Integrating Youth Voice in Health Plan Quality Improvement

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Received for publication January 21, 2021; accepted March 13, 2021.

Keywords: youth and family engagement; quality improvement; health plans

Academic Pediatrics 2022;22:S68−S69

Incorporating youth and family voice to inform healthcare policies and practices has increasingly become recognized as essential to the delivery of quality health care.[1] Underlying these efforts is the belief that involving youth and their families leads to more acceptable and accessible services and that consumers of health care have a rightful role and the requisite experience to offer important contributions in the design and delivery of services,[1,2] despite limited evidence of its impact on outcomes.[3,4] Even as interest in obtaining youth voice to inform quality improvement (QI) and care design grows, there is limited guidance about how best to engage youth effectively.[1]

This commentary describes lessons learned from working with health plans to incorporate youth voice in QI approaches to improve adolescent depression care. Youth MOVE National (YMN), an advocacy organization run by individuals with lived experience in mental health care during adolescence, worked with the National Committee for Quality Assurance to lead a learning collaborative where participating plans agreed to involve youth and families in their QI efforts. The learning collaborative provided opportunities to share learnings as plans worked to integrate youth perspective as advisors (providing input) to QI activities.[5]

Building Buy-In from Health Plan QI Teams to Include Youth Voice

Plans varied in their openness and experience in engaging youth. YMN provided basic youth engagement training, resources and toolkits to highlight the different ways plans can incorporate youth perspectives. During the collaborative, three plans moved forward with engaging youth; a fourth plan eventually took that step towards the end of the collaborative after meeting other plans' youth representatives and hearing the value of the partnerships during an in-person learning session. The concrete examples of how the other plans worked to integrate youth voice was the critical impetus for this plan to engage youth directly; previously the plan relied on input from a child psychiatrist about youth needs.

Strategies for Integrating Youth Voice

In developing their initiatives for collecting youth voice, health plans found difficulty in identifying youth to integrate in their QI activities. Outreach directly to youth receiving mental health care was not considered possible due to legal concerns in using mental health diagnoses to identify youth; further, parental consent is required to involve youth in focus groups about perceptions of care. YMN worked with plan QI teams to partner with youth or family-focused organizations within their region and to establish informal contracts that outlined the scope of work and expected support.

The plans varied in their type of partnership. One plan met monthly with a leader from a youth-run organization that already had a large presence in the region; this youth leader provided feedback on youth-facing materials.

Another plan partnered with a youth and family organization that had experience facilitating youth-focused committees, thus providing access to a wider range of youth voices. A third developed a youth council, involving up to 10 youth, to regularly provide feedback. This plan initially partnered with a family-focused organization to help facilitate monthly youth council meetings, but later changed to facilitating the sessions themselves by tailoring approaches used for their existing adult advisory council to engage youth directly.

The fourth plan was specifically interested in understanding cultural attitudes towards mental health and stigma. They partnered with a family-focused organization that worked directly with the plan's local Hispanic population to provide case management and mental health programs. The partner was only able to facilitate focus groups with youth and their families, instead of youth-only groups. While the plan did not get clear perspectives from youth through this partnership, they learned valuable

lessons about the need to adapt engagement approaches with different populations.

Plans also noted the importance of setting clear expectations and understanding the strengths of partnering organizations, as well as the need to vet potential consumer partner organizations for goodness of fit. For these plans, clear processes and structures could have strengthened their partnerships.

HEALTH PLAN LEARNINGS FROM ENGAGEMENTS

Most health plans found value in their youth engagement efforts. One plan described working with youth and families as having "lightbulbs go off" to look at QI efforts from a consumer perspective. Another plan found that, through their partnership with a youth-focused organization, they were able to get a better understanding of how to better engage adolescents by adopting developmentally appropriate language and approaches. For example, during a listening session, one plan heard directly from youth that using terms like "crazy" in casual conversation may be perceived as ableist to those with mental health challenges.

As the plans developed their strategies to improve adolescent depression care, they tailored their QI initiatives based on what they learned directly from youth. From its focus groups, one plan learned that some providers were conducting the Patient Health Questionnaire-9 (PHQ-9) with family present, a practice that is not recommended because young people may be reluctant to answer depression screening questions truthfully when a family member or caregiver is present.[6] The plan encouraged providers to adjust administration to a private environment. Another plan worked with its advisory council to pilot a phone app for social support and as a potential mechanism to complete screenings; based on the pilot, the plan adopted the app for broader use.

CONCLUSIONS

Plans found value in working with an experienced youth leader to integrate youth voice in QI efforts. Their approaches to youth engagement varied and evolved over time as they learned how to employ deliberate approaches to engage youth perspectives. Importantly, plans learned that building genuine relationships with youth and family takes an investment of time and trust that can provide rich and useful information for QI. All participating plans arranged to continue or expand their engagement efforts based on their experience. One plan hired a full-time staff member to outreach to youth and family moving forward. The plans that reported greater barriers noted that they will continue and seek new approaches to youth engagement. To reach greater levels of youth and family engagement in QI initiatives, plans may need to dedicate resources for active and adaptive efforts.

ACKNOWLEDGMENTS

This project was supported by grant number U18HS025296 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

This article is published as part of a supplement sponsored by the US Department of Health and Human Services, the Centers for Medicare and Medicaid Services, and the Agency for Healthcare Research and Quality.

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