Expanding Frontiers of Neonatal Care

Expanding Frontiers of Neonatal Care:

An Interdisciplinary Approach

Edited by

Elvidina Adamson-Macedo
and Christopher Barnes

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TABLE OF CONTENTS

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PREFACE

ELVIDINA N ADAMSON MACEDO
& CHRISTOPHER BARNES

Prematurity is a global public health issue and recent figures show that it impacts around 15 million newborns globally each year, and is a leading cause of death and disability. The consequences are considerable and, for some, the effects are severe with lifelong limitations. ***Expanding Frontiers of Neonatal Care: A Multidisciplinary Approach*** is a book about the hospitalised preterm and sick newborn, their family and those that support them. It is written by a dedicated multidisciplinary and international team of psychologists, medical doctors, nurses and psychiatrists who all commit and work to enhance the quality of those impacted by prematurity.

Whilst most books that discuss the topic of prematurity are aimed at parents (self-help type) or have a highly specific focus (e.g., treatment of the [physical] complications of prematurity), this book has three important and distinct purposes:

(i) To offer a full and comprehensive overview for students or professionals who wish to understand prematurity as part of their education, continuous professional development (CPD), or for those who have a general interest in the area.
(ii) To provide a multi-disciplinary and international perspective on prematurity and neonatal care.
(iii) To support the needs of educators who wish to teach the topic of prematurity with the aid of concisely written summaries and pedagogic features.

Therefore, we believe this book will fully engage readers with interdisciplinary perspectives, contemporary reflections and easily accessible science.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to all the families who have generously shared their stories and experiences with me over the years. Your resilience, strength, and unwavering love have inspired this book. I am also indebted to the many dedicated healthcare professionals whose expertise and compassion have helped shape the landscape of neonatal care; your commitment to supporting families during their most vulnerable moments is truly remarkable. Finally, to Vanessa, Maia and Espen—thank you for the support, encouragement and inspiration you bring to my life. **CB**

From 1978 to date, my "scientific passion" has been (and will continue to be) the babies born prematurely, their parents and their hospital caregivers. I am—and always will be—in debt to all of you. Without you, I would not be here, today, writing this message. I would not be writing—with my outstanding and dedicated colleagues—this book about you. So…I humbly say, "Thank You," with my brain and heart! I wish to say, "Thank You," to my beloved late husband, Colin, for his love and patience, teaching me that "when there is a will, there is a way." To my beloved son, Francisco, who has been my "rock," I say, "Thank You," for walking with me during moments of great pain. Last, but not least, I thank my dedicated co-author and all of the contributors to this book for your high-quality work, your dedication, and commitment. **ENAM**

SECTION I:

THEORETICAL FOUNDATIONS OF NEONATAL CARE

CHAPTER 1

PSYCHOLOGICAL AND THEORETICAL APPROACHES TO NEONATAL CARE

CHRISTOPHER BARNES
& ELVIDINA N. ADAMSON-MACEDO

Overview

In this chapter, we discuss the impact that premature birth has on families and newborn development during hospitalisation. We provide an overview of psychological theory and use it to offer a framework for understanding the broad context within which development and parenting take place. This chapter also incorporates a major section on the application of Bronfenbrenner's Ecological Systems Theory to map out the multi-level and cross-system interactions between the newborns and their families, the professionals who work with them, the context of the neonatal environment and the community-level factors, as well as policy implications, that may influence support at this time.

This chapter will…

- provide a definition of prematurity, its incidence, and outcomes;
- provide an overview of psychological theory and research that aids in the understanding of prematurity and its impact on the family;
- offer a theoretical framework for mapping the broad context in which development happens for prematurely born newborns.

Key Terms

Neonatal Health Psychology; Developmental Systems Theory; Bioecological Model; Prematurity

Introduction

In the UK, there are reported to be around 60,000 babies born prematurely each year (<37 weeks gestational age), which equates to roughly 8 % of all live births (BLISS 2022). When a baby is born prematurely, they can be categorised as infants of moderately early age (32–37 weeks gestation), very early age (28–32 weeks gestation), or extremely early age (less than 28 weeks gestation). Birthweight follows a similar classification, with those born at a low (<2.5 kg), very low (<1.5 kg) or extremely low weight (< 1 kg). Babies who are born both early and of low birthweight are commonly referred to as preterm.

The highest incidence of preterm birth tends to happen in low-income or developing countries (WHO 2022), with global rates estimated at between 5 % and 18 %. Therefore, prematurity and the complications associated with it may affect up to fifteen million babies and their families globally each year. Consequently, there is a high risk of neonatal morbidity (~ one million children) and lifelong complications. Some children may also go on to develop an increased risk of blindness and respiratory problems, mental disabilities and/or cerebral palsy. However, whilst not all children will encounter the most severe types of adversity, there are still likely to be short- or medium-term challenges to their development and relationship formation with others.

The proceeding sections give an overview of two of the most prominent theories that can be applied to prematurity: one that was established to act as a theoretical and disciplinary hub from which to organise, capture and promote our understanding of the development of newborns in neonatal care (Neonatal Health Psychology [NNHP]); and the other that offers a theoretical framework to conceptualise and study human development within specific contexts (Developmental Systems Perspectives).

Pathways in the Emergence of Neonatal Health Psychology

The science of neonatology was in rapid development in the 1970s and neonatologists were specially trained to look after those tiny babies who were sick in Special Care Baby Units (SCBUs). At around the same time, Macedo's research began in London-based Special Care Baby Units. It became clear that the development of these newborn infants was significantly lacking, with respect to psychological and behavioural sciences. In addition,

a policy of minimal handling was established in some hospitals, meaning that parents were sometimes not even permitted to visit their babies on demand.

Nevertheless, following the establishment of *prenatal and perinatal psychology and medicine* (Fedor-Freybergh 1988) and *neonatology*, the sub-discipline of *environmental neonatology* (Gottfried and Gaiter 1986) was formalised, which sought to encompass the study of newborn special care facilities, including their impact on the medical and developmental statuses of sick infants. Two years later, Wolke (1987) proposed the addition of the word "developmental" (to environmental and developmental neonatology) as a way to acknowledge the importance of the developmental change and progress of the hospitalised newborn.

At about the same time, studies of the unborn baby (such as those that investigated prenatal learning) started to "lend" important information to those born prematurely. Those advancements were, of course, helped by the continuing development of neonatology. Delivering care for the newborn, and particularly the preterm neonate, is now a matter of multidisciplinary knowledge, skills and procedures, including continuing assessment. It took many years for the recognition of this reality; as babies survived and new procedures were investigated, this knowledge has increased the quality of survival of the baby born preterm.

Health psychology was established as a sub-discipline in 1994 and is now defined as "a specialist area of psychology that focuses on how biological, psychological and social factors influence health, illness and healthcare. It explores how people stay healthy, why they get ill and how they respond once they are ill. It is a combination of science and practice" (NHS 2023).

Nevertheless, despite the growing interest and attention towards both paediatric and child health psychology (Johnson and Johnson 1991; Eiser *et al*. 1994; Collier 1997), there was a theoretical gap in the 1990s that required bridging. Thus, the opportunity to do this appeared through the formalisation of an area of interest that would account for the unique set of circumstances presented when a baby is born early and unwell. Hence, a new sub-discipline was created and named "neonatal health psychology" (NNHP; Adamson-Macedo 2000) with a specific focus on the first twenty-eight days of life (the neonatal period), for both healthy and sick preterm newborns. The new sub-discipline was designed to draw on social, cognitive, clinical, physiological, developmental and organisational

psychology, and from several other disciplines, especially epidemiology, physiology, immunology, and clinical medicine.

Therefore, NNHP was defined by Adamson-Macedo (1997) as the scientific study of psycho-biological and behavioural processes in the health, illness, and healthcare of the preterm neonate during their first twenty-eight days of life and the relationship of such processes to later outcomes. Of several rationales of system analysis applied to developmental psychology, and on the grounds of comprehensive interdisciplinary plausibility, Adamson-Macedo favoured the theory of experiential canalisation (Gottlieb 1991). The scope of NNHP, which is a system development theory, based on Gottlieb's theoretical assumptions, is divided into three major areas: assessment procedures and diagnostic methods; sensory nurturing interventions, including support for babies and their caregiver; and proposals for new paradigms.

Developmental Systems Perspectives

Set within the broad area of developmental science, developmental systems theory (DST) originated and has evolved from a broad range of theories (including but not limited to the Bioecological Theory of Developmental Processes [Bronfenbrenner 1979], Developmental Contextualism [Lerner and Kauffman 1985], and Epigenesis [Gottlieb 2014]). These theories have helped shape a framework that enables developmental scientists to conceptualise, theorise and understand the contextual factors at play in relation to individual development. DST acknowledges that individuals can spontaneously and actively shape their own development rather than simply being reactive to external environmental factors, and that they can adapt, regulate and organise their own development set within their specific environmental context (Overton 2013). The framework also enables scientists to acknowledge the varied components of development of an individual (physical/biological, cognitive and socioemotional domains of functioning), whilst acknowledging any inheritable and evolutionary factors. In addition, a DST perspective adopts relational positions (Overton 1998; 2006), which means scientists are interested in understanding the dynamic, reciprocal and multi-level relationships that form within and between people, set in their familial, community, sociocultural and historical contexts (Owen and Barnes 2023). Furthermore, this perspective shares several guiding principles that offer a way to understand the nature of human development:

(i) ***Change and relative plasticity***—that there is a potential for change across the lifespan, though this may be limited by past developments (such as severe trauma) or current environmental or contextual conditions (such as living in an area or region of high deprivation) (Lerner and Kaufman 1985).

(ii) ***Relationism and integration across the levels of organisation*** (Bronfenbrenner 1974; Ziegler 1998)—that developmental change happens as a consequence of the relations between the multiple levels of organisation within an individual (spanning inner biological [e.g., genetic] and psychological [e.g., cognitive, attitudinal and emotional states]), between people (familial, community or broader societal level) and their environment (including the individual's physical setting, as well as the political and cultural standing of the time); that the nature of these relations across multi-level systems are sometimes referred to as "relational units" and that there is potential for any level to impact factors in any other.

(iii) ***Historical embeddedness and temporality***—that patterns in developmental change may be different across historical periods and that it matters where in a person's lifespan that changes or events happen (temporality).

(iv) ***The limits of generalisability, diversity, and individual differences***—that not all skills and attributes are generalisable and, instead, that we should focus on diversity. Diversity, in this instance, may include things such as people, though it could also be extended to the types of relations, settings, or times of measurement. In this sense, the broader point, here, is the consideration of how individual differences may arise between people resulting in action on the developmental system. In addition, it is proposed that the sociocultural and political environment in which development exists is considered.

Bronfenbrenner's Ecological Systems Theory

The Ecological Systems Theory is one of several developmental systems theories and was created by Urie Bronfenbrenner (1979) as a way to conceive of human development. In contrast to many other major theories that examined the individual as the sole context of development, Bronfenbrenner proposed that there were external influences placed on the individual and their family. Some of these influences may never come into contact with the individual directly but may still have a substantial impact.

The model accounts for both genetic potential and environmental influence on development (Bronfenbrenner and Ceci 1994). Therefore, Bronfenbrenner's model, in keeping with other developmental systems theories, explains human development through the same interrelated ecological levels (or systems) that we referred to early on in the chapter (i.e., from inner biological systems to our social and political contexts). However, Bronfenbrenner used other specific terms to describe the levels and systems that represent the ecology of human development. Moreover, Bronfenbrenner used the term *microsystem* to describe the context within which the individual exists and most directly interacts with. In this chapter, the sorts of microsystems that premature or sick infants might interact with would include their family, health professionals and the hospital setting. The term *mesosystem* was used to describe those systems that represent interactions between the microsystems. For example, the relationship between family and the neonatal intensive care unit represents a mesosystem that has been intensively studied, despite a lack of research that examines the impact it might have on the developing child. In addition, an *exosystem* involves the relationship between at least two systems. For example, the relationship between a child's parent and their workplace may impact the child indirectly. In this instance, whilst a child may not directly interact with their caregiver's workplace, the caregiver's mood, cognitions or behaviour may be impacted by their workplace and this may indirectly influence the developing child. Next, the *macrosystem* represents the cultural context within which the individual exists and macrosystems (such as government and public policy) can influence the interactions seen at all other levels of human development. For example, the parental leave policy associated with childbirth or prematurity may impact the ability of a parent to be present for their child and/or their partner during a time of need. Finally, the chronosystem highlights the need to consider development in relation to time and is both historically and lifespan bound. Therefore, our understanding of these systems, how they interrelate to one another and what might result in change, is an essential feature across all systems.

Applying the Bioecological Model to Prematurity

In the coming sections, we illustrate how Bronfenbrenner's Ecological Systems Theory can be applied to the development of the hospitalised preterm or sick newborn and their family. Figure 1 illustrates a systems approach to examining prematurity, and the complex interactions across these levels are also examined.

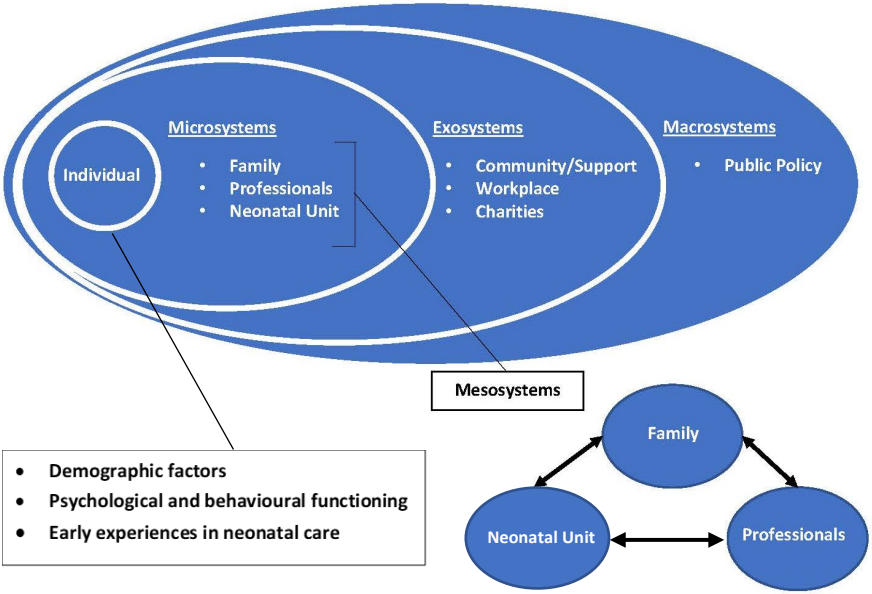

Figure 1: An Ecological Model of Development for Children Born Prematurely or Sick

Time to Consider:

Before you read any further, consider the following:

- In what ways do you think the experiences of pregnancy, labour and delivery are different between prematurely born babies and those that are born at term?
- What sort of factors do you think determine and shape the way a person parents when they have a child in neonatal care?
- What sort of personal characteristics may help a parent cope better in this type of situation?

Individual

The severity of prematurity, sorts of treatments the baby is receiving and the way the baby looks can all vary greatly compared to a full-term baby and other preterms too. Premature babies will be different in terms of their size, weight, appearance and pattern of crying, as well as self-regulated

behaviours (Levy-Shiff *et al.* 1989). Preterms will also not just look different, they will also behave differently too. This is why we see that during the early period after birth they are low in alertness and have fewer periods of wakefulness (Harrison 1992), and are much less active and less likely to be responsive to social stimulation (Crnic *et al.* 1983; Eckerman *et al.* 1994). This means that preterms are more difficult to bring to an alert state and can easily be overstimulated (Eckerman *et al.* 1994; Fearon *et al.* 2002). Therefore, this makes the parent's job of reading their baby's behavioural cues a difficult process; especially when the babies may respond in a particularly disorganised and unpredictable way. Failure to interpret the baby's behaviour correctly has been linked to asynchrony in parent-baby interactions. This may result in a longer-term impact on the infant's psychological development, hindering their ability to interact socially and causing psychological difficulties and delays in the future (Krebs 1998).

Physical, Psychosocial and Behavioural Functioning

The reasons why mothers give birth prematurely are not fully understood but some studies indicate that premature labour may result following intrauterine infection, cervical thinning or length reduction (Iams 2003), premature rupture of the membranes surrounding the foetus (Kenyon *et al.* 2003) or multiple births. There are also other known factors that increase the likelihood of having a premature baby and these include living in adverse or deprived social circumstances (e.g., poorer home environment), maternal age (mothers who are either young—below fifteen years—or older—over thirty-five years of age), hereditary, alcohol, drugs and cigarette smoking **(**Jewell *et al.* 2001). However, the number of conditions and the potential mortality of a premature baby are related to the severity of their prematurity. One of the most comprehensive pieces of research into the short-term outcomes of extremely preterm birth was conducted by Costeloe *et al.* (2012). Their study compared two birth cohort studies from 1995 and 2006, and their findings illustrate a 44 % increase in the number of 22–25-week-gestational-age preterms being born. This suggests that the total number of children in the community with lifelong health problems attributable to preterm birth is likely to keep rising as a result of advancing medical capability.

Time to Consider:

In light of the medical fragility of preterm newborns, what are the challenges for professionals and researchers when working with families in the context of a neonatal unit?

The Importance of Birth Weight

The Centre for Longitudinal Studies (CLS; http://www.cls.ioe.ac.uk/) is an Economic and Social Research Council resource centre. It is based at the Department for Quantitative Social Science, UCL Institute of Education, University of London. The CLS has conducted several of the most important longitudinal follow-up studies. The centre is responsible for running four exceptional and internationally renowned cohort studies including

- The 1958 National Child Development Study
- The 1970 British Cohort Study
- The Millennium Cohort Study
- Next Steps

Whilst each of these studies looks for slightly different things, the two most relevant that we will cover in more depth are the study from 1958 and the Millennium Cohort Study. The 1958 National Child Development Study (NCDS) has tracked the lives of 17,000 people born between 3 and 9 March 1958 in England, Scotland and Wales. Importantly, it has collected information about these individuals at regular intervals—in 1965, 1969, 1974, 1981, 1991, 1999–2000, 2004, 2008 and 2013. The study is important to many scientists but of relevance to psychology because of its focus on physical and educational development, economic circumstances, employment, family life, health behaviour, wellbeing, social participation and attitudes.

Some of the most notable analyses come from the effects of birthweight (BW) and socioeconomic class (SES) on the cognitive outcomes of the people when they were of school age. Jeffers *et al.* (2002) analysed data for 10,845 males and females and were interested to see how BW and SES were associated with various cognitive tests—reading, maths, copying designs, verbal and non-verbal ability tests—when the children were 7, 11, and 16. The findings suggest that both BW and SES produce independent effects on cognitive performance. Nevertheless, performance on the tests improved significantly as BW increased; however, this effect was weaker than that seen for SES. SES produced a much stronger effect in relation to

performance in maths and the highest adult qualification they held at age 33.

The Millennium Cohort Study (MCS), on the other hand, has followed the lives of 19,000 children born in the UK between September 2000 and January 2002 in England, Scotland, Wales and Northern Ireland. This study aimed to be more representative of the UK population than other cohort studies but did include higher numbers of those living in disadvantaged circumstances and children from minority ethnic backgrounds. Data has been collected at five time points so far—2001/2, 2004/5, 2006, 2008, 2012 and 2015—measuring a varied and diverse range of outcomes, including parenting; child behaviour and cognitive development; child and parental health; parents' employment and education; income and poverty; social capital; and ethnicity. Some of the findings suggest that (Platt *et al.* 2014) the parents' education and family income were the most powerful predictors of cognitive test performance at age 11; that there were significant, but statistically small, differences in cognitive performance between males and females; and that girls were generally more risk averse than boys.

By contrast to the two birth cohort studies described above, the EPICure studies (http://www.epicure.ac.uk) were designed to investigate the survival and later health status (e.g., disability) of extremely premature babies (<27 weeks gestation) and are split into two main parts: the original EPICure, which began in 1995, and EPICure 2, which began in 2006. Although the number of births prior to 27 weeks gestation is relatively small (1 %), the enhancements in medical technologies mean that more babies are surviving and likely to have long-term disabilities or poorer prognoses for life.

EPICure 1 (1995)

In the original EPICure study, details of all births and initial outcomes were mapped across all 276 maternity units in the UK and Republic of Ireland. The study documented births occurring over a ten-month period, starting on 1 March, with a total of 4,004 registered births; of these, less than a quarter were admitted to a neonatal unit (n=811), with only a third of these babies being discharged home (n=314). Of those discharged home, a series of studies started when the infant was 1 year old and continued at 2.5, 6, 11, 16 and 19 years of age.

In Hospital and One-year Follow-up

- No differences in neonatal care across major and minor units were identified, i.e., no change in survival rates.

- Around 191 babies had one or more problems when reaching equivalent to 40 weeks gestational age (e.g., brain injury, retinopathy of prematurity or oxygen dependency).
- Disabilities recorded at one year: there were ninety-five infants with either developmental or neurological problems, or oxygen dependency, and forty who had more than two of these problems.

Two-and-a-half-year Follow-up

- At this follow-up, twelve babies had either died or were not living in the UK and 283 families agreed to take part.
- Disability: approximately 138 babies had no disability, with sixty-nine having a non-severe disability and a further sixty-nine having a severe disability (e.g., Cerebral Palsy, neurological problems or developmental delay). Motor and cognitive functioning was measured using the Bayley scales.
- Growth: as you might expect, these babies were generally smaller and lighter than babies born at term, and were reported to be an average of 3 lbs lighter.
- Medical problems: the most common problems were related to breathing and affected around half of the cohort.

Six-year Follow-up

- At this follow-up, 241 families agreed to take part.
- Children in this stage were compared to typically developing children in the same school class.
    - They had poorer hand-eye skills and attention.
    - Their growth did not match their peers but was progressing.
    - They were doing reasonably well at school.
    - They had normal behaviour patterns.

Eleven-year Follow-up

- At this follow-up, 219 families took part.
- Moderate to severe physical disabilities, such as in mobility, vision and hearing, were rare (approx. 10 %).
- Learning problems (e.g., problem solving and reasoning) were more common.
- A sixteen-year follow-up is underway.

EPICure 2 (2006)

The EPICure 2 study was initiated, in part, because, when comparing survival rates, there appeared to be more babies surviving by 2006, compared to in 1995 when the EPICure 1 trial began. This study set out to compare the children from both cohorts to see if there were differences in the problems they experienced as a result of advances in neonatal care. The focus of this study was babies born in England at less than 27 weeks gestational age; however, in EPICure 2, additional details about the mothers and their pregnancies were also collected. This study included approximately 1,031 babies and has, to date, followed up after the period of hospitalisation, at 2–3 years of age, with further updates pending.

In Hospital

- The number of babies admitted to neonatal care rose significantly (44 %) from those reported in 1995, and survival also increased (13 %).
- As a result of treatment and maternity care enhancements, the care that mothers and that their babies receive has also improved.
- The types of problems experienced by extremely prematurely born babies (e.g., brain abnormalities, and respiratory, digestive and eye problems) has largely remained unchanged. However, the health outcomes for babies born at 24 and 25 weeks are slightly better than in the 1995 EPICure 1 study (Costeloe *et al.* 2012).

Two-to-three-year Follow-up

- Developmental scores have increased, meaning proportionately fewer children may develop problems as pre-schoolers (Moore *et al.* 2012).
- Despite the proportion of babies with the most serious problems being similar to the 1995 study, the number of babies receiving care has actually risen.

What these results mean…

- Birth weight and socioeconomic status are highly influential factors on later development.
- Parents' education and family income are two of the most powerful predictors of cognitive performance in children.

- The earlier a baby is born, particularly in extremely premature babies, the higher the risk to their survival, and the higher the chance of long-term disability, and poorer motor and cognitive functioning.
- Survival of babies born extremely prematurely increased from 1995 to 2006 but the problems experienced by them have remained largely unchanged. This means there are a greater number of children with significant health and developmentally related problems.

Microsystems

There are several contextual microsystem factors that may influence the development of the hospitalised premature or sick newborn. These microsystems include the family, (healthcare) professionals and the environment of the neonatal unit.

Family

There are many factors that a parent of a premature or sick newborn has to cope with and the first of these is the surprise and shock of going into premature labour or finding out that (perhaps due to complications) the baby has to be delivered straight away. For many parents, this will be unexpected and will represent a significant change in their plans for their baby's arrival (Zichella 1992). In some instances, this will mean emergency transport to hospital; but, however this occurs, parents will ultimately face a substantially different experience than if their pregnancy had gone to term. There is an abundance of literature too, ranging from parental accounts (Leung 2004; Manns 2004), to clinical observations (Knepfer and Johns 1989), to scientific research (Padden and Glen 1997; Vazquez and Cong 2014), that documents just how stressful this can be.

It is also not uncommon for parents to experience a reduction in, or a complete loss of, their ability to make decisions or act as caregivers for their newborn (Foster-Cohen *et al.* 2010) as a consequence of their circumstances and hospitalisation. This is perhaps why Blackburn and Harvey (2019) suggested that parents may experience psychological distress in the immediate term (Carson *et al.* 2015) and experience mental health difficulties in the years to come. Indeed, Adama, Bayes and Sundin (2016) conducted a recent meta-synthesis and found that parental confidence in their ability to parent their child was increased through effective support, though they still experienced concerns for their child's survival and may have still become overprotective at the expense of their own needs.

Furthermore, the stress experienced in the neonatal unit may also lead parents to develop depression, anxiety disorders, fatigue, and sleeping disorders that may impact the bond they feel with their baby and impact newborn social, behavioural and functional development (Busse *et al.* 2013; Huhtala *et al.* 2012). Malouf *et al.* (2022) added that the prevalence of anxiety is naturally high amongst the parents of babies admitted to a neonatal unit. It is unsurprising, then, that the time after the birth is typically referred to as a time of crisis (Graham 1995; Redshaw and Harris 1995). The seminal work of Kaplan and Mason (1960) suggests that parents progress through four major psychological tasks to successfully master the crisis situation and these include, firstly, anticipatory grief—preparation for the possible loss of the baby. Research by Miles and Holditch-Davis (1997) suggests that no matter how healthy the baby is viewed as by the health professionals caring for the newborn, the parents often view their baby as mortally ill, are pessimistic and generally only focus upon the negative information. Secondly, they are said to acknowledge their feelings of failure due to not delivering a "normal" full-term baby; guilt and blame about the possible reasons for the early birth (Rosenblatt 1997), such as working, drinking or smoking heavily during pregnancy; and anger that professional staff were unable to diagnose and prevent the early delivery. Thirdly, once the mother feels that the baby may survive she will be able to continue the process of relating to the baby. This period is said to be triggered by an event that leads the mother to feel she can begin to believe that her baby will survive (e.g., a gain in weight or change in appearance). Lastly, mothers must understand the individual needs of their premature baby, including their special needs and growth patterns, but they must also make sure that they do not deprive either themselves or their baby of meaningful and enjoyable interactions.

Needless to say, the experience and impact of having a premature baby can have a varied, though significant, effect on the mental health of parents and may ultimately impact the parent-child relationship and developmental outcomes. This has led some researchers to explore physical and emotional closeness as a way to promote parent and infant wellbeing (Thompson *et al.* 2020). They define physical closeness as being achieved through either actual physical (skin-to-skin) contact (see Chapter 9 in this book for an overview) or being in close proximity to their child. Emotional closeness, on the other hand, is represented by the psychological bond (Flacking *et al.* 2012), such as the love, care, affection or connection between parent and child. Indeed, much of the work presented in this book refers to the former (see Chapters 8). However, there is much less empirical research that has acknowledged the barriers and facilitators of the latter (Flacking, Thomson

and Axelin 2016); although, Flacking and colleagues highlight that parents who kept an emotional closeness diary were better equipped to maintain their closeness, in psychological, physical, spatial, relational, cognitive and social terms. Therefore, a strong sense of emotional closeness is likely to result in positive health outcomes that benefit parents (psychologically), the parent-infant relationship and child outcomes (Thomson *et al.* 2020).

It is also important to note that, whilst we have covered the impact of prematurity on the family, here, much of that work has been predominantly conducted with mothers. Indeed, there is considerably less emphasis and research that specifically targets fathers or other partners (such as those from LGBTQ+ communities). Nevertheless, Hemle *et al.* (2021) conducted some recent research that explored the lived experiences of fathers. They suggested that fathers, whilst satisfied with the infant's care during their hospital stay, felt excluded and not fully responsible for their child at that moment. The fathers would also prioritise the needs of their partner above their own needs and were naturally occupied by thoughts of concern for the health of their newborn. Furthermore, work by Hagen, Iversen and Svindseth (2016) illustrates that parents' coping mechanisms may differ: fathers would focus on the needs of the mother, who would, in turn, focus on the needs of the infant. Where this is the case, it may negatively impact the amount of involvement that fathers have in their infants' care during hospitalisation (Feeley *et al.* 2013).

Time to Consider:

Considering the previous section,

- What do you think determines the type of fathering role a person has in this type of context?
- How might professionals work better with parents from diverse, minority or marginalised groups?

(Healthcare) Professionals

Typically, there will be a range of highly skilled professionals managing the care of a premature and/or sick newborn: paediatricians, dieticians, midwives or other children's nurses, and specialist doctors. However, it is more common for newborns to be seen and cared for by a neonatal nurse, who will do things such as (i) preparing and checking medications, (ii) managing a baby's fluids, (iii) recording observations and documenting a

baby's care, and (iv) initiating appropriate basic resuscitation in an emergency (NHS 2023).

Staff in the unit are also likely to try and minimise the number of harsh environmental stimuli (such as light and noise) that the baby is exposed to, in an attempt to avoid overstimulating them. However, beyond these types of general activities, several strategies have been developed that focus on the nature of care and the creation of a supportive environment. Most notably, one approach that has attempted to create a developmentally appropriate environment is the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). This programme was established to balance and manage the physiologic, motor, and state systems of premature infants (Lee, Park and Cho 2020). Whilst there is some variation in the components of this programme, globally, the most common elements include family-centred care (FCC), a healing environment, positioning, oral feeding support, pain and stress management, protected sleep, handling, skincare, and sensory stimulation (Lee, Park and Cho 2020). In most cases, specially trained nurses are the ones to deliver and manage the creation of these types of supportive environment. Some of the benefits reported through the use of this approach include an enhancement of neurodevelopment and physical growth (Coughlin, Gibbins and Hoath 2009; Legendre *et al.* 2011; Burke 2018), a reduction in health-related complications (Legendre *et al.* 2011) and hospital stay (Moody *et al.* 2017), a reduction in the incidence of severe morbidity, an improvement in physical development, support for breastfeeding (Pavlyshyn *et al.* 2023), and minimised developmental delay (Moody *et al.* 2017).

The Neonatal Unit Environment

The environment of a neonatal unit can be an overwhelming place in which to establish parenting. This unique microenvironment is (naturally) highly medicalised, it is filled with the sounds of lifesaving equipment and the hush of professional and family conversations (Miles *et al.* 1991), and it contains a mix of medical staff and families sharing each other's lives and emotions as the babies lie in their cots or incubators. It is not surprising that the neonatal unit is described as an intimidating environment, where parents may witness babies (and not always their own) receiving medical procedures and monitoring (Levy-Shiff *et al.* 1989). In some circumstances, babies are surrounded by multiple types of medical equipment: tubes, wires, respirators and intravenous feeds, and this can be a constant source of stress that parents are exposed to. Parents often share rooms, which means they will not only have to deal with their own emotional reactions but quite

probably those of other parents too (Redshaw and Harris 1995). The stress experienced by parents may be made worse if the newborn needs to be moved to a more specialised hospital or if the mother has been discharged home and can no longer stay close by.

Research suggests that this highly technological environment can create feelings of shock, fear, and stress, which may impact the mother-infant interaction and the transition to motherhood (Howe *et al.* 2014; Medina *et al.* 2018; Roque *et al.* 2017; Whittingham *et al.* 2014). Parents will also experience a degree of separation from their infant. This will include the natural physical barriers, such as those encountered by having a child in an incubator, as well as barriers to accessing readily available information about their child. This, in turn, may affect parental mental health and child development too (Malouf *et al.* 2022).

However, when a neonatal unit is designed well, there is the potential to enhance developmental outcomes and reduce illness; for example, in units where noise and light are attenuated for, and that include support areas for families (O'Callaghan, Dee, and Philip 2019; Shepley *et al.* 2014; Tandberg *et al.* 2019). In addition, where space allows for the inclusion of "single-family rooms," there is evidence to suggest that they can lead to increased weight gain, a reduction in painful procedures, decreased infection rates, and improved cognitive and language development (Lester *et al.* 2014; 2016; Vohr *et al.* 2017).

Mesosystems

Mesosystems are the components of Bronfenbrenner's model that represent the interaction of any two microsystems for a given individual. In this chapter, we have provided examples and evidence of contextual relations between professionals and parents, as well as of parent-to-parent peer support.

Professional-Parent Support

During their time in special care, parents (and particularly mothers) may experience isolation, or mixed feelings about whether to share the experience of having a baby on a neonatal unit (Flacking, Breili and Eriksson 2019). Friends and family may also be unsure how to respond, not knowing how best to speak or offer support. Nevertheless, research by Coppola *et al.* (2013) suggests that, despite these mutual uncertainties, many parents would still prefer to have someone to talk to. Furthermore,