FINAL VERSION:
ACP SUBMISSION TO CONSULTATION ON NEONATAL CARE COMMISSIONING FRAMEWORK AND NEONATAL STANDARDS

Deadline for submission: 16 April 2009
Contributors: Asha Phillips, Carol Hanson, Anna Fitzgerald, Christine Porter, Jenifer Wakelyn, Jane Elfer, Claudia de Campos, Louise Emanuel
Drafted by: Laura Smith

NB: Please note that the final submission had to be given in the form of an online questionnaire; this document provides the text used to answer the individual questions.

Introduction and general comments

The Association of Child Psychotherapists, the professional body for psychoanalytic child and adolescent psychotherapists in the UK, welcomes this consultation on the development of neonatal standards and a commissioning framework. In common with the Department of Health/NHS Neonatal Taskforce, we hope that together these guidelines will deliver improved services and outcomes for babies and their families.

We welcome the recognition that neonatal care requires a range of multi-disciplinary medical care and should include emotional and psychological support for mothers and their infants, and for families. There is a need for emotional and psychological help to be embedded throughout all aspects of neonatal care. A specialist neo- and peri-natal infant mental health service should be made available as part of CAMHS provision for premature, ill or disabled babies and their families in Special Care Baby and Neo-Natal Intensive Care Units. This is not only for parents and infants and other family members, but also for doctors, nurses and other medical staff who are impacted on by trauma when caring for very vulnerable babies and their families, and need training in understanding the emotional impact of trauma. Such emotional and psychological support should continue for babies and families in the important transition period after discharge, with perinatal mental health support made available in in-patient and outpatient units, for example in Chronic Lung and Feeding Clinics, and through local Child and Adolescent Mental Health Services (CAMHS) in the form of a specialist service. A recognition of this should be embedded throughout the documents' recommendations.

Child and adolescent psychotherapists have a long history of work within hospital neonatal units, supporting babies, parents and staff. It is our experience that families' access to psychological and emotional support in neonatal care is patchy and we believe it should be an integral part of every service. This submission has been put together by child and adolescent psychotherapists working alongside other CAMHS professionals who have specialist training and expertise in prenatal mental health, including psychologists and perinatal psychiatrists. Child and adolescent psychotherapists are recognised as core members of CAMHS teams, as set out in Standard 9 of the National Service Framework for Children, Young People and Maternity Services (2004). They perform a specialist function as part of a multi-disciplinary team in this setting, using their in-depth training in observational skills to observe subtle nuances in the mother-baby relationship that may otherwise be missed. Child and adolescent psychotherapists are also trained to work with the emotional

aspects of becoming a parent and the changes that it entails. This is of particular importance when the birth has been traumatic or in the case of pre-maturity. Fostering a good attachment between mother and baby is vital for the child's emotional health and supporting mothers and their babies in these early days can prevent long term emotional and behavioural difficulties (Lynch, M. A. & Roberts, J. 1977, British Medical Journal Vol 624).

Section 1: STANDARDS

(NB: see Neonatal Standards for Stakeholder Comment document here: http://www.neonatal.org.uk/standardsquestionnaire/)

Standard 1: Organisation of Neonatal Services

(agree - no comments)

Standard 2: Staffing of neonatal services

2.4 Allied Health Professionals:
2.4.2 (p8): Child and family mental health professionals should be included as an integral part of the multi-disciplinary team providing neonatal care alongside physiotherapy, occupational therapy, speech and language therapy, as listed here, and play specialists. All units providing neonatal care should provide access for mothers, parents and families to emotional and psychological support provided by trained CAMHS professionals who have specialist training and expertise in prenatal mental health. This should include child and adolescent psychotherapists, who play a vital role in the training and emotional support of medical staff, including junior doctors, registrars, midwives and neonatal nurses. They also participate in hospital-organised conferences with regard to the psychological and emotional needs of babies, parents and staff in the Neonatal Intensive Care Unit (NICU) and Special Baby Care Unit (SCBU).

2.4.3 (p9): Perinatal mental health support for mothers, infants and families should be available in in-patient and out patient units and as part of the multi-disciplinary neuro disability teams that provide care for infants and families following discharge. Infants who have had a difficult beginning are more likely to present with emotional and behavioural difficulties later in childhood and early interventions can help prevent this. The first research (Marlow et al, 2005) in the UK to follow a group of babies born extremely prematurely, 28 weeks or less, found that almost 50 per cent went on to develop a disability or learning difficulty. Research from the US and UK has shown that many babies born prematurely will experience long-term difficulties; a 10-year follow up study showed that premature babies are three times as likely to be low achievers or to have other special needs at school, were likely to be less socially successful and likely to have fewer friends at school than their peers. In England a follow up study of babies born between 32 and 35 weeks found that about a third had problems with their learning or behaviour at school.

2.5 (p9): Follow-up provision for mothers and babies on an outpatient basis after discharge is an area which has been identified as requiring more input. The transition from hospital to community services can be difficult for families who have had a sick or premature baby or have a disabled baby. Many parents do not feel able to seek

emotional support until well after the medical side of things has been resolved. Some who have suffered bereavement or whose child has been left with disabilities will need specialist ongoing support. Those parents who were able to make use of the psychological support service during their stay in the special care unit may be keen to be seen by the same professional in an outpatient clinic, offering important continuity of care. Others may not want to go back to the hospital for this help, as they find it painful to recall the hospitalisation of their infants, yet feel too vulnerable to join post-natal support groups provided at a universal level. A targeted service aimed at promoting ease of transition for families post-discharge, and providing continuing emotional and psychological support, is recommended. There is often a gap in provision of a liaison co-ordinator to facilitate pre-and post-discharge of families where there is a premature or ill baby, or where there has been a still birth. The presence of an individual responsible for discharge planning, as set out here, will provide a consistent presence to help manage the family's transition from hospital into community care.

2.6.1 (p9): The presence of a child and adolescent psychotherapist, as part of a multidisciplinary team, would be important for the following competencies listed here: developmental needs and care of the baby; palliative care; bereavement support; and support for siblings. Such an input can also help foster attachment between mother and baby.

Standard 3: Care of the baby and family experience

(p11): We welcome the document's emphasis on family-centred care, aimed at enhancing attachment between a baby and the family, resulting in improved long-term outcomes for both. Parents require emotional and psychological support at different stages of the infant's care. Every parent should have the opportunity to meet with a CAMHS professional to receive support related to the impact of trauma as part of in-patient care. A child and adolescent psychotherapist can observe and discuss with the parent the infant's emotional needs and development, as well as the parent's and their other children's needs in dealing with this painful and difficult experience. Specialisst CAMHS support needs to be available following discharge, both through outpatient clinics, offering the valuable continuity of care of seeing the same professional the family saw as inpatients, and in local community settings. It is often after the immediate medical concerns have been resolved that parents need to reflect on the emotional impact of the experience. Those parents who suffer bereavement or whose child has been left with disabilities will need ongoing support.

It is our experience that parents whose first experience of their baby is in a neonatal unit can struggle to feel they have a valid place and contribution to make. Separated to varying degrees from talking to and touching the baby, providing human contact and comfort, and unable to feed them, mothers can sometimes feel as though the baby 'belongs to the hospital'. The opportunity to talk through and address some of these feelings of fear and impotence with a specialist CAMHS professional is an essential part of family-centred care.

Standard 4: Transfers

(agree - no comments)

Standard 5: Professional competence, education and training

5.5 (p15): 1. Training: As noted in part here, ("all staff should be trained and competent in developmental needs, care of the baby…") it is important that all staff working in neonatal care be trained in the emotional development of the baby. Child and adolescent psychotherapists as part of a multidisciplinary CAMHS team should be involved in the education and training of staff in this regard. The Royal College of Paediatrics and Child Health have produced the Child in Mind series of training sessions which includes one for a neonatal setting. Child and adolescent psychotherapists are well placed as trainers of this material because of their in-depth experience of working with mothers and babies.

It is often difficult for staff working in a highly medicalised and pressured environment to remember that each baby has feelings, experiences and needs beyond the essential physical and medical care and will be affected by their environment. Child and adolescent psychotherapists can help bring the baby's emotional life into focus for staff. Nurses and junior doctors should be encouraged to speak in gentle tones to the infants they treat in order to soothe the baby and help reduce trauma (Scheeringa & Gaensbauer, 2000). They should also be reminded of the use of sucrose for babies having minor procedures to reduce pain (Cochrane Review, 2004 – see references). Training for healthcare staff, as well as midwives, health visitors and primary mental health workers, should also be given in post-natal depression, so that workers are able to recognise the difference between the 'baby blues', post-natal depression and Peurperal Psychosis in mothers. The early identification and treatment of women at risk of, or experiencing, post-natal depression should be a high priority as research shows that post-natal depression results in a disruption of the bonding process in mother and infant at a critical time in the developing relationship.

2. Support: The needs of medical staff for emotional and psychological support should also be recognised. Doctors, nurses and other medical staff are impacted on by trauma when caring for very vulnerable babies and their mothers and families and may need support to cope with this and the possible outcomes of disability and bereavement. Medical staff also need training in understanding the emotional impact of trauma on the parents and on the baby.

Standard 6: Surgical services

6.3 (p17): The support services that should be readily available for babies receiving neonatal surgery should include perinatal mental health services for infants, parents and families as part of CAMHS provision in multi-disciplinary neonatal teams. Such provision should include a child and adolescent psychotherapy presence because of their unique training in work with mothers and babies.

Standard 7: Clinical Governance

7.4 (p18): Child and adolescent psychotherapists, along with other specialist CAMHS professionals, have the skills and competencies to be involved in 'Counselling of parents where babies will require specialist services' (first bullet point).

Standard 8: Data requirements

(agree - no comments)

Additional Information

References:

Anscombe, E (2008) The dichotomy of containing trauma amidst joy: New life and a neonatal death; the experience of working with the parents of twins on the NICU; Infant Observation 11:2 pp147-160

Bender, H (1990) On the outside looking in: sibling perceptions, dreams and fantasies of the premature infant. International Journal of Perinatal Studies, 2, 144-143

Cohen, M (2003) Sent before my time. Karnac, London.

Cohn, N (1994) Attending to the emotional issues on a special care baby unit. In Obholzer. A & Vega, Z.R. (eds) The Unconscious at work: Individual and organisational stress in the human services. Routledge, London.

Currid T (2004) Improving perinatal mental health care. Nursing Standard; **19**:40-43.

Fischer JE, Calame A, Dettling AC, Zeier H, Fanconi S (2000) Experience and endocrine stress responses in neonatal and pediatric critical care nurses and physicians. Critical Care Medicine; **28**:3281-8.

Harris, J (2005) Critically ill babies in hospital - considering the experiences of mothers. INFANT OBSERVATION. The international Journal of Infant Observation and its Applications, 8 (3) 247 - 258

Jotzo M, Poets CF (2005) Helping parents cope with the trauma of premature birth: an evaluation of a trauma-preventive psychological intervention. Pediatrics; **115**:915-919.

Mendelsohn, A & Phillips, A (2005) Introduction to working in the NICU: Our work in Context. International Journal of Infant Observation, Vol.8 (3) (special issue about babies in hospital)

Mendelsohn, A (2005) Recovering Reverie: Using infant observation in interventions with traumatised mothers and their premature babies. International Journal of Infant Observation, Vol.8 (3) (special issue about babies in hospital)

Miller, B (2001) 'Sharing the thought'; work in a neo-natal unit: Infant Observation 4:3 pp97-108

Reid, M (1992) Joshua - life after death: The replacement Child JCP, 18 (2) 109-138

Scheeringa & Gaensbauer, (2000) Post traumatic stress disorder, in Zeanah, C (ed) Handbook of Infant Mental Health, second edition, New York, Guidford Press

Stevens B, Yamaada J, and Ohlsson A (2004) Sucrose for analgesia in new born infants undergoing painful procedures, Cochrane Database of Systematic Reviews Issue 3

Sloper, P (2000) Predictors of distress in parents of children with cancer: a prospective study. Journal of Pediatric Psychology; **25**:79-91.

Smith LK, Draper ES, Manktelow BN, Dorling JS, Field DJ (2007). Socioeconomic inequalities in very preterm birth rates. Archives of Diseases in Childhood – Fetal and Neonatal Edition; **92**:F11–F14.

Swanson JD, Wadhwa PM (2008) Developmental origins of child mental health disorders. Journal of Child Psychology and Psychiatry; **49**:1009-19.

Szur, R (1981) Children in Hospital, Journal of Child Psychotherapy, 7 (2), 137-141

Appendix 5: RCOG - Standards for Maternity Care (relating to the newborn)

At Standard 17, Care of babies born prematurely (p39), the psychological needs of babies and families in NICU should not be forgotten. The effect of a premature birth can be traumatic on both the mother and the baby. In our experience, the mother can

often become quite afraid, perhaps blaming herself for hurting the baby or wondering whether the baby is going to survive, which can impair her capacity to relate to her baby and lead to a distorted relationship between mother and baby. There is some evidence that, for their part, babies in the NICU show behaviour consistent with a diagnosis of Post-Traumatic Stress Disorder (PTSD) (Scheeringa & Gaensbauer, 2000).

Section 2: FRAMEWORK

(see Neonatal Framework document here: http://www.neonatal.org.uk/standardsquestionnaire/)

3. Evidence-Based Service Objectives

3.2: We are concerned that clinical psychology is the only discipline listed with regard to emotional and psychological support for parents and families with the impact of neonatal illness. Clinical psychology is also listed at point 2. on page 15 (under Monitoring and Contracting). In fact, emotional and psychological support for infants and their parents, when special neonatal care is required, is provided by mental health professionals from the range of core Child and Adolescent Mental Health Services (CAMHS) disciplines, as set out in Standard 9 of the National Service Framework for Children, Young People and Maternity Services (2004). These include child and adolescent psychotherapy, child psychiatry *and* clinical psychology, with training in child and family mental health, and further training in infant mental health and parent-infant emotional care and support.

Child and adolescent psychotherapy is integral to delivering care 'in a way that aims to minimise the physical and psychological impact of neonatal care on the baby and their family and to be responsive to the medical and psychosocial needs of babies and their families' (3.2, p12). Child and adolescent psychotherapists have worked with neonates and their families in hospitals since the 1980s (Szur R, 1981) and have published extensively in the field. Their training, in particular its focus on infant observation, makes them an important asset in any multi-disciplinary paediatric team. The role of a child psychotherapist in such a team includes sharing information about the patient in team meetings, which can help the team to bear in mind the emotional impact of neonatal care on parents and therefore improve the care offered to mothers and babies. The presence of a child psychotherapist in meetings where doctors are delivering difficult news can be of great benefit to both doctor and patient.

3.3: In our experience, parents often find they need time with a child and adolescent psychotherapist in order to think about questions they may want to ask the medical staff, which contributes to their making informed decisions about treatment. They are often also frightened for psychological reasons of engaging with their infants and a child and adolescent psychotherapist can help unravel what is impeding their capacity to bond with their newborn and so encourage attachment between parents and baby.