



BUILDING RESILIENCE FROM LIVED EXPERIENCE

AMCHP's Collection of Public Health Emergency Preparedness and Response Stories

Project Summary

In partnership with the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), this project was originally conceptualized as a collaborative effort to develop a toolkit for improving performance and capacity of states and territories to plan for and respond to the unique needs of maternal and child health (MCH) communities (including individuals with medical complexities) before, during and after public health emergencies. Now at its closing, this project has been transformed into an anthology of narratives from individuals, caretakers, families, and professionals with the lived expertise of personal and professional impacts of emergencies that can:

- Build the evidence base for policies and practices that support equity-centered emergency responses;
- Prompt meaningful action at all levels, including among Title V MCH and related program staff within jurisdictional health agencies; and
- Ensure others with lived experience feel seen and consider sharing their stories.



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NOT ANOTHER TOOLKIT...

- Families, community leaders, and professionals expressed “toolkit fatigue” and want multi-modal interactive products to build their knowledge base and capacity to respond during public health emergencies. Public Health must be flexible, adaptable, and responsive to feedback from its workforce and from communities.
- Collaboration and partnership are at the center of this project and are foundational in elevating the stories from individuals, families, and communities with lived expertise.
- Stories and narratives from people with lived experiences are invaluable because they shed light on often invisible and ignored factors (e.g., historical trauma) that impact outcomes.



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LESSONS LEARNED

CENTERING FAMILIES & FAMILY VOICE IN PROGRAMMING & POLICY

- Families have unique needs, cultures, and communication norms that must be prioritized during public health emergencies.
- Families are underutilized as potential sources for quality improvement processes.
- Successful partnership with families requires mutual respect, open and honest communication and environments that foster family leaders.

EXPERIENTIAL EVIDENCE IS ACTIONABLE EVIDENCE

- Personal experiences often prompt discussion about the need to change policies, and the stories we collected have the potential to drive what policies look like and how they are implemented.
- Qualitative data, including stories, are critical complements to other forms of evidence like population-level disaster data.
- Stories answer the questions of **how** and **why** to add context to known and unknown facilitators and barriers. *How* did successful efforts come together? *Why* didn't other efforts work?

HONORING LIVED EXPERTISE IN ADDRESSING SYSTEMS

Centering lived experience in this work creates a bridge for the necessary bidirectional dialogue between families and systems.

Hearing from families and professionals with lived experience helps us to evaluate the intention and “theory” of policy vs. the outcomes; making policies actionable and being able to truly measure impact.

When systems are designed to accommodate individuals with complex and chronic health care needs, all other populations are benefactors.



THINGS WE MISSED...

- Collaboration with doulas and birth workers is vital in supporting the needs of pregnant and birthing people.
- Partnerships with payers, such as Medicaid, are essential to support resources that address health-related social needs, especially during public health emergencies.
- Collaboration with youth and young adults could have deepened our knowledge of non-traditional messaging and communication strategies and provided insight to their unique needs during emergencies.

RESOURCES NEEDED TO FULLY SUPPORT THIS PROJECT

- Funding for quality audio recording, video editing, and incorporation of digital storytelling (i.e. use of photos and illustrations).
- A clear dissemination plan inclusive of social media, newsletters, and direct email correspondence. Search engine optimization would also be helpful in connecting people with stories.
- An evaluation plan for communications engagement to demonstrate the effectiveness of dissemination and usability.

IMPLICATIONS FOR CONTINUED & FUTURE PROGRAMMING & POLICY

- Promote the use of collected stories to prompt emergency planning action and innovation. Centering lived experience is how we can best prepare systems to meet the needs of people at their most vulnerable.
- Disasters, heat emergencies and other extreme weather events are inevitable and are increasing in frequency and severity. Jurisdictional Title V programs need sustained technical assistance on how to gather and leverage wisdom from stories in ways that describe and advance equitable solutions.
- Build sustainability for storytelling in public health by developing, supporting and funding systematic processes for gathering stories and engaging storytellers. Embed storytelling and lived experience in programming and policy.



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Revisit the anthology: bit.ly/AMCHP-BRFLE

