

## Key Facts & Evidence Sources

“The # 1 wish families want more than anything is a cure for their child. Second is to catch up on sleep, so they can handle the next challenge...and the one after that.”

*Jonathan Cottor*  
Proud Dad, Founder/CEO

Fact	Evidence/Source
<b>93% of medically fragile children and families have ZERO access to even one Children's Respite Home.</b>	Currently only 7 dedicated pediatric palliative care home programs exist in the U.S., these communities represent 7% of the U.S. population.  <a href="https://childrensrespitehomes.org/">https://childrensrespitehomes.org/</a>  Source: NCPPCH Tracking & Analysis
<b>1 Million medically fragile children in the U.S.</b>	There is no U.S. database that tracks this population. Estimation of this vulnerable population is starts with Census Facts as follows:  U.S. Total Population = 333.3 Million (2022) X 28.5% (%age of Gen Pop < 21 Years (Birth thru Age 20)). Source: U.S. Census  X <1% of All Children are living with Medical Complexities Source: <a href="#">American Academy of Pediatrics</a>  = Approx. 1 Million
<b>The U.S. is lagging in access to care</b>	The World's first dedicated pediatric palliative care respite and hospice home is <a href="#">Helen House</a> , which opened in 1982 in Oxford, England. Today, the United Kingdom has 54 such community-based programs.  Source: <a href="https://www.togetherforshortlives.org.uk/">https://www.togetherforshortlives.org.uk/</a>  With 5 times the population, the U.S. would need 266 for families to have the same access to his critical care.
<b>Medically fragile children account for more than 33% of ALL children's healthcare spending, and 40% of ALL children's hospital deaths in the U.S.</b>	Sources: Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status complexicus? the emergence of pediatric complex care. <i>Pediatrics</i> . 2018;141(Suppl 3):S202-S211. doi: 10.1542/peds.2017-1284E [doi].  Berry JG, Agrawal RK, Cohen E, Kuo DZ. The landscape of medical care for children with medical complexity. <i>Children's Hospital Association</i> . 2013:1-15.
<b>Today, 72 children in the U.S. will die from complex medical conditions.</b>  <b>Every 20 Minutes a child with complex medical conditions dies in the U.S.</b>	In the U.S., the Centers for Disease Control (CDC) tracks causes of deaths (“Mortality”). According to the CDC, 45,187 people under 21 died in 2020. Using CDC mortality data, NCPPCH can identify those children that died from accidents or trauma, separate from complex medical conditions to complete this analysis.  For more related insights from this analysis please visit our website page at: <a href="https://www.ncppch.org/insights-references">https://www.ncppch.org/insights-references</a>

There is a growing body of published research and evidence supporting medically fragile children and family needs for pediatric palliative care services. Please reach out to us with questions to relevant publications and sources.

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Children's Respite Homes of America (CRHA) is the unifying program building the movement for nationwide respite care within the National Center for Pediatric Palliative Care Homes (NCPCH). Healthcare providers, institutions, and policymakers: connect with NCPCH at [www.ncppch.org](http://www.ncppch.org). To join this nationwide movement to open 50 homes in 50 cities in five years, learn about CRHA at [childrensrespitehomes.org](http://childrensrespitehomes.org).