

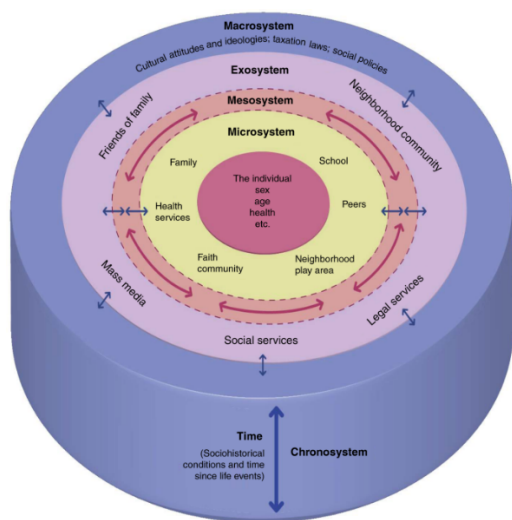
Prof Nicola Doherty – Written evidence (PRT0078)

Neonatal and longer-term care and support

- How neonatal care can improve outcomes for babies born preterm.
- How postnatal care and psychological support for women who have given birth preterm and parents can improve outcomes.
- Integration between neonatal care for babies born preterm and postnatal care for women.
- Longer-term impacts, care and support for preterm babies and their families.

All four questions above will be answered together by considering a systemic model. Bronfenbrenner's (2005) *Ecological Systems Theory* is proposed as a useful framework to understand the dynamic influence families have on child development. This theory is based on the premise that a person's development is impacted through multiple levels of their environment (Bronfenbrenner, 1979). These levels reflect six systems: ontogenetic level, microsystem, mesosystem, exosystem, macrosystem and chronological system (Bronfenbrenner, 1979). The ontogenetic level represents individual characteristics including age, gender and health status. The microsystem is the immediate environment in which the child lives and includes proximal relationships or organizations the child interacts with such as the family; peers and school (Ashiabi & Neal, 2015). The mesosystem consists of interactions between the multiple levels in the microsystem such as the family's interactions with schooling or health care. When living with a chronically ill child/infant in NICU, families have specific needs that highlight the significance of family-school relationships and associations with the health care team (Kazak et al., 1995). The exosystem describes social structures such as a parent's

workplace and has an indirect influence on child development. The macrosystem constitutes the cultural, economic and societal factors that impact development (Bronfenbrenner, 1979). A change on one level of the system could affect the other levels, influencing a child's outcomes directly or indirectly through contextual changes (Bronfenbrenner, 1979). A systems perspective caters for the examination of how interactions within these systems influence each other and affect developmental outcomes (Bronfenbrenner, 1979).



The importance of the family in influencing child development is highlighted within Bronfenbrenner's model and family characteristics and processes are considered central to social and emotional development. Family factors are key and attention needs to be given to parents. The prevalence of post-partum depression in the general population is 10-15% but it is estimated to increase to 39% among mothers of infants admitted to the neonatal ICU (Lefkowitz et al., 2010). Furthermore, elevated levels of psychological distress were reported in one third of mothers and one fifth of fathers in the first weeks after delivery of a child with CHD (Doherty et al., 2009). Not enough attention is paid to these parents.

One longterm study (across past 25 years) has looked specifically at children born sick and often requiring neonatal care. The Congenital Heart Intervention Program (CHIP) is a family focused intervention, based on the theoretical premise that interventions targeted at the level of the parent will improve neurodevelopmental and behavioural outcomes for the child with CHD (Doherty & McCusker, 2016). The findings have been found to be generalisable to other populations and would be relevant for all children born preterm and their families.

CHIP programs used a *Problem Prevention Therapy* approach, that encouraged parents to take an active, solution-focused, approach to navigating the worries, fears and developmental challenges posed by CHD (Doherty & McCusker, 2016). A second strand to these interventions centred around the concept of *meaning-making*. Using a narrative therapy approach to help families process emotions and develop an empowering narrative about their situation permeated both CHIP interventions (Doherty & McCusker, 2016). Recent analysis (Phillips et al – DclinPsych thesis) of how parents are doing when their children are between 19 and 26 years of age highlighted that those who took part in the intervention were more likely to have processed the trauma and tended to fall into a theme of 'surviving and thriving' whilst those who had not tended to fall into a theme of 'living with ghosts'.

#The best outcome for babies will involve a full system transdisciplinary approach. A model of care needs to be developed which encompasses all the key systems. Infant, parents, siblings, staff as immediate foci and the systems the infant will pass through including and especially education and health.

We need psychologically informed environments as described by Atkins & Syed-Sabir (2022) in their article in Clinical Psychology Forum and also

highlighted by Long et al 2023) in their paper on brain based care. PIE provides a whole system approach to improving psychological wellbeing in all those in the environment the infant inhabits.

Evidence highlights the importance of family factors and narrative work of facilitating support for the telling of stories and how this processes outcomes eg. O'Boyle-Finnegan et al (2022), Suarez et al (2022), Doherty & Utens (2016), Doherty & McCusker (2016), Gower et al (2016)

Other topics

- *Data collection and monitoring in relation to preterm birth, including variation in the recording of data.*

Identifying and tracking babies born early is really important. We can achieve much when we can provide the psychoeducation to the systems that these infants inhabit as they grown but we need to tell the systems key facts. Psychoeducation makes a difference. Electronic identifiers of infants born preterm are necessary to track them and allow the systems they inhabit to become aware of their potential risk and intervene early! Schools must start to ask salient questions about early life including gestational age at birth and early hospitalisation.

- *Research priorities to prevent preterm birth and improve care for babies and mothers, with a focus on developing evidence-based practice.*

Involvement of the parents. The key to positive outcomes as highlighted by the CHIP project (McCusker et al 2009; 2016) as well as FiCare.

Implementation science – we have a lot of the knowledge but there is a lack of implementation into workspaces. There is a lack of support for clinicians to pursue research activities and then implement it and a need for academics and clinicians to work hand in glove.

Follow up studies e.g. Neurodevelopmental interventions as we know that they improve some outcomes in infancy and childhood (Calderon et al. 2020; McCusker et al. 2009)

PAIN – not enough attention is paid to this area. I have recently supervised a number of research projects in the area one is under review in terms of staff attitude and understanding and highlights significant need for agreement and training and I also refer you to the work of Ruth Grunau below.

- *Learnings from the devolved administrations and other countries around the world.*

Reference – INFANT – In Cork, Irelands first dedicated perinatal research centre launched in 2013 it studies pregnant women and children from 0-5 including preterm and term new born babies. The BiHIVE study is examining the investigation and validation of predictive biomarkers in Hypoxic-ischaemic encephalopathy.

CHIP studies as described above and referenced below. Commenced in NI in 2000 and still ongoing followup. Studies using CHIP protocol in other conditions and also replicated in Netherlands and now in Sweden.

In Vancouver, Clinical Psychologist, Dr Ruth Grunau leads the Early Human Experience Unit where her groundbreaking research is restricted to 32 weeks or less. Within this window she described cytotoxic processes and the impact of pain on the cytoarchitecture especially as the gross macrostructure not in place. The connections between some brain structures are not complete in babies born less than 32 weeks so procedures can cause greater impact than when the structures are complete. Vulnerability varies according to gestational age with cytotoxicity is thought to be greatest at 24-28 weeks then 29-32 weeks with less vulnerability after 32 weeks. A second point is that mature oligodendrocytes produce myelin late in the third trimester but this myelin

comes from the premature form so if a baby is born early and compromised this myelin is impacted due to its high vulnerability to excitotoxicity. In effect there is a double whammy, direct and latent impacts on the myelin.

She looks at the programming of stress systems in infants born preterm. Facilitated tucking for pain management and comfort of the infant is advocated there. The facilitated tucking is thought to help modulate the physiological response. Other centres advocate the use of sucrose which the team in Vancouver have concerns about due to longterm metabolic and neurodevelopmental impacts.

Dr Martha Welch is associate Professor of Psychiatry in the Department of Pediatrics and Pathology & Cell Biology at Columbia University Medical Centre. She is also the Director of the Nurture Science Program in Pediatrics as well as Director of the basic research BrainGut Initiative in Developmental Neuroscience. Her work has led her to posit that the origins and control of behaviour and emotions are based on mother-child autonomic coregulation, rather than the individual's top down central nervous system self regulation (N). She leads a team understanding the family nurture phenomenon and is testing the 'Calming Cycle Theory' and 'Family Nurture Intervention' (FNI). She is testing the FNI in prematurely born infants and infants aged 0-5 years and is also validating an instrument called the Welch Emotional Connection Scale (WECS).

References

Atkins, E. & Syed-Sabir, H. (2022) PIE in PICU and NICU: Developing Psychologically Informed Environments. *Clinical Psychology Forum* 359, 9-19

Long, D.A., Waak, M., Doherty, N.N. & Dow, B.L. (2022)

Brain directed care: Why neuroscience principles direct PICU management beyond the ABCs. *Children*, 9, 1938. <https://doi.org/10.3390/children9121938>

O'Boyle-Finnegan, U., Graham, C., Doherty, N., Adair, P. (2022) *Exploring the contribution of psychological flexibility processes and self-compassion to depression, anxiety and adjustment in parents of preterm infants* *Journal of Contextual Behavioural Science* (24) 149-159

Suarez, C., Adair, P., Doherty, N.N., McCormack, D. (2022) *Exploring Adjustment and Parent-Infant Relations in Mothers of Premature Infants: Thematic Analysis Using a Multisensory Approach* *Journal of Pediatric Psychology* jsac007

Doherty N.N. & Utens, E. 'A Family Affair', Chapter in *Congenital Heart Disease and Neurodevelopment, 1st edition*. Edited by Christopher McCusker and Frank Casey

Elsevier 2016.

Doherty, N.N. & McCusker, C.G. 'The Congenital Heart Disease Intervention Programme & Interventions in Infancy' Chapter in *Congenital Heart Disease and Neurodevelopment, 1st edition*. Edited by Christopher McCusker and Frank Casey

Elsevier 2016.

Gower, C., Higgins, A., Doherty, N. & McCormack, D. (2016) *Understanding the experiences of fathers of children with congenital heart disease: An interpretative phenomenological analysis. J. Health Psychology* 22:1-11

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments in nature and design*. Cambridge, MA: Harvard University Press.

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