

SUPPORTING CHILDREN WITH DISABILITIES: LESSONS FROM THE PANDEMIC

7 MAIN THEMES

As we look forward beyond the pandemic, the innovative strategies and lessons learned to support children with disabilities and their families can be organized into seven main themes:

1 Lived Expertise

- Include those with lived expertise as leaders.
- Respect and value the perspective of families with a limited capacity to participate.
- Address the needs of people from multiple marginalized identities.

2 Partnerships and Coalitions

- Support some existing partnerships and coalitions.
- Form new coalitions between schools and public health systems.
- Bring together stakeholders.

3 Flexibility

- Expand telehealth access and reimbursement.
- Exercise flexibility with administrative roadblocks (such as prior authorization requirements or state-to-state licensing rules).
- Extend Medicaid waiver flexibilities.
- Pay families for the care labor they provide.

4 Technology

- Telehealth is valuable to children with disabilities and their families.
- Disparities in access to technology present a challenge for future telehealth use and expansion.
- Make broadband access a public good.
- Continue and expand payments for telehealth.
- Respect preferences about technology use.

5 Children with Disabilities have Rights

- Ensure that they receive accommodations and services that they are entitled to.
- Issues: Unfunded mandates, lack of clarity around children's rights, and lack of adequate training.
- While they are guaranteed a free appropriate public education, the pandemic disrupted many services and virtual school was not always appropriate.
- Clarify Early and Periodic Screening, Diagnostic and Treatment (EPSDT) care coordination benefit.
- Increase the Federal Medicaid Assistance Percentage.

6 Coordination and Communication

- Need for improved coordination and communication with children with disabilities and their caregivers to better ensure that needs are met.
- Have decision-makers and those directly impacted at the table.
- Maternal and Child Health Bureau and Title V agencies could help facilitate communication, particularly during emergencies.

7 Political and Social Determinants of Health

- Importance of food security, adequate housing, and economic stability to health outcomes.
- Children are not able to access needed health care due to barriers, red tape, and perverse incentives.
- Simplify access to programs and improve access to all families.



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