

**Institute for Nonprofits**  
**North Carolina State University**  
*Building a Child Health Collaborative: A Network Analysis*  
**Draft Executive Summary**  
**December 2005**

**Background**

This report, commissioned by the John Rex Endowment, provides data gathered from organizations that offer health-related services and referrals to medically underserved children in Wake County, North Carolina. It describes the results of a comprehensive assessment of the Wake County children's health community that included a telephone survey and several focus groups and offers recommendations that the Endowment may wish to consider to facilitate collaboration, to begin capacity building and affect public policy. The Endowment can use the information in this report to plan and develop activities designed to bring about significant, lasting changes in the provision of health services to Wake County's underserved children.

**Methods**

In order for the John Rex Endowment to realize its goals of building a community collaborative, and building capacity to improve underserved children's access to care, it must know which organizations are currently or potentially committed to the same goals. This project systematically surveyed the community to identify those organizations using three phases of data collection.

Phase 1 consisted of a telephone survey of 1275 local nonprofit, for-profit, government and faith-based organizations. The purpose of the survey was to screen organizations and identify those that had contact with underserved children. We were able to contact 748 of the 1275 organizations on the Phase 1 list. Of those, 423 met screening criteria for inclusion in Phase 2.

An in-depth telephone survey designed to determine organizations' current capacity to meet the target population's needs, services currently offered, capacity-building needs, participation in existing networks, and perceived gaps in underserved children's access to health services was the focus of Phase 2 of the research. Two hundred and twelve individuals completed the survey.

Phase 3 consisted of a series of focus groups. Survey participants, who expressed the highest degree of interest in and intention to join a children's health network, were invited to attend one of three focus groups conducted. Sixteen individuals, employed by public and nonprofit, health and human services organizations in Wake County, which provide services to medically underserved children participated.

**Findings**

**Survey Results**

Survey participants represented a broad range of organizations offering a variety of services to the community. The analysis of survey results focused on the following areas: services provided, current collaborations, referral patterns, barriers to access, gaps in service provision, interest in network participation and barriers to participation. Key findings for each of these areas are outlined below.

Services provided: The top three most frequently identified health-related services offered were vision screening, speech and hearing screening and developmental assessments. The three least frequently mentioned were emergency dental services, psychiatric evaluation and routine dental treatment.

Current collaborations: Very few organizations were mentioned as collaborators by more than one organization and these few were primarily government agencies or government-supported programs. The top two goals of these collaborative efforts were identified as: “to provide direct service to children” and “to improve children’s general health and well-being”. The least frequently reported goals were: “to raise and disburse funds” and “to increase children’s access to resources and services.” The collaborations most frequently identified were with Smart Start, Wake County Public Schools and Wake County Human Services.

Referral patterns: The majority of organizations referred primarily to organizations of the same type as their own (i.e. day care providers referred to other day care organizations). The need for specialty care was overwhelmingly identified as the most frequent reason for making referrals, followed by the need for follow-up care.

Barriers to access: Few organizations identified barriers that might prevent children from access to services provided by their own organizations and the majority of agencies indicated that their organizations did not have waiting lists. This was contradicted by some reports that funding cutbacks had forced agencies to which respondents made referrals to maintain long waiting lists or turn away children in need of services. The most frequently identified barriers to accessing their own agency’s services were: caregiver work schedules, transportation, and the inability to speak English. Inadequate resources; poverty, lack of insurance and an inability to pay for services; and a complex medical system that is difficult to navigate were most frequently identified as community barriers to access.

Gaps in service provision: Too few healthcare providers, especially those who accept Medicaid and NC Health Choice patients; lack of insurance and an inability to pay for services; caregivers’ limited abilities to navigate the children’s healthcare system; transportation difficulties; difficulty scheduling appointments that fit into caregivers’ work schedules; and language barriers and the lack of multi-lingual staff were identified as the major gaps in service provision.

Interest in network participation: The vast majority of respondents reported being strongly or moderately interested in establishing new collaborative child health relationships; stated that their agencies were strongly or moderately interested in participating in the development of a child health network; strongly agreed or agreed that they would recommend that their organizations become involved; strongly agreed or agreed that a network would be consistent with the mission and goals of their organization; and strongly agreed or agreed that a children’s health network would increase children’s access to health services in Wake County. Most respondents said their organizations would benefit from participating in a children’s health network. The most frequent responses that participants articulated as ways that a network might improve children’s access to health care were: increasing the amount and accessibility of information about community resources that can meet children’s needs and provide practitioners with a better resource for making referrals; enabling agencies to serve more children by helping them publicize their services to other agencies and professionals, and offering opportunities for staff education and training to improve quality and effectiveness of services.

Barriers to participation: Fifty-four respondents did not identify any barriers that might prevent network participation. Other respondents expressed concern about resources that members might

be asked to contribute to a network including staff time and cost. Most respondents indicated that if participation required any financial contribution from their organization that they would not be able to participate. Others identified administrative, structural and/or mission constraints as potentially problematic.

### **Focus Group Results**

In general, the focus groups confirmed our survey findings. Common themes that arose in the focus groups were: poverty is an overriding issue; families need more help than they are getting; agencies need a mechanism for exchanging information; systemic issues complicate provision of services; it's hard to get children to services and services to children; children need medical homes and families need advocates.

### **Conclusions**

Analysis of the information provided by survey and focus group participants revealed that a functional, well-differentiated network does not exist within the community that provides health-related services to Wake County's underserved children. Community members strongly supported the idea of forming a Child Health Collaborative; stated that their agencies were interested in participating in such a collaborative; and identified benefits for Wake County's underserved children and for their agencies, that could be expected from involvement with a collaborative. Respondents were clear that financial costs and staff demands were potential barriers to participation.

Our findings also point to service gaps that could be the focus of initial activities undertaken by a Child Health Collaborative and/or could be addressed by the John Rex Endowment through collaborative grants and other capacity-building initiatives. A priority activity overwhelmingly supported by respondents is the development of a system to enable professionals to exchange agency and referral information. Additional activities include but are not limited to the development of services to help families navigate the complex health system; the provision of transportation to medical services; the expansion of service provider hours of availability; and increasing agencies' abilities to address language barriers.

Finally, it is clear that systemic issues cause significant child health access problems that cannot be solved solely by program grants or capacity building initiatives. Advocacy and lobbying are needed to change systems that result in such problems as: the lack of, or inadequate insurance, for the working poor; low provider reimbursement rates for the treatment of publicly insured children; and difficulties facing providers in obtaining comprehensive medical records on the children they serve. The Rex Endowment should consider what role, if any, it wishes to play in affecting public policy change to address these and other systemic problems that impact child health access.

### **Recommendations**

Survey and focus group data, and what is known about the process of community change, suggest a number of activities that the John Rex Endowment may wish to consider to facilitate collaboration, begin capacity building efforts, and address policy issues. These activities are designed to help the Endowment bring about significant, lasting changes that will improve the provision of health services to Wake County's underserved children.

We have suggested 17 activities (described in detail in our full report), which fall under four major categories. These categories are:

- Develop a Child Health Network
- Address Service Gaps
- Evaluate Network Progress
- Work for Systemic Change.

We recommend that as its next step to “Build a Child Health Collaborative” that the Endowment launch a Wake County Child Health Collaborative by sponsoring a Child Health Summit. We suggest that planning the Summit with interested agency representatives begin as soon as possible in order to capitalize on agency interest in a Collaborative that developed through participation in our research project. We recommend that the Summit be held in Spring 2006. We suggest that those individuals who completed our survey and decision makers from other agencies who provide health services to Wake County’s underserved children be invited to participate.

We propose that the Summit be used to further interest in a Wake County Child Health Collaborative and to gain agency commitment to participate. Event activities could include:

- Dissemination of our research results.
- Presentation by an inspirational speaker(s) who can share personal experience on the benefits of health collaboratives.
- Small and large group facilitated work sessions to develop collaborative goals.
- Networking opportunities during meals and breaks.

The purpose of these activities would be to:

- Promote interaction among participants.
- Begin the process of forming the collaborative.
- Select top priorities for initial efforts of the Child Health Collaborative.
- Begin discussions on key elements necessary for a coordinated Wake County information-sharing and referral system and explore how the Child Health Collaborative might develop such a system.

### **Acknowledgements**

We would like to thank Ann Goodnight, chair, and the members of the board of directors of the John Rex Endowment for their support of this research and their commitment to serving Wake County’s underserved children.

We are grateful to Kevin Cain, President and CEO, and McAllister Ross Myhra, Director of Operations of the Endowment, for providing us with all the information we needed, in a timely fashion and for the collaborative manner in which they worked with us.

This research would not have been possible without the efforts of Tyler Finnerty, MA candidate in Communication, who served as our graduate research assistant and our undergraduate research assistants from the departments of Communication and Social Work.

We would like to thank Jeff Leiter, PhD, Professor of Sociology and Research Director for the Institute and Deena Murphy-Medley, PhD candidate in Psychology and Research and Program Associate for the Institute for their contributions to this project.