Organisational factors affecting transition from children’s to adult services by young adults with life-limiting conditions in Ireland


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Category: Palliative care organisation and health care services

Title: Organisational factors affecting transition from children’s to adult services by young adults with life-limiting conditions in Ireland.

Research aims: To provide an overview of the transition services provided to young adults with life-limiting conditions in Ireland, identifying models of good practice and the factors influencing the quality and continuity of care.

Study population: Service providers in statutory and non-statutory organisations providing care to young adults with life-limiting conditions; young adults with life-limiting conditions and their parents.

Study design and methods: A realist evaluation approach using a mixed methods design with four phases of data collection: a questionnaire survey of health, social, educational and charitable organisations providing transition services to young adults in Northern Ireland and one Health Service Executive area in the Republic of Ireland with 104 individual responses from 29 organisations; interviews with eight young adults, two focus groups with parents/carers and 17 interviews with service providers.

Method of analysis: Data from the survey, interviews and focus groups were thematically analysed seeking to explain the impact of services and interventions, and to identify organisational factors influencing the quality and continuity of care. The two jurisdictions were analysed separately and a comparative analysis undertaken.

Results: Eight interventions were identified associated with a successful transition to adult care: an early commencement, effective communication between children’s and adult services, orientating the young adult to adult services, service providers adopting a person centred approach, the availability of a transition coordinator, using an interdisciplinary and interagency approach, developing the young adults’ autonomy, and supportive parents. Factors influencing the quality and continuity of care included the presence of a capable and willing adult service and children’s services using the time made available by an early commencement to support parents in ceding control to facilitate the development of the young adults’ autonomy.