

## FAMILY ENGAGEMENT AND CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Family engagement means patients, families, their representatives, and health professionals are working in active partnership at various levels across the health care system, from direct care, organizational design and governance, to policy making.<sup>1</sup> It ensures the consumer voice is included to improve care for children and youth with special health care needs (CYSHCN).



### CYSHCN

Family engagement on the individual level is a key element of family-centered care, proven to enhance the well-being of CYSHCN and families.<sup>3</sup> CYSHCN and families are most directly affected by decision-making, therefore partnerships between families, CYSHCN, and health care providers lead to better health outcomes and better resource allocation.<sup>3</sup>



### PAYERS & POLICYMAKERS

Engaging with family leaders moves systems work forward more efficiently and effectively, helping to inform policy improvements. Organizations such as Family Voices can help recruit, support, and connect families from all communities to family leadership opportunities. Family leaders who represent the diversity of a community are effective ambassadors and cultural brokers for underserved populations.



### FAMILIES

Active partnership between professionals and families helps ensure that the lived experience of families informs care and support services. It also helps families by providing physical and mental health benefits to caregivers, by building on strengths, supporting families, and reducing stress.<sup>3</sup> Programs that support peer mentoring are critical in supporting families in partnering at all levels.



### PROVIDERS

Family engagement at the organizational level occurs within institutions, for example through hospital advisory committees, which can promote a shift towards family-centered care. Family-centered care has benefits for children, families, and providers. Families who are informed, empowered, and active care partners are more likely to inform, understand, and utilize clinical recommendations, improving care and outcomes.<sup>4</sup>



## RESOURCES



### State Financing Strategies

This page links to examples of the innovative strategies states are using to support family partnership, such as partnerships with family-run organizations.

<http://cahpp.org/project/the-catalyst-center/financing-strategy/family-supports/>



### Dancing with Data: Using Data to Support Your Message

This guide exhibits the benefits of using data and stories in efforts made on behalf of CYSHCN, and provides tips for using these tools effectively.

<http://cahpp.org/resources/dancing-with-data-using-data-to-support-your-message/>



### Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities

This tutorial clarifies the language used to describe these inequities and provides tools and examples of policies, programs, and partnerships.

<http://cahpp.org/resources/inequities-tutorial>



### Family Voices

Family Voices is a national family-led organization of families and friends of CYSHCN. They connect a network of family organizations across the United States that provide support to families of CYSHCN.

<http://familyvoices.org/>

**DEFINING CYSHCN:** According to the federal Maternal and Child Health Bureau, CYSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and who also require health and related services of a type or amount beyond that required by children generally.<sup>2</sup>

## CITATIONS

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