

## **Dr Rachel Collum, Lauren Ingledow, PERIScope Team - Written evidence (PRT0016)**

### **Overview**

This evidence relates to the category of **neonatal and longer-term care and support**. I am a lecturer in Psychology at the University of Sunderland (Also mum to a baby born at 29+1 gestation in 2017) and my research is focused on co-producing work with adults born pre-term around what they would like professionals to know about the life-long impacts of their prematurity. This project has been conducted with integral input from Lauren Ingledow, Co-Founder of the Adult Premie Advocacy Network CIC (APAN).

Over the last few decades, advances in neonatal medicine and technology have meant that babies born pre-term have positive life expectancies in line with a typical population, with many thousands developing to thrive (Taha, Simpson & Sharkey, 2023). This means that, unlike 50+ years ago, we now have a population of healthy adults born pre-term who were unlikely to have lived beyond early childhood previously. With this positive development in medicine comes the significant need to ensure we understand what prematurity looks like as it expands into the later life course and to work with adults born pre-term to acknowledge and support their individual needs, unique to their pre-term start in life. This has historically been a gap, with the majority of research focusing on the years immediately following discharge from the neonatal unit but tending to plateau around age 10 or earlier (Jansen et al., 2021). A search for 'prematurity in adulthood' on science literature search engines returns a lot of research into the *medical* impacts of prematurity in the longer-term but there's a scarcity of literature exploring the more 'day to day' impacts that adults born pre-term would like professionals to be aware of.

Our co-produced project involves 8 adults born pre-term, who have co-developed a set of interview questions to explore what prematurity looks

like in adulthood. To date, the group have conducted 6 interviews with other adults born pre-term and we will shortly be conducting a group framework analysis on this data. We have pulled some initial, anecdotal, themes from the interviews to present here, and these themes have been reiterated multiple times by conversations of lived experiences within our group:

### **Prematurity as a diagnosis**

The individuals interviewed often articulated that prematurity is either considered 'to blame' or completely dismissed when accessing services regarding physical or mental health issues. Individuals felt that it was sometimes used as a blanket statement, such as "Oh, it's just because you were premature" but without any consideration of what that might look like or how the related issues should therefore be managed. One of the recurring issues to come out was the concept of sitting under other diagnostic thresholds (Such as with autism) because the symptoms or traits were not considered significant enough or to impact on daily functioning to diagnostic levels. However, it was still felt that support was needed with some of these issues, such as anxiety in social situations or ongoing hyper-sensitivities. Several individuals in our group are keen that prematurity be recognized as a distinct diagnosis, or at the very least considered as a screening question, with appropriate support pathways to better acknowledge some of these daily challenges.

### **Masking in prematurity**

Akin to the masking seen in autism (Miller, Rees & Pearson, 2021), adults born pre-term suggested in this work that they also often feel the need to mask some of their 'atypicalities' in order to fit in with work and social situations. Individuals commented on how mentally exhausting this could be and of the probable link between the mental effort of this and some of

their physical health issues. The group felt that having a separate and distinct diagnosis of prematurity would avail the need to mask to such an extent, as better professional understanding and more social awareness would mitigate the need for 'hiding' some of their greatest challenges.

### **Prematurity as a spectrum**

Another consistent view from our group was that any diagnosis of prematurity should be considered, like autism, as a spectrum. Rather than this spectrum denoting 'functioning', however, the group felt that it should be more an encapsulation of the individual profiles each person born pre-term might have, such as sensory issues; difficulties with social interactions; impact of attachment patterns on relationships; health issues, etc. It is clear from our conversations that this list is not exhaustive, and every individual speaks about very different patterns of what they consider to be their own challenges and strengths. The focus on strengths is also really important to our group and many have spoken about feeling they're resilient, have overcome adversities, are 'strong' and so on. However, there is also a concern amongst our group that professionals can pay too much attention to the positive aspects of prematurity and use this almost as a dismissal of where there might be other difficulties. Therefore, acknowledging the full profile within a spectrum-type model would be a robust way to understanding what prematurity can look like for any one person.

### **The long and wide approach**

Finally, most of our interviews revealed that individuals see the importance of professionals taking a life-long view of prematurity, which might begin even before neonatal admission and continues throughout the entire lifespan. This should also be a wide lens where the baby born pre-term is at the centre, but a systemic approach is also taken to

understanding their broader relationships. Typically, most research on mental health in neonates focuses on the parents supporting the babies in the neonatal unit and on transition to home (Galea, Park & Hegadoren, 2022) but far less considers the *reciprocal* relationships between the baby and parents (or siblings) and how this might shape longer-term family dynamics. Our group expressed recurring themes in feeling they were either 'too clingy' or 'distant' in some of their relationships and several queried whether this was due to their prematurity. Better research and knowledge from professionals around this to help adults born pre-term navigate some of these issues would be very beneficial.

## **Summary**

To conclude, our work strongly indicates that adults born pre-term would like to be considered as a distinct group, with better research, knowledge and understanding around how to support the challenges they face in order to scaffold their existing strengths. We would like to propose that a steering group of adults born pre-term be employed who can work alongside key professionals (Such as psychologists, GPs, social workers, etc.) to develop a training package around the key issues that adults born pre-term face. This could inform a larger piece of work around diagnostic and support pathways in the longer term. What is clear is that prematurity has many unique facets separate from other diagnoses and the only way to fully understand these is by working with adults born pre-term to understand their lived day-to-day experiences.

## **References**

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