

## **Prof Camilla Gilmore, Prof Samantha Johnson - Written evidence (PRT0017)**

### **About the authors:**

Samantha Johnson is a Professor of Child Development in the Department of Population Health Sciences, University of Leicester. She is an expert in the study of the long term impact of preterm birth. She is a member of the Executive Committee of the British Association for Neonatal Neurodevelopmental Follow-up and was a member of the National Institute for Health and Care Excellence (NICE) Guideline Committee who produced the current recommendations for the developmental follow-up of children born preterm. Professor Johnson led the Premature Infants' Skills in Mathematics (PRISM) Study that sought to improve educational support for children born preterm. Professor Camilla Gilmore is an expert in developmental and educational psychology with a focus on mathematics learning and education. She leads the Economic and Social Research Council (ESRC) Centre for Early Mathematics Learning and is a member of the PRISM Study team. Together with colleagues, Professors Johnson and Gilmore developed the PRISM e-learning resource to provide FREE training to help professionals support preterm born students ([www.pretermbirth.info](http://www.pretermbirth.info)). Professor Johnson provided oral evidence to the Committee on 11<sup>th</sup> March 2024. This submission provides further evidence in support of that.

### **Summary of submission:**

- This submission supports the oral evidence previously given to the Committee by Professor Samantha Johnson on 11<sup>th</sup> March 2024.
- We present evidence that preterm birth has adverse impacts on children's educational outcomes with negative consequences for their future life chances.

- We also present evidence that there is an urgent need to improve understanding of prematurity in the education sector.
- We provide five key recommendations for enhancing educational support in order to improve long term outcomes for children and families.

### **Summary of recommendations:**

- Ensure implementation of the NICE guideline (NG-72) regarding the provision of a developmental assessment at four years of age for children born extremely preterm.
- Healthcare professionals should routinely share information about children's development with educational settings for instructional purposes.
- Schools and early years settings should ask parents for information about a child's birth history on admission.
- Schools and early years settings should instigate enhanced monitoring of children born preterm on admission.
- Provide the educational workforce with access to high-quality evidence-based information and training about preterm birth.

### **This submission relates primarily to two of the inquiry's topics of interest:**

- The implementation of existing NICE and NHS guidance on preterm birth.
- Longer-term impacts, care and support for preterm babies and their families.

## **Evidence on the long term impact of preterm birth on educational outcomes:**

Children born preterm are at increased risk for a range of developmental problems and disorders, especially cognitive and motor impairments, attention, social and emotional problems, attention-deficit/hyperactivity disorders (ADHD) and Autism<sup>1</sup>. The more preterm a baby is born, the greater the risk of these problems later in life. As such, babies born very preterm (before 32 weeks of gestation), and especially those born extremely preterm (before 28 weeks of gestation), are at greatest risk. These problems can persist throughout the lifespan and can have an adverse impact on a child's performance at school.

Indeed, our research has shown that children born preterm are at higher risk for special educational needs (SEN) than children born at term. The risk is highest among children born very and extremely preterm. For example, in a recent analysis of UK data<sup>2</sup>, Professor Johnson and colleagues reported that 27% of very preterm born children had SEN at age 11, over three times the rate for children born full term (11%). We have also shown that 66% of children born at the lowest gestations, before 26 weeks of gestation, have SEN<sup>3</sup>.

Preterm birth not only impacts levels of SEN, but also impacts academic achievement. Together with colleagues, Professor Johnson has shown that very preterm born children have lower levels of achievement than their full term born peers, both at the end of primary school (Key Stage 2; age 11) and at GCSEs (Key Stage 4; age 16). Amongst children born in England in 2000-2001<sup>4</sup>, almost 40% of very preterm born children failed to achieve the expected standard in English and mathematics at the end of primary school (age 11), in comparison to 16% of full term born

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<sup>1</sup> Wolke et al., 2019 <https://doi.org/10.1146/annurev-devpsych-121318-084804>

<sup>2</sup> Alterman et al., 2021 <https://doi.org/10.1136/archdischild-2020-320213>

<sup>3</sup> Johnson et al., 2009 <https://doi.org/10.1136/adc.2008.152793>

<sup>4</sup> Alterman et al., 2022 <https://doi.org/10.1371/journal.pone.0271952>

children. By GCSEs (age 16), 60% of very preterm born children failed to achieve five GCSE passes at Grades A-C including in English and mathematics, compared to 44% of children born full term. Our research has also identified that very preterm born children have particular difficulties with mathematics in both primary<sup>3,5</sup> and secondary school<sup>6</sup>. Given the well-established relationship between mathematical skills and future life chances, this can have long term negative consequences for preterm born children's wealth and quality of life in adulthood<sup>7</sup>.

### **Evidence on the need for increased understanding of prematurity in the education sector:**

Our research has shown that education professionals have poor knowledge of the impact of preterm birth on children's development and learning, and of how to support them in schools and early years settings<sup>8</sup>. In our national survey, only 16% of teaching staff had received any training about preterm birth and, in most cases, this was extremely limited. Our results also indicated that education professionals lacked understanding that preterm born children may have mathematics difficulties, social-emotional difficulties and attention problems. This is concerning as it indicates that preterm born children may not be receiving support in the areas they need it the most. The lack of understanding of prematurity in the education sector is also of major concern to parents. A recent report by The Smallest Things Charity found that 43% of parents felt that staff didn't understand the developmental or learning needs of their child and 84% felt that more awareness of prematurity was needed in education settings<sup>9</sup>. Given that two children in every average sized class may have been born preterm, all education professionals will be

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<sup>5</sup> Simms et al., 2015 <https://doi.org/10.1038/pr.2014.184>

<sup>6</sup> Clayton et al., 2022 <https://doi.org/10.1080/09297049.2021.1955847>

<sup>7</sup> Basten et al., 2015 <https://doi.org/10.1177/0956797615596230>

<sup>8</sup> Johnson et al., 2015 <https://doi.org/10.1111/dmcn.12683>

<sup>9</sup> The Smallest Things, 2021; <https://www.thesmallestthings.org/after-nicu-a-post-pandemic-report-2021>

responsible for identifying difficulties and providing support for preterm born children at some point in their career. Moreover, our research shows that children born preterm tend to be quiet and compliant and internalise their difficulties; they are no more likely than term born children to be aggressive, delinquent or anti-social and they tend not to be involved in fights or to disrupt the classroom<sup>1</sup>. As such they may not come to a teacher's attention as needing support in the same way that other children with SEN or with externalising behaviour problems do and therefore their difficulties may go undetected. Indeed, parents often refer to their preterm born children as 'slipping under the radar' as their difficulties may be subtle and tend to be missed. Putting all this together, there is an urgent need to increase understanding of prematurity in the education sector to enable professionals to identify children's difficulties and provide appropriate support for children and families.

### **Recommendations to improve outcomes for children and families:**

To improve longer term outcomes for children and families we make the following five key recommendations.

#### **Recommendation 1: Ensure implementation of the NICE guideline regarding the provision of a developmental assessment at four years of age for children born extremely preterm**

- The NICE guideline (NG-72) "Developmental follow-up of children and young people born preterm"<sup>10</sup> recommends that all children born before 28 weeks of gestation receive enhanced developmental surveillance, including a face-to-face assessment at four years of age. This assessment should include the use of an IQ test and parent questionnaires to assess children's development and identify attention, social and emotional problems. Importantly, NICE recommends that the

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<sup>10</sup> <https://www.nice.org.uk/guidance/ng72>

results of these assessments should “inform the development of a plan for intervention and support, including educational support” if needed. If the results of assessments at two or four years of age suggest any developmental problems, NICE recommends that healthcare professionals should “ask parents or carers for permission to share this information with education services”.

- If the four year assessment is carried out, and the information is shared with staff in the child’s school or early years setting, this has significant potential to improve the provision and quality of educational support for this highly vulnerable group of children.
- As outlined in the oral evidence given to the Committee by Professor Johnson and colleagues on 11<sup>th</sup> March 2024, the four year assessment is not routinely happening in the vast majority of neonatal services nationally, therefore we recommend that resources are made available to support the provision of this assessment for all children who are eligible for enhanced developmental surveillance at four years of age.

**Recommendation 2: Healthcare professionals should routinely share information about children’s development with educational settings for instructional purposes**

- As noted above, the NICE guideline recommends that healthcare professionals “ask parents or carers for permission to share information with education services” if the results of assessments at two or four years of age suggest any developmental problems.
- We recommend that information from developmental assessments carried out as part of neonatal follow-up should routinely be shared with educational settings, with parental consent, in order that any difficulties are identified and that enhanced monitoring, and additional support can be instigated from the earliest opportunity, if needed.

### **Recommendation 3: Schools and early years settings should ask parents for information about a child's birth history on admission**

- As outlined above, preterm born children's developmental difficulties may be missed in educational settings, or they may not be identified until they have already impacted on their learning and academic achievement. Therefore, it is important that staff are aware if a child is born preterm so that they can identify problems early and provide appropriate support, if needed.
- Routinely asking parents for information about their child's birth history on admission would allow schools and early years settings to put in place enhanced monitoring of children's development and progress.
- Asking about a child's birth history on admission to school or an early years setting will also allow parents to be able to share information about their preterm born child's health and developmental needs and to discuss their child's development as a routine part of their educational journey. This will allow parents' voices to be heard and for them to have greater opportunity to advocate for their preterm born child.
- Information about the child's birth history and any developmental or learning needs should routinely be shared from early years settings to primary schools, and from primary schools to secondary schools, during the child's transition between education settings. This will ensure that children can receive appropriate support from the outset of their admission to each new setting. It will also avoid parents having to re-tell their story each time their child enters a new setting, which can trigger feelings of anxiety or stress as a result of the trauma that may be experienced in relation to a preterm birth.

**Recommendation 4: Schools and early years settings should instigate enhanced monitoring of children born preterm on admission**

- Given the increased risk for developmental problems and disorders and poor academic achievement amongst children born preterm, schools should instigate enhanced monitoring of all children born preterm on admission to their setting.
- To do this, schools and early years settings should add preterm born children to their “vulnerable children’s list” or other method for identifying children who require additional monitoring due to the presence of risk factors for developmental problems (e.g., looked after children; pupil premium students) on admission. This will ensure that additional support needs can be quickly identified and appropriate support put in place if developmental problems arise.

**Recommendation 5: Provide the educational workforce with access to high-quality evidence-based information and training about preterm birth**

- In the NICE guideline for the developmental follow-up of children and young people born preterm (NG-72), it is recommended that “primary and secondary education professionals should be aware that preterm birth may be a factor in learning or behavioural problems, that these problems can emerge at any point during a child or young person’s education, and that prompt referral to educational support services may be needed”.
- It is therefore crucial that high-quality, evidence-based training about the developmental and educational needs of preterm born children is undertaken by staff in education settings in order for them to better understand the long term impact of preterm birth, identify children with difficulties and provide support. This should include information to



make professionals aware that not all preterm born children will have developmental or educational problems later in life in order to circumvent any potential negative effects of labelling.

- If Recommendations 1 to 4 are implemented, it is essential that education professionals undertake training about preterm birth. It is only appropriate for information to be shared between health and education settings (Recommendations 1 and 2) and for education professionals to ask and use information about a child's birth history (Recommendations 3 and 4) if staff know what to do with this information and are appropriately prepared to support children and families.
- The PRISM Study e-learning resource ([www.pretermbirth.info](http://www.pretermbirth.info)) provides free, evidence-based training about the longer-term consequences of preterm birth and how education professionals can support children's learning and development. The training takes less than one hour to complete. Our research has shown that use of this e-learning resource significantly improves teachers' knowledge of prematurity and their confidence in supporting preterm born children in the classroom<sup>11</sup>. We recommend that all staff in primary and secondary schools and in early years settings undertake this training.
- We also recommend that schools and early years settings are encouraged to achieve the "Prem Aware Award" ([www.thesmallestthings.org/prem-aware-award](http://www.thesmallestthings.org/prem-aware-award)) developed by UK charity 'The Smallest Things'<sup>12</sup>. Achieving this award involves schools implementing 3 simple steps: (1) key school staff complete the PRISM training and cascade this learning within their setting; (2) admission procedures are amended so that parents are routinely asked about their child's birth history on admission; (3) staff seek feedback from parents on how they feel their preterm born child is supported. To date,

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<sup>11</sup> Johnson et al., 2019 <https://doi.org/10.1136/bmjopen-2019-029720>

<sup>12</sup> <https://www.thesmallestthings.org/>

79 schools or early years settings in the UK have achieved the Prem Aware Award with excellent feedback from staff and parents on its benefits; a further 58 are currently completing the award. In Northern Ireland (NI), the Department of Education NI have funded 'Tiny Life Charity' to support all schools in NI to achieve the "TinyLearner Award"<sup>13</sup> which is based on the same model as the Prem Aware Award, similarly incorporating use of the PRISM training for staff.

### **How to foster positive change to improve outcomes:**

We ask the Committee to consider our recommendations to foster positive change for preterm born children and their families by:

- ensuring the provision of enhanced developmental surveillance during the preschool years for children born extremely preterm,
- improving information sharing between health and education services to inform educational planning,
- creating an education workforce that is better prepared to identify preterm born children's difficulties and provide appropriate intervention,
- enhancing educational monitoring and support for preterm born children and their families, and
- improving preterm born children's long term developmental and educational outcomes.

### **Why our recommendations are timely and important:**

Information obtained from research and from parents clearly shows that education is an area in which there is significant progress to be made in reducing the adverse impact of preterm birth for individuals, families and societies. After neonatal care, the greatest economic cost to society for

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<sup>13</sup> <https://www.tinylife.org.uk/support-for-schools/>

extremely preterm birth lies in education, not healthcare<sup>14</sup>. Preterm babies may spend 12 days, 12 weeks or 12 months in neonatal care, but they spend at least 12 years in education. This presents a hitherto untapped window of opportunity to intervene in which greater awareness, training and investment has the potential to alter developmental trajectories and improve lifelong outcomes for preterm born children and their families.

*25 March 2024*

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<sup>14</sup> Petrou et al., 2009 <https://doi.org/10.1111/j.1524-4733.2009.00580.x>