

The North Carolina Innovative Approaches Initiative

Parents with Children and Youth with Special Health Care Needs (CYSHCN) experience a complex system of uncoordinated services. The aim of the Innovative Approaches (IA) initiative is to thoroughly examine and foster improvement for community-wide systems of care that will effectively meet the needs of families of children and youth with special health care needs, resulting in increased family satisfaction with services received and improved outcomes for children and youth with special health care needs. The goals of IA are based on the national Maternal and Child Health Bureau outcome measure focused on the percentage of children with special health care needs receiving care in a well-functioning system. To ensure access to needed and continuous systems of care for children and youth with special health care needs, IA goals focus on the six components of a well-functioning system noted below.

The Children and Youth Branch has awarded Innovative Approaches grants to five local health departments to service fourteen counties: **Albemarle Regional Health Services** (Pasquotank, Perquimans, and Camden Counties), **AppHealthCare** (Watauga, Ashe, and Alleghany Counties), **Cabarrus Health Alliance** (Cabarrus, Rowan, and Union Counties), **Granville-Vance District Health Department** (Granville and Vance Counties), and **Robeson County Department of Public Health** (Robeson, Bladen, and Columbus Counties).

The six goals of Innovative Approaches are:

| | Current State % |
|--|-----------------|
| Increase the percent of CSHCN whose families are partners in shared decision-making for child's optimal health | 74.6 |
| Increase the percent of CSHCN who receive coordinated, ongoing, comprehensive care within a medical home | 45.1 |
| Increase the percent of CSHCN who have adequate health insurance and financing to pay for needed services. | 58.4 |
| Increase the percent of CSHCN who are screened early and continuously for special health care needs | 78.7 |
| Increase the percent of CSHCN who can easily access community based services | 70.3 |
| Increase the percent of youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence | 43.7 |

North Carolina report from the 2009/10 National Survey of Children with Special Health Care Needs. * NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved May 2017 from www.childhealthdata.org.

Innovative Approaches uses a systems change approach rather than a program based approach to address community improvements for families of CYSHCN. **Systems change is the core of Innovative Approaches.**

Systems Improvement: A Primer for Creating and Sustaining Systems of Care That Work for Children, Youth and Families indicates that systems change is a shift in the way that a community makes decisions about policies, programs, and the allocation of its resources, usually through regulations, procedures, and protocols set down in formal written documents, and ultimately, in the way it delivers services to its citizens. To undertake systems change, a community must build collaborative bridges among multiple agencies, community members, and other stakeholders.

To bring about community change, the IA initiative encourages an ongoing and comprehensive analysis to identify all the policies, both formal and informal, that impact how services are provided, and then to revise those that pose barriers to the system of care for CYSHCN, or to create new more supportive policies, procedures, or practices. IA engages decision-makers to look at the total service delivery system, identifying gaps, duplication, and overlaps in services. Working from this information, leaders of the IA initiative can set up mechanisms to facilitate inter-agency communication and coordination; such as wrap around services, joint decision making, unified assessment and intake processes, and shared information systems. These system improvements will help ensure that families of CYSHCN encounter a seamless path through the services they need*.

The federal Maternal and Child Health Bureau and the American Academy of Pediatricians defines Children and Youth with Special Health Care Needs (CYSHCN) as "children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." CYSHCN have conditions that are expected to last more than 12 months, are often diagnosed with more than one condition, and frequently experience several functional difficulties, including respiratory problems, learning or behavior problems, difficulty with gross or fine motor skills, or chronic pain.

*(Adapted from The Systems Improvement Training and Technical Assistance Project Toolkit Number 5: *Systems Improvement: A Primer for Creating and Sustaining Systems of Care That Work for Children, Youth and Families* prepared by the Institute for Educational Leadership under grant number 99-JS-FX-0004 from the Office of Juvenile Justice and Delinquency Prevention, OJJDP), U.S. Department of Justice, 2002).