



New Zealand Newborn Clinical Network

Practice Recommendations for 2 year follow-up of infants, at high risk of developmental disability

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Statement

The Paediatric Society of New Zealand is committed to equity of outcomes for Māori and Pasifika children. As publicly-funded providers of health care in Aotearoa New Zealand we recognise our role as Treaty partners under Te Tiriti o Waitangi. The Waitangi Tribunal's WAI 2575 findings, the epidemiology below and our own clinical experience demonstrate clearly that we have much work to do to be better Treaty partners with whānau, hapū and iwi to reduce and eliminate inequitable outcomes for tamariki and whānau Māori in particular.(1, 2)

Aim

This New Zealand Practice recommendation on 2 year follow up of infants at high risk of developmental disability aims to achieve equitable care by early identification of abnormal neurodevelopmental signs and to improve referral to early intervention services and outcomes for these infants. It also aims to support the infant /carer relationship and referral to the right support services for families.

Guiding principles

1. The first 1000 days are a time critical period for the development of brain architecture.(3)
2. Early and accurate identification and diagnosis of developmental disabilities / difficulties is crucial to the implementation of diagnosis specific early intervention which optimises motor, cognitive plasticity, prevents secondary complications and enhances caregiver wellbeing. (4)
3. Evidence based practice should be followed.
4. All pēpi/infants should have equitable access to paediatric services and developmental services for developmental assessment and intervention/support by health providers who are culturally sensitive and have proficient knowledge and skills in early growth and development.
5. Caregiving relationships that are sensitive and responsive to the pēpi/infant's needs are critical to development and thereby constitute a basic right of infants.(5)
6. Facilitating emotional support for mothers, fathers and caregivers is an important component of fostering the optimal development and wellbeing of the pēpi/infant.(5)
7. A health provider's acceptance and knowledge of Māori culture, values and beliefs will impact on the effectiveness of the provider-whānau relationship and outcomes.
8. A positive outcome is achieved when a health provider and the whānau / family have mutual trust, respect and understanding.
9. Parents have the right to receive information and advice regarding the developmental needs of their pēpi / infant or tamariki/children.

Kohikohi ngā kākano, whakaritea te pārekereke, kia puāwai ngā hua

Gather the seeds, prepare the seedbed carefully,
and you will be gifted with abundance of food

Within Te Ao Māori, there are many examples of the cultivation of kai being used as a metaphor for nurturing our tamariki through their childhood.

This particular whakatauki highlights the importance of creating an environment that will empower tamariki to reach their potential through working collectively to provide the right environment for each child to reach their full potential.



Background

Infants at high risk for abnormal growth and developmental disability

For the majority of tamariki in Aotearoa New Zealand, usual surveillance of health, growth and development takes place in primary care and/or at the well child clinic.

Newborn infants who are at high risk of abnormal growth and developmental disability can be identified following birth and are worthy of a more structured and specialised programme of follow-up assessment.(6)

Infants with a higher risk of developmental disability are very preterm infants, infants born with Neonatal Encephalopathy (NE), but also more general, infants who have needed Neonatal Intensive Care treatment.(7) Preterm birth and NE are the most common risk factors for abnormal neurodevelopment.

Preterm birth

In 2017, a total of 4,503 (7.5%) of infants were born preterm in Aotearoa New Zealand, with a gestational age under 37 weeks.(8) Of all births, 1.3% and 0.45% of infants were born at or under 32 weeks' and 28 weeks' gestation respectively. Currently, there is inequity with more Māori (8.1%) and Pacific (7.8%) whānau affected more by preterm birth than European/other groups (7.2%).(8)

Preterm infants have a higher risk of abnormal outcome in terms of growth and development, which leads to short-term and long-term resource utilisation, including hospital readmissions, health-care costs and burden on public health and education.(9)

Neonatal encephalopathy

The incidence of NE in Aotearoa New Zealand is about 1.3 per 1000 term births.(10) The incidence is increasing in Pacific mothers and in communities with increasing deprivation.(10) In an Australian population based study, it appears that about 13% of neonatal survivors of term encephalopathy develops CP.(11)

Inequities of outcome

Māori have an increased risk of complications and poorer outcomes, not only due to higher rates of infants born preterm, but also due to low birth weight, and diabetes in pregnancy.(12) There were significantly higher neonatal death rates for infants without congenital anomalies of Māori, Pacifica, and Indian mothers compared to mothers of other ethnic groupings.(13) Neonatal death rates are higher in Māori (3.8 per 1000 live births), Pacific peoples (5.7) and Asian (3.1), compared to the rates in European/other (2.4).(14)

Some of the reasons for the difference between the health of Indigenous children and other children are deeply embedded in Aotearoa New Zealand society. Others are at play in the interactions that health professionals have with children and their families and therefore can be directly influenced by health care providers. All childhood health inequities are preventable.(15)

Early identification of developmental difficulties

Research has shown that infants who are admitted for neonatal care are at high risk for developmental problems later in life, be that a result of a premature birth or a complicated full-term delivery. For those babies that go on to have problems, the most common difficulties are in the areas of cognitive function, learning, motor co-ordination, sensory processing, social interaction and mental health. These are often evident in infancy and persist throughout the lifespan.

Early identification of developmental difficulties leads to early intervention and additional support for the infant and their whānau/family. Intervention delivered in the first two years of life, during a period of rapid brain maturation and neurodevelopmental plasticity, may have lifelong benefits on a child's health and well-being.

Some of the problems in growth or development can be ameliorated or prevented if detected early. Early intervention to prevent adverse outcomes and the effective integration of services once problems are

identified may reduce the prevalence and severity of certain outcomes and will contribute to an efficient and effective use of health resources.(4, 6)

Infant and parental mental health

A high-risk birth can have a major impact on the whānau/family as a whole, affecting parents' mental health and well-being and their interaction with their infant, which can in turn influence infants' outcomes. It is important that development is optimised and parents are supported from the earliest opportunity to ensure parental wellbeing and that every infant has the best possible start in life.(16)

The term "infant mental health" is used to reflect the social, emotional, and cognitive well-being of children from birth-to-three in the context of secure and nurturing relationships with their parents. This approach also supports relational health by guiding the development of healthy social and emotional behaviours.(17)

Preterm and hospitalised infants are exposed to more painful and stressful experiences than healthy term infants and may experience long periods of separation from their parents. Addressing infant mental health needs in the NICU requires care that promotes the healthy brain development of the infant, reduces infant stress and supports attuned caregiver-infant interactions.

Utilisation of evidence-based infant mental health principles, approaches and strategies in the neonatal intensive care unit and community can contribute to the promotion of optimal outcomes for infants and their parents. In order to integrate mental health best practices into developmental follow-up, an emphasis on infant and family regulation, optimal nurturing relationships and reflective practice is offered.(18-20)

New Zealand follow-up practice

Research about follow-up practices of preterm infants in New Zealand shows that there is a tremendous variation across Aotearoa New Zealand in the criteria for routine preterm follow-up, the timing of visits and the assessments performed.(21) There is inequity in resources for follow-up, where some District Health Boards (DHBs) do not have the resources to provide routine follow-up and can only provide services for children who have an already identified disability.(21)

In Aotearoa New Zealand, neurodevelopmental assessment and developmental support by a Speech Language Therapist (SLT), Occupational Therapist (OT), Physiotherapist (PT) or Visiting Neurodevelopmental Therapist (VNT) in the neonatal period mostly happens at tertiary centres only. Regional DHBs are not funded for providing neurodevelopmental support in the Neonatal Unit, this leads to further inequities of services babies and families in Aotearoa New Zealand receive.

According to research performed in Australia and New Zealand, the level of experience of the therapist and the type of standardised assessments performed in the Neonatal Unit varies hugely.(22) Given evidence-based findings regarding infant (and family) outcomes related to neuroprotective and developmentally supportive interventions in the NICU and the role of the neonatal therapist, consideration around more adequate staffing of neonatal therapy must be addressed.(20, 23, 24)

Guidelines and resources, relevant for the New Zealand context.

The most important and relevant resources needed to develop a practice recommendation for the NZ context are:

- WAI2575 report which identifies four Te Tiriti principles and describes them in detail: Principle of partnership, the principle of active protection, the principle of equity and the principle of options.(1)
- An Australia and New Zealand multi-disciplinary expert panel provided a document and a Checklist of Child and family outcomes to be considered at different ages, including a minimal checklist for busy clinicians. But, for the New Zealand setting, this is more aspirational than practical or implementable.(6)
- A systematic review by Novak et.al. provides best available evidence for early, accurate diagnosis of Cerebral Palsy (CP) and summarises the best available evidence about CP-specific early intervention that should follow early diagnosis to optimise neuroplasticity and function.(4)

- The Australia and New Zealand Neonatal Network (ANZNN) is a collaborative network that monitors the care of high risk newborn infants by pooling data to provide quality assurance for this resource consuming care. Babies included in this database are babies born with a gestational age < 32 weeks and/or with a birthweight < 1500 grams and other babies (received ventilation or CPAP > 4 hours, after major neonatal surgery or received therapeutic hypothermia treatment for NE). For babies born < 28 weeks' gestation a formal developmental assessment is required at 2-3 years of age, including a neurological examination, vision, hearing checks and a developmental assessment as e.g. Bayley Scales of Infant Development-III, Griffiths Mental Developmental Scale, or another developmental assessment to assess cognition, language and motor development.(25)
- The National Institute for Health and Care Excellence (NICE) has developed an evidence-based guideline on developmental follow-up of children and young people born preterm.(26)

Process

After a presentation by N. de Vries on the research of follow-up practices in Aotearoa New Zealand for preterm infants, the Newborn Network Clinical Reference Group (NN-CRG) decided in 2019 to develop a practice recommendation for follow-up of all infants at high risk of developmental disabilities.

A working group was established with 3 members of the NN-CRG (Dr. Nathalie de Vries-chair, Dr. Oliver Grupp, Assoc. Professor Nicola Austin) and an expert member Danielle Atkins, Occupational Therapist, Central Region Visiting Neurodevelopmental Therapy Expert.

The working group has presented several drafts to the NN-CRG in their meetings and feedback has been provided by the members.

The provided recommendations are aligned with the Cerebral Palsy Working group.

From February 2021 – May 2021, stakeholders were consulted to provide feedback.

Feedback was collated and the near to final version of the practice recommendations were presented to the Newborn Network in November 2021.

After further feedback was implemented, including from Māori Health Representatives (see list of acknowledgments), the practice recommendations were submitted to the Paediatric Society in February 2022.

Practice Recommendation

This document is not a Guideline, but an evidence-based practice recommendation based on Aotearoa New Zealand's biculturalism, research, experience and international recommendations. The primary goal is to provide a minimum set of assessments for follow-up in the first two years of life for infants at risk of developmental disability outcome in order to improve equity of access and a more consistent approach of follow-up in this group of infants in order to obtain equitable outcomes.

Providing a minimum set of assessments means that all infants at risk will get all the assessments, unless the assessment is abnormal. If an assessment is abnormal, a further individualised assessment, intervention and care plan will need to be provided. This is outside the scope of this document.

Cultural responsiveness of follow-up services

All services involved in neonatal follow up should:

- Have a plan for equity, including partnering with whānau, hapū and iwi to plan and monitor services and monitoring of engagement rates and outcomes, dis-aggregated by ethnicity.
- Develop culturally competent practitioners with the values and skills to engage with whānau.
- Implement the use of tikanga Māori in practice, e.g., inclusion of karakia, whakawhanaungatanga, manaakitanga where and when required/requested by whanau.
- Allow practitioners more time to engage with whānau Māori
- Paediatricians and Paediatric Trainees should follow the guidance from the RACP position statement "Indigenous child health in Australia and Aotearoa New Zealand" to understanding the role in the elimination of health inequity.(15)

Developmental Pathway

Risk factors

For this practice recommendations, the criteria for high risk of developmental disability are defined as:

- Prematurity, born < 28 weeks' gestation
- Encephalopathy (NE grade 2 or 3), neonatal seizures (excluding benign neonatal seizures)
- Severe Intra-uterine growth restriction (IUGR), < 3rd centile or <1000 gram
- Brain abnormality (Intraventricular Haemorrhage (≥gr III), stroke, microcephaly (<3rd percentile), structural abnormalities)
- Significant neonatal surgery, including cardiac surgery, diaphragmatic hernia
- Significant neonatal complications (Necrotising enterocolitis, Chronic lung disease which requires home oxygen)
- Brain infections, bacterial or encephalitis (not viral meningitis).
- Chromosomal abnormalities, with significant risk for abnormal development.

Other relative risk factors for developmental disability can be:

- Born 28+0 – 29+6 weeks' gestation, especially if there are other risk factors
- Significant antenatal risk factors
- Maternal low socioeconomic status
- Maternal substance abuse
- Clinical concern or parental concern.
- Prolonged tube feeding beyond discharge

- Born >30⁺⁰ weeks' gestation and specific concern about developmental problem or disorder

In the Special Care Baby Unit or Neonatal Intensive Care Unit:

In the Special Care Baby Unit (SCBU) or Neonatal Intensive Care Unit (NICU), babies are identified who are at high risk of developmental disability.

In the neonatal period, often imaging in the form of Head Ultrasound Sonography (HUSS) is undertaken and is routine for babies under 32 weeks. An MRI should be considered in the high risk group taking into account the HUSS findings and clinical concerns. An MRI will ideally be performed before sedation is required. Interpretation of MRI results can be in discussion with a Paediatric radiologist in a tertiary centre, if the baby has already been transferred to a regional hospital.

Assessments recommended in the Neonatal period are:

- General Movement Assessments (GMA)
- Newborn Behavioural Observation (NBO)
- For consideration: Hammersmith Neonatal Neurological Examination (HNNE) and the Test of Infant Motor Performance (TIMP)

When a baby is transferred from a NICU to a regional SCBU, it is important to continue the developmental pathway and hand over the clinical findings.

Neonatal Therapy (OT/PT/VNT)

Neonatal Therapists (NTs) apply knowledge of neonatal medical conditions, intensive care equipment, preterm infant development and necessary handling precautions, and family system dynamics to contribute to the development of a collaborative management plan that promotes age-appropriate infant neurobehavioral organization and interactions. Interventions provided by NTs optimize long-term development, prevent adverse sequelae, nurture the infant-family dyad, and support education needs of the family and NICU team.(27)

Most centres have therapists who are trained in the assessment of General Movements (GMs), and the number of HNNE, TIMP and NBO trained therapists/clinicians is growing. However, regional DHBs do not have funding for therapists in the SCBU, which makes administration of the GMA, HNNE, TIMP or NBO and access to early intervention in the neonatal period difficult. The role of the neonatal therapist and consideration around more adequate staffing of neonatal therapy in regional DHBs must be addressed to reduce this inequity.

Speech Language Therapists

Speech Language Therapists have a specific role in the early identification and management of feeding and swallowing difficulties. They can facilitate positive feeding experiences and support feeding development from the beginning of the parent and infant's feeding journey to reduce the risk of known prolonged feeding difficulties.(28) They have a role in assessment and management of and in supporting families to promote effective early communication and interactions with their preterm and sick infants, improving early attachment and bonding and maximising speech, language and communication outcomes post discharge and beyond into adolescence.(23)

Social Work

Social workers are often involved to support families during their neonatal journey. The wellbeing of the parent(s) and siblings is very important and sometimes screening for depression and referral to Maternal / Paternal Mental Health service will take place.

A multidisciplinary assessment or meeting before discharge is recommended where strengths and challenges will be identified, and discharge planning can be done with the family.

Kaimahi Hauora Māori (Māori Health Support Worker)

Kaimahi Hauora Māori offer cultural support for pēpi/whānau/staff and are part of the multi-disciplinary team (MDT). Their objective is to support pēpi/whānau/staff to assist in providing a seamless journey where possible through the health system. Kaimahi Hauora Māori can be present at all hui pertaining to the pēpi/whānau when required/able.

Homecare

Neonatal Homecare services provide ongoing nursing care after discharge, including infants at high risk for developmental disability. Experienced nurses (with support from Neonatal/Child Health Services) provide support for the management of chronic medical conditions e.g. respiratory problems, cardiac problems of for infants after surgery. They also provide specialist feeding advice and intervention, monitor clinical progress and growth and until appropriate transfer to primary health or paediatric services. The service ensures that all referrals to primary providers, allied health professionals, VNT and surveillance and screening services have been made. Home care nurses also evaluate family coping and supports. Referral to social/mental health support or cultural and community agencies are made when appropriate.

Child Development Service

The Child Development Service (CDS) has an experienced team of paediatric SLT's, OTs, PTs and/or VNTs who are involved in the ongoing care of the infant and whānau once they have transitioned home. The therapists provide specialist neurodevelopmental assessment and intervention in all developmental domains including motor, cognitive, sensory, communication, social and emotional development and support infant-parent occupations e.g. feeding and sleeping. They also support the infant-parent/carer relationship and parental adjustment to having a newborn and arrange referral to appropriate services to support maternal / paternal mental health and any social concerns. Most CDS's can also access cultural support for whānau/families, and Social Workers and Psychologists that can provide ongoing care if required.

Medical Review (paediatric outpatient clinic)

Although ideally follow-up happens in a multi-disciplinary setting, at the moment this has not appeared to be feasible in Aotearoa New Zealand. Mostly, paediatric follow-up happens separate from allied health follow-up.(21)

Paediatric assessments focus on: growth, nutrition, hearing, vision, development, medical issues (e.g. lungs, cardiac) and family wellbeing. Usually a general paediatric physical examination, including a neurologic examination, takes place. If there are any concerns, the family will be referred to a CDS (if they are not yet known to a service) or to any other appropriate service.

Most paediatric services see babies born < 28 weeks to 2 years of age, with those ≥ 28 weeks for shorter lengths.

Early identification of Cerebral Palsy

The assessments in the first year of life are mainly focused on motor function and the early identification of CP. To make an early clinical diagnosis of CP before 6 months' corrected age, a combination of assessments with strong predictive validity coupled with clinical reasoning is recommended. The most accurate method for early detection of CP in infants with newborn-detectable risks and younger than 6 months (corrected age in case of prematurity) is to use a combination of a standardised motor assessment, neuroimaging and history taking about risk factors.(4)

The Cerebral Palsy Network has developed a guideline for early identification of CP and will be published soon. (<https://www.starship.org.nz/health-professionals/cerebral-palsy-clinical-network/>)

The three tools with the best predictive validity for detecting CP before 6 months' corrected age are:

- Neuroimaging - MRI (86%-89% sensitivity)(29)
- Standardised motor assessment - Precht Qualitative Assessment of GMs (98% sensitivity).(29, 30)
- Standardised neurological assessment - Hammersmith Infant Neurological Examination (HINE) (90% sensitivity).(31)

High-quality evidence indicates that a trajectory of abnormal GMs or HINE scores, in combination with abnormal MRI, producing congruent findings, is more accurate than individual clinical assessments in isolation.(4, 29)

Furthermore any 'absent fidgety' abnormal GMs score should activate the need for further investigations, assessments and referral for early intervention based on "high risk of CP".

An experienced clinical team should ideally conduct and interpret the standardised assessments and then communicate the news compassionately to the family or carers.(32) Infants identified as high risk of CP should be referred for early intervention and their parents should have access to support. The CP guideline advises to determine preliminary severity and topography, to assess for associated impairments, to communicate findings with parents compassionately and to monitor and confirm diagnosis at later age. Infants with CP or high-risk of CP should also be referred to the CP register.

In contexts where the GMs assessment is not available, or MRI is not safe or affordable, early detection of CP in infants with newborn-detectable risks and younger than 6 months (corrected age) is still possible and should be carried out to enable access to early intervention. The HNNE, HINE and Test of Infant Motor Performance (TIMP) have the best predictability in the early months and the HINE and the Alberta Infant Motor Scale (AIMS) are the best predictors of atypical motor development in the later months, 4 to 12 months corrected age.(33)

Developmental delay – not cerebral palsy

Whilst CP is the commonest single cause of neurological disability in young children it is extremely important to think about and to rule out other conditions e.g. genetic, metabolic, neuromuscular disorders that may lead to neurological abnormality.

Very preterm infants may show a different pattern of motor skill development which rather than abnormal may be associated with the extended need for intensive care.(33) Their motor delay is often associated with generalised hypotonia and have low truncal tone and slower motor milestones particularly sitting without support and walking. It is seen particularly in babies on prolonged respiratory support due to extreme prematurity, Chronic lung disease and some surgical conditions e.g., Congenital diaphragmatic hernia and gastroschisis with prolonged TPN. They may score in the 40-72 range in the HINE (49) and have mild delay in the Bayley assessment at 2 years(33).

Early motor delay increases the risk of Development Coordination Disorder (DCD) which can be assessed using the Movement ABC assessment (from age 4).(34) Children with DCD may have functional difficulties associated with their motor problems including difficulty dressing, tying shoelaces, using utensils, writing, riding bicycles, and playing team sports.

Developmental Support

(Adapted from the NICE Guidelines(26))

Developmental support after discharge is typically provided by the multidisciplinary team. A range of approaches should be used when providing enhanced developmental support and should be tailored to take account of individual and cultural preferences and needs.

Clinicians should have the appropriate knowledge and skills for working with infants/children and whānau / families. Research suggests that services are most beneficial when they are delivered in a trauma informed, family centred and relationship-based approach that addresses the infants concerns but also the parents identified needs.(35, 36)

At each visit the clinician should discuss with carers any concerns they may have regarding their child's development and carefully evaluate and review any developmental concerns. Any concerns identified should be discussed with whānau / family. The clinician might provide developmental advice or guidance if appropriate or consider further investigation and/or a referral to the appropriate service.

At each visit the clinician should check for signs and symptoms of developmental problems and disorders as appropriate, such as:

- CP (see CP guidelines)
- global developmental delay and learning disability (intellectual disability)
- visual impairment
- hearing impairment
- feeding problems
- sleep problems, including sleep apnoea
- speech, language and communication problems
- motor problems
- problems with inattention, impulsivity or hyperactivity
- autism spectrum disorder
- emotional and behavioural problems
- executive function problems
- potential special educational needs.

The clinician should also recognise the following as possible early motor signs of CP:

- delayed motor milestones, such as late sitting, crawling or walking (correcting for prematurity)
- unusual (abnormal or absent) fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement
- abnormalities of tone, including hypotonia (floppiness) or spasticity (stiffness)
- persistent feeding difficulties.

Follow-up after 2 years' corrected age.

Most children will be discharged around the corrected age of 2 or sometimes earlier when they are growing, walking and talking typically for their age and there are no other concerns. Most severe developmental problems will have been detected by 2 years of age, however, problems affecting learning and emotional development may be detected later. This is beyond the scope of this practice recommendation. These children might be identified via early education, school or B4School check, or because of parental concerns.

Follow-up in Primary care.

All parents are advised to enrol their baby with a GP and Well Child Tamariki Ora provider. In primary care, growth and development are monitored, immunisations are given, and vision and hearing are checked. Primary care is usually the first point of call for new concerns raised by the parents.

We would advise Primary Health care providers to consider referring a child for a paediatric assessment if the child: (ages are corrected age in case of prematurity)

- has persistent head lag beyond the age of 4 months
- keeps the hands / one hand fisted after the age of 4 months
- has stiffness in the legs between 6-12 months
- is unable to sit independently by 9 months
- has got hand preference before the age of 12 months

Communication

It is extremely important for health care providers to communicate well with the parents as well as with each other.

FOLLOW-UP PRACTICE RECOMMENDATION

Parents have the right to receive information and advice regarding the developmental prognosis and developmental needs of their child. Communication should be clear, timely, culturally appropriate and focus on the infant's strengths.

With the parents' consent, it is the health care provider's responsibility to inform other providers about their findings. A tool to improve the communication of findings between health care providers is the Follow-up Findings tool on the back of the Developmental pathway flow-chart.

Assessments and Screening Tools

Prechtl’s Qualitative Assessment of General Movements

The quality of GMs are highly predictive of neurodevelopmental outcome.(37) Normal GMs are shown to have high correlation with normal outcome. Systemic review of large cohorts of mainly preterm infants indicates that an abnormal GMs assessment score of ‘absent fidgety (F-)’ movements at 12-20 weeks corrected age is 95-98% predictive of CP.(29) In particular ‘cramped synchronised’ (CS) in the ‘writhing’ period follow by ‘absent fidgety’ at 12-20 weeks corrected age.(38)

Furthermore any ‘absent fidgety’ GMs (F-) score should activate the need for further investigations, assessments and referral for early intervention based on “high risk of CP”. Abnormal GMs accurately detect the likelihood of risk of CP and a detailed GM assessment predicts later severity of CP.(39) GMs can detect both mild and severe forms of CP.

The distinction between the predictive validity of writhing and fidgety periods is critical. Abnormal writhing movements can normalise and clinicians should focus on ensuring that they obtain a trajectory of general movements including the fidgety age.

As the majority of infants are no longer hospital inpatients during the fidgety period, concerted effort for infants to be assessed at this age in an outpatients setting is of high importance.

A basic GM training course is required, and certification is required for reliability.(37, 40) Basic training and advanced training courses are available in New Zealand. Clinicians assessing infants in the NICU/SCBU should be experienced/advanced level practitioners with mentoring and training specific to working with neonates in the neonatal setting.

Practice points from international guidelines – Prechtl’s Assessment of General Movements (GMs)

Screening Time Period	Normal Result	Abnormal Result
“Writhing” age Preterm age - up to 6-9 weeks post-term age	Normal GMs Continue ongoing developmental follow-up.	‘Poor repertoire’ GMs (PR) Not predictive of CP Continue ongoing developmental follow-up.
		‘Cramped Synchronised’ GMs (CS) (Predictive if persistent) Continue ongoing developmental follow-up and consider referral for early intervention
		‘Chaotic’ (Rare and non-predictive) Continue ongoing developmental follow-up

		and consider referral for early intervention
<p>'Fidgety' age</p> <p>Seen from 6-9 weeks post-term age up to 20 weeks</p> <p>Best assessed between 12-16 weeks post term age</p> <p>Two recordings in the 'fidgety' period are recommended.</p>	<p>Fidgety movements present (F+): Low risk for CP</p> <p>Continue ongoing developmental follow-up.</p>	<p>'Absent fidgety movements' (F-): High risk of CP</p> <p>Referral for early intervention and parent supports</p>
		<p>'Abnormal fidgety' (AF)</p> <p>Less common, possible increased risk of neurological condition</p> <p>Continue ongoing developmental follow-up and consider referral for early intervention</p>

Cerebral.palsy.org.au

Test of Infant Motor Performance

The TIMP is a 25- to 35- minute functional motor scale that can be used with infants from 32 weeks' postconceptional age through to 4 months' corrected age (or 4 months' chronologic age in infants born at term). The TIMP is sensitive to age-related changes in motor performance ($r=0.83$), and children with many medical complications have significantly lower scores than healthier children.(41)

Test-retest reliability of the TIMP was excellent with the intra-class coefficient of 0.99. The test-retest reliability for 116 pairs of tests of $r = .89$ over 3 days; no significant difference between testers.(42)

Standardised data used to diagnose motor developmental delay from 34 weeks postconceptional age through 4 months post term is based on age standards developed from a sample of 990 U.S. infants of all races/ethnicities that were at risk of developmental concerns.

The TIMP is predictive of 12-month motor performance with sensitivity 92% and specificity 76% and preschool motor performance with sensitivity 72% and specificity 91% at 3 months of age.

In the case of TIMP, its validity was measured by comparing it with AIMS and correlation between scores on the TIMP and the AIMS was highest for TIMP tests at 90 days and AIMS testing at 6 months ($r=0.67$, $p=0.0001$) concluding that TIMP can be used clinically to identify infants likely to benefit from intervention.(43)

Hammersmith Neonatal Neurological Examination

The HNNE is a quick, practical and easy to perform exam encompassed in 34 items assessing tone, motor patterns, observation of spontaneous movements, reflexes, visual and auditory attention and behaviour.(44) It was initially developed by Dr Lilly Dubowitz and Prof Victor Dubowitz in 1981, and updated with Dr Eugenio Mercuri, in 1998. Many studies have been performed using it in different clinical groups of full term and preterm infants at different ages within the neonatal period. A suboptimal performance has been associated with neurodevelopmental delay.(45)

Training is available online and further information on how to administer and score the HNNE can be found at <https://hammersmith-neuro-exam.com/> Clinicians assessing infants in the NICU/SCBU should be

experienced/advanced level practitioners with mentoring and training specific to working with neonates and their families in the neonatal setting.

Hammersmith Infant Neurological Examination

The HINE is recommended in the International Clinical Practice Early Diagnosis of CP Guidelines, particularly in situations where the most predictive tools (GMs and MRI) are not able to be used.

The HINE can be used on infants aged between 2–24 months of age. It can assist in the early detection, diagnosis and prognosis of infants at risk of developing CP.

In the context of CP, the scores from the HINE after 5-6 months can be used to predict the later ability to sit and walk. In general, the lower the scores the more severe the impairment and CP. Scores for children with milder hemiplegia may be in the normal range but the number of asymmetries and the asymmetry score developed by Hay et al. will help in suggesting this diagnosis.(46)

The HINE is a simple, scoreable, standardised clinical neurological examination for infants between 2 and 24 months of age. Specific cut-off scores for predicting CP both in pre-term and full-term infants have been published.

The HINE has good sensitivity and high predictive value for risk of CP in high risk populations under 5 months.

Over 5 months age corrected for prematurity it has 90% predictive accuracy for detecting the risk of CP.(47, 48)

It provides objective information about likely motor severity and distribution of CP.(49) Scores below 40 predict non-ambulant CP.

HINE scores at 6,9 or 12 months

- <73 indicates high-risk of CP
- <40 indicates abnormal outcome, almost always indicate non-ambulant CP
- < 10th percentile is suspect and should be monitored closely.

A HINE score <57 at 3months are 96% predictive of CP (sensitivity 96%; specificity 87%) in infants older than 5 months (corrected for prematurity) but less than 2 years of age.(49)

The HINE is easily performed, accessible to all clinicians as no certified training is required. It has good inter-observer reliability for all levels of clinical experience.(48, 50, 51)

Training is available online and further information on how to administer and score the HINE can be found at <https://hammersmith-neuro-exam.com/>

Newborn Behavioural Observation

For all references see: <https://www.newbornbehaviorinternational.org/nbo-research-2006-2020>(52)

The NBO system consists of a set of 18 neurobehavioral observations, which describe the newborn's capacities and behavioural adaptation from birth to the third month of life. While it describes the infant's capacities, the NBO provides parents with individualised information about their infant's behaviour, so they can appreciate their baby's unique competencies and vulnerabilities and thereby understand and respond to their baby, in a way that meets her/his developmental needs.

The NBO can be used with healthy infants from a gestational age of 36 weeks to three months "post-term", and with preterm or medically fragile infants who are stable enough to be close to hospital discharge or who are post discharge at home.

There are 18 items in total that can be observed on the NBO. Each session is individual, because the baby will guide the clinician and the parents, but it will typically cover:

- Capacity to habituate to light and sound (sleep protection)
- Motor tone and activity level
- Capacity for self-regulation (including crying and consoling)
- Response to stress (indices of the infant's threshold for stimulation)
- Visual, auditory and social-interactive capacities.

Inspired by the Neonatal Behavioral Assessment Scale (NBAS), the NBO was designed as a relationship-building tool that can be flexibly administered and that offers individualised information to parents about their baby, with a view to promoting a positive bond between parent and child and between themselves and the parents and family. It is inherently interactive and family-centred, because parents are involved as partners in the NBO session throughout. So, while the NBO aims at fostering positive parent-infant interaction, it also aims at promoting a positive relationship - a partnership - between clinician and parents.

A number of randomised control studies have demonstrated the NBO's effectiveness as a form of parenting support. In a study by McManus et al, infants receiving the NBO with their mothers had greater gains in cognitive and adaptive functions at 6 months.(53) In a number of studies, the NBO was associated with enhanced mother–infant engagement. Studies have also shown that mothers who participated in the NBO sessions demonstrated a reduction in postpartum depressive symptomatology. Moreover, NBO practitioners demonstrated higher perceived confidence in working with low- and high-risk newborns and their families.

In a series of non-randomized observational studies the NBO has been associated with enhanced mother–infant engagement, a greater understanding of the baby's communication cues, increased levels of confidence among parents, positive parental perceptions of their interactions with their high-risk infants, increased levels of father involvement, and higher perceived confidence and enhanced practitioner mentalisation among service providers in working with low- and high-risk newborns and their families.

Training in the NBO is available online and additional course work is required to achieve certification. Clinicians implementing the NBO with infants in the NICU/SCBU should be experienced/advanced level practitioners with mentoring and training specific to working with neonates and their families in the neonatal setting. Further information on training in the NBO can be found at the NBO Training Site for Australia and New Zealand.

<https://www.thewomens.org.au/health-professionals/clinical-education-training/nbo-australia>

It is advised that NBO-trained practitioners encountering unusual or abnormal behaviour in the neonate/infant should be able to turn to a practitioner trained in the NBAS for support or to conduct a more detailed and diagnostic assessment of neonatal behaviour. Referral to

For further information on training in the NBAS please contact brazeltonnz@gmail.com

Alberta Infant Motor Scales

The Alberta Infant Motor Scale (AIMS) is a norm-referenced assessment of motor development for infants from birth to 18 months of age. It looks to identify delayed motor development and studies have found the AIMS to be a reliable tool for evaluating motor development in infants born at term and infants born prematurely.

The predictive capacity of the AIMS varies based on the age that the child was evaluated. The AIMS is less reliable in infants of very young age (<4 months) and infants approaching independent ambulation (after 12 months) because of limited test items in these age ranges.(54) Greatest reliability is in the mid-range between these ages and infants and below the 5th percentile at 8 months can be considered valid and reliable indicators of motor developmental delay or disability.

It is important to note that preterm infants have been shown to have different motor trajectories from those of infants born at term, which may result in the motor development of preterm infants incorrectly being labelled as 'abnormal'. Longitudinal assessments, rather than a single assessment, are more predictive because they give information on developmental progression including monitoring peaks, plateaux, and, in some cases, regression of infants. For this reason, it is important to ensure that assessment tools can be used at more than one time point in the infant's development.(33)

The AIMS does not require specific training, however experienced therapists familiar with infant motor development and movement analysis are more reliable testers. (Womack et al., 2010)

Feeding Matters Checklist

Feeding Matters' innovative Infant and Child Feeding Questionnaire® (ICFQ©) was authored in partnership with internationally renowned thought leaders representing multiple disciplines related to feeding. The ICFQ© is an age specific tool designed to identify potential feeding concerns and facilitate discussion with all members of the child's healthcare team.

According to Silverman et al., the ICFQ© has been shown to accurately identify and differentiate paediatric feeding disorder (PFD) from picky eating in children 0-4 years of age based on caregiver responses to 6 specific questions.(55) This 6-question quick screener continues to undergo research as Feeding Matters strives to promote the early identification of PFD.

The Infant and Child Feeding Questionnaire and further information can be found at <https://questionnaire.feedingmatters.org/questionnaire>

Communication and Symbolic Behaviour Scales Developmental Profile Infant Toddler Checklist

The Communication and Symbolic Behaviour Scales Developmental Profile Infant Toddler Checklist (CSBS DP™ ITC) is the first step in routine screening to see if a developmental evaluation is needed.(56) Rather than waiting to refer a child who is not yet talking for evaluation, the ITC enables you to take an early look at a collection of 7 key predictors of later language delays.

A study by Pierce et al. found that using the CSBS DP™ ITC as a screening tool at children's 1-year check-up was a promising way for health care professionals to identify children in need of further evaluation for autism and other developmental delays.(57)

The CSBS DP™ ITC

- is used with infants and toddlers whose functional communication age is between 6 months and 24 months (chronological age from about 6 months to 6 years)
- can be completed by caregivers and professionals trained to assess young children (e.g., speech-language pathologists, early interventionists, or psychologists);
- professionals scoring takes 5–10 minutes to complete

The CSBS DP™ ITC is available to download for free at <https://brookespublishing.com/wp-content/uploads/2012/06/csbs-dp-itc.pdf>. The most efficient manner of scoring and interpreting the checklist is to use the CSBS DP™ ITC and Easy-Score CD-ROM. Simply input basic child data and select responses to the 24 checklist questions. The program calculates the child's chronological age and tallies the

scores derived from the norms reported in the CSBS DP Manual. It also includes a report letter for you to give families that summarises the screening results and comments on future action as appropriate.

Ages and Stage Questionnaire

Ages & Stages Questionnaires®, Third Edition (ASQ®-3) is a developmental screening tool designed for use by early educators and health care professional.(58) It relies on parents as experts, is easy-to-use, family-friendly and creates the snapshot needed to identify delays *and* celebrate developmental progress.

ASQ-3 questionnaires

- take just 10–15 minutes for parents to complete and 2–3 minutes for professionals to score
- capture parents' in-depth knowledge
- highlight a child's strengths as well as concerns
- teach parents about child development and their own child's skills
- highlight results that fall in a "monitoring zone," to make it easier to keep track of children at risk
- can be completed at home, in a waiting room, during a home visit, or as part of an in-person or phone interview.

The ASQ-3 is

- highly valid, reliable, and accurate
- cost-effective
- easy to score in just minutes
- researched and tested with an unparalleled sample of diverse children
- a great way to partner with parents and make the most of their expert knowledge
- fun and engaging for infants and children

Further information can be found at <https://agesandstages.com/>

Bayley Scales of Infant Toddler Development IV

The Bayley Scales of Infant and Toddler Development – Fourth Edition (BSID-4) may be used to identify developmental delays, chart a child's progress, and teach parents about the child's development.(59) The test is designed to be used with children ages 1 to 42 months. It consists of five scales: Cognitive, Language (Receptive and Expressive), Motor (Fine and Gross), Social-Emotional, and Adaptive Behaviour (Conceptual, Social, and Practical).

For the first time the BSID-4 has been culturally adapted and fully standardised for Australia and New Zealand with census matched data collected on over 716 infants and children. In addition to this, clinical data has been collected on various clinical groups, including children born preterm. The BSID-4 ^{A&NZ} provides the most accurate and comprehensive measurement of early development for early childhood professionals working in Australia and NZ.

Features and benefits

- Census matched Australian and NZ standardisation
- Normed on 716 children in Australia and New Zealand, including clinical studies.
- Choose from paper or digital record forms for administration
- Digital delivery option via Q-global combines the record form and administration manual, which allows greater flexibility, ease of use and improved accuracy.
- Use caregiver responses to support the scoring of certain items.
- Determine the need for further in-depth assessment.

FOLLOW-UP PRACTICE RECOMMENDATION

- Comprehensive assessment of the five developmental domains: Cognitive, Language, Motor, Social Emotional, and Adaptive Behaviour.
- Flexible administration: Administer one or more domains.
- Save significant time through shortened adaptive behaviour content adapted from Vineland 3.
- Content updates made based on research and user feedback
- Online and Face to Face Training options available. Noted cost of kits and training.

Further information can be found at

<https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Cognition-%26-Neuro/Bayley-Scales-of-Infant-and-Toddler-Development-%7C-Fourth-Edition/p/100001996.html>

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List of abbreviations

AIMS	- Alberta Infant Motor Scale
ANZNN	- Australia and New Zealand Neonatal Network
ASQ	- Ages & Stages Questionnaires
BSID-4	- Bayley Scales of Infant and Toddler Development – 4 th Edition
CDS	- Child Development Service
CS	- Cramped Synchronised
CSBS DP™ ITC	- Communication and Symbolic Behaviour Scales Developmental Profile Infant Toddler Checklist
CP	- Cerebral Palsy
GMA	- General Movement Assessment
GM(s)	- General Movement(s)
HINE	- Hammersmith Infant Neurological Examination
HNNE	- Hammersmith Neonatal Neurological Examination
HUSS	- Head Ultrasound Sonography
IUGR	- Intra-uterine growth restriction
NBO	- Newborn Behavioural Observation
NE	- Neonatal Encephalopathy
NICU	- Neonatal Intensive Care Unit
NN-CRG	- Neonatal Network – Clinical Reference Group
OT	- Occupational Therapist
PT	- Physiotherapist
SCBU	- Special Care Baby Unit
SLT	- Speech Language Therapist
TIMP	- Test of Infant Motor Performance
VNT	- Visiting Neurodevelopmental Therapist

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