

National Center for Pediatric Palliative Care Homes Public Policy Agenda

THE NEED: An estimated 1 million U.S. children (<21) are currently living with very complex medical conditions, less than 1% of all kids. These children and their families face significant challenges which impose incredible stress on the families.

The United States lags far behind other industrialized nations with regard to providing respite, palliative and hospice services to these families. Presently, there are only seven homes in the United States providing these services to children and their families. (See accompanying map).

THE CHALLENGE: Thirty-seven community groups, concerned families, and citizens in twenty-five states have organized to open new homes. All existing and proposed new homes face regulatory and financial challenges.

THE SOLUTION: The National Center for Pediatric Palliative Care Homes (NCPCH) is committed to working with supporters of these homes to reduce regulatory and financial barriers and facilitate the opening of many more homes to meet the needs of these children and their families.

THE ISSUES:

1. Licensing and Regulation

Licensing of these homes is a state function. State licensing laws in the 50 states are designed for adults. We work with the State Licensing Agencies to amend their Statutes and Regulations as necessary to streamline the Licensing and adjust the Regulations to match the mission of caring for these children and their families. Ultimately, uniformity among the State Licensing Laws and Regulations would be optimal.

2. Funding for Services

Existing homes rely significantly on philanthropy for capital and operating funds. Two homes have recently qualified to receive Medicaid reimbursement for services provided to eligible children and families. We believe that homes providing these services actually generate healthcare cost-savings.

The need for services provided by these homes cannot be met with philanthropy alone. We advocate for government and private payor reimbursement for the services provided by these homes.

