NICHQ National Institute for Children's Health Quality

Insights

Children

Over 13 million children live in rural areas and of them, nearly a quarter live in poverty. There is an urgent need to understand and respond to the disparities in health outcomes for this population of children, says NICHQ Chief Health Officer Elizabeth Coté, MD, MPH.

"Rural children in poverty are effectively invisible to decision makers and power structures of society," explains Coté. "These are children who don't live near pediatric hospitals or even their primary care provider. They are children who have fewer opportunities to play at public playgrounds, attend community events or engage with other families—*they have fewer opportunities to be seen*. So too often, policies and funding are not directed at these children, health systems don't account for their families' unique circumstances, and they fall through the cracks. It's invisibility as much as a lack of resources that leaves these children vulnerable to poor health outcomes."

Coté has treated these children. She has witnessed first-hand how fragmented systems can fail rural families.

“I met Anna* when I was working in northern Maine as the clinical director for the Micmac Service Unit,” she says. “She was a 2-year-old child whose mother came into our clinic because Anna had been nauseous and lethargic, and our clinic was nearby and open.”

After discovering a high number of ketones in Anna’s urine test, Anna was rushed to the hospital for ketoacidosis, a complication that occurs when your body cannot produce enough insulin. She was hospitalized with a new diagnosis of type 1 diabetes, a potentially life-threatening condition if left unmanaged. Anna’s post-discharge plan was multifaceted:

- A referral to an endocrinologist located more than a two hour drive from Anna’s home
- Regular follow-up appointments with Anna’s primary care provider whom she and her mother had rarely seen
- Directions and prescriptions for Anna’s now-regular insulin treatments, which had to be titrated and changed on a daily basis

“It’s an overwhelming amount of information and next steps for anyone,” says Coté. “But it’s especially overwhelming for a mother living in a remote area without a car, access to transportation, or a working phone. For a mother who, even with Medicare, didn’t have the money for co-payments and prescriptions. Anna’s mother, like many other caregivers in rural areas, simply didn’t have the resources to support the care her child needed.”

Coté and an equally dedicated nurse chose to follow Anna’s care even though she was now under the care of a local pediatrician. When they learned that Anna had started missing appointments, they reached out to her mother directly to offer support—walking her through Anna’s treatment instructions from the hospital, helping her schedule the endocrinologist referral, working with her community to fund the transportation to far away specialty appointments, obtaining test strips and insulin at a lower cost, texting with the endocrinologist to better facilitate adoption of her treatment recommendations, and securing a dedicated phone service for Anna’s mother so she and her providers could connect.

These additional voluntary efforts ensured that Anna’s mother received the resources they needed, and Anna’s health improved. But because these efforts were separate from the established health system, they are not scalable beyond Anna’s individual case.

“Anna’s life would likely have gone very differently had we not been able to step in,” says Coté. “She would have been another unseen child, a name in a computer with very little connection to her health providers. Her missed appointments and lapses in care would have been blamed on her mother, rather than seen as the result of a fragmented system whose bureaucratic requirements compound the burden of families living with illness in rural poverty.”

A needed spotlight

Cycles of poverty, low education, limited job opportunities and isolation are among the social determinants that adversely affect the health of children living in poverty. Addressing these challenges often looks different for rural children than their urban and suburban counterparts, explains Coté. Shining a light on their unique barriers can help systems-change efforts pursue high-impact solutions for an overlooked population of children.

“Children in rural areas are more likely to have complex diseases, such as severe asthma and uncontrollable diabetes, and suffer from the effects of adverse childhood experiences,” says Coté. “Because they live in rural areas, it’s harder for them to get help—often having to travel more than 50 miles to a pediatric hospital. This can be impossible for families without a car, with limited resources and access to credit, and few public transportation options.”

Coté explains that even when rural children can get treatment, that treatment is often more expensive, due to the complexity of their cases, *and less effective*. Rural children are more likely to be readmitted back into the hospital, ultimately starting an expensive, ineffective cycle all over again.

Anna’s story illustrates two clear opportunities for improvement, says Coté

First is the need to better integrate rural health practices and rural providers with larger systems of care, particularly specialty care, given rural children’s high rate of complex medical needs. Anna’s treatment improved once Coté was able to converse with Anna’s endocrinologist (who was 120 miles away), exchanging texts with non-sensitive patient information so that Coté could facilitate Anna’s care in their rural community.

It’s critical, says Coté, that providers in underserved areas are connected to the resources needed to provide quality care in that complex setting.

“Establishing telemedicine, offering professional education opportunities at larger hospitals to rural providers, creating online communication portals between health professionals—these are all opportunities to connect rural providers to a larger health network, helping ensure that families have a cohesive care team despite the miles between them. Establishing these networks not only supports more effective preventative care, but it also lays the ground work for a stronger discharge plan so that there are fewer readmissions.”

Coordinated care also means establishing linkages with public social services, Coté continues, especially in terms of transportation and phone lines.

“Anna and her mother were able to travel to Anna’s appointment because their community gave them funds for a ride and hotel. Many other rural children are even more isolated and not so lucky. Those children deserve systems that explicitly address the barriers rural families face.”

Anna’s story also illustrates the need to empower parents and caregivers as advocates for their children. When a hospital discharges a child, the discharge plans relies heavily on the parent. For Anna’s mother, this meant leaving the hospital overwhelmed with information and tasked to follow a complex care regimen in a medically underserved area. While a more robust discharge plan that connected her to coordinated social services would have helped, that plan would be even more effective if it purposefully empowered her as a caregiver by connecting her with other families in similar situations, says Coté.

“We need to do more than hope that the parent has the health literacy, disease specific education, confidence, telephone, and transportation to get their child to a provider when questions arise, things don’t go as planned, or check-ups are scheduled,” says Cote. “We need

to help them not feel so alone. Online chatrooms and tele-parenting classes can help them talk about their experiences with their peers, while public spaces such as schools or town halls can bring families together for common play and conversation."

Read more about the power of multi-generation approaches in this NICHQ article.

Moreover, like their children, rural parents also face significant barriers to mental and physical health. And when a parent's health suffers, children are left vulnerable. Empowering a caregiver to be the advocate a child needs means leveraging intergenerational approaches to care where a child's health is viewed within the context of the caregiver's.

"Ultimately, these opportunities reflect an imperative for systems to not only coordinate services—pediatric and family health, education, housing, transportation, etc.—but to specifically account for the needs of rural families," says Coté, "thus building capacity in communities that have been overlooked."

Interested in hearing more from Coté? Read her recent article on the opioid epidemic and its effect on children's health.

*Names have been changed to respect privacy.