



## Evidence, experience, and law: why is preterm care still lagging behind?


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Prematurity and its consequences have become a global public health problem.<sup>1</sup> In Brazil, despite scientific advances and investments in maternal and child health, the process of identifying, analyzing, and referring children at risk still lacks organization, especially among preterm newborns living in vulnerable regions.<sup>2</sup> Early and systematic care significantly improves prognosis, promotes functional development, controls associated health conditions, and fosters school inclusion and social participation.<sup>3,4</sup> Nevertheless, the current models of child health care remain limited in addressing the specific needs of these babies and treating their development.<sup>2,5</sup>

In September 2025, Law no. 15.198 was enacted in Brazil, addressing actions to confront preterm birth and establishing “*Novembro Roxo, o Dia Nacional da Prematuridade e a Semana de Conscientização da Prematuridade*” (Purple November”, the National Prematurity Day, and the Prematurity Awareness Week). This law emphasizes the importance of raising awareness about prematurity starting in prenatal care, as well as defining basic care measures to be followed by health units, such as post-discharge follow-up in specialized outpatient clinics with a multidisciplinary team up to at least two years of age, guidance and training

for preterm infants' parents regarding special care needs, and early referral to specialized services.<sup>6</sup> These measures aim to improve the functioning of health services and expand the focus on preterm infants and their families.

Although the law upholds the principles of the *Política Nacional de Atenção Integral à Saúde da Criança* (National Policy for Comprehensive Child Health Care) and the national maternal and child health guidelines,<sup>6</sup> in practice, *Atenção Primária à Saúde* (Primary Health Care), organized by *Estratégia Saúde da Família* (Family Health Strategy), is responsible for absorbing this demand. However, healthcare networks still face challenges in providing interdisciplinary and care continuous, mainly due to service overload and the prioritization of more severe health conditions.

In *Atenção Primária à Saúde* (Primary Health Care), a specific service for the follow-up and comprehensive care of preterm infants does not exist.<sup>7</sup> This gap may compromise the care continuity and the implementation of early intervention strategies, as children with more severe clinical conditions are prioritized when compete for available positions.<sup>7</sup> Such a dynamic perpetuates a “wait to see” approach, in which limitations must first become evident before specialized care is offered.<sup>5</sup>



DATASUS data (2018–2022) show that Brazilian preterm infants receive, on average, less than one early intervention appointment during their first year of life. Moreover, the high centralization of specialized care represents a major barrier for universal health coverage. In Brazil, 64.8% of the pediatricians are concentrated in capitals and metropolitan regions, and 51% are located in the Southeast region.<sup>8</sup> Additionally, most specialized outpatient follow-up services adopt a reactive approach based on a “wait to see” logic, leading to late referrals only after clinical confirmation of developmental delays.<sup>5</sup>

Such limitations hinder the early identification of children at risk for developmental disorders, leading to long-term negative impacts on health and the family’s quality of life.<sup>5</sup> They also make healthcare for preterm infants particularly challenging, especially in socioeconomically disadvantaged regions.<sup>2</sup> In these less developed areas, it is often common to face resource shortages and social barriers, such as lack of transportation, financial difficulties, and low schooling level of the caregivers.<sup>2,5</sup> The combination of these factors contributes to the invisibility of these families in the most vulnerable regions.

Preliminary data from an observational study conducted by our research group at a referral maternity hospital for high-risk pregnancies in the Northeast of Brazil showed that only 7.4% of preterm infants attended the outpatient follow-up service within the first month of life, besides the routine of the pediatric appointment. This finding suggests a gap in the continuum of care, low adherence to follow-up during the hospital-to-home transition, and possible barriers to access services.<sup>9</sup> These factors may negatively affect the development of preterm infants.

Another way to interpret this low adherence to follow-up services is to consider that many families have limited understanding of the importance of developmental monitoring and early intervention.<sup>10</sup> In a recent study with mothers of preterm infants hospitalized in a referral maternity hospital, most participants demonstrated little knowledge about the meaning of prematurity, developmental milestones, and early intervention.<sup>10</sup> These findings reinforce the need for structured, family-centered developmental care pathways that not only facilitate access to services but also strengthen caregivers’ understanding of their role in their child’s development.

In European countries, it was found that treating severe developmental conditions during early childhood can result in savings of up to one million euros per individual over a lifetime.<sup>3</sup> These results highlight the importance of reducing the time to investigation, diagnosis, and referral in early childhood, as this improves the prognosis of at-risk children and optimizes public

health investments. However, developing countries and socioeconomically disadvantaged regions, such as Brazil, face even greater challenges in achieving these outcomes.

In this context, implementing protocols based on standardized tools and procedures to identify risks of growth and developmental delays during hospitalization combined with a regulatory system for home-based care that empowers caregivers to support preterm infants’ development may represent a feasible and economically sustainable solution. This new approach, focused on the hospital-to-home transition, is supported by successful experiences in countries such as the United States and Australia, where monitoring strategies during this period are widely applied.<sup>4,11</sup>

Programs such as Supporting Play, Exploration, and Early Development Intervention (SPEEDI) combine early intervention with family support, involving parents and caregivers of high-risk newborns from the neonatal period through the home environment.<sup>11</sup> Previous studies on the SPEEDI program have shown promising results: preterm infants who received the intervention demonstrated better motor development at three months of corrected age, greater problem-solving ability at five and seven months, and higher cognitive, language, and motor scores at twelve months compared with those receiving standard care.<sup>11,12</sup>

Adopting similar strategies within the Brazilian context could empower families to better support their children’s development and promote a more equitable, efficient, and family-centered health system. This proposal does not replace existing neonatal follow-up programs but rather aims to enhance the quality of services offered, and strengthen caregivers’ understanding their role in their child’s development, ensuring that families of these “little warriors” can continue promoting development and stimulation during the transition from hospital to home. We have scientific evidence, international experience, and now a new legal framework, what are we waiting to change the way we care for our preterm infants?

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## Authors’ contribution

Silva RC: conception, study design, literature review, manuscript writing.

Montemezzo D: conception, study design, literature review, manuscript drafting.

Silva NF: conception, study design.

Lima-Alvarez CD and Pereira SA: conception, study design, manuscript writing, supervision.

All authors approved the final version of the article and declare no conflicts of interest.

## Data availability

All datasets supporting the results of this study are published within the article.

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