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

An Innovation Station Best Practice

Purpose: This document is intended to support MCH professionals to implement a practice found in Innovation Station. This resource provides the information needed to replicate the practice and is divided into two sections: the first section provides a high-level overview of the practice while the second section describes how to implement the practice. For additional information on any of the content provided below, please reach out to the practice contact located at the bottom of this document.

Section I: Practice Overview

Location:	North Carolina	Title V/MCH Block Grant Measures Addressed
Category:	Best Practice	**NOM #17.2** Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system **NPM #06** Percent of children, ages 9 through 35 months, who received a developmental screening using a parent-completed screening tool in the past year **NPM #11** Percent of children with and without special health care needs, ages 0 through 17, who have a medical home **NPM #12** Percent of adolescents with and without special health care needs, ages 12 through 17, who receive services necessary to make transitions to adult health care **NPM#15** Percent of children, ages 0 through 17, who are continuously and adequately insured
Date Submitted:	11/2018	

Practice Description

The purpose of the Innovative Approaches (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. Since 2010 targeted efforts, including continuous quality improvement (CQI) efforts, to both build capacity and implement change strategies have resulted in service delivery system improvements, which over the long-term lead to meaningful improvements in the lives of CYSHCN and their families in NC.

Purpose

The federal Maternal and Child Health Bureau and the American Academy of Pediatrics define 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.

Data from the 2016-2017 National Survey of Children's Health reflects for the Title V National Outcome Measure #17.1: Percent of children ages 0-17 with special health care needs, North Carolina (NC) has a higher than national average % of children and youth with special health care needs (21.1% versus the national average of 18.8%).[1] In addition, the NC Rural Center reports that of NC's 100 counties, 80 are considered rural (population density of 250 per square mile or less).[2] Rural areas face a variety of access to services barriers including health professional shortages in primary medical care, dental, or mental health providers. Rural CYSHCN are less likely to be seen by a pediatrician than urban children. They are more likely to have unmet health care needs due to transportation difficulties or because care was not available in the area. Families of rural CYSHCN are more likely to report financial difficulties associated with their children's medical needs and more likely to provide care at home for their children.

The North Carolina Division of Public Health (DPH), Children & Youth (C&Y) Branch uses a variety of methods to identify and track the needs of families of CYSHCN. One of those methods is the Children with Special Health Care Needs' Help Line. The Help Line provides a toll-free information and referral source for parents of and professionals working with CYSHCN. Data from calls to the Help Line assist C&Y Branch staff members in gauging challenges that families of CYSHCN have and areas of the system that are frustrating and not meeting family's needs. Based on data from the Help Line and other data sources, DPH C&Y developed the NC Innovative Approaches (IA) initiative to support the development of community-based and family-focused systems of care for CYSHCN.

A system of services that is family centered, well-coordinated, accessible, comprehensive and culturally competent is critical to the success of 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

---

[1] Child and Adolescent Health Measurement Initiative. 2016-2017 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved [1/18/19] from www.childhealthdata.org. CAHMI: www.cahmi.org.

[2] NC Rural Center, densities calculated by the Rural Center based on 2014 US Census population estimates. Retrieved (8/30/18) from https://www.ncruralcenter.org/about-us/

work for families of CYSHCN. The North Carolina Division of Public Health, 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.

Innovative Approaches uses a family-driven systems 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. 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.

Practice Foundation

The goals of Innovative Approaches are based on the Title V National Outcome Measure #17.2: Percent 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, projects developed by the Innovative Approaches initiative sites focus on the following components of a well-functioning system:

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.

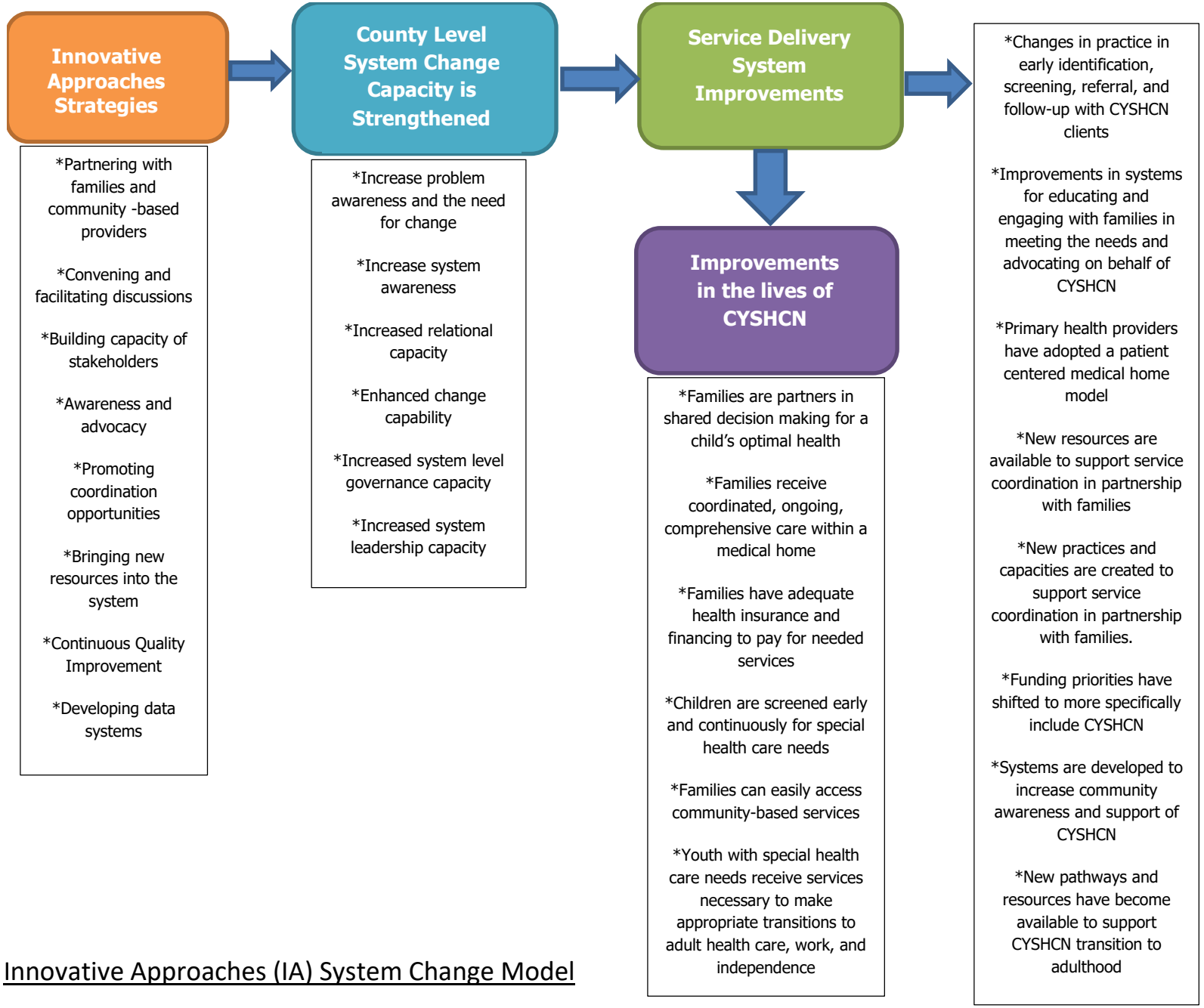
3. Families of CYSHCN have adequate health insurance and financing to pay for needed services.

4. All children will be screened early and continuously for SHCN.

5. Services for CYSHCN and their families will be organized in ways that families can easily use them.

6. All CYSHCN will receive the services necessary to make appropriate transitions.

The Innovative Approaches Systems Change Model is a frame through which families, agencies, and practitioners across a wide array of fields shift human services and community systems to create better and more just outcomes and improve the status quo. A series of Innovative Approaches strategies are implemented to support the development of community-based and family-focused systems of care for CYSHCN. IA Coordinators lead local efforts to identify a committee of stakeholders. 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. Implementing these strategies leads to strengthened county-level system-change capacity. This increase in system-change capacity leads to service delivery system improvements, which over the long-term leads to meaningful improvements in the lives of CYSHCN and their families.



Innovative Approaches (IA) System Change Model

Core Components

The goal of the Innovative Approaches initiative is to support the development of community-based and family-focused systems of care for families of CYSHCN. The core components of IA include counties assembling an effective coalition of stakeholders, coalition assesses community systems and identifies areas of improvement, coalition develops and implements strategies to address areas, counties build capacity to undergo systems change, improvements are made to the community service delivery system, and CYSHCN get the support and resources they need to thrive.

Practice Activities

Core Component	Activities	Operational Details
Counties assemble an effective coalition of stakeholders	IA Coordinators and Parent Outreach Coordinators lead local efforts to identify a committee of stakeholders.	Steering Committee leadership should consist of three co-chairs (one parent of a CYSHCN, the health director, and DSS director) to lead the committee in the creation and implementation of the system change IA action plan. Parent Advisory Council established to advocate and educate other families, government agencies and health care professionals on issues that affect CYSHCN.
Coalition assesses community systems and identifies areas of improvement	Develop a current and comprehensive needs assessment, updated annually.	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.
Coalition develops and implements strategies to address areas	Develop and maintain an action plan to include system change objectives, action steps, and results utilizing the IA Strategic Results Framework.	Innovative Approaches Strategies • Partner with families and community-based providers • Convene and facilitate discussions • Build capacity of stakeholders • Promote awareness and advocacy of CYSHCN issues • Promote coordinating opportunities

		• Bring new resources into the system (when appropriate) • Promote continuous quality improvement • Develop data systems as needed
Counties build capacity to undergo systems change	Sample training and technical assistance topics areas: • Defining CYSHCN problems in terms of the need for policy/systems/environmental change • Identifying types of stakeholders who influence the policy process • Types of policy approaches and elements of a policy's structure • Identifying policy and media advocacy strategies • Strategically consider funding opportunities to seek community change	IA strategies strengthen county level systems change capacity by: • Increasing problem awareness and appreciation of the need for change • Increased system awareness • Increased relational capacity • Enhanced change capability • Increased system level governance capacity • Increased system leadership capacity
Improvements are made to the community service delivery system	Continuous quality assurance/ improvement activities (ex. PDSA Cycles, Casual Loop diagrams, Results Based Accountability Turn the Curve, etc.)	Examples of IA service delivery improvements: • Change in practices in early identification, screening, referral, and follow up with CYSHCN clients • Improvements in systems for educating and engaging families in meeting the needs of and advocating on behalf of CYSHCN • Primary health providers adopt patient centered medical home model • New practices and capacities are created to support service coordination in partnership with families • Funding priorities have shifted to more specifically include CYSHCN • Systems are developed to increase community awareness and support of CYSHCN • New paths and resources available to support

		CYSHCN transition to adulthood
CYSHCN get the support and resources they need to thrive	Sustainability plan including strategies for: a. Identification and coaching of a county lead agency to continue IA work b. Funding sources to provide a stable base of resources c. Transfer of assets, if applicable, to the newly identified agency d. Securing broad based community support for involvement in CYSHCN projects e. Use of CYSHCN data and research to shape policy in response to changing community conditions f. Assuring families ongoing and meaningful input into systems for CYSHCN.	Sustainable IA projects lead to service delivery improvements impacting the lives of CYSHCN (6 IA goals): 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. Families of CYSHCN have adequate health insurance and financing to pay for needed services. 4. All children will be screened early and continuously for SHCN. 5. Services for CYSHCN and their families will be organized in ways that families can easily use them. 6. All CYSHCN will receive the services necessary to make appropriate transitions.

Evidence of Effectiveness (e.g. Evaluation Data)

IA undertook a two-year (2014-2016), five phase data collection and analysis process led by North Carolina State University.

The evaluation was guided by three questions:

1. What strategies did the IA steering committees use to promote system change?
2. To what extent and in what ways has the Innovative Approaches initiative strengthened county capacity to engage in system change work?

3. In what ways has the Innovative Approaches initiative led to significant changes in the community system for serving children and youth with special health care needs?

The following methods were used for data collection and analysis:

1. Content analysis of IA initiative documentation and training curricula
2. Seventy-seven (77) one-on-one key informant interviews
3. Year 1 survey data from 222 IA initiative stakeholders
4. Eleven focus groups (five with CYSHCN parents and six with service delivery representatives)
5. Year 2 survey data from 258 county system stakeholders including parents and service delivery providers

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 regard 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.

Evaluation Report Citation:

Nowell, B., Hano, M.C., Velez, A.K., Yang, Z., McCartha, E.B., & Albracht, B.S. (2016). Innovative Approaches Initiative Final Summative Evaluation Report. School of Public and International Affairs North Carolina State University, Raleigh, NC.

Evidence of Effectiveness

	Example Policy Change	Example System Change	Example Environmental Change
Action ⟶ PSE Change Policy, Systems and Environments (PSE)	Govern behavior and/or process	Where we live, work, study and play	Social and structural determinants of health
IA Goals			
1. Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.	Revision of foster parent training curriculum to include CYSHCN topics and AAP guidelines	Implementation of Compassionate Schools a trauma responsive infrastructure	Innovative Approaches and Active Routes to School collaboration to promote accessibility and inclusion of the CYSHCN population in school environments
2. All CYSHCN will receive coordinated ongoing comprehensive care within a medical home.	Integration of universal screening tools and the creation of a foster care management team	Implementation of a Medical Home Promotion Resource Fair and Special Olympics Healthy Athletes MedFest	Creation/utilization of a Mental Health Flow Chart to promote navigation of the mental health system for families of CYSHCN
3. Families of CYSHCN have adequate health insurance and financing to pay for needed services.	Advocacy for adequate insurance and financing via "I Am Medicaid NC" toolkit to demonstrate how public policy impacts everyday citizens	Development and incorporation of a Health Care & Financing Guide for Families of CYSHCN by health care providers in their work with families	Uninsured patients referred to county Health Check Coordinator embedded in office clinic to identify additional community-based resources that could provide families of CYSHCN with financial assistance options
4. All children will be screened early and continuously for SHCN	Integration of an Adverse Childhood Experiences (ACE) Provider Toolkit for medical professionals into the patient intake process	Incorporating screening for special health care needs into continuing medical education training for medical providers	Learn the Signs, Act Early (LTSAE) State System grantee work to support the implementation of LTSAE materials and early identification infrastructure efforts
5. Services for CYSHCN and their families will be organized in ways that families can easily use them.	Revision of law enforcement annual crisis intervention training to include CYSHCN Topics	Implementation of therapeutic recreational activities within county level Parks and Recreation Dept. programming for CYSHCN	Fostering enhanced emergency preparedness and response for CYSHCN within child care centers through collaboration with the NC Office on Disability and Health
6. All CYSHCN will receive the services necessary to make appropriate transitions.	Primary care providers adopt a formal transition policy and modify their practice to include a transition checklist to ensure that foster care youth successfully transition into adult health care	Establishment of Adolescents Transitioning to Leadership and Success (ATLAS) college YSHCN peer mentoring program	Collaboration between the Blue Cross and Blue Shield of North Carolina Institute for Health and Human Services and the University of North Carolina's TEACCH Autism program Asheville regional center to co-locate a satellite TEACCH Office in Boone, NC

Replication

The Cabarrus Health Alliance applied and was selected to receive a 2017 AMCHP Best Practices Replication grant (grant period October 207 – April 2018) to replicate the Emerging Practice of Innovative Approaches – Community Systems Building Grants for Children and Youth with Special Health Care Needs. The specific element of practice to be focused on during the replication was convening a diverse group of stakeholders who serve CYSHCN and their families with the intent to expand the supportive network of community partners available to meet the needs of families with CYSHCN. Activities to increase community awareness and engagement of Innovative Approaches and to broaden involvement of policy makers and community leaders included deploying a marketing communication plan, hosting technical assistance training on systems integration, hosting a Legislative Breakfast and dinner reception for business leaders and philanthropic organizations. Results of this replication project included:

1. The project strengthened collaborations and partnerships in the community. By engaging a more diverse group of stakeholders, Cabarrus IA has adopted an integrated systems approach enhancing: system linkages; awareness of available services/supports; and collaborative problem solving around shared challenges.
2. The project moved community partners beyond their silos to examine how each of their individual systems interface with families of CYSHCN. The importance of engaging the greater community to leverage their collective impact on policies, funding, and opportunities contributing to a more inclusive workplace became more evident. Event participants highlighted the value and impact of family stories, and that family engagement is imperative in impacting systems change.
3. Cabarrus IA learned the importance of the following steps: putting in up-front work to get the message out broadly in the community; engaging business leaders one-on-one before trying to bring them to the collective table; and identifying the value your message has for those you wish to engage.

The AMCHP Best Practices Replication grant afforded the Cabarrus Health Alliance and NC DPH, C&Y Branch the opportunity to further refine and develop this initiative, assisting in moving Innovative Approaches from an Emerging Practice (designation obtained November 2016) to a Best Practice (designation obtained November 2018) in the AMCHP Innovation Station Database.

An opportunity for replication among local health departments not selected through the competitive request for application process for Innovative Approaches is to utilize funding provided by the NC Division of Public Health, Children and Youth Branch through the Child Health activity option. The Child Health activity affords all NC local health departments a menu of options for the provision of preventive and primary health care services and/or other evidence-based or evidence-informed initiatives for children and youth that promote healthy behaviors and support optimal physical, social and emotional health.

Innovative Approaches provides a start-up or a full-scale option that can be selected in the category of other evidence-based/evidence-informed child health services for the Child Health activity. The start-up option focuses on assessing system readiness and enhancing capacity building to improve the system of care for CYSHCN. Through this option key LHD staff are orientated on the systems change approach rather than a program based approach to addressing community improvements for families of CYSHCN; formal mechanisms to receive

input from parents of CYSHCN via surveys and focus groups are coordinated and a formal data summary report is compiled; and promotion of networking, partnerships, and identification of service gaps based on the data collection results is fostered by convening two community meetings with local organizations (such as schools, early childhood education, child care, DSS, health care providers, family support organizations, etc.) that serve CYSHCN. A budget of $10,000 - $20,000 is recommended for the start-up option focusing on assessing system readiness and enhancing capacity building. The full-scale option affords local health departments the opportunity to replicate Innovative Approaches as outlined in this Innovation Station Practice Summary and Implementation Guidance document.

For interested parties external to North Carolina an Innovative Approaches Project Implementation Manual is available which shares resources and lessons learned in establishing successful IA initiatives across the state. While this implementation manual is written to guide North Carolina Division of Public Health funded IA projects, the Children and Youth Branch hopes it can also be used to assist communities with other sources of funding create new Innovative Approaches sites.

Section II: Practice Implementation

Internal Capacity

Innovative Approaches Project Staff Recommendations (1.5 FTE):

The Innovative Approaches Coordinator (1 FTE) is a consultative position to improve the community-wide systems of care to best meet the needs of families of CYSHCN. The consultant staffs and maintains a steering committee of community agencies and parents to assess system issues affecting families of CYSHCN, facilitates the development of an action plan driven by parent and provider data, facilitates the completion of action items, and assists with all evaluation efforts. Preferred candidates for this position have previous experience working with CYSHCN and work with policy, systems, and environmental change initiatives.
The IA Parent Outreach Coordinator position (.5 FTE) performs outreach activities to engage parents of CYSHCN and to recruit their active involvement in the Innovative Approaches initiative. This position works collaboratively with parents, primary care providers and community agencies to improve the system of care for CYSHCN up to age 21. The position assists with carrying out action plan projects for IA which address education and support needs for parents and caregivers of CYSHCN. In addition, the position provides information and linkage for care providers and community agencies serving CYSHCN regarding available resources and how to the access/navigate the service system. Preferred candidates for this position are parents/guardians of CYSHCN with lived experience navigating the system of care.

Support Structure for Innovative Approaches:

- NC Division of Public Health, Children and Youth Brach provides public health consultation and coordination of training and technical assistance via 1 FTE position (Director, Innovative Approaches)

- Local Health Department (LHD) serves as the lead agency and convener of the local IA initiative employing1.5 FTE IA staff
- 3 co-chair structure (LHD Director, DSS Director, Parent of CYSHCN) guides IA Steering Committee meetings
- Themed subcommittees oversee IA project execution
- Parent Advisory Council serves in an advisory capacity for the initiative ensuring all work is family driven
- IA Coordinator Network provides for peer colleague information sharing and problem solving

Collaboration/Partners

IA requires a strong collaborative partnership between local health departments, 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. Required representatives on the IA Steering Committee include family members of CYSHCN, local health department director, department of social services director, social service agency representatives (foster care and child protective services), Smart Start (NC early childhood initiative for 0-5), mental health agency representation, school system representative (school nurse and exceptional children), local health care providers, and representatives from other community agencies involved in the targeted system changes. Steering Committee leadership is comprised of three co-chairs (one parent, the health director, and the DSS director). When applying for IA funding, letters of commitment/support are required demonstrating a commitment from these agencies and family members to participate in the initiative.

The Innovative Approaches Parent Advisory Council (PAC) is a diverse group of parents and guardians of CYSHCN. 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, surveys, and key informant interviews. Members of the PAC receive an honorarium for their time and are afforded professional development opportunities such as attending the annual Association of Maternal and Child Health Conference to enhance their skillset.

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 Strategic Results process and tools help to engage and sustain involvement of IA community partners, determine systems change, provides a structure for project evaluation, and inform continuous quality improvement efforts.

Practice Cost

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. The following is a sample budget which includes project evaluation.

Budget			
Activity/Item	**Brief Description**	**Quantity**	**Total**
Innovative Approaches Coordinator	Community Development Specialist II, Salary Grade GN13	1 FTE	$60,000
Parent Outreach Coordinator	Public Health Educator I, Salary Grade GN09	0.5 FTE	$19,860
Fringe Benefits for 1.5 Staff	FICA, Medicare, Retirement, Health + Life Insurance, Health Reimbursement Account, Unemployment Insurance, Worker's Compensation, and Insurance and Bonds	Calculated @ 28% for 1.5 FTE	$22,360
CYSHCN Parent Honorariums	@ $20 per hour for participation in IA meetings and/or trainings (12 parent x 2 hrs. x $20 x 12 months)	12 CYSHCN Parents	$5,760
Training and Technical Assistance (TA)	DPH required training and TA for IA sites	1	$10,000
Professional Development	AMCHP Conference IA Coordinator + 1 CYSHCN Parent	2	$5,000
Mileage	300 miles per month for 1.5 staff x 12 months x IRS mileage rate $.58	300 miles	$2088
Meals	Meal @ state rate of $11 for 24 Steering Committee members x 12 months Meal @ state rate of $11 for 12 Parent Advisory Council (PACP members x 12 months	24 Steering Committee Members 12 PAC Members	$4,752
Office Supplies/Postage/ Communications	Items used for meeting presentations, postage, communications, mobile Wi-Fi	$120 x 12 months	$1,440
Copies/Translation	Printing/copying, text translation	$95 x 12 months	$1,140
Evaluation by Partner University	Impact/Outcome Evaluation	Multi-Year Evaluation	$33,100
		Total Amount:	**$165,500**

***** State of North Carolina Job Classifications and Salary Grades available via: https://oshr.nc.gov/state-employee-resources/classification-compensation/class-specs

Practice Timeline

A year 1 timeline is presented below in which the phases to develop a clearly written operational plan to organize and maintain a steering committee to collect data, identify systems issues, and develop a clear and actionable plan to address the identified system changes is defined.

The Innovative Approaches action plan is implemented after a 6-9-month planning process. Action plans should have clearly written objectives and activities to change policies, procedures or practices that improve the system of care for CYSHCN. The system change activities outlined in the action plan must be the result of needs identified by families of CYSHCN in the community and result in a long-standing change in the system of care.

Practice Timeline				
Phase	**Description of Activity**	**Date/Timeframe**	**# of hours needed to complete/ oversee activity**	**Person(s) Responsible**
Planning/ Pre-implementation	**Engage/Shift in Thinking** Engage community partners to serve on the IA Steering Committee Identify family members to serve on IA Steering Committee and Parent Advisory Council Conduct needs assessment of local CYSHCN service system (i.e. the current services available in the community, numbers of CYSHCN served) Provide orientation on the systems change approach via presentations, webinars, systems change exercises, graphics or printed materials) Introduce Strategic Result Framework and Result Trails for Systems Change and Steering Committee members (i.e. Orientation webinar) Develop strategies for communication with Steering Committee members (e.g. email, newsletter, Facebook)	**1st – 3rd Months**	IA Coordinator 1 FTE devoted to initiative, Parent Outreach Coordinator 0.5 FTE devoted to initiative Steering Committee Meetings average 2 hrs 1 x a month Subcommittee Meetings average 1.5-2 hrs 1x a month Parent Advisory Council Meetings average 2 hrs x 1 month	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** **Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator, and State Project Director for IA**

	Assess/Prioritize Complete data collection process with families of CYSHCN and community providers (i.e. Surveys, Focus Groups, interviews) Analyze data to identify gaps/barriers and priority themes from data collection process Identify and analyze root cause issues using appropriate QI tools (i.e. Fishbone Diagram, Pareto Chart, "5 Whys") Involve Steering Committee members in reviewing and prioritizing identified system problems to address as members "**move from discussion to action"** Provide training and support for IA parent representatives to facilitate their participation and input in the planning process Determine need to develop targeted subcommittees to address action areas	**4th – 6th Months**	Steering Committee Meetings average 2 hrs 1 x a month Subcommittee Meetings average 1.5-2 hrs 1x a month Parent Advisory Council Meetings average 2 hrs x 1 month	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator, and State Project Director for IA
Implementation	**Move to Action** Develop system change objectives (SCO) based on the identified system problems Provide orientation for IA Steering Committee members on use of the Strategic Results Framework for the Action Plan (i.e. TRI Orientation webinar) Identify community efforts that tie in with system change objectives to leverage collaborative partnerships and increase collective impact Develop action plans utilizing Action Plan template and components of the Strategic Results Framework, including:	**7th – 9th Months**	Steering Committee Meetings average 2 hrs 1 x a month Subcommittee Meetings average 1.5-2 hrs 1x a month Parent Advisory Council Meetings average 2 hrs x 1 month	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** Themed Subcommittees Parent Advisory Council Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator, and

	a) Results Trails b) Project Milestones c) Project Result Plan Begin Implementation of the project activities on the Action Plan			State Project Director for IA
	Collaboration in Motion Provide targeted training as needed for those directly involved in implementing Action Plan projects Utilize tools to facilitate communication and continued participation among SCO teams (e.g. Base Camp, Google Docs) Leverage community resources to implement the Action Plan SCO (e.g. grants, community projects) Utilize tools that can be used for tracking results among team members, such as Base Camp teams site for specific projects Engage additional community partners on IA Steering Committee as project moves forward, and additional system change objectives are identified	**10th – 12th Months**	Steering Committee Meetings average 2 hrs 1 x a month Subcommittee Meetings average 1.5-2 hrs 1x a month Parent Advisory Council Meetings average 2 hrs x 1 month	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** Themed Subcommittees Parent Advisory Council Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator, and State Project Director for IA
Sustainability	**Sustainability Plan Development** Funding sources to provide a stable base of resources. Securing broad based community support for involvement in CYSHCN projects. Use of CYSHCN data and research to shape policy in response to changing community conditions.	**Continuous throughout life of initiative**	Steering Committee Meetings average 2 hrs 1 x a month Subcommittee Meetings average 1.5-2 hrs 1x a month Parent Advisory Council Meetings	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator, and

	Assuring families ongoing and meaningful input into systems for CYSHCN		average 2 hrs x 1 month	State Project Director for IA
	Sustainability Checklist Determine project owner Senior leaders are involved and keeping everyone focused on the project Systems and processes are independent of the people involved in implementing the project Create, adapt, or use existing tools Continuously monitor data	**Continuous throughout life of IA project(s)**	Subcommittee Meetings average 1.5-2 hrs 1x a month	**Themed subcommittee members** Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator
	Program Sustainability Assessment Tool (PSAT) Understand 8 factors that influence capacity for sustainability 1. Strategic Planning 2. Environmental Support 3. Funding Stability 4. Partnerships 5. Organizational Capacity 6. Program Evaluation 7. Program Adaptation 8. Communications Assess via PSAT Review sustainability report Develop an action plan to increase likelihood of sustainability	**Continuous throughout life of initiative**	Educate on 8 sustainability domains- 2 hours PSAT assessment 15-20 minutes to complete Develop Sustainability Action Plan 2-4 hours Sustainability Action Planning- Ongoing	**Steering Committee Co-Chairs (Health Dept. Director, DSS Director, CYSHCN Parent)** Consultation and Technical Assistance provided by local IA Coordinator, Parent Outreach Coordinator

Resources Provided

- Profile of the North Carolina Innovative Approaches initiative on the Health Resources and Services Administration (HRSA) Rural Health Information Hub: https://www.ruralhealthinfo.org/project-examples/907

- Association of Maternal and Child Health Programs (AMCHP) Implementation Road Maps Web-Based Learning Module. Innovative Approaches selected as one of three state projects featured in an AMCHP interactive web-based learning module which highlights work in the focus area of improving systems of care for children and youth with special health care needs. http://www.amchp.org/AIMRoadmap/story_html5.html?lms=1

- Association of Maternal and Child Health Programs (AMCHP) National Performance Measure (NPM) #6 Implementation Toolkit. Innovative Approaches selected as one of eleven state projects featured in the NPM # 6 Developmental Screening Toolkit highlighting strategic approaches in the focus area of systems coordination. https://create.piktochart.com/output/29573423-npm-6-implementation-toolkit

- Association of Maternal and Child Health Programs (AMCHP) Learn the Signs. Act Early. (LTSAE) State Systems Grants. NC selected as one of eleven states/territories to participate in the 2016-2018 State System Grants. This grant is a partnership between Innovative Approaches and faculty from the Carolina Institute for Development Disabilities at the University of North Carolina at Chapel Hill to integrate Center for Disease Control and Prevention Learn the Signs. Act Early. (LTSAE) campaign materials into local systems of care. The LTSAE State Systems Grant was extended for a third year (FY 18-19). http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/CDC%20Act%20Early%20Grants/Documents/2016-18ActEarlyStateSysGrants_OverviewV2.pdf

- 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/ResourceCafe

- 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/

- North Carolina Medical Journal (2016):77(1):30-36 Disability and Exposure to High Levels of Adverse Childhood Experiences: Effect on Health and Risk Behavior. Article highlights the work of the Buncombe IA site to incorporate Adverse Childhood Experiences (ACE) assessment and ACE prevention into primary care. http://www.ncmedicaljournal.com/content/77/1/30.full

- HSC Foundation. (2016). *Special Connections: Community Health Workers Supporting Families with Children and Youth with Special Health Care Needs.* Boston, MA: Judith

Palfrey and Aubry Threlkeld. NC Innovative Approaches work is highlighted in curriculum Module 10 “How Do We Take What We Have Learned Back to Our Communities?” 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. NC Innovative Approaches is a partner in piloting, testing, and evaluating the curriculum.

Lessons Learned

Assets of this Practice:

- 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 Associated with this Practice:

- 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 six 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.

Replication

- 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.

- 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.

Next 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. With the selection of counties for the 4th cohort of funding (FYs 2019-2022), twenty-two of North Carolina's one hundred counties will have engaged in community systems building for CYSHCN

A summative evaluation was conducted of Innovative Approaches in the 2nd cohort of funding (FYs 2013-2016). As Innovative Approaches reaches the 10-year mark in the 4th cohort of funding evaluation efforts will focus on impact/outcome data related to components of a well-functioning system as indicated by the Title V/MCH Block Grant Measures addressed by this project.

Practice Contact Information
For more information about this practice, please contact: **Danielle Matula, MPA** Best Practices Unit Manager Division of Public Health, Children and Youth Branch NC Department of Health and Human Services Office Phone: (919) 707-5620 Email: Danielle.Matula@dhhs.nc.gov