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INTERVIEW



Bringing the Voices of Kids into the Boardroom

Schonay Barnett-Jones shares professional and personal experience in advocating for children's health

BY AISHA SYEDA

hildren in the U.S. are experiencing a wide array of serious challenges, from mental health conditions, to poverty, to obesity and abuse. Their voices and needs must receive increased recognition from health care organizations and communities to begin

to reach their full potential for good health.

Children's National Hospital is a freestanding 323-bed facility that provides wraparound services to children in the Washington, D.C., region. It offers the same services through its outpatient clinics in D.C., Maryland and Northern

Virginia. The hospital's commitment to community extends from its #2 ranked NICU through its teen and adolescent support service specialties. Children's National is the first pediatric hospital to form an in-house Advocacy Institute that focuses primarily on advocating for system and policy changes aimed at achieving health equity for all children.

Schonay Barnett-Jones, a trustee at Children's National Hospital, started her journey as a parent of a six-month old diagnosed with idiopathic cardiomyopathy. Her daughter ultimately received a heart transplant at the Children's Hospital of Philadelphia. The experience energized her to volunteer and fueled her passion for enhancing the voices of patients and their families. Over the years, she chaired the Children's National Patient and Family Advisory Council, and eventually, the hospital board. She currently serves as a director for Bearacuda RE, the Children's National Insurance Captive, which provides risk mitigation services to the organization, and as a board member for Health Services for Children with Special Needs, Inc. (HSCSN) — the Washington, D.C. Medicaid health plan for children and young adults. In an interview with Aisha Syeda, senior program manager for strategic initiatives with the American Hospital Association, Barnett-Jones shared how board members at pediatric hospitals can contribute

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to improved health and well-being for the children they serve. This interview has been edited and condensed for clarity.

Aisha Syeda: How is Children's National identifying and addressing health inequities?

Schonay Barnett-Jones: At Children's National, or Children's, our goal is for children to "Grow Up Stronger." In addition to improving clinical results, our objective is to ensure children experience better outcomes within their communities. To address health disparities, we began to assess patient neighborhoods using the Child Opportunity Index (COI). It underscored the interplay between health and various indicators such as education, environment, socio-economic conditions and racial inequities. We identified neighborhoods with limited grocery stores, lack of proper early childhood education and high unemployment rates, which all impact disparities in accessing health insurance coverage and healthy foods. This critical information allows us to strategically engage with community and hospital stakeholders to tackle priority indicators within each neighborhood leading to better community outcomes.

In 2019, in partnership with a wide range of health and education professionals, Children's National developed principles of a School-Friendly Health System (SFHS); an initiative to help health systems support children and families from early childhood through high school and beyond. Children's National, along with seven partnering children's hospitals and a community health center, piloted

the SFHS framework with local school districts. A key component of the program involved Children's National working with the District of Columbia Public Schools and its primary care practices on an attendance data-sharing initiative to identify families and students who chronically miss school. Students are often absent due to health or socio-economic reasons about which their providers are unaware. As a result of this pilot, Children's National developed the CARE-H Family Engagement Playbook to help health care professionals provide outreach and medical attention to these children. We also included the CARE-H consent form in the 2023-24 school year enrollment packet to expand the program across the school district. By engaging with our community partners, we hope to make an early impact on the children we serve.

Syeda: That is quite remarkable. Congratulations on embarking on that journey. In addition to the disparities you mentioned earlier, how is Children's National addressing other emerging health challenges?

Barnett-Jones: The rise in violence and firearm injuries among juveniles in D.C. has increased over the years. In 2023, more than 50 juveniles were shot or killed. Gun violence not only affects the impacted and their families, but also takes a toll on the overall well-being and mental health of the entire community. Our Youth Violence Intervention Program provides children and their families with support by offering resources and community connections to build a safer future. The consequences

of gun violence coupled with the COVID-19 pandemic have rocketed mental health concerns to the forefront of our conversations. Similar to other pediatric hospitals in the nation, since the COVID-19 pandemic, we are also seeing a rise in mental health conditions among kids. Limited access to mental health professionals, services and resources, along with inadequate insurance coverage hinders many families.

Our challenge is that kids may develop long-term effects which will hinder their growth if the right team, resources and treatment plans are not readily available. Unfortunately, this has become a real concern in D.C. At Children's, we are training our primary care clinicians to provide some mental health services, along with co-locating primary care and mental health support in many of our community-based clinics. However, we recognize that it is not enough. To best support children, mental health organizations need a pipeline of trained staff and a repository of resources to tackle this issue collectively. Addressing children's mental health is a national challenge which will require creativity and innovation to solve.

Syeda: How can trustees elevate the importance of youth mental health needs?

Barnett-Jones: Trustees play a pivotal role in ensuring that mental health is a primary focus for our organizations. It demands a deliberate approach, by posing questions about institutional readiness, engagement, staffing, resourcing and the specific challenges faced by each of our organizations concerning mental health. By engaging our health care leaders



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and staff in solution-driven conversations, we can continue to prioritize the critical questions that drive this challenge. Are our systems equipped for effective follow-up? Do we have established community partnerships for referrals? How are we screening for mental health? Asking these pertinent questions is essential for strategizing and creating improved opportunities and outcomes for children and youth.

Additionally, we must also be willing and prepared to advocate at the local, state and federal levels for the necessary resources to address mental health needs. Recognizing that mental health is a long-term challenge, it is crucial to understand that no single organization can tackle it in isolation. Hospitals, as central hubs, play a unique role in connecting communities, resources and health care providers. However, addressing mental health challenges requires a collaborative team effort and a commitment to long-term strategies and solutions to navigate the complexities of the current landscape.

Syeda: How can trustees contribute to building community partnerships?

Barnett-Jones: It is important to acknowledge that our opportunity to affect change is very broad. Trustees can make a substantial impact both within and outside the boardroom by leveraging their influence. This process starts with intentional collaboration with local partners at various levels, active participation in community conversations and firsthand listening to health care concerns. To facilitate meaningful dialogue and formulate action plans aligned with

community needs, a comprehensive understanding of the organization's Community Health Needs Assessment and organizational priorities is essential. For example. Children's National has established a Community Health Advisory Council to amplify the voices of residents. This council convenes monthly with hospital teams and local subject matter experts, contributing valuable insights into community health priorities, initiatives and practices. The council plays a pivotal role in shaping a Community Health Improvement Plan. This approach offers a unique opportunity for community members, whose perspectives may not be frequently represented, to actively participate in decision-making, program design and evaluation which directly impact the community. The council subsequently presents these plans to the board, fostering real-time feedback, awareness and active engagement.

Syeda: What strategies can pediatric hospitals implement to provide more holistic care?

Barnett-Jones: My daughter, Olivia, faced complex cardiac health challenges at six months old, and received a life-changing heart transplant at age one. It has been a long journey. Today, she is a college sophomore majoring in art history and looking forward to studying in London this summer. Over the last 18 years, we have spent a significant amount of time in hospitals. Reflecting on this, I emphasize the necessity to create wellness spaces. Kids and youth need medical "procedure free" zones, where they can simply share moments without the stress of medical interventions or

fear of being "poked." Older kids also benefit from spaces that are geared towards adolescent activities. These safe spaces not only enable families to preserve their unity within the hospital environment, but also provide a semblance of normalcy amidst challenging circumstances. By recognizing and addressing this need, families can do the work of healing.

Several years ago, Children's National built a healing garden and Olivia helped to cut the ribbon. I remember thinking that this type of space would have been a great place to retreat to when she was little (with the necessary support close by, of course). The need to have spaces where kids and youth can breathe fresh air and feel the sun, and where caregivers can enjoy an outside environment provides a different kind of healing. It is healing for the spirit that helps to create lasting memories and refreshes the soul. Holistically, integrating cardiac evaluations into routine pediatric wellness care and youth sports requirements is crucial. Undetected heart conditions claim too many young lives. By requiring early protocols for preventive care, outcomes can be improved. Patient advocates can be assigned to families whose children have complex needs as well. Caregivers managing multiple responsibilities (appointments, insurance claims, medications, etc.) often require assistance in navigating the health care system. Advocates play a crucial role in empowering families, providing the confidence needed to ask questions and voicing their needs effectively. I believe that these necessary supports can reduce the safety risks for the child.



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Finally, transitioning to adult care demands thoughtful planning and a warm handoff to the new care providers. Usually, kids and youth with complex needs have built long lasting and trusting relationships with their care teams over many years. The transition to adult providers may feel scary and unsettling, coupled with newfound adult responsibilities which can be overwhelming for young people. Olivia is now 19 and is on the path to transition to adult care. I am more nervous than she. However, her cardiac team has not only set up appointments with adult transplant clinics, but also provided support during those calls. She has been able to meet and start building her

own relationships with the new care team. That makes me feel supported and provides a level of reassurance for her next steps.

Syeda: What advice do you have for trustees at pediatric hospitals?

Barnett-Jones: In pediatric hospitals our mission is exceptional: safeguarding the health and well-being of future generations. I encourage trustees to be intentional and committed in pursuing the changes they envision for their communities. We have an opportunity to leverage our expertise, serve and drive meaningful change, not just occupy seats. By embracing adaptability and innovation, we can offer impactful guidance both within and beyond

the boardroom to strengthen our organizations and create healthy environments for kids to thrive.

The key question for trustees of pediatric hospitals remains: How can you use your influence and talent to advance health care for the children in your communities?

Aisha Syeda, MPH, is a senior program manager for AHA's strategic initiatives.

Visit AHA's Better Health for Mother and Babies page for more resources.

Please note that the views of interviewees do not always reflect the views of the AHA.

<u> </u>	American Hospital Association*	www.aha.org March 2024 5