NICHQ National Institute for Children's Health Quality

Insights

Family Advocates Demand More From Their Government



In 2016, Tabitha Williams sat in her hospital's

intensive care unit with her unresponsive 5-year old daughter; she had suffered a severe asthma attack brought on by exposure to lead dust in their home.

Williams and her daughter live in Grand Rapids, Michigan; it's just under a two hour drive west of Flint, Michigan, where lead exposure in water caused a national public health crisis. Williams knew about the risks of lead and unsafe water, but she didn't realize that her own home could be a danger zone.

Right now, in the U.S., <u>millions of children</u> live in homes contaminated by lead. Children can come in contact with lead in numerous ways: contaminated drinking water, imported costume jewelry and cosmetics, and commonly, like Williams' daughter, through small amounts of dust from chipped lead paint in their homes. Lead exposure has <u>serious health consequences</u> for children's developing brains and nervous system and, if high enough, can even cause a child's death. Thankfully, Williams' daughter recovered. And Williams, having realized that her home was harming her daughter and no one in her city or state had protected them, was determined to seek change.

"As a parent, I was upset that I couldn't protect my daughter," says Williams. "And I was really upset because I knew that people were talking about lead, and I wanted to know why parents weren't part of those conversations—why solutions were being considered without hearing from parents. As a young black mother, the biggest challenge for me was looking for that support to enter spaces where change was supposed to happen."

Fed up with systems that resulted in unsafe homes and confident that family voices were needed for change, Williams launched Parents for Healthy Homes, an advocacy group led by and for parents and community members. Working alongside other community members including Sarah Edgington, a fellow mother committed to family-led civic engagement, Williams and her team spearheaded a campaign for funding to address lead in the homes throughout Grand Rapids. They collected signatures from families across the city, met with each of their county commissioners, and attended public meetings. After six months of family-led advocacy, they received the funding they needed to test more homes and protect more children. Today, two parents from their group sit on the mayor's task force for lead prevention.

The <u>MCEH CoIIN</u> is led by the <u>Association of Maternal and Child Health Programs</u> and is funded by the Health Resources and Services Administration Maternal and Child Health Bureau. NICHQ <u>supports the nine participating state teams</u> by providing quality improvement expertise and technical assistance, collaboration and data collection tools, and project management.

Parents for Healthy Homes illustrates the vital impact families play in advocating for policy change on behalf of children. That's why the Maternal and Child Environmental Health Collaborative Improvement and Innovation Network (<u>MCEH CollN</u>)—a national initiative that seeks to improve the health of children and families exposed to lead—has engaged both Williams and Edgington as family partners and experts on the Michigan state team.

"Parents and people who live in the community that are facing this problem are really the experts," says Edgington.

"When we offer them a seat at the decision-making table, they will surprise us with their knowledge and understanding."

Interested in helping more family partners shape and drive policy change? Here, Williams and Edgington share their experiences and advice for supporting family-led civic engagement.

Never underestimate parents' influence

Parents trying to raise a family are uniquely invested in the health of their communities and intimately aware of the barriers to health and wellness families face. Remembering this and remembering that they elect their officials gives parents incredible power to enact change.

"We are leaders in our families, we are leaders in our community, and we'll never stop working to protect them" says Edgington. "We need to remember that it doesn't matter what level of government someone is in; they are there because they were elected, and their job is to listen to us and learn about the problems facing our community—problems that families know about and they don't. It's important to remind parents and community members that they have the same skills and leadership that many government officials have and they have the right to be included in the solutions of getting lead out of our houses and communities. We have power to tell them what needs to be fixed in our community because they are there because of us."

Know that knowledge empowers

Parents for Healthy Homes' approach to family advocacy is to 'educate, involve, advocate' in that order, explains Williams. Education is the foundation for family involvement and advocacy because knowledge empowers families to speak up when talking to city and state representatives. This education should be comprehensive and include teaching families about the issues they are discussing (e.g., the effects of lead on children in Grand Rapids), identifying who they need to talk to (e.g., different county commissioners), and knowing what's needed to solve the problem (e.g., funding and employees needed to test for lead in homes).

Encourage families to share their stories

While data and clear-cut facts are important for outlining problems, family stories are powerful because they turn numbers into human-beings. Sharing real experiences with representatives helps them more deeply understand the effects of inefficient systems and unjust policies. And since many families are eager to share their stories, asking for volunteers offers a platform for their participation.

"Our personal stories tell legislators, 'I am a human being and so are you, and we want a healthy house just as much as you do'," says Edgington. "These stories have changed lives. Your story can save families from experiencing what you went through."

Set small and achievable goals

Civic engagement can be overwhelming when first starting out. That's why both Edgington and Williams recommend looking at what needs to be accomplished on a large scale and then mapping out the small achievable goals that will help you get there. Starting with these smaller goals helps engage families and ultimately energizes them to do even more.

"If you are waiting for change to happen, you are going to wait forever," says Edgington. "But if you have a vision for how your community can be, then just start by taking those small steps towards achievable goals, and then you make the change and that is really powerful. Change takes passion and energy and knowing that this is not a sprint; it is a marathon."

Know how to recruit family partners

Identifying family advocates is the first step to engaging them in improvement work. Williams, who recruited many of the families working with her on Parents for Healthy Homes, recommends tapping into families' energy to share their stories. Health department employees and local doctors' offices often know the families who are passionate about change and can connect you with them. These same families know other families, which ultimately builds more momentum and engagement.

Offering to help families be leaders in their own lives also attracts families, adds Williams. Providing leadership training and community organizing training not only garners interest; it also empowers families to embark on advocacy work. "We're excited to partner with these families because we know they'll push us to make changes and overcome barriers," says Angela Medina, Michigan team lead. "As we learn from their successes, we can help more families while also supporting their work in Grand Rapids."

Interested in learning more about partnering with families? Read this <u>article on family partnership</u> from family partners on the Early Childhood Comprehensive Systems CollN.