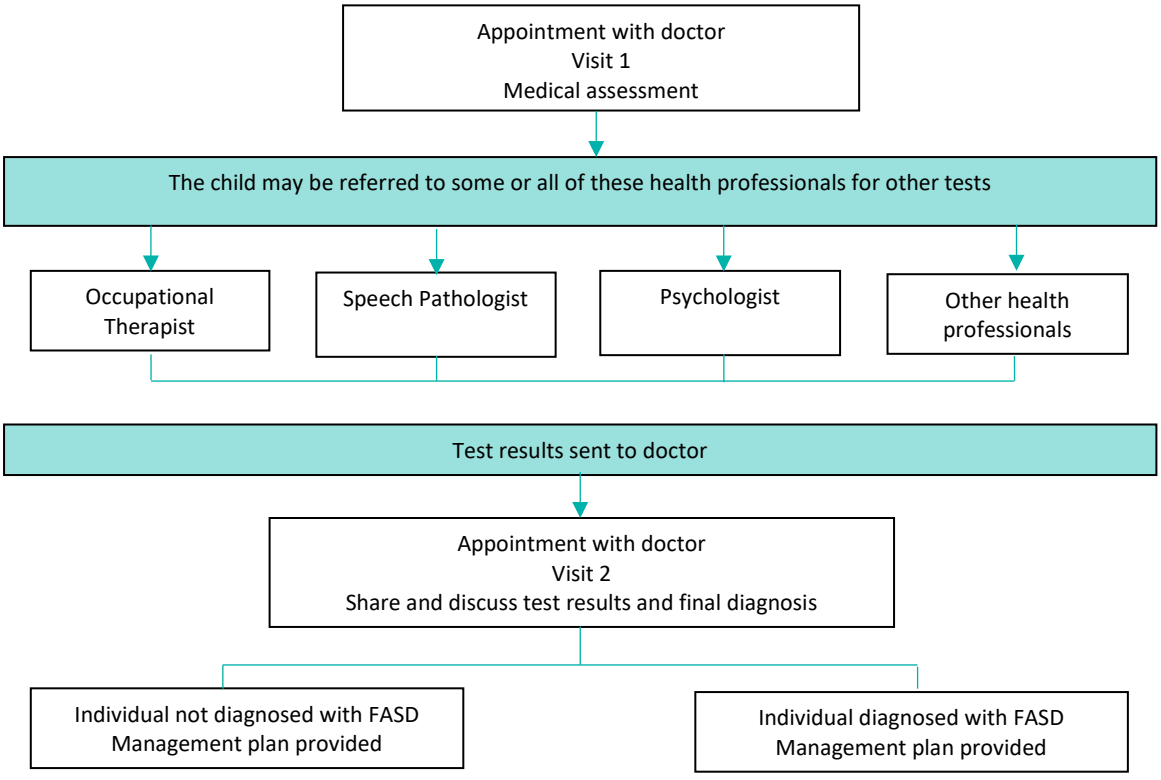
Appendix A4: Information on FASD diagnostic assessment for individuals and caregivers

Who is this information for?

Diagnostic assessment for Fetal Alcohol Spectrum Disorder (FASD) can be conducted with people of all ages. However diagnostic assessment is most commonly conducted with children under the age of 18 years. Ideally an individual should have a diagnostic assessment as early as possible.

The information in this document is for parents and caregivers. In this document the word 'child' refers to a person under the age of 18. However, the information could also be used to explain the FASD Diagnostic Assessment to a person of any age undergoing diagnostic assessment. The number of appointments and how these are arranged will also depend on where a person has their assessment conducted e.g. hospital, community clinic, paediatrician in private practice.

What is involved in getting a diagnosis?



What documents do I need?

The doctor will need to record some information about your child. As a parent or caregiver, you may be asked to complete a form before you come to the appointment or to bring the information with you to the appointment. The following is a list of the type of information you may be asked to bring. You may not have all of this information but bring as much as you can.

- Birth records – date of birth, weight, length
- Child health records – history of growth, weight, height
- Medical history such as illnesses, surgery, vision or hearing problems
- School reports and any issues that have been raised by teachers or the school
- Photos of the child where you can see their face at different ages

The doctor will complete a medical assessment which will take about one hour. This will include testing hearing and vision, measuring height and weight and reviewing the documents you have brought to the appointment. During your appointment tell the doctor about the child's strengths and weaknesses, behaviour, any memory problems and how they relate to other people. Depending on the age of the child, let them talk about their own experiences. The doctor may take a photo of the child's face or look at the face and take measurements.

Your child may be referred to other health professionals who are skilled in doing different assessments. Make sure you have clear instructions on where each appointment is, the time of each appointment, how long each appointment may take and what to do after all the assessments have been completed.

Occupational Therapist

- The occupational therapist will assess motor skills (such as walking, running, tying shoelaces), sensory processing (how we receive, organise and understand visual and auditory messages) and visual perceptual skills (making sense of what we see). For a young child this may involve doing things with their hands, like drawing, writing letters, matching shapes, cutting with scissors, threading beads, asking about the things they like or don't like to play with because of the way they feel, taste, move or sound. This assessment may take about an hour.

Speech Pathologist

- A speech pathologist will assess understanding of language, use of language, verbal reasoning and use of speech sounds. For a young child this will involve talking with them and showing some pictures or toys, finding how many words they know, how well they can talk about things and how well they can understand words and questions. This assessment may take an hour.

Psychologist

- The psychological assessment involves tests of memory, problem solving skills, academic abilities and cognitive abilities (how we think, remember and learn). To assess a child, a psychologist, who has had special training in how children learn and how the brain works, will assess what your child knows and test their memory and

understanding. This will involve answering questions, and for a young child working with puzzles and blocks and doing some writing activities. This assessment may take 2 hours.

Other health professionals

- A range of other health professionals could be consulted for their expertise, for example a geneticist or radiologist.

How much does the assessment cost?

Depending on your personal circumstances the cost will vary. In a public system the cost of each assessment may be covered but you will need to ask if there are any extra expenses. If you have a diagnostic assessment in the private system you will need to ask the clinic or doctor's practice about the cost of all the assessments and how much is covered by Medicare. If you have private health insurance contact them to find out how much you will be able to claim.

What happens after all the assessments?

Usually your child will have another appointment with the doctor. You may like to ask a support person, friend or relative to accompany you to this appointment. The doctor will share and discuss the medical assessment and test results and final diagnosis which may be Fetal Alcohol Spectrum Disorder or any other diagnosis. You or your support person should ask questions and request a copy of the findings and diagnosis. Discuss with the doctor what the 'next steps' are and plan where to go for treatment and services. Also ask if you can phone the doctor with questions once you have had time to read the information and discuss the diagnosis with members of your family.

If you would like to talk to someone before, during or after the diagnostic assessment the National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD Australia) and the Russell Family Fetal Alcohol Disorders Association are Australian support groups that provide information, advocacy and support for families caring for people who have or are suspected of having Fetal Alcohol Spectrum Disorder.

Australian FASD support groups

- National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia)
  http://www.nofasd.org.au or phone 1800 860 613
- Russell Family Fetal Alcohol Disorders Association
  http://rffada.org or phone 0412 550 540
- If you are a foster carer you can also contact the foster care association in your state or territory (See page 58)

Why is diagnosis important?

To get to know the child better

A diagnostic assessment looks at all the things a child is good at and where they need help. It gives health professionals, parents, carers, family members, teachers and the child a better understanding of how to manage and or care for the child.

To access services that can help the child

A diagnosis may help you access services in the community that best meet the child's needs.

To answer your questions

A diagnostic assessment helps you understand more about the child. If you are wondering why the child has challenges in some areas of their life (for example, school, behaviour, memory) the diagnosis will help answer your questions.

To improve the quality of life

A diagnosis and management plan can contribute to positive long term outcomes for the child and their family.

Parents have said getting a diagnosis:

- Was the catalyst that opened the door to meeting their child's needs.
- Brought relief and provided a reason for their child's difficulties.
- Removed the blame from them and the child and that alcohol's effect in pregnancy. was to blame for the child's behaviour difficulties.
- Enabled them to find out more specific information about the disability.
- Gave them the knowledge they needed to be stronger advocates.
- Helped them understand that the child had brain differences and the child's behaviours were "normal" for them.
- Paved the way for trying different parenting approaches and to see the child as one who maybe "can't do" rather than one who "won't do".
- Enabled them to change goals and set realistic expectations for the child.

Children and young people and getting a diagnosis:

- "… I am the same person but have more of an idea why I do the things I do. My parents understand me better now."
- "… our past does not dictate our future."

Informed consent

Explanation of consent for the diagnostic assessment

- Informed consent is recommended in order for the diagnostic assessment to be completed.
- Consent can be withdrawn at any time.
- Informed consent can be withdrawn either verbally or in writing.
- Any information gathered before, during and after the diagnostic assessment will be treated as confidential.
- Information from the diagnostic assessment will only be shared with health professionals, and you as the child's parents or carers.
- Copies of any reports from the completed diagnostic assessment will be available to you.

Consent after the diagnostic assessment

- The recommendations from the diagnostic assessment should be implemented as appropriate between the child who has undergone the diagnostic assessment, their family and health professionals.
- For a child who is attending school you may be asked to give consent to sharing the diagnostic assessment results with people within the education system to enable the school to develop an appropriate plan for the child. This may include the teacher, principal, school psychologist and support services within the education department.

You will be provided with a copy of the Australian FASD Diagnostic Assessment Consent Form to review.

Information about Fetal Alcohol Spectrum Disorder

Information about Fetal Alcohol Spectrum Disorder is available on the following websites. There are many other websites that are not listed in this information sheet. Please note that these websites may use a variety of terms of describe FASD and that some of the international websites refer to programs and services that are available in Australia.

Australian websites

- FASD Hub Australia
  https://www.fasdhub.org.au/
- National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia)
  http://www.nofasd.org.au/ or phone 1800 860 613
- Russell Family Fetal Alcohol Disorders Association (rffada)
  http://raffada.org or phone 0412 550 540

International websites

Please note that these websites and resources may refer to services and programs that are not available in Australia.

Terms used to describe FASD may also be different to terms used in Australia.

Country	Support Group	Research/Other
New Zealand	FASD Care Action Network (FASD-CAN) https://www.fasd-can.org.nz/	Fetal Alcohol Network New Zealand (FANNZ) http://www.ahw.org.nz/Issues-Resources/Fetal-Alcohol-Spectrum-Disorder
Canada	Support for FASD – lists Canadian support groups by province https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/support.html	CanFASD – Canada FASD Research Network https://canfasd.ca/
USA	National Organisation on Fetal Alcohol Syndrome (NOFAS) https://www.nofas.org/	Centers for Disease Control and Prevention https://www.cdc.gov/ncbddd/fasd/research.html
UK	National Organisation for Foetal Alcohol Syndrome – UK http://www.nofas-uk.org/	

Appendix A5: Australian FASD Diagnostic Assessment Consent Form

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT CONSENT FORM

Name of person undergoing diagnostic assessment	
Date of birth (Day/Month/Year)	/ /

I am legally responsible for the person named above and have the authority to consent to the diagnostic assessment because:

☐ I am his/her PARENT ☐ I am his/her LEGAL GUARDIAN

The doctor has explained the diagnostic assessment process to me and my child and any questions we have asked have been answered to our satisfaction. The doctor has explained that she/he may take a photo of my child as part of the assessment.

☐ I consent to a photo of my child being taken as part of the assessment.

I, _____consent to this diagnostic assessment
Give Names Surname

on behalf of my child _____
Given names Surname

Signature of parent/legal guardian: _____

Date: _____ (Day/Month/Year)

I, _____
Doctors full name

have explained the diagnostic assessment process to the signatory above who stated that he/she understood and gave informed consent on behalf of his/her child.

Signature of doctor: _____

Date: _____ (Day/Month/Year)

A copy of the signed consent form to be given to the parent/legal guardian

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT CONSENT FORM

Name of person undergoing diagnostic assessment	
Date of birth (Day/Month/Year)	/ /

The doctor has explained the diagnostic assessment process to me and any questions I have asked have been answered to my satisfaction. The doctor has explained that she/he may take my photo as part of the assessment.

☐ I consent to my photo being taken as part of the assessment.

I, _____consent to this diagnostic assessment
Give Names Surname

Signature: _____

Date: _____ (Day/Month/Year)

I, _____
Doctors full name

have explained the diagnostic assessment process to the signatory above who stated that he/she understood and gave informed consent

Signature of doctor: _____

Date: _____ (Day/Month/Year)

A copy of the signed consent form to be given to the signatory.

Appendix A6: Information for clinicians: Issues that individuals and their caregivers may experience during the FASD assessment process

The effects of alcohol on the fetus are not widely known. While there are many reasons why people use alcohol, overwhelmingly the majority of birth mothers do not intentionally seek to harm their children. It is important that any language used by clinicians explains that any harm is caused by alcohol rather than the mother's behaviour and avoids *blaming the mother*. The more appropriate language to explain Fetal Alcohol Spectrum Disorder (FASD) is *"when alcohol was consumed during pregnancy"* or *"when the fetus is exposed to alcohol during pregnancy"*. It is important to offer non-judgemental support and advice. An early diagnosis and well-structured management and treatment plans can greatly improve the health outcomes and life of a person with FASD and their families.

Respect is paramount to successful treatment. It is a vital tool in the elimination of discrimination and stigma and is pivotal to creating an environment where the issue of prenatal alcohol exposure can be discussed.

Adopt a consulting style that enables the person and their caregivers to participate as partners in all decisions about their healthcare and take fully into account their race, culture, and any specific needs. People with FASD should have a comprehensive care plan that is agreed between them and their caregivers, and their care providers.

The strategy for treatment should be individualised according to the degree of severity within the syndrome; other medications and comorbidity; the lifestyle and preferences of the family and/or carers.

Speaking to the person and their caregivers

The diagnostic assessment process is a particularly sensitive and emotive time for the individual and their caregivers, especially for birth parents. They may like to ask a support person, friend or relative to accompany them to the appointment.

Before the diagnostic assessment process

- Use clear language.
- Explain the assessment process and any medical terminology.
- Explain that the assessment process may or will involve taking a photo of the person's face, being aware that some individuals and their caregivers may find this confronting or experience some discomfort.
- Discuss the Information on FASD diagnostic assessment for individuals and caregivers and provide a copy (Appendix A4).
- Discuss the Australian FASD Diagnostic Assessment Consent Form (Appendix A5) and gain informed consent for the assessment and provide a copy.
- Some parents or caregivers may themselves be affected by fetal alcohol exposure – be aware of the possibility of intergenerational alcohol harm.

Speaking to a person undergoing diagnostic assessment for FASD

During the diagnostic assessment process

- Make eye contact with the person and use their name.
- Keep instructions brief and use language that is not ambiguous.
- Ask simple and single questions needing one answer - that is, closed questions.
- Don't speak too quickly, use repetition and ensure the person has understood the instructions and what is required of them.
- The use of visual cues can be useful.
- Don't assume that because the person is able to speak well that he or she can also understand what you are saying and follow through with suggestions or advice.

After the diagnostic assessment process

- Discuss the content of the reports from the occupational therapist, speech pathologist, psychologist or other health professionals with the person and their parents/caregivers and provide a copy of each report.
- Provide a definite referral and 'next steps' plan and ensure they are appropriate for the diagnosis whether FASD or any other diagnosis.
- Provide some written information on the diagnosis and management plan so the person and their parents or caregivers can take it away and read it at a later time and discuss it with other people.
- For a child of school age, discuss how this information will be important to share with their school. Parents or caregivers will need to provide consent for any reports to be sent directly to the school; however, the parent or caregiver may take their copy of the reports to the school to develop an appropriate plan and access services through the education system.
- Allow the person, caregivers or their support person to ask questions during the appointment and provide contact details for follow up communication if required.

Listen to the concerns raised by the parents or caregivers

Many people will have tried numerous avenues to obtain a diagnosis. For the person and their parents or caregivers this may result in them feeling frustrated, disempowered and not being believed. They may have also experienced health professionals as unwilling or not confident to raise the issue of fetal alcohol exposure as a possible cause. The person and their parents/caregivers may experience grief, loss, anger and guilt and require validation that these are normal feelings.

Encourage the person and their parents or caregivers to talk to a counsellor or contact a support group that provides information, advocacy and support for people living with FASD and families caring for people living with FASD.

- National Organisation for Fetal Alcohol Spectrum Disorders Australia (NOFASD Australia)
  http://www.nofasd.org.au/ or phone 1800 860 613
- Russell Family Fetal Alcohol Disorders Association (rffada)
  http://raffada.org or phone 0412 550 540

Appendix A7: Information for individuals and caregivers after a diagnostic assessment

What happens after all the assessments?

- The doctor will share and discuss with you the results of the medical and other assessments.
    - The doctor will also discuss the diagnosis**,** which may be Fetal Alcohol Spectrum Disorder or another diagnosis.
    - In some cases, the doctor may need to obtain extra information before making a diagnosis.
- You should ask any questions you have and ask for a copy of the assessment findings. These may be in the form of a letter or a report and the doctor may be able to provide this to you at the appointment or if not, post it to you after the appointment. Ask how long it might be before you can expect a letter or a copy of the report.
- You can discuss with the doctor or another member of the team **any specific goals** you have for your family member and for the family as a whole. This is part of developing a management plan for the person with FASD.
- Depending on the person's specific needs, the doctor or another team member may make a referral to other health professionals for therapy, for example to an occupational therapist, speech therapist or a psychologist.
- Ask about where to go for any therapy or other services and if there are any costs and waiting times to access these services. You may also want to ask about any private therapy services that are available locally and how much these are likely to cost.
- In the case of a child who is going to school, part of the child's ongoing therapy goals may involve the school. The doctor or another team member may be able to approach the school about this and provide the school with the report or a copy of the child's management plan.
- Also ask if you can phone the doctor or another member of the team with any questions once you have had time to read the information the doctor has given you and you have had an opportunity to discuss the diagnosis with members of your family.

Support organisations for individuals and families

National Organisation for Fetal Alcohol Spectrum Disorder Australia (NOFASD)

An incorporated association and health promotion charity. The mission is to be an effective voice for individuals and families living with FASD, while supporting initiatives across Australia to promote prevention, diagnosis, intervention and management.

- Ensuring the voice and concerns of the parents and carers of children and adults living with FASD is represented and included where it needs to b
- A helpline, advisory and referral service for those who have FASD or are supporting someone who has FAS
- A regular newsletter providing the latest information on all aspects of FASD for all relevant stakeholder
- Community and digital education and training service
- An up-to-date comprehensive website of curated resources and links to assist in all aspects of FAS
- Service provider training to increase sector knowledge and further FASD awareness

How to contact NOFASD Australia

Website: https://www.nofasd.org.au/contact-us/

Email: enquiries@nofasd.org.au

Phone: 1800 860 613

Russell Family Fetal Alcohol Disorders Association (rffada)

A not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a “no blame no shame” ethos.

The mission is to support families, to provide information, training and education to increase the capacity of communities, organisations and individuals to support those people living with FASD to live to their full potential.

How to contact rffada

Website: https://rffada.org/

Email: elizabeth@rffada.org

Phone: 0412 550 540

Foster Carer Associations

- Foster Carer Association of WA (Inc) https://www.fcawa.com.au/
- Fostering NSW http://www.myforeverfamily.org.au/splash-page/1
- Foster Carer Queensland http://www.qfkc.com.au/
- Foster Carers Association NT http://fostercarersnt.org.au
- Foster Carers Association of Tasmania http://www.fostercare.tas.gov.au/foster_care_association_of_tasmania
- Connecting Foster Carers – South Australia http://cfc-sa.org.au
- Foster Carers ACT https://www.acttogether.org.au/our-services/foster-care/

Other Australian resources

FASD Hub Australia

Information on FASD for Australian health, justice and education professionals, service providers, researchers, policy makers and parents and carers.

- Understanding FASD - What is FASD and Living with FASD
- Alcohol and pregnancy
- FASD assessment and diagnosis
- Managing FASD
- Preventing FASD
- Resources
- Research Publications
- Training opportunities
- List of clinics and services across Australia
- FASD Research Australia Centre of Research Excellence

Website: https://www.fasdhub.org.au/

Email: fasdhub@telethonkids.org.au

Some FASD websites and resources from overseas

Please note that these websites and resources may refer to services and programs that are not available in Australia.

Terms used to describe FASD may also be different to terms used in Australia.

Country	Support Group	Research/Other
New Zealand	FASD Care Action Network (FASD-CAN) https://www.fasd-can.org.nz/	Fetal Alcohol Network New Zealand (FANNZ) http://www.ahw.org.nz/Issues-Resources/Fetal-Alcohol-Spectrum-Disorder
Canada	Support for FASD – lists Canadian support groups by province https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/support.html	CanFASD – Canada FASD Research Network https://canfasd.ca/
USA	National Organisation on Fetal Alcohol Syndrome (NOFAS) https://www.nofas.org/	Centers for Disease Control and Prevention https://www.cdc.gov/ncbddd/fasd/research.html
UK	National Organisation for Foetal Alcohol Syndrome – UK http://www.nofas-uk.org/	

Appendix A8: Information and resources for clinicians after a diagnostic assessment

The following are some approaches to providing support and intervention for an individual and/or their parents or caregivers after a diagnosis of FASD has been made. They are relevant for children, adolescents and adults. These approaches are also important to address patient needs even when the diagnostic assessment is inconclusive or FASD has been excluded.

1. Explain the diagnosis:

Using a *non-judgemental approach* that recognises the range of emotions that might be experienced by individuals, parents or caregivers when a diagnosis of FASD is given, explain that making a diagnosis can:

- Improve understanding of FASD.
- Improve understanding of the individual's difficulties while also identifying their strengths and help parents and carers adjust their expectations and provide support accordingly.
- Provide opportunities for individuals, parents and caregivers to express and/or process a possible range of emotions.
- Facilitate early intervention to improve a child's development.
- Identify individuals and/or their family members who are in need of assistance e.g. referral to alcohol and other drug services.

2. Provide individuals, parents and caregivers with:

- The reports of assessments from health professionals.
- The outcomes of the assessments, e.g. diagnoses; provisional diagnoses; need for further assessment.
- The details and implications of a FASD diagnosis (or non-diagnosis).
- Some 'plain English' information about FASD and contact details for NOFASD Australia (Printable information on pages 63 and 64), and/or contact details for RFFADA.
- A contact number for a clinician who can respond to any questions that arise following diagnosis about the assessment and/or management plan.

3. Develop a management plan with individuals and/or their parents and caregivers so they:

- Can identify their priorities and goals for inclusion in the management plan.
- Are aware of therapy options and family support mechanisms available as appropriate interventions put in place.
- Are empowered during future assessments, management and support.
- Are aware of accessible parent, caregiver, family and personal networks in their community.
- Are aware of support organisations.

- Are aware of the need for referrals and further medical review and of potential waiting times for services.
- Receive a copy of the management plan.

4. Consider support and interventions:

Build therapeutic interventions around the individual's:

- Strengths, interests and positive attitudes.
- Willingness to participate in family, school or institutional activities and routines.
- Engagement with their family, peers and/or caregivers.

Key approaches include:

- Educating individuals, parents and caregivers about FASD and related impairments.
- Improving parent, caregiver and teacher understanding of interactions with the child, adolescent or adult living with FASD.
- Ensuring appropriate educational support and accommodations are implemented.
- Targeting therapy programs towards supporting the individual's key functional difficulties.
- Medication (when indicated and appropriate).
- Advocating for the individual e.g. in education, child protection or justice systems.

Challenges to address may include:

- Challenges of daily life – e.g. caregiver fatigue, the need for routine and repetition for many individuals living with FASD, emotional or behavioural problems including aggression.
- Family's need to access multiple health services, potentially with limited communication between different service providers.
- Service providers with limited knowledge about FASD.
- Need for individuals, parents and caregivers living with FASD to educate teachers, health and other professionals about FASD.
- Lack of recognition of a FASD diagnosis as a disability, providing a hurdle to obtaining funding for educational and other assistance.
- Lack of recognition of co-existing mental, developmental or physical health conditions.

Eight Magic Keys

- These eight strategies underpin successful strategic interventions for students with FASD and are one example of an approach that can be taken.
- They are simple, functional strategies to use with young people with FASD and can be used by caregivers, teachers and health professionals.
- They were developed for use by the FASD Centre for Excellence, Substance Abuse and Mental Health Services Administration http://come-over.to/FAS/brochures/EightMagicKeysBroch.pdf.


1. Concrete Terms
•Children living with FASD do well when parents/carers and educators talk in concrete terms. Refrain from using words with double meanings, idioms etc. The social emotional understanding of children living with FASD is often below their chronolgical age, therefore it helps to 'think younger' when providing assistance, giving instructions etc. It is also important not to make deficit judgements.
2. Consistency
•Due to the difficulty that children with FASD experience in generalising learning from one situation to another, they do best in an environment with few changes. This includes consistency in language and routines. Educators and parents/carers should coordinate with each other to use the same words and/or gestures for key phrases. Communication books are effective ways of sharing what's happening and advising on language use and behaviours in classrooms and homes.
3. Repetition
•Children with FASD have chronic short term memory problems. They forget things they want to remember, as well as information that has to be learned and retained for a period of time. In order for them to commit something to long-term memory, it often needs to be repetitively retaught.
4. Routine
•Stable routines and consistent visual cues that do not change from day to day make it easier for children with FASD to know what to expect next, and decrease their anxiety, enabling them to learn.
5. Simplicity
•Remember to keep input short and sweet. Children with FASD are easily over-stimulated, leading to 'shutdown', at which point they can take in no more information. Breakdown tasks and always communicate the task in the positive: "we walk inside" instead of "don't run".
6. Specific Lanaguage
•Say exactly what you mean. Remember that children with FASD have difficulty with abstractions, generalisations and 'filling in the blanks' when given an instruction. Tell them step-by-step what to do. This will help them develop appropriate habit-forming patterns. Keep instructions concise and broken into achievable chunks.
7. Structure
•Structure is the 'glue' that enables a child with FASD to make sense of the world. If this glue is taken away things fall apart. A child with FASD achieves and is successful because his or her world provides appropriate structure as a permanent foundation for learning.
8. Supervision
•Due to their cognitive challenges, children with FASD bring a naivety to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behaviour and ensure safety and wellbeing at all times.

Printable information on Fetal Alcohol Spectrum Disorder and post diagnosis support for individuals and caregivers

This information was provided by NOFASD Australia

Fetal Alcohol Spectrum Disorder (FASD) is a condition that may be diagnosed in a person who, before they were born, was exposed to alcohol. The alcohol in any alcoholic drink (beer, wine or spirits) is rapidly absorbed into the mother's blood stream and crosses the placenta to the unborn child to change otherwise healthy development. FASD is characterised by damage to the developing brain, leading to abnormalities in how the brain works. This can show up in several different ways, such as problems with learning, memory, language, judgement, decision-making and planning, movement or sensation. Some, but not all individuals can also have facial features that are characteristic of FASD.

Alcohol can cause harm to the unborn child at any time during pregnancy (including before pregnancy is confirmed) and the level of harm depends on the pattern of the mother's alcohol use - the percentage of alcohol in drinks, the number of drinks, and over what time the alcohol drinks were consumed. Binge drinking for example, means a high level of alcohol is consumed in a shorter period of time.

In addition to the alcohol exposure, the vulnerability of a pregnancy and an unborn child may also be affected by other factors like genetics, family alcohol use across generations, the father's alcohol use prior to conception, the mother's age and general health (for example, nutrition, tobacco use) and other environmental factors like stress (exposure to violence, living with poverty, factors at work).

FASD is not always obvious at birth and might not be noticed until the child doesn't reach developmental milestones or behaviour and learning difficulties become a worry once the child starts school. FASD can also be first diagnosed in adolescence or adulthood. Different professionals might need to be involved to assess the areas of the child's life where help is most needed.

A person who was exposed to alcohol before they were born might now be any age. A proper diagnosis, appropriate services and support can help any person living with FASD to prevent behaviour from worsening, encourage attendance and participation at school, and help sustain work and build understanding, social relationships and friendships. Parents, families and communities need to be involved in this individual's life and work together.

FASD lasts a lifetime but with the right help and caring, a good quality of life is possible. Care at home is incredibly important but can be challenging. Parents and carers need to care for themselves and be offered support too. NOFASD Australia can help. Please contact us on 1800 860 613.

With grateful acknowledgement to NOFASD Australia, a non-government national organisation registered as an incorporated association in South Australia under the Associations Incorporation Act 1985.

Post Diagnosis – Support

NOFASD Australia is a strong and effective voice for people living with FASD and offers information, resources and ongoing support to individuals and families via telephone, email, online or by post. NOFASD Australia has a wide network of parents and carers in most locations across Australia and we can connect you with other experiences parents, and people who understand what you are going through. FASD lasts a lifetime but a better quality of life is always possible. Our knowledge and experience in supporting individuals, parents and families before and after diagnosis can help you. We work with people to share information, resources and offer professional support to service providers who might already be supporting your family or we can help connect you with these people in your community.	**CONTACT DETAILS** Telephone: 1800 860 613 Email: enquiries@nofasd.org.au Website: http://www.nofasd.org.au Online contact: http://www.nofasd.org.au/contact-us

NOFASD Australia raises public awareness of FASD through community education for individuals, parents/carers or groups and we deliver training to service providers who support families.

Parents, carers and their supporters can join the NOFASD Network and receive our monthly e-newsletter. If you do not have email, we can post out copies of the newsletter each month. NOFASD Australia has a Facebook page on which we post daily news and items of interest for individuals, parents and families from Australia and around the world.

The information you provide is private and confidential, we will always seek your written consent to share any personal information for any purpose and we respect your right to choose anonymity.

NOFASD Australia is non-government national organisation registered as an incorporated association in South Australia under the Associations Incorporation Act 1985 and has held Health Promotion Charity status since 2007.

Australian FASD websites and resources

Organisation	Website
FASD Hub Australia	https://www.fasdhub.org.au/
NHMRC Guidelines to Reduce Health Risk from Drinking Alcohol	https://www.nhmrc.gov.au/about-us/publications/australian-guidelines-reduce-health-risks-drinking-alcohol
Australian Indigenous Alcohol and Other Drugs Knowledge Centre	https://aodknowledgecentre.ecu.edu.au/learn/health-impacts/fasd/
Women Want to Know Project and Resources	https://beta.health.gov.au/initiatives-and-programs/women-want-to-know-initiative?utm_source=alcohol.gov.au&utm_medium=redirect&utm_campaign=digital_transformation&utm_content=%2Finternet%2Falcohol%2Fpublishing.nsf%2FContent%2Fwwtk

International websites

Country	Support Group	Research/Other
New Zealand	FASD Care Action Network (FASD-CAN) https://www.fasd-can.org.nz/	Fetal Alcohol Network New Zealand (FANNZ) http://www.ahw.org.nz/Issues-Resources/Fetal-Alcohol-Spectrum-Disorder
Canada	Support for FASD – lists Canadian support groups by province https://www.canada.ca/en/public-health/services/diseases/fetal-alcohol-spectrum-disorder/support.html	CanFASD – Canada FASD Research Network https://canfasd.ca/
USA	National Organisation on Fetal Alcohol Syndrome (NOFAS) https://www.nofas.org/	Centers for Disease Control and Prevention https://www.cdc.gov/ncbddd/fasd/research.html
UK	National Organisation for Foetal Alcohol Syndrome – UK http://www.nofas-uk.org/	

Australian Parenting Information and Programs

- The Australian Parenting website http://raisingchildren.net.au/
- Parent helplines and hotlines http://raisingchildren.net.au/articles/hotlines.html
- Triple P – Positive Parenting Program http://www.triplep.net/glo-en/find-out-about-triple-p/

Foster Carer Associations

- Foster Carer Association of WA (Inc) https://www.fcawa.com.au/
- Fostering NSW http://www.myforeverfamily.org.au/splash-page/1
- Foster Carer Queensland http://www.qfkc.com.au/
- Foster Carers Association NT http://fostercarersnt.org.au
- Foster Carers Association of Tasmania http://www.fostercare.tas.gov.au/foster_care_association_of_tasmania
- Connecting Foster Carers – South Australia http://cfc-sa.org.au
- Foster Carers ACT https://www.acttogether.org.au/our-services/foster-care/

Appendix A9: Referral and screening guidelines for FASD

A. Referral guidelines

The following are principles for referral for FASD diagnostic assessment in Australia:

- Consideration of prenatal alcohol exposure should be part of 'mainstream' clinical practice for all health professionals taking a pregnancy history.
- FASD should be considered as a possible diagnosis in any individual with unexplained neurodevelopmental problems.
- If there are concerns about prenatal alcohol exposure (PAE) and/or possible FASD, referral to appropriate services for formal assessment is recommended.

It is recommended that:

- Discussion of maternal drinking and associated risks should be integral to *all* prenatal and postnatal care of women and children by *all* health care professionals. This should be conducted in a *sensitive and respectful manner.*
- Obstetric history taking should *always* include discussion of alcohol use in pregnancy and assessment of the risk of prenatal alcohol exposure – *as standard practice* – as for any other significant prenatal exposure e.g. medications, illicit drugs and infection. Standardised validated screening tools such as the AUDIT-C should be used to assess alcohol intake.*
- FASD should be part of the differential diagnosis for any individual presenting with significant developmental or behavioural problems, until prenatal alcohol exposure is excluded.
- Supports should be provided for individuals, caregivers and families as part of the referral process, including appropriate intervention if alcohol misuse is ongoing.

Referral for a FASD diagnostic assessment should occur when the following are identified:

- Prenatal alcohol exposure is at high risk levels*.
- Neurodevelopmental impairment and/or distinctive facial features and confirmed or suspected prenatal alcohol exposure.
- The individual, their parent or caregiver is concerned that there was PAE and/or may be a FASD diagnosis (regardless of the above).

***** *Please refer to the Australian Guide to the diagnosis of FASD - Section A: Assessing maternal alcohol use*

Referral threshold for individuals at increased risk of FASD

The threshold for referring for a FASD diagnostic assessment should be lower for individuals in the following high-risk groups and/or settings.

Children, adolescents or adults:

- Who are living in out-of-home care (adoption/foster/extended family). (1,2)
- Who are in contact with the justice system. (3)
- Who have a family member with Fetal Alcohol Spectrum Disorder.

- Who have a birth mother with a known alcohol-related illness or dependency.
- Who live in a community where there are high rates of alcohol consumption.(4)

Depending on age, location and available services, individuals could be referred to:

Assessment teams:

- Specialist FASD assessment clinic
- Child development assessment service (with multidisciplinary team)

Specialists:

- General or developmental paediatrician – public or private
- Adolescent physician
- Child and adolescent psychiatrist
- Adult psychiatrist
- Clinical geneticist

These specialists can work with local mental and allied health clinicians to complete a multidisciplinary assessment.

Specialist FASD diagnostic clinics in Australia currently include:

Please refer to the FASD Hub for information on clinics and services across Australia: https://www.fasdhub.org.au/services/

Screening tools for FASD

- There are *no validated* standardised screening tools for FASD (e.g. equivalent to the M-CHAT for Autism Spectrum Disorder).
- This is partly related to the wide spectrum of possible neurodevelopmental impairments in FASD and hence the variation in presenting symptoms.
- Further research is required to develop reliable validated screening tools.
- Some non-validated tools are available:
    - National Screening Tool Kit for Children and Youth Identified and Potentially Affected by FASD (5)
    - Youth Probation Officers' guide to FASD screening and referral (6)

B. Primary developmental surveillance

Canadian and US data indicate that FASD is a common and preventable developmental disability, with similar prevalence rates to Autism Spectrum Disorder (7).

Primary care developmental surveillance, such as that done by Child Health and School Nurse programs, should identify children with or at risk of developmental and behavioural problems. Some of these children may have FASD (with or without other conditions).

Infants and children from high risk groups or settings for FASD warrant close developmental surveillance. They are at higher risk of neurodevelopmental problems as they are more likely to have been exposed to alcohol in utero as well as other adverse pre and postnatal factors.

References:

1. Breen C & Burns L. Improving services to families affected by FASD. National Drug and Alcohol Research Centre University of New South Wales. November 2012.
2. Chasnoff I, Wells M, King L. Misdiagnosis and Missed Diagnoses in Foster and Adopted Children with Prenatal Alcohol Exposure. Pediatrics 2015; 135 (2): 264–70.
3. Canadian Department of Justice (DOJ), FASD prevalence in the justice population. 2016. Online report. http://www.fasdjustice.ca/fasd-basics/prevalence-justice-population.html
4. Fitzpatrick J, Latimer, J, Carter M, Oscar J, Ferreira M, Carmichael Olson H, Lucas B, Doney R, Salter C, Try J, Hawkes G, Fitzpatrick E, Hand M, Watkins R, Martiniuk A, Bower C, Boulton J, Elliott E. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: The Lililwan Project. Journal of Paediatrics and Child Health 2015; 51: 450–457.
5. Canadian Northwest FASD Research Network. National screening tool kit for children and youth identified and potentially affected by Fetal Alcohol Spectrum Disorder. 2010. Canada: Canadian Association of Paediatric Health Centres.
6. Conry, J., & Asante, K. Youth probation officers' guide to FASD screening and referral. 2010. British Columbia: The Asante Centre
7. May P, Baete A, Russo J, Elliott A, Blankenship J, Kalberg W, Buckley D, Brooks M, Hasken J, Abdul-Rahman O, Adam M, Robinson L, Manning M, Hoyme H. Prevalance and Characteristics of Fetal Alcohol Spectrum Disorder. Pediatrics 2014; 134 (5): 855 – 866.

Appendix B: Standard drink sizes for commonly consumed drinks

NUMBER OF STANDARD DRINKS – BEER

1.1
285ml
Full Strength
4.8% Alc. Vol

0.8
285ml
Mid Strength
3.5% Alc. Vol

0.6
285ml
Low Strength
2.7% Alc. Vol

1.6
425ml
Full Strength
4.8% Alc. Vol

1.2
425ml
Mid Strength
3.5% Alc. Vol

0.9
425ml
Low Strength
2.7% Alc. Vol

1.4
375ml
Full Strength
4.8% Alc. Vol

1
375ml
Mid Strength
3.5% Alc. Vol

0.8
375ml
Low Strength
2.7% Alc. Vol

1.4
375ml
Full Strength
4.8% Alc. Vol

1
375ml
Mid Strength
3.5% Alc. Vol

0.8
375ml
Low Strength
2.7% Alc. Vol

34
24 x 375ml
Full Strength
4.8% Alc. Vol

24
24 x 375ml
Mid Strength
3.5% Alc. Vol

19
24 x 375ml
Low Strength
2.7% Alc. Vol

These are only an approximate number of standard drinks. Always read the container for the exact number of standard drinks.

NUMBER OF STANDARD DRINKS – WINE

1.5
150ml
Average
Restaurant Serving
of Red Wine
13% Alc. Vol

1
100ml
Standard Serve
of Red Wine
13% Alc. Vol

0.8
60ml
Standard Serve
of Port
17.5% Alc. Vol

1.4
150ml
Average
Restaurant Serving
of White Wine
11.5% Alc. Vol

0.9
100ml
Standard Serve
of White Wine
11.5% Alc. Vol

1.4
150ml
Average Restaurant
Serve of Champagne
12% Alc. Vol

7.1
750ml
Bottle of Champagne
12% Alc. Vol

7.7
750ml
Bottle of Red Wine
13% Alc. Vol

41
4 Litres
Cask Red Wine
13% Alc. Vol

21
2 Litres
Cask Red Wine
13% Alc. Vol

6.8
750ml
Bottle of White Wine
11.5% Alc. Vol

36
4 Litres
Cask White Wine
11.5% Alc. Vol

18
2 Litres
Cask White Wine
11.5% Alc. Vol

28
2 Litres
Cask of Port
17.5% Alc. Vol

These are only an approximate number of standard drinks. Always read the container for the exact number of standard drinks.

NUMBER OF STANDARD DRINKS – SPIRITS

1
30ml
High Strength
Spirit Nip
40% Alc. Vol

22
700ml
High Strength
Bottle of Spirits
40% Alc. Vol

1.1
275ml
Full Strength
RTD*
5% Alc. Vol

1.2
330ml
Full Strength
RTD*
5% Alc. Vol

2.6
660ml
Full Strength
RTD*
5% Alc. Vol

1.5
275ml
High Strength
RTD*
7% Alc. Vol

1.8
330ml
High Strength
RTD*
7% Alc. Vol

3.6
660ml
High Strength
RTD*
7% Alc. Vol

1
250ml
Full Strength
Pre-mix Spirits
5% Alc. Vol

1.2
300ml
Full Strength
Pre-mix Spirits
5% Alc. Vol

1.5
375ml
Full Strength
Pre-mix Spirits
5% Alc. Vol

1.7
440ml
Full Strength
Pre-mix Spirits
5% Alc. Vol

1.4 – 1.9
250ml
High Strength
Pre-mix Spirits
7% – 10% Alc. Vol

1.6
300ml
High Strength
Pre-mix Spirits
7% Alc. Vol

2.1
375ml
High Strength
Pre-mix Spirits
7% Alc. Vol

2.4
440ml
High Strength
Pre-mix Spirits
7% Alc. Vol

These are only an approximate number of standard drinks. Always read the container for the exact number of standard drinks.

* Ready-to-Drink

D002X10(08)

Appendix C: Assessment of Sentinel Facial Features

1. Measuring Palpebral Fissure Length

Follow these steps to accurately measure PFL manually:

- Use a small transparent ruler
- Align yourself directly in front of the patient's eye
- Remove glasses, if the patient wears them
- Place the ruler as close to the eye without touching the lashes
- Get the patient to open their eyes wide by looking up at the ceiling without tilting their head upwards
- Repeat this for the other eye

Using the PFL Z-score calculator

The mean PFL measurement (average of the left and right PFL) is typed into the PFL calculator (on the right of the screen). The patient's birth date and the date of measurement is also entered in order to calculate the patient's current age.

The PFL Z scores are then automatically calculated (right column).

To download the PFL Z-score calculator follow this link:

https://depts.washington.edu/fasdpn/htmls/diagnostic-tools.htm#pfl

Palpebral Fissure Length (PFL) Z-score Calculator

Instructions: Enter data in yellow cells. All remaining cells will automatically compute.

Patient birth date (mm/dd/yyyy)	Date PFL Measured (mm/dd/yyyy)	Patient's age (years)	Patient's PFL (mm)
July 9, 2012	August 25, 2015	3.13	21.00

PFL Normal Growth Chart	Applicable Age Range	Mean PFL for Normal Population (mm)	Patient's PFL Z-score*
Caucasian Male or Female (Hall, 1989)	0-16 yrs	**24.97**	**-3.01**
Canadian Female (Clarren et al., 2010)	6-16 yrs	**Too Young**	**Too Young**
Canadian Male (Clarren et al., 2010)	6-16 yrs	**Too Young**	**Too Young**
Scandinavian Female (Stromland et al., 1999)	0-18 yrs	**23.35**	**-2.07**
Scandinavian Male (Stromland et al., 1999)	0-18 yrs	**23.80**	**-2.41**

Using software to assess PFL

PFL can be measured on *digital facial photographs using software developed by the University of Washington*. https://depts.washington.edu/fasdpn/htmls/face-software.htm

Considerations

- Manual measurement of palpebral fissure length is prone to error and variation between examiners.
- Measurement by photographic facial analysis is more accurate
- If clinicians may not have access to the software then direct manual measurement should be used.
- When software is available, using both manual and photographic facial analysis is recommended. If there is significant discrepancy between measurements, clinical judgement is required regarding which is more accurate.
    - For example, manual measurements may have been inaccurate due to a child moving or not opening their eyes properly.
    - Photographs might be affected by similar issues leading to poor quality photos for analysis.

2. Measuring the Philtrum and Lip

The lip and philtrum can be assessed clinically by direct examination using Lip-Philtrum guides developed by the University of Washington.

To obtain Lip and Philtrum Guides

- Digital version for smart phones or tablets can be downloaded
- Hard copies can be ordered.
- Following this link: https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm

Using the Lip-Philtrum Guides during assessment

To use the guide properly, the clinician should:

- Be just below eye level in front of the patient, at the so-called frankfort level.
    - The *frankfort horizontal plane is* a line (green line) that passes through the patient's external auditory canal and the lowest border of the bony orbital rim (eye socket).
    - The physician's eyes (or camera lens) should be directly in line with this plane (see photo on page 77).
    - This is important, e.g. if the physician stands above the plane looking down on the patient, the patient's upper lip could appear thinner than it truly is.
- Hold the guide next to their face (see photo on page 77).
- The patient must have a relaxed facial expression, because a smile can alter lip thinness and philtrum smoothness.
- A short video tutorial on assessing the lip and philtrum using the guides is available at: https://depts.washington.edu/fasdpn/htmls/lip-philtrum-guides.htm.

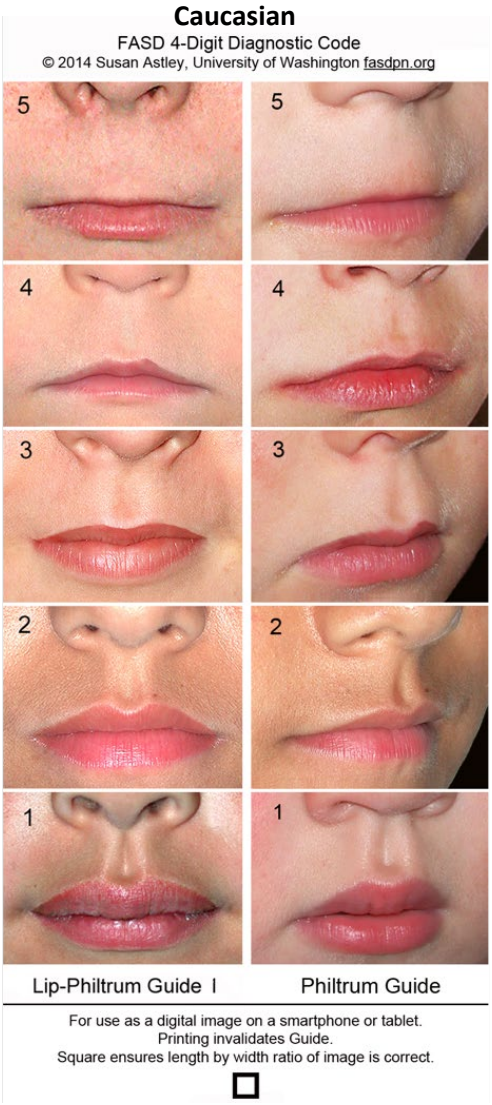
Using software to assess the lip and philtrum

The lip and philtrum can be assessed by *analysis of digital facial photographs using software* developed by the University of Washington.

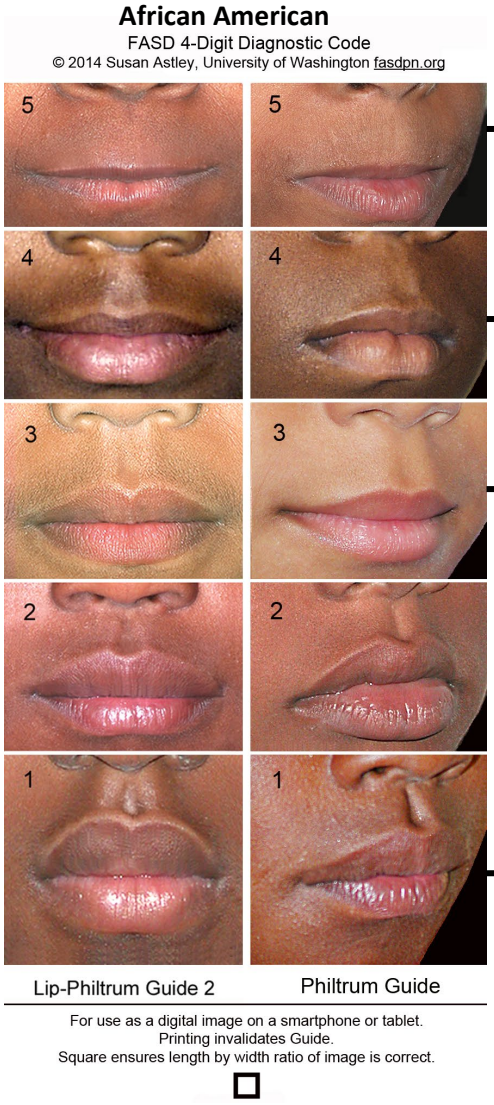
The software allows the clinician to visually re-assess the patient using the digital photographs, and to calculate lip thickness (lip circularity).

https://depts.washington.edu/fasdpn/htmls/face-software.htm

Lip Philtrum Guides



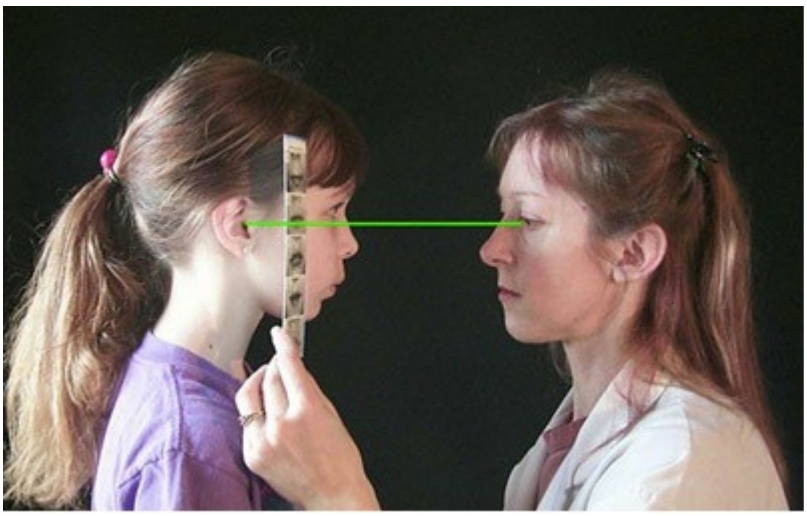
Frontal view and ¾ view



Frontal view and ¾ view

Sentinel Facial Features

Not associated with prenatal alcohol exposure, **below diagnostic threshold for FASD**



Images: Courtesy of Professor Susan Astley

Photo demonstrating how to use lip-philtrum guides including positioning at the *frankfort* level (green line).

Appendix D: Syndromes with constellations of features which overlap with FASD

Syndrome	Overlapping features	Features of this syndrome that differentiate it from FASD
Aarskog syndrome	Widely spaced eyes, small nose with anteverted nares, broad philtrum, mid-facial recession	Round face, down-slanted palpebral fissures, widow's peak, prominent "lop" ears, specific contracture of digits on extension. Inherited as an x-linked trait. Molecular defect identified.
Brachman-deLange or Cornelia deLange syndrome	Long philtrum, thin vermillion border of upper lip, depressed nasal bridge, anteverted nares, microcephaly	Single eyebrow across eyes and forehead (synophrys), long eyelashes, downturned corners of mouth, short upper limbs particularly involving ulnar side, very short stature. Molecular defect identified.
Dubowitz syndrome	Short palpebral fissures, widely spaced eyes, epicanthal folds, variable ptosis (droopy eyes) and blepharophimosis, microcephaly	Shallow supraorbital ridges, broad nasal tip, clinodactyly
Fetal anticonvulsant syndrome (includes fetal hydantoin and fetal valproate syndromes)	Widely spaced eyes, depressed nasal bridge, mid-facial recession, epicanthal folds, long philtrum, thin vermillion border of upper lip	Bowed upper lip, high forehead, small mouth
Maternal phenylketonuria (PKU) fetal effects	Epicanthal folds, short palpebral fissures, long poorly formed philtrum, thin vermillion border of upper lip, microcephaly	Prominent glabella, small upturned nose, round face
Noonan syndrome	Low nasal bridge, epicanthal folds, wide spaced eyes, long philtrum	Down-slanted palpebral fissures, wide mouth with well-formed philtrum, protruding upper lip. Molecular defect identified.
Toluene embryopathy	Short palpebral fissures, mid face hypoplasia, smooth philtrum, thin vermillion border upper lip, microcephaly	Large anterior fontanelle, hair patterning abnormalities, ear abnormalities
Williams syndrome	Short palpebral fissures, anteverted nares, board long philtrum, maxillary hypoplasia, depressed nasal bridge, epicanthic folds, microcephaly	Wide mouth with full lips and pouting lower lip, stellate pattern of iris, periorbital fullness, connective tissue dysplasia, specific cardiac defect of supravalvular aortic stenosis in many. Chromosome deletion on 7q (by chromosome microarray or specific 7q FISH (fluorescent in situ hybridization) probe analysis.
Other chromosome deletion and duplication syndromes	Many have short palpebral fissures, mid-facial hypoplasia, smooth philtrum	Chromosomal analysis by chromosome microarray

Adapted from: Chudley AE, Conry J, Cook JL, Loock C, Rosales T, LeBlanc N. Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis. *Can Med Assoc J*. 2005;**172**:S1-S21, (with permission of the author & journal)

Additional reference: Leibson T, Neuman G, Chudley AE, Koren G. The Differential Diagnosis of Fetal Alcohol Spectrum Disorder. *J Popul Ther Clin Pharmacol.* 2014; **21:** e1-30. https://jptcp.com/index.php/jptcp/article/view/347