



**ON 15<sup>th</sup> ANNIVERSARY OF AMERICANS WITH DISABILITIES ACT, REPORT FINDS THE SEARCH FOR CAUSES AND CURES FOR BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES COULD BE IMPROVED**

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**Washington, DC, July 26, 2005** – Trust for America’s Health (TFAH) today released a new report that finds that improvements in tracking information about birth defects and developmental disabilities could greatly enhance research efforts toward identifying causes, improving treatment, and discovering cures.

The report, “Birth Defects and Developmental Disabilities: The Search for Causes and Cures,” finds gaps in the collection of information about birth defects and developmental disabilities as well as missed opportunities to connect data collected by education and social service functions to health research studies. Among the report findings:

- Only 14 states receive funds from the Centers for Disease Control and Prevention (CDC) to track the number and types of birth defects in states. While 38 states have an existing birth defects surveillance program and nine additional states are actively planning such a network, most of these programs were started within the past five years and do not receive enough resources to be fully operational;
- Only 18 states receive funds from CDC to track autism. Most of these programs only began within the past several years and are at the initial stages of their development;
- Only five states track other developmental disabilities beyond autism, such as cerebral palsy or mental retardation;
- The detailed information collected through schools and social services are not being used or integrated with health research efforts on a systematic basis.

“Today, on the 15<sup>th</sup> anniversary of the Americans with Disabilities Act, we should take a moment to celebrate the tremendous progress we’ve made as a nation toward helping many individuals with birth defects and developmental disabilities live rich, full lives,” said Lowell Weicker, Jr., President of the Board of TFAH, former three-term U.S. Senator and Governor from Connecticut, and the lead sponsor of the original Americans with Disabilities Act. “However, there is much more we can do to build on this positive legacy. We should redouble efforts to search for potential causes and cures for these conditions.”

To help advance scientific research related to birth defects and developmental disabilities, TFAH recommends:

- Systematically and comprehensively **tracking birth defects and developmental disabilities and connecting this data with information about possible contributing factors** to help identify possible environmental contributing factors or genetic links.
  - Currently, one in every 33 babies (120,000 annually) is born with a birth defect in the U.S. The causes of over 60 percent of these are unknown, according to the CDC.

- Seventeen percent of children are estimated to have some form of developmental disability, and approximately two percent of school aged children have a serious developmental disability. A majority of the causes of developmental disabilities are also unknown.
- For the questions to be answered, the country must develop and maintain strong state- and community-based monitoring programs.
- Additionally, a comprehensive National Health Tracking Network should be established to monitor and investigate potential causes for all chronic diseases in the U.S.
- Ensuring that **existing education and social service agency data is connected to health research and data-collection efforts**. Education and social service agencies already routinely collect data as required by the Individuals with Disabilities Education Act (IDEA). This data should be used in a way that protects the individual's privacy, but used in aggregate, provides important information about patterns and trends of birth defects and developmental disabilities in neighborhoods and across the country.
  - According to participating school reports, over eight percent of students throughout the country receive services for developmental disabilities.
- **Expediting scientific research** to understand the reasons behind the recent escalation in developmental disabilities, ranging from Attention Deficit-Hyperactivity Disorder (ADHD) to autism spectrum disorders.
- **Creating a coordinated system to track efforts to screen newborns** for birth defects and developmental disabilities.
  - Of the 17 percent of children with a developmental or behavioral disability in the U.S., less than 50 percent are recognized as having a problem before school. Early intervention efforts have been shown to have strong results toward improved management of disabilities.
  - This data would also help better inform research investigating causes and cures.
- **Establishing a national repository for blood samples** that can help identify the causes of birth defects and developmental disabilities.
- **Investing in ongoing studies** including the National Birth Defects Prevention Study, the National Children's Study, and the Centers for Autism and Developmental Disabilities Research and Epidemiology case-cohort study.

The full report is available on TFAH's Web site at [www.healthyamericans.org](http://www.healthyamericans.org).

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*Trust for America's Health is a non-profit, non-partisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority.*

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