

Will Your Preterm Need Early Intervention Services?

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The National Coalition for Infant Health is a collaborative of more than 180 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

Every parent in the NICU is thinking the same thing. With every alarm, with every struggle, the future of their preterm infant is likely to have lasting effects. Discharge day from the NICU is a milestone for sure but every parent feels a clock ticking to get to the "catch up by age 2" mandate given by the NICU team. Walking out the door, parents have no idea that this catch up by age 2 is not hard set and sometimes is never reached. And with state-by-state Early Intervention guidelines being set for a higher percentage of delay, many families will go home with little or no supports in place to help stimulate that baby. This can affect the child and the taxpaying society as well.

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Preterm infants are at high risk for developmental delays in both the physical and cognitive realms and this can result in 1 in 3 requiring school services for the long-term. Add to this that as that child grows into adulthood it leaves them at risk for ongoing chal-

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lenges in life. Much as an adult stroke patient responds positively to therapy so we too should push for better supports for these babies as they head home from the NICU. Doing so can dramatically mitigate the effects of prematurity early on and for long-term.

These delays cannot always be predicted. Although our neurodevelopmental assessments can often give us an idea of the relative risk, there are certain environmental and situational effects that do not enter the rubric until the baby has left the NICU. We emphasize these risks as we go over discharge planning with the parents, but no amount of preparation and counseling can prepare them for the reality of having a child with special needs.

Early intervention provides hope and support. Preterm infants are twice as likely to have developmental delays and other problems related to learning challenges may occur at a rate five times that of those babies born at a term gestation. The reality is that roughly one in three preterm infants will require support services at school.

Early intervention can help preterm infants. By providing appropriate stimulation, language and communication skills can be enhanced. Skilled instruction can help build more effective learning techniques. Social and emotional support can be provided where indicated. Physical challenges can also be ameliorated by early intervention. Importantly, these early interventions can prevent mild difficulties from developing into major problems.

Although services vary from state to state, early diagnosis can

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qualify their baby for a state's early intervention services. Parents may be unaware of these special services or have limited resources to access the proper channels. When disparity and poverty complicate discharge, it is vital that extra effort be provided to the discharge plan to ensure that stop gap measures exist to provide for early identification.

NICU staff, nurses, pediatricians, social workers and anyone involved in discharge planning should talk with NICU families about challenges that their baby may face.

These services can vary from extra tutoring to those predicated by an individualized education program (IEP). This program defines the individualized objectives of a former preterm infant who has a disability or requires specialized accommodation, as defined by federal regulations. The IEP describes not only the disability but can define how that at risk infant can best learn. Implicit in this process is the selection of the least restrictive learning environment to provide the best possible long term outcome.

The IEP is not meant to be a life long stigma. Rather, it is meant to provide resources for the child until the child can test out and be appropriately mainstreamed. The program is designed to encourage interaction with peers and provide a sense of normalcy while addressing the educational needs of the child.

Awareness, referral and timely enrollment in early intervention programs can help infants thrive and grow.

Visit CDC.gov to find additional contact information about state early intervention programs.

References:

1. Cheong JLY, Thompson DK, Olsen JE, Spittle AJ. Late preterm births: New insights from neonatal neuroimaging and neurobehaviour. *Semin Fetal Neonatal Med.* 2019;24(1):60-5.
2. Ong SL, Abdullah KL, Danaee M, Soh KL, Soh KG, Lee DSK, et al. The effectiveness of a structured nursing intervention program on maternal stress and ability among mothers of premature infants in a neonatal intensive care unit. *J Clin Nurs.* 2019;28(3-4):641-9.
3. Schonhaut L, Martinez-Nadal S, Armijo I, Demestre X. Reliability and agreement of ages and stages questionnaires(R):

Results in late preterm and term-born infants at 24 and 48 months. Early Hum Dev. 2019;128:55-61.

4. Shah PS, Dunn M, Aziz K, Shah V, Deshpandey A, Mukerji A, et al. Sustained quality improvement in outcomes of preterm neonates with a gestational age less than 29 weeks: results from the Evidence-based Practice for Improving Quality Phase 3 (1). *Can J Physiol Pharmacol.* 2019;97(3):213-21
5. <https://www.cdc.gov/ncbddd/actearly/index.html>

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National Coalition for Infant Health Values (SANE)

Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equality. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.