

Issue Brief

Partnering to Promote Follow-Up Care for Premature Infants

AMCHP's Role

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. We work with partners at the national, state and local levels to expand medical homes; provide and promote family-centered, community-based, coordinated care for children with special health care needs; and facilitate the development of community-based systems of services for children and their families.

U.S. Preterm Birth and the Role of Title V

In the United States, premature birth, defined as birth of an infant prior to 37 weeks gestation, is the most frequent cause of infant mortality and morbidity.¹ The approximately 500,000 premature babies who survive their first year of life are at higher risk of developing respiratory, cardiovascular, neurologic, gastrointestinal, metabolic, visual and hearing disorders compared to their full term counterparts.¹ According to the National Vital Statistics Report, in 2010, the preterm birth rate was 11.99 percent.² While the preterm birth rate has declined over the past four years, 10 to 15 percent of babies born in the United States continue to require treatment in the Neonatal Intensive Care Unit (NICU).² Furthermore, the cost of preterm and low birth weight births averages \$58,000 compared with the average term infant cost of \$4,300. The American Academy of Pediatrics reports, "Infants born preterm with low birth weight who require neonatal intensive care, experience a much higher rate of hospital readmission and death during the first year after birth compared with healthy term infants. Careful preparation for discharge and good follow-up after discharge may reduce these risks."³

A number of national initiatives are currently underway to lower state prematurity rates and address the issue of elective delivery before 39 weeks. These include the Association of State and Territorial Health Officials' (ASTHO) Healthy Babies Presidential Challenge and the March of Dimes' Healthy Babies Are Worth the Wait Program. State Title V programs are key players in these, and other initiatives, to lower the national preterm birth rate and improve birth outcomes.

State Title V programs are also key leaders and partners in developing and supporting NICU follow up programs. Neonatal Intensive Care Unit follow-up programs can ensure a healthy and effective transition for every infant from the NICU to the home and improve outcomes for premature infants. Through NICU follow-up programs, Title V agencies are working to facilitate access to a medical home for families, provide follow-up services and home visitation for NICU infants; conduct developmental, physical and environmental assessments; and provide education and guidance. They also connect families to services within their own communities, and ensure that infants receive developmental screening, referral and service coordination.

This document provides a series of case studies on state models to support NICU follow-up programs. It also includes national resources for state Title V programs as they continue to develop and support similar programs.



State Models of NICU Follow-Up Programs

Arizona: High Risk Perinatal Program/Newborn Intensive Care Program (HRPP/NICP)

Overview

For nearly 40 years, the Arizona High Risk Perinatal Program/Newborn Intensive Care Program (HRPP/NICP) has supported the provision of emergency maternal and neonatal transports, hospital and inpatient physician services, and community health nursing follow up. Administered by the Arizona Bureau of Women's and Children's Health, which operates the state Title V program, HRPP/NICP enrolls eligible infants, offering a financial safety net for eligible families. Leadership for planning, program development, and management of the program is provided by the Office of Children's Health within the Bureau of Women's and Children's Health.

The HRPP/NICP program requires Level II Enhanced Qualification and Level III perinatal centers to have a NIDCAP[®] (Neonatal Individualized Developmental Care and Assessment Plan) trained developmental specialist to provide individualized developmental care for infants and their families.

To ensure the continuum of care, higher level hospitals have weekly discharge meetings where a representative of the local community health nurse (CHN) contractor is updated on NICU infants enrolled in the program, and where they are in relation to discharge. When discharged, a special form is sent to the appropriate CHN agency summarizing the NICU experience and including the last developmental evaluation. The community health nursing component includes the following services:

- Follow up to support the family during transition from the hospital to home
- Developmental, physical and environmental assessments
- Education and guidance
- Direct families to programs and services

During home visits, community nurses also assess other children in the home to identify children at risk and screen mothers for postpartum wellness.

Partners/Funding

HRPP/NICP contracts with 13 different agencies to supply the community nursing visits. State funds support the transport, hospital and a portion of the community health nurse component, while Title V funds enable the program to offer more nursing visits and aid to support professional development of the nurses. In an effort to support the perinatal system, the state Medicaid agency reimburses Arizona Perinatal Trust (APT) certified hospitals at a higher rate.

About Title V Programs

State Title V MCH programs have a 77-year history of building comprehensive, integrated systems to ensure the health and well-being of women, children, including children with special health care needs, and their families. All states and U.S. territories receive funds from the Title V Maternal and Child Health Services Block Grant program (Title V Block Grant) to build a comprehensive system of programs, services and supports for these populations. This federal program provides critical funds to states for programs, services, supports and leadership in areas including improving infant and child health outcomes, reducing infant and maternal mortality rates and providing prenatal care to low-income pregnant women.

The federal Title V Block Grant also includes important requirements for coordination between state Title V and Medicaid programs. By federal law, state Title V programs are required to:

- Assist with coordination of Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT)
- Establish coordination agreements with their state Medicaid programs
- Provide a toll-free number for families seeking Title V or Medicaid providers
- Provide outreach and facilitate enrollment of Medicaid eligible children and pregnant women
- Share data collection responsibilities
- Provide services for children with special health care needs (CSHCN) not covered by Medicaid

Sources: Understanding Title V of the Social Security Act, Health Resources and Services Administration, Maternal and Child Health Bureau, Accessed on 1/28/13 at: mchb.hrsa.gov/about/understandingtitlev.pdf; EPSDT and Title V Collaboration to Improve Child Health, Health Resources and Services Administration, Maternal and Child Health Bureau, Accessed on 1/28/13 at mchb.hrsa.gov/epsdt.

Successes

HRPP/NICP came about as a result of the poor infant mortality rates in Arizona in the late 1960s. Since the inception of the program in the 1970s and the advances in medical technology, the rate of neonatal deaths has decreased from 17.8 per 1,000 live births in 1970 to 3.8 per 1,000 live births in 2010. Infant deaths (within the first year of life) have decreased from 6.3 per 1,000 live births in 2008 to 6.0 per 1,000 live births in 2010 and post neonatal deaths (from 28 to 365 days of life) have slightly increased from 2.1 per 1,000 live births in 2008 to 2.2 per 1,000 live births in 2010. Based on the actual number of infant deaths and live births in 2010, the infant mortality rate of 6.0/1,000 was the second lowest infant mortality rate ever recorded in state history.

As of FY 2011, 3,863 infants were enrolled in NICP, community health nurses made 8,211 visits to medically fragile infants and their families after they were discharged, 862 critically ill pregnant women were transported to the appropriate level of care, and 777 critically ill newborns were transported to the appropriate level of care.

For more information on the Arizona NICU follow-up program, visit:

azdhs.gov/phs/owch/children/highrisk.htm.

California: Children's Services High Risk Infant Follow-Up Program

Overview

The California Children's Services (CCS) High Risk Infant Follow-Up (HRIF) Program was established to identify high-risk infants who might develop CCS-eligible conditions after discharge from a CCS-approved NICU. CCS is administered by the California Department of Health Care Services (DHCS), Systems of Care (SOC) Division, which collaborates with the California Department of Public Health, Maternal, Child and Adolescent Health Program on Title V activities related to CSHCN, such as HRIF. CCS program standards require that each CCS-approved NICU ensure the follow-up of discharged high-risk infants and that each NICU shall have an organized HRIF Program or a written agreement for the provision of these services by another CCS-approved NICU.

CCS-approved HRIF Programs provide three multidisciplinary outpatient visits to identify problems, institute referrals, and monitor outcomes of HRIF-eligible children from birth to three years of

age. The following are reimbursable diagnostic services:

- Comprehensive history and physical examination with neurologic assessment
- Developmental assessment (Bayley Scales of Infant Development (BSID) or an equivalent test)
- Family psychosocial assessment
- Hearing assessment
- Ophthalmologic assessment
- Coordinator services (including assisting families in accessing interventions and facilitating linkages to other agencies and services)

Entry into the HRIF Program is limited to those infants who have met CCS medical eligibility criteria for NICU care or had a CCS-eligible medical condition during their stay in a CCS-approved NICU. The HRIF Program also is available to infants who have a CCS-eligible medical condition upon NICU discharge.

Partners/Funding

The HRIF Program is a special care center under the CCS program of the California DHCS, and is supported by Title V funding to SOC Division. The funding source for a county CCS program is a combination of monies appropriated by the county, state general funds and the federal government.

Successes

In 2006, CCS redesigned the HRIF Program and started the Quality of Care Initiative (QCI) with the California Perinatal Quality Care Collaborative (CPQCC). The CCS/CPQCC HRIF QCI developed a Web-based reporting system to collect HRIF data to be used in quality improvement activities. This reporting system will be able to identify quality improvement opportunities for NICUs in the reduction of long-term morbidity; allow programs to compare their activities with all sites throughout the state; allow the state to assess site-specific successes; and support real-time case management. As of February 2013, 65 of 66 CCS-approved HRIF Programs are reporting online. Between 2009 and February 2013, 26,041 HRIF Program referrals/registrations forms have been reported online.

For more information on the California NICU follow-up program, visit:

dhcs.ca.gov/services/ccs/Pages/HRIF.aspx and ccshrif.org.

Colorado: Ensuring the Transition to a Medical Home for Premature Infants

Overview

In 2011, the Colorado Department of Public Health and Environment (CDPHE) Health Care Program for Children with Special Needs (HCP) recognized the needs of parents of premature and late premature infants were not being addressed in current policies and priorities for Colorado families. Part of the CDPHE Children with Special Health Care Needs Unit, which operates the state Title V children and youth with special health care needs (CYSCHN) program, brought together a committee to determine how to develop a smooth and sustainable transition program for premature infants, including late premature and high risk infants, and their families that focuses identification, referral, and follow-up services to the primary care provider and medical home. Previously, the NICU project, funded by the Colorado Division of Developmental Disabilities, Early Intervention Colorado and Part C of the Individuals with Disabilities Education Act (IDEA), worked with hospital staff to identify infants either because they have been diagnosed with a physical or mental condition known to have a high probability of resulting in significant delays in development or because they were demonstrating developmental delays. This project was discontinued due to funding cuts, thus, it was recognized that broad agency and community support was needed to implement and sustain such a program. In addition, it was recognized that a mechanism was needed to identify late premature infants and infants with less significant medical needs to ensure that their families were connected to community-based resources.

In order to address these needs, in 2012, HCP convened a “Key Stakeholder Colorado Premature Infant Summit: Assuring Premature Infant Follow Up through a Medical Home.” The goal of the summit was to “optimize the health and developmental outcomes of premature and high-risk infants and their families by sharing best practices and systems of care that support the transition home from the NICU and hospital to the medical home and supportive community-based services.” The summit brought together key stakeholders to identify strategies that would support families as they transition home from the hospital due to the impact of prematurity on the family and health care system as a result re-hospitalization and ongoing health, support

services, and educational needs. The objectives of the summit were to prioritize next steps in meeting the follow-up needs of premature and late premature infants and their families, and implement coordinated strategies to carry out the recommendations from the summit.

Partners/Funding

The Key Stakeholder Colorado Premature Infant Summit was funded through support of the Colorado Title V Maternal and Child Health Program and a grant received by a nonprofit, Special Kids, Special Care. Broad agency and community support is now in place, including collaborative efforts with the Title V Maternal and Child Health Program, HCP Colorado Perinatal Care Council, Early Intervention Colorado, Family Voices, Colorado American Academy of Pediatrics, Colorado Academy of Family Physicians, Health Care Policy and Finance, and the University of Colorado, JFK Partners and School of Medicine. The summit participants from these organizations identified six action steps that needed to be in place to support the family’s and infant’s smooth transition from the hospital to the community and to ensure connections to resources, such as primary health care, early intervention, and HCP care coordination, which is supported by Title V.

Successes

Colorado is now addressing the action steps identified at the summit:

- Disseminate best practices around the transition from the NICU to the families home community, including a *Tool Kit for Follow-up Care of the Premature Infants*
- Increase parent support efforts and access for parents of premature infants
- Increase availability and access to educational programs for health care professionals regarding the needs of premature infants and high-risk infants and their families
- Develop connected data systems to better understand the Colorado population of premature and high-risk infants and their needs
- Include needs of premature infants and their families in policy discussion and decisions
- Continue collaboration across agencies and organization to meet the needs of premature and high-risk infants and their families

For more information on the Colorado HCP program, visit hcpcolorado.org or contact jane.gerberding@state.co.us.

Iowa: Child Health Specialty Clinics

Overview

Child Health Specialty Clinics (CHSC) is the Iowa Title V program for CYSHCN, and facilitates the development of family-centered, community-based, coordinated systems of care for CYSHCN. Child Health Specialty Clinics and the Iowa Department of Public Health (IDPH) are signatory partners in Early ACCESS, the Iowa Part C, IDEA system of care for infants and toddlers. CHSC provides service coordination for eligible children zero to three years old with special health care needs enrolled in Early ACCESS. CHSC and IDPH work with NICUs to ensure that graduates have appropriate newborn screening and follow up along with seamless transitions to medical homes and community services. CHSC family navigators are trained to become Early ACCESS service coordinators, and assure that infants and toddlers with health conditions causing or having the potential to cause a developmental delay receive support and services in their own communities. CHSC engages health care professionals, families, community leaders, and policymakers in quality improvement to raise the standard of child health care.

Partners/Funding

CHSC is funded partially by the federal Title V, MCH Services Block Grant in addition to funding provided by the Iowa Department of Public Health, the Iowa Department of Education, the Iowa Department of Human Services, other community partners, and program income. In April 2010, CHSC contracted for additional funds from the Early ACCESS Lead Agency (Iowa Department of Education), originating from the American Recovery and Reinvestment Act (ARRA). Through collaborations between CHSC and the Iowa Chapter of the American Academy of Pediatrics, Iowa applied for and became a participant in the National Improvement Partnership Network (NIPN). Iowa named this partnership the *Partnership to Improve Child Health in Iowa* (PI-CHI). Throughout a two-year period, PI-CHI conducted ongoing stakeholder phone calls and face-to-face events related to improving the care of late pre-term infants.

Successes

The Iowa Department of Public Health facilitated meetings between Heartland Area Education Agency (AEA) and two NICUs in Des Moines (Blank Children's Hospital and Mercy) to discuss

how Early ACCESS could have a presence in NICUs and meet with families when infants were being discharged. As a result of the meetings, Heartland AEA contracted with Title V agencies for a registered nurse (RN). This RN spent approximately one day per week in each NICU to ensure that babies were being referred to Early ACCESS and facilitate communication between NICU graduates and providers. This culminated in helping to get Early ACCESS on the floors of NICUs and the work continues today.

For more information on the Iowa NICU follow-up program, visit: chsciowa.org/.

Utah: Neonatal Follow-Up Program

Overview

The Utah Neonatal Follow-Up Program (NFP) is a statewide program that provides developmental screening and evaluation to early gestation and high-risk graduates from various NICUs across the state. Administered by the Bureau of Children with Special Health Care Needs, the Utah Title V CYSHCN program, NFP uses a multidisciplinary approach in which various medical and developmental specialists gather to monitor and evaluate each qualifying child. Children who participate in NFP are seen by the development team four to six times from four months of age through the preschool years. In 2011, 339 children were recruited for the program from referring NICUs around the state, representing 23 of 28 Utah counties. Currently, more than 1,050 children are enrolled.

Current enrollment criteria include:

- Birth weight \leq 1250 grams
- Gestational age \leq 26 weeks
- Diagnosis of hypoxic ischemic encephalopathy (HIE)
- ECMO support

Children who do not meet the above criteria, but are NICU graduates, may be referred for enrollment by the NICU, medical home or parent/guardian.

The program assists with or refers families to appropriate intervention and financial services, when indicated. A summary of each evaluation is sent to the child's medical home and to the referring NICU. With parent approval, the summary is sent to other providers in the child's care. The program also provides psychosocial support as needed. The NFP is currently collaborating with the

University of Utah to offer counseling to mothers on risk for future preterm births. so that they can plan future pregnancies accordingly.

Partners/Funding

The Title V MCH Services Block Grant funds the majority of NFP clinical and administrative activities. Although services are billed to third-party payers, including private insurance and Medicaid, limited service fees are recouped from these sources due to the screening and evaluative nature of the clinic. Parents are not directly charged to participate in NFP and no patient or family is denied services based on inability to pay. The program also receives a small income from providing evaluation services to NICU graduates enrolled in various neonatology-based research studies.

Key partners include: all Level III NICUs in Utah, University of Utah Department of Pediatrics, University of Utah Maternal and Fetal Medicine division in the Department of Obstetrics and Gynecology, University of Utah Department of Neonatology, the Utah School for the Deaf and the Blind, Utah County Health Department, and the Utah Department of Health Bureaus of Children with Special Health Care Needs and Maternal and Child Health.

Successes

NFP garners a high level of parent satisfaction. More than 85 percent of parents recently surveyed indicated that they were “very” or “extremely” satisfied with program providers, testing and evaluation methods and reporting mechanisms, and facilities. In the past five years, NFP has developed a robust relational database and is currently integrating the database with a recently acquired electronic medical record system. This database is allowing NFP to improve the sharing of outcome measures with referring NICUs. NFP also is working to share information with other State of Utah Children’s Health Programs through the Child Health Advanced Records Management (CHARM) data integration system.

For more information on the Utah NICU follow-up program, visit: health.utah.gov/nfp/.



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Conclusion

Neonatal Intensive Care Unit follow-up programs can ensure a healthy and effective transition for every infant from the NICU to the home and improve outcomes for premature infants. State Title V MCH and CYSHCN programs can play a critical role in providing leadership for, developing and supporting NICU follow up programs. The findings and successes presented in this document may be used to inform the implementation of NICU follow-up programs nationwide.

Acknowledgement

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References

1. Centers for Disease Control and Prevention. Preterm Birth. cdc.gov/reproductivehealth/maternalinfanthealth/PretermBirth.htm. Updated Mar. 23, 2012.
2. Martin JA, Hamilton BE, Ventura SJ, Osterman M, Wilson EC, Mathews TJ. Births: Final Data for 2010. *National Vital Statistics Report*. 2012; 61 (2).
3. American Academy of Pediatrics, Committee on Fetus and Newborn. Hospital discharge of the high-risk neonate. *Pediatrics*. 2008; 122(5): 1119.

Additional Resources

Toolkit for the Follow-Up Care of the Premature Infant

premietoolkit.com/index.aspx

Multidisciplinary Guidelines for the Care of Late Preterm Infants

nationalperinatal.org/lptguidelines.php

American Academy of Pediatrics

aap.org

ASTHO President’s Challenge: Healthy Babies

astho.org/healthybabies/

March of Dimes

marchofdimes.com/39weeks

marchofdimes.com/professionals/medicalresources_hbww.html

National Premature Infant Health Coalition

npihc.org/