



Integrated care for children living with complex care needs: navigating the long and winding road

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An increasing number of children are living with complex care needs resulting from multiple concurrent conditions. Due to these conditions, various health problems can arise and necessitate screening, prevention, and treatment at different ages during childhood. Each child has an individual constellation and combination of health problems, which implies that multiple health and social care providers across various sectors are required to address these health problems. In addition, most healthcare services focus predominantly on single diseases and related treatment decisions are often mainly directed at improving medical outcomes. As a result, this single-disease-centered approach in care delivery is insufficiently responsive to children living with complex care needs; it is not optimally tailored to their needs and preferences, especially regarding functional outcomes. Previous research has highlighted that children living with complex care needs and their relatives encounter difficulties in accessing adequate and consistent psychological support, community and social services, and health education [1], which highlights the importance of addressing both medical and functional outcomes for children living with complex care needs.

An example of a patient group living with complex care needs is children with Down syndrome. Although children with Down syndrome share a typical appearance, intellectual

disability, physical conditions, and cognitive impairments [2], each individual with Down syndrome is unique and has his/her combination of conditions. Given these conditions, children with Down syndrome require a large number and variety of healthcare services and support. They often need (general) medical care from, for example, the general practitioner and pediatrician, speech therapy, physiotherapy and cardiology care, among others. Next to these medical services, children with Down syndrome may benefit from psychological, and educational, and parenting support. Although each particular condition is often well known, it is the personal tailoring of the screening, prevention, and treatment for children with Down syndrome which makes the organization and delivery of integrated yet patient-centered care for children living with complex care needs complex.

The work by Cassidy and coworkers [3] is paving the way for more empirical research on integrated care for children living with complex care needs. In their evolutionary concept analysis, including 22 articles, the authors illustrate the attributes, antecedents, and consequences of integrated care for children with complex care needs and present a new definition of integrated care for children with complex care needs. While it is good to see that there has been significant attention over the past decade in the literature to support the development of integrated care for children with complex care needs, there has been a resultant lack of action, with patient care continuing to be poorly integrated across care and social services. This results from the fact that the perspective of the children and their relatives who, although living with complex care needs, also need to be supported to avoid further illness, be empowered to be involved in their own care decisions, and be able to live life to the fullest, is often missing. The absence of the perspective of children and their relatives is considered limitation of this work, as mentioned by Cassidy and coworkers [3], and provides research opportunities to those responsible for delivering integrated care for these children. The work by Peters and coworkers [4] in the context of DS care delivery has shown

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that utilizing the perspective of children and their relatives can contribute to increased responsiveness and integration of healthcare services for children with complex healthcare needs. Future studies should include the perspective of children, their relatives, and healthcare professionals involved to capture a more comprehensive view of care delivery for children with complex care needs that is both integrated and patient-centered.

Cassidy and coworkers [3] also call for action on delivering integrated care that is adequate and accessible for children living with complex care needs. Although increased attention has been paid to this topic within the last 5 years, children and relatives still experience a lack of adequate and accessible services resulting in fragmented care delivery. Therefore, integration of healthcare services and services outside healthcare deserves more attention to prevent fragmented care delivery. A systemic approach towards integrated care for children living with complex needs would allow for integrating healthcare services outside healthcare, such as educational and social services [5]. This may stimulate a more outward view among health care professionals, which goes beyond health care, and a more holistic approach towards children living with complex care needs. In doing so, we move away from more traditionally oriented healthcare organized around single diseases within separate silos and, instead, we can deliver care focusing on functional outcomes and overall wellbeing instead of (para)medical outcomes of separate disease entities. This calls for interdisciplinary work on delivering integrated yet patient-centered care for children living with complex care needs [4]. However, this can only be achieved when multidisciplinary, cross-service delivery is

coordinated and collaborative and highlighted by Cassidy and coworkers [3] as a suggested research avenue. Future studies should apply a more systemic approach to integrated care for children living with complex care needs because integration of *all* services is needed, including healthcare services and services outside healthcare. It implies that the process of providing such care is a lengthy and often arduous journey, but one that is worth the effort.

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