Discharging infants with complicated problems from the neonatal intensive care unit (NICU) is always a challenge, but it is even more difficult when the family lives in a rural area where health care resources are limited. Rural areas have shortages of pediatricians and other primary care providers and almost no specialty care providers, such as speech and physical therapists and home health nurses. Families often must travel long distances to obtain specialty care at considerable personal and financial costs. The cost of travel and time away from work is especially burdensome because children in rural areas are more likely to live in poverty. Though parents from rural areas learn how to take care of their infants at the NICU before discharge, this is just the beginning of a difficult adjustment for these families.

**Preparation For Discharge Begins at Admission**

Social workers are key to planning and preparing for discharge, beginning with an assessment of the family’s resources and needs when their infant is admitted. Social workers also assist in obtaining financial support as well as providing emotional and mental health support, when needed.

Education is essential to ensure that parents are capable and confident in caring for their infant at home. Everyone helps prepare parents for discharge: nurses, social workers, physicians, nurse practitioners, respiratory therapists, pharmacists, physical and occupational therapists, nutritionists, and lactation consultants.

As discharge nears, parents often room with their infant and provide most of the care in order to anticipate what the process at home will be. Usually both parents learn how to care for their infant though this may be difficult or impossible for parents with limited resources who live long distances from the NICU and have other children to care for.

**A Complicated Home-Coming**

Prior to discharge from the hospital, home health care agencies need to be contacted...
Having a premature infant or infant that requires care in a NICU is very difficult for families. If their home is far from that NICU, the challenges of separation and travel begin at birth. It takes a team of health care workers along with federal, state, and local public health programs to support these families. ♠

**Pediatric Specialists**

Most pediatric specialists practice in urban areas though they may establish outreach clinics in moderate-sized communities in rural areas. Unfortunately, specialists are usually available only once or twice a month so clinic appointments may be difficult to obtain. Pediatric pulmonologists are the most common specialists seen by NICU graduates, helping manage chronic lung disease in infants needing oxygen or ventilators.

Most infants discharged from the NICU, especially the most premature infants, should have on-going formalized neurodevelopmental follow-up in addition to developmental screening by the primary care provider. Very premature babies should be examined by an ophthalmologist at least every five years throughout life. Infants also may need to see a pediatric surgeon for follow-up if they have had bowel surgery or if they need hernia repair.

**In Summary**

Having a premature infant or infant that requires care in a NICU is very difficult for families. If their home is far from that NICU, the challenges of separation and travel begin at birth. Most NICU graduates do very well, but they are at higher risk for ongoing medical problems and learning difficulties when they reach school age. It takes a team of health care workers along with federal, state, and local public health programs to support these families.

**RESOURCES**

- The Center for Children with Special Needs
  Seattle Children’s Hospital [http://cshcn.org](http://cshcn.org)

- Early Support for Infants and Toddlers

- National Center for Medical Home Implementation [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

- National Rural Health Association [www.ruralhealthweb.org](http://www.ruralhealthweb.org)

- Washington State Medical Home [http://medicalhome.org](http://medicalhome.org)

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REFERENCES

