

**Management and integration of care for children living with complex care needs at the acute–community interface in Europe**

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## Abstract

With improvements in neonatal and paediatric care, more children living with complex care needs are surviving beyond infancy into late childhood and adulthood than in the past. We examined the current approach to the management and integration of care of children living with complex care needs in 30 European countries, as well as the implications for primary care service delivery. This descriptive study, with an embedded qualitative aspect, consisted of questions adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs, and included questions on a complex care European survey of change, adapted from the Eurobarometer survey. The analysis indicates that few systems are in place in countries across Europe to identify all the health-care providers who deliver care to a child living with complex care needs, and that less than half of all countries surveyed have policies in place to support care coordination for these children. Primary care physicians have little involvement in care planning for children before their discharge to the community setting, and there is little parental participation in policy development. Access to, and governance of, care for these children varies widely. Particular issues identified pertain to parents as catalysts of optimum integration of care, pathways to specialist care, and the need for comprehensive national integrated care programmes.

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