



## JOINT COMMISSION ON HEALTH CARE

### SUMMARY OF PUBLIC COMMENTS:

#### Work Group on Preterm Infants: Follow-Up Care and Tracking Systems

#### 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 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 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.
- 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.

## Summary of Comments

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:

<u>Policy Option</u>	<u>Number of Comments in Support</u>
1	0
2	1
3	2
4	2
5	1
6	2
7	2
8	1

## Excerpts from Some Individual Comments

### 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.