

# How to Address Challenges With Early Intervention for Infants of Underrepresented Families: Helping the Babies at the Medical University of South Carolina's High-Risk Clinic

Daijah Washington, Patricia Coker-Bolt

Medical University of South Carolina, Charleston, South Carolina, United States

DOI: 10.5014/ajot.2022.76S1-PO214

Date presented: April 2, 2022

Primary Author and Speaker: Daijah Washington, [washidai@musc.edu](mailto:washidai@musc.edu)

**INTRODUCTION:** Practices in neonatal care have improved the survival rates of fragile infants. Unfortunately, a large number of at-risk infants demonstrate developmental delays by school age (Doyle et al., 2021). Families of lower socioeconomic status are disproportionately impacted, tend to be less satisfied with services or have difficulty accessing services (Little et al., 2015). Early intervention (EI) programs have the potential to ameliorate long-term developmental deficits for infants born extremely premature. Several recent studies have highlighted family-centered EI models, there are few, if any, currently being used in SC (Little et al., 2015).

**PURPOSE:** The aim of this needs assessment is 1) explore current EI models used in SC, 2) the perceptions of families who receive EI services, and 3) the perceptions of therapists and EI staff who deliver services.

**METHOD:** This was a prospective study with collection of quantitative and qualitative data using surveys, interviews and observations. Results were analyzed using descriptive statistics, frequency of responses, and thematic analysis. Participants included EI providers and families of infants born extremely premature.

**RESULTS:** Twenty-eight early intervention providers completed the survey with a majority having over 15 years of experience from more populated counties, which included 32% OTs, 32% PTs, 25% EIs, and 11% SLPs. A majority of providers believe that parents are receptive to receiving early intervention services in the home (85%) and a majority of providers believe infants and children who qualify for early intervention receive services in a timely manner (60.7%). Sadly, a majority of providers agree that all children who need early intervention and early therapy do not receive the necessary services (67.9%). Overall, only 65% of EI providers surveyed feel early intervention services are doing what it is intended to do well, and out of these providers EI, who are the most involved, have the lowest perception rate at 57%. Fifteen families participated in interviews, three from MUSC's NICU and 12 from MUSC's High-Risk Clinic, all with infants born high-risk/extremely premature. 100% of families agree that their child's needs were being addressed during EI visits and families also agree that they have an understanding of the purpose of early intervention and therapy for their child (75%). Unfortunately, families were split with their decision on if their child received services in a timely manner, with 50% of families disagreeing with this statement, which is different than perceptions of providers of EI services. Families were also split on having a good understanding about early infant development (50%) and their belief on parents' needs being addressed during visits with EI providers (50%).

**CONCLUSION:** The results of the study demonstrate the EI providers and families of high-risk infants feel that the current EI system is having difficulty fully serving families and high-risk infants. Families in rural areas have difficulty getting EI services, many families feel education on development and "red flags" is needed, and there is a need to improve communication between providers and families. The results of this study will support the development of new resources and programming offered by the MUSC High-Risk Clinic to enhance EI services for underrepresented families and at-risk infants born extremely premature. Methods to improve communication with families will involve the use of teach-back methods and development of new families education materials with adherence to health literacy principles. Practitioners should meet language and cultural needs of families and consider use of pictures/graphics, videos and organization of parent educational materials.

## References

- Bristol, S., & Coker-Bolt, P. (2017). Goal-directed, protocol-driven, and parent-led home-based infant enrichment programs. *SIS Quarterly Practice Connections*, 2(2), 9–11.
- Doyle, L. W., Spittle, A., Anderson, P. J., & Cheong, J. (2021). School-aged neurodevelopmental outcomes for children born extremely preterm. *Archives of disease in childhood*, *archdischild-2021-321668*. Advance online publication. <https://doi.org/10.1136/archdischild-2021-321668>
- Hutchon, B., Gibbs, D., Harniess, P., Jary, S., Crossley, S. L., Moffat, J. V., Basu, N., & Basu, A. P. (2019). Early intervention programmes for infants at high risk of atypical neurodevelopmental outcome. *Developmental medicine and child neurology*, 61(12), 1362–1367. <https://doi.org/10.1111/dmnc.14187>
- Little, A. A., Kamholz, K., Corwin, B. K., Barrero-Castillero, A., & Wang, C. J. (2015). Understanding Barriers to Early Intervention Services for Preterm Infants: Lessons From Two States. *Academic pediatrics*, 15(4), 430–438. <https://doi.org/10.1016/j.acap.2014.12.006>