

## NICU discharge to Early Intervention services: Parent perspectives on potential improvements

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**Background:** Early Intervention (EI) therapies promote physical and cognitive development in preterm infants after neonatal intensive care unit (NICU) discharge. In the transition from NICU to EI, there are multiple steps and stakeholders that may cause a delay or even complete failure of the referral, evaluation, and administration processes. This study focused on understanding the perspectives of parents during this transition.

**Methods:** We evaluated previously performed open-ended, semi-structured interviews of individual participants and focus-groups (n=21) using inductive-deductive thematic analysis. Participants had been recruited from a high-risk infant clinic at a quaternary urban safety-net children's hospital in Los Angeles in 2017. The participants were English (n=17) or Spanish (n=4) speaking parents enrolled in Medicaid and had infants with complex healthcare needs.

**Results:** Two common themes emerged from parent suggestions for improvement of the transition from NICU to EI services: Parents desired an advocate to support them through the process of referral up to receipt of EI services (n=12), and they wanted supplemental resources to facilitate their own ability to assist in their child's early development (n=10).

**Conclusion:** Parent feedback is an essential resource for effectively and efficiently improving some of the challenges that families face during the transition from NICU to EI services. We found that parents desired more education, so that they could work with their child to ensure appropriate development while waiting to schedule EI therapies. Furthermore, even for highly motivated parents, the process of obtaining services for a child after referral may be stressful and demanding. Many of the parents interviewed described repeated follow up prior to successfully accessing services. Given that not all parents have the resources and time to do so, the use of patient advocates is a promising solution.

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