

Stakeholders' Perceptions of Care Coordination: A Participatory Process

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ABSTRACT

Objective: Children with special health care needs or chronic conditions are more likely to have unmet health needs than other children. The purpose of this study was to use a community engagement research strategy to assess the essential elements of care coordination that can serve as the foundation for a system-wide care coordination model for children with special health care needs.

Study Design: As part of a summit designed to review the status of pediatric care coordination within the state of Arizona and a call to action, a qualitative descriptive study was conducted to solicit anonymous feedback from 104 stakeholders (family, health care provider, or community entity) on the strengths and areas of improvement in the current system that provides care to Arizona children with special health care needs. Data were analyzed using inductive content analysis.

Results: Five essential categories crucial to building an effective and seamless care coordination model were extracted from the data: *Communication, Insurance, Health Care Capacity, Provider Knowledge, and Family Education.*

Conclusions: The results from this study can serve as the working foundation to build a system-wide model for pediatric care coordination throughout the state. Providing care coordination services involves many activities across a wide range of organizations and locations. Research that is inclusive of community stakeholders can determine essential components for building a foundation for care coordination. *J Pediatr Health Care.* (2017) ■, ■-■.

KEY WORDS

Children, community engagement, special health care needs

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INTRODUCTION

Children with special health care needs (CSHCN) have conditions that require health and related services beyond what is required by children generally (Kastner, 2004). These conditions can be a combination of physical, mental, or developmental problems. The concerns that CSHCN confront include access to consistently high quality care, adequate insurance, a medical home, and support for the family (Drummond, Looman, & Phillips, 2012). The physical and mental health of these children requires specific and continual care (Ghandour, Perry, Kogan, & Strickland, 2011), often from several types of health care professionals including (but not limited to) physicians, surgeons, specialist nurses, dentists, therapists, psychologists, and other pediatric specialists.

With proper care and support, quality of life can be good for CSHCN and their families, much better than

people often expect—particularly as care is continued throughout adolescence and the transition to adulthood (Lewis & Vitulano, 2003; Payot & Barrington, 2011). That being said, the obstacles to getting proper care can be overwhelming. The burden of care coordination often falls on family members, who are managing health care while raising other children, running the home, and/or working. This deeply affects the family's finances, employment stability, health, and well-being. Barring a family history with a particular condition, no family comes equipped to manage a child's special health care needs or to navigate the increasingly complex systems of insurance and medical care.

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Care coordination is pivotal to the quality of life and well-being of CSHCN and their families. Children with complex and special health care needs have extensive networks of health care, school, and community providers involved in their daily lives. Parents and family members report spending up to 6 hours or more each week communicating with health professionals and insurance companies, arranging for services and following up when services are not accessible or delivered in a timely way (Kuo et al., 2013). Without patient- and family-centered care coordination, care for children with special health care needs is unlikely to be effective, efficient, safe, or timely.

CSHCN or those with chronic conditions are more likely to have unmet care coordination needs than other children. Care coordination has been shown to reduce the cost and length of inpatient stays, decrease unmet needs, and enhance parent/family experience. The purpose of this study was to use a community engagement research strategy to examine overarching themes identified by state stakeholders who provide care to Arizona CSHCN in terms of strengths and areas of improvement in the current health system.

METHODS

A care coordination summit that included panels of parents and private and public organizations convened to review the status of pediatric care coordination within the state of Arizona and a call to action. State leaders were invited to implement change through active community partnerships. At this summit a qualitative descriptive study was conducted to solicit anonymous feedback from invited attendees (family, health care

provider, or community entity) on the strengths and areas of improvement in the current system that provides care to Arizona CSHCN. The study was approved by the hospital institutional review board. The inclusion criterion for invitation to the summit was the individual's involvement in caring or coordinating care for CSHCN in Arizona.

Each attendee of the summit was provided sticky notes to provide responses about the strengths and areas of improvement that exist in the current system. Once a response was written on the sticky note, the attendee posted it onto one of three poster boards displayed at the summit: Family Board, Health Care Provider Board, and Community Entity Board. Attendees could provide more than response and post to more than one board if they identified with more than one role.

Data were analyzed using deductive content analysis to test categories and concepts (Elo & Kyngas, 2008). The research team, consisting of three members (two doctoral prepared nurse researchers and a nursing doctoral student), analyzed the responses. The process included three phases: preparation, organizing, and reporting. Preparation included selecting the unit of analysis and making sense of the data as a whole. The organizing phase included developing a categorization matrix and coding the data according to the categories. Reporting included the results of the analyzing process.

RESULTS

The units of analysis used during the preparation phase were the attendees' responses on the sticky notes. Each member of the research team reviewed each response individually and created initial categories to explain the data. During the organizing phase, the research team members discussed and agreed on the categories. The team members then individually created an organization table and sorted the attendees' responses into each category. The tables were compared and contrasted among the research team members. During the reporting phase, the research team discussed any disagreements in the coding. Each team member reread the responses that were not coded similarly and indicated whether she would maintain her initial coding. The codes were adjusted after reviewing all the potential disagreements, with a result of 100% agreement among all the team members.

The five essential categories the research team members extracted from the responses and agreed upon were *Communication*, *Insurance*, *Health Care Capacity*, *Provider Knowledge*, and *Family Education*. *Communication* was defined as sharing of information and collaboration among providers, families, community, technology, and data. *Insurance* was defined as payment for services or care. *Health Care Capacity* was defined as lack of services, care, and resources. *Provider Knowledge* was defined as lack of provider

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