



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

November 30, 2020

Maternal and Child Health Bureau  
Health Resources and Services Administration  
5600 Fishers Lane  
Rockville, MD 20857

To the Maternal and Child Health Bureau,

The [Association of University Centers on Disabilities](#) (AUCD) writes to provide input on the draft version of *A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Families (Blueprint)*. AUCD supports and promotes a national network of university-based interdisciplinary programs. AUCD's mission is to advance policies and practices that improve the health, education, and social and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting our members in research, education, health, and service activities that achieve our vision.

We are grateful to the Bureau and its partners for their commitment to pursuing goals and framing efforts at the federal, state, and community levels that prioritize health equity, access to services and supports, family and child well-being and quality of life, and financing of services. We offer responses to 'questions to consider' 1, 2, and 3 for your consideration below:

**1. Are there items that are missing from the draft goals and objectives?**

We first urge the Bureau to consider updating the language used to describe CYSHCN to **'children and youth with disabilities'**<sup>1</sup> in order to better reflect and inform the four key areas identified in this Blueprint. The definition and use of CYSHCN adopted in 1998<sup>2</sup>, while progress from previous, more harmful frames, perpetuates an outdated understanding of disability identity and the myriad systems and services that serve this population. The reality is that the 13.5 million American children and youth that meet the definition of CYSHCN do not exist in a healthcare silo, but rather benefit from a range of eligibility systems: IDEA, Parts B and C; Section 504; SSI; civil rights protections such as the ADA; and so on. Efforts to operationalize the Blueprint will be most successful when they utilize updated language that acknowledges and affirms how the disability experience and identity impacts every area of life for children and youth with disabilities and their families<sup>3</sup>.

*Health Equity*

- We appreciate the Bureau's recognition that a working definition of 'health equity' is necessary to this work and suggest that it be expanded to better reflect the many existing definitions in the public health and social justice spheres. We suggest that HRSA expound upon its definition to outline more clearly the ethical and human rights issues at stake when discussing health disparities and equity, including the consequences of long-standing systemic health and social inequities for racial and ethnic minority groups<sup>4,5</sup>.
- In recognition of the outsized role of systemic racism as a barrier to health equity, we recommend that a goal is included that specifically addresses the need for systems and providers to engage in anti-racist efforts in order to move toward more equitable access to health services for CYSHCN and their families<sup>6</sup>.
- We recommend that the Objective concerning public health data systems also include a call for supporting public health surveillance and services for adults with disabilities

1100 Wayne Avenue, Suite 1000  
Silver Spring, MD 20910  
t: 301-588-8252  
[www.aucd.org](http://www.aucd.org)

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John Tschida, MPP  
*Executive Director*

previously identified as CYSHCN. Such longitudinal data collection and analysis is necessary to understanding health equity for CYSHCN and their families across the lifespan.

#### *Family/Child Well-Being and Quality of Life*

- In addition to identifying access to “high-quality, cost-effective, community-based programs” as a goal, we recommend that the Bureau also identify ‘high-quality educational systems’ as a necessary support for psychosocial well-being for children and families. This language reflects that the rights and services guaranteed under the Individuals with Disabilities in Education Act (IDEA) Parts B, C, and Section 619, and Section 504 of the Rehabilitation Act are not only integral to the physical wellbeing of CYSHCN, but also to long-term social-emotional wellbeing and quality of life.
- We also urge the Bureau to add a goal affirming that CYSHCN and their families have access to information, services, and supports regardless of location, language, literacy level, citizenship status, or income level<sup>7</sup>. Addressing these social determinants of health greatly impacts quality of life for all CYSHCN and their families.

#### *Financing of Services*

- We suggest the Blueprint include the following goal: “Changes to eligibility, enrollment, and referral processes for health care coverage, financial assistance programs, and other social services are identified early and addressed to ensure uninterrupted coverage and decrease the burden on CYSHCN and families.” Children and youth who have continuous health care coverage are more likely to be in better health<sup>8</sup>. Continuous health care coverage is also critical to protecting families of CYSHCN from financial burden and hardship<sup>9</sup>.

### **2. What steps need to be taken to implement these goals at the community, state and federal levels?**

Achieving the Blueprint goals will require significant changes and expansions to existing systems and structures at the community, state, and federal levels. The unfortunate reality is that, due to numerous systemic and financial hurdles, implementation of the full Blueprint is unlikely. We urge the Bureau to create and make public a plan for how it will ensure sustained systemic and political commitment to improvements, as well as how it will secure a budget to support these changes. Additionally, we recommend the Bureau provide training to medical personnel, health insurance providers, families, and other stakeholders on the final Blueprint once complete.

### **3. How should families, providers and other key programs and systems be involved in the implementation of the goals and objectives outlined in the Blueprint?**

We recommend that the Bureau continue to include families in all design, implementation, and monitoring stages through funded roles. This work must be integrated into all efforts and reflect the reality that states focus one-third of their block grant budget on this population. Continuous input from families of CYSHCN with an array of healthcare needs, backgrounds, and demographics will ensure that any system changes achieve intended purposes. Providing financial compensation is necessary to reducing additional stress and burden for participating families, as well as reflects the Blueprint vision of “dignity, autonomy, and participation” for CYSHCN and their families.

AUCD appreciates this opportunity to provide feedback to the Bureau on the proposed Blueprint. We look forward to continuing a productive working relationship in pursuit of creating equitable systems that ensure health, social-emotional wellbeing, and dignity for all CYSHCN and their families.

Sincerely,



John Tschida  
Executive Director  
Association of University Centers on Disabilities

1. Gernsbacher, M. A., Raimond, A. R., Balinghasay, M. T., & Boston, J. S. (2016, December 19). "Special needs" is an ineffective euphemism. Retrieved 2020, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5256467/>
2. Genetic Alliance; Family Voices. Children and Youth with Special Healthcare Needs in Healthy People 2020: A Consumer Perspective. Washington (DC): Genetic Alliance; 2013 Feb. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK132165/>
3. Wallis, K., Imparato, A., & Rodgers, R. (2019, September 24). Disability Identity: A Conversation with AUCD's Andy Imparato and Rylin Rodgers. Retrieved 2020, from <https://policylab.chop.edu/blog/disability-identity-conversation-aucd-s-andy-imparato-and-rylin-rodgers>
4. Braveman P. (2014). What are health disparities and health equity? We need to be clear. *Public health reports (Washington, D.C. : 1974)*, 129 Suppl 2(Suppl 2), 5–8. <https://doi.org/10.1177/00333549141291S203>
5. Braveman, P., Arkin, E., Orleans, T., Proctor, D., & Plough, A. (2017, May 1). What is Health Equity? Retrieved 2020, from <https://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html>
6. Crear-Perry, J., Maybank, A., Mitchell, N., & Godbolt, D. (n.d.). Moving towards anti-racist praxis in medicine. *The Lancet*, 396(10249). doi:[https://doi.org/10.1016/S0140-6736\(20\)31543-9](https://doi.org/10.1016/S0140-6736(20)31543-9)
7. Office of Disease Prevention and Health Promotion. (2020). Social Determinants of Health. Retrieved 2020, from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>
8. Medicaid.gov. (2020). Continuous Eligibility for Medicaid and CHIP Coverage. Retrieved 2020, from <https://www.medicaid.gov/medicaid/enrollment-strategies/continuous-eligibility-medicaid-and-chip-coverage/index.html>
9. Chen, A. Y., & Newacheck, P. W. (2006). Insurance coverage and financial burden for families of children with special health care needs. *Ambulatory pediatrics : the official journal of the Ambulatory Pediatric Association*, 6(4), 204–209. <https://doi.org/10.1016/j.ambp.2006.04.009>