NEON Recommendations for Achieving Quality Comprehensive Follow-up Care

Systems	• Develop guidelines in the NICU to begin to determine levels of post-discharge care. • Start a database with meaningful, de-identified data that can be shared, possibly using online survey software. • Choose small group of data points to gather from all units and build incrementally. • Educate hospitals, insurers, and society that time in the NICU is treatment. • Work toward establishing universal nutrition guidelines for NICU and beyond. • Build consensus that breast milk is best. • Develop more family friendly NICUs that encourage more skin-to-skin time with babies. • Gather data to support that formula-fed premature infants need post-discharge preterm formula for the length of time that it is necessary. • Engage state and national professional medical organizations to promote support for quality comprehensive follow-up care, including advocacy to ensure ECI has adequate resources to provide timely and appropriate early intervention services. • Work to ensure ECI and follow-up providers are using the same developmental tests to eliminate repeated testing. • Educate ECI to change the culture away from waiting for a problem to occur to a prevention-orientation. • Educate WIC on corrected versus chronological age and dietary issues.
Families	• Follow-up programs need to be a place where families feel supported and hear about their children's progress and what families are doing well, rather than just their deficits. • Empower parents. • Give educational information in multiple modalities addressing the needs of the adult learner (e.g. web-based resources, handouts, information videos, "just-in-time" educational or interactive tools). Information should be varied and repetitive to enhance learning and overall impact. • Help parents learn how to engage with health care professionals. • Provide education that time in the NICU is a treatment and impacts brain development. • Facilitate appropriate discharge with training and preparation for parents. • Provide education to families on how to breastfeed and use a breast pump and ensure the best kind of pump is immediately available. • For formula-fed infants, ensure families know how to mix formulacorrectly. • Arrange initial follow-up visits (and link with ECI) before NICU discharge. • Post-discharge, continue support with outpatient care, home visits, and phone calls. • Set up Life Line for families to call for guidance and assistance finding resources and family support groups such as Hand to Hold. • Create a Text for Baby for preterm babies modeled on the program for term babies. • Keep in mind what matters to families, e.g. will my child go to kindergarten with the rest of the children? • Teach parents about the role of early intervention to decrease the stigma.
Providers	• Educate neonatologists about why follow-up is part of the NICU continuum of care. • Educate community pediatricians that follow-up supports, not supplants, their work. • Develop guidelines for community pediatricians caring for NICU survivors. • Educate providers to help ensure they are helping families use evidence-based, developmentally appropriate feeding practices.

Source: Gong A, Johnson YR, Livingston J, Matula K, Duncan AF (2015). Newborn intensive care survivors: A review and plan for collaboration in Texas. Maternal Health, Neonatology, and Perinatology, 1:24, 1-9. DOI: 10.1186/s40748-015-002502