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Formation, Operation, and Maintenance of a Community Advisory Board for Research with LGBTQ+ Parents

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Formation, Operation, and Maintenance of a Community Advisory Board for Research with LGBTQ+ Parents

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Abstract

Community-engaged research is becoming increasingly popular to promote health equity.

The purpose of this article is to describe the formation, operation, and maintenance of a community advisory board (CAB) of LGBTQ+ parents and healthcare providers who work with LGBTQ+ parents. Using Newman and colleagues' outline, we describe the formation, operation, and maintenance phases of our CAB process. Inclusion criteria for CAB members are as follows: CAB members must be 18 years of age or older, live in the U.S., and (a) self-identify as LGBTQ+ and have had a child in the NICU more than five years prior to study initiation, or (b) work in a NICU with LGBTQ+ families and self-identify as LGBTQ+ or an ally. We recruited six CAB members to guide the development of a research study focused on understanding the experiences of LGBTQ+ parents who had a child hospitalized in the NICU. All members identified as LGBTQ+ parents who had a child in the NICU or providers who worked in the NICU. Reflections from CAB members are included. In primarily focusing on the formation and initial phases of the CAB, we underscore the importance of community engagement in research.

Keywords: *queer, community-engaged research, community advisory board, LGBTQ+, NICU, health equity*

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Researchers must consider ethical practices when engaging in research with human participants. Historical instances of egregiously unethical research conducted on human participants led to the development of ethical codes and guidelines for researchers. However, since many of these instances of unethical research practices targeted people from marginalized backgrounds, like the Black men who participated in the U.S. Public Health Service Untreated Syphilis Study at Tuskegee, in which researchers intentionally withheld treatment for syphilis (Centers for Disease Control and Prevention, 2022), mistrust between researchers and participants from marginalized backgrounds may persist. Further, the lack of inclusion of individuals from diverse backgrounds in research studies has also led to health inequities. Over time, researchers have begun advocating for community-engaged research, which represents research *with* (rather than *on*) human participants (particularly research with individuals from marginalized backgrounds) that includes the voices of the community being studied as part of the research process to focus on the community's needs (Quinn, 2004). Community-based participatory research (CBPR) is a commonly cited example of community-engaged research that some consider the gold standard (Key et al., 2019), and many researchers who conduct CBPR are guided by community advisory boards (Quinn, 2004).

Community Advisory Boards

Community advisory boards (CABs) are an important step in formalizing the relationship between academic researchers and community members. CABs primarily consist of non-scientist community members who are sought out to help inform a research study based on their knowledge and experiences as part of a given community (Ortega et al., 2018). The composition

of a CAB may vary depending on the study goal and community of interest; however, each CAB member shares an interest or identity relevant to the research. As such, CABs offer an opportunity for community members to influence research methods related to a specific community and ensure the research is appropriate, respectful, and beneficial to the community that the CAB represents (Hirshey et al., 2023; Newman et al., 2011). However, we must also recognize that CABs are not without bias, and thus, while their perspectives are needed, subjectivity should be monitored. Ultimately, a CAB assists researchers with understanding the concerns and priorities of a certain group or community (Hirshey et al., 2023). In practice, CABs vary in size, composition, and goals; however, many are focused on health-related issues (Zadvinskis & Hoying, 2023). Although research involving CABs is growing, we found little research on CABs representing the lesbian, gay, bisexual, transgender, queer, or other sexual and gender minority identities (LGBTQ+) community.

A Need for Research with LGBTQ+ Families

In the U.S., LGBTQ+ individuals comprise approximately 7% of the population (Brown, 2023). Despite experiencing health disparities and other social adversity including discrimination, the LGBTQ+ population has great strengths both individually, as a community, and within families headed by LGBTQ+ parents (Farr et al., 2022). Research on LGBTQ+-headed households recognizes positive family outcomes including satisfying relationships with their parents and engagement in positive parenting practices; furthermore, children in LGBTQ+ families develop positively and experience positive adjustment (Farr, 2017; Goldberg & Allen, 2020; Golombok, 2015).

Although research on LGBTQ+ parents and families has been established and continues to grow, research related to LGBTQ+ parental experiences in the Neonatal Intensive Care Unit

(NICU) remains understudied. Parenting in the NICU is a stressful experience for any parent, wrought with worry, decreased parenting confidence, and increased likelihood of developing mental health conditions (Ghorbani et al., 2014; Janvier et al., 2016; Lundqvist et al., 2014). For LGBTQ+ parents, the experience of stress and worry may be exacerbated due to stigma and discrimination associated with their sexual orientation or gender identity. Therefore, our team of researchers set out to understand the experiences and needs of LGBTQ+ parents who have had a child in the NICU via the Neonatal Intensive Care for Queer Families (NICQu Families) project. To achieve this, we recognized that it was essential to involve and be guided by the voices of LGBTQ+ individuals who have had a child in the NICU, as well as providers who work with LGBTQ+ families in the NICU, to inform and conduct our research.

The purpose of this article is to discuss the systematic formation, operation, and maintenance of a community advisory board composed of LGBTQ+ parents who have had a child in the NICU or those who work in the NICU, following the phases of CAB development outlined by Newman and colleagues (2011).

Method

Research Team Positionality and Preparation

The senior members of the research team (first, second, third, and fourth authors), who have been facilitators of the meetings with CAB members, have backgrounds in social work, music therapy, psychology, and family medicine, respectively. We identify as parents and as members of the LGBTQ+ community, one of whom has had personal experience with their infant receiving care in the NICU. Our families have been formed through adoption, assisted reproductive technology (ART), and traditional conception. We draw from our professional and

personal backgrounds to investigate the needs and experiences of LGBTQ+ parents who had a child in the NICU.

We began preparing to develop a community advisory board (CAB) by searching the literature on best practices for CABs and consulting with colleagues who have developed CABs as part of their research. We also sought training from a member of the LGBTQ+ community who is part of a CAB related to substance use. This training covered best practices and allowed the research team to ask questions of someone who has served on a CAB about what it takes to form and maintain a successful CAB.

Formation

According to Newman et al. (2011), the formation phase of a CAB consists of clarifying the purpose, functions, and role of the CAB in addition to determining membership composition and recruitment strategies. At the outset of the study, we concluded that the CAB would serve in an advisory and collaborative capacity. Although senior members of the research team determined the study aims and design (to better understand experiences of LGBTQ+ parents who have had a child in the NICU through semi-structured interviews), we decided that we would ask CAB members to (a) advise us throughout the research process, (b) assist with refining the method and research questions as needed, and (c) engage in other recruitment, research, and dissemination activities (including co-authorship) in accordance with CAB members' preferences.

Next, we considered CAB membership composition and recruitment strategies. We decided that all CAB members must be 18 years of age or older, live in the U.S., and either (a) self-identify as LGBTQ+ and have had a child in the NICU more than five years prior to study initiation, or (b) work in a NICU with LGBTQ+ families and self-identify as LGBTQ+ or an

ally. We chose to limit inclusion to participants in the U.S. because that is where we live and work, and we recognize that parents navigating the U.S. healthcare system may have unique needs and challenges. We chose to exclude parents whose infants had been born within the past five years from CAB membership because we planned to interview parents whose infants had been in the NICU within the past five years in Phase 2 of our study, and we did not want there to be overlap between CAB membership and participation in interviews in Phase 2 of the study.

We developed a pre-screening survey in Qualtrics and included a link and QR code to the pre-screening survey in our recruitment materials. After obtaining IRB approval for the development of the CAB, we distributed our CAB recruitment flier via social media, through various relevant listservs, and within our professional networks. We also posted printed flyers on campus, at our campus healthcare facility, and in local LGBTQ+ owned business establishments.

We used snowball sampling by asking existing CAB members to share recruitment materials electronically within their networks. CAB members did not have to be located in the same state as the research team; we aimed to recruit participants from diverse geographical regions within the U.S. and shared materials

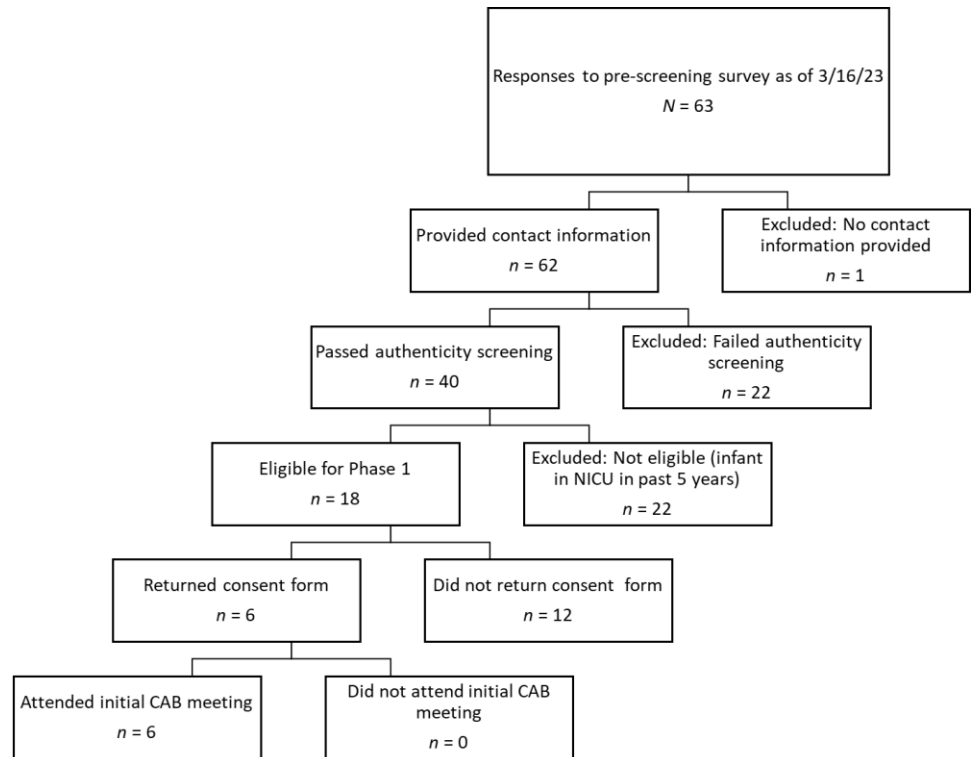


Figure 1 – Screening & Recruitment

electronically to reach potential CAB members living in other states and regions. Figure 1 is a flowchart detailing the screening and recruitment process.

Once we determined that a prospective CAB member was eligible via the pre-screening survey, we emailed them a consent form and a link to a Qualtrics survey to determine which aspects of involvement with the CAB they were interested in. Figure 2 shows the tasks that CAB members could select.

<p>We would like for the CAB to assist with several tasks as we prepare for Part 2 of the NICQu Families study, but not every member of the CAB needs to assist with every task. Which of these tasks do you think you would be interested in helping with? Please check all that apply. You can always change your mind later.</p> <ul style="list-style-type: none">● Sharing about your own experiences with the NICU as a parent or healthcare provider● Developing and refining interview questions for LGBTQ+ parents of NICU infants● Developing and refining recruitment methods (locating eligible participants) for NICQu Families Study Part 2● Recruiting participants (locating eligible participants) for Part 2 of the NICQu Families studies● Reviewing themes identified in interviews with NICQu families● Preparing a toolkit for LGBTQ+ parents and healthcare providers in the NICU● Disseminating the toolkit (finding the best ways to share the toolkit with parents and healthcare providers)
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Figure 2 – Possible Tasks for CAB Members

Results

The CAB consists of six members, three of whom identify as LGBTQ+ parents of infants who had been in the NICU, two of whom are healthcare professionals who work with LGBTQ+ parents in the NICU, and one who is a healthcare professional who works in the NICU who also identifies as an LGBTQ+ parent who had an infant in the NICU. All CAB members identified as cisgender women who were a five or higher on the MacArthur Scale of Subjective Social Status, a single-item measure of one’s perceived socioeconomic status (Adler et al., 2000). A score of five or higher means that CAB members perceive themselves to be at least middle class. CAB members came from suburban areas of the Southeast ($n = 3$), Northeast ($n = 1$), and Mid-Atlantic ($n = 1$), or from rural areas of the Midwest ($n = 1$). One CAB member identified as African

American, one identified as Hispanic/Latina, and the remaining four identified as white/European American.

Operation

The operation phase is defined by establishing operating procedures and principles, leadership, balancing power, and decision-making. Once the research team had six CAB members, we hosted our first synchronous meeting with the CAB via Zoom in March 2023, during which members of the research team and the CAB members introduced themselves and described their relevant experiences, discussed group dynamics and agreements, introduced CAB members to project goals, described roles and composition of the CAB, and explained how CAB members would be paid for their time. Members of the research team explained in greater detail the various ways in which CAB members could choose to fulfill their role.

The CAB members were integral in developing and implementing the research project. Throughout the operation phase, we gave CAB members time to provide input and feedback on all activities related to the research. The first part of the research focused on developing semi-structured interview guides relating to the experiences of LGBTQ+ parents who had a child hospitalized in the NICU in the last 5 years. After the initial meeting, we realized the challenges inherent in scheduling meetings with all six CAB members and the research team. To accommodate the schedules of the CAB members, we held two separate meetings in April 2023, during which we discussed the same content and gave CAB members the option to attend either one.

During these meetings, the research team and the CAB began drafting semi-structured interview questions aimed at answering our overall research questions for use in Phase 2. The research team generated a list of questions to start the process. The CAB provided feedback on

the questions, developed new questions, and assisted with the flow of the questions. The research team then refined the semi-structured interviews and held meetings in May 2023 to obtain feedback from CAB members on the revised interviews and the interview process. For CAB members who could not attend the Zoom sessions held in April and May 2023, the research team emailed the interview draft for CAB member feedback. Five CAB members attended meetings in April and May 2023, and four CAB members provided additional feedback on the semi-structured interview guides via email in June 2023.

Once the CAB approved the semi-structured interview questions, the research team submitted a modification request to the IRB in order to obtain approval for Phase 2 of the research study. After obtaining IRB approval in September 2023, the research team hired three graduate students to assist with conducting the interviews. To prepare for this phase of the study, the research team held a training course for the students on how to conduct qualitative interviews in September 2023.

Once the questions for the semi-structured interview were finalized, the research team piloted the semi-structured interview guides with members of the CAB who served as interviewees. During and after the interviews, the CAB member and interviewer could discuss the flow of the questions and identify confusing prompts or wording. In October 2023, three of the existing CAB members agreed to participate in mock interviews with the graduate students so they could practice; one CAB member also invited her spouse to participate in mock interviews. After the mock interviews were conducted in October 2023, the research team began recruiting LGBTQ+ parents who have had a child in the NICU to participate in the interviews. As of April 2024, we have completed Phase 2 interviews and plan to ask CAB members to assist with reviewing themes extracted from interviews. We plan to work with the CAB to develop a

survey that can be distributed among a larger, broader, more diverse sample of LGBTQ+ parents. We will also work with CAB members to develop a toolkit for LGBTQ+ parents on navigating the NICU and for NICU healthcare providers on supporting LGBTQ+ parents.

Maintenance

The last phase of the CAB process refers to maintenance, which may include evaluation of the partnership process and sustainability. Although Newman and colleagues (2011) described this as the last phase of the CAB process, we considered maintenance throughout our project due to our research timeline. Developing and conducting a multi-phase, mixed-methods study (such as ours, since future phases of NICQu Families research will include quantitative data collection and implementation studies) takes time; there were periods during which the research team was finalizing documents and working through institutional processes to conduct the research. The IRB approval process for Phase 2 was the most time-consuming portion of this process, lasting about two months between initial submission and final approval. During this time, the research team sent two emails to all CAB members checking in, providing information about the process, and explaining what they could expect next. We used these emails as a means of maintenance during the operation phase to ensure CAB members received clear communication about what was occurring and when they could expect to hear from the research team again. Because our research is ongoing, the research team has not yet conducted a formal evaluation of the CAB with all the members of the CAB; however, here, we include reflections from two CAB member co-authors to center their perspectives on CAB involvement.

Reflection from CAB Member 1

I am a board-certified music therapist with specialized training in supporting infants and families in the NICU. My clinical work is guided by patient and family-centered care, trauma-

informed care, and recognition of individual identities and experiences. I've witnessed the importance of fostering a safe, affirming space when providing psychosocial support for families. Parents with a hospitalized infant deserve to be included in care, supported by the interdisciplinary care team, and empowered as they embrace their identity as parents.

After learning about the NICQu study and a rich conversation with the second author, I was confident the goals of the research team and the aims of the study aligned with my personal and professional passions and values. The decision to join the CAB was easy. The research team is comprised of skilled scholars and researchers from the fields of medicine, music therapy, psychology, and social work. Working alongside a research team dedicated to improving care for LGBTQ+ families in the NICU has provided opportunities for community, learning, collaboration, and growing my skills as a clinician and researcher. I continue to feel honored to serve as a member of the Community Advisory Board and contribute to the NICQu study.

Reflection from CAB Member 2

Being part of the CAB has been a positive experience for me, and I am hopeful that my contributions are valuable to the researchers and to future LGBTQ+ NICU parents. Having a child in the NICU was an incredibly emotional experience at a very important moment in the creation of our family. While going through it, there wasn't much time or emotional space for reflection or doing much other than reacting to the next challenge (or joy) in front of us. Participating in this project reminded me how vulnerable and raw parents are in the NICU, and how members of any minority group are even more vulnerable than others in those vulnerable moments. It was interesting to hear about the similarities and differences in other CAB members' experiences to ours, and to consider how these experiences may relate to those of future LGBTQ+ parents. I want future LGBTQ+ parents to feel confident going through a

NICU experience that they will not suffer more because of their sexual orientation or gender identity and to feel confident that their children will not suffer more for who their parents are.

Discussion

This article details the formation, operation, and ongoing maintenance of a Community Advisory Board (CAB) focused on the experiences of LGBTQ+ parents in the NICU, using the practices outlined by Newman and colleagues (2011) as a guide. A CAB serves as a central point for directing research endeavors, fostering a continuous partnership to tackle community health issues, and creating a means to enhance capabilities within both the community and the academic institution (Quinn, 2004). CABs such as the one our research team established represent an important component of Community-Based Participatory Research (Key et al., 2019; Quinn, 2004).

Limitations and Challenges

This was our first experience with a CAB as a research team, and our experience was not without its challenges. We initially hoped to recruit 8-10 individuals for the CAB; however, we were only able to recruit six CAB members despite multiple attempts over the course of more than one year. We received more than 20 responses to our online pre-screening survey that we determined were inauthentic and learned that we needed to carefully examine the details of responses to provide an additional layer of oversight for screening out bots and scammers.

Although our CAB is geographically and racially diverse, all members identified as cisgender women, indicating a lack of gender diversity. Our CAB also lacked members from lower socioeconomic status backgrounds and from urban areas. Furthermore, since we did not ask CAB members about disability or mental illness, it is unclear whether perspectives of

disabled parents are represented within our CAB. We hope to recruit additional CAB members in the future to address these limitations of representation.

Since our CAB hailed from various regions of the U.S., we were not able to interact with CAB members in person. We also faced institutional challenges related to paying the CAB members in a timely manner because the institution that employs the senior researchers and administers grant funding for our research has specific limitations related to how and when CAB members could be paid.

Reflections and Suggestions for Future Researchers

Although each CAB will function uniquely, we share our experiences of developing a CAB in hopes that future researchers will find the lessons we learned useful. Establishing and maintaining a CAB demands a significant investment of time and effort. Before the formation phase, the research team invested time in learning how a CAB works, identifying who we thought should comprise the CAB, and considering how our personal and professional identities might impact the development of the CAB. Recruitment can be challenging, especially when working with members of marginalized communities who may be mistrustful of participation in research (CDC, 2022). To address this, we recommend that researchers carefully consider their own identities and positionalities and take steps throughout the research process to be transparent and respectful to promote felt safety and trust among CAB members.

Prior to and during the CAB formation, we discussed the topic of power imbalance. We recognize that there can be a power differential between academics who are trained as researchers through formal doctoral programs and community members without this training and background. In response, the senior researchers made concerted efforts to build relationships with CAB members during initial meetings, which continued throughout the process. During the

first CAB meeting, the senior researchers shared personal information, such as pronouns, sexual orientation, and gender identity, and described how our own families were formed. Additionally, we shared our roles in the process, discussed the role of the CAB, and asked for feedback from CAB members. The research team leaned on the CAB members as the experts while we acted as facilitators of the research. Throughout the process, the CAB members were paid for their time as another means to balance power between the CAB and the research team. We suggest that future researchers attempting to create CABs recognize that participating on a CAB is an investment of time and energy and seek ways to adequately compensate CAB members.

Conclusion

The establishment and operation of a CAB were crucial in ensuring the inclusivity, relevance, and ethical integrity of the NICQu Families study. By adhering to best practices outlined by Newman and colleagues (2011), our research team has gained a deeper understanding of the importance of doing research *with* (not *on*) participants and the power of community engagement in research endeavors, particularly when addressing underrepresented or marginalized populations. Through the systematic formation, operation, and maintenance of the CAB, we have underscored the importance of collaboration and partnership between researchers and community members. The CAB not only provided valuable insights and perspectives but also served as advocates for the LGBTQ+ community within the research process. Their involvement in refining research questions, shaping interview protocols, and providing ongoing feedback has enriched the study and ensured its alignment with the needs and priorities of the community.

Our experience highlights the need to proactively address power differentials and promote equitable participation within research partnerships. By fostering open communication,

transparency, and mutual respect, we sought to mitigate potential power imbalances and empower CAB members as equal stakeholders in the research process. Providing compensation for CAB members' time and expertise served as a tangible acknowledgment of their contributions and helped to uphold the principle of reciprocity. While our manuscript primarily focuses on the formation and initial phases of the CAB, it also underscores the ongoing nature of community engagement in research. As we continue with future phases of the NICQu Families study, the CAB will remain integral to the research process, offering ongoing guidance and validation of findings.

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