



FACT SHEET: NEW YORK

SICK KIDS



HOW MANY

More than 54,000 children in NY have a complex medical problem that limits their life expectancy

(based on 2019-2020 NSCH)

Cost = \$82,000/yr/child

HOSPICE FOR KIDS

NY has the most infants to adolescents enrolled in pediatric hospice care of any state

(based on 2011-2013 Medicaid)



IN THE CONGRESSIONAL DISTRICTS



NYC (CD 3-16) = 6464

Syracuse (CD 22) = 443

Long Island (CD 1,2) = 1268

Rochester (CD 24,25) = 297

Binghamton (CD 19) = 190

Buffalo (CD 23,26) = 20

PEDIATRIC HOSPICE ROCKS

- Pain & symptom management
- Medical care concurrent with hospice (ACA, section 2302)
- Care continuity
- Family support



.... BUT



- Care starts at 6 months to live
- Coordinating hospice and medical care is complicated
- 16 out of 69 NY hospices have a pediatric program
- Care is not comprehensive

IMPROVING POLICY



> 54,000 NY families would benefit from a comprehensive, coordinated policy



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