

Session 7:

Voices From the Start: Using Infant Experience to Shape Better Care and Family Support



‘Hold our story with us’

Helping parents and professionals understand the impact of neonatal care

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The Relational Practice

Neonatal care: A long-lasting legacy



Overwhelming sensory environment meeting immature nervous system

Unpredictable & repeated pain & medical trauma

Multiple stressors that accumulate and overwhelm their ability to maintain physiological stability & 'organize'

Happening during a time of critical brain change and development

Prolonged separation from caregiver & reduced opportunities to relate

Changes to stress responses and neurodevelopment in the longer term

Introducing Theo



- Theo was born at 25 weeks weighing 1lb 14oz
- We spent 123 days in hospital
- He experienced the typical challenges of an extremely pre-term baby, these included, but were not limited to:
 - BPD, PDA, Bilateral grade 2-3 IVHs, Sepsis, 6 weeks invasive ventilation, 10 blood transfusions, Grade 3 ROP.

Life after NICU: What we saw (and others often didn't)

Sensory challenges

Developmental delay

Behaviour/outbursts

ARFID

Periventricular leukomalacia

Deaf

EHCP

School

Social emotional relationships

Support for medical

Similar stories, isolated journey



The hope...

To create a resource that:

- Acknowledges and validates parents' worries
 - Gives them a sense that they're not alone in this
 - Helps them to understand what their child might be experiencing
 - Gives them the tools and the confidence to respond and to seek further support as needed
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- An accessible, supportive source of both information and signposting without the anxiety and stigma associated with 'Developmental Trauma'



What does it need to include?

What people see..

Difficulties with:

- Language & Communication
- Feeding / Eating
- Attention & Concentration
- Sleep and routine
- Thinking and learning
- Behaviour
- Friendships and relationships
- Toilet training

What might be under the surface?

Differences related to:

- Physical / Emotional regulation
- Sensory processing
- Body memory of trauma
- Attachment and relationships
- Survival responses
- Executive function
- Interrupted language / motor / cognitive building blocks

Making this accessible

Making sense of your child's needs after neonatal care

A resource for parents and carers

[Go to physician form](#)

Why have we made this resource for parents and professionals?

Families describe mixed feelings as their baby comes home from neonatal care. Given all they've been through neonatal babies don't always follow the "expected" trajectory of development and it can be difficult for parents to understand what they're seeing and know when to ask for help. We want to empower parents to feel confident in meeting their child's needs and to be able to seek appropriate support from professionals.



[Play the video to learn more about why we made this resource.](#)

Looking under the surface

When we have a worry about how a child is behaving, or a stuckness in their development, it's easy to get caught up in a behaviour (or lack of it) specifically. To help move them through it, we need to spend a bit of time thinking about what's under the surface and from that we can understand a bit more about how to help.



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WHAT YOU MIGHT SEE

There is some evidence that children born pre term may be slightly slower to toilet train (although this is a mixed finding). Whatever stage that children are learning to toilet train, though, we know that this is actually quite a complex process that involves lots of brain and body components – all of which might be slightly different for babies born sick or preterm.

🔊 Click the image below to hear more from a physician about what you might see.



[+ Transcript](#)

Does this feel relevant to you?

Yes, let's continue.



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WHAT DO YOU OBSERVE?
Which of the descriptions below feel like they might describe your and/or your child's experience?

🗨️ Respond to each of the prompts below.

My child struggles to recognize when they need to use the potty.

Yes No

Submit Answer Edit Answer

My child seems more sensitive to smell than I would expect, so they might be avoiding the potty.

Yes No

Submit Answer Edit Answer

My child is resistant to removing clothing or being exposed to the brighter lighting of the bathroom.

Yes No

Submit Answer Edit Answer

My child is overwhelmed by the sound of hand dryers in public toilets.

Yes No

Submit Answer Edit Answer

Customised form for your doctor

Child's date of birth: Save Edit

Date this form was last updated: Save Update

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Toilet training

I have observed challenges with:

- **Sensory integration:** finding it harder to have a clear sense or understanding of the signals within their body, meaning that they find it harder to recognise when they need to use the potty / toilet.
- **Sensory integration:** struggling with the cold of removing clothes, or the brighter lights of a toilet cubicle or bathroom.
- **Body memory:** experienced a great deal of physical pain or discomfort in their early life may have developed dissociation as a coping mechanism; struggles to identify when they need to toilet.

Additional notes for physician:

Option to include additional notes here

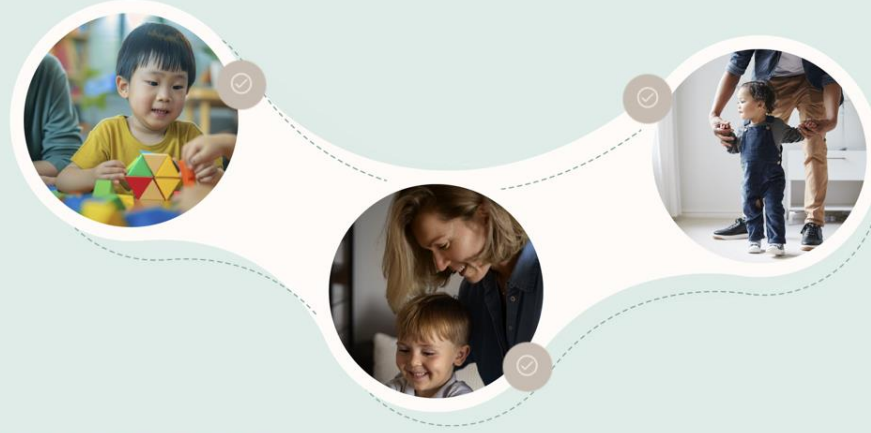
Save Edit

🖨️ Print this page

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THINGS TO TRY

As always, what you try will depend on which of the building blocks are contributing to the difficulty. However, these are some broad principles that might help:



When to seek support

All children will develop at different rates in different areas. Children who have been born early or sick may show particularly more variation in the stages at which they develop different skills. You know your child best, and will know whether a particular difficulty seems in keeping with their overall profile of skills and struggles.

As a general rule of thumb, however, seek support from your GP, health visitor or nursery/school if your child:

- Is 2.5 years old and shows no interest in toilet training
- Is 3 or older and isn't dry during the day
- Appears to be struggling with constipation or withholding
- Appears very anxious about toileting or is going in unusual places

Next steps

- First draft of all content is now complete and back with parents and specialist professionals to review
- Building the online framework in the background so we can pull it all together
- Hoping to disseminate by Summer 2026
- Let us know if you're interested to find out more!





Thank you!

Questions?

