



A Service Evaluation;
The EllenorLions Hospices Children and Young People's Service.
Executive Summary

August 2011

The Children and Young People's Service was established in 1994 by the EllenorLions Hospices. The service aims to enable children and young people (0-19yrs) with life-limiting and life-threatening conditions to receive care in their (and their families') place of choice. This is overwhelmingly in their home. Their categories of conditions suitable for referral are encompassed in the four broad definitions of groups of children and young people aged 0-19 years of age requiring palliative care as described in "A Guide to the Development of Children's Palliative Care Services (2005).

The needs of children with life-threatening/life-limiting conditions and their families have been recognised to be unique and the Association of Children's Palliative Care (ACT) have developed a set of national standards within a three stage care pathway (ACT 2007). This care pathway is recognised as an appropriate benchmark for practice with this group and should guide professionals in planning appropriate care for children with life-limiting and life-threatening conditions and their families,

The Children and Young People's Service (chYps) offer care 24 hours a day, 7 days a week and 365 days a year in the family home. All families have access to a 24 hour telephone support and advice service, and a 24 hour on-call service. In the period of the evaluation, the service operated in Dartford, Gravesham, Swanley and Bexley, and was being introduced in the Mid and South West Kent area

Between January and June 2011, the EllenorLions Hospices commissioned a team from Canterbury Christ Church University to independently review the Children and Young Peoples Service to evaluate the integrated service model which delivers both palliative care and community oncology to children and young people with life threatening and life limiting illnesses. The project brief was conducted in two phases. In Phase 1 an information review was undertaken and in Phase 2 the effectiveness and usability of the service for service users and staff was analysed by qualitative methods (individual and focus group interviews). 10 families, 4 young people, and 12 Professional/ Support Staff were involved. The evaluation team presented the draft report to the EllenorLions Management Team in June 2011 and the final report was presented in August 2011.

The Evaluation Findings

The EllenorLions Hospices Children and Young People's Service is a highly effective example of an integrated model of care for children and young people with life limiting and life threatening illnesses. At the current time, community based services are considered to play an important role in changing the way in which the UK health system operates and this evaluation suggests that the chYps arrangements for this group of children and their families, in terms of the integration of palliative and curative approaches, is a good example of seamless care.

With regard to the specific areas the following key points are made;

1. Is the Integrated model cost effective?

There is evidence that the development of good community based services and a planned care pathway could deliver savings and an improved service.

- But there is an absence of data with regard to a model which is directly comparable to the chYps model so no firm conclusions can be made regarding overall cost effectiveness

However in related literature it has been noted within the delivery of similar services that;

- Any savings are related to economies of scale;

In addition it was recognised that services take time to be established so, in areas where support is poor, the more cost effective option is likely to be;

- The merger of small teams
- Or the expansion of existing teams.

This supports the EllenorLions strategy which has resulted in the recent expansion of their established service provision into Mid and South West Kent.

Furthermore we have found some potential financial savings to the NHS in the following areas;

- The operation of the on-call service, which reduces hospital admissions and visits
- The delivery of Cytotoxic medications within the community setting which would normally require a hospital admission.

The breakdown of costs provided within this evaluation offer the organisation information to allow comparison for future development.

2. The chYps model of care; Integration, comparison and unique aspects?

The data presented in this report allows the evaluation team to conclude that the EllenorLions Children and Young Peoples Service model is an integrated model, reflects the best practice guidance within the ACT model and has a number of unique features. The integration is evidenced in multiple ways.

- The Children and Young People's Service is unique as it has developed from within an adult hospice organisation and but has successfully established links with a number of different children's hospices across the region.
- The model supports referral and acceptance of any child or young person who meets the ACT criteria, which is applied in its broadest sense. This fully inclusive approach to the ACT criteria is unusual across the UK.
- In line with the ACT pathway, the chYps service model is integrated in the external environment, as staff work in partnership working with other health and social care organisations and services to ensure that children/young people remained the focus of the care delivered during their life.

- The chYps model integrates palliative and curative care within the community based team so families have no service transition to negotiate when moving along the ACT Pathway – which is unique within local oncology service provision.
- The chYps model operates in an integrated manner internally where the organisations' own support services were mobilised to meet new or evolving needs of the family, such as access to Youth Worker, Play or Music Therapist, chaplaincy or counselling or bereavement support.
- The support offered was similar to that in other paediatric palliative care services however the chYps support interventions are distinctive in terms of accessibility and use.
- Uniquely chYps recognises that 'family' not only encompasses siblings and relatives but also includes friends who support the child / young person. Also access to chYps support services are not bounded by the receipt of nursing elements of the service, but are open to those with relevant diagnoses who are being cared for elsewhere.
- The chYps model includes access to social activities and on occasions respite care in the home or within a hospice environment – promoting social inclusion.
- Since those life-threatened by cancer may experience complete or partial remission, the chYps service remains contactable during remission, and families can continue to access supportive services. This is unusual but families found this continued contact beneficial.

3a). Is the service effective and usable for staff?

The staff team are supported to operate effectively within the service and the established processes and practices are user friendly.

- The management practices in relation to recruitment, induction and professional development of staff are appropriate and have resulted in a team with variety of relevant prior backgrounds. The palliative experience of all nursing staff engaged in the care process is viewed as a distinctive strength of the service.
- The referral process was safe, effective and well developed with some NHS providers; the service could be marketed more widely to improve the care situation for a greater number of the relevant population.
- The chYps nurse specialists working practices are supported by appropriate guidance to support the delivery of a quality service across both palliative and community oncology domains. The chYps nurses align their oncology practice with Tertiary centres and contemporary published guidance.
- Risk management was evident; informal and formal communication strategies were found. The care provided appeared to be safe and this was supported by feedback from families.
- The nurse specialist working practices were adapted flexibly to accommodate the priorities and demands of the workload and the on call.
- Nurses developed strong bonds with the families and vice versa.
- Staff development opportunities are available to sustain the service and psychological support was available for staff to engage with. All staff expressed satisfaction in working for the organisation.

3b). Is the service effective and usable for service users?

The children, young people and families interviewed provided extensive evidence to support the conclusion that the chYps model is effective and that the processes and practices employed to support care aim to promote access and are user friendly.

- Service users identified that the chYps team play a pivotal role in the family's care due to the relationship which has been developed and the valuable insight into the progress of the disease, the family's level of understanding and their individual needs.
- The children and families from the oncology trajectory directly identified the relevance and inclusiveness of the children and young people's service which meant they were part of the entire process of care.
- The families identified that chYps provision takes into account the child or young person's and their family's physical, emotional, cultural and practical needs in a way that promotes choice, independence, creativity and quality of life and is responsive to local need.
- The chYps staff take into account the life-long and developmental needs of children including the transition to adult services. Their model of care illustrates a system of support to the child and family based on choice and access with care promoted as an active approach to management. It is not just 'what you do when nothing else is left'.
- Families were provided with access to continual support since the chYps nursing service is provided across the seven day period, with 24 hour on-call cover provided which provided immense psychological benefit for families and when used was seen to prevent hospital admissions/visits so children and families stayed at home where appropriate.
- Families recognised and praised the Children and Young People's Service for the support, flexibility and responsiveness of the service to their individual needs. Particular recognition was given to the team members who are dedicated in their efforts to provide the best possible services to the children/young People and families who require their support. This dedication continues during the remission phase and the bereavement phase of care.
- Families highly regard the social events which form part of the multiple approaches to support provided by the chYps service. In addition families, who had received respite support, placed high value on this supportive intervention; however families were not always aware of this element of support.
- The Children and Young People's Service can be accessed as a complete care package or in a more limited way as some children/young people or family members access the service partially for specific support not available from their key providers.

3c). What outcomes were important to families?

The families surveyed all had differing needs but the outcomes that they considered most important were;

- That the provision of the chYps service allows care in the home, where the family behaviour can be 'natural'.
- The development and quality of the inter-personal therapeutic relationship with the chYps team, which was supported by the positive personal and professional qualities of the staff
- The on-going emotional care and support provided to parents, which was underpinned by compassionate, honest, open, communication which promoted realistic expectations.

These outcomes allow the evaluation team to conclude that Children and Young People's Service within the EllenorLions Hospices is an 'enabling organisation' which supports the collective wellbeing of this group in the local community.

4. Is care delivered in an interprofessional, child centred and integrated way?

The evaluation team conclude that effectiveness and current success of chYps model is predicated on the ability of chYps staff to work flexibly, responsively and interprofessionally, since the children

and young people in their care are generally in receipt of care packages that transcend normal boundaries. In the opinion of the evaluation team this is achieved to a very high standard.

- Staff and families provided numerous examples of effective interprofessional working with 'experts' who guided care delivery from tertiary or local centres, or liaison, advice, training or education for other professionals supporting the child and /or family in environments outside health and social care (schools, clubs, etc).
- The chYps team have a clear understanding of the local facilities available and the barriers within the local health and social care sector, and act to circumvent the impact on families when possible. Staff aimed to ameliorate the illnesses impact on day to day life.
- There is a clear emphasis on involving the child or young person in decision making or choice, underpinned by the development over time of an honest, open relationship within the family's home.
- Whilst the child or young person remains the focus of care, the chYps team offers support for any member of the family or significant supporter, to promote psychological health and wellbeing.
- The chYps nurse specialists work as key workers in the community setting, collaboratively seeking expert advice, both reactively and proactively, to support the child and family negotiating care.
- The knowledge and expertise of the chYps nurse specialists, which is built up with families is recognised, since chYps staff are actively sought by hospital based colleagues to provide nursing management advice during hospital admissions.

The underpinning of the service by this integrated, interprofessional approach to care where professionals share relevant knowledge is an example of how the delivery of holistic care can support the attainment of full potential, even in the most difficult of circumstances.

5. Areas of Good or Commendable Practice

The evaluation team consider the following elements to represent good or commendable practice.

Organisational development

- The chYps is unique as it has developed from within an adult hospice organisation in response to local need and has successfully established links with a number of different children's hospices across the region.
- The recent development of a 'young adults' facility, within a dedicated area of the adult hospice addresses and supports those going through transition.

Equality and Access

- The chYps team offers a fully inclusive service to all life threatened and life limited children and their families and does not differentiate its provision to exclude oncology patients.
- The chYps services can be accessed as a complete care package or in a more limited way as some children/young people or family members access the service partially for specific support not available from their key providers. This unique inclusive approach to offering wider community support is commendable.

Care delivery

- The families consistently discussed the benefits of the service providing care and support in their own homes.

- The multi-agency working by the chYps team met the individual care needs of the child/young person with life-limiting/life –threatening illness and their families.
- Whilst the primary environment of care is the home this is transcended when chYps team work alongside families in other environments.
- The support offered by the chYps team encompasses the whole family, not just the child with palliative care needs. The chYps staff team support children and young people, siblings, parents, grandparents, extended family and supporting friends both on an individual and group level.
- The provision of the on-call service by chYps meets acknowledged needs. Families praised the service for the support it provides and the unique flexibility and responsiveness of the service to their individual needs
- The emotional nature of the care and the support the chYps team provide was recognised by the children/young people and their families.
- The delivery of home based respite care provides similar benefits to hospice based care but without the additional stress of having to ‘pack up’.

The development of the chYps nurse specialists

- The personal and professional qualities of the chYps team were frequently discussed by the children/young people and their families. The importance of the families’ relationships with staff were often emphasised as they frequently referred to the staff as extensions of the family.
- The grounded experience of palliative care experience in the chYps nurses contributes to the unique nature of service delivery.
- The expertise of chYps nurses is now being sought out by other professionals, so acknowledging their unique insight and knowledge.

The integration of support and volunteer staff

- The breadth of support services offered as part of the integrated approach to chYps mirrors that within other local paediatric hospice environments however such interventions were distinctive in terms of accessibility and use.
- Several aspects of the care provided were identified by the families for particular recognition: these included the multi-level approach to supporting the whole family, sibling support, bereavement support, and bringing the families together through the social events organised.
- The use of Volunteer drivers to deliver blood samples demonstrates good organisational support since it releases staff for hands on care.

Working Practices

- Joint decision making at MDT is considered an area of good practice as exposure to such decision making will also act as a developmental tool for newer staff and the decision making is transparent.
- The introduction of netbooks, which will allow completion of contemporary records in the home.
- The use of the ‘infoflex’ system, which allows online access to patient information at all times.

6. Recommendations

A summary of the recommendations is shown below across four key areas

Service delivery

- Enhanced dissemination of the referral criteria is required to all key stakeholders.
- Enhanced network of links in tertiary centres and re-engagement with multilayer marketing campaign which includes support groups, local and specialist children's hospitals, local and national volunteer groups.
- To aid exposure in the Health and Social Care sector, offer student placement opportunities to all relevant pre-registration health and social care professionals.
- The creation of a directory of services and staff available to support children and families receiving chYps care for both the National Health Service(NHS) and Private, Voluntary and Independent (PVI) sector.

Potential developments

- Further development of the role of volunteers within the Children and Young People's Service and within any future service iterations, including support and potential training.
- The development and delivery of Continuing Professional Development bespoke training packages, for other local authority, voluntary sectors, NHS providers, and schools.
- An e- health facility for the community, with diary of social events and an on line discussion forum to increase the social networking possibilities among families/young people who might be able to offer each other support even if geographically distant or if travel and transport are problematic.

Respite provision

- Direct engagement with commissioners of children and young people's service to ensure chYps is linked into the strategic planning of palliative/respice services.
- The commissioning of a full 'respice' needs assessment across the current life limited / life threatened population to assist in determining the type and level of resource required to meet the established need and allow a review of and planning for any required capacity building.
- The development of systems and resources which enhance equitable access to respice services. This could include an on line booking system for respice care.

Working practices

- The introduction of team leaders with responsibility for either oncology or palliative care would offer clear lines of support to newer staff and enhance consistency in care however this needs to be balanced against the integrated nature of the service.
- A mapping of the role development to ensure clarity in expectations for both staff and the organisation. This could support the subsequent development an incremental training need analysis and educational development plan to avoid the service becoming vulnerable.
- A review of the policies/guidance to support safe and effective working practices; specifically initial joint / dual visit approach, reporting back on completion of the shift for all staff and the management of on-call in an expanding catchment area, and the extent to which nurses should assist in areas covered by other HSC professionals. Any plans in place should be shared and any future plans which will influence working practices should take account of staff opinion and experience to assist the change process.
- Assistance for staff in establishing improved working practices with regard to contemporary record keeping using technology
- The introduction of clinical supervision a compulsory requirement of the role to assist in maintaining the mental health and wellbeing of the staff.
- Additional education to support understanding of adolescent behaviour and appropriate management may be advantageous for those not trained in this area.

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