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# Supporting Children with Disabilities: Lessons from the Pandemic

A Workshop

Division of Behavioral and Social Sciences | Board on  
Children, Youth, and Families

*Amy Houtrow, MD, PhD, MPH*

*Professor of PM&R and Pediatrics*

*University of Pittsburgh*





# Committee Members



Emily Hotez



Natasha Strassfeld



Yetta Myrick



Marc Tasse



Chandra Jones

# Panel Presentations

## • Monday

- Lived Expertise:  
Children with  
Disabilities and  
Caregivers
- Hospital and  
Outpatient Settings  
–Telehealth
- School and  
Educational Settings

## • Tuesday

- Home Care Settings
- State and Federal  
Policy
- Health Equity:  
Promising Practices

## • Wednesday

- Public  
Health/Emergency  
Planning
- Planning for  
Recovery

# Thank you to our sponsor

US Health Resources and  
Services Administration (HRSA)

Maternal and Child Health  
Bureau (MCHB)

**Mission:** To improve health outcomes and achieve health equity through access to quality services, a skilled health workforce, and innovative, high value programs

**Goal 1:** Take actionable steps to achieve health equity and improve public health

**Goal 2:** Improve access to quality services.

**Goal 3:** Foster a health workforce and health infrastructure able to address current and emerging needs

**Mission:** To improve the health and well-being of America's mothers, children, and families



# Blueprint for Change

**A national framework for a system of services for children and youth with special health care needs (CYSHCN) where they enjoy a full life and thrive in their community from childhood through adulthood**



## ARTICLES

### **Introducing the Blueprint for Change: A National Framework for a System of Services for Children and Youth With Special Health Care Needs**

Treeby W. Brown et al

### ***A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families***

Sarah E. McLellan et al

### **Children and Youth With Special Health Care Needs: A Profile**

Reem M. Ghandour et al

### **Progress, Persistence, and Hope: Building a System of Services for CYSHCN and Their Families**

Michael D. Warren et al

### **Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future**

Amy Houtrow et al

### **Quality of Life and Well-Being for Children and Youth With Special Health Care Needs and their Families: A Vision for the Future**

Cara L. Coleman et al

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

Dennis Z. Kuo et al

### **Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems**

Jeff Schiff et al

<https://publications.aap.org/pediatrics/issue/149/Supplement%207>

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## A SUPPLEMENT TO PEDIATRICS

### *Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs*

Treeby W. Brown, MA, Sarah E. McLellan, MPH, Marie Y. Mann, MD, MPH, FAAP, and Joan A. Scott, MS, CGC, Guest Editors

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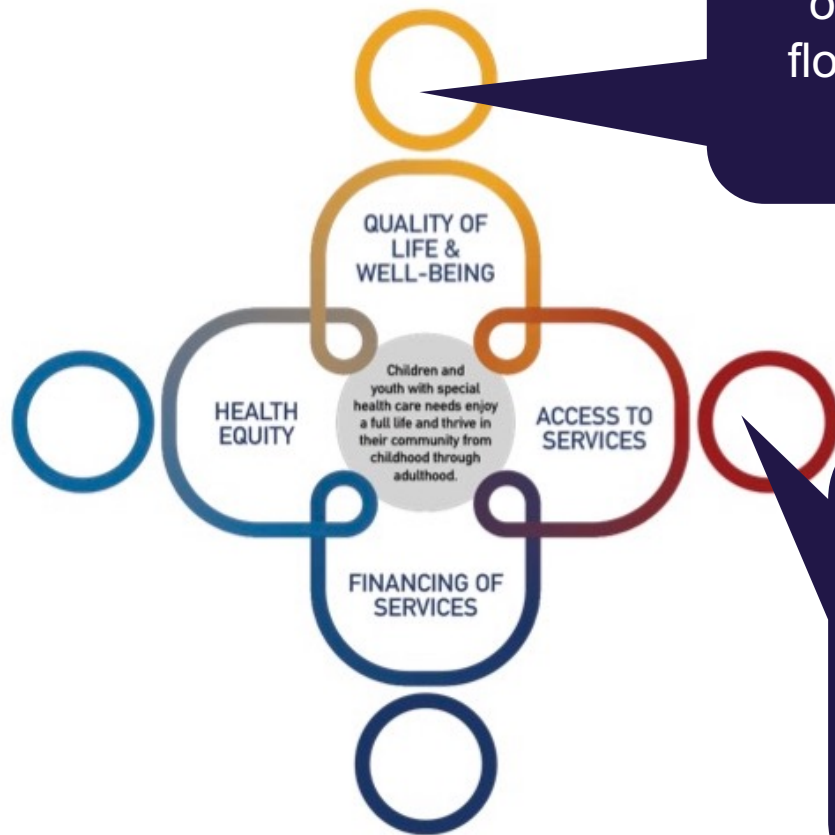
The views expressed in this publication are solely the opinions of the authors and do not necessarily reflect the official policies of the US Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the US Government.



# Critical Areas for a Well-Functioning System



# Visions



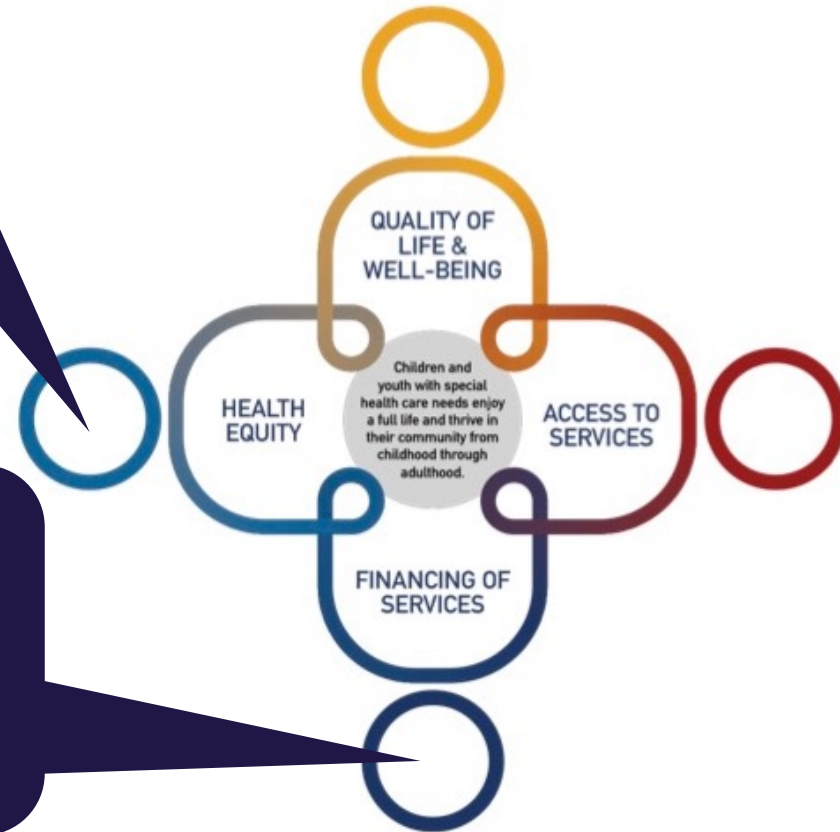
The service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families.

CYSHCN and their families have timely access to the integrated, easy-to-navigate, high-quality health care and supports they need, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course



All CYSHCN have a fair and just opportunity to be as healthy as possible and thrive throughout their lives (eg, from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live.

Health care and other related services are accessible, affordable, comprehensive, and continuous; they prioritize the well-being of CYSHCN and families.



# Understanding the Population

**CYSHCN** have a chronic physical, developmental, behavioral or emotional condition AND require health and related services of a type or amount beyond that required by children generally

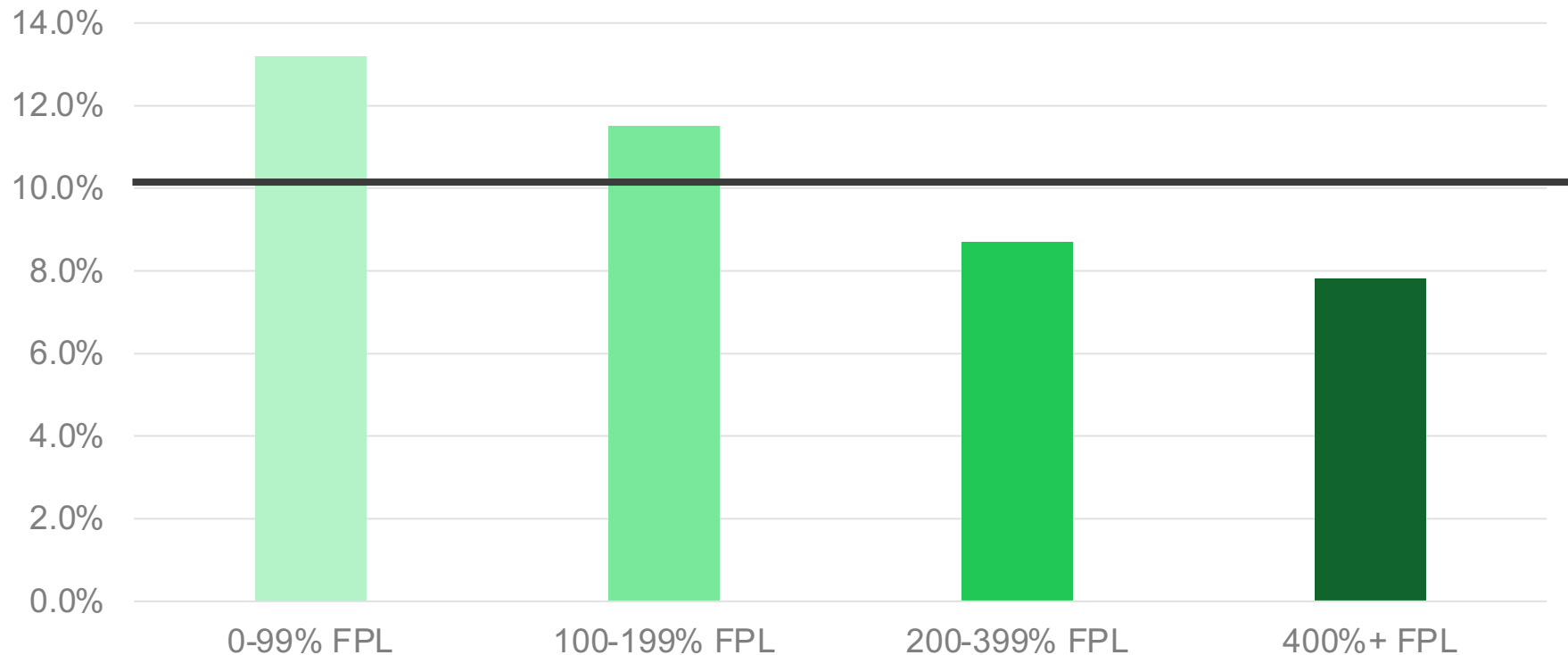
~73 million  
Children in the United States

~59 million  
Children do not have special health care needs

19.4% or ~14 million have special health care needs

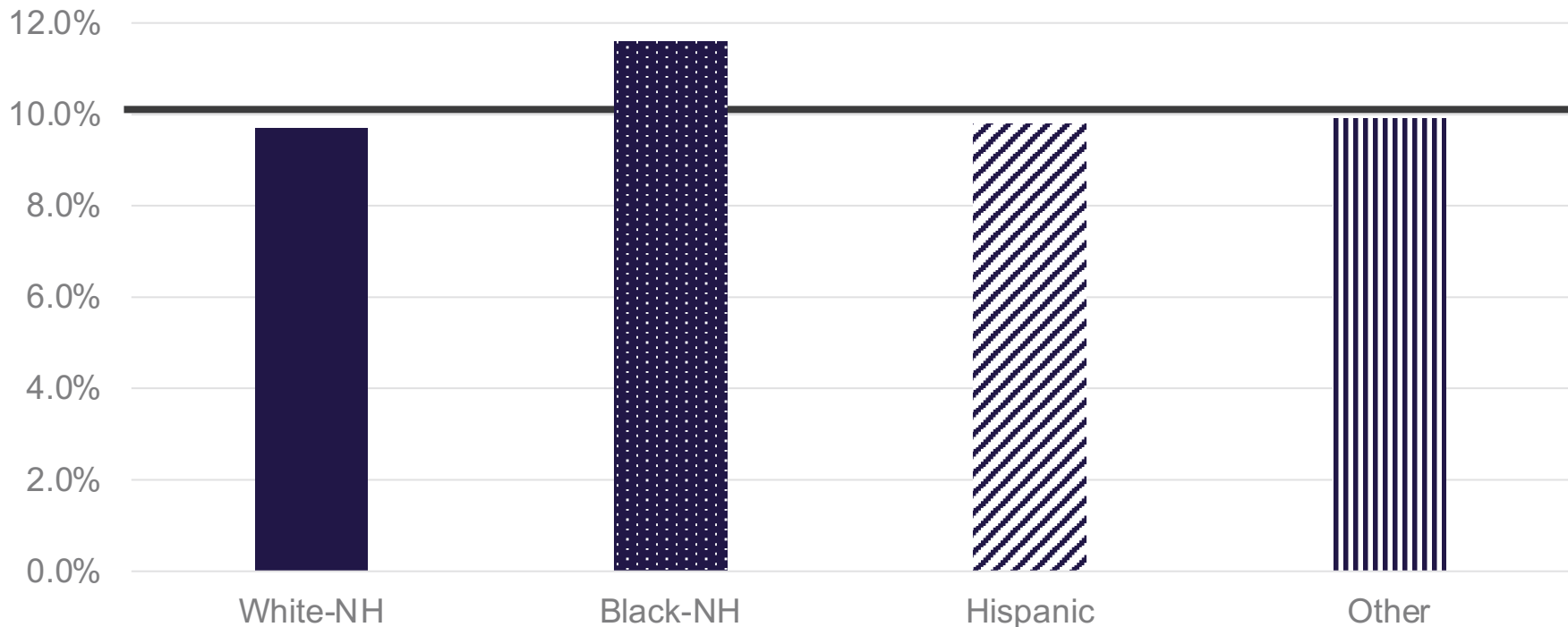
10% or ~7.3 million have disabilities (a health condition that consistently and often a great deal affects their daily activities)

# Percentage of Children with Disabilities by % of the Federal Poverty Level in 2019-2020



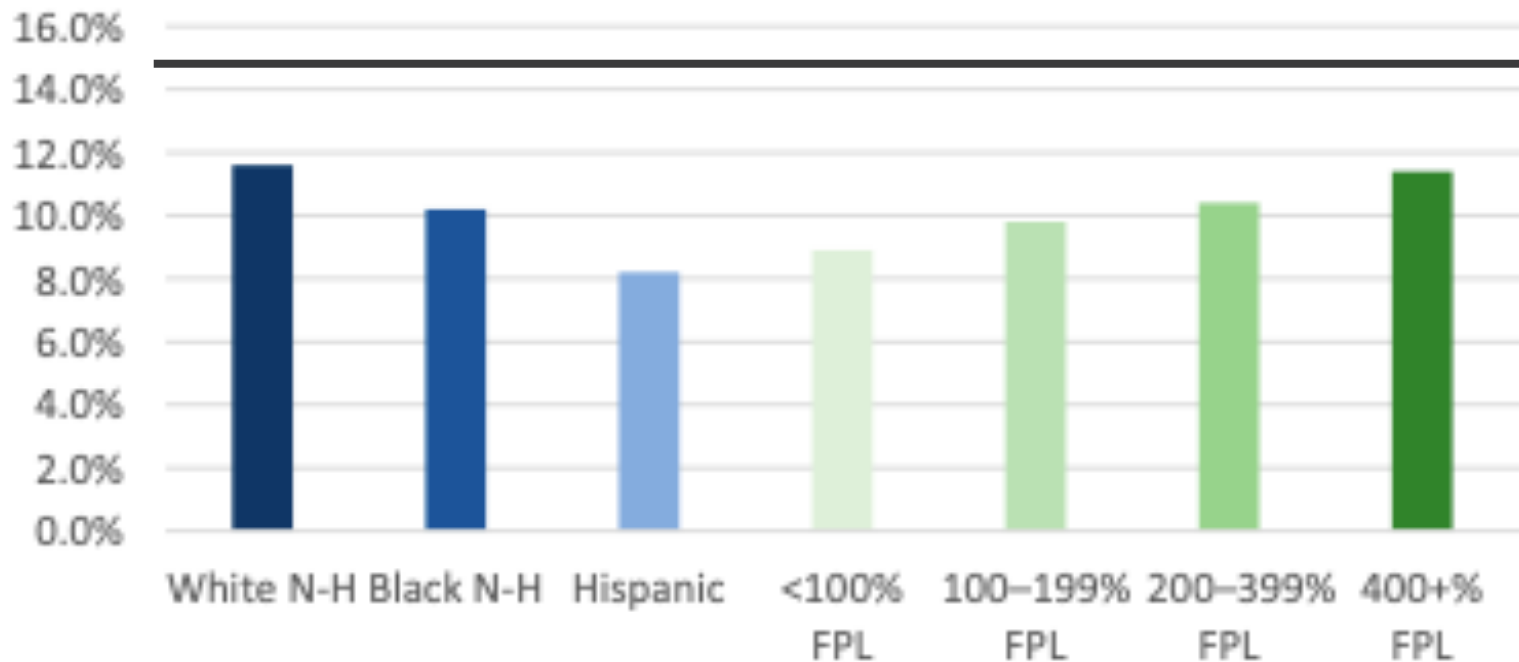


# Percentage of Children with Disabilities by Minoritization in 2019-2020





# Care in a Well-functioning System for Children with Disabilities (2016-2019)







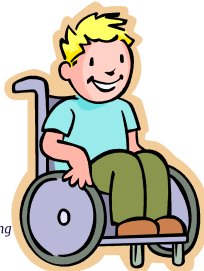
# Quote from the Blueprint for Change

“Over the past 2 years, families have felt the weight of the pandemic, natural disasters, social and economic unrest, and the traumatic toll these crises have on their children. Families with children and youth with special health care needs (CYSHCN) often experienced this trauma more acutely in their ability (or inability) to access needed health care and supportive services. ...Families of CYSHCN tell us that the current system of services is not working for their children. There are vast inequities experienced by families in accessing and paying for services and support to care for their children; the system is not responsive to their needs or values. If the system is not working for CYSHCN, it is likely not working for children generally, any of whom could have a special health care need at some point in childhood. We have opportunities to take advantage of rapid changes in the health care landscape, including advances in technology and new mechanisms to finance care to advance the existing system and address equity through a fresh new lens.”

# Planning Committee Charge

Explore promising approaches and innovative strategies employed during the pandemic to address challenges faced by children with disabilities and their families, including access to clinical service and treatment needs, home caregiving, and mental health treatment with an emphasis on underserved/under resourced children and families

Consider policies and/or practices that might be sustained or implemented beyond the pandemic to support children with disabilities and their families





# Impacts of the COVID-19 Pandemic on Children with Disabilities

- Fear
- Immediate loss of services and routines
- Feeling overlooked or not prioritized
- Financial strains
- Loss of loved ones

“...wondering how [my son] might be treated should he present to the hospital...? ... [his] disabilities could throw us back into dreaded quality-of-life and utilization-of-resources discussions... would they...take his ventilator?”

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“The part-time nurse also worked at a major hospital (with a newly established COVID unit)...so my husband is doing two night shifts a week and I have 12-14 hour day shifts... Our home care agency has sent us nothing in the way of protocols or practical support.”

# Impacts of the COVID-19 Pandemic on Children with Disabilities

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Special education services

Safely restarting therapies

Getting equipment and supplies

Accessing vaccines

Shift to a personal risk assessment model of public health



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Families of Children with Special Health Care Needs reported:

More employment changes  
-laid off  
-furloughed  
-reduced hours  
-job loss

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- Feeling overlooked or not prioritized
- Financial strains
- Loss of loved ones

As of October 31, 2021, an estimated 149,300 children in the US had lost a primary caregiver (a parent or a custodial grandparent) during the pandemic.

Unwin and Hills et al. Global, regional, and national minimum estimates of children affected by COVID-19-associated orphanhood and caregiver death, by age and family circumstance up to October 21, 2021: an updated modelling study. *Lancet Child and Adolescent Health*, 2022.

# Lived Expertise: Children with Disabilities and Caregivers

- Presenters
  - Emily Cowen
  - Kasey Hodges
  - Roseani Sanchez
  - Doris Tellado
  - Lauren Ware