REPORT OF THE
JOINT COMMISSION ON HEALTH CARE

Follow-Up Care and Tracking Systems for Preterm and Low-Birth Weight Infants

TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA

REPORT DOCUMENT NO. 146

COMMONWEALTH OF VIRGINIA
RICHMOND
2008

Code of Virginia § 30-168.

The Joint Commission on Health Care (the Commission) is established in the legislative branch of state government. The purpose of the Commission is to study, report and make recommendations on all areas of health care provision, regulation, insurance, liability, licensing, and delivery of services. In so doing, the Commission shall endeavor to ensure that the Commonwealth as provider, financier, and regulator adopts the most cost-effective and efficacious means of delivery of health care services so that the greatest number of Virginians receive quality health care. Further, the Commission shall encourage the development of uniform policies and services to ensure the availability of quality, affordable and accessible health services and provide a forum for continuing the review and study of programs and services.

The Commission may make recommendations and coordinate the proposals and recommendations of all commissions and agencies as to legislation affecting the provision and delivery of health care.

For the purposes of this chapter, "health care" shall include behavioral health care.

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Preface

This is the second year of a study undertaken by the Joint Commission on Health Care (JCHC) examining the need for a tracking system for babies born early and/or with low-birth weights. Preterm/low-birth weight infants are subject to an increased risk of developmental delay by the circumstances of their birth. Immediate delays may not be readily apparent at birth or soon after, but are often recognized once the child enters school. Moreover, the optimal time for providing services is early in life when the development of the brain and central nervous system may be influenced. By the time a child reaches school age, this time has passed.

In 2006, JCHC staff convened a workgroup to examine the adequacy of follow-up services and the potential need for a tracking system for preterm/low-birth weight infants in Virginia. The workgroup cited anecdotal evidence that families were having difficulty accessing services, with contributory factors including a general lack of understanding regarding the importance of follow-up services, the cost of services, and the restrictive eligibility criteria for public programs. It was difficult to determine the extent to which service access was a problem since preterm/low-birth weight status generally is not tracked. JCHC subsequently voted to convene a workgroup in 2007 to determine whether existing data and tracking systems could be adapted to provide the needed information.

In 2007, the JCHC-convened workgroup verified that no State data system specifically identifies and tracks children who were preterm/low-birth weight at birth. While a number of State programs serve <u>some</u> of these children, no program consistently identifies specifically which of the children served were preterm/low-birth weight. Obstacles to instituting this type of tracking include the lack of common identifiers across agencies, the need for a coordinated interagency approach to tracking children across agencies, and the restrictions contained in the privacy provisions of the federal Family Educational Rights and Privacy Act. JCHC members authorized the Chairman to make a number of letter requests which are first steps in determining the State's ability to address the aforementioned obstacles. The letters request the following actions:

- The Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) make low-birth weight and preterm information <u>mandatory</u> data fields when local partners electronically submit Part C early intervention.
- The Virginia Department of Health (VDH) report to JCHC in 2008 regarding service information collected through the Pregnancy Risk Assessment Monitoring System survey.

- VDH and DMHMRSAS report to JCHC in 2008 on the status of using the same unique identifier for children served by two programs the agencies administer (Virginia Infant Screening and Infant Tracking System and the Infant and Toddler Connection) and on the feasibility of studying outcome data on low-birth weight and preterm infants who receive Part C services.
- VDH report to JCHC in 2008 on the status of the pilot linking birth certificate information to certain children's records maintained by the Department of Medical Assistance Services.
- VDH, with assistance from DMHMRSAS, report to JCHC in 2008 on the feasibility of studying outcome data on low-birth weight and preterm infants that receive Part C services. (Restrictions on VDH's ability to access educational records protected by the Family Educational Rights and Privacy Act are the primary obstacle.)

On behalf of the Joint Commission and staff, I would like to thank the numerous individuals who assisted in this study, including representatives from the Comprehensive Health Investment Project of Virginia; Department of Education; Department of Health; Department of Medical Assistance Services; Department of Mental Health, Mental Retardation and Substance Abuse Services; March of Dimes; The Medical Society of Virginia; Virginia Association of Community Services Boards; Virginia Association of Health Plans; and Virginia Hospital and Healthcare Association.

Kim Snead
Executive Director

June 2008

Table of Contents

Follow-Up Care and Tracking Systems for Preterm and Low-Birth Weight Infants

Executive Summary

Authority for Study

Preterm and low-birth weight (LBW) infants are subject to an increased risk of developmental delay by the circumstances of their birth. Immediate delays may not be readily apparent at birth or soon after, but are often recognized once the child enters school. The optimal time for providing services is early in life when the development of the brain and central nervous system may be influenced. By the time a child reaches school age, this time has passed.

In October 2005, JCHC was briefed by Dr. Susan Brown regarding the importance of providing follow-up services for preterm and low-birth weight (LBW) infants. JCHC subsequently voted to request a study in 2006 to determine the availability and adequacy of follow-up services and the potential need for a tracking system for preterm and LBW infants. The JCHC-convened workgroup cited anecdotal evidence that families are having difficulty accessing services for their preterm and low-birth weight infants, with contributory factors including a general lack of understanding regarding the importance of follow-up services, the cost of services particularly since reimbursement for services is low, and the restrictive eligibility criteria for public programs. One main theme was that *"It is difficult to determine the extent to which access to services is a problem since data that is specific to preterm and low-birth weight infants is lacking."* The JCHC study was continued in 2007 to determine whether existing data and tracking systems can be adapted to provide information about preterm and low-birth weight infants.

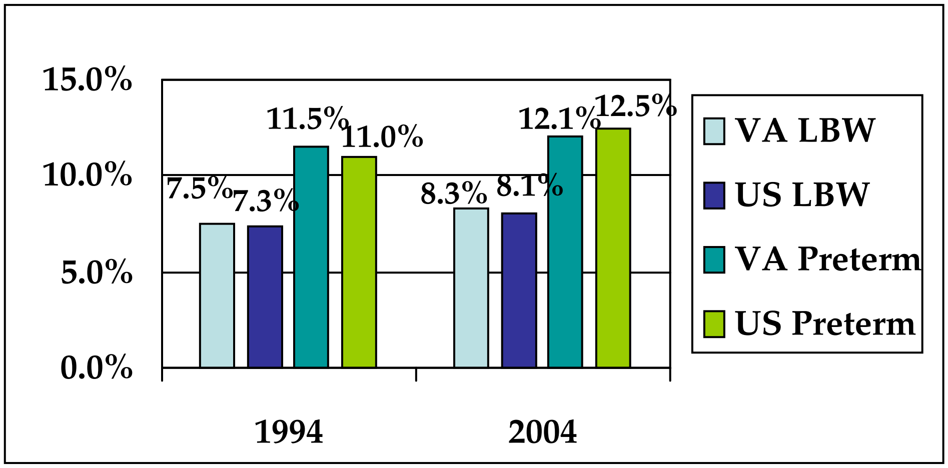
Prevalence of Premature and LBW Births

The National Center for Health Statistics (NCHS) defines premature and LBW infants as:

- Premature birth - delivery occurring at less than 37 completed weeks of gestation (full term = 38 to 42 weeks).
- Low Birth Weight (LBW) - Less than 2,500 grams or 5.5 pounds; very low birth weight < 1,500 grams or 3.25 pounds.

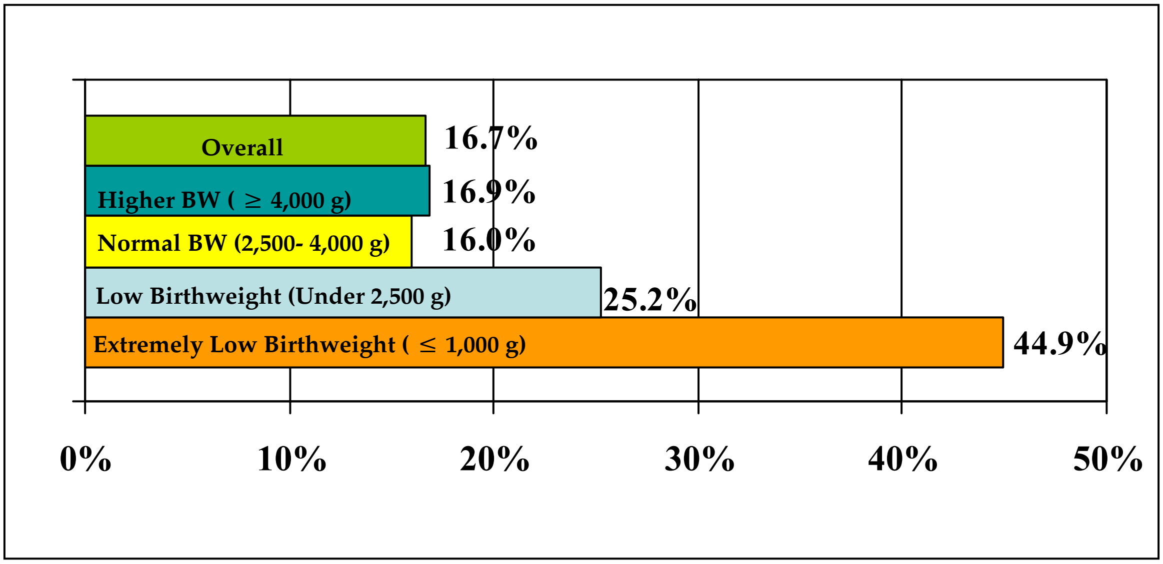
Historical data suggests a strong correlation between these two birth indicators. National and Virginia data indicate that the percentage of preterm and LBW infants increased from 1994 to 2004 (Figure 1). According to the Virginia Department of Health (VDH) of the live births in Virginia in 2004, 8,587 were LBW and 11,261 were preterm.

Figure 1
Preterm and Low Birthweight Infants in Virginia and the US for 1994 & 2004[1]



LBW infants, especially if their birthweight was extremely low, are at an increased risk of developmental delay. Figure 2 shows the relationship between school-identified disabilities and birthweight. As shown, more than 25 percent of LBW children had identified disabilities, while nearly 45% of the extremely LBW children (2.2 lbs. and below) had disabilities.

Figure 2
Percentage of School Identified Disabilities by Birthweight[2]



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[1] March of Dimes Peristats website accessed 7/27/07

[2] Source: Avchen, Scott, Mason: Birth Weight and School-age Disabilities: A Population-based Study. American Journal of Epidemiology 154:10, 895 (2001)

Importance of Follow-Up Services

Early intervention services in the first years of life are crucial for preterm and LBW infants. During the first years of a child's life, the brain is especially receptive to the positive effects of intervention services. The provision of follow-up services to preterm and LBW babies soon after their birth frequently results in increased developmental scores. Studies have found that long-term public savings may be achieved if follow-up services are provided early in a child's life. These savings result from decreased grade repetition and spending in special education, welfare, and juvenile justice programs; and ultimately from increased tax revenues and enhanced productivity.

Many developmental delays may not be obvious to a parent and are unrecognized until their child enters school and without the early intervention services that places the child at an increased risk of academic failure, behavioral problems, and socio-emotional disturbance. Types of developmental delays relate to communication, social, motor skills and problem solving. The optimal time for providing services for the most benefit is 0-5 years of age.

Strengthening Tracking of Preterm and Low-Birth Weight Infants

In 2007, a workgroup was convened by JCHC staff to examine existing data and tracking systems for: preterm and low-birth weight infants in order to improve access to services, utilization of services, and long-term outcomes. Participants of the workgroup included representatives from:

- Comprehensive Health Investment Project of Virginia (CHIP)
- Department of Education (DOE)
- Department of Health (VDH)
- Department of Medical Assistance Services (DMAS)
- Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)
- March of Dimes (MOD)
- Medical Society of Virginia (MSV)
- Virginia Association of Community Services Boards (VACSB)
- Virginia Association of Health Plans (VAHP)
- Virginia Hospital and Healthcare Association (VHHA)

The workgroup primarily addressed three areas of concern. First, which State data systems identify young children and could those systems provide for improved tracking of preterm and LBW infants. Second, what services are provided for children born preterm or LBW, which organizations provide these services and to what extent can (or do) these organizations track service utilization for these children. Third, to what extent are outcomes associated with the provision of services tracked, and is the tracking specific to children who were born preterm and LBW.

State Data Systems and Identifiers. It is difficult to track the services provided to a child across agencies without the use of a common identifier. In Virginia, there is no process for assigning children a unique common identifier. The social security number, an identifier historically used as a common link between records, is no longer used by most agencies and also, is not issued immediately upon a child's birth. VDH issues a birth certificate with a certificate identification number for all newborns, which includes whether the child is preterm or LBW. However, this identifier is not disseminated or used when services are accessed by a child outside of VDH.

State Services Provided for Children Who Were Preterm/LBW. Most State-sponsored programs fail to identify which children served were preterm/LBW because those characteristics are not pertinent to service eligibility. It is likely that a number of the children served in the following programs were born preterm/LBW:

- DMAS-administered programs:
  - Early and Periodic Screening, Diagnosis, and Treatment Services (EPSDT)
  - Baby Care
- DOE administered program:
  - Individuals with Disabilities Education Act (IDEA) – Part B
- Virginia Head Start Association
- VDH-administered programs:
  - Early Hearing Detection and Intervention Program
  - Care Connection for Children
  - Child Development Services Program

The DMHMRSAS-administered IDEA – Part C program inconsistently collects preterm and LBW information. Although the application form includes a field for LBW and preterm information, it is not a mandatory data field. It would be very useful to be able to identify and track which of the children were LBW or preterm and served by the following programs:

- Virginia Congenital Anomalies Reporting and Education System
- Early Hearing Detection and Intervention Program and
- Part C Child Find System.

System Improvements

The JCHC-convened workgroup identified seven specific options to improve the identification and tracking of LBW/preterm children, in order to monitor and improve the effectiveness of the services provided.

Pregnancy Risk Assessment Monitoring System (PRAMS) Survey. PRAMS is a joint VDH-Centers for Disease Control project designed to improve the health of mothers and newborns in Virginia. The project involves surveying new mothers within a few months of giving birth. (The first survey was distributed in May

2007.) VDH intends to survey approximately 600 mothers of LBW infants and 600 mothers of normal birth-weight infants each year on a wide range of topics. A potential tracking improvement would be to send a follow-up survey to each mother two years after the initial survey. The follow-up survey could include targeted questions as to the child's access to services, services received, and the child's progress. While the survey would not actively track all LBW and preterm children receiving services, the surveys would provide some information regarding children's access to services, the services provided and some outcomes data.

Forwarding of Unique Identifier by VDH When Referring Child to Part C. A second option for improvement involves VDH forwarding the child identification number used within the Virginia Infant Screening and Infant Tracking System (VISITS) when referring a child to the Infant and Toddler Connection (which is administered by DMHMRSAS). When VISITS identifies a child as possibly having a developmental delay, that child's name is forwarded to the Infant and Toddler Connection, which is responsible for providing services to address developmental delays in children from birth to two years. (The Infant and Toddler Connection is Virginia's program for providing services under Part C of the federal Individuals with Disabilities Education Act). The children referred by VDH and served by the Infant and Toddler Connection typically cannot be tracked over time because a unique identifier has not been included in the referral. VDH is working to include the identification number from the child's birth certificate so children can be tracked between the two systems, but as of yet this project is not completed.

Requirement for Mandatory Preterm/LBW Status Field. A third option for improvement involves making preterm/LBW birth a mandatory data field for Part C programs. As noted previously, the electronic intake forms for Part C programs currently include an optional field for preterm/LBW status. The intake forms are filled out electronically at the local level and submitted to the Part C Office within DMHMRSAS. Having preterm/LBW status for all children served by Virginia's Part C programs would provide very useful information.

Pilot Project to Merge Some Information from VDH and DMAS. A fourth tracking improvement involves a pilot project currently underway by VDH and DMAS. VDH is conducting an evaluation of the Family Planning Waiver, which includes merging some information from VDH's electronic birth certificate with DMAS client information into a database. The pilot project was not designed specifically to track LBW/preterm infants and the receipt of DMAS services, but it could be expanded to do just that. If the data-merging pilot is successful, it could be expanded to all children served by DMAS and allow for tracking of all DMAS LBW/preterm children.

Demonstration Project to Show Current Tracking Abilities. The fifth option proposes a demonstration project to track a small group of children receiving State services through the various State agencies. The purpose of this project would be to determine the Commonwealth's ability to systematically track across agencies the services provided to specific children. Many children receive services from multiple State agencies.

Workgroup members noted the absence of a coordinated interagency approach that would allow for tracking a child through different State agencies. Currently, young children receiving services in the Commonwealth cannot be tracked from agency to agency and in some cases cannot be tracked even within one agency (when services are provided by different programs). The ability to track children across agencies and services is essential for a comprehensive evaluation of program effectiveness and for identifying children in exigent circumstances.

Follow-up with Previously Ineligible LBW and Preterm Children*.* A sixth option is for the DMHMRSAS Part C program to follow-up with LBW and preterm children that did not meet initial eligibility requirements for services. Children can develop developmental delays that would qualify for services, after the initial eligibility test. Funding would be needed for making the additional contacts as well as for providing developmental services for the additional children found eligible.

Review Long-Term Effectiveness of Part C Services. The last option asks VDH, with assistance from DMHMRSAS, to explore the feasibility of studying outcome data for LBW and preterm infants who receive Part C services. Although educational achievement would be an excellent measure of long-term improvement, federal Family Education Rights and Privacy Act (FERPA) restrictions make it difficult to access educational records. Children's educational records from Part C and DOE are covered by FERPA. If VDH found that outcome information could not be studied due to FERPA restrictions, VDH could report on the restrictions and present ideas for potential statutory changes to remedy that issue.

Policy Options

Option 1: Take no action.

☑ **Option 2:** Request by letter of the Chairman that the Virginia Department of Health report to JCHC in 2008 on the status of the PRAMS follow-up survey, including the proposed timeline and information the survey results will provide regarding the type, frequency and providers of developmental services.

☑ **Option 3:** Request by letter of the Chairman that VDH and DMHMRSAS report to JCHC in 2008 on the status of an automated referral system that includes a unique identifier between the Virginia Infant Screening and Infant Tracking System (VISITS) and the Infant and Toddler Connection.

☑ **Option 4:** ~~Introduce a budget amendment that provides additional funding for~~ By letter of the Chairman, request DMHMRSAS to make LBW and preterm information mandatory data fields when local Part C early intervention systems electronically submit a Part C eligible child's initial evaluation ~~(amount to be determined)~~.

☑ **Option 5:** Request by letter of the Chairman that VDH report to JCHC in 2008 regarding the status of the pilot for linking birth certificate information to DMAS's children's records.

Option 6: Request by letter from the JCHC Chairman that the Secretaries of Health and Human Resources, Education, and Technology in consultation with the Office of the Attorney General conduct a demonstration project to track a small group of children receiving services through State agencies and through other state-funded organizations as deemed appropriate. The purpose of this project would be to determine the Commonwealth's ability to track across agencies the services provided to specific children. The letter would include the request to report to JCHC in 2008.

Option 7: Introduce a budget amendment that provides additional funding (amount to be determined) for the DMHMRSAS Part C program to follow-up with LBW and preterm children who were not initially eligible for services.

☑ **Option 8:** Request by letter from the JCHC Chairman that VDH and DMHMRSAS explore the feasibility of VDH studying outcome data on LBW and preterm infants that receive Part C services. Restrictions on VDH's ability to access educational records protected by the Family Educational Rights and Privacy Act (FERPA) are the primary obstacle. The letter would include the request for VDH to report to JCHC in 2008.

Public Comments on Study

Comments on the work group recommendations were submitted on behalf of:

- CHIP of Virginia
- Virginia Association of Community Services Boards, Inc.
- Virginia Department of Health

The number of comments received in support of each Policy Option is shown below:

Policy Option	Number of Comments in Support
1	0
2	1
3	2

4	2
5	1
6	2
7	2
8	1

Excerpts from some individual comments follow.

Option 2 – 8
(Especially 4, 6, 7, 8)
CHIP of Virginia commented:

> I am writing in support of the policy options developed by the study group that address critical improvements in the Commonwealth's efforts to track and follow up with preterm infants. As evidenced by Virginia's low "child-find" rates in Part C early intervention services, our systems are fragmented and spread across a variety of state agencies. Given the small window of opportunity for early intervention services, it is essential that our follow up and tracking systems be efficient and effective. Some of the data necessary to follow up and track these infants exists, some does not. Although intentions are good, barriers (real and perceived) limit interagency cooperation.
>
> We need to ensure that publicly funded agencies are part of the solution, not part of the problem. The knowledge and technologies exist. Early intervention is a cost effective way to minimize the impact of LBW on children's development. We must address the barriers that limit our ability to help these high-risk children meet their potential.

Option 6
Options 3, 4, 7 with funding qualifiers
Virginia Association of Community Services Boards commented:

> With a few exceptions, most Infant Toddler Connection (Part C, IDEA) programs are administered through local CSBs….These early services are key to a more normal life and future health care and education savings. This program is a federal program with support from state and local funds. There are requirements for entry into this program and children at risk are not mandated.
>
> Since the infants in the scope of this study would not be eligible for Part C unless there were indications of a disability, funding would have to be made available for services and tracking of

> these infants. That said, the relatively small investment in such funding can reap substantial benefits to the Commonwealth as these children enter school and may need more intensive health care. The VACSB is supporting Policy Option 6 and Options 3, 4, and 7 with funding qualifiers.
>
> Policy Option 6 requests agencies conduct a demonstration project to track a small group of children across agencies and services during a certain number of years in early life. A demonstration project would certainly pick out the flaws and the gaps in the information systems and collection of data on services and outcomes.
>
> The VACSB suggests that the demonstration group contain children with developmental disabilities and delays as well as those with low birth weights or premature with the reminder that funding will be needed for those infants not eligible for Part C funding.

Virginia Department of Health
Robert B. Stroube, MD, MPH, the State Health Commissioner provided comment, without supporting or opposing any specific option. Dr. Stroube's comments, in part, indicated:

> As you know, VDH staff participated in the discussions of the work group. I am pleased that staff was able to share the progress that we have made to date on the electronic birth certificate (EBC), and the potential that system holds for linking to other child health data sets. As the work group recommendations indicate, VDH data – especially the EBC and the Pregnancy Risk Assessment Monitoring System – can play a significant role in tracking the outcomes of infants born preterm and/or low birth weight. Furthermore, data linkages made possible by working with the unique identifier in the EBC should assist various programs' staff in tracking children across agencies, which should result in better outcomes through earlier referral and intervention.
>
> I understand that the focus of this work group was on the potential for using existing data systems to track infants, primarily among state agencies. We look forward to seeing providers in the health care delivery system partnering with each other, and with state agencies, to facilitate seamless data collection and monitoring in further support of tracking these infants.

> We will be please to report back to the Commission next year on the progress with data enhancements and linkages as recommended. Thank you for the opportunity to work with your staff on this important issue.

JCHC Staff for this Report
Stephen W. Bowman
Senior Staff Attorney/Methodologist

Preterm Infants:

Follow-Up Care and Tracking Systems

Presented to the:
Joint Commission on Health Care

September 19, 2007

Stephen W. Bowman
Senior Staff Attorney/Methodologist

Agenda

- Study History
- Issue Overview
- Virginia Initiatives and Programs
- Policy Options

Study History

Study History

- October 2005 - Dr. Susan Brown briefed JCHC on the importance of providing follow-up services for preterm and low-birth weight (LBW) infants
  - Virginia does not do a good job of informing parents of the developmental risks and resources available
  - No tracking system is available

- November 2005 - JCHC requested staff study preterm and LBW infants:
  - Availability and adequacy of follow-up services
  - Potential need for a tracking system

JCHC Preterm and LBW Infant Study Group (2006)

- Workgroup convened twice.
- Findings:
  - Anecdotal evidence that families are having difficulty accessing services for their preterm and low-birth weight infants. Important factors included:
    - General lack of understanding regarding the importance of follow-up services,
    - Cost of services particularly since reimbursement for services is low, and
    - Restrictive eligibility criteria for public programs.
  - *"It is difficult to determine the extent to which access to services is a problem since data that is specific to preterm and low-birth weight infants is lacking."*

Source: JCHC 2007 Report Document 96 "Follow-Up Care and Tracking Systems for Preterm and Low-Birth Weight Infants"

2006 Recommendations

- November 2006 - JCHC recommended sending a letter from the Chairman requesting that representatives from invested associations and state agencies participate in a JCHC staff-convened workgroup
- The focus was to assess amending <u>existing</u> data and tracking systems to strengthen tracking abilities for:
  - Preterm and low-birth weight infants
  - Access to services
  - Utilization of services
  - Long-term outcomes

Workgroup to Strengthen Tracking of Preterm and Low-Birth Weight Infants (2007)

- Staff convened a workgroup with representatives from:
  - Department of Health (VDH)
  - Department of Education (DOE)
  - Medical Society of Virginia (MSV)
  - Virginia Association of Community Services Boards (VACSB)
  - Virginia Association of Health Plans (VAHP)
  - Virginia Hospital and Healthcare Association (VHHA)
  - Department of Medical Assistance Services (DMAS)
  - Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS)
  - March of Dimes (MOD) *
  - Comprehensive Health Investment Project of Virginia (CHIP)*

* Organizations not named in Letter from Chairman

Issue Overview

Premature & Low-Birth Weight Infants

Preterm - < 37 completed weeks of gestation

Very Preterm< 32 completed weeks of gestation

Low-Birthweight (LBW) -
< 2,500 grams or 5.5 lbs.

Extremely Low-Birthweight -
< 1,000 grams or 2.3 lbs.

Full term - 38 to 42 weeks

Normal Birthweight
2,500g - 4000g
5.5 lbs - 8.8 lbs

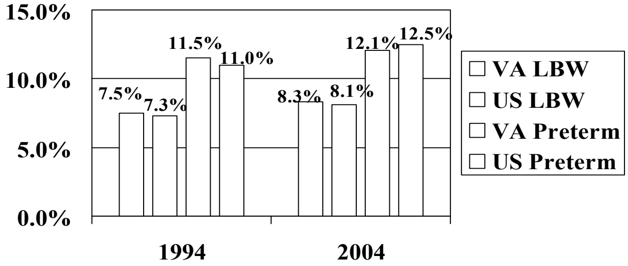
Source:* National Center for Health Statistics Website (2007)

Prevalence of Preterm & LBW Births

2004 Virginia Preterm Births - 11,261 (10.9%)*

2004 Virginia LBW Infants - 8,587 (8.2%)*

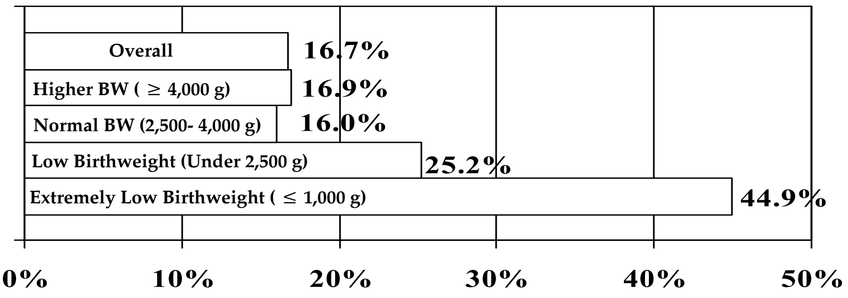
Preterm and Low Birthweight Infants in Virginia and the US (1994 & 2004)**



Sources: *VDH Division of Health Statistics Data, **March of Dimes Peristats website accessed 7/27/07

LBW Infants have an Increased Risk for Disabilities

% of School Identified Disabilities by Birthweight



Source: Avchen, Scott, Mason: Birth Weight and School-age Disabilities: A Population-based Study. American Journal of Epidemiology 154:10, 895 (2001)

Developmental Delays

- Delays may not be obvious to parent, but are often recognized once the child enters school.
- Types of delays include:
  - Communication
  - Personal social
  - Motor skills
  - Problem solving
- Optimal time for providing services for the most benefit is 0-5 years of age.

Importance of Follow-Up Services

- Brain is especially receptive to the positive effects of intervention services in first years of a child's life.
  - Providing follow-up services soon after birth frequently results in increased developmental scores.

- If delays undetected until attending school, there is an increased risk of:
  - academic failure
  - behavioral problems
  - socio-emotional disturbance

Virginia's Initiatives and Programs

Tracking Preterm and LBW Infants in Virginia

- No State data system specifically tracks infants or children who were born preterm or LBW.
  - Virginia Department of Health is the only agency that collects LBW or preterm information on a consistent basis.
- Preterm and LBW children receive State services but are not identified as such

Programs that Serve Some Preterm or LBW Infants

- DMAS provides services such as:
  - Early and Periodic Screening, Diagnosis, and Treatment Services (EPSDT)
  - Baby Care
- IDEA Part B
- IDEA Part C
- Head Start

Programs that Serve Some Preterm or LBW Infants (cont)

- VDH offers several programs that assist children with developmental delays including:
  - Early Hearing Detection and Intervention Program
  - Care Connection for Children
  - Child Development Services Program

- *VDH is conducting an evaluation of the Family Planning Waiver*
  - *Includes merging the electronic birth certificate information and DMAS information*

Developmental Disability Tracking Programs

- Information on children who have disabilities or documented delays are tracked to some extent by various agencies.
  - Virginia Congenital Anomalies Reporting and Education System (VaCARES)
  - Early Hearing Detection and Intervention Program
  - Part C Early Intervention Services

PRAMS Can Track Some LBW Infants

- Pregnancy Risk Assessment Monitoring System (PRAMS)
  - Administered through VDH
- 1,200 mothers randomly selected each year
    - 600 Low-Birth Weight Infants
    - 600 Normal-Birth Weight Infants
- 50 surveys are distributed monthly to each population
- Wide range of topics addressed
- Follow-up surveys possible

Workgroup Themes

- Workgroup convened twice
  - Four intergovernmental meetings occurred

- Most state developmental services provided are based on the child's need

- Virginia has limited to no ability to track state services provided to a specific child.

Workgroup Themes

- The ability to track the services to children across agencies need to improve in order to determine:
  - Provision of services for specific children's
  - Coordination of children's services
  - Overall effectiveness of services

- Obstacles for improving tracking abilities include:
  - Lack of common identifiers across agencies
  - Lack of a coordinated interagency approach to be able to follow a child through different state agencies
  - Family Educational Rights and Privacy Act (FERPA)

Policy Options

Policy Options

Option 1: Take no action.

Option 2: Request by letter of the Chairman that the Virginia Department of Health report to JCHC in 2008 on the status of the PRAMS follow-up survey including the proposed timeline and information the survey results will provide regarding the type, frequency and providers of developmental services.

Policy Options

Option 3: Request by letter of the Chairman that VDH and DMHMRSAS report to JCHC in 2008 on the status of an automated referral system that includes a unique identifier between the Virginia Infant Screening and Infant Tracking System (VISITS) and the Infant and Toddler Connection.

Option 4: Introduce a budget amendment that provides additional funding for DMHMRSAS to make LBW and preterm information mandatory data fields when local Part C early intervention systems electronically submit a Part C eligible child's initial evaluation. (amount to be determined)

Policy Options

Option 5: Request by letter of the Chairman that VDH report to JCHC in 2008 regarding the status of the pilot for linking birth certificate information to DMAS child records.

Option 6: By letter from the JCHC Chairman request that the Secretaries of Health and Human Resources, Education, and Technology in consultation with the Office of the Attorney General conduct a demonstration project to track a small group of children receiving services through state agencies and through other state-funded organizations as deemed appropriate. The purpose of this project would be to determine the Commonwealth's ability to track across agencies the services provided to specific children. The letter would include the request to report to JCHC in 2008.

Policy Options

Option 7: Introduce a budget amendment that provides additional funding (amount to be determined) for the DMHMRSAS Part C program to follow-up with LBW and preterm children who were not initially eligible for services.

Option 8: By letter from the JCHC Chairman request that VDH and DMHMRSAS explore the feasibility of VDH studying outcome data on LBW and preterm infants that receive Part C services. Restrictions on VDH's ability to access educational records protected by the Family Educational Rights and Privacy Act (FERPA) are the primary obstacle. The letter would include the request for VDH to report to JCHC in 2008.

Public Comments

- Written public comments on the proposed options may be submitted to JCHC by close of business on October 10, 2007. Comments may be submitted via:
  - E-mail (sareid@leg.state.va.us)
  - Facsimile (804/786-5538) or
  - Mail to Joint Commission on Health Care
    P.O. Box 1322
    Richmond, Virginia 23218
- Comments will be summarized and presented to the JCHC during its October 17th meeting.

Internet Address

Joint Commission on Health Care website
http://jchc.state.va.us

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