

Parent Carer Council Cornwall: Co-production in developing a palliative care strategy

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Background

In 2012 the Primary Care Trust (PCT) offered to fund the forum to develop a palliative care strategy, working with all the agencies involved in supporting children and young people with a life limiting or life threatening condition in Cornwall and the Isles of Scilly. The purpose of the strategy was to improve the outcomes and experiences of these children and young people, by having a choice and range of services available to enable them to live as full a life as possible. To deliver this would require a fully integrated approach among the key delivery partners in Cornwall and Isles of Scilly from both statutory and voluntary sectors.

What happened

The Parent Carer Council for Cornwall employed three parent carers to work on this, including one parent whose child had a life limiting condition with complex needs, and another whose child had died from a life limiting condition. It was seen as essential to have parents with this personal experience leading this work.

Consulting with parents and professionals

At first they found it difficult to reach parents of children with life limiting conditions as many professionals would not advertise events to parents as they were unsure what the parents knew about their child's conditions. This led to the forum setting up a Facebook page called the Palliative Care Network. This allowed parents to self-identify that this work was relevant to them and provided a mechanism for parents to be able to communicate with other parents who have children with a life limiting or life threatening condition.

As previous consultations had been carried out with parents and professionals, information was collected from these to identify themes requiring improvement. Twelve themes were agreed on and a questionnaire put together for parents and professionals, asking them to rank which theme would be their highest priority, and which would be their lowest priority.

The forum then ran a Square Table event attended by parents and staff from all the agencies involved in supporting the children, including hospitals, special needs

schools, hospices, community nurses and Diana nurses. This provided an opportunity for people to discuss and comment on the questionnaire in small working groups.

The questionnaire was then sent out to families and professional workers asking them to say what they thought the priorities should be.

A conference was organised attended by parents, paediatricians, portage workers, clinical psychologists, community nurses, hospice workers, social workers, early years workers, a head teacher and teaching staff. They heard speakers from a newly opened hospice, a paediatrician who has completed research on children's end of life experiences with bereaved parents, and three parents. A film was shown with a life limited teenager and his siblings expressing their views. After this questionnaires were distributed to both parent carers and professionals and completed during the event.

Parent and professional priorities

The results showed interesting differences between what the parents and the professionals thought should be a priority in the strategy.

The highest two priorities for both parent carers and professionals was to appoint families with a key worker and increase emotional support.

Families had been complimentary regarding some areas of provision, particularly that of Children's Hospice South West, Diana nurses and Community nurses. The parents did not see this as a priority for the strategy, but were unaware of how stretched the nursing teams were. The professionals who were aware of this issue thought this should be a priority.

The parents had financial hardship as a priority high on their list. However, professionals placed it very low. This suggests that professionals don't fully understand financial pressures can have a huge impact on families' resilience and ability to cope. Also an improved equipment and adaptations service was high on the parents list, but low on the professionals list.

Developing the strategy

Together for Short Lives had recently produced a framework for the development of integrated multi-agency care pathways for children with life threatening and life limiting conditions (2011), and the pathway produced is clear to follow. There are five standards within this pathway and all of the priorities the consultation identified fitted within these standards.

The parents used this framework to develop the strategy, seeking feedback from relevant agencies for different sections. Once it was written the full strategy was sent out for consultation to all stakeholders. A few minimal changes were needed as a result of this consultation.

Actions were agreed for each of these five standards, including the agencies involved in each, and the expected benefits and outcomes and when they should be achieved, based on the priorities agreed by parents and professionals.

Recommendations were also made about continuing to have Cornwall and IOS Children's Palliative Care forum meetings at the local hospice attended by all agencies that provide support to children and families, including parents. The network will be able to steer the strategy to ensure outcomes for children and families improve.

Time and time again during the consultation challenges were encountered when trying to reach parents, as professionals reported that they did not know how much the families have been told about their child's diagnosis and prognosis. This was particularly difficult for those agencies outside of the health service, within social care, education and the voluntary sector. These practitioners talked about being fearful of inadvertently telling parents that their children have life limited conditions. It was agreed an integrated way of working which involves transparency with both parents and other agencies was essential, as was the need for careful records to be made about what conversations have taken place with parents so when a change of staff occurs the new staff understand what has already been shared with the parents.

Outcomes

Some improvement in service have already been seen:

- the new Facebook page for parents of children with life limiting conditions allows them to communicate with each other and gain advice and support
- work between GPs and out-of-hours' services has improved to ensure better communication, so children dying at home can easily have the pain relieving medication they require.

In April 2013, the NHS Kernow clinical commissioning group become responsible for commissioning palliative care and the PCT was disbanded. NHS Kernow has identified a person from the clinical commissioning group who is taking this work forward.

The forum's professional approach to this work also led to further work being commissioned including running disability awareness training in Year 6 at schools, pathfinder work and reviewing the short breaks provided by NHS Kernow.

Why did this work?

The strategy was developed in co-production with families, professionals and key delivery partners from both statutory and voluntary sectors. There was a commitment to the strategy by all partners.

The forum found parents with direct experience of these services to help lead the work. They were persistent in reaching affected families when this initially proved difficult.

The consultation included all the different people involved in receiving and delivering the service, so different perspectives were heard and understood.

The forum avoided duplication of effort by making use of previous consultations and the framework developed by Together for Short Lives. They also made efficient use of people's time by working closely with relevant people for different sections of the strategy and then allowing everyone to comment on the final draft.

This is one of a series of case studies showing how parents helped improve health services for disabled children. You can browse all of these in our Success Stories section at

www.cafamily.org.uk/parentcarerparticipation

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