Establishing Systems of Care for Babies and Young Children with Special Health Care and Developmental Needs and Their Families

Using an analytic framework and hypotheses based on the principles of social network analysis to evaluate current efforts

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Introduction

Even under the best of circumstances, families of babies and young children with special health care and developmental needs must navigate a complex system comprised of multiple organizations and providers in order to access basic services from qualified professionals. Ideally, these children would have a medical home from which to coordinate care, navigate systems, and access necessary resources. Medical homes provide appropriate, family-centered, culturally responsive, accessible services and supports to young children and their families.

At present, the existing systems of care do not provide such coordinated, family-centered services for this population. Developing comprehensive systems depends upon strong collaborative efforts among a multitude of stakeholders who understand needs of consumers. In many states, public health collaboratives (PHCs), made up of a diverse range of organizations serving babies and young children, are forming to address this problem. Using a collaborative governance approach, these organizations are working toward strengthening the interconnected statewide system of services available for this population.

While these efforts are growing, they lack three important elements that can inform their effectiveness. These include: 1) knowledge of whether the families of babies and young children are adequately served by coordination and strengthening of the statewide system, 2) an analytic approach to evaluate these efforts, and subsequently, 3) a framework for strategically thinking about how to make changes to their efforts to achieve better outcomes.

The Case Study: WONDERbabies

In 2005, The Colorado Trust funded a strategic planning process for the WONDERbabies (Ways of Nurturing Development through Enhancing Relationships) Partnership for Health to enhance the system of care for babies and young children which special health care and developmental needs, address specific Healthy People 2010 goals, and achieve measurable systems change through a collaborative process.

Methods

A case study was conducted, modeled in a Community Based Participatory Research (CBPR) approach.

In this project, key stakeholders throughout the state of Colorado, as well as families and providers, worked together with the research team in providing information, feedback, and insight to: 1) identify the problem with the current system of care through a six-month long strategic planning process; 2) define broad goals (as blueprints) of what an improved system of care might look like; and 3) develop an analytic approach to meet those goals. In total, data collection included involvement from over 200 stakeholders participating through a variety of methods including strategic planning meetings, focus groups (as partnership discussions and community forums), and unstructured interviews.

Hypotheses:

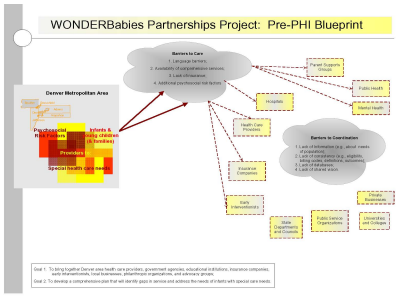
H_1: There is a discrepancy between the existing health services system of care for babies and young children with special health care and developmental needs, and personal networks in which families are embedded and which they utilize to access necessary services and supports.

H_2: The larger the discrepancy, the *less* likely families will experience positive health and developmental outcomes including having medical homes for their children. .

H_3: Provision of technical assistance (modeled as strategic collaborative management) at the systems level will lead to improved health and developmental outcomes, including strengthening or establishing medical homes.

Results

Current comprehensive health service systems of care for babies and young children with special health care and developmental needs are characterized as fragmented by stakeholders:



Families also see the system as fragmented:

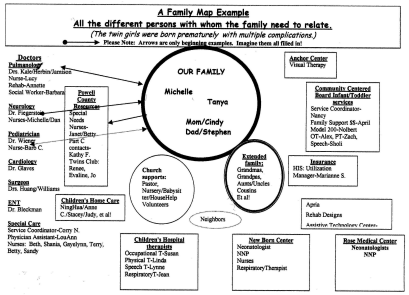


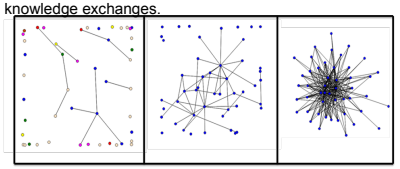
Figure provided courtesy of Debra Paul, OTR

Analytic Framework:

First, data will be collected from the statewide stakeholder systems of organizations involved in delivering care, identifying the types of partnerships which have been formed, describing the quality and content of these partnerships, and correlating the development of partnerships with achieving systems goals to create medical homes and improve outcomes for babies and young children.

Next, data on the personal networks of providers and families for babies and children with special health care and developmental needs will be gathered. Data include demographic information about families and data on the relationships that families and providers identify in their social and service support networks.

Finally, social network analysis (SNA) will be implemented to evaluate the efforts made at the systems and ego-centric levels, and assess the appropriate "match" between the systems. SNA is a methodology that helps to explain how actors connect to one another, thus elucidating the structural makeup of collaborative relationships, and how those relationships produce varying effects. The fundamental property of network analysis is the ability to determine, through mathematical algorithms, whether network members are connected — and to what degree — to one another in terms of a variety of relationships like communication, resource sharing, or knowledge exchanges.



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