

# **Improving Child Health: The Role of Policy Makers in Prevention and Treatment of Birth Defects and Developmental Disabilities**

**August 5, 2007**

**Boston, MA**

## **Summary**

The conference was successful in addressing the specific aims outlined in the conference plan. Eighteen state legislators (three more than proposed in the application) representing diverse geographic and demographic areas and federal personnel from the National Institutes of Health (NIH), National Institute for Child Health and Human Development (NICHD), Agency for Healthcare Research and Quality (AHRQ), Health Resources and Services Administration (HRSA), and the Centers for Disease Control and Prevention (CDC), and other expert faculty attended the meeting. Through faculty presentations, discussion and information sharing, state legislators and the National Conference of State Legislatures (NCSL) staff were able to identify and learn more about various policy approaches utilized by state and federal policymakers to address the prevention and treatment of birth defects and developmental disabilities. Several presentations given during the meeting informed participants about emerging strategies to prevent and treat birth defects and developmental disabilities such as pulse oximetry to screen for congenital heart disease and preimplantation genetic diagnosis, which were discussed during a presentation by Michael Watson with the American College of Medical Genetics. Federal personnel from NIH/NICHD, AHRQ, HRSA and the CDC presented information about each agency's role in the prevention and treatment of birth defects and developmental disabilities, including agency involvement in research activities, if applicable. By educating state legislators about different ways in which states may play a role in preventing and treating birth defects and developmental disabilities, including a presentation on state promising practices by Melanie Lockhart of the March of Dimes, the meeting may achieve its ultimate goal to better the lives of children through improved quality and access to care as the attendees take what they have learned back to their states.

One weakness of the meeting was the limited time for discussion in the morning portion of the program.

An expert Organizing Committee comprised of 19 members, including three NCSL staff, provided much valuable input in developing the agenda. This resulted in a very full agenda and reduced the amount of time for discussion. While the afternoon breakout sessions did allow participants and experts time to talk over issues, more time in the morning to process all of the information that was presented would have been beneficial to the legislators. Using a preconference evaluation to survey legislators' prior knowledge also was a problem with only three responding. However, the majority of the legislative participants responded to the post conference evaluation and were able to name new ways to prevent and treat birth defects and developmental disabilities that they had learned about, including advances in screening technologies, how public health programs can interface with provider communities, insurance and privacy concerns, and integration of information and data systems.

Because the conference was held on August 5, 2007, in conjunction with NCSL's Annual Meeting, the web site and publications being produced following the meeting remain in progress and are scheduled to be completed by the end of the grant cycle