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The neonatal journey: Developing psychological services in neonatal care in England and Northern Ireland

Dr Aiveen Higgins, Consultant Clinical Psychologist, Service Lead, Paediatric & Neonatal Clinical Psychology service, Antrim Area Hospital, Northern Health and Social Care Trust

Dr Angela Marsh , Consultant Clinical Psychologist, Yorkshire & Humber Neonatal ODN

The Neonatal Journey: Agenda

- Connecting with experience of babies & families
- Responding to the voice (needs) of the neonatal baby
- Needs of systems around baby
- Psychological work on a unit – what it looks like
- Strategic work - Amplifying this voice so that it is heard consistently and where power is held
- Opportunity to reflect on how Psychology can give voice to infants and families within your own work.

Neonatal Care - Context

1 in 7 babies

90,000 babies annually

22+ weeks GA

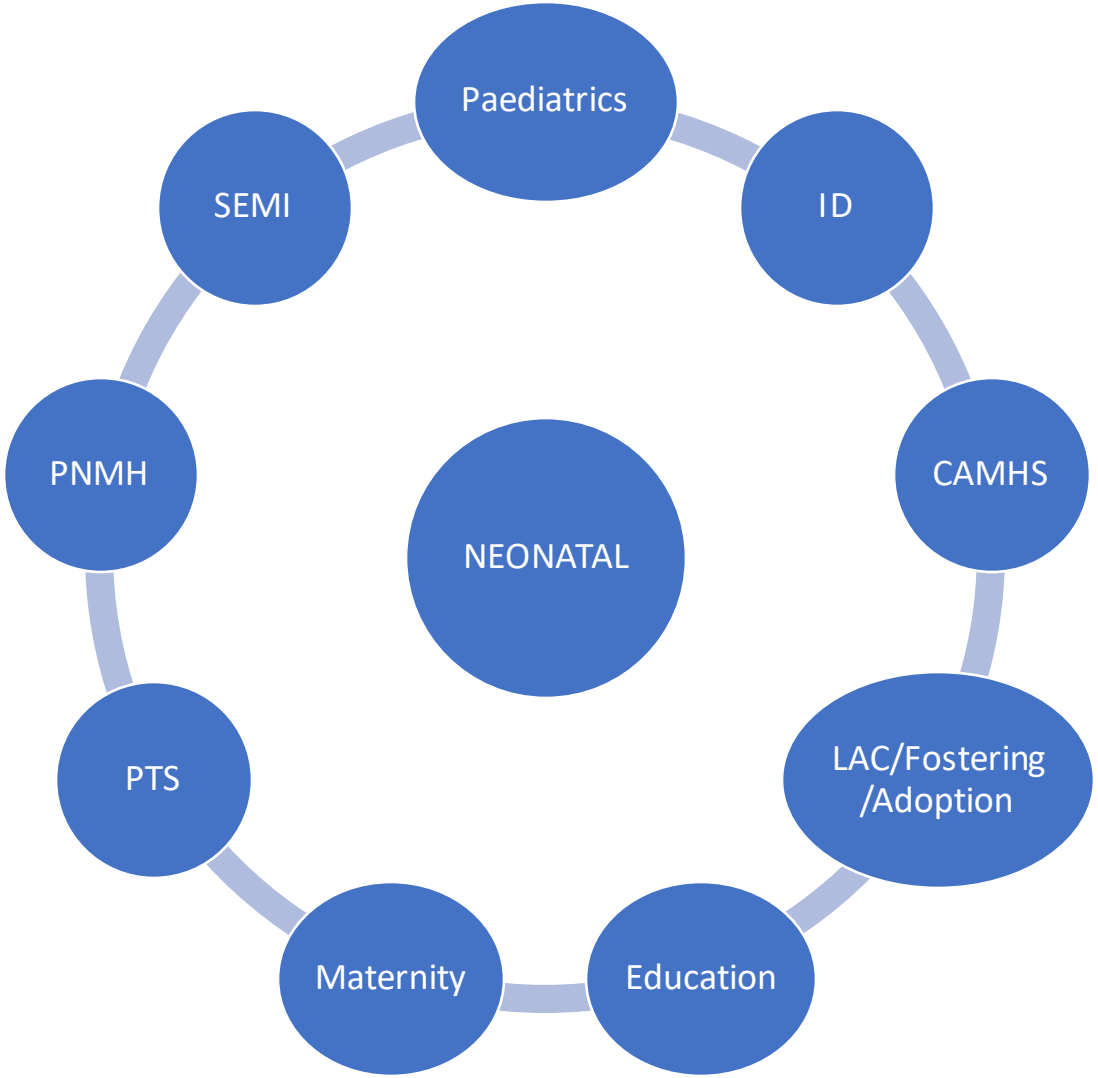
Medical needs:

- Prematurity
- Infection
- Hypoglycemia
- Jaundice
- Surgical
- Cardiovascular disease
- Congenital abnormalities
- HIE
- Respiratory conditions

Gestation of baby at birth	Average length of stay (days)	Average age at discharge (gestational age in weeks)
Before and up to 27 weeks	92	39.4
28-31 weeks	44	36.4
32-36 weeks	12	36.6
More than 37 weeks	4	40.3
Average	7	38.6

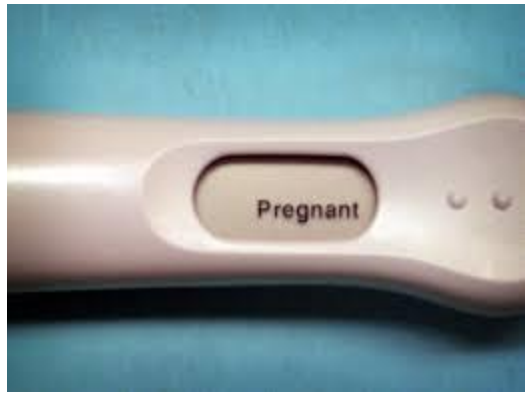
bliss.org.uk

Where Neonatal Babies/Families go?



Let's Start at the Very Beginning

It's a very good place to start



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WELCOME
HOME
ETHAN


y Hamilton - CHOA

Challenges for baby

- Separation: “Why are you leaving me?”; “Where are you going?”
- Safety: “Who will keep me safe when you’re gone.” “Am I in danger?”
- Physical barriers: “Where are my cuddles?” “Why can’t I see you?”
- “Can you see me?”; “Do I matter?”
- Multiple caregivers: “Why are there so many of you?”
- Exhaustion: “Why is this such hard work?”
- World as threatening: “Why is it so sore/bright/noisy?” “Am I unsafe?”
- Self as threatening: “Why are you so scared of me?”

Challenges for parents

- Arriving on the unit (unexpected; expected)
- Separation (first separation; physical barriers; leaving baby; siblings; partner)
- Fragility

  "She doesn't look like my baby. I feel I lost her the day we arrived."

- **Loss** (current; revisited; future)

  "It's not how I imagined it would be"

Challenges cnt.

- **Trauma** (premorbid; pregnancy; birth; NICU; proxy); "Lizard brain"
- **Attachment** and bonding

  "If I can't imagine a future, how do I fall in love?"
- Disruption to family life (siblings; partners)
- Tensions in relationships (partner/staff)
- Loss of control & feelings of powerlessness
- Feelings of guilt/shame
- Cultural narratives

Challenges cnt.

- Delayed parenting

"I feel like my baby belongs to the neonatal unit and not to me"

- Transition to parenthood
- Postnatal emotions
- Physical health

Going Home

- Safety net of nurses removed
- Shared parenting to full responsibility
- Processing of trauma
- Uncertain future

"How do I manage my fear of cot death and still enjoy him. If he is going to die it is even more important to enjoy my time with him"

Particular challenges for Dads/ Partners ("Forgotten Parent")

"I don't want to be weak in front of my wife. I don't think she knows how bad I am hurting right now."

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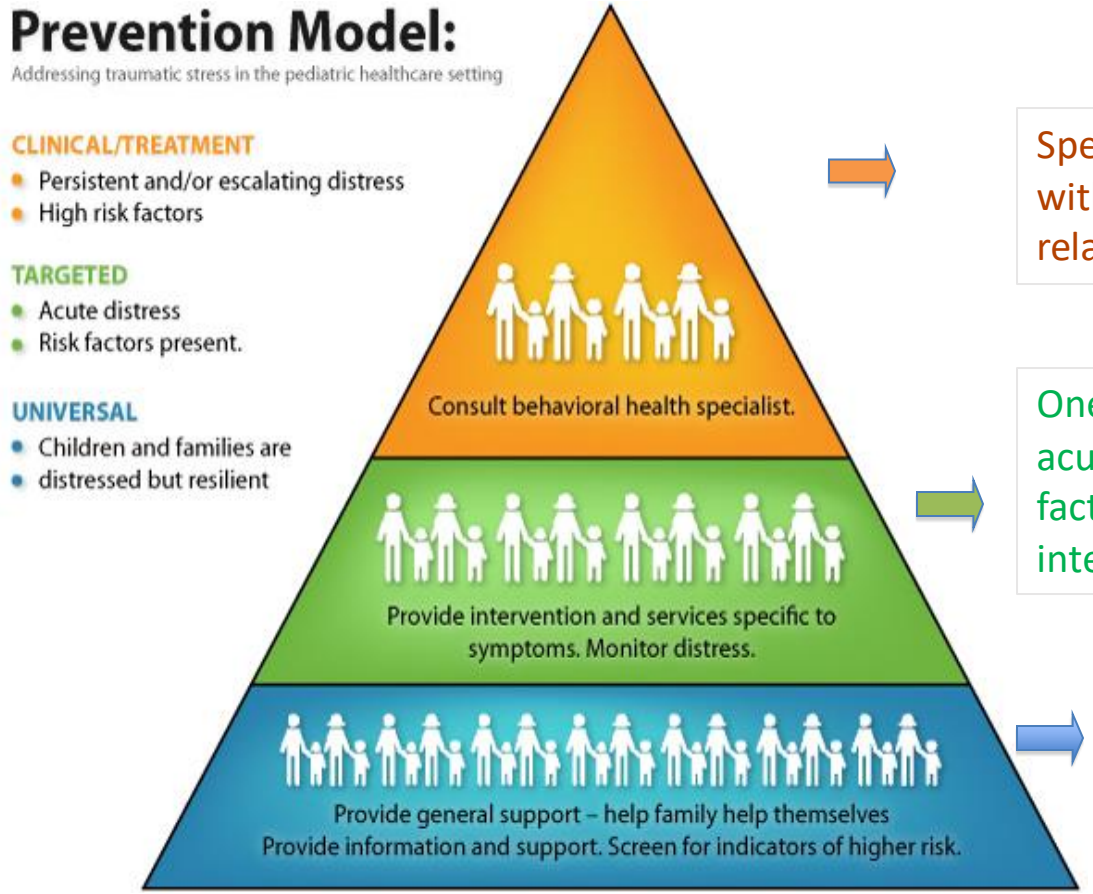
Challenges for siblings

- “Where is my baby brother?”
- “Why can’t I visit him?”
- “Why are you always at the hospital. Do you prefer her to me?”
- “Am I not important too”?
- “Why does she look so different in the photos?”
- “Will you still come to my sports day mummy?”

Prematurity, separation and birth trauma can have far reaching consequences in terms of neurodevelopmental and psychosocial outcomes for babies (Lean et al., 2018) with attachment theory facilitating our understanding.

- Trauma-repairing
- Trauma-reducing
- Preventative

Paediatric Psychosocial Preventative Health Model



Specialist one-to-one support to families with persistent psychological distress related to the experience of being in NNU

One-to-one or group input for families in acute distress or where psychological risk factors warrant short-term early intervention from psychological services.

Preventative psychology input provided to all families either directly via psycho-educational literature /drop-in clinics or indirectly by supporting or up-skilling staff.

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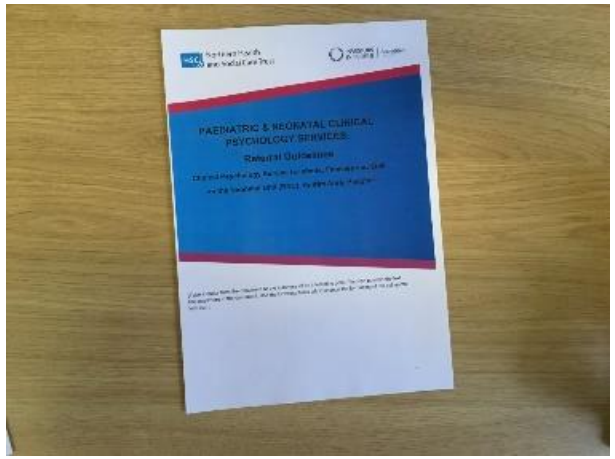
Service Model Antrim Area Hospital

- 2 days (0.4 WTE) CCP & 3-4 days TCP (0.6-0.8 WTE)
- Largely inpatient with liaison with HV, telephone follow-up post-discharge and signposting as necessary (some exceptions)
- One-to-one input available for families (including sibs and grandparents)
- No forms; no waiting lists
- Anyone can refer including families themselves
- Usually seen within 24 hours of referral
- Flexibility of service



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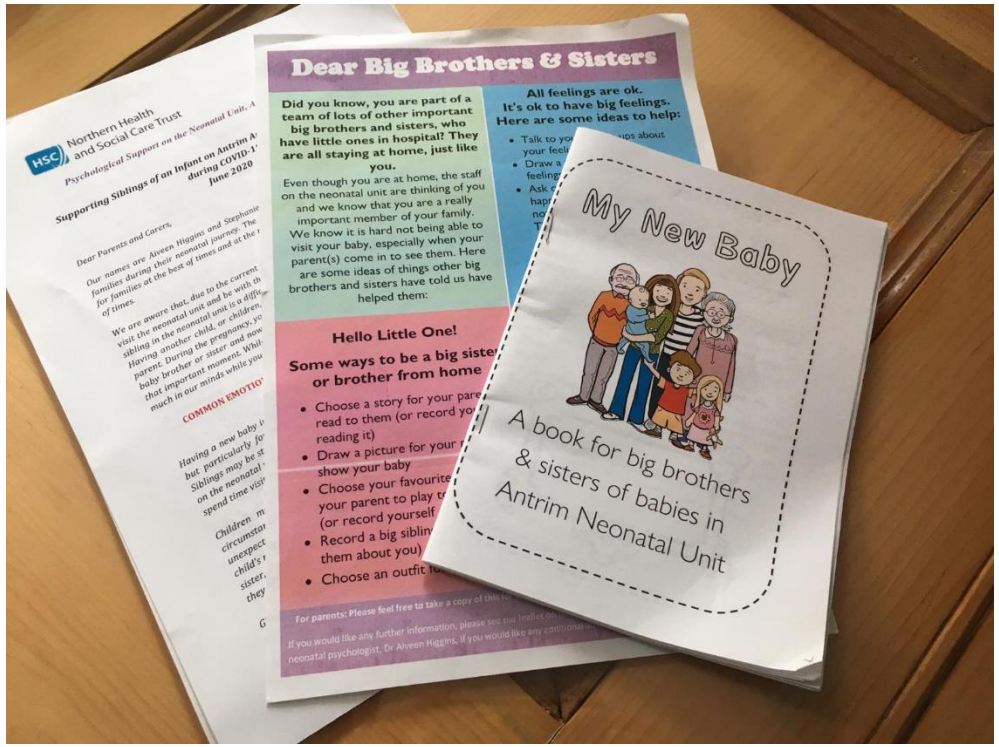
Universal services: shared humanity

- Service visibility (validating/normalising)
- Sharing relevant knowledge
    - leaflets
    - podcasts
    - notice board topics
- Contribution to physical environment (WBD)
- Staff support and training

Sibling Resources



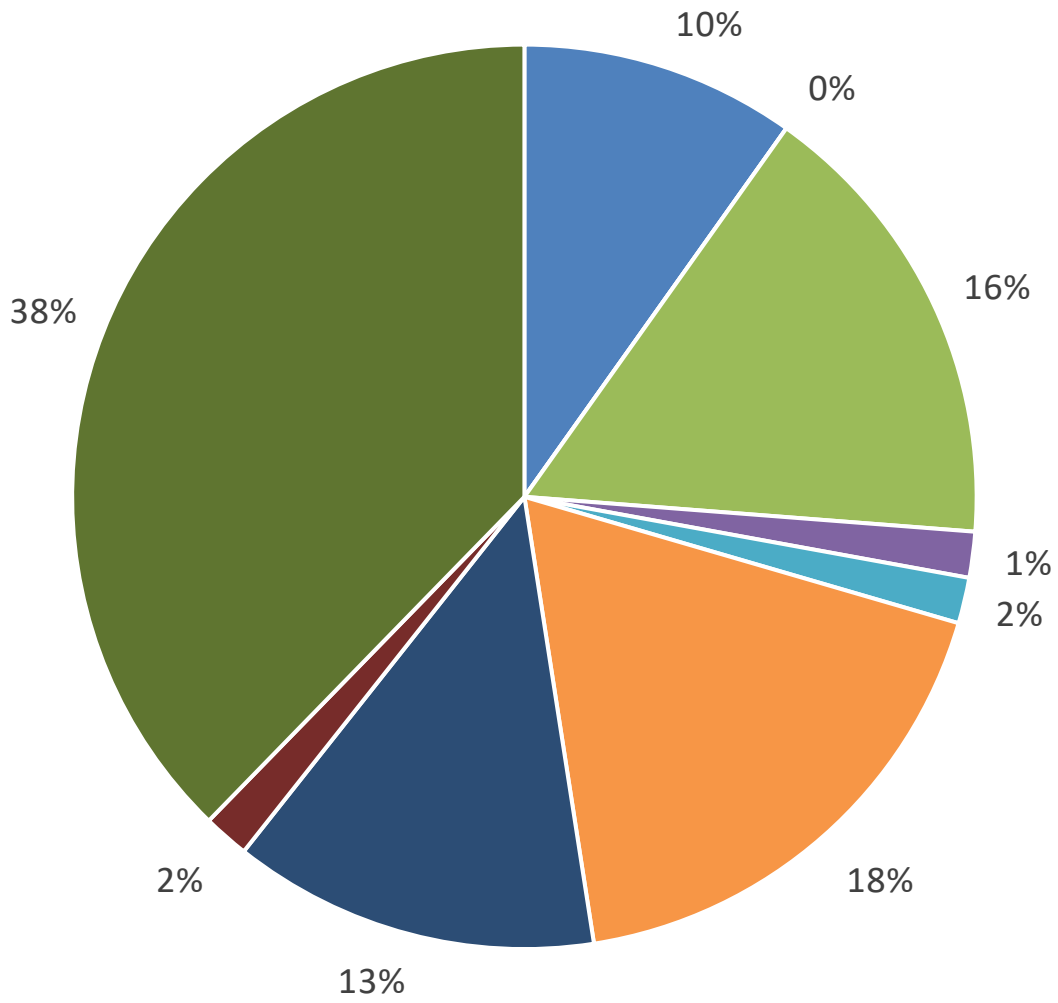
Let's Talk Podcast

Northern Trust PNCPS Website with Podcasts

Targeted

- Birth trauma
- Disability/uncertain diagnosis
- Transferred
- Born extremely early/sick
- Poor prognosis/end of life
- Multiple pregnancy
- History of loss
- History of mental health difficulties
- Past traumas
- PNMH history
- Families where baby may be placed in care

Referral Reasons



- Adjustment
- Anx/Stress Mng
- Sib Adjustment
- Attachment
- Loss/grief
- Parental mental helath
- Trauma
- Other
- Intro to psychology

Therapeutic frameworks

- Systemic
- Trauma informed care
- Attachment informed
- VIG
- Compassion focused therapy
- Mindfulness
- Psychodynamic
- CPP

Roles of Psychologist

- Containing; “I see you, I am here”
- Naming: Rumpelstiltskin
- Less doing, ore “being with” (containing)
- Moment to moment therapeutic conversations (rather than manualised)
- Systemic “both/and”
- Formulating: Making sense of versus inability to form a coherent narrative

Triangle of Trauma (Cohen 1994): Working with Whole System

- Developing and maintaining a sustainable workforce of skilled staff who can shoulder the burden of their work depends upon them having opportunities for emotional processing and support from wider systems
- Maintaining a compassionate & psychologically-minded workforce: significant part of the service

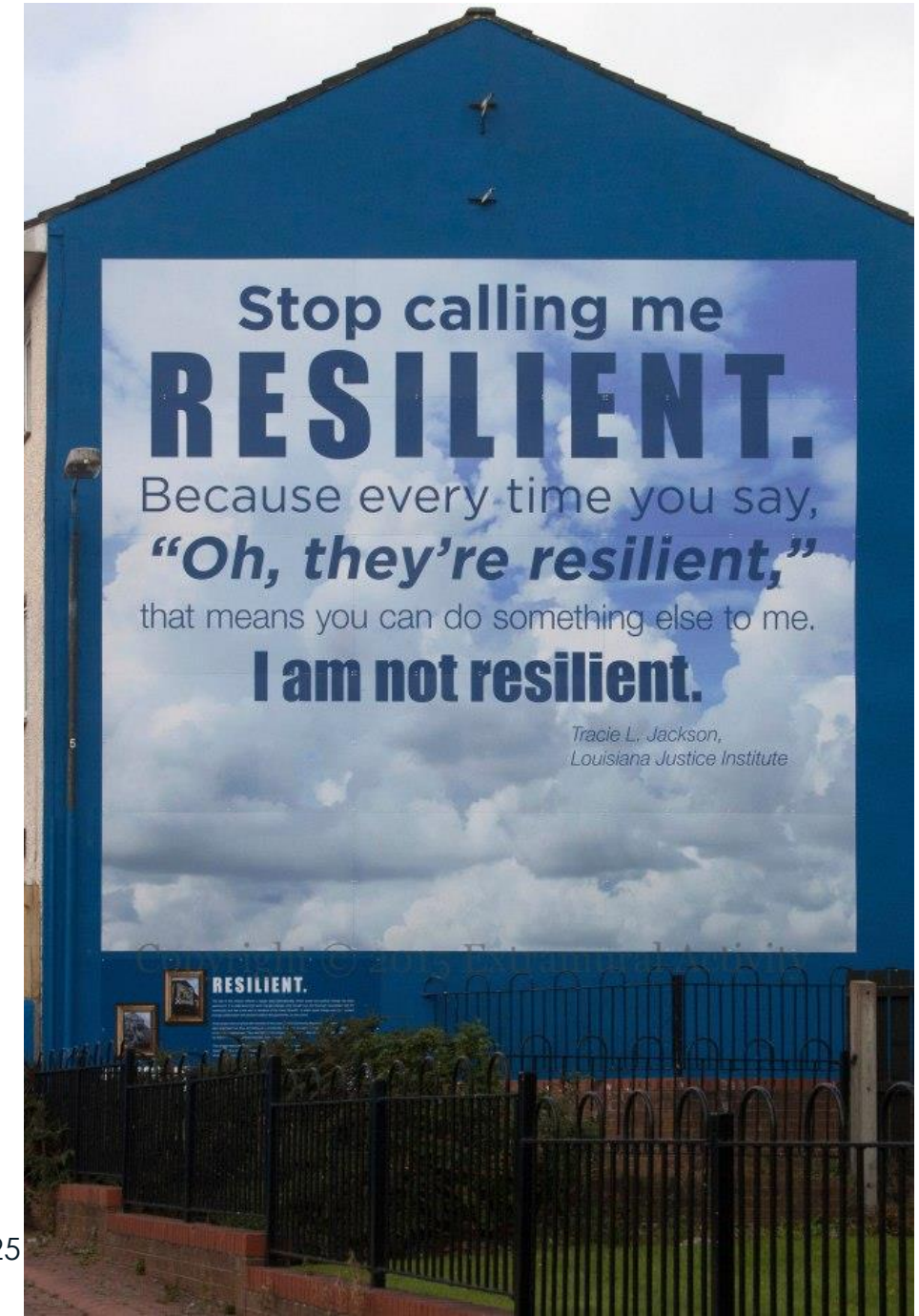
Prevalence

- Trauma: 49%
- Burnout:55%

Staff Support & Training: Community of Care

- Support amongst staff
- Providing input to families
- Mindful Mondays
- Debriefs
- One-to-one check-in and signposting
- Psycho-education on staff care: e.g., monthly newsletters; posters;
- Teaching/training & elevating knowledge of staff

Northern Ireland Context



What's Different?

- No waiting lists
- Unpredictable diaries
- Psychology fully integrated
- Psychological care fully shared
- Time carved out for early intervention

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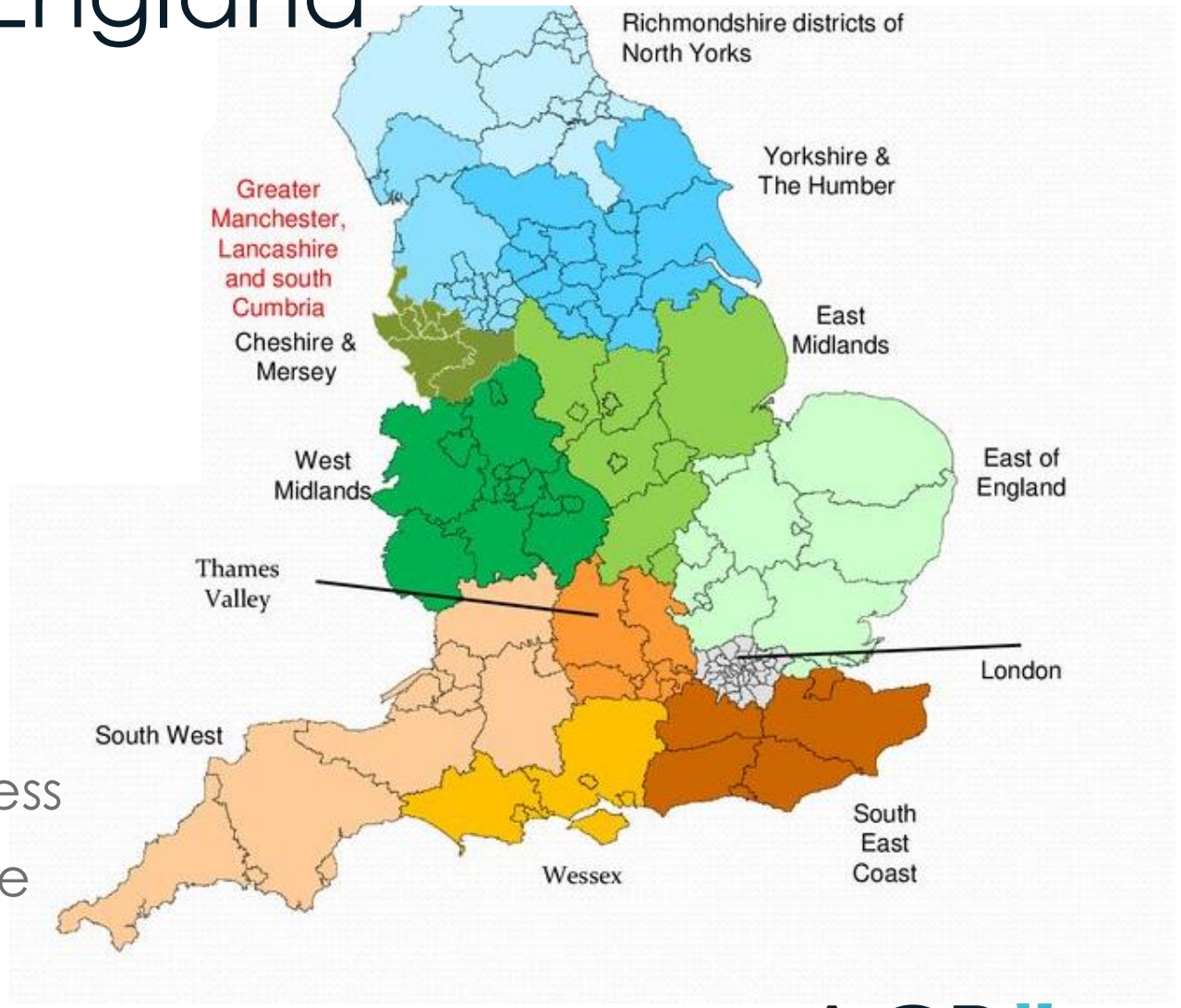
Neonatal psychology in England

- Operational and political context
- Lead roles
- Scoping, Benchmarking and Recommendations
- Where we have got too and how
- Reflections hints and tips

Neonatal Networks in England

- 10 networks
- Varying size & no of hospitals
- Regional and strategic organisation of neonatal care
- Improve quality of care
- For infants and families to receive the care they need:
  - Close to home as possible
  - Consistent, fair & equitable access
  - Promote and share best practice
  - Develop the expert workforce



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1

Toolkit for High Quality Neonatal Services (2009)

recognition of need for AHP support

2

Poppy Report (2009)

Family centered care

3

BAPM Service Standards for Hospitals Providing Neonatal Care (2010)

4

Neonatal Critical Care Review (2019)

Increasing specificity around AHP's as core to neonatal workforce and staff education

5

Getting It Right First Time (GIRFT 2020)

Benchmarking workforce provision and 'deep dives' into network provision

6

Neonatal Network strategic roles

Neonatal Critical Care Review

1. Neonatal capacity
2. Transport Pathways
3. **Neonatal nursing workforce**
4. **Medical staffing**
5. **Develop strategies for the allied health professions**
6. **Develop and invest in support for parents**
7. local implementation plans

Neonatal units require key contributions from an essential group of AHPs
……inc ***psychologists****,*

"NHS Trusts should develop an AHP strategy as part of workforce planning

Network Level: *"ODNs, should identify where action needs to be taken at ODN level & assist in directing resources to the appropriate places"*

Lead psychology roles

NeoLeaP

NEONATAL LEADS FOR PSYCHOLOGICAL PRACTICE

- Range of experience & contributions
- But part time roles &hugely wide job descriptions
- Relationship building & collaboration required!!!

Lead psychologist roles

Grow the workforce

Scope staff provisions
Implementing staffing recommendations
Engaging stakeholders
Bids/Business Cases

Clinical Support

Clinical supervision
Communities of Practice
Clinical Troubleshooting
Peer support

Clinical Governance

Audit/Benchmarking
QIP
Clinical Guidelines/Policies
Working groups

Education & Training

Online (e.g. social media, FiNC, HEE)
Collaboration with PAG & Care coordinators (FiCare)
Postgraduate training

Staffing Recommendations

Psychology Staffing on the Neonatal Unit

Recommendations for Psychological Provision

Neonatal Consultant Clinical Psychologists, ODN Psychology Leads

July 2022

Endorsed by

British Association of Perinatal Medicine

NEONATAL NURSES ASSOCIATION

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the british psychological society promoting excellence in psychology

Sands

SCAN ME

- **Preventative**
- **Normalising**
- **Holistic**
- **Embedded**
- **Specialist**

"The knowledge & exposure the psychologist has of the neonatal journey… is totally unique and invaluable"

www.acpuk.org.uk

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Recommendations for Psychological Provision

https://acpuk.org.uk/member-networks/psychology-staffing-on-the-neonatal-unit/

Level of Care	WTE per 20 cots	WTE per 3 units (hub)*
Inpatient (minimum)	1 WTE (8a)	0.4 WTE (8b/c)[a]
Inpatient (higher)[b]	1.2 WTE (8a)	0.6 WTE (8b/c)[a]

- Evidence-based
  - economic
  - psychological wellbeing
- Per 20 cots (not per cot)
- Sits with wider NHS agenda (LTP & People plan)

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Growing and supporting the workforce

Phase 1

- Mapping of provision across region
- Staffing standards

Phase 2

- Engaging units & Stakeholders
- **Prioritization and planning**
- **Demonstrating the value of psychological approaches through training and other offers**

Phase 3

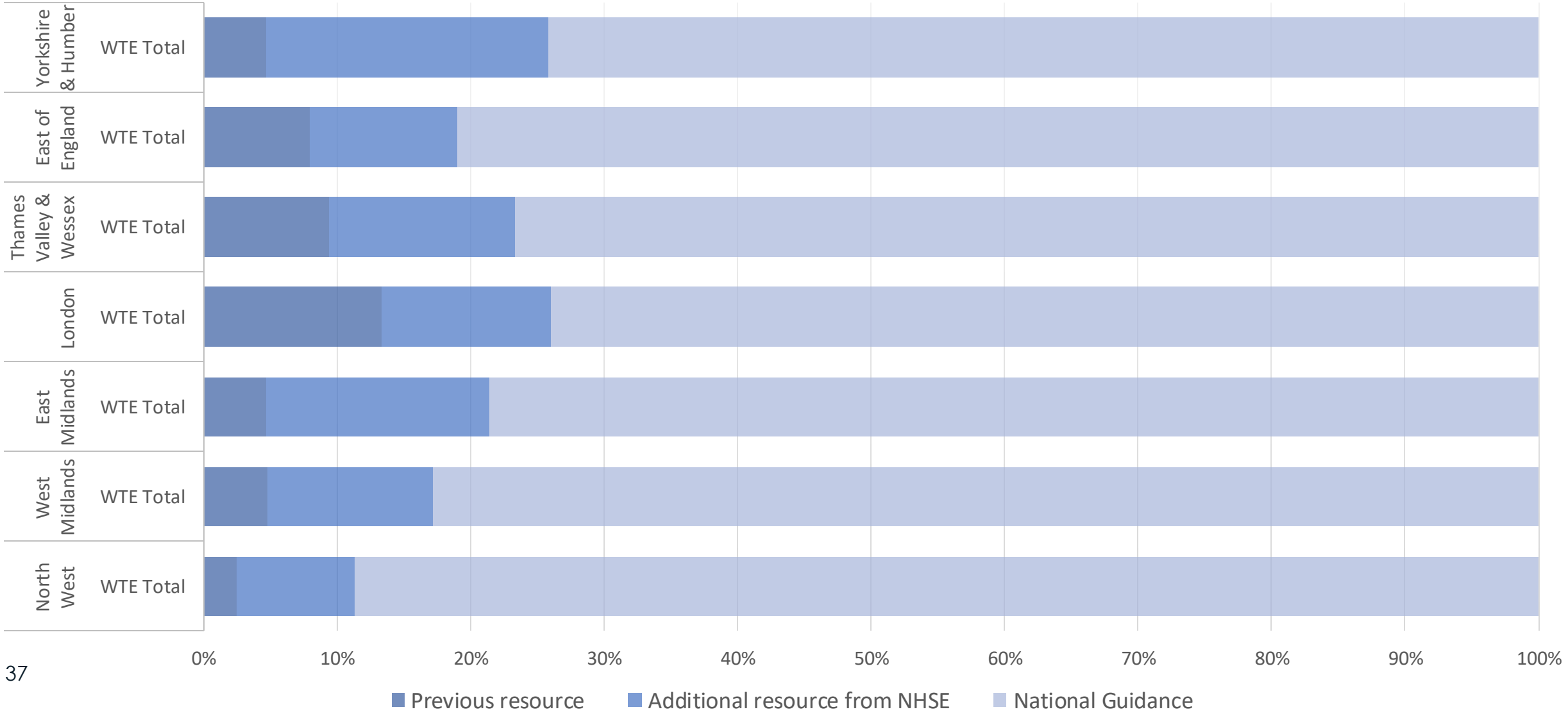
- Growing the workforce via NHS-E funding
- Developing e-learning modules for all staff
- Targeted webinars and discussion papers

Phase 4

- **Ongoing support for units growing the workforce**
- Development of training offers for all professions
- Ongoing 'hearts and minds' work

Supporting the existing workforce

INCREASING WORKFORCE PROVISION



Psychological Working at Strategic Levels

Culture work – Maternity Transformation Board – NHSE
Research & publications to promote best practice - Infant articles etc. BAPM webinars

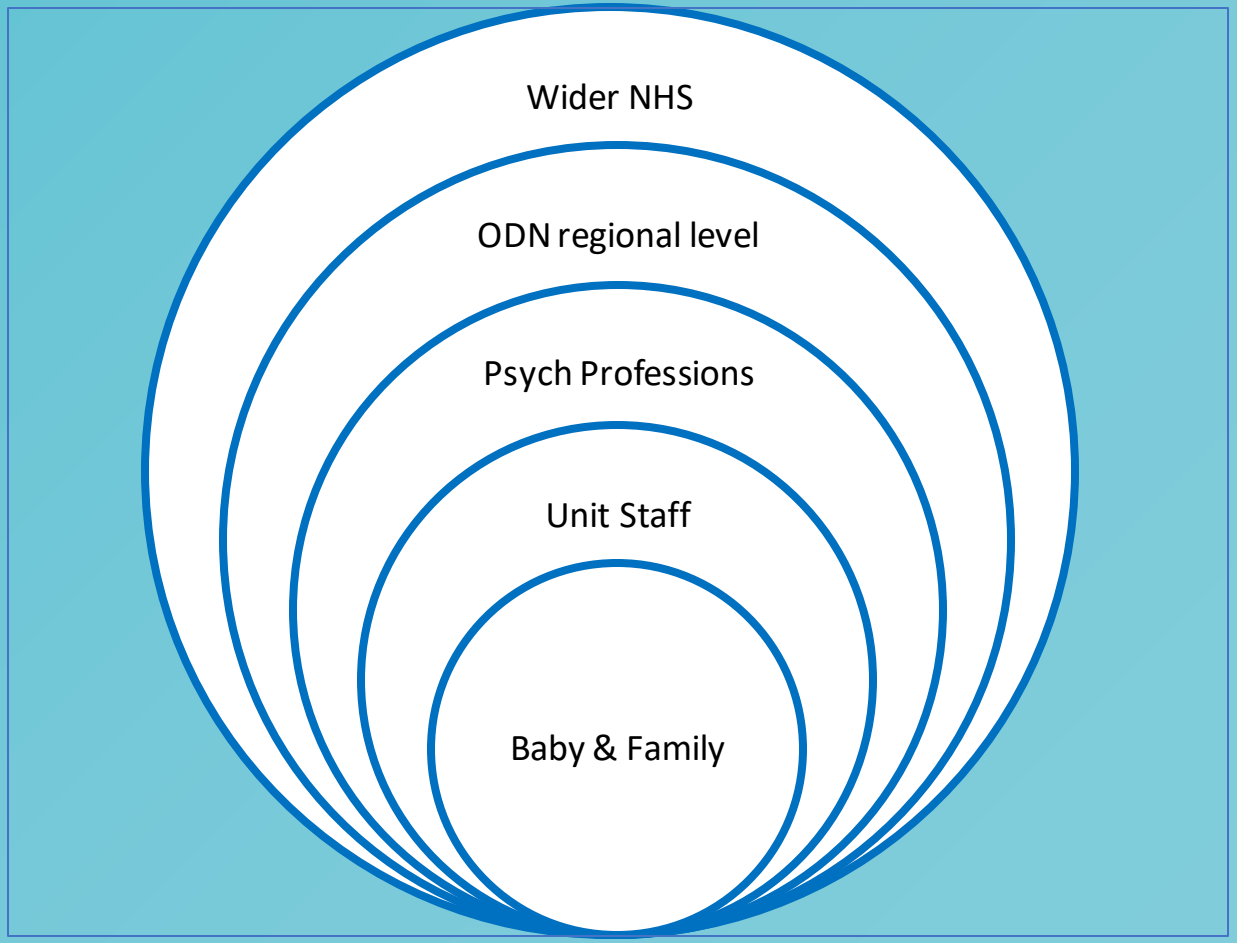
Promoting Psychologically Informed Neonatal Care at System Level: through various workstreams (e.g. FiCare, guidelines, teaching, BAPM working groups etc).

Development & sustaining workforce
Community of Practices - regional
National workshops & conferences

Development of national modules – HEE
(PINC) implementation of psychological teaching within national curriculum (e.g. QIS)

Increased Psychological professionals on units

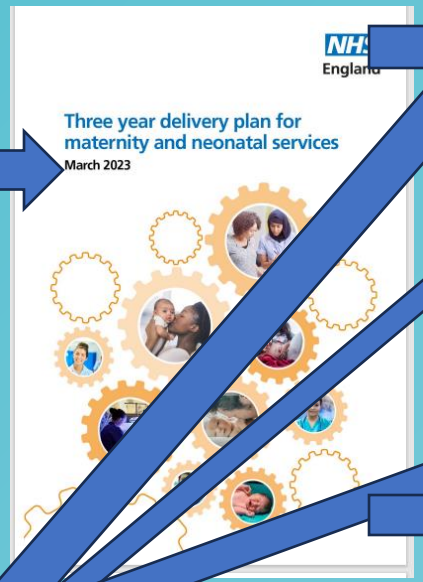
Distinct Psychological voice – working with leads, NIB, partnership board, BAPM.



An example: asserting the psychological staffing need

NHSE Listening events

Ockenden money



Service Specs

ICB's

Neonatal outreach

Follow up

Trusts

GAPS

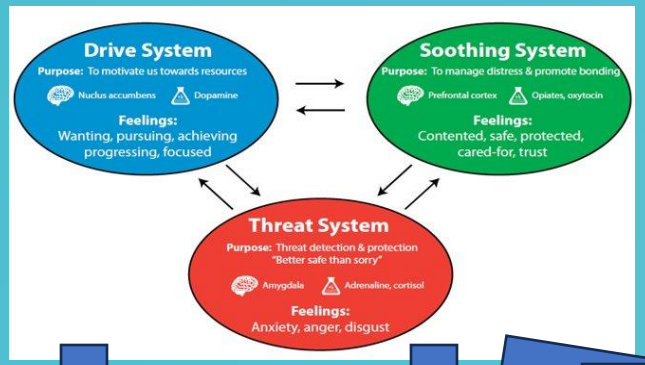
Birth trauma Parliamentary inquiry

Benchmarking

Defining, developing, supporting Psychological Professional posts

Further benchmarking data monitoring, building evidence base

An example: Psychological language and understanding



Maternity and neonatal reports e.g. Ockenden, Kirkup

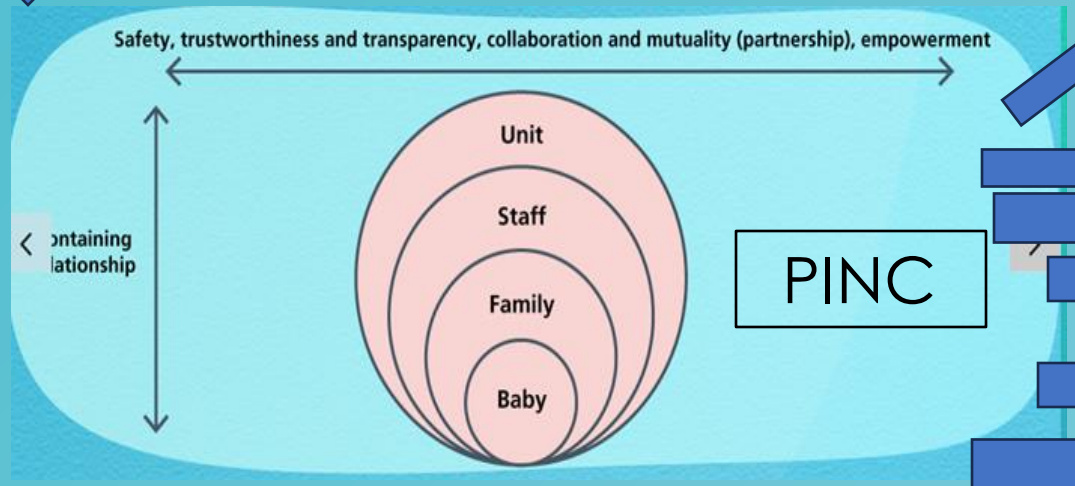
NHSE maternity & neonatal culture team

Response to Lucy Letby case

Canopie App- for parents

Anatomy of compassion articles

Unit Staff



Unit Psychological professionals

Education Strategy

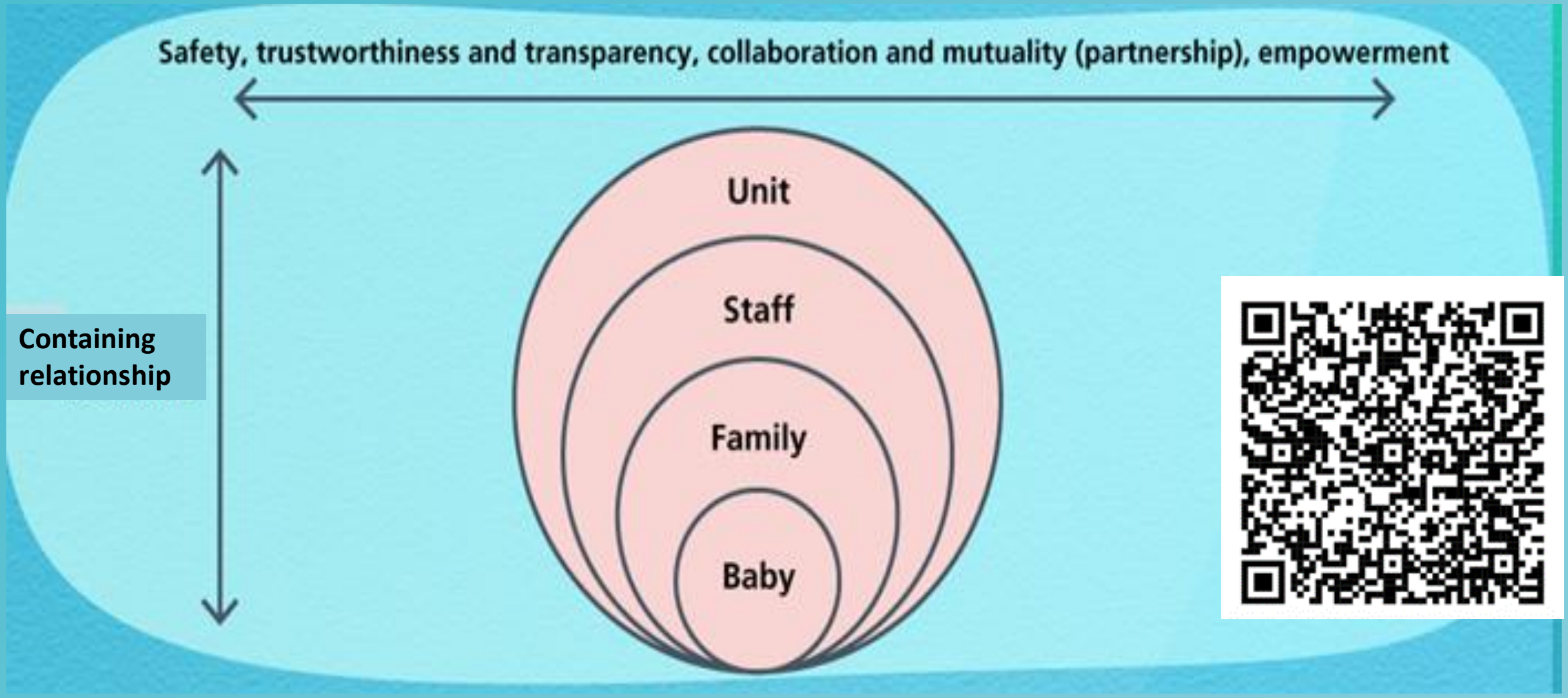
PINC

NNA

AHPs

Developmental care guidelines

Psychologically informed Neonatal Care (PINC)



Strengths & Opportunities

- ✓Leadership at a regional & national level
- ✓Answering a need – evidence based as well as morally and intuitively right.
- ✓Time to think & implement
- ✓Using psychological skills and knowledge to influence practice beyond direct psychological care
- ✓Shared values & goals - Working alongside different Psychological Professionals on units nationally
- ✓Building relationships with key stakeholders

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Challenges

- × NIB – assumptions about representation
- × Grouping PPs with AHPs
- × Everyone thinks they can be a Psychologist!
- × Units thinking about get well, get home
- × Dominance of the medical model.
- × Clinical Psychologists in ODN lead roles
- × Silo services
- × Not knowing where the influence is (scatter gun and sewing seeds)
- × Threat responses in the system

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Next steps

Phase 1

- Develop national policy & practice documents
- Continue to benchmark to compare regional and nationally

Phase 2

- Work with stakeholders to introduce new services
- Work with psychological professionals & their managers

Phase 3

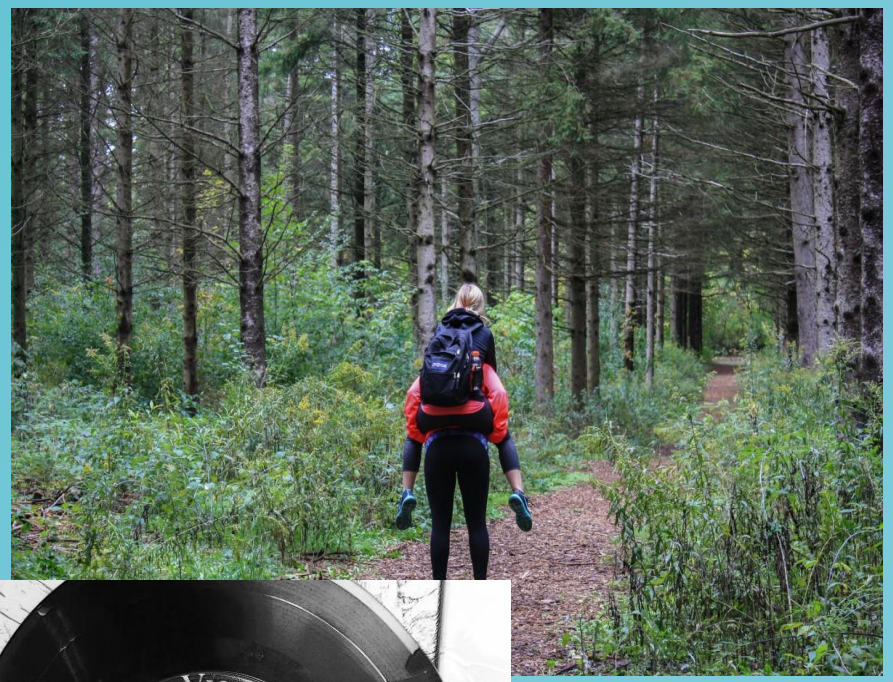
- Support new posts from inception to embedded in team
- Support units & therapy teams/managers

Phase 4

- Support **business cases**
- **lobbying**
- Support with data & commentary for NHS-E assurance process

Tips on making progress

- Collaborating – finding your tribe
- Get to know the context
- Finding another way in
- Getting Parents alongside us
- Confident about knowledge base & what Psychology brings
- Persistent – clear & consistent message - Broken records
- Finding the helpful & shared narratives



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Links:

- Psychology_Staffing_on_the_Neonatal_Unit.pdf (hubble-live-assets.s3.amazonaws.com)
- Psychologically informed Neonatal Care (PINC) -
  - Neonatal Psychology - elearning for healthcare (e-lfh.org.uk)
- Anatomy of compassion –
  - https://www.researchgate.net/publication/376033116_The_anatomy_of_compassion_part_2_nurturing_compassionate_cultures_of_maternity_and_neonatal_care