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A MODEL OF CARE IN A CHILDREN'S HOSPICE – REPORT ON AN INDEPENDENT EVALUATION

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This paper reports on a Department of Health funded independent evaluation of a Children's Hospice service model. Over 150 stakeholders; hospice staff, representatives from external agencies, children, young people and families; acted as participants. The findings and recommendations are widely applicable in children's hospice care, identifying issues of international relevance.

A mixed methods approach was adopted, involving focus groups with family members and hospice staff, individual face-to-face or telephone interviews with family members, hospice staff and external staff and a web-based survey for parents. Topics covered included participants' perceptions of the service model and the provision of care, the use of assessment and outcome measures, and the current and potential use of emerging technologies within hospice care. Interviews were recorded and transcribed verbatim and analysed using thematic coding.

Findings Perceptions of the model were inconsistent: some respondents viewed the intent of the model positively but had concerns about its achievement in practice. Tensions between teams and the impact of end of life care on respite were identified as concerns. Families reported high levels of satisfaction with care, but the impact of late postponement or cancellation of respite care was a potentially serious problem. Transition to adult services was viewed as increasingly important as life expectancies increase.

The evaluation of individual care episodes, rather than overall service provision, did not appear to be undertaken systematically. While emerging technologies have the potential to impact positively on care, their adoption was seldom noted by participants.

Key recommendations Revision of internal communication systems, to improve links between hospice centres, and between professional groups and teams; clearer definition of the model of service; evaluation of potential uses of emerging technologies and a review of the impact of end of life care on respite would all be of benefit to the effectiveness of care delivery.