



Children and Youth with Special Health  
Care Needs National Research Network

# Research Project Brief

## **PROJECT** | Assessment of caregiver experiences and unmet healthcare needs following discharge home after a critical illness in a child or youth with special healthcare needs

- *Term: September 2019 to February 2021*
- *Grantee: CYSHCN*
- *Sub-recipient: UCLA*
- *Funding Agency: Health Research Services Administration, MCH Research Networks Program*
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**Background** | CYSHCN are at increased risk for poor health outcomes including poor quality of life, new functional impairments and mortality following ICU and hospital discharge.. While likely multi-factorial, there is currently limited understanding of the mechanism behind the drastic and poor health outcomes of these children following resolution of their acute critical illness. This knowledge gap leaves CYSHCN and their families without the necessary care or potential interventions that could lead to improved health and better quality of life. Improving processes of care during discharge and transition to home has to potential to benefit patients by reducing caregiver burden and addressing needs. With limited availability of home nursing and home-based medical care, many families take on a large burden of care, leading to caregiver depression and financial difficulty. In addition, family members may also be underprepared, leading to inadequate care and unmet healthcare needs. In other populations, unmet health care needs have been associated with poor health outcomes. This modifiable factor may also play a role in the decline in health occurring in CYSHCN following critical illness. The goal of this proposed research is to understand caregiver experiences, burden and unmet educational, healthcare and support needs in children and youth with special healthcare needs during transition to home following a pediatric intensive care unit admission. To do so, we will conduct a longitudinal qualitative study of caregivers of CYSHCN following a critical illness which may have a significant impact on the child's health and care needs.

**Potential Impact** | Understanding the short- and long-term caregiver experience with unmet needs and caregiving burden during transition to home after a critical illness will provide insight into solutions to improve the care for these children and families. In addition, many healthcare providers express an urgent need to better understand family and patient perspectives following critical illness to improve quality of care for these patients. Our proposal will provide an improved understanding of a vulnerable population during a critical time that has not been well-studied through direct assessment of family experiences after hospital discharge. Improving care and reducing unmet needs following a critical illness for CYSHCN will lead to improved quality of care for these children and their families and will promote better quality of life and improved health outcomes.



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