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A Children's Respite Home is Where the Heart is

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A Glaring Gap in Services

Caring for children with significant medical complexities is a demanding task that requires continuous and intensive care. This can leave parents and caregivers exhausted, with no place or person to turn to for rest or sleep. Relatives and friends who step up to help do not typically have the skills or training to provide the required care. While medical advancements have extended the lifespan of some children with life-limiting conditions, it also means that families are expected to provide much of the child's daily care for even longer periods.

Currently, an estimated one million children in the U.S. are living with very complex medical conditions, nearly one percent of all U.S. kids. Their intensive needs account for over a third of all children's healthcare spending and 40% of all child hospital deaths.

Being "medically fragile" and "sick" are distinctly different. The majority of a medically fragile child's life is spent living in the family's own home, not in a hospital or nursing home, which are utilized for periods of sickness. Cancer, muscular dystrophy, or thousands of "rare genetic diseases" typically have no cures, no treatments, and may dramatically shorten a child's life.

Families and caregivers are exhausted, stressed, and feeling lonely and isolated from a lack of support. Primary insurance eludes coverage, deferring to a state's Medicaid system for those who are enrolled. There is simply a severe lack of providers available to deliver care.

For Elli and her family, finding the right resources has been an arduous journey. Elli is a 22-month-old child with a brain abnormality who was living in New Jersey with her parents as her sole caregivers. Without support, they could not work, shuttling back and forth to appointments, leaving them only a few hours each week to run errands and rest.

Historically, the U.S. healthcare system has primarily focused on supporting aging adults and individuals with disabilities, leaving children's care mainly in the hands of parents. While major cities in the U.S. have welcomed the establishment of children's hospitals, which have become centers of excellence with specialists for children with complex medical conditions, a significant gap has emerged in dedicated children's respite services and resources for families when their child is living at home.

"This is such a niche field of pediatric, palliative, and respite care. We had to find the doctors comfortable enough even saying palliative to us. And that was just one hurdle." Elli's mom said. "When we did find a doctor in Jersey who was pediatric palliative trained, she couldn't even be our baby's doctor because she was heading the inpatient part of a children's hospital."

Elli's parents and the doctor worked hard to find creative solutions but ultimately fell into the system's cracks.

"Other than admitting her into the inpatient unit, there was no way to make respite happen for insurance purposes," mom said. "She would not qualify because she doesn't have a trach[eostomy] or a G-tube."

Those cracks in the system back many parents against the wall, expecting them to become full-time caregivers and stay breadwinners.

Elli's dad found a hint of help through their private insurance, providing several days and hours' worth of home health aides. But when his employer switched insurance plans, that support disappeared, and suddenly, mom needed more help than ever from dad.

"At that point, we had been doing that for about 20 months straight with very little sleep, and my husband ended up losing his job," Mom said. "So, we just didn't know where to go."

Leading by Example

In the early 2000s, dedicated pediatric respite, palliative, and hospice programs emerged in the U.S. These programs were inspired by successful care models established in the United Kingdom in the 1980s, starting with the world's first dedicated children's hospice home, Helen House, in Oxford, England. Efforts to improve the quality of life for children on life-limiting journeys had started even earlier, with some success in developing in-home services or ancillary programs in adult facilities. However, in the U.S., due to a lack of clear licensing and Medicaid reimbursement funding for pediatric care, launching dedicated pediatric "Homes" required relying solely on philanthropic strategies.

The first two dedicated pediatric "Homes" that emerged were George Mark Children's House in San Leandro, California, and Ryan House in Phoenix, Arizona. Each house was founded by passionate leaders who understood the glaring need for respite for parents and caregivers for children with significant medical complexities. The founding teams quickly learned the challenges of opening these programs within the current U.S. healthcare system. They relied on communicating the story of the real need for these homes, and private philanthropy. These founding programs became mentors, and along with other leaders who had begun pursuing care homes in their communities, came together as a coalition known as "Like Houses."

In 2018, Crescent Cove in Brooklyn Center, Minnesota, became the third dedicated pediatric "Home" inspired by the U.K. models to open its doors. Another variation, A Rosie Place for Children in South Bend, Indiana, focuses on providing overnight respite in a free-standing facility and has been actively sharing knowledge within the Like House Coalition since its opening in 2011.

The goals of these dedicated pediatric "Homes," are twofold. First, they aim to become an extension of a family's own home, providing essential support and care for children with life-limiting conditions and their whole families. Second, they serve as models for other communities seeking to establish similar initiatives. By sharing their knowledge and experiences, these programs collaborate to enhance the quality of life for children on life-limiting journeys.

Forming a Collaborative Center

By the summer of 2021, there was growing momentum to establish a national collaborative Center to share knowledge and address the challenges of opening pediatric care homes in communities across the country. Because no other national or state organization is positioned or prioritizing resources to address the need of provider growth at a local level, the National Center for Pediatric Palliative Care Homes (NCPCH) was established, welcoming community-based program leaders passionate about driving change to come together and share a common vision to grow the community-based provider network.

Children's Respite Homes of America (CRHA), <https://childrensrespitehomes.org/>, aims to raise awareness about the need for respite services for medically fragile children and their families. CRHA is the public face and fundraising arm of NCPCH. By creating a unified brand, CRHA amplifies the voices of grassroots programs and shares the stories of unmet needs in families.

The NCPCH organization, <https://www.ncppch.org/>, focuses on educating professionals about community-based respite and palliative and hospice care, aiming to create a collaborative national center for learning and addressing policy gaps. NCPCH champions practical needs to scale, strengthen, and sustain these important care models around business model optimization, licensing, and reimbursement methods. This is about closing the gap by building provider capacity.

NCPCH also collaborates with other like-minded associations, organizations, and coalitions that share a common purpose to enhance the quality of life for medically fragile children and families and improve healthcare delivery systems, recognizing that together, we're a powerful voice.

A Mission to Scale, Strengthen, and Sustain

Currently, there are 54 dedicated children's respite homes in the United Kingdom, compared to only a handful of known homes in the United States, despite the latter having nearly five times the population. To achieve the same level of family access to these critical care models would mean that someday, there will be at least 266 homes across the U.S. There is still so much work to be done!

Founders of new community providers can be anyone; what is common is a deep connection to this vulnerable population. Often, their dream struggles to take shape because they lack experience or knowledge on the business side of how to form an organization, become a nonprofit, develop effective boards, create strategic plans, and fundraising. They feel excited and relieved to discover they are not alone.

The overall goal is to develop the U.S. healthcare system to support these programs financially and operationally, ensuring their continued existence and impact in serving the needs of children with complex medical conditions and their families.

Education and awareness are essential in this journey

"Every story shared, every policy influenced, brings us closer to a world where our children's needs are understood and met," Jonathan Cottor, CEO and Founder of NCPCH, said. "The awareness raised is our voice, reaching out to those who can make our dream of accessible respite care a reality."

CRHA's awareness efforts have already begun to reach new passionate leaders who are connecting with NCPCH for inspiration and help to realize their dreams of opening a dedicated respite home in their community. Recently formed home programs in a number of U.S. cities, "Emerging Homes," can now leverage the expertise of NCPCH's

Government Affairs and National Advisory Councils to more clearly shape their own vision and business plans, which create a more aggressive timetable towards opening. CRHA's social media campaigns are working to reach more passionate leaders to expand this vital care network, including Elli's doctor in New Jersey, who has connected with NCPPCH to discover more ways to expand these services in her area.

CRHA's website, <https://childrensrespitehomes.org/>, maintains an up-to-date map of the existing and emerging conversations with new passionate leaders who are part of this national collective. This is an easy reference to find passionate leaders in cities nationwide. Encouraging others to become involved and creating forums of support are ways the community-based home provider network will expand to support more families.

A Future Hope

The need for dedicated children's respite services and support for medically fragile children and their families is clear. By taking action, a more inclusive and supportive healthcare system that meets the needs of all children, including those with significant medical complexities, can be a reality. Every new home that opens gives care access to 5,000 children and families.

"Early on, especially in our situation, my husband and I were allergic to the idea of hope. There's no hope for a cure or hope that she will live on and lead a typical life. So we didn't want that word involved. But now, I think our hopes are more modest. They are really to make sure that if you end up in a situation like ours, you're way more supported than we were," Elli's mom said. "We're sort of in the dark ages of caring for the families as a whole when they have medically complex kids. So that's kind of the hope, and it's like a future hope. And it's something we're just seeing scraps of right now. These things will happen, but hopefully, the country is more prepared."

A community-based children's respite home is an extension of a family's own home and a temporary haven. If you want to get involved and learn more about existing programs, emerging programs, or where talks of additional homes are happening, please visit <https://childrensrespitehomes.org/> or <https://www.ncppch.org/>.

We invite you to join our mission to scale, strengthen, and sustain community-based children's respite, palliative, and hospice home programs. Together, we can ensure that every family with a medically fragile child has access to the respite services they need and deserve.