

Access to Services for Children and Youth With Special Health Care Needs and Their Families: Concepts and Considerations for an Integrated Systems Redesign

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abstract

Access to services for children and youth with special health care needs (CYSHCN) have typically emphasized coverage, service, timeliness, and capability. Yet families of CYSHCN continue to describe a fragmented health care system with significant unmet needs. For many years, the concept of access to services has focused on the services themselves, rather than starting with the needs of CYSHCN and their families. Meeting these needs should be grounded in health equity, address systemic racism and ableism, and emphasize the life course and journey of those with such needs and their families. In this paper, we start with the simple concept of asking that care is available for CYSHCN regardless of when, where, and how they need it. Access to services is built on relationships instead of a series of transactions. Opportunities for innovation include creating a single point of service entry; determining services based on need instead of diagnosis; and emphasizing service continuity, transition, and a place-based approach. The innovations reimagine access throughout the life course, centering care around a proactive, human-centered system that addresses health and all of its determinants. The landscape of antipoverty investments, cultural humility, workforce changes, technology, and human-centered thought in design have the potential to further transform the conceptual framework to improve access to services for CYSHCN and their families.

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By definition, children and youth with special health care needs (CYSHCN) require additional services to address chronic health conditions and maximize health, development, and wellness.¹ Under the Health Resources and Services Administration, Maternal and Child Health Bureau's *A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs and Their Families*, there are 4 components of access to health care: coverage, suggesting that the service is paid for; service, describing a transaction or good that meets the need of the child; timeliness, suggesting the service is provided when needed; and capable, suggesting the workforce is effective, qualified, and culturally competent. Although the focus of this paper is on access to health services and supports, many other services are necessary for well-being and improved quality of life, including food, housing, child care, and education. Achieving health and wellness for CYSHCN requires care delivery frameworks designed to meet their interrelated medical, social, behavioral, and educational needs.^{2,3}

The presumption of access to services is that obtaining a specific service or good, such as a doctor visit, orthotic, or home aide, will help meet the special health care need. However, it is important to recognize that services that are known and supported by existing financing mechanisms and societal expectations can limit our understanding about how to improve health and wellness. The existence of known services should not prevent us from thinking more expansively by acknowledging patient and family priorities and needs to achieve the goals of health, wellness, and optimal development for CYSHCN.

Care for CYSHCN requires a life course approach just as for any other child, including addressing social determinants of health and building resiliency.^{4,5} Some special health care "need" may be a result of societal inequities that create an overlay of such "need." An example might be a child living in poverty in subpar environmental conditions who develops asthma. Thus, although the health care "need" may be addressed by access to a subspecialist, improving the environmental conditions would actually eliminate the need. Societal inequities for CYSHCN exist based on location (where one lives), financing (cost sharing),⁶ family structure (sole caregiver), communication barriers (deaf or hard of hearing, limited spoken English proficiency and/or reading proficiency), and societal bias (racism, poverty).⁷

The coronavirus disease 2019 (COVID-19) pandemic highlighted the perils of relying too much on a single paradigm of service delivery, specifically, the heavy reliance on educational entities for in-person developmental and health services for CYSHCN that then were interrupted when schools closed.⁸ On the other hand, the pandemic led to policy and regulatory changes that promoted widespread adoption of telehealth, sparking an alternative design and reframing of care delivery.⁹ Many other scenarios could lead to significant disruption to access to services in the future. For example, realigning financial incentives and payment structures under a value-based insurance design could reward better care and impact access to supportive services for CYSHCN.¹⁰

We propose that achieving the outcomes of optimizing of health and wellness for all CYSHCN requires moving beyond the 4 access components of coverage:

service, timeliness, and capability for individual encounters, services, and goods. Access to services for CYSHCN must include a system serving CYSHCN and their families that is designed to be proactive and equitable, supporting the life course, and incorporating the lived experience. In some scenarios, individual support services meeting the expressed needs of CYSHCN and their families are not widely available, do not exist, or have not been conceptualized within the health care system. More than ever, an integrated, proactive system of services that meets the needs of families requires partnership, flexibility, and innovation of design: the proverbial thinking outside of the box.

The state of access to services by CYSHCN can be described in multiple ways, including how services are organized, the workforce that provides them, and entry into those services.

Current State: Organization of Services

Families of CYSHCN and providers alike state that services are often disorganized. They have been described as fragmented, unaffordable, stressful, and untimely, with no available roadmap on how to access them. Further disparities exist by race and ethnicity.¹¹⁻¹³ A positive lived experience of care can be described as personal, convenient, timely, and affordable, but what constitutes a positive lived experience may be constrained by limited expectations. Additional considerations for CYSHCN include the inherent dependence on caregiver adults; the overarching role of the education system; pediatric specialty services concentrated in tertiary care centers¹⁴; and demographics, because these children are more ethnically diverse and have higher

rates of poverty compared to adults.¹⁴

Access to services can be described in quantifiable terms from data sources such as the National Survey of Children's Health. Starting with family-identified needs enables a description of system users. In the 2018–2019 National Survey of Children's Health, almost one-third (30.9%) of families of CYSHCN reported not receiving needed care coordination, compared to 11.0% of non-CYSHCN families. Of families of CYSHCN, 7.8% reported forgone health care, compared to 2.0% of non-CYSHCN. A similar percentage (8.3%) of families of CYSHCN reported being frustrated in efforts to get services, compared to 1.3% of non-CYSHCN families.

Further disparities in access to services are seen within CYSHCN, specifically, by race and ethnicity, income level, and functional status. More than two-fifths (42.1%) of families of CYSHCN with ≥ 2 functional difficulties reported not receiving needed care coordination. For CYSHCN identified as Hispanic, 11.2% of families reported forgone health care, as did 13.1% of families of CYSHCN with ≥ 2 functional difficulties. A higher proportion (10.4%) of Black and Hispanic families reported frustration in trying to get services, as did families living in poverty (10.2%) and those reporting ≥ 2 functional difficulties (13.9%).

Current State: Workforce

"Workforce" is often defined by the numbers or distribution of specific providers. The widely described geographic maldistribution of pediatric subspecialists and shortages in specific subspecialties^{15,16} suggest deficiencies in access to services. These deficiencies in turn may result in limitations in the scope of practice expectations for primary

care providers, who have increasingly described inadequate support in caring for CYSHCN.¹⁷ Families often see themselves as care coordinators and providers in home nursing care: roles families historically have assumed but that go underrecognized.^{3,18–20}

Current State: Entry Into Services

Less than one-half of families of CYSHCN report care consistent with the medical home.²¹ Children are demographically more diverse compared to adults and now survive previously lethal diseases; yet, they also have increasing rates of chronic disease, medical complexity, disability, and mental health diagnoses.^{22–24} It is not clear whether service availability has kept up with changing needs and demographics.

Entry into services may be facilitated by programs that themselves might create additional services that must be accessed. Such programs include home health programs, family peer support, respite, transition, telehealth, and care coordination.²⁵ If not carefully implemented, these approaches can build layers on layers of services, perhaps creating a need for coordinating the coordinators,³ which adds additional challenges for families to navigate. These approaches may not adequately address some fundamental flaws of the current system of services, such as a legacy of systemic racism and ableism, and a fee-for-service reimbursement system based on quantity of care rather than quality of care.

Other Blueprint Focus Areas

Access to services can be seen as the operational guts of the other critical areas of the *Blueprint for Change*. Intersections with the other focus areas are described below.

Health Equity

Optimal access to services entails an intentional design that addresses underlying barriers as a civil rights issue. There are analogies in existing laws, such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act of 1990, which inform how health care is approached with an equity lens. Accessed services need to be equally effective for the child and family, regardless of underlying disparities.

Family and Child Well-Being and Quality of Life

Services support CYSHCN and their families to achieve dignity, autonomy, and independence while considering community and culture.

Financing of Services

Services address and incentivize access and quality, providing return on investment and valuing outcomes that are meaningful to different stakeholders. The financing system supports needed types and uses of services, including those services that may be uncompensated or unrecognized, such as family caregiving. Financing should also account for policies that support family well-being outside of the medical sector. For example, antipoverty initiatives are essential for the health and wellness of CYSHCN, given the association with and differential impact of poverty on CYSHCN.

DISCUSSION

Vision for the Future

Existing access to service initiatives appear to place bandages on a fragmented system that was formed to meet historical clinical objectives. The vision presented here draws on a human-centered design (HCD) approach increasingly used in business and service sectors to address lived experience.²⁶ When applied to access to services for

CYSHCN, HCD emphasizes considering the experience of users when meeting their needs, which can include children, families, and providers alike. The HCD approach for access to services should start with an equity lens, given the historical underpinnings of structural racism and ableism in health system design. What follows is a vision for how services could be designed for CYSHCN, families, providers, and all other stakeholders to achieve health and well-being for all children.

CYSHCN and their families should receive services that are proactive, rather than reactive, to promote health, growth, and development. Proactive care is designed and planned to ensure necessary services are in place before a need is perceived. Such care can be navigated predictably and periodically revisited and updated. The stages of parenting a child with special needs have been described as proceeding from diagnosis to grief to moving forward.^{27,28} Families describe the need for a roadmap at the time of diagnosis, including navigation, facilitation, advocacy, and transition, among services.²⁹ Relationships are key to supporting the roadmap, a concept sometimes called “relational coordination.”³ A single point of access with universal eligibility determination could facilitate engagement with various health, educational, and social services, and ease entry into the roadmap. Overpreparation for anticipated events and transitions helps mitigate potential crises, such as a 504 education plan for accommodations and modifications to address contingencies like disease flares.

The access to services roadmap paradigm should follow the child, rather than be based on location, financing, or legal statute. This

paradigm builds on the principles of place-based care.³⁰ Determination and redetermination of service need often are influenced by time (eg, yearly), eligibility thresholds (eg, income level), statutes (eg, transition from early intervention to school), and financing (eg, previous authorization), thus impacting access in ways that prioritize service providers, not the needs of CYSHCN and their families. Instead, access to services should start based on where and how families desire services and supports that prioritize family health and wellness. As an example, telehealth and comanagement protocols are potential options for bridging current divides related to geography.^{31,32}

Access to services for CYSHCN should openly address equity and cultural humility. Children of color are now the majority of children in the United States.³³ Children as a group have high rates of poverty and near poverty with disparities by race and ethnicity.³⁴ The civil rights movement inspired laws and regulations that guarantee a free, appropriate public education and an array of services to which CYSHCN are legally entitled. For maximum effectiveness of service delivery, cultural humility should be the design underpinning, not a programmatic addition. The workforce ideally should reflect the community and be aligned with family goals for coordination of care and quality of life. If appropriate personnel are not available, workforce expansion should work to bridge potential divides and ensure engagement.

Challenges to Achieving the Vision

Challenges to this lived experience and roadmap vision are myriad. Shifts in demographics and disease burden mean designs that may have

worked 30, or even 10 years ago, may not work today. One-half of all children are now children of color, and almost 20% are CYSHCN. Chronic care and mental health visits are increasing, and a higher percentage of hospitalizations are because of medical complexity.^{35–37} The percentage of children who have Medicaid insurance has increased from 20% to 37.5% in the last 20 years.^{38,39} The financing design of access to services remains largely fee-for-service, which can promote fragmentation and siloes, thus stifling innovation and systems transformation because of limited availability of funds and regulatory constraints. In addition, health care finance literacy within families of CYSHCN is understudied.⁴⁰

The goal of cross-sector, interdisciplinary training to meet the needs of CYSHCN and families also remains a challenge.³ Different laws, training, and systems have arisen to support CYSHCN, but different underpinnings of financing and legality continue to support siloes.¹³ Schools are a primary provider of support services, such as therapies and counseling; yet, school budgets are often determined on the local level, which may lead to disparities in services. As witnessed during the COVID-19 pandemic, school closures led to large number of CYSHCN not receiving necessary services, even as other students received virtual services that did not always meet their educational and social needs.

Opportunities for Innovation

Opportunities for innovation begin with understanding that access to services is not simply to enable individual service transactions, but rather must encompass a lived experience journey for CYSHCN that improves their well-being and optimal health. Accordingly, innovation should address all

determinants of health, not just health care services, in an integrated manner, beginning with a framework of equity. A shared plan of care resource can address issues around integration of services.⁴¹ Some integration demonstration projects address cross-sector services but originate from the health care sector.⁴²⁻⁴⁵ Further innovations use emerging technologies that include integrating screeners and referral pathways, community navigators, and a single place of referral across sectors.

Services and eligibility currently are largely diagnosis based; for example, a diagnosis of autism may enable a specific set of behavioral and educational services that may not be available without a formal diagnosis. A system focused on need and function for service eligibility prioritizes access to services instead of having to first chase down a diagnosis. Need and function should reflect a life course, cross-system, and civil rights frame of disability. Accordingly, data collection related to populations, systems, and outcomes should accurately reflect race, ethnicity, primary language, sex, and economic status, as well as report on disparities, as part of system reform.

The maternal and child health field should prioritize the family experience of the journey across needed services, which often has been described as frustrating and a barrier in and of itself.^{13,40} The framework of patient- and family-centered care should be considered carefully as part of this journey.²⁹ The roadmap to care can start with a single point of access based on need (not necessarily diagnosis) and shared across sectors, such as education (including special education), health care, and community living. Roadmaps already exist in other non-health care fields; for example, an educational

roadmap means the vast majority of parents and caregivers plan to enroll their children in formal schooling between the ages of 3 and 5. The roadmap to care for CYSHCN should also address the well-described economic and emotional impact of caring for CYSHCN on families and review systems integration with housing, food, parenting, social, and psychosocial supports.

The place-based approach to care for CYSHCN similarly focuses on the journey of the child and family. The goal of this approach is a single eligibility system and plan of care across all agencies (health, education, social services) driven by patient and family care goals. Furthermore, it must be strength-based and support the level and location or modality of an intervention a family prefers. Innovation should address the relational aspect of care by expanding access and maximizing new technologies. Alignment of private sector innovation, public health programs, policy makers, and services across all agencies can catalyze innovation.

RECOMMENDATIONS

Ample opportunity remains to address equitable access to services for CYSHCN over the next 10 to 15 years. The shifting demographics landscape and current reliance on existing metrics demand a discussion about reconceptualizing how we think about service access. There is a fundamental need to consider access to health as a designed and predictable experience, focusing on meeting the needs of the child and family, and emphasizing health equity. That notion, as simple as it sounds, truly represents a paradigm shift. Instead of thinking of access as a means of providing a service, the new paradigm is understanding service

access as a pathway to improved quality of life and well-being.

The passage of the American Recovery Act, encompassing the largest antipoverty measures in 50 years, presents a unique opportunity to invest in the health and wellness of CYSHCN. Resources are available to address poverty, hunger, homelessness, unemployment, and other areas that also finance the system of services for CYSHCN outside of direct payment to providers. With pathways to health as the foundation, this report presents 5 broad recommendations.

1. Access to services should be proactive (planned) rather than reactive. A planned, proactive pathway to health should be designed as an experience, beginning at diagnosis (or even before diagnosis) and rooted in empathy and ease of attaining health.
2. Access to services should be simplified to reduce complexities. A pathway to services, starting with common intake by a care manager, should serve as an entry point. Instead of navigating across services, the intake should be aligned across sectors. Increased navigation support means retraining the workforce (and considering navigation across systems as essential training). It also requires alignment of timelines for initial eligibility determinations and redeterminations.
3. Access to services is based on need rather than diagnosis. A paradigm shift should examine what the child needs, based on symptoms or behavior, and use that assessment to drive the provision of services. This concept may be important to individuals who may have a dual diagnosis that is not yet

known, such as a child with Down syndrome and autism.

4. Access to services should be based on health equity and cultural humility to address the underpinnings of centuries of structural racism and ableism.⁷
5. Access to services should prioritize continuity between services. Every CYSHCN transitions across services and sectors, and entering a different service sector often requires completing a new application that requires demonstrating a well-established need. Examples include the transition from Part C Early Intervention services to Part B Preschool 619 services; reapplying for home nursing determination; transitioning from hospital to home to congregate living facility, thus setting up new systems of care; and moving from the pediatric to the adult system. These transitions are magnified by moves to new states or school districts. Sharing data across systems to maintain access is critical in optimizing care across the lifespan.

CONCLUSIONS

For too long, the system of services for CYSHCN and families has been designed around the services themselves. Health system metrics that describe CYSHCN access to services largely have not changed over time, including reports of unmet need and receipt of care coordination. Although there has been no lack of effort in addressing access to care, the ongoing expansions of Medicaid are 1 such example, the landscape of CYSHCN has also evolved, including in demographics, disease, workforce, and statutes, resulting in an evolution of needs. The existing care model simply may be outdated.

The mantra of asking that care become available for CYSHCN when

and where they need it wraps the system design around the needs of the child and family. Reimagining the system around the life course of the CYSHCN entails thinking about a proactive, human-centered system that addresses health through all of its determinants, and views access as a journey built on relationships instead of a series of transactions. The landscape of antipoverty investments, cultural humility, workforce changes, technology, and use of innovative thought in design have the potential to transform our thinking about how care is accessed. Financial, legal, regulatory, and statute barriers remain and sometimes seems daunting, but the journey to accessing services begins with changing our expectations about how health and wellness are designed for CYSHCN.

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ABBREVIATIONS

COVID-19: coronavirus disease 2019
CYSHCN: children and youth with special health care needs
HCD: human-centered design

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