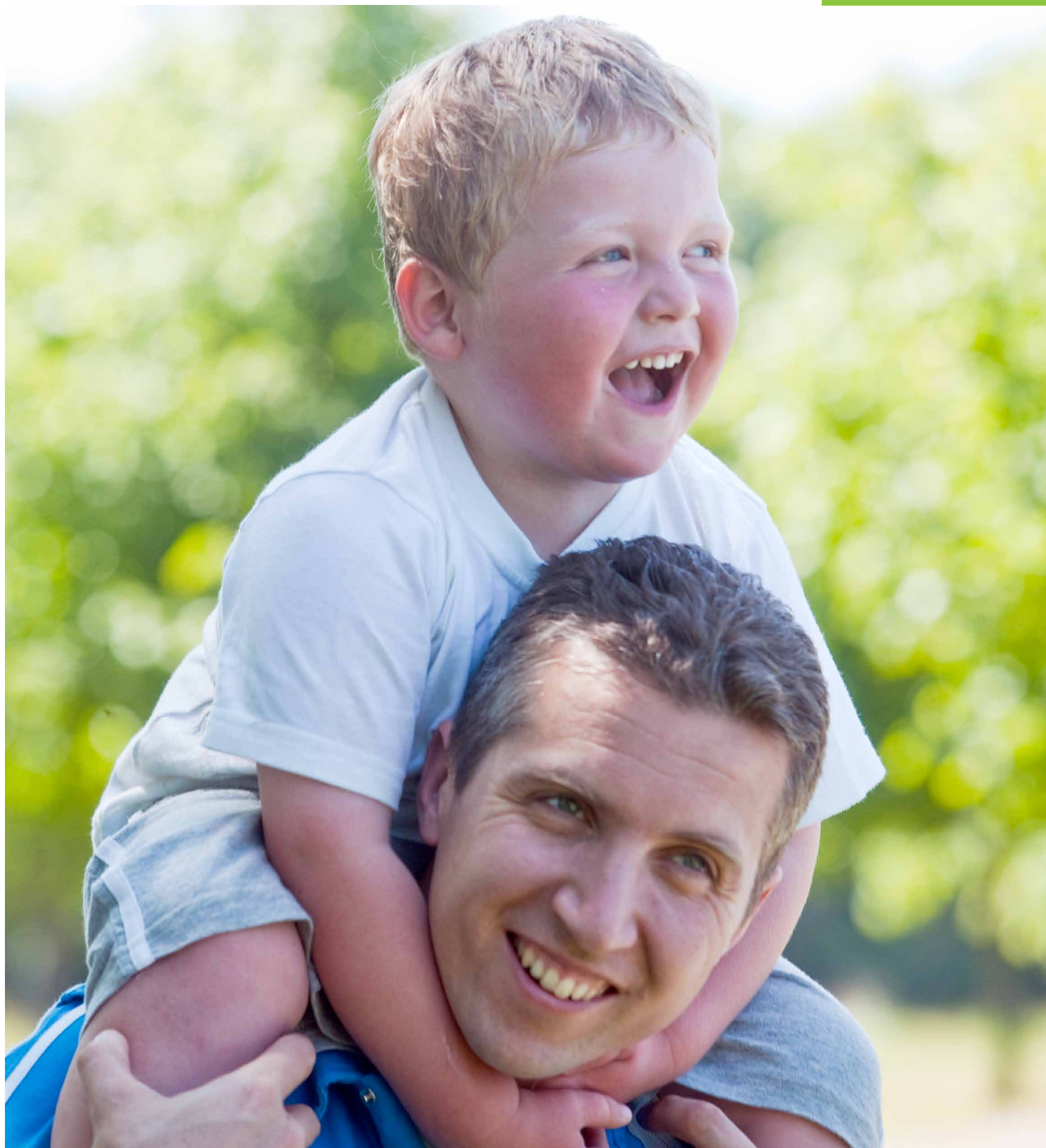


Local Learning and Evaluation Report

**SQUARE
TABLE**

Speak. Listen. Change.



Executive summary



“It’s a minefield and you get frightened going through it. Services don’t join up and people don’t explain things to you ... they don’t tell you what all the services actually do ... by the time I had made it all fit together my child had passed away. That makes me sad that he could have had so much more out of life”

Parent, Noah’s Ark Square Table

In Spring 2011, 37 unique events took place across England designed to deepen the level of shared understanding of children’s palliative care. Each event brought together life-limited and life-threatened young people and their families, a range of health, education and social care professionals and providers as well as countless other representatives from across the community including faith and business leaders. The events were called ‘Square Tables’, symbolising the equal weight and importance of all participants’ views. They created an environment for open and honest discussion and increased understanding between those who provide children’s palliative care, those who experience it and those that play a wider part in supporting children, young people and families in a particular community.

A number of common themes arose from the rich, inspired and inspiring discussions. These are highlighted in more detail within this report and are summarised below. The themes have informed the planning for a UK wide Square Table event held in London on 17 November 2011.

AWARENESS AND LANGUAGE IS SEEN AS A BARRIER TO SERVICE ACCESS

There is a low level of awareness about the services available to life-limited and life-threatened children and young people in many areas. Many parents were surprised about the breadth of services available, at least in theory, to them. Similarly, some hospital based professionals (particularly those working in an acute hospital setting) and GPs were unaware of the range of support available through children’s hospice services and other community based palliative care providers. Many participants felt that language and terminology played a significant role in creating a barrier for parents. This was understandably also the case for those people who do not speak English as a first language. Wider awareness amongst schools and the general public was also considered to be lacking.

PARENTS SAY THEY STRUGGLE WITH THE CURRENT ASSESSMENT PROCESS

Parents find the current assessment system – which requires them to repeat the information about their child and family circumstances on multiple occasions

Executive summary

to different agencies across health, education and social care – a major challenge. Many professionals also said they were frustrated by the system and the lack of a joined up approach. Current assessment tools such as the Common Assessment Framework (CAF) were seen as positive, although it was notable that the framework had not yet been implemented in several areas.

PARTNERSHIP WORKING IS SEEN AS KEY TO ENSURING THE BEST OUTCOMES FOR LIFE-LIMITED AND LIFE-THREATENED CHILDREN AND YOUNG PEOPLE

There was universal understanding amongst those who attended Square Tables that the best outcomes for children and young people are achieved when parents, professionals and volunteers work together in partnership. Key workers are seen by many as critical in helping to achieve this, ensuring effective partnership across agencies and supporting parents throughout the journey of caring for a child with a life-limiting or life-threatening condition. Yet it was notable that the majority of parents attending Square Tables did not have access to a key worker.

WORKFORCE TRAINING AND DEVELOPMENT IS CONSIDERED A PRIORITY BY PARENTS AND PROFESSIONALS

Whilst most parents spoke very highly of the professionals involved in the care of their child or young person, many still felt training was inadequate for those generalist professionals who have only limited day-to-day contact with life-limited and life-threatened children and young people. Training for these professionals would help improve general awareness of the needs of life-limited children and young people, improve experiences at the point of initial diagnosis and ensure greater inclusion. Many Square Tables also discussed the potential for the role of volunteers to be developed to support children, young people and families.

PARENTS FEEL SUPPORT FOR YOUNG PEOPLE MAKING THE TRANSITION TO ADULTHOOD IN SOME AREAS IS LACKING

Many parents said they are facing their child's transition to adulthood with great anxiety due to the limited support available to them. The young adults who attended Square Table events were dissatisfied with the range of opportunities available to them. Whilst in some areas there was clear evidence of strategic thinking and partnership working between children's palliative care providers and adult services, in other areas many said that there was virtually no provision and little forward planning.

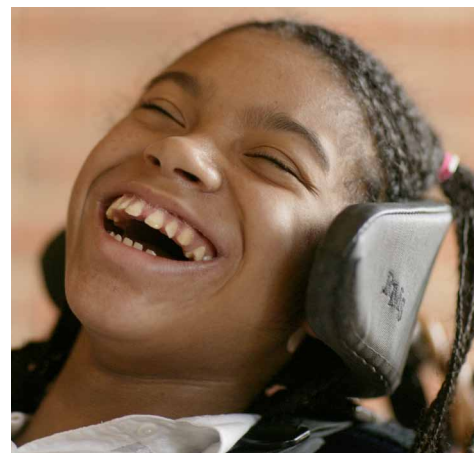
THERE IS A GREATER NEED FOR SUPPORT FOR PREMATURE BABIES AND CHILDREN WITH VENTILATION

Some parents and professionals felt that children's palliative care services across England are not fully prepared to respond to the increasing numbers of premature babies with complex health needs which are now surviving due to technological advancements. Many also felt that support to enable children with long term ventilation needs to have time outside of a hospital environment was also inadequate.

FUNDING AND THE FUTURE SUSTAINABILITY OF CHILDREN'S PALLIATIVE CARE PROVISION IS A CONCERN

There was widespread concern in all areas about the potential impact of public sector cuts and the general fragility of the economy on both the charitable and statutory sectors. Discussions at many Square Tables focused on the emerging Government health and social care reforms, particularly in relation to the opportunities and concerns presented by the proposed introduction of GP commissioning. However, there was no general consensus on the solution to the best funding mechanism or whether the system of direct payments was working for children, young people and families.

What is a Square Table event?



The strength of this exercise is that it presents the opportunity for service providers, commissioners and children and families and the wider community to deepen their understanding of what the current issues are and the challenges facing children's palliative care. It should make a great impact on those able to set the strategy for children's palliative care across the country.

The Children's Hospices UK and ACT Square Table Programme created a structured environment in which the aspirations of children and young people with life-limiting and life-threatening conditions, together with the views and concerns of their parents and key carers, were discussed and shared in common forum with key representatives across the entire community.

The programme took the form of a series of 37 Square Table Events across England which were organised in partnership with a project team from Children's Hospices UK and ACT.

Each Square Table event aimed to accommodate up to 30 participants and each was attended by invitation only in order to ensure a consistent range of representation of children, young people and families and other stakeholders including providers and commissioners. More than 1,000 people took part in the events. Over 100 families took part including over 40 life-limited and life-threatened young adults. Events were generally moderated by a respected member of the local children's palliative care community. Each of these Square Table moderators received training and support to take on the role. All events followed an agreed structure and

format. The Square Table format ensured that every representative's view was given equal weight and importance.

The Square Table programme inspired much enthusiasm for the project across the country. Bringing parents, young people and professionals and the wider community together in common forum provided a tremendous opportunity to deepen understanding of children's palliative care. There was an evident willingness at all events to share experiences – however positive or negative – and a real sense of urgency about wanting to move problems and issues forward.

The verbatim notes from each Square Table have been reviewed in the process of writing this evaluation which will be distributed to all Square Table participants, those who were invited but could not attend and other interested parties at a local, regional and national level. This document identifies the common themes which emerged from the Square Tables and consideration will now be given as to how these may be best addressed at the UK wide Square Table event due to be held in London in November 2011.

Local Square Table programme themes



Each Square Table moderator was asked to select two or three themes on which to focus the discussions.

The attendee list had a bearing on the choice of themes in that an effort was made to ensure that the discussions would reflect the range of experience of those who attended. Two Square Tables chose to focus on just one topic. These were neonatal care in the one case, and the other was transition for young people into adult palliative care services.

Parents, siblings and young people with life-limiting or life-threatening conditions were present at all but one event and appropriate transport, interpretation services and child minding services were made available to parents to facilitate their attendance.

The themes from which each moderator was able to make their selection were:

Theme 1 ACCESSIBILITY OF SERVICES

- How can we increase the ability of all to access children's palliative care services?
- What information do families need and how can it reach them?
- What information do others such as GPs need?

Theme 2 PARTNERSHIPS

- Can we develop better partnerships locally?
- Are there any barriers to our doing so and how can we remove them?
- "Joined up working" – do services need to be redesigned?

Theme 3 WORKFORCE AND THE ENGAGEMENT OF LOCAL COMMUNITIES INCLUDING VOLUNTEERS

- How to understand the needs and preferences of the local community's children and families, including the diverse needs of different cultures?
- How are children, young people, their families and communities engaged and involved?
- How can the wider community become more effectively involved in our work and what are the barriers preventing them?
- How could volunteers assist children's palliative care providers, both charitable and public sector?
- Are there new ways to involve volunteers?

Theme 4 EMERGING ISSUES IN CHILDREN'S PALLIATIVE CARE

- What are the emerging issues? These may include for example transition to adult services; services for neonates; ventilated children; choice of place of care for children and families.

Theme 5 FUNDING

- How could we fund children's palliative care more sustainably?
- What is the likely impact of GP commissioning?
- What is the impact of budgets being divided between health and social care providers – does this lead to duplication?

Theme 1

Accessibility of services

“Make it a life of quality however short”

Local Square Tables in all regions raised wide ranging and complex issues around the accessibility of services provided to children with life-limiting and life-threatening conditions and their families. Many parents talked about the lack of available services for their children and themselves in their area. When challenged about their perceptions by service providers at the table, many parents expressed surprise at the breadth of services in their locality which were unknown to them. It quickly became clear as the programme unfolded that many parents do not understand the roles and responsibilities of many of the professionals who are available to help and support them and thus the nature of the services which could be on offer to them.

“We don’t know what services are out there. We learnt from parents of older children. I wish we had been given a pack. It’s all done by word of mouth”

Some hospital based professionals and GPs also expressed surprise at the support provided to children and families by children’s hospices and other community based palliative care providers. Professionals working in acute hospital settings in several regions were clearly unaware of the possibilities available to children outside of a hospital setting.

It became apparent during the overall course of the Square Table events that it is the very lexicon of language in use around the country which may in fact be a primary stumbling block for both families and professionals trying to find services for the children in their care. It leads them to perceive that there are fewer services available than is, in reality, the case.

Numerous parents across the country rejected the term “palliative care” as having any relevance to their children or family lives. Most considered these to be services aimed at children and young people reaching the end of their lives, suggesting a misunderstanding of the term palliative care as it applies to children.

Whereas adult palliative care is much more focused on the end-of-life phase, children’s palliative care is about a whole trajectory of care from the point of diagnosis. Many parents commented that they would proactively avoid using any services which were described as “palliative” fearing that they would, by engaging with such services, be prematurely forced to face up to the reality of their child’s life-limiting condition and death.

“Getting the diagnosis is bad enough – you don’t want to be pushed into the place of thinking about that all the time”

“I hate the term “palliative care” – it’s too medical. It feels like a death sentence. I won’t use it – it makes people wary of me”

“Any family might have to face end-of-life care for their child – but they don’t have to live with labels all their life”

The importance of support for parents at the point of diagnosis surfaced as a significant issue at several Square Table events. There appear to be two key issues here. Parents described how they felt vulnerable and isolated when given the news of their child’s condition and prognosis. Whilst there were some excellent examples of consultant paediatricians taking the time to explain carefully to parents the implications of their diagnosis, many parents said that they were not given enough information or were rushed through the process in a busy out-patient clinic or maternity ward. Some parents identified the apparent lack of sensitivity of the doctors and nurses in dealing with them at this difficult time.

“I was told that my son had this condition. There was a woman in the room with the doctor. He said “this is your palliative care nurse”. I had no idea what that meant or what she did. I realise now though that I was one of the lucky ones. Some parents just end up back in the waiting room with nothing”

Theme 1

Accessibility of services

“I was told over the telephone that my daughter was life-limited. I was on my own in the house”

It was particularly noted at some Square Tables in areas of diverse populations that skilful and sensitive translation services are of critical importance to those families who don't have English as their first language.

Some suggested that those working in this arena should have specialist training to equip them to manage the emotional context of interpreting the breaking of bad news to families. Some Asian fathers shared that all information about their child's condition and prognosis was directed through the child's mother even though their language skills may be less developed.

Some parents of older children expressed frustration that they were unable to really engage with services until their child had received a firm diagnosis. These parents were particularly isolated.

Many parents cited bureaucracy and delays in decision making as one of their greatest barriers to accessing services for their children.

“We don't ask to be put in this position and we try to do the best we can but we are constantly thwarted by bureaucracy and delays and it is our children who suffer as a result”

Failures in the procurement system for equipment and medical aids was another cause of concern in some areas.

“By the time my child got the equipment he needed to help him stand up he could no longer stand at all and was in a wheelchair – it took months and months”

Some Square Table discussions, most notably in the West Midlands and London, described the successful use of the Common Assessment Framework (CAF), the team around the child model (TAC) and the use of Advanced Care Plans (ACP) in mitigating the need for constant repetition of information and prevention

of unintended outcomes. These systems were seen by many participants as one of the key areas where a more cohesive approach nationally could enable quite significant cost savings across services.

Even in these areas where the frameworks were being effectively used, the need for training for both professionals and parents in the appropriate use of these frameworks was emphasised. Many generalist professionals were unaware, for example, that an ACP will detail the family's wishes for how the child's care at the end of their life is approached and may in particular express their decisions regarding resuscitation of their child in an emergency. Ambulance crews and staff in Accident and Emergency departments in some areas were identified as being particularly in need of additional training in this area.

“One family in our area had an Advanced Care Plan but did not know that they had to show it. At a very difficult time for the family they ended up with the police and the coroner involved because the ambulance crew did not know that the child was not to be resuscitated”.

Yet in several areas it appeared that these frameworks had not been implemented. In many areas parents were still having to repeat the information about their child and their family circumstances time and time again to a range of professionals working with them. Parents described this as painful, upsetting and very frustrating.

Several Square Tables discussed the viability of some kind of “health passport” which could travel with the child at all times, whilst one pragmatic young adult with Muscular Dystrophy at the Brighton Square Table felt that all his information should be held on his iPad or other portable electronic device.

Theme 2

Working in partnership



Service providers from whatever discipline must work collaboratively and develop strategic partnerships to ensure that there are greater choices for life-limited and life-threatened children, young people and their families. Families need an advocate who is independent, who can continue working with them over a long period and can be their key point of contact with the wide range of services they may come into contact with.

Many of the Square Table events addressed the issue of partnership working. Whilst some discussions addressed partnership working in terms of collaborative working arrangements across disciplines, other events explored the potential for strategic partnerships spanning different organisations and even working across geographical boundaries.

There was a universal understanding amongst all professionals that the best outcomes for children and young people are achieved when the parents and professionals are working in partnership. The central theme that emerged in these discussions was the need for a key worker role to co-ordinate services for families and act as their advocate and support when liaising with external agencies. This was the most keenly debated topic in the whole local Square Table programme.

“The key worker is someone who can go round to see what they can find to build a team around the child”

There were many notable examples of excellent key worker arrangements which are transforming the lives of children, young people and their families in some areas of the country. In Bristol participants heard that:

“The most valuable thing in the whole package of care was a key worker doing all the liaison. They had a dedicated budget to spend on anything the family needed. They could buy in anything within days. They brought the agencies together regularly to meet with the family”

It was apparent that in many areas in the country there is no key worker system in place. The majority of parents attending Square Tables did not have a key worker and portrayed their lives in the language of warfare, describing “constant battles” to secure services, feeling “under siege” and “always wondering when the next bombshell will drop”.

Theme 2

Working in partnership

There was significant debate as to who that key worker should be and even whether it was necessary for the key worker to be a paid professional, with some parents and civic community attendees wondering why this person could not be a trained volunteer.

It was universally agreed that the individual needed to be someone with whom the family could build up a relationship of mutual trust and understanding over a period of years. Several parents expressed their concerns about key workers being appointed from the statutory social care sector fearing:

“Putting social workers in charge of finding services stigmatises parents – they won’t say that they are not coping in case their children are taken away”

A key worker must be a “can-do” person who is not afraid to address barriers and challenge perceptions even with very senior health and social care professionals. Many parents and professionals across all disciplines suggested that the key worker role must be seen as a full time role in itself and should not be dependent on individual professionals trying to find additional hours in their day to take on these responsibilities.

“The lead professional role always sits on top of the day job and there is nothing else to drop. We need to source the lead professional role in its own right. I am managing 11 children with very complex needs – how can I be on top of everything which all those families need?”

The experiences of parents, as described at many events supported this assertion:

“The whole service relies on “can-do” individuals who work outside of their remit, take work home and risk their jobs and their own health and wellbeing. Then they get stressed out and leave their job and we are left with nothing again”

“My key worker was my rock but she took on too much and got sick and actually that just made the situation worse”

There was a clear frustration at many Square Tables amongst professionals that the key worker system is not yet universally accepted or working in many parts of the country.

“There used to be a key worker system twenty years ago – we know it works. This is so disappointing. We know all the stories, we know exactly what needs to be done. Why aren’t we delivering on this after all this time? I don’t want to see another document about whether or not it is a good idea – I just want somebody to help me to do it”

Some Square Table discussions looked at ways in which partnerships could strengthen relationships for the strategic benefit of the sector. In these discussions the issue of pooled health and social care budgets was a common theme. Separate budgets were seen as symptomatic of a lack of adequate joining up of health and social care services with parents left in the middle. There was a general consensus that pooled health and social care budgets needed to be addressed at a national level by Government. The pragmatic view of one parent was:

“If you all merged budgets – where you all get a little bit – if you pulled these little bits together you could actually do something meaningful”

Some discussions moved on to explore the inherent difficulties in such thinking. Many commented on the very real difficulties presented by differing governance arrangements between the voluntary and statutory sectors. Some voluntary sector based senior managers feared that:

“The impact of the NHS reforms may lead to gaps and loss of services – this could lead to a secularisation and a lack of co-operation as the charities find themselves exposed”

Theme 3

Workforce and engagement with the local community including volunteers



Workforce training – particularly with those generalist professionals who have less contact with life-limited and life-threatened children and young people – is seen by parents as lacking in some parts of the country

Most parents spoke very highly of the professional workforce involved in the care of their children.

“My journey is more positive than negative because of the professionals involved. You do so much that is right”

Many professionals attending events, however, raised concerns about parents having to act as professional carers. It was noted that whilst parents may know what is best for their child, the burden on them of providing nursing care and performing medical procedures for their children is too great. This can rob parents of the opportunity to simply be Mum or Dad to their child and enjoy the experience of parenting itself.

“It’s also about giving permission for a parent to be a parent as well so that they can enjoy being a parent. This is their special time with their child and that time may be short. We should not expect them to do all the caring and nursing things”

Many of the discussions about workforce issues focused on the apparently inadequate skills of some generalist professionals who have only limited day-to-day contact with life-limited and life-threatened children and young people. Mainstream schools and school transport services were particular areas of discussion although parents did indicate that in some locations there were some excellent examples of special school teachers and auxiliary staff providing significant

Theme 3

Workforce and engagement with the local community including volunteers

support to families. Many parents complained that their well children were not given enough flexibility in school to help them to cope with broken nights, prolonged periods of hospitalisation and the general stresses and strains of living in a household with a brother or sister with complex disabilities.

Parents also felt they were not always taken seriously by professionals when they had concerns about their child.

.....
“When his epilepsy medication was changed by the consultant, the newly qualified GP would not take my word for it. I wouldn’t just change the medication and put my child’s life at risk. Why would I do that? It is so frustrating”
.....

Other Square Table events noted that the constant advances in “technology medicine” are leading to more and a greater number of life-limited and life-threatened children with ever higher levels of clinical dependency. It was noted that the community children’s nursing service is inadequately resourced and this impacts most on ventilated children and those with complex health care needs. This exacerbates the demands on parents who often have to take on the role of managing their child’s nursing needs at home. Indeed in some more rural locations parents may need to be available to care for the child even when they are on a hospital ward.

At several Square Table events parents and young adults challenged the communications between professionals. Parents described situations where they found themselves caught up in conflict between hospital based staff and community nursing teams with each openly criticising the other’s work to parents. This caused further anxiety and stress for the parents as they then had to weigh up which piece of advice they should take in the best interests of their children. Whilst this issue was by no means widespread it was a feature of a minority of Square Table events and is clearly causing significant distress for those parents concerned.

Rather more prevalent and no less distressing for parents is the emerging issue of budget discussions

sometimes taking place between professionals in front of parents and children at multi-disciplinary meetings, occasionally even in the family’s home. Many parents expressed concern about the additional pressure this placed on them. Some parents said that they felt guilty when it is made obvious to them that their child will only get a service at the expense of another family losing out.

Many Square Tables noted the importance of volunteers in the lives of both families and organisations caring for life-limited and life-threatened children and their families. Poor communication about the need for wider community and volunteer involvement was a common issue. In many cases there was a regret that more families and professionals did not reach further into their local communities for help and support. Nonetheless there were some excellent examples of local volunteer support for children and their families, whether formally or informally arranged.

.....
“We had 24 hour support because we are part of our church. We never cooked a meal or did any washing in those last few days. Friends looked after our other children whilst our son was dying”
.....

Some faith leaders who attended the events indicated that it had helped them to increase their understanding of the complexity of the needs of life-limited and life-threatened children and their families. Many parents and professionals recounted anecdotal experiences of children and families being excluded from places of worship, events and tourist attractions because of their child’s condition.

.....
“My daughter has been excluded from our local church because they say she is too noisy. We all miss it”
.....

One event noted that the lack of any discussion in schools about death, palliative care and services for children meant that young people have no knowledge of the issues involved and so do not readily step forward to volunteer to work with life-limited and life-threatened children and young people.

Theme 4

Emerging issues in Children's Palliative Care



Other key themes arose from the discussions included the growing need to support young people making the transition to adulthood, premature babies and children needing long term ventilation.

Many of the Square Table events addressed the issues of emerging themes within children's palliative care.

The wide regional variations in service provision and support for young people making the transition to adulthood and their families were discussed. Whilst in some areas there was clear evidence of strategic thinking and partnership working between children's palliative care providers and adult services, in other areas there was virtually no provision and little forward planning. There were examples of imaginative ideas for finding solutions to the particular problems of this age group from many professionals. Overall, however, it is clear that many parents are facing their child's transition from children's services with great anxiety. All young

adults who attended Square Table events were dissatisfied with the range of opportunities available.

"There should be a through life service"

"There is hardly any support for those that have the children's services, and nothing to replace these services. I am worried that our network of support from respite and school will disappear when we need help the most"

Within the discussions about transition issues across the country, an issue which surfaced several times related to the needs of life-limited and life-threatened young people with cognitive impairment. Parents of

Theme 4

Emerging issues in Children's Palliative Care

this group of young people urged that the needs of these young people are recognised as different to those young people with a normal cognitive ability. Parents felt that much of the current discussion around transition for young people focuses on their aspirations for independent living, further education and employment. As one parent put it:

“My daughter will only ever be two years old mentally although she is now almost sixteen. She will never be able to make any decisions or have any adult quality of life and I won't be around forever to take care of her”

Several parents expressed their profound fears about the impact of their own ageing, deteriorating health and growing need for social care support on their ability to care for their children.

The care of neonates was another frequently addressed issue, especially the care of premature babies who may have complex needs. One professional said:

“As a society we are getting very good at making babies survive, but we are not really ready for this and we are unable to provide enough support for parents. We are investing huge sums in technology to keep the infant alive but we are not investing in the services they need when they have survived”

It was recognised at several Square Table events that the care of babies who survive premature births with ensuing life-limiting and life-threatening conditions is placing an increasing pressure on services in some areas. Professionals may find themselves ill-equipped to deal with these new challenges in the community.

“Some of these children are so complex they take everyone out of their comfort zone”

The care and support of permanently ventilated children was discussed at several events with many professionals asserting that such children must be enabled to spend at least part of their lives outside

of a hospital environment. The dearth of investment in community children's nursing services was widely bemoaned and this impacted significantly on the capacity of local teams to provide the level of care that is needed. Community children's nursing was seen as an essential part of the total package of care, but that without adequate resourcing it was difficult for these teams to be able to respond in a sustainable way to the growing demand. It was widely acknowledged that much new and valuable work is being done in relation to ventilated children in the children's hospice sector in particular.

Care in the home was debated by several Square Tables with a range of views expressed. Whilst many professionals described care, or hospice, in the home as a normalising experience for the child and the family and something to be aspired to for families, some parents were vehemently opposed to such arrangements.

“Professionals say that we as parents don't want residential short breaks for our children but we do. There is a huge push for care in the home and yet, if your child is in the room next to yours, you are going to be disturbed anyway. In fact it's worse, lying there wondering what is happening to your child”

However, there was a more widespread acceptance that as many children and young people as possible should be supported to die at home if that is their or their family's choice. Parents were very keen to impress on professionals at various Square Table meetings that the option for their child to die at home should only be discussed where services are available to support this.

Whilst many bereaved parents described positive experiences of being supported to enable their child to die at home, there were some parents for whom this had been a negative and traumatic experience in which they have been inadequately supported. Many professionals expressed particular concern about the impact of public sector cuts and dwindling funding in this regard.

Theme 5

Funding

Funding and the future sustainability of children's palliative care provision is a concern, particularly in the context of spending cuts and a fragile economy.

The issue of funding was not addressed directly as a thematic topic by many of the Square Tables. However, perhaps not surprisingly, funding and in particular the future sustainability of existing services amid the current public sector cuts and recessionary economic climate permeated many of the discussions on other thematic areas, right across the country. The issue of the costs of a lifetime of care for highly technology dependent children with complex health care conditions was of particular concern.

The use of direct payments and personalised budgets was raised at many Square Tables. Examples of good practice were found in several parts of the country. Sussex, for example, was seen as having been pioneers in the use of personal budgets for social care and there were several good examples cited of families for whom the system works very well. It was suggested that this could be developed as an example of good practice for implementation in other areas.

It was noted in some areas that whilst the direct payments system is already in place there are no provider agencies available from which to purchase social care services.

"It's like having a pocket full of money but all the shops are shut"

Several Square Table events explored the possibilities for bringing together parents, carers, retired professionals and others into some form of social enterprise activity in their area which might be able to provide care services in the home to respond to this need. It was suggested that bereaved parents and grand-parents might have a significant role to play in this regard after a suitable period of recovery.

Inevitably discussions at many Square Tables focused on the possibilities presented by the current Government

planned NHS reforms and in particular issues relating to the proposed introduction of GP commissioning. Some parents and professionals, including the GPs who attended some events, expressed the view that handing responsibility for commissioning services for life-limited and life-threatened children and their families to the family GP is a bold and potentially forward thinking move. Many parents cited their GP as the one constant health practitioner in their whole family life – the one person who would see all the issues affecting the family in the round. However, some parents and professionals were concerned about the budgetary capacity of GP consortia to fund such complex and expensive service provision.

Other parents were, however, completely dismissive of the concept explaining that they hardly ever saw the family GP, as all clinical services for their children were provided in a hospital setting and that they only ever liaised with the child's consultant paediatrician. Several paediatricians attending Square Table events lamented the "over-specialisation" of services to life-limited and life-threatened children in this way and commented that GPs and Practice Nurses could have a much larger role to play in, for example, taking blood tests and other routine monitoring activities.

Thank you



We are grateful to all who engaged in local Square Tables. The richness of discussion and debate summarised in this document was made possible by the experience and views brought to the tables by the range of professionals from across the statutory and voluntary sectors, and enhanced by the courageous and frank contributions of parents and young people.

Thank you to the moderators whose valuable skills enabled a plethora of views and experiences to emerge.

Thank you to Stephanie O'Sullivan for her work as co-ordinator of the programme of 37 Square Tables across England and her key role in writing this report.

Finally, thank you to the Department of Health for funding this project as part of their £30 million funding for children's palliative care programme (2010–11).

Moderators

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Professor Sir Alan Craft; Trudy Ward, South Downs NHS Trust; Jonathan Smith, CEO, Cheshire & Merseyside Child Health Development Programme; Linda Parker, Programme Director, Children and Families South West Development Centre; Robin Knowles, Chair, Children's Hospices UK; Janice Fidler, Chair, Lancashire & Cumbria Palliative Care Network; Clair Blake, Network Lead, Hastings and Rother PCT; Andy Cole, CEO, BLISS; Andy Smith, CEO, Havens

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