

Background

- Effective implementation of pediatric clinical guidelines and pathways may be enhanced by family engagement; not clinical adherence alone
- Family-Centered Care (FCC): collaboration, shared decision-making, and respect for parent experience
- BRUE (Brief Resolved Unexplained Event): Clinically benign diagnosis but associated with high parental anxiety; caregiver education is essential and part of guideline and pathway update
- Closing the Gap: Parent volunteers reviewed BRUE materials to improved clarity, empathy, and align with FCC principles

Project Aims

To partner with parents and caregivers by incorporating their input into one phase of clinical guideline development or implementation by September 30, 2025

BRUE Clinical Guideline and Pathway



Family Education Materials

English Version



Spanish Version



Methods

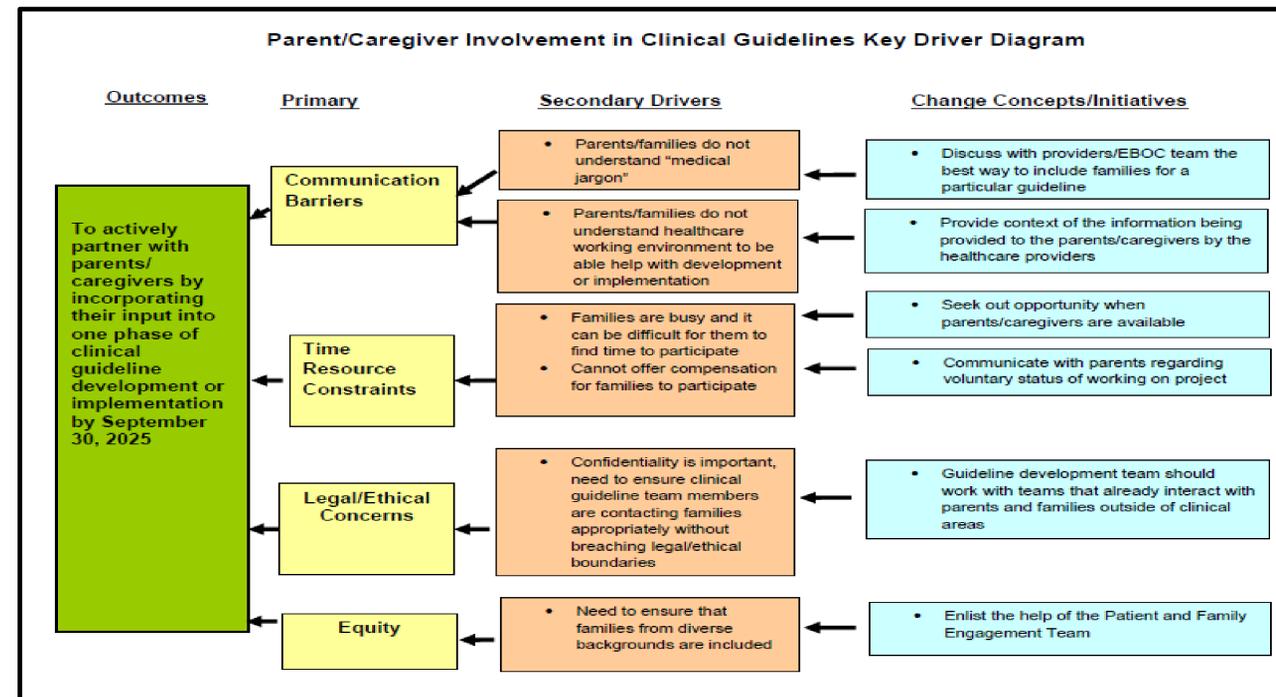


Figure 1. Key drivers informing integration of family voice into BRUE guideline and pathway implementation

PDSA Cycle 1: Partnering with Family Support Specialist

Plan/Do: Met with Family Support Specialist to assess feasibility of parent involvement
Study: Identified actionable strategies for engaging families able to participate
Act: Developed plan to engage Family Advisory Council for structured feedback

PDSA Cycle 2: Engaging the Family Advisory Council

Plan/Do: Conducted structured meeting with Family Advisory Council to review BRUE content
Study: Analyzed caregiver feedback on clarity, tone, and educational needs
Act: Incorporated family recommendations into handout language and framing

PDSA Cycle 3: Developing Family Education Handouts

Plan/Do: Collaborated with clinical experts and marketing to draft family-facing materials
Study: Evaluated feedback from caregivers and providers
Act: Finalized English and Spanish versions of BRUE handouts

PDSA Cycle 4: Dissemination & Accessibility Plan/Do:

Partnered with education and digital teams for internal and external dissemination
Study: Monitored usability and accessibility on hospital websites
Act: Planned ongoing updates aligned with guideline and pathway revision

Qualitative Results

- Families expressed interest in contributing to project without compensation
- Empathetic wording proposed by parents
- Proposed language helped promote sense of shared decision-making
- Previewed by providers did not show any changes in clinical meaning

Sustainability Plan

- Update materials with guideline revisions
- Expand family partnership to other pathways in ways that fit guideline's

Key Takeaways

- Family engagement is feasible in clinical guideline/pathway work
- QI methods provide structure to the inclusion of parent/caregiver voice
- Parent feedback improved clarity and empathy without altering meaning

References

- American Academy of Pediatrics (2022). Brief resolved unexplained event: What parents and caregivers need to know
- Dworetzky et al. (2023). Family engagement at the systems level
- Tieder et al. (2016). BRUE clinical report