

## Survey Shows How State Programs Serve Children & Youth with Special Health Care Needs

The Association of Maternal & Child Health Programs released a new report that explores how state agencies dedicated to serving children and youth with special health care needs (CYSHCN) carry out their mission and how their leaders believe they can improve their systems of care.



Based on a survey of state and territorial agencies that provide services with federal Title V funding, the [National Title V Children and Youth with Special Health Care Needs Program Profile](#) offers insight into the structure and strengths of CYSHCN programs, the roles they play in systems of care, their partnerships, financing of care, and emerging issues.

“This survey reveals the breadth and value that Title V programs have in systems of care for these children with special health care needs, and highlights opportunities to enhance the capacity of CYSHCN programs,” said Lori Freeman, CEO of AMCHP. “Health care leaders can use the results to compare and improve CYSHCN systems of care, foster cross-state connections, and spread promising practices and strategies.”

Some 11.2 million children and youth in the United States\* have a special health care need, and they are as diverse as the nation: They range from children with chronic conditions and medically complex health issues to those with developmental, behavioral and emotional conditions.

Within each state and territory, the Maternal and Child Health and CYSHCN programs funded through Title V of the Social Security Act provide family-centered, community-based coordinated care for these children. The programs have evolved over their 85-year history, and in 2015-16, with support from the Lucile Packard Foundation for Children’s Health, the Association of Maternal and Child Health Programs (AMCHP) fielded a survey to gain insight into the structure, strengths, roles and emerging issues of Title V CYSHCN programs across the U.S.

Among the findings:

- The services most often facilitated by CYSHCN programs are family support services, enabling services (such as transportation, outreach and respite care) and coordination of care.
- Key strengths among CYSHCN programs include developing partnerships, collaborating with stakeholders, engaging families and communicating the value of CYSHCN programs to build better systems of care for children and youth.
- In many states, CYSHCN programs can strengthen their involvement with Medicaid, the Children’s Health Insurance Program and state insurance agencies in financing efforts to enhance existing systems of care.



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- Most CYSHCN programs play a leadership role in their states in ensuring support services for young people transitioning from those programs to adult health care systems.
- Among emerging issues, program leaders indicate opportunities for Title V CYSHCN programs to build their capacity in such areas as policy, financial capacity, data capacity and cultural competency.

[Download the full report](#), including an executive summary. For more information, visit AMCHP's CYSHCN website: <http://www.amchp.org/programsandtopics/CYSHCN/>.

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\* Under age 18

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AMCHP is the national membership association of state maternal and child health leaders. As an advocate, resource and partner, AMCHP's mission is to protect and promote the optimal health of women, children, and families. We envision a nation that values and invests in the health and well-being of all women, children, families, and communities. For more information, visit [www.amchp.org](http://www.amchp.org) or connect with AMCHP on [Facebook](#) or [Twitter](#).