Learning from Adult Services: Expert Patients to Expert Parents

Christine Twomey, Mary Busk
Haven House Children's Hospice, Essex, UK; Interface, Essex, UK

A project funded under DH £30 million for children's palliative care.
Introduction The Expert Parents project was based on the adult expert patients programme to give self-confidence to adult patients to take responsibility for the management of their own long term condition while encouraging them to work collaboratively with health and social care professionals. Haven House Children’s Hospice and Interface (a parent led forum in Redbridge) worked together in partnership to deliver 30 knowledge and skills training sessions in 3 months across Redbridge. The project aimed to help parents manage their child’s condition effectively.

Aims The sessions aimed to empower, inform and educate parents/carers to become more expert in the care of their own children. The project aimed to raise the profile of disabled children and views them to be both a local and national priority. The project was aimed at all groups of children with disability and palliative care needs. The project aimed to provide knowledge, skills and information for parents about services so that they can make informed choices. Information was provided about care pathways and transition. The project aimed to build supportive relationships between parents and professionals.

Method Parents and carers completed a standard questionnaire to evaluate each session.

Results Parent’s valued learning with other parents, gaining support and experience diminished isolation. They had an increased awareness of the services available and started to develop a new network of contacts. There were 287 attendances by parents/carers overall.

Discussion It was felt that the sessions allowed parents to open up and discuss issues, gave them hope for the future and made them feel positive. The project surpassed the expectations of the project team.

Conclusion Many parents requested further training and highly rated the value of their sessions to become Expert parents.