Children's Hospital of Philadelphia PolicyLab

"Difficult to Find, Stressful to Navigate": Parents' Experiences Accessing Affirming Care for Gender-Diverse Youth

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Purpose: Gender-diverse youth (GDY) face significant health disparities, which can be mitigated by gender-affirming medical care. Understanding parents' experiences seeking care for their GDY can identify barriers to care and improve access. This study sought to understand parents' experiences accessing gender-affirming medical care with their GDY.

Methods: We asked parents of GDY in the United States to describe their experiences with gender-affirming medical care through a single open-ended item on an online survey disseminated through social media in February of 2020. Open-ended survey responses were analyzed through inductive thematic analysis by two authors using an iteratively developed codebook adjudicated by consensus. This codebook was used to identify key themes.

Results: We analyzed 277 responses from majority White (93.9%) parents from 41 U.S. states. Themes included (1) Experiences accessing care: finding a provider, financial and insurance-related considerations, the impact of geography on care access; (2) Experiences receiving care: factors in successful or unsuccessful patient-provider interactions, differing approaches to initiating care, sense of community with other families; and (3) Outcomes related to receiving care: how care for their child was perceived to be lifesaving or helped their child thrive.

Conclusions: Parents highlighted how access to gender-affirming medical care improved their GDY's health and wellbeing, and described numerous barriers they experienced with finding and receiving this care. Given the evidence that gender-affirming medical care mitigates health disparities, providers, policymakers, insurance companies, and health systems leaders should urgently address these challenges to ensure equitable receipt of care for all GDY.

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