Gaining Perspectives: Using Social Network Analysis to Understand Systems of Care

Abstract

Evidence that SOCs effectively meet the complex needs of children with serious mental health challenges is difficult to obtain given limitations of methodologies that examine either systems-level outcomes like collaboration among programs/agencies or individual outcomes like symptom reduction, behavioral improvement, and consumer satisfaction. The current paper uses social network data to characterize formal systems of care and personal networks and applies the data using a strategic collaborative management approach aimed at enhancing systems of care. Social network analysis results suggest that systems-level and personal networks differ with respect to coordination, key actors, and perceptions of system success. Formal systems are more coordinated and comprised of state and local service delivery organizations while personal networks are less centralized and comprised of both informal and formal support sources. Implementation of a strategic collaborative management approach within a statewide collaborative enhanced the functioning of a system of care for babies and young children with special health care and developmental needs. Examining the system of care from the perspectives of formal members of the service delivery system and from the perspective of family members as consumers of the formal system and assemblers of their own networks of care may afford greater understanding about how systems of care function in the lives of children with complex needs and their families. Implications for systems of care for children’s mental health are discussed and recommendations to for assessing the functioning of systems of care and implementing systems change are detailed.
Introduction

Current approaches to addressing the problems families face when navigating complex service systems on behalf of their children rely largely on efforts to fund state or nationally driven efforts through the development of Systems of Care (SOC). These efforts are often implemented at the local level and tasked with coordinating services and creating an integrated, connected system spanning independent sectors (Hodges, Friedman, & Hernandez, 2008). SOC are designed to be child-centered, family-focused, culturally responsive, and community-based service systems that address the complex and changing needs of children and their families. Since Stroul and Friedman’s (1986) original monograph defining SOCs, considerable investment has been made in creating systems of care to effectively address the complex needs of children with serious mental health challenges. In 2010, Stroul, Blau, & Friedman updated the definition of a SOC, describing it as “a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth [emphasis added], and addresses their cultural and linguistic needs, in order to help them function better at home, in school, in the community, and throughout life,” (p. 6).

Inherent to the SOC approach are the guiding principles of individualized, community-based, accessible, family-driven and youth-guided, coordinated services that consider family and cultural factors (Spencer, Blau, & Mallery, 2010). Yet specific attention to the role that families’ personal, largely informal social support networks play in SOC has been neglected in research. In fact, operationalizing meaningful family involvement within systems of care remains a challenge, leaving many communities struggling to implement family-driven frameworks (Baxter, 2010). Although ample evidence exists to show that SOC approaches (see Stroul &
Blau, 2008) hold significant promise in addressing the needs of children who struggle with serious mental health challenges (e.g., improved coordination and responsiveness to client needs through provision of wraparound services), systems-level efforts may be far removed from personal social networks created by families to address the needs of their children, and even further removed for child outcomes.

To date, informal support resources (e.g., extended family, faith organizations, friends and neighbors) have been characterized as resources to be utilized by the formal system of care rather than as resources internal to the system of care and that in and of themselves directly influence child and family outcomes (Cook & Kilmer, 2010). Importantly, while more distal influences (e.g., health insurance coverage, housing, food security) and contextual factors significantly influence individual functioning (Hodges et al., 2006), systems of care traditionally focus on formal service systems, at times failing to capture or include informal supports and, thereby, potentially limiting the impact of systems on child and family outcomes (Cook & Kilmer, 2010). Much of what we know about formal SOC as they relate to children’s mental health needs is based on evaluation of formal service delivery systems, efforts at coordination of the formal service delivery system, and efforts to engage consumers (e.g., families and youth).

Although it is clear that well-managed, coordinated SOC are a legitimate undertaking and can be successful in increasing service coordination and responsiveness to client needs (Spencer, Blau, and Mallery, 2010), it is unclear whether these SOC have even greater potential for success if mechanisms for coordination were implemented with personal networks in mind. In other words, while the majority of SOC may currently be more successful than at any point in the past, a more complete understanding of system functioning must consider the personal networks within which families are embedded and how these personal networks connect to formal systems.
of care largely comprised of service delivery systems. As such, personal networks are an
essential “piece” of the puzzle when examining how systems of care operate and, to date, are
often among the missing pieces.

This paper seeks to operationalize SOCs as social networks (both at the systems and
personal network levels) and demonstrate how this perspective can yield data relevant to SOC
functioning. While SOC efforts are growing, they lack three important elements that can inform
their effectiveness: 1) broad characterizations of systems that include proximal and distal
influences through formal and informal networks, 2) an analytic approach to evaluate systems of
care, which are inherently dynamic and highly individualized at both the community and
personal levels, and subsequently, 3) a framework based on quality improvement processes that
is data-driven and can be used to enhance individual systems’ functioning and, ultimately, to
achieve better population and individual outcomes.

Using social network methodology, this paper will characterize and quantify how SOC
are perceived at the systems level and by the personal networks of families. We will demonstrate
how this type of analysis can be used to implement change to affect systems functioning. This
effort is based on the following working hypotheses:

1. Assessing or evaluating only the formal SOC fails to adequately capture the multitude of
   influences on child and family outcomes. Characterizing personal networks offers
   another perspective into the influences on child and family outcomes for children with
   complex needs.

2. Systems functioning can be improved using data-driven management approaches.
Systems Building Approaches

Strickland and colleagues (2011, p. 224) note that, “Increasingly, Title V Children with Special Health Care Needs (CSHCN) programs have moved away from providing direct services to children with special health care needs toward a public health infrastructure-building approach to ensure a seamless system of services and access to care for children with special health needs and their families”. Recent conceptualizations of the SOC approach have both recognized the potential of public health approaches for the system of care for children with mental health and other challenges and called for applying the concept to different populations (Stroul, Blau, & Friedman, 2010). As articulated in the introductory paper of this special issue (Cook & Kilmer, in press), successful SOCs facilitate collaboration among programs/organizations/agencies at the systems-level and enhance connections within the personal networks of families of children with serious mental health challenges and among the providers and community supports that constitute these personal networks of care. Such collaboration and connection, in turn, has greater potential to improve child and family outcomes. While the six key system building blocks, developed by MCHB together with Title V agencies (Strickland et al., 2011), articulate what families of CSHCN can expect as outcomes of a successful system, they rely on a functional, inter-connected system that is largely absent of any mention of the role that a family’s personal network plays in relation to these outcomes.

In the United States, more than 12 million children are identified as having special health care needs (Newacheck, Strickland, Shonkoff, Perrin, McPherson, McManus, et al., 1998). In most states, a fragmented early childhood system attempts to provide coordinated, family-centered services for this population, particularly early in life. Families must often navigate a complex system comprised of multiple organizations and providers in order to access basic
services from qualified professionals. Intensive involvement with health care systems and management of chronic conditions for many years often creates additional stress for the families of these children (Sullivan & Knutson, 2000; Centers for Disease Control and Prevention, 2001). For CSHCN and children with serious mental health challenges, complex needs require involvement in cross-sector service systems for long periods of time, often draining informal and formal resources and supports. In this paper, we contend that the familial burden of identifying, navigating, accessing, coordinating, and maintaining relationships – that is, creating and tapping into personal networks – with programs, individual providers, and players across various sectors (e.g., education, mental health, physical health) is similar across both populations.

**Systems of Care as Social Networks**

Social network analysis is a quantitative methodology that focuses on relationships between and among social entities, measuring and mapping relationships and flows between people, groups, organizations, or computers (Cross, Laseter, Parker, & Velasquez, 2006). Using this approach, we can identify the members of a network, the quantity and quality of relationships among those members, and other characteristics such as resource exchange, reciprocity, and trust among members (Scott, 1991; Wasserman & Faust, 1994). Collecting network data allows us to visualize, using network maps, the connections among stakeholders and clients. Unlike standard social and behavioral science statistics, the measurements taken on by these entities are functions of more than one entity, so that the data arising from network studies are not the standard cases x variables datasets. Rather, these methods apply to the analysis of relational data measured on dyads or groups of social actors. In this paper, data are analyzed at the systems level to describe the composition of the SOC (e.g., service providers, funders, community programs, state departments), the number and quality (trust and value) of
relationships among stakeholders, and the contributions made by each stakeholder (e.g., services, technical assistance, information exchange; Singer & Kegler, 2004). Personal networks are operationalized similarly.

For example, Figure 1 depicts the personal network identified by the parents of twins with special health care and developmental needs in their first year after birth (identifying information has been changed or removed). Evident in this figure is the complex nature of a family’s personal network and the lack of connectivity among the members of this network. The number of health care, social, and instrumental sources is instantly overwhelming and generally fragmented. Creating, managing, and sustaining relationships with each of these presumed resources are critical to the network of care for these babies. Yet, the burden of maintaining these relationships in order to access necessary resources falls primarily on parents and primary caregivers and siphons time, energy, and valuable resources away from the developing parent-child relationship and family.

![Figure 1. Personal Network](image-url)
While such examples can provide a guiding framework about how SOC operate, they cannot accurately measure the functionality of formal and personal systems of care. The network of services and supports would likely be represented differently depending on who was being asked to describe the system of care. Members of the formal system of care, traditionally comprised of service delivery systems, might identify relationships among each other, with few relationships to the informal system of care other than the one with the family. Family members, who are connected to both formal and informal systems, might describe yet other relationships that are important in providing for their children’s needs including those between themselves and members of the formal and informal systems and among the members of these systems. When family experiences with systems of care differ from systems-level perceptions regarding how systems operate, this discrepancy poses a challenge in that most information about SOC is obtained from individuals and organizations within the system with considerably less information from clients (families). Taken together, the information above suggests that examining the system of care from the perspectives of formal members of the service delivery system and from the perspective of family members as consumers of the formal system and assemblers of their own networks of care may afford greater understanding about how systems of care function in the lives of children with complex needs and their families.

Social Network Analysis: A Method for Understanding and Managing SOC Functioning

Operationalizing SOC as social networks enables us to accomplish two objectives. First, it allows us to characterize the system of care using an empirical methodology (social network analysis) that enables us to: 1) identify players (i.e., who comprises the system of care); 2) detail levels of coordination, collaboration, trust, and value among key players (i.e., how do they interact? What is the strength of their relationships?); 3) identify resource contributions within
the system and among players (i.e., who does what and with what resources?); and 4) identify perceptions of success (i.e., to what extent have goals of the SOC been accomplished?). This approach moves beyond “counting noses” at collaborative meetings where being part of the system is contingent upon attendance at meetings and beyond internal ratings of collaboration where, again, only those seated at the table can report on success of the collaborative.

A second and perhaps more critical objective involves utilizing data to inform practical decision-making and change how systems of care function. Strategic Collaborative Management (SCM) is a framework developed by the authors outlining a series of process steps for assessing and planning action steps to improve SOC functioning (Varda, 2011). To implement SCM, network data are used to inform each decision and move a strategic thinker to the next process step. In any type of community collaborative, one or several members of the collaborative can take on the leadership role of moving the group to the next step.

Inherent to SCM is the premise that a clear specification of goals and a series of steps identified to reach those goals (Fitzpatrick, Sanders, and Worthen, 2003) will result in better process outcomes. For a SOC, goals may include: fully connecting the network (making sure everyone who should be at the table is at the table), reducing redundancy in the network to increase effectiveness and efficiency (identifying connections that can be eliminated or reduced because the benefit has been reached without it), leveraging resources that maximally take advantage of each organization’s capabilities without over-taxing any one organization, or developing trust within the group in order to achieve greater success at working together.

In the remainder of this paper, we describe how systems of care can be characterized using social network analysis and further, how this type of information can be used to inform a strategic approach to provide specific, concrete recommendations that can inform system change.
efforts. We demonstrate how operationalizing SOC as social networks in a system of care for babies and young children with special health care and developmental needs can help us better understand these systems and inform systems change.

**Methods**

We collected social network data at the systems and personal levels to inform a data-driven strategic process aimed at affecting systems change. This study was conducted following the Dillman Total Design Survey Method (Hoddinott & Bass, 1986) and utilizing the PARTNER online survey. PARTNER (Program to Analyze, Record, and Track Networks to Enhance Relationships – see www.partnertool.net for detailed information) is a social network data collection and analysis tool, created and maintained by the second author and funded by the Robert Wood Johnson Foundation in 2006, 2008, and 2010. This project and the activities detailed below were approved by the Institutional Review Board of the University of Colorado. Participant consent was obtained at the time of survey completion.

The entire project has implemented a community-based participatory approach getting input from stakeholders and families in research/survey design, data interpretation, and implementation of action steps for performance improvement in a SCM framework. Specifically, the WONDERbabies (Ways of Nurturing Development through Enhancing Relationships) Partnership for Health Collaborative (a Colorado-based group comprised of a statewide stakeholder network - organizations, programs, providers, and services working together to enhance systems of care for young children with special health care and developmental needs) actively participated in this research project, both providing data and implementing systems change based on the results (described below in detail).
Social Network Data Collection to Assess the Statewide SOC

Social network data were collected to assess the level of “connectivity”, including the number, type, and quality of ties within a statewide system of care for babies and young children with special health care and developmental needs. The PARTNER survey was administered to collect system stakeholders data (referred to here as the System Survey) used to characterize the statewide systems of care by describing the quality and content of partnerships identified by systems stakeholders, and link the development of partnerships with reaching systems goals to create comprehensive systems of care for clients. Data were exported to UCINET (Borgatti, Everett, & Freeman, 2002) for the social network analysis to determine the similarities and/or differences among characteristics and measurable dimensions of the two networks, and to create network maps. Demographic data were analyzed in Excel and SPSS.

Using a name generator/snowball sampling technique, the members of the WONDERbabies collaborative (N=12) identified 65 stakeholders throughout the state that “work on issues related to babies and young children with special healthcare and developmental needs”. The System Survey was sent to these 65 stakeholders (N=65) with a response rate of 49%. Responses to this survey yielded an additional 230 stakeholders who subsequently were sent the System Survey. In total, 295 stakeholders were invited to complete the survey with a response rate of 34% (N = 100). Table 1 details the questions asked in the System Survey.

Case Studies to Assess Families’ Personal Networks in Relation to SOC

Following completion of the System Survey data collection, we used a purposeful sample of 10 families as case studies to assess families’ perceptions of the SOC in which they are embedded, including both formal and informal supports. Families were chosen from a list of recommended participants (provided by WONDERbabies). Each family was approached and
asked to commit to participate in this study which includes providing data and being available for follow-up interviews and focus groups. We chose case studies as an exploratory method to assess families’ personal networks in order to gather preliminary data because no evidence of this approach exists in the literature. For the case studies, each family completed the PARTNER survey, with questions adapted to determine who they consider part of their SOC around caring for their CSHCN. Families completed the survey online and received a $20 gift card for their participation. Responses to the survey were used to analyze family perceptions of their SOC.

Table 1 details questions in the family survey.

**Table 1. Questions for the Systems and Personal Network Surveys**

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<th>Systems Survey Questions</th>
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<tr>
<td><strong>Demographic Questions (organizational description):</strong> job title, location (county), % of time working on SOC issues, types of activities engaged in, outcomes achieved, resources contributed to SOC.</td>
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<tr>
<td><strong>Perception of Success:</strong> How successful have the efforts in your county been in creating an integrated SOC?</td>
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<tr>
<td><strong>Outcome Questions:</strong> Collaborative outcomes achieved; Factors contributing to more integrated services</td>
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<tr>
<td><strong>Relational Questions:</strong> “Please list all organizations/divisions/agencies/programs with whom you have a relationship with to meet your goals for the needs of babies and young children with special health care and developmental needs.”</td>
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Once these SOC members were identified, the respondent was asked to answer the following questions:

1) Frequency of Working Interaction

2) Types of activities the relationship consisted of

3) Extent of: a) Power/Influence, (b) Level of Involvement, (c) Resource Contribution?

4) Extent that partner is: a) Reliable, b) In Support of the Mission, and (c) Open to Discussion.

<table>
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<th>Personal Network Survey Questions</th>
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**Demographic Questions:** Role of respondent (to child), age of child, type of special health care need, county where services are accessed, types of care child is receiving.

**Perception of Success:** “How successful would you say the SOC is at providing coordinated, comprehensive care for your child? (definitions of SOC and “coordinated, comprehensive” provided)

**Relational Questions:** “Some families with children with special needs develop a “support network” that they use to access services and provide emotional, physical, and financial support. We want to learn more about the people, places, and other resources that you access for your child… Please list all of the people, places, organizations, and other resources that you would include in your support network… We will then ask you to tell us a little more about each person/organization/program that you tell us about.”

   1) Length of relationship, importance of relationship
   2) Role of actor, extent that actor works with others in your network, extent that actor talks with other
   3) Support from other, level of trust, types of support

**Strategic Collaborative Management**

Using a strategic collaborative management approach, the WONDERbabies collaborative applied these social network data to enhance systems functioning. Implementation included the following action steps: 1) take note of potential and existing partners, 2) assess the characteristics/quality of relationships, 3) consider the connectivity among members of the network, and 4) match evaluation to collaborative’s goals.

**Results**

**Social Network Analysis**

**Characteristics and specific roles of SOC members.** For the System Survey, 100 respondents identified a total of 452 statewide stakeholders and a total of 785 partnerships (dyadic relationships). Each dyadic relationship, represented as a “line” in network maps, included each relationship the respondents nominated. Organizations representing different
sectors of the SOC are listed here by type and number of times the sector was nominated: Public Health (n=45), Early Childhood Councils (n=34), Part B (n=34), State Funded Programs/State Departments (n=31), Health Clinics/Primary Care (n=30), Educator Sector (n=29), Part C of IDEA (n=28), Hospitals (n=25), Nonprofits (n=23), Locally Funded Programs/Local Departments (n=23), Early Care and Education (n=22), Mental Health (n=21), Advocacy Groups (n=21), BOCES (n=14), Allied Health Services (n=13), Specialty Care (n=10), Professional Orgs (n=7), Resources (e.g. housing, transportation) (n=5), Funders (n=3), Federal Program/Departments (n=3), Law Enforcement (n=2), Faith-Based (n=1), Private Provider (n=1), and Other (n=24).

When asked about the types of activities with which each respondent is involved within the system of care, overwhelmingly, 48% of respondents reported that “Service Delivery” was the most important activity in which they are involved. At one end, 65% of respondents reported spending less than 50% of their time on issues related to the population while at the other approximately 22% reported spending more than 91% of their time focused on this work.

In examining the results of the System Survey for value and trust among the key actors and other network members, some organizations rank high on both the value and trust scale, while others show more variation. For example, the State Part C program scores 3.61 and 3.47 for value and trust, respectively, out of a 4.0 scale, with 4 being the highest rating. In contrast, a family advocacy group that appears lower on value (2.98) is rated very high on trust (3.67). In general, however, most organizations that show up high on the list for value also show up high on the list for trust.

**Personal networks.** All ten family respondents were mothers of children ranging in age from 15 months to 17 years. Most children were diagnosed with some kind of developmental
delay, two had medical conditions, two experienced social/emotional delays, and almost all required extra or special care giving on a daily basis. All 10 families lived in urban areas of the state. These 10 families identified a total of 38 unique types of support partners and a total of 88 partnerships (dyadic relationships) as part of their personal networks.

Personal networks are comprised predominantly of informal, personal connections such as family, friends, online support groups, schools, and pediatricians (a formal connection). We found surprising variations in responses to value and trust questions within personal networks (see Table 1 for questions). While the top ten key actors all rank high in terms of “importance to child” and on “trust”, they rank lower on “working with others in the network” and “talking with others in the network”, suggesting that there are lower levels of coordination in personal networks among the partners they listed. Many different types of support were provided by the members of personal networks, with emotional support ranking highest. However, the levels of support provided were inconsistent despite the fact that these key players were deemed important and trusted. This suggests that in personal networks, support is variable and that players who are deemed important are not necessarily those that provide necessary support (see Figure 2).

Importantly, the highly valued and trusted organizations at the state systems-level (the formal system of care) do not necessarily appear as frequently identified actors in the Personal Networks with the exception of primary care providers.
Network mapping. Network maps were constructed based on the data where the lines indicate a relationship (a working relationship in the System Survey and a support relationship in the Personal Network survey) between the nodes that they connect. Figure 3 depicts two images, one of the System Network and the other of the Personal Networks. It is immediately apparent that the Systems Network represents a highly centralized structured (indicated by the core/periphery layout of the nodes – hub and spokes), with a large number of relationships among the nodes. On the other hand, the cases used to visualize the personal networks depict a much less centralized structure. Although fewer connections exist in personal networks, this does not necessarily mean that the structures of the networks should differ. While families seem to rely on a specific set of people/organizations for support, there is a somewhat “dispersed” reporting of those that are common across families’ personal networks. No single network member serves as the “centralized” node, although the pediatrician is mentioned most frequently.
### Key actors

Identifying the key actors in each system is an important part of analyzing the similarities/differences between the two networks. For this analysis, we identified “key actors” as those with the most number of nominations that each organization got from respondents in the survey when asked to identify “working partners” or “supporters” (called “in-degree centrality”). We coded the key actors in each network as orange nodes in the maps above to highlight their position in the network. Most striking about the line-up of key actors in each network is that in the System Network, the top ten key actors are comprised of organizations that represent state departments, statewide advocacy groups, and primary care providers. In the Personal Network,
these same organizations do not appear by name except on the periphery of the network. Instead, the key actors in the Personal Network include the family’s pediatrician, schools, other families, extended families, friends, online support groups, immediate family, other health care providers, and agencies tasked with providing intervention and service coordination. Most noticeably, the formal SOC is largely absent from this client perspective, with informal supports dominating the “key player” positions.

Perceptions of SOC success. We asked all respondents to report their perceptions of how successful the SOC has been in achieving its goals. The System Survey respondents showed a pattern of agreement with the majority (53%) rating the system as “somewhat successful”, 30% “successful” and 15% “very successful”. The respondents to the Personal Network survey showed more variability, with 20% reporting “Not Successful”, 30% “Somewhat Successful”, 20% “Somewhat Successful”, and 30% “Very Successful”. No respondents in either survey said the system is “completely successful” and only respondents in the Personal Network survey reported “not successful”.

Using Social Network Analysis for Strategic Collaborative Management

While these network data provide unique insight into this SOC, affording both a closer look at the quantity and quality of interactions among members of the SOC and access to family perceptions of their SOC, the question of how these data impact SOC functioning remains. Beyond serving as a diagnostic tool to uncover many of the otherwise unknown aspects of SOC, social network analysis can be used to move a system toward implementing real change, using tangible data to inform strategic thinking and decision making for action steps for improved SOC functioning. To illustrate this point, we describe implementation of a Strategic Collaborative Management approach by the WONDERbabies Partnership for Health collaborative aimed at
improving the system of care for young CSHCN. The following section details how social
network data informed each step and outlines the action steps implemented by WONDERbabies
and other community partners to make systems change.

**Step 1: Take note of potential and existing partners.** Using social network data from
both the System and Personal Network Surveys, WONDERbabies partners identified key actors
participating in the systems of care for the population. As noted above, the formal system of care
is comprised of organizations, state agencies, and service providers. In contrast, the personal
networks of families include both formal (e.g., early intervention service agency) and informal
(extended family) sources of support. The iterative process by which data were collected for the
System Survey and the self-nominated “supports” selected by the families produced evidence
that families perceive existing partners to include more than the usual partners identified by
stakeholders in system of care evaluations (i.e., those partners who “sit at the table”). In fact,
social network methodology allows all respondents to self-define the system and include low-
incidence of partners who might be missed in a more traditional environmental scan.

**Action steps for systems change.** Based on the identification of partners at the systems
level, first new organizations/agencies/programs/community resources were invited to engage in
SOC activities by the conveners of the initiative. As an example, a statewide organization
providing home visits to families of newborns was invited to join the collaborative. In becoming
a partner, this organization connected the system of care to a large number of newborns and their
families and added materials about CSHCN to those they distributed at visits. Another example
involved county-level analyses. When data were analyzed by county, it became immediately
apparent that in some communities, key actors in the system of care did not identify relationships
with other key actors. In these communities, outreach to contacts within agencies and programs
that did not appear connected were made. Lastly, the collaborative developed an online resource
directory of all partners identified through the systems level social network analysis, listing these
partners by county. This resource directory can be accessed and used by participants in the
system of care as well as by its consumers.

**Step 2: Assess the characteristics/quality of relationships.** The data enabled us to
examine similarities and differences within the formal and personal networks. As discussed
above, chief among these are the seemingly higher levels of coordination (as indicated by reports
of greater numbers of connections per respondent with more frequent interaction) within the
formal system and the differences in key players nominated by the formal system and by families
for their personal networks. In contrast to the formal system, personal networks are comprised of
informal sources of support and a few key service providers (e.g., pediatrician, early intervention
provider) and are also comprised of highly supportive members with considerably less
coordination and communication among the partners.

**Action steps for systems change.** In light of the above characterizations of both the
Systems and Personal Networks, the WONDERbabies collaborative engaged in several
activities. First, within the formal system of care, a dialogue (both in work groups and broader
SOC meetings) around the contributions of partners to the system of care began based on the
data collected in the social network analyses. Presentations of these findings to key actors
likewise generate discussions and action plans around distribution of resources and provide an
opportunity for partners to form, maintain, or enhance their relationships. These discussions have
led to actual systems change. For example, agency memorandums of understanding have been
revised to include mechanisms for data sharing and funding for cross-sector personnel to work
collaboratively on issues related to the system of care goals (e.g., a database of developmental
screening efforts maintained by the early intervention state program and shared with the Assuring Better Child Health and Developmental (ABCD) program for use in technical assistance with pediatric primary care providers). Second, in recognition of the fact that primary care providers were the only key actors represented in both the System Survey and Personal Networks, the WONDERbabies collaborative reexamined its goals and objectives and agreed to focus on the medical home approach as a systems outcome (e.g. community trainings and engagement of primary care providers). Using the data on primary care providers as the link between formal and personal networks, WONDERbabies strategized around how to highlight the salience of primary care providers in the system of care and engaged in outreach and education to community organizations around this issue. Parallel information is being distributed to families and to stakeholders through another initiative, the Medical Home Task Force.

Lastly, data from the personal networks suggest potential mechanisms for strengthening these networks and improving their functioning. For example, helping families create “passports” for their children that include relevant physical, mental health and psychosocial information in addition to information about care plans and care providers could decrease the burden of having to individually communicate information to each member of the personal network. Also, as described above, families are being trained to identify medical homes and utilize state and local resources to better meet the needs of their children.

**Step 3: Consider the connectivity among members of the network.** In the System Survey, the network is centralized around the Health Department, and the Part B and Part C programs that serve children with developmental delays. The extent to which these state-level entities play a role at the local level varies from community to community. In some communities, the local health departments are connected to a myriad of
programs/agencies/providers that serve the population while in others, the local health departments may have considerably fewer connections.

In both the System Survey and the Personal networks, a number of SOC members are located on the periphery of the network. Examples of peripheral actors include hospital, therapists for low-incidence disabilities and disability-specific advocacy associations within the Personal Networks and specific agencies/programs, school districts, and community-based grant initiatives within the Systems network. It may be the case that these members play a limited role in the SOC or be a function of methodological limitations (not responding to the survey or not invited to respond to the survey). However, being on the periphery of the SOC does not inherently diminish a member’s significance within the SOC. Many members on the periphery may be essential to the SOC in that they link more central members to others that are less frequently engaged but still essential. In the case of personal networks, these members may be as significant as other members of the network, but unique to each family.

**Action steps for systems change.** For WONDERbabies, connectivity data confirmed the importance of having representatives from the Health Department and the Part C and Part B programs involved and engaged in efforts at improving the SOC. Representatives of programs with funding (state and federal) and decision-making power have the ability to facilitate systems change. The central role played by state entities is expected since these agencies receive federal funding and administer both state and federal funding to local communities and peripheral agencies and entities. While it is natural that organizations driven by funding streams fall into formal governance/leadership roles, over time a “flattening” of the network and the opportunity for multiple organizations to play multiple leadership, facilitation, and coordinating roles is recommended (Varda et al., 2008). In this case, the social network data will be used to consider
alternatives to this very centralized network structure; for example, considering implementation of SOC at the local level and working to engage less central entities (e.g., primary care providers) who appear in both formal and informal SOC. Future directions include working with local communities to identify connections among network members and develop data-driven action plans for communities. Personal network data can be used to identify those providers that would best serve families as coordinators within medical homes.

**Step 4: Match evaluation to systems collaborative’s goals.** The success of SOC can be measured in many ways. In this paper, the majority of respondents to both the System Survey and the Personal Network analysis rated the system of care for babies and young children with special health care and developmental needs as “somewhat successful” or less. Perceptions of success are important in identifying the extent to which systems of care are meeting goals.

**Action steps for systems change.** Considerable work lies ahead in terms of linking success to SOC functioning, particularly because of the varying perceptions of success by both families and stakeholders. As one of the intended outcomes of SOC to improve child and family functioning, gathering data that directly measures child and family functioning is critical to evaluating this outcome. In partnership with communities and advocacy groups, WONDERbabies is continuing to gather more personal network data and collect data on child outcomes, access to medical home, and other variables that will more directly link personal networks to child and family outcomes. Further exploratory work includes developing formal definitions that operationalize “success” as perceived by both stakeholders and families.

**Discussion and Recommendations**

The need for evaluation and a better understanding of how systems of care operate in the daily lives of consumers is profound. Overall, the findings reported in this paper provide unique
perspectives on this SOC. If we were to rely solely on the report of coordination and service provision from systems stakeholders, and attributed attendance at partnership meetings to successful SOC, we would have a very different perception regarding the success of the system of care to meet the needs of children and families. However, if we look at the results of the data gathered from families, we find that the important members of their personal support networks vary from the ones identified by stakeholders and that families overall do not report that these members are coordinated or able to provide them with adequate supports.

Below are recommendations for using social network data to improve SOC functioning. The notable differences between stakeholder-defined systems of care and personal networks have tremendous implications for the development and evaluation of SOC. Findings from the current paper can be used to develop responsive, comprehensive, and collaborative systems of care that provide the necessary supports and resources and fund accessible, coordinated services. Given the demonstrated usefulness of applying Social Network methodology to evaluate SOC, our first recommendation is to utilize social network data to characterize and understand how systems of care operate at both the systems level and the client level. Social network data can be used to identify key actors, understand the connectivity and interactions among these actors, examine perceived outcomes, roles, and value and trust among partnerships in the system, providing empirical and quantifiable data about systems of care. The PARTNER (www.partnertool.net) provides a free tool and the technical assistance for conducting such an analysis. Guided by such data, SOC facilitators can use network data to engage in strategic planning, decision-making, and creation of action steps. Collection of data is paramount to the SCM framework and with tools such as PARTNER, SOC leaders can implement an evidence-based approach to systems functioning.
Our second recommendation is to *collect and utilize information derived from the systems level and personal networks of families to strengthen resources and develop innovative supports available to families (using a SCM framework)*. When asked, families are able to articulate what they require and what they do to meet the needs of their children, and they work to fill in system gaps with little support in the form of funding and other resources. Implementing this recommendation will necessitate innovative data collection strategies, including those described in the current paper. On a policy level, it will likely require altering funding streams to provide families with greater control and decision making around how to use the “resources” they have available to them instead of relying on federal and state allocations that mandate what services are available and how they will be used. Innovative funding streams and programming should be designed to increase the “match” between personal networks and formal systems of care. Successful systems of care will ultimately yield greater alignment between systems-level and personal networks with respect to key actors, value and trust, and outcomes and should be evaluated on these merits and not exclusively on traditional systems indicators.

Partnership and collaboration is essential to a wide range of public management priorities including creating a comprehensive system of care to address complex mental health needs of children. Findings from the current study indicate that to adequately capture how systems of care operate in the lives of children with significant needs, whether they are mental health or special health care needs, the broader context in which these children function must be taken into consideration. As such, our final recommendation is that *systems of care be examined in their entirety rather than focusing on one or a few selected sectors*. Mental health systems of care do not exist independently of other formal and informal systems in which children with serious mental health challenges must function (e.g., schools, families, community organizations,
neighborhoods). Looking at mental health services, resources, and providers alone is too narrow and restrictive to fully appreciate how systems of care work has positively impacted the lives of these children. It will be critical that future evaluation of the impact of systems of care include non-mental health stakeholders in data collection to fully capture the formal and informal actors.

Limitations of Social Network Approaches

Several limitations exist when using social network analysis. One limitation of using network data involves the inability to correlate the practice of collaboration with or to predict population health outcomes, a similar dilemma across the field of public health systems and services research. While the methodology introduced is novel and has potential to improve our ability to link systems of care efforts to outcomes, we acknowledge that operationalizing outcomes as “networks” does not adequately measure population health or individual level health indicators as outcomes. However, our ongoing work involves correlating county level health indicators with relationships among systems-level and personal networks to examine population well-being at the local level. Additionally, we are collecting individual health outcomes data (e.g., diagnoses, number and types of services used, medications, etc.) and correlating network characteristics with these health outcomes. Data will be utilized in future efforts in targeted communities to enhance systems of care and effect change. A second limitation includes the limited resources to continually increase the sample size (in a snowball sampling method) and the time-intensive requirement of network surveys. As with other data collection efforts, social network data are only as comprehensive as the respondents who choose to participate in characterizing the networks in question. Finally, obtaining a 100% response rate is difficult when conducting survey research but without it, not all stakeholders can be represented in the data. However, social network analysis is based on identification of relational patterns. It is likely that
in our data, the patterns of interactions (and identification of key players) would not change considerably with a higher response rate, giving us confidence in these findings.

**Conclusion**

Comprehensive and coordinated systems of care are vital to health outcomes including social-emotional development and family well-being. Developing such systems depends upon strong collaborative efforts among a multitude of stakeholders. While funding and focus remains on formal, organizational stakeholders, largely ignoring the importance of informal personal networks (made up of family, friends, schools, pediatricians, and schools), we anticipate that without new evaluation tools that include examination at both the systems level and the client level we will continue to see mixed results from families in terms of satisfaction and a continued lack of adequate support and coordination of systems of care designed to address the complex needs of children and their families. Social network analysis, when used in combination with a Strategic Collaborative Management approach, is a powerful, data-driven tool that can inform and enhance how systems of care function and ultimately, how systems of care impact the lives of the children and families they serve.
References


