

# Occupational therapy in neonatal services and early intervention

*Practice guideline*

Royal College of Occupational Therapists



Royal College of  
Occupational  
Therapists



Specialist Section  
Children,  
Young People  
and Families

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This publication  
is endorsed by

**Bliss**  
for babies born  
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An associated document: *Practice guideline supplement. Evidence tables* (see Appendix 2) is available to download from the Royal College of Occupational Therapists' website.

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*The term 'parent', as used in the guideline, should be considered to be inclusive of guardians or caregivers*

This guideline was developed using the processes defined within the *Practice guideline development manual* (College of Occupational Therapists [COT] 2017a).

Readers are referred to the manual to obtain further details of specific stages within the guideline development process, available at:

[www.rcot.co.uk/practice-resources/rcot-publications/downloads/practice-guideline-development-manual](http://www.rcot.co.uk/practice-resources/rcot-publications/downloads/practice-guideline-development-manual)

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# Foreword

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As the mother of a 29-weeker and now proud ambassador for Bliss Scotland, I was delighted to be asked to provide a forward to this practice guideline.

This document provides an essential resource, not only for occupational therapists in a neonatal setting, but also for all neonatal healthcare practitioners. This guideline will assist and facilitate the development of coordinated care plans for each and every baby going through the neonatal care pathway.

Of particular note, the facilitating of parental involvement in the care of their infant is paramount. This guideline recognises not only the key role a parent can play in their child's care, but also the emotional needs of the parents themselves, as they learn how to parent in what is often a very difficult environment. This guideline assists by supporting occupational therapists as they provide this essential therapy.

I would like to thank the authors of the document in developing this guideline. Families like mine are indebted to the skilled specialists and experts whose tireless work will result in improved outcomes for premature babies.

***Lady Sarra Hoy***  
*Bliss Scotland Ambassador*

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# Foreword

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Neonatal Intensive Care is a young discipline. Early attempts to provide such care concentrated on survival and saving lives, and was highly successful. Over the past 15 years, neonatal care has increasingly been reorienting itself to providing high-quality outcomes, as we have understood the importance of postnatal care and of the family in promoting the best outcomes for our fragile charges. Since the original Standards for Hospitals Providing Neonatal Intensive Care (BAPM 1996), the role of occupational therapy, alongside all of the infant-focused allied health disciplines, has been recognised as important. The unique nature of the 'occupation' for the baby and family in neonatal care, with the complex combination of developmental and destructive disturbances, alongside the need for professional recognition of the value of family input, makes the occupational therapist an important and central member of the neonatal team, from whom we can all learn.

This guideline is welcomed and emphasises the core role of the occupational therapist in supporting the family and the neonatal team in providing developmentally focused and appropriate interventions. It spans the breadth of neonatal care, from kangaroo mother care to minimising painful interventions, and is supported by a wealth of research data to support neonatal teams in their assessment of the need for such expertise within the team. It also acknowledges the critical importance of taking the mother and family on the journey, so that their input may support and extend the value of the developmentally appropriate advice and support. Multidisciplinary developmental care is critical in delivering improved long-term outcomes, for the baby and for the family, minimising the stress and fear which may interrupt normal rearing practices.

One of the strengths of occupational therapy in a neonatal setting is the ability to support an individual's developmental care after discharge from hospital. In keeping with current guidance this is suggested to extend to two years after discharge, but in practice should continue for as long as it is required. Careful assessment and multidisciplinary engagement are important in children for whom there are developmental concerns. The assessment and provision of timely early interventions during infancy is the likely long-term benefit and avoidance of developmental problems where they can be foreseen. This continuity is highly valued by parents, and is a very necessary contribution to ensuring high-quality outcomes.

This guideline is of equal importance as it demonstrates the need for adequate occupational therapy support within neonatal teams. It importantly has been developed using the most robust methodology we have and thus represents the state of the art within current knowledge. This ensures that it is of relevance and demonstrates the strong 'need' for such services within Neonatal and High Risk Follow-up services.

At a time when all National Health Services are under review and scrutiny, such a valuable contribution is to be welcomed. The NHS Five Year Forward View recognises the importance of strengthening our workforce. This guideline provides evidence that occupational therapists should be at the heart of the neonatal team and resourced from within neonatal financial envelopes.

**Neil Marlow DM FMedSci**  
*Institute for Women's Health, University College London*



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# Foreword

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Research over the last thirty years has shown, all too well, that babies 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. A high-risk birth can also have a major impact on the family as a whole, affecting parents' mental health and well-being and their interaction with their child, which can in turn influence children's outcomes. 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. Thus it is important that infant development is optimised and parents are supported from the earliest opportunity to ensure that every baby discharged from neonatal care has the best possible start in life. It is exactly this vital role that occupational therapists have to play.

The publication of this guideline is testament to the unique contribution that occupational therapy has to offer neonatal care and neurodevelopmental follow-up. I am delighted to have the opportunity to congratulate the guideline development group on their review and appraisal of the literature, the development of evidence-based recommendations and the production of a comprehensive yet accessible document which will no doubt become a cornerstone for best practice in the field. I am pleased to see that the recommendations provide guidance for optimising infants' cognitive, motor and social-emotional development – the most common difficulties these children are likely to face – and opportunities for working collaboratively with parents to help nurture their relationship with their child. This holistic approach is especially important for high-risk babies whose problems are likely to span multiple developmental domains. Even those infants without significant morbidity in the first few years of life may go on to have subtle difficulties at school age and may benefit from preventive intervention. Investment in children's development should start at birth to provide the building blocks for future health and well-being. I sincerely hope that implementation of this guideline leads to improved outcomes for this highly vulnerable group of infants.

***Dr Samantha Johnson***

*Reader in Developmental Psychology, Department of Health Sciences, University of Leicester*



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# Introduction

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This practice guideline aims to define the best and most effective practice for occupational therapy for high-risk<sup>1</sup> infants in neonatal and early intervention settings.

As a primary resource for occupational therapists practising in this area, the guideline can assist decision making about areas for assessment and intervention, in addition to describing the profession's contribution to the neonatal care pathway.

The guideline may also be of use to other neonatal practitioners and commissioners with regards to the inclusion of occupational therapy within neonatal multidisciplinary teams.

Occupational therapy makes a unique contribution to the neonatal team, and the services it provides to infants and families. Occupational therapists have specific skills and knowledge which can enhance the delivery of neonatal care:

- Unlike other professions, one of the distinctive characteristics of occupational therapy education is that it incorporates both physical and mental healthcare models, resulting in a holistic approach. This is particularly relevant because preterm infants are at risk of developing emotional and behavioural problems later in life (Mathewson et al 2017). Occupational therapists' particular interest in the antecedents to these issues makes them key contributors to a preventative healthcare model with this client group. In addition, parents/caregivers may experience issues around psychological adjustment, and mental health issues may adversely affect parenting efficacy. Occupational therapists can support infants and their caregivers to develop successful psychological and practical coping strategies.
- Preterm infants are at risk of, and often present with, sensory processing problems, which is a specialised area of practice for occupational therapy (Bröring et al 2017). Early sensory and motor exposures lay the building blocks for development and lifelong adaptation as well as for successful parent-child interaction. Occupational therapists can provide a specialist role in educating parents on promoting developmentally appropriate sensory stimulation and experiences for their babies.
- Occupational therapy is based on systems theory models (Reed and Sanderson 1992; Kielhofner 2002), which emphasises that dynamic interactions within families, within the neonatal unit and within the community are part of a problem-solving paradigm.

This guideline refers to the 'occupations' in which infants and parents participate. Occupation is 'the context in which people develop skills, express their feelings, construct relationships, create knowledge and find meaning and purpose in life' (Townsend and Polatajko 2007, xxi). Infant 'occupations' are the activities that they engage in as they strive to master the skills they will need to adapt to their environment, to make close relationships, to learn and to move towards independence. The parent 'occupations' are the activities through which they support their infants' efforts to achieve these goals, providing a nurturing and developmentally appropriate environment with opportunities to master the skills they will need for life. These processes begin at birth and, in the newborn period in particular, require close

synchrony; hence the term ‘shared occupations’. (For full definitions of terms used in the guideline, see the glossary in Appendix 1.)

It is recognised that all neonatal healthcare professionals will be expected to have a range of common core skills and that there will be considerable professional overlap (Barbosa 2013). This is an advantage in the delivery of neonatal care. A transdisciplinary model of teamwork is particularly economical and effective when working with infants, who have a relatively uncomplicated range of abilities compared with adults. This means that the different disciplines can agree to share and overlap in order to simplify services for families. Although different professional roles may overlap, each profession brings to those roles its own perspectives and skills, which adds a richness of knowledge and experience to the team. The range of practice for each profession will be influenced by the presence or absence of other allied health professionals and the skills they bring to the team. Between them they can collaborate to cover all areas, and the ways in which they do this will vary from team to team, and from time to time.

The occupational therapist may not be available on a daily basis for families in the same way that a nurse will be, but they can be a resource for nurses and other members of the team in order to support problem solving and to facilitate individual developmentally supportive care plans. The occupational therapist’s primary role is to keep all aspects of development in mind when nurses and doctors may be necessarily focused on the medical and technical challenges around the care of the infant. Occupational therapists come to neonatology with a different set of skills and knowledge, including a long-term perspective on the outcomes for infants and families. Where the multidisciplinary team includes members of different professions with different levels of experience, those that are more senior or more experienced will share knowledge and skills to support those from other professions who are new to this area of work.

It is acknowledged that evidence of varying levels has been used to develop the recommendations included in the guideline. The quality of the research available is influenced by the limitations of robust randomised trial designs in evaluating complex interventions. This is particularly the case in the neonatal setting where specific interventions are individualised to support each infant’s neurobehavioural competencies. Samples included in the studies tend to be heterogeneous and often small due to small numbers of eligible infants and families. Additionally, when measuring outcomes over the life course (infancy, childhood, adolescence and adulthood), these are likely to be influenced by many unmanageable variables. As described further in the guideline, a formal process of appraising and grading the evidence has been undertaken to enable judicious use of the evidence in developing the recommendations.

Finally, this resource is proposed as the first stage in a series of potential developments. These may include resources that will provide specific practical guidance on assessment and interventions appropriate for use in the United Kingdom, a knowledge and skills framework for occupational therapy practice, and continuing education frameworks. It is anticipated that these proposed developments will add increasing specificity to the provision of occupational therapy services in neonatal settings in the United Kingdom.

## Note

- 1 ‘High-risk’ has been used to describe the target population of this guideline, which includes all infants born preterm, high-risk infants born at term (e.g. infants with neonatal hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care, and their parents.

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# Key recommendations for implementation

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The aim of this guideline is to provide specific evidence-based recommendations which describe the most appropriate care or action to be taken by occupational therapists working in neonatal services or early intervention.

Recommendation statements should not be taken in isolation and must be considered in conjunction with the contextual information provided in this document, together with the details on the strength and quality of the recommendations. The statements are graded based on the Grading of Recommendations Assessment, Development and Evaluation (GRADE) process (GRADE Working Group 2004) as described in the College of Occupational Therapists' *Practice guideline development manual* 3rd edition (COT 2017a). The strength of the recommendations is identified via a scoring of 1 (strong) or 2 (conditional), and the quality of the supporting evidence via a grading on a scale of A (high) to D (very low). It is strongly advised that readers study section 10 to understand the guideline methodology, together with the evidence tables in Appendix 2, to be fully aware of the outcome of the literature search and overall available evidence.

The guideline aims to support the occupational therapist's decision making and clinical reasoning. Being based on evidence, it cannot cover all aspects of occupational therapy in neonatal services or early intervention.

The recommendations for occupational therapy intervention, based on the best available evidence to date, are set out in ten categories:

1. Occupation-based assessment
2. Developmentally supportive care
3. Pain management
4. Skin-to-skin (kangaroo) care
5. Positioning
6. Infant feeding
7. Parent engagement
8. Parent support
9. Identifying developmental concerns
10. Early intervention.

In each of the recommendations outlined, the collective term of 'high-risk infant' is used, and includes all infants born preterm, high-risk infants born at term (e.g. infants with hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care and their parents.

## Recommendations by category

The recommendations are not presented in any order of priority or relative importance. They loosely represent the stages of an infant's journey through a neonatal unit admission and beyond. The overall quality of evidence grade reflects the robustness or type of research supporting a recommendation, but not necessarily the recommendation's significance to occupational therapy practice.

**'It is recommended. . .'** Benefits appear to outweigh the risks (or vice versa) for the majority of the target group; most service users would want or should receive this course of intervention or action.

**'It is suggested. . .'** Risks and benefits are more closely balanced, or there is more uncertainty in likely service user values and preferences; the majority of service users would want this intervention but not all, and therefore they should be supported to arrive at a decision for intervention consistent with the benefits and their values and preferences.

### Occupation-based assessment

- |  |    |
|--|----|
| 1. <b>It is recommended</b> that occupational therapists safely and appropriately assess the neurobehavioural status of the high-risk infant, in order to plan/deliver developmentally supportive care.<br><i>(Als et al 2003 [A]; El-Dib et al 2011 [C])</i>  | 1A |
| 2. <b>It is recommended</b> that occupational therapists assess neurobehavioural and neurodevelopmental status to provide guidance and identify infants appropriate for developmental follow-up following discharge.<br><i>(Bartlett 2003 [C]; Crowle et al 2015 [D]; Liu et al 2010 [D]; Sucharew et al 2012 [C])</i> | 1C |
| 3. <b>It is recommended</b> that occupational therapists liaise with community teams and assess neurodevelopmental status for high-risk infants in the first two years of life to provide guidance and implement early intervention services where indicated.<br><i>(Liu et al 2010 [D])</i>                           | 1D |

### Developmentally supportive care

- |   |    |
|---|----|
| 4. <b>It is recommended</b> that developmentally supportive care principles are implemented for high-risk infants admitted to neonatal units to enhance short term health and developmental outcomes.<br><i>(Als et al 2003 [A]; Legendre et al 2011 [B]; McAnulty et al 2010 [B]; McAnulty et al 2009 [A]; Symington and Pinelli 2006 [A]; Wallin and Eriksson 2009 [B])</i> | 1A |
| 5. <b>It is recommended</b> that occupational therapists promote an appropriate developmental environment, based on the infant's age and status and individual needs.<br><i>(McAnulty et al 2010 [B]; Symington and Pinelli 2006 [A]; Symington and Pinelli 2002 [A])</i>   | 1A |

## Pain management

- |  |    |
|--|----|
| 6. <b>It is recommended</b> that occupational therapists promote and support parent provision of skin-to-skin care with their infant during appropriate, planned, painful caregiving procedures (e.g. heel lance).<br><i>(Ferber and Makhoul 2008 [A]; Johnston et al 2011 [A]; Cong et al 2012 [B]; Kostandy et al 2008 [C])</i>          | 1A |
| 7. <b>It is recommended</b> that occupational therapists promote the use of facilitated tucking by all caregivers (parents and practitioners) for pain management during relevant caregiving procedures (e.g. endotracheal suctioning).<br><i>(Axelin et al 2006 [A]; Obeidat et al 2009 [B])</i>  | 1A |
| 8. <b>It is recommended</b> that occupational therapists support parent understanding and facilitate engagement in appropriate pain management strategies to enable them to provide sensitive support to their infants and promote parent self-efficacy.<br><i>(Franck et al 2012 [C]; Franck et al 2011 [A]; Axelin et al (2006) [A])</i> | 1A |
| 9. <b>It is recommended</b> that occupational therapists work with the neonatal team to promote routine assessment of neonatal pain and identification of appropriate pain management strategies.<br><i>(Gibbins et al 2015 [C])</i>   | 1C |

## Skin-to-skin (kangaroo) care

- |  |    |
|--|----|
| 10. <b>It is recommended</b> that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote breastfeeding, pain management, physiological regulation and parent self-efficacy.<br><i>(Ludington-Hoe et al 2004 [A]; Morelius et al 2015 [A]; Chan et al 2016 [A]; Boo and Jamli 2007 [A]; Cong et al 2009 [A]; Gathwala et al 2008 [A]; Hake-Brooks and Anderson 2008 [A]; Cho et al 2016 [B]; Head 2014 [B]; Bloch-Salisbury et al 2014 [C]; Blomqvist et al 2013 [C]; Carbasse et al 2013 [C]; Kostandy et al 2008 [C])</i> | 1A |
|--|----|

## Positioning

- |   |    |
|---|----|
| 11. <b>It is recommended</b> that occupational therapists collaborate with the neonatal team to facilitate individualised positioning recommendations for infants that promote infant motor outcomes, self-regulatory behaviours and prevent respiratory compromise.<br><i>(Gouna et al 2013 [C]; Grenier et al 2003 [C]; Liaw et al 2012 [C]; Nakano et al 2010 [C])</i> | 1C |
|---|----|

12. <b>It is recommended</b> that occupational therapists review the selection and use of neonatal positioning aids for their ability to promote infant motor outcomes, the development of infant postural control and self-regulatory behaviours. <i>(Madlinger-Lewis et al 2015 [B]; Zarem et al 2013 [C])</i>	1B
13. <b>It is recommended</b> that occupational therapists use a positioning assessment tool to support the education of the neonatal team and promote individualised positioning of high-risk infants in the neonatal unit. <i>(Coughlin et al [D])</i>	1D

## Infant feeding

14. <b>It is recommended</b> that occupational therapists collaborate with the neonatal team to support parents in reading and responding to infant feeding readiness cues to promote the shared occupation of feeding in the neonatal unit and following transition to home. <i>(Ross and Browne 2013 [B]; Brown and Pridham 2007 [C]; Caretto et al 2000 [C]; Swift and Scholten 2010 [C]; Ward et al 2000 [C]; Chrupcala et al 2015 [D]; Waitzman et al 2014 [D])</i>	1C
15. <b>It is recommended</b> that occupational therapists promote an appropriate environment in the neonatal unit to support parent/infant participation in early feeding experiences. Environmental support factors may include space, seating, privacy, sensory environment and NICU culture. <i>(Flacking and Dykes 2013 [C]; Pickler et al 2013 [C])</i>	1C

## Parent engagement

16. <b>It is recommended</b> that occupational therapists work with parents of high-risk infants to support parenting roles and relationships, and to provide sensitive and appropriate parent engagement in the infant's care in the neonatal unit. <i>(Dudek-Shriber 2004 [C]; Ganadaki and Magill-Evans 2003 [D]; Gibbs et al 2015 [A]; Price and Miner 2009 [D])</i>	1A
17. <b>It is recommended</b> that occupational therapists facilitate the development of shared occupations of feeding, dressing and play activities of daily living with preterm and low-birthweight infants to ensure sensitive and appropriate caregiving and promote occupational performance of infants and parents. <i>(Chiarello et al 2006 [C]; Kadlec et al 2005 [C]; Winston 2015 [D])</i>	1C
18. <b>It is recommended</b> that occupational therapists working with families of high-risk infants build a positive therapeutic collaboration with parents to enhance parental learning about their infant both during and following the transition to home. <i>(Harrison et al 2007 [C])</i>	1C



19. **It is suggested** that occupational therapists explore both traditional and innovative means (e.g. video-conferencing) of supporting families post-discharge from the neonatal unit as a means of promoting parent confidence and competence in caring for their infant following the transition to home.

(Gund et al 2013 [C])

2C

## Parent support

20. **It is recommended** that occupational therapists support engagement in parenting occupations in the neonatal unit and following discharge (including, but not limited to reading infant cues, guided participation in care, skin-to-skin, positive touch and holding) to promote decreased parent stress and positive improvements in parent-infant relationship and self-efficacy.

(Evans et al 2014 [A]; Matricardi et al 2013 [B]; Melnyk et al 2006 [A]; White-Traut et al 2013 [A]; Zelkowitz et al 2011 [A])

1A

21. **It is recommended** that occupational therapists employ parent-focused interventions that incorporate parental sensitivity elements (e.g. reading infant cues and responding in developmentally appropriate ways) in order to reduce the psychosocial impact of delivering a high-risk infant, foster sensitive nurturing behaviour and promote the cognitive development of preterm infants.

(Als et al 2003 [A]; Benzies et al 2013 [A]; Kraljevic and Warnock 2013 [B]; Melnyk et al 2001 [A]; Nordhov et al 2010 [A])

1A

22. **It is suggested** that occupational therapists engage parents in brief activity-based interventions during their infant's admission to the neonatal unit and that this can have a short-term effect in lowering parent anxiety.

(Mouradian et al 2013 [C])

2C

## Identifying developmental concerns

23. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to cognitive performance and social interaction, in order to support the development of the infant's occupations, with referral to early intervention services as indicated.

(Maitra et al 2014 [A]; Magill-Evans et al 2002 [C]; Pineda et al 2015 [C]; Sajaniemi et al 2001 [C])

1A

24. **It is recommended** that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to functional motor skills, in order to support the development of the infant's occupations, with referral to early intervention services as indicated.

(Maitra et al 2014 [A]; Bigsby et al 2011 [B]; Watkins et al 2014 [C]; Fewell and Claussen 2000 [C])

1A

25. <b>It is recommended</b> that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to sensory processing difficulties, in order to support the development of the infant's occupations, with referral for early intervention services as indicated. (Witt Mitchell et al 2015 [B]; Crozier et al 2016 [C])	1B
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Early intervention	
26. <b>It is recommended</b> that occupational therapists provide early developmental intervention programmes for preterm infants to promote improved cognitive performance through the preschool years. (Orton et al 2009 [A]; Spittle et al 2015 [A]; Spittle et al 2007 [A])	1A
27. <b>It is recommended</b> that occupational therapists provide home-based early intervention programmes for infants born <30 weeks gestation in the first year of life as this may result in decreasing parent anxiety. (Spencer-Smith et al 2012 [A])	1A
28. <b>It is recommended</b> that occupational therapists facilitate individualised functional motor interventions for high-risk infants and young children to promote engagement in early occupations such as play, exploration and participating in personal care (activities of daily living). (Lekskulchai and Cole 2001 [A])	1A
29. <b>It is recommended</b> that occupational therapists incorporate home routine/ occupation-based approaches in early intervention programmes for children at risk for developmental delay as a means of promoting occupational performance. (Hwang et al 2013 [B])	1B
30. <b>It is recommended</b> that occupational therapists be routinely referred preterm infants with the following co-morbidities: septicaemia, extremely low birth weight (ELBW), chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III–IV), for early intervention. (Hintz et al 2008 [C])	1C
31. <b>It is recommended</b> that occupational therapists working in early intervention settings with high-risk infants consider key elements when building a therapeutic collaboration with parents – promoting effective collaboration amongst multi-agency providers, supporting family social/emotional needs in addition to infant developmental concerns, and consistency of service provision. (Ideishi et al 2010 [D])	1D

It is additionally recommended that occupational therapists use the audit tool that is available to support this guideline (see section 7) to undertake audit against the above recommendations. Recommendations, for which there is a transdisciplinary component, may be usefully audited jointly with other members of the multidisciplinary team. Likewise, the occupational therapist may be involved in audits related to other frameworks, such as the Bliss Baby Charter Standards and audit tool (Bliss 2015).

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# 1 Background

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The Neonatal Intensive Care Services Review Group (Department of Health 2003) found that as the effectiveness of neonatal care has become apparent, due to a number of factors such as increasing technical advancements, demand for this highly specialist care has grown. Intensive care is now offered to infants of significantly lower gestational age and birth weight. Indeed, research has shown a 14 per cent improvement in the survival rates of those born at 25–31 weeks gestation from 1997 to 2011 (Marlow 2015).

Neonatal occupational therapy has also commensurately evolved during this time to provide sensitive, individualised and family-centred developmental interventions to support this increasingly complex clinical group. Linked with occupational therapy interventions in the days, weeks and months following preterm or high-risk term delivery, it is the presentation of these infants with subsequent developmental concerns that provides a strong impetus for occupational therapy prevention and early intervention.

A further emerging element that is relevant to neonatal occupational therapy is the impact of parental factors and subsequent involvement in child development. Developmentally supportive care interventions provided by occupational therapists in neonatal units, and early intervention/prevention models used in follow-up, are embedded within a family-centred care approach. Understanding parental mental health outcomes following preterm birth is important due to the potentially negative effects on a child's health and development. Associated concerns relate to parental impairment in ability to recognise/respond to infant cues that have been shown to demonstrate an impact on development of synchronicity in interaction, the provision of fewer learning opportunities, an increase in child behaviour/emotional regulation issues, and an impact on language and cognitive development (Treyvaud 2014, Treyvaud et al 2011).

This guideline focuses on evidence to inform occupational therapy in neonatal services and early intervention in the United Kingdom (UK).

## 1.1 Practice requirement for the guideline

Occupational therapists make a significant contribution to the care of preterm and high-risk infants, as their professional remit uniquely provides a focus on the developing occupations of infancy and childhood, including for those infants receiving care in a neonatal unit. This approach includes occupational performance components such as adaptation to the environment, systems theory and the enablement of occupational roles (e.g. parenting in neonatal care). Enabling occupational engagement of parents and infants includes an understanding of body functions and structures (e.g. sensory processing, cognition, emotional regulation, motor development etc.). This guideline is intended to support occupational therapists in these roles.

## 1.2 Topic identification process

In 2013, the Neonatal Occupational Therapy Clinical Forum (under the auspices of the Royal College of Occupational Therapists' Specialist Section – Children, Young People and Families) was established. This built on a previous model of a special interest group of occupational therapists working in neonatal services. In both its previous and current iterations, there has been a long-standing identification of the need for the development of a UK-specific guideline for occupational therapy practice in this specialist area.

The reasons underpinning the need for the development of the guideline include:

- The development of a resource that is specific and sensitive to the UK occupational therapy context. Although guidelines relating to skills and competencies for occupational therapists working in neonatal care have been published by the American Occupational Therapy Association (AOTA) since 1993, there are some key differences in scope of occupational therapy practice between the two nations.
- As neonatal occupational therapy is a specialised area of practice, occupational therapists can find themselves in a position of being asked to commence service delivery to neonatal services without specific experience. Given a therapist will usually have a background of paediatric occupational therapy service delivery, there is a significant increase in skills and knowledge required to be able to practise effectively and safely in this area. The development of a guideline will ensure that all therapists (experienced and otherwise) who are providing neonatal services are doing so informed by the best available evidence.
- The guideline covers occupational therapy from birth to two years corrected age – this supports the key window of neuroplasticity and ensures that early intervention models are considered that support prevention or reduction of impact on later educational, social and economic areas of performance.

The National Institute for Health and Care Excellence (NICE) has accredited the process used by the Royal College of Occupational Therapists to produce its practice guidelines. Accreditation is valid for five years from January 2013 and is applicable to guidance produced using the processes described in the *Practice guideline development manual* 3rd edition (COT 2017a).

A guideline project proposal was developed by the Neonatal Occupational Therapy Clinical Forum and this was subsequently approved by the Royal College of Occupational Therapists' Practice Publications Group in December 2015.

## 1.3 National context

Over 96,000 infants in the UK are born premature or ill each year, and often admitted to a neonatal unit, usually because of relatively minor problems with adaptation after birth or risk of serious illness (National Data Analysis Unit 2015, Bliss 2014). Many of these infants are surviving birth at younger gestational ages than in the past.

A large body of research highlights the impact of the increase in survival of infants born prematurely and provides clarity around the range of neurodevelopmental issues with which preterm infants commonly present. These include cognitive impairment, cerebral palsy, impairments in motor planning, visuo-spatial, sensorimotor and attention functions, behavioural issues, increased incidence of autism spectrum disorders, neurosensory impairment, cognitive impairment and delayed social-emotional

competence (Johnson et al 2009, Marlow et al 2007, Larroque et al 2008, Delobel-Ayoub et al 2009, Johnson et al 2014, Guy et al 2015).

Additionally, infants born at term who experience complications such as hypoxic ischaemic encephalopathy will need ongoing developmental support and monitoring. Nearly half of these infants will experience adverse outcomes, such as cerebral palsy or motor/cognitive impairment (Pin et al 2009). Furthermore, children who do not show signs of severe developmental outcomes initially may later experience subtle issues, such as learning difficulties (Pin et al 2009).

Neonatal care is divided into three types: special care (Level I), high-dependency care (Level II) and neonatal intensive care (Level III). Special care is for infants who need additional care, while high-dependency care is for infants requiring highly skilled staff, though with a lower nurse-to-patient ratio than a neonatal intensive care unit. Neonatal intensive care is for infants who are 'most unwell or unstable and have the greatest needs in relation to staff skills and staff to patient ratios' (British Association of Perinatal Medicine [BAPM] 2011, p 3). It provides the full range of medical neonatal care. Finally, transitional care is where the mother cares for the infant with support from a midwife or healthcare professional who may not have specialist neonatal training (BAPM 2011).

## 1.4 Context of service delivery

Across the nations<sup>1</sup> of the UK, government documents have outlined principles or frameworks to support the delivery of neonatal services. These include:

- Toolkit for High Quality Neonatal Services (Department of Health 2009)
- Neonatal care in Scotland: A quality framework (Scottish Government 2013)
- All Wales neonatal standards 2nd edition (NHS Wales 2013).

These documents provide structure for the delivery of neonatal services, including elements of geographical organisation, facility requirements, staffing recommendations, education and training standards, and clinical governance. They also emphasise the importance of placing infants and families at the core of service delivery with the implementation of a family-centred care approach.

Additionally, a NICE quality standard 'provides clinicians, managers and parents with a description of what high-quality specialist neonatal care should look like' (National Institute for Health and Care Excellence 2010). This contains a quality statement about the need for a skilled and multidisciplinary workforce, which includes access to specialist occupational therapists. Service delivery will also be influenced by national commissioning specifications (NHS England 2015) and local policies and guidance.

What all have in common is the idea that the family is the central element of care provision, and occupational therapists, as part of multidisciplinary teams (MDTs), work towards that aim. Occupational therapists are uniquely placed to ensure that the occupations so critical to parents' and infants' identities are not lost in the neonatal unit, helping to keep the family at the centre of care.

### Note

<sup>1</sup> No similar document could be found for Northern Ireland.

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## 2 The occupational therapy role

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Occupational therapy is centred on promoting health and wellbeing through enabling engagement and participation in everyday occupations. It uses a framework which focuses on the relationship between the person, their environment and the occupations that they need or would like to do. When working with high-risk infants, occupational therapists promote optimal development of the child and work with families to support them to engage and participate in their role as parents/carers.

Over the past 20 years, occupational therapists have become established as service providers for high-risk infants and their families (Limperopoulos and Majnemer 2002, Vergara et al 2006), with clearly defined roles and competencies articulated in the professional literature (Vergara et al 2006). In the UK, occupational therapists provide services to high-risk infants across a range of neonatal services, including neonatal units (levels 1–3), transitional care units, maternity units, Paediatric Intensive Care Units (PICUs), acute paediatric inpatient wards and within early intervention services in the community.

There are currently no national guidelines that provide specific recommendations for occupational therapy practice in this area. Although guidelines relating to skills and competencies for occupational therapists working in neonatal care have been published by the American Occupational Therapy Association since 1993, there are some key differences in scope of occupational therapy practice between the two nations. Within the context of the UK, the British Association of Perinatal Medicine (BAPM) has published service standards for hospitals providing neonatal care (BAPM 2010). These standards highlight the benefit of collaboration within the professional team, sharing of knowledge and leadership in relation to the implementation of developmental care practices (BAPM 2010). Specific skills and competencies related to neonatal occupational therapy practice are contained in the BAPM document (BAPM 2010, p14).

Additionally, Bliss has published its Baby Charter, which provides a practical framework for neonatal units to self-assess the quality of family-centred care it provides. Units assess themselves against seven principles, which include treating the infant as an individual and with dignity, making decisions based on the infant's interest and parental involvement, and that parents are given the information and support they need to understand their infant's care and how to care for them (Bliss 2015).

While the BAPM standards and Bliss Baby Charter provide some initial guidance with regards to the service scope for occupational therapy services, there is a need for a more detailed guideline to support practice in this area. To that end, an outline of the scope of occupational therapy services is presented below.

Occupational therapy services within neonatal settings are focused on supporting the development of the high-risk infant and their family. Occupational therapists work collaboratively with parents of high-risk infants to facilitate the infant's and parents' occupational roles, support the parent–infant relationship and ensure a successful transition from hospital to home and community. In addition, occupational therapists contribute to the provision and promotion of developmentally supportive care of high-risk infants. This approach serves to minimise the potential for harm of the neonatal unit environment on the infant's developing brain and support their growth and

development in order to promote early engagement with their parents, including shared occupations such as nurturing touch and the introduction of feeding, bathing and handling. As the infant is discharged from the unit and grows older, ongoing intervention and/or guidance provides continued opportunities to support the development of infant occupations around self-care, learning and play. Through educating parents on strategies to support and engage their infant with appropriate sensory and motor experiences, occupational therapists can provide building blocks for developmental progression and parent–infant interaction.

The breadth of practice and degree of specialised care required in the neonatal unit require the occupational therapist to demonstrate advanced knowledge and skills in neonatal care in order to provide complex interventions to critically ill neonates and their families (Vergara et al 2006). The American Occupational Therapy Association has provided guidance on the specialist knowledge and skills required by occupational therapists when practising in this area. These include knowledge of emerging competencies in infant occupation, child development and medical knowledge, family-centred practice and developmental approaches (Vergara et al 2006).

Although there are some differences in practice scope between the United States and the UK, this knowledge and skills framework can be used as a structured way of ensuring that occupational therapists have the relevant knowledge and skills to practise in this specialist area. Full details of the AOTA Knowledge and Skills Framework can be found in Appendix 3.

Finally, although this guideline is focused on the provision of neonatal occupational therapy services, it is imperative that occupational therapists work collaboratively with other professionals in the neonatal unit and follow-up settings in order to promote the best outcomes for infants and their families, which support their mutual participation and enjoyment of occupations that align with their family values and priorities.

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# 3 Objective of the guideline

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The guideline objective is:

***To provide evidence-based recommendations to inform occupational therapy in neonatal services and early intervention in the United Kingdom.***

Neonatal occupational therapy services aim to provide sensitive, individualised and family-centred developmentally supportive interventions to support high-risk infants and their families. The use of an occupation-centred approach to practice enables occupational therapists not only to support the high-risk infant, but also to ensure that parents of high-risk infants are enabled to become sensitively involved in the care of their infant and to develop parenting occupations.

The guideline addresses occupational therapy intervention for high-risk infants and their families at any point from birth until the infant reaches two years of corrected age. Although the guideline focuses on this group of high-risk infants, it is recognised that where resources are available, occupational therapy services may benefit all infants admitted to a neonatal unit (e.g. those born moderate to late preterm). The objective serves to support the clinical reasoning of occupational therapists in regards to:

- Providing and promoting individualised care of high-risk infants and supporting their engagement with relevant occupations (e.g. sleeping, feeding, exploring).
- Working with individual families to negotiate their meaning of parenting and parent-infant shared occupations.
- Providing sensitive opportunities for parenting occupations to create more ordinary and positive experiences for parents and their infants within the neonatal unit.

The application of the guideline will also inform the delivery of evidence-based services.

This guideline should be used in conjunction with the current versions of the following professional practice documents (knowledge of and adherence to these standards is assumed):

- Standards of conduct, performance and ethics (Health and Care Professions Council [HCPC] 2016).
- Standards of proficiency – occupational therapists (HCPC 2013).
- Code of ethics and professional conduct (COT 2015).
- Professional standards for occupational therapy practice (COT 2017b).
- Position statement: Occupational therapists' use of standardised outcome measures (COT 2013).

Occupational therapists should also be familiar with their relevant country-specific policy documents and performance measures, and cognisant of the following guideline:

- Developmental follow-up of preterm babies (NICE In press).



Finally, occupational therapists should have awareness of other documents related to the provision of neonatal occupational therapy services:

- Bliss Baby Charter (Bliss 2015).
- Working Together to Safeguard Children (HM Government 2015).
- Service Standards for Hospitals Providing Neonatal Care (BAPM 2010).
- Toolkit for High-Quality Neonatal Services (Department of Health 2009).
- Specialized Knowledge and Skills for Occupational Therapy Practice in the Neonatal Intensive Care Unit (Vergara et al 2006).

Occupational therapists must only 'provide services and use techniques for which [they] are qualified by education, training and/or experience', and within their professional competence (COT 2015, p32). This guideline should be used in conjunction with the therapist's clinical expertise and, as such, the clinician is ultimately responsible for the interpretation of the evidence-based recommendations in the context of their specific circumstances and the infants' and families' individual needs.

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# 4 Guideline scope

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## 4.1 Clinical question

The key question identified in the scope for this guideline was:

***What is the evidence to support occupational therapy in neonatal services and in early intervention?***

### 4.1.1 Key outcomes

The guideline development group members identified key outcomes as a result of occupational therapy intervention(s), from their knowledge of the evidence-base and clinical expertise. These include the following:

- Earlier discharge from an initial inpatient admission.
- Fewer readmissions.
- Improved parent well-being (e.g. increased confidence, improved self-efficacy, reduced anxiety).
- Increased opportunities for parent engagement on the neonatal unit.
- Promotion of parent–infant relationship.
- Fewer missed appointments in early intervention services due to the collaborative partnerships formed between parents and therapists.
- Earlier identification of emerging developmental concerns and implementation of appropriate early intervention services or referral to relevant specialist services.

The heterogeneity of the population means that it can be difficult to identify the specific outcomes that will be the most important to an individual infant or parents. A person-centred perspective underpins occupational therapy practice, and intervention must be compatible with the families' preferred outcomes or, where appropriate, in their best interest.

It is recognised that the evaluation of outcomes is complex, and will be influenced by a variety of factors. The ability to quantify the achieved outcomes will depend on the personalised goals set with each individual family (for example, increased time at the infant's bedside, increased engagement in skin-to-skin care).

### 4.1.2 Key areas for inclusion in the guideline scope

Occupational therapy interventions will be based on gestational age, medical status and appropriate levels of support for family engagement. Using an occupation-centred approach, specific interventions to be considered for inclusion are:

- The provision and promotion of infant and family developmentally supportive care of high-risk infants.

- Assessment and guidance regarding the infant's neurobehavioural state – this includes key working with parents in understanding the infant's cues and preparing parents for interaction with their infants. By helping to sensitise parents to their infant's behavioural cues, appropriate interactions and levels of stimulation can be enabled.
- Guidance of positioning of infants to support neurobehavioural regulation (for example, habituation to external stimuli, motor responses and consolidation of and transition between sleep/wake states). Supportive positioning helps to promote infants' self-regulation of their autonomic and motor systems and reduces the risk of muscle imbalance.
- Adaptation of environment to modify sensory input, minimise stress and facilitate interactive behaviours.
- Follow-up assessment and/or intervention for infants as defined by national guidelines in accordance with additional risk factors. Specific local guidelines may also inform identification of gestation and birthweight indicators for formal follow-up services.
- Supporting individual families to negotiate their meaning of parenting and facilitating parent and infant shared occupations.
- Identifying caregiving activities that are meaningful to parents and foster opportunities for engagement.
- Provision of psychosocial support for parents, including reassurance, encouragement and information.
- Provision of opportunities for parents to attain a physical connection with their infant (e.g. containment holding, skin-to-skin holding), and to work to increase opportunities for parents to participate in physical touch of their infant as the infant's stability increases.
- Work to influence the multidisciplinary team to promote an NICU culture that supports and values parental engagement in care, including the promotion of staff communication styles that are empowering and enabling of parents.
- Contribute to discharge planning in a cohesive and collaborative manner.
- Work collaboratively with the multidisciplinary team in the identification of safeguarding concerns.
- The provision of intervention and/or guidance to support the development of infant occupations around self-care, learning and play.
- Developmental activities with guidance on suitable toys, play opportunities and activities for developmental stage and individual needs, increasing caregivers' awareness of developmental needs and ability to respond appropriately to those needs within everyday home/community-based routines.
- Early identification and implementation of interventions for infants identified at risk of significant neurodevelopmental sequelae which may lead to motor, sensory and cognitive dysfunction. Deficits in these domains may result in sub-optimal participation in and development of occupations, including participation in play opportunities, exploring the environment, early learning and developing independence in self-care occupations.

- Provision of infant equipment, particularly to promote safe and optimal participation in infant occupations such as play, bathing, feeding/eating, mutual engagement in family routines and activities.

#### **4.1.3 Key areas for exclusion from the guideline scope**

Some areas of occupational therapy practice overlap with those of other therapy service providers in the neonatal setting. Other aspects fall into areas outside the remit of occupational therapy practice in the UK, and require additional skill and expertise. Therefore, the following areas are being excluded from the scope of this guideline:

- Mechanical aspects of feeding (including formalised swallowing assessments and dysphagia management).
- Supporting elements of volume/flow/latch for breastfeeding.
- Management of chest clearances and other respiratory support.
- Management of musculoskeletal abnormalities of the lower limb.
- Assessment/treatment of torticollis.

## **4.2 Target population**

The guideline covers the predominant presentations of infants who receive services from occupational therapists working in neonatal services. A collective term of 'high-risk infants' has been used to describe this population, which includes all infants born preterm, high-risk infants born at term (e.g. infants with neonatal hypoxic ischaemic encephalopathy, neonatal abstinence syndrome, congenital conditions or having undergone complex surgical procedures), infants receiving palliative care, and their parents. In alignment with the British Association of Perinatal Medicine and the Neonatal Toolkit, the guideline also encompasses occupational therapy provision for these infants from birth to two years of corrected age to ensure promotion of relevant support and intervention during the key window for neuroplasticity and the developing parent-infant relationship.

## **4.3 Target audience**

The principal audience for this guideline is occupational therapists working in neonatal and affiliated services, including paediatric settings.

This guideline is applicable to occupational therapy staff delivering services to parents and infants in a range of settings, including neonatal units, maternity units, transitional care units, paediatric intensive care units and children's wards (for older infants previously treated within a neonatal unit). Additionally, the guideline includes recommendations to inform practice in the provision of follow-up and early intervention services for high-risk infants. These settings may include hospital clinics and outpatient settings, child development services, early-years services, home-based services, private clinics and early education providers.

This guideline is also relevant to a wider audience:

- Occupational therapists who provide information and education to other clinical providers such as health visitors and general practitioners.

- Members of the multidisciplinary team: to provide a greater understanding of the role of the occupational therapist in neonatal settings and early intervention. This will promote closer working between disciplines (including nursing, medical and other multidisciplinary team staff), with the potential for improved outcomes for infants and their parents.
- Managers and commissioners: to provide evidence of the role of occupational therapy, and thus inform business planning and commissioning of services.
- Education providers: as an educational tool, orientating individuals to an evidence-based resource to support the occupational role in neonatal and early intervention services.
- Parents: providing information to enable them to be more informed about the occupational therapy process in neonatal and early intervention services.

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# 5 Recommendations and supporting evidence

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The recommendations developed by the guideline development group are underpinned by the evidence available to date which supports the delivery of occupational therapy neonatal services and early intervention in the UK. Details of the guideline methodology, including the development process and the literature search strategy, are set out in sections 9 and 10.

Synthesis of the evidence resulted in the emergence of recommendations for occupational therapy services which promote the performance of infant occupations, parent occupations and parent-infant shared occupations. These recommendations have been categorised in the following core areas:

- Occupation-based assessment
- Developmentally supportive care
- Pain management
- Skin-to-skin care (kangaroo care)
- Positioning
- Infant feeding
- Parent engagement
- Parent support
- Identifying developmental concerns
- Early intervention.

These themes cut across the desired outcomes identified (see section 4.1) but, while the recommendation statements have been set out within these categories, it is essential to recognise that there are overlaps. Individual recommendations should not be considered in isolation, but in the wider context.

Where available, qualitative service-user feedback obtained during service-user engagement events and the guideline consultation process has been used to provide a user perspective as an adjunct to the published evidence (see section 6).

The strength of the recommendations is identified via a scoring of 1 (strong) or 2 (conditional), and the quality of the supporting evidence via a grading on a scale of A (high quality) to D (very low quality). A recommendation grading takes into account the consistency in the direction of the outcomes from the individual items of evidence used to support that recommendation (see section 10.4 for more detail).

Twenty-nine of the 31 recommendations were agreed by the guideline development group as being strong; that is, most infants and/or parents would want to, or should, receive the course of intervention or action stated. The other two recommendations were conditional; that is, the majority of infants and/or parents would want the

intervention, but not all would, with the risks and benefits being more closely balanced. Additional details on individual studies (for example, on study design, methodological limitations, recruitment numbers and statistical significance) can be accessed in the evidence tables (Appendix 2).

Outcomes desired, risks, generalisability and social determinants of health associated with the recommendations are outlined in section 5.11. Potential financial and organisational barriers are discussed in section 7.2.

This guideline focuses specifically on the delivery of occupational therapy services as defined in the scope, and does not set out to compare occupational therapy services with other interventions or professional scope of practice in the neonatal setting. Given the degree of overlap in relation to the delivery of developmentally supportive care interventions in the neonatal setting, occupational therapists should, however, be aware of the scope of their interventions which may overlap with services provided by neonatal physiotherapists, speech and language therapists and neonatal nurses. Often, the planning of how developmentally supportive care services are delivered is managed on a unit by unit basis, based on the availability of professional input within the multidisciplinary team. While the recommendations for practice outlined below all fit within the core scope of occupational therapy practice in the UK, occupational therapists need to recognise the scope of practice of other members of the neonatal multidisciplinary team, and collaborate to provide a consistent family-centred approach to neonatal care delivery (Barbosa 2013).

Recommendations are based on a synthesis of the best available evidence (sourced from English language publications). It should, therefore, be noted that the guideline is not able to reflect the full range of possible interventions. It does, however, support those for which evidence was available, and for where there was agreement among the guideline development group of the inclusion of the intervention within the core scope of neonatal occupational therapy practice.

The guideline recommendations are presented under the core categories that reflect the particular areas of assessment and intervention that an occupational therapist may provide in the neonatal unit and in follow-up services after discharge from hospital (e.g. early intervention services). Assessment refers to the approach that an occupational therapist uses to evaluate an infant's strengths and vulnerabilities to help direct where support can be provided to facilitate engagement in infant occupations. Interventions refer to those activities that occupational therapists provide to support infants and their families to engage in mutually satisfying parent–infant shared occupations.

## **5.1 Occupation-based assessment**

### **5.1.1 Introduction**

In order to best support high-risk infants and their families, occupational therapists should provide appropriate, safe and sensitive assessment. Underpinning the approach to assessment is the consideration of an individual infant's early engagement patterns during routine caregiving and other elements associated with occupational performance. Inherent in an occupation-based assessment approach is the consideration of family values, concerns and priorities, and the physical and social environment of the infant (Vergara and Bigsby 2004).

Identification of an infant's strengths and vulnerabilities as they experience caregiving interactions in the neonatal unit allows the occupational therapist to work collaboratively with the infant's parents and the multidisciplinary team. Together they can identify and implement appropriate strategies to support the infant's development and their participation in parent-infant shared occupations. In recognising that some high-risk infants are at increased risk for developmental sequelae, appropriate use of assessment also ensures that occupational therapists provide timely guidance, and identify those infants and families who would benefit from more structured support and ongoing service delivery.

Occupational therapy approaches are underpinned by systems theory in which the successful performance of daily activities and tasks is recognised as being influenced by a constant interplay between the person and their surrounding environment. Occupational therapy training programmes equip therapists to conduct detailed analysis of the person and environmental factors that contribute to performance. In relation to high-risk infants, occupational therapists bring an approach to assessment that considers the potential impact of the physical and social environment on an infant's ability to manage their neurobehavioural self-regulation and subsequently identify strategies that appropriately support the infant's strengths and vulnerabilities.

The completion of an occupation-based assessment allows in-depth analysis of the activities and underlying capacities that the infant must master to support their participation in specific caregiving activities or family engagement. This analysis can be used to identify and recommend specific interventions that enable their occupational performance.

Occupation-based assessment		
1. <b>It is recommended</b> that occupational therapists safely and appropriately assess the neurobehavioural status of the high-risk infant, in order to plan/deliver developmentally supportive care. (Als et al 2003 [A]; El-Dib et al 2011 [C])		1A
2. <b>It is recommended</b> that occupational therapists assess neurobehavioural and neurodevelopmental status to provide guidance and identify infants appropriate for developmental follow-up following discharge. (Bartlett 2003 [C]; Crowle et al 2015 [D]; Liu et al 2010 [D]; Sucharew et al 2012 [C])		1C
3. <b>It is recommended</b> that occupational therapists liaise with community teams and assess neurodevelopmental status for high-risk infants in the first two years of life to provide guidance and implement early intervention services where indicated. (Liu et al 2010 [D])		1D

### 5.1.1 Recommendation 1: Assessment of neurobehavioural status to support the delivery of developmentally supportive care

Als et al (2003) conducted a randomised controlled trial which included 92 infants drawn from three neonatal units in the United States. The study aimed to test the effectiveness of individualised developmental care across multiple sites that involved NICU settings with different nursing-assignment patterns (primary and conventional care) and that served transported and inborn infant populations. Infants in the



experimental group received the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) intervention, with the infants in the control group receiving standard care.

Each infant in the experimental group received structured NIDCAP observations on a weekly basis. These structured observations provided detailed and sensitive assessment of the infant's strengths and vulnerabilities. The observations were then used to provide recommendations for strategies to promote the infant's stability and competence. Infants receiving the NIDCAP structured observations and interventions demonstrated significantly improved medical outcomes at two weeks corrected age in relation to feeding outcomes, length of hospital admission, lower incidences of necrotising enterocolitis, and better growth (weight, weight gain, height and head circumference). From a developmental perspective, infants who had received the NIDCAP approach also demonstrated significantly improved outcomes.

**El-Dib et al (2011)** conducted a cohort study with 67 infants who were recruited from a single neonatal unit in the United States. This study aimed to identify a correlation between an infant's performance on the NICU Network Neurobehavioral Scale (NNNS) at term-equivalent age and their developmental outcomes at 18 months (as assessed by the Bayley Scales of Infant Development). The NNNS is a non-invasive neonatal assessment tool which assesses the full range of infant neurobehavioural performance, including neurological integrity, behavioural functioning and infant stress signs (Lester et al 2014). The study findings supported an association between concerns identified on the NNNS and neurodevelopmental delay at 18 months corrected age. Neurodevelopmental delay was associated with poorer behavioural regulation, non-optimal reflexes, increased hypertonicity and an increased need for infant handling strategies to support the infant to maintain an alert state.

### Evidence overview

Occupational therapists can make a significant contribution to the delivery of developmentally supportive care in the neonatal unit. A key component of the delivery of developmental care is appropriate assessment of the infant's neurobehavioural status throughout the neonatal unit admission to support the implementation of an individualised plan that changes as the infant matures. The evidence supports the use of sensitive assessments that reflect the infant's fragility, and uses structured infant observation. The evidence supporting this recommendation consists of one well-structured randomised controlled trial and one cohort study, with an overall high level of evidence grading.

## 5.1.2 Recommendation 2: Assessment of infant neurobehaviour and neurodevelopment to provide guidance and identification for developmental follow-up

**Sucharew et al (2012)** conducted a cohort study which aimed to evaluate the impact of low-level prenatal and early-childhood exposure to a variety of environmental factors on child health and development. The study included 355 infants, with detailed assessment conducted with the NNNS at five weeks of age, and the Bayley Scales of Infant Development-II at 12, 24 and 36 months. The study identified that infants who were considered to have a hypotonic profile at five weeks of age were more likely to have difficulties with motor performance in early childhood.

A cohort study by **Liu et al (2010)** aimed to ascertain whether the NNNS was a predictor of negative medical and behavioural findings from one month to 4.5 years of age. The study included 1,248 infants in the United States who were recruited as part of the Maternal Lifestyle Study. Infants were assessed with the NNNS at one month of age, and with other developmental and IQ assessments administered when the children were 4, 8, 12, 24, 36, 48 and 52 months of age. The study findings confirmed that infants who were of high risk (due to prenatal drug exposure, gestational age and low birth weight, and neurological concerns) demonstrated discrete profiles on the NNNS that were significantly associated with issues related to behavioural problems, school readiness and IQ through to 4.5 years of age.

**Crowle et al (2015)** conducted a cohort study which aimed to explore whether the General Movements Assessment could identify common risk profiles in high-risk infants who had undergone major surgery. The study incorporated 170 infants from a single unit in Australia. The most common profile seen in this group of infants was poor repertoire (47%). Eight per cent of infants were identified with cramped synchronised movements, which have the highest indication for identification of cerebral palsy.

**Bartlett (2003)** conducted a cohort study with 60 infants in Canada which aimed to use the Alberta Infant Motor Scale (AIMS) to measure and describe the patterns of motor development in eight-month-old preterm infants. The study identified that the AIMS could be used to confirm infants with neurological abnormalities, but did not have ongoing utility with this population in terms of monitoring future motor development. There is the ability to use the AIMS as a discriminative assessment for infants considered to have normal or suspect motor development, and it had ongoing utility as a monitoring tool for infants demonstrating suspect motor development.

### **Evidence overview**

A key component of the delivery of neonatal occupational therapy is appropriate assessment of the infant's neurobehavioural status throughout the neonatal unit admission and neurodevelopmental status in preparing for transition to home. Occupational therapists must select assessments with appropriate sensitivity and specificity. Supporting an infant's and family's transition to home via the provision of individualised guidance is essential, as is ensuring appropriate follow-up services for children identified as at risk of developmental sequelae. The evidence supports the use of appropriate assessments that reflect the infant's age and status, to gain a comprehensive understanding of the infant's strengths and vulnerabilities in order to provide ongoing support and management (Sucharew et al 2012, Crowle et al 2015, Liu et al 2010, Bartlett 2003). The evidence supporting this recommendation consists of four cohort studies – two of which were considered low levels of evidence, and two considered very low levels of evidence.

## **5.1.3 Recommendation 3: Assessment of neurodevelopmental status through the first two years of life**

**Liu et al (2010)** conducted a cohort study which aimed to ascertain whether the NNNS was a predictor of negative medical and behavioural findings from one month to 4.5 years of age. The study included 1,248 infants in the United States who were recruited as part of the Maternal Lifestyle Study. This was a longitudinal study of children considered at risk due to prenatal drug exposure and prematurity. Infants were assessed with the NNNS at one month of age, with other developmental and IQ assessments administered when the children were 4, 8, 12, 24, 36, 48 and 52 months of

age. The study findings confirmed that infants who were of high risk (due to prenatal drug exposure, low gestational age and birth weight, and neurological concerns) demonstrated discrete profiles on the NNNS that were significantly associated with issues related to behavioural problems, school readiness and IQ through to 4.5 years of age.

### **Evidence overview**

High-risk infants are at increased risk for neurodevelopmental and functional sequelae that can impact on their participation in infant and child occupations. Occupational therapists can provide a significant contribution to monitoring the developmental outcomes of these infants to ensure early identification of concerns and appropriate referral to early intervention services where indicated. The evidence supports the use of neurodevelopmental assessments in identifying children at later risk of experiencing difficulties across a range of occupational domains (Liu et al 2010). The evidence supporting this recommendation consists of one cohort study of very low-level evidence.

A range of relevant assessments was reviewed in the evidence appraisal process; however, the papers identified do not reflect the full range of assessment tools available for use with this population. The selection of specific assessment tools is a matter of clinical judgement, and includes issues such as availability and training. Examples of assessments used within neonatal occupational therapy services are provided in Appendix 4.

## **5.2 Developmentally supportive care**

### **5.2.1 Introduction**

Infant and family-centred developmentally supportive care (European Foundation for the Care of Newborn Infants 2017) is a term that refers to the use of strategies that are 'derived from neurodevelopmental, environmental and human sciences to improve the potential of infants who are disadvantaged by premature birth or adverse perinatal events' (Warren and Bond 2010, p14). For ease, the term developmentally supportive care will be used throughout this document to refer to a range of models and approaches. The aim of developmentally supportive care models is to alter the focus of neonatal care from the traditional task-oriented or procedure-oriented approach to a focus on processes and relationships, including the increased involvement of families (Westrup 2007).

The term developmentally supportive care comprises a range of specific interventions, or intervention programmes, such as NIDCAP (Lawhon 2002, Als 2008), Family Integrated Care (O'Brien et al 2013) and the Mother-Infant Transaction Program (Rauh et al 1990). Although programmes designed to deliver developmentally supportive care differ in components and approach, they employ a range of common attributes (National Association of Neonatal Nurses 2001). These include:

- Individualised, flexible care based on identification of and responsiveness to each infant's competencies, vulnerabilities and emerging abilities.
- Providing developmentally supportive individualised environments.
- Supporting the development of parent-infant relationships.

- Recognising the rights of parents within a family-centred care model.
- Collaborative practice by all practitioners.
- Consistency of caregivers to promote continuity of care.

As developmentally supportive care programmes have evolved, research has been undertaken to understand their efficacy in improving the developmental outcomes of high-risk infants. Although there is some inconsistency in the research findings, the potential benefits of developmentally supportive care have emerged, with many neonatal units now adopting this approach (Vergara and Bigsby 2004).

Occupational therapists are well placed to both implement and act as a resource for the multidisciplinary team in relation to the delivery of developmentally supportive care as a result of their approach of considering the interplay of human, occupation/activity and environmental factors on performance. Sensitive assessment of the impact of the caregiving environment on the infant can support the selection of appropriate strategies that match the infant's individual capacities, and minimise stress and trauma.

Developmentally supportive care		
4.	<b><i>It is recommended</i></b> that developmentally supportive care principles are implemented for high-risk infants admitted to neonatal units to enhance short term health and developmental outcomes.  <i>(Als et al 2003 [A]; Legendre et al 2011 [B]; McAnulty et al 2010 [B]; McAnulty et al 2009 [A]; Symington and Pinelli 2006 [A]; Wallin and Eriksson 2009 [B])</i>	1A
5.	<b><i>It is recommended</i></b> that occupational therapists promote an appropriate developmental environment, based on the infant's age and status and individual needs.  <i>(McAnulty et al 2010 [B]; Symington and Pinelli 2006 [A]; Symington and Pinelli 2002 [A])</i>	1A

### 5.2.2 Recommendation 4: Developmentally supportive care to improve health and developmental outcomes

**Wallin and Eriksson (2009)** conducted a systematic review which aimed to assess the effects of individualised developmentally supportive care on the psychomotor development, neurological status, medical outcomes and parent perceptions of preterm infants. The review incorporated 12 papers drawn from the reporting of six randomised controlled trials that had been conducted in the United States and Sweden using NIDCAP as the experimental intervention compared with traditional care. Approximately 250 infants were included across the six studies.

The collated results of the studies demonstrated a trend for positive findings for the infants receiving the NIDCAP intervention in relation to motor and cognitive development. Five studies reported an improvement in psychomotor development as measured by the Assessment of Preterm Infant Behavior (APIB) at two weeks corrected age. Three of the studies reported improved cognitive outcomes at nine months to two years as measured by the Bayley Scales of Infant Development (I and II) (Mental Development Index). The authors did report that the variability in how infant outcomes were reported across the study posed difficulties in conducting more complex meta-analysis of the findings. A common methodological concern across the studies was small sample sizes, yielding low statistical power.

**McAnulty et al (2009)** conducted a randomised controlled trial which aimed to assess the effect of NIDCAP on medical outcome and on behavioural and electrophysiological function. The study included 107 infants who were recruited from one neonatal unit in the United States. Infants in the experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. The outcomes for all infants in the study were measured at two weeks corrected age and nine months corrected age using a variety of outcome measures.

The study identified that the infants who had received NIDCAP demonstrated a significant reduction in major medical morbidities of prematurity, and significant improvements in their overall neurodevelopmental function at two weeks corrected age. At nine months corrected age, the infants who had received NIDCAP were still demonstrating significant improvements over those in the control group in relation to their neurobehavioural functioning.

The randomised controlled trial conducted by **Als et al (2003)** included 92 infants drawn from three neonatal units in the United States. The study aimed to test the effectiveness of individualised developmental care for the first time across multiple sites that involved NICU settings with different nursing-assignment patterns (primary and conventional care) and that served transported and inborn infant populations. Infants in the experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. Structured NIDCAP observations were completed on a weekly basis, which provided recommendations for strategies to promote the infant's stability and competence. Outcomes related to medical status, developmental status and parent functioning were measured at two weeks corrected age.

Infants receiving the NIDCAP intervention demonstrated significantly improved medical outcomes at two weeks corrected age in relation to feeding outcomes, length of hospital admission, lower incidences of necrotising enterocolitis, and better growth (weight, weight gain, height and head circumference). From a developmental perspective, infants who had received the NIDCAP approach also demonstrated significantly improved outcomes. They showed better regulation in their autonomic and motor systems, and improved self-regulation. Finally, in relation to parent functioning, parents of infants supported by the NIDCAP approach also perceived their infants as having improved regulation. They also experienced enhancements in their own parental competence, with a corresponding reduction in stress experiences.

**Symington and Pinelli (2006)** conducted a Cochrane systematic review, incorporating 36 studies involving 2,220 infant participants. The aim of the review was to identify whether developmental care interventions reduced neurodevelopmental delay, poor weight gain, length of hospital stay, length of mechanical ventilation, physiological stress and other clinically relevant adverse outcomes in preterm infants. These papers included a range of developmental care interventions grouped on the basis of: i) positioning; ii) clustering of nursery care activities; iii) modification of external stimuli; and iv) individualised developmental care interventions. The included studies were conducted in a range of international settings including the United Kingdom, Switzerland, Sweden, Israel, Canada and the Netherlands, with the majority undertaken in the United States.

The overall results from the review indicated that developmental care interventions demonstrated some effect in enhancing neurodevelopmental outcomes, and identified limited benefits in relation to improved family outcome. This review experienced some difficulties with the collation of the study findings due to variability of results, which may have been linked to small sample sizes in the individual studies and variations in

outcome measurement. The review also highlighted that none of the studies had considered the cost of the interventions and personnel.

A second randomised controlled trial undertaken by **McAnulty et al (2010)** aimed to explore the continuity of NIDCAP effectiveness into school age, by testing the predictability of brain function in the infant period with school-age neuropsychological results. The study involved 22 children, 11 of whom had received NIDCAP interventions during an admission to a neonatal unit in the United States, and 11 who had received standard care. The children were assessed at eight years corrected age.

This study included only a small sample of children, which may impact on the precision of the results, but children who had received NIDCAP interventions during infancy demonstrated significantly better spatial visualisation and mental control. Electroencephalogram assessment also demonstrated improved cortical connectivity, corroborating the neuropsychological findings with the development of neural pathways.

Finally, **Legendre et al (2011)** conducted a systematic review that aimed to document the short-term medical and developmental effects of the NIDCAP programme. The review included 15 papers that were drawn from 13 randomised controlled trials and two cohort studies.

Findings across the studies in relation to short-term medical outcomes were mixed. There was greater consistency in reporting improvements in infant behavioural organisation for infants who received a NIDCAP approach, specifically in relation to state regulation, attention and motor control. Only two of the included studies focused on sleep outcomes – the first indicated that infants receiving NIDCAP demonstrated improved self-regulation and fewer sleep-wake cycles, with the second demonstrating improved wake periods by 34 weeks post-menstrual age. Due to the variability in the reporting in the original studies, only descriptive analysis of the findings was possible. The majority of these studies focused on short-term outcomes (at two weeks corrected age); the evidence for the effectiveness on longer term developmental outcomes remains weak.

### **Evidence overview**

The evidence supporting the positive impact of developmentally supportive care interventions for high-risk infants is drawn from three systematic reviews, and two randomised controlled trials. It is recognised that due to factors that influence the design and methods when conducting studies in the NICU, there are weaknesses in the methods used within the primary studies and limitations in the transferability of the findings. The delivery of developmentally supportive care can lead to benefits for the infant and family, including improved infant neurodevelopmental and neurobehavioural outcomes, improved short-term growth and feeding development, decreased respiratory support, decreased length and cost of hospital stay, and improved parent confidence and stress levels.

No specific risks were reported in any of the studies for the infants receiving developmental care interventions.

The search strategy only identified evidence predominantly relating to evaluation of NIDCAP interventions. Occupational therapists should recognise that there is a range of developmentally supportive care programmes and approaches that may also be used to enhance the care provided to high-risk infants and their families. Such programmes and



approaches include, but are not limited to, the Infant Behavioural Assessment and Intervention programme (IBIAP) (Hedlund 1998), Family Integrated Care (O'Brien et al 2013), the Mother–Infant Transaction Program (MITP) (Rauh et al 1990) and Family Nurture Intervention (Welch et al 2012).

### 5.2.3 Recommendation 5: Developmentally supportive care implications for the neonatal environment

**Symington and Pinelli (2006, 2002)** conducted a Cochrane systematic review, incorporating 36 studies involving 2,220 infant participants. The aim of the review was to identify whether developmental care interventions reduced neurodevelopmental delay, poor weight gain, length of hospital stay, length of mechanical ventilation, physiological stress and other clinically relevant adverse outcomes in preterm infants. One of the components of developmental care interventions considered in the review was the provision of individualised interventions based on the infant's age and status.

The creation of an appropriate developmental environment, based on each individual infant's requirements, was demonstrated to reduce the likelihood of moderate to severe chronic lung disease and necrotising enterocolitis. Positive neurodevelopmental outcomes for infants have also been demonstrated in relation to cognitive and learning function when assessed at 9–12 months of age, though there is some inconsistency across study findings. One study, which included a longer follow-up period, identified retained benefits in relation to behaviour and movement skills at five years of age.

**McAnulty et al's (2010)** randomised controlled trial (as detailed previously), which aimed to explore the continuity of NIDCAP effectiveness into school age, captured some potential long-term benefits for infants who receive appropriate individualised interventions to their care environment. These children demonstrated better perceptual and cognitive function than those who had received standard care. Additionally, for the infants who had undergone routine neurobehavioural assessments during the neonatal period (as part of the provision of individualised developmental care), these measures were more predictive of neuropsychological function at eight years than more commonly used demographic or medical outcome variables.

#### Evidence overview

The evidence supporting the positive impact of developmental care interventions, particularly when focusing on the creation of an individualised, developmentally appropriate environment for high-risk infants, is of high and moderate quality. It is recognised that due to factors that influence the design and methods when conducting studies in the NICU, there are limitations in the transferability of the findings. The delivery of these interventions can lead to benefits for the infant, including improved infant neurodevelopmental outcomes and decreased risk for moderate to severe respiratory and gastrointestinal complications of prematurity.

Because of occupational therapy's focus on how the environment impacts on parent and infant roles, it is an important aspect of the occupational therapist's role to recommend how to create a supportive environment that promotes and supports infant occupational participation (e.g. supporting sleep, facilitating parent–infant interaction). Managing the neonatal unit sensory environment is a key part of individualised developmental care interventions.

No specific risks were reported in any of the studies for the infants receiving developmental care interventions.

## 5.3 Pain management

### 5.3.1 Introduction

Being born prematurely or sick and needing admission to a neonatal unit unfortunately exposes infants to painful procedures that are required as part of their caregiving. Procedures that cause pain and/or stress to high-risk infants include blood sampling, endotracheal intubation, tracheal suctioning, orogastric or nasogastric tube insertion and retinopathy of prematurity examinations (Coughlin 2014).

The neuroanatomical and neuroendocrine mechanisms that facilitate the transmission of a painful stimulus are functional in the developing foetus at 20–22 weeks gestation (Bellieni 2012). Infants born preterm may also experience non-noxious stimuli (e.g. nappy change) as painful or stressful due to heightened sensitivity, and broader neuronal receptors. The presence of hypersensitivity is complicated by delayed maturation of the descending pain pathways in the infant, which help to modulate the pain experience (Bhutta and Anand 2002).

Studies have demonstrated that preterm infants may have prolonged experiences of pain (Bhutta and Anand 2002). When pain is prolonged and unmanaged or undermanaged, infants may experience decreased energy expenditure and enter a state of passivity, decreased heart and respiratory rate, and decreased oxygen consumption (American Academy of Pediatrics [AAP] et al 2006). Infants who experience repeated exposure to painful stimuli may develop a hyperalgesia or increased responsiveness to the experience (AAP et al 2006). Regional alterations in brain structure may also be a result of exposure to stress (including pain) in the neonatal unit (Smith et al 2011).

Neonatal unit staff try to manage infants' experiences of pain through the use of pharmacological pain management and other strategies. Occupational therapists can also contribute to infant pain management through the use of two approaches. First, detailed and sensitive observation of an infant's neurobehavioural regulation during painful and caregiving procedures can support identification of the infant's stress or pain signs. These can be shared with parents and other caregiving staff to increase awareness of the infant's response to stress/pain and when they need additional support. Additionally, occupational therapists can work with parents to identify strategies that parents could/may use in the non-pharmacological management of their infant's pain.

Pain management	
6. <b>It is recommended</b> that occupational therapists promote and support parent provision of skin-to-skin care with their infant during appropriate, planned, painful caregiving procedures (e.g. heel lance). <i>(Ferber and Makhoul 2008 [A]; Johnston et al 2011 [A]; Cong et al 2012 [B]; Kostandy et al 2008 [C])</i>	1A
7. <b>It is recommended</b> that occupational therapists promote the use of facilitated tucking by all caregivers (parents and practitioners) for pain management during relevant caregiving procedures (e.g. endotracheal suctioning). <i>(Axelin et al 2006 [A]; Obeidat et al 2009 [B])</i>	1A



8. <b>It is recommended</b> that occupational therapists support parent understanding and facilitate engagement in appropriate pain management strategies to enable them to provide sensitive support to their infants and promote parent self-efficacy. <i>(Franck et al 2012 [C]; Franck et al 2011 [A]; Axelin et al (2006) [A])</i>	1A
9. <b>It is recommended</b> that occupational therapists work with the neonatal team to promote routine assessment of neonatal pain and identification of appropriate pain management strategies. <i>(Gibbins et al 2015 [C])</i>	1C

### 5.3.2 Recommendation 6: The provision of parental positive touch during painful caregiving procedures

**Ferber and Makhoul (2008)** conducted a randomised controlled trial which aimed to examine the effect of skin-to-skin care on preterm infants who were undergoing a painful procedure. The study included 30 infants, between 28 and 34 weeks gestation, who were recruited from a single NICU in Israel. Infants were assessed during blood sampling (via heel lance) and observed in either skin-to-skin care with their mother or in a standard care setting in the incubator. The study identified that infants' pain reactions were different across the study conditions. When held in skin-to-skin care, there was a noted decrease in the infant's motor disorganisation and extension movements, and an increase in attention signs. Additionally, significant neurobehavioural changes were sustained in the follow-up period (20 minutes) after the blood sampling in comparison with incubator care.

**Johnston et al (2011)** conducted a randomised crossover trial which aimed to evaluate skin-to-skin care provided by mothers and fathers to reduce pain from heel lance (blood sampling). The study involved 75 preterm infants (28–36 weeks gestation) and was conducted in three neonatal units in Canada. Skin-to-skin care was provided for the infants for at least 15 minutes prior to the blood test, maintained during the procedure, and then continued for a minimum of 15 minutes afterwards. The study demonstrated that the infant pain scores were lower for infants receiving skin-to-skin care from either their mothers or fathers when compared with procedures conducted when the infants were in the incubator. There were different results between mothers and fathers during skin-to-skin care, with mothers identified as providing marginally more comfort for their infants.

In a randomised controlled trial conducted by **Cong et al (2012)**, the length of the provision of skin-to-skin care (30 minutes versus 15 minutes) prior to and then throughout a blood sampling procedure was compared to incubator care. The study findings indicated that heart rate decreases occurred in a small group of infants across all conditions, though this occurred more frequently during incubator care. Heart rate changes were noted to differ significantly across the three groups, occurring more frequently in the incubator care group. Infants who received 15 or 30 minutes of skin-to-skin care prior to the procedure were also noted to spend more time in quiet sleep.

**Kostandy et al (2008)** conducted a pilot crossover trial with ten infants born at 30–32 weeks gestation to explore the effect of skin-to-skin care on crying responses to pain. Infants were evaluated in either skin-to-skin care with their mother, or in an incubator during a blood sampling procedure (heel stick). Infant crying time was significantly less when the procedure was conducted during skin-to-skin care.

### **Evidence overview**

The evidence supporting the provision of parental skin-to-skin care as a means of pain management during planned painful procedures such as heel lance is strong. The provision of skin-to-skin care during heel lance has been demonstrated to support infant neurobehavioural regulation, promote sleep and reduce infant pain behaviours. This recommendation is supported by three randomised controlled trials and a pilot crossover trial.

Occupational therapists can promote parent engagement in skin-to-skin care as a means of pain management during planned painful procedures such as heel lance.

### **5.3.3 Recommendation 7: Facilitated tucking**

**Axelin et al (2006)** conducted a randomised crossover trial which aimed to examine the effectiveness of facilitated tucking in pain management during endotracheal suctioning of preterm infants. Facilitated tucking involves the parents using their hands to support the infant in a flexed position in the incubator during caregiving procedures. The study included 20 infants from a single neonatal unit in Finland. The infants' pain experience was assessed through the use of an infant pain profile, and heart rate and oxygen saturation recording. The study findings indicated that the use of facilitated tucking alleviated behavioural pain signs in preterm infants. Additionally, 95 per cent of parents involved in the study reported that they preferred being able to participate in their infant's pain management approach compared with passive observation.

**Obeidat et al (2009)** conducted a descriptive systematic review which aimed to determine the efficacy of facilitated tucking as a non-pharmacological pain management strategy in preterm infants. The review included five papers, all of which used crossover study designs. The age of the infants in the original studies ranged from 23 to 36 weeks, and incorporated between 12 and 40 infants. The pain procedures most commonly explored were blood sampling (heel lance) and endotracheal suctioning. While no meta-analysis of the findings was completed, some consistencies in infant outcomes were observed. All studies demonstrated a lower infant heart rate during the painful procedure with facilitated tucking, and three of four also demonstrated improved oxygen saturation levels. Infant behavioural responses to pain were noted to decrease with facilitated tucking in three of four studies.

### **Evidence overview**

There is strong evidence for the provision of facilitated tucking during caregiving procedures, such as endotracheal suctioning, as a means of alleviating infant pain behaviours, and promoting parent engagement in supporting their infant's pain management. This recommendation is supported by one randomised crossover trial and a descriptive systematic review. Although the sample sizes in the individual studies are small, they demonstrate consistent findings in supporting infant outcomes relating to neurobehavioural/state regulation during painful caregiving procedures. Occupational therapists can promote the use of non-pharmacological pain management strategies during planned painful procedures such as heel lance.

### 5.3.4 Recommendation 8: Parent engagement in neonatal pain management

**Franck et al (2011)** conducted a randomised controlled trial which aimed to demonstrate feasibility and estimate the effect of an intervention to increase parental involvement in infant pain management in the NICU on parents' stress and post-discharge parenting competence and confidence. The study included 169 parents recruited from four neonatal units across the UK. All parents received an information booklet about generic neonatal unit care. Parents in the experimental arm also received a booklet that presented evidence-based information about pain and comforting infants in the neonatal unit. They were also supported by two sessions with a nurse who demonstrated how to use the techniques described in the booklet. The study findings showed no differences between the two groups in relation to their experience of stress. However, parents in the experimental arm demonstrated significantly more satisfaction with pain information, being supported to read infant cues and comforting techniques, and preference for involvement in painful procedures.

In a conjoint qualitative study, **Franck et al (2012)** aimed to understand parents' perceptions and feelings of having participated in the trial, and refine the understanding of parental experience of involvement in infant pain management. Parents' perceptions were gathered via open text responses to the Parent Attitudes about Neonatal Pain survey. The findings demonstrated that parents expressed strong preferences for more information about all aspects of infant pain management, including improved timing of information provision, and facilitated opportunities for involvement. Parents desired increased sensitivity and consistency in relation to infant caregiving, with increased use of specific pain-relieving interventions by neonatal unit staff. Parent involvement in pain management for their infants was also influenced by contextual factors such as the parents' own emotional state and the communication and support received from neonatal unit staff.

**Axelin et al (2006)** conducted a randomised crossover trial which aimed to examine the effectiveness of facilitated tucking in pain management during endotracheal suctioning of preterm infants. In addition to exploring infant pain responses, the study authors sought to understand parents' experiences of being involved in pain management strategies. The study included 20 infants from a single neonatal unit in Finland. Ninety-five per cent of parents involved in the study reported that they preferred being able to participate in their infant's pain management approach compared with passive observation.

#### Evidence overview

There is strong evidence that parents who have received education and facilitation in how to support their infant during painful procedures feel more confident in their parental role, and overall satisfaction with the care they received (Franck et al 2012, Franck et al 2011). Parents also reported preferring engagement in pain management as an alternative to observing care (Thoyre 2007). This recommendation is supported by two randomised controlled trials and one qualitative study.

In facilitating opportunities for the development of parenting occupations, occupational therapists can promote parent engagement in supporting their infant during painful caregiving procedures.

### 5.3.5 Recommendation 9: Assessment of neonatal pain

**Gibbins et al (2015)** conducted a mixed-methods study which aimed to understand how healthcare professionals assessed and managed procedural pain for preterm infants. The study included 59 neonatal staff of varying disciplines drawn from four neonatal units in Canada. Staff perceptions were collected via individual or focus group interviews and by completion of a brief survey. The study served to identify that pain in extremely preterm infants is complex, unpredictable and challenging to assess and manage. There was strong agreement on the experiences of pain by these vulnerable infants and the importance of identifying appropriate pain management strategies in neonatal care. Participants suggested the need for easily accessible and flexible training and education on pain assessment for this high-risk population, to ensure consistency and continuity of care.

#### **Evidence overview**

In acknowledging that neonatal care exposes the high-risk infant to painful procedures, the implementation of appropriate pharmacological and non-pharmacological pain management for infants is imperative. This involves routine assessment of infant pain behaviours in order to plan and provide individualised developmentally supportive care. Occupational therapists can promote the use of infant pain assessment tools as linked with their sensitive assessment of infant neurobehavioural regulation and stress cues. It has been demonstrated that neonatal practitioners recognise the complex issues in managing infant pain, including the challenges in ensuring appropriate pain assessment (Gibbins et al 2015). This recommendation is supported by one low-level qualitatively driven mixed-methods study.

## 5.4 Skin-to-skin (kangaroo) care

### 5.4.1 Introduction

Positive touch is described as a specially adapted touch for infants who are premature or fragile, and is given according to the individual behavioural and physiological responses of an infant (Warren and Bond 2010). The provision of skin-to-skin care is one of the most well-recognised strategies for supporting parent and infant engagement in positive touch experiences. Skin-to-skin care is a popular means of providing warmth, sleep and tactile comfort, as well as opportunities for close parent–infant connection and interaction for preterm infants in the neonatal unit (Vergara and Bigsby 2004). Skin-to-skin care (SSC) in the neonatal unit context has been defined as ‘skin-to-skin, chest-to-chest placement of the infant with a parent, ideally the mother’ (Ludington-Hoe 2013, p73). SSC is considered a key element of developmentally supportive care as it impacts the following attributes of neonatal care provision: modification of the macro- and micro-environments so that they are calm and soothing for the infant and their family; positioning of the infant in ways that support physiologic stability and motor development; monitoring of all handling of the infant to minimise adverse physiologic responses and provide periods of rest; promoting infant self-regulation; promoting state regulation by providing care in tune with the infant’s sleep–wake cycles and a quiet soothing environment; and ensuring that all caregiving events are evaluated in terms of infant stress (Als and Gilkerson 1995, Ludington-Hoe 2013).

In addition to the physiological and environmental benefits fostered during SSC, occupational therapists promote SSC as a key opportunity for enabling a shared

occupation between infants and their parents. The close, nurturing contact provided during SSC supports the development of early infant–parent reciprocal interaction. SSC and other forms of positive touch also provide parents with an opportunity to engage in nurturing occupations that they anticipated during pregnancy, thereby promoting their perceptions of self-efficacy.

The guideline development group recognises that there are many other forms of positive touch that have benefits for infants and parents and may be promoted in the neonatal unit (e.g. containment holding, massage etc). The following recommendations are based on the evidence identified within the literature search. Occupational therapists employing other strategies should be cognisant of additional specialised training or certification that is required to support care delivery.

### Skin-to-skin (kangaroo) care

- |  |    |
|--|----|
| 10. <b><i>It is recommended</i></b> that occupational therapists collaborate with the neonatal team to facilitate parent engagement in skin-to-skin care for high-risk infants to promote breastfeeding, pain management, physiological regulation and parent self-efficacy. | 1A |
|--|----|

*(Ludington-Hoe et al 2004 [A]; Morelius et al 2015 [A]; Chan et al 2016 [A]; Boo and Jamli 2007 [A]; Cong et al 2009 [A]; Gathwala et al 2008 [A]; Hake-Brooks and Anderson 2008 [A]; Cho et al 2016 [B]; Head 2014 [B]; Bloch-Salisbury et al 2014 [C]; Blomqvist et al 2013 [C]; Carbasse et al 2013 [C]; Kostandy et al 2008 [C])*

#### 5.4.2 Recommendation 10: Promoting skin-to-skin care

**Ludington-Hoe et al (2004)** conducted a randomised controlled trial to assess whether skin-to-skin care improved heart rate, oxygen saturation rate and abdominal skin temperature outcomes. The study involved 24 infants of 33–35 weeks gestation in a single unit in the United States. Infants in the intervention arm participated in skin-to-skin care with their mother for one inter-feeding interval (ranging from 2.75 to 3.25 hours). The study demonstrated that healthy preterm infants tolerated three hours of skin-to-skin care while maintaining physiological stability. Infants in the experimental arm did not experience any episodes of apnoea, bradycardia or periodic breathing. Regular breathing increased for infants receiving skin-to-skin care compared with those infants receiving standard care.

**Morelius et al (2015)** conducted a randomised controlled trial to assess the effect of continuous skin-to-skin care on salivary cortisol, parental stress, depression and breastfeeding. The study involved two neonatal units in Sweden and included 37 families. On average, the experimental group participated in 19 hours of skin-to-skin care per day, compared with seven hours for the control group. Those infants who received continuous skin-to-skin care had decreased cortisol reactivity in response to handling, and also improved concordance between mother and infant cortisol levels.

A systematic review conducted by **Chan et al (2016)** explored the factors that affect the adoption of skin-to-skin care. One hundred and twelve original qualitative studies were included in the descriptive review. The study findings highlighted the variability of skin-to-skin care in neonatal units and how it is dependent on setting and context. Six themes were identified that served as barriers or enablers to the adoption of skin-to-skin care: buy in and bonding, social support, time, medical concerns, access, and context.

**Boo and Jamli (2007)** conducted a randomised controlled trial to compare weight gain, head growth and breastfeeding rates in very low-birthweight infants with or without exposure to short-term skin-to-skin care while in a neonatal unit. The study included 126 infants whose birth weight was <1500 grams, receiving continuous positive airway pressure (CPAP) or inhaled oxygen and tolerating 50 per cent of enteral feedings. The study was conducted in Malaysia. Parents and infants participating in the skin-to-skin intervention were engaged in skin-to-skin care for at least one hour per day. Infants who participated in skin-to-skin care had better average weekly increases in head circumference, and increased breastfeeding rates at discharge.

A randomised crossover trial conducted by **Cong et al (2009)** assessed whether skin-to-skin care assisted in mediating infants' pain responses to heel stick procedures. The study included 14 infants who were 30–32 weeks gestation, and were between two and nine days old. Infants in the experimental group participated in skin-to-skin care for 60 minutes prior to the blood sampling procedure. Infants in the experimental group demonstrated greater autonomic stability at baseline, during and at recovery from the blood sampling than infants receiving standard care in an incubator.

**Gathwala et al (2008)** conducted a randomised controlled trial to determine whether the implementation of skin-to-skin care to low-birthweight infants would promote mother–infant interaction and attachment. The study included 100 infants with a birth weight of <1800 grams from a single neonatal unit in India. Mothers in the study participated in a structured interview to assess maternal–infant attachment. Infants who received skin-to-skin care experienced a significantly decreased length of stay compared with the control infants. Maternal–infant attachment was reported to be higher in the skin-to-skin group, with mothers being significantly more involved in parenting activities such as bathing and nappy changing. They were also noted to derive more pleasure from their infants.

**Hake-Brooks and Anderson (2008)** conducted a randomised controlled trial which assessed whether exclusive breastfeeding rates would be higher and of longer duration for infants participating in skin-to-skin care with their mother. The study included 66 mothers and infants who were drawn from two neonatal units in the United States. The study findings indicated that infants and mothers who had participated in skin-to-skin care breastfed for significantly longer than the control dyads (5.08 months compared with 2.05 months). They were also shown to breastfeed more exclusively at discharge, 1.5, 3 and 6 months of age. The average amount of time per day that infants and mothers spent in skin-to-skin care during the neonatal unit admission was 4.47 hours.

A quasi-experimental study conducted by **Cho et al (2016)** analysed the effects of skin-to-skin care on infant physiological measurements, maternal–infant attachment and maternal stress. The study included 40 infants from a single unit in South Korea who were >33 weeks gestational age. The study demonstrated no differences between the groups in relation to body temperature and oxygen saturation. For infants receiving skin-to-skin care, their respiration rate was shown to stabilise significantly in comparison with the control group. Parents who participated in skin-to-skin care were also demonstrated to have higher maternal–infant attachment scores and decreased maternal stress.

**Head (2014)** conducted a systematic review exploring the effect of skin-to-skin care on the neurodevelopment of preterm infants. The review included ten original studies which explored a variety of effects of skin-to-skin care. In the descriptive analysis, there is limited evidence for the longer-term benefits of skin-to-skin care on neurodevelopmental outcome. However, it was recognised as a positive strategy for



promoting neurodevelopment via the mechanisms of: improving early environmental conditions, modifying the infant's experience of stress, promoting organised sleep, and supporting the development of maternal–infant attachment.

**Bloch-Salisbury et al (2014)** conducted a cohort study to detect any beneficial effect of skin-to-skin care on infants' cardiorespiratory stability. The study included 11 infants of less than 35 weeks gestational age from one neonatal unit in the United States. Each infant was assessed during an incubator control period. This was followed by a feeding, with skin-to-skin care provided in the following inter-feeding interval. The study findings demonstrated that the respiratory stability of the preterm infant was influenced by sensory perturbations of the caregiver's heart beat during skin-to-skin care. During skin-to-skin care, infant respiration and apnoea episodes were each directly related to the variability of the caregiver's heart rate. In contrast, during the control period in the incubator, the infant's respiratory instability was directly related to its own heart rate instability.

A descriptive study by **Blomqvist et al (2013)** aimed to understand the factors which influenced the time and extent of skin-to-skin care, including who provides it, when and for how much time. The study involved 104 infants from two neonatal units in Sweden. The study identified that both mothers and fathers were involved in the practice of skin-to-skin care. Only three infants experienced skin-to-skin care at birth, with 34 participating in skin-to-skin contact within the first hour and 85 within 24 hours. The remaining infants experienced their first skin-to-skin care between 24 and 72 hours after birth. Skin-to-skin care commenced earlier in infants whose first skin-to-skin contact was with their father. The earlier skin-to-skin care was initiated, the longer the duration that each infant was cared for in skin-to-skin contact per day during their admission.

**Carbasse et al (2013)** conducted an observational cohort study to assess the safety and effectiveness of skin-to-skin care with vulnerable very preterm infants in the neonatal unit and the impact of respiratory support and infant birth weight in response to skin-to-skin care. The study included 96 infants who were born before 33 weeks gestation and were recruited from a single neonatal unit in France. The study findings demonstrated that infants receiving skin-to-skin care showed significant increases in oxygen saturation with decreased oxygen requirements, and a decrease in heart rate instability. However, they were noted to have a transient and moderate decrease in axillary temperature following the skin-to-skin transfer. Apnoeic and bradycardic episodes occurred in 13 per cent of skin-to-skin periods, but did not require the need to terminate skin-to-skin care. The authors concluded that skin-to-skin care in the neonatal unit seemed safe and effective even in ventilated very preterm infants.

Finally, **Kostandy et al (2008)** conducted a pilot crossover study which aimed to assess the effect of skin-to-skin care on crying responses to pain. The study was conducted with ten infants born at 30–32 weeks gestation. Infants were evaluated in either skin-to-skin care with their mother, or in an incubator during a blood sampling procedure (heel stick). Infant crying time was significantly less when the procedure was conducted during skin-to-skin care.

**Evidence overview**

The provision of skin-to-skin care for high-risk infants has been heavily researched, with a strong body of evidence demonstrating a range of positive impacts on infants and families. Skin-to-skin care during a neonatal unit admission has been shown to influence increased breastfeeding, as a way to support infants during painful procedures, to support an infant's physiological regulation, and to support parents' confidence in their parental role while their infant is in a neonatal unit.

No specific risks were reported in any of the studies for the infants receiving skin-to-skin care.

## 5.5 Positioning

### 5.5.1 Introduction

The delivery of developmental care for infants in the neonatal unit includes the use of individualised positioning strategies for infants. Positioning and handling are two essential components of the care of infants in the neonatal unit (Vergara and Bigsby 2004). An infant's position may have a positive or negative effect on various body systems, including autonomic/physiologic, neuromotor, state, interactive and self-regulation. The use of appropriate, supportive positioning will promote self-regulation and facilitate an infant's participation in normal sensorimotor experiences, such as bringing their hand to their mouth and face (Vergara and Bigsby 2004). Conversely, inadequate or incorrect positioning may contribute to physiological instability, behavioural disorganisation, soft-tissue integrity and postural alignment (Vergara and Bigsby 2004).

The goal of positioning in the neonatal unit is 'to provide postural and self-regulatory supports that normalize infants' sensorimotor experiences as much as possible while accommodating the many constraints imposed by their medical conditions and environment' (Vergara and Bigsby 2004, p183). The provision of positioning support aims to deliver a non-intrusive intervention that enables infants to develop adaptive responses similar to those of term infants. This is achieved through the use of positioning aids, of which both commercial and bespoke options are available. The key goals of neonatal positioning (Vergara and Bigsby 2004, p187) are to:

- Provide containment and a sense of security for a smoother adjustment to the extrauterine environment.
- Discourage extension and promote flexion to achieve postural and movement patterns that resemble those of healthy term infants.
- Optimise physiological stability and neurobehavioural organisation to enhance infant self-regulation.
- Promote hand to mouth activity to enhance the infant's ability to self-calm.
- Maintain proper body alignment to prevent postural asymmetries.
- Expose the infant to a variety of postures to prevent the development of fixed postural patterns.
- Maintain skin integrity and prevent skin breakdown.



- Maximise the infant's developmental potential and engagement in family-expected age-appropriate occupations.

By considering each infant's specific cot environment and assessing an infant's neurobehavioural cues, occupational therapists can identify positioning recommendations that will best support each infant. Implementing positioning techniques that are specific to each infant has been shown to promote infant motor outcomes, improve their self-regulatory behaviours and prevent compromise of their breathing. The positioning recommendations refer to interventions provided to high-risk infants within the neonatal unit. All infants must be transitioned to established safe-sleep principles prior to their discharge from the neonatal unit.

Positioning	
11. <b>It is recommended</b> that occupational therapists collaborate with the neonatal team to facilitate individualised positioning recommendations for infants that promote infant motor outcomes, self-regulatory behaviours and prevent respiratory compromise. <i>(Gouna et al 2013 [C]; Grenier et al 2013 [C]; Liaw et al 2012 [C]; Nakano et al 2010 [C])</i>	1C
12. <b>It is recommended</b> that occupational therapists review the selection and use of neonatal positioning aids for their ability to promote infant motor outcomes, the development of infant postural control and self-regulatory behaviours. <i>(Madlinger-Lewis et al 2015 [B]; Zarem et al 2013 [C])</i>	1B
13. <b>It is recommended</b> that occupational therapists use a positioning assessment tool to support the education of the neonatal team and promote individualised positioning of high-risk infants in the neonatal unit. <i>(Coughlin et al [D])</i>	1D

### 5.5.2 Recommendation 11: Individualised positioning recommendations

**Gouna et al (2013)** conducted a cohort study to compare breathing patterns and respiratory variables measured in supine, left lateral and prone positions in preterm infants. The study included 19 infants (gestational age 26–30 weeks) from a single neonatal unit in France. Respiratory variables were recorded for three hours after each position change experienced by the infant following a feeding interval. The results demonstrated that the fraction of expired oxygen was similar across all three positions. Arterial oxygen levels and lung volume were higher in the left lateral and prone position than in supine. The authors concluded that the left lateral and prone positions improve pulmonary function by optimising ventilatory strategy and lung volume.

A retrospective cohort analysis conducted by **Grenier et al (2003)** examined the existence of a relationship between preterm infant position and the frequency of motor-based self-regulatory and stress behaviours. The study included 15 infants born between 23 and 30 weeks gestation recruited from a single neonatal unit in the United States. Infants were observed during non-caregiving periods, with their behaviours categorised as those that suggested stress or motor efforts of self-regulation. The number of motor self-regulatory and stress behaviours observed in the infants was related to infant position, with the highest ratios of behaviours observed when the

infants were side-lying and un-nested, and the lowest observed in a prone, nested position. The incidence of more self-regulatory and stress behaviours was related to longer periods of fussing and crying. Longer periods of light sleep were related to fewer stress behaviours. Infants were observed to perform the fewest stress behaviours in prone nested, prone un-nested or side-lying nested. The authors concluded that these positions may benefit infants in the neonatal unit by reducing their need for motor-based self-regulatory behaviours, thereby potentially conserving energy for growth.

**Liaw et al (2012)** conducted a cohort study which explored the effects of 24-hour caregiving, positioning and the use of non-nutritive sucking in the neonatal unit on preterm infants' sleep and wake states, and identified factors associated with state changes. Thirty infants (27–37 weeks gestation) were recruited from a single neonatal unit in Taiwan. Infants had increased occurrences of quiet sleep when they were not interrupted for caregiving and were positioned in side-lying.

**Nakano et al (2010)** conducted a cohort study to evaluate how a positioning programme influenced the movement patterns of preterm infants. Twelve infants were recruited for the study from two neonatal units in Japan. Infants were positioned with the support of a nesting aid in either supine, prone or side-lying. Spontaneous infant movements were recorded when the infants reached 38–39 weeks post-menstrual age. The study findings indicated that the velocity of movements of the positioning group had more variability than those of the control group, with increased incidence of hands brought together. The authors concluded that infants who had received positioning support exhibited movement patterns similar to those of term-born infants.

### **Evidence overview**

The goals of neonatal positioning with the preterm infant include promoting flexion, prevention of head flattening and external rotation of the hips, and promotion of midline orientation to prevent asymmetrical posture and movement. This position is also beneficial for supporting the infant's self-regulation. Occupational therapists can promote the use of individualised positioning recommendations for infants on the basis of neurobehavioural assessment. Individualised infant positioning has been demonstrated to promote infant motor outcomes, improve infant self-regulatory behaviours and prevent respiratory compromise. This recommendation is supported by four cohort studies, which are considered a low level of evidence.

### **5.5.3 Recommendation 12: Neonatal positioning aids**

**Madlinger-Lewis et al (2015)** conducted a randomised controlled trial to investigate the effects of a new positioning device compared with traditional positioning methods used with preterm infants. The study included 100 infants (born <32 weeks gestation) from a single neonatal unit in the United States. Infants who had been nursed using the positioning device demonstrated less asymmetry of their reflex and motor responses compared with those who had used traditional positioning methods.

A survey conducted by **Zarem et al (2013)** explored the perceptions of neonatal nurses and therapists about different methods of positioning used in the neonatal unit. Seventy-six staff participated in the survey and were employed in one neonatal unit in the United States. Both nurses and therapists agreed on the importance of positioning for the well-being of preterm infants. They differed in their perceptions of the use of commercial versus traditional positioning techniques in relation to promoting sleep.

Staff reported their preference for a commercial device which was perceived to be the easiest to use in terms of placing the infant in good alignment.

### **Evidence overview**

Infant positioning can be supported through the use of commercial and bespoke positioning equipment. At present, there is no definitive evidence promoting one type of positioning device over another. When developing positioning recommendations for high-risk infants, occupational therapists should ensure the individualisation of the recommendations in order to promote more symmetrical postures and improved self-regulation in infants. This recommendation is supported by one randomised controlled trial and one qualitative/questionnaire study, which collectively are considered a moderate level of evidence.

## **5.5.4 Recommendation 13: Positioning assessment tools**

**Coughlin et al (2010)** completed a cohort study which aimed to develop a positioning assessment tool that could be used to standardise best practices in neonatal positioning and evaluate its effectiveness in teaching consistent positioning practice. The Infant Positioning Assessment Tool (IPAT) was implemented in six neonatal units in the United States and used as part of a training package about developmentally supportive interventions. The positioning assessment tool was used as a baseline measure, and following receipt of staff training. The post-training evaluation demonstrated significantly higher positioning scores in each of the neonatal units. All infants assessed during the post-training evaluation were optimally positioned.

### **Evidence overview**

Infant positioning can be supported through the use of a positioning tool on a routine basis to facilitate staff education and the implementation of individualised positioning recommendations for infants. This recommendation is supported by one cohort study of low-quality evidence.

## **5.6 Infant feeding**

### **5.6.1 Introduction**

Feeding is one of the primary occupations of infants. When learning to feed, an infant is also engaged in a shared experience and scaffolding relationship with their family (Vergara and Bigsby 2004). Although feeding is a dependent task for infants, it is one in which they engage in a shared occupation with their parent. They are active participants in feeding activities. Infants learn to feed through a dyadic relationship with their caregiver. For feeding success, this involves an interplay between the infant adaptively responding to the caregiver's feeding style and the caregiver responding to the infant's feeding style (Vergara and Bigsby 2004).

Infants receiving care in the neonatal unit may experience feeding difficulties. This is particularly the case in infants who experience gastroesophageal reflux or have chronic lung disease or neurological complications, but is also common among preterm infants without these concerns (Thoyre 2007). When infants in the neonatal unit are ready, oral feeding will be gradually introduced. Supporting early and consistent parent involvement in feeding begins the learning process and development of the feeding

relationship between the parent and their infant prior to and in preparation for the transition to home.

Parents will work with a range of professionals during this time (e.g. nurse, speech and language therapist, lactation consultant) as their infant matures and develops new skills in relation to feeding. Occupational therapists can also make a contribution in supporting the development of infant feeding in the neonatal unit and following transition to home. Occupational therapists' knowledge of assessing and supporting self-regulatory capacities of high-risk infants enables them to support parents to read and respond appropriately to their infant's neurobehavioural cues during feeding, and enhance the feeding experience for both babies and their parents. This can also help build parents' confidence around feeding after discharge to home. Occupational therapists also provide specific interventions to support infant feeding in relation to recommendations for appropriate positioning support and/or equipment and behavioural adaptations.

### Infant feeding

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| 14. <b>It is recommended</b> that occupational therapists collaborate with the neonatal team to support parents in reading and responding to infant feeding readiness cues to promote the shared occupation of feeding in the neonatal unit and following transition to home.<br><br>(Ross and Browne 2013 [B]; Brown and Pridham 2007 [C]; Caretto et al 2000 [C]; Swift and Scholten 2010 [C]; Ward et al 2000 [C]; Chrupcala et al 2015 [D]; Waitzman et al 2014 [D]) | 1C |
| 15. <b>It is recommended</b> that occupational therapists promote an appropriate environment in the neonatal unit to support parent/infant participation in early feeding experiences. Environmental support factors may include space, seating, privacy, sensory environment and NICU culture.<br><br>(Flacking and Dykes 2013 [C]; Pickler et al 2013 [C])   | 1C |

### 5.6.2 Recommendation 14: Supporting infant feeding readiness

**Ross and Browne (2013)** conducted a systematic review which aimed to ascertain the evidence on breastfeeding rates, feeding skills or problems, and growth outcomes in preterm infants at the time of discharge from the neonatal unit. The study incorporated 55 papers. The study concluded that supporting parents and infants to engage in a range of strategies that promote breastfeeding (e.g. skin-to-skin care, non-nutritive sucking, tube feeding instead of bottle feeding) was associated with improved breastfeeding rates, including exclusive breastfeeding at the time of discharge. The majority of papers identified the decrease in breastfeeding rates over the infant's first year of life. The study also identified that at discharge, the infants in the included papers were not receiving full oral feeds, or were demonstrating some ongoing difficulties with suck-swallow-breathe co-ordination. Finally, the authors identified that preterm infants experience delayed skills in feeding attainment, even after correcting for prematurity. This links with continuing feeding concerns for parents following discharge that require ongoing support.

**Brown and Pridham (2007)** conducted a longitudinal cohort study of 37 infants and their mothers which aimed to explore the contribution of adaptiveness of early maternal feeding behaviour to the adaptiveness of later infant feeding behaviour. The study was conducted in a single neonatal unit in the United States and followed infants

from the onset of oral feeding until four months post-term age. The quality of maternal feeding behaviour in the neonatal unit was explored in relation to positive affective involvement and sensitivity/responsiveness (e.g. sensitivity, responsiveness to infant cues, expression of positive affect and enjoyment), and the mother's regulation affect and behaviour (e.g. structuring of a feeding, mediating the feeding environment, positive social-emotional experience). The study indicated the association between maternal and infant behaviours, with the quality of maternal feeding behaviours associated with the quality of infant feeding behaviour at four months.

A qualitative study conducted by **Caretto et al (2000)** aimed to understand the current trends in parent education related to feeding in the neonatal unit, and the role that occupational therapists play in providing education to parents. In a survey of 100 neonatologists in the United States, occupational therapists were identified as being responsible for providing parent education with regards to positioning, infant development, and infant states and cues. They were also highly engaged in supporting parental education about infant feeding.

**Swift and Scholten (2010)** conducted a qualitative study which aimed to develop a model to identify considerations for neonatal unit staff that would improve the delivery of family-centred care. The study included nine mothers and two fathers from a single neonatal unit in Australia, whose preterm infants experienced ongoing feeding issues at 36 weeks post-menstrual age. Parent perceptions highlighted the struggle between wanting to take their infant home, and the presence of feeding issues preventing this from occurring. This served to shift the experience of parent-child interaction and co-occupations to one of intake and weight gain. Recommendations were made for the ongoing support of infant feeding in the neonatal unit as an interactive experience between parents and their infant.

**Ward et al (2000)** conducted a qualitative study which aimed to explore the perceptions of occupational therapists and parents regarding services provided in the neonatal unit. The study was conducted in the United States and had a strong focus on the provision of feeding interventions for preterm infants. Mothers in this study appreciated the information provided to support feeding engagement, including oral stimulation and reading infant cues. Equally, they concurred that support was predominantly provided via hands-on demonstration and facilitation. Both mothers and therapists recognised that time availability impacted on the ability to provide consistent support during the development of early parent-infant feeding co-occupations.

A service evaluation conducted by **Chrupcala et al (2015)** aimed to increase the number of infants in a neonatal unit who were fed according to feeding readiness cues prior to discharge and potentially decrease length of hospital admission. The evaluation was conducted in a single neonatal unit in the United States and involved 170 infants (20 infants prior to the implementation of cue-based feeding). In the ten months post-implementation, infant-driven feeding became a more integrated part of routine neonatal practice. Infants who were able to be fed according to their feeding readiness cues achieved full oral feedings more quickly, and subsequently had decreased length of stay.

**Waitzman et al (2014)** conducted a qualitative study which aimed to examine the content validity of the Infant-Driven Feeding Scales (IDFS). The IDFS are comprised of three scales used to assess preterm infants' oral feeding readiness, measure the quality of feeding performance, guide feeding intervention and provide a standardised format

for documentation. The IDFS were designed for infants who are medically stable and are 33 weeks gestation (Waitzman et al 2014). The study recruited 12 experienced neonatal therapists who participated in a Delphi methodology to refine the language of the IDFS and improve the content validity. Language changes were made to the feeding readiness scale as a result of practitioner feedback, and existing consensus confirmed for the quality and caregiver techniques scales.

### **Evidence overview**

The body of evidence provides support for the benefits of focusing on the parent–infant relationship during feeding to improve parent understanding of infant feeding readiness, parent confidence, parent sensitivity and sensitive introduction of oral feeding for the infant. This recommendation is supported by low-quality evidence, drawn from one descriptive systematic review and six cohort studies.

No specific risks were reported in any of the studies with regard to the adoption of a feeding readiness approach to the introduction of oral feeding.

Working alongside specialist neonatal colleagues, including speech and language therapists, nurses and lactation consultants, occupational therapists add to the support structure surrounding the developing parent–infant relationship. This is facilitated through supporting parents to read infant cues, providing support for the infant's developing self-regulatory capacities and considering the interplay that occurs between parents and infants during a shared occupation such as feeding. Given the involvement of occupational therapy services for infants and young children experiencing long-term feeding issues, early engagement in supporting the occupation of feeding serves to equip parents with guidance that they can utilise after their infant's transition from hospital to home.

### **5.6.3 Recommendation 15: Managing the environment during infant feeding**

**Flacking and Dykes (2013)** conducted a qualitative, ethnographic study which explored parents' practices and experiences of feeding their preterm infant, particularly in relation to the environment. The study involved 52 mothers, 19 fathers and 102 neonatal unit staff drawn from four units (two in Sweden and two in the UK). Care practices across the units ranged from couplet care to cotside chairs, with parental rooming only prior to infant discharge. The study findings provide a strong sense of the role that the neonatal environment played in the development of attuned feeding between parents and their infant. These were categories in relation to the level of ownership parents felt they had of the space and place, the feeling of 'at-homeness', the experience of a door against people entering (for privacy, for enabling a focus on the parent–infant interactions and for regulating socialising), and the window of opportunity. The findings showed that the construction and design of space and place were strongly influential on the developing parent–infant relationship and for experiencing a sense of connectedness and a shared awareness with the infant during feeding, an attuned feeding.

**Pickler et al (2013)** conducted a qualitative component within a randomised controlled trial to ascertain the effect of the environment (open bay and single-family room) on the volume taken in by infants who were born at 30–32 weeks of age. Environmental attributes were recorded for 87 infants during each oral feeding (from first oral feed until discharge). The study identified that typical feeding times of 9 a.m., 12 p.m. and



3 p.m. were associated with the highest levels of light and sound. Conversely, feeding times of 12 a.m., 3 a.m. and 6 a.m. where light levels were moderated were associated with improved feeding outcomes. Additionally, the infant's level of wakefulness (feeding readiness cue) was associated with volume of feed taken.

### **Evidence overview**

Two low-level studies highlight two important aspects by which the neonatal environment can influence parent–infant feeding occupations. First, that unit environment and design can impact on parents' involvement in feeding. The environment provides strong cues to parents in terms of their sense of place at their infant's cotside, which plays an important role in supporting involvement in breastfeeding. Second, an infant's ability to cope with sensory input will influence the success of their feeding. It is important to consider the wider environmental context when supporting parent–infant feeding development, and incorporate environmental modifications which support an infant's self-regulatory capacities.

With a strong background in the consideration of the environment on the performance of daily occupations, occupational therapists can facilitate an appropriate environment for parent–infant feeding activities.

## **5.7 Parent engagement**

### **5.7.1 Introduction**

The birth of an infant who requires admission to an NICU represents a major life-changing crisis for parents, which could impact on the acquisition of their parenting role and engagement in parenting occupations (Gibbs et al 2015). Becoming parents of a full-term, healthy infant is generally experienced as a normative, developmental process. In contrast, the experience of parenting a medically fragile infant is very different. The impact of a high-risk pregnancy and/or the delivery of a preterm infant may cause significant stress, particularly due to feelings of grief and guilt over the loss of the full-term pregnancy and the impact on the infant of the premature birth (Lasiuk et al 2013). Once an infant is admitted to an NICU, parents are forced to practise parenting in a setting where there are significant constraints upon how they interact with their infant (Lupton and Fenwick 2001).

The recognition that the birth of a high-risk infant may influence the acquisition of parental role and the engagement in parenting occupations is becoming more recognised in the occupational therapy literature. Dudek-Shriber (2004) identified that the most stressful aspect of having an infant in an NICU is related to altered parental role and relationship with their infant. It was recommended that occupational therapists retain a strong focus on facilitating a positive parent–infant relationship and provide interventions that focus on supporting the parents' occupational role (Dudek-Shriber 2004). Consideration has also been given as to how the experiences of parenting a high-risk infant can be viewed within an occupational therapy practice framework, considering the person, environment and occupational transactions that all come into play as parents begin their parenting journey in the neonatal unit (Gibbs et al 2010).

Occupational therapists can support the care provided by the neonatal multidisciplinary team by incorporating the use of occupation-centred frameworks. This approach provides a structure through which an understanding of how each infant and their family accommodate to the neonatal unit experience can be achieved and, more

specifically, can be used to direct the delivery of family-centred care and support parent engagement (Gibbs et al 2010).

Parent engagement	
16. <b>It is recommended</b> that occupational therapists work with parents of high-risk infants to support parenting roles and relationships, and to provide sensitive and appropriate parent engagement in the infant's care in the neonatal unit. <i>(Dudek-Shriber 2004 [C]; Ganadaki and Magill-Evans 2003 [D]; Gibbs et al 2015 [A]; Price and Miner 2009 [D])</i>	1A
17. <b>It is recommended</b> that occupational therapists facilitate the development of shared occupations of feeding, dressing and play activities of daily living with preterm and low-birthweight infants to ensure sensitive and appropriate caregiving and promote occupational performance of infants and parents. <i>(Chiarello et al 2006 [C]; Kadlec et al 2005 [C]; Winston 2015 [D])</i>	1C
18. <b>It is recommended</b> that occupational therapists working with families of high-risk infants build a positive therapeutic collaboration with parents to enhance parental learning about their infant both during and following the transition to home. <i>(Harrison et al 2007 [C])</i>	1C
19. <b>It is suggested</b> that occupational therapists explore both traditional and innovative means (e.g. video-conferencing) of supporting families post-discharge from the neonatal unit as a means of promoting parent confidence and competence in caring for their infant following the transition to home. <i>(Gund et al 2013 [C])</i>	2C

### 5.7.2 Recommendation 16: Supporting parenting occupations/parental role

**Price and Miner (2009)** conducted a qualitative study that explored the use of occupation-based practices by experienced occupational therapists in the neonatal unit. This study was a single case study involving one mother, one infant and one occupational therapist.

Observations of the interactions between the therapist and infant/parent, and interviews with the therapist, identified two key elements for inclusion in neonatal occupational therapy clinical reasoning. These are the importance of negotiating the meaning of parenting activities and parenting co-occupations with each family, and ensuring that opportunities are provided for parents to participate in co-occupations with their infant throughout the neonatal unit admission. Supporting this connection and opportunity for meaningful engagement with their infant also leads to the optimal conditions for promoting infant development.

A pilot cohort study, conducted by **Ganadaki and Magill-Evans (2003)**, involved ten families and aimed to explore whether there were any differences between fathers' and mothers' interaction patterns with infants and young children who were receiving early intervention services. Differences were observed between mothers' and fathers'



interaction styles with their children, with mothers generally receiving higher scores in categories that relate to promoting the development of skills in their child. This is an important point when considering how occupational therapists work with both parents or primary caregivers for a high-risk infant to support the development of their own parenting role, but also in the delivery of advice and guidance that promote the development of their infant.

**Gibbs et al (2015)** conducted a meta-ethnographic synthesis which aimed to explore the concept of parenting as an occupation as a means of supporting parent engagement in the neonatal setting. The synthesis included 35 individual papers of qualitative research design that collectively included 453 parents (311 mothers and 142 fathers). Parents were noted to move through key transitions as they adapted to their experiences of parenting a high-risk infant: relinquishing the anticipated role of parent; feeling vulnerable and powerless; juggling roles and responsibilities; claiming an alternative parental role; navigating environmental boundaries; developing partnerships with staff; coming to know the infant; and adapting to parenting.

The findings illustrated that events leading to, and including, the birth of a preterm infant may cause significant occupational disruption to parents. As parents struggle to come to terms with the events surrounding their infant's admission to a neonatal unit, this disruption leaves a void in their developing parental identity. During the admission, parents began to participate in a process of transition as they worked to reclaim their parental role and learn new occupations associated with parenting a preterm infant. The authors identify the importance in moving the acknowledgement of parent involvement in the NICU beyond involvement in basic caregiving activities, and highlight the importance of transforming parent involvement into opportunities for participation in nurturing and caring for their infants in ways that are meaningful to them.

**Dudek-Shriber (2004)** conducted a cohort study which aimed to determine the frequency of stress experienced by parents, the parent/infant characteristics that result in different stress scores, and the influence of parent and infant characteristics in predicting stress. The study involved 181 parents whose infants were admitted to a neonatal unit for longer than seven days. Using the neonatal unit Parent Stressor Scale (PSS; NICU) the results showed high scores of general stress, indicating that the stress experienced by parents in the neonatal unit is often diffuse. However, when looking at the individual subscales of the measurement tool, the results indicated that parents perceived that the most stressful aspect of their neonatal admission was an altered parental role and relationship with their infant.

### **Evidence overview**

Occupational therapists can make a significant contribution to the support of parents and their engagement in caregiving in the neonatal unit. A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on parenting experiences, including their participation in activities/occupations that relate to their parental role. The studies have consistently identified that parents who experience the birth of a high-risk infant may find it difficult to adapt to their new role. The evidence supporting this recommendation consists of one well-structured qualitative meta-synthesis, two cohort studies and one qualitative study, ranging from high to very low levels of evidence.

Occupational therapists can provide a key role in supporting parents as they adapt to a different parenting role from the one they had perhaps anticipated. It is recommended that occupational therapists employ an intervention approach that supports parents' engagement in sensitive and appropriate caregiving for their infant in the neonatal unit, promoting parenting activities that will serve to build awareness of their infant's needs, sensitivity, and skills in supporting the development of their infant/child's occupations.

### **5.7.3 Recommendation 17: Supporting parent and infant engagement in shared occupations**

**Kadlec et al (2005)** conducted a descriptive correlational study which aimed to examine the caregiver–child interaction qualities associated with activities that were part of daily routines of children born prematurely or of low birth weight, with or without white matter disorder, as well as children born at term. The study included 36 pairs of caregiver–child dyads and the study was undertaken when the children were 30 months of age.

As expected, children who had been identified with white matter disorder had a lower performance on both the cognitive and motor scales of the Bayley Scales of Infant Development, supporting their identification as a group of infants at increased risk for emerging developmental concerns who benefit from follow-up and early intervention.

The study looked specifically at caregiver positive engagement and caregiver directiveness. For children born at low birth weight (with and without white matter disorder), positive engagement by their caregivers was moderately to strongly correlated with caregiver directiveness. This association was not observed in the group of children born at term. These findings suggest their caregivers may be adjusting the level of their social and emotional assistance during caregiver–child interactions to the level of their children's abilities. By being both positive and directive, these caregivers may be interacting in ways that facilitate and sustain their child's engagement with activities.

**Chiarello et al (2006)** conducted an observational study with 20 children and their mothers and fathers. The aim of the study was to compare motor behaviour, playfulness and parent–child interactions during mother–child and father–child play in children who were experiencing motor delay. Observations were carried out when the children were three years of age.

Six of the children within the study were noted to perform differently depending on which parent they were interacting with. In some cases improved performance was noted with mothers, and in other cases with fathers. Overall, there were no real differences in motor behaviour performance with either parent. Mothers and fathers demonstrated similar levels of achievement, orientation, affect/affirmation and directiveness, while mothers were noted to be more responsive. The findings of this study indicate the importance of including both parents, where possible, in occupational therapy service provision, due to the strengths and skills that both bring to supporting their child's development in participating in early self-care and play occupations.

A qualitative study, which formed a component of a larger mixed-methods project, was conducted by **Winston (2015)** to examine the lived experience of mothers who were mothering a young child with feeding difficulties. The study included five women, whose children were between 12 and 36 months of age. Two emergent themes from the study findings were presented in detail: dealing with the system; and the complexity of feeding. Both of these themes revealed strong connections with maternal work and perceptions of maternal role around the negotiation of mealtimes with their children.

Ongoing feeding issues arise for some children who have experienced admission to a neonatal unit. It is important to consider how best to support families who experience this, particularly in support of the parent's own occupations.

### **Evidence overview**

There are differences in how parents of children with emerging or ongoing developmental concerns interact with their children and promote optimal development. Parents report requiring additional support when their child has specific occupational performance concerns (e.g. participation in feeding). Children of parents/caregivers who are able to provide sensitive nurturing and appropriate facilitation of their child provide optimal conditions for supporting the development of early self-care, play and learning occupations. This recommendation is supported by evidence of low and very low quality.

Occupational therapists can facilitate parents' engagement in sensitive and appropriate caregiving both in the neonatal unit and beyond, supporting parenting awareness of their infant's needs, sensitivity and skills in enhancing the development of their infant/child's occupations.

## **5.7.4 Recommendation 18: Supporting parents post-discharge**

**Harrison et al (2007)** conducted a qualitative study which aimed to describe how mothers feel therapists help them learn about their child with special needs, and how their learning is affected by their relationship with their child's therapist. The study was conducted in Canada and incorporated nine mothers of children aged 19 months to 5 years who were receiving therapy services in an early intervention setting.

Mothers identified that a positive relationship served to enhance their learning from their child's therapist. Two specific themes were presented in detail: relationship (both the therapist's relationship with their child, and the parent valuing their expertise and emotional support); and learning (including the provision of learning in a variety of ways and how the strength of the relationship influenced the successfulness of learning).

### **Evidence overview**

There is low-level evidence to support the association between a positive relationship between parents and providers and parent response to learning strategies that supported their child's development. The evidence for this recommendation is drawn from one qualitative study.

Occupational therapists also provide post-discharge services to high-risk infants who have been identified as having ongoing developmental concerns. They can provide a key role in supporting parents who are accessing ongoing therapies for their infant. Building a positive, collaborative relationship with parents has been shown to enhance parents' learning about their infant in relation to how they could support their development.

## **5.7.5 Recommendation 19: Models of service delivery**

In a randomised controlled trial, **Gund et al (2013)** aimed to investigate whether the use of video-conferencing or a web application improved parent satisfaction in taking care of a preterm infant at home, thereby decreasing the need for home visits, and to explore nurses' attitudes to the use of technology. Conducted in Sweden, the study included 34

families. Video-conferencing was conducted using Skype, and the web application was a platform that allowed parents and nurses to communicate and exchange health-related information.

The parents who were using the web application or video-conferencing found them to be useful, increasing their confidence in caring for their child. While the authors concluded that these types of technology may be a relevant tool to support resource management in providing ongoing support and care for families following discharge from the neonatal unit, they did acknowledge that some staff were reluctant to engage with the technology.

### **Evidence overview**

The potential and use of mobile health (m-Health, or the use of web-based and telephone communication) technologies in improving healthcare delivery and outcomes is of increasing interest. m-Health applications provide a novel way of delivering healthcare information to service users.

There is low-level evidence from a single, small, randomised controlled trial to suggest that consideration of the use of m-Health applications as a means of providing support for families as they transition home from the neonatal unit supports parents' competence and confidence in caring for their infant.

It is suggested that occupational therapists consider the strategies and service delivery models they employ when partnering with parents to build an ongoing relationship and a facilitatory learning environment.

## **5.8 Parent support**

### **5.8.1 Introduction**

In recognition of the importance of parent–infant attachment, there has been increasing focus on the implications of an NICU admission on the development of the parent–infant relationship. A review of the research conducted into preterm infant–parent interaction identified a range of factors that impact on the development of this relationship (Bozzette 2007). In the development of reciprocal social interaction with their preterm infants, parents are often required to carry the major load of the interaction, with increased vocalisation and smiling in an attempt to engage the infant. Parents may also perceive their preterm infants as more vulnerable than term infants, and engage in compensatory parenting strategies. Support for early efforts of parents to become acquainted sensitively with their infants was noted to be extremely important (Bozzette 2007).

The NICU has been acknowledged as a difficult place to establish meaningful and positive parent–infant interaction (Moehn and Rossetti 1996). The impact of the medical environment required to support such vulnerable infants in the neonatal unit contributes to the difficulties many infants experience with self-regulation and organisation. This can result in the disruption of two of the critical attributes of parent–infant attachment: proximity and reciprocity.

There is also increasing understanding of the specific influences a preterm birth and neonatal unit admission may have in the development of parent–infant relationships

and later child development. Treyvaud et al (2009) specifically explored the impact of parenting behaviour on the early neurobehavioural development of very preterm infants. Key findings of this study indicated a strong, positive association between parent-child synchrony and child cognitive development and social-emotional competence at two years corrected age. The researchers determined that the synchronicity of the interactions between the parent and child was a significant attribute – relating to how well the parent and child responded to each other, and dependent upon the parent's understanding of how to communicate effectively with their child (Treyvaud et al 2009).

An infant's admission to an NICU can also be a period of intense stress for parents, arising from the premature birth and medical sequelae. Studies have examined the prevalence of maternal psychological distress and parenting stress following the birth of a very low-birthweight preterm infant. Singer et al (1999) identified that mothers of high-risk preterm infants reported higher levels of psychological distress than the low-risk or term infant mothers, particularly in relation to depression, anxiety and obsessive-compulsive behaviours. Parenting stress was also high in the mothers of high-risk preterm infants and continued until the children were three years old. This was reflected in the participants' perception of their children as more distractible, hyperactive and demanding. Given the often continued involvement of occupational therapists in providing follow-up services to preterm infants and their families, this longitudinal impact may continue to influence the development of parent-therapist partnerships in the outpatient and community setting. Mothers of both high- and low-risk preterm infants also reported higher levels of family stress that continued until the infants were two years old, in comparison with the mothers of term infants (Singer et al 1999). Similarly, Segre et al (2014) reported that 25.5 per cent of mothers whose infants had been admitted to an NICU reported clinically significant symptoms of depression. The presence of anxiety symptoms was also noted, with presentation ranging from mild (30.3%), moderate (17.4%) to severe (10.3%) (Segre et al 2014).

The presence of parent stress and mental health issues has also been demonstrated to be linked to family functioning. The Treyvaud et al (2011) investigation indicated that 21 per cent of parents of very preterm infants reported clinically significant symptoms of mental health issues at two years post birth, with a high representation of mothers among this group. Parent mental health problems at two years were also found to be associated with higher parental stress.

There is an increasingly strong picture emerging of the potential for high rates of psychological distress among NICU parents. Accompanied by the potential for preterm infants to experience lifelong medical and/or developmental issues, this provides a strong driver to continue to work to incorporate family-centred care both into the policies, procedures and culture of the neonatal unit (Gooding et al 2011) and into the provision of neonatal occupational therapy services.

Occupational therapists receive dual training in the areas of physical and mental health. They are therefore uniquely placed to identify and support parents/caregivers who may be experiencing issues around psychological adjustment. Occupational therapists can support parents to develop successful psychological coping strategies and mediate the impact that parent mental health concerns may have on the development of parenting efficacy.

Parent support	
20. <b>It is recommended</b> that occupational therapists support engagement in parenting occupations in the neonatal unit and following discharge (including, but not limited to, reading infant cues, guided participation in care, skin-to-skin, positive touch and holding) to promote decreased parent stress and positive improvements in parent-infant relationship and self-efficacy. <i>(Evans et al 2014 [A]; Matricardi et al 2013 [B]; Melnyk et al 2006 [A]; White-Traut et al 2013 [A]; Zelkowitz et al 2011 [A])</i>	1A
21. <b>It is recommended</b> that occupational therapists employ parent-focused interventions that incorporate parental sensitivity elements (e.g. reading infant cues and responding in developmentally appropriate ways) in order to reduce the psychosocial impact of delivering a high-risk infant, foster sensitive nurturing behaviour and promote the cognitive development of preterm infants. <i>(Als et al 2003 [A]; Benzies et al 2013 [A]; Kraljevic and Warnock 2013 [B]; Melnyk et al 2001 [A]; Nordhov et al 2010 [A])</i>	1A
22. <b>It is suggested</b> that occupational therapists engage parents in brief activity-based interventions during their infant's admission to the neonatal unit and that this can have a short-term effect in lowering parent anxiety. <i>(Mouradian et al 2013 [C])</i>	2C

### 5.8.2 Recommendation 20: Decreasing parent stress and promoting self-efficacy

**Evans et al (2014)** conducted a systematic review which aimed to investigate the efficacy of parent interventions in improving the quality of the relationships between mothers and preterm infants. The review included 14 individual randomised controlled trials.

A range of specific parent-support interventions were identified as having a positive effect on the maternal-infant relationship. These included: supported by guided participation in their infant's caregiving; participating in skin-to-skin care with their infant, both throughout the neonatal unit admission and up to three months post-discharge; the provision of individualised family-based intervention during the neonatal unit admission; and the provision of home visits that focused on supporting parents with their infant's developing state regulation post-discharge up to five months of age. Although the variability in outcomes did not support deeper analysis to see whether intervention effects were greater in one set of interventions than another, all of the interventions that demonstrated effectiveness had common elements of supporting close, nurturing connections between parents and infants, supporting parents to read their infant's neurobehavioural state and respond sensitively, and actively engaging parents throughout their infant's neonatal unit admission.

A randomised controlled trial undertaken by **Matricardi et al (2013)** aimed to examine the effects of a parental intervention to reduce stress levels for mothers and fathers during hospitalisation of very preterm infants. The study was conducted in Italy and involved 42 parents. The intervention focused on supporting parents to observe their infant's neurobehavioural cues, and to improve physical closeness between parents and their infant.

The stress scores of the parents who received the intervention showed a decrease (though not significant). Mothers demonstrated higher levels of stress than fathers, particularly in focusing on the alteration of their parental role. The intervention approach appeared effective in promoting parents' understanding of the behaviour of their infant, and gave parents a strengthened sense of their parental identity.

**White-Traut et al's (2013)** randomised controlled trial examined the impact of a specific parent-focused intervention, H-Hope (Hospital to Home: Optimizing the Infant's Environment), on mother and infant interaction patterns during feeding and play at six weeks corrected age. The study was conducted in the United States and included 198 preterm infants and their mothers. The H-Hope intervention includes an infant-directed sensory programme, and a maternal-directed component focusing on education and social support through the provision of individualised participatory guidance during the hospital stay and post-discharge. The intervention began when the infants reached 32 weeks post-menstrual age.

For the infants and mother dyads who received the intervention, there were slightly higher scores on the NCAST tool, which evaluates maternal-infant interaction during feeding (though these did not reach statistical significance). The level of mutuality observed between the infant and mother during play also demonstrated high responsivity for those who received the interventions when compared with those in the control group. The authors concluded that supporting maternal-infant interaction should be a key component in building a high-risk infant's capacity to engage in social interactions and promote development.

**Melnik et al (2006)** conducted a randomised controlled trial which aimed to evaluate the efficacy of an educational-behavioural intervention programme which was designed to enhance parent-infant interactions and parent mental health outcomes. The Creating Opportunities for Parent Empowerment (COPE) programme is a four-phase programme that aims to provide parents with information on the appearance and behavioural characteristics of their infant to guide how parents can participate in their care, and incorporates activities that guide parents in implementing this new knowledge when caring for their infants. The study was conducted in the United States and included 260 parents or caregivers of preterm infants.

A range of positive outcomes was noted for the parents and infants who had received the COPE intervention. Length of admission to the neonatal unit was noted to be 3.8 days shorter than for those in the comparison group. Mothers in the COPE programme reported significantly less overall parental stress in the neonatal unit than mothers in the comparison group. There were no differences noted in fathers' reporting of stress. Mothers and fathers in the COPE programme reported significantly higher parental beliefs about their role, and what characteristics and behaviours to expect from their preterm infants. Both mothers and fathers also demonstrated more positive parenting interactions with their infants during the neonatal admission. By two months corrected age, mothers who had received the COPE intervention reported significantly less anxiety and fewer symptoms of depression than mothers in the comparison group.

A randomised controlled trial carried out by **Zelkowitz et al (2011)** aimed to determine the effect of a brief skills-based intervention on the anxiety of mothers of very low-birthweight (VLBW) infants. The Cues Programme is an intervention designed to reduce anxiety and develop sensitive interaction skills for mothers of VLBW infants. It is a brief intervention delivered over six sessions of 45–75 minutes in length. The intervention included educating mothers on strategies to reduce feelings of anxiety, and recognising



and interpreting their infants' cues to respond with sensitivity. Mothers in the comparison group also received six direct contacts from a researcher who provided them with information on standard infant care information (e.g. immunisations, safety). The study was conducted in Canada and included 121 infant-mother dyads.

Both groups of mothers demonstrated significant reductions in their experience of anxiety immediately following the intervention period. Their experiences of stress were similar, and both groups of mothers were equally sensitive in their interaction with their infants. The authors concluded that while no key differences were found between the intervention and comparison groups, the key factor may have been the availability of a supportive practitioner who was proactive in reaching out to mothers, providing information and reassurance.

### **Evidence overview**

The evidence that supports the relationship between supporting parent engagement in parenting occupations (decreases in parent stress and improvements in parent-infant relationship) and parent self-efficacy is strong. Although there is some inconsistency across the findings of individual studies, it is clear that an approach that includes parent-directed interventions and engagement is a key attribute of success. The evidence for this recommendation is drawn from one systematic review and three randomised controlled trials which are of high quality, and a further randomised controlled trial of moderate quality.

Supporting parent engagement in parenting occupation-based activity has been demonstrated as an effective way to decrease parent stress, promote positive improvements in parent-infant relationship and support parents to feel that they are contributing to their infants' care. Such activities can include learning to read and respond to infant cues, guided participation in caregiving, skin-to-skin care and positive touch.

### **5.8.3 Recommendation 21: Supporting maternal/parental sensitivity**

**Benzies et al (2013)** conducted a systematic review which reviewed early interventions aimed at promoting parent outcomes and identified the key components associated with maternal and child outcomes. The review incorporated 18 individual studies with study sample sizes ranging from 23 to 985 parents. There was a broad geographical representation, including studies from Australia, England, Germany, Italy, Japan, the Netherlands, Norway and the United States.

Eleven of the included studies reported maternal outcomes of stress, anxiety, depression, self-efficacy and sensitivity/responsiveness in infant interactions. Positive and clinically meaningful effects were demonstrated for the reduction of symptoms of depression and anxiety, and the promotion of parent self-efficacy. Interventions that included a specific element of psychosocial support resulted in improved outcomes for mothers. In four studies that included a component of maternal psychosocial support, improved infant outcomes were also reported.

A systematic review conducted by **Kraljevic and Warnock (2013)** set out to assess how effective early informational and behavioural interventions are in reducing the incidence of maternal anxiety, depression, stress, parenting stress and symptoms of post-traumatic stress disorder (PTSD) for mothers who experience psychological trauma associated with preterm birth. The review included eight individual studies, which



collectively involved 1,005 mothers. Interventions were diverse, but used an educational and/or a behavioural approach to support mothers. Maternal sensitivity training (to infant cues) was a component of the majority of the study interventions.

The findings of the review confirmed that mothers often experience early onset of significant depression, anxiety, parenting stress and symptoms of acute stress disorder during their infant's admission to the neonatal unit. There were inconsistent outcomes across the studies in terms of their efficacy in reducing maternal psychological symptoms – half of the reviewed programmes had a positive impact on one to three psychological outcomes. As a result of this variability of the interventions, the authors were unable to draw conclusions regarding the overall effect. However, while the outcomes of specific interventions were inconsistent, this is an important review in highlighting the early presentation of psychological distress of mothers of preterm infants, and suggests that parent well-being should be a key consideration in neonatal caregiving approaches.

**Nordhov et al (2010)** conducted a randomised controlled trial to analyse whether the Mother–Infant Transaction Program (MITP) led to more nurturing child-rearing attitudes. The study was conducted in Norway and included 146 preterm or low-birthweight infants. The intervention comprised a daily one-hour session, delivered for seven consecutive days. The aim of the intervention was to enable parents to appreciate and recognise their infant's unique characteristics, temperament and developmental potential, with a specific focus on the infant's cues, especially those signalling stimulus overload, distress and readiness for interaction, in order to optimise parent–infant interaction and play.

Using a questionnaire that assessed maternal attitudes around child-rearing, mothers in the intervention group reported significantly greater nurturing attitudes when their children were 12 and 24 months of age. However, it was also noted that there were changes in maternal attitudes across mothers of both term and preterm infants over time, indicating that changes in child-rearing attitudes also develop independently of early intervention and birth history.

In a randomised controlled trial undertaken by **Melnyk et al (2001)**, the researchers aimed to evaluate the Creating Opportunities for Parent Empowerment (COPE) programme in terms of maternal coping and infant cognitive development. The study was conducted in the United States and included 42 mothers of preterm infants. The COPE intervention commenced 2–4 days following the infant's birth, and continued to one week post-discharge.

The COPE intervention was demonstrated to result in significantly higher mental development scores (as measured by the Bayley Scales of Infant Development) at three months corrected age, compared with the infants in the comparison group. This difference was noted to have widened further by the time the infants were six months corrected age. In relation to the experience of parent stress, mothers who had participated in the COPE programme were reported to be significantly less stressed by the sights and sounds of the neonatal unit environment than the mothers in the comparison group, and held significantly stronger beliefs about what behaviours and characteristics to expect from their preterm infants.

Finally, the randomised controlled trial conducted by **Als et al (2003)**, which, as previously described, included 92 infants drawn from three neonatal units in the United States, tested the effectiveness of individualised developmental care. Infants in the

experimental group received the NIDCAP intervention, with the infants in the control group receiving standard care. Outcomes related to medical status, developmental status and parent functioning were measured at two weeks corrected age. Parents of infants supported by the NIDCAP approach perceived their infants as having improved regulation. They also experienced enhancements in their own parental competence, with a corresponding reduction in stress experiences.

### **Evidence overview**

The evidence supporting the relationship between the provision of parent-focused interventions incorporating maternal sensitivity elements and the experience of psychosocial impacts resulting from the delivery of a high-risk infant is strong. Providing parent-focused interventions that incorporate strategies to support the development of parent sensitivity has also been demonstrated as an effective way to reduce psychosocial impacts (such as anxiety and depression) of the birth of a high-risk infant on parents, and foster sensitive nurturing behaviour. These types of interventions have also been demonstrated to promote the cognitive development of preterm infants. This recommendation is supported by one systematic review and three randomised controlled trials of high quality, and a further systematic review of moderate quality.

## **5.8.4 Recommendation 22: Interventions to decrease parent anxiety**

**Mouradian et al (2013)** conducted a mixed-methods quasi-experimental study which aimed to reduce parent stress in the neonatal unit through participation in an art-based occupation group. The intervention consisted of a weekly group of two hours in length which ran consecutively over a five-month period. Any parents whose infants were admitted to the neonatal unit during that time were invited to participate. The group was based around an art activity (scrapbooking). This activity was selected due to the long history in the use of expressive arts by occupational therapists and its link to creativity, a fundamental element of occupational therapy practice. The study was conducted in the United States and included 45 parents.

Parents completed an anxiety measure before and after their participation in the group activity. There was noted to be a statistically significant reduction in state anxiety for the participants, which linked to a clinically significant reduction in anxiety symptoms in approximately 25 per cent of parents.

### **Evidence overview**

Providing opportunities for parents to engage in occupation-based activity in the neonatal unit (e.g. scrapbooking) has been demonstrated as an effective way to achieve short-term stress reduction. This has been included as a conditional suggestion as it is recognised that staff and material resources across neonatal units may influence the process of implementing this suggestion into practice. However, it contributes to an overall recommendation that occupational therapists utilise an occupation-based framework for practice in the neonatal unit that, in addition to supporting the development of the infant, also works to support sensitive and appropriate parent engagement in caregiving. The evidence for this suggestion is drawn from one quasi-experimental study of low quality.

## 5.9 Identifying developmental concerns

### 5.9.1 Introduction

A large body of research has highlighted the impact of the increase in survival of infants born prematurely and provided clarity around the range of neurodevelopmental issues with which preterm infants commonly present. The presentation of ex-preterm infants with subsequent developmental concerns provides a strong impetus for occupational therapy prevention and early intervention for preterm infants.

Specific concerns attributable to gestational age include:

- Extremely preterm infants (22–26 weeks gestation): serious cognitive impairment impacting on 40 per cent of ex-preterm infants in comparison with 1.3 per cent of controls; identification of cerebral palsy in 17 per cent of ex-preterm infants; impairments in motor planning, visuo-spatial, sensorimotor and attention functions (Johnson et al 2009, Marlow et al 2007).
- Very preterm infants (born before 33 weeks gestation): 32 per cent had a moderate cognitive impairment and 12 per cent had a severe cognitive impairment; overall disability (a variable composed of neuromotor and neurosensory impairment) was identified as severe in 5 per cent of children, moderate in 9 per cent of children and mild in 25 per cent of children; parents of ex-preterm infants were twice as likely to report behavioural issues in their children compared with full-term controls in relation to increased activity/inattention, increased emotional lability and issues with peer relationships (Larroque et al 2008, Delobel-Ayoub et al 2009).
- Moderate to late preterm infants (32–36 weeks gestation): increased incidence of autism spectrum disorders, neurosensory impairment, cognitive impairment and delayed social-emotional competence (Johnson et al 2014, Guy et al 2015).

Infants born at term who experience complications, such as post-asphyxia hypoxic ischaemic neonatal encephalopathy, also require ongoing developmental support and monitoring. The proportion of infants experiencing adverse events (neonatal death, cerebral palsy or motor/cognitive impairment) is 47 per cent, of which 44 per cent were in evidence prior to three years of age (Pin et al 2009). Additionally, children without presentations of severe developmental outcomes initially were subsequently identified as experiencing subtle deficits such as learning difficulties and visual-perceptual difficulties (Pin et al 2009).

Ensuring early identification of any emerging developmental concerns, and subsequent referral to relevant early intervention services, is important. This will include screening and assessment for developmental concerns across a range of performance domains (e.g. cognitive, motor and sensory) in order to promote the infant/child's engagement in age-appropriate activities of daily living.

Occupational therapists are concerned with occupational performance – that is, the dynamic relationship between a person, a person's environment and their occupations. Occupational therapists are able to screen or assess for areas of concern across a range of performance domains (cognitive, sensory processing and functional movement skills) and consider the impact this has on the infant/child's developmental progression. Equally, they address the constraining and enabling factors that the environment may have on the child's performance and how attributes in their environment may also be enhanced to promote acquisition of developmental goals.

Identifying developmental concerns	
23. <b>It is recommended</b> that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to cognitive performance and social interaction, in order to support the development of the infant's occupations, with referral to early intervention services as indicated.  (Maitra et al 2014 [A]; Magill-Evans et al 2002 [C]; Pineda et al 2015 [C]; Sajaniemi et al 2001 [C])	1A
24. <b>It is recommended</b> that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to functional motor skills, in order to support the development of the infant's occupations, with referral to early intervention services as indicated.  (Maitra et al 2014 [A]; Bigsby et al 2011 [B]; Watkins et al 2014 [C]; Fewell and Claussen 2000 [C])	1A
25. <b>It is recommended</b> that occupational therapists should be involved in the screening and assessment of high-risk infants for problems related to sensory processing difficulties, in order to support the development of the infant's occupations, with referral for early intervention services as indicated.  (Witt Mitchell et al 2015 [B]; Crozier et al 2016 [C])	1B

### 5.9.2 Recommendation 23: Cognition and social interaction

**Maitra et al (2014)** conducted a systematic review which aimed to determine whether low birth weight (LBW) or preterm birth led to difficulties in mental, neuro-musculoskeletal and movement-related tasks at school age. Child outcomes of interest were IQ, attention, executive function, emotional-behavioural characteristics, academic skills, visual-motor function, visual-perceptual function, hand skills, sensory motor performance, and motor co-ordination and control. The review included 40 individual studies, including 6,553 children born LBW or preterm and 24,624 typically developing children.

Following a meta-analysis it was identified that children born with LBW demonstrated considerable difficulties in mental functions compared with children of normal birth weight. Children born preterm also demonstrated significant difficulties in mental functions compared with term-born peers. Children born with LBW or preterm made more mental function errors, took longer during decision-making tasks and received lower scores on mental function assessments than their typically developing counterparts. The study also demonstrates a strong link between cognitive difficulties and problems with motor performance in preterm and LBW infants. Based on the work of Spencer et al (2008), the review authors suggest that children born either LBW or preterm were associated with reduced grey matter density in the temporal brain structures that continued into childhood, and that this atypical brain structure and associated cortical dysfunction within the temporal lobe may result in poor cognitive functioning, because of the important role that temporal lobe structures play in relation to memory, language and learning.

In a longitudinal observational study undertaken by **Magill-Evans et al (2002)**, the researchers aimed to compare the cognitive and language development of children at

ten years of age born preterm with those born at term. The children were assessed using an IQ and language scale. The study was conducted in Canada and included 43 children.

The children born preterm were identified with subtle delays. They demonstrated a significantly lower performance on the performance scale of the Wechsler Intelligence Scale for Children (WISC-III), and on the language scale. In relation to the IQ performance scale, children appeared to have most difficulty with items requiring visual-spatial skills.

**Pineda et al (2015)** conducted a cohort study which aimed to assess whether neonatal social characteristics are related to risk of autism at two years corrected age. The study included 62 infants who had been born at <30 weeks gestation. The infants were assessed at term-equivalent age, prior to their discharge from the neonatal unit, using the NICU Network Neurobehavioral Scale. They were re-assessed at two years of age using the Bayley Scales of Infant and Toddler Development and the Modified Checklist for Autism in Toddlers. The study was conducted in the United States.

The researchers were trying to ascertain whether there were infant behaviours in the neonatal period that may be linked to later presentations of autism. However, atypical social interactions in infancy were not observed among infants who later screened positive for autism risk. Instead, some of the items (gaze aversion and endpoint nystagmus) were linked with better developmental outcomes.

**Sajaniemi et al's (2001)** cohort study aimed to assess whether occupational therapy intervention affected cognitive skills and attachment patterns for infants born with extremely low birth weights. The intervention involved weekly occupational therapy sessions of 60 minutes in length when the infants were between 6 and 12 months of age. The focus of the intervention was to educate parents on adaptation of the sensory environment, interventions to support sensory modulation difficulties, and facilitation of handling to promote sensory motor development. Follow-up assessment was carried out when the infants were two and four years of age. The study was conducted in Finland and included 115 infants.

Overall, infants who had received the intervention demonstrated significantly higher cognitive scores (as measured by the Wechsler Preschool and Primary Scale of Intelligence – WPPSI) at four years than those in the control group. At two years of age, the risk factor and cognitive scores were significantly lower for boys. By four years of age, boys in the intervention group were demonstrating better verbal performance than those in the control group. Finally, evaluation of the parent-child attachment demonstrated significantly different patterns of attachment between the intervention and control groups, with the intervention group demonstrating more normative patterns. This particular study highlights the positive effect that early intervention for an at-risk population may promote in relation to cognitive development and parent-infant attachment.

### Evidence overview

A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on later cognitive and social interaction function. The studies, while not all high quality, have consistently identified an association between high-risk infants and later cognitive and social-emotional functions that are important in the performance of childhood occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed. The evidence for this recommendation is drawn from one high-level and three low-level quality studies.

Occupational therapy plays an important role in the assessment and management of cognitive/learning difficulties (e.g. IQ, attention, executive function, emotional-behavioural characteristics and academic areas such as spelling, reading and mathematics) in order to maximise a child's potential. They can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.

### 5.9.3 Recommendation 24: Functional motor skills

The systematic review conducted by **Maitra et al (2014)**, as described earlier, identified following a meta-analysis that children born with low birth weight demonstrated significant difficulties with neuro-musculoskeletal and movement-related tasks when compared with children of normal birth weight. Similarly, children born preterm also demonstrated considerable difficulties with neuro-musculoskeletal and movement-related tasks compared with their term-born peers. Children born LBW or preterm made more neuro-musculoskeletal and movement-related errors, took more time to complete tasks and received lower scores on neuro-musculoskeletal and movement-related assessments than their typically developing counterparts.

In a cohort study conducted by **Biggsby et al (2011)**, the researchers aimed to compare the quality of movement of infants born preterm (<33 weeks gestation), who had experienced prenatal cocaine exposure at four months corrected age, with that of unexposed preterm infants using the Posture and Fine Motor Assessment of Infants. The study was conducted in the United States and included 903 infants.

It was identified that infants prenatally exposed to cocaine had significantly lower posture scores than infants in the unexposed group. There were no main effects noted of cocaine exposure on the performance of fine motor skills at four months of age. Gestational age at birth had an independent effect on both posture and fine motor performance at four months corrected age.

**Watkins et al (2014)** conducted a retrospective analysis of cohort data in order to investigate the association between receiving occupational therapy and physiotherapy services between nine months and two years of age, and preschool motor performance. The study included 500 VLBW children, born in the United States, who had received therapy services. Functional motor skills were evaluated using an early screening inventory, the Bruininks-Oseretsky Test of Motor Proficiency, and the Movement Assessment Battery for Children.

Children born with VLBW who had received physiotherapy and occupational therapy services between 9 and 24 months were more likely to show improved performance on motor items that require complex motor planning at preschool age (e.g. skipping, walking backwards etc) compared with children who had not received the intervention, though this difference was not statistically significant.

In a cohort study conducted by **Fewell and Claussen (2000)**, the researchers aimed to use developmental milestone data to report developmental fine and gross motor trajectories over the first two years of life, to identify whether maternal cocaine use has short- or long-term harmful effects on motor skills. The study was conducted in the United States and included 73 children with assessments conducted at 6, 12, 18 and 24 months of age. The average gestational age at birth for the infants was 38.3 weeks. Infant fine and gross motor skills were assessed using the Peabody Developmental Motor Scales.

Fine and gross motor skills scores were below the normative scales of the assessment for children prenatally exposed to cocaine. The difference between children's scores from the normative scores increased over time, with fine motor skills showing a greater decrease in performance compared with gross motor skills.

### **Evidence overview**

A number of studies have been undertaken to explore the impact of the birth of a high-risk infant on functional motor outcomes. The studies vary in quality but identify an association between high-risk infants and functional motor skills that are important in the performance of childhood occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed. The evidence for this recommendation is drawn from one high-level, one moderate-level and two low-level evidence sources.

Occupational therapy plays an important role in the assessment and management of motor skills, particularly in relation to posture and fine motor functions that are key to performance of preschool and school occupations. Occupational therapists can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.

### **5.9.4 Recommendation 25: Sensory processing**

**Witt Mitchell et al (2015)** conducted a systematic review which aimed to explore the prevalence and type of sensory processing disorders in children aged birth to three years who had been born preterm. The review included 45 individual studies which collectively involved 2,584 children.

Sensory processing dysfunction has the potential to influence the development of play, social participation, education, and self-care occupations. Sensory processing dysfunction is an umbrella term which includes sensory modulation disorder (SMD), sensory discrimination disorder (SDD) and sensory-based motor disorder (SBMD).



Witt Mitchell et al (2015) describe these categories as:

- Sensory modulation disorder: a mismatch between the demands of the environment and a person's emotional and attentional responses based on the ability of the central nervous system to effectively alter neural messages from sensory input. Sensory modulation disorder consists of three sub-types: sensory over-responsivity, sensory under-responsivity and sensory seeking.
- Sensory discrimination disorder: the inability to interpret qualities of sensory stimuli, such as the location of stimuli or similarities and differences between stimuli.
- Sensory-based motor disorder: postural instability or deficits in voluntary movement caused by problems processing sensory input in one or more sensory systems.

A substantive proportion of the findings from the individual studies suggested that children born preterm may be at risk for sensory processing dysfunctions. Evidence of sensory modulation disorders, particularly sensory over-responsivity, was most prominent.

A cohort study conducted by **Crozier et al (2016)** also aimed to examine the prevalence and type of sensory processing differences in children born preterm and understand the risk factors for atypical sensory processing difficulties. The study was conducted in Canada and included 160 children who had been born at <25 weeks gestation and <800 grams. Assessment was conducted in a follow-up clinic when the children were 4.5 years of age.

Forty-six per cent of the children in the cohort presented with atypical sensory processing patterns. In contrast to Witt Mitchell et al (2015), the majority of infants in this study (40%) demonstrated greater under-responsiveness or sensory seeking (high threshold for sensory stimulation). Approximately one-third of children demonstrated a low threshold for visual, auditory, chemosensory, movement and tactile sensory input.

### **Evidence overview**

Two studies have been undertaken to explore the impact of the birth of a high-risk infant on the development of atypical sensory processing performance. The studies clearly identify an association between high-risk infants and sensory processing difficulties that may influence the development of play, social participation, education, and self-care occupations.

It is recommended that occupational therapists routinely provide screening and assessment of high-risk infants in this area in order to support the development of infant occupations, and/or provide referral to early intervention services as needed. The evidence for this recommendation is supported by one moderate-level systematic review and one low-level cohort study.

Occupational therapy plays an important role in the assessment and management of sensory processing skills, particularly in supporting children and families to develop strategies that support their sensory processing patterns and optimise their engagement in childhood occupations. Occupational therapists can provide a key contribution to the early identification of performance concerns in these domains and ensure timely referral for targeted early intervention support.



## 5.10 Early intervention

### 5.10.1 Introduction

Infants who are considered high risk as a result of prematurity or other health factors may experience ongoing developmental concerns that can impact on their participation in infant and child occupations. Early intervention (EI) services encompass a range of services designed to provide therapeutic interventions and family support that promote optimal development for the infant and their family.

In its most comprehensive form, early intervention 'enables every infant, child and young person to acquire the social and emotional foundations upon which our success as human beings depends' (Allen 2011, p3). The term early intervention does not constitute a single programme, but refers to different packages of services that may vary within and across localities with regard to service delivery models and the professional disciplines involved (McManus et al 2013).

Early experiences will influence the developing architecture of a child's brain, and it is therefore imperative that maximum opportunities are provided to high-risk infants and their families to engage in experiences that will promote their future cognitive, physical and social-emotional development.

In the UK, developmental follow-up services are usually provided for infants who have experienced a neonatal unit admission and are considered to be at risk for emerging or ongoing developmental concerns. In many areas, occupational therapists are included within multidisciplinary teams providing formal developmental follow-up services using screening, assessment, and consultation and referral advice. Further information and guidance for the provision of developmental follow-up services for preterm babies can be obtained in the NICE guidance (NICE In press).

For the purposes of this guideline, early intervention occupational therapy services will refer to a variety of service models provided by neonatal and paediatric occupational therapists which aim to promote child development across all relevant domains to support the child's and family's participation in meaningful occupations.

Occupational therapy early intervention services may be provided in hospitals (outpatient settings), community settings (e.g. child development centres) and in the family's home environment. Intervention can be provided on a one-to-one basis, in group settings or by using a consultation/advice model.

#### Early intervention

- |   |    |
|---|----|
| 26. <b><i>It is recommended</i></b> that occupational therapists provide early developmental intervention programmes for preterm infants to promote improved cognitive performance through the preschool years.<br>(Orton et al 2009 [A]; Spittle et al 2015 [A]; Spittle et al 2007 [A]) | 1A |
| 27. <b><i>It is recommended</i></b> that occupational therapists provide home-based early intervention programmes for infants born <30 weeks gestation in the first year of life as this may result in decreasing parent anxiety.<br>(Spencer-Smith et al 2012 [A])                       | 1A |

28. <b><i>It is recommended</i></b> that occupational therapists facilitate individualised functional motor interventions for high-risk infants and young children to promote engagement in early occupations such as play, exploration and participating in personal care (activities of daily living). <i>(Lekskulchai and Cole 2001 [A])</i>	1A
29. <b><i>It is recommended</i></b> that occupational therapists incorporate home routine/ occupation-based approaches in early intervention programmes for children at risk for developmental delay as a means of promoting occupational performance. <i>(Hwang et al 2013 [B])</i>	1B
30. <b><i>It is recommended</i></b> that occupational therapists be routinely referred preterm infants with the following co-morbidities: septicaemia, extremely low birth weight (ELBW), chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III–IV), for early intervention. <i>(Hintz et al 2008 [C])</i>	1C
31. <b><i>It is recommended</i></b> that occupational therapists working in early intervention settings with high-risk infants consider key elements when building a therapeutic collaboration with parents – promoting effective collaboration amongst multi-agency providers, supporting family social/ emotional needs in addition to infant developmental concerns, and consistency of service provision. <i>(Ideishi et al 2010 [D])</i>	1D

### 5.10.2 Recommendation 26: Promotion of cognitive performance

**Spittle et al (2015)** conducted an update to the Cochrane systematic review originally conducted by **Spittle et al (2007)** which aimed to compare the effectiveness of early intervention programmes (for preterm infants) over time. The review included 25 individual studies (19 randomised controlled trials, 5 quasi-experimental studies and 1 cluster analysis), which collectively included 3,615 children. The interventions included in the studies aimed to improve cognitive and/or motor outcomes and included a focus on the development of the parent–infant relationship and/or infant development. Most of the programmes included in the review commenced after the infants were discharged from the neonatal unit.

As expected, the studies contained a degree of variability in relation to the focus of the intervention being offered, the intensity of service provision, the characteristics of the infants and parents included and the length of follow-up. The meta-analysis demonstrated that interventions improved outcomes in infancy and for preschool-aged children, though not for school-aged children. Motor outcomes were also noted to improve in 12 of the studies, indicating a positive response to early developmental interventions during infancy.

These findings were reflected in the systematic review conducted by **Orton et al (2009)** which also aimed to assess the efficacy of early intervention programmes in relation to cognitive and motor development. The review identified 18 studies that met the inclusion criteria, but only 11 papers were suitable for inclusion in the meta-analysis.

Studies that focused on cognitive outcome in infancy showed that the provision of early developmental intervention resulted in an increased developmental quotient on cognitive testing when compared with those infants who were receiving standard neonatal follow-up. At preschool age, this improved outcome (as measured by average IQ) was maintained for infants receiving early intervention. By school age, no differences in cognitive outcome were noted.

### **Evidence overview**

The evidence supporting the positive impact of the provision of early intervention to promote cognitive development through to preschool age in high-risk infants is strong. For those infants with identified developmental concerns, early intervention programmes that begin following the infant's discharge from hospital have been shown to benefit cognitive development/learning. The impact of these interventions in infancy and early childhood is a key finding supporting the proactive provision of early intervention services, rather than delaying until children present with difficulties at preschool or school age. The evidence for this recommendation is drawn from two high-quality systematic reviews (one of which has undergone updating/review).

No specific risks were reported in any of the studies for the infants receiving early developmental interventions.

### **5.10.3 Recommendation 27: Supporting parent experience of anxiety**

**Spencer-Smith et al (2012)** conducted a randomised controlled trial which aimed to determine the longer-term effectiveness of the VIBeS Plus programme by reviewing caregivers and children at preschool age. VIBeS Plus is a home-based preventative care programme which aims to educate primary caregivers about evidence-based interventions for improving infant self-regulation, postural stability, co-ordination and strength, parent mental health and the parent–infant relationship. The programme is provided for infants born <30 weeks gestation as a series of nine home visits of 1.5–2 hours in length over the first 12 months of life following discharge from the neonatal unit. The study was conducted in Australia and included 120 children. The follow-up review was conducted when the children were four years corrected age.

The findings of the study showed little difference in cognitive and motor outcomes for children receiving the VIBeS Plus intervention compared to those receiving standard follow-up services. However, key differences were noted for parents who had participated in the VIBeS Plus programme in relation to reporting fewer anxiety symptoms, and fewer were likely to be at risk for an anxiety disorder. This finding is particularly important given the high rates of parental distress after a preterm birth.

### **Evidence overview**

There is strong evidence that the delivery of targeted early intervention offered in a preventative/health promotion model for high-risk infants can have positive impacts on parent mental health. In acknowledging the ongoing stress and anxiety that parents can experience following the birth of a high-risk infant who is either at increased risk for, or displaying, emerging developmental concerns, it is important that early intervention services are structured in a way that supports the promotion of parent mental health in addition to, and in support of, optimising infant development. The evidence for this recommendation is drawn from one high-level randomised controlled trial.

## **5.10.4 Recommendation 28: Promoting motor skills for participation in childhood occupations**

**Lekskulchai and Cole (2001)** conducted a randomised controlled trial which aimed to examine the motor performance of infants born preterm following the provision of a programme designed to facilitate motor development. The study, conducted in Thailand, included 84 infants. The intervention was provided as a follow-up developmental physiotherapy programme; a set of developmental activities was provided to families each month from term equivalent to three months corrected age, with support for the parents in learning how to provide appropriate facilitation for their infants. The motor-based interventions incorporated in the programme focused on functional movement skills, e.g. weight bearing in prone, development of supported sitting, bringing hands together in midline and to mouth, and the promotion of reach (for exploration of toys etc.).

The results from the study indicated that infants who were receiving the home-based intervention showed significantly greater improvement in the acquisition of their functional motor skills than infants in the comparison group. By four months corrected age, infants who had received the intervention were demonstrating the performance of motor skills which were comparable with those infants in the comparison group who had been identified as at minimal risk for motor delay.

### **Evidence overview**

There is good evidence that the provision of early intervention programmes for high-risk infants in the first months following discharge from the neonatal unit can promote positive outcomes in the acquisition of functional motor skills.

No specific risks were reported in the study for the infants receiving early motor developmental interventions. The evidence for this recommendation is drawn from one high-quality randomised controlled trial.

The development of functional motor skills is a key component of occupational therapy practice, as motor and postural control provides a base for the ongoing development of refined motor control required to promote successful engagement in play, and early activities of daily living.

### 5.10.5 Recommendation 29: Incorporating occupation-based routines into practice

**Hwang et al (2013)** carried out a randomised controlled trial that aimed to compare traditional home visiting with a routines-based early intervention (RBEI) model with children at risk of, or with, developmental delay. The study was conducted in Taiwan and included 38 children up to three years of age. RBEI is an approach that focuses on the provision of a coaching model for parents to support their child's participation in self-care and family routines, rather than traditional developmental domains.

When measured by the performance of relevant ADL skills (by the Paediatric Evaluation of Disability Inventory), children and families who were receiving the RBEI model demonstrated faster progress in developing independence in self-care and social functions, at both the conclusion of three months of intervention and at six-month follow-up. Evaluation of the use of collaborative goal setting between parents and providers also demonstrated faster attainment of family goals for the children and families receiving RBEI than those receiving standard care. While both RBEI and traditional home-visiting early intervention models supported the children's developmental progress, the RBEI was more effective in promoting functional outcomes and reaching family-centred goals.

#### Evidence overview

There is moderate-quality evidence that the provision of an early intervention model that focuses on the child's participation in family routines and activities shows improved attainment of functional skills for children at risk of, or with, developmental delay when compared with a traditional early intervention home-visiting model. While both RBEI and traditional home-visiting early intervention models supported the children's developmental progress, the RBEI was more effective in promoting functional outcomes and reaching family-centred goals.

The focus of integrating intervention approaches into everyday tasks and routines is a key theory underpinning occupational therapy practice across all domains, and provides good evidence of the benefits of incorporating a family-centred, occupation-based approach when working with young children and their families.

### 5.10.6 Recommendation 30: Identification of at-risk infants for early intervention

**Hintz et al (2008)** conducted a retrospective analysis of a cohort of extremely preterm infants in the United States, who were routinely followed up as part of the National Institute of Child Health and Human Development (NICHD) Neonatal Research Network. The review was conducted when the children were 18–22 months corrected age, and aimed to determine the special outpatient service (SOS) use, need, associated factors, and the neurodevelopmental and functional outcomes for infants born extremely preterm. The analysis included data from 2,315 children and families. Specialist outpatient services referred to a community nurse, occupational therapy, physiotherapy, speech and language therapy, early intervention, social work, medical specialist support, and neurodevelopmental and behavioural services.

The study indicated that 54.7 per cent of extremely preterm infants had or were using three or more specialist outpatient services by 18–22 months, with 19 per cent accessing more than six specialist services. The most common risk factors associated with

increased use of SOS were sepsis, birth weight, postnatal corticosteroid use, chronic lung disease, periventricular leukomalacia (PVL) or intraventricular haemorrhage (IVH) (grade III or IV). Male infants were also identified as more commonly requiring support from SOS.

### **Evidence overview**

The evidence for the identification of high-risk infants who ultimately require provision of specialist outpatient services is low. However, the study involves a large, comprehensive cohort of extremely preterm infants. This study indicates that the prevalence of the need for access to specialist outpatient services for this group of infants is high. Infants who are considered high risk as a result of prematurity or other health factors may experience ongoing developmental concerns that can impact on their participation in infant and child occupations. It is therefore recommended that infants born with specific medical issues such as sepsis, ELBW, BPD chronic lung disease, PVL or IVH (grade III–IV) are routinely referred for specialist outpatient services, including occupational therapy.

## **5.10.7 Recommendation 31: Parent–therapist partnerships**

**Ideishi et al's (2010)** qualitative study aimed to explore the perspectives of parents and therapists of the role of a therapist in co-ordinating care between early intervention and medical services. This study was conducted in the United States and included 50 participants (16 parents and 34 healthcare providers).

This study provided some illumination as to how these collaborations are orchestrated between parents and providers. Parents identified that therapists often assisted by interpreting medical information into useful and understandable terms for them. They also acknowledged that, as parents, they often needed to provide a bridge between providers involved in their child's care who seemed to have little time to communicate with other providers. The different approaches used by different providers often caused confusion for parents, as did situations when conflicting views and recommendations were offered by people involved in their child's care. Therapists in community-based services emphasised the need to provide support for a family's social and emotional needs, more so than hospital-based therapists. Therapists also identified that they often lack knowledge about the role/scope of other providers that might be involved in the care of a child.

### **Evidence overview**

The quality of the evidence for the impact of collaborative parent–therapist partnerships is low. This study identifies the likelihood that high-risk infants with emerging developmental concerns may be referred to a range of early intervention providers, with potential for inconsistency between service models and approaches. This leaves parents needing to navigate and advocate for services that comprehensively support their child's and family's ongoing developmental needs. Therefore, it is recommended that therapists working in early intervention services should acknowledge the role that parents play in managing their contacts with multiple service providers, ensuring clear communication across agencies and supporting the child and family as a whole.

## 5.11 Potential impact of the recommendations

The potential impact of the recommendations has been considered across a range of domains.

### 5.11.1 Desired outcomes

The development of this guideline has produced a robust evidence-based resource that provides recommendations for occupational therapy assessment and intervention with the aim of improving services for high-risk infants and their families. It is the opinion of the guideline development group that these recommendations may contribute to the following outcomes:

- Each high-risk infant and their family have the opportunity to be referred to/receive specialist occupational therapy services within each neonatal network.
- High-risk infants and their families who receive specialist occupational therapy services perceive benefit from occupational therapy input.
- High-risk infants (and their parents) experience individualised, adequate and consistent pain management throughout the neonatal admission.
- High-risk infants (and their families) benefit from smoother transitions between hospital and community neonatal services, which ensure continuity of support for families and enables more effective service delivery.

The recommendations contained within the guideline provide sound evidence and a base from which occupational therapy and neonatal services can work collaboratively with commissioners to support the commissioning of neonatal services that include occupational therapy as part of multidisciplinary teams within neonatal networks, with the aim of ensuring that high-risk infants and their families have access to comprehensive MDT services which support consistent provision of developmentally supportive care for infants and sensitive parent support.

The potential value added by the integration of occupational therapy services into a neonatal MDT and neonatal network is easily articulated, resulting in improved understanding of, and support for, the contributions of occupational therapy services to neonatal care.

The recommendations contained within the guideline support occupational therapists working with (or aspiring to work with) high-risk infants and their families to identify and pursue appropriate knowledge and training to ensure safe and effective service delivery.

They support the development of increased availability and comprehensive occupational therapy services for high-risk infants in the first two years of life to maximise developmental gains, participation in childhood occupations and the provision of guidance for parents.

Increased access to occupational therapy services may result in cost savings across both the health and education sectors as a direct result of decreased hospital admission for infants, reduced need for ongoing medical appointments, decreased incidence of developmental/educational concerns due to earlier identification and support, and decreased incidence of mental health concerns for both parents and high-risk infants through early childhood.



The identified recommendations support the articulation of the scope of a specialist occupational therapy service, which enables projections to be made for service needs.

The guideline is used to support the development of subsequent tools and resources that will further enhance the provision of occupational therapy, such as the development of complementary competency standards, education initiatives to support occupational therapy training etc.

### **5.11.2 Risk management**

#### **5.11.2.1 Sensitive and appropriate assessment**

The evidence review did not indicate specific assessment tools to include in the recommendation. It is appreciated that there is a range of specific and sensitive assessments for the neonatal population which occupational therapists may utilise. However, in all instances, the choice of assessment should consider each specific infant's vulnerabilities, including gestational age and medical co-morbidities, to ensure that at no time is the infant placed under additional stress. For fragile infants, detailed, structured neurobehavioural observations provide rich information on the infant's strengths and vulnerabilities, and support the identification of parent and caregiver strategies to include in a developmental care approach. The selection of specific assessment tools will be both informed by an individual practitioner's clinical judgement and influenced by practical elements such as availability and training/certification competencies. Many neonatal neurobehavioural assessments require specialist training and certification, and occupational therapists working in neonatal units must not utilise these assessment tools unless they have been appropriately trained.

#### **5.11.2.2 Sensitive handling**

Equally, high-risk infants may present with a range of vulnerabilities in which their health status can be significantly compromised via inappropriate and insensitive handling. When working with these infants, occupational therapists must have developed competence in handling skills appropriate to this population. All infant handling should be constantly monitored, based on the infant's neurobehavioural cues, to ensure that the pacing and timing of interventions remain supportive at all times.

#### **5.11.2.3 Knowledge and skills across all occupational performance domains**

The knowledge and skills required to practise in the neonatal unit are not core elements of standard occupational therapy training pathways. Therefore, occupational therapists providing services into neonatal units must undertake specialist knowledge and skill development to support their practice, and manage potential risk to vulnerable infants and parents. Specialist training pathways may include continuing education and mentoring. The AOTA position paper (Vergara et al 2006) on the knowledge and skills required by occupational therapists working in this setting provides a robust outline of the attributes required by occupational therapists working in the neonatal unit. Equally, the recommendations outlined in this document may be used for individual therapists to consider their own knowledge and skills in the provision of safe and effective interventions incorporating developmental care, positioning, pain management, feeding, psychosocial support of parents and early intervention. Occupational therapists working in neonatal settings should not provide intervention elements in which they have not developed appropriate competencies.

#### **5.11.2.4 Occupational therapy expertise**

On the basis of the specialist knowledge and practice skills required by occupational therapists working in the neonatal setting, we would suggest that these roles are commensurate with experienced/senior therapists. In line with the BAPM (2010)



recommendations, occupational therapy positions in neonatal services should be banded at a minimum Band 7 level. Indeed, in many instances/units it may be appropriate for these roles to be considered at a clinical specialist level (Band 7/8). We also recommend that therapists beginning practice in the neonatal setting have existing robust experience in children's occupational therapy services, with refined occupation-based assessment and intervention skills with infants, and recognise the importance of working within a family-centred care approach. This would form a practical basis from which to extend knowledge and skills development into the specialist area of the neonatal unit.

#### **5.11.2.5 Training availability**

It is acknowledged that developing specialist skills and knowledge in neonatal occupational therapy can be difficult in the United Kingdom due to the paucity of defined and funded roles in neonatal units and limited access to experienced occupational therapists for shadowing and mentoring opportunities. However, recent developments in neonatal occupational therapy and developmentally supportive care approaches have made basic and intermediate-level training far more accessible. Knowledge and skill development can be accessed through a variety of education modes, including face-to-face training, online training modules and lectures, and clinical supervision. Occupational therapists considering developing practice skills in the neonatal setting should avail themselves of these training opportunities. Additionally, specialist certifications in areas of neonatal assessment and practice are available from a range of national and international providers; these certifications may be pursued by individual therapists to continue to refine and enhance their therapy service provision. There remain some limitations to training availability at the competent to expert practitioner level, with some specialist training programmes being unavailable in the United Kingdom.

#### **5.11.2.6 Collaborative team working**

While this document provides recommendations for occupational therapy practice, it is recognised that some areas of practice outlined will overlap with a range of other professionals working in the neonatal setting. In all instances, occupational therapists should work collaboratively within the MDT to ensure the delivery of a comprehensive and consistent approach to service delivery for infants and their parents throughout admission and with other agencies following discharge.

#### **5.11.2.7 Financial risk**

It is recognised that some neonatal networks will not currently have access to, or funding for, occupational therapy services. The provision of occupational therapy services within the scope outlined in this document may not be achievable with current financial resources. The cost-benefit of enhancing neonatal services to incorporate occupational therapy provision as part of the multidisciplinary team is a decision for local networks. Neonatal networks and/or units wishing to establish or enhance current levels of occupational therapy service provision may find the guideline document and recommendations of use when working with specialist commissioners and building business cases for service development.

Additionally, employing occupational therapists who are without prior experience in neonatology to work in neonatal units will require financial investment in skills and knowledge training to ensure relevant practice competencies.

### **5.11.3 Generalisability**

Due to the broad scope of the guideline objective, the studies included in the evidence review were heterogeneous, with variations in sample populations, in the type, amount and frequency of specific interventions, and in the availability of occupational therapy services within the service model.

Geographical variations in the core domains of occupational therapy practice in neonatal settings have been taken into account in the development of the recommendations, to ensure that findings are pertinent to the UK context. Additionally, variation in intervention approaches and evidence outcomes have been reviewed in detail when judging the generalisability to the UK population. Despite the core evidence being drawn from diverse contexts, all of the infants within the individual studies were comparable with the guideline scope.

### **5.11.4 Social determinants of health**

The reality of having a high-risk infant and the potential requirement for ongoing access to early intervention services can be influenced by a range of existing and emerging issues for families. Issues to be considered within the implementation of the guideline include:

- The increasing awareness of the relevance of epigenetics and the impact of the infant's early experiences on long-term disease processes, as a driver for the importance of ensuring that all high-risk infants receive individualised, family-centred, developmentally supportive care.
- Supporting parents in understanding the crucial importance of their relationship with their infant's well-being and development in both the short and long term (UNICEF United Kingdom 2016), to underpin approaches that enable parent engagement.
- Reducing the late presentation of children with occupational performance concerns at school age.
- Ensuring service provision is both family centred and culturally sensitive to support parent engagement of all families of high-risk infants.
- Supporting positive parent engagement in service provision as a means of building empowerment – leading to increased confidence in the longer term in relation to advocating for services/support for their growing children.
- Supporting positive parent–infant engagement and occupational participation for parents who may be experiencing mental/emotional distress, stress, depression or anxiety as a result of the birth of their preterm infant/s.
- Providing appropriate support for families who may have experienced prenatal mental health conditions.
- Recognising the financial burden of having an infant who requires intensive care services.
- Supporting the recognition of geographical inequalities in relation to the type/frequency of occupational therapy services available in neonatal units and affiliated services.

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# 6 Parent perspectives

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The target audience of the full guideline document is primarily occupational therapists working in neonatal and affiliated services, including paediatric settings. While of potential interest to parents, the guideline development group acknowledged that it was not written specifically for a lay audience.

Parent perspectives are integral to the guideline development process and involvement took place through consultation on the draft scope and draft guideline (see section 9.3).

Parents were also engaged in the drafting of the guideline recommendations. Parent engagement was sought in two ways:

- Through an invitation disseminated on the Bliss Facebook page advising parents of the guideline project and seeking their feedback on the draft recommendations.
- Through direct invitation to current and previous parents affiliated with neonatal services represented by the guideline group membership.

Mechanisms for providing input into the development of the draft recommendations were also enabled in two ways:

- Two parent engagement events were conducted in November 2016, where the draft recommendations were discussed with parents. Discussion about the recommendations was facilitated by a guideline group member. Key comments from parents were minuted. Parent input was also sought in shaping the wording of the recommendations. Summary written comments from the parents were collected using a pro forma template. These events were held in Leeds and London, with one parent contributing in Leeds and five in London.
- A direct phone/email link was provided to one of the members of the guideline group for interested parents to contact and provide feedback on the draft recommendations. Ultimately no parents provided feedback in this way.

Parent feedback was specifically sought in the following areas:

***Q1: Do you think the recommendations are easy to understand? Are there any changes you would suggest?***

Most parent respondents reported that the recommendations were fairly easy to understand, but recognised that some of the terminology was more complex and may require more detailed explanation. Some parents also reported that the use of occupation-centric language was unfamiliar to them, and so suggested simplifying some of the recommendations accordingly. These recommendations were reviewed, and amendments made accordingly.

***Q2: Do you think the recommendations reflect your experiences of being involved with neonatal occupational therapy services?***

There was variability in the response of parents which closely reflected the degree to which they had been involved with occupational therapy services while their infant was admitted to a neonatal unit. Three parents who had received ongoing support by

occupational therapy during their neonatal unit admission concurred that the recommendations were reflective of their experiences of occupational therapy. Another response recognised that there is some overlap in the recommendations with services provided by other members of the MDT, and that, in their situation, some domains were supported by other professionals. Finally, one parent shared that while the recommendations did not reflect her and her infant's specific experience, they served to outline what is best practice.

*"Not all are relevant. . . feeding was discussed by the midwife on the ward"*

*"Unfortunately not – but best practice is what each unit should aspire for"*

**Q3: Do you think the practice recommendations would be of benefit to you and your child (now or in the past), even if this level of service wasn't available to you at the time?**

Parents generally reported that the recommendations would be/were of benefit, though recognised that in each of their individual situations, some would be more relevant than others. One parent identified the scope of the guideline ending at two years of age, commenting that understanding what happened beyond this point in terms of service transition would be advantageous.

*"Absolutely!"*

*"Yes, a lot of the recommendations would have been helpful"*

**Q4: Are there any areas of practice that you feel are missing from the recommendations?**

Based on their experiences, there were no areas of practice identified by parents that were not covered in the recommendations. One parent did share the value in occupational therapists providing information/support in both verbal and written forms, due to the high information processing demands parents are faced with when their infant is receiving care in a neonatal unit.

*"The availability of written information/guidance to support (verbal) information. . .when dealing with a difficult time on the ward, it is sometimes difficult to take in any information"*

**Q5: In your experience, what do you think is the most important support that neonatal occupational therapists could/did provide to you and your baby?**

Parents provided a variety of responses about what they considered to be the most important support provided by an occupational therapist. This highlights the individuality of all families with which occupational therapists work, and the importance of practising within a family-centred care model, that is, one that works with families to identify their specific strengths and support needs. Parents identified important areas of support as education on developmental milestones specific to preterm infants, learning to read infant cues, to increase parent confidence, and support with positioning, feeding and motor development. Access to occupational therapy services during a neonatal unit admission was also highlighted by one parent.

*"Reassurance – some support that our daughter was progressing well. It was positive that the OTs look at the 'person' not a scan; as a parent this is what you want to hear"*

*"Helping us to feel confident about babies' needs and developmental care"*

*"Just having easy access to an OT"*

The parent feedback was then considered collectively in refining the final recommendations. The responses provided invaluable insights and comments and led to amendments, and the inclusion of specific quotes, within this final guideline.

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# 7 Implementation of the guideline

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This practice guideline aims to support occupational therapists to provide specific recommendations to support the use of an occupation-focused approach in neonatal and early intervention settings.

Familiarity with the guideline document will be an important first step for both individual practitioners and their managers. It is, therefore, imperative that occupational therapists and managers working in this clinical area take responsibility to review the guideline recommendations within the context of their practice.

Bringing the guideline to the attention of colleagues within the multidisciplinary team and service commissioners should also be a priority.

A further action to facilitate implementation must be for lead therapists to consider the 'levers' and 'barriers' within their local organisation and culture that may have an impact on any changes that may be necessary to practice. Section 7.2 identifies some potential barriers that may be applicable, while section 7.3 provides details of resources to facilitate implementation.

## 7.1 Dissemination and promotion

Awareness and implementation of this practice guideline are important if it is to influence and have an impact on occupational therapy practice.

Following publication, the full practice guideline has been made available to download freely from the Royal College of Occupational Therapists' website.

The guideline has been promoted to its key target audience of occupational therapists and to relevant others using professional networks and publications, the internet and social media channels.

## 7.2 Organisational and financial barriers

The recommendations stated within this guideline document are intended to help occupational therapists to deliver occupation-focused practice. It is recognised, however, that there will be potential barriers, both organisational and financial, which may influence application of the recommendations. It is important that occupational therapists take these into account when implementing this guideline. The most likely barriers, described below, were identified via consensus agreement of the clinical experts in the guideline development group.

The availability of occupational therapy services in neonatal units across the United Kingdom is inconsistent. While this guideline will help build awareness of the potential contribution of occupational therapy to the neonatal MDT, it is recognised that this will be accompanied by some workforce and funding pressures. First, while there may be a recognised need for occupational therapists, limited resources may mean the funds are not available to create new posts in units that do not currently employ occupational therapists. In these circumstances, it is suggested that neonatal units liaise with their

local acute or community paediatric occupational therapy service to consider service development opportunities. This may involve the development of a joint business case to present to specialist commissioners for funding to either establish new or enhance existing funding for occupational therapy services for high-risk infants and their families in the neonatal unit and follow-up services. As neonatology is an area of specialised practice, this guideline highlights the need for appointing senior-level therapists in this setting. This is an additional cost factor that needs to be considered in planning funding for service development.

It is also recognised that there is currently a small pool of occupational therapists with experience of working within neonatal services across the United Kingdom. Therefore, workforce development plans will need to consider how to ensure appropriate skills and knowledge for occupational therapists. There are a number of elements to be considered:

- Occupational therapists newly appointed to neonatal services should have significant existing experience in the paediatric setting.
- A specific mentoring/supervision plan (alongside a specialist training plan) should be implemented to facilitate occupational therapists' specific development regarding NICU services. This could be conducted as a hybrid model with a local neonatal practitioner (e.g. practice development nurse, allied health professional), with an external occupational therapist mentoring arrangement. The practicalities and costs of supporting these arrangements would need to be considered. The identified future development of competency standards for occupational therapists working in neonatal care would form an ideal adjunct for therapists commencing work in this area to help shape the training and supervision approach.
- Access to specialist training will need to be enabled. While a range of early to mid-career training regarding neonatal skills and knowledge is available in the United Kingdom for occupational therapists to access, there are costs involved in participating in these training programmes. Other mechanisms by which to access specialist training from an international platform (e.g. online webinar training from high-quality providers) can prove a pragmatic and more affordable means of ensuring access to specialist learning. At the highly experienced/specialist end of the career spectrum it should be recognised that some training programmes are of very high cost, and some are only available internationally.
- The use of some specific assessment and clinical tools requires specialist training and certification before they are able to be used by occupational therapists in neonatal services (e.g. Neonatal Behavioural Assessment Scale, General Movements Assessment, Assessment of Preterm Infant Behaviour, Bayley Scales of Infant Development etc), and will therefore have financial costs and implications before being introduced into practice.

In the consultation process, awareness was raised about the potential difficulties that may arise from an individual therapist's or an organisation's ability to implement the recommendations in a particular setting. The guideline development group recognises that the recommendations included in these guidelines will not necessarily be able to be implemented in a standard way across every setting. This is primarily due to access to, and funding for, occupational therapy services. It should be noted that the recommendations in the guideline overlap with key service delivery areas of a range of other professionals in the neonatal unit. Therefore, it is anticipated that the implementation of the recommendations will be planned and delivered in a local,

specific context, based on service need, funding resources and the overall contributions of the neonatal MDT.

Occupational therapy in neonatal services will require ongoing linking via networks of practitioners. Occupational therapists should ensure involvement in the activities of their local neonatal network to continue to build awareness of the occupational therapy contribution to neonatal care delivery. To prevent isolation, ensure currency of knowledge and awareness of ongoing developments, occupational therapists should also ensure they access a relevant professional forum. Within the United Kingdom, the Neonatal Occupational Therapy Forum (as part of the Child, Young People and Families Specialist Section) provides a collegiate link with other therapists and is a place to share resources and ideas. Additionally, other professional networks (such as those run by Bliss, or the National Association of Neonatal Therapists) may also be useful in ensuring access to support and information.

## 7.3 Implementation resources

Three core implementation resources are available to support this practice guideline.

### 7.3.1. Quick reference guide

The quick reference guide lists the recommendations and indicates their strength and the quality of the evidence leading to their development.

This is intended to be used by practitioners as an easily accessible reminder of the recommendations for intervention. It should ideally be used once the practitioner has read the full guideline document, to ensure an appreciation of the context and development of the recommendations.

The quick reference guide includes the following:

- Introduction.
- List of the recommendations, their strength, and the quality of the evidence leading to their development.
- Evidence overview.
- Outline of context and occupational therapy role.

### 7.3.2 Audit form

It is recommended that occupational therapists use the Royal College of Occupational Therapists' audit tool that supports this guideline.

The audit form for this guideline provides a template for individual occupational therapists or services to audit and review their current interventions against the recommendations. The aim is to encourage reflection on current practice and to consider, where this does not follow the recommendations, the clinical reasoning in place to support decisions.

A baseline assessment conducted using the audit tool can be repeated to enable review of progress on actions identified from the audit. It can be useful to undertake a routine audit every one or two years to monitor ongoing compliance.



The audit form, while initially providing a tool for use within an individual/service context, offers the potential for future benchmarking and wider comparative analysis.

Recommendations, for which there is a transdisciplinary component, may be usefully audited jointly with other members of the multidisciplinary team. Likewise, the occupational therapist may be involved in audits related to other frameworks, such as the Bliss Baby Charter Standards and audit tool (Bliss 2015).

### 7.3.3 Continuing professional development/knowledge transfer resource

The continuing professional development resource is interactive and can be tailored for local use. The session can be used for group or self-directed learning, or for raising awareness of the guideline at multidisciplinary meetings, study days or events.

A feedback form is also available to provide comment on the guideline and implementation resources to the Royal College of Occupational Therapists.

### 7.3.4 Other associated resources

Additional resources available include:

- Occupational therapy evidence fact sheet.
- Implementation tips.

#### Accessing the implementation resources

The quick reference guide, audit form and continuing professional development session resources are available as separate documents.

These can be downloaded, together with the full guideline document, from the publications section (Practice guidelines) of the Royal College of Occupational Therapists' website: <https://www.rcot.co.uk/practice-resources/rcot-practice-guidelines>

### 7.3.5 Implementation in practice and future developments

The development of this guideline serves to bring together the large body of evidence that contributes to occupational therapy practice with high-risk infants in the neonatal unit and early intervention settings. It is beyond the scope of this guideline to specify models for occupational therapy services, or provide discrete recommendations for specific assessment tools and intervention strategies.

To support the consideration of how neonatal occupational therapy services can be delivered, some examples have been provided within Appendix 4. Two key elements are provided:

- A framework for the identification and prioritisation of infants to be referred to occupational therapy services based on biomedical and psychological factors. This tool has been adapted to reflect the content of the guideline recommendations and provides a process by which services can be prioritised, with suggested occupational therapy approaches.
- Five examples of occupational therapy services in neonatal settings, including details on staffing, referral criteria, funding, and assessment and intervention approaches

utilised in practice. These examples aim to give a sense of the variety with which occupational therapy services may be implemented within neonatal networks.

It was recognised by the guideline development group that this resource is the first stage in a series of potential developments that will add increasing specificity to the provision of occupational therapy services in neonatal settings in the United Kingdom. Potential resources that have been proposed for development include:

- A summarised version of the guideline that is written with and for parents of high-risk infants.
- A clinical handbook for neonatal occupational therapy practice which provides specific recommendations on assessment and intervention approaches for use in the United Kingdom.
- Knowledge and skills framework for occupational therapy practice.
- Exemplar job descriptions for occupational therapy positions in neonatal services.
- Exemplar business case templates for the establishment of occupational therapy positions in neonatal services.
- Recommendations for continuing education requirements within the field, incorporating a range of training modes (e.g. continuing education programmes, mentoring etc.)

The Royal College of Occupational Therapists Specialist Section – Children, Young People and Families Specialist Section (Neonatal Forum) will be responsible for the implementation of ongoing work streams to develop future resources.

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# 8 Recommendations for future research

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The review of the evidence within the guideline scope identified a small body of occupational therapy primary research and a larger body of occupational therapy relevant research, confirming a need for further research which explores and evaluates the added value of neonatal occupational therapy services for high-risk infants and their families.

Future research topics identified from the evidence and from the expertise of the guideline development group include:

- **Economic evaluation.** Economic evaluations and health economic data are needed to establish the cost-effectiveness of neonatal occupational therapy early intervention, provided for high-risk infants and their family, in reducing later expenditure on health, education and social care support services. This includes the impact that an improved continuity of care from occupational therapy services from within the neonatal unit to home has, and the subsequent impact on service utilisation.
- **Outcomes and effectiveness.** Studies to determine the effectiveness of the implementation of neonatal occupational therapy as a component of a complex intervention supporting high-risk infants and their families, taking into account factors such as:
  - The association between referral for neonatal occupational therapy early intervention and child outcomes at preschool, school age and beyond.
  - Identification of the most effective tools and/or approach for occupation-based assessment with high-risk infants and families.
  - The outcomes for interventions that specifically guide and support parents in sensitive and contingent occupational engagement with their high-risk infants, in terms of infant development and parent self-efficacy.
  - Evaluation of the sensitivity of neonatal caregivers in individualised infant care following education and training delivered by occupational therapists.
- **Parent perspectives.** Studies which explore parent's experiences, including:
  - Perceived health/developmental benefits of neonatal occupational therapy for high-risk infants of parents and neonatal staff.
  - Parents' perceptions of the psychological impact of participating in an occupation-centred occupational therapy service during their infant's admission to a neonatal unit.
  - Parents' perceptions of the attainment of parenting occupations in relation to participation in caregiving occupations, and empowering parents to facilitate inclusion in family-centred care (e.g. participation in developmental care rounds).

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# 9 Guideline development process

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Detailed information on the following steps in the guideline development process can be found in the *Practice guideline development manual* 3rd edition (COT 2017a).

## 9.1 Guideline development group

The membership of the core guideline development group comprised 11 occupational therapists with expertise in the neonatal field, a representative from Bliss and a representative from the Royal College of Paediatrics and Child Health (Appendix 5).

The occupational therapy core group members were all practising therapists, educators or researchers. All group members undertook guideline development work in their own time, with some support from employers (for example to attend meetings).

Three individuals who were involved in neonatal research and practice were co-opted as additional appraisers.

All comments received from stakeholders, parents and end users on the draft scope and draft guideline document were reviewed by the guideline development group. Where appropriate, revisions were incorporated into the scope form or guideline document prior to submission, for approval, to the College's Practice Publications Group. Conflict of interest declarations were noted and reviewed for any necessary action.

In the interests of openness and transparency, details of the comments submitted as part of the consultation activities are available on request from the Royal College of Occupational Therapists.

## 9.2 Stakeholder involvement

Stakeholders expected to have an interest in the guideline topic were identified by the core group membership at the preliminary guideline meeting. Specific attention was paid to identifying professional bodies that represent those working with infants and their parents, and national charitable or voluntary organisations that may represent service users.

### 9.2.1 Scope consultation with stakeholders

A core group of stakeholders were approached to comment on an initial draft of the scope, which was provided in the form of a Stakeholder Information Document (together with a comments pro forma and conflict of interest declaration form).

The following stakeholders were invited to comment on the scope document:

- Professional bodies: Royal College of Paediatrics and Child Health; Royal College of General Practitioners; Association of Paediatric Chartered Physiotherapists; Royal College of Speech and Language Therapists (Neonatal Special Interest Group);

Neonatal Nurses Association; British Association of Perinatal Medicine; British Association of Social Workers.

- Training Centres: Brazelton Centre UK; NIDCAP Centre UK.
- Charities: Bliss, National Autistic Society, SENSE, SCOPE, Best Beginnings.

Comments received were reviewed by the guideline development group and, where these could be endorsed, the scope was amended accordingly.

### **9.2.2 Draft guideline consultation with stakeholders**

The draft guideline was sent to each of the stakeholders who had been contacted as part of the scope consultation (section 9.2.1) for their review and comment.

Feedback from additional stakeholders was also invited:

- Neonatal networks
- British Psychological Society
- Royal College of Nursing
- Royal College of Midwives
- Council of Occupational Therapists Educational Directors.

The guideline document and consultation form were placed in the public domain, for the one-month consultation period, on the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families webpage and the College’s practice guideline webpage (12/12/16–13/01/17).

All comments were discussed at a meeting of the guideline development group and taken into account during the revision of the final guideline.

## **9.3 Service user involvement**

### **9.3.1 Scope consultation with parents**

Two parents identified by guideline development group members were approached to provide comments on the scope. Comments received were reviewed by the guideline development group and, where these could be endorsed, the scope was amended accordingly.

### **9.3.2 Draft guideline consultation with parents**

Service user/lay-person consultation activities were undertaken to obtain views on the guideline recommendations and document. Parents were contacted through Bliss’ network and the guideline group’s own networks. One discussion group took place in early November in London, while a second was offered in Leeds (though feedback was ultimately given on paper due to parent unavailability). Additionally, parents who were unable to attend a discussion group were able to express their views via a semi-structured telephone interview.

To facilitate the discussion groups, the draft recommendations were provided prior to the discussion/interviews. This included a rationale for the guideline, the recommendations and an overview of the evidence. It also identified areas where parental feedback would be particularly valuable.

The guideline development group recognised that the parents engaging in the consultation process would not necessarily be representative of all individuals with experience of neonatal occupational therapy services. However, overall the value of feedback provided by parents exceeded any concerns about representativeness.

All comments were duly considered for inclusion within the final guideline.

## 9.4 End-user consultation

The primary target group of end users of the guideline are occupational therapists and, specifically, those working in neonatal and early intervention services. Ongoing awareness of the progress of the guideline development project was communicated to the members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families via their e-newsletter.

### 9.4.1 Scope consultation with end users

Members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families were invited to participate in the scope consultation by the Specialist Section Chair via the membership email. Members of the Council of Occupational Therapy Education Directors and the Royal College of Occupational Therapists Neonatal Clinical Forum were also asked to participate. A copy of the scope documentation was provided with a request for feedback and comment.

Comments received were reviewed by the guideline development group and, where these could be endorsed, the scope was amended accordingly.

### 9.4.2 Draft guideline consultation with end users

A one-month consultation period enabled members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families to comment on a draft of the full guideline.

The consultation was additionally open to any member of the British Association of Occupational Therapists and was promoted via the monthly professional magazine, *OTnews*. The draft guideline and a consultation feedback and conflicts of interest form were made available to members (and the public) via the College's website.

All comments were duly considered for inclusion within the final guideline.

## 9.5 External peer review

Two independent peer reviewers were invited by the guideline development group to critically appraise a draft of the full guideline. Reviewers were selected for their known clinical and research expertise in the field, and/or their guideline development experience or knowledge. The external peer reviewer form asked for comment on both the presentation and content of the draft guideline, taking into account factors such as its purpose, robustness and unbiased nature. The detailed views and expert opinions received were discussed by the guideline development group and used to inform the content of the final guideline.

## 9.6 Conflicts of interest

All guideline development group members (core group and co-opted), stakeholders, end users and external peer reviewers were required to declare any pecuniary or non-pecuniary conflicts of interest, in line with the guideline development procedures (COT 2017a).

Parents were also asked to verbally declare any particular conflicts of interest.

The nature of the potential or actual conflicts made in the declarations (Appendix 6) was not determined as being a risk to the transparency or impartiality of the guideline development.

## 9.7 Declaration of funding for the guideline development

This practice guideline was developed by a group led by a Specialist Section of the Royal College of Occupational Therapists. Specialist Sections are official branches of the College with specialist interests which, through their membership, are able to engage expert practitioners, educators and researchers in the development of guidelines, and access the required clinical and research expertise.

As a membership organisation, the major source of funding for the Royal College of Occupational Therapists and its Specialist Sections is the membership. Other sources of income are primarily from advertising and events.

The development and publication of this practice guideline were funded by the Royal College of Occupational Therapists and the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families. The Royal College of Occupational Therapists provided specific resources to cover the meeting venue, travel expenses, literature search, and editorial and publication support. A small ring-fenced allocation was made by the National Executive Committee of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families to fund any other costs associated with the development and promotion of the practice guideline.

There were no external sources of funding.

The project lead, who chaired meetings, was a member of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families, but was not a National Executive Committee member so had no direct decision-making relationship with the allocated funding for the project.

The editorial leads for the guideline were the project lead and an officer at the Royal College of Occupational Therapists, who attended guideline meetings as an 'officer in attendance'. The recommendation statements and guideline content were developed and finalised by the guideline development group with the involvement of stakeholders, parents, end users and external peer review. The views of the Royal College of Occupational Therapists have not, therefore, unduly influenced the final recommendations in this guideline.

## 9.8 Appraisal and ratification process

The guideline proposal, scope and final document were all reviewed and subsequently ratified by the Royal College of Occupational Therapists' Practice Publications Group, in line with the requirements of the *Practice guideline development manual* 3rd edition (COT 2017a).

The scope was approved by the Practice Publications Group in December 2015 and the final version of this guideline was approved by the Practice Publications Group in April 2017.



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# 10 Guideline methodology

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## 10.1 Guideline question

***What is the evidence to support occupational therapy in neonatal services and in early intervention?***

The PICO framework (Richardson et al 1995) was used to assist in developing the specific practice question further (Table 1). PICO describes the specific care group or condition being studied, and the nature of the intervention to be investigated. A comparative treatment can be specified where applicable, together with the anticipated outcomes (the desired/undesired or expected results of the intervention). This level of specificity is important in developing the question so that it addresses the requirements of the scope (COT 2017a).

**Table 1: PICO framework**

<b>Patient (service user), Population or Problem/circumstance</b>	Infants born preterm or born at term but deemed high risk, from birth to aged two years Parents of high-risk infants
<b>Intervention under investigation or action</b>	Occupational therapy interventions
<b>Comparison, which is an alternative intervention or action</b>	None
<b>Outcome desired</b>	Earlier discharge from an initial inpatient admission. Fewer readmissions. Increased parent confidence. Improved parent self-efficacy. Increased opportunities for parent engagement on the neonatal unit. Promotion of secure parent–infant relationship. Improved quality of interventions. Fewer do not attends (DNAs) in early intervention services due to the collaborative partnerships formed between parents and therapists. Earlier identification of emerging developmental concerns and implementation of appropriate early intervention services or referral to relevant specialist services.

## 10.2 Literature search strategy and outcomes

The literature search was carried out by the Royal College of Occupational Therapists' librarians, experts in the field of occupational therapy literature, using a search strategy defined following discussion and agreement with the guideline development group. The search strategy involved two distinct searches: first, literature that was occupational

therapy specific, and second, a broader search on interventions used by, but not specific to, occupational therapy.

### 10.2.1 Key terms

The overall strategy involved combining concept groups of key words. Nine key categories or concepts and their related terms were identified: pure neonate terms, paediatric terms, population- and setting-related terms, interventions, related interventions, occupational therapy, occupational therapy-related terms, finance and value terms, and setting terms (Appendix 7, Table A6). The combination of strings searched aimed to identify the most relevant results to meet the requirements of the guideline scope.

Specific exclusions identified were material published pre-2000 (occupational therapy-specific literature) or pre-2006 (intervention-specific literature) and language other than English (due to lack of resources for translation). A ten-year time frame was identified as appropriate for the intervention-specific literature but, given the perceived limited nature of the occupational-specific research in this area of practice, a 16-year time frame was agreed as appropriate to ensure inclusion of profession-specific seminal research.

### 10.2.2 Databases

The databases searched reflected the most likely sources of published peer-reviewed occupational therapy neonatal and early intervention evidence. Six core databases were searched from 1 January 2000 (occupational therapy specific) or 1 January 2006 (intervention specific) to the dates the individual searches were carried out (in 2016) as detailed in Table 2.

**Table 2: Database searches**

Core databases	Occupational therapy specific	Intervention specific
Cumulative Index to Nursing and Health Literature (CINAHL)	13/01/16 and 26/01/16	25/02/16 and 18/03/16
MEDLINE		
Allied and Complementary Medicine (AMED)	13/01/16, 15/01/16 and 26/01/16	No search undertaken
Social Policy and Practice		
Health Management Information Consortium (HMIC)		
PsycINFO		

Additional specialist databases were also searched: OTDBASE, OT SEARCH, OTSeeker, the Cochrane Library and the Royal College of Occupational Therapists Library online catalogue. Hand-searching was not systematically employed, but articles were included when brought to the attention of College officers or guideline development group members.

Searches included title, abstract or descriptor fields. The date of each search, search fields and search result numbers are detailed in Appendix 7 (Tables A7 and A8).

Full search histories are available on request from the Royal College of Occupational Therapists.

### **10.2.3 Search results**

The search identified a total of 1,139 results related to occupational therapy. These were scrutinised for duplicates, both within-database searches and cross-database search returns, by the Royal College of Occupational Therapists' Research and Development Officer. A total of 549 duplicates were removed.

Additionally, a separate search for intervention-specific literature returned 2,531 results. After searching for duplicates within and across databases, 1,627 were removed.

The unique results lists from both searches were provided to the project lead and guideline development group member undertaking the screening activity.

## **10.3 Criteria for inclusion and exclusion of evidence**

The resultant 590 occupational therapy-related and 904 intervention-specific search findings (title and abstracts) were each independently screened by two different members of the guideline development group against an eligibility checklist:

- Inclusion criteria:
  - Infants from birth to two years.
  - Occupational therapy specific and relevant.
  - Research.
  - Relevant to guideline question.
- Exclusion criteria:
  - Descriptive or contextual articles.

While one article was co-authored by one of the screeners, a second reviewer ensured no undue bias. Where the screeners had a yes/no variation in opinion as to whether an abstract should be included or excluded for appraisal, the abstract was further reviewed against the eligibility criteria by the reviewers to come to a consensus decision.

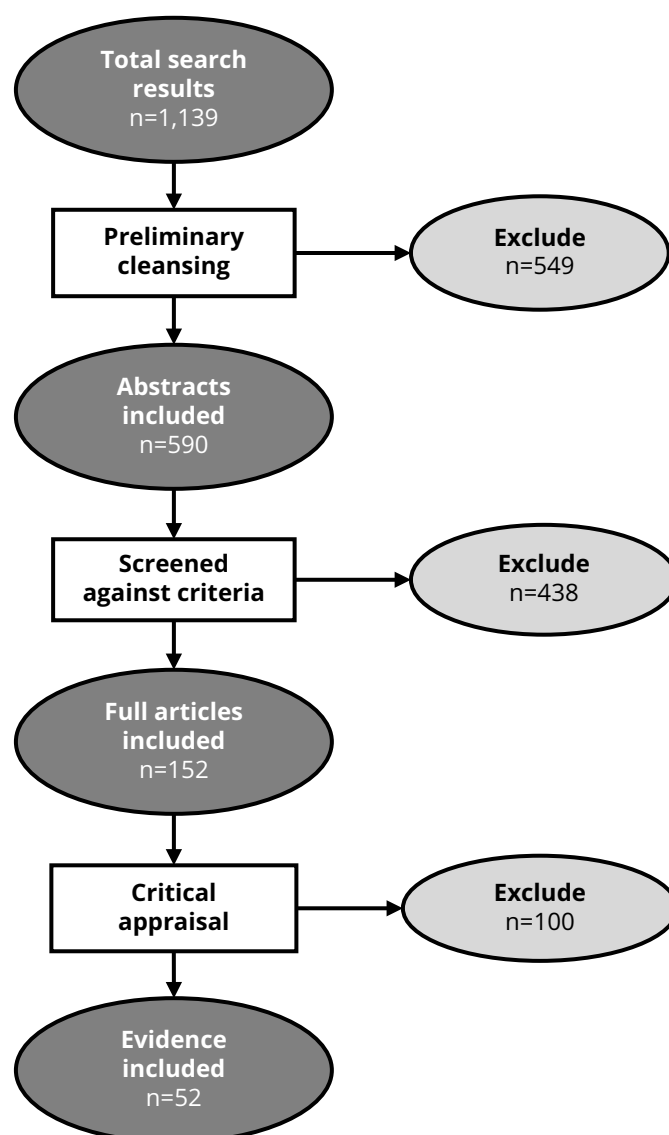
This process enabled the identification of abstracts that would be potentially relevant to the practice guideline and should therefore be included within the critical appraisal process.

### **10.3.1 Occupational therapy-specific literature results**

Following the screening, 438 occupational therapy-specific items were further excluded, resulting in a total of 152 items identified for full paper review and critical appraisal.

During the critical appraisal process, 24 articles were identified as inappropriate because they were out of scope, resulting in 128 articles which were fully critically appraised and details transferred into evidence tables (see section 10.4); 52 items of evidence were subsequently used in developing the recommendations (see section 10.5).

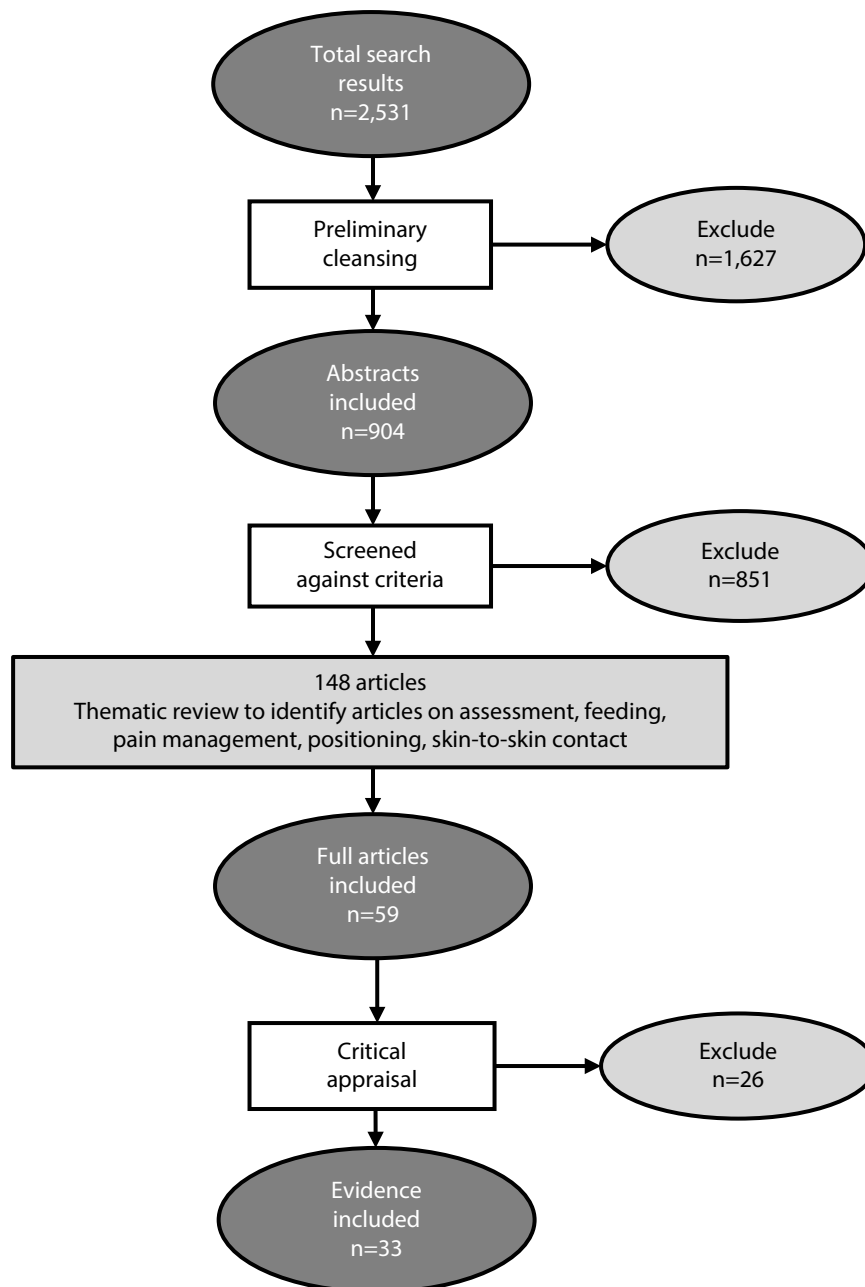
An overview of the occupational therapy-specific literature search outcomes is provided in Figure 1.



**Figure 1 Occupational therapy-specific literature search outcomes**

### 10.3.2 Intervention-specific literature results

After screening the intervention-specific literature, a total of 148 articles were identified as relevant (Figure 2). However, given the guideline's focus is only occupational therapy, the guideline development group agreed these results would be used as further evidence if the occupational therapy-specific literature was not felt to provide a substantive enough evidence base. Once the occupational therapy-specific literature had been appraised and discussed, the guideline development group agreed that literature relating to the following topics would also be appraised: assessment, feeding, pain management, infant positioning and skin-to-skin contact. The guideline development lead categorised the intervention-specific literature, resulting in 59 articles for appraisal. During the appraisal process, six were identified as out of scope, resulting in 53 which were fully critically appraised and whose details were transferred into evidence tables.



**Figure 2 Intervention-specific literature search outcomes**

## 10.4 Strengths and limitations of body of evidence

Each of the 181 articles identified as potential evidence was critically appraised by two independent reviewers. Appraisals were undertaken by all members of the guideline development group, with additional support provided by co-opted members. The allocation process ensured that reviewers did not appraise any evidence which they had authored or co-authored. Any discrepancy in grading was discussed and the final grading agreed and confirmed via group consensus.

The quality of the evidence was initially assessed and recorded using forms based on the Critical Appraisal Skills Programme (CASP) checklists (CASP 2013). Assessment took into account factors such as the appropriateness of the study design and recruitment

strategy, procedural rigour in data collection and analysis, confounding factors and potential biases, transferability, precision of results and the value of the findings.

A quality of evidence grade was then assigned to each individual article using the *Grading of Recommendations Assessment, Development and Evaluation* (GRADE) approach, as defined within the *Practice guideline development manual* 3rd edition (COT 2017a). The grading reflects the research design and the confidence in the research findings.

The initial grading was allocated as follows:

- Randomised controlled trial (RCT)/systematic review = High.
- Observational study = Low.
- Any other evidence = Very Low.

Limitations in the design of a study or its implementation may, however, bias the estimates of the treatment effect. If there were serious limitations, then downgrading of the quality of the evidence was considered, as in Table 3.

**Table 3: Grading evidence up or down** (after GRADE Working Group 2004)

<p><b>Decrease* grade if</b> * Each quality criterion can reduce the quality by one or, if very serious, by two levels</p>	<ul style="list-style-type: none"> <li>• Serious or very serious limitation to study quality.</li> <li>• Important inconsistencies in results.</li> <li>• Some or major uncertainty about directness of the evidence.</li> <li>• Imprecise or sparse data (relatively few participants and/or events).</li> <li>• High probability of reporting bias.</li> </ul>
<p><b>Increase grade if</b></p>	<ul style="list-style-type: none"> <li>• Magnitude of the treatment effect is very large and consistent.</li> <li>• Evidence of a large dose-response relation.</li> <li>• All plausible confounders/biases would have decreased the magnitude of an apparent treatment effect.</li> </ul> <p><i>Only studies with no major threats to validity should be upgraded.</i></p>

A decision to increase or decrease the initial grade of the evidence was recorded and justified on the critical appraisal forms. A moderate category became relevant only if there was a suggested change in the initial grading of an article due to up- or down-grading. Evidence was ultimately graded in one of four categories as detailed in Table 4.

If there was no reason to up- or down-grade the evidence, then the original grading remained.

**Table 4: GRADE quality of evidence grading** (after GRADE Working Group 2004)

Quality of evidence	Grading	Characteristics	Confidence
<b>High</b>	A	Based on consistent results from well-performed randomised controlled trials, or overwhelming evidence of an alternative source, e.g. well-executed observational studies with strong effects.	True effect lies close to that of the estimate of the effect. Further research is very unlikely to change confidence in the estimate of the effect.
<b>Moderate</b>	B	Based on randomised controlled trials where there are serious flaws in conduct, inconsistency, indirectness, imprecise estimates, reporting bias or some other combination of these limitations, or from other study designs with special strengths.	True effect likely to be close to the estimate of the effect but the possibility that there could be a substantial difference. Further research is likely to have an important impact on confidence in the estimate of effect and may change the estimate.
<b>Low</b>	C	Based on observational evidence, or from controlled trials with several very serious limitations.	True effect may be substantially different from the estimate of the effect. Further research is very likely to have an important impact on confidence in the estimate of the effect and is likely to change the estimate.
<b>Very Low</b>	D	Based on case studies or expert opinion.	Any estimate of effect is very uncertain and may be far from the true effect.

Once the methodological quality of each piece of evidence was assessed, details for each item of evidence were collated, from the two independent appraisals, into an evidence table (Appendix 2).

A summary of the evidence used to develop the recommendations is provided in Table 5.

**Table 5: Summary of evidence used to develop the recommendations**

Topic area	Author	Year	Evidence quality
Occupation-based assessment	Als et al	2003	A
	Bartlett	2003	C
	El-Dib et al	2011	C
	Sucharew et al	2012	C
	Crowle et al	2015	D
	Liu et al	2010	D
Developmental care	Als et al	2003	A
	McAnulty et al	2009	A
	Symington and Pinelli	2006	A
	Symington and Pinelli	2002	A
	Legendre et al	2011	B
	McAnulty et al	2010	B
	Wallin and Eriksson	2009	B
Pain management	Axelin et al	2006	A
	Ferber and Makhoul	2008	A
	Franck et al	2011	A
	Johnston et al	2011	A
	Cong et al	2012	B
	Obeidat et al	2009	B
	Franck et al	2012	C
	Gibbens et al	2015	C
	Kostandy et al	2008	C
SSC/kangaroo care	Boo and Jamli	2007	A
	Chan et al	2016	A
	Cong et al	2009	A
	Gathwala et al	2008	A
	Hake-Brooks and Anderson	2008	A
	Ludington-Hoe et al	2004	A
	Morelius et al	2015	A
	Cho et al	2016	B
	Head	2014	B
	Bloch-Salisbury et al	2014	C
	Blomqvist et al	2013	C



Topic area	Author	Year	Evidence quality
Positioning	Carbasse et al	2013	C
	Kostandy et al	2008	C
	Madlinger-Lewis et al	2015	B
	Gouna et al	2013	C
	Grenier et al	2013	C
	Liaw et al	2012	C
	Nakano et al	2012	C
	Zarem et al	2013	C
	Coughlin et al	2012	D
Infant feeding	Ross and Browne	2013	B
	Brown et al	2007	C
	Caretto et al	2000	C
	Flacking et al	2013	C
	Pickler et al	2013	C
	Swift and Scholten	2010	C
	Ward et al	2000	C
	Chrupcala et al	2015	D
	Waitzman et al	2014	D
Parent engagement	Gibbs et al	2015	A
	Chiarello et al	2006	C
	Dudek-Shriber	2004	C
	Gund et al	2013	C
	Harrison et al	2007	C
	Kadlec et al	2005	C
	Ganadaki and Magill-Evans	2003	D
	Price and Miner	2009	D
	Winston	2015	D
Parent support	Evans et al	2014	A
	Melnyk et al	2006	A
	Melnyk et al	2001	A
	White-Traut et al	2013	A
	Zelkowitz et al	2011	A
	Matricardi et al	2013	B
	Mouradian et al	2013	C

Topic area	Author	Year	Evidence quality
Identifying developmental concerns	Maitra et al	2014	A
	Bigsby et al	2011	B
	Witt Mitchell et al	2015	B
	Crozier et al	2016	C
	Fewell and Claussen	2000	C
	Magill-Evans et al	2002	C
	Pineda et al	2015	C
	Sajaniemi et al	2001	C
	Watkins et al	2014	C
Early intervention	Leskulchai and Cole	2001	A
	Orton et al	2009	A
	Spencer-Smith et al	2012	A
	Spittle et al	2015	A
	Spittle et al	2007	A
	Hwang et al	2013	B
	Hintz et al	2008	C
	Ideishi et al	2010	D

## 10.5 Method used to arrive at recommendations

The evidence tables were used by the guideline development group to synthesise the evidence available, and as the basis to evaluate and judge the potential contribution of each item of evidence to the development of the guideline recommendations.

The evidence tables were grouped in categories identified by the guideline project lead, and these were used as the starting point for developing recommendations.

Once a recommendation had been developed, an overall quality of evidence rating was determined. This overall rating was established as follows:

- Where the evidence outcomes pointed in different directions towards benefit and towards harm, the lowest quality of evidence determined the overall quality grade of evidence.
- Where the outcomes pointed in the same direction towards either benefit or harm, the highest quality of evidence was appropriate to recommend an intervention and determined the overall quality of evidence.
- In circumstances where the balance of benefits and harm was uncertain, the lowest grade of quality of evidence was assigned.

Strength of recommendation was the second element of the GRADE system applied, using the categories, strong or conditional, to reflect the strength (Table 6).

**Table 6: Strength of grade** (after Guyatt et al 2008)

Strength	Grade	Benefits and risks	Implications
<b>Strong</b>	<b>1</b> <i>'It is recommended. . .'</i>	Benefits appear to outweigh the risks (or vice versa) for the majority of the target group.	Most service users would want or <i>should</i> receive this course of intervention or action.
<b>Conditional</b>	<b>2</b> <i>'It is suggested. . .'</i>	Risks and benefits are more closely balanced, or there is more uncertainty in likely service user values and preferences.	The majority of service users would want this intervention but not all, and therefore they should be supported to arrive at a decision for intervention consistent with the benefits and their values and preferences.

The development of the recommendations, including assignment of the overall quality and strength grading, was a consensus decision obtained at the guideline development group meeting, and by subsequent email correspondence as required for any revisions. There were no recommendations that were not agreed by all members, so that no formal voting system was required. Eighty-five items of evidence were used to develop the recommendations.

A recommendation decision form was completed for each recommendation developed. This recorded key information about the evidence used to form the basis of that recommendation, the overall allocation of the quality of evidence and strength of the recommendation. The form also facilitated discussion and recording of any specific or associated risks and benefits, and this was reflected in the final strength of recommendation. Any judgement by the guideline development group was documented as part of this decision-making process (the forms are available on request from the Royal College of Occupational Therapists).

## 10.6 Limitations and any potential bias of the guideline

Evidence included in the development of the guideline recommendations was sourced from published, peer-reviewed journal articles. Relevant policy documents or grey literature have been referenced within the contextual information where applicable.

The literature search identified a body of primary research, relating to practices and interventions that are provided in the neonatal and early intervention settings by occupational therapists. The outcome of the literature search, appraisal, and synthesis of the evidence resulted in 85 papers being used to support the guideline recommendations.

A total of 50 per cent of the evidence was derived from studies of high or moderate quality:

Grade A = 34% (n=29)

Grade B = 16% (n=14)

Grade C = 39% (n=33)

Grade D = 11% (n=9)

The guideline development group downgraded 17 of the studies, initially graded A or C, due to limitations identified from the appraisal and a resultant lack of confidence in the estimate of the research effect. Three studies were upgraded due to their specific strengths in the study design. These decisions and comments on individual studies are noted in the evidence tables (Appendix 2).

The role of the Royal College of Occupational Therapists and the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families in the development, authoring and funding of this practice guideline is fully acknowledged (section 9.7). Involvement is inherent because of the organisational structure of the professional body and its relationship with members of the British Association of Occupational Therapists.

The potential for any bias in development and authoring was, however, minimised through the rigorous nature of the guideline development process. This was achieved through the systematic methodology adopted, the contributions of stakeholders and parents, the valued opinions of the external peer reviewers and occupational therapy end users, and the judicious management of any potential or actual conflicts of interest.

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# 11

## Updating the guideline

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The National Executive Committee of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families is responsible for ensuring the future review of this guideline, and will provide a focal point for any feedback received on the guideline following its publication.

Occupational therapists have a continuous personal responsibility to keep abreast of occupational therapy-specific evidence.

Members of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families National Executive Committee should discuss any significant developments in evidence relevant to the guideline that may be identified in the period prior to its formal review.

This practice guideline is scheduled for update by 2022. The review date may be brought forward, however, if there is significant new evidence which may impact on practice or the guideline recommendations.

Dissemination of information updates will primarily be achieved via the Specialist Section website, newsletter distributions, and any updates on the evidence-base presented at their annual conference.

The wider membership of the British Association of Occupational Therapists will be made aware of any significant developments in the evidence-base via the publication *OTnews*.

*Information about the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families is available at: <https://www.rcot.co.uk/about-us/specialist-sections/children-young-people-and-families-rcot-ss>*

Accessed on 20.06.17.

# Appendix 1: Glossary and abbreviations

<b>APIB</b>	<b>Assessment of Preterm Infant Behavior</b> A neurobehavioural assessment of preterm and full-term newborns aligned to the NIDCAP.
<b>ATVV</b>	<b>Auditory Tactile Visual Vestibular intervention</b> This is an approach used primarily in the USA that includes step by step instructions on how to introduce the sensory stimuli in a specific order to a premature baby. It involves the use of voice (auditory), massage (touch), eye contact (visual) and rocking (vestibular).
<b>Autistic spectrum disorder/autism (ASD)</b>	'Autism is a lifelong developmental disability that affects how people perceive the world and interact with others. Autism is a spectrum condition.' <a href="http://www.autism.org.uk/autism">http://www.autism.org.uk/autism</a>
<b>BAOT</b>	<b>British Association of Occupational Therapists</b> BAOT is the professional body for all occupational therapy staff in the United Kingdom. <a href="https://www.rcot.co.uk/about-us/governance/how-we-are-run">https://www.rcot.co.uk/about-us/governance/how-we-are-run</a>
<b>Bliss</b>	A registered charity supporting babies born premature or sick to receive the best care in the UK. They achieve this through empowering families, influencing policy and practice, and enabling life-changing research. <a href="http://www.bliss.org.uk/why-we-exist">http://www.bliss.org.uk/why-we-exist</a>
<b>Bliss Baby Charter</b>	The Bliss Baby Charter is a practical framework for neonatal units to self-assess the quality of family-centred care they deliver against a set of seven core principles. It enables units to audit their practices and develop meaningful plans to achieve changes that benefit babies and their families. With the Bliss Baby Charter, units are given a clear focus that is based on, and supports, national standards. <a href="http://www.bliss.org.uk/Pages/Category/bliss-baby-charter">http://www.bliss.org.uk/Pages/Category/bliss-baby-charter</a>
<b>BSID</b>	<b>Bayley Scales of Infant Development</b> Standardised assessment of development used widely in research. The most recent version is the BSID III which is comprised of five sections: cognitive, expressive and receptive language, fine and gross motor. Used from birth to 42 months.
<b>CASP</b>	<b>Critical Appraisal Skills Programme</b> The Critical Appraisal Skills Programme supports the development of skills in the critical appraisal of scientific research, and provides a number of critical appraisal tools to support this activity. (CASP 2013) <a href="http://www.casp-uk.net">http://www.casp-uk.net</a>

<b>Cerebral palsy</b>	<p>'Cerebral palsy is a condition that affects muscle control and movement caused by an injury to the brain before, during or after birth. Children with a diagnosis of cerebral palsy may have difficulties in controlling muscles and movements as they grow and develop.'</p> <p><a href="http://www.scope.org.uk/support/families/diagnosis/cerebral-palsy">http://www.scope.org.uk/support/families/diagnosis/cerebral-palsy</a></p>
<b>CI</b>	<p><b>Confidence interval</b></p> <p>'There is always some uncertainty in research. This is because a small group of patients is studied to predict the effects of a treatment on the wider <i>population</i>. The confidence interval is a way of expressing how certain we are about the findings from a study, using statistics. It gives a range of results that is likely to include the "true" value for the population.</p> <p>'The CI is usually stated as "95% CI", which means that the range of values has a 95 in a 100 chance of including the "true" value. For example, a study may state that "based on our <i>sample</i> findings, we are 95% certain that the 'true' population blood pressure is not higher than 150 and not lower than 110". In such a case the 95% CI would be 110 to 150.</p> <p>'A wide confidence interval indicates a lack of certainty about the true effect of the test or treatment – often because a small group of patients has been studied. A narrow confidence interval indicates a more precise estimate (for example, if a large number of patients have been studied).'</p> <p>Glossary: <a href="http://www.nice.org.uk/website/glossary/glossary.jsp">http://www.nice.org.uk/website/glossary/glossary.jsp</a></p>
<b>CLD</b>	<p><b>Chronic lung disease</b></p> <p>Previously known as bronchopulmonary dysplasia (BPD), this refers to an oxygen requirement at 28 days of age, characteristic lung changes on x-ray and an oxygen requirement at 36 weeks gestational age.</p>
<b>Corrected gestational age</b>	<p>The baby's age calculated from the due date and used for all aspects of development until the child is 24 months corrected age.</p>
<b>Developmentally supportive care</b>	<p>Term that refers to the use of strategies that are 'derived from neurodevelopmental, environmental and human sciences to improve the potential of infants who are disadvantaged by premature birth or adverse perinatal events'. (<i>Warren and Bond 2010, p14</i>)</p>
<b>Dysphagia</b>	<p>Difficulty in swallowing.</p>
<b>Early intervention</b>	<p>Identification of infants and families at risk of developmental difficulties and provision of appropriate intervention.</p>
<b>EEG</b>	<p><b>Electroencephalography</b></p> <p>A method to record electrical activity in the brain using electrodes positioned on the skull.</p>
<b>ELBW</b>	<p><b>Extremely Low Birth Weight</b></p> <p>Birth weight of less than 1000g (2 pounds 3 ounces) regardless of gestational age.</p>

<b>Facilitated tucking</b>	Supporting the baby to be in a flexed position with arms and legs tucked up towards the torso.
<b>FINE</b>	<b>The Family and Infant Neuro-developmental Education (FINE)</b> An education programme for healthcare professionals that consists of three levels of training; available in the UK and used throughout Europe. Level One is accredited through the Royal College of Nursing. <a href="http://www.bliss.org.uk/fine">http://www.bliss.org.uk/fine</a>
<b>Gavage feeding</b>	Feeding an infant directly into the stomach using an orogastric (through the mouth) or nasogastric (through the nose) tube. This is the accepted way to feed a premature or sick baby when they are not able to participate in oral feeding.
<b>Gestational age</b>	'The age of the fetus or newborn, usually expressed in weeks dating from the first day of the mother's last menstrual period.' <i>Anderson (2002)</i>
<b>GRADE</b>	<b>Grading of Recommendations Assessment, Development and Evaluation</b> GRADE is a systematic and explicit methodology to assist in the judgement of the quality and strength of guideline recommendations. <a href="http://www.gradeworkinggroup.org">http://www.gradeworkinggroup.org</a>
<b>HIE</b>	<b>Hypoxic-ischaemic encephalopathy</b> A brain injury caused by oxygen deprivation to the brain, also commonly known as intrapartum asphyxia. It is the cause of death and severe impairment among infants. It is more common in term infants. <a href="http://www.cerebralpalsy.org/about-cerebral-palsy/cause/hypoxic-ischemic-encephalopathy">http://www.cerebralpalsy.org/about-cerebral-palsy/cause/hypoxic-ischemic-encephalopathy</a>
<b>High risk</b>	For the purpose of this guideline, high-risk infants includes all infants born prematurely as well as term infants with neonatal encephalopathy, neonatal abstinence syndrome, neurological abnormalities, congenital conditions or who have undergone complex surgical procedures.
<b>IVH</b>	<b>Intraventricular haemorrhage</b> Graded I, II, III or IV. An IVH involves the germinal matrix, the immature capillary network, which overlies the head of the caudate nucleus. The haemorrhage may be confined to the germinal matrix, may extend into the ventricle or involve the parenchyma. An IVH usually occurs within 72 hours of birth. The germinal matrix disappears at about 32 weeks gestation so haemorrhage is uncommon beyond this gestation. Grade I: isolated germinal matrix haemorrhage Grade II: IVH without ventricular dilatation Grade III: IVH with acute ventricular dilatation Grade IV: parenchymal haemorrhage venous infarct



<b>Kangaroo care/SSC</b>	Refers to the practice of holding a baby with skin-to-skin contact between the baby's chest and mother/father's chest. Uses principles from kangaroo mother care, which has three components: skin-to-skin contact, exclusive breastfeeding and support for the mother–infant dyad. <i><a href="http://www.skintoskincontact.com/an-introduction.aspx">http://www.skintoskincontact.com/an-introduction.aspx</a></i>
<b>LBW</b>	<b>Low birth weight</b> Birth weight of less than 2.5kg (5 pounds 8 ounces) regardless of gestational age.
<b>Moderate to late preterm</b>	Infants born between 32 and 37 weeks gestational age.
<b>Neonatal abstinence syndrome (NAS)</b>	A behavioural pattern of irritability, tremulousness and inconsolability exhibited in newborns exposed to addictive opiate drugs. <i>Anderson (2002)</i>
<b>Neonate</b>	An infant under 28 days of life. <i><a href="http://www.who.int/topics/infant_newborn/en/">http://www.who.int/topics/infant_newborn/en/</a></i>
<b>Neurobehavioural regulation</b>	The presence and success of an infant's efforts to achieve a balance between the subsystems of development as outlined in Als' Synactive Theory of Newborn Behavioral Organization and Development (1982). The subsystems are: autonomic/physiological, motor, state and attention. <i>Als (1982)</i>
<b>Neurobehavioural state</b>	This is the level of alertness of the infant and can be divided into six separate states: deep sleep, light (or REM sleep), drowsy, quiet alert, active alert and crying. The state of the infant is related to how they are able to block out external stimuli in order to be able to interact with the world. <i>Brazelton and Nugent (1995)</i>
<b>Neuroplasticity</b>	The brain's ability to reorganise itself by forming new neural connections throughout life. Neuroplasticity allows the neurons (nerve cells) in the brain to compensate for injury and disease and to adjust their activities in response to new situations or to changes in their environment.
<b>NHS</b>	<b>National Health Service</b> The NHS refers to the publicly funded health care systems in the United Kingdom.
<b>NICE</b>	<b>National Institute for Health and Care Excellence</b> NICE (formerly the National Institute for Health and Clinical Excellence) provides national guidance and advice to improve health and social care. <i><a href="http://www.nice.org.uk">http://www.nice.org.uk</a></i>

<b>NICU Levels I, II and III</b>	<p><b>Neonatal Intensive Care Units – Levels 1, 2 and 3</b></p> <p><b>Level 1 units</b> provide special care but do not aim to provide any continuing high-dependency or intensive care. This term includes units with or without resident medical staff.</p> <p><b>Level 2 units</b> provide high-dependency care and some short-term intensive care as agreed within the network.</p> <p><b>Level 3 units</b> provide the whole range of medical neonatal care but not necessarily all specialist services such as neonatal surgery.</p> <p><a href="http://www.bapm.org/publications/documents/guidelines/hosp_standards.pdf">http://www.bapm.org/publications/documents/guidelines/hosp_standards.pdf</a></p>
<b>NIDCAP</b>	<p><b>The Newborn Individualized Developmental Care and Assessment Program (NIDCAP)</b></p> <p>‘Originated in 1984 by Heidelise Als, PhD, is a comprehensive, family centered, evidence-based approach to newborn developmental care. NIDCAP focuses on adapting the newborn intensive care nursery to the unique neurodevelopmental strengths and goals of each newborn cared for in this medical setting. These adaptations encompass the physical environment and its components, as well as the care and treatment provided for the infant and his or her family, their life-long nurturers and supporters.’</p> <p><a href="http://nidcap.org/en/programs-and-certifications/program-overview/">http://nidcap.org/en/programs-and-certifications/program-overview/</a></p>
<b>NNNS</b>	<p><b>The NICU Network Neurobehavioral Scale (NNNS)</b></p> <p>‘Examines the neurobehavioural organization, neurological reflexes, motor development – active and passive tone, and signs of stress and withdrawal of the at-risk and drug-exposed infant. It was designed to provide a comprehensive assessment of both neurological integrity and behavioural function. Additionally, the NNNNS documents the range of withdrawal and stress behavior likely to be observed in assessment and intervention with substance-exposed infants. This neurobehavioral assessment is applicable to term, normal healthy infants, preterm infants and infants at risk due to factors such as prenatal substance exposure.’</p> <p><a href="https://www.brown.edu/research/projects/children-at-risk/about">https://www.brown.edu/research/projects/children-at-risk/about</a></p>
<b>NNU</b>	<p><b>Neonatal unit</b></p> <p>A term which may be used synonymously with neonatal intensive care unit, but is most commonly used to refer to level 2 units.</p>
<b>Occupation</b>	<p>Occupation refers to practical and purposeful activities that allow people to live independently and have a sense of identity. This could be essential day-to-day tasks such as self-care, work or leisure. Infant ‘occupations’ are the activities that they engage in as they strive to master the skills they will need to adapt to their environment. These include participating in feeding, bathing, nurturing, play and learning, and early relationships.</p> <p><a href="https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy">https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy</a></p>

<b>Occupation-based assessment</b>	Occupation-based assessment describes the consideration of an individual infant's early engagement patterns during routine caregiving and other elements associated with occupational performance. This includes identification of an infant's strengths and vulnerabilities as they experience and participate in caregiving interactions in the neonatal unit.
<b>Occupational therapist</b>	An occupational therapist provides practical support to empower people to facilitate recovery and overcome any barriers that prevent them from doing the activities (occupations) that matter to them. This helps to increase people's independence and satisfaction in all aspects of life. Occupational therapists work with adults and children of all ages with a wide range of conditions, most commonly those who have difficulties due to a mental health illness, physical or learning disabilities. They can work in a variety of settings including health organisations, social care services, housing, education, re-employment schemes, occupational health, prisons, voluntary organisations or as independent practitioners. <a href="https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy">https://www.rcot.co.uk/about-occupational-therapy/what-is-occupational-therapy</a>
<b>p value</b>	<b>Probability</b> 'The p value is a statistical measure that indicates whether or not an effect is statistically significant. 'For example, if a study comparing two treatments found that one seems more effective than the other, the p value is the <i>probability</i> of obtaining these results by chance. By convention, if the p value is below 0.05 (that is, there is less than a 5% probability that the results occurred by chance) it is considered that there probably is a real difference between treatments. If the p value is 0.001 or less (less than a 1% probability that the results occurred by chance), the result is seen as highly significant. 'If the p value shows that there is likely to be a difference between treatments, the <i>confidence interval</i> describes how big the difference in effect might be.' Glossary: <a href="http://www.nice.org.uk/website/glossary/glossary.jsp">http://www.nice.org.uk/website/glossary/glossary.jsp</a>
<b>Paediatric Intensive Care Unit</b>	Hospital ward specialising in the care of critically ill infants and children.
<b>Parent</b>	Parent refers to the primary caregivers for the infant rather than the biological mother and father. For brevity in the document the word parent is used.

<b>Periventricular leukomalacia (PVL)</b>	<p>'Periventricular leukomalacia is a type of brain injury that is most common in babies born too soon (premature) or at low birth weight. The white matter (leuko) surrounding the ventricles of the brain (periventricular) is deprived of blood and oxygen leading to softening (malacia). The white matter is responsible for transmitting messages from nerve cells in the brain so damage to the white matter can cause problems with movement and other body functions.'</p> <p><a href="http://www.gosh.nhs.uk/medical-information-0/search-medical-conditions/periventricular-leukomalacia">http://www.gosh.nhs.uk/medical-information-0/search-medical-conditions/periventricular-leukomalacia</a></p>
<b>Preterm infant</b>	An infant born before 37 weeks gestational age.
<b>RCOT</b>	<p><b>Royal College of Occupational Therapists</b></p> <p>The Royal College of Occupational Therapists is a wholly owned subsidiary of BAOT and operates as a registered charity. The College sets the professional and educational standards for the occupational therapy profession and represents the profession at the national and international levels.</p> <p><a href="https://www.rcot.co.uk/about-us/governance/how-we-are-run">https://www.rcot.co.uk/about-us/governance/how-we-are-run</a></p>
<b>RCOT SS – Children, Young People and Families</b>	<p><b>Royal College of Occupational Therapists Specialist Section – Children, Young People and Families</b></p> <p>RCOT SS – Children, Young People and Families is a branch of the College that represents occupational therapists working with children, young people and their families in a wide range of settings. It promotes high standards of professional practice within children's occupational therapy.</p> <p><a href="https://www.rcot.co.uk/about-us/specialist-sections/children-young-people-and-families-rcot-ss">https://www.rcot.co.uk/about-us/specialist-sections/children-young-people-and-families-rcot-ss</a></p>
<b>RCT</b>	<p><b>Randomised controlled trial</b></p> <p>'A study in which a number of similar people are randomly assigned to two (or more) groups to test a specific drug or treatment. One group (the experimental group) receives the treatment being tested, the other (the comparison or <i>control group</i>) receives an alternative treatment, a dummy treatment (<i>placebo</i>) or no treatment at all. The groups are followed up to see how effective the <i>experimental treatment</i> was. <i>Outcomes</i> are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce <i>bias</i>.'</p> <p>Glossary: <a href="http://www.nice.org.uk/website/glossary/glossary.jsp">http://www.nice.org.uk/website/glossary/glossary.jsp</a></p>
<b>Septicaemia or sepsis</b>	Also known as blood poisoning. A potentially life-threatening infection of the bloodstream.
<b>Shared occupation</b>	Shared occupations are caregiving activities in which parents and infants actively engage that address infant needs but also support the developing parent–infant relationship (including positive touch, nurturing, feeding, bathing, early reciprocal interaction).

<b>SIGN</b>	<b>Scottish Intercollegiate Guideline Network</b> SIGN develops evidence-based clinical practice guidelines for the National Health Service (NHS) in Scotland. <i><a href="http://www.sign.ac.uk">http://www.sign.ac.uk</a></i>
<b>Torticollis</b>	A dystonic condition defined by an abnormal head or neck position which has a variety of causes.
<b>Transitional care</b>	Level of care provided to babies who may need support for feeding or medical matters that do not require admission to the neonatal unit. Transitional care units are usually located in maternity and mothers are not separated from their baby.
<b>VLBW</b>	<b>Very low birth weight</b> Birth weight of under 1.5kg (3 pounds 5 ounces) regardless of gestational age.
<b>Washout period</b>	The period during a clinical study when the participants do not receive any treatment that is under investigation.
<b>White matter</b>	'Nerve tissue of the central nervous system that is paler in colour than the associated grey matter because it contains more nerve fibres and thus larger amounts of the insulating material myelin.' <i>Martin E (ed) (2003)</i>

All websites in the glossary were accessed on 05/05/2017.

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## Appendix 2: Evidence tables

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Each item of evidence used to support the recommendations has an associated evidence table.

The evidence tables are detailed in a separate document, *Practice guideline supplement: Evidence tables*, which can be downloaded from the Royal College of Occupational Therapists' website at: <https://www.rcot.co.uk/practice-resources/rcot-practice-guidelines>

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## Appendix 3: Knowledge and skills frameworks

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The British Association of Perinatal Medicine's service standards for hospitals providing neonatal care details about the neonatal occupational therapy specialist role (BAPM 2010, p14):

- Assessing the interaction of biological, developmental and psychosocial aspects of human function as expressed in daily activities and occupations.
- Administering complex standardised neurobehavioural assessments that provide information on the infant's neurobehavioural organisation, state control and self-regulatory behaviours.
- Using reliable non-invasive neurological assessments to identify early signs of neurological impairment.
- Identifying and advising on sensory issues affecting irritable babies and providing advice on developmentally supportive positioning to help prevent postural and developmental delays later in infancy.
- Helping to sensitise parents to their infant's behavioural cues, thereby enabling appropriate interactions and levels of stimulation, and providing developmental programmes as appropriate.
- Providing follow-up after discharge, using evidence-based standardised developmental, cognitive and motor assessments.

The American Occupational Therapy Association's knowledge and skills for occupational therapy practice in the NICU (Vergara et al 2006, pp661–662):

- Medical knowledge base as a foundation for understanding infant behaviour.
- Factors that may influence infant and child development, including prenatal, perinatal and postnatal conditions and complications.
- Knowledge of the developmental course, abilities, and vulnerabilities of infants in the NICU (including neurobehavioural organisation, sensory development and processing of sensory information, motor function, and social-emotional development).
- Emerging competencies in infant occupation (including factors that influence participation in daily life activities, ability to cope with and participate in caregiving, engaging in nurturing interventions, and the inter-relationship between medical and developmental domains).
- Knowledge of evolving developmental approaches in the neonatal unit.

Specific skills related to occupational therapy practice in the neonatal unit, including consultation/communication with other professionals; safe and effective use of equipment; conduct appropriate assessments; assess the effects of physical environment, caregiving practices, positioning, and nurturance on the infant's neurobehavioural organisation, sensory, motor, and medical status; and to formulate an individualised therapeutic intervention plan that supports the infant's current level of

function and facilitates optimal social-emotional, physical, cognitive, and sensory development of the infant within the context of the family and the NICU.

- Work from a family-centred perspective through acknowledgement of the family as a basis for collaboration, recognising adult learning styles, supporting parent–infant interactions, and supporting the transition of the infant and family from hospital to home.



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## **Appendix 4: Examples of occupational therapy services in neonatal settings**

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Occupational therapy services provided in neonatal settings across the United Kingdom differ in structure, scope and resourcing.

The information included in this appendix aims to provide information and examples of current services that may be useful when considering the development of neonatal services.

Identification of high-risk infants who may benefit from occupational therapy services can be supported by the implementation of a framework that combines infant biological-biomedical and psychosocial-physical environment risk criteria to identify those infants who are at risk for poor developmental outcomes (Laadt et al 2007). Laadt et al (2007) developed a System of Risk Triage (SORT) that assists therapists to identify each infant's risk for subsequent developmental problems, and identify those who would benefit from referral for early intervention services.

The SORT framework has been modified with permission to reflect the provision of neonatal services in the United Kingdom.

## Framework to guide referral and developmental intervention decisions in the neonatal unit

**Table A1: Infant biomedical axis for triage tool**

<b>INFANT BIOMEDICAL AXIS</b>	<b>A Low Biomedical Risk</b>	Inpatient: Any infant who is separated from his mother due to medical needs. Outpatient: Any infant not in another risk category whose parents have concerns about their development.
	<b>B Moderate Biomedical Risk</b>	Moderate risk of developmental delay or disability, e.g. due to birth weight 1000–1250g; gestational age 28–32 weeks; IUGR >34 weeks; >week hospitalised for stabilisation.
	<b>C High Biomedical Risk</b>	High risk of developmental delay/disability, e.g. due to birth weight <1000; gestational age <29 weeks; surgery with prolonged hospitalisation; low Apgar score at 10 mins; identified CNS injury (e.g. HIE, seizures, meningitis, IVH Grade IV; bilateral PVL); abnormal tone or movements; delayed/disorganised feeding; ventilation >10 days; moderate sensory loss.
	<b>D Established Biomedical Risk</b>	Infants with conditions that are associated with disability, e.g. syndromes and congenital disorders such as Down Syndrome, foetal alcohol syndrome; significant neurological findings on US or MRI and signs of abnormal movements, persistent irritability, dysfunctional feeding; congenital malformations affecting development; severe sensory loss; palliative care.

**Table A2: Psychosocial environment axis for triage tool**

<b>PSYCHOSOCIAL ENVIRONMENT AXIS</b>		
<b>1 – Adequate Environment</b>	<b>2 – Moderate Risk Environment</b>	<b>3 – Established Risk</b>
Family with adequate psychosocial, physical and material resources to support their infant's growth, developmental progress and general well-being.	Family in need of help to identify resources to support infant growth, development and well-being, e.g. due to other demands, lack of engagement with community, substance abuse, poverty, history of psychiatric problems or learning disability, life-threatening conditions etc. Lack of family support.	Psychosocial environmental circumstances are precarious and infant's future safety is in question, e.g. history of violence in the home, no prenatal care, history of other children removed from home; criminal record; involvement with child protection; maternal isolation; homelessness; refugee status; substance abuse.

Table A3: Decision-making framework

		PSYCHOSOCIAL ENVIRONMENT AXIS		
		1. Adequate Environment	2. Moderate Risk Environment	3. High-Risk Environment
INFANT BIOMEDICAL AXIS	A Low Risk	Advocates for and promotes appropriate developmental environment for all infants and families in the NNU, e.g. light, sound, seating for skin-to-skin, parent and infant participation in shared occupations*** etc.	Facilitation of parent-infant shared occupations***; guidance to promote attunement, awareness of behavioural regulation and self-confidence.	Assessment of parenting efficacy.
	B Moderate Risk	Specific environmental adaptations appropriate for age and stage of development to support all domains,* e.g. optimal positioning for autonomic regulation, head shape, motor organisation; to facilitate behavioural organisation. Support parental role, e.g. parent-focused interventions with maternal sensitivity elements (e.g. reading and responding to infant cues) to reduce psychosocial impact. Pre-discharge neurobehavioural /neurodevelopmental assessment and anticipatory guidance.	<b>As for 2A and 1B plus:</b> Individual guidance re: parenting occupations using adapted techniques to match infant's sensitivity and to facilitate behavioural organisation. Monitor parental/family organisation/ vulnerability and recommend support/ coping strategies.	<b>As for 3A and 2B plus:</b> Contributes to multidisciplinary/multi-agency developmental plan with safeguarding in mind.
	C High Risk	<b>As for 1B plus:</b> Individualised developmentally supportive care plans** a) to protect infant from secondary 'disabilities', e.g. postural, feeding; b) to promote behavioural competence in all domains; c) to reduce stress/pain; d) to support parenting role. Developmental surveillance and therapeutic interventions at home with emphasis on occupational competence (based on cognitive/ executive functions, social, behavioural, sensory processing and functional motor skills).	<b>As for 2B and 1C plus:</b> Build strong relationship with family and support them to engage with services, e.g. follow-up clinics, community services, and to make the transition to child development services as needed.	<b>As for 3B plus:</b> Individualised developmentally supportive care plans on NNU and developmental plan to facilitate transition to ongoing carer arrangements and services post-discharge.
	D Established Condition	Therapeutic interventions to promote development and prevent disability (e.g. contractures), e.g. positioning, handling and movement; sensory; splinting. Incorporates strategies and family education into daily care activities (occupations). Discharge planning. Liaison with community resources.	<b>As for 1D and 2C</b>	<b>As for 1D and 3C</b>
	All groups	Active role in managing a developmentally appropriate sensory and social environment for infant and family-centred care. Guidance about appropriate educational materials for staff and parents. Promote assessment of neonatal pain and identification of appropriate pain management strategies.		
Notes		<p>*Behavioural domains are autonomic, motor, states of arousal, attention and self-regulation.</p> <p>**Developmentally supportive care plans include recommendations for promoting autonomic stability (including digestion and energy conservation), positioning comfort and efficacy, pain management, protection of sleep, social interaction, sensory processing and feeding readiness.</p> <p>***Shared occupations are caregiving activities in which parents and infants actively engage that address infant needs but also support the developing parent-infant relationship (including positive touch, nurturing, feeding, bathing, early reciprocal interaction etc.)</p>		

Adapted with kind permission by Virginia Laadt, PhD, OTR/L from Laadt et al 2007

**Table A4: Examples of neonatal service delivery**

Neonatal occupational therapy services differ across the UK. Below are five models being used currently that include designated posts, joint posts with paediatrics or in-reach from community services. There are a number of similarities with all posts, the most common are:

- Contributes to developmental care policies, guidelines and projects.
- A resource for nursing, medical and therapy team in terms of preterm infant development and environmental modification.

### Summary of unit and occupational therapists' band/time

Unit details	Occupational therapy banding and Time
<b>Joint neonatal and acute paediatric post (London)</b> Two neonatal units (Level III and Level II) in two locations, approximately 42 beds. Four paediatric wards and large PICU on same site as Level II unit. Early implementer of Integrated Family-Centred Care.	1.0 WTE Band 8a clinical specialist 0.6 WTE neonates 0.4 WTE paediatrics
<b>Neonatal post (London)</b> Level II unit with 30 beds – 4 ITU, 6 HDU, 10 SCBU and 10 individualised care rooms where families stay with their baby from admission to discharge.	0.4 WTE 15 hours per week of Band 8a clinical specialist Neonates only
<b>Joint neonatal and acute paediatric post (London)</b> Level III unit with approximately 52 neonatal beds. Acute neurology paediatric wards and a large Paediatric Intensive Care Unit (PICU) on the same site.	WTE Band 8a clinical specialist 0.2 WTE neonates 0.8 WTE acute paediatrics
<b>Joint neonatal and community paediatric post (Scotland)</b> Level III unit serving North and South of the county with 8 ICU, 10 HDU cots and 11 special care cots and transitional care. Community time allows follow-up of babies at home and flexibility to transfer infant to colleagues in North and South teams when appropriate.	0.6 WTE Band 7 advanced practitioner 0.3 WTE on neonatal unit and in outpatient clinics 0.3 WTE days community follow-up
<b>Community occupational therapist with neonatal/developmental follow-up speciality (rural Scotland setting)</b> Level II neonatal unit with 12 beds for babies over 30 weeks GA. Those babies born extremely preterm or requiring surgery are repatriated after their stay on a Level III unit. Provide a region-wide joint therapy follow-up service with outpatient clinics held at two sites. Community caseload service is offered to families as appropriate.	Band 7 clinical specialist 1–1.53 days per month on developmental screening 2–3 days per month on assessment and treatment of infants identified as requiring this 1 day per month (averaged) in supporting neonatal unit round, including planned project work, training (shared among therapy team) Band 6 paediatric occupational therapist 12 days per month on developmental screening 1 day per month on assessment and treatment of infants identified as requiring this

**Table A5: Summary of occupational therapists' roles**

Post	Role on neonatal unit	Role in follow-up	Benefits of structure
<b>Joint neonatal and acute paediatric post (London)</b>	<p>Blanket referral system used, based on medical and psychosocial need</p> <p>Individualised assessments and interventions for infants from admission to discharge across both intensive care and special care</p> <p>Attends multidisciplinary ward rounds dependent on capacity.</p>	<p>Babies with identified developmental needs or expected neurological sequelae are referred to their local child development service before discharge</p> <p>Twenty-four-month corrected developmental assessments (Bayley III)</p> <p>Participate in Next Steps baby group. Runs as an eight-week programme all year</p> <p>Ad hoc appointments as needed for specific occupational therapy input in particular if concerns about neurological sequelae noted and neonatologist unsure whether the baby requires full referral to community</p> <p>Neurological assessments for babies with brain malformations identified as part of the foetal medicine clinic jointly with physiotherapy or with neurologist.</p>	<p>Facilitates transfer from neonatal unit to paediatrics when necessary for ongoing care</p> <p>Familiar face on paediatrics who knows the baby's story if admitted after discharge from the neonatal unit</p> <p>Resource for paediatrics in terms of specialist assessment of preterm infants and neonates</p> <p>Training and education for therapists, nurses and doctors on working with small babies and their families on paediatrics</p> <p>Opportunities to up-skill paediatric occupational therapists as succession planning.</p>

Post	Role on neonatal unit	Role in follow-up	Benefits of structure
<b>Neonatal post (London)</b>	<p>Blanket referral system used, based on medical and psychosocial need</p> <p>Individualised assessments and interventions for infants from admission to discharge across both intensive care and special care</p> <p>Attends multidisciplinary ward rounds</p> <p>Responsible for the organisation and delivery of 'Little Stars', a five-week follow-up group, offered to all families following a NICU admission</p> <p>Responsible for the organisation and delivery of 'Supper Club', an evening group for all family members to provide support and developmental advice</p> <p>Responsible for the rolling education programme that runs for all families as part of the parents' support group</p> <p>Responsible for parent newsletter</p> <p>Co-opted member of network board, feeding data directly back to board level, provide information on role of occupational therapy for network website.</p>	<p>All infants born less than 30 weeks or who have had an MRI will be offered neurodevelopmental follow-up</p> <p>Newborn Behavioural Assessment Scale (NBAS) and Prechtl, neurological assessment of general movement provided at term</p> <p>Bayley III provided at 3 months corrected with Prechtl</p> <p>Bayley III provided at 6 months, 1 year and 2 years</p> <p>Ad hoc appointments as needed for specific occupational therapy input.</p>	<p>Integrated model of practice, where occupational therapist is a core member of the neonatal team</p> <p>Proactive model not waiting for problems to occur, but providing developmentally supportive advice from the outset</p> <p>Familiar face in follow-up who knows the baby's story</p> <p>Resource for paediatrics in terms of specialist assessment of preterm infants and neonates</p> <p>Training and education for therapists, nurses and doctors on working with all babies and their families in neonatal care.</p>

Post	Role on neonatal unit	Role in follow-up	Benefits of structure
<b>Joint neonatal and acute paediatric post (London)</b>	<p>Referral criteria system used, based on medical and psychosocial need</p> <p>Individualised assessments and interventions for infants from admission to discharge across both intensive care and special care</p> <p>Consultative style model in respect to supporting colleagues with complex cases</p> <p>Attends multidisciplinary ward rounds.</p>	No input to follow-up clinic	<p>Facilitates transfer from neonatal unit to paediatrics when necessary for ongoing care</p> <p>Familiar face on paediatrics who knows the baby's story if admitted after discharge from the neonatal unit</p> <p>Resource for paediatrics in terms of specialist assessment of preterm infants and neonates</p> <p>Training and education for therapists, nurses and doctors on working with small babies and their families on paediatrics</p> <p>Opportunities to up-skill paediatric occupational therapists as succession planning</p> <p>Limitations of this structure:</p> <ul style="list-style-type: none"> <li>• Does not support transition of infants and families into community</li> <li>• No opportunity for continued specialist neonatal assessment to inform infants' likely trajectory</li> <li>• Limited opportunity to provide anticipatory guidance to families once discharged.</li> </ul>

Post	Role on neonatal unit	Role in follow-up	Benefits of structure
<b>Joint neonatal and community paediatric post (Scotland)</b>	<p>Criteria for therapy follow-up – babies born before 29 weeks GA, IVH grade III or IV, HIE and any baby at the discretion of the consultant</p> <p>Individualised assessments and interventions for infants from admission to discharge across intensive care and special care</p> <p>Meet with parents to explain therapy role and follow-up, in conjunction with discharge liaison midwife in the Neonatal unit.</p>	<p>Neonatal care pathway for therapy provision for babies preterm and HIE until 24 months corrected age</p> <p>Babies with identified developmental needs or expected neurological sequelae can be followed up in the community by the Band 7 advanced practitioner or transferred to paediatric occupational therapy colleagues</p> <p>Neurodevelopment clinics twice a month with consultant neonatologist, occupational therapist, physiotherapist and/or speech and language therapist. Babies assessed using Bayley III at 6, 12 and 18 or 24 months corrected age.</p>	<p>Resource for specialist assessment of preterm infants and neonates to provide early therapy intervention</p> <p>Facilitates transfer from neonatal unit to therapy outpatient clinics and if required to community caseload with continuity of therapist</p> <p>Training and education for therapists, nurses and doctors on working with small babies and their families</p> <p>Opportunities to facilitate training of paediatric occupational therapists as succession planning.</p>
<b>Community occupational therapy with neonatal/developmental follow-up speciality (rural) in South West Scotland</b>	<p>Attendance at the weekly medical unit round is shared between the Joint Therapy Baby Service team members (occupational therapist (OT), physiotherapist (PT), and speech and language therapist (SLT)). Referrals are identified and made as per the pre-set criteria (in line with national guidelines) to feed into the therapy follow-up service</p> <p>Informal advice provided by occupational therapist, physiotherapist and/or speech and language therapist as required during inpatient period within the unit round capacity</p> <p>Attends multidisciplinary unit rounds.</p>	<p>Joint service provision from OT, PT, SLT with links to wider MDT including health visiting and consultant paediatricians</p> <p>Referrals are fed into either the Baby Clinic (preventative screening) care pathway or Baby Caseload care pathway should any additional concerns or indicators be present</p> <p>Infants born before 29 GA are seen for follow-up until 24 months corrected age and infants between 29 and 32 GA until 18 months corrected age</p> <p>Planned reviews at post-discharge, 4 months, 8 months, 12 months, 18 months (and 24 months as above) corrected ages for informal and formal assessment including use of developmental assessments, e.g. Bayleys III</p> <p>Additional review appointments can be made depending on need. Clients can transfer between clinic and caseload care pathways as required.</p>	<p>Facilitate transfer from neonatal unit to therapy follow-up/caseloads when necessary for ongoing care</p> <p>Resource for transdisciplinary team in terms of developmental care and later occupational outcomes.</p> <p>Training and education for therapists, nurses and doctors on working with small babies and their families on paediatrics</p> <p>Opportunities to up-skill paediatric occupational therapist as succession planning.</p>



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# Appendix 5: Guideline Development Group

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## Appendix 6: Conflicts of interest declarations

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Declarations were made in line with the conflicts of interest procedures (section 9.6, COT 2017a) as follows:

- Guideline group members, co-opted critical appraisers and end users involved in the consultation activity identified their membership of one or more professional organisations or specialist neonatal-related forums, which included the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families, Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and National Association of Neonatal Therapists (NANT).
- One member of the guideline development group was a co-author of evidence included within the guideline. Careful allocation of critical appraisal, and the consensus approach taken in the guideline development meetings, meant there was no undue bias from any authorship.
- Two members of the guideline group are involved in the development of European standards for developmental care. Another group member is a member of the NICE guideline group for developmental follow-up of preterm infants.
- Three group members are involved in the Brazelton Centre UK, a further member is a NIDCAP trainer, one member is a FINE trainer via Bliss and one member is involved with the Bobath Centre.
- One co-opted appraiser was the chair of the Royal College of Occupational Therapists Specialist Section – Children, Young People and Families – Neonatal Forum.
- The co-Editorial Lead was an officer of the Royal College of Occupational Therapists.
- Stakeholder and peer reviewer declarations included interests related to neonatal organisations, services and research/publications.

The nature of declarations, made by all those involved in the guideline development, was related to professional interests and expertise in clinical practice, education or research.

There were nil service-user conflicts of interest declared, other than personal experience of a neonatal and/or early intervention occupational therapy service.

No commercial or financial interests were declared.

The adherence to the Royal College of Occupational Therapists' conflicts of interest policy, the nature and management of the above declarations, together with the robust guideline development methodology, mean that the potential for any bias has been taken into account and mitigated.

## Appendix 7: Literature search strategy

**Table A6: Search terms and strings**

String 1 – Pure neonate terms	String 2 – Paediatric terms	String 3 – Population and settings-related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
Neonat* OR Preterm OR Premature OR Preemie* OR Low Birthweight	Paediatric OR Pediatric OR Newborn* OR Infant OR Baby OR Babies	Matern*	Assessment* OR Screen* OR Identif* OR Developmentally supportive care OR Positioning OR Pain management OR Massage OR Feeding OR Co-occupant* OR Sensor* OR Cognit* OR State regulat* OR Neurobehav* OR Parent OR Parents OR Parenthood OR Parenting OR Stress OR Stressful OR Stressed OR Environment* OR Neurodevelopment* OR Neuro-development* OR	Developmental care OR Skin-to-skin OR Kangaroo care OR Couplet care OR NIDCAP OR Individualised developmental care OR Developmentally supportive care OR Positioning OR Pain management OR Massage OR Feeding OR Co-occupat* OR Sensor* OR Cognit* OR State regulat* OR Neurobehav* OR Parent OR Stress management OR Environment OR	Occupational therap*	Occupation* OR Rehabilit* OR Enable* OR Enabling OR Enabled OR Multidisc* OR Activit* OR Self care OR Self-care OR Participat* OR Engage OR Engaged OR Engaging OR Engagement OR Therapy OR Therapies	Econom* OR Cost* OR Financ* OR Saving* OR Afford OR Affordable OR Expens* OR Inexpens* OR Loss making OR Loss-making OR Expenditure* OR Fiscal OR Fund* OR Value n2 for OR Cost effective* OR Cost-effective* OR Cost benefit* OR Cost-benefit* OR Cost-control OR Benefit-cost* OR Health care cost* OR	NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Critical care OR Paediatric intensive care OR Neonatal unit OR Local neonatal unit OR LNU OR Paediatric intensive care unit OR Neonatal environment OR

String 1 – Pure neonate terms	String 2 – Paediatric terms	String 3 – Population and settings-related terms	String 4 – Interventions	String 5 – Related interventions	String 6 – Occupational therapy	String 7 – Occupational therapy related terms	String 8 – Finance and value terms	String 9 – Setting terms
			Neuro development* OR Developmental outcome* OR Early intervention* OR Ultra-early intervention* OR Ultra early intervention* OR Transitional care OR Family* OR Families OR Familial OR Parent engagement OR Attachment OR Attunement	Neurodevelopment OR Developmental outcomes OR Early intervention OR Ultra-early intervention OR Transitional care OR Family centred OR Parent engagement OR Family integration OR Family intervention OR Attachment OR Attunement OR General movements			Hospital cost* OR Health expenditure* OR Capital expenditure* OR Health economic* OR Fiscal OR Financial OR Finance OR Deductible* OR Coinsurance OR Coinsured OR Fee OR Fees OR Charge* OR Budget* OR Socioeconomic OR Insurance OR Insure OR Insured	Transitional care unit OR Maternity unit OR Hospital clinic OR Early-years service* OR Early intervention service OR Private clinic* OR Education provider* OR Child care setting OR Nursery school OR Child* ward

## Core databases or platforms

A title/abstract/descriptor search was undertaken for the various search string combinations.

### Key:

ab = abstract    de = descriptors    hw = heading words    id = key words  
 kw = keyword    oh = outline heading    sh = subject heading    su = subject  
 ti = title

**Table A7.1: Core databases or platforms: occupational therapy-specific search**

Database or platform and search date	EBSCO*	Ovid*
	13.01.2016 and 26.01.2016	13.01.2016, 15.01.2016 and 26.01.2016
<b>Search term strings (below) and fields searched (right)</b>	ti, ab, su	ab, de, hw, id, oh, sh, ti
Strings: 1 AND 6	257	66
Strings: 1 AND 3 AND 6	15	3
Strings: 1 AND 4 AND 6	136	50
Strings: 1 AND 6 AND 7	169	66
Strings: 1 AND 6 AND 8	40	2
Strings: 1 AND 6 AND 9		34
Strings: 1 AND 3 AND 4 AND 6	12	2
Strings: 1 AND 3 AND 6 AND 7	15	3
Strings: 1 AND 3 AND 6 AND 9		1
Strings: 1 AND 6 AND 8 AND 9		1
Strings: 2 AND 6 AND 9	215	
Strings: 2 AND 6 AND 9		26
Strings: 2 AND 3 AND 6 AND 9	4	1
Strings: 2 AND 4 AND 6 AND 9	119	24
Strings: 2 AND 6 AND 8 AND 9	35	1
Strings: 2 AND 6 AND 7 AND 9*	145	26
Strings: 2 AND 3 AND 6 AND 7 AND 9*	4	1
Strings: 2 AND 3 AND 4 AND 6 AND 9	2	1
Strings: 3 AND 4 AND 6	74	25

Database or platform and search date	EBSCO*	Ovid*
	13.01.2016 and 26.01.2016	13.01.2016, 15.01.2016 and 26.01.2016
Strings: 3 AND 6 AND 7 AND 9	4	1
Total results	1,246	334
Removed via platform de-duping and/or filter options (date/language)	856	145
<b>Total for cleansing</b>	390	189

Medline, CINAHL – accessed via EBSCOHOST platform

AMED, HMIC, PsycINFO, Social Policy and Practice – accessed via Ovid platform

\*EBSCOHOST consisted of two searches and Ovid consisted of three searches, with details available upon request.

**Table A7.2: Core databases or platforms: intervention-specific search**

Database or platform and search date	EBSCO*	Ovid
	25.02.2016 and 18.03.2016	25.02.2016
<b>Search term strings (below) and fields searched (right)</b>	ti, su	ti
Strings: 1 AND 5 AND 9	1,008	256
Strings: 2 AND 5 AND 9	1,112	331
Total results	2,120	587
Removed via platform de-duping and/or filter options (date/language)	0	176
<b>Total for cleansing</b>	2,120	411

\*EBSCO consisted of two searches, with details available upon request.

**Table A8: Specialist databases or platforms – occupational therapy specific**

Database or platform	Fields	Terms	Number retrieved	Date of search
<b>OT Search</b>	ti OR su	String 1 OR String 2	<b>185</b>	29/01/16
<b>Cochrane</b>	ti OR ab OR kw	String 2 AND (String 9 OR String 1) AND String 6	<b>68</b>	04/02/16
<b>OTSeeker</b>	ti	String 1 OR NICU OR SCBU OR Special care baby unit* OR PICU Newborn* OR infant* OR Baby or Babies OR toddler* OR pre-school OR preschool OR 'early childhood' NICU OR Neonatal intensive care OR SCBU OR Special care baby unit OR NIC OR PICU* OR Paediatric intensive care OR Pediatric intensive care OR Neonatal unit OR Transitional care unit OR Maternity unit OR Early-years service* OR Early intervention service OR Education provider* OR Child care setting OR Nursery school OR Child* ward	<b>264</b>	04/02/16
<b>OTDBASE</b>	ab	Neonate OR Neonates OR Neonatal Newborn OR Newborns OR Low birthweight	<b>41</b>	19/01/16
<b>Handsearch</b>	N/A	N/A	<b>2</b>	Various

No searches were carried out in these specialist databases for intervention-specific literature.



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## Appendix 8: Acknowledgements

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The guideline development group would like to thank all those who have contributed to the development of this practice guideline.

### A8.1 Parent consultees

- The five parents who attended a group discussion at the Royal Free NHS Trust.
- Mrs Sarah Fulton.

### A8.2 Stakeholders

Seventeen organisations or individuals commented on the draft guideline consultation. The following wished to be acknowledged in the guideline:

- Bliss
- Hilary Cruikshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian/Chair Association of Paediatric Chartered Physiotherapists
- Linda Hunn, Associate Director/Lead Nurse, Trent Perinatal and Central Newborn Networks
- Dr Helen Mactier, Consultant Neonatologist, British Association of Perinatal Medicine Honorary Secretary
- Ruth Moore, Manager/Lead Nurse, Staffordshire, Shropshire and Black Country Newborn and Maternity Network
- Northwest Neonatal Operational Delivery Network
- Julia Petty, Senior Lecturer in Children's Nursing, University of Hertfordshire/Neonatal Nurses Association Executive Member
- Royal College of Midwives
- Royal College of Paediatrics and Child Health, on behalf of five members
- Julie Taylor, Clinical Governance Lead for Paediatrics and Neonates, Dudley Group NHS Foundation Trust – Russells Hall Hospital

The following organisations commented on the guideline scope: Neonatal Nurses Association UK; Royal College of Speech and Language Therapists (Neonatal Special Interest Group); Bliss; Association of Paediatric Chartered Physiotherapists (Neonatal).

### A8.3 External peer reviewers

Two independent reviewers appraised the draft guideline:

- Dr Roberta Pineda, PhD OTR/L, Assistant Professor, Washington University School of Medicine/Co-Chair Neonatal Therapy National Certification Board.

- Dr Anne Gordon, Senior Consultant Occupational Therapist, Evelina London Children's Hospital, Guy's and St Thomas' Hospital NHS Foundation Trust/Visiting Senior Lecturer, Institute of Psychiatry, Psychology and Neuroscience, King's College London

## **A8.4 Co-opted critical appraisers**

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Seven occupational therapists responded to the draft guideline consultation and the following wished to be acknowledged in the guideline:

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# Occupational therapy in neonatal services and early intervention

## *Practice guideline*

This publication provides specific evidence-based recommendations which describe the best and most effective practice for occupational therapy for high-risk infants in neonatal and early intervention settings. It will assist decision making about areas for assessment and intervention, in addition to describing the profession's contribution to the neonatal care pathway. It may also be of use to other neonatal practitioners and commissioners with regards to the inclusion of occupational therapy within neonatal multidisciplinary teams.



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