

BUILDING RESILIENCE FROM LIVED EXPERIENCE



NAME

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SUMMARY

In this **brief written narrative**, a mother of children with special health care needs describes her family's experience navigating uncertainty at the outset of and during the COVID-19 pandemic.

KEY WORDS

Services and supports
System leadership and communication
Mental health

SYSTEMIC FACTORS ADDRESSED

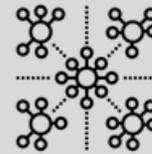
Ableism
Fragmentation / silos
Politicization of public health



LOCATION

Kansas

EMERGENCY TYPE(S)



Disease Outbreak

MAJOR TAKEAWAYS



FOR INDIVIDUALS AND FAMILIES

Be clear about what "safe" means for your family, set boundaries that can help manage your stress, and make difficult decisions together.



FOR HEALTH AND RELATED SYSTEMS

Children and youth with special health care needs receive a significant amount of support through the education system, so advance coordination can ensure health is effectively prioritized during emergencies.



FOR COMMUNITIES

Decision-makers should be actively seeking the perspectives of families with complex health needs in developing and refining public safety guidance.

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