Ei SMART CIO - Written evidence (PRT0024)

Early intervention for infants born preterm at high risk of developmental difficulties to improve longer-term outcomes: a proposal for best practice for neonatal and longer term support.

This evidence in submitted in order to raise awareness of:

- the efficacy of early intervention support for infants at high risk of developmental challenges and their families.

- the need to make evidence based early intervention more available.

- the lack of specialised training in this area.

- the existence of the Ei SMART framework as a vehicle for change.

- suggest Ei SMART as part of training for all healthcare providers involved in early intervention right from birth.

Key messages

- The Ei SMART framework has been developed by healthcare professionals and parents to guide early intervention for infants at high risk of atypical neurodevelopmental outcomes associated with preterm birth.
- The Ei SMART framework represents a clinical consensus arrived at following multidisciplinary group discussions (including parents with lived experience of high-risk infants), supported by a review of published literature.
- Ei SMART addresses all areas of the child's development: sensory, motor, attention and regulation and relationships, whilst working together with parents co-producing the intervention plan focussed on integrating therapeutic activities and support strategies into everyday life.

- The Ei SMART framework promotes a multidisciplinary team-working ethos centred around appropriate assessment and intervention and working Together with parents.
- Ei SMART is a charity developed by healthcare professionals and parents to improve developmental outcomes for babies with cerebral palsy, developmental delays and other difficulties. Ei SMART believes this is most effective when undertaken by parents working Together with healthcare professionals in the co-production of the intervention plan.
- Parents need to be equipped with the knowledge they need to support their child's development.
- Healthcare teams can learn how to be more effective whilst listening to and learning from parents.

1. **Ei SMART is a UK registered charity** focussed on improving the neurodevelopmental outcome of infants at high risk of developmental difficulties as a result of preterm birth or other birth trauma.

Our framework, Ei SMART, is the product of intensive work by a multidisciplinary group of clinicians, academics and parents.[1]

1.1 There is abundant research about the neurodevelopmental difficulties associated with preterm birth but there is less evidence about remediation of those difficulties. As a group we decided to address this gap and to review and highlight the evidence in support of early intervention through the formation of the Ei SMART framework. Our team is made up of parents with lived experience, occupational therapists, physiotherapists, and speech and language therapists, a paediatric neurologist, neonatologists and paediatricians, a parent infant psychotherapist and neonatal nurses. In addition, we have an expert advisory panel who are all leaders in their field of neurodevelopmental assessment and early

intervention for high risk infants including paediatric neurologists, psychology, occupational, physio and speech and language therapy and others concerned with the developing brain and neuroprotection.

1.2 Our board of Trustees includes Professor Topun Austin, Consultant Neonatologist, Addenbrooke's Hospital, Cambridge and Director of the Evelyn Perinatal Imaging Centre. He shares our vision to improve early intervention for high risk infants.

1.3 Ei SMART has identified and integrates key areas of development to maximise infant developmental outcomes. This includes addressing the Sensory, Motor, Attention and regulation needs of the infant, promoting parent-infant Relationships and healthcare professionals and parents working Together in the co-production of an intervention plan.

1.4 Our mission is to lead and transform the face of early intervention, so every infant with developmental challenges is supported using an Ei SMART approach, from birth for as long as support is needed.

2. What is early intervention?

2.1 "Over one million new neural connections form every second during a child's first years of life. This underscores the critical importance of early intervention to support safe, stable, nurturing relationships, beginning in the neonatal (or, arguably, the prenatal) period."[2]

2.2 A definition of early intervention, typically initiated within the first year of life, is "to promote child health and well-being, enhance emerging competencies, minimise developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning."[3]

2.3 There is published evidence on the beneficial effects of early intervention: a recent Cochrane systematic review identified early intervention programmes given to babies born preterm may improve mental and physical development in infancy (zero to three years) and do improve mental development at preschool age (three to five years). There

is a lack of good-quality evidence for mental and physical development at school age (five to less than 18 years). Future research in this area should focus on whether interventions in the first year of life are of benefit as children grow older.[4]

3. Current early intervention programmes:

When reviewing the literature in relation to the way provision and delivery of early intervention is currently organised, we found that there has been no single evidence-based early intervention approach designed specifically for use by a multidisciplinary team. Programmes are often delivered by individual therapists guided by their own beliefs, skills and expertise. As such, early intervention is typically not as coordinated, structured or evidence based as it should be. Parents tell us about their experience of receiving conflicting information from multiple health care providers.

4. The Ei SMART Framework:

In order to address some of these issues, the Ei SMART framework places the infant and family at the heart of care. The adoption of a holistic approach and working not just in partnership with parents but using co-production to develop a 'doable' intervention programme which can be easily integrated into everyday life and activities.

Review of the evidence demonstrates the following to be the core components of effective early intervention and care.[1,5]

- Actively involving, educating, and supporting parents in the biopsychosocial aspects of care.
- Supporting a consistent and responsive relationship between the parent(s) and infant.
- Recognising, supporting, and promoting self-regulatory behaviour in the infant.

- Supporting the infant's progress towards the next developmental steps in cognition, motor skills, sensory skills, and communication.
- Working together with parents to modify the infant's environment as necessary to ensure that they get the 'just right challenge' and can take part in a wide variety of self-initiated, self-produced motor, play and learning activities.
- Ensuring parental well-being.

From these principles, the Ei SMART framework was developed.

5. The Ei SMART threads explained:

The S, M, A, R and T are the essential components in the Ei SMART framework. We refer to them as threads since threads can be woven together in numerous ways and patterns to create strength, cohesion and complexity, forming connections, generating ideas which are interlinked and the integration of diverse perspectives, showcasing the power of interconnectedness.

5.1 Sensory:

The S in SMART stands for sensory. The sensory system plays a vital role in how babies perceive and interact with the world around them, influencing their cognitive, social, and emotional development. For babies with developmental delays, sensory processing difficulties can impede their ability to make sense of their environment, communicate effectively, and engage in typical developmental activities. By learning about sensory development, caregivers and healthcare professionals can better understand and address the unique needs of these infants, providing targeted interventions and support to promote optimal growth and learning. Recognising the importance of sensory development in baby development, particularly in those with developmental delays, can lead to early identification and intervention strategies that enhance their overall quality of life and future outcomes.

5.2 Motor:

The M is for motor, traditionally the area where most therapy is focussed in early intervention programmes. However, our review of the literature showed little effect on motor outcomes if the early intervention was solely focused on motor difficulties. The evidence suggests the need to move away from traditional models of therapy and consider which theorical frameworks, and which specific interventions will have more consistent efficacy in promoting cognitive and social emotional outcomes as well as motor improvements in high risk infants. We propose that neuronal group selection theory[6] (NGST) is such a framework which helps us understand how the brain learns new tasks and how neuronal patterns develop in the brain. In order to treat disordered motor behaviours in children NGST emphasises the importance of the child's active participation in both the initiation and the execution of the movement. This can be challenging for early intervention therapists as some infants with low levels of arousal or severe learning difficulties may need very significant help in order to be motivated.

5.3 Attention and Regulation:

The A is for attention and regulation, both of which in early development are deeply embedded in the child's relationships with others. Very young infants depend on caregivers to help them manage their emotional responses – over time infants develop their own self calming strategies. Many studies have shown the link between an infant's ability for sustained attention and better emotional regulation and executive functioning and cognitive control as the child gets older. Embedded within the parent infant relationship and the development of attunement is the infant's developing self-regulatory abilities.

Attention difficulties can be a problem for many children born prematurely or those exposed to early childhood stress. Many parents have reported that they were not told about the possibility of attention difficulties or about strategies to help ameliorate these.

Attention and regulation are intrinsically linked with sensory-motor behaviour and none of these areas can be addressed in isolation. A baby learns to regulate sleep/wake cycles as well as feeding needs, activity levels and interactions.

When babies are typically developing they learn how not to become overloaded with stimulation. In interactions they learn to look away to take time out as needed. In order to address attention and regulatory skills one has to become sensitive to the complex dynamics of infant behaviour, and the infant's physiological stability, as well as the infant's attempts at self-regulatory strategies. All of these can be addressed in early intervention programmes using the Ei SMART framework as a guide for identifying gaps in knowledge and learning needs.

5.4 Relationships:

The R is for relationships. Given the linked experience and outcomes of high risk infants and their parents following admission to neonatal units, there is an increasing recognition of the importance of supporting the parent-infant relationship and parent-infant well being in the delivery of early intervention. Research shows that increased sensitivity in the responsiveness of the parent has been found to support resilience in the infant. Supporting and promoting the parent infant relationship is an essential goal in early intervention. Increasing parents' awareness of their infants' competences and providing anticipatory guidance for areas of difficulty can promote a parent's sense of competence. This helps clinicians form a supportive partnership with parents and provide relationship based care which is central to the success of the Ei SMART approach.

5.5 Together:

The T in Ei SMART refers to:

- Integrating all the threads (S, M, A and R) Together in the intervention programme
- Working Together with parents in coproduction of the intervention plan
- All members of the multidisciplinary team working Together with a shared understanding and vision.

Ei SMART has a proposed structure for organising care for all members of the multidisciplinary team, integrating each member's strengths and expertise and facilitating good communication. It provides a common framework so that all members have a shared understanding of what the others are doing and why, ensuring parents get the support they need and feel equipped to support their infants needs.

6. Ei SMART resources and ongoing work:

6.1 Our resources include developmental leaflets and posters available free to download from our website. These have proved to be hugely popular and widely used in the UK with many translations also being downloaded for use outside the UK. Parents describe our leaflets as something they use constantly to support and promote their child's development. One parent described them as a lifeline. (See parents testimonial page on our website: https://eismart.co.uk/parent-testimonials/)

6.2 We feel very fortunate to have heard recently that we have been successful in our application to the National Lottery Fund and have secured funding to develop 5 short videos for parents taking their baby home from the neonatal unit. The videos will explain how to support and promote the infant's development in Sensory, Motor, Attention and Regulation, whilst supporting the parent-infant Relationship and working Together with healthcare professionals.

The videos will equip parents to provide timely and appropriate developmental activities hence ensuring their baby has the best possible start in life. Healthcare professionals including health visitors will also find the videos informative and relevant to their work with this population. Parents report such videos would have helped bridge the gap between needing intervention but not getting it due to waiting lists and attitudes to early intervention where parents describe there is often a prevailing 'wait and see' attitude.

The aim is that every parent in the UK leaving the neonatal unit would access the videos through our links with neonatal units and our website.

6.3 Co-production is a key principle of Ei SMART and our resources are developed jointly with parents with lived experience. This has united many healthcare professionals throughout the UK who have embraced Ei SMART as an effective way of working together with parents and within their own team. Ei SMART brings together nurses, doctors, occupational therapists, physiotherapists and speech and language therapists in hospitals and in community settings around a common framework.

6.4 The current lack of specialised services and limited understanding of the importance of early intervention results in long waiting times. Intervention is often not available during the most crucial period, the first few months of life, when the brain has abundant plasticity and there is the potential for rewiring and repair as a result of intervention. Ei SMART address this sensitive period of development to optimise neurodevelopmental outcomes for this population.

6.5 The Ei SMART parent and healthcare professional team are all volunteers and have worked together for 7 years building this novel and innovative framework. All our parents have a child with developmental challenges and have the lived experience of the difficulties they faced accessing appropriate, timely and effective early intervention. Our aim is to improve the experience for other parents and to improve developmental outcomes for babies with cerebral palsy, developmental

delays and other difficulties. We believe this is best done by parents and healthcare professionals working Together in the co-production of resources and educational materials so that parents are equipped with the knowledge they need to support their child's development and health care teams can learn how to be more effective whilst listening to and learning from parents.

7. Challenges:

7.1 There are challenges in terms of training and updating the healthcare professionals involved in this field. Ei SMART is attempting to address this area albeit we are limited by the fact we are a small voluntary group but we have trained hundreds of therapists in the last 5 years and have increasing participation from nurses, doctors and other healthcare professionals. Our themed monthly newsletter is now distributed to over 1200 people including parents. Ei SMART and the training we offer has been referenced in the NHSE CYP transformation team's cerebral palsy pathways of care framework for commissioners. In addition to our courses for therapists and other healthcare professionals we have just launched a new one day course for neonatologists and paediatricians. The aim of this training is to equip doctors with the skills they need to Integrate early intervention and anticipatory guidance to their neurodevelopmental follow up clinics for high-risk infants post discharge.

7.2 Resources in the NHS are limited and it is crucial healthcare providers allocate resources effectively and target support where it is most needed. Early identification of at risk infants enables timely intervention strategies to be implemented maximising the likelihood of positive outcomes and improving the overall developmental trajectory of these children. Early assessment and neuro-imaging techniques are now reliably able to identify infants at high risk of developmental challenges in order to be able to target those infants who may benefit from early intervention.[7]

However despite this parents report they are frequently told to 'wait and see' and they describe this as a very difficult period as they feel they are losing time and not getting the help they need to progress their child's development.

7.3 More research in this area is needed but it is challenging to conduct due to the diversity and variability of multiple complex factors. In clinical practice, therefore, a pragmatic approach may be required, based on a combination of elements that are effective in isolation. Evaluation of the contribution of individual components to the overall outcome may not be possible, but this does not preclude evaluation of the intervention package (e.g. the effect of having an early intervention team on child and family outcomes). In Ei SMART we are particularly interested in outcomes in relation to parents' experience.

7.4 Within the team we are considering how we could reliably measure the following:

- how parental well being is positively impacted by attending our early assessment and early intervention course? (referenced below by parents).
- Were parents sleeping better, feeling less anxious, felt closer to their baby, were proud to be more knowledgeable, had an explicit joint, agreed goal between them?
- Did the course have any impact on their home environment?

We consider these to be the important questions in terms of adaptive parenting and overall family functioning and well being, and ultimately improving longer terms outcomes for infants born preterm.

8. **Case example:** from Lauren mother of Evan. 'Look at what Evan can do now'

“Evan couldn't put his left leg up on the bar by himself before the (EI SMART) course, but now he's done it a few times!

Our son Evan was born at 26 weeks and unfortunately at 72 hours of life had medical complications relating to the blood supply to his brain, which sadly are not uncommon in extremely preterm babies. This has resulted in a weakness in Evan's left side of his body. We regularly attend early intervention physio and OT sessions at Cerebral Palsy Cymru (a charity based in Wales providing early intervention support) and through the NHS, as well as practising early intervention techniques at home in our day-to-day life.

Following our attendance at the recent Ei SMART early intervention infant course he is now able to put both feet on his pram bar. He can now also reach out and feel our faces with his left hand too.

The enhancements we've seen in his left hand side are down to the extremely valuable early intervention techniques we've learnt and which we work hard to put into practise at home. There was a time where we couldn't think too much about his future, what he was or wasn't going to be able to do but we are now very optimistic for his future and that is a wonderful feeling”.

(read the full story with photos in our July 2023 newsletter - https://mailchi.mp/1ecdde36edfe/11405037-13561200

9. **From a course participant**: Jo Archard, OT Sheffield Children’s NHS Trust says:

Nothing prepared me for how much I was going to learn and take away from this course. The focus has been on what the baby can do and their strengths. Start with the baby where you find them – use the position the baby is in when they arrive. Don’t get stuck on one correct position as many positions can be made to be therapeutic to support the baby’s development. We should aim for variability and help the baby build on

their repertoire of skills. Support the baby's exploratory inner drive. Remember to combine the S, M, A and R for effective interventions and involve parents all the way through in co-production.

(read more in our February 2023 newsletter - https://mailchi.mp/cf637f0a3139/11405037-13536340)

10. From a parent and an ANNP: (via email)

My Name Is Leah Wright

I am a Advanced Neonatal Nurse Practitioner and the mother of a 2 wonderful Children.

My son Noah was born at 29+5 weeks gestation in March 2021 after a very difficult pregnancy, he was admitted to the NICU where he spent the first 3 months of his life.

I cannot begin to explain how difficult this was and how totally helpless I felt as a parent. Due to the complex nature of my pregnancy and Noah's subsequent premature birth we were told that it was highly likely Noah's neurodevelopment would be affected but until he developed it was impossible to tell exactly how. This served only to serve me and my family further anxiety and worry.

Of course, our next question was well what can we do?

The response was wait and see.

As an ANNP I understood this approach, As a Parent I was devastated by it and so my next question was what can I do about it?

There was no answer, no guidance. There would be no intervention until we saw a delay...this felt counterproductive. As a medical professional I was well aware that as a discipline we now understand a bit more about the brain of a premature baby and its neuroplasticity and the importance of early intervention as a preventative measure for these little babies. An incredible amount of time and money has gone into funding research, yet

although we now have this knowledge we have little in the way of resources to implement it.

At present allied Health professionals are losing funding waiting lists on the NHS are long and resources are low especially in low social and economic areas promoting a real inequality in child health.

Faced with navigating a system like this to try to ensure my son got the help he needed was very stressful and so worrying .

I first came into contact with Ei-SMART in 2022 when Noah was 9 months old. Ei- SMART is a framework of care for babies that promotes early intervention and had specific resources aimed at parents to assist them in helping to promote their neurodevelopment. This is exactly what we needed. As parents everyone wants the best for their children and here was a charity understanding and recognising that we were more than able to provide this guidance and they were prepared to educate us and show us how.

Ei SMART is now attempting to bring this resource to the NHS.

I believe doing so will go a long way to addressing so many problems that currently exist within the NHS and it will most certainly improve the quality of care our babies and their families receive on the NICU

11. From Matt and Claire, parents of Poppy: (via email)

Our well being was greatly impacted by attending the early assessment and early intervention course 3 times. Despite the fact that Poppy had a major brain injury and we were told early on she would have cerebral palsy we came away from every session feeling more positive as Poppy had acquired new skills, and particularly after the first one, gave us the belief that what we did at home could really influence her development. The worries were still there about Poppy and her future, but we came away more hopeful about the outlook, knowing that the early intervention was the best thing for her, and would make a difference. We felt we had more resilience when things seem overwhelming, and more

confidence to liaise with her community therapy team about goals and support required. After the third session, we had more awareness of Poppy's communication cues.

It was helpful to know what realistic goals we were trying to achieve, the reasons behind them, and the ways in which we could help achieve them. It was useful to be able to spend a good amount of time on her development, and watch the therapists work with our child. We came away feeling less anxious and encouraged, stemming from the therapists on the course and being so enthusiastic and sharing in our joy in each new thing that Poppy was able to do.

(read more about Poppy's journey and other babies and families in our February 2024 newsletter: https://mailchi.mp/6f51b2ece86e/11405037-13655608)

12. Summary

12.1 EiSMART is an evidence based framework to give high risk babies the best start in life. We span all aspects of a child's development: **S**ensory, **M**otor, **A**ttention and Regulation, and **R**elationships. Professionals and parents work **T**ogether to support premature and sick infants from birth (**E**arly **I**ntervention). It is the product of intensive work by a multidisciplinary group of clinicians, academics and parents.

12.2 The Ei SMART framework focusses on parents and considers our role is to work together to enhance, promote and encourage development – attention is directed towards what a child can do and this promotes a sense of competence. We encourage young children to use what they have – we all do things in many ways, there is more than one path to success!

12.3 The Ei SMART framework is based on current evidence and research, which provides a strong foundation for early intervention starting in the

neonatal unit. We strive to stay informed about the latest developments and findings in the field to ensure that our approach remains up-to-date and aligned with the best available evidence. When new research indicates a shift in understanding or suggests alternative strategies or approaches, we are open to revising and updating our framework accordingly.

For more information on Ei SMART and what we are trying to achieve visit our website and review our content and read our newsletters. www.eismart.co.uk

13. References:

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26 March 2024