RESPONSE TO THE MCHB's BLUEPRINT FOR CHANGE
INSTITUTE FOR EXCEPTIONAL CARE
NOVEMBER 24, 2020

The Institute for Exceptional Care is a non-profit organization working with and for people with intellectual and developmental disabilities (IDD) to thrive across the lifespan – by improving healthcare and driving the integration of clinical, educational, and social services. We applaud the Maternal and Child Health Bureau’s focus on children and youth with special health care needs (CYSHCN), and the opportunity to comment on A Blueprint for Change (the Blueprint).

We concur with the assumptions underpinning the Blueprint: That CYSHCN have more and different service needs, that current care systems do poorly in serving those needs, that racism and social drivers of health compound challenges to better health outcomes, and that any redesign of care systems must respect the right of people with disabilities to fully participate in society.

We would encourage MCHB to consider that serving youth well also includes preparing them for the transition to adulthood, a period of high risk for lapses in care coordination, in access to insurance coverage, changes in care providers with attendant loss of knowledge of their medical history, and shifts in other life stresses and needs such as employment, housing, and guardianship. It is not uncommon for CYSHCN to remain with their pediatric care providers longer than appropriate because of anxiety about transitioning care, and/or lack of access to appropriately prepared adult care clinicians.

Our comments focus on specific steps critical to achieving the goals and objectives defined in the Blueprint.

Most generally,

A. The objectives for improving health equity focus on removing policies that further inequities, improving access to services, building cultural sensitivity, implementing best practices, and investing in public health data systems for surveillance.

Action steps in this area should include:

• Codifying best practices for different types of providers and clinical care settings, and then including such rubrics in voluntary and mandatory educational, certification and accreditation programs for practitioners and clinical organizations.

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• Creating and scaling opportunities for health care practitioners to interact with patients and caregivers in their natural living situations, and/or accompany them on specific care encounters as observers. Such hands-on exposure outside of the usual care relationship resets the power dynamic between clinicians vs. patient/families, while inspiring and helping clinicians to “walk a mile” in patients’/families’ shoes as families try to navigate systems of services.

• Promoting the inclusion of patient/family councils in the work of co-designing and assessing care models

• Developing focused quality performance scorecards for providers serving CYSHCN and other IDD populations. Such scorecards should be parsimonious in the number of measures but could include both broadly generalizable outcome metrics such as quality of life or functional status, and more targeted measures reflecting the relevant clinical context for a given type of clinician or practice setting. For example, a scorecard for mental health providers could include metrics on functional status and QOL, but also measures related to management of anxiety, depression, or other mental health comorbidities for both patients and families. These data should be publicly available.

• Investment in not just public health data systems, but also in data standards for electronic medical records to capture functional status and social drivers of health. Structured data fields help set expectations that clinicians will ask about, record, and address these critical elements of care. The Assistant Secretary for Planning and Evaluation recently published a report on the importance of such data standards, now being developed by the Office of the National Coordinator on HIT, CMS, ACL, and other HHS agencies. While those efforts began with a focus on aged and disabled Medicare and Medicaid beneficiaries, they present an opportunity to generalize to other populations.

B. The objectives on family/child well-being and quality of life focus on promoting resilience and self-management, shared decision-making, promoting family-centered care, metrics that capture these outcomes that are reliable and usable, and a well-trained workforce that routinely assesses and addresses social drivers of child/family well-being.

Action steps in this area should include:

• Development of easily accessible toolkits and/or technology-enabled self-management strategies for patients/families for specific, common situations. These toolkits should be available in plain language and translated into multiple languages.

• Data standards as described in Section A above

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• Development of lower-cost metrics on QOL and well-being, and methods of data collection to support care improvement (e.g., simplified scales, delivered by text, tracked and shared with clinicians on a frequent basis).4

C. The objectives for improving access to services and supports focus on streamlined eligibility systems; proactive guidance to families on how to access care; physical proximity of essential services; access to telehealth and other virtual communication tools and modes of service delivery; regionalized specialty services; and bringing population health management strategies to the CYSHCN population. In considering this goal, IEC recognizes that CYSHCN require specialized services that may be in particularly short supply5, but that all patients/families require essential services such as primary care, where it is difficult to separate “access” from the meaningfulness and impact of the care that’s available. Access to primary care that does not meet patients’ needs is not true “access.”

Specific action steps should include:
• Supporting the relaxing of state licensure limitations or conversely, promoting reciprocal licensure across state boundaries such as occurred during the COVID public health emergency, to allow reader access particularly to specialty care or other services in short supply such as behavioral health support.
• Defining basic competencies that all clinicians should have for their practice settings to be prepared to serve CYSHCN and families and promoting the development of “CYSHCN-friendly” practices that families can readily identify. Multiple resources are already available to guide clinicians and practices in approaching CYSHCN and IDD care. For example, providers can use simple “watch lists” of issues that commonly arise at different stages of development for CYSHCN; plain language and other communication alternatives to ensure all patients have their preferences heard and can fully participate in decision-making; and simple modifications to the clinical setting to accommodate patients (e.g., strategies to reduce anxiety around blood draws); patients/families can provide input (e.g. Patient and Family Advisory Councils [PFACs]) on how to best accommodate and provide meaningful care. A synthesis or distillation of the best and/or common elements from these resources could form the basis of national guidance.
• Supporting the provision of services based on functional needs rather than labels.
• Promoting reasonably priced, capitated or episodic payment structures that allow providers the flexibility they need to deliver coordinated, team-based, tailored services that incorporate the voice of patients/families.
• Developing criteria to identify and establish a designation for practices/centers that provide CYSHCN care excellence, and promoting their acceptance by Medicaid and commercial insurers.

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• Promoting the establishment of widespread regional specialist care centers that will offer expert resources for practices and families.
• Promoting higher reimbursement for CYSHCN care (for example, through risk adjustment of payment rates), particularly for capitated/episodic payments or for specialty services. Higher reimbursement is essential to growing the supply of CYSHCN focused providers and the willingness of non-specialized providers to serve CYSHCN. Crafting appropriate payment structures will require sound administrative and clinical data on diagnoses, functional status, and service utilization.

D. The objectives for improving financing and payment for CYSHCN services focus on: adoption of a clear and comprehensive definition of CYSHCN; systems to identify and track needs and services; promoting team-based and enhanced primary care; increasing and creatively sourcing financing for all CYSHCN services including virtual care, care coordination and integration, and direct family support; promoting value-based payment approaches linked to meaningful patient/family outcomes; and minimizing the financial burden on families.

IEC wholeheartedly agrees that current financing and payment approaches are inadequate for promoting comprehensive, tailored, and coordinated care for CYSHCN. We also recognize that improving financing and payment is not just a matter of policy will but also require specific technical solutions and infrastructure that are not yet readily available to insurers and the providers they contract with, including comprehensive data, risk adjustment methods, and quality performance scorecards.

Specific action steps should include:

• Focused incentives or campaigns to promote the systematic screening, identification, and diagnostic coding of CYSHCN in clinical and claims billing systems. To the extent that some CYSHCN do not have all of their issues appropriately coded (e.g., a patient with intellectual disability whose autism is not coded), or some CYSHCN remain “invisible” in data systems because their primary care provider is unaware of non-clinical issues, payers will face challenges in recognizing the magnitude of the financing problem they need to address, in designing appropriate pricing structures in payment arrangements, and in risk adjustment. Building financial arrangements, whether between healthcare purchasers and insurers, or between insurers and providers, requires robust data to produce transparent and trustworthy business rationales.
• Identify and promote “best in class” among current financing and payment approaches, in both public and private sectors.
• Define coherent subgroups among the CYSHCN population, based on expected levels and types of service need.
• Design risk adjustment or risk stratification methodologies that reflect the expected quality outcomes and/or spending and service utilization for the subgroups defined as above.

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Design and promote payment methods based on sound risk adjustment, that are linked to meaningful quality performance measures and that incentivize care coordination and integration with other service sectors. For example, payers can offer providers explicit bonuses or a higher budget for using a structured data system to make referrals to social service agencies.

In general, populations such as CYSHCN that need complex services tailored to patient/family-specific circumstances are better served by episodic (bundled) or capitated payment structures that give providers flexibility within a predictable budget, so they do not have to worry about generating fee-for-service revenues. Such episodic/capitated arrangements would also be more compatible with sustainable reimbursement for low-intensity telehealth services such as email and phone calls.7

We appreciate the opportunity to comment on the Blueprint and will continue to engage on many of its goals and objectives to improve healthcare for this vulnerable population.

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7Berenson RA and Shartzer A. The Mismatch of Telehealth and Fee-for-Service Payment. *JAMA Health Forum*. Published online October 2, 2020. doi:10.1001/jamahealthforum.2020.1183