



Testimony Re: Senate Bill 2075 – Children’s Catastrophic Illness Fund
Senate Health & Human Services Committee
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Mr. Chairman and members of the committee, thank you for the opportunity to provide testimony today. Rhode Island KIDS COUNT would like to offer its support for Senate Bill 2075 which would establish the Children’s Catastrophic Illness in Children Relief Fund to provide financial assistance to families for medical expenses not covered by state or federal programs or insurance contract. We would like to thank Senator Lawson for her leadership on this issue and for sponsoring this important bill and thank Senators DiMario, Valverde, Miller, Coyne, Burke, Murray, Cano, and Quezada for cosponsoring.

Rhode Island’s Strong Commitment to Children’s Coverage

Rhode Island has a strong commitment to ensuring all Rhode Island children have access to high-quality, affordable health care coverage. As a result of a sustained and strong commitment to children’s coverage, 98.1% of Rhode Island children under age 19 were insured in 2019. Rhode Island ranks 2nd best in the U.S. on this measure.¹

Despite almost universal health insurance coverage, families of children with special health care needs in Rhode Island continue to experience financial hardship as a result of their children’s conditions. This fund would help fill the gaps left by traditional insurance coverage and support families.

Children with Special Health Care Needs and Medical Expenses

In Rhode Island, an estimated 21% of children have a special health care need and 66% of those children have two or more health conditions.² The cost of caring for a chronically ill child can be overwhelming, even to a family with health insurance. High insurance premiums, deductibles, co-insurance and co-payments, combined with medical and medically related expenses incurred because of coverage limitations and exclusions, can result in a serious drain of a family’s financial resources. The bills incurred can send the family into extreme debt and cause severe emotional stress. According to the Kaiser Family Foundation, although the chances of falling into medical debt are greater for people who are uninsured, most people who experience difficulty paying medical bills have health insurance. Medical debt can arise when people must pay out-of-pocket for care not covered by health insurance or to which cost-sharing (such as deductibles and co-insurance) applies. Medical debt also might result from health insurance premiums that individuals find difficult to afford. The consequences of medical debt can be severe. People with unaffordable medical bills report higher rates of other problems – including difficulty affording housing and other necessities, credit card debt, bankruptcy, and barriers accessing health care.² One study by Himmelstein, et al, showed that medical debt is responsible for 62% of all bankruptcies nationally.³ In the 2018 National Survey of Children’s Health (NSCH), 9% of families with children with special health needs in Rhode Island

reported having problems paying for their child's medical/ health care bills within the past 12 months.⁴

Family Strain

The impact of a child's illness can have severe ripple effects. The time and energy necessary to care for a sick child often place further debilitating strain on a family and result in loss of employment of one or both parents. (In 2018, **18% of Rhode Island families with children with special health needs reported having to cut back or stop working due to their child's condition.**⁵) In such situations, the family loses not only income, but frequently also loses continuity of health benefits, since access to health insurance is often through one's employer. The family must then identify other insurance coverage, which may involve accessing a different provider network for their child and paying higher health insurance premiums, further adding to family stress. There are also many expenses resulting from a child's medical condition that are not covered by insurance.

Children in Poverty in Rhode Island

This issue impacts families of all income levels, including those living in poverty. Between 2014 and 2018, about one in six (18%) of children in Rhode Island (a total of 37,402 children) lived in poverty.⁶ Children under age six are at the highest risk of living in poverty in Rhode Island.⁷ According to the *Rhode Island Standard of Need*, it costs a single-parent family with two young children \$55,115 a year to pay basic living expenses, more than two and a half times the federal poverty level for a family of three.⁸

The Children's Catastrophic Illness in Children Relief Fund would thus provide valuable or stabilizing financial and emotional relief for families facing incredible life challenges.

Other States with Children's Catastrophic Illness in Children Relief Funds

To date, New Jersey and Massachusetts have established Children's Catastrophic Illness in Children Relief Funds. In 2018, the Massachusetts fund completed its 18th year of providing critical assistance to families. According to the FY2018 Summary:

- 190 families in Massachusetts received nearly \$1.62 million in reimbursements.
- The median reimbursement was \$5,615 per family
- Approximately 80% of the families who received assistance had annual incomes of less than 200% FPL (\$50,200 for a family of four in 2018).
- Approximately half (49%) of the children who were helped by the fund were under the age of five.⁹

Thank you for the opportunity to offer this testimony and for your work to ensure that children and families can meet their health care needs.

References

¹ U.S. Census Bureau, American Community Survey, 2019. Table R2702.

² K. Pollitz, C. Cox et alia, Medical Debt Among People with Health Insurance, January 2014.

<https://kaiserfamilyfoundation.files.wordpress.com/2014/01/8537-medical-debt-among-people-with-health-insurance.pdf>

³ D.U. Himmelstein, D. Thorne, E. Warren, S. Woolhandler. Medical Bankruptcy in the US: Results of a National Study. *American Journal of Medicine*. August 2009. Volume 122, Issue 8, Pages 741-746.

^{4,5} Child and Adolescent Health Measurement Initiative. 2016 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website, <http://www.childhealthdata.org/>

⁶ U.S. Census Bureau, American Community Survey, 2017. Table C17024.

⁷ Koball, H., & Jiang, Y. (2018). Basic facts about low income children: Children under 18 years, 2016. New York, NY: National Center for Children in Poverty, Columbia University Mailman School of Public Health.

⁸ The 2018 Rhode Island standard of need. (2018). Providence, RI: The Economic Progress Institute

⁹ *Catastrophic Illness in Children Relief Fund Annual Report: Fiscal Year 2018*. (2020). Massachusetts.