

DIAGNOSTIC PATHWAYS

Helping families and carers with understanding the pathways to diagnosis for children with additional needs in East Gippsland



2024



Children With Additional Needs
Working Group

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ACKNOWLEDGEMENT

The members of the Children with Additional Needs Working Group would like to acknowledge the First Custodians of the land, the Gunaikurnai people and the Monero and Bidawel people in the far East, of the land that encompasses East Gippsland Shire and on which we work and play. We deeply acknowledge their ongoing connection to culture and country and acknowledge that their land was never ceded.



Important for Noting

Some families and carers are happy to have their child move through life without any form of intervention or diagnosis. The CWANWG acknowledge that each family/carer unit is unique, and all decisions made by any family/carer will be supported. All advice provided is general in nature and should not be taken as personal advice for your situation. It does not take into account your personal situation. The CWANWG can be contacted on **admin@cwanwg.com.au** if any of the information contained in the document is incorrect or requires updating.



WHY THIS DOCUMENT?

The Children with Additional Needs Working Group (CWANWG) was formed in 2016 with the purpose of identifying issues and challenges for children with additional needs and their families and carers and how improvements can be made. The area of diagnostic pathways is one of the priorities for the CWANWG in 2023.

The work of the Bushfire Resilience and Recovery Project (BRRP) clearly identified that as a community in East Gippsland, there are still many children and youth 'falling through the cracks' and that more support was needed to help families/carers with a diagnostic pathways for families and carers who think their child may have a learning delay, developmental delay or neurodiverse conditions like Autism/ADHD. For some families and carers, anecdotal evidence suggests finding out what is going on can take upwards of twelve months to two years.

This document aims to help families and carers better understand and identify the different types of pathways that can be used and some of the services both within East Gippsland and across Victoria (and even nationally) that can assist and how to potentially fund the necessary reports and assessments to help find out what may be going on for your child.

This document may be relevant to you if:

You have a feeling that there might be something going on, and/or

You may have done some reading to figure out what might be going on, and/or

You have been approached by someone who cares for your child, (like a teacher, caregiver or friend) who may have noticed some differences

WHAT DO WE MEAN BY DIAGNOSTIC PATHWAY?

Put simply, diagnostic pathways mean just that...a pathway (or pathways) to a diagnosis for your child. If you have a 'feeling' that something may be a bit 'different' or you are seeing some things that you are not quite sure how to explain with your child, it is worth having a conversation with your health practitioner or allied health professional.

WHO IS NORMALLY INVOLVED IN A DIAGNOSIS?

There are many people who may be able to help on your pathway to a diagnosis. It is important to understand the differences so that you can advocate on behalf of your child and work with the right people at the right time.



PRIMARY HEALTH CARERS

Primary Health Care people are your first point of entry into the health system. You would expect to be working with people like a General Practitioner (GP) or Paediatrician to help with a diagnosis pathway.

Primary Health Specialists	
General Practitioner (GP)	Someone who is the first port of call and treats acute illness or chronic illness. GPs can also refer to Paediatricians.
Paediatrician	A doctor who specialises in infants, children and youth.
Psychiatrist	A doctor who specialises in the diagnosis, prevention, treatment and study of neurodevelopmental conditions like autism and attention deficit/hyperactivity disorder (ADHD).
Nurse	Someone who provides acute care support and helps manage conditions.

Important to note

A GP is often needed to provide a referral to a paediatrician or psychiatrist. Some self-referrals can be done (you do it on your own without a referral), but you would need to check this out with the practitioner as the pathway may vary.

SECONDARY HEALTH CARERS

Secondary Health Carers are services that are received after a referral from a primary health carer has been made. Self-referrals can be made, just be aware that a self-referral may be more expensive. You will need to make the decision that is right for you.

The list below captures those practitioners who may be the most important to assist with a diagnosis. This can vary, depending on what is happening for your child. There are many other areas of Allied Health that can assist your child once a diagnosis has been made. Your care team (those who helped you with your diagnosis) will assist with your next steps to support.

Secondary Health Specialists

Allied Health Specialist - Occupational Therapist

An occupational therapist will assist you with assessments to help you with a diagnosis. Occupational Therapists can help with a child's self-care, playing and transitioning between activities and places as well as everyday life skills.

Allied Health Specialist - Speech Therapist

A speech therapist will assist you with assessments to help you with a diagnosis. Speech Therapists can also help when your child might have trouble talking with or understanding others. They can also help with using technology to communicate and help with reading and spelling.

Psychologist

A psychologist can determine a diagnosis through assessments. You can self refer to a Psychologist for a diagnosis OR work with a Psychologist as part of a broader Allied Health team (like a Speech and Occupational Therapist) to achieve a diagnosis.

If you are working with others like school teachers, nurses, chaplain, social workers or counsellors (or anyone else!) while you are waiting for a diagnosis, you can ask them to write down what they are seeing with your child. This will help the person helping you with the diagnosis see the bigger picture for your child.

PATHWAY OPTION 1

There are a couple of pathways to a diagnosis within East Gippsland. Each have their own positives and negatives. Your decision will be based purely on what you need, what you can afford, time and your energy!



Pathway 1 - GP to Paediatrician

"I have some concerns about my child. They are displaying ..."



A Paediatrician is likely to refer you to an **Allied Health Specialist** like an Occupational Therapist and/or Speech Therapist/Psychologist for assessments and reports. They may also request to have reports and observations from school or formal carers to get the big picture and then hold a 'case conference' to determine what is happening.

A 'case conference' is a meeting where all your practitioners will discuss what they have seen and the outcomes of the assessments. The Paediatrician will make the final diagnosis based on the information provided.

Good bits	Bad bits
<p>This pathway can trigger funding through Medicare so out of pocket costs are lower. A pathway can include specialised 'one stop shop' approaches so testing can be done at the same time by Allied Health specialists (like a Testing Clinic - make sure you ask!)</p> <p>Allied Health specialists may be able to support you and your child while you are on your 'diagnostic pathway'. Support may involve education, therapy or strategies to help support the child and family/care.</p>	<p>This pathway can take up to 2 years. There is often a waitlist to see a paediatrician of up to 6-12 months here locally in East Gippsland. There is also a shortage of Allied Health Specialists which result in waitlists BUT as in 'good bits' - ask your Paediatrician if there are "one stop shops" for assessments so you can get everything done at the same time.</p> <p>To lessen time on waitlists - you may need to travel out of East Gippsland.</p>

PATHWAY OPTION 2

This means that you find a psychologist/psychiatrist who can diagnose neurodivergent conditions like Autism Spectrum Disorder, ADHD, Intellectual Disability, Anxiety, Depression and learning difficulties. If you are looking to receive a diagnosis online, it is wise to ask whether their assessment will be recognised before you commit.



Pathway 2 - Self Referral

"I have some concerns about my child. They are displaying ..."



Good bits	Bad bits
<p>Private providers may be able to circumvent long wait times.</p> <p>You will be able to access people that 'fit your family'.</p> <p>You may not require the GP for a referral and can go directly to individuals (but you will need to pay privately).</p> <p>Psychologist/Psychiatrists can diagnose a range of things.</p> <p>Good option while you are waiting on a Paediatrician (who you will still likely need at some stage for your child).</p>	<p>This may be a more costly way to a diagnosis and you may need to travel further to access help.</p> <p>Some of the assessing may be required to be done online. Check out the provider first to ensure it is going to be the best fit for you and your family.</p> <p>You will still need a referral to a Psychiatrist (remembering there is a difference between a Psychiatrist and a Psychologist) from your GP. You can self-refer to a psychologist if you are self-funded.</p>

OTHER SUPPORTS

While you are waiting for help from specialists, let's have a look at how others may be able to support you. It is very likely you will have been referred to an Allied Health Specialist as a first point of contact. As discussed previously, Allied Health Professionals can assist you in navigating a diagnosis as well as providing early intervention support and strategies.

It is absolutely OK to have your name on multiple waitlists for Allied Health Professionals, Paediatricians and Psychologists, in fact it is supported! By taking an approach of being on many waitlists, it will help to minimise the time you may be waiting for help.

If you are working with Allied Health (and those Other Supports on the following page), ask them to share their observations of your child in a particular setting and/or write a letter which outlines their observations about your child. It will all be really helpful as evidence.



OTHER SUPPORTS



Other Supports that can help while you wait!

"I have some concerns about my child. They are displaying ..."

Schools

Can access Allied Health Specialists like speech/ occupational therapy and psychology.

May be able to assist with support while you are waiting for specialists

May be able to fund assessments - you will need to ask.

NDIS (0-6 years old)

If your child is 0-6 years, contact the NDIS as they may be able to assist if your child is considered as having a developmental delay. You don't need assessments to work with the NDIS for this age group. An early childhood partner can also provide supports to children who are not eligible for the NDIS as well.

Maternal Health Nurse

Maternal and child health nurses can give information, support and advice on a variety of topics including development and learning and cater for children between the ages of 0 and starting school.

Child and Adolescent Mental Health Service (CAMHS)

CAMHS provide a range of services starting with initial intake to provide advice, information and screening, moving through to assessment and treatment. Services include crisis assessment, case management, multi-modal treatments, individual, family and group therapy and parent or carer support.

OTHER SUPPORTS



Other Supports that can help while you wait!

"I have some concerns about my child. They are displaying ..."

Kinder/Early Childhood Educators

An early childhood setting (like kinder/school) can help you identify what might be happening for your child and some strategies you can use to help.

Carers Gateway

Carers Gateway is an Australian Government program which provides free services and support for carers including support groups, support packages (to help access respite), phone and face to face counselling, skills courses and access to emergency respite.

Support Groups like PlayConnect and Mytime (which run in East Gippsland)

Mytime is a group that brings together parents and carers of children with a disability, developmental delay, chronic medical condition or other additional needs (or on the pathway to a diagnosis) to share ideas and experiences. Playconnect - supported playgroups

Disability Advocates and general information

We are lucky to have access to several disability advocates here in East Gippsland. Advocates can help provide advice and support as you are travelling through the process. Gippsland Disability Advocacy and Association for Children with a Disability both operate from Gippsland. The Children with Additional Needs Working Group can also help if you require support. You are also very welcome to join the group.

OTHER THINGS YOU CAN DO BEFORE YOU MEET WITH YOUR GP/SPECIALIST

If your child is displaying some behaviours or things that just don't feel right, one of the best things you can do is write down some of things you would like to ask about. "My child struggles to focus on one task at a time", "they are a picky eater", "they hate wearing certain clothes", "they have really big emotions, and I don't know if it age appropriate or not".

There are some terrific websites that can help you work out what is actually age appropriate and whether your child may be requiring some extra support. One of the best websites is the Raising Children Network (www.raisingchildren.net.au). It has a whole host of information about child development and is supported by the Australian Government's Department of Social Services. It also has pages that provide information about autism and disabilities.

It may also be useful to jot down some points about your day. Just one day. Think about how you might help your child through the day. Do you help, support and/or prompt just about everything? What happens when big emotions are displayed? Any mannerisms or routines that you are just not sure about? It just may help.

Get ready to ask questions. Be prepared to seek a Plan B and Plan C. Ask who else is available that may be able to assist, particularly to navigate around long wait lists. The CWANWG also has a localised Service Provider list which may help when seeking therapists and help. Ask your specialist about their knowledge and experience assessing children of your child's age group.



DECISION MAKING

Below are the things to take into consideration when making an informed decision:



It is really important to understand before you move into a system that can be quite tricky to navigate.

FUNDING FOR REPORTS AND ASSESSMENTS

There are a number of ways that you can fund reports and assessments and even start receiving sessions from service providers like Occupational Therapists, Speech Therapists and Psychologists. The most important thing is to consider what it is going to be the best fit for your family and circumstances. Please ensure you speak to your practitioner about funding (how they charge and whether it can be done through Medicare, private health or out of your own pocket) before booking any appointment.

MEDICARE

Below is a snapshot of Medicare Benefits for people under 25. Remember, Medicare will not cover the full cost of your appointment. You may still be out of pocket so it is best to check before entering the system to meet your family needs.

Referral Details	Chronic Disease Management Plan/ Team Care Arrangements	Better Access Initiative (Mental Health Plan)	Complex Neuro-developmental Disorders *One off item
Referral by GP	✓	✓	✓
Referral by Psychiatrist	✗	✓	✓
Referral by Paediatrician	✗	✓	✓
How often?	Resets every year	Resets every year	*One off
Number of sessions	5	10 individually and 10 group sessions	20
Speech Therapist	✓	✗	✓
Occupational Therapist	✓	✓	✓
Psychologist	✓	✗	✓
Audiologist	✓	✗	✓
Optometrist	✓	✗	✓
Orthoptist	✓	✗	✓
Physiotherapist	✓	✓	✓
Group Sessions	✗	✓	✗

*One off means that an individual can access this Medicare Rebate but it is only a one off plan.

*You can use all plans concurrently

MEDICARE

A side note

For those interested, the “Complex Neurodevelopment Disorder” is identified by the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) which includes the category of “neurodevelopment disorders” as being:

- ✓ intellectual disability
- ✓ communication disorders
- ✓ autism spectrum disorder
- ✓ attention-deficit/hyperactivity disorder (ADHD)
- ✓ specific learning disorder
- ✓ motor disorders

Simply put – a pathway to diagnosis is likely to occur under DSM-5 which is regularly reviewed and updated by specialists across the world.



PRIVATE HEALTH INSURANCE

Private Health Insurance may cover some of the funding costs towards reporting and assessment, remembering Psychiatrists and Psychologists are able to diagnose complex neurodevelopmental disorders. It will be important to have that conversation with your specialist to confirm arrangements. The bonus is that you may find someone a bit quicker if you are prepared to travel and they are happy to work privately under insurance. Wait times will vary between 6 weeks and 12 months. Again, it is important to check in with your private health insurer before booking an appointment to confirm what is covered and how much.

NO INTEREST LOAN SCHEMES (NILs)

No interest loan schemes are just that – loans with no interest. These loans can be accessed by people on lower incomes or a health care card and can cover up to \$2000 in medical costs so can be used to help pay for assessments and reports.

Just google the 'NILS' and your region (eg. 'East Gippsland') to ensure you receive the most up to date information.



SO...OPTIONS FOR WHO CAN HELP

Private Health Insurance may cover some of the funding costs towards reporting and assessment, remembering Psychiatrists and Psychologists are able to diagnose complex neurodevelopmental disorders. It will be important to have that conversation with your specialist to confirm arrangements. The bonus is that you may find someone a bit quicker if you are prepared to travel and they are happy to work privately under insurance. Wait times will vary between 6 weeks and 12 months. Again, it is important to check in with your private health insurer before booking an appointment to confirm what is covered and how much.

SOME IDEAS OUTSIDE EAST GIPPSLAND

UNIVERSITY PSYCHOLOGY CLINICS

Australian Catholic University Melbourne Psychology Clinic

www.acu.edu.au/about-acu/faculties-directorates-and-staff/faculty-of-health-sciences/facilities-and-services/psychology-clinics/melbourne-psychology-clinic

University of Melbourne Psychology Clinic

www.psychologicalsciences.unimelb.edu.au/psychology-clinic/educational-and-developmental-psychology

Krongold Clinic (through Monash University)

www.monash.edu/education/krongold-clinic/services

SEARCH FOR A THERAPIST BY SPECIALISATION AND LOCATION THROUGH:

Find a Psychologist

www.psychology.org.au/find-a-psychologist

Find an Occupational Therapist

www.otaus.com.au/find-an-ot

Find a Psychiatrist

www.yourhealthinmind.org/find-a-psychiatrist

Find a Speech Pathologist

www.speechpathologyaustralia.org.au//SPAweb/General_Information/Find_a_Speech_Pathologist/SPAweb/General_Information/Find_a_Speech_Pathologist/Find_a_Speech_Pathologist.aspx?hkey=0b04c883-80b2-43e7-9298-7e5db5c75197

Find a Paediatrician

<https://healthengine.com.au/find/text/Australia?search=Paediatrician>

ONE LAST NOTE

The CWANWG acknowledge that this can be an extremely trying time for you all as a family. Rest assured, there is plenty of support out there if you know where to find it. Hopefully this document provides some ideas for you to try and find the right fit for you and your family that places you at the centre of decision making.

This stuff is hard. We want you to know that we see you and hear you. Please reach out if you need any further assistance.

CONTACT US



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