Innovative Approaches: Community Systems Building Grants for Children and Youth with Special Health Care Needs

Location: North Carolina
Date Submitted: 11/2016
Category: Emerging Practice

BACKGROUND

A system of services that is family centered, well-coordinated, accessible, comprehensive and culturally competent is critical to the success of children and youth with special health care needs (CYSHCN) and their families. The barriers to the creation of effective systems of care are many: categorical service provision, care that is uncoordinated, categorical funding streams, incompatible data systems, inadequate access to services, and the inability to assess system performance and carry out quality improvement activities are just a few of the notable barriers to the creation of effective systems of care that work for families of CYSHCN.

The North Carolina Division of Public Health (DPH), Children and Youth Branch and local health departments receiving Innovative Approaches (IA) funding are partners in finding and sharing innovative solutions to reducing the complexity of the system of care and improving health outcomes for CYSHCN.

The purpose of the IA initiative is threefold: (1) to thoroughly examine the community system of care for CYSHCN; (2) to facilitate community identification of sustainable system changes and promising practices; and (3) to coordinate the implementation of these practices with agencies, providers, and families in the community.

PROGRAM OBJECTIVES

The following five Health Resources and Service Administration (HRSA) Maternal and Child Health Bureau critical indicators to measure the quality of a system of care for CYSHCN are addressed via projects developed by the Innovative Approaches initiative sites:

<table>
<thead>
<tr>
<th>TITLE V/MCH BLOCK GRANT MEASURES ADDRESSED</th>
</tr>
</thead>
<tbody>
<tr>
<td>#06 Percent of children, ages 9 through 71 months, receiving a developmental screening using a parent-completed screening tool</td>
</tr>
<tr>
<td>#11 Percent of children with and without special health care needs having a medical home</td>
</tr>
<tr>
<td>#12 Percent of children with and without special health care needs who received services necessary to make transitions to adult health care</td>
</tr>
</tbody>
</table>

1. Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
2. All CYSHCN will receive coordinated ongoing comprehensive care within a medical home.
3. All children will be screened early and continuously for SHCN.
4. Services for CYSHCN and their families will be organized in ways that families can easily use them.
5. All CYSHCN will receive the services necessary to make appropriate transitions.

TARGET POPULATION SERVED

The federal Maternal and Child Health Bureau and the American Academy of Pediatrics defines children and youth with special healthcare 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. Innovative Approaches specifically focuses on CYSHCN ages Birth – 21.
PROGRAM ACTIVITIES

Innovative Approaches uses a family-driven system change approach rather than a program based approach to address community improvements for families of CYSHCN. Family-driven systems change is the core of Innovative Approaches.

North Carolina local health departments are eligible to apply for Innovative Approaches: Community Systems Building Grants for CYSHCN via a competitive request for application process from the NC Division of Public Health, Children and Youth Branch. Innovative Approaches grants are awarded for three-year funding cycles.

The IA grant provides for the hiring of 1 full time equivalent (IA Coordinator) who leads local efforts to identify a committee of stakeholders who serve CYSHCN and their families. The committee works together to assess community capacity to meet the needs of CYSHCN, identify areas in need of improvement, and develop strategies for addressing those areas. Through this process as well as through the provision of county coordinators and technical assistance, community capacity for creating systems change is strengthened.

Targeted efforts to both build capacity and implement change strategies result in service delivery system improvements, which over the long-term lead to meaningful improvements in the lives of CYSHCN and their families.

IA provides families of CYSHCN the opportunity to be actively involved in examining and fostering improvement of community-wide systems of care resulting in increased family satisfaction with services received and improved outcomes for CYSHCN. The IA grant also provides for the hiring of a part-time IA Parent Outreach Coordinator position to ensure authentic parent engagement in planning, implementation, and evaluation of all projects. Innovative Approaches utilizes family members as co-chairs of the Steering Committee and subcommittees and each IA site has a Parent Advisory Council.

The Innovative Approaches Parent Advisory Council (PAC) is a diverse group of parents and guardians of children and youth with special health care needs. The PAC is committed to advocacy and educating other families, government agencies and healthcare professionals on issues that affect CYSHCN. The PAC has representatives from across the counties served by the local health department’s Innovative Approaches initiative. PAC members meet monthly with service providers and agencies to promote collaboration and make recommendations as appropriate to the IA Steering Committee. In addition, IA is driven by family centered data from focus groups and key informant interviews.

PROGRAM OUTCOMES/EVALUATION DATA

IA undertook a two-year (2014-2016), five phase data collection and analysis process led by North Carolina State University. Evaluation results indicate that IA has had a positive impact on increasing community capacity for systems change. The areas in which the strongest evidence of IA’s influence on county level system-change capacity were in increasing system awareness, increasing issue awareness, and strengthening relationships within and across sub-systems. In regards to community understanding of the issues, needs, and challenges faced by CYSHCN, 65% of survey respondents indicated that IA moderately or greatly increased their understanding of these issues. In addition, 72% of all responding service delivery providers and 73% of all responding family members and advocates of CYSHCN reported new or strengthened relationships as a result of IA.

IA had notable gains in parent engagement as well as building leadership capacity of IA members. Evaluation survey responses indicated IA had the greatest impact building skills in the areas of how to use community data to identify strategic priorities for change, how to use systems thinking to identify barriers to system change, and how to identify and engage key stakeholders in creating system change.

The areas of county level service delivery improvements for which the most change across counties were found included the development of new resources to support service coordination, opportunities for social and recreational activities, and improvements in early screening.

The evaluation report notes that there is significant evidence that Innovative Approaches is leading to important changes in both community capacity for change as well as notable improvements to the service delivery system. The greatest and most consistent changes across IA counties are reported in the area of capacity building.

PROGRAM COST

The Innovative Approaches initiative cost $662,000 to assist five local health departments per year ($132,400 per local health department). Innovative Approaches grants are awarded in three-year funding cycles ($1,986,000 per funding cycle). This initiative is funded by the Title V-Maternal and Child Health Services Block Grant Program and is supported though the NC Division of Public Health, Children and Youth Branch.
ASSETS & CHALLENGES

Assets
- One of the criticisms of evidence based strategies is that they limit innovation. Innovative Approaches serves to encourage and promote innovation in policy and practice on behalf of CYSHNC while maintaining model fidelity for adherence, integrity, and quality of implementation for selected strategies.
- Innovative Approaches is a true grassroots collaboration in which existing partner networks are leveraged allowing for streamlining development and implementation of IA projects.
- IA projects solve local system of care issues and lead to actionable workflows, tools, and EHR templates that can be replicated statewide. Innovative Approaches work aligns with other current quality improvement and population health efforts.

Challenges
Effectively changing the system via policy and practice change at the local level takes time. It requires relationship building and effectively communicating why accessibility and inclusion of CYSHCN is a priority for family-focused systems of care.

Overcoming Challenges
Sustainability of practice and/or policy changes must be built into the design of interventions from their onset. It is easier to sustain a practice/policy change if its logistics have been implemented, tested, and refined with genuine feedback from families of CYSHCN.

LESSONS LEARNED

An Innovative Approaches Strategic Results Framework was needed to assess the impact of system change efforts related to the five IA goals. Innovative Approaches worked with the Rensselaerville Institute to develop a results framework with a collaborative impact project design and strategy. The framework is used by all IA sites and allows for defining and verifying project results, tracking success, and matching to metrics. The IA Results Framework establishes a shared measurement system and builds capacity within local steering committees. Specifically, the capacity of each steering committee member to define, track, achieve, and report on results delivered through IA projects is enhanced. The Results Framework provides a method to communicate clearly about the difference each stakeholder group has made and which system changes they have contributed to.

The Strategic Results Framework facilitates tracking success by determining key activities and stakeholder milestones. This involves identifying who will facilitate the accomplishments, what resources will be required to make this sustainable over time, and the assumptions about why the results will be achieved. The Strategic Results Framework provides for clarity of IA projects and stakeholders, shared focus to show connection between investment and effort to achieve results, and moves individuals and organizations into ownership for results achieved by them.

FUTURE STEPS

The Innovative Approaches initiative was launched in 2010 in four pilot counties. Since 2010, the initiative has grown to include counties in all regions of North Carolina including the Mountain region, Piedmont region, and Coastal Plains region. As of the 2016-2019 funding cycle, nineteen NC counties have participated in this initiative. A 2019-2022 RFA cycle is planned to further expand the number of NC counties engaged in community systems building for CYSHCN.

COLLABORATIONS

IA requires a strong collaborative partnership between local health departments, local Community Care of North Carolina networks, social service agencies, early childhood education, mental health representatives, local health care providers, other community agencies involved in targeted system changes, and most importantly families of CYSHCN as leaders improving the system of care for CYSHCN.

PEER REVIEW & REPLICATION


Innovative Approaches was selected for oral presentation at:

- Association of Maternal and Child Programs Annual Conference, Washington DC; April 6-9, 2016, Session J6- From Silos to Solutions: A Collaborative
System Change Approach to Improving Local Systems of Care for CYSHCN

- North Carolina Public Health Association Fall Education Conference, Winston Salem, NC, September 15-18, 2015, Session - Elevating Community-Based Research into Action at the Systems Level: A Family Center Initiative for Children and Youth with Special Health Care Needs in NC
- Association of Maternal and Child Programs Annual Conference, Washington DC, January 24-27 2015, Session C2- System Change Ying and Yang, How to Promote Quality Improvement and Adaptability While Maintaining Fidelity Across Communities and Partnerships

Palfrey JS, Threlkeld A D.  
*Supporting Families with Children with Special Health Care Needs: A Curriculum for Community Health Workers.*  
NC Innovative Approaches work is highlighted in curriculum Module 2: *What are Special Health Care Needs* in the Stories from the Field section of the curriculum.  
Stories from the Field highlight inspirational and positive experiences of fellow community health workers who have been working with CYSHCN and their families.  
Each story is centered on a common experience or value among community health workers.

An Innovative Approaches project implementation manual has been created by the NC Division of Public Health, Children and Youth Branch to serve as a guide in replication of this initiative as is available by request to IA Director at the NC Division of Public Health.

RESOURCES PROVIDED

Profile of North Carolina Innovative Approaches highlighted on the HRSA Rural Health Information Hub:  
https://www.ruralhealthinfo.org/community-health/project-examples/907

The North Carolina GlaxoSmithKline Foundation Child Health Recognition Awards program honors local health departments, public health staff and individuals for innovative, collaborative programs that improve the lives of North Carolina’s children.  
See p. 4 Robeson County Health Department Innovative Approaches Initiative, 2014 Child Health Award Winner:


The Robert Wood Johnson Culture of Health award honors communities that are creating powerful partnerships and deep commitments to drive local change, ensuring all residents have an opportunity to make healthy choices in their schools, workplaces and neighborhoods.  
Article references Buncombe County’s Innovative Approaches initiative as a mechanism to improve collaboration among groups leading to better health for CYSHCN.


IA Snapshot of Success stories highlight Innovative Approaches strategies at work.  
The success stories provide a background of the approach selected, the National Maternal and Child Health Bureau Performance Measure addressed, results, related community efforts, timeline, community partners, lessons learned, and project impact on families of CYSHCN.  
IA Snapshots of Success are available by request to IA Director at the NC Division of Public Health.

The Resource CAFÉ (Connections and Access for Families through Education) is a website created by the Cabarrus Innovative Approaches site especially for families and parents of children with special health-care needs and is designed to offer support, resources, and links to services available.  
http://www.cabarrushealth.org/190/Resource-Cafe

The Buncombe ACE’s (Adverse Childhood Experiences) website was created by the Buncombe Innovative Approaches site and provides information regarding building resilience, local community resources, and a variety of toolkits for medical providers and families.  
http://buncombeaces.org/home/

Key words: Children and Youth with Special Health Care Needs (CYSHCN), Family-Driven, Community Systems Building, Public Health, Systems Change, Strategic Results

**For more information about this program please contact:**

Heidi E. Austin, EdD, MCHES, CFLE
Director of the NC Innovative Approaches Initiative
Division of Public Health, Children and Youth Branch
North Carolina Department of Health and Human Services
Office Phone: (919) 707-5603
Email: Heidi.Austin@dhhs.nc.gov