

# NICU “graduates” Follow-up: Goals Achieved and Future Perspectives of a NIDCAP Team

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## Background

Preterm infants require individualized care and family support after NICU discharge, both to close the gap from discharge to first follow-up appointment, and to support neurodevelopment throughout the first 1000 days from conception. *EFCNI's Standards of Care* emphasize the need of a multidisciplinary follow-up (FU) program for premature infants after NICU discharge. A fundamental component of good nurturing care is supporting parents to be co-regulators in their child's neurodevelopment. Parents of premature infants are at high risk of short- and long-term mental health difficulties, partly due to an abrupt change in the caregiving environment after discharge - from a highly supportive environment in the NICU to a relatively isolated home environment - especially during the COVID-19 pandemic.

## Aim

To describe a new modality used in our preterm infants FU program, which incorporates NIDCAP-based principles of care.

## Methods

Since 2015, our FU program has been reorganized as follows: application of the NIDCAP approach, combined with structured neurobehavioral evaluations (which includes naturalistic observations of parent-infant interaction and the Hammer-smith Infant Neurological Examination (HINE)) and a NIDCAP observation report for the family in which the infant's strengths, achievement of neurodevelopmental milestones, future challenges, and key recommendations are emphasized. This reorganization was possible because the FU team included NIDCAP professionals and trainees. The FU evaluation also includes two psychologists to support the families and to administer psychometric tests to infants. The FU is scheduled at 3, 6, 12, 24 and 36 months of corrected age (CA). Bayley Scale of Infant Development III ed. (BSID) is administered at 12, 24 and 36 months CA.

## Results

Since 2015, 173 ELBW-VLBW attended the FU program. Prevalence of cerebral palsy was 5.2%, according to Gross Motor Function Scale (9/173), lower than previously reported for a comparable population in literature (10-15%). BSID data were

collected from 171, 127, and 80 infants at 12, 26 and 36 months CA, respectively. Poorer outcomes were correlated with lower gestational ages (GA). Cognitive scores  $\leq 75$  were detected in about 5% of cases (9/171 at 12 months CA, 6/127 at 24 months CA, 4/80 at 36 months CA).

Single infant's neurodevelopmental trajectories showed an improvement of BSID motor scores through the years even at lower GAs. However, up to 25% of infants showed low performance scores at 24 and 36 months CA in the expressive domain of BSID language scale.

During the same period, our NICU transitioned from standard care to NIDCAP-based care and a NIDCAP Training Centre opened in 2020.

## Relevance to NIDCAP

Developmental care is to be continued long after NICU discharge, in order to support parents in providing appropriate developmental experiences to their infants. A NIDCAP-trained team in the FU program afforded the continuation of individualized family centered care for parents and infants long after discharge.

## Conclusion

Improvement in single infants neurodevelopmental motor trajectories, low prevalence of poor cognitive outcome and cerebral palsy (CP) were observed during a FU that included the principles of the NIDCAP care for infants and families also after discharge from NICU.

To enhance individualization and multidisciplinary support in the follow-up program, future steps in our Unit will be the introduction of videotaped naturalistic observations, APiB assessments and measurement of parents' perceived experience.

Investigation of the role of the application of the NIDCAP approach during the follow-up period deserves future studies.

## NIDCAP Trainers Meeting Feedback

“We are challenged to integrate research findings into NIDCAP work.”