

BUILDING RESILIENCE FROM LIVED EXPERIENCE

AMCHP

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

NAME

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SUMMARY

In this [MCH Bridges podcast episode](#), leaders from the University of Illinois Chicago's Division of Specialized Care for Children (DSCC), The Arc of Illinois, and Illinois Healthcare and Family Services (Medicaid agency) describe and reflect in detail on their experience approving and ultimately implementing an amendment for the Medically Fragile Technology Dependent Waiver that enabled backup generators to be purchased with service funds. This policy change was prompted by families' advocacy in the aftermath of a thunderstorm that caused major power loss across the state. At the time of the podcast recording, their combined efforts have resulted in 24 approved providers installing 191 generators in the homes of children with special health care needs – ensuring that those with the most complex considerations are less vulnerable to the impact of future severe weather events.

KEY WORDS

State policy | Medicaid waivers | Family leadership | Community voice | Interagency collaboration

SYSTEMIC FACTORS ADDRESSED

Health insurance access
Housing instability



LOCATION

Illinois

EMERGENCY TYPE(S)



Natural disaster or severe weather

MAJOR TAKEAWAYS



FOR INDIVIDUALS AND FAMILIES

Susan: "Don't be afraid to ask [for something you and others need] because the answer might be 'yes'."

Molly: "Assess the situation and understand [if] this is the experience of one or is this the experience of many."



FOR HEALTH AND RELATED SYSTEMS

Stephanie: "Listen [to families' experiences and needs], brainstorm, and coordinate... to figure out a solution."

Courtney: "Things aren't always as complicated... as we think that they might be."

Molly: "Form a good partnership with many of our families and the individuals who we serve and are here to serve."



FOR COMMUNITIES

It is critical that families have established, trusted mechanisms for articulating their needs when emergencies arise, as well as sustainable connections to staff from government programs who can: (a) translate those needs into feasible policy solutions and (b) activate the necessary partners to deliver those solutions.

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