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APPG for Children inquiry into children's social care

Call for written evidence

The All Party Parliamentary Group for Children (APPGC) has launched a new inquiry to address local arrangements for the delivery of children's social care services in light of changes in resources and demand, a new inspection framework and diversity in performance and outcomes. While the focus of the inquiry will be on services in England, the inquiry will seek to draw upon evidence of challenges and effective responses across the devolved nations in order to share examples of practice across the UK.

To inform the inquiry, the APPGC is calling on stakeholders across the children's sector to submit written evidence on the current state of arrangements for the provision of children's social care, including services for safeguarding children and for helping looked after children and children in need. The Group would also welcome hearing about the delivery of early intervention services which enable children to remain with their family.

Evidence indicates that, over the past five years in England, overall demand for children's social care services has increased, while English local authorities' spending power has decreased. The nature of children's need has also change, with greater concerns, for example, about radicalisation and child sexual exploitation. In addition, children's social care services are implementing a range of reforms following recent changes to the legislative framework, such as those relating to special education needs and disability and adoption. These are taking place at the same time as the implementation of reforms to social work practice led by the Chief Social Worker for children and families.

In light of these ongoing and emerging challenges facing children's social care services, the APPGC has decided to conduct an inquiry to:

- bring together evidence about the current resourcing of children's social care services and changes in the nature and level of demand
- explore the impact (or potential impact) of these changes on the delivery of children's social care services and on children and young people
- build a picture of the key elements of a successful children's services department and the challenge facing areas that are struggling to improve, and share examples of good practice

- assess whether changes are needed to policy and legislation in order to improve the delivery of children's social care services and in turn outcomes for children
- identify any learning that can be shared from Northern Ireland, Scotland and Wales.

Local authority leaders and service providers from across the United Kingdom will be invited to present examples of good practice in the delivery of children's social care services, and to outline the barriers to improvement they are facing. The inquiry will also hear directly from children and young people about their experiences of children's social care services.

Oral evidence sessions will be held in Parliament between April and July 2016, and findings from the inquiry will be published by early 2017.

Deadline for submissions is Monday 7th March 2016 – please see call for evidence form below.

APPG for Children inquiry into children's social care: call for evidence form

The All Party Parliamentary Group for Children would welcome written evidence from a range of stakeholders including:

- Directors of Children's Services
- Children's social services managers and practitioners
- Chairs of Local Safeguarding Children's Boards
- Children's services providers – including the private and voluntary sector
- Children in Care Councils
- Organisations representing the voices and interests of children and young people

Written submissions will inform the setting of oral evidence sessions, which will be held between April and July 2016. The questions below cover a range of issues relating to the delivery of children's social services. Please feel free to answer only those which relate to your area of expertise.

Contact details

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Please indicate if you would be prepared to give oral evidence: **Yes**

1. Changing demand and funding for children's social care services

How has demand and funding for children's social care services in England changed? What changes are expected in the future?

In December 2010 the government committed £800m in funding for short breaks to make sure local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011 over the course of the parliament. However, the Every Disabled Matters (EDCM) partnership found that 58% of local authorities who responded to their freedom of information requests had cut their short breaks spending during this period, by an average of 15% (**Every Disabled Child Matters (2015). Short Breaks in 2015: An uncertain future. Available to download from: <http://bit.ly/1OTPWyt>**). This has a direct impact on families - the same survey found that only 9% of respondents to the survey of parent carers agreed or strongly agreed that families with disabled children can access the short breaks they need.

Together for Short Lives is the leading UK charity for all children with life-shortening conditions and all those who support, love and care for them. Life-shortening conditions are those for which there is no reasonable hope of cure and from which children are expected to die, or for which curative treatment may be feasible but can fail. Children with life-shortening conditions need continuing palliative care throughout the trajectory of their illness.

Children and young people with life-shortening conditions need palliative care from the point at which their condition is diagnosed or recognised - often at birth - until the end of their lives. Families also need care and support throughout the trajectory of their child's illness, including after they have died. A comprehensive local children's palliative care service spans health, social care and education. It is a whole-family approach.

The number of children and young people with life-shortening conditions is increasing. For example, a 2015 report showed a 50% increase over a ten-year period in the number of children and young people with life-shortening conditions in Scotland; their numbers have risen from 4,334 in 2004 to 6,661 in 2014 (Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: <http://bit.ly/1Krn2EU>. This is a dramatic rise; if it has been replicated across the UK as a whole, the number of children and young people with life-shortening conditions could be much more than the current estimate of 49,000.

Worryingly, the number has never been monitored. As a result, the UK Government, the NHS and local councils are failing to budget enough money to meet the needs of children and young people with life-shortening conditions.

Children with life-shortening conditions - and their families - rely on frequent short breaks to enable them to spend time as a family, doing the things that other families do. Short breaks have three main functions:

1. To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.
2. To support the family in the care of their child by providing a break (respite) from caring and to provide opportunities for siblings to have fun and receive support in their own right.
3. Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Short breaks are essential to relieve some of the pressures on families of children with life-shortening conditions. Free from being responsible for providing round the clock care for a few hours or days, short breaks give parents a chance to recharge their batteries, make memories with their seriously ill child or spend more time with their siblings. For children and young people with life-shortening conditions, short breaks give them an important opportunity to be with their peers and be more independent.

However, not all families of children and young people with life-shortening conditions can access short breaks because commissioners do not always commission services which meet their complex care needs. CCGs and local authorities should jointly commission short breaks for this group of children, young people and families.

Short breaks away from home for children and young people with life-limiting conditions are provided by a range of organisations, including children's hospices. Short breaks for children and young people with life-limiting conditions should include clinical care to meet their often complex health needs. Therefore, clinical commissioning groups have a specific role in jointly commissioning these services with local authorities.

Anecdotally, local authorities tell us that there is less capacity in the statutory sector to meet the growing demand for short breaks. This is corroborated by voluntary sector children's palliative care providers: one, for example, has told us that due to significant cuts across all the local authority areas in which they work, it is experiencing an increase in requests for social care support for children with life-shortening conditions. One of its local authorities is planning to shut a funded respite centre for children with complex needs; the council is hoping to re-allocate children to respite foster homes and to the children's palliative care provider.

One local authority has told us that, overall demand for short breaks has changed and that it has experienced a decline in the number of families requesting overnight short breaks. The council says that while more parents of children with challenging behaviour are requesting overnight short breaks, there are fewer settings that can meet their needs. As a result, the council is using residential places offered at schools.

2. The impact of changes on the delivery of children's social care services

What has been, or could be, the impact of any changes to funding and demand on the delivery of children's social care services?

Together for Short Lives is disappointed that the government's new 2% Council Tax precept that local authorities can levy is limited to funding adult social care. The needs of children with life-shortening conditions are ignored in this formulation as the extra funding will not be extended to children's services. With local authorities struggling to cope with rising demand, we believe that social care services that families rely on to keep going, including short breaks, will become much more scarce.

A Together for Short Lives survey in 2015 (**Together for Short Lives and Hospice UK [2015]. Commissioning and statutory funding arrangements for hospices in England: Survey results 2015. Available to download from: <http://bit.ly/1NbijwD>**) found that over half (58%) of children's hospices found it either difficult or very difficult to apply for short breaks services. This will become even more difficult amid the cuts that local authorities face. We would like the government to set out how funding will be directed to local areas to support them to provide the range of services required to deliver high-quality children's palliative care.

3. The impact of changes on outcomes for children and young people

What has been, or could be, the impact of any changes to funding, demand and service delivery on children and young people?

Where families are caring for a child with a life-shortening condition and providing round the clock care, relationships often suffer, with 36% experiencing a breakdown of the family **(Steele R. [2000] Trajectory of certain death at an unknown time: children with neurodegenerative LTC illnesses. Cancer Journal of Nursing Research 32, 49-67).**

As demand for short breaks increases, it is vital that funding for them is not cut. If this is the case, then more families of children with life-shortening conditions could experience breakdown. This will increase instances of poor mental health among families and demand for acute services. It could also increase demand for benefits. We strongly believe that it is more cost-effective for government and local authorities to make sure that social care for children with life-shortening conditions - including short breaks - is funded fairly and sustainably.

4. The role of the local authority children's social care services

What are local authorities doing to respond to changes in demand and funding? What barriers do they face to meeting these challenges? What distinguishes the best performing children's social care services from those that are not performing so well?

Local authority commissioning of children's palliative care is patchy and inconsistent. For example, a Together for Short Lives survey in 2015 (**Together for Short Lives and Hospice UK [2015]. Commissioning and statutory funding arrangements for hospices in England: Survey results 2015. Available to download from: <http://bit.ly/1NbjwD>**) found that 35% of children's hospices received no funding at all from their local authorities in 2014/15. 26% received over £100,001.

Mean funding from local authorities per children's hospice was £111,000 in 2014/15. This represents only 3% of the average annual cost of care provided by children's hospices. This has been a trend over the last six years, with local authority support remaining broadly static and representing a small part of services' commissioned income.

Cuts in local authority funding do appear to be having a negative impact on the way in which social care for children with life-shortening conditions is provided. For example, one local authority has told us that as part of an austerity review in 2012, it reviewed cases of children and families receiving short breaks and reduced what it was offering. The council says that it has experienced some cases where families have been close to breakdown and not asked for help. It states that the families did this purely because they did not think that they would be offered help.

The local authority has also said to us that:

- it occasionally finds it difficult to find providers who can offer flexible short breaks support.
- it struggles to keep carers to a minimum for children with complex health needs - and to keep the carers to be consistent.

Anecdotally, we hear that local authorities are increasingly exploring ways of offering short breaks in families' homes. One voluntary sector children's palliative care provider has told us that its local councils have issued tenders which it has considered bidding for, but has felt that the funding available has not been sufficient to deliver the service safely - and in a way which could make sure that children with complex needs have access to staff with the right mix of skills.

5. The policy and legislative framework

Is the current and developing policy and legislative framework sufficient to enable children's social care services to meet children's needs in the current context? How could it be improved?

The importance of social care for children with life-shortening conditions is referred to in a number of England-wide frameworks and strategies:

- 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' (<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>) states that health and social care are equal partners in providing end of life care.
- The special educational needs and disability (SEND) code of practice (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf) recommends that joint strategic needs assessments should include children who need palliative care; it also recommends that children's palliative care should be included in local offers.
- The National Framework for Children and Young People's Continuing Care (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/499611/children_s_continuing_care_Fe_16.pdf) states that unless there is a good reason for this not to happen, continuing care should be part of a wider package of care, agreed and delivered by collaboration between health, education and social care.

Together for Short Lives would like the UK Government to make sure that the number and needs of children and young people with life-shortening conditions is more accurately monitored. This will mean that we can:

- all understand the true demand for children's palliative care
- identify the gaps in care for children with life-shortening conditions
- make sure that care is planned and funded more effectively to meet the needs of children with life-shortening conditions.

We would like the government to repeat the £800m funding for short breaks it allocated to local authorities in 2010 - and to provide guidance to local authorities on how this funding should be used. We would like the UK Government to set out long-term plans to fund children's palliative care services fairly and sustainably and in a way that reflects the growing demand for these services - and makes sure that statutory funding sources across health and social care correlate and complement each other.

We would like the UK Government to enable and hold local authorities to account to increase funding for short breaks for disabled children - providing vital respite and support that in the long term saves the state money by reducing the number of hospital visits as well the incidence of family breakdown.

6. Learning from the devolved nations

Are national and local authorities in Northern Ireland, Scotland and Wales facing similar challenges? How are they responding to these challenges? What learning and examples of effective responses could be shared across the UK?

Scotland and Wales are attempting to respond to the challenge of making sure that children with life-shortening conditions can access the social care they need.

In 2015, the Scottish Government published 'Strategic Framework for Action on Palliative and End of Life Care, 2016-2021' (<http://www.gov.scot/Resource/0049/00491388.pdf>). The Scottish Government has defined the following outcomes for palliative and end of life care for both children and adults:

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

As part of its work to implement the strategy, the Scottish Government has committed to supporting and promoting the further development of holistic palliative care for the 0-25 years age group.

In 2016, the Scottish Public Health Network (ScotPHN) published a report entitled 'Palliative and end of life care in Scotland: The rationale for a public health approach' (http://www.scotphn.net/wp-content/uploads/2016/03/2016_02_26-PELC-FINAL.pdf). This recommends that:

- The Scottish Government should ensure that palliative and end of life care is visible in relevant health and social care strategies and policies.
- All generalist and specialist health and social care professionals should be supported and empowered to provide high quality palliative and end of life care.
- A strategic approach should be taken to develop a sustainable and innovative programme of palliative and end of life care research that directly informs clinical practice, health and social care policy - and reduces in inequalities in access to and quality of palliative and end of life care.

In 2014, the Welsh Government published 'Together for Health - Delivering End of Life Care: A Delivery Plan up to 2016 for NHS Wales and its Partners' (<http://gov.wales/docs/dhss/publications/130416careen.pdf>). In the strategy, the Welsh Government states that end of life is not an issue confined to health services and that social services in particular have a vital role to play. It also states that support must be given to those who work in local communities, in particular in social care, to have the skills to support individuals and their families at the end of life.

7. Sharing good practice

Finally, we welcome examples of good practice from across the United Kingdom, and in particular examples relating to one of more of the following themes:

- improving local arrangements in the delivery of children's social care services including:
 - services for children in care and adopted children
 - safeguarding and child protection services
 - services for disabled children and children with special educational needs
 - early intervention services including for example family support, housing, and public and mental health services
- collaboration across cities/areas/regions in the delivery of children's social care services
- the use of evidence (e.g. on local need/demand) and best practice in informing the commissioning, configuration and delivery of children's social care services
- securing effective leadership

Together for Short Lives has published online a range of family stories which emphasise the importance of short breaks for children with life-shortening conditions:

http://www.togetherforshortlives.org.uk/families/family_stories

Children's palliative care providers offer a range of social care services to children and families. For example, one voluntary sector provider of children's palliative care has provided three examples of social care it has provided to children with life-shortening conditions:

1. Following a request from a local authority, it provided a place of safety for a child whose parents arrived at the school drunk and abusive; there was no local authority-provided accommodation for the child to go due to the complexity of their needs.
2. It reported concerns to a local authority about a vulnerable parent who was emotionally distressed, stating they were unable to cope therefore putting themselves and their child at risk. In addition to reporting to the statutory authorities, the service immediately increased support to the family through hospice at home care and outreach support.
3. It reported concerns in relation to a child who had not arrived for a short break; the school had also expressed concerns that the child had not attended school for a number of days; the school and the provider were unable to contact the family, which had been the subject of safeguarding concerns. Following agreement with the social worker it was agreed that the service would undertake an unannounced visit to the family home. During this visit, staff were able to see the child and alert the other agencies that parents would be re-engaging with services.

Together for Short Lives provides a resource entitled 'Jointly commissioning palliative care for children and young people' (www.togetherforshortlives.org.uk/jointcommissioning). Our resource designed to support clinical commissioning groups (CCGs) and local authorities in England to effectively commission palliative care for children and young people aged 0–25. Produced as part of our Department for Education-funded special educational needs and disability (SEND) project, our resource also supports health and wellbeing boards to understand their role in the commissioning process.

The guide is consistent with the new SEND system and the joint commissioning duty in the Children and Families Act 2014. It sets out the duties on each body and what they should do to jointly commission children's palliative care services. It also provides a step-by-step, which follows the established joint commissioning cycle, including advice for CCGs, local authorities and health and wellbeing boards on what they must and should do.

Together for Short Lives is actively seeking examples of local areas which are jointly commissioning children's palliative care to publish and share with CCGs, local authorities and the children's palliative care sector. One such example is Luton CCG and Luton Borough Council, which have given us permission to publish their joint children's palliative care strategy. While the CCG and council do not pool their funds in Luton, they jointly agree budgets and desired outcomes - and align their plans.

The model relies on the community children's palliative care nurse acting as a key worker. Local statutory and voluntary sector services work together to provide the services. The arrangement is overseen by the local children's trust board and the health and wellbeing board.

Completed forms should be returned to hransom@ncb.org.uk by Monday 7th March.
Submissions received after this date will still be considered, but may not inform oral evidence sessions.