Abstracts

- Empowerment meetings have resulted in patients and guardians feeling more informed about the care they receive and more in control.
- Focus group discussions with beneficiaries have resulted in changing practice at the services themselves.
- Empowerment meetings have been most successful when participants identify their own key concerns and have the space to explore solutions with others.
- Experience sharing and testimonies have played a great part in encouraging and learning from each other.
- The workshop with the project beneficiaries and Minister for Health allowed policy makers to hear first hand the experience of those living with life-limiting illnesses resulted in the minister pledging support to children's palliative care in Malawi.

The project is of interest to others who are working to support development of children's palliative care. We would like to share our approach and learning with others, and to encourage discussion about participation and empowerment in any palliative care setting.

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WHO HAS DREAMS FULFILLED AT END OF LIFE? AN AUDIT OF A DREAM FULFILMENT ORGANISATION FOR CHILDREN AND YOUNG PEOPLE

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10.1136/bmjspcare-2013-000591.129

Dream fulfilment provides a positive focus, hope and a sense of future for children and young people whose lives may be filled with hospital visits, pain or worry. This paper will present the results of an audit of a dream fulfilment charity's database. The audit systematically analyses user demographics to find out more about who uses charities such as these. This project fits with the strategic exercise conducted by the NHS in England to 'map' palliative care services across England so that both health professionals and the public can see what services are, and where they are available.

The data reported in this paper are drawn from Dreams Come True's records of children and young people with life limiting and long term conditions and their families, and the dreams that they have had.

Descriptive statistics are used to summarise the clinical and socio-demographic characteristics of the children/ families who have used the charity's services over the last five years. Results highlight the range of health conditions that children who use the charity have, as well as reporting on other factors such as the child's age, family size, gender and the type of dream requested. Analysis also suggests gaps in service reach which may reflect the unmet need in the sector as a whole.

Results will be of interest to health care professionals working in the fields of paediatric palliative care, and care of children with long term conditions, as well as to other dream fulfilment charities. The audit's findings have implications for referring organisations, such as hospices, and potential lessons for the adult sector.

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THE TRANSITION TASKFORCE - MAKING THE DIFFERENCE FOR YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS

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10.1136/bmjspcare-2013-000591.130

Background Context Recent research from Leeds University shows there is a far greater number of young people who would benefit from palliative care, than previously believed. The study shows that the number of young people aged 16-19 with life-limiting conditions is growing and has increased by 44.8% over the past 10 years. Services, including hospices, do not currently serve this growing population of young people and their families well.

Aim The project aims to make a real and tangible difference to the experience of young people with life-limiting conditions as they make the transition to adult services.

Approach Used Building on the growing evidence base, in particular findings from the STEPP Project, the project will adopt a two-pronged action-focussed approach to putting research and policy into practice:

- At national level, developing guidance, raising awareness, providing training and support for adult providers ensuring that the 'push' from children's services is balanced by a 'pull' from adult services.
- At local/regional level, supporting the development of services and partnerships between children's and adult services, so that the research and good practice that exists is implemented on the ground and disseminated nationally.

Outcomes The outcomes of the project will be that:

- young people and their families have more choice and control to make informed decisions about their care
- children's and adult services in the voluntary and statutory sector work together to support young people through transition
- wider services, such as housing, education, employment and independent living provide services that meet the needs of young people with life-limiting conditions

Application to Hospice Practice Adult hospice services can learn how to plan and deliver the care that young adults with life-limiting conditions need.

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TRANSITION IN PALLIATIVE CARE STUDY DAY SERIES

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10.1136/bmjspcare-2013-000591.131

Background / Context Medical advances have led to more children with life-limiting conditions surviving into adulthood with an increasing number accessing adult Specialist Palliative Care (SPC) services. These young adults often have conditions unfamiliar to adult SPC professionals, who may be inexperienced in caring for their complex needs. Results from previous research carried out by the same team, identified a need for a training/education programme for adult SPC professionals and provided recommendations regarding content and delivery.

Aim To develop a training programme to help up skill and build confidence in adult SPC professionals regarding the care of young adults with life-limiting conditions.

A48 SPCare 2013;3(Suppl 1):A1–A74