



Assuring a System of Care for Iowa's Children and Youth with Special Health Care Needs

## **Partnership to Improve Child Health in Iowa (PI-CHI):**

### **Late Preterm Infants**

### **Final Report**

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# Improving the System of Care for Iowa's Late Preterm Infants

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*Report to Iowa Department of Education (Early Childhood Bureau) and  
The Iowa Council on Early ACCESS*

*June 30, 2011*

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## BACKGROUND AND INTRODUCTION

In April of 2010, the Iowa Department of Education (Early Childhood Bureau) and the Iowa Council for Early ACCESS (ICEA) charged Iowa’s Title V Maternal and Child Health Program for children with special health care needs (Child Health Specialty Clinics (CHSC)) with developing an improvement partnership focused on pediatric health care quality improvement efforts for Neonatal Intensive Care Unit (NICU) graduates/preterm infants. As discussions on preterm infants progressed, it was determined that it was important to focus more specifically on *late preterm* infants (born 34-36 weeks gestation)<sup>1</sup>.

The emphasis of the project was to build the infrastructure for a system of care for late preterm infants to ensure seamless, effective, efficient, family centered care including access to medical homes and integrated community-based services. A system of care is an organizational philosophy and framework that involves collaboration across agencies, families, and youth for the purpose of improving access and expanding the array of coordinated community-based, culturally and linguistically competent services and supports for children and youth with special healthcare needs and their families.<sup>2</sup>

Through a contract supported by funds from American Recovery and Reinvestment Act (ARRA), the Department of Education and ICEA charged CHSC to:

- Develop an improvement partnership focused on pediatric health care quality improvement efforts for NICU graduates/late pre-term infants. Membership of the partnership will include agency representation from a stakeholder meeting that occurred in fall 2009 to discuss issues regarding prematurity. The network will initiate planning for a system of care that incorporates science of improvement principles.

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<sup>1</sup> Definition of Late Preterm Infant from AAP Healthy Children, Ages & Stages, “Caring for a Premature Baby”, accessed June 30, 2011. Available at: <http://www.healthychildren.org/English/ages-stages/baby/preemie/Pages/Caring-For-A-Premature-Baby.aspx?nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token>.

<sup>2</sup> Sheila A. Pires, Human Service Collaborative, “Building Systems of Care: A Primer”, Washington, DC Spring 2002. (for National Technical Assistance Center for Children’s Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center and supported by Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services), accessed June 30, 2011. Available at: <http://gucchd.georgetown.edu/72382.html>.

- Build the infrastructure for a system of care for this group of infants to ensure seamless, effective, efficient, family centered transitions and linkages to medical homes/ neighborhoods and needed services.
- Improve coordination of stakeholder efforts (e.g., families, medical providers, Early ACCESS (EA) providers, social service agencies, etc.).
- Build on existing work being done by: i) Iowa Chapter of American Academy of Pediatrics; ii) CHSC via contract with Area Education Agency (AEA 10) using Department of Human Services, American Recovery and Reinvestment Act (ARRA) funds to improve child find and referral efforts for children ages 0-1 years from hospitals and other referral sources; and iii) CHSC via Early ACCESS(EA) Early Childhood (Part C/IDEA) funds in AEA 11 to improve NICU referral/follow-up planning.
- Utilize the expertise of the National Improvement Partnership Network (NIPN) to help Iowa create its own Improvement Partnership (IP). Bring together stakeholders from the public and private sectors, including parents who have interest or investment in the healthy development of children, in order to design a durable child health improvement partnership in Iowa.

Early ACCESS is the Early Intervention Individuals with Disabilities Education Act (IDEA)/Part C organization in Iowa for families of children birth to three years of age who have or are at-risk for developmental delays. Providers from the four Early ACCESS agencies signatory partners -- Iowa Department of Education, Department of Public Health, Child Health Specialty Clinics, and the Department of Human Services – work with families in identifying, coordinating and providing needed services and resources that help children achieve optimal growth and development.

The ICEA advises and assists the EA signatory agencies and the Iowa Department of Education, Individuals with Disabilities Education Act (IDEA)/Part C, in the implementation of a statewide system of early intervention services. Council members represent the interests of early childhood stakeholders and are appointed by the Governor.

Monitoring of a child’s development through early and continuous screening beginning at birth is one of the nation’s goals for child health. Yet in Iowa such screening is not done on any consistent or continual basis for late preterm infants.

Even when screening is completed and a child is referred and then determined to be ineligible for Early ACCESS, there may not be other services available. Home visiting, behavioral intervention parenting classes, parent education, and child care setting positive interventions should be options for many of the children ineligible for early intervention. It is important to develop seamless connections between community based services, including services that address the “social determinants of health,” to improve a “system of care” for late preterm

infants. Equally important is the need to develop seamless connections between those that care for late preterm infants; primary care providers and community based services.

1. The initial stakeholder meeting was held in 2009. The focus was on the event of preterm deliveries and its effect on infants and their families. Between 1998 and 2008, both the numbers of total births has been increasing (from 37,262 to 40,221)<sup>3</sup> and the rate of late preterm births has been trending upward (from 7.6 to 8.3 percent).<sup>4</sup> This increasing number of infants born late preterm in Iowa is a serious concern, and the ability to provide these children with needed services is compromised by many factors. Early ACCESS, as a system, is seeing more children each year (46% more over the past five years), while Federal funding has not kept pace. The ICEA has stated it's concerned that if this trend continues, children and families will not receive needed services.<sup>5</sup> Additionally, the research indicates that the earlier that intervention services begin, the better the outcomes for children,<sup>6</sup> but in Iowa only 20 percent of infants who enter the Early ACCESS system are 0-1 years of age.<sup>7</sup>
2. Despite the fact that the signatory partners of Early ACCESS strive to provide seamless services, there are many significant barriers to realizing coordination and collaboration. Some services still exist within distinct "silos." The healthy development of Iowa's children requires a system of care that involves *all* entities which touch the lives of young children – health care, child care, public health, behavioral health services, social service agencies, nutrition programs etc. – and which provides a seamless web of integrated services.
3. A significant barrier to efforts to support early brain development, children's mental health, and children's health in general is the disconnect between early childhood services provided by public and private education, medical, child care, early intervention and public health programs.

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<sup>3</sup> Iowa Department of Public Health, Bureau of Health Statistics, Lucas State Office Building, 321 East 12th Street, Des Moines, Iowa 50319-0075, "Promoting and Protecting the Health of Iowans, 2009 Vital Statistics of Iowa", accessed June 30, 2011. Available at:

[http://www.idph.state.ia.us/apl/common/pdf/health\\_statistics/2009/vital\\_stats\\_2009.pdf](http://www.idph.state.ia.us/apl/common/pdf/health_statistics/2009/vital_stats_2009.pdf).

<sup>4</sup> March of Dimes Peristats, "Iowa, Late preterm birth: 1998-2008, Percent of live births", accessed June 30, 2011. Available at:

<http://www.marchofdimes.com/peristats/level1.aspx?dv=ls&reg=19&top=3&stop=240&lev=1&slev=4&obj=1>

<sup>5</sup> Iowa Council for Early ACCESS, "Early ACCESS Governor's Report, FY 2010-2011", January 2011, accessed June 30, 2011. Available at: [http://educateiowa.gov/index.php?option=com\\_content&task=view&id=633&Itemid=597](http://educateiowa.gov/index.php?option=com_content&task=view&id=633&Itemid=597).

<sup>6</sup> National Early Intervention Longitudinal Study (NEILS), SRI International with funding from the Office of Special Education Programs, U.S. Department of Education, Final Report, January 2007, "Early Intervention for Infants and Toddlers With Disabilities and Their Families: Participants, Services and Outcomes", accessed June 30, 2011. Available at: [http://www.sri.com/neils/pdfs/NEILS\\_Final\\_Report\\_02\\_07.pdf](http://www.sri.com/neils/pdfs/NEILS_Final_Report_02_07.pdf).

<sup>7</sup> State of Iowa, Iowa Department of Education, Bureau of Early Childhood Services, Grimes State Office Building, Des Moines, Iowa 50319-0146, "Annual Performance Report, IDEA Part C FFY 2009 (2009-2010)", Submitted February 1, 2011, accessed June 30, 2011. Available at:

[http://educateiowa.gov/index.php?option=com\\_content&task=view&id=633&Itemid=597](http://educateiowa.gov/index.php?option=com_content&task=view&id=633&Itemid=597).

This project was initiated to address late term prematurity as a possible factor affecting healthy development, and to study and recommend actions that could result in the realization of an effective system of care that would integrate and improve existing services.

This report was generated from input from a diverse statewide stakeholder group interested in improving the quality of health for Iowa's late preterm infants. In preparing this report more than a dozen meetings were held, to enable a forum for Iowa experts to discuss late preterm infants in Iowa. A two-day conference was held in Des Moines in December 2010 to:

- Inform stakeholders about current activities for late preterm infants and their families;
- Define the work yet to be done in Iowa;
- Solidify the importance of creating the structure and purpose of a child health Improvement Partnership (IP).

In addition to these methods, a survey was conducted on variety of late preterm infant topics, and results tallied to gather information about issues facing late preterm infants. Survey results are provided later on in this report.

## **DEVELOPMENT OF AN IOWA CHILD HEALTH IMPROVEMENT PARTNERSHIP**

Iowa needed to establish itself as a state within the NIPN network while simultaneously working on issues affecting late preterm infants. On December 7 - 8, 2010, a diverse group of stakeholders – many of whom were involved in bringing focus to late term prematurity – gathered to learn about Improvement Partnerships (IPs). Judith Shaw, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director and Paula Duncan, MD, Youth Health Director for VCHIP and Clinical Professor of Adolescent Medicine in the Department of Pediatrics, University of Vermont, presented information to the group about what IPs are and the important work they are doing. Dr. Shaw and Dr. Duncan presented information and facilitated group discussions on children's health care quality improvement efforts, the work of VCHIP, National Improvement Partnership Network (NIPN), Bright Futures, Early Periodic Screening Diagnosis and Treatment (EPSDT) and Adolescent Medicine.

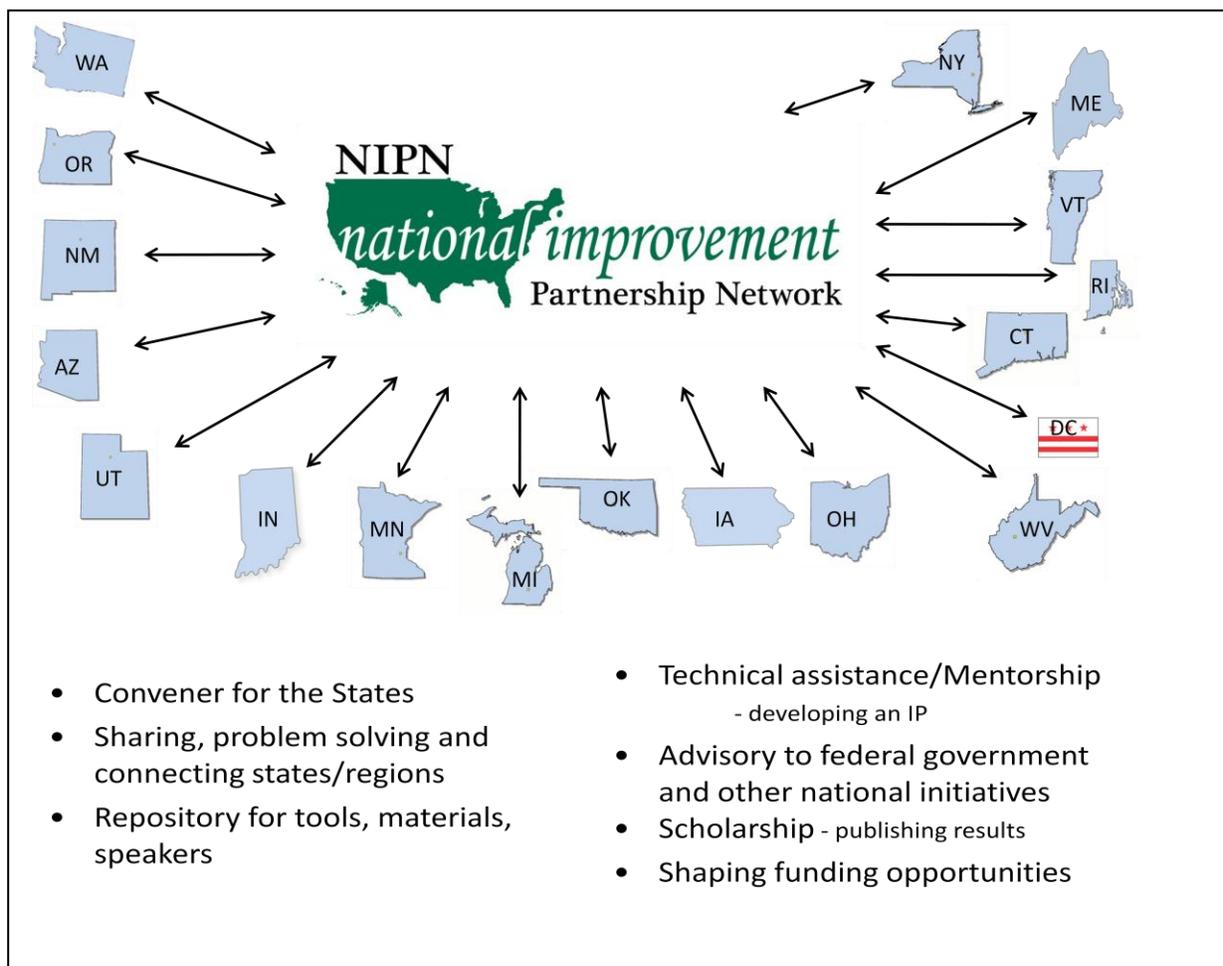
VCHIP, the nation's first IP, provides leadership to the NIPN<sup>8</sup> network -- a *"durable, regional collaboration of public and private partners that uses measurement-based efforts and a systems approach to improve the quality of children's health care"* -- and delivers Technical Assistance to states within the network. The NIPN stakeholder organizations commit to provide resources,

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<sup>8</sup> National Improvement Partnership (NIPN), accessed June 30, 2011. Available at: <http://www.med.uvm.edu/vchip/improvementpartnerships/HP-DEPT.ASP?SiteArealD=513>.

materials and web-based information for care coordinators, primary care providers and other medical home staff, health professionals, and other key stakeholders. Today, eighteen states have instituted or are in the process of implementing their own IPs. Successful IPs recognize and embrace local expertise; i.e. *“all improvement is local”* and recognize the importance of diverse partner organizations working together around a common goal. IPs develop/test tools, measures and strategies; serve as a resource for improvement assistance; translate knowledge through engagement of national and local experts; disseminate findings, spread successful approaches, inform policy; and serve as convener or, “honest broker.”

Technical Assistance provided by NIPN was instrumental in guiding the planning for the Partnership to Improve Child Health in Iowa (PI CHI).



As one of the deliverables of the EA ARRA funded project, the Partnership to Improve Child Health in Iowa (PI CHI) was established. PI CHI membership includes agency representation from an initial stakeholder meeting that occurred in October 2009 where issues regarding prematurity were discussed. PI CHI’s diverse stakeholder group includes, but is not limited to healthcare providers, representatives of state/county/municipal government, members of

professional organizations, legislators and policy makers, family advocacy group representatives and consumers, health insurers, and faculty and staff from academic institutions. This project introduced the Science of Improvement principles to the diverse stakeholder group; principles that are key to the work of building a system of care that that will realize our mission to improve the health of children in Iowa.

In addition, a webpage for PI CHI has been established as part of the Iowa Chapter of the American Academy of Pediatrics (IA AAP) website and a logo is in development<sup>9</sup>.

## PI CHI VISION/MISSION

The Vision/Mission for PI CHI was developed during the fall of 2010 based on input from the diverse stakeholder groups and adopted by the initial advisory committee composed of the members of the Project Linking Action to Unmet Needs in Child Health (LAUNCH), Interagency Coordinating Committee.

PI CHI is a public-private partnership that will work collaboratively to support clinicians in their efforts to improve children's health care by providing the tested tools and techniques of *quality improvement*.

### *Vision*

PI CHI will strengthen the system of care so that all Iowa's children and adolescents receive the highest quality of health care possible. This will improve outcomes for children and adolescents so they develop and realize their full potential, satisfy their needs, and work successfully with the professionals who interact with them.

### *Mission*

In order to enhance PI CHI's ability to improve the quality of health for Iowa's children, adolescents, and their families -

#### *PI CHI will:*

- Foster partnerships with children and their families that guide quality improvement in health care.
- Maintain a community focus and encourage collaboration throughout the state.
- Ensure seamless, effective, efficient, family centered linkages and transitions to medical homes, neighborhoods and community services.
- Utilize demonstrated Quality Improvement (QI) methodologies to promote change across the system of care.

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<sup>9</sup> Partnership to Improve Child Health in Iowa (PI CHI), accessed June 30, 2011. Available at: [http://www.iowaped.org/index.php?option=com\\_content&view=article&id=95:pi-chi-late-preterm-infants&catid=38:advocacy-news&Itemid=37](http://www.iowaped.org/index.php?option=com_content&view=article&id=95:pi-chi-late-preterm-infants&catid=38:advocacy-news&Itemid=37).

- Incorporate evidence-based medicine; engage local and national experts; orchestrate learning opportunities; provide tools for screening and assessment; link community resources; help to measure progress; share findings with stakeholders and policy makers.
- Disseminate information through publications and presentations in order to share knowledge on successful quality improvement initiatives.
- Engage all health care professionals, families, community leaders and policy makers in quality improvement efforts so that the partnership raises the standard of child health care.

## LATE TERM PREMATURETY

The long range goal for establishing an improvement partnership is to improve child health in Iowa. A more immediate goal for this project – and for PI CHI is to address late term prematurity and improve the health of those infants who are born at 34-36 weeks gestation.

### The Problem

Late preterm infants are the fastest growing group of preterm infants and account for over 70 percent of all premature births. Late preterm births have increased more markedly than preterm births (less than 34 weeks' gestation), while little change has occurred in the number of births between 32 and 33 weeks' gestation. Thirty-seven percent of preterm infants are born at 36 weeks' gestation. The distribution of preterm births among the remainder of babies born prematurely is 21% at 35 weeks' and 13% at 34 weeks' gestation. Late preterm infants represent 33% of total NICU admissions. With increasing gestational maturity, the percentage of preterm infants requiring intensive care decreases. Estimates suggest that 50% of infants born at 34 weeks' gestation require NICU admission, in contrast to 15% of infants born at 35 weeks gestation and 8% of babies at 36 weeks gestation.<sup>10</sup>

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<sup>10</sup> Viral A. Dave, MD, DCh and Deborah E. Campbell, MD., “Chapter 92: Care of the Late Preterm Infant”, Pediatric Care Online, National Center for Health Statistics, final natality data, accessed June 30, 2011. Available at: [https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter\\_92: care\\_of\\_the\\_late\\_preterm\\_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token](https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter_92: care_of_the_late_preterm_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token).

In Iowa, preterm births have increased 7.5 % from 1998 to 2008 (See chart below).<sup>11</sup> While some of this increase is due to multiple births, the increase in late term prematurity for singleton births in Iowa for the same period has been 9 percent.

	<b>Preterm births in Iowa</b>	<b>Late Preterm births in Iowa</b>
2008	11.5 %	8.3 %
2006	11.6 %	8.3 %
2004	11.8 %	8.6 %
1998	10.7 %	7.6 %

All of the articles that we reviewed on the health problems of late preterm infants wrote that one of the biggest concerns is that these late preterm infants are often considered “normal.” In a 2009 article in *Pediatrics* on perinatal outcomes associated with preterm births, the authors stated, “These late-preterm infants have traditionally been labeled as ‘near-term’ infants, treated as ‘near-normal’ infants, grouped along with the well newborns, and discharged on the same schedule as term-born infants. The care of these infants has slowly moved away from neonatal units to transitional care units and to rooming in with parents in many cases.”<sup>12</sup>

The higher birth weights of late preterm infants, often within the normal birth weight range of over 2500 grams, result in many late preterm infants being treated the same as their developmentally more mature full-term counterparts. The assumption that late preterm infants have similar risks as term infants is common. Issues such as transient tachypnea of the newborn (more rapid and labored breathing than normal), cold stress (impaired ability to prevent heat loss and to increase body heat production in response to low environmental temperatures), and hypoglycemia (low blood sugar) can be easily missed during the early hours after birth if particular attention is not paid to these aspects of the transition.<sup>13</sup>

In an article published in 2009, Ramachandrappa and Jain wrote that treatment of late preterm infants had been so successful that such births were no longer considered of concern.

“However, there is now growing evidence that this population is not as healthy as previously thought...” Other complications cited by the authors include respiratory distress syndrome,

<sup>11</sup> March of Dimes, Peristats, Online source for perinatal statistics, Preterm and late preterm birth data, accessed June 30, 2011. Available at:

<http://www.marchofdimes.com/peristats/tlanding.aspx?dv=lt&reg=19&top=3&lev=0&slev=4>.

<sup>12</sup> Minesh Khashu, MD, FRCPCHa, Manjith Narayanan, MD, MRCPCHb, Seema Bhargava, MD, MRCPCHc, Horacio Osiovich, MD, FRCPCc, “*Perinatal Outcomes Associated With Preterm Birth at 33 to 36 Weeks’ Gestation: A Population-Based Cohort Study*”, *Pediatrics* Vol. 123 No. 1 January 1, 2009, pp. 109 -113 DOI: 10.1542/peds.2007-3743.

<sup>13</sup> Viral A. Dave, *op cit*.

persistent pulmonary hypertension, respiratory failure, temperature instability, jaundice, feeding difficulties, and prolonged NICU stay.” Deaths resulting from congenital malformations, immaturity, asphyxia, infection, and sudden infant death are 4 to 26 times higher among this group of babies than those born between 38 and 41 weeks' gestation<sup>14</sup>. The authors of a study of the relation between weight for gestational age and late preterm mortality found that if a late preterm infant is also smaller for gestational age, he/she has more than 44 times the likelihood of dying in the first month of life, and is 22 times more likely to die in the first year of life as compared with the appropriate for gestational age infants.<sup>15</sup>

Jason R. Kessler, MD, FAAP, CHBE, Medical Director of the Iowa Medicaid Enterprise (IME) noted that; *“most late preterm infants in Iowa are born in community hospitals and cared for by family physicians, nurse practitioners or physician assistants. General pediatricians also may not recognize the needs of late preterm infants. Spurred by a culture that encourages getting the baby born for the comfort of the mother and early discharge of all infants, many are higher risk than is easily recognized. If problems are not evident in the first 48 hours, most will simply go home and be at extreme risk for feeding problems, breastfeeding failure, jaundice and even respiratory issues”*. Further, Dr. Kessler recommends; *“an approach that encourages no early discharges for preterm infants. He recommends early follow up and identification of these infants after hospital discharge. To that end, in the future, the Iowa Health Information Network (HIN) may permit some of that type of information to be pushed out into clinicians' electronic health records from hospital data. The unique challenge to that recommendation is maintaining the infants' identities with possible name changes or transfers from one provider or institution to another”*.

A 2009 article in the journal *Pediatrics* reported on a large retrospective cohort study of late preterm and term infants enrolled for one year in a large national database of commercially insured members. The results were striking:

McLaurin, Hall, Jackson, Owens, Mahadevia (2009):

The average length of stay of the birth hospitalization for term infants was 2.2 days, and the average cost was \$2,061. Late-preterm infants had a substantially longer average stay of 8.8 days and average cost of \$26,054. Total first-year costs after birth discharge were, on average, 3 times as high among late-preterm infants (\$12,247) compared with term infants (\$4,069). Late-preterm infants were re-hospitalized more often than term infants (15.2% vs. 7.9%). A subset of late-preterm infants that were discharged late from their birth hospitalization

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<sup>14</sup> Ashwin Ramachandrappa, MD, MPH, Lucky Jain, MD, MBA, *“Health Issues of the Late Preterm Infant”*, *Pediatr Clin N Am*: 56 (2009) 565–577, DOI: 10.1016/j.pcl.2009.03.009.

<sup>15</sup> Laurie S. Pulver, MD, MPH, Ginger Guest-Warnick, MPH, Gregory J. Stoddard, MPH, Carrie L. Byington, MD, Paul C. Young, MD, *“Weight for Gestational Age Affects the Mortality of Late Preterm Infants”*, *Pediatrics*, June 2, 2009: 123, 1072-1077.

had the highest rates of re-hospitalization and total health care costs. Higher costs during re-hospitalization of late-preterm infants, especially those with a late discharge, indicate their propensity to have more severe illness<sup>16</sup>.

In a study that used data from the British Columbia Perinatal Database Registry, all singleton births between 33 and 40 weeks' gestation from April 1999 to March 2002 in the province of British Columbia, Canada were analyzed. The birth cohort was divided into two groups; a late preterm group (34-36 weeks) and a term group (37-40 weeks). Comparing mortality and morbidity data and associated maternal factors, the study found that stillbirth rate and perinatal, neonatal, and infant mortality rates were significantly higher in the late-preterm group. Infants in this group needed resuscitation at birth more frequently than those in the term group. Late-preterm infants had a significantly higher incidence of respiratory morbidity and infection and had a significantly longer duration of hospital stay<sup>17</sup>.

Data on long term outcomes for children born prematurely are less available than for children born low birth weight. However, new data have emerged over the past few years that show that late preterm infants are more likely to have poorer neurodevelopmental outcomes than term infants.

A long term follow up study in Denmark in 2010 valued basic school completion rates for children born at less than 31 weeks' and 31 to 36 weeks' gestation compared with children born at full term. The cohort included all Danish infants born 1988 to 1989, and reviewed school achievement records for the year 2007. *"Of the subjects born before 37 weeks' gestation, 11.5% (95% confidence interval: 10.7–12.4) did not complete basic school compared with 7.5% (95% confidence interval: 7.3–7.6) of those born at term. The percentage of subjects who did not complete basic school increased with decreasing gestational age. While the increase was steeper at <31 weeks (4.2% per week gestation), there was still an increase in non-school completion for 31 to 36 weeks' gestation (0.5% per week gestation)."*<sup>18</sup>

A very recent article published in 2011 in *Pediatrics*, compared a study sample of 6,300 term and 1,200 late preterm infants from the Early Childhood Longitudinal Study-Birth Cohort. The

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<sup>16</sup> Kimmie K. McLaurin, MS, Caroline B. Hall, MD, E. Anne Jackson, FSA, MAAAd, Oksana V. Owens, BSd, Parthiv J. Mahadevia, MD, MPH, *"Persistence of Morbidity and Cost Differences Between Late-Preterm and Term Infants During the First Year of Life"*, *Pediatrics* Vol. 123 No. 2 February 1, 2009, pp. 653 -659 DOI: 10.1542/peds.2008-1439.

<sup>17</sup> Minesh Khashu, MD, FRCPCHa, Manjith Narayanan, MD, MRCPCHb, Seema Bhargava, MD, MRCPCHc, Horacio Osiovich, MD, FRCPCc, *"Perinatal Outcomes Associated With Preterm Birth at 33 to 36 Weeks' Gestation: A Population-Based Cohort Study"*, *Pediatrics* Vol. 123 No. 1 January 1, 2009, pp. 109 -113, DOI: 10.1542/peds.2007-3743.

<sup>18</sup> René Mathiasen, MD, PhD, Bo M. Hansen, MD, PhD, Anne-Marie N. Nybo Andersen, MD, PhD, Julie L. Forman, PhD, Gorm Greisen, MD, DMSc, *"Gestational Age and Basic School Achievements: A National Follow-up Study in Denmark"*, *Pediatrics* Vol. 126 No. 6 December 1, 2010, pp. e1553 -e1561, DOI: 10.1542/peds.2009-0829.

authors used general estimating equations to get weighted odds of having developmental delay, mental index scores (MDI) or psychomotor index scores (PDA) less than 70, at 24 months of age.<sup>19</sup> The conclusion of the study was that “late preterm infants have poorer neurodevelopmental outcomes than term infants and have increased odds to have a mental and/or physical developmental delay.” After controlling for statistically significant and clinically relevant descriptive characteristics, late preterm infants still had higher odds of mental or physical developmental delay.<sup>20</sup>

Another study published in *Pediatrics* in 2009 compared pre-kindergarten and kindergarten outcomes for healthy late preterm infants with healthy term infants and found that late preterm infants displayed a greater risk for developmental delays and school problems throughout the first five years of life.<sup>21</sup>

Michael J. Acarregui, MD, former Director of the Iowa Statewide Perinatal Care Program<sup>22</sup>, wrote in a 2007 issue of the *Iowa Perinatal Letter*, that infants at 34-35 weeks gestation have brains that are only 60% the size of their term cohorts.

Acarregui (2001) wrote:

Since a significant amount of brain growth occurs in the last 5-6 weeks of gestation, investigation into the effects of late preterm delivery on brain development is of interest. Autopsy data has demonstrated significant incidences of periventricular leucomalacia in late preterm infants. This may explain some of the difficulties observed in children that were born at 34-37 weeks gestation, which include increased risk of subtle neurological abnormalities, learning difficulties, poor scholastic achievement, and behavioral problems. Over 19% of infants born between 34-37 weeks gestation have clinically significant behavioral problems at the age of 8.

Dr. Acarregui’s conclusion was corroborated by a June 2011 article in *Pediatrics*. The article’s authors conducted a systematic review of early childhood outcomes in late-preterm infants. Of 4,581 studies culled from nine electronic databases, only 10 met all the criteria for inclusion in

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<sup>19</sup> “The Bayley Scales of Infant Development” yield scores on two indices – the Psychomotor Development Index (PDI) and the Mental Development Index (MDI). These can be used to assess a child’s level of function in each of these areas at approximately one year of age. Among healthy infants, both indices have a mean value of 100.

<sup>20</sup> Melissa A. Woythaler, MS, DO, Marie C. McCormick, MD, ScD, Vincent C. Smith, MD, MPH, “Late Preterm Infants Have Worse 24-Month Neurodevelopmental Outcomes Than Term Infants”, *Pediatrics* 2011; 127:3 622-629, *Pediatrics* Vol. 127 No. 3 March 1, 2011, pp. e622 -e629, DOI: 10.1542/peds.2009-3598.

<sup>21</sup> S.B. Morse, H. Zheng, Y. Tang, and J. Roth, “Early School-age Outcomes of Late Preterm Infants”, *Pediatrics* Vol. 123 No. 4 April 1, 2009, pp. e622 -e629, DOI: 10.1542/peds.2008-1405.

<sup>22</sup> Michael J. Acarregui, MD, Iowa Department of Public Health, Iowa’s Statewide Perinatal Care Program, The Iowa Perinatal Letter, “Shades of Immaturity-Late Preterm and Early Term Infants”, Vol. XXIX, No. 3, July/August/September 2007, accessed June 30, 2011. Available at:

[http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal\\_newsletters/perinatal\\_jul\\_aug\\_sept\\_07.pdf](http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal_newsletters/perinatal_jul_aug_sept_07.pdf)

the analysis. Poorer outcomes for late-preterm infants “were reported in relation to neurodevelopmental disabilities, educational ability, early-intervention requirements, medical disabilities, and physical growth in comparison to term-born children.” The authors note that none of the studies included healthy, non-admitted late pre-term infants in a comparison group. Attention to the early childhood and long term developmental outcomes of late-preterm infants has been sparse. While the evidence suggested that these infants are at increased risk for negative developmental outcomes, the authors suggest that focused long-term follow up studies are needed.<sup>23</sup>

Thus, evidence is clear that, “late preterm infants make up a majority of preterm births, take up a significant amount of healthcare resources, have increased mortality/morbidity, and may even have long-term neurodevelopmental consequences secondary to their late prematurity”.<sup>24</sup>

The March of Dimes<sup>25</sup> has ranked and graded all 50 states on their rates of premature births relative to the nation’s 2010 objective. For 2010, Iowa received a grade of “D,” which was the overall grade for the entire nation. A snapshot of Iowa’s perinatal data is available in Appendix B and compares a number of perinatal outcomes against the U.S. 2010 objectives.<sup>26</sup>

### **Etiology of Late Preterm Infants**

In a 2008 issue of the Iowa Perinatal Newsletter, Lori Day, MD, Associate Fellow Division of Maternal-fetal Medicine, University of Iowa Hospitals and Clinics and Stephen Hunter, MD, PhD, Maternal-Fetal Medicine Specialist, University of Iowa Hospitals and Clinics (OB/GYN) (University of Iowa Hospitals and Clinics) wrote that the etiology of preterm birth is multi-factorial. Spontaneous (or physiologic) preterm birth differs from induced (iatrogenic). Approximately two-thirds of the preterm births in the U.S. are spontaneous. They cite one reference who proposed four major etiologies of spontaneous prematurity:

- (1) infection or inflammation;
- (2) pathologic uterine distension;
- (3) activation of the maternal-fetal hypothalamic-pituitary-adrenal (HPA) axis; and
- (4) uterine bleeding or abruption.

Premature rupture of membranes accounts for many of the births associated with infection and inflammation; multiple gestations contribute to uterine over-distension. Maternal smoking and

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<sup>23</sup> Jennifer McGowan, RN, Fiona A. Alderdice, PhD, Valerie Homes, PhD, RGN, and Linda Johnston, PhD, RN, “Early Childhood Development of Late-Preterm Infants: A Systematic Review”, *Pediatrics* Vol. 127 No. 6 June 1, 2011, pp. 1111 -1124, DOI: 10.1542/peds.2010-2257.

<sup>24</sup> Ramachandrappa, *op cit*.

<sup>25</sup> March of Dimes mission is to help moms have full-term pregnancies and research the problems that threaten the health of babies, accessed June 30, 2011. Available at: <http://www.marchofdimes.com/>

<sup>26</sup> March of Dimes Peristats, an online source for perinatal statistics, accessed June 30, 2011. Available at: <http://www.marchofdimes.com/peristats/>

drug use increase the risk of placental abruption and activate the maternal-fetal HPA axis. Iatrogenic, or medically indicated, preterm births account for the majority of the additional number of preterm births in the last ten years.<sup>27</sup>

According to a 2009 article in *Pediatric Clinics of North America*, nationally nearly one in four births is delivered by induction of labor. Rates have more than doubled since 1990 (from 9.5% to 22.5%) with late preterm and term births showing the largest increase in induction rates. The authors also noted:

In addition, cesarean sections have continued to increase over the last decade and are at the highest reported level (31.1% of all live births or nearly one in three live births). If a woman has a primary cesarean section, she has a 92% probability of having a repeat cesarean section; primary cesarean sections have thus contributed to the dramatic increase in the total cesarean section rate...with the majority of the increases seen among the late preterm (34–36 weeks) and early term infants (37–39 weeks). There is also an increasing demand for cesarean sections at maternal request, spurred by the perceived safety of surgical procedures, desire for smaller families, and the fear of complications/risks associated with vaginal birth. A national consensus meeting in 2006 convened by the NIH [National Institutes of Health] coined the term “cesarean section on maternal request” for cesarean births with no medical indication. It is estimated that nearly 2.5%–18% of all live births are being delivered by cesarean section on maternal request, although others disagree, contending that the increase in cesarean section rates is largely caused by changing maternal demographics and practice standards of medical professionals, and the ever-increasing risk of malpractice litigation.<sup>28</sup>

In Iowa in 2008, 29.3% of live births were cesarean deliveries, and 70.7% were vaginal deliveries. Between 1998 and 2008, the percent of live births delivered by cesarean section in Iowa increased more than 49%. In Iowa in 2008, the rate of vaginal births after a previous cesarean (VBAC) was 9.4% of live births among women who had a previous cesarean delivery.<sup>29</sup>

In the British Columbia perinatal outcomes study referenced in the previous section, factors that were more common in the late-preterm group included chorioamnionitis, hypertension,

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<sup>27</sup> Lori Day, MD and Stephen K. Hunter, “The Rising Pre-term Delivery Rate in Iowa—Three Things We Can Do Now”, *Iowa Perinatal Letter*, Vol. XXIX, No. 1, January/February/March 2008, accessed June 30, 2011. Available at: [http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal\\_newsletters/perinatal\\_jan\\_feb\\_mar\\_08.pdf](http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal_newsletters/perinatal_jan_feb_mar_08.pdf)

<sup>28</sup> Ramachandrapa, *op cit*.

<sup>29</sup> March of Dimes Peristats, *op cit*.

diabetes, thrombophilia, pre labor rupture of membranes, primigravida, and teenage pregnancy<sup>30</sup>.

### **Iowa's Legislative Efforts to Better Serve All Premature Infants**

In 2009 an attempt was made to introduce legislation for regulation of premature infants' hospital discharge and follow-up care (SF296/HF548-Appel/Mascher) to ensure resources for families with premature infants. The proposed bill charged the Iowa Department of Public Health (IDPH) to develop written educational publications or to provide linkages to existing resources, to provide information and support to families with premature infants. The language of the bill is as follows: information was to be provided in a manner that is accessible and understandable to parents regardless of their socioeconomic status, educational level, gender, or age. The bill directed the department to consult with other appropriate organizations, agencies, and programs including those that focus on premature infants or pediatric health care in developing the written educational publications and in providing linkages to the existing resources, and directs the department to make the information available through various types of media and through a variety of sources including the department's internet website and other existing appropriate entities. These bills did not move forward in the 2009 legislative session and have not been reintroduced in subsequent sessions.

### **PREVENTION OF PRETERM BIRTHS**

Although preterm birth is multi-factorial, Day and Hunter, in 2008 suggest interventions that would benefit specific obstetric populations to minimize their risk of preterm delivery: *"We recommend three practices that will have a positive impact on the increasing pre-term delivery rate in Iowa; (1) adopt a zero tolerance policy for any elective delivery before 39 0/7 weeks based on good OB dating, (2) utilize Progesterone therapy in woman who have a history of pre-term birth, and (3) increase our efforts to diminish exposure to cigarette smoke, both primary smoke and second-hand smoke"*.<sup>31</sup>

An Iowa Department of Public Health report entitled, *"Births to Women on Medicaid: Iowa 2008 Smoking During Pregnancy,"* reported that the percent of women smoking during pregnancy and who were financed by Medicaid was significantly higher than non-Medicaid financed women – 25.2 percent and 6.5 percent respectively. Almost 40 percent of Medicaid

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<sup>30</sup> Minesh Khashu, MD, FRCPCHa, Manjith Narayanan, MD, MRCPCHb, Seema Bhargava, MD, MRCPCHc, Horacio Osioyich, MD, FRCPCc., *"Perinatal Outcomes Associated With Preterm Birth at 33 to 36 Weeks' Gestation: A Population-Based Cohort Study"*, *Pediatrics* Vol. 123 No. 1 January 1, 2009, pp. 109 -113, DOI: 10.1542/peds.2007-3743.

<sup>31</sup> Lori Day, MD and Stephen K. Hunter, *"The Rising Pre-term Delivery Rate in Iowa—Three Things We Can Do Now"*, *Iowa Perinatal Letter*, Vol. XXIX, No. 1, January/February/March 2008, accessed June 30, 2011. Available at: [http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal\\_newsletters/perinatal\\_jan\\_feb\\_mar\\_08.pdf](http://www.idph.state.ia.us/hpcdp/common/pdf/perinatal_newsletters/perinatal_jan_feb_mar_08.pdf).

financed women smoked before pregnancy. Smoking during pregnancy by non-Medicaid financed women was associated with a 32.5 percent increase in preterm births compared with non-smoking women. The increase in preterm births Medicaid financed women who smoked was only three percent, suggesting that other factors and stresses among low income women may affect preterm births.<sup>32</sup>

Dave and Campbell in Pediatric Care Online<sup>33</sup> note that behavioral difficulties are twice as common in low birth weight children and have been shown to be related to maternal psychological distress at term (40 weeks), gestational age and a history of tobacco exposure. *“Whether the effects of smoking are primary or a proxy for other environmental factors or stressors that influence parental well-being and their ability to support their child’s maturation is unclear.”*

Iowa’s Medicaid program covers medications to help stop smoking. As Day and Hunter note, *“Iowans have an advantage when attempting to quit smoking.”* They note that **Quitline Iowa**<sup>34</sup> is a statewide toll-free smoking cessation hotline at 866-U-CAN-TRY (866-822-6879) and is staffed by trained counselors from the Iowa Tobacco Research Center.

Educational and informational materials are available for pregnant women that focus on prevention. Healthy Mothers Healthy Babies “text4baby,”<sup>35</sup> is an easy to use system where text messages are delivered via cell phone to pregnant women or new mothers. Messages are timed to the due date or birth date of the newborn, and provide a way to deliver information in a timely way. The March of Dimes website has many free downloadable informational materials, brochures, and flyers. Additional materials on the last weeks of pregnancy and information for women thinking about scheduling a C-section are also available on the website.<sup>36</sup>

## **FOLLOW-UP CARE FOR INFANTS BORN LATE PRETERM**

The previous section references some of the best practices related to reducing late preterm births and the attention to pregnant woman in the primary care office setting. Best practices

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<sup>32</sup> Department of Public Health, Bureau of Family Health, 321 E. 12th Street, Des Moines, IA50309; 1-800-383-3826 *“Births to Women on Medicaid: Iowa 2008 Smoking During Pregnancy”*, accessed June 30, 2011. Available at: [http://www.idph.state.ia.us/apl/common/pdf/health\\_statistics/2009\\_medicaid\\_smoking.pdf](http://www.idph.state.ia.us/apl/common/pdf/health_statistics/2009_medicaid_smoking.pdf).

<sup>33</sup> Viral A. Dave, MD, DCh and Deborah E. Campbell, MD., *Chapter 92: Care of the Late Preterm Infant*, Pediatric Care Online. Access June 30, 2011. Available at: [https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter\\_92:\\_care\\_of\\_the\\_late\\_preterm\\_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token](https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter_92:_care_of_the_late_preterm_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token).

<sup>34</sup> Quitline Iowa, accessed June 30, 2011. Available at: <https://www.quitnow.net/iowa/>

<sup>35</sup> Text4baby, accessed June 30, 2011. Available at: <http://www.text4baby.org/>

<sup>36</sup> March of Dimes, information on scheduling a C-section and why the last weeks of pregnancy count, accessed June 30, 2011. Available at: [http://www.marchofdimes.com/Pregnancy/csection\\_lastweeks.html](http://www.marchofdimes.com/Pregnancy/csection_lastweeks.html)

also exist for the care of infants who are born late preterm. The Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN) has issued a comprehensive evidence-based resource developed to guide nursing care for this population: *Assessment and Care of the Later Preterm Infant Evidence-based Clinical Practice Guidelines*.<sup>37</sup>

A chapter in American Academy of Pediatrics *pediatriccareonline.org*, “Care of the Late Preterm Infant,”<sup>38</sup> previously referenced, also provides evidence based guidelines. Both sets of guidelines for care of the late preterm infant include best practices for discharge planning. However, in reviewing articles for this report, very little was found concerning what should happen long term for late preterm infants. This PI CHI project addresses this topic.

In a recent article on the *Journal of Pediatric Health Care*, the authors suggest that follow up care include anticipatory guidance for parents’ of late preterm infants. This guidance should include recommending an infant cardio-pulmonary resuscitation course, educating about sudden infant death syndrome prevention protocol (Back to Sleep), and advising parents to avoid public places and limit visitors for the first few weeks after being discharged from the hospital. In addition, the authors suggest that consistent follow-up medical care, weekly weight checks and up to date immunizations can help preterm infants avoid complications<sup>39</sup>.

MedImmune Advocacy<sup>40</sup> (this site is published by MedImmune, LLC, which is solely responsible for its contents) has been involved in this work to improve the quality of health for Iowa’s late preterm infants since work began in late 2009. MedImmune Advocacy recognizes the “uncharted journey” faced by parents of preterm infants. They are engaged participants in the prematurity community, working with national, state, and local organizations to help connect families with comprehensive information and supports. MaryEllen Baker, has been involved with building a Prematurity Network in the central United States (Illinois, Iowa, Minnesota, Missouri, Nebraska, North Dakota, South Dakota, Wisconsin, Wyoming) these networks are focused on and bring together interested parties focused on the health and well-being of premature babies.

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<sup>37</sup> AWHONN, Assessment & Care of the Late Preterm Infant Guideline, 2010, accessed June 30, 2011. Available at: <http://www.awhonn.org/awhonn/store/productDetail.do?productCode=LPI-2010>

<sup>38</sup> Viral A. Dave, MD, DCh and Deborah E. Campbell, MD., *Chapter 92: Care of the Late Preterm Infant*, Pediatric Care Online. Access June 30, 2011. Available at: [https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter\\_92:\\_care\\_of\\_the\\_late\\_preterm\\_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token](https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter_92:_care_of_the_late_preterm_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token).

<sup>39</sup> Ana Souto, Miriam Pudiel and Donna Hallas, “Evidence-based Care Management of the Late Preterm Infant”, *Journal of Pediatric Health Care*, Volume 25, No. 1, January/February 2011. pp 44-49

<sup>40</sup> MedImmune Advocacy, accessed June 30, 2011. Available at: <http://specialdeliveryhandlewithcare.com/main/index.php?L=en&M1=1>

MedImmune Advocacy suggest that the following items – which MedImmune has been promoting nationwide -- should be incorporated into Iowa’s approach to addressing the issue of late preterm births (these items are embedded in the recommended learning collaboratives detailed in a later section).

- Include information and links on the Iowa Department of Health web site: services for late preterm infants, education, early intervention, etc.
- Make available to parents and birthing hospitals informational and/or educational pieces around prematurity and late preterm infants including disparities
- Provide follow-up program information to all patients in the NICU to ensure optimizing follow-up care of all high-risk infants
- Create a standardized discharge checklist<sup>41</sup>
- Track the re-hospitalization of premature infants to ensure they are getting the appropriate care and to pinpoint areas for improvement
- Create a ‘preemie’ registry using concept of Diabetes or birth defects registry to track care of late preterm infants and outcomes
- Require appointments are scheduled with the infant’s care provider before the infant is discharged from the hospital

The above mentioned prevention, patient education and medical follow-up suggestions for change do not address the long term neurodevelopmental problems that some late preterm infants face. In the “Pediatric Care Online” chapter on care of the late preterm infant, the authors state

*“ . . . the clinician should monitor the child’s behavioral and educational progress because the late preterm infant is not typically considered automatically eligible for early intervention services and may not even be viewed as at-risk under early intervention guidelines from the Child Find Initiative.”*

The authors also state that all newborn screening procedures should be conducted. Newborn hearing screening using either automated auditory brainstem response (AABR) or otoacoustic emission (OAE) testing devices is feasible and should be completed before the infant is discharged from the newborn nursery. Follow-up care should include a home nurse visit or an office visit with the primary care physician within 48 to 72 hours of the newborn's discharge from the hospital. If the newborn is younger than 5 days at the time of nursery discharge, is

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<sup>41</sup> The Oklahoma Infant Alliance has developed a guide for medical practitioners with the tools necessary to manage these often fragile infants; “Caring for the Late Preterm Infant, A Clinical Practice Guideline”, accessed June 30, 2011. Available at: [http://www.oklahomainfantalliance.org/uploads/LPI\\_Clinical\\_Practice\\_Guideline\\_Sample.pdf](http://www.oklahomainfantalliance.org/uploads/LPI_Clinical_Practice_Guideline_Sample.pdf)

breastfeeding, or has any risk factors for potential difficulties, then follow-up should occur within 48 hours of hospital discharge.<sup>42</sup>

## **FAMILY STORY**

The realities facing parents with late preterm infants are exemplified by one family's story:

*In the early hours of March 21, 2010, I went into labor. Several hours later at our birthing hospital, my twin sons were delivered by Cesarean section at 34 4/7 weeks gestation. At birth, Sam weighed 5 pounds 5 ounces and Joe weighed 4 pounds 11 ounces – substantial weights for preemies but still in need of care in the NICU.*

*My husband and I thought we were prepared for a preterm delivery. We had known the risk of preterm birth was higher since we had learned we were having twins very early in my pregnancy, and I had been counting off the weeks of the second half of my pregnancy according to preterm birth prognosis rates. We had told our family and friends that a preterm delivery was likely, and I had a bag packed for the hospital for weeks – just in case. But the reality of walking through the NICU to see our tiny infant sons hooked up to monitors and tubes was much more difficult than I had anticipated.*

*Sam and Joe were relatively robust and healthy, requiring only nasogastric feeding tubes, oxygen, IV's and bili lights. The experience of walking down a hallway filled with infants that were more premature, smaller, and battling significant health challenges left my husband and me with a strange mix of feelings – gratitude that our children were healthy, guilt that our children didn't share some of the ailments and struggles of other infants in the NICU, and the feeling that we (and our sons) somehow didn't belong in a NICU.*

*At 22 days old, Sam and Joe were stable and strong enough to come home for the first time. Our first visit to the pediatric clinic was a routine check two days after being released from the hospital, followed by their 1-month checkup just a week or so later.*

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<sup>42</sup> Viral A. Dave, MD, DCh and Deborah E. Campbell, MD., "Chapter 92: Care of the Late Preterm Infant", Pediatric Care Online, National Center for Health Statistics, final natality data, accessed June 30, 2011. Available at: [https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter\\_92:\\_care\\_of\\_the\\_late\\_preterm\\_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token](https://www.pediatriccareonline.org/pco/ub/view/AAP-Textbook-of-Pediatric-Care/394092/all/chapter_92:_care_of_the_late_preterm_infant?amod=aapea&login=true&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token).

*The next few months were a blur as everyone adjusted to life with twins in the house. The boys learned to smile and laugh, to sit up and crawl, and we checked off early developmental milestones.*

*At 9 months old, my husband and I filled out our first Ages & Stages Questionnaire (ASQ) and got our first real objective view of the twins' development. We had always felt they were more or less in the normal range for developmental milestones, if perhaps a little late. And the ASQ seemed to show the same thing – some slight delay, but nothing to warrant immediate intervention. Meanwhile, both boys seemed happy and healthy. Their catch-up growth was tremendous, and they were both active and engaged.*

*Our pediatrician recommended another ASQ at 12 months, and we found the same result for Joe as at 9 months – some minor delays, but nothing to worry about. Sam, however, was still lagging behind in terms of communication skills. It will be a few months before his specialty appointment, but in the mean time we have filled out questionnaires, consulted our insurance company, and will wait to see what the intervening months bring. Based on our experiences in the NICU, we anticipate a high level of care and concern of the providers, though I cannot help but wonder if we will feel the same strange sense of not belonging that we did in the NICU.*

*We are fortunate; however, to have a pediatrician who understands our concerns and are grateful to have the necessary resources close by so that our children can get the early intervention that they need.*

*The above story illustrates the need for improved collaboration with Early ACCESS*

## **EFFECTIVENESS OF EARLY INTERVENTION SERVICES**

As noted earlier in this report, the body of research on the long term impact of late preterm births on later child development is beginning to grow. However, studies that look specifically at the impact of interventions on the long term health of children born between 34-36 weeks gestation are perhaps nonexistent. In fact, most evaluations and impact studies have focused on low birthweight infants or infants and children at risk due to many different factors, including being born to a teenage mother or into a low income household. However, the

considerable evidence of the positive benefits of early intervention services on children's long term outcomes can reasonably be applied to those infant born 34-36 weeks gestation.

A Rand Corporation research brief published in 2005 was a study that synthesized what is known in the scientific research literature about the short and long-term benefits from early intervention programs. The Rand study focused on programs that provide child development services from the prenatal period until kindergarten entry and that had scientifically sound evaluations. Twenty such programs were identified, and fifteen were judged to have strong evidence base; four were too early in their measurement to be included as the children were not yet in kindergarten, though the evidence in these programs were designated "promising." The nineteen programs which had strong or promising evidence base varied in approaches: some that concentrate on providing parent education and other family supports through home visiting or in other settings, early childhood education, and an approach that combines both.

Key findings of this study were:

- Early childhood intervention programs have been shown to yield benefits in academic achievement, behavior, educational progression and attainment, delinquency and crime, and labor market success.
- Interventions with better-trained caregivers and smaller child-to-staff ratios appear to offer more favorable results.
- Well-designed early childhood interventions have been found to generate a return to society ranging from \$1.80 to \$17.07 for each dollar spent on the program.

In the Rand research brief, it is also noted that the evidence indicates that there can be longer-lasting gains in outcomes such as special education placement and grade retention, high school graduation rates, labor market outcomes, social welfare program use, and crime.<sup>43</sup>

In March of 2006, an 18 year follow-up study of the Infant Health and Development Program (IHDP) was published in *Pediatrics*.<sup>44</sup> Robert Wood Johnson Foundation, one of the study funders, wrote on its website that the study "...provides the best evidence to date of the sustained, positive effects of early educational intervention on children's long term outcomes."<sup>45</sup> Additionally, improvements in cognitive and behavioral development were evident into

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<sup>43</sup> Rand Corporation: Objective Analysis. Effective Solutions, Research Brief, "Proven Benefits of Early Childhood Interventions", accessed June 30, 2011. Available at: [http://www.rand.org/pubs/research\\_briefs/RB9145/index1.html](http://www.rand.org/pubs/research_briefs/RB9145/index1.html)

<sup>44</sup> M.C. McCormick, J. Brooks-Gunn, SL Buka, J. Goldman et al, "Early intervention in low birth weight premature infants: results at 18 years of age for the Infant Health and Development Program", *Pediatrics* Vol. 117 No. 3 March 1, 2006, pp. 771 -780, DOI: 10.1542/peds.2005-1316.

<sup>45</sup> Robert Wood Johnson Foundation, Publications and research, "Study Reveals Prolonged Effectiveness of Early Intervention Program", Improvements in cognitive and behavioral development evident into adolescence, published March 2006, accessed June 30, 2011. Available at: <http://www.rwjf.org/pr/product.jsp?id=21796>

adolescence. This study was a large, multi-site, randomized trial that was much larger than most previous research. The IHDP intervention served lower and higher-weight preterm infants. The original 36 month intervention consisted of home visits every week for the first year of the child's life and every other week in the second and third year, along with daily center-based education beginning at 12 months, and a support group for parents of participating children. The follow-up only (control) group received frequent pediatric assessments and community services when needed during the intervention period.

Assessments of the children in both groups were done at 3, 5 and 8 years of age and then at 18 years of age. "Positive long term benefits observed for the heavier low birth weight babies (2,001-2,499 grams) in the intervention group are highly comparable to normal birth weight babies. (There was a lack of observable benefits for the lighter low birth weight group).

The Rand study found programs that were less intensive than the IHDP study also had economic returns that were positive.

Finally, in a review of the home visiting research literature, the research organization Mathematica assessed the evidence of effectiveness of home visiting models that serve families with pregnant women and children from birth the age five. This study was done under contract with the U.S. Department of Health and Human Services to determine which home visiting programs were evidence based.

Under the Patient Protection and Affordable Care Act of 2010, states must use at least 75 percent of the expanded funding for the Maternal, Infant, and Early Childhood Home Visiting Program on an evidence based program.

The researchers reviewed the evaluation literature and found eleven programs that fit their rigorous criteria and which were designed to improve outcomes in at least one of eight domains specified in the legislation: (1) child development and school readiness; (2) child health; (3) family economic self-sufficiency; (4) linkages and referrals; (5) maternal health; (6) positive parenting practices; (7) reductions in child maltreatment; and (8) reductions in juvenile delinquency, family violence, and crime. Seven of these eleven programs were found whose positive outcomes were based on clear evidence. All seven showed improvements in the domain of child development and school readiness.<sup>46</sup>

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<sup>46</sup> U.S. Department of Health and Human Services, "*Home Visitation Evidence of Effectiveness*", a transparent review of the home visiting research literature and assessment of evidence of effectiveness for home visiting programs, submitted by Project Director: Diane Paulsell, Mathematica Policy Research, submitted to: Office of Planning, Research and Evaluation, Administration for Children and Families, November 2010, accessed June 30, 2011. Available at: <http://homvee.acf.hhs.gov/outcomes.aspx>.

The problems associated with late preterm births are clear, best practices for preventing or caring for late preterm infants are known, and the benefits of early interventions have been shown to be significant. However, the current programs and services that impact infants and children and their families are not well coordinated and connected in Iowa. A “system of care” that ties together the many individuals, agencies and systems that touch the lives of children born preterm is key to realizing positive impacts for these children.

## DEFINING A SYSTEM OF CARE FOR LATE PRETERM INFANTS

A **system of care** incorporates a broad array of services and supports that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery and policy levels. In a document, *Building a System of Care: A Primer for Child Welfare*<sup>47</sup>, the guiding principles of a system of care specify that services should:

- Be comprehensive, incorporating a broad array of services and supports
- Be individualized
- Be provided in the least restrictive, appropriate setting
- Coordinated both at the system and service delivery levels
- Involve families and youth as full partners
- Emphasize early identification and intervention

The authors of this PI CHI report suggest that another guiding principle for a system of care should be “prevention.”

As the term implies, a system of care is inclusive of all parts of the system, from the experience of children and families (patients) through the environment of policy, payment, regulation etc. Donald Berwick has elucidated the four levels of interest of a system of care in a 2002 paper entitled *A User’s Manual for the IOM’s ‘Quality Chasm’ Report*.<sup>48</sup> These four levels are now often cited as the framework for redesign of the U.S. health care system. They are:

- Level A: The experience of patients – the goal of all other levels.

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<sup>47</sup> Sheila A. Pires, in partnership with Katherine J Lazear and Lisa Conlan, “*Building Systems of Care: A Primer for Child Welfare*”, for National Technical Assistance Center for Children’s Mental Health, Center for Child and Human Development, Georgetown University, supported by Children’s Bureau, Administration for Children and Families, Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, Spring 2008, accessed June 30, 2011. Available at: <http://gucchd.georgetown.edu/72382.html>

<sup>48</sup> Donald M. Berwick, “*A User’s Manual for the IOM’s ‘Quality Chasm’ Report*”, *Health Affairs*, Volume 21, No. 3, 2002, DOI:10.1377/hlthaff.21.3.80, accessed June 30, 2011. Available at: <http://content.healthaffairs.org/content/21/3/80.full.html>.

- Level B: The functioning of small units of care delivery (or “Microsystems”)
- Level C: the functioning of the organizations that house or otherwise support Microsystems
- Level D: The environment of policy, payment, regulation, accreditation, and other such factors that shape the behavior, interests, and opportunities of the organizations at Level C.

Berwick notes that the above model is hierarchical because *“it asserts that the quality of actions at Levels B, C, and D ought to be defined as the effects of those actions on Level A, and in no other way.”*<sup>49</sup>

A system of care for late preterm infants must engage all levels in a system redesign. Direct providers of services must be supported by the management and structure of their individual organizations, which in turn need the leadership and support structures of larger health care systems, nonprofit and public health and human services systems, and educational organizations.

Critical to systems redesign is the broader environment. To create a system of care for late preterm infants and their families, there must be active and committed engagement: of public (Medicaid) and private payers; the policy level representatives of state maternal and child health, services for children with special health care needs, and early intervention; hospital systems at the broadest level; faculty and staff involved in professional education and continuing education around best practices; medical professional organizations in pediatrics, family practice and obstetrics/gynecology; state policy representatives of human services; and families of late preterm infants.

**“Service Integration”** is another term that, as defined, describes a model of care delivery that achieves better outcomes for children. In a document entitled *“Achieving Service Integration for Children with Special Health Care Needs...”*<sup>50</sup> prepared for the Federal Maternal and Child Health Bureau’s (MCHB), Division of Children with Special Health Care Needs, the authors developed the following definition of “service integration” based on a survey of the literature: *“an ongoing process of combining resources across medical, health, mental health, social and education systems to support and assure a high quality program of care for the child and the family.”*

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<sup>49</sup> Ibid.<sup>48</sup>

<sup>50</sup> Prepared by Ian Hill, Renee Schwalberg, Beth Zimmerman, and Wilma Tilson, Health Systems Research, Inc., Washington, DC for The Division of Children with Special Health Care Needs, Maternal and Child Health Bureau, *“Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models, Volume I: Synthesis of Study Results”*, Health Resources and Services Administration, Rockville, MD Cooperative Agreement No.: 93-110-C, (July 1999).

The state policy levers and actions highlighted in this study emphasize the following five strategic themes at the broad environmental and policy level that are crucial in affecting change. While these are focused primarily on payment mechanisms, they bear noting. These are:

- 1) *Leadership and convening*: bringing public and private payers and stakeholders together and brokering multi-payer agreements;
- 2) *Payment incentives*: using a variety of strategies to pay primary care providers for key elements infrequently reimbursed by other payers and to reward outcomes;
- 3) *Support for infrastructure*: shared services to create a team-based approach, state supported and organized learning, and information exchange;
- 4) *Information feedback and monitoring*: data collection and reporting on process and outcomes; and
- 5) *Certification and recognition*: meeting characteristics deemed necessary for optimal primary care using the certification of external organizations (such as the National Committee for Quality Assurance) or through state-conducted audits to ensure compliance.

A system of care for late preterm infants at the Level A bedrock level, inclusive of all the guiding principles, would begin with early pregnancy (or even pre conceptually) and extend through ongoing follow-up care and/or early and continuous screening.

**Prevention** should include at least four efforts that would have an impact on late preterm births:

- (1) *Education about the importance of NOT smoking during pregnancy* and avoiding second hand smoke should occur in a coordinated community and medical practice effort. Smoking cessation programs should be promoted both by physicians or nurse midwives and community organizations, and messages should be consistent and coordinated.
- (2) Guarantee the patient information created by the March of Dimes on the *importance of allowing infants to develop in utero*, would be visible and available within medical practices and through community organizations.
- (3) Adoption of best practices within prenatal care practices that decrease the chances of preterm births, including addressing the causes of spontaneous prematurity such as infection or inflammation and uterine bleeding or abruption, and utilizing Progesterone therapy in woman who have a history of pre-term birth
- (4) Coordination between prenatal care providers, Early ACCESS and community based service providers is critical for women facing the stresses of poverty and/or mental

health issues. Care coordination that is comprehensive and holistic that addresses nutrition, safety, housing, counseling, parenting supports etc. will improve outcomes for pregnant women.

**Birth facility practices** include adoption of best practices in hospital care during delivery, in the nursery, and include appropriate discharge planning. These best practices would include a zero tolerance policy for any elective delivery before 39 0/7 weeks based on good OB dating and utilization of a standardized discharge checklist.

**Ongoing family-centered follow-up** care in community-based settings:

- (1) Optimal hand-off from the hospital to primary care providers.
- (2) Home visitation for some infants
- (3) Care coordination that focuses on all aspects of the child and family's lives, with families facing barriers of poverty or mental illness.
- (4) Early, continuous screening and monitoring of late preterm infants provided by medical home, Early ACCESS, etc.
- (5) Collaboration between primary care providers, community services/early intervention providers and families should be a "two-way" street where services are coordinated, easily accessible, and continuous. Care planning that is continually developed from a child's infancy through early childhood and beyond. Good communications between families and providers and among providers from different systems are the key to better outcomes.

## **IMPROVING IOWA'S SYSTEM OF CARE FOR LATE PRETERM INFANTS WILL REQUIRE SYSTEMS REDESIGN AND MODELS FOR IMPROVEMENT**

There are existing initiatives in Iowa focused on both screening for developmental and behavioral issues in children and on improving communications and linkages between medical providers and community based services, including Early ACCESS, but challenges remain. Developing a system of seamless services among providers has been a goal of Iowa's Maternal and Child Health planning. Stakeholders from a wide array of organizations and systems are committed in principle to developing a system of care for women and children.

*Iowa's Statewide Perinatal Care Program* provides professional training, development of standards/guidelines of care, consultation to regional and primary providers and evaluation of the quality of care delivered to reduce the mortality and morbidity of infants. Through a

contract with the University of Iowa Hospitals and Clinics, these services are provided to all hospitals that perform deliveries.

Thus, there is “will” and there is “knowledge” to realize change and improvements. While the efforts of the Perinatal Care Program realize significant improvements in selected aspects of prenatal care, they do not address systems level improvements. Connections between providers within a single organization are often fragmented. Connections between organizations are even more fragmented. Similarly, the goals of the state through its MCH Plan set forth clear aims for change, but execution faces significant barriers.

## Barriers to Change

There are many barriers to moving towards a system of care – the redesign of the service delivery system for children’s health care.

Charles Bruner of the Child and Family Policy Center in a draft policy paper, “Clinical and Social Determinants of Health: Using New Federal Opportunities to Meet Children’s Needs”,<sup>51</sup> noted that

*Bruner (2010): “in most instances, however, primary child health practices and the entire array of non-medical professional and community services that serve children are not structured or financed to enable practitioners to routinely access them for their families.” Bruner continued: “While there often are an array of publicly-funded programs and services within communities to respond to these social determinants of health, either through providing specific services to the children or their families, they usually are funded for discrete purposes. They usually are limited in the number of children or families they can serve, often closed to any additional clients or customers. Moreover, it is time-consuming for child health practices to keep track of these resources and know which are available and what they can provide. Even then, there may not be a good match between services that are available and the immediate needs identified by the practitioner for the child or family.”*

PI CHI conducted a non-scientific survey in 2010 to a broad group of participants to gain insight on what they felt were the issues around our late preterm infants in Iowa. This survey provided a picture of barriers to a system of change as viewed by stakeholders within the state. For purposes of this survey the 19 questions were specific to late preterm infants (34-36 weeks gestation) and were categorized by the groups listed below when they were summarized. The survey was open August 23 – August 29, 2010 & November 29 – December 3, 2010. The survey

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<sup>51</sup> Charles Bruner, Child and Family Policy Center, January 22, 2010, “Clinical Practice and Social Determinants of Health: Using New Federal Opportunities to Meet Children’s Needs -- Draft Paper”, personal correspondence with Report Authors.

was sent to over 200 individual email addresses, but we are unable to determine how many more may have forwarded the message. There were 37 respondents from a diverse stakeholder group:

- a) Primary Care Physician - 3
- b) Neonatologist - 3
- c) ARNP - 5
- d) RN = 6
- e) State/County/Municipal Agency Representative - 7
- f) Legislator - 0
- g) Parent/Consumer - 3
- h) Family Advocacy Group Representative - 3
- i) Commercial Health Insurer - 0
- j) Other (please specify) - 7

*High Level Summary/Observations of results:*

- Resources: Awareness of home visiting resources is high, but not a clear understanding of eligibility criteria
- Protocols: Standard protocols specific to needs of late preterm infants is not in place and respondents felt that it would improve the care by having them
- Health Info: Families are sometimes getting the information they need from physicians, other health care providers, agencies not consistently providing information to families.
- Coordination and Communication: Families do need extra help in arranging/coordinating their late preterm infants care among different health care providers/service agencies.
- Coordination and Communication: Physicians and healthcare providers need to communicate with early intervention programs, child care providers and other service agencies because they are not doing it now and respondents are dissatisfied with communication today.
- Care and Risks: Physicians and Parents/family members are the most influential in affecting families decisions on the care of late preterm infants. Awareness is high that late preterm infants may be at risk for developmental delays and increased risk for respiratory illness.
- Education: Top 3 ways you stay up-to-date with current best practices regarding the care of late preterm infants; Face to face, professional meetings, self-directed study, on-line
- Education: Top 3 preferred methods of learning on this topic: On-line, self-directed study, professional meetings

The committee that developed the Institute of Medicine report, *The Quality Chasm*, developed a set of six “*Aims for Improvement*,” which all stakeholders throughout U.S. health care should embrace. They are safety, effectiveness, patient-centeredness, timeliness, efficiency and equity.

*“The committee minced no words in its assessment of the capacity of today’s health care system to achieve these six aims: In its current form, habits, and environment, American health care is incapable of providing the public with the quality of health care it expects and deserves.”<sup>52</sup>*

The obstacles to implementation of the quality aims exist at every level, according to the IOM report. Among the many obstacles, some of those most pertinent to realizing a system of care for late preterm infants include: diffuse or unstable aims; measurement unconnected to aims; gaps in leadership of change; toxic financing schemes; and professional education without a system view.

On the Institute for Healthcare Improvement (IHI) website, it is noted that health care around the world is in need of revolutionary change.

*“We are not performing at the level our patients deserve. There are huge gaps between knowledge and practice. Adverse events harm patients far too often. Too many people do not get the care they need. And the system propagates waste: waste of time, resources, and good will.”*

Yet there are now many examples of projects around the country that have shown that breakthrough improvement in health care is possible – at the systems level.

### **Realizing Systems Change**

Creating a system of care for late preterm infants in Iowa requires broad-based systems change. The ability to develop, test, and implement change will be essential for any individual, group or organization to continuously improve. Utilizing proven Science of Improvement methodologies to implement these kinds of system wide changes will be important to our success.

Knowing what needs to change and knowing how to make that change are very different skills. Individuals at the service level, the management and administrative level, and at the policy level have the knowledge of what needs to be done, and are often involved in plans to make changes. Usually, these individuals do not have the tools for making change.

The Institute for Healthcare Improvement (IHI) has worked with systems for many years to effect real systems change. The National Initiative for Children’s Healthcare Quality (NICHQ) founded in 1999 is an independent, not-for-profit, quality improvement organization dedicated to achieving a world in which all children receive the high quality of healthcare they need. Vermont Child Health Improvement Program (VCHIP) has leveraged the experience of IHI and

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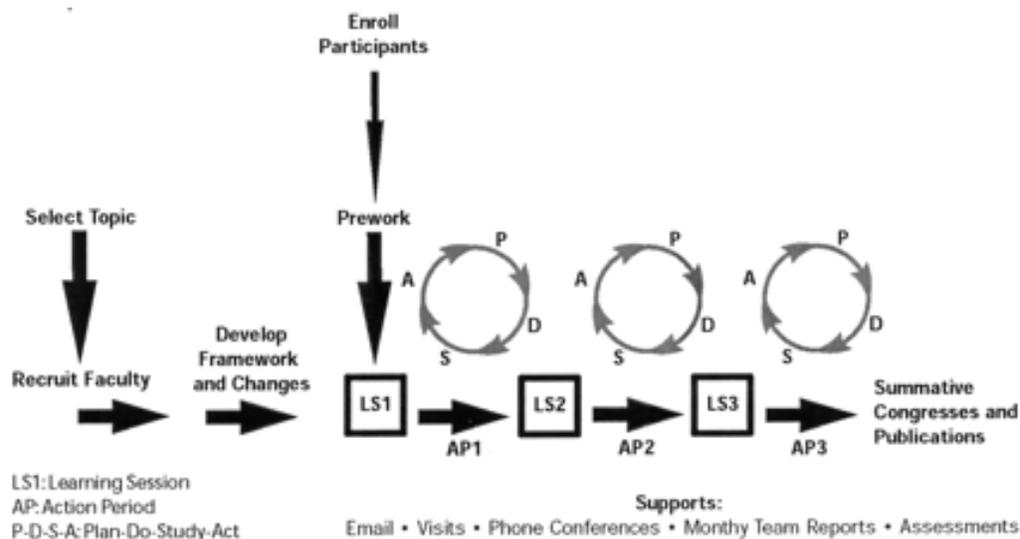
<sup>52</sup> Donald M. Berwick, “A User’s Manual for the IOM’s ‘Quality Chasm’ Report”, *Health Affairs*, Volume 21, No. 3, 2002, DOI:10.1377/hlthaff.21.3.80, accessed June 30, 2011. Available at: <http://content.healthaffairs.org/content/21/3/80.full.html>.

NICHQ to create an ongoing, durable structure that harnesses the knowledge of what needs to be done into a continuous improvement process to realize better outcomes for children.

VCHIP utilizes is the “Breakthrough Series,” developed by IHI in 1995 to achieve “breakthrough” improvements via collaborative learning that improves health by supporting change. The key to this process of realizing breakthrough improvements is the learning that takes place by teams on use of tools for making change.

## **THE BREAKTHROUGH SERIES**

The Breakthrough Series is graphically shown below in *Figure 1*. It involves (1) Experts refining a “change package,” (2) recruitment of teams for participation, (3) teams working over a year’s time in learning sessions with other teams, and action periods in between where teams test changes through a Plan-Do-Study-Act process; and (4) development of toolkits at the end of the process and sometimes ongoing learning sessions and action periods. Teams are composed of those individuals working at the “service level” alongside their organization’s management or leadership. A state team composed of policy level individuals is an important component to realizing true systems change. Because the Breakthrough Series is such a powerful tool for change, a description of the model is being presented here.



**Figure 1.**

The Breakthrough Series<sup>53</sup> is a Collaborative Model developed by the Institute for Healthcare Improvement (IHI) in the mid-90s. The Breakthrough Series (BTS) was created to help health care organizations make “breakthrough” improvements in quality while reducing costs. A Breakthrough Series Collaborative is a short-term (6- to 15-month) learning system that brings together a large number of teams from health care provider practices and hospitals or clinics to seek improvement in a focused topic area. It is a structure in which interested organizations can easily learn from each other and from recognized experts in topic areas where they want to make improvements. The driving vision behind the BTS is that sound science exists on the basis of which the costs and outcomes of current health care practices can be greatly improved, but much of this science lies fallow and unused in daily work. In other words, there is a gap between what we know and what we do.

A BTS Collaborative Learning Model uses the Model for Improvement<sup>54</sup> as its Improvement Methodology. The Model for Improvement, developed by Associates in Process Improvement<sup>55</sup>, is a powerful tool for accelerating improvement. This model has been used very successfully by hundreds of health care organizations in many countries to improve many different health care

<sup>53</sup> *The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement*. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement; 2003, accessed June 30, 2011. Available on [www.ihl.org](http://www.ihl.org).

<sup>54</sup> Science of Improvement: How to Improve, tool for accelerating improvement, accessed June 30, 2011. Available at: <http://www.ihl.org/knowledge/Pages/HowtoImprove/ScienceofImprovementHowtoImprove.aspx>

<sup>55</sup> Langley G., Nolan K., Nolan T., Norman C., Provost L, Jossey-Bass Publishers; “*The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*”, 2<sup>nd</sup> Edition, April 2009.

processes and outcomes. In general, the Model for Improvement defines how to test and implement changes rapidly and efficiently. The model has two important steps toward implementing sustainable improvements:

**The First Step:** Ask three fundamental questions<sup>56</sup>:

- 1) **What are we trying to change?** - Improvement requires setting aims. An aim is a written statement summarizing what a team hopes to achieve and gets everyone on the same page. The aim should define the focus of our population, concentrate on the greater good, and include what we will improve, for whom, how much and by when.
- 2) **How will we know that the change is an improvement?** - Measures play an important role in a team's efforts to improve care. They tell us whether a change we make actually leads to improvement and enhances our learning. A measurement should be designed to accelerate improvement, not slow it down. Effectiveness will depend on our ability to measure. Collect only enough measurement to answer the question, and no more.
- 3) **What changes can we make that will result in an improvement?** - All improvement requires making changes, but not all changes result in improvement. Organizations therefore must identify the changes that are most likely to result in improvement.

**The Second Step:** Plan-Do-Study-Act (PDSA):<sup>57</sup>

The PDSA cycle is the method for testing a change quickly in the real work setting to see how it works by planning it, trying it, observing the results, and acting on what is learned. It is the primary way we turn ideas into action and connect action to learning and guides the test of a change to determine if the change is actually an improvement. PDSA cycles are a tested practical method for initiating testing, measuring and implementing the changes.

### **The Change Package**

Creating a system of care for late pre-term infants requires broad-based major systems change. While all changes do not lead to improvement, all improvement requires change. The ability to develop, test, and implement changes is essential for any individual, group, or organization that wants to continuously improve. There are many kinds of changes that will lead to improvement, but these specific changes are developed from a limited number of change concepts.

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<sup>56</sup> Science of Improvement: How to Improve, fundamental questions tool for accelerating improvement, accessed June 30, 2011. Available at:

<http://www.ihl.org/knowledge/Pages/HowtoImprove/ScienceofImprovementHowtoImprove.aspx>.

<sup>57</sup> Science of Improvement: Testing Changes, tool for testing change, accessed June 30, 2011. Available at:;

<http://www.ihl.org/knowledge/Pages/HowtoImprove/ScienceofImprovementTestingChanges.aspx>.

A change concept<sup>58</sup> is a general notion or approach to change that has been found to be useful in developing specific ideas for changes that lead to improvement. Creatively combining these change concepts with knowledge about specific subjects can help generate ideas for tests of change. After generating ideas, run Plan-Do-Study-Act (PDSA) cycles to test a change or group of changes on a small scale to see if they result in improvement. If they do, expand the tests and gradually incorporate larger and larger samples until you are confident that the changes should be adopted more widely.

A change package is a set of materials and ideas that guide and enable Collaborative teams to implement breakthrough change in their setting. There are four main components:

- 1) A conceptual framework that describes features of the ideal system for prenatal care
- 2) A set of changes or strategies that have proven to be effective in achieving improvements (often called “change concepts”).
- 3) The Model for Improvement (an approach for testing and refining changes).
- 4) A set of measures that enable teams to track progress to Collaborative aims

### **Measurement**

Measurement<sup>59</sup> is the primary indicator of change used in a Collaborative. Participating teams use data resulting from measurement to track the implementation of changes in their office systems and whether patients receive a proven prenatal intervention as a result. Additionally, the measurement strategy provides a feedback mechanism and is used to monitor progress over time. This informs the improvement process at the practice and Collaborative level. Our recommendation would be to design or leverage an existing specific measurement strategy that would allow participants to track the specific data points identified for each area to be studied. The measures should be targeted to promote improvement where a gap in the current level of care and best practice recommendations existed, and where changes could reasonably be implemented. Data collection surveys and tools should be placed electronically where they can be easily accessed by the Collaborative team. Data collected from practice sites should be used to create run charts that will illustrate improvement over time.

## **POTENTIAL IMPROVEMENT PROJECTS RELATED TO LATE PRETERM BIRTHS**

Following are potential projects related to late pre-term infants that could be inaugural projects for the PI CHI. To do any of these projects would require staff dedicated to do this work,

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<sup>58</sup> Science of Improvement: Using Change Concepts for Improvement, accessed June 30, 2011. Available at: <http://www.ihl.org/knowledge/Pages/Changes/UsingChangeConceptsforImprovement.aspx>.

<sup>59</sup> Science of Improvement: Measures, accessed June 30, 2011. Available at: <http://www.ihl.org/knowledge/Pages/Measures/default.aspx>

involving project specific consultants, ongoing oversight and input from an advisory group of key stakeholders.

### 1. *Decreasing/Eliminating non-medically indicated cesarean deliveries and inductions*

The March of Dimes, California Maternal Quality Care Collaborative (CMQCC), and the California Department of Health, Maternal Child and Adolescent Health Division have developed a toolkit to transform maternity care entitled “*Elimination of Non-medically Indicated (Elective) Deliveries before 39 Weeks Gestational Age*”.<sup>60</sup> This toolkit provides the framework for collaborative involving changes in physician practice and education of women about the importance to the health of their babies for the pregnancy to go to 39 weeks. This toolkit is a change package that provides the expert clinical information, clinician and patient education materials, implementation strategies, data collection forms, and a description of a rapid cycle QI methodology. This tool kit is a “guide and support to obstetrical providers, clinical staff, hospitals, and health care organizations to develop a successful quality improvement program to eliminate elective deliveries less than 39 weeks and help more babies be born healthy.” The March of Dimes is working with hospital partners in five states - New York, California, Florida, Illinois and Texas

A collaborative based on the March of Dimes 39 Weeks Toolkit would focus solely on reducing non-medically indicated deliveries prior to 39 weeks gestation. In New York, the March of Dimes is partnering with the New York State Department of Health and the American Congress of Obstetricians and Gynecologists (ACOG) to address late preterm births utilizing the toolkit.<sup>61</sup> A collaboration involving the ACOG’s Iowa members, the Iowa Department of Public Health, the March of Dimes Iowa Chapter and a hospital system (e.g. Iowa Health System) could implement an improvement project based on the 39 Weeks Toolkit, which is available at no charge.

### 2. *Reducing late preterm births through reduced smoking rates by pregnant women*

Reducing smoking by women during their pregnancies (and before) is an outcome that would have an impact on lowering the rate of late preterm births – and reduce other long term health and behavioral concerns for young children. Collaboration between public health, human services, and health care providers focused on a prevention message and

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<sup>60</sup> March of Dimes, California Maternal Quality Care Collaborative (CMQCC), and the California Department of Health, Maternal Child and Adolescent Health Division, “*Elimination of Non-medically Indicated (Elective) Deliveries before 39 Weeks Gestational Age*”, 2010. Accessed June 30, 2011, Available to download with registration at: [http://www.marchofdimes.com/professionals/medicalresources\\_39weeks.html](http://www.marchofdimes.com/professionals/medicalresources_39weeks.html)

<sup>61</sup> Press Release from American Congress of Obstetricians and Gynecologists, *March of Dimes partners with New York State Department of Health and American Congress of Obstetricians and Gynecologists to address Late Preterm Birth*, November 30, 2010, accessed June 30, 2011. Available at: [http://www.acog.org/acog\\_districts/dist\\_notice.cfm?recno=1&bulletin=3629](http://www.acog.org/acog_districts/dist_notice.cfm?recno=1&bulletin=3629)

behavior change would be unique among improvement projects. Most health care improvement projects have a clinical provider focus rather than a health education focus. A coordinated campaign to get the message about smoking's impact on children to individual and families through community settings, mass media and physician offices would have an impact on reducing smoking during and following pregnancy if also combined with support, referrals and provision of smoking cessation programs.

The Change Package developed by NICHQ and detailed in the next section, does have "systems change" and "office change" actions related to smoking cessation. However, these are more exclusively clinically focused.

### 3. *Comprehensive Neonatal Outcomes Project*

Another model for a major improvement project is the National Initiative for Children's Healthcare Quality (NICHQ) "Neonatal Outcomes Improvement Project."<sup>62</sup> This project was initiated by the Centers for Medicare & Medicaid Services (CMS), and the New York State Department of Public Health, in partnership with NICHQ, and is designed to build the infrastructure of state partners to support quality improvement initiatives. Specifically this project will work to:

- 1) Improve newborn and maternal outcomes
- 2) Reduce health care costs, and
- 3) Establish capability within the state for ongoing quality improvement/transformation with Medicaid and the Department of Health in key leadership roles

The states of Ohio, New York, North Carolina and Arkansas are piloting the evidence based clinical interventions. NICHQ also works with single states in providing technical assistance.

CMS has selected nine interventions along with a Summary of Key Change Concepts<sup>63</sup> developed in 2007, based on available scientific evidence and expert consensus, that States can use to significantly reduce the burden of mortality and morbidity associated with premature birth.<sup>64</sup> The nine interventions are:

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<sup>62</sup> Neonatal Outcomes Improvement Project , accessed June 30, 2011,

[http://www.nichq.org/expert\\_services/sample\\_projects/neonatal\\_outcomes\\_improvement/](http://www.nichq.org/expert_services/sample_projects/neonatal_outcomes_improvement/)

<sup>63</sup> Summary of Key Change Concepts for NICHQ Neonatal Improvement Project, accessed June 30, 2011,

[http://www.nichq.org/expert\\_services/sample\\_projects/neonatal\\_outcomes\\_improvement/NeonatalCMSSummaryChangePkgforwebsite.pdf](http://www.nichq.org/expert_services/sample_projects/neonatal_outcomes_improvement/NeonatalCMSSummaryChangePkgforwebsite.pdf)

<sup>64</sup> Centers for Medicare & Medicaid Services (CMS), New York State Department of Public Health, NICHQ , Interventions,

[http://www.nichq.org/expert\\_services/sample\\_projects/neonatal\\_outcomes\\_improvement/nine\\_interventions.html](http://www.nichq.org/expert_services/sample_projects/neonatal_outcomes_improvement/nine_interventions.html)

- 1) Identification and treatment of chronic medical conditions (diabetes, hypertension, heart disease, depression, etc.) and high risk behaviors (smoking, substance abuse, domestic violence).
- 2) Early identification of mothers at high-risk for prematurity (including those in rural areas) and prenatal transfer of these expectant mothers to facilities with tertiary care NICUs.
- 3) Use of antenatal steroids in pregnant women at risk of preterm delivery.
- 4) For those premature babies born at facilities without tertiary care NICUs, optimal resuscitation and stabilization of the baby before transfer to the appropriate facility.
- 5) Prophylactic or early administration of the first dose of surfactant to premature infants at risk for Respiratory Distress Syndrome.
- 6) Nutrition Care Bundle in the NICU for infants at-risk for poor growth and bronchopulmonary dysplasia (BPD).
- 7) Proper Infection Control Practices in the NICU and hospital to prevent hospital-acquired infection.
- 8) Coordinating NICU discharge planning.
- 9) Optimizing follow-up care of high-risk infants.

NICHQ has developed a change package for each of these nine interventions. Depending on the scope of the intervention, the change package content includes the appropriate site of change: Systems, Office, Hospital, and Perinatal Center.

#### 4. *Healthy Development Collaborative*

VCHIP completed a 12 month quality improvement project in September 2005; “Healthy Development Collaborative,”<sup>65</sup> aimed at improving “the delivery of anticipatory guidance, parent education and other preventive and developmental care to young children.” As noted on VCHIP’s website:

VCHIP (2005):

*This project supported primary care practices in partnering with families to promote positive developmental outcomes for children less than five years of age in Vermont and North Carolina, through a partnership with primary care practices, community organizations and state government (including the health department and Medicaid). VCHIP assisted pediatric and family practices in implementing office systems to improve the delivery of anticipatory guidance, parent education and other preventive and developmental care to young children. Fifteen practices in Vermont*

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<sup>65</sup> Healthy Development Collaborative, accessed June 30, 2011. Available at: <https://www.med.uvm.edu/VCHIP/TB2+BL+Cl.asp?SiteAreaID=738>

*and North Carolina were selected to participate in the project. These practices received coaching on quality improvement methodology and measurement support to implement current recommendations for developmental care.*

A toolkit entitled, *A Practical Guide for Healthy Development*,<sup>66</sup> is a set of materials and tools designed and tested in the Healthy Development Learning Collaborative and available through the Commonwealth Fund. The modules of this toolkit include:

- **Module 1: Assessing Your Practice's Office Systems**—helps you assess the degree to which office systems are in place in your office.
- **Module 2: Developmental Screening and Surveillance**—incorporates structured screening tools into your office practice.
- **Module 3: Family Psychosocial Screening and Surveillance**—incorporates family psychosocial screening (e.g. domestic violence, maternal depression, substance abuse) into your office practices.
- **Module 4: Eliciting Parents' Concerns**—highlights methods to elicit parental concerns to improve communication between health care providers and parents.
- **Module 5: Anticipatory Guidance and Parental Education**—addresses meeting the informational needs of parents and families.
- **Module 6: Linking with Your Community**—focuses on the important step of linking your practice and patients to the resources available in your community.

This VCHIP Healthy Development Learning Collaborative worked with primary care practices, which is key to follow up screening for infants and young children, including those children born preterm. Linkages between the practice and community-based resources are also key. Inclusion of persons from those community resources on the learning collaborative teams would be a way to (1) integrate those linkages into the day to day practices of both the primary care providers and the community organizations, and (2) to create more seamless linkages between the various community resources.

## *5. Endorsement & Inclusion of Bright Futures as Best Practice*

Another extremely valuable resource in efforts to address the follow up care of late preterm infants is Bright Futures, developed through the American Academy of Pediatrics. Bright Futures is a set of principles, strategies, and tools that are theory-based, evidence-driven,

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<sup>66</sup> The Center for Children's Healthcare Improvement and the Vermont Child Health Improvement Program, "A Practical Guide for Healthy Development", The Commonwealth Fund, April 2006. Copyright © 2005 by The University of North Carolina at Chapel Hill for its Center for Children's Healthcare Improvement and by the Vermont Child Health Improvement Program at the University of Vermont, accessed June 30, 2011. Available at: <http://www.commonwealthfund.org/Publications/Fund-Manuals/2006/Apr/A-Practical-Guide-for-Healthy-Development.aspx>

and systems-oriented that can be used to improve the health and well-being of all children. It uses a developmentally based approach to address children’s health needs in the context of family and community.

As noted on the Bright Futures website<sup>67</sup>, the centerpiece is a comprehensive set of health supervision guidelines developed by multidisciplinary child health experts that provide a framework for well-child care from birth to age 21 years. “These guidelines are designed to present a single standard of care and a common language based on a model of health promotion and disease prevention.”

Bright Futures is based on the idea that successful child health promotion and care is rooted in a partnership of families, communities, health care providers, and public health officials. So in addition to developing programs and materials for families, Bright Futures materials are used by health professionals who care for children, including pediatricians, nurse practitioners, school nurses, public health workers, family physicians, nurses, physician assistants, dentists, child care workers, and others.

In addition to use in clinical practice, many states implement Bright Futures principles, guidelines and tools to strengthen the connections between state and local programs, pediatric primary care, families, and local communities.

## RECOMMENDATIONS AND NEXT STEPS

### *Recommendations*

We propose that PI CHIs first project would be the creation of a system of care for preterm infants that encompasses prevention through long-term follow up. The system would incorporate a broad array of services and supports that are organized into a coordinated network. It would integrate care planning and management across multiple levels, be culturally and linguistically competent, and build meaningful partnerships with families and youth at service delivery and policy levels.

### *How will we accomplish the recommendations?*

The goal of creating a system of care for late preterm infants and their families would be realized through implementation of a three year project that would involve *two* learning collaboratives that would address all or some of the nine CMS recommended interventions mentioned earlier.

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<sup>67</sup> American Academy of Pediatrics, Bright Futures, Prevention and health promotion for infants, children, adolescents, and their families, accessed June 30, 2011. Available at: <http://brightfutures.aap.org/>

The first learning collaborative would focus on prevention by utilizing the IDPH “Guidelines for Perinatal Services” and the NICHQ “Neonatal Outcomes Project” which also incorporates selected March of Dimes resources from the “39 Weeks” toolkit.

The second learning collaborative would focus on the follow up care of late preterm infants and would encompass the creation of a coordinated network between primary care practices, Early ACCESS, home visiting services, and community early childhood and child health organizations. Further, it would seek integrated services among the community organizations. Ongoing screening and monitoring of children and then seamless linkages to a continuum of community services are the desired outcomes. This “coordinated system” is key to a system of care for children with special needs.

The composition of the improvement teams for both learning collaboratives would vary from the NICHQ and the VCHIP collaboratives in that teams will include Early ACCESS, public health and human services providers from the community, in addition to providers from primary care practices or hospitals.

The underlying assumptions of this proposed project are that: (1) health care and community services providers desire to close the gap between the current situation and what is known to be best practices and (2) closing this gap requires systems change and the learning and adoption of tools for change. Thus, this improvement project would utilize the Breakthrough Series and the Model for Improvement as developed by the Institute for Health Care Improvement.

The proposed project would:

- 1) Build on existing efforts (e.g. Statewide Perinatal Care Program, NICHQ’s Neonatal Project, Iowa Project LAUNCH, March of Dimes, Early Childhood Iowa, Early ACCESS, Help Me Grow, IDE’s Positive Behavioral and Intervention Supports)
- 2) Build the infrastructure for a durable, collaborative mechanism to provide continuous child health improvement activities. PI CHI is envisioned to provide the framework of this infrastructure.
- 3) Utilize the “Breakthrough Series” process and the “Model for Improvement” to ensure that the aims of the many individuals working cooperatively are realized through small changes made continuously throughout the project.

*The measurable outcome goals for the project would include:*

1. Reduce the percent of births that are late preterm from 11.5 percent to 9 percent by the end of three years.
2. Reduce hospital readmissions in the first 90 days after initial discharge of late preterm infants by 15 percent by the end of the three year project period.

3. Increase the percent of infants and children born between 34-36 weeks gestation who receive early, continuous screening for developmental and social-emotional issues from a baseline of less than 10% (estimate) to 80% among the teams participating.

### *Costs for the Project*

A tentative budget for the proposed three year project has been developed and is *Attachment I* of this report.

The total \$900,000 budget over the three year period is based on a timeline that is very ambitious and involves the completion of two learning collaboratives, the second of which will require a great deal of research and planning. The first learning collaborative would utilize the Neonatal Outcomes change package and expert support and consultation of NICHQ. NICHQ has the experience with several states in implementing and changing and refining its Neonatal Outcomes Project. Iowa would benefit from the years of work and utilize the complete curriculum with some minor adaptations to fit the state's specific needs. Faculty experience from participation in earlier NICHQ learning collaboratives could be leveraged. Minimal time would be expended in upfront development of the change package, the learning session agendas, monthly measures, and action period consultations and conference calls.

The second learning collaborative would involve working closely with VCHIP to adapt that organization's Healthy Outcomes Learning Collaborative Project. Additional research, in the first year, will identify resources and work completed in other states around integrated community-based services, research of best practices, and bring together a diverse team of experts to create a "change package" for this Follow-up/Early Intervention Learning collaborative.

The budget does include funds in years one and two for consultants from NICHQ to assist in the development of the first learning collaborative; and in years two and three with VCHIP for work in development of the second learning collaborative. Iowa has the expertise to complete this project both in quality improvement and subject matter content. As the project progresses, more and more consultation would come from in-state experts in quality improvement and the Breakthrough Series.

Utilizing NICHQ's expertise for the first learning collaborative will provide the PI CHI staff and Advisory Committee with content, framework, as well as many of the tools and strategies staff would need to carry out a new project. Learning how to help teams understand "tests of change," develop effective/usable monthly measures, identify long term outcome measures, and provide monthly feedback to teams are just some of these tools.

The timeline and cost for the project includes hiring a Director for PI CHI, who also would serve as the project manager for this inaugural PI CHI Learning Collaborative project. In addition to the work involved in recruiting teams for the Neonatal Outcomes Project, the Director would immediately begin the work of creating a long-term plan and strategy for PI CHI involving all the key stakeholders.

### *Year One*

- The Project Director, working closely with the Advisory Committee, will develop a three year work plan (the Advisory Committee is composed of the membership of the statewide Interagency Coordinating Committee for Project LAUNCH)
- The Project Director and the Advisory Committee will identify Iowa leadership in performance improvement efforts and in child health to serve as project oversight group and/or faculty.
- The Project Director will begin work with the NICHQ advisors to begin Neonatal Outcomes Project: Recruit teams, establish faculty for first learning session, and establish dates/locations for the three learning sessions of the Neonatal Outcomes Project.
- The Project Coordinator will be hired to direct the administrative work of the project.
- Learning Session I for the Neonatal Outcomes Project will be held in the eighth month of the project – 10 teams from throughout the state will participate.

### *Year Two*

- The Neonatal Outcomes Project will complete its year of work with learning sessions and action periods. Final report and toolkit will be developed during the year.
- Working closely with VCHIP, the PI CHI Project Director, Advisory Committee and others will begin research and work on the change package for the Follow-Up/Early Intervention Learning Collaborative.
- PI CHI will work with a team of experts to expand on the change packages of VCHIP and other states to incorporate community public health, human services and early childhood organizations into the learning collaborative teams.
- An additional half time Project Coordinator for the Follow-up/Early Intervention Learning collaborative will be hired.
- Teams for the second learning collaborative will be recruited and dates and locations for learning sessions will be established.

### *Year Three*

- The Long Term Follow-up/Early Intervention Learning Collaborative will be held during the Third Year.

- Spread within the organizations/practices participating in the Neonatal Outcomes Project will be facilitated.
- The PI CHI staff will develop opportunities on a regional basis for new teams to participate in learning opportunities/collaboratives encompassing the Neonatal Outcomes Change Package.
- At the end of the Long Term Follow-up Early Intervention Collaborative, PI CHI staff will facilitate spread within the practices participating in the collaborative.
- PI CHI staff, improvement team participants, and collaborative faculty will make presentations at professional meetings, grand rounds, symposia, perinatal conferences and will write articles for both professional and consumer publications.
- The PI CHI staff and advisory committee will develop a comprehensive change package/tool kit based on the Long Term Follow-up/Early Intervention Learning Collaborative, create a plan and seek funding support to recruit new teams.
- An evaluation and report of the Follow-up/Early Intervention Learning Collaborative will be completed.

*The budget is based on the following assumptions:*

- Approximately 10 teams will be involved in each of the Learning Collaboratives. Each team will include 6-8 individuals.
- There would be three learning sessions per learning collaborative and the teams would participate for one year -- attending all learning sessions and doing monthly action period work between sessions.
- The learning sessions will be statewide, bringing all the teams to a central location. Costs could be reduced by having one of the three sessions per collaborative be a virtual session. Regional learning sessions would add to costs.
- Primary Care practices may need some financial support to allow providers time away from their practices.
- Hospitals involved may be asked to pay tuition (not included in the attached budget).
- All teams must include family representation, preferably at least two parents each from a different family.
- Any work in addition to that briefly outlined in the timeline above would require additional staff.

## **STAKEHOLDERS TO BE INCLUDED IN ANY RECOMMENDATION**

The proposed three year project will only be successful if there is active involvement of all the key stakeholders and commitment to realize real change. The following stakeholder groups should be included in any activities going forward:

- Area Education Agency (AEA)
- Centers for Disabilities and Development (CDD), University of Iowa
- Child and Family Policy Center (CFPC)
- Child Health Specialty Clinics (CHSC)
- Consumers and Families
- Early ACCESS
- Health Plans
- Home Healthcare
- Hospitals/NICU personnel (Physicians, Neonatologists, Nurses)
- Iowa Academy of Family Physicians (IAFP)
- Iowa Chapter of the American Academy of Pediatrics (IA AAP)
- Iowa Department of Education
- Iowa Department of Human Services (DHS)
- Iowa Department of Public Health (IDPH)
- Iowa Health System (IHS)
- Iowa Medicaid
- Legislators
- State Medical Home Advisory Council
- The University of Iowa

A Learning Collaborative is successful when it embodies what its name implies – people coming together to learn together and to learn from each other. A saying used often in these learning collaboratives is: “Share seamlessly, steal shamelessly”. Improvement involves constant experimentation and testing of small changes. It also involves making full use of the experience and knowledge gained by others – the building upon what has gone before. The following organizations are rich in experience and knowledge. The proposed project should build on the following.

1. The work and long history of successful early intervention services of **Early ACCESS**<sup>68</sup> which has improved outcomes for children with special health care needs for many years. Early ACCESS is a collaboration of the Iowa Departments of Education, Public Health and Human Services, and Child Health Specialty Clinics.
2. The **Statewide Perinatal Care Program**,<sup>69</sup> which provides professional training, development of standards/guidelines of care, consultation to regional and primary providers and evaluation of the quality of care delivered to reduce the mortality and

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<sup>68</sup> Early ACCESS, for children and families, accessed June 30, 2011. Available at: <http://www.earlyaccessiowa.org/>

<sup>69</sup> Iowa’s Statewide Perinatal Program, accessed June 30, 2011. Available at: [http://www.idph.state.ia.us/hpcdp/statewide\\_perinatal\\_care.asp](http://www.idph.state.ia.us/hpcdp/statewide_perinatal_care.asp)

morbidity of infants. Through a contract with the University of Iowa Hospitals and Clinics, these services are provided to all hospitals that perform deliveries. The IDPH “Guidelines for Perinatal Services, 8<sup>th</sup> Edition” provides a framework of best practices and a coordinated care system.

3. The **National Initiative for Children’s Healthcare Quality (NICHQ)**,<sup>70</sup> comprehensive “Neonatal Outcomes Improvement Project,” the work of VCHIP and its Healthy Development Learning Collaborative Project, Bright Futures, the March of Dimes’ tool kit, and other existing models.
4. **Iowa’s Family Health Plan 2011**,<sup>71</sup> which outlines the strategic plan for the next five years, is designed to “*improve the health and well-being of all Iowa women, children and their families.*” One of the priority goals speaks directly towards the problem identified in this proposal: “*Provide and promote family-centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community-based systems of service for children and their families.*” Among Plan’s strategies are to establish partnerships across public and private sectors, provide technical assistance in quality improvement, coordinate service delivery, and monitor development of Iowa’s Health Information Exchange and to advocate for inclusion of MCH public health data in that HIE.
5. The work of the **Child and Family Policy Center**,<sup>72</sup> located in Des Moines, Iowa, has developed many key policy statements, guidelines and frameworks that can guide the work of creating strong systems of care for children in Iowa. One publication, *The Health Child Story Book: Policy Opportunities to Improve Children’s Healthy Development*, is one example of the Center’s work that can help guide Iowa’s response to the problem of late term prematurity and other issues affecting the healthy development of children.
6. Iowa **Project LAUNCH**,<sup>73</sup> which seeks to develop the necessary infrastructure and system integration to ensure that Iowa children are thriving in safe, supportive environments and entering school ready to learn and able to succeed. The project targets children ages 0–8 years and their families in a seven-zip-code area in inner-city Des Moines (Polk County, Iowa), with a focus on the low-income and minority families who are traditionally underserved. Outreach, recruitment, and retention efforts specifically target African American, Hispanic, Asian, non-/limited English-Speaking immigrant/refugee, and low-income populations. The steering group for Project LAUNCH includes the key policy

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<sup>70</sup> Neonatal Outcomes Improvement Project, accessed June 30, 2011. Available at:

[http://www.nichq.org/expert\\_services/sample\\_projects/neonatal\\_outcomes\\_improvement/](http://www.nichq.org/expert_services/sample_projects/neonatal_outcomes_improvement/)

<sup>71</sup> Iowa’s Family Health Plan, accessed June 30, 2011. Available at:

[http://www.idph.state.ia.us/hpcdp/common/pdf/family\\_health/family\\_plan\\_2011.pdf](http://www.idph.state.ia.us/hpcdp/common/pdf/family_health/family_plan_2011.pdf)

<sup>72</sup> Child and Family Policy Center, accessed June 30, 2011. Available at: <http://www.cfpciowa.org/>

<sup>73</sup> Project LAUNCH, helping children soar, accessed June 30, 2011. Available at:

<http://projectlaunch.promoteprevent.org/>

partners who will serve as an Advisory Committee to the Partnership to Improve Child Health in Iowa (PICH).

7. The efforts underway in **communities throughout Iowa** that promote improvement in services, promote collaboration at the service level, and/or implement activities to identify and link to services children with special needs: First Five Initiative, Help Me Grow, Early Childhood Iowa-Community Empowerment and Iowa Department of Education implementation statewide of the “Positive Behavioral and Interventions Supports” (PBIS) developed by the Center on the Social and Emotional Foundations for Early Learning (CSEFEL).
8. **PI CHIs** work on this project, “Improving the System of Care for Iowa’s Late Preterm Infants” -- which in turn was built on the work of the Iowa chapter of American Academy of Pediatrics, CHSC which brought together stakeholders to envision a structure to create a system of care for late preterm infants.
9. The work of **March of Dimes** and **MedImmune Advocacy** in providing leadership in identifying and addressing the issue of late preterm births.
10. The **Iowa Health System** participation in the IHI’s “Improving Perinatal Care” learning collaborative and its quality improvement services.

## ACKNOWLEDGMENTS

- Michael Acarregui, MD, MBA, former Program Director, Neonatologist, Department of Pediatrics, University of Iowa, Director Iowa Statewide Perinatal Care Program
- Samir Alabsi, MD, Blank Children’s Hospital, Neonatology
- MaryEllen Baker, MedImmune Advocacy Development Manager
- Ken Cheyne, MD, FAAP, President Iowa Chapter of the American Academy of Pediatrics
- Abby Gossman, State Government Affairs, MedImmune Advocacy
- Threase Harms, MA, President/CEO, Advocacy Strategies
- Vicki Hunting, Project Director, Improvement Advisor, Partnership to Improve Child Health in Iowa (PICH), Late Preterm Infants project
- Jason R. Kessler, MD, FAAP, CHBE – Medical Director, Iowa Medicaid Enterprise
- Barbra Khal, MA, Director Public Health Division, Child Health Specialty Clinics
- Kathy Leggett, Director, Center for Advocacy and Outreach, Blank Children’s Hospital
- Rae Miller, RN, CHSC Early ACCESS State Liaison & Program Coordinator
- Ann Ricketts, MS, MPH, Consultant to Child Health Specialty Clinics
- LauraBelle Sherman-Proehl, Chief Bureau of Early Childhood Services, Iowa Department of Education
- Debra Waldron, MD, MPH, FAAP, Vice-President Iowa Chapter of the American Academy of Pediatrics
- Donna Wong-Gibbons, Executive Director, Iowa Chapter of the American Academy of Pediatrics

## APPENDIX A

### Outline of Stakeholder/Team Meetings

Meeting Date/Time	# of Attendees	Topics of Discussion/ Presenters
June 9-10, 2011 NIPN Annual Meeting, Seattle, WA Hunting/Khal attending for Iowa	20	<u>Topics:</u> <ul style="list-style-type: none"> <li>• IP Innovations, Improving Children’s Healthcare: Update on National Initiatives</li> <li>• Federal/National Opportunities through IPs</li> <li>• IPs: Working Across the Healthcare System to Improve Children’s Healthcare Quality</li> <li>• MOC and the IP</li> <li>• Measuring Quality of Care in Pediatrics: What are the Challenges</li> <li>• Use of QI TeamSpace for Quality Improvement document and measurement management</li> </ul>
May 26, 2011 10:00am-Noon Altoona Public Library	23	<u>Topics:</u> <ul style="list-style-type: none"> <li>• PI CHI Status Update</li> <li>• Help Me Grow Grant Overview</li> <li>• Late Preterm Infant Final Report Overview</li> <li>• Family Story</li> </ul>
March 20-22, 2011 Institute for Healthcare Improvement 12th Annual International Summit on Improving Patient Care In the Office Practice and the Community, Dallas, TX Waldron/Hunting	1000’s	<u>Topics:</u> <ul style="list-style-type: none"> <li>• Conference focused on “building new partnerships”</li> <li>• Recognizing Patients as Change Managers to Improve Primary Care Practice</li> <li>• Tools for Building your Medical Neighborhood</li> <li>• Academic Practices for the New Millennium: The Patient-Centered Medical Home Approach</li> <li>• Plain Talk about Physician Culture and Change</li> <li>• Using Teamwork to Provide Family-Centered Care</li> <li>• How Detailed Comparative Data can Stimulate Collaborative Improvement</li> <li>• Rapid Fire E: The Patient Experience</li> </ul>
Monthly TA Calls with NIPN (4 <sup>th</sup> Thursday each month) March 2010 - Current	20+ avg	Meeting with NIPN member states (Hunting, Khal, and Waldron). Various topics.
Monthly Team Meetings April 2010-May 2011	2-5	Various topics: Project progress, resource gathering, stakeholder meeting logistics, etc. Various attendees: Baker, Cheyne, Gossman, Harms, Hunting, Khal, Leggett, Ricketts, Waldron, Wong-Gibbons
December 8, 2010 Late Preterm Infant Stakeholder Group Meeting	39	<u>Topics:</u> <ul style="list-style-type: none"> <li>• Improving the Quality of Health for Iowa’s Late Preterm Infants</li> <li>• Funding</li> </ul>

		<ul style="list-style-type: none"> <li>• IP Overview</li> <li>• Overview: Issues Related to Late Preterm Infants</li> <li>• Family Story</li> <li>• Advocating for Late Preterm Infants</li> <li>• Group Discussion</li> <li>• EPSDT &amp; Bright Futures Discussion</li> <li>• Adolescent Medicine &amp; Bright Futures Discussion</li> </ul> <p><u>Presenters:</u>  Michael Acarregui, MD, MBA  Samir Alabsi, MD  Donna Wong-Gibbons, Family Story  Threase Harms, MA  Mary Ellen Baker  Abby Gossman  Judith Shaw, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director  Paula Duncan, MD, Youth Health Director, VCHIP; Clinical Professor of Adolescent Medicine, Department of Pediatrics, University of Vermont</p>
December 7, 2010 PI CHI Stakeholder Group Meeting	30	<p><u>Topics:</u></p> <ul style="list-style-type: none"> <li>• Creating Iowa’s Quality Improvement Partnership – Envisioning Future Possibilities</li> <li>• State of the State in Iowa for Late Preterm Infants</li> <li>• VCHIP IP Experience</li> <li>• Group Discussion</li> </ul> <p><u>Presenters:</u>  Debra Waldron, MD, MPH, FAAP  Ken Cheyne, MD, FAAP  Judith Shaw, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director  Paula Duncan, MD, Youth Health Director, VCHIP; Clinical Professor of Adolescent Medicine, Department of Pediatrics, University of Vermont</p>
September 9, 2010 10:00am-Noon Methodist West Hospital	28	<p><u>Topics:</u></p> <ul style="list-style-type: none"> <li>• Conveners/Stakeholders</li> <li>• Project Work to Date</li> <li>• Project Deliverables</li> <li>• Legislative Updates</li> <li>• Family Perspectives</li> <li>• US/Iowa Data Discussion</li> <li>• Survey</li> <li>• IP/Model for Improvement</li> <li>• National Premie Health Coalition</li> <li>• National AAP Efforts</li> </ul>
July 28-30, 2010 Annual Meeting, Burlington, VT	26 (15 States)	VCHIP Symposium: Partnerships for Care Quality, Integration & Coordination

Hunting attended for Iowa		
March 10, 2010 Convener Group Meeting	5	<u>Topics:</u> <ul style="list-style-type: none"> <li>• Iowa Chapter Role/primary focus</li> <li>• Needs assessment/Survey</li> <li>• Premature Infant registry</li> <li>• Questions/unknowns</li> <li>• Next Steps</li> </ul> Presenters: <ul style="list-style-type: none"> <li>• Jessica Phillips/March of Dimes</li> <li>• MaryEllen Baker/MedImmune Advocacy</li> </ul>
October 5, 2009 Stakeholder Group Meeting	19	Premature Infant Care Stakeholders Meeting Sen. Staci Appel Kathy Leggett (Blank/IHS)

## Minutes of Stakeholder Meetings

### Premature Infant Care Stakeholders Meeting

October 5, 2009

#### Addressing Premature Infant Birth and Care Issues

Throughout Iowa, there are a number of organizations focused on the prevention of premature births. There has not been a body to act as a forum for providers, professionals, advocacy groups, and parents to come together to discuss the specific issues, to share best practices, and discuss resources. The Iowa Chapter of the American Academy of Pediatrics and Blank Children's Hospital hosted this initial meeting to spark discussion, act as an ongoing resource for these groups, and develop solutions with the ultimate goal of reducing the rate of premature births and to improve the continuum of care for premature infants and their families.

#### Participants

Sen. Staci Appel  
Kathy Leggett (Blank/IHS)  
Dr. Ken Cheyne (Blank/IHS)  
Dr. Samir Alabsi (Blank/IHS)  
Dr. Debra Waldron (AAP)  
Donna Wong Gibbons (AAP)  
Dr. Michael Acarregui (UIHC)  
Dr. John Klein (UIHC)  
Dr. Jeffrey Segar (UIHC)  
Dr. Edward Bell (UIHC)  
Eric Nemmers (Iowa Medical Society)  
Brenda Moore (Child Health Specialty Clinics)  
Kim Piper (Iowa Dept. of Public Health)  
Jessica Philips (March of Dimes)  
Sally Nadolsky (Iowa Dept. of Human Services)  
Abby Gossman (MedImmune)  
MaryEllen Baker (MedImmune)  
Threase Harms (Advocacy Strategies)  
Chad Russell (Advocacy Strategies)

#### Review of Discussion:

**Blank Welcome-** Dr. Cheyne welcomed everyone to the meeting and outlined the importance of the work the group was doing.

**Dr. Waldron-** Dr. Waldron facilitated the discussion as the AAP representative. She discussed her strong interest in advocating for children and making sure that all kids receive the care they need. She outlined Dr. Ed Bell's work on the policy statement regarding Hospital Discharge of the High-Risk Neonate.

**March of Dimes Overview-** Jessica Philips from MOD discussed November prematurity month activities and the report card. Last year Iowa scored a D.

Areas of focus are on late preterm birth and prevention of elective c-sections. Hospitals participating noted they have instituted policies against elective c-sections prior to 39 weeks. Nov. 17<sup>th</sup> will be the day of media activities for MOD Prematurity Awareness. IA MOD is releasing an updated report card at this event.

**Perinatal Program-** Overview given of perinatal program. A mix of federal and state funds used. Visit every program in the state that delivers babies. Meets with over 400 physicians and nurses and focuses on education and medical home issues.

**Senator Appel Legislative Update-** Discussed her bill SF296/HF548 (Mascher) that would improve education and awareness to providers and parents regarding premature infant health issues. She asked the group for feedback on what should be done legislatively to help this population. Given the budget deficit ideas without a large fiscal impact would have the most chance of passage.

#### **Meeting Discussion Topics:**

**Follow-up care for preemies-** No one well coordinated system for follow-up care like perinatal program. 0-3 Dept. of Education early access program is available, but health piece is not as strongly represented for follow-up. Early access works really well in some communities but is “variable” throughout the state. Desire for electronic format follow-up system with web-based application was mentioned as an ideal. Hospitals shared their follow-up procedures which varied as well. In some areas once discharge from NICU occurs there is no follow-up connection back to NICU staff. Discussion of best practices occurred. Discussion around lack of understanding and education on the need of the late preterm population which accounts for 70% of all preemies. Many of these babies born outside of major centers and do not receive specialized care. Role of home care services and home visits discussed. Need to include these partners in the discussion. Education needs to start on day 1 in the NICU.

**Medicaid Update-** Plan to support needs of population in Medicaid population through maternal health centers. Telephone care coordination services for pregnant women on Medicaid. Focus on pregnancy and obtaining best birth outcome. A few years ago CMS had an RFA to help with preterm care and follow-up programs. Iowa missed application in first round was ready for second round, but opportunity disappeared. Current birth defects registry discussed and follow-up on blood spots and now hearing screening.

#### **Potential Resources Discussed:**

- **Website with Premie Infant Health Information and Follow-up Resources.** It was mentioned Iowa is behind other states in this area.

- **Electronic registry/follow-up system with web-based application.** CID and fetal deaths tracked and maintained by the University of Iowa (Public Health) but they do not collect specific data on prematurity. It was recommended that the group review the VT Oxford database as a template.
- **Medicaid coverage of progesterone to prevent preterm labor.**
- **Follow New York model of follow-up centers where all specialists are available at central sites throughout the state and babies are seen every 3-6 months to monitor development. (Mentioned payment is an issue with this model.)**
- **More education on needs of late preterm infants and the special issues they still face.** (Dr. Acarregui mentioned the incidence for early intervention needs in the late preterm infant is the same as those under 1500 grams if you remove babies with major co-morbidities.) Parent involvement is a key component.

### **Areas Highlighted in Facilitated Discussion Notes:**

#### **Prevention**

- Social Determinants
- Coordinated Efforts
- Late Pre-term births (34-36 weeks, 37-39 weeks)

#### **Perinatal Team**

- Statewide system targeting hospital providers
- Funded through state and federal resources

#### **Community Preparedness**

##### *Partners:*

- American Association of Pediatrics
- Iowa Academy of Family Physicians
- Iowa Medical Society
- Iowa Department of Public Health
- Iowa Department of Human Services → Iowa Medicaid Enterprise benefits (incl. progesterone prescriptions)
- Child Health Specialty Clinics

##### *NICU Care Coordination*

- Physicians
- Advanced Registered Nurse Practitioners
- Parent/Family groups/advocates
- Visiting Nurse Services

#### **NICU – High Risk Follow-up**

##### *Blank Children's Hospital:*

Blank provides in hospital parental education and services via a multi-disciplinary team. They provide coordination of care and specialty services up to discharge and provides

post discharge service recommendation. (Need to check on specific services until/post discharge)

*UIHC:*

UIHC provides substantial NICU follow-up and collects substantial data as well. (Need to check on data such as below weight percentages, developmental data, etc.)

## **Solutions**

*Regionally Based Clinics to provide comprehensive services including:*

- Neonatologists
- Pediatric development
- Speech therapy
- Ophthalmology
- Social Work services
- Parental Support and education

## **Postnatal High Risk Infant Follow-up**

Tertiary care programs in the state. There is a follow-up role for CHSC to partner with regional hospitals for follow-up care.

- UIHC- ARNPs and MDs
- Blank- ARNPs
- Mercy- ARNPs and MDs
- Cedar Rapids- ARNPs and MDs
- Waterloo?
- Council Bluffs (through Omaha)

## **Resources**

1. Web-based resources: there is no clear web-based tool that offers easy access to comprehensive information.
2. Early Access: (these vary depending on facility) The 10 AEA regions provide some services, but there are difficulties in areas such as, lack of standardization, cross covering of areas, and trained health personnel. Relationships are not as strong between AEA personnel and doctors.
3. There is no comprehensive database/registry although the College of Public Health does compile certain statistics
4. Education of Primary Care Practice on near preterm and preterm births.

## **Recommendations**

*Focus:*

1. Audience
2. Target Populations: late preterm infants

The following goals have been outlined:

- Dept of Health recommended a needs assessment be developed and implemented. March of Dimes mentioned they did a needs assessment and hence their focus on late preterm issues.
- Priorities need to be clearly defined.
- Develop effective partnerships, especially with parents

## Improving the Quality of Health for Iowa's Late Preterm Infants Partnership to Improve Child Health in Iowa (PI CHI)

September 9, 2010, 10:00 a.m. - 12:00 p.m.

Twenty-eight attendees representing diverse stakeholders participated in discussions on Improvement Partnerships (IPs), National Improvement Partnership Network (NIPN), issues related to late preterm infants, three family's stories, advocating and legislation, and next steps.

### *Meeting Objectives:*

1. To identify the gaps in advocacy and family support and what happens to the **late preterm infants** (34-36 weeks gestation) when they go home. What are the social and economic factors that contribute to late preterm births?
2. Look at preliminary aggregate data from survey monkey, and plan for additional collection.
3. Review timeline to date.

### *Discussion:*

#### *Who are the Conveners:*

- American Academy of Pediatrics, Iowa Chapter
- Blank Children's Hospital/Iowa Health System
- Child Health Specialty Clinics/University of Iowa
- March of Dimes
- National Premie Health Coalition

#### *Project Work to Date:*

- October 5, 2009 Premature Infants care initial stakeholder meeting
  - Prevention
  - Community Preparedness
  - Potential Solutions
  - Next Steps
- December 2009, Early ACCESS gets involved
- February/March 2010, work with National Improvement Partnership Network (NIPN) began
- April 2010, American Recovery & Reinvestment Act funds available

#### *Project Deliverables:*

By June 30, 2011:

- Establish pediatric health improvement partnership network. Membership will include diverse agency representation
- Initiate planning for a system of care that incorporates science of improvement principles.

- Receive technical assistance from the National Improvement Partnership Network (NIPN).
- Submit a final progress report and proposal for a system of care for preterm infants to Department of Education/Early ACCESS

### *Legislative Updates*

Abby Gossman & Senator Staci Appel shared the bill relating to resources for families with premature infants (SF296/HF548 (Mascher)). This would improve education and awareness to providers and parents regarding premature infant health issues. Senator Appel noted the importance of coordination of services after discharge. Solution should include prevention strategies. Frank Stork, Wellmark-Vice President & Senior Counsel, Regulatory & Government Affairs should be included in this group as well as Jack Hatch and Chris Bell. Insurance (Medicaid) has strict cutoff of 1300 grams, what happens to the rest?

### *Family Perspectives*

Three families shared their stories of their preterm infant experiences:

- A family with twins born 25 weeks gestation
- A family with a child born at 30 weeks gestation
- A family with a child born 23 weeks gestation

Additional group discussion: There are a lack of resources for care coordination and support for families (i.e. transportation). Could tele-health be used to support this population? Respite support is important for families. Multidisciplinary approach to care is needed. Consider option of having all specialized appointments scheduled same day, same location so families can organize/plan/ consolidate their appointments to minimize time away from work. Waiver service availability is crucial for some cases. Consider creation of “preemie waiver”. Families need informal supports as well. There is lack of clear understanding of Early ACCESS definition or eligibility requirements for prematurity. There are implications when preemies start kindergarten, does educational system understand that an adjustment is needed? Need to combat the attitude of “the birth was on a little bit early so it’s not a problem”, many appear to be just smaller, not necessarily sick.

### *U.S. & State of Iowa Data Discussions*

#### March of Dimes (MOD) Overview

Jessica Phillips reviewed data gathered for US & Iowa specific:

- Perinatal Data Snapshots for Iowa available at [www.marchofdimes.com/peristats](http://www.marchofdimes.com/peristats)
- MOD 2009 Premature Birth Report Card – Iowa gets a “D”: Preterm birthrate greater than or equal to 9.4%, but less than 11.3%.
  - Iowa’s Preterm Birth Rate is 11.6%
  - US Preterm Birth Rate is 12.7% (also a “D”)

#### *PI CHI informal Poll results*

- Survey sent to over 75 individuals including Primary Care Physicians, Neonatologists, ARNPs, RNs, State/County/Municipal Agency Reps, Parent/Consumers, and Family Advocacy Group Reps.

- Survey open August 23 – August 29, 2010
- 19 questions
- 18 Respondents
- Summary of results:
  - Resources: Awareness of home visiting resources is high, but not a clear understanding of eligibility
  - Protocols: Standard protocols specific to needs of late preterm infants is not in place and respondents felt that it would improve the care by having them
  - Health Info: Families are sometimes getting the information they need from physicians, other health care providers, agencies not consistently providing information to families.
  - Coordination/Communication: Families do need extra help in arranging/coordinating their late preterm infants care among different health care providers/service agencies.
  - Coordination/Communication: Physicians and healthcare providers need to communicate with early intervention programs, child care providers and other service agencies because they are not doing it now and respondents are dissatisfied with communication today.
  - Care and Risks: Physicians and Parents/family members are the most influential in affecting families decisions on the care of late preterm infants. Awareness is high that late preterm infants may be at risk for developmental delays and increased risk for respiratory illness.
  - Education: Top 3 ways you stay up-to-date with current best practices regarding the care of late preterm infants; Face to face, professional meetings, self-directed study, on-line
  - Education: Top 3 preferred methods of learning on this topic: On-line, self-directed study, professional meetings

### *Improvement Partnerships/Model for Improvement*

**National Improvement Partnership Network (NIPN)** is a network of over 15 states that have developed *Improvement Partnerships* to advance quality and transform healthcare for children and their families. An *Improvement Partnership* is a durable collaborative of public and private partners in a state or region that use the science of quality improvement and a systems approach to change healthcare infrastructure and practice. An Improvement Partnership (IP) is a durable state or regional collaboration of public and private partners that uses measurement-based efforts and a systems approach to improve child health outcomes and the quality of their healthcare.

In Iowa the **Partnership to Improve Child Health in Iowa (PI CHI)** is bringing together key players from a diverse group statewide who can effect desired change in improving the experience of care, the health of populations and reduction of the costs of health care.

**Model for Improvement** has three questions which provide a framework for trial and learning.

1. What are we trying to accomplish?

- a. Write it down to assure understanding; What, For Whom, How Much, By When?
2. How will we know change is an improvement?
  - a. Establish measures, gather data, see what it tells us, use PDSA cycles
3. What change can we make that will result in an improvement?
  - a. Select change to be implemented, implement and spread

### ***National Preemie Health Coalition***

MaryEllen Baker gave an overview of the coalition:

1. Created and supported by members from NANN, MOD and AAP, Inaugural meeting Summer 2010
2. Representatives from 12 premature infant health networks attended
  - a. Goal of the meeting: Provide an opportunity for all the networks to share best practices and ideas; IL – Legislation enacted tracking hospitalization and provide educational resources for parents upon discharge from the NICU. MN – Creating a web site for parents and health care providers. MD – Creating a discharge checklist
3. Work groups were created to address the following areas that are impacting the lives of premature infants; Continuity of Care, Late-preterm, Access to Care, Resources
4. Board of directors (being formed). Quarterly conference calls, annual meeting in DC
5. Resources:
  - a. [preemievoices.com](http://preemievoices.com) : A new umbrella website containing national events, news, legislative issues and updates for the prematurity community.
  - b. [SpecialDeliveryHandleWithCare.com](http://SpecialDeliveryHandleWithCare.com): 16 customizable one-pagers (RSV, Late Pre-Terms, Glossary of Terms, Medical Care Costs, etc.). Over 150,000 disseminated to date. All Neonatology Nursing groups utilizing as a “member benefit.”
  - c. **HCP Advocacy Toolkit** – “Voices For the Voiceless”: Provides guidance and resources to help HCPs become an advocate for premature infants *beyond the bedside*.

### ***National AAP Efforts***

Dr. Waldron talked about work at the National American Academy of Pediatrics:

- Perinatal Pediatrics is the home organization for specialists in Neonatal-Perinatal Medicine and also members working in related disciplines. The priority is to ensure optimal health and well-being of babies and mothers through core activities; advocacy, education, outreach and support of clinicians and researchers. Mission is to improve the health of the pregnant mother, the unborn fetus and the newly-born child through the sponsorship of programs which encourage the professional growth of the neonatal-perinatal providers, continuously improve clinical care delivery, support continuing and postgraduate education, foster basic, clinical and outcomes research and seek to attain federal and local funding for programs directed towards maternal/child health.  
<http://www.aap.org/sections/perinatal/index.html>

- Committee on Fetus and Newborn studies issues and current advances in fetal and neonatal care; makes recommendations regarding neonatal practice; collaborates with the American College of Obstetricians and Gynecologists (ACOG) to consider peri-natal issues on which the practices of obstetrics and pediatrics merge; and works cooperatively with ACOG on new editions of [Guidelines for Perinatal Care](#); an authoritative guidance on high-quality care of pregnant women, their fetuses and their neonates.
- AAP Clinical Report: “Late-Preterm” Infants: A Population at Risk. Abstract: Late-preterm infants, defined by birth at 34 0/7 through 36 6/7 weeks’ gestation, are less physiologically and metabolically mature than term infants. Thus, they are at higher risk of morbidity and mortality than term infants. The purpose of this report is to define “late preterm,” recommend a change in terminology from “near term” to “late preterm,” present the characteristics of late-preterm infants that predispose them to a higher risk of morbidity and mortality than term infants, and propose guidelines for the evaluation and management of these infants after birth. William A. Engle, MD, Kay M. Tomashek, MD, Carol Wallman, MSN and the Committee on Fetus and Newborn (<http://aappolicy.aappublications.org/cgi/reprint/pediatrics;120/6/1390.pdf>). A statement of reaffirmation for this policy was published on August 1, 2010.

Lowering Developmental Screening Thresholds and Raising Quality Improvement for Preterm Children. Areas identified for improvement are; parental concerns elicited in standardized manner, developmental risk & protective factors are tracked, screening with standardized tool (ASQ/ASQ-SE), referral process standardized, reliable (parents, clinicians, developmental-behavioral agencies (EI/ECSE).

### *Closing/Next Steps*

- Work underway to bring **Judith Shaw**, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director and **Paula Duncan**, MD, Youth Health Director, VCHIP; Clinical Professor of Adolescent Medicine, Department of Pediatrics, University of Vermont to Iowa to talk to us about Improvement Partnerships, successes in Vermont, and benefits of National Improvement Partnership Network (NIPN) membership.
- Survey will remain open through early December.
- Summary notes of this meeting will be available within 2 weeks.

## **Partnership to Improve Child Health in Iowa (PI CHI) Creating Iowa's Quality Improvement Partnership – Envisioning Future Possibilities**

December 7, 2010, 6:30 p.m. – 8:30 p.m.

Thirty attendees participated in discussions on the benefits of Improvement Partnerships, current status of overall health in Iowa, Vermont Child Health Improvement Project (VCHIP), National Improvement Partnership Network (NIPN), Bright Futures, and Early Periodic Screening Diagnosis and Treatment (EPSDT).

Welcome and Introductions were made by Ken Cheyne, MD, FAAP, President Iowa Chapter of the American Academy of Pediatrics and Debra Waldron, MD, MPH, FAAP, Vice President Iowa Chapter of the American Academy of Pediatrics. Presentations were made by Judith Shaw, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director and Paula Duncan, MD, Youth Health Director, VCHIP; Clinical Professor of Adolescent Medicine, Department of Pediatrics, University of Vermont.

### ***Monitoring Overall Health in Iowa's Children:***

Dr. Waldron talked about the importance of monitoring overall health in children. While Iowa is doing pretty well compared to the nation in Child Health Indicators, numbers are still unacceptably low in many areas; e.g. reading to young children, smoking in household, neighborhood amenities, etc. Dr. Waldron also shared information on the AAPs Vision of Pediatrics (VOP) 2020 Task Force in 2008 that was charged with identifying forces that affect child and adolescent health and their implications for the field of pediatrics. It determined that shifts in demographics, socioeconomics, health status, health care delivery, and scientific advances mandate creative responses to these current trends. Eight megatrends were identified as foci for the profession to address over the coming decade. The VOP 2020 Task Force concluded that *our profession needs to adopt an ongoing process to prepare for and lead change*. The task force proposed that pediatric clinicians, practices, organizations, and interest groups embark on a continual process of preparing, envisioning, engaging, and reshaping (PEER) change. This PEER cycle involves (1) preparing our capacity to actively participate in change efforts, (2) envisioning possible futures and potential strategies through ongoing conversations, (3) engaging change strategies to lead any prioritized changes, and (4) reshaping our futures on the basis of results of any change strategies and novel trends in the field. By illustrating this process as a cycle of inquiry and action, we deliberately capture the continuous aspects of successful change processes that attempt to peer into a multiplicity of futures to anticipate and lead change. Dr. Waldron then introduced the speakers from Vermont, who presented a vibrant, effective structure to enable us to realize the kinds of changes we need for improving child health in Iowa.

### ***State Improvement Partnerships:***

Dr. Shaw and Dr. Duncan presented information on Child Health Quality, Partnership Model & the Vermont Experience, NIPN Development, Bright Futures, and VCHIP Projects. VCHIP project was the first in the country of its kind and many other states have now instituted these Improvement Partnerships (IP). An Improvement Partnership (IP) is a *“durable, regional*

*collaboration of public and private partners that uses measurement-based efforts and a systems approach to improve the quality of children's health care.*" Successful IPs recognize and embrace local expertise; i.e. *"all improvement is local"*. Innovation and success in states is often not connected nor broadly disseminated, limiting the impact on child health outcomes. We need diverse organizations (partners; practitioners, researchers, policymakers) to come together and work jointly to be successful. IPs develop/test tools, measures and strategies; serve as a resource for improvement assistance; translate knowledge through engagement of national and local experts; disseminate findings and spread successful approaches and inform policy; and serve as convener or, "honest broker". We need to bring people together around a common goal, be the answer to someone's 'problem', and listen to the "I wish I could" statements to see where there is work to be done. We need to gather data, find out what the priorities are in the state, what are the key issues, where is the passion, who is working on what (Medicaid, MCH, DE, insurers, etc.) and bring them together to discuss how an IP can help and determine projects. We have experts/researchers in Iowa and we need to figure out how to involve them. We also need to explore grant opportunities for sustainability.

#### ***PI CHI Next Steps:***

- Determine institutional home PI CHI
- Organize an Advisory Group/Think Tank for the state to keep stakeholders talking regularly on topics related to improving the quality child health in Iowa, consider groups already organized around child health
- Setup meeting to debrief, communicate to stakeholder group

## **Partnership to Improve Child Health in Iowa (PI CHI) Improving the Quality of Health for Iowa's Late Preterm Infants**

December 8, 2010, 10:00 a.m. – 12:00 p.m.

Thirty-nine attendees representing diverse stakeholders participated in discussions on Improvement Partnerships (IPs), National Improvement Partnership Network (NIPN), issues related to late preterm infants, one family's story, advocating and legislation, and next steps.

Welcome and introductions were made by Debra Waldron, MD, MPH, FAAP, Vice President Iowa Chapter of the American Academy of Pediatrics, Director and Chief Medical Officer, Child Health Specialty Clinics. LauraBelle Sherman-Proehl, Iowa Department of Education thanked everyone for participating in this important work and reiterated that we need to spend more time on prevention if we want to improve the outcomes for late preterm infants. Presentations and discussions were lead by Judith Shaw, Ed.D., M.P.H., R.N., Vermont Child Health Improvement Program (VCHIP) Executive Director and Paula Duncan, MD, Youth Health Director, VCHIP; Clinical Professor of Adolescent Medicine, Department of Pediatrics, University of Vermont.

### ***State Improvement Partnership Overview***

This overview included information on the IP model & the VCHIP experience, and National Improvement Partnership Network (NIPN) development. Successful IPs embrace local expertise and includes diverse organizations (partners; practitioners, researchers, policymakers, families) to come together and join in to be successful. For the Late Preterm Infant project we need to bring people together around improving the quality of health for these babies and their families and ensure they get the ongoing care when needed.

**Overview of Issues related to Late Preterm Infants** was led by Dr. Mike Acarregui, with Dr. Samir Alabsi. Late preterm infants account for 70-75% of all preterm infants in Iowa (about is 3200 kids/year). They are mature in appearance, likely to be relatively stable at delivery, and often cared for in well baby nurseries so they don't get the same care that NICU babies do. However, they consume a significant amount of healthcare resources, have an increased mortality/morbidity rate and can have long term neurodevelopmental consequences. They can have issues with respiratory, feeding and nutrition, instability of temperature, hypoglycemia, sepsis and have a higher readmission rate (1-3 times higher than term infants). There are several studies from Sweden and the Netherlands with data on long-term outcomes. A good number of these children will have some issues. It is a hard group to identify as they are not on the 'radar' after hospital discharge. There are a limited number of 'slots' available in Early ACCESS due to system limitations. What is enrollment criteria/filter by which we determine if they are followed or not, how to follow them? What kinds of resources do we send home with families? How do we involve home healthcare to follow these kids? Do we need to do more to educate parents on importance of sleep/feeding patterns once they go home?

General guidelines for managing late preterm infants should be considered; remember the risks, manage with high degree of suspicion and prompt intervention for problems, and avoid

early discharge, educate the family about what to expect before, during, and after delivery (the fewer surprises the better and families who understand the issues are usually more supportive and involved with care), advocate and educate regarding the risks of the late preterm infants.

**Family Story** was shared by Donna about their twin boys born at 34 4/7 weeks gestation. They were 4lbs 12 oz and 5lbs 5 oz and spent 22 days in the NICU with incubators, bili lights, NG tubes, IVs and oxygen. Today they are happy, healthy 9 month old boys!

**Advocating and Legislation for Late Preterm Infants** Threase Harms, Mary Ellen Baker, Jenny Schulte and Abby Grossman shared information on preemie hospital discharge and follow-up care legislation passed in 2010 by Illinois. **Voices for the Voiceless: A Premature Infant Advocacy Training Guide** is a resource for Advocating for Premature Infants and their Families. Discussions covered what we should be doing in Iowa given; new governor, house leadership, and including several that know and understands healthcare. The IP concept is an opportunity to bring forward new information and utilize our advocacy expertise to educate new state leaders on child health priorities in Iowa.

### *Other Discussion Items*

Parents need a good plan of what to expect upon hospital discharge. Target newborn nursery staff, what kind of info is given to families upon discharge from the hospital? Late preterm infants don't seem to be on the 'radar' of general primary care physicians. Is there a way to link to 'school readiness' to prevent problems now, reduce costs down the road? Find the "Bright Spots"; emphasize what is working now and use it as a motivator.

We need to;

- Determine who is not at the table and invite them.
- Share what other IPs have done, share their proven results and let them know this is not something we dreamt up on our own but are leveraging successful work done by others.
- Look at the priorities in Iowa for stakeholders (AAP, FAAP, Medicaid, DE, academia, those who study evidence based information) and have them share what they have learned and build on that. Data is important.
- Look for non-traditional partners in this work as well (those interested in women's health, preventive healthcare, etc.).
- Form or tap into an existing stakeholder groups for an Advisory Group to meet regularly to discuss projects, common research, and priorities in the state.
- Educate: Parents don't know what they don't know about their late preterm infants. These infants 'look' like term babies and are treated as such by some medical professionals so parents take their cues from them.
- Look at Minnesota survey to birthing hospitals. Is it relevant to Iowa, do we need to do a survey, maybe we already have that information in some way?
- Investigate the MedImmune repository for information on standards of care.
- Create Charter and write down our delivery of change method. Why are we working on this now? Reframe the issue in a way the group we are talking to (legislators, educators, medical professionals, families, advocacy organizations, etc.) can relate to it.

- Stakeholders need to consider what is their role and unique contribution to improving the quality of health for late preterm infants. How do you contribute to the topic and what can you share?

*Next Steps:*

1. Locate Iowa specific data; what do we have that can serve as existing benchmarks.
2. Document what statewide organizations are already doing and resources available.
3. Gather data to begin report on recommendations for care of late preterm infants in Iowa; needs assessment/current situation, work plan, estimated cost.
4. Communicate to stakeholder group.

## **Partnership to Improve Child Health in Iowa (PI CHI)**

May 26, 2011, 10:00 a.m. - 12:00 p.m.

Twenty-three attendees representing diverse stakeholders participated in discussions on; current activities of PI CHI, Help Me Grow, highlights of the Late Preterm Infant report to Department of Education, American Recovery and Reinvestment Act (ARRA) Part C/IDEA/Early ACCESS (EA).

Welcome and introductions were made by Debra Waldron, MD, MPH, FAAP, Vice President Iowa Chapter of the American Academy of Pediatrics, Director and Chief Medical Officer, Child Health Specialty Clinics (CHSC).

### ***PI CHI Update***

Funds from DE/EA/ARRA allowed PI CHI to lay groundwork for an Improvement Partnership (IP) in Iowa, conduct surveys and gather information on the current environment regarding late preterm infants, bring in advisors from Vermont Child Health Improvement Program (VCHIP) for face-to-face meeting in December 2010, and make recommendations for care of this population in Iowa. Vicki Hunting reviewed PI CHI Vision/Mission and notified the group that the PI CHI Logo is under development and that we are now indicated on the National Improvement Partnership Network (NIPN) as a member state. We participate in monthly calls with NIPN network to discuss ongoing projects (and challenges) in other IP states – trusted and experienced resources. Currently PI CHI's web presence is a page on the Iowa Chapter of the American Academy of Pediatrics (IA-AAP) website. PI CHI's institutional home is under IA-AAP and University of Iowa, Department of Pediatrics. IA-AAP is supportive of PI CHI efforts (financially and mobilization of membership). Possible opportunities for PI CHI to partner with other groups are surfacing; partnering with IA Chapter of Family Practitioners (meetings upcoming); advantage of being able to get FPs on board with projects as they roll out Partnering with Nurse Practitioner Association (mostly PNP's); Ken Cheyne will look into getting PNP's involved as well. Involvement of residency programs; importance of getting practicing providers involved with IP efforts and practices so that residents recognize that it isn't just part of residency. Working with IME to look at QI on a variety of child health measures may also be a possibility. Work continues with Iowa Department of Public Health (IDPH) Statewide Perinatal Project to improve birth outcomes and reduce neonatal mortality. March of Dimes is releasing a <39 weeks QI project that organizations/practices can order; available 4<sup>th</sup> quarter 2011, including a free download.

## *PI CHI Vision/Mission*

### *Vision*

The **Partnership to Improve Child Health (PI CHI) in Iowa** will strengthen the system of care so that all Iowa's children and adolescents will receive the highest quality of health care possible. This will enable improved outcomes to help children and adolescents: develop and realize their potential; satisfy their needs; and help them to work successfully together with the professionals who interact with their families.

### *Mission*

In order to enhance our partnership's ability to improve the quality of health for Iowa's children, adolescents, and their families -

#### *PI CHI will:*

- Foster partnerships with children and their families that guide quality improvement in health care.
- Maintain a community focus and encourage collaboration throughout the state.
- Ensure seamless, effective, efficient, family centered linkages and transitions to medical homes/neighborhoods and community services.
- Utilize demonstrated Quality Improvement (QI) methodologies to promote change across the system of care.
- Incorporate evidence-based medicine; engage local and national experts; orchestrate learning opportunities; provide tools for screening and assessment; link community resources; help to measure progress; share findings with stakeholders and policy makers.
- Disseminate information through publications, and presentations in order to share knowledge on successful quality improvement initiatives.
- Engage all health care professionals, families, community leaders and policy makers in quality improvement so that the partnership raises the standard of child health care.

PI CHI is a public-private partnership that works collaboratively to support clinicians in their efforts to improve children's health care by providing the tested tools and techniques of *quality improvement*.

### *Help Me Grow*

Barb Khal and Sonni Vierling shared information on the Help Me Grow (HMG) grant.

Background: started in CT and now in 12 other states; focused on early and effective

developmental surveillance, screening and coordination of services for at-risk kids. IA-AAP was lead applicant as neutral entity for HMG grant (\$40k over 2 years; includes \$20k/year match); Alabama and Massachusetts are other new states with Iowa who were approved for funding in 2011. This grant will help to continue to build on the good things that have already happened in Iowa related to assuring kids at-risk are identified early. PI CHI can be involved in advisory capacity throughout the project. Sonni emphasized building on existing successes and looking at adapting HMG model to meet Iowa's needs (including geographic differences).

Communication centers vs. call-in centers are used to emphasize using social media, texting, etc. to reach younger parents. Iowa does not have a statewide foundation like CT does, but there are many community-based foundations or health-care based foundations in our communities. HMG will build on local expertise of 1<sup>st</sup> Five care coordinators. Important component is to help make sure that the services and providers that are linked to through the HMG network are providing evidence-based, high quality care. Benefit to having IA-AAP involved to make sure that medical concerns are not overlooked even when developmental and behavioral are addressed. Health may not always play as strong a role as it can/should. ASQs mailed out to families and having them scored in a central location could help Early ACCESS (and others) have information and data about familial concerns, particularly before children are seen either for home visits or in a clinical setting. Workforce issues are a huge issue in rural Iowa and represent unique challenges within Iowa.

HMG Four Components:

1. Centralized telephone access point for connection to services and care coordination.
2. Community outreach to promote the use of *HELP ME GROW* and to provide networking opportunities
3. Physician outreach to support early detection and early intervention
4. Data collection on developmental programs and services

### ***Late Preterm Infant Report Status***

Vicki and Debra reported that the Late Preterm Infant report is currently in internal review and is expected by the end of June 2011. Once submitted, it will be reviewed by Iowa Department of Education (Early Childhood Bureau) and the Iowa Council on Early ACCESS, requested edits will be made prior release. Vicki and Debra outlined areas to be covered in the report; current situation, issues related to late preterm infants, contributing factors, Iowa survey results, minimization of risks/interventions, care of late preterm infants, system of care, improvement through prevention, methodology/Science of Improvement. Debra highlighted issues related to epigenetics; stress related to being in a NICU (or stress of re-hospitalization) may also affect developmental milestones. Additional discussion about considering issues of cost/coverage that may affect elective C-sections among some parents. In the case of twins, there is a chance for increased cost if two separate deliveries; one twin delivered naturally and one delivered by C-section. Tobacco prevention activities should be included in any solution. Environmental Toxins

can also contribute to issues associated with late preterm infants. Additional report by CHSC from ARRA funds will address tobacco smoke. Governor Branstad wants Iowa to be the healthiest state in the U.S. – Make sure we take our message to the Governor re the importance of early child healthy development to support this initiative. Public/private partnerships are needed to ensure work continues. Help legislators interpret the printed report and the information given them; outline what steps to be taken by them.

### *Closing & Next Steps*

Report finalized and forwarded to DE for review/approval. Once released for publication, it can be distributed.