

# Preterm Infants: Follow-Up Care and Tracking Systems



*Presented to the:*  
**Joint Commission on Health Care**

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## Agenda

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

# Study History

## Study History

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- 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)

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- 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”

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## 2006 Recommendations

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- 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 existing data and tracking systems to strengthen tracking abilities for:
  - Preterm and low-birth weight infants
  - Access to services
  - Utilization of services
  - Long-term outcomes



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## 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

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## 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



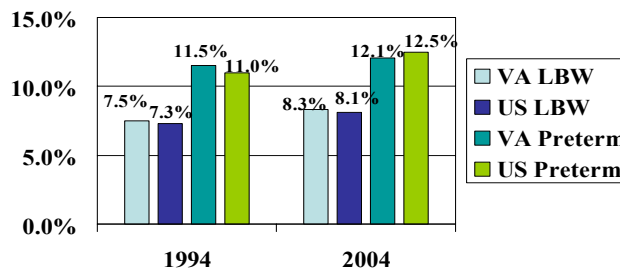
Source: National Center for Health Statistics Website (2007)

# Prevalence of Preterm & LBW Births

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

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

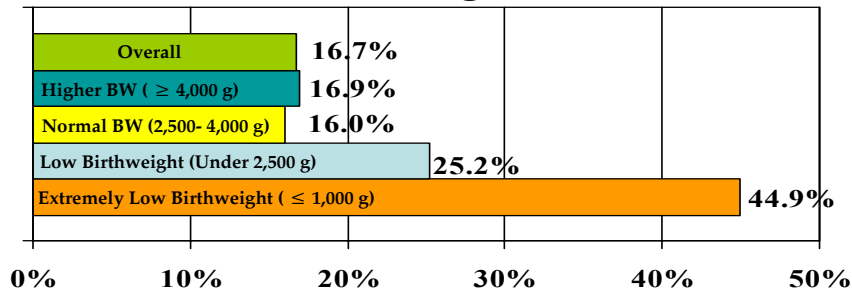
Preterm and Low Birthweight Infants in Virginia and the US (1994 & 2004)\*\*



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)

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## 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.



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## Importance of Follow-Up Services

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- 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

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- 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

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- 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)

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- 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

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- 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

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- 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

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- 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

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- 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

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**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

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**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

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**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

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**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](mailto: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 17<sup>th</sup> meeting.



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## Internet Address

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

### Contact Information

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