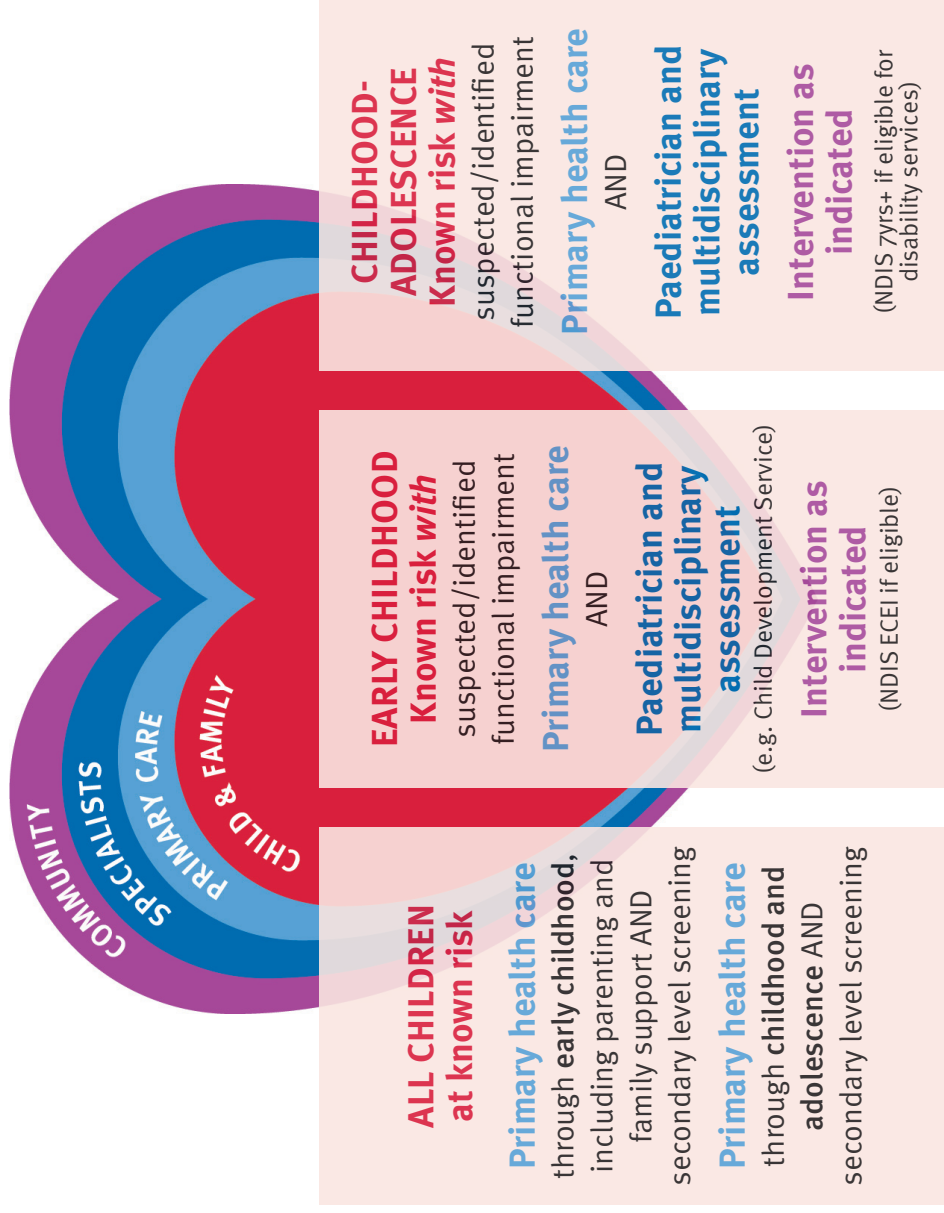


# Long-term care pathway for children with congenital heart disease following open heart surgery before 12 months of age



**KNOWN RISK**

Children undergoing open heart surgery for congenital heart disease under 12 months of age are at high risk for neurodevelopmental deficits.

**FAMILY-CENTRED**

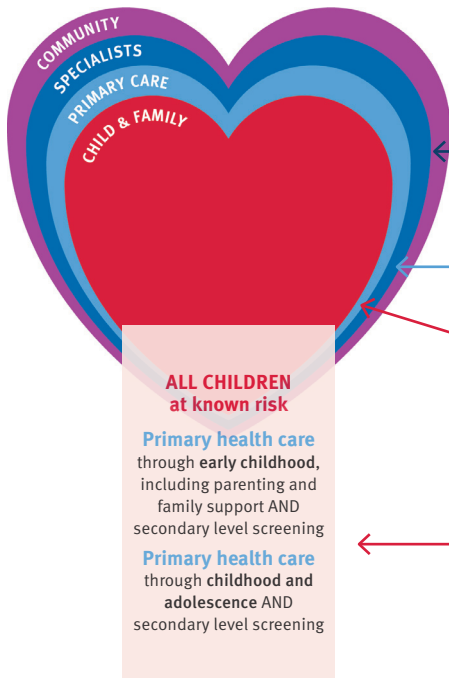
Services and supports should be family-centred, and provided by the right people, in the right place, at the right time. GPs provide important support to the family throughout the lifespan, including supporting transition to adult services as required

**LONG TERM**

Surveillance, screening or assessment into adolescence at recommended age points is required as deficits may emerge over time. Long term outcomes and statewide service needs will be well understood through meaningful, collaborative data collection



# Long-term care pathway for children with congenital heart disease following open heart surgery before 12 months of age



All families are encouraged to access services within their community that support growth and development (e.g. Education system, non-health services).

Most children will have a Cardiologist monitoring cardiac care through the lifespan. Children may also have a General and/or Developmental Paediatrician, or other medical/allied health specialists.

All families are encouraged to link with a local General Practitioner (GP) for overall health management, including supported transition to adult services.

The child and family are at the centre of care.

**Early childhood: 0 to 8 years | Childhood-Adolescence: 9 to 18 years**

**Primary health care:** Families may access primary health care through their GP, a child health service or indigenous health service. Rural and remote families may access services through alternative providers as available within the Hospital and Health Service (HHS).

**Secondary level screening:** in addition to use of *Parental Evaluation of Developmental Status*, secondary level screening using the *Ages and Stages Questionnaire* is recommended for targeted screening given known clinical risk (can be used for children under 5 1/2 yrs).

**EARLY CHILDHOOD**  
Known risk with suspected/identified functional impairment

Primary health care AND Paediatrician and multidisciplinary assessment (e.g. Child Development Service)

Intervention as indicated (NDIS ECEI if eligible)

**CHILDHOOD-ADOLESCENCE**  
Known risk with suspected/identified functional impairment

Primary health care AND Paediatrician and multidisciplinary assessment

Intervention as indicated (NDIS 7yrs+ if eligible for disability services)

**Primary health care:** Ongoing links with primary care is recommended throughout childhood and adolescence, particularly with a GP for wellbeing support and transition to adult services as required.

**Formal assessment:** It is recommended assessments are selected based on functional presentation of the child in line with best evidence. Further information about recommended assessments are outlined in the *Pink Book*. Multidisciplinary assessment may include General or Developmental Paediatrician review, and may occur through a Level 4 paediatric hospital outpatient department, a child developmental service, a Level 5/6 paediatric hospital (e.g. Queensland Children's Hospital (QCH)) or private practice, depending on availability of service within the HHS and eligibility criteria.

**Intervention:** Intervention may be provided through Level 4 paediatric hospital outpatient department, a child developmental service, National Disability Insurance Scheme (NDIS) provider, a Level 5/6 paediatric hospital (LCCH), or private practice, depending on availability of services within the HHS and eligibility criteria.

**KNOWN RISK**

Children undergoing open heart surgery for congenital heart disease under 12 months of age are at high risk for neurodevelopmental deficits.

**FAMILY-CENTRED**

Services and supports should be family-centred, and provided by the right people, in the right place, at the right time. GPs provide important support to the family throughout the lifespan, including supporting transition to adult services as required

**LONG TERM**

Surveillance, screening or assessment into adolescence at recommended age points is required as deficits may emerge over time. Long term outcomes and statewide service needs will be well understood through meaningful, collaborative data collection

**Known risk:** Information outlining why these children are at risk, typical neurodevelopmental profile and recommended developmental domains to monitor can be found in the *Pink Book*.

**Family-centred:** Where possible, families should be encouraged to access formal and informal services and supports within their local community that provide developmental support.

**Long term:** Key time points for screening/assessment: 6mths, 12mths, 18mths, approx. 2yrs, 4-5yrs, 11-12yrs, 15+yrs (based on international guidelines and in line with current primary care health check schedule). Families should be encouraged to access surveillance at key time points, even if no concerns were identified at earlier screening.

Recommendations re: developmental domains and standardised tools are available in the *Pink Book*. Screening and assessment results should be documented and/or scanned into iMR (where available) and local providers may be contacted to provide results where parents have consented.

The CHD LIFE Program database collects routine clinical care data on the neurodevelopmental and functional health outcomes of children undergoing OHS before 12 months of age and their families. This data will improve understanding of long term outcomes and how they may change over time. It can also be shared with local health care providers to support service development.

