Research Agenda for Implementation of Principles of Care for Children and Youth With Special Health Care Needs

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Abstract

Objective: Children and youth with special health care needs (CYSHCN) have a range of medical, educational, and support service needs to achieve optimal health and wellness. Principles of care for CYSHCN have been well described, but the literature is lacking particularly on implementation and integration of care across different settings and systems. The objective of this manuscript is to define a research agenda for principles of care for CYSHCN.

Methods: Literature review examined principles of care for CYSHCN. Existing research gaps and priorities for principles of care were drawn from the literature review, a recently developed national research agenda for CYSHCN, and stakeholder consensus.

Results: Specific implementation areas of inquiry include family partner roles within and across systems; life course approach for CYSHCN; roles and training of interdisciplinary team members; and implementation, spread, and sustainability studies. Proposed methods include implementation science-based and comparative effectiveness research. A common set of metrics including health care utilization, clinical outcomes, and family and provider needs should be considered to evaluate implementation of principles of care.

Conclusions: Implementation science and comparative effectiveness methods are needed to further understanding about how to adopt and spread principles of care for CYSHCN. The evolving demographics of CYSHCN add relevance and urgency for research findings.

Keywords: children and youth with special health care needs; children with medical complexity; model of care

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What's New

Principles of care for children and youth with special health care needs (CYSHCN) are well described. Studies examining principles of care for CYSHCN should focus on implementation and dissemination of care models for CYSHCN.

Principles of care can inform the elements and processes of how a model of health care delivery is developed and delivered.[1,2] Children and youth with special health care needs (CYSHCN) have a range of medical, educational, and support service needs to achieve optimal health, growth, and development.[3] Following established principles of care for CYSHCN should ideally lead to equitable, reliable, and replicable health outcomes, and produce improved and measurable outcomes valuable to CYSHCN, families, and health systems. Health care for CYSHCN typically require the provision and coordination of significantly more services compared to non-CYSHCN.[4] The number of services needed, often across different sectors such as education and community-based, may lead to a risk of fragmented care and unmet needs which in turn may result in poor health and development outcomes. Research and evidence for implementing the care principles across diverse settings for CYSHCN are needed to inform operational decisions about staffing, training, roles, financing, and expectations for care outcomes.

Current Literature on the Principles of Care for CYSHCN

A substantial body of literature outlines the ideal principles of care for CYSHCN, providing guidance on how care should be delivered. The scope of the principles addresses the practice (the medical home), hospital, and system levels.[4−8] Principles of care for CYSHCN have been developed and refined for several decades, resulting in reports such as the Surgeon General Report of 1987,[9] Joint Principles of the Medical Home,[7] and more recently,

the Association for Maternal and Child Health Programs standards for the system of care for CYSHCN.[10] As noted in the callout box, the principles emphasize essentials for care delivery for CYSHCN, including identification of CYSHCN in a practice; access to services; ensuring that all CYSHCN have a medical home (comprehensive care); community support; transitions in care; health information technology; and quality improvement.

Summary of Existing Knowledge on Principles of Care for Children and Youth with Special Health Care Needs

1. Numerous principles of care for CYSHCN include identification of CYSHCN in a practice; access to services; ensuring that all CYSHCN have a medical home (comprehensive care); community support; transitions in care; health information technology; and quality improvement.
2. The principles of care focus on systems building and practice transformation tools that support the medical home concept.
3. Less than 5‘0% of families of CYSHCN report receiving care consistent with a medical home, suggesting gaps in implementation.

The literature is less robust about how to actually implement and integrate the principles of care across different settings and systems, such as education and social services that support the health and development of CYSHCN. One implementation framework is the Chronic Care Model, first developed by Wagner and associates during the 1990s[11,12]. The Chronic Care Model framework is well known and utilized, particularly in adult medicine, and implies cohesion and integration of care components and processes that can apply well to CYSHCN. The framework specifies supportive community and health system environments, including support for decision-making, self-management, clinical information systems, and delivery systems, leading to an “informed, activated patient” and “prepared, proactive practice team.”

The Medical Home care principles were first described by the American Academy of Pediatrics in the 1960s, and refined through additional stakeholder consensus including families and providers. The principles state that care should be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.[5] The medical home model has evolved to become the standard of comprehensive care for all children, but the components and processes continue to be specifically applicable to CYSHCN.[13] Multiple medical societies, states, accrediting bodies such as the National Committee for Quality Assurance, and health care policymakers have endorsed the Medical Home concept.[7] Bright Futures, the preventive care recommendations from the American Academy of Pediatrics, additionally describes the life course approach, including promotion of growth and development, addressing social determinants of health, and linkages to community-based assessments and services specifically for CYSHCN.[3]

Some recent primary care transformation literature addresses population health-based and value-based payment initiatives.[14] CYSHCN are often the focus of these initiatives in pediatric practices, with emphasis placed on population management, family partnerships, care coordination services/practices, and utilization of tools such as the Shared Plan of Care.[15] These practice transformation initiatives, however, often apply directly to early adopter practices. They do not describe widespread implementation across different settings, including underserved populations, nor do they address system reforms such as sustainable value-based payments.

Findings from a recently developed national research agenda for CYSHCN, including a modified Delphi/Rand Appropriateness Method (RAM) process,[16] identified a number of key research priorities relevant to the principles of care. RAM findings highlighted the need to emphasize specific components of the best care models and prioritize implementation and dissemination of interdisciplinary, team-based care, with accompanying domains and metrics to assess care. In addition, RAM findings inquired about need for integration of different sectors of care including education and mental health, as well as community supports. Integration of palliative care principles was the sole new care process that emerged as a research priority.

Less than 50% of US families of CYSHCN report care consistent with the medical home concept.[17] Given extensive literature documenting care principles and practice-level projects, this finding suggests widespread implementation of principles of care for CYSHCN has not been successful. Considerations may include changing demographics of CYSHCN; shifts in disease burden, eg, increasing rates of neurodevelopmental conditions such as autism; lack of health insurance; a shifting landscape of services and laws, including the Individuals with Disabilities Education Act and the Americans with Disabilities Act.

In sum, existing literature articulates numerous principles intended to guide care delivery for CYSHCN. The principles describe the importance of systems building and integration that then support individual components of care at the practice and community levels. The literature is stronger on the impact of practice team-based care; use of practice transformational tools; and intensive case management, albeit generally at the practice level.[14,18] Some recent literature extends the principles of care to accountable care organizations and community-based services.[19,20]

Knowledge Gaps for the Principles of Care in Health Care Delivery

Knowledge gaps for well-established principles of care for CYSHCN include the components and processes that are necessary for widespread and uniform implementation across different settings. Gaps include the roles of family partners; implementation of the pediatric life-

course mode for CYSHCN; the specific roles and training needs for interdisciplinary team members; and the implementation/scalability across systems. Specific implementation areas of inquiry include:

FAMILY PARTNER ROLES WITHIN AND ACROSS SYSTEMS

Family-centered care (FCC) is regarded as a foundational principle of the Medical Home. The FCC literature emphasizes the importance of FCC to care integration, care systems, and applicable evaluation tools. Literature describing FCC implementation is stronger on the inpatient hospital setting ("family-centered rounds") although the literature is not specific to CYSHCN who are hospitalized.[21,22] Literature gaps include variations in the definition of FCC, how FCC is operationalized into clinical practice, and specific outcomes linked directly to the care of CYSHCN.[23,24] Specific gaps include the processes needed to support family partner roles that lead to a shared plan of care and shared decision-making for CYSHCN to achieve the child and family's goals.

The replicability and sustainability of family partner roles within and across systems has been a consistent gap in the literature. Organizational roles may be created for family partners as a key intervention to implement FCC. The impact, standardization, and measurement and funding of different family roles, including advisors, collaborators, parent advisory council members are specific literature gaps, as well as the training and co-learning needed for family partners. The roles of family partners in addressing organizational diversity, cultural agility and cultural competence are additional and timely gaps in the literature.

LIFE COURSE APPROACH FOR CYSHCN

The life course approach to care emphasizes the impact of childhood events on the trajectory of childhood development and long-term childhood and adult outcomes. The Bright Futures principles of care emphasize the importance of promoting growth and development for all children, including CYSHCN, with health equity as an underlying foundation.[3,25] Achieving health equity in pediatrics also entails addressing underlying structural racism and other determinants of health, targeting historical social constructs and drivers.[26]

There is a lack of studies that examine the life course approach to care specifically for CYSHCN and the validity of screeners, tools, and interventions to CYSHCN.[27,28] Bright Futures guidelines encourage the use of psychosocial screening tools, positive parenting supports, and community referrals and partnerships as part of routine care for all children.[3] Such screeners, tools, and supports may apply differently to CYSHCN. For example, a standardized developmental screener for a child that is already enrolled in an Early Intervention program may not be utilized under the impression that the child's needs are already being met. Many of these screeners and interventions are not tested or standardized for CYSHCN, particularly those with developmental disabilities and mental health conditions.[28]

ROLES AND TRAINING OF INTERDISCIPLINARY TEAM MEMBERS

CYSHCN care principles encourage the use of team-based care, including team members outside the practice and integrating care throughout the community.[29] A designated care coordinator is often a recommended key team member to tie the pieces together.[18,30] Variations in background and training of care coordinators limit the evidence base on replicability and sustainability of team-based care members.[30] For example, care coordinator training or experience may include a background or license in nursing, social work, education, or as a parent/caregiver. Proactive care planning processes that team members may undertake include identifying and closing outstanding care gaps, supporting the life course approach, and addressing unmet needs.

The scope of the interdisciplinary team has similarly extended from the practice level to the community and/or accountable care organization.[20] Research gaps include lack of knowledge of how care expectations extend to community-based roles and the necessary training to sustain these roles. As an example, community-based health workers may be important partners in the care of CYSHCN to address social determinants of health,[31,32] with opportunities to address how such team members may be deployed to address a broad range of diagnoses and settings. Finally, additional knowledge gaps exist about how to train such care teams and assure bidirectional communication between team members.

IMPLEMENTATION, SPREAD, AND SUSTAINABILITY

The current evidence for principles of care generally comes from early adopter settings, specific populations, and high-intensity interventions.[33–35] Gaps continue to exist on the implementation, efficacy and fiscal viability of CYSHCN principles of care across the broad landscape where CYSHCN receive care. Settings where knowledge gaps for implementation exist include rural primary care and Federally Qualified Health Centers where CYSHCN may seek care. Examples of spread and sustainability gaps in such settings include the impact of multidirectional communication systems, external practice supports, electronic tools such as clinical registries, application of evidence/consensus-based care standards, and support for team-based care roles, including family partnerships.

Innovative payment and funding designs that can support care principles for CYSHCN, including the aforementioned roles and tools, have not been extensively studied. Specific questions include which funding mechanisms or alternative payment models, such as bundled payments or value-based payments, are best to encourage optimal management of health care services. The value and impact of each system

component, such as a care coordinator, has not been well studied. The research gaps also include how each system component improves access to and delivery of clinical care for CYSHCN, stratified by medical, psychosocial, and utilization complexity.

PROPOSED STUDIES

Studies for the care principles for health care delivery should address how the well-established principles translate into clinical care and outcomes across a wide range of settings. Implementation science-based studies address how principles are best put into practice, while comparative effectiveness research can look at differences in outcomes between different implementation strategies and across settings. A common set of metrics including health care utilization, clinical outcomes, family and provider needs should be developed, consistent with existing frameworks of outcomes such as the Institute for Healthcare Improvement Triple Aim.[36] Beyond existing system performance metrics,[8] specific metrics are needed to evaluate clinical outcomes, and their alignment with patient- and family-centered goals; metrics around "right care, at the right time, and in the right place"; and quality of life outcomes across systems.[16]

FAMILY ROLES

Studies should define the roles and responsibilities of family involvement at different levels of clinical care that are associated with best implementation practices and optimal outcomes.[37] Research questions should address the roles of the parent/guardian caregiver, the parent navigator, the family advisor, and the parent leader for the child and family, who may be different individuals. An example of such a study might be:

- *Specific aims / hypotheses.* Family caregiver training, utilizing a standardized and comprehensive curriculum that is developed and supported by family organizations, will lead to fewer emergency room visits, higher satisfaction, and improved growth and development.
- *Approaches for methods.* Implement a standardized training curriculum for specific roles performed by family partners focusing on specific medical conditions. Interventions should adhere to known frameworks of self-management, FCC, and health equity principles. Investigators can utilize formalized partnership agreements with family organizations to provide support and training to family members. Study methods can utilize hybrid effectiveness-implementation designs, blending components of clinical effectiveness and implementation research that enable the research team to learn about the best approaches for implementation while doing the study. A stepped-wedge design can be used to develop a comparison group if a randomized controlled trial is not feasible.[38] Outcomes include implementation process measures, FCC metrics and health care utilization outcomes.
- *Feasibility to conduct.* Pilot trainings and family partners roles have already been developed so a smaller scale study should have high feasibility. Implementation science methods often require larger population sizes and multipronged iterative approaches that account for multiple dimensions of care delivery. Widespread applicability may be challenging without adequate funding.
- *Implications.* Structured and replicable family involvement in care models may optimize health outcomes and enhance scores on FCC metrics through efficient care, self-management, and home care.

LIFE COURSE

Studies should address the processes across systems that support growth, development and social determinants of health for CYSHCN specifically. An example of a study with higher feasibility based on size and scope might be:

- *Specific aims / hypotheses.* Understand the processes that impact the efficacy of psychosocial and social determinants of health screenings, referrals, and follow-ups for CYSHCN and their families that support growth and development for CYSHCN.
- *Approaches for methods.* Studies can utilize structured psychosocial screening, but target CYSHCN identified in clinical registries and/or by their families, including subgroups of children with disabilities, developmental delay, and medical complexity. The studies should develop referral process with community partners and family partners, including facilitated contact and documentation of referral completion. Follow-up includes contacting families and community partners after a defined period of time to examine efficacy of process. Study outcomes include description of service needs, detection of needs, successful facilitation of referrals, referral completion, and 1- to 2-year follow-up of impact on families.
- *Feasibility to conduct.* Implementation is highly feasible as methods can be adapted from existing studies including WE CARE trials, which examined the utility and follow-through of a structured psychosocial screener in primary care practices.[39] Getting a network of large enough sample size may be difficult without a research network, and implications may be limited to specific conditions that are examined.
- *Implications.* Understanding effective and facilitated processes of psychosocial screening, cross-system communication and interventions to complete referrals may impact the life course of CYSHCN by optimizing healthy growth, development, and social determinants of health.

TEAM-BASED CARE

Studies on team-based care define needed team member roles and necessary training or licensure for effective team-based care of CYSHCN. The studies may draw on the business literature for a framework of highly effective teams and re-orient training from an acute care-based,

patient flow orientation to one of population and targeted care management.

- *Specific aims / hypotheses.* Define the competencies, training and funding for care coordination roles within a medical practice that impact team functioning, overall delivery of care across the care continuum, and CYSHCN health care outcomes.
- *Approaches for methods.* Utilize a multisite, mixed-methods implementation science approach,[38] informed by qualitative studies, including formative and summative evaluations during implementation. Studies should focus on the training requirements and staffing needs of care coordinators, and implement a training curriculum that addresses case management and community linkages. The framework may draw on the principles of palliative care. Study outcomes can include evaluation of team member impressions of care, efficiency of care delivery (including time and payment-based studies), and health care outcomes. Data from these outcomes may add weight to the business case of payment for such staffing.
- *Feasibility to conduct.* Small scale can be feasible in a learning collaborative with iterative mixed-methods approaches, providing findings on implementation. A larger study will require health care system level studies, which could add difficulty to adherence to protocols.
- *Implications*. It is widely recognized that team-based care is essential for CYSHCN. Definition of team-based care roles, training, and support are needed to replicate effective and sustainable outcomes across different settings.

Implementation Across Settings

Studies define the core components of care and focus on which interventions work for which population, where the interventions work, and what is needed to successfully implement these interventions.

- *Specific aims / hypotheses.* Define the components of care for CYSHCN that are critical across a variety of practice and geographical settings.
- *Approaches for methods.* Large scale comparative effectiveness research methods can examine the feasibility and effectiveness of specific components of care across multiple settings, including a designated care coordinator, clinical registry, family partner, and potential supports by pharmacy, nutrition and social work. Outcomes include family-defined goals, health care utilization and clinical and functional outcome. Population includes those that may have conditions that do not permit cure or improvement.
- *Feasibility to conduct*. Difficult because of need for existing large scale spread, requiring health care system level involvement and dedicated funding for comparativeness effectiveness research for this population. State or ACO level data however could be used to examine different care delivery models at a smaller scale.
- *Implications.* Successful understanding of fiscal viability, replicability, and dissemination potential (or scale) enables implementation of the care principles across different populations, regions, and payers.

Conclusion

The care principles for CYSHCN have been well defined in the literature through stakeholder analysis, qualitative studies, and interventions, including the Shared Plan of Care. Implementation science and comparativeness effectiveness studies are needed to help practices, hospitals, and health care systems adopt and spread the care principles. Implementation science is iterative, focusing on core principles, the flexibility needed in specific situations, and actionable steps; comparative effectiveness studies at the health system level will help with key investments and sustainability of specific components.

The critical components and processes of effective delivery systems needing further investigation include, but are not limited to, promotion of child and family health and wellness, reduction of health care disparities, and clinical and functional outcomes and costs at the individual and population levels. The evolving demographics of CYSHCN, including the increasing number of children with disabilities and medical complexity, may also explain the lack of movement on existing outcomes metrics and add relevance and urgency for further research. Notable opportunities exist on the scalable implementation of the principles of care across care settings. Medicaid, health care systems, and managed care organizations are increasingly interested in replicable models of care to address the needs of high resource utilizers. Challenges include the need for dedicated support for care delivery research, the use and spread of implementation science methods, and the support for comparative effectiveness studies of sufficient scale. Foundations, state, and federal funding sources may consider working with research networks and health care systems to generate care delivery research studies that can help families, practices, payers, and systems spread the change with actionable and sustainable steps.

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