

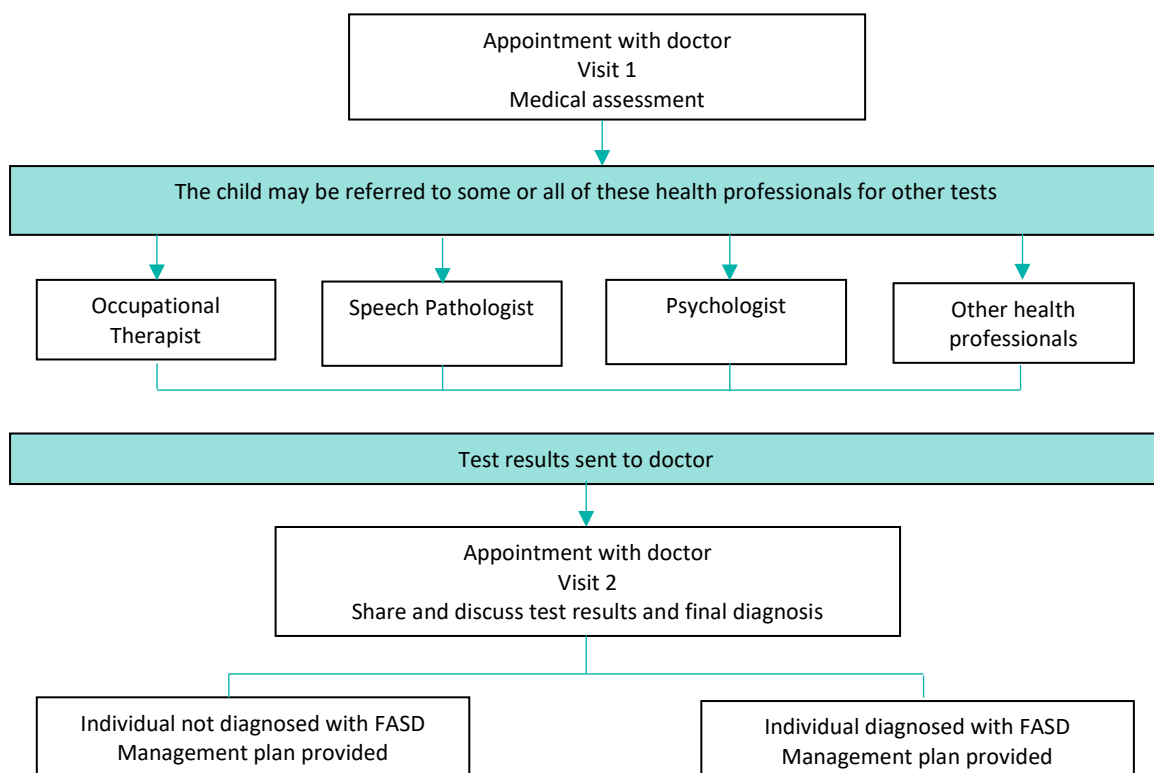
Appendix A4: Information on FASD diagnostic assessment for individuals and caregivers

Who is this information for?

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

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

What is involved in getting a diagnosis?



What documents do I need?

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

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

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

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

Occupational Therapist

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

Speech Pathologist

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

Psychologist

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

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

Other health professionals

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

How much does the assessment cost?

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

What happens after all the assessments?

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

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

Australian FASD support groups

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

Why is diagnosis important?

To get to know the child better

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

To access services that can help the child

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

To answer your questions

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

To improve the quality of life

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

Parents have said getting a diagnosis:

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

Children and young people and getting a diagnosis:

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

Informed consent

Explanation of consent for the diagnostic assessment

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

Consent after the diagnostic assessment

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

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

Information about Fetal Alcohol Spectrum Disorder

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

Australian websites

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

International websites

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

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

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