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Abstract

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PI Title:

Project Title: Children Dependent on Technology--Family and School Care

Abstract: *DESCRIPTION: Children who are medically fragile/technology dependent (mf/td) have complex, chronic conditions. They require expensive, skilled nursing care to survive. At one time, such children were hospitalized for long periods. Increasingly, however, these children are cared for at home, by their families, with the assistance of in-home support services. One goal of such care is to allow the children and their families to live a more normal life, engaging in family activities and sending the children who are mf/td to school with their peers. Families and educators believe that children who are mf/td should attend school to facilitate their growth as social beings and to regularize family routines. These children usually need both special education services and constant care and observation while at school to keep them safe and provide for their health and developmental needs. Little is known, however, about how families and educators create stability and a semblance of normality in either family life or children's socialization while dealing with such demanding yet chronic care. The broad objectives of this study are to identify and describe the social processes and dynamics that occur as families work with schools to define and construct a relatively normal life for children who are mf/td and their families, and to analyze the children's socialization experiences at school. Specific aims are: 1) to identify and describe the process used by families to create a relatively normal life while raising a child who is mf/td, including comparing these families' experiences and perception to published findings about normalization in other populations, 2) to discover how services, programs, and resources available through schools impact families' experiences of normal life, and 3) to describe the numbers and types of social interactions that children who are mf/td have at school by mapping their school based social network. This study will employ three types of ethnographic methods:*

semi-structured interviews, observation, and review of documents. This triangulation of methods will create a variety of information sources, permitting comparison and cross checking of personal accounts and perceptions with observed behavior recorded in the field and written depictions and claims. Data will be further analyzed across cases and sites to compare how social processes are constructed and evolve within various family and school settings. Findings will allow development of empirically grounded interventions, policies, and practices to optimize the health and well being of children who are mf/td and their families.

Thesaurus Terms:

*child with disability, childrearing, elementary school, social support network
child care, family structure /dynamics, role, socialization
behavioral /social science research tag, clinical research, human subject, middle
childhood (6-11)*

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