

Childhood-onset heart disease (CoHD), developmental delay and the NDIS Early Childhood Approach



Childhood-onset heart disease and developmental delay/disability

Developmental delays/disabilities are more common in children with childhood-onset heart disease (CoHD) than the general population. Whilst most children with CoHD have no developmental disability or developmental delay, some children with CoHD may have developmental concerns.

It is important if developmental concerns are present that support is given to children and their families as early as possible to help them develop skills and live their best lives. This is an area that the NDIS provides funding and support through the **NDIS Early Childhood Approach**.

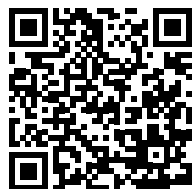
What is the NDIS Early Childhood Approach and who can access the support?

The NDIS Early Childhood Approach helps children younger than 6 with developmental delay, or children younger than 9 with a disability and their families to access the right support when they need it. Children younger than 6, where there are concerns about their development, do not need a diagnosis to get support through the NDIS Early Childhood Approach.

The approach is available across all of Australia. It supports families to help children develop the skills they need to take part in daily activities and achieve the best possible outcomes throughout their life.

A child must meet residency requirements to be eligible for funded NDIS Early Childhood Approach supports, and you may need to provide evidence of your child's disability. **Any child** experiencing difficulties or delays in their development, as indicated by a relevant health professional, is eligible for support.

Scan or click on the QR code to watch a video from the NDIS on the NDIS Early Childhood Approach.



What if my child with CoHD also has developmental delay?

Sometimes children who aren't meeting developmental milestones may have developmental delay. The developmental concerns might be noticed by you, or by a healthcare, childcare or education professional. Developmental delay for a child can be subtle, but may involve slower development of physical, emotional, social and communication skills than expected for their age. It is essential that if you think that your child could have developmental delay that you speak with a health professional so that assessment and support can begin as early as possible. Early supports give the maximum benefit to your child.

What should I look for?

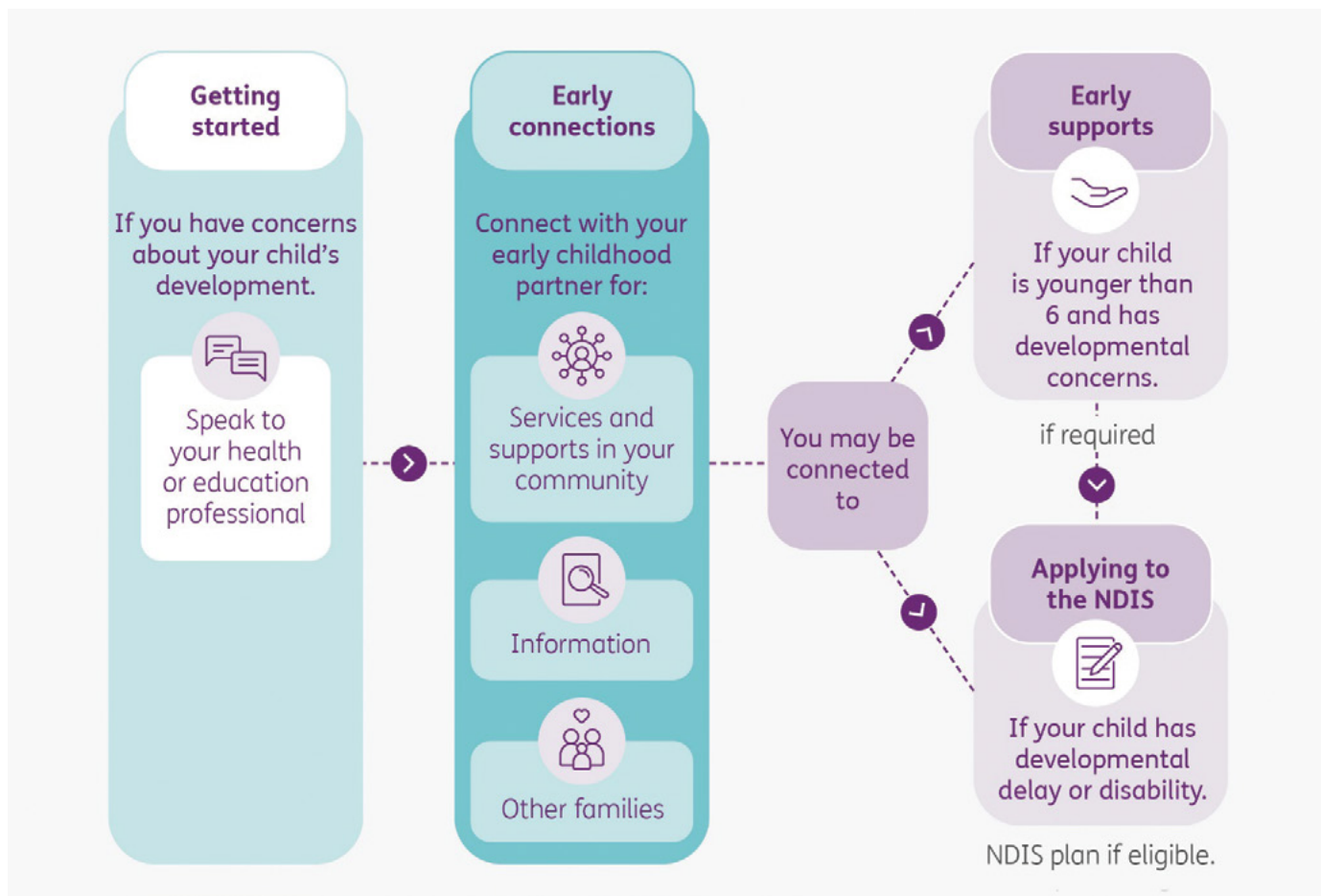
Areas of development to look out for could be:

- **Physical skills** (examples could be not walking/crawling, clumsiness, poor grasp, difficulty in manipulating objects)
- **Learning (cognitive) skills** (examples could be not keeping up with peers with reading, writing and maths)
- **Speaking, and communicating socially with others** (examples could be unclear speech, difficulty controlling behaviour)
- **Self-Care** (examples could be poor feeding, unable to dress themselves, problems toileting)

Who can I talk to?

If you are concerned that your child has developmental delays, discuss these with an early childhood professional. This could be:

- Your GP, if they have early childhood experience
- Your specialist doctor
- Your paediatrician
- Your early childhood educator
- Your midwife or child health nurse (if your state offers this program to you).



NDIS (2023), Help for your child younger than 9, Early childhood help for your child factsheet, <https://www.ndis.gov.au/media/5248/download?attachment>

How can early childhood intervention help my child?

The NDIS Early Childhood Approach can help provide early childhood intervention which **gives children the specialised support they need to grow, thrive, reach their full potential and participate** in their communities. It also helps families support their children's development.

Scan the QR code to watch a video that explains the role and importance of early childhood intervention.



How do I access the NDIS Early Childhood Approach for my child?

This is a simple process but is probably best started by having a chat with a healthcare or education professional around your concerns for your child's development. The process is shown in the diagram above.

Early childhood partners are provided by the NDIS to help guide access to the early childhood approach. There are many **early childhood partners**, in every state and territory across Australia who can assist families with planning and accessing early intervention services for their child. To find an **early childhood partner**:

You can visit the NDIS website at **NDIS.gov.au** or call **1800 800 110**

Alternatively you can scan or click on the QR code provided below to search online by your suburb.



What do I do after I find my local early childhood partner?

The process will often include:

- Calling the **early childhood partner** to refer your child to the NDIS Early Childhood Approach scheme.
- Completing an over-the-phone survey, or referral form to gather your personal details, and a summary of your child's needs as they relate to disability or developmental delay (**not to their heart condition**). You can ask your local GP, paediatrician, child health nurse, or any health professional working with your child, to help you fill out the form.
- Await contact from your coordinator to book your first meeting. During this time you may like to gather your documents that show a diagnosis of disability, or any reports you have from your doctor or early childhood educator that will be useful for the **early childhood coordinator** to see.

What happens after I submit the referral form?

When you have provided all necessary information, the NDIA will decide whether you are eligible for the NDIS and send you a letter to inform you of their decision. If you are eligible you will be contacted by your **early childhood partner** to make an appointment for your child's planning meeting. If you are not eligible you can still get information and a referral from the **early childhood coordinator** to access supports and services, or you can request to have the decision reviewed.

Find out more information about the NDIS Early Childhood Approach by scanning the QR codes below:

NDIS info on states and territories



Raisingchildren.net.au



NDIS info on Early Childhood Approach

