In western industrialized countries, long-term life-support technologies such as ventilators and nutrition systems allow many children to survive diseases and injuries previously considered fatal. Most are cared for in their homes, where they are cherished members of their families. These children have complex continuing care needs that stem from multi-organ system involvement and cognitive and/or developmental problems. Incidence and prevalence rates are unknown because different terms are used to classify this small but growing pediatric population.

Each of us has conducted research with these families in Canada, the US and UK respectively. Although these countries have different models of health and social service provision, our findings are similar. Our combined findings corroborate those of other researchers, indicating that radically new forms of childhood, parenthood and family life have been created, but are poorly understood. We know that these children commonly receive sub-optimal long-term care because they ‘fall between the cracks’ due to ambiguous categories, exclusionary criteria or service gaps. Nevertheless, most parents emphasize the important benefits that they derive from raising them and the enhancements they make to family life. However, daily life is extremely constrained also by extraordinary physical, psychological, social and financial challenges.
Most parents (especially mothers) describe ongoing strain, chronic fatigue and emotional distress related to concerns about their children’s physical, psychological and social well-being. They feel overwhelmed by the scope and relentlessness of their caregiving and parenting responsibilities, the need to maintain crucial devices and concern about their other children. They also incur significant expense and forfeit employment opportunities, leisure time and social interactions. Families are relatively housebound because transporting these children is extremely challenging, their conditions are precarious, specialized care is unavailable, and/or architectural and other barriers restrict their inclusion. Unfortunately, social isolation is exacerbated by exclusionary behaviours, inequitable policies and stigmatizing practices.

In contrast, we know very little about the effects of the social, health and financial costs incurred by these families. Despite the powerful rhetoric favouring home care, comparisons of different living contexts, care-giving arrangements and children’s preferences for places and providers of care are unknown. Albeit inadvertently, professionals, policymakers and the public idealize ‘the family’ and ‘the home’. Because both are taken-for-granted ‘goods’, regardless of personal circumstances, most parents feel that they have no choice but to care for these children with inadequate support in communities that are replete with physical, social and policy barriers. Although some home-care programmes do provide coordinated comprehensive health and social services within children’s communities, they are the exception. Rarely has research been conducted directly with these children because they are considered especially vulnerable, many have severe communication disabilities or they are difficult to access. As a result, virtually nothing is known about their lives, everyday geographies, experiences of embodiment and relationships with life-support technologies, family members and other providers.

The dominant legal and ethical models that pertain to these children centre on the best interests standard and respect for parental surrogate decision-making. The interests of families as a whole are underacknowledged and ethical considerations tend to be restricted to critical, episodic decision-making moments. The everyday concerns, dilemmas and moral distress experienced by these children, their siblings, parents, health care professionals, schoolmates and teachers need to be illuminated and discussed.

To begin to grapple with the issues that these families face and to redress the inequities that they experience, strong interdisciplinary, interprofessional bridges must be built among clinicians, health scientists, social scientists and humanists — linking childhood, disability, gender, housing and science and technology studies scholars together with critical geographers, architects, ethicists, economists, educators and health professionals. New insights are needed to forge new lines of scholarship that will lead to innovative practices and policies, in order to ensure that care-giving responsibilities and costs are distributed fairly and that these children enjoy the rights of citizenship and the entitlements of contemporary childhood.
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References


