BUILDING RESILIENCE FROM LIVED EXPERIENCE

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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
Polticization of public health

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.

LOCATION
Kansas

EMERGENCY TYPE(S)
Disease Outbreak

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