

ACADEMIC PEDIATRIC ASSOCIATION AMERICAN PEDIATRIC SOCIETY ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRS SOCIETY FOR PEDIATRIC RESEARCH

Advancing child health through public policy

Washington Update

July 17, 2014

IN THIS UPDATE:

President Calls for Emergency Aid in Child Border Crossings

IOM Releases Report on National Children's Study, Recommends Changes

Senator Announces Plan to Introduce Research Funding Bill

Representatives Release Medicaid Proposal for Medically Complex Children

NICHD Releases State Funding Map

House Establishes Working Group to Address Regulatory Burden on Research Universities

President Calls for Emergency Aid in Child Border Crossings

On July 8, President Obama <u>requested</u> \$3.7 billion in emergency supplemental funds from Congress to address the influx of unaccompanied children crossing the U.S. border. Nearly half of these funds would be appropriated to the Department of Health and Human Services (HHS) to ensure that the agency would have the resources to provide care and housing for the children currently projected to come into the custody of the Department of Homeland Security (DHS), while putting in place more stable, cost-effective arrangements for these children going forward. The proposal would also support the ongoing HHS medical response activities for unaccompanied children to address the surge at border patrol facilities. Since October 2013, over 57,000 unaccompanied children have attempted to cross the U.S. border from Mexico. Most of these children originate from Guatemala, El Salvador, and Honduras, where there is little state protection from drug traffickers and gangs that recruit children as early as age 10. Children are subject to a high level of danger and deprivation, especially crossing through Mexico where there is a high risk for violence and sex trafficking.

While most Mexican children apprehended at the border are returned to Mexico immediately with a maximum screening time of 48 hours, children from non-contiguous Central American countries are automatically screened by U.S. Customs and Border Patrol within a 72 hour period and then referred to the HHS Office of Refugee Resettlement (ORR). ORR then begins the process of evaluating the child, identifying a sponsor or family member for placement, and initiating the immigration process. Some members of Congress have called for a reduction in the time allowed for government custody of immigrant children from Central American countries and for policies to immediately return children to their country of origin who have entered the U.S. illegally.

On July 9, the Senate Committee on Homeland Security and Government Affairs held a hearing titled, "Challenges at the Border: Examining the Causes, Consequences, and Responses to the Rise in Apprehensions at the Southern Border" to examine the issue, with the Senate Committee on Appropriations held its own hearing on July 10 to review the president's request. The AAP released a statement offering support to the federal government it its actions to provide care for these children.

IOM Releases Report on National Children's Study, Recommends Changes

On June 16, an Institute of Medicine (IOM) panel released a <u>report</u> issuing analysis and recommendations concerning the architecture of the National Children's Study (NCS). The NCS, mandated by the Children's Health Act of 2000 (PL 106-310), is the largest longitudinal study of children and adolescents ever undertaken, involving tracking over 100,000 children from conception to age 21. Congress convened the IOM panel amid concerns that the recruitment methods used by the NCS would not be representative of the broader population. While the panel approved several aspects of the study, the report called for tracking all children in the study starting prenatally, rejecting the recent NCS study design that proposed tracking half of children beginning at birth. Due to a lack of data, the report was unable to address other issues requested for comment by the Department of Health and Human Services (HHS) including geographic sampling techniques and the overall cost-effectiveness of the study. In <u>response</u> to the report, the Director of the National Institutes of Health (NIH) Francis Collins, MD, PhD put the start of the main arm of the NCS on hold to convene an advisory panel to investigate the financial feasibility of the study and implementation of changes needed to the study. The full study, tentatively set to start in 2015, will now be delayed pending recommendations of the new NIH panel. The PPC will develop an advocacy strategy for the NCS later this summer.

Senator Announces Plan to Introduce Research Funding Bill

In early July, Sen. Tom Harkin (D-Iowa) announced that he would introduce the *Accelerating Biomedical Research Act*. The bill was announced in response to growing concern that federal budget cuts associated with the *Budget Control Act of 2011*, also known as sequestration, are limiting the purchasing power of the National Institutes of Health (NIH) and its ability to maintain important biomedical research programs that have historically received bipartisan support. The <u>bill</u> would create a budgetary cap adjustment over the remaining years of sequestration in order to replace the original inflation-

adjusted purchasing power of the NIH projected prior to the across-the-board budget cuts. The adjustment would be triggered if the Labor-HHS-Education Appropriations Committees appropriate at least \$29.9 billion for the NIH, after which appropriators would have the option to provide up to \$46.2 billion of additional funding to the NIH over the FY 2015 – 2021 period. The bill is set to be introduced later in July.

Representatives Release Medicaid Proposal for Medically Complex Children

On June 20, Reps. Joe Barton (R-Texas) and Kathy Castor (D-Fla.) introduced the *Advancing Care for Exceptional Kids Act of 2014* (H.R. 4930). The <u>legislation</u> would provide a number of additional resources for medically complex children enrolled in Medicaid and would create new coordination methods for children that require care from a range of providers.

Currently, medically complex children make up 6% of the Medicaid population but represent 40% of total Medicaid spending on children. The legislation would establish nationally designated children's healthcare networks based at children's hospitals that would coordinate between a range of home, acute, and post-acute care providers. Children would be matched with a network based on their specific healthcare needs, and savings would be produced through a risk-based payment model and seamless coordination of care. Over 60 children's hospitals supported the legislation in coordination with the Children's Hospital Association.

NICHD Releases State Funding Map

On June 18, the Eunice K. Shriver National Institute of Child Health and Human Development (NICHD) released its 2013 funding data for grants and contracts. The data can be broken down by state, congressional district, and type of contract or grant, and is presented in both <u>interactive map</u> and <u>report</u> formats. In 2013 alone, NICHD contributed over \$1 billion to the states to fund grants and contracts with California and Maryland receiving the most funding at \$140 million and \$101 million respectively.

House Establishes Working Group to Address Regulatory Burden on Research Universities

On Monday, the House of Representatives passed the *Research and Development Efficiency Act* (H.R. 5056) by voice vote. The <u>bill</u>, introduced by Rep. Larry Bucshon (R-Ind.), would establish a working group under the authority of the National Science and Technology Council to issue recommendations on how to minimize the federal regulatory burden and streamline reporting requirements for universities performing biomedical research. The working group would receive input from a number of non-federal stakeholders and would be expected to report out on implementation of its recommendations to both the House Committee on Science, Space, and Technology and the Senate Committee on Commerce, Science, and Transportation.