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# **BUILDING A CHILD HEALTH COLLABORATIVE: A NETWORK ANALYSIS**

**A REPORT TO THE JOHN REX ENDOWMENT**

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## INTRODUCTION

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The mission of the John Rex Endowment is to invest in the development and support of activities, programs, and organizations that improve the health of underserved people in Wake and surrounding counties. Since its founding, the John Rex Endowment has played a key role in improving the health of Wake County's at-risk children by improving access to health services.

In summer 2004, the Endowment contacted the Institute for Nonprofits at North Carolina State University to explore how the Institute might assist the Endowment in identifying strategies the Endowment could use to expand its efforts to address children's access to health care. A series of discussions culminated in the Institute's development of a research proposal "Building a Child Health Collaborative: A Network Analysis". The Endowment commissioned this study, which commenced in October 2004 and was completed in December 2005. Natalie Ames, Ed.D., Assistant Professor of Social Work and Celeste Farr, Ph.D., Assistant Professor of Communication, conducted the study. It included a telephone survey and three focus groups, which collected information from organizations that offer health-related services and referrals to medically underserved children in Wake County, North Carolina. See Appendix A for information on the Institute for Nonprofits and the research team.

This report presents our findings and recommendations. The results provide the Endowment with the information necessary to:

- guide its future grant making priorities through the development of strategies designed to address the barriers and service gaps we identified.
- aid in decision-making regarding the creation of a collaborative network and to develop strategies to launch a collaborative using our findings.
- help it assess the role it may wish to play in the public policy arena by focusing on the key public policy issues we identified.

They can be used to plan and implement activities designed to bring about significant, lasting changes in the provision of health services to Wake County's underserved children.

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## CHILDREN'S ACCESS TO HEALTH CARE

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Developing strategies designed to improve at-risk children's access to health care requires an understanding of the key issues that affect access. The following provides an overview of the research literature about this issue.

**Lack of access to health care, both medical treatment and preventive care, affects children's immediate well-being and has potential consequences for their physical and mental health as adults.**

Many of the factors that decrease access to health care also increase the likelihood that children will have lower overall health status. Poverty is the most important determinant of children's overall health status and access to health care. Other significant factors, many of which overlap

and are associated with poverty, include: lacking health insurance coverage, having no regular source of health care, being Black or Hispanic, and having immigrant or non-immigrant parents who do not speak English or parents with low educational attainment (Meezan, 2000; Weinick & Krauss, 2000).

Research indicates the most vulnerable children are those who:

- are involved in the child welfare system.
- need assessment and treatment for mental health and developmental problems.
- need specialty or dental care.
- are adolescents.

**The best predictor of access to health care is having health insurance.**

Uninsured children have lower overall health status and more unmet health needs (Fox, Moore, J., Davis, R., & Heintzelman, 2003; Wise, 2004). They are half as likely as insured children to receive well-child care (Chung & Schuster, 2004). Having insurance, however, does not guarantee that children will receive the health care they need (Chung & Schuster, 2004; Dick et al., 2004).

**Families play a vital role in children's access to health care.**

Most children with private health insurance are covered by their parents' employer-based insurance. If parents do not have health insurance, they are responsible for enrolling their children in Medicaid or the State Children's Health Insurance Program (SCHIP). Caregivers must understand the importance of preventive care, be able to recognize signs and symptoms of acute and chronic conditions, and have the knowledge and resources to seek treatment when needed. Parents without transportation, financial resources to pay for care, or language skills to communicate with providers may delay treatment until a health condition becomes serious or a crisis occurs.

**Publicly insured children (i.e., those covered by Medicaid or SCHIP) have less access to health services than children with private insurance** (Lourie & Hernandez, 2003; Simpson, Zodet, Chevarley, Owens, Dougherty & McCormick, 2004).

Because of low reimbursement rates, many physicians will not treat patients with public insurance (Simpson, Zodet, Chevarley, Owens, Dougherty, McCormick, 1999; Wise, 2004). These children also have difficulty getting referrals to specialists (Simpson et al., 2004). Gaps in public insurance programs often leave adolescents and young adults who have severe medical conditions with no coordinated health care or support services for conditions that will continue to affect them as adults (Wise, 2004).

Note: The State Children's Health Insurance Program (SCHIP), called NC Health Choice in North Carolina, covers low-income children from families that earn too much to be eligible for Medicaid but lack affordable employer-based health insurance. Research indicates that enrollment in SCHIP reduces, but does not eliminate, unmet health needs (Dick et al., 2004; Fox et al., 2003).

**A regular source of primary care is a critical factor in children's access to health care** (American Academy of Pediatrics, 2000; Chung & Schuster, 2004; Jaudes, Bilaver, Goerge, Masterson & Catania, 2004).

Children without insurance are less likely to have a regular source of health care and are the least likely to receive regular health services. Families without a regular source of health care often use emergency departments for non-emergency needs (Chung & Schuster, 2004; Waibel, 2001).

**It is often difficult for families to obtain treatment for children's mental health problems.**

Children who begin treatment for mental health problems frequently drop out (Staudt, 2003). Children involved in the child welfare system, whether they are in foster care or living at home, are at especially high risk for mental health problems (American Academy of Pediatrics, 2000; Burns, Phillips, Wagner, Barth, Kolko, Campbell, et al., 2004). Those who remain at home after a child welfare investigation are least likely to receive services (Burns et al., 2004).

**Children involved with the child welfare system have the poorest health of all children whether they live in foster care or with their biological parents** (Jaudes et al., 2004; Silver, DiLorenzo, Zukoski, Ross & Schlegel, 1999).

They often need assessment and treatment for a wide range of physical, mental, dental, and developmental needs (Silver et al., 1999) but are the least likely to get these services. Infants and young children are the fastest growing population entering foster care (American Academy of Pediatrics, 2000). Very young children subjected to physical abuse, emotional neglect, malnutrition, and sickness may have lifelong adverse consequences without early intervention (American Academy of Pediatrics, 2000; Silver et al., 1999).

*Clearly, many factors affect children's access to health care. This complicates efforts to develop and implement strategies designed to improve access and points to the need for comprehensive, coordinated activities to address this complex social issue.*

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## COMMUNICATION NETWORKS

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A primary goal of this project was to evaluate the nature of any existing communication network among Wake County organizations working with underserved children. Creating a collaborative network of organizations requires an understanding of the communication theory that describes the function and benefits of networks. Below is an overview, from the research literature, that describes what a communication network is and how it functions.

### **The definition of a communications network**

A communication network can be defined as "a set of nodes connected together by links of one kind or another. The nodes may be persons, groups, or other units" (Klov Dahl, 1985, p.1203). A network of organizations can be the vehicle for coordinating efforts to address social problems such as lack of access to health care.

### **The function of communication networks**

Multi-organizational networks can empower individual organizations when they use a democratic management process that allows members to share information and power, make cooperative decisions, and collectively design, implement and control efforts to achieve group-defined goals (Goodman et al., 1998; Israel, Checkoway, Schulz, & Zimmerman, 1994). Many inter-organizational networks evolve from informal, loosely linked organizations that exchange information to formal networks with formal linkages that foster and encourage engagement in joint activities (Alter & Hage, 1993; Goodman et al., 1998). Some scholars have suggested that “communities with more evolved inter-organizational networks are better able to mobilize to address public health or social problems than communities with networks in earlier developmental stages” (Goodman et al., 1998, p.268).

*If the goal is to increase children’s access to health care, a highly evolved inter-organizational network would serve Wake County well.*

### **The function of communication links in information exchange**

In order to evaluate the potential for information exchange within a communication network, it is important to assess the number of existing links. The links are the available routes for distributing information and affect the likelihood that information will reach any particular network member (Weenig & Midden, 1991). The more communication links that exist among network members, the more likely that all members of the network will receive the information regardless of how strongly they are linked to the network.

*Many links among network members would foster greater information exchange.*

### **The impact of the strength of communication links on network effectiveness**

The strength of communication links in a network encompasses the time and emotional intensity members invest, the degree of intimacy they develop, and the reciprocal activities they engage in (Granovetter, 1973). Communication links among members of a network can be either weak or strong. Both types are necessary in a communication network.

Weak links allow flexibility and promote efficient, effective information exchange among organizations. They help to transmit messages across organizational barriers because they require less cohesion and less perception of homogeneity among members than do strong links (Nelson & Matthews, 1991). Weak links “should promote the efficiency, adaptability, and information exchange necessary for high performance” (Nelson & Matthews, 1991, p.370).

Indicators of strong links include multiple contacts with key people or organizations; group dialogue sessions that build trust and confidence; an atmosphere of respect and cooperation; the exchange of resources, information, activities, and learning through group sessions; and follow-up work groups (Kramer & Wells, 2005). Strong links can foster the loyalty needed to overcome self-interest, encourage the coordination necessary for high performance, and can help to maintain common expectations among network members (Nelson & Matthews, 1991, p.370). In a strongly linked network, we would expect to see a large contact base, many shared projects,

and frequent exchanges among network members. Strong links within a network provide more opportunities to distribute information than do weak links. However, strong links may result in the formation of subgroups within the larger network (Weenig & Midden, 1991).

*A balance between strong and weak links is necessary to maximize network effectiveness.*

### **Identifying communication networks**

To determine the nature of the communication network in a specific community, researchers must evaluate the links between the nodes or entities that comprise the network. This can be done by examining:

- structural characteristics, such as the number of links;
- relationships among network members, such as the number, intensity and frequency of contact;
- benefits that members receive from their linkages, such as access to social contacts or tangible support; and
- organizations' perceptions of reciprocal favors or obligations (Goodman et al., 1998; Kramer & Wells, 2005).

For the purpose of this study, the nodes were government, faith-based, nonprofit and community health and human service organizations and for-profit organizations that work with medically underserved children.

*A network analysis, designed to evaluate the links between nodes, can provide information about whether a network exists, and if so, identify the strength of the links among network members.*

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## **METHODS**

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For the John Rex Endowment to realize its goal of increasing at-risk children's access to health care, it must know which organizations are currently or potentially committed to the same goals. The Endowment must also have an understanding of the nature and function of the communication network that exists among these organizations. This research project systematically surveyed the community to identify those organizations, and to assess the status of the communication network among them, using three phases of data collection.

### **Phase 1**

Phase 1 consisted of a telephone survey of 1275 local nonprofit, for-profit, government and faith-based organizations. We created the contact list from the United Way's 2-1-1 list of human services providers. Additions to that list included daycare centers (excluding in-home providers), schools, and John Rex Endowment grantees. We were able to contact 748 of the 1275 organizations on the Phase 1 list. The 59% response rate (i.e., the number of organizations on the contact list divided by the number of contacts attempted) for Phase 1 is an acceptable rate for a telephone survey.

The purpose of the Phase 1 survey was to screen organizations and identify those that had contact with underserved children. (See Appendix B.) To qualify for participation in Phase 2, organizations had to serve children or families with children under the age of 18. The organizations' clients also had to meet at least one of the following criteria that signal healthcare risk:

- Live in a single parent-household.
- Live with an unemployed parent.
- Receive welfare assistance.
- Live with a parent(s) with less than a high school diploma or GED.
- Have no health insurance.
- Meet income eligibility guidelines to receive services.
- Be homeless.

The 423 organizations that met the screening criteria were asked if they provided direct services, referrals, or both. They were also asked to provide the contact information for the individuals in their organization who: (a) had authority to make organizational decisions, (b) could best describe the services provided, and (c) could best describe the referral process.

The final Phase 1 interview question asked respondents to name any persons or organizations that they felt we should contact regarding a children's health network. This resulted in an additional 93 individuals being added to our contact list, which brought the total number of individuals to be contacted in Phase 2 to 516.

**Phase 2**

Phase 2 was an in-depth telephone survey designed to identify the populations that the respondents' organizations served, the services they provided, the referrals they made, and the barriers that prevent access to care. (See Appendix B.)

We were able to contact 340 individuals out of the 516 on the list. Of those contacted, 212 individuals, representing 203 eligible organizations, fully completed the survey. The Phase 2 data analysis is based on their responses. There were 112 individuals who, once contacted, declined to participate, did not finish the Phase 2 survey, or gave data that were not useful for analysis. (A summary of the reasons they did not fully participate is listed below.) Twenty-two individuals were determined not to meet the criteria for participation. An additional 192 individuals never responded to any of our various contact attempts. The Phase 2 survey, therefore, had a response rate of 43% (i.e.,  $212 / (212 + 112 - 22 + 192)$ ).

Respondents' reasons for nonparticipation	# of respondents
Not interested in the survey	44
Respondent did not feel qualified to respond	25
The respondent was unable to participate	11
Respondent determined that they did not fit the criteria	5
Felt they had completed the survey but in fact had not	3
Did not complete survey	2

The 43% response rate we achieved is equivalent to or greater rate than that of many published organizational surveys. Although we would have preferred a response rate in excess of 50%, we analyzed the data recognizing that we must be cautious about interpretation given the modest response rate.

### **Phase 3**

In October 2005, we conducted three focus groups as a follow-up to the community-wide telephone survey. Their purpose was to explore, in more depth, issues related to children's access to health care. Participants were selected based on their responses to the telephone survey. We invited survey respondents who expressed the highest degree of interest in and intention to join a children's health network. We attempted to contact 66 individuals by telephone to invite them to attend. We reached 46, of whom 31 agreed to attend. A total of 16 actually participated. Two cancelled prior to the focus group meetings, and 13 did not show up. Eight of the nine scheduled for the first group attended; five of the eight scheduled for the second group, and three of the 12 scheduled for the third group attended. The best response was for an early morning breakfast meeting. This may have implications for scheduling future network activities.

Participants were employed by health and human services organizations in Wake County that provide services to medically underserved children. They represented both governmental (Wake County Human Services) and nonprofit organizations. Fourteen held administrative positions; two were direct service providers.

The interview protocol consisted of the following six questions:

1. In your opinion, what barriers prevent children's access to health care in Wake County?
2. How would you suggest our community address the barriers you identified?
3. If your agency's resources (i.e., time, staff, funds) were unlimited, what would it do to increase children's access to health care?
4. What, besides money, would help your agency play a more effective role in increasing children's access to health care?
5. What do you think would be the most effective way for your agency to interact with other organizations in this community to increase children's access to health care?
6. What is the most important thing a children's health network could accomplish to increase children's access to health care in this community?

Each focus group was audio taped and a co-facilitator took notes. A professional transcriptionist transcribed the tapes verbatim. All groups lasted one and one-half hours. The second and third groups responded to all six questions and a final summary question: Is there anything we haven't discussed that you think we should know? The first group discussed the first four questions and the final summary question.

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## SURVEY FINDINGS

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Survey participants represented a broad range of organizations offering a variety of services to the community. Individuals classified their organizations as nonprofit (n = 112), for-profit (n = 56), government (n = 31), and faith-based (n = 4).

### Survey Findings Regarding Services

To learn more about available services, we asked what services organizations offered and about barriers to service access and gaps in service provision.

#### **Services offered**

The following table summarizes the health-related services offered by respondents' organizations. The most frequently mentioned services were vision screening, speech and hearing screening, and developmental assessment. Some organizations offered multiple health-related services. The table represents the total number of times each service was identified.

<b>Health-related services offered</b>	<b># of times identified</b>
Vision screening	68
Speech and hearing screening	61
Developmental assessment	52
Mental health assessment	29
Mental health treatment	23
Well-child exams	21
Immunization	17
Routine dental treatment	16
Psychiatric evaluation	16
Emergency dental services	8

#### **Translation/interpretation services**

Language is a critical element in service provision (i.e., communication between healthcare consumers and providers). Because there is a significant and growing immigrant population in this area, we asked survey participants about the languages spoken by their clients. We found that 88 percent of the respondents (n = 186) reported working with children who spoke languages other than English. Not surprisingly, the language most identified was Spanish (n = 175).

Sixty-nine percent (69%) of the respondents who serve non-English speaking children (n = 143) have access to resources for translation and interpretation. Of these, 113 respondents reported having in-house resources. Some organizations reported using external resources for

translation/interpretation services. The following chart summarizes the types of external community resources organizations use.

<b>Community resources utilized for translation/interpretation</b>	<b># of times identified</b>
Community nonprofit/faith-based organizations	28
Bilingual staff or volunteers	21
Government programs or services	21
Phone/Internet translation services	12
Bilingual literature	10
Contract translation/interpretation services	9
Bilingual parents or family members	7

### **Barriers to access**

We asked survey respondents about barriers families encountered in trying to obtain health-related services both within and outside their organizations. As the following table illustrates, a relatively small number of respondents identified barriers that might prevent children from access to the services provided by their organizations.

<b>Barriers to your agency's services</b>	<b># of times identified</b>
Caregiver-provider schedule conflicts	24
Transportation	22
Inability to speak English	16
Caregiver physical or mental illness	9
Responsibility for other children	7
Inability to pay	5

Barriers in the community that prevent children from receiving health services were identified by 199 respondents. Common barriers, identified both within and outside respondents' organizations, were transportation, inability to pay and caregiver-provider schedule conflicts.

<b>Community barriers to access</b>	<b># of times identified</b>
Inadequate resources (too few providers; providers unaware of children's needs; providers refusing to accept Medicaid or NC Health Choice)	74
Inability to pay for services (poverty, lack of insurance)	62
Complex healthcare system difficult for many parents to navigate	46
Transportation	30
Caregiver-provider schedule conflicts	22

The majority of respondents told us their organizations did not maintain waiting lists. However, some reported that funding cutbacks had forced agencies to which they referred to maintain long waiting lists or turn away children in need of services.

### **Gaps in service provision**

An examination of the barriers that prevent access to health care discloses gaps in service provision. Some of these gaps can be addressed at the local level; others will require policy change. The *Recommendations* section of this report discusses potential actions at the local and policy levels. Following is a summary of areas of concern.

#### ***Inadequate community resources***

Some respondents reported that there were too few providers available, especially providers who accepted Medicaid and NC Health Choice patients. There was also the suggestion that some healthcare providers were not knowledgeable about children's health needs.

#### ***Poverty, lack of insurance and inability to pay for services***

Children with public insurance coverage may have difficulty finding practitioners who will treat them. Close to 50% of survey respondents provide services to children who are uninsured. Many of these children's families do not qualify for public insurance programs, cannot pay out-of-pocket for health care, and do not have access to employer-based insurance or cannot afford it if it is available.

#### ***A complex healthcare system difficult for parents to navigate***

Caregivers' knowledge of the healthcare system, health literacy, educational achievement, and language abilities all have an impact on their ability to make their way through the systems that provide children's healthcare.

#### ***Transportation***

Families without cars may depend on a public transportation system that may not run when and where they need it. Even for those who regularly use public transportation, finding out how to use the bus to get to an unfamiliar location can be difficult.

#### ***Caregiver work schedules and service providers' hours of availability***

Parents or other caregivers who work late shifts or multiple jobs or whose employers will not give them time off during the day, may have difficulty making appointments that fit their schedules.

#### ***Language barriers and lack of multi-lingual staff***

Wake County is home to increasing numbers of families who speak languages other than English.

## Survey Findings Related to a Child Health Network

In addition to asking about services provided, we also asked respondents questions to determine whether a network exists among organizations that provide services to medically underserved children. This section of the survey included questions about current collaborations, referral patterns, interest in participating in a child health collaborative, perceived benefits of participation and barriers to participation.

### **Current collaborations**

To build future collaborations, it is important to determine the nature of existing collaborations. Collaboration among human services organizations should enable them to share resources and information, use community-wide resources efficiently, and improve clients' overall access to services that meet their needs. A total of 142 survey respondents reported that their organizations collaborated with others. The table below illustrates the general goals of these collaborative efforts.

Goals of collaborative efforts	# of times identified
Provide direct services to children	52
Improve children's general health and well-being	40
Educate families, professionals or community members about issues or resources	27
Increase children's access to resources or services	18
Raise and disburse funds	5

The fact that the community does not function as a well-integrated network is exemplified by the reported collaborations among organizations. In a well-integrated network, collaborating organizations should frequently overlap, so that the majority mentions a few organizations frequently. This is not what we found. In general, very few organizations were mentioned by more than one organization. Of the few that were mentioned most frequently, almost all were government agencies or government-supported programs. The following table outlines the organizations most frequently mentioned as collaborators.

*The agency names have been removed from this table to maintain confidentiality.*

Collaborators most frequently mentioned	# of times identified
	19
	16
	15
	14
	7
	6
	6

### **Referral patterns**

Organizational referral patterns include how often referrals are made, to which organizations, and for what services. Eighty-four percent (n = 178) of respondents reported that their organizations referred children to other agencies in the community for health-related services. The following table outlines the reasons respondents gave for making referrals.

Reasons for making referrals	# of times identified
Children need specialty care	116
Children need follow-up care	49
Families cannot pay for treatment	22
Respondents' agencies lack capacity to serve the number of children in need of services	15

Referrals are only effective if children receive the services for which they are referred; therefore we asked respondents whether they did any follow-up of referrals. Most respondents (n = 136) did report doing so to ensure that children received the services. Of the 127 respondents who described how their organizations followed up on referrals, 72 indicated that they “usually,” “often,” “sometimes” or “on a case-by-case basis” followed up by calling, writing or speaking with the child’s parents. Twenty-eight described routinely receiving verification from agencies to which they referred. Eight reported that referral services were performed on-site thus ensuring that children received them. Two followed up with either the family or the agency to which they referred. Fourteen indicated they did some follow-up but did not say with whom. Three respondents said they “make sure [the children] go” but did not specify how they did so.

Referral patterns are one way of examining the inter-relationships among members of a network. In a well-developed network, members would refer children to many different organizations offering a variety of services both similar to and different from their own. We did not find this among the organizations we surveyed. Although many respondents referred children to government agencies or health providers, one important finding was that the majority of organizations referred primarily to other organizations of the same type as their own (e.g., daycare centers named other daycare centers).

Further evidence that a network does not currently exist in Wake County was revealed by asking respondents for the names of other organizations they thought should be included in a survey about children’s health issues. Respondents mentioned primarily government agencies, health providers, or organizations of the same type as their own. In a well-developed network, we would expect organizations to suggest organizations in the community that provide services different from those offered by their own organizations.

The following table lists the categories of resources to which respondents reported making referrals.

Organization category	# of times identified
Government programs	102
Physical, dental and mental health providers	86
Education (schools/daycare centers)	66
Associations	54
Private nonprofits	36
Churches/faith-based	35
Group homes/shelters	16
Youth sports/activities	16
Library	1

**Interest in a child health collaborative**

The community appears to be ripe for the development of a health network to increase underserved children’s access to health care. The responses of the 212 survey respondents to the following questions illustrate the community’s desire to develop such a network:

***“How interested are you in establishing new collaborative relationships to work on children’s health issues?”***

127 were “strongly interested” and 41 “moderately interested.”

***“How interested would your organization be in participating in the development of a children’s health network?”***

123 individuals were “strongly interested” and 40 were “moderately interested.”

***“I would recommend that my organization become involved in a children’s health network.”***

80 individuals “strongly agreed” and 115 “agreed.”

***“A children’s health network would be consistent with the mission or goals of my organization.”***

88 individuals “strongly agreed” and 107 individuals “agreed.”

***“A children’s health network would increase children’s access to health services in Wake County.”***

112 “strongly agreed” and 92 “agreed.”

There were no negative responses (i.e., disagreed, strongly disagreed) to this statement, which indicates strong support in the community for the development of a children’s health network.

### **Perceived benefits of a children's health network**

Answers to a question about the perceived benefits of forming a children's health network offer additional information about perceived gaps in current capacity as well as ideas for areas on which a network might focus. Of the 203 individuals who answered this question, 188 said their organizations would benefit from participating in a children's health network and many cited multiple areas of need. Although 34 focused on generic benefits such as maintaining and improving children's health and increasing access to services, many respondents articulated specific areas in which a network might improve children's access to health care by:

- increasing the amount and accessibility of information about community resources that can meet children's needs and provide practitioners with a better resource base for making referrals (n = 54);
- enabling agencies to serve more children by helping them publicize their services to other agencies and professionals (n = 41);
- offering opportunities for staff education and training to improve quality and effectiveness of services (n = 40);
- developing a coordinated, centralized system to provide information on health topics and referral resources (n = 28);
- coordinating efforts among agencies to encourage continuity of care and reduce duplication of services (n = 28);
- facilitating the development and availability of specific resources such as transportation, screenings, dental care, and mental health treatment (n = 22);
- facilitating partnerships with specific types of agencies or practitioners, primarily social services, public health, and physicians (n = 18);
- improving inter-agency communication to expedite referrals and exchange of information about programs and services (n = 18);
- connecting children with services by bringing specific services such as screenings, examinations, and treatment on-site or providing a means to transport clients to services (n = 16); and
- providing information, instruction, and/or opportunities for grant writing and other kinds of fundraising (n = 16).

### **Barriers to participation**

Before discussing recommendations based on this network analysis, we must consider the barriers community members identified that might prevent them from participating in a children's health network.

There were 194 responses to a question about organizational barriers that might prevent network participation. Although 54 respondents identified no barriers that would prevent their agencies from participating in a children's health network, many organizations do face potential barriers. Half of the respondents (n = 97) expressed reservations about resources members might be asked to contribute to a network. These concerns centered around demands on agency staff, time required (including the possibility of additional paperwork), and expenses. Among respondents with resource concerns, 68 specifically stated that time and staff constraints might preclude

participation. Of the 29 who specifically mentioned cost, most indicated that if participation required any financial contribution, their organization would not participate.

Forty-five respondents identified administrative, structural and/or mission constraints within respondents' organizations as potentially problematic. For example, some indicated their agencies would need approval from 'higher-ups' in order to participate. Others said their agencies focused very specifically on issues such as homelessness, foster care or mental health and indicated that any role they might play in a network would have to be consistent with their organization's primary goal/mandate and involve work with their specific target populations.

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## **FOCUS GROUP FINDINGS**

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The majority of the issues that focus group participants identified were consistent with those identified in the telephone survey. However, focus group participants also brought up several issues of concern that did not emerge from the telephone survey.

### **Focus group findings that support survey results**

#### **Poverty is an overriding issue.**

Most participants described working with families who are poor and who have multiple needs. They often lack transportation to take their children to medical appointments. This, in turn, affects their ability to keep appointments. Parents who cannot afford to take time off from work, or who have employers who will not allow time off, do not have access to services available only during working hours. Participants pointed out that families classified as working poor, who have no insurance, "fall between the cracks." Their children have less access to care than those who are publicly or privately insured.

Participants recognized that when families are struggling to survive financially, basic needs such as food and shelter come before health care unless the condition is urgent. These families may only use the healthcare system for crises or emergencies and often do not recognize their children's health needs.

#### **Families need more help than they are getting.**

Parents, who are poor and who have little formal education and/or who do not speak English, often do not know where to take their children for health care and are unaware of existing local resources. They may not understand the health information professionals provide to them. They may also have difficulty navigating the complex healthcare system to find and take advantage of what their children need.

#### **Agencies need a mechanism for exchanging information.**

Agency representatives told us that they lack information about "who's out there doing what" that would enable them to connect families with the health-related services their children need. Practitioners may be aware that children they see need services they do not provide, but often

they do not know where to send them for those services. Participants also said they have difficulty getting information about their services out to the public, professionals who work with children, and families whose children could benefit from their services.

To address the problems outlined above, participants wanted a mechanism for exchanging information about agencies and services. They expressed a strong desire for a directory despite acknowledging the difficulty and expense of keeping such a tool up to date. Although some currently use the United Way's 2-1-1 service, they agreed that as currently structured, it is unable to respond to the specific questions practitioners have. Some would be happy with an on-line resource that could easily be kept current. Others strongly desire a print directory "in hand" because they do not have "time to run and call someone" although they recognized that such a directory would quickly become dated.

**"It's hard to get children to services and services to children."**

Participants felt that one way to improve access would be to provide services in local communities. This could serve to alleviate transportation problems, offer providers more access to patients, and make information, education and health services more accessible to families. Participants' ideas for implementing community-based services ranged from instituting mobile clinics to using churches and community buildings and included not only direct service provision but also outreach and public education.

**Organizations can benefit from participating in a children's health network.**

Focus group participants' indicated that a children's health network could help them to address both agencies' and children's needs. They wanted it to serve as a vehicle for providing current information about community services to families, caregivers, daycare providers, and teachers and exchanging information between "the folks who are providing services so you know about me and I know about you." They felt a network could create a directory of services.

Participants thought it would be important to involve in the network professionals with "passion or compassion...who will have a commitment to do something." They also recognized the need to include the decision-makers responsible for agency policies and procedures. They saw a network, as a means to get providers to communicate and examine ways to pool resources to collectively meet needs individual agencies cannot meet alone. One group pointed out that having to share funding could serve as a mechanism for forcing agencies to "share policies, procedures, and referral systems" and to examine and address duplication of services.

Participants expressed enthusiastic support for the idea of a children's health network. They also wanted to be sure that they conveyed the message that funding is never far from their minds. Although some use volunteers, they cannot depend on volunteers to provide services. They must be able to pay staff. As one participant put it: "You've got to have somebody to provide services, and reach out to the community, and do the education, and provide the transportation. You can only do so much. You have to care about people but you need the money to provide services."

## **Additional issues identified by focus groups**

### **“The system” complicates provision of services.**

Governmental agencies struggle to incorporate and adhere to frequently changing state mandates, rules, and definitions. Especially problematic are legislative mandates that require state agencies to provide new services or initiate new procedures for which they receive no funding.

Participants described a healthcare landscape in which decreasing funding for mental health services and developmental assessment has reduced children’s access to care. They noted that public or private insurers rarely fund dental care. For families without insurance, obtaining any of these services is especially problematic.

The Medicaid system itself presents barriers to access. Low Medicaid reimbursement makes many providers reluctant to take Medicaid patients. Additionally, because families of publicly insured children are poor and often lack transportation, they also have a higher “no show” rate, which discourages providers from serving them. For families, the application process is complicated as is the process for maintaining their children’s eligibility. Participants expressed the wish for a way to educate public about how to use Medicaid program, “who can be eligible, what you need to do.”

### **“It’s all about money.”**

The need for more funding was a recurring theme. Many participants expressed a desire for additional staff. The majority of survey respondents told us their agencies did not have waiting lists. In contrast, focus group participants indicated that adding healthcare professionals to their staffs would help them reduce long waiting lists and that adding support staff would give them the resources to advise, counsel, advocate for and follow families, and coordinate services, especially for families who do not speak English.

While grateful for foundation grants, participants would like to see more flexibility and coordination among funders. If funders required less paperwork and worked together to coordinate the type of reporting they asked for as well as the timing of those reports, agency staff could use the time they saved to provide services. Participants also pointed out that grants that fund additional services can strain their agencies’ capacity. One participant reported being able to get money to cover the cost of delivering specific services, “However, I can’t build capacity because I’ve already doubled the service with no change in office space, no change in secretaries, no change in billing, no receptionist, no ability to pay the health insurance of new hires.... I could hire more people to deliver that service, but I can’t support them. I don’t have an office to put them in.... it’s almost impossible to find any source of income that will pay for that.”

### **Children need medical homes.**

Participants felt strongly that children need a “medical home” to ensure continuity of care. Children without a “medical home” often see many providers. Without a system for coordinating services and information, practitioners cannot get vital health information about children they may see only once or occasionally. Participants described “a fully functioning medical home” as

a system that would begin at or before birth to comprehensively identify children’s health needs. It would encompass screening, diagnosis, treatment, and follow up, and help parents obtain all the services their children need. Children’s health records would be stored in one place and accessible to practitioners working with that child.

**Families need advocates.**

Participants pointed out how difficult it is for people who are educated and insured to obtain the health-related services their children need, especially if the children have special health needs. All agreed that these difficulties can be overwhelming to parents with little education and few resources who live in poverty. Medical care for their children is often fragmented and inadequate. These families may only seek care for their children when a serious illness or crisis occurs.

One proposed solution to improve continuity of care and assist parents who lack the requisite education and knowledge to make their way through the healthcare system was to train paraprofessionals from the community as family advocates or mentors to help families navigate the healthcare system. Their role would be to make home visits “to show families how to access different agencies and to receive services.” They would offer families information; teach them about parenting, prevention and health issues; connect them with appropriate services; assist them to navigate the system, and follow up to make sure children actually received appropriate services. Such a system could be incorporated within a medical home or stand alone as a service to families.

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## **RECOMMENDATIONS**

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Survey and focus group data, and what is known about the process of community change, suggest a number of strategies that the John Rex Endowment may wish to consider as it plans to expand its efforts to improve child health access in Wake County. These strategies fall within four major categories: addressing service gaps, developing a child health collaborative, evaluating progress, and working for systemic change. We have described projects designed to facilitate establishment of a functioning child health network and, concurrently, address service gaps and barriers to children’s access to health care. A report section that provides supporting documentation for these recommendations follows.

**Address Service Gaps**

1. Develop a centralized system to enable professionals to exchange agency and referral information to facilitate contact, communication, collaboration and resource coordination.
2. Address gaps in access for medically underserved children by funding an initiative to develop a “pediatric patient navigator” system to assist families of underserved children.
3. Ensure continuity of care for all children in the child welfare system, particularly those in foster care, by expanding upon the Rex Endowment funded Children's Health and

Development Program. With Wake County Human Services, develop a “Health Passport” database system and liaison services to provide health information to all individuals involved in caring for these children.

4. Identify organizations that work with the most vulnerable children and offer them organizational assessment support followed by capacity-building support.
5. Offer partnership grants to organizations willing to collaborate to address specific service gaps or barriers to service, over a period of time, to achieve measurable outcomes.

### **Develop a Child Health Network**

6. Convene a Children’s Health Summit designed to launch the Network at which organizational representatives can exchange information, identify priorities and initiate working partnerships.
7. Provide task-oriented workshops to community organizations designed to assist in the formation and effective functioning of the Network and the partnership grant projects.
8. Provide administrative and technical support for the Network through a neutral party.
9. Offer mini-grants to small organizations willing to make a minimum one-year commitment to engage in specific Child Health Network activities.

### **Evaluate Progress**

10. Evaluate the Children’s Health Summit.
11. Monitor ongoing activities of the Child Health Network in order to guide changes and fine-tune efforts.
12. Evaluate individual projects and capacity-building activities that emanate from the Network’s efforts and disseminate findings on “what works” (evidence-based practices).
13. Build evaluation capacity and promote the use of outcomes assessment as an organizational learning tool among the Network’s grantees that are funded with partnership grants.
14. Re-evaluate the community, to assess progress, at regular intervals, in order to determine long-term, community-wide change and guide future strategic grant making efforts.

### **Work for Systemic Change**

15. Advocate for North Carolina to create a “medical home” system for children.
16. Advocate for insurance coverage for the working poor who earn too much to be eligible for public insurance and too little to afford private insurance.
17. Advocate for higher Medicaid and NC Health Choice reimbursement levels to encourage providers to treat publicly insured children.
18. Advocate for universal health coverage for all Americans.

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## SUPPORT FOR RECOMMENDATIONS

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This section of the report provides our rationale, based on a comprehensive review of the academic literature and our survey and focus group findings, for the previously listed recommendations for action.

### Address Service Gaps

1. *Develop a centralized system to enable professionals to exchange agency and referral information to facilitate contact, collaboration and resource coordination.*

**Explanation:** Survey respondents noted that they often need, but cannot locate, information about community resources to meet specific health needs for the children with whom they work. Focus group participants identified this need as well. Many organizations also expressed interest in forming collaborative relationships, but do not have a tool they can use to identify organizations with which they should initiate contact. A centralized resource would save time and enable them to make appropriate contacts, which will in turn facilitate referrals and begin building collaborative relationships.

2. *Address gaps in access for medically underserved children by funding an initiative to develop a “pediatric patient navigator” system to assist families of underserved children.*

**Explanation:** Survey respondents indicated that many children do not receive needed health care because the healthcare system is too complex and fragmented for their parents. Focus group participants also reported this. The ability to link children’s caregivers with patient navigators could address many of the barriers to care survey respondents identified. The patient navigator’s role includes providing patient education, emotional support, transportation, translation services, and referrals to needed health services. Some patient navigators provide services to patients with specific illness such as cancer. Others work with specific populations such as Native Americans. Potential candidates for this role include nurses, social workers, retired nurses or other hospital employees, and the parents of former patients (Curran, 2003).

3. *Ensure continuity of care for all children in the child welfare system, particularly those in foster care, by expanding upon the Rex Endowment funded Children's Health and Development Program. With Wake County Human Services, develop a “Health Passport” database system and liaison services to provide health information to all individual involved in caring for these children.*

**Explanation:** A health or medical passport is a paper or computerized health record with all of a child’s significant health information. Its purpose is to ensure continuity of care and avoid gaps in the services children receive. A model health passport system in California used a centralized computerized database to maintain and distribute health and education records for children in out-of-home care and employed public health nurses to review health information and consult with foster parents, social workers, and health providers (Lindsey & Chadwick, 1993). A Guilford County, NC, health passport program

uses a public health nurse as liaison between agencies and families and as a case manager to ensure provision of health assessments and follow-up services. The nurse works with social workers, trains foster parents, and gives a health passport packet to foster families or other caregivers for children in protective custody (National Academy for State Health Policy, n.d.).

**4. *Identify organizations that work with the most vulnerable children and offer them organizational assessment support followed by capacity-building support.***

**Explanation:** The groups of children most likely to be medically underserved include children whose parents lack insurance, children in foster care, and children with immigrant and non-immigrant parents who do not speak English. Our survey has identified 22 nonprofits that work with Wake County's most vulnerable children. We have listed these organizations in Appendix C. The Endowment may wish to offer these nonprofits organizational assessment support followed by capacity-building support.

The first step in organizational capacity building should be to assess the assets nonprofits have to work with (Jones, 2003). This can only be accomplished if organizations have the resources to support the time and effort such assessment requires. "Bringing organizational capacity up to scale to deliver essential services and programs is one of the continual challenges of the nonprofit sector" (De Vita, Fleming, & Twombly, 2001, p.19). Capacity-building grants could motivate organizations to assess capacity-building needs. Such grants could also support specific capacity-building activities and projects.

Technical assistance to nonprofits for capacity building is generally under-funded, yet nonprofits can benefit from funding provided to intermediaries with the expertise to provide technical assistance. Intermediaries can help nonprofits to develop interventions designed to meet their needs and address problems they define (Draper, 2000).

**5. *Offer partnership grants to organizations willing to collaborate to address specific service gaps or barriers to service, over a period of time, to achieve measurable outcomes.***

**Explanation:** These gaps and barriers could include those identified through the survey and focus groups, i.e., transportation, service provider hours of availability and language barriers. The Endowment could issue a Request for Proposals (RFP) for partnership projects that encourage organizations to collaborate. Such proposals should clearly identify the roles and responsibilities of the partnering organizations and discuss how proposed partnerships would achieve outcomes more far-reaching than those achievable by agencies working independently.

## Develop a Child Health Network

- 6. Convene a Children's Health Summit, designed to launch the Network, at which organizational representatives can exchange information, identify priorities and initiate working partnerships.*

**Explanation:** A summit is a powerful tool for bringing disparate organizations together to problem-solve, network, and engage in collaboration. This event would be “a formal meeting of individuals, from various organizational groupings, temporarily called together, away from organizational the organizational setting, for the purposes of increasing understanding, agreement, and interactions related to common organizational goals” (Johnson et al., 1996, p.234). The common goal would be to increase underserved children's access to health services in Wake County. *The Priorities and Next Steps section of this report describes the steps necessary to host a Children's Health Summit.*

- 7. Provide workshops to community organizations to assist in the formation and effective functioning of the Network and the partnership grant projects.*

**Explanation:** Many survey participants identified “opportunities for staff education and training” as a potential benefit of a Child Health Network. Professional development opportunities would provide an incentive to join and remain involved in the Network. We suggest a series of workshops early in the Network's development designed to increase participants' knowledge, skills and abilities in effective collaboration. An “action-oriented” curriculum with “hands-on” activities could assist participants to formalize the Network and promote its effective functioning. Workshop topics could include collaborative leadership, strategic planning, grant writing and advocacy. Other workshops could address issues that many organizations currently face (e.g., those associated with the growth of the Latino population). As the Network progresses, the need for additional workshops may emerge from the specific goals established, and projects undertaken, by the Network.

Affiliating with a college or university to develop and deliver such programs would provide the opportunity for participants to earn CEUs. This would be of particular benefit to Network members whose professions require continuing education for licensure or certification.

- 8. Provide administrative and technical support for the Network through a neutral party.*

**Explanation:** As previously noted half of the survey respondents expressed reservations about resources that member agencies might be asked to contribute to a network. These concerns included demands on agency staff and time required to support network activities. To alleviate this barrier and ensure that the Network has the support it needs to carry out its activities, the Endowment could consider providing financial support for administrative and technical assistance. It is recommended that such assistance be provided by a neutral party, rather than by one or more of the participating agencies, so that needs and priorities of the Network, rather than the needs or priorities of an individual or a small group of organizations are promoted.

9. *Offer mini-grants to small organizations willing to make a minimum one-year commitment to engage in specific Child Health Network activities.*

**Explanation:** Survey respondents identified cost and lack of funds as constraints that could limit participation in a community-wide network. These constraints are particularly critical for small organizations. Grants to offset the costs of participation could reduce the impact of shortages of funds, personnel, and time that might compromise small organizations' ability and willingness to participate. A "health action fund," which has proven helpful in other communities, might encourage involvement (Maurana & Clark, 2000). However, such grants should not be awarded to organizations to simply "show up" at Network meetings. We suggest developing criteria for organizational participation in, and contributions to, the Network's activities.

### **Evaluate Progress**

10. *Evaluate the Children's Health Summit.*

**Explanation:** The summit is a vital step because it will launch network development in Wake County. On pages 27-32 of this report we have suggested activities for the Summit that can provide the basis for identifying outcomes for the Summit. A sound evaluation will measure participants' beliefs, attitudes, feelings, and behaviors and compare those responses to the desired outcomes. While it is essential to assess outcomes, it is also important to collect data before and during an event in order to determine its effects over time (Rossi, Lipsey, & Freeman, 2004). Data from this report can be used as a pre-intervention measure, but similar items would need to be measured both during and after the Summit for this data to be useful.

11. *Monitor ongoing activities of the Child Health Network in order to guide changes and fine-tune efforts during implementation.*

**Explanation:** "Without sufficient evaluation, the effectiveness of a community program can not be assured" (Goodman, 1999, p.211). The literature also notes that "skillful evaluation can facilitate the ongoing improvement of program efforts; gaining of community support, grant money, and donations; overcoming resistance to the program, detecting unforeseen challenges and side effects of the program; identifying intermediate successes; and increasing program responsiveness and accountability to community stakeholders" (Goodman, 1999, p.211-212).

12. *Evaluate individual projects and capacity-building activities that emanate from the Network's efforts and disseminate findings on "what works" (evidence-based practices).*

**Explanation:** "Program evaluation is the use of social research methods to systematically investigate the effectiveness of social intervention programs in ways that are adapted to their political and organizational environments and are designed to inform social action and improve social conditions" (Rossi et al., 2004, p.16). Building in a system for monitoring efforts while they are under way makes it possible to make changes to improve effectiveness during a project's implementation phase. Therefore, research on capacity-building activities should be embedded in the process (Backer, 2001).

Documenting and disseminating information about what works and what does not can help others to replicate successful efforts and avoid repeating unsuccessful ones (Jones, 2003).

***13. Build evaluation capacity and promote the use of outcomes assessment as an organizational learning tool among the Network's grantees that are funded for partnership initiatives.***

**Explanation:** Evaluating capacity-building efforts requires developing measurable outcomes, and many nonprofits do not have the knowledge or skill to do this (DeVita et al., 2001). The Endowment can help organizations overcome this barrier by connecting them with consultants who can provide the technical assistance needed to create realistic, measurable outcomes. Knowledge about the success and failure of funded activities will better equip community organizations to design and support programs that will affect change.

***14. Re-evaluate the community, to assess progress, at regular intervals, in order to determine long-term, community-wide change and guide future strategic grant making efforts.***

**Explanation:** Program evaluation is needed to identify the total effect of community-wide efforts. Some network activities may yield fairly rapid results. Others require more time to become evident. Repeated evaluations over time will provide information about the progress and success of the community's drive toward the goal of increasing children's access to health care in Wake County.

### **Work for Systemic Change**

The previous recommendations are stopgap measures designed to address problems created by underlying social factors and an imperfect healthcare system. While the measures we have suggested can improve children's access to health care, they do not change the systems that create barriers. The following recommendations would work toward the creation of a healthcare system that meets the fundamental needs of all children.

We recognize that the John Rex Endowment, acting alone, cannot bring about the global changes suggested below. However, working in partnership with other funders and members of a Wake County Child Health Network, the Endowment could become an opinion leader and change agent on issues affecting child health access.

***15. Advocate for North Carolina to create a "medical home" system for children.***

**Explanation:** The American Academy of Pediatrics recommends a medical home for all children (Sia, Tonniges, Osterhus, & Taba, 2004). The Academy defines a medical home as providing medical care to "infants, children, and adolescents [that is] accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective" (American Academy of Pediatrics, 2004, p.1543). A medical home is particularly important for underserved children. A review of the literature indicates that

underserved populations with medical homes receive more effective and more equitable care (Starfield & Leiyu, 2004).

***16. Advocate for insurance coverage for the working poor who earn too much to be eligible for public insurance and too little to afford private insurance.***

**Explanation:** Health insurance coverage in the United States is tied to employment. Those who are not employed, whose employers do not offer health insurance or who cannot afford the premiums go without. If parents have no insurance, it directly affects their children's access to health care. Uninsured children have lower overall health status and more unmet health needs (Fox et al., 2003; Wise, 2004) and are half as likely as insured children to receive well-child care (Chung & Schuster, 2004). According to survey and focus group participants, the children in this community with the least access to health care are those whose families earn too much to be eligible for public insurance and too little to afford private insurance.

***17. Advocate for higher Medicaid and NC Health Choice reimbursement levels to encourage providers to treat publicly insured children.***

**Explanation:** Survey and focus group participants as well as the literature indicate that because of low Medicaid and State Children's Health Insurance Program (NC Health Choice) reimbursement rates, many physicians will not treat patients with these forms of coverage (Simpson et al., 1999, Wise, 2004). Higher reimbursement rates could increase the pool of providers willing to treat children covered by public insurance.

***18. Advocate for universal health coverage for all Americans.***

**Explanation:** The U.S. spends more money per capita on health care than any other industrialized nation. Despite this, it ranks 26<sup>th</sup> in the world in infant mortality (Poppo & Leighninger, 1996; Suppes & Wells, 2003). Universal coverage may be the only way to guarantee all children access to a basic level of health care.

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## **PRIORITIES AND NEXT STEPS**

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Using survey and focus group results, we have identified two priority areas that we recommend the Endowment consider for action in the near future. The first is to begin developing a Wake County Child Health Network. The second is to develop a centralized system to enable professionals to exchange agency and referral information to facilitate contact, communication, and collaboration.

**Priority 1: Establish a child health collaborative.**

**Step 1: Convene a Children's Health Summit.**

We recommend that the Endowment's first step toward launching a Child Health Network be to sponsor a Wake County Children's Health Summit. This meeting would capitalize on interest

developed through participation in our survey and would provide an opportunity to:

- gain agency commitment to participate in a Child Health Network.
- begin formulation of potential collaborative priorities and goals.
- facilitate networking among agencies working with medically underserved children.

The following items explain the content we recommend and are constructed to facilitate the development of measurable outcomes.

- a. Invite survey participants to begin the process of building a community-wide network of organizations by meeting together to develop initiatives to improve the health of medically underserved children in Wake County.*

**Explanation:** The organizations that participated in the survey have not had an opportunity to interact, network, or communicate as a group. Building a successful and functional Child Health Network depends on the willingness of community organizations to support this initiative. The Summit will provide organizations with an opportunity to discuss their concerns about children's health issues and to begin the process of creating an action plan to address mutually identified concerns.

- b. Provide attendees with information about the health-related issues, service gaps and barriers that affect underserved children in Wake County.*

**Explanation:** Network involvement can be increased when organizations share "positive attitudes toward coordination, recognition of a mutual need or purpose, resource scarcity, failure of existing efforts to address the problem" (Butterfoss, Goodman & Wandersman, 1993, p.320). Survey participants expressed positive attitudes toward coordination and recognition of a mutual purpose. They are also well aware of resource scarcity and the failure of existing efforts to address the problems of medically underserved children. Some respondents wanted more information about health-related services and issues. The Summit will be a forum for providing this information. Increasing knowledge should help to increase organizations' commitment to jointly addressing the health concerns of underserved children.

- c. Offer sessions in which participants identify and agree to work on potential Network initiatives designed to address the health concerns of underserved children.*

**Explanation:** The first step in building a network is to mobilize community organizations (Florin, Mitchell, & Stevenson, 1993). Active participants must be identified and engaged in the process of decision-making. Survey and focus group findings suggest a high level of interest among community organizations. The crucial task is to convert that interest to action by encouraging the community organizations to make a commitment to initiatives determined by Summit participants. "Sufficient community ownership must be generated throughout this process to produce eventual institutionalization" (Florin et al., 1993, p.418).

- d. Facilitate discussion about attendees' organizations' common meanings, values, beliefs, and attitudes.*

**Explanation:** Messages are most effective when their content matches the target audience's attitudes (Hullett & Boster, 2001). If we can identify the values, beliefs, and attitudes of the collective community organizations, it will be easier to craft messages designed to persuade them to become involved in the Network.

- e. Provide "free time" for organizational representatives to informally interact in order to become acquainted with each other, learn about other organizations' services and build connections.*

**Explanation:** The academic literature is clear about the need to build "free time" or informal interaction into formal meetings to allow participants "to discuss ideas, attitudes, and issues, and also become better acquainted with each other" (Johnson et al., 1996, p.237). We observed that, at the end of the focus groups, participants would often converse informally and exchange business cards. Such networking among community organizations may help establish a communication network among organizations and lead to increased collaborative relationships in the future.

- f. Provide organizations with an opportunity to decide on how, when and where to continue to interact.*

**Explanation:** For a network to function, the individuals and organizations that comprise it must be connected through contacts called links. The strength of links is based on "frequency of contact, reciprocal favors or obligations, emotional intensity, and intimacy" (Nelson & Matthews, 1991, p.369). Increasing each of these factors will increase the strength of Network links that will, in turn, increase communication and interaction within the network. Scheduled meetings will increase the frequency of contact among members; Network events that address members' needs will increase emotional intensity; and collaborative projects or activities will increase reciprocal favors/obligations and intimacy among Network members. Although the community must suggest the nature of any prospective activities, the Endowment can encourage members to become more active, thus increasing the links within the Network.

- g. Engage attendees in setting group goals, committing to work toward those goals, and developing a feeling of joint obligation to the success of the Network.*

**Explanation:** One of the more important elements in building a network is direction setting, which occurs when "potential members reconcile the pursuit of individual goals with a sense of common purpose" (Butterfoss, Goodman & Wandersman, 1993, p.320). Among the elements that encourage participation in joint activities are a clearly explicated decision-making process, the ability to influence decision-making, and the opportunity to collaborate in conflict resolution (Weiner, Alexander, & Shortell, 2002).

## Step 2: Formalize the Child Health Network structure and functions.

The following items outline the recommended process for formalizing the Child Health Network.

- a. *Establish a formal organizational structure (bylaws, norms, etc.) that clarifies the roles of the Network members. This will also help to clarify the cost and benefits of participation.*

**Explanation:** The literature strongly suggests that formal structures are necessary for the successful implementation and maintenance of network activities. “Formalization is the degree to which rules, roles, and procedures are defined precisely” (Butterfoss et al., 1993, p.321). Increases in formalization have been noted to also increase the investment of resources and exchanges among organizations (Butterfoss et al., 1993; Marrett, 1971), satisfaction with the effort (Butterfoss et al., 1993; Schermerhorn, 1981), and commitment among members. Finally, formalization often increases the likelihood that the initiative will be maintained and sustained (Butterfoss et al., 1993; Goodman and Steckler, 1989). A mutually agreed upon and recognized governance system has been found to be a crucial factor affecting network success (Parker et al., 1999).

- b. *Support the selection and election of strong leaders who will acknowledge individual organizations’ concerns and maintain a commitment to the Network’s goals. These individuals should be skilled at negotiation, problem-solving and conflict resolution, garnering resources, and promoting equality among all network members.*

**Explanation:** Strong leadership is an important ingredient in the implementation and maintenance of network activities (Butterfoss et al., 1993). Leaders must believe they can bring about change and have a solid educational background, and the political knowledge, commitment, competence, and the administrative skills necessary to run efficient meetings, set agendas, and delegate responsibilities (Butterfoss et al., 1993).

- c. *Facilitate creation of subgroups, which will simultaneously support the Network and foster an increased sense of homogeneity among subgroup members.*

**Explanation:** When groups work with others whom they feel are similar to them, trust, communication, and group cohesion increase (Goodman, et al, 1998). This allows a network to build strong ties among members, which will ultimately increase network cohesion. For a strong network to exist, there must be interactions among groups that are similar and different.

- d. *Ensure that the Network includes and encourages participation of a diverse group of organizations.*

**Explanation:** It will be important to encourage the entire community to engage in the change process because for a network to be effective in bringing about change, it must include many different kinds of organizations (Florin et al, 1993). The more diverse the organizations involved in the Network, the less likely that children will slip through the cracks of an imperfect system. If the goal is to increase access to health care among all underserved children, including only traditional channels could result in losing some children within the system.

## **Priority 2: Develop a centralized information exchange and referral system.**

We recommend developing a centralized information exchange and referral system as a priority because it would be useful to a large number of organizations. Eighty-four percent (84%) of survey respondents reported that their organizations referred children to other agencies in the community for health-related services. Over one quarter expressed the desire for more health-related information and more easily accessible information about community resources to meet children's needs. Focus group participants told us that they lacked information about "who's out there doing what." We also observed during the focus groups that individuals serving common populations expressed surprise to learn of each other's existence and services. Because completion of such a system would facilitate links among Network members, we also see this as a means of fostering Network development and of sustaining the Network's existence because it would serve as a way to connect members.

### **Step 1: Solicit participation from interested community organizations.**

**Explanation:** Survey and focus groups respondents overwhelmingly stated their need and desire for a centralized information exchange and referral system that would allow them to exchange agency and referral information and facilitate contact, communication, collaboration, and resource coordination. Rather than have the entire network attempt to work together to design a system, a few highly interested, motivated, and representative organizations could engage in discussions around the design, purpose, methods of access, and other concerns relating to the development of an effective system. Identification of individuals interested in collaborating on this project could begin at the Children's Health Summit.

### **Step 2: Research methods of constructing, housing, and maintaining a centralized information exchange and referral system.**

**Explanation:** Survey respondents suggested wide range of possible formats. These included a bound book, a telephone access point that would enable them to call a person for assistance, and an internet-accessible system for professionals with more comprehensive and current information than the United Way's 2-1-1 system. Each of these methods, as well as any other creative solutions that could be developed, should be evaluated in terms of time to create, ease of maintenance, cost, accessibility, etc. There are many technological solutions to address this kind of need. Time should be invested in considering the solution that will be most useful and practical for all involved parties.

### **Step 3: Evaluate the results of Step 2, gather community feedback, and make a decision.**

**Explanation:** After considering the options and costs of constructing a system, as well as organizations' needs, a decision should be made about which method to use to constructing, housing and maintaining a centralized information exchange and referral system. Before making this decision, a survey of prospective users (perhaps with a random selection of community organizations) should be completed to ensure that the method selected will be used and appreciated by the general community. No system will please all members of the community. The goal should be the development of a system that meets the needs of the majority, and an indication from the minority that they could use it.

**Step 4: Construct and launch the centralized information exchange and referral system.**

**Explanation:** Construction of the system should include field-testing it with a few organizations and fine-tuning it to ensure that it works as anticipated. Once the system is completed and tested, it can be launched for general use and announced to the greater Wake County community. Given the goal of increasing children’s access to health care in Wake County, it should be publicized in a variety of ways to ensure reaching all organizations that have contact with medically underserved children.

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## FINAL THOUGHTS

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Our survey and focus groups findings demonstrate that Wake County’s at-risk children, their families, and the organizations that serve them are faced with numerous barriers and gaps that impact their ability to access needed health care services. Our findings also demonstrate that a coordinated, well-functioning network of organizations dedicated to improving child health access does not exist at present. Based on our review of the academic literature and our findings, we believe that the establishment of a Wake County Child Health Network has the potential to have a significant positive impact on improving child health access and we are encouraged by the interest expressed in forming a network for this purpose.

We are grateful to the John Rex Endowment for providing us with the opportunity to conduct this research and look forward to watching the continued progress the Endowment makes in achieving its goals.

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## **APPENDIX A: INSTITUTE FOR NONPROFITS AND THE RESEARCH TEAM**

### **Institute for Nonprofits**

Founded in Fall 2003, the mission of the interdisciplinary Institute for Nonprofits at North Carolina State University is to “build the capacity of nonprofit organizations to serve the public through teaching, engagement and the generation and application of new knowledge”. The Institute draws upon faculty and students from across the NC State Campus, other UNC System schools, and beyond to achieve its mission. For further information on the Institute, visit our website at [www.ncsu.edu/instituteformnonprofits](http://www.ncsu.edu/instituteformnonprofits) or call us at (919) 513-7031.

### **Natalie Ames, Ed.D., Co-Investigator**

Dr. Ames is an Assistant Professor in the Department of Social Work. She has a BA in history from the University of California at Riverside, an MSW and an Ed.D. from West Virginia University. In addition to professional experience in public welfare and medical social work, she taught health education at the college level for five years and has over 10 years experience in health promotion, community outreach, program development and administration at a university health sciences center. She has served as a facilitator for focus groups on health issues. As a consultant, she developed low literacy health education materials at West Virginia University’s Mary Babb Randolph Cancer Center and developed pamphlets and fact sheets published and disseminated by the National Cancer Institute. Her health-related work has been published in the *Journal of the National Cancer Institute* and *Health Education*. She has presented at national conferences sponsored by organizations that include the American Public Health Association, the National Cancer Institute, the Society for Public Health Education, the National Association of Extension 4-H Agents, and the National Institute on Social Work and Human Services in Rural Areas.

### **Celeste Farr, Ph.D., Co-Investigator**

Dr. Farr is an Assistant Professor in the Department of Communication. She has a Ph.D. from Michigan State University, Curriculum and Instruction Emphasis: Interpersonal Persuasion, and Health Communication; and MA in Communication, Organizational Communication Emphasis and a BA in Communication and Psychology, both from Eastern Michigan University. Dr. Farr has been published in the *Journal of Health Communication* and in JHU/CCP and Ethiopia National Office of Population. She has presented several papers at national conferences sponsored by the National Communication Association. In addition to her research, Dr. Farr has taught at the University level for over six years.

### **Barbara Metelsky, MPA, Project Director**

Ms. Metelsky is the founding Director of the Institute for Nonprofits and Lecturer in Public Administration at North Carolina State University. She was previously with Seton Hall University’s nationally ranked program in nonprofit management for nine years, most recently in

the position of director of the Nonprofit Sector Resource Institute. Ms. Metelsky also served as an adjunct professor in the Graduate Department of Public and Healthcare Administration where she taught courses in nonprofit organization management. Prior to her career in higher education, Ms. Metelsky worked for 11 years in nonprofits that provide services to persons with developmental disabilities. Her most recent position was as director, Northwest Regional Office of United Cerebral Palsy Associations of New Jersey, Inc. Ms. Metelsky has written and lectured on a variety of topics including nonprofit capacity building, CEO succession planning, leading volunteers, grantsmanship and the prevention of developmental disabilities. She has a Masters of Public Administration degree, with a concentration in Nonprofit Organization Management from Seton Hall University and a BA in Psychology from Rutgers University. Ms. Metelsky is a member of the Leadership Council for the Raleigh's Ten-Year Plan to End Homelessness, Chair of the Service Committee and member of the Class of 2005 of Leadership North Carolina, and past Board Member and Chair of the Diversity Committee of the Association of Fundraising Professionals, Triangle Chapter.

## APPENDIX B: PHASE 1 - SCREENING TOOL

### Building A Child Health Collaborative: A Network Analysis Phase 1 - Screening Tool

Interviewer name: \_\_\_\_\_

Date: \_\_\_\_\_

Time: \_\_\_\_\_

#### Pre-Screening

1. Organization name: \_\_\_\_\_
2. Org. mailing address: \_\_\_\_\_
3. Org. email address: \_\_\_\_\_
4. Org. fax: \_\_\_\_\_
5. Org. phone number: \_\_\_\_\_
6. Org. website: \_\_\_\_\_
7. Person you spoke with: \_\_\_\_\_
8. Title of person spoke with (if you can get it): \_\_\_\_\_

#### Screening Questions

1. Does your organization have any contact in person or by telephone with families who have children under the age of 18 years old?

YES      NO

**\*\*\* If the responses to item #1 is “NO”, then skip to question 10.\*\*\***

2. Does your organization provide any services to children (under the age of 18):

- a. Who live with only one parent?  
YES      NO      DON'T KNOW

- b. Who have a parent(s) with less than a high school diploma or GED?  
YES      NO      DON'T KNOW

- c. Who have a parent(s) that is unemployed?

YES NO DON'T KNOW

d. Who live within a family that receives welfare assistance?

YES NO DON'T KNOW

e. Who have no health insurance?

YES NO DON'T KNOW

f. Whose families are homeless?

YES NO DON'T KNOW

g. Whose family must meet income eligibility guidelines to receive services?

YES NO DON'T KNOW

3. Does your organization provide children with:

a. mental or behavioral health services?

YES NO

b. dental health services?

YES NO

c. physical health services?

YES NO

4. Does your organization refer children to other organizations for:

a. mental or behavioral health services?

YES NO

b. dental health services?

YES NO

c. physical health services?

YES NO

**\*\*\* If the responses to items #3 and #4 do NOT contain at least 1 “YES”, then skip to question 10.\*\*\***

5. Who has the authority to speak for (or is in charge of) your organization?

Name:

Title:

Phone:

Email:

Fax:

Mailing Address:

6. Who can answer questions about the (health-related) services your organization provides to children?

Name:

Title:

Phone:

Email:

Fax:

Mailing Address:

7. Who can answer questions about the referrals your organization makes for children's health related services?

Name:

Title:

Phone:

Email:

Fax:

Mailing Address:

8. Does your organization have contact with children in need of health related services that you do not provide?

YES      NO      DON'T KNOW

9. Does your organization have more children in need of your health related services than you can serve?

YES      NO      DON'T KNOW

10. Can you think of other organizations that we should contact who have an interest in children's health issues? (Gather names and contact info (as much as possible))

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## APPENDIX C: PHASE 2 - SURVEY TOOL

### Building A Child Health Collaborative: A Network Analysis Phase 2 – Survey Tool

Interviewer's name:

Interview date:

Time begun:

Time ended:

Respondent's name:

Respondent's title:

Employer:

#### **Demographic/Risk Assessment Information**

1. Is your organization classified as:

nonprofit? \_\_\_\_

for-profit? \_\_\_\_

governmental? \_\_\_\_

faith-based? \_\_\_\_

other? *(please write their response)* \_\_\_\_\_

2. Do you serve a designated geographical area?

YES      NO

**If YES:** What is your designated area?

***Please note that the word children refers to those who are age 18 and younger.***

3. What age children does your organization provide services to?

4. Does your organization provide services to:
- a. Children living in foster care?  
 YES      NO      DON'T KNOW
- b. Children known to be involved in the child welfare system who are not in foster care?  
 YES      NO      DON'T KNOW
- c. Children whose parents are immigrants?  
 YES      NO      DON'T KNOW
5. Does your organization provide services to children whose parents speak languages other than English?  
 YES      NO      DON'T KNOW

**\*\*\* If the responses to item #5 is "NO", then skip to question #6.\*\*\***

**If YES, what languages do they speak?**

\_\_\_ Spanish      \_\_\_ Vietnamese      \_\_\_ French      \_\_\_ Arabic      \_\_\_ African languages  
 \_\_\_ Cambodian      \_\_\_ Russian      \_\_\_ other (list)\_\_\_\_\_

- a. Does your organization have any resources for working with children whose families do not speak English?  
 YES      NO      DON'T KNOW

**If YES: Do you have in-house resources for translating/interpreting?**

YES      NO

- b. What, if any, community resources do you use for translating/interpreting? (*list*)

6. Does your organization collect any data on how much education the parents of the children you serve have? (*i.e., how far they went in school*)  
 YES      NO      DON'T KNOW

7. Approximately what percentage of the children your organization serves are:

Caucasian? \_\_\_\_\_

African American? \_\_\_\_\_

Hispanic? \_\_\_\_\_

Asian? \_\_\_\_\_

Other? (*list*) \_\_\_\_\_

Organization does not collect that data \_\_\_\_\_

8. How many children does your organization provide with services per month/year? \_\_\_\_\_

Organization does not collect that data \_\_\_\_\_

9. Do you refer children to other organizations for physical, mental, developmental or dental health-related services?

YES      NO

**\*\*\* If the responses to item #9 is “NO”, then skip to question #12.\*\*\***

a. Does your organization have any resources for working with children whose families do not speak English? *Check all that apply*

They need routine services or treatment we don't provide. \_\_\_\_

They need follow-up care we don't provide. \_\_\_\_

They need specialist services or treatment we don't provide. \_\_\_\_

More children need our services than we can treat. \_\_\_\_

They can't afford to pay for services. \_\_\_\_

Other \_\_\_\_\_

b. How many children do you refer to other agencies for health-related services per month/year? \_\_\_\_\_ DON'T KNOW

10. What kind of health-related services do you make referrals for (*list below*)?

For what kind of services do you refer?	To what organizations do you refer?
Ex: Dental	Ex: Dental Clinic of Raleigh

11. When your organization refers children for health-related services, is there any follow-up to see if they have received the services for which you have referred them?

YES      NO      DON'T KNOW

**IF YES:** What kind of follow-up?

12. What health-related services does your organization provide to children under the age of 18? (*Read the list and check all that apply.*)

- a. None ***IF NONE, SKIP TO QUESTION 16***
- b. Well-child exams/check-ups
- c. Immunizations
- d. Acute care (treat sick children)
- e. Emergency care
- f. Developmental assessments
- g. Psychological evaluations
- h. Psychiatric evaluations
- i. Mental health assessments
- j. Mental health treatment
- k. Emergency dental services
- l. Routine dental services
- m. Speech/hearing screening
- n. Vision screening
- o. ADD/ADHD assessments
- p. Other (*list*) \_\_\_\_\_

13. Does your organization provide health-related services to:

a. Children who are uninsured?

YES NO DON'T KNOW

b. Children who are covered by either Medicaid or the NC State Children's Health Insurance Program?

YES NO DON'T KNOW

14. Does your organization have a waiting list for the children's health services you provide?

YES NO SOMETIMES

**\*\*\* If the responses to item #14 is "NO", then skip to question #15.\*\*\***

How long is the waiting list (how long do they generally have to wait to be seen)?

a. What criteria do you have for admission to the waiting list? *Check all that apply.*

financial eligibility \_\_\_\_

type of services needed \_\_\_\_

urgency of need \_\_\_\_

other (list) \_\_\_\_\_

b. What percentage of children on the waiting list will receive your services? \_\_\_\_\_

15. What barriers do families encounter when they try to obtain health-related services from your organization? *(please list)*

transportation \_\_\_\_

child care for other children \_\_\_\_

parental physical or mental illness \_\_\_\_

caregiver work schedule \_\_\_\_

inability to pay \_\_\_\_

inability to speak English \_\_\_\_

other \_\_\_\_\_

16. What do you see as the most significant barriers to meeting the health needs of children in Wake County? *(please list on another piece of paper)*

## Attitudes

The John Rex Endowment, which is funding this survey, would like to increase access to health care for “at-risk” children in Wake County. (At risk children are children who are poor or otherwise disadvantaged.) One suggested method to achieve this goal is to establish a children’s health network made up of community organizations committed to working together to meet children’s health needs. Given this underlying goal:

17. How interested would your organization be in participating in the development of a children’s health network?
  - a. strongly interested
  - b. moderately interested
  - c. somewhat interested
  - d. uninterested
  
18. If a children’s health network were developed, from your perspective, what benefits would your organization gain from participation? *(please list on a separate piece of paper)*
  
19. If a children’s health network were developed, what barriers would prevent your organization’s participation/involvement? *(please list on a separate piece of paper)*
  
20. To what extent do you agree with the statement: A children’s health network would be consistent with the mission or goals of my organization.
  - a. strongly agree
  - b. agree
  - c. disagree
  - d. strongly disagree
  
21. To what extent do you agree with the statement: A children’s health network would increase children’s access to health services in Wake County.
  - a. strongly agree
  - b. agree
  - c. disagree
  - d. strongly disagree
  
22. To what extent do you agree with the statement: A children’s health network would increase health providers’ knowledge of children’s health needs in Wake County.
  - a. strongly agree
  - b. agree
  - c. disagree
  - d. strongly disagree

23. To what extent do you agree with the statement: If a children's health network is developed, I would recommend that my organization become involved.
- strongly agree
  - agree
  - disagree
  - strongly disagree
24. To what extent do you agree with the statement: Working with the children's health network would increase my organization's standing in the community.
- strongly agree
  - agree
  - disagree
  - strongly disagree
25. To what extent do you agree with the statement: A children's health network would help practitioners in Wake County stay connected.
- strongly agree
  - agree
  - disagree
  - strongly disagree
26. To what extent do you agree with the statement: A children's health network would help children in Wake County remain healthy.
- strongly agree
  - agree
  - disagree
  - strongly disagree
27. To what extent do you agree with the statement: A children's health network would help parents to learn more about health issues that affect their children?
- strongly agree
  - agree
  - disagree
  - strongly disagree
28. To what extent do you agree with the statement: A children's health network would help parents gain access to the health services their children need?
- strongly agree
  - agree
  - disagree
  - strongly disagree

29. To what extent do you agree with the statement: A children's health network would increase community awareness of barriers that hinder children's access to health services.
- strongly agree
  - agree
  - disagree
  - strongly disagree
30. To what extent do you agree with the statement: A children's health network would influence policy-makers to make changes in the health care system.
- strongly agree
  - agree
  - disagree
  - strongly disagree

31. Please rank the following statements in order of their importance to your organization from 5 for MOST important through 1 for LEAST important.

\_\_\_ A children's health network would be consistent with the mission or goals of my organization.

\_\_\_ A children's health network would increase children's access to health services in Wake County.

\_\_\_ A children's health network would increase health providers' knowledge of children's health needs in Wake County.

\_\_\_ If a children's health network is developed, I would recommend that my organization become involved.

\_\_\_ Working with the children's health network would increase my organization's standing in the community.

I expect a children's health network would be:

A follower	1 2 3 4 5 6 7	A leader
Interesting	7 6 5 4 3 2 1	Dull
Informed	7 6 5 4 3 2 1	Uninformed
Passive	1 2 3 4 5 6 7	Active
Successful	7 6 5 4 3 2 1	Unsuccessful
Reactive	1 2 3 4 5 6 7	Proactive

## **Collaboration**

The next few questions are about your organization's collaboration with other agencies. By collaboration, we mean that your agency contributes staff time or money to a joint project or program or that it has a contractual agreement to work with another agency.

32. Does your organization collaborate with any organizations in Wake County on children's health-related issues or programs? YES NO

**\*\*\* If the responses to item #32 is "NO", then skip to question #35.\*\*\***

**IF YES**, What organizations in Wake County does your organization collaborate with? *(please list on a separate piece of paper)*

33. What are the goals/purposes of the collaborative programs your organization takes part in? *(please list on a separate piece of paper)*
34. In general, would you describe your organization's contributions to the collaborative programs it takes part in as:
- a. less than those of other collaborators.
  - b. more than those of other collaborators.
  - c. equal to those of other collaborators.
35. What kind of collaborative efforts would help your organization better meet children's health needs? *(please list on a separate piece of paper)*
36. How interested are you in establishing new collaborative relationships to work on meeting children's health needs?
- a. strongly interested
  - b. moderately interested
  - c. somewhat nterested
  - d. not interested

***Thank you very much for taking the time to answer my questions. Your answers will help the John Rex Endowment to achieve its goal of improving at-risk children's access to health care.***

