

Australian Guide to the diagnosis of FASD

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

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April 2016

Suggested citation: Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)".

This project is supported by funding from the Australian Government Department of Health



Australian Government
Department of Health

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Acknowledgements

We acknowledge the contribution of the following:

*Steering Group (and Expert Panel identified by *)*: Mr Scott Avery, Professor Carol Bower*, Dr Felicity Collins, Dr Jennifer Delima, Professor Elizabeth Elliott*, Dr James Fitzpatrick*, Ms Andrea Lammel, Ms Vicki Russell*, Dr Doug Shelton*, Dr Lydia So, Dr David Thomas, Dr Amanda Wilkins*, Dr Marcel Zimmet*

Development of the domains section of the Guide: Dr Marcel Zimmet contributed extensively

Dr Carmela Pestell, Ms Barbara Lucas and Ms Natalie Kippin provided expert advice.

Post-doctoral Fellow: Dr Rochelle Watkins

Senior Research Officer: Ms Juanita Doorey

Development of modules and graphic design: Dr Rob Phillips, Dr Marcel Zimmet and Professor Elliott developed the content for the modules

Website: Heather Jones

Our thanks to the clinicians who participated in testing the feasibility of the Instrument, Guide and modules

Sincere thanks to Dr Jocelynn Cook, who, on behalf of the authors of the new Canadian guidelines, was extremely generous and collegial in providing additional information and assistance during the revision of the Australian Guide in 2016

We also acknowledge the contribution of the following to the development of the diagnostic instrument in 2011-2012 (led by Professors Carol Bower and Elizabeth Elliott):

Members of the Australian FASD Collaboration: Dr Lucinda Burns, Ms Maureen Carter, Ms Heather D'Antoine, Dr James Fitzpatrick, Associate Professor Jane Halliday, Ms Lorian Hayes, Associate Professor Jane Latimer, Ms Anne McKenzie, Ms Sue Miers AM, Dr Raewyn Mutch, Dr Colleen O'Leary, Dr Elizabeth Peadon, Ms Elizabeth Russell, Dr Amanda Wilkins

Project team: Ms Heather Jones, Dr Rochelle Watkins, Ms Laura Bond

Department of Health and Ageing observer: Dr Bill Kean

Our thanks to the participants in the Delphi process and Community Conversations.

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

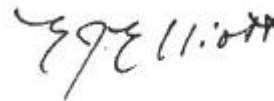
consultation with community and advocacy groups. Three diagnostic categories were recommended: Fetal Alcohol Syndrome (FAS); Partial Fetal Alcohol Syndrome (PFAS) and Neurodevelopmental Disorder-Alcohol Exposed (ND-AE). (15) During 2015, the instrument was trialled in clinical practices around Australia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

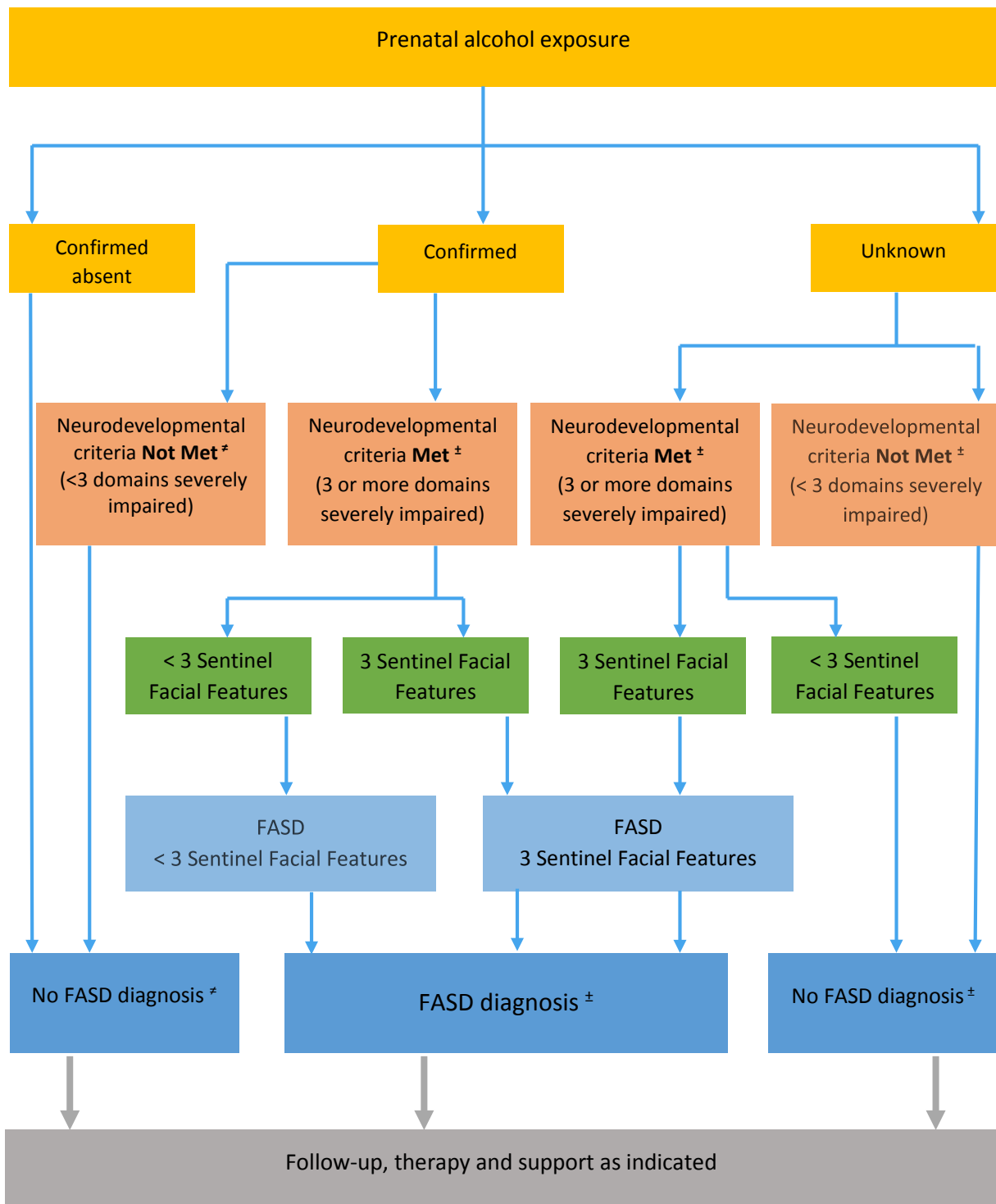
FETAL ALCOHOL SPECTRUM DISORDER		
Diagnostic criteria	Diagnostic categories	
	FASD with 3 Sentinel Facial Features	FASD with < 3 Sentinel Facial Features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains <ul style="list-style-type: none"> - Brain structure/Neurology - Motor skills - Cognition - Language - Academic Achievement - Memory - Attention - Executive Function, 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 <ul style="list-style-type: none"> - 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 individual 6 years of age and over

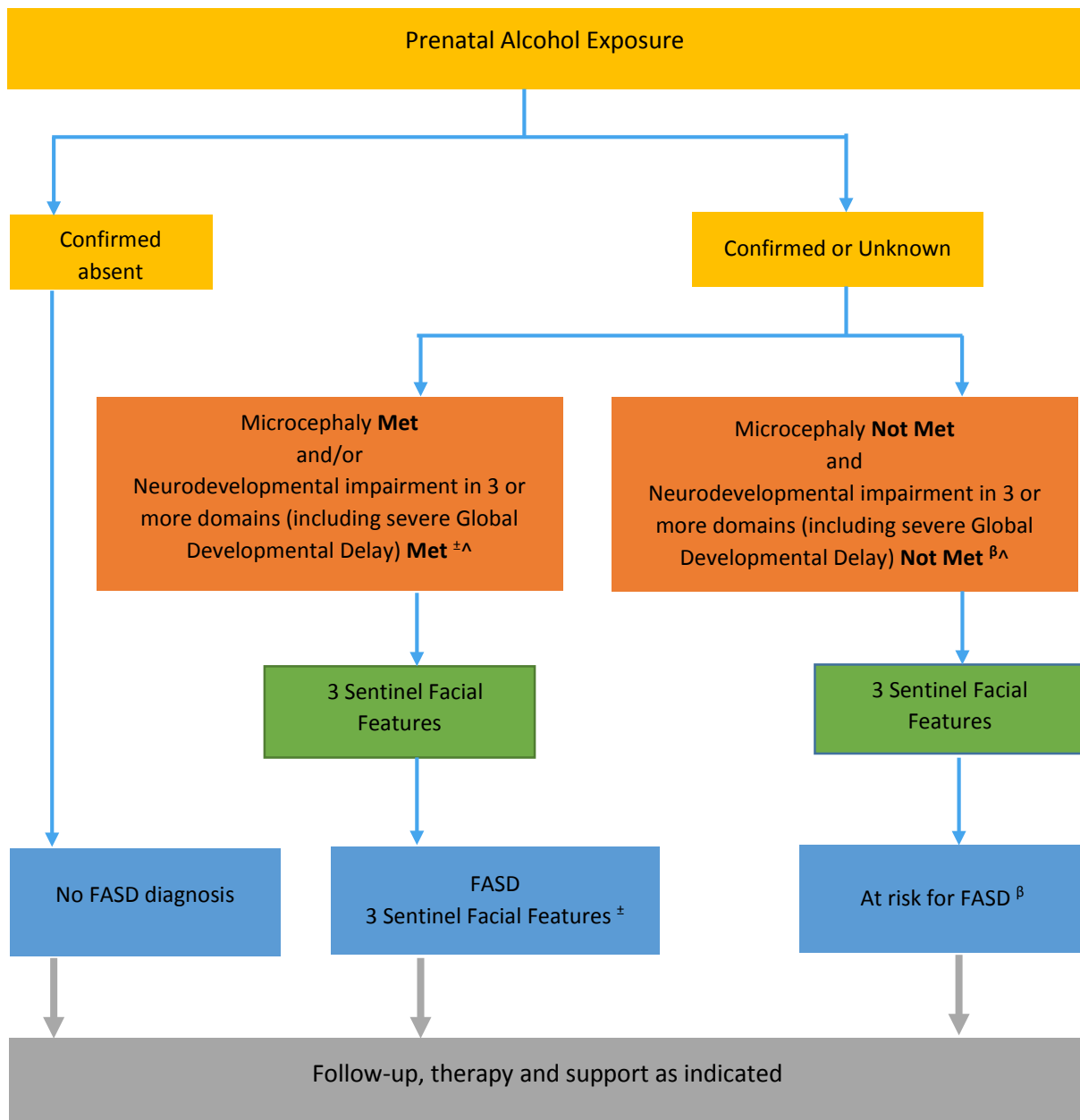


‡ Assessment fully completed and other diagnoses have been considered. Currency of assessment is also assumed.

≠ 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).

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

Figure 2: Diagnostic algorithm for child under 6 years of age



± Assessment fully completed and other diagnoses have been considered. Currency of assessment is also assumed.

β If neurodevelopmental criteria not met e.g. microcephaly or severe Global Developmental Delay, the child remains 'at risk of FASD' and requires follow up and reassessment after 6 years of age.

^To make a diagnosis of FASD In children < 6 years of age, **3 sentinel facial features are required**, in addition to confirmed or unknown PAE and either microcephaly or neurodevelopmental impairment in 3 or more domains (including severe Global Developmental Delay) or both.

If PAE is confirmed and three or more neurodevelopmental domains are impaired but there are < 3 facial features, the child remains at risk of FASD and requires follow up and reassessment after 6 years of age.

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.

<http://alcoholpregnancy.telethonkids.org.au/fasd-clinical-network/> 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).

<http://alcoholpregnancy.telethonkids.org.au/Australian-FASD-Diagnostic-Instrument>

- Information on FASD Diagnostic Assessment for Individuals and Caregivers (Appendix A4)

Information about the diagnostic assessment process for parents/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 patients and their parents or caregivers may experience during the FASD diagnostic assessment and of which clinicians should be aware.
- Information for individuals and families after a diagnostic assessment (Appendix A7)

Provides information and resources for parents 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 patients and their families 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 no conclusive 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).

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**. The level of risk for 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)

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:

<http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/drinksguide-cnt>)

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). A Standard Drinks Guide can be downloaded (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? No Yes Unknown

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

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

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	Monthly	2-4 times	2-3 times	4 or more times
	[skip Q2+Q3]	or less	a month	a week	a week
<input type="checkbox"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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
<input type="checkbox"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> 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	Weekly	Daily or
		monthly			almost daily
<input type="checkbox"/>	<input type="checkbox"/> ₀	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

AUDIT-C score during this pregnancy: (Q1+Q2+Q3)=_____ Scores= 0=no risk 1-4= confirmed 5+= confirmed high-risk

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 B₁₂, 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/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 cutoff*' 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 ($< 3^{\text{rd}}$ 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, child'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 (e.g. OFC) and neurodevelopmental skills (e.g. Griffiths (30)) and document impairment (e.g. verbal reasoning, fine motor skills, expressive language, attention skills). 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, 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 possible when standardised tests are not available (e.g. when using DSM 5 (31) 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 (32) (direct assessment) and the Vineland motor scale (33) (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 all individuals are assessed for *Adaptive function*. (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 (34-36) 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. (37) These include:

- Developmental and behavioural conditions e.g. Language disorders, ADHD, anxiety disorders, Autistic 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. A full medical examination should be performed in every child and investigations conducted as required and according to clinical need.

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, historical trauma, high rates of mental disorders, substance abuse, social disadvantage and marginalisation, contact with legal system or incarceration, and chronic stress 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, and are not influenced by culture, particularly if they provide a practical context (e.g. use pictures) and involve spatial processing. One example is the Universal Non-Verbal Intelligence Test (UNIT). (38)
- 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). (39)

Key definitions:

The '**clinical cutoff**' 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 ($< 3^{\text{rd}}$ 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 (31) a diagnosis of Intellectual Disability requires scores of ≤ 2 SD on tests of intelligence and adaptive functioning such as the Wechsler Intelligence Scale for Children-V (36) and Vineland Adaptive Behaviour Scales - 2nd Edition (33) respectively.
- Some tests e.g. the Bruininks-Oseretsky Test of Motor Proficiency (BOT-2) (40), which is used for assessing motor skills, consider a score of < 1 SD to be indicative of *clinically significant* impairment, though this would not qualify as a child as having severe impairment in this domain.

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). (39)

Clinical judgement

Clinical judgement 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.
- In the presence of confirmed PAE, neurodevelopmental impairment is present in fewer than three domains
- Neurodevelopmental impairment is present in three or more domains but impairment not sufficiently severe to meet criteria.

These individuals may be considered at risk of FASD and require follow-up and may need reassessment.

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 limited in scope compared to that available for older children e.g. IQ assessment
- Some functional manifestations of FASD may not become apparent until later in childhood e.g. academic achievement; behaviours that become progressively problematic and recognised as developmentally inappropriate in the school setting

FASD diagnostic criteria for neurodevelopmental impairment apply to children under 6 years of age with the following exceptions and considerations:

- In a child under 6 years of age **evidence of severe Global Developmental Delay is by definition severe impairment in 3 or more domains** of neurodevelopment.
- To make a diagnosis of FASD in children < 6 years of age **3 sentinel facial features are required** in addition to confirmed or unknown PAE and either microcephaly or neurodevelopmental impairment in 3 or more domains (including severe Global Development Delay) or both.
- Infants and children under 6 years of age with **confirmed or unknown PAE, all three sentinel facial features and microcephaly** can be given a diagnosis of **FASD with 3 Sentinel Facial Features**, even without evidence of severe neurodevelopmental impairment in 3 domains. (41, 42)
- Infants and children under 6 years of age with **confirmed or unknown PAE, all three sentinel facial features and severe Global Developmental Delay** can be given a diagnosis of **FASD with 3 Sentinel Facial Features**
- Infants and children under 6 years of age with confirmed PAE or unknown PAE and all three sentinel facial features who do not currently meet criteria for neurodevelopmental impairment may in time fulfil FASD criteria and hence need ongoing monitoring 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 or in supervised residential care 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 learning from consequences can be suggestive of 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 and neurology	Definition	Brain structure and neurology includes: <ul style="list-style-type: none"> ▪ Abnormal occipitofrontal head circumference ▪ Structural brain abnormalities ▪ Seizure disorder not due to known postnatal causes ▪ Significant neurological diagnoses otherwise unexplained
	Direct/indirect assessment	<p>Severe impairment is present when one or more of the following are identified:</p> <ul style="list-style-type: none"> ▪ Occipitofrontal head circumference is <3rd PC or ≤2 SD <ul style="list-style-type: none"> ○ 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 imagingⁱ <p>Examples include:</p> <ul style="list-style-type: none"> ○ Reduction in overall brain size ○ Corpus callosum (agenesis, hypoplasia) ○ Cerebral cortex (reduced gyrification or anterior cingulate cortex surface area) ○ Reduction in volume in specific areas: cerebellum, hippocampus, basal ganglia – caudate ▪ Seizure disorder in which other aetiologies have been excluded. ▪ Significant neurological diagnoses otherwise unexplained are identified e.g. cerebral palsy, visual impairment, sensorineural hearing loss <i>when other aetiologies have been excluded</i>
	Considerations	<p>Microcephaly</p> <p>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.</p> <p>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</p>

		<p>used to judge whether this discrepancy reflects persistent microcephaly or may reflect measurement error.</p> <p>Neuroimaging</p> <p>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.</p>
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). (43, 44)
	Direct assessment	<p>Severe impairment in motor skills is present <i>when</i>:</p> <ul style="list-style-type: none"> ▪ A composite score derived from a validated test of motor skills is below the clinical cut-off; <i>or</i> ▪ When 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]. (40) <p>Examples of standardised tests:</p> <ul style="list-style-type: none"> ○ 4 - 6y; BOT2 (40) (gross motor and fine motor), ○ 2y – adult; Beery (32) (visual motor integration) ○ 6y – 21y; BOT2 (40) (gross motor and fine motor); ○ 3y – 16y 11m; Movement-ABC 2 (45)
	Indirect assessment	<p>Clinical assessment may provide supporting evidence of severe impairment: e.g. report of problems with balance, coordination.</p> <p>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.</p> <p>Clinical evidence of impairment in speech articulation or oral-motor function may be considered in combination with direct assessment of motor skills</p>
	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 ($\leq 16^{\text{th}}$ centile). If this is documented during

		<p>assessment it is important to ensure adequate therapeutic supports are in place, even if criteria for severe impairment ($\leq 2SD$ or $< 3^{rd}$ PC) are not met.</p> <p>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) (40) which provides separate composite scores for gross and fine motor function to inform therapy. An overall motor composite score may hide a child's relative strengths and weaknesses.</p> <p>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)</p>
3. Cognition	Definition	<p>Cognition includes IQ, verbal and non-verbal reasoning skills, processing speed, and working memory.</p>
	Direct assessment	<p>Severe impairment is present when standardised tests of cognition or intelligence show:</p> <ul style="list-style-type: none"> ▪ a composite score below the clinical cut-off - e.g. full scale IQ < 70 <i>or</i> ▪ a major subdomain score below the clinical cut-off e.g. for the WISC (35) this includes Verbal Comprehension, Visual Spatial, Fluid Reasoning, and Processing Speed <i>or</i> ▪ there is a significant discrepancy among major subdomain scores. <p>Examples of standardised tests:</p> <ul style="list-style-type: none"> ▪ < 6 years <ul style="list-style-type: none"> ○ Wechsler Preschool and Primary Scale of Intelligence (WPPSI-IV) (35); 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; (50) up to 21 y ▪ > 6 years <ul style="list-style-type: none"> ○ Wechsler Intelligence Scales for Children (WISC-V ANZ)(36); 6y - 16y 11m ○ Stanford-Binet Intelligence Scales (SB-5); (48) up to 85 y ○ Wechsler Adult Intelligence Scale (WAIS-IV) (36); 16 - 90 years ○ Differential Abilities Scales (DAS-II); (49) up to 17 y ○ Universal Nonverbal Intelligence Test (non-verbal test) (38); 5 - 21y 11m ○ Wechsler Non-Verbal Scale of Ability (WNV); (50) 4 -21y

		<ul style="list-style-type: none"> ○ Naglieri Nonverbal Ability Test - Second Edition (NNAT-2) (51) 4 - 18 y
	Considerations	<p>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).</p> <p>If working memory alone is severely impaired (below the clinical cut-off), this should be considered evidence of impairment in the <i>Executive functioning</i> domain rather than in the <i>Cognition</i> domain.</p> <p>A test that is independent of language and culture e.g. the Universal Non-verbal Intelligence Test (38) may be appropriate for certain populations e.g. Australian Aboriginal, refugee or immigrant children.</p>
4. Language	Definition	Language includes expressive and receptive language skills.
	Direct assessment	<p>Severe impairment is present when:</p> <ul style="list-style-type: none"> ▪ a composite score assessing core language, receptive language, and/or expressive language is below the clinical cut-off <i>or</i> ▪ when there is a significant discrepancy between receptive and expressive composite scores <i>or</i> ▪ when 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) <p>Examples of standardised tests:</p> <ul style="list-style-type: none"> ○ Clinical evaluation of language fundamentals (CELF-4);(52) 5y - 21y 11m ○ Pre-School Language Scales, 5th Ed; (53) birth - 7y 11m
	Considerations	<p>This domain should be assessed as if it is a single entity, e.g. it is inappropriate to use scores on verbal IQ sub-tests as a measure of <i>both</i> language and cognition.</p> <p>When possible, testing should be done in the individual's first language. Specific tests may be available e.g. for some Indigenous languages.</p> <p>Clinical judgment regarding severity of impairment is required if:</p> <ul style="list-style-type: none"> ▪ testing is not standardised ▪ testing is not in an individual's first language ▪ direct assessment is not possible.

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: <ul style="list-style-type: none"> ▪ a <i>composite score</i> below the clinical cut-off <i>or</i> ▪ when there is a significant discrepancy between cognition and either reading, mathematics, and/or written expression. Examples of standardised tests: <ul style="list-style-type: none"> ○ Wechsler Individual Achievement Test (WIAT) (54) ○ Woodcock–Johnson Achievement Test (WJAT) (55)
	Indirect assessment	The following information can be used as supporting evidence for severe impairment: <ul style="list-style-type: none"> ▪ The National Assessment Program Literacy and Numeracy (NAPLAN) test results (56) ▪ 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 <i>Cognition</i>), impairment can also be given in the domain of <i>Academic achievement</i> because some individuals with mild intellectual disability perform in the low average academically. Both domains should be tested and considered separately. If an individual has a Specific Learning Disorder according to DSM5 (31) they fulfil criteria for severe impairment in academic achievement, providing testing shows evidence of impairment at clinical cut-off of at or below 2SD
6. Memory	Definition	Memory includes overall memory, verbal memory, and visual memory
	Direct assessment	Severe impairment in memory is present when: <ul style="list-style-type: none"> ▪ a composite score for overall memory and/or verbal memory, and/or visual memory score is below the clinical cut-off (i.e. 2 SD below the mean) <i>or</i>

		<ul style="list-style-type: none"> ▪ when there is a significant discrepancy between verbal and nonverbal memory <p>Examples of standardised tests:</p> <ul style="list-style-type: none"> ○ Developmental Neuropsychological Assessment (NEPSY-II) (57), Memory and Learning sub-tests; 3 - 16 years ○ Wide Range Assessment of Memory and Learning, 2nd Edition (WRAML-II); (58) 5 - 90 years ○ Children’s Memory Scale (CMS), (59) 5 - 16 years
	Considerations	A deficit in <i>working memory</i> should be considered in the <i>Executive function</i> rather than <i>Memory</i> domain.
7. Attention	Definition	<p>Attention has several components:</p> <ul style="list-style-type: none"> i) <i>selective</i> attention (i.e. focusing on a particular stimuli) ii) <i>divided</i> attention (i.e. attending to 2 or more stimuli at the same time) iii) <i>alternating</i> attention (i.e. switching focus from one stimuli to another) iv) <i>sustained</i> attention (i.e. attending for a long period of time and resistance to distractions). <p>Attention deficits usually manifest as problems with concentration, task focus and work organisation.</p> <p>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.</p> <p>Deficits in inhibition, impulse control or hyperactivity should be considered in the domain of <i>Executive function, Impulse control and Hyperactivity</i> rather than <i>Attention</i>.</p>
	Direct assessment	<p><i>Severe impairment in attention is present on direct assessment</i> when two or more subtest scores are below the clinical cut-off on continuous performance tests or other neuropsychological measures of selective, divided, alternating or sustained attention.</p> <p>Examples of standardised tests:</p> <ul style="list-style-type: none"> ○ Conner’s Continuous Performance Test: 3rd Ed (60); 8 - 60+ years ○ Test of Everyday Attention for Children (Tea-CH) (61); 6 - 16 years ○ Delis-Kaplan Executive Function System (DKEFS) (62) i.e. Trail Making Test, Colour/Word Interference; 8 - 89 years.

		<ul style="list-style-type: none"> ○ Developmental Neuropsychological Assessment (NEPSY-II)(57), Attention sub-tests; 3 - 16 years ○ Children’s Colour Trails Test (63) ; 8 - 16 years ○ Adult Colour Trails Test; (64) 18 - 89 years
	Indirect assessment	<p><i>Severe impairment in attention by indirect assessment</i> is present when two or more <i>assessments</i> provide converging evidence of impairment e.g.:</p> <ul style="list-style-type: none"> ▪ clinical interview by different professionals ▪ scores at or below the clinical cut-off on standardised observer rating scales e.g. Connors 3 (parent, teacher or self-report) (60) ▪ file review ▪ direct clinical observation during neurodevelopmental testing <p>Examples of standardised rating scales:</p> <ul style="list-style-type: none"> ○ Connors 3rd Edition (60); 6 - 18y ○ Connors Comprehensive Behaviour Rating Scales (65); 6 - 17y 11m ○ Connors Adult ADHD Rating Scales (CAARS) (66); 18 - 50+ y ○ Achenbach scales - Child Behaviour Check List and Teacher Report Form (67)
	Considerations	<p>A diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) based on DSM-5 criteria (31) – either <i>inattentive</i> or <i>combined</i> presentation - fulfils criteria for severe impairment in the domain of <i>Attention</i>. Valid direct or indirect assessment methods and cutoffs should be used to make this diagnosis. ADHD hyperactive-impulsive presentation contributes to impairment in the <i>Executive function, Impulse Control and Hyperactivity Domain</i>.</p> <p>Direct tests of attention which are part of testing in other domains (e.g. WISC, memory testing) can be used as evidence of impairment.</p> <p>When indirect and direct tests of attention do not concur, clinical judgment is required to determine whether severe impairment exists. Consideration that <i>indirect</i> assessment may better reflect attention deficits in real life situations (e.g. at work or in school) may be pertinent.</p>

8. Executive function, impulse control and hyperactivity	Definition	<p>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.</p> <p>For the purposes of FASD diagnostic criteria, the domain of <i>Executive Function</i> 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.</p> <p>Impulse control deficits are characterised by actions without forethought, which often have potential for harm to self or others.</p> <p>Hyperactivity is characterised by inappropriate and excessive levels of motor activity or speech.</p>
	Direct assessment	<p><i>Severe impairment in Executive functioning by direct assessment</i> is present when at least two or more subtest scores below the clinical cut-off are obtained on neuropsychological measures of executive function.</p> <p>Examples of standardised assessment tools:</p> <ul style="list-style-type: none"> ○ Developmental Neuropsychological Assessment (NEPSY-II) (57) Executive Functioning sub-tests – from 3 - 16 years. ○ Delis-Kaplan Executive Function System (DKEFS) (62) – from 8 - 89 years. ○ Rey-Osterrieth Complex Figure (ROCF) (68)
	Indirect assessment	<p><i>Severe impairment in executive function by indirect assessment</i> is present when a clinical assessment provides converging evidence of impairment from multiple sources, including scores at or below the clinical cutoff* on standardised rating scales and supporting evidence from clinical interview, file review and direct clinical observation during neurodevelopmental testing.</p> <p>Examples of standardised rating scales</p> <ul style="list-style-type: none"> ○ Behavior Rating Inventory of Executive Function (BRIEF-II) (69) ○ Comprehensive Executive Function Inventory (CEFI) (70) –5 - 18 years ○ Frontal Systems Behaviour Scale (FrsBe) (71) –18 - 95 years. ○ Impulsivity is typically measured on rating scales for attention listed in the <i>Attention</i> domain above (e.g. Conners 3) (60)

	Considerations	<p>A diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) – either combined or hyperactive-impulsive presentation - based on DSM-5 criteria (31), does <u>not</u> fulfil criteria for severe impairment in the domain of <i>Executive function, Impulse Control and Hyperactivity Domain</i>. Additional evidence is required from other indirect and direct assessments to fulfil criteria for severe impairment.</p> <p>Assessment may show a discrepancy between <i>direct</i> and <i>indirect</i> tests in this domain due to the varying conceptualisations of executive function and related tests. In the situation where <i>indirect</i> tests show impaired scores but <i>direct</i> tests scores are normal, significant weight should be given to the <i>indirect</i> 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 cutoff, then the <i>Executive Function, Impulse Control and Hyperactivity</i> domain is considered severely impaired.</p>
9. Affect regulation	Definition	Affect regulation includes mood and anxiety disorders.
	Direct assessment	Not possible
	Indirect assessment	<p><i>Severe impairment in affect regulation by indirect assessment</i> is present when an individual meets the DSM-5 (31) criteria for</p> <ul style="list-style-type: none"> ▪ 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. <p>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.</p> <p>Standardised rating scales include:</p> <ul style="list-style-type: none"> ○ Spence Children’s Anxiety Scales (SCAS); (72) 8-15y ○ Behaviour Assessment System for Children-III (73); 2 - 21y ○ Beck Youth Inventories, 2nd Edition (BYI-II) (74) ○ Children’s Depression Inventory 2 (CDI-2), (75)7 – 17y ○ Multidimensional Anxiety Scale for Children 2nd Edition (MASC 2) (76) ○ Child Behaviour Checklist (67) 6 – 18y (note these are broadband scales)

		<ul style="list-style-type: none"> ○ Conners Comprehensive Behaviour Rating Scales (65); 6 - 17y 11m (note these are broadband scales)
	Considerations	<p>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).</p> <p>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 was before the age of 10 years.</p>
10. Adaptive behaviour, social skills, or social communication	Definition	<p>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.</p> <p>These include: (31)</p> <ul style="list-style-type: none"> ▪ <i>Conceptual</i> skills - language, reading, writing, math, reasoning, knowledge, and memory ▪ <i>Social</i> skills - empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships ▪ <i>Practical</i> skills - self-management in areas such as personal care and daily living skills, job responsibilities, money management, recreation, and organising school and work tasks. <p>Social communication is a critical component of adaptive function but can be assessed separately.</p>
	Direct assessment	<p><i>Severe impairment in social communication by direct assessment</i> is present when a composite score measuring <i>social language, social communication skills or pragmatic language skills</i> is below the clinical cut-off.</p> <p>Examples of standardised assessment tools for individuals >6 years of age:</p> <ul style="list-style-type: none"> ○ The Social Language Development Test – Elementary (SLDT-E) (77); 6y - 11y11m ○ The Social Language Development Test – Adolescent (SLDT-A) (78); 12y - 17y11m
	Indirect assessment	<p><i>Severe impairment in adaptive behaviour, social skills or social communication by indirect assessment</i> is present when, according to a standardised interview or rating scale completed by a key informant a:</p> <ul style="list-style-type: none"> ▪ <i>Composite score</i> is below the clinical cut-off <i>or</i> ▪ <i>a major subdomain score</i> is below the clinical cutoff

		<p><i>For children and most adolescents</i>, standardised observer rating scales for adaptive function (typically for caregiver and/or teacher) should be used, although this may not be possible e.g. a child in detention.</p> <p>Examples include:</p> <ul style="list-style-type: none"> ○ Vineland Adaptive Behaviour Scales, 2nd Ed (33) (VABS-II); birth - 90 y ○ Adaptive Behaviour Assessment System (ABAS-III); (79) birth - 89y ○ Behaviour Assessment System for Children – 3 (BASC-3) (79); 2 - 21 y ○ Pragmatic Language Observation Scale (PLOS) (80); 8 – 17y 11m ○ Children’s Communication Checklist, 2nd Edition (81); child and adult versions available. ○ Clinical Evaluation of Language Fundamentals (CELF-4 Australian) (52) Pragmatics Profile; 5 - 21y 11m
	Special considerations	<p>Severe impairment in <i>social skills and social communication</i> is present when on formal testing an individual meets the DSM-5 (31) criteria for:</p> <ul style="list-style-type: none"> ▪ Autism Spectrum Disorder ▪ Social (Pragmatic) Communication Disorder <p>When individuals individual meet DSM-5 criteria for Conduct Disorder and/or severe Oppositional Defiant Disorder, this provides supporting evidence for impairment in the <i>Adaptive behaviour, social skills, social communication</i> 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).</p> <p>Older adolescents and adults</p> <p>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.</p> <p>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.</p>

		<p>For example, assessment of <i>adaptive function</i> 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:</p> <ul style="list-style-type: none">• Documented inability to function in key aspects on independent living (inability to manage money, maintain a household of reasonable 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. <p>For <i>social communication</i> 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).</p>
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Section C: Assessing Sentinel Facial Features

Fetal exposure to alcohol affects development of facial features, primarily during the first trimester. 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**

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 anomalies 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 (82, 83). 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 (84, 85)

Other dysmorphic features

Other dysmorphic features have been observed in FASD but are not specific to FASD.

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 with 3 sentinel facial features (also referred to as FAS). (86)

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 FAS (or FASD with three sentinel facial features). (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.

In children exposed to prenatal alcohol exposure growth deficiency is relatively consistent over time (3) and correlates with severity of CNS dysfunction.(42)

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)

For example:

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 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 parent/caregiver 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, provided written information about FASD and provide contact details for NOFASD Australia - National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia <http://www.nofasd.org/> or phone 1300 306 238.

- For information and resources for 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 women 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

http://www.kemh.health.wa.gov.au/services/register_developmental_anomalies/

South Australian Birth Defects Registry

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

References

1. Jones KL, Smith DW. Recognition of the fetal alcohol syndrome in early infancy. *Lancet*. 1973;302(7836):999-1001.
2. Sokol R, Delaney-Black V, Nordstrom B. Fetal Alcohol Spectrum Disorder. *Journal Of the American Medical Association*. 2003;290(22):2996-9.
3. Astley SJ. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*. Third ed. Seattle: University of Washington; 2004.
4. Chudley A, Conry J, Cook J, Look C, Rosales T, LeBlanc N. Fetal Alcohol Spectrum Disorder: Canadian Guidelines for Diagnosis. *Can Med Assoc J*. 2005;172:S1 - S21.
5. Hoyme HE, May PA, Kalberg WO, Kodituwakku P, Gossage JP, Trujillo PM, et al. A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: Clarification of the 1996 Institute of Medicine Criteria. *Pediatrics*. 2005;115:39-47.
6. Landgraf MN, Nothacker M, Heinen F. Diagnosis of fetal alcohol syndrome (FAS): German guideline version 2013. *European Journal of Paediatric Neurology*. 2013;17(5):437-46.
7. Stratton K, Howe C, Battaglia F. *Fetal alcohol syndrome: diagnosis, epidemiology, prevention, and treatment*. Washington: Institute of Medicine and National Academy Press; 1996.
8. May PA, Gossage JP. Maternal Risk Factors for Fetal Alcohol Spectrum Disorders: Not As Simple As It Might Seem. *Alcohol Research & Health*. 2011;34(1):15-26.
9. Ramsay M. Genetic and epigenetic insights into fetal alcohol spectrum disorders. *Genome Med*. 2010;2(4):27.
10. National Health and Medical Research Council. *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*. Canberra, Australian Capital Territory: Commonwealth of Australia, 2009.
11. Popova S, Lange S, Burd L, Rehm J. The Economic Burden of Fetal Alcohol Spectrum Disorder in Canada in 2013. *Alcohol and Alcoholism*. 2015.;51:367-375.
12. House of Representatives Standing Committee on Social Policy and Legal Affairs. *FASD: The Hidden Harm, Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*. Canberra: The Department of the House of Representatives, 2012.
13. Elliott E, Payne J, Bower C. Paediatricians' knowledge, practice and opinions about fetal alcohol syndrome and alcohol consumption in pregnancy. *Journal of Paediatrics and Child Health*. 2006;42:698-703.
14. Payne J, Elliott E, D'Antoine H, o'Leary C, Mahony A, Haan E, et al. Health professionals' knowledge, practice and opinions about fetal alcohol syndrom and alcohol consumption during in pregnancy. *Australian & New Zealand Journal of Public Health*. 2005;29(6):558-64.
15. Watkins RE, Elliott EJ, Wilkins A, Mutch RC, Fitzpatrick JP, Payne JM, et al. Recommendations from a consensus development workshop on the diagnosis of fetal alcohol spectrum disorders in Australia. *BMC Pediatrics*. 2013;13:156.
16. Cook JL, Green CR, Lilley CM, Anderson SM, Baldwin ME, Chudley AE, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Canadian Medical Association Journal*. 2016;188(3):191-7.
17. Peadon E, Fremantle E, Bower C, Elliott EJ. International survey of diagnostic services for children with Fetal Alcohol Spectrum Disorders. *BMC Pediatrics*. 2008;8:12.
18. Astley SJ. *Diagnosing Fetal Alcohol Spectrum Disorders (FASD)*. Prenatal Alcohol Use and FASD: A Model Standard of Diagnosis, Assessment and Multimodal Treatment: Benthan Science Publishers Ltd; 2011.
19. Bertrand J, Floyd RL, Weber MK. Guidelines for identifying and referring persons with fetal alcohol syndrome. *MMWR: Morbidity & Mortality Weekly Report*. 2005;54(RR-11):1-14.

20. Stratton K. FAS diagnosis, epidemiology, prevention and treatment. 1996.
21. Feldman H, S., K.L. J, Lindsay S, Slymen D, al e. Prenatal alcohol exposure patterns and alcohol-related birth defects and growth deficiencies: prospective study. *Alcohol Clin Exp Res.* 2012;36:670-6.
22. Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders, editor Consensus statement on recognising alcohol-related neurodevelopmental disorder (ARND) in primary health care of children: A conference organized by the Interagency Coordinating Committee on Fetal Alcohol Spectrum Disorders (ICCFASD) Oct. 31-Nov. 2, 2011, Rockville, MD. Available from http://www.niaaa.nih.gov/AboutNIAAA/Interagency/Documents/ARND%20Conference%20Consensus%20Statement%20Booklet_Complete_LOW.pdf2011.
23. Sampson PD, Streissguth AP, Bookstein FL, Barr HM. On categorizations in analyses of alcohol teratogenesis. *Environmental Health Perspectives.* 2000;108 (Suppl 3):421-8.
24. O'Leary CM, Bower C. Guidelines for pregnancy: What's an acceptable risk, and how is the evidence (finally) shaping up? *Drug and Alcohol Review.* 2012;31(2):170-83.
25. Bush K, Kivlahan DR, McDonnell MB, Fihn SD, Bradley KA. The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. Ambulatory Care Quality Improvement Project (ACQUIP). Alcohol Use Disorders Identification Test. *Arch Intern Med.* 1998;158(16):1789-95.
26. Bradley KA, Bush KR, Epler AJ, Dobie DJ, Davis TM, Sporleder JL, et al. Two brief alcohol-screening tests From the Alcohol Use Disorders Identification Test (AUDIT): validation in a female Veterans Affairs patient population. *Archives of Internal Medicine.* 2003;163(7):821-9.
27. Bradley KA, Kivlahan DR, Williams EC. Brief approaches to alcohol screening: practical alternatives for primary care. *Journal of General Internal Medicine.* 2009;24(7):881-3.
28. Dawson DA. Defining risk drinking. *Alcohol Research and Health.* 2011;34(2):144-56.
29. O'Leary CM, Bower C, Zubrick SR, Geelhoed E, Kurinczuk JJ, Nassar N. A new method of prenatal alcohol classification accounting for dose, pattern, and timing of exposure: Improving our ability to examine fetal effects from low to moderate exposure. *Journal of Epidemiology and Community Health.* 2010;64:956-62.
30. Griffiths R. Griffiths' Mental Development Scales, Third Edition (GMDS): Hogrefe Ltd; 2006.
31. Association AP. Diagnostic and Statistical Manual of Mental Disorders (Fifth ed.). Arlington, VA: American Psychiatric Publishing; 2013.
32. Beery K, Beery N, Buktenika N. Beery-Buktenica Developmental Test of Visual-Motor Integration (VMI) 5th edition. 2004.
33. Sparrow S, Cicchetti D, Balla D. Vineland Adaptive Behavior Scale, Second Edition (Vineland-II). Circle Pines, MN: AGS; 2006.
34. Wechsler D. Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV). San Antonio, TX: The Psychological Corporation; 2008.
35. Wechsler D. Wechsler Preschool and Primary Scales of Intelligence, Fourth Edition (WPPSI-IV): Pearson; 2012.
36. Wechsler D. Wechsler Intelligence Scale for Children, Fifth Edition: Australian and New Zealand Standardised Edition (WISC-V A&NZ): Pearson; 2016.
37. Popova S, Lange S, Shield K, Mihic A, Chudley AE, Mukherjee RAS, et al. Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis. *The Lancet.* 2016;387(10022):978-87.
38. Bracken B, McCallum S. Universal Non Verbal Intelligence Test. Itasca, IL Riverside Publishing; 1998.
39. Flanagan DP, Kaufman AS. Essentials of WISC-IV Assessment (2nd Revised Edition): John Wiley & Sons; 2009.

40. Bruininks R, Bruininks B. Bruininks-Oseretsky Test of Motor Proficiency, Second Edition. Minneapolis, MN: NCS Pearson; 2005.
41. Astley SJ. Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Can J Clin Pharmacol*. 2010;17(1):e132-64.
42. Astley SJ. Validation of the fetal alcohol spectrum disorder (FASD) 4-Digit Diagnostic Code. *J Popul Ther Clin Pharmacol*. 2013;20(3):e416-67.
43. Doney R, Lucas BR, Jones T, Howat P, Sauer K, Elliott EJ. Fine Motor Skills in Children With Prenatal Alcohol Exposure or Fetal Alcohol Spectrum Disorder. *J Dev Behav Pediatr*. 2014;35:598-609.
44. Lucas BR, Latimer J, Doney R, Ferreira ML, Adams R, Hawkes G, et al. The Bruininks-Oseretsky Test of Motor Proficiency-Short Form is reliable in children living in remote Australian Aboriginal communities. *BMC Pediatr*. 2013;13(1):135.
45. Henderson AJ, Sugden DA, Barnett AL. Movement Assessment Battery for Children - Second Edition (Movement ABC-2). London: The Psychological Corporation; 2007.
46. Lucas BR, Latimer J, Fitzpatrick JP, Doney R, Watkins RE, Tsang TW, et al. Soft neurological signs and prenatal alcohol exposure: a population-based study in remote Australia. *Developmental Medicine & Child Neurology*. 2016;DOI:10.1111/dcmn.13071.
47. Jones KL, Hoyme HE, Robinson LK, del Campo M, Manning MA, Prewitt LM, et al. Fetal alcohol spectrum disorders: Extending the range of structural defects. *American Journal of Medical Genetics Part A*. 2010;152A(11):2731-5.
48. Roid G. Stanford-Binet Intelligence Scales - SB5: Pro-Ed; 2003.
49. Elliott CD. Differential Ability Scales®, Second Edition (DAS®-II): Pearson; 2007.
50. Wechsler D. Wechsler nonverbal scale of ability. San Antonio: Harcourt Assessment; 2006.
51. Naglieri JA. Naglieri Nonverbal Ability Test® - Second Edition (NNAT®-2): Pearson; 2011.
52. Semel E, Wiig EH, Secord WA. Clinical Evaluation of Language Fundamentals®, Fourth Edition (CELF®-4). Sydney: Pearson; 2003.
53. Zimmerman IL, Steiner VG, Pond RE. Preschool Language Scale, Fifth Edition (PLS-5): Pearson; 2011.
54. Wechsler D. Wechsler Individual Achievement Test 2nd Edition WIAT-II: Pearson; 2001.
55. Woodcock RW, McGrew KS, Mather N. Woodcock-Johnson Tests of Achievement (WJ-III): Riverside Publishing; 2001.
56. Australian Curriculum Assessment and Reporting Authority (ACARA). National Assessment Program - Literacy and Numeracy. Summary Report. Sydney: ACARA, 2011.
57. Korkman M, Kirk U, Kemp S. NEPSY®, Second Edition (NEPSY®-II): Pearson; 2007.
58. Sheslow D, Adams W. Wide Range Assessment of Memory and Learning (WRAML2): Pearson; 2003.
59. Cohen M. Children's Memory Scale (CMS): Pearson; 1997.
60. Conners CK. Conners' Continuous Performance Test 3 (Conners' CPT 3): MHS; 2014.
61. Manly T, Robertson IH, Andersen V, Nimmo-Smith I. Test of Everyday Attention for Children (TEA-CH): Pearson; 1998.
62. Delis DC, Kaplan E, Kramer JH. Delis-Kaplan Executive Function System. San Antonio: Harcourt Brace & Company; 2001.
63. Llorente AM, Williams J, Satz P, D'Elia LF. Children's Color Trails Test™ (CCT™). Lutz, FL: PAR; 2003.
64. D'Elia LF, Satz P, Uchiyama CL, White T. Color Trails Test™ (CTT™): PAR; 1996.
65. Conners CK. Conners' Comprehensive Behavior Rating Scales (Conners CBRS™). Toronto, ON: MHS; 2008.
66. Conners CK, Erhardt D, Sparrow E. Conners' Adult ADHD Rating Scale (CAARS™): MHS; 1999.
67. Achenbach TM, Rescorla LA. Child Behavior Checklist (CBCL). Burlington, VT: University of Vermont; 2000.

68. Rey A, Osterrieth P. Translations of excerpts from Rey's 'psychological Examination of Traumatic Encephalopathy' and Osterrieth's 'The Complex Figure Test'. *the Clinical Neuropsychologist*. 1993;7:2-21.
69. Gioia GA, Isquith P, Guy SC, Kenworthy L. Behavior Rating Inventory of Executive Function (BRIEF): PAR; 2000.
70. Naglieri JA, Goldstein S. Comprehensive Executive Function Inventory® (CEFI®): MHS; 2012.
71. Grace J, Malloy PF. Frontal Systems Behavior Scale (FrSBe): PAR; 2001.
72. Spence SH. A measure of anxiety symptoms among children - Spence Children's Anxiety Scales (SCAS). *Behaviour Research and Therapy*. 1998;36:545-66.
73. Reynolds CR, Kamphaus RW. Behavior Assessment System for Children, Third Edition (BASC-3): Pearson; 2015.
74. Beck JS, Beck AT. Beck Youth Inventories - Second Edition (BYI-II): Pearson; 2005.
75. Kovacs M. Children's Depression Inventory 2™ (CDI 2): Pearson; 2010.
76. March JS. Multidimensional Anxiety Scale for Children: Pearson; 2012.
77. Bowers L, Huisingsh R, LoGuidice C. Social Language Development Test Elementary: Pro-ed Australia; 2006.
78. Bowers L, Huisingsh R, LoGuidice C. Social Language Development Test Adolescent: Linguisticsystems; 2007.
79. Harrison P, Oakland T. Adaptive Behavior Assessment System®, Second Edition (ABAS®-II): Pearson; 2003.
80. Newcombe P, Hammill DD. Pragmatic Language Observation Scale (PLOS): Pro-Ed; 2009.
81. Bishop D. Children's Communication Checklist - Second Edition (CCC-2): Pearson; 2003.
82. Astley SJ, Clarren SK. Measuring the facial phenotype of individuals with prenatal alcohol exposure: correlations with brain dysfunction. *Alcohol Alcohol*. 2001;36(2):147-59.
83. Astley S. FAS Facial Photographic Analysis Software. 1.0.0 ed. Seattle: FAS Diagnostic & Prevention Network, University of Washington; 2003.
84. May PA, Gossage JP, Smith M, Tabachnick BG, Robinson, L.K., Manning M, et al. Population differences in dysmorphic features among children with fetal alcohol spectrum disorders. *J Developmental and Behavioral Pediatrics*. 2010;31:304-16.
85. Fang S, McLaughlin J, Fang J, Huang J, Autti-Ramo I, Fagerlund A, et al. Automated diagnosis of fetal alcohol syndrome using 3D facial image analysis. *Orthod Cranio Fac Res*. 2012;11:162-71.
86. Leibson T, Neuman G, Chudley A, Koren G. The differential diagnosis of fetal alcohol spectrum disorder. *J Popul Ther Clin Pharmacol*. 2014;21((1)).
87. Ogden CL, Kuczmarski RJ, Flegal KM, Mei Z, Guo S, Wei R, et al. Centers for Disease Control and Prevention 2000 growth charts for the United States: improvements to the 1977 National Center for Health Statistics version. *Pediatrics*. 2002;109(1):45-60.
88. Nwosu BU, Lee MM. Evaluation of short and tall stature in children. *American Family Physician*. 2008;78(5):597-604.

List of Appendices

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

Appendix A1 Australian FASD Diagnostic Assessment Form

Appendix A2 Australian FASD Diagnostic Assessment Summary Form

Appendix A3 Australian FASD Management Plan Form

Appendix A4 Information on FASD Diagnostic Assessment for Parents and Carers

Appendix A5 Australian FASD Diagnostic Assessment Consent Form

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

Appendix A7 Support for individuals and families after a diagnostic assessment

Appendix A8 Information for clinicians after a diagnostic assessment

Appendix A9 Referral and Screening guidelines for FASD

Appendix B Standard drink sizes for commonly consumed drinks

Appendix C Assessment of Sentinel Facial Features

Appendix D Syndromes with constellations of features which overlap with FASD with 3 Sentinel Facial Features

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	
Hospital number (if applicable)	
Sex	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Other
Date of birth (DD/MM/YYYY)	/ / Age at assessment:
Racial/ ethnic background	
Preferred language	
Referral source, date, provider number and contact details	
Name of person(s) accompanying patient	
Relationship (s) to the patient	
Patient's primary carer <small>(select 1 or more)</small>	<input type="checkbox"/> Birth mother <input type="checkbox"/> Birth father <input type="checkbox"/> Foster carer <input type="checkbox"/> Adoptive parent/s <input type="checkbox"/> Other
Birth mother's name	
Birth father's name	
Patient in care of	<input type="checkbox"/> Department of Child Protection <input type="checkbox"/> Juvenile justice <input type="checkbox"/> Not applicable
Consent form for assessment completed	<input type="checkbox"/> No <input type="checkbox"/> 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.

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT FORM

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
<input type="checkbox"/>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 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
<input type="checkbox"/>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 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
<input type="checkbox"/>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4

AUDIT-C score during this pregnancy: (Q1+Q2+Q3)= _____ Scores= 0=no risk 1-4= confirmed use 5+= confirmed high-risk

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 None Confirmed use Confirmed-high risk

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

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT FORM

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

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT FORM

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*
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis						
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis						

PFL reference chart used: Stromland Clarren Other

Philtrum

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis	
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis	
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis	

Upper lip

Date	Age	Assessment method	UW Lip-Philtrum Guide 5-point rank
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis	
		<input type="checkbox"/> direct measure <input type="checkbox"/> photo analysis	
		<input type="checkbox"/> direct measure <input type="checkbox"/> 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 AND NEUROLOGY DOMAIN

BRAIN STRUCTURE

Occipitofrontal Circumference (OFC)

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

*correct for gestational age when < 2 years old

Parental OFC (if available)

Mother's OFC (cm)	Father's OFC (cm)	Percentile	Reference used

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 and Neurology domain summary

Evidence of brain structure/neurological 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: <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

3. COGNITION

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Cognition impairment: <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

4. LANGUAGE

(Expressive and Receptive)

Test/subtest name	Age/Date	Score	%ile/SD	Interpretation
Other information:				
Language impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

5. ACADEMIC ACHIEVEMENT

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Academic achievement impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

6. MEMORY

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Memory impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

7. ATTENTION

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Attention impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

8. EXECUTIVE FUNCTION, IMPULSE CONTROL AND HYPERACTIVITY

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Executive function, impulse control and hyperactivity impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

9. AFFECT REGULATION

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Affect regulation impairment: <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

10. ADAPTIVE BEHAVIOUR, SOCIAL SKILLS, SOCIAL COMMUNICATION

Test/subtest name	Age/ Date	Score	%ile/SD	Interpretation
Other information:				
Adaptive behaviour, social skills, social communication impairment <input type="checkbox"/> None <input type="checkbox"/> Some <input type="checkbox"/> Severe <input type="checkbox"/> Not assessed				

NEURODEVELOPMENTAL DOMAINS SUMMARY

Number of neurodevelopmental domains with evidence of severe impairment: <input type="checkbox"/> None <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 or more (specify) _____
--

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT FORM

DIAGNOSIS:

For derivation of the Australian FASD diagnostic categories, please refer to the Australian FASD Diagnostic Criteria and FASD Diagnostic Pathway Algorithms on pages 12-14 below (Table 1 and Figures 1 and 2). 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)

Appendix A2: Australian FASD Diagnostic Assessment Summary Form

AUSTRALIAN FASD DIAGNOSTIC ASSESSMENT SUMMARY FORM

PATIENT DETAILS

NAME	
Hospital number (if applicable)	
Sex	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Other
Date of birth (DD/MM/YYYY)	/ / Age at assessment:
Racial/ethnic background	

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 None Confirmed use Confirmed-high risk

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 and Neurology	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> Not assessed	
2 Motor Skills	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
3 Cognition	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
4 Language	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
5 Academic achievement	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
6 Memory impairment	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
7 Attention	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
8 Executive function, impulse control and hyperactivity	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
9 Affect regulation	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> Not assessed
10 Adaptive behavior, social skills, social communication	<input type="checkbox"/> None	<input type="checkbox"/> Some	<input type="checkbox"/> Severe	<input type="checkbox"/> 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 *Tick 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)

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 and Neurology				
2 Motor skills				
3 Cognition				
4 Language				
5 Academic achievement				
6 Memory				
7 Attention				
8 Executive Function, Impulse Control and Hyperactivity				
9 Affect regulation				
10 Adaptive behaviour, social skills, social communication				

AUSTRALIAN FASD MANAGEMENT PLAN FORM

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 Parents and Carers

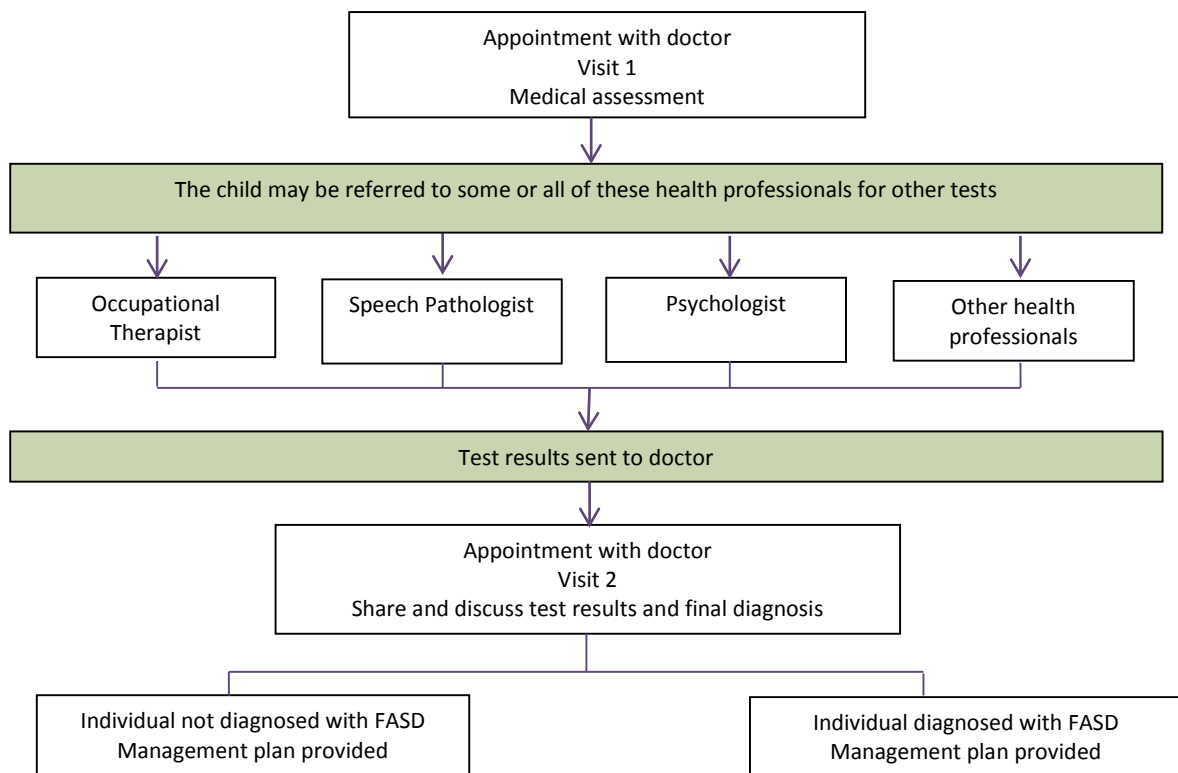
INFORMATION ON FASD DIAGNOSTIC ASSESSMENT FOR PARENTS AND CAREGIVERS

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 a child 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

Where does the diagnostic assessment happen and how long will it take?

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 shoe laces), 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 (NOFASD Australia)
<http://www.nofasd.org.au> or phone 1300 306 238
- Russell Family Fetal Alcohol Disorders Association (rffada)
<http://rffada.org/> or phone 1800 733 232
- If you are a foster carer you can also contact the foster care association in your state or territory

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 to describe FASD and that some of the international websites refer to programs and services that are available in Australia.

Australian websites

- National Organisation for Fetal Alcohol Spectrum Disorders (NOFASD Australia) <http://www.nofasd.org.au/> 1300 306 238
- Russell Family Fetal Alcohol Disorders Association (rffada) <http://rffada.org/> or phone 1800 rffada
- Telethon Institute for Child Health Research: Alcohol, Pregnancy and FASD <http://alcoholpregnancy.childhealthresearch.org.au/>

International websites

- Asante Centre <http://www.asantecentre.org/>
- Finding Hope <http://findinghope.knowledge.ca/home.html>
- Strategies parents find helpful in raising their children with FASD <http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>
- FASD Strategies not Solutions http://www.faslink.org/strategies_not_solutions.pdf
- Fetal Alcohol Spectrum Disorder – Care Action Network <http://www.fasd-can.org.nz/#!resources/c61b>

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

INFORMATION FOR CLINICIANS: ISSUES THAT INDIVIDUALS AND THEIR CAREGIVERS MAY EXPERIENCE DURING THE FASD DIAGNOSTIC ASSESSMENT

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 person 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 Parents 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)
<http://www.nofasd.org.au/> or phone 1300 306 238
- Russell Family Fetal Alcohol Disorders Association (rffada)
<http://rffada.org/> or phone 1800 733 232

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

Support for individuals and families 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

These Australian organisations are independent and not-for-profit. You can contact them at any stage of the diagnostic process - before, during or after a diagnostic assessment.

National Organisation for Fetal Alcohol Spectrum Disorder Australia (NOFASD)



What is NOFASD Australia?

NOFASD Australia is the national organisation representing the interests of individuals and families living with Fetal Alcohol Spectrum Disorder.

What does NOFASD provide?

- Support for parents/caregivers before, during and after a diagnostic assessment.
- An online and free telephone support and advocacy service.
- A website with many resources for individuals, parents/caregivers and families
- Strategies to care for your child
- A National Parent Advisory Group
- Up-to-date information on FASD Support Groups around Australia
- *FASD in Australia* – a series of YouTube videos
- *Education and training workshops in your child's school*
- *Fact Sheets about common behaviours and ways of managing these behaviours:*
 - ❖ Impulse control, behaviour and consequences
 - ❖ Information processing
 - ❖ Memory
 - ❖ Patterns and connections
 - ❖ Sensory issues and attention
 - ❖ Sleeping and eating

How to contact NOFASD Australia

Website: <http://www.nofasd.org.au/>
Phone: 1300 306 238
Email: enquiries@nofasd.org.au

Russell Family Fetal Alcohol Disorders Association (rffada)



What is the Russell Family Fetal Alcohol Disorders Association (rffada)?

The Russell Family Fetal Alcohol Disorders Association is a national organisation dedicated to prevention and ensuring the individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning.

What does rffada provide?

- A website with lots of resources for families and individuals;
- Face to face support groups for parents of children with FASD in some parts of Australia;
- Facebook groups for parents and carers, people living with FASD and birth parents;
- Training for organisations

How to contact rffada?

Website: <http://www.rffada.org/> (**Contact Us** section on website)

Postal address: PO Box 6795 Cairns Queensland 4870

Other Australian resources

Living with Fetal Alcohol Spectrum Disorder – A guide for Parents and Caregivers

This guide includes:

- Understanding FASD
- Primary disabilities and secondary conditions
- FASD from infancy to adulthood
- Care strategies – understanding behaviours, the importance of structure

Produced by the Drug Education Network in Tasmania, Australia.

<http://www.den.org.au/wp-content/uploads/2014/11/Living-with-FASD-A-Guide-for-Parents-and-Caregivers.pdf>

Alcohol- effects on unborn children

This website includes:

- What is FASD:
- How alcohol can affect developing babies;
- What are some of the problems caused by FASD;
- Contact numbers and links

Produced by the Government of South Australia, Women's and Children's Health Network

<http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=122&id=1950>

Telethon Kids Institute – Alcohol, Pregnancy & FASD

This website includes:

- What is FASD?
- Diagnosing FASD
- Our research
- Resources



<http://alcoholpregnancy.telethonkids.org.au/understanding-fasd/what-is-fasd/>

The Australian Parenting website

This website does not specifically refer to FASD, but may provide you with some useful general information

<http://raisingchildren.net.au/>



This website provides

- Information, discussion forums other resources for parents, including pregnancy, newborns, toddlers, pre-school, school, pre-teens and teens
- One section of the website provides information on Disabilities
- Includes a free downloadable app on *Children with Autism Spectrum Disorder*
- Parent helplines and hotlines <http://raisingchildren.net.au/articles/hotlines.html>

Foster Carer Associations

- Foster Carer Association of WA (Inc) <http://www.fcawa.com.au>
- Fostering NSW <http://www.fosteringnsw.com.au>
- Foster Carer Queensland <http://fcq.com.au>
- Foster Carers Association NT <http://fostercarersnt.org.au>
- Foster Carers Association of Tasmania <http://www.fcatas.org.au>
- Connecting Foster Carers – South Australia <http://cfc-sa.org.au>
- Foster Carers ACT www.fcaact.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.

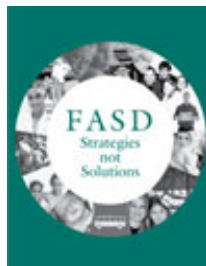
FASD Strategies not Solutions_(Canadian)

<http://edmontonfetalalcoholnetwork.org/resources/strategies-not-solutions/>

This manual is designed for caregivers who, in their everyday lives, encounter children and youth affected by Fetal Alcohol Spectrum Disorder.

It includes information about:

- How to guide your child's behaviour
- Choice making
- Impulse control
- Communication
- Calming Techniques
- Feelings and emotions
- Age-specific strategies: eating, play time, sleep and wake time, self-care, recreation, relationships and sexuality and self-harming



Parenting children affected by Fetal Alcohol Syndrome – A guide for daily living (Canadian)

http://fasd.typepad.com/fasd_support_in_alberta/2006/11/parenting-child.html

This guide includes:

- *Parenting suggestions:* effective communication, consequences and positive feedback, transitions, structure and routines, supervision.
- *Guidelines for daily living:* routines, dressing, the bathroom, mealtime, bedtime, sleep, managing hyperactivity, managing impulsivity, sensory considerations, social skills, handling money
- *Special considerations for infants:* sensitivity, illness, crying, feeding, sleep, take care of you.
- *Special considerations for adolescents:* structure and supervision, life skills, adolescents in the justice system

Strategies parents find helpful in raising their children living with FASD (Canadian)

<http://come-over.to/FAS/PDF/TorontoStrategiesParents.pdf>

This booklet highlights strategies families have found helpful raising their children with FASD, in a variety of ages and topics.

- Infants and toddlers (0 – 2 years)
- Preschoolers (3- 5 years)
- School age (6 – 12 years)
- Adolescents (13-17 years)
- Young adults and adults (18+ years)

FASD: Finding Hope – Knowledge Network (Canadian)

<http://findinghope.knowledge.ca/home.html>

Online videos about:

- About FASD; Prevention; Assessment and diagnosis
- Resources for parents (please note some of these are applicable to Canada only)

Let's Talk FASD: Parent Driven Strategies in Caring for Children with FASD (Canadian)

<http://von.ca/fasd/online/default.aspx>

National Organisation for Fetal Alcohol Syndrome (NOFAS-USA)

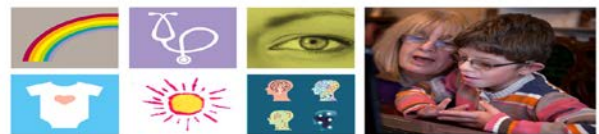
<http://www.nofas.org/about-nofas/>

- Not-for-profit organisation committed to FASD primary prevention, advocacy and support

National Organisation on Foetal Alcohol Syndrome (NOFAS-UK)

<http://www.nofas-uk.org>

- Dedicated to supporting people affected by Fetal Alcohol Spectrum Disorder (FASD) and their families and communities;
- Provides information on FASD for the general public and medical professionals



Appendix A8: Information for clinicians after a diagnostic assessment

Information and resources for clinicians after a diagnostic assessment

The following are some approaches to providing support to the child and caregivers after a diagnosis. This information is also relevant for older adolescents and adults who may have been diagnosed with FASD.

1. Explain the diagnosis:

Using a non-judgemental approach that recognises the range of emotions that might be experienced by parents/caregivers, explain that a diagnosis:

- Can improve parent/caregiver understanding of FASD.
- Can improve parent/caregiver understanding of the child's difficulties and helps parents adjust their expectations of the child.
- Identifies the child's strengths and needs.
- Facilitates early intervention to improve the child's development.
- Identifies women in need of assistance e.g. referral to alcohol and other drug services.
- Provides opportunities for parents/caregivers to express and/or process a possible range of emotions.

2. Provide parents/caregivers with:

- The results of reports from health professionals involved in the assessment.
- The outcome of the assessment e.g. diagnoses; provisional diagnosis; need for further assessment.
- The details and implications of a FASD diagnosis.
- Some 'plain English' information about FASD and contact details for NOFASD Australia:
*Information on Fetal Alcohol Spectrum Disorder
Post-Diagnosis Support – NOFASD Australia*
- A contact number for a clinician to respond to any post-diagnosis/assessment and/or management questions.

3. Develop a management plan:

- Empower parents/caregivers and their children in the diagnostic and assessment process.
- Identify parent/caregiver priorities and goals and include these in the management plan.
- Identify parent/caregiver/family personal networks accessible to the parents/caregivers or discuss options if required and how these may be accessed in their community.
- Provide information about support organisations
e.g. NOFASD Australia 1300 306 238 <http://www.nofasd.org.au/>.
- Discuss times/options for therapy if advised.
- Discuss the need for further medical review.
- Discuss need for referrals and referral process (including potential waiting times).
- Provide parent/caregiver with a copy of the management plan.

4. Consider interventions:

Build therapeutic interventions around:

- The child/young person's strengths and interests.
- The child/young person's positive attitudes.
- Willingness to participate in family activities and household routines.
- Strong engagement with their families.
- Willingness to seek and receive help.

Key approaches include:

- Improving child- parent/caregiver understanding and interaction.
- Educational support and accommodations.
- Specific therapies.
- Medication.
- Educating parents/caregivers.
- Advocacy for child e.g. in school or juvenile justice system.

Key challenges include:

- Challenges of daily life: ongoing strain of caring, the need for routine and repetition, and having to deal with aggression.
- Children having significant health issues and other diagnoses.
- Parents and caregivers having to access multiple health services, often with poor communication between these different practitioners.
- Service providers having no or very limited knowledge about FASD and parents/caregivers having to continually educate teachers, health and other professionals about FASD.
- The lack of recognition of a FASD diagnosis as a major hurdle to obtaining funding for educational assistance.

Breen C & Burns L. Improving services to families affected by FASD. National Drug and Alcohol Research Centre University of New South Wales. November 2012.

<https://ndarc.med.unsw.edu.au/project/improving-services-families-affected-fetal-alcohol-spectrum-disorders-fasd>

Eight Magic Keys

- These are strategies that underpin successful development of interventions for students with FASD.
- 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://www.fasdcenter.samhsa.gov/documents/EightMagicKeys.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 chronological 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 repeatedly 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 that 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 no more information. Breakdown tasks and always communicate the task in the positive: "we walk inside" instead of "don't run"

6. Specific Language

- 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.



INFORMATION ON FETAL ALCOHOL SPECTRUM DISORDER

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 1300 306 238.

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 experienced parents, 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: **1300 306 238**

Email: enquiries@nofasd.org.au

Website: <http://www.nofasd.org.au>

Online contact <http://www.nofasd.org.au/contact-us>

Face book
<https://www.facebook.com/NOFASD.Australia/>

Postal address:

NOFASD Australia, GPO Box 448, WYNYARD TAS
Australia 7325

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

Australian FASD support organisations

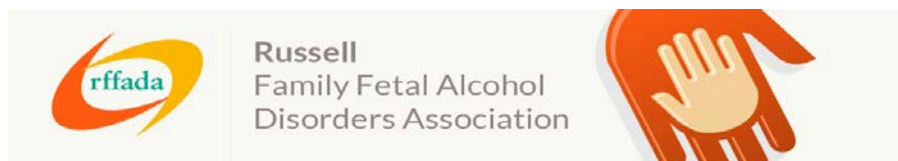


<http://www.nofasd.org.au/> 1300 306 238

NOFASD Australia is the national organisation representing the interests of individuals and families living with Fetal Alcohol Spectrum Disorders.

NOFASD Australia provides:

- Support for individual/ parents/caregivers/families before, during and after a diagnostic assessment.
- An online and free telephone support and advocacy service.
- A website with resources for individuals, parents/caregivers and families
- Up- to- date information on Australian FASD Support Groups
- *FASD in Australia* – a series of YouTube videos
- *Education and training workshops in your child's school*
- *Fact Sheets about common behaviours and ways of managing these behaviours:*



<http://www.rffada.org/>

The Russell Family Fetal Alcohol Disorders Association is a national organisation dedicated to prevention and ensuring the individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning.

rffada provides:

- A website with resources for families and individuals
- Support groups and Facebook groups
- Facebook groups for parents and carers, people living with FASD and birth parents
- Training for organisations

Australian FASD websites and resources

- Alcohol, pregnancy and FASD – Telethon Kids Institute, Perth, Western Australia
<http://alcoholpregnancy.telethonkids.org.au/>
- Understanding FASD – A Guide for justice professionals
A series of videos produced by the Alcohol, Pregnancy and FASD group at the Telethon Kids Institute
<http://alcoholpregnancy.telethonkids.org.au/fasd-justice/professional-development/>
- Understanding and addressing the needs of children and young people living with Fetal Alcohol Spectrum Disorders (FASD) – a resource for teachers
<http://www.kimberleyfasdresource.com.au/>

International FASD websites

University of Washington FAS Diagnostic and Prevention Network

<https://depts.washington.edu/fasdpn>

Centers for Disease Control and Prevention

<http://www.cdc.gov/ncbddd/fasd/diagnosis.html>

American Academy of Pediatrics – FASD toolkit

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/fetal-alcohol-spectrum-disorders-toolkit/Pages/default.aspx>

Substance Abuse and Mental Health Services Administration

<http://www.samhsa.gov/>

The Asante Centre

<http://www.asantecentre.org/>

Canada FASD Research Network

<http://www.canfasd.ca/>

National Organisation for Foetal Alcohol Syndrome – UK

<http://www.nofas-uk.org/>

Fetal Alcohol Network New Zealand

<http://www.fan.org.nz/>

Other Australian websites and resources

NHMRC Guidelines to Reduce Health Risk from Drinking Alcohol.

<https://www.nhmrc.gov.au/health-topics/alcohol-guidelines>

Australian Indigenous Alcohol and Other Drugs Knowledge Centre

<http://www.aodknowledgecentre.net.au>

- **AODconnect:** a national directory of alcohol and other drug treatment services for Aboriginal and Torres Strait Islander people. An app for health professionals working in the alcohol and other drugs sector looking for a culturally appropriate service in different states of Australia
- **Stay strong and healthy pregnancy videos:** includes a guide for health professionals in discussing alcohol with Aboriginal pregnant women, assessing risk to mother and baby and providing appropriate advice in a culturally sensitive environment.
- Resources and training material to support prevention and management of FASD in FASD Indigenous communities

Women Want to Know Project and Resources

<http://www.alcohol.gov.au/internet/alcohol/publishing.nsf/Content/wwtk>

- Resources - online e-learning courses, videos - for health professionals to routinely discuss alcohol and pregnancy with women and to provide advice that is consistent with the National Health and Medical Research Council's Australian Guidelines to Reduce Health Risks from Drinking Alcohol.

Foundation for Alcohol Research and Education <http://www.fare.org.au/>

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/>

Australian Foster Carer Associations

- Foster Carer Association of WA (Inc) <http://www.fcawa.com.au>
- Fostering NSW <http://www.fosteringnsw.com.au>
- Foster Carer Queensland <http://fcq.com.au>
- Foster Carers Association NT <http://fostercarersnt.org.au>
- Foster Carers Association of Tasmania <http://www.fcatas.org.au>
- Connecting Foster Carers – South Australia <http://cfc-sa.org.au>
- Foster Carers ACT www.fcaact.org.au

Appendix A9: Referral and Screening guidelines for FASD

Referral and Screening Guidelines for Fetal Alcohol Spectrum Disorder (FASD)

A. Referral guidelines

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

- Consideration of prenatal alcohol exposure and FASD should be part of standard 'mainstream' clinical practice for health professionals.
- 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 drinking in pregnancy and assessment for prenatal alcohol exposure – *as standard practice* – as for any other significant pregnancy complication or prenatal exposure e.g. other drugs, medications and infection. Standardised validated screening tools such as the AUDIT-C should be used.*
- 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 the individual, caregiver and/or family, as part of the referral process, including appropriate support and intervention if ongoing alcohol misuse is an issue.

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

- Prenatal alcohol exposure is at high risk levels*
- There is neurodevelopmental impairment and/or distinctive facial features and prenatal alcohol exposure is confirmed or suspected.
- Parent/Caregiver has concerns (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.

These include children, adolescents or adults:

- Who are living in out-of-home care (adoption/foster) (1,2)
- Who are in contact with the juvenile justice system. (3)
- Who have a birth mother with a known alcohol-related illness or dependency.
- Who have a family member with Fetal Alcohol Spectrum Disorder.
- Who are living in a community known to have high rates of alcohol consumption.(4)

Depending on the location and services available individuals could be referred to a:

- Specialist FASD assessment clinic
- Child development assessment service (with a multidisciplinary team).
- General or developmental paediatrician – public or private.
- Adolescent physician.
- Child and adolescent psychiatrist.
- Adult psychiatrist.
- Clinical geneticist.

All of these services may work with local allied health professionals to complete a multidisciplinary assessment.

Specialist FASD diagnostic clinics in Australia currently include: ^β

1. FASD Clinic, Community Child Health, Southport Health Precinct
Gold Coast Health, Queensland
2. FASTRACK Clinic, The University of Western Australia
3. PATCHES Paediatric Child Health & Education Services, Western Australia
4. Sydney Fetal Alcohol Spectrum Disorders Assessment and Diagnostic Clinic, Sydney
Children's Hospitals Network at Westmead

^β Please refer to the Telethon Institute website for up-to-date contact details:
<http://alcoholpregnancy.telethonkids.org.au/fasd-clinical-network/fasd-clinicservices/>

B. Screening tools for FASD

- There are no validated standardised screening tools for FASD (such as an 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)

C. Primary developmental surveillance

Primary care developmental surveillance - such as Child Health and School Nurse programs - should identify children with or at risk of developmental and behavioural problems. A proportion of these children will have FASD (with or without other conditions).

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

Infants and children at higher risk of FASD warrant close developmental surveillance both due to their increased chance of having been exposed to alcohol in utero as well as associated pre and postnatal risk factors which place them at higher risk of neurodevelopmental problems.

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

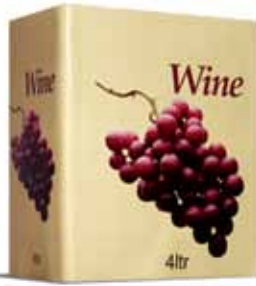
Bottle of Champagne
12% Alc. Vol



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

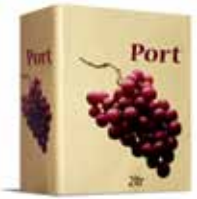
Cask White Wine
11.5% Alc. Vol



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	22	1.1	1.2	2.6	1.5	1.8	3.6
30ml	700ml	275ml	330ml	660ml	275ml	330ml	660ml
High Strength Spirit Nip	High Strength Bottle of Spirits	Full Strength RTD*	Full Strength RTD*	Full Strength RTD*	High Strength RTD*	High Strength RTD*	High Strength RTD*
40% Alc. Vol	40% Alc. Vol	5% Alc. Vol	5% Alc. Vol	5% Alc. Vol	7% Alc. Vol	7% Alc. Vol	7% Alc. Vol
							
1	1.2	1.5	1.7	1.4 – 1.9	1.6	2.1	2.4
250ml	300ml	375ml	440ml	250ml	300ml	375ml	440ml
Full Strength Pre-mix Spirits	Full Strength Pre-mix Spirits	Full Strength Pre-mix Spirits	Full Strength Pre-mix Spirits	High Strength Pre-mix Spirits	High Strength Pre-mix Spirits	High Strength Pre-mix Spirits	High Strength Pre-mix Spirits
5% Alc. Vol	5% Alc. Vol	5% Alc. Vol	5% Alc. Vol	7% – 10% Alc. Vol	7% Alc. Vol	7% Alc. Vol	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

Appendix C: Assessment of Sentinel Facial Features

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
- 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 side). 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

- Manual measurement of palpebral fissure length is prone to error and variation between examiners.
- Measurement by photographic facial analysis is more accurate
- However, clinicians may not have access to the software and direct manual measurement should be used in this situation.
- 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

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

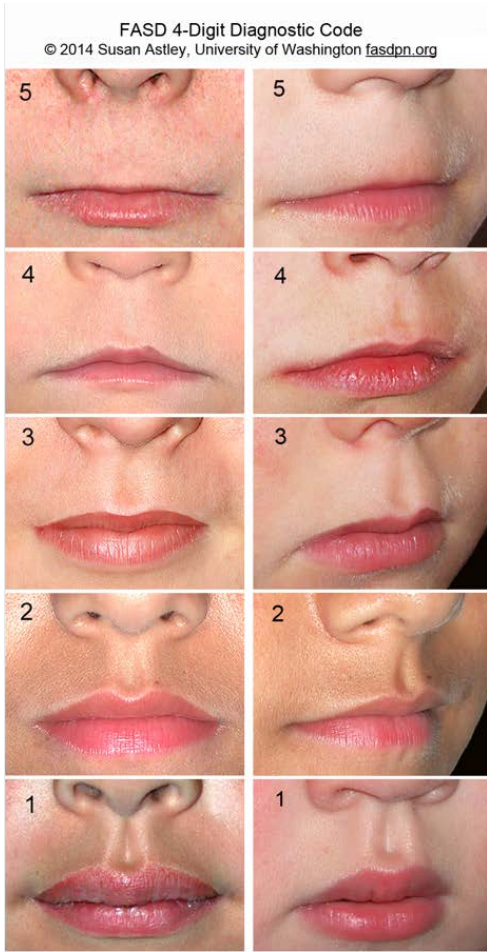
To use the guide properly, the clinician should:

- Be just below eye level in front of the patient (at the so-called frankfort level).
- Hold the guide next to their face (see photo below).
- 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. If the physician stood above this plane looking down on the patient, the patient's upper lip could appear thinner than it truly is. For a short video tutorial see: <https://depts.washington.edu/fasdpn/htmls/fas-tutor.htm#frankfort>
- The patient must have a relaxed facial expression, because a smile can alter lip thinness and philtrum smoothness.

The lip and philtrum can be assessed clinically by direct examination, and/or by photographic facial analysis software developed by the University of Washington.

This allows the clinician to visually re-assess the patient using the photographs, as well as calculating a measurement of lip thickness (lip circularity)

Lip Philtrum Guides

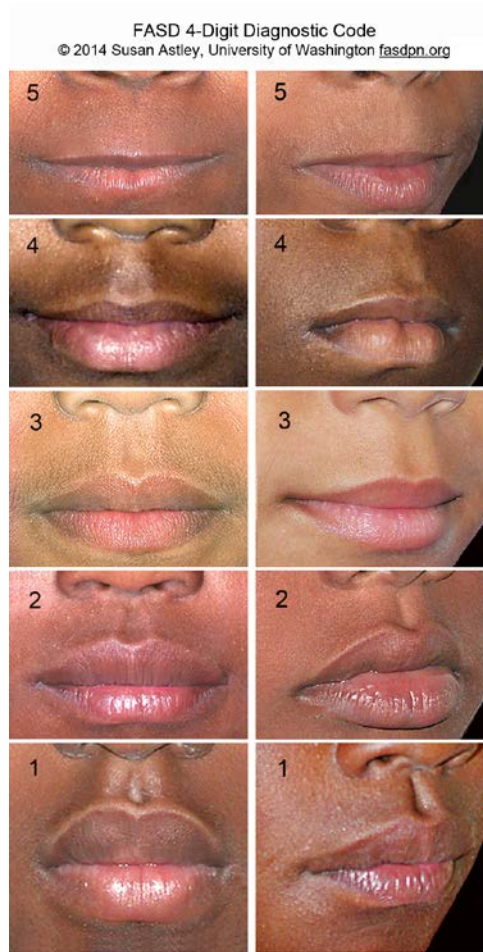


Lip-Philtrum Guide 1 Philtrum Guide

For use as a digital image on a smartphone or tablet.
Printing invalidates Guide.
Square ensures length by width ratio of image is correct.



Frontal view and ¾ view



Lip-Philtrum Guide 2 Philtrum Guide

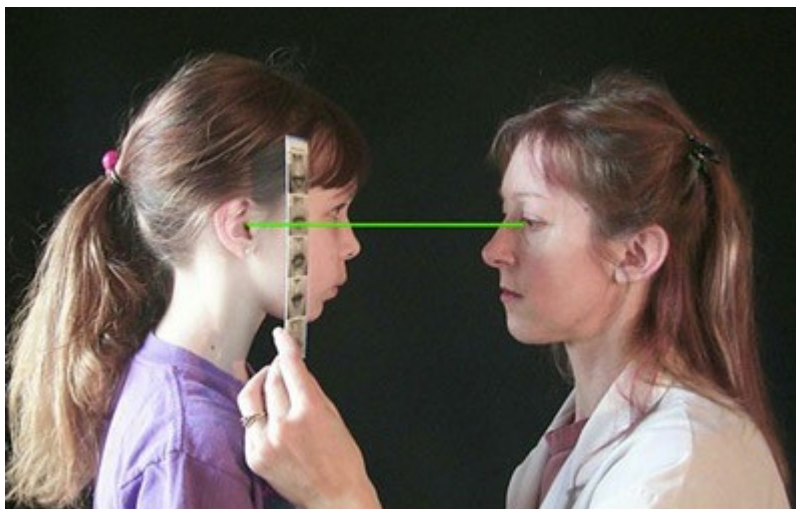
For use as a digital image on a smartphone or tablet.
Printing invalidates Guide.
Square ensures length by width ratio of image is correct.



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

Appendix D: Syndromes with constellations of features which overlap with FASD with 3 Sentinel Facial Features

Syndromes with constellations of features that overlap with those of FASD with three Sentinel Facial Features

Syndrome	Overlapping features	Features of this syndrome that differentiate it from FASD with 3 Sentinel Facial Features
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 vermilion 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 vermilion 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 vermilion 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 vermilion 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.
<http://www.jptcp.com/pubmed.php?articleId=448>