Select Committee on the Long-Term Sustainability of the NHS
Written evidence from Together for Short Lives

September 2016

Summary

1. Government, the NHS and local government should become more aware of the way in which long-term conditions are changing and becoming more prevalent. Only in doing so can sufficient financial resources can be budgeted for our health and care system. For example, as a result of advances in medical technology, the number of children and young people with life-shortening conditions is increasing. Worryingly, this number is not being monitored. We 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.

2. Providers of health and care, particularly in the voluntary sector, can bring social value to their communities when funded by the state. This is in addition to the positive health and wellbeing outcomes they can achieve.

3. There are a range of commissioning funding models now available to commissioners of health and care in England to use. There are also a number of ways in which integrated budgets can be achieved. In England, the NHS and local authorities have a duty to jointly commission services for disabled children and young people aged 0-25. Personal budgets and initiatives such as Integrated Personal Commissioning also offer opportunities to join up budgets for children and young people with long-term conditions.

4. The extent to which these are being applied to commissioning palliative care for children and young people with life-shortening conditions varies widely across local areas. Government and NHS England have an important role in guiding health and care commissioners on how to apply these different models; making sure NHS and local government commissioners are aware of their responsibilities; gathering and sharing best practice; and holding commissioners to account for the outcomes they achieve.

5. We believe that sustainability and transformation plans (STPs) have potential to integrate planning and funding across health and care; we also believe that they can help to create economies of scale in commissioning services for small populations (such as children and young people with life-shortening conditions) which might not otherwise be prioritised by individual CCG and local authorities.

6. We do not have enough health and care professionals with the skills and experience needed to meet the increasingly complex needs of people with long-term conditions. This is certainly the case for children and young people with life-shortening conditions. A shortage of nurses is a particular issue and we call on the government to reverse the decision to remove student bursaries.

7. We believe that public health policy should include approaches to engage communities in playing a greater role in providing palliative care to children and young people.

About Together for Short Lives

8. Together for Short Lives is a UK wide charity that, together with our members, speaks out for the 49,000 children and young people in the UK who are expected to have short lives. Together with everyone who provides care and support to these children and

families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can’t change the diagnosis, but we can help children and families make the most of their time together.

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Our written submission

The future healthcare system

1. Taking into account medical innovation, demographic changes, and changes in the frequency of long-term conditions, how must the health and care systems change to cope by 2030?

9. As a result of advances in medical technology, 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[1]. 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.

10. Worryingly, this number is not being 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. The complex care they need from multiple agencies and professionals is not joined up enough and families are having to fight to get the services they need.

11. ***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.***

12. In addition, we believe that health and care system must make the most effective use of the limited resources available to it. This means planners and funders of health and social care working much more closely together to jointly commission care and support for people with long-term conditions.

Resource issues, including funding, productivity, demand management and resource use

2. To what extent is the current funding envelope for the NHS realistic?

a. Does the wider societal value of the healthcare system exceed its monetary cost?

13. Together for Short Lives believes that it does. Voluntary sector (VCS) healthcare providers, including children's hospices, bring social value to communities. VCS children's palliative care provider organisations can encourage volunteers to help to provide care and support to seriously ill children and young people. These organisations are part-funded from statutory sources, including from NHS England and clinical commissioning groups (CCGs).

14. Together for Short Lives' Family Support Volunteer Project, which is funded by two charitable trusts, co-ordinated by us and provided by organisations working in London,

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[1] Fraser et al. (2015). Children in Scotland requiring Palliative Care: identifying needs and numbers. Available to download from: http://bit.ly/1Krn2EU

Bristol and Warwickshire, is recruiting and training volunteers to work with families in their homes and communities. Through this project, volunteers assist families caring for a life-shortening condition with practical support in their homes. This provides crucial support for families and helps to develop community cohesion.

15. The children's palliative care sector relies heavily on volunteers to provide care and support for children with life-shortening conditions. In 2014 it was conservatively estimated that there are 100,000 volunteers involved in hospice care (both children's and adult), which has an approximate economic value of £112m.[2] Hospices and children's palliative care depends heavily on volunteers for service delivery, governance, income generation, and engagement with local communities.

16. Research shows that volunteers bring benefits to children with life-shortening conditions, their families and also to staff. Naylor et al. suggest that volunteers enhance the role of paid staff and also significantly enhance the care experience for the child.[3]

17. Gurguis-Younger, Kelley, and McKee suggest that professionals have increasingly moved to a more medical model of care, and that volunteers have an ever-more important role to play in bridging the gap by bringing a unique dimension of human compassion as they accompany patients on their journey to end of life.[4]

18. We believe that work to engage volunteers and wider communities is vital in helping remove the stigma and fear of talking about life-shortening conditions in children and young people. This is also crucial to make sure that professionals and organisations do not overlook the need of this small population which has highly complex needs.

b. What funding model(s) would best ensure financial stability and sustainability without compromising the quality of care? What financial system would help determine where money might be best spent?

19. Together for Short Lives believes that the funding models set out in the NHS Five Year Forward View, in addition to those already available to NHS commissioners, can be used by commissioners to fund children's palliative care. These include:

    - grants (which can still be used in funding voluntary sector providers[5])
    - year of care models
    - capitated budgets
    - personal budgets
    - per-patient models (including currencies and tariffs)
    - spot purchases.

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[2] http://www.togetherforshortlives.org.uk/assets/0000/7989/TfSL_Volunteering_-_Vital_to_our_Future__FINAL_.pdf

[3] Naylor, C., Mundle, C., Weaks, L., & Buck, D. (2013). Volunteering in Health and Care: Securing a Sustainable Future. London: The Kings Fund.

[4] Guirguis-Younger, M., Kelley, M., & McKee, M. (2005). Professionalization of hospice volunteer practices: what are the implications? Palliative and Supportive Care 3(2), 143-144.

[5] NHS England. 2015. A bite sized guide to grants for the voluntary sector. Available to download at: http://bit.ly/1LY0hdk

20. Together for Short Lives calls on the Department of Health, Department for Education and NHS England to work with us and the Local Government Association (LGA) and the Association for Directors of Children's Services (ADCS) to develop a guide for NHS and local government commissioners. This should set out how they can apply these different models in funding children's palliative care services in local areas.

c. What is the scope for changes to current funding streams such as a hypothecated health tax, sin taxes, inheritance and property taxes, new voluntary local taxes, and expansion on co-payments (with agreed exceptions)?

N/A

d. Should the scope of what is free at the point of use be more tightly drawn? For instance, could certain procedures be removed from the NHS or made available on a means-tested basis, or could continuing care be made means-tested with a Dilnot-style cap?

21. We believe that the scope of what is funded by the state is already drawn too tightly for children and young people with life-shortening conditions: evidence gathered by Together for Short Lives[6] shows, for example, that only 21% of the charitable costs incurred by children's hospices in England are reimbursed by the state (when taking NHS England's, CCGs' and local authorities' contributions into account). This is far less than adult hospices, which receive an average of a third of their funding from statutory sources.

22. Statutory funding for voluntary sector children's care palliative care providers is neither fair nor sustainable and varies according to local area. 39% of clinical commissioning group (CCG) funding across England supports just two hospices, while one hospice receives no funding at all from their CCG.

23. Anecdotally, local authorities tell us that there is less capacity in the statutory sector to meet the growing demand for short breaks (respite care).[7] 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.

24. Similarly, a children's hospice told us that cuts to NHS and local authority services mean that they are no longer able to guarantee delivery of their own services, such as supporting patients and the end of life phases to be discharged home if that is their preference.

25. Seven CCGs (4%) and two local authorities (2%) have told us that they do not commission children's hospices because they are charities[8]. This is despite the Department of Health, NHS England and Public Health England recognising the voluntary, community and social enterprise (VCSE) sector is an important partner for

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[6] 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/1Rqayzr

[7] A definition of short breaks is available here: https://www.bristol.gov.uk/social-care-health/short-breaks-for-disabled-children

[8] Together for Short Lives. 2016. Commissioning map of children's palliative care. Available to download from: www.togetherforshortlives.org.uk/datamap

statutory health and social care agencies in playing a key role in improving health, well-being and care outcomes[9].

Workforce

3. What are the requirements of the future workforce going to be, and how can the supply of key groups of healthcare workers such as doctors, nurses, and other healthcare professionals and staff, be optimised for the long term needs of the NHS?

a. What are the options for increasing supply, for instance through changing entry systems, overseas recruitment, internal development and progression?

26. We are concerned that the removal of student bursaries for nurses, midwives and allied health professionals could have an adverse effect on the number of students choosing to study these courses. Although under the current UK government proposals students would still have access to funding through student loans, we share the concern of the Royal College of Nursing that potential students may be put off by the prospect of accruing more long-term debt. We call on the government to reverse the decision to remove student bursaries.

b. What effect will the UK leaving the European Union have on the continued supply of healthcare workers from overseas?

27. EU workers make up 55,000 of the NHS's 1.3 million workforce and 80,000 of the 1.3 million workers in the adult social care sector. Many organisations are concerned about the impact of the UK withdrawal on workforce and several organisations, including the Royal College of Nursing, have issued statements in support of migrant from the EU working within the NHS:

    a. Nursing: EU immigrants make up 4% of registered nurses. The editor of Nursing Times has written that she fears many nurses from overseas may leave due to insecurity over their future/visas and their career longevity. However, it is highly unlikely that future government policy would be designed to prevent overseas nurses from working within the UK – they are already listed on the 'shortage occupation list', allowing employers to recruit from outside the EU.

    b. Social care: EU immigrants make up an estimated 6% of social care workers in England. These jobs are often low-paid and there is a fear that it will be impossible to fill these posts following the UK withdrawal from the EU. Care England has pledged to lobby the government on this issue.

    c. Doctors - 10% of doctors in the UK qualified in another EU country and over 25% of those registering each year are now from the EU. The president of the Royal College of Physicians has warned that these doctors are feeling 'anxious and confused' about their present and future situation.

c. What are the retention issues for key groups of healthcare workers and how should these be addressed?

28. There is very real and **growing pressure to have a sustainable children's palliative care nursing workforce** which must be addressed as a matter of urgency. Whether or not children are able to exercise choice over **how and where their care is provided** largely depends on whether they have access to skilled and competent professionals.

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[9] VCSE Review. 2016. http://bit.ly/1XBY5jx

29. Together for Short Lives' survey of voluntary sector children's palliative care organisations (http://bit.ly/1Ltfjqr) shows that they employ approximately 1,500 nurses in the UK. The average vacancy rate for these organisations is 10%, which is higher than the 2015 NHS nurse vacancy rate (7%). This has resulted in two thirds of services reducing their offer of care to families - closing beds, reducing respite care, or having an effect on continuity of care. This survey also shows that over a quarter of nurses for voluntary sector children's palliative care organisations are over the age of 50 and many of these will be eligible to retire at 55.

30. Nearly 60% of vacancies reported by voluntary sector children's palliative care organisations were defined as hard to fill (vacant for over three months).

31. The voluntary and community children's palliative care sector has a further recruitment challenge caused by the difference in terms and conditions between NHS and voluntary sector providers – the most commonly suggested reason for nursing vacancies was terms and conditions, including salary, shift systems and annual leave. Our research shows that the voluntary children's palliative care sector provided placements for over 600 nursing students during 2014-15. Most of the students were in the second or third year of their training – but one third of organisations said they supported first year students too. The proposed increase in nurse training places offers an opportunity to further develop the links between universities that provide nurse training and voluntary organisations that deliver children's palliative care. However, currently 40% of voluntary sector children's palliative care providers receive no funding for providing these placements, while others receive approximately £80 per week. These organisations provide valuable experience to trainee nurses.

32. All universities have different systems for organising these placements and provide varying levels of funding. This is makes it very difficult to predict the number of nurses who will be available to work within the children's palliative care in the coming years.

4. How can the UK ensure its health and social care workforce is sufficiently and appropriately trained?

a. What changes, such as the use of new technologies, can be made to increase the agility of the health and social care workforce?

b. What are the cost implications of moving towards a workforce that is equipped with a more adaptable skill mix being deployed in the right place at the right time to better meet the needs of patients?

c. What investment model would most speedily enhance and stabilise the workforce?

Our answer to a, b and c:

33. We want the government and Health Education England to work together to plan the workforce needed to meet the rising numbers of children and young people with life-shortening conditions. This should involve better understanding the numbers and needs of this population and commissioning sufficient number of education and training places for prospective children's palliative care professionals.

34. We want of university undergraduate nurse programmes to adopt Together for Short Lives' recognised best practice curricula for children's palliative care nurse training.

35. We want the Council of Deans to encourage university undergraduate nurse programmes to adopt Together for Short Lives' recognised best practice curricula for children's palliative care nurse training.

36. We want the UK government to reimburse voluntary sector children's palliative care providers for offering placements to people training to be nurses. This would help make sure that providers can maximise the number and quality of placements on offer.

Models of service delivery and integration

5. What are the practical changes required to provide the population with an integrated National Health and Care Service?

a. How could truly integrated budgets for the NHS and social care work and what changes would be required at national and local levels to make this work smoothly?

How integrated budgets can work

37. Children and young people with life-shortening conditions require holistic support from a range of providers spanning health, social care, education, leisure and housing services. CCGs should commission in partnership with local authorities using agreements under section 75 of the National Health Services Act 2006[10] to ensure an integrated service for children and young people with life-limiting conditions. The SEND Code of Practice[9] describes how, under section 75 of the National Health Service Act 2006, local authorities and CCGs can pool resources and delegate certain NHS and local authority health-related functions to the other partner(s) if it would lead to an improvement in the way those functions are exercised.

38. CCGs and local authorities also need to be aware of their duties under the Children and Families Act 2014[11]. These **require** them to commission services for all disabled children and young people aged 0 to 25 jointly with local authorities. They **must** also co-operate with local authorities in ensuring that single assessments and education, health and care (EHC) plans are put in place. EHC plans are for children who have learning difficulties and disabilities which result in special educational needs. EHC plans should focus on the outcomes which young people wish to achieve. This will include some children and young people with life-limiting conditions.

39. The SEND code of practice[9] explicitly states that joint commissioning must include services for 0-25 year old children and young people with SEN or disabilities, both with and without EHC plans. Children and young people with cancer or leukaemia may not have an SEN or EHC plan - but should still be able access jointly commissioned children's palliative care. The code also states that local authorities, NHS England and their partner CCGs must make arrangements for agreeing the education, health and social care reasonably required by local children and young people with SEN or disabilities.

40. The NHS and local authorities in England already have a duty to jointly commission services for disabled children and young people aged 0-25 as a result of the Children and Families Act 2014. Preparing for Adulthood Joint Commissioning in Action describes joint commissioning as "a method for two or more partner agencies to commission

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[10] Great Britain. National Health Services Act 2006: Elizabeth II. Part 3 (2006). Available to download from: bit.ly/11IcfQo.
[11] Great Britain. Children and Families Act 2014: Elizabeth II. Part 3 (2014). Available to download from: http://bit.ly/1rmlG7b

collaboratively to secure better outcomes for a defined population than either can achieve on their own".[12] **We believe that the government and NHS England should hold clinical commissioning groups and local authorities to account to make sure that they implement the joint commissioning duty.**

41. Together for Short Lives provides a guide to help CCGs, local authorities and local health and wellbeing boards to jointly commission palliative care for children and young people aged 0-25[13]. In the guide, we set out the steps that we think commissioners should take to follow the established joint commissioning cycle:

    - establish the right local partnerships
    - understand how many children and young people they need to commission services for - and plan for what they need
    - create economies of scale
    - plan a local journey for children and young people with life-limiting conditions
    - ensure that services are provided jointly
    - fund children's palliative care services in the context of the development palliative care funding currency
    - review services.

42. In commissioning jointly, we believe that health and care planners and funders have an opportunity to improve outcomes for people with long-term conditions in addition to making sure that limited resources are used more effectively. Families of children with life-shortening conditions tell us that they have to manage multiple appointments and relationships with a wide range of professionals. They often have to repeat their story several times and undertake a number of different assessments. More integrated plans, assessments and services will give time back to people with long-term conditions and their families; in the case of children and young people with life-shortening conditions, for whom time is limited, this is especially important.

43. We recognise that there are a range of approaches which the NHS and local authorities can take to integrate budgets. Specifically for children and young people with life-shortening conditions, these include:

    - personal budgets
    - capitated budgets
    - year of care models
    - grants made jointly by the NHS and local authorities to fund specific services.

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[12] Preparing for Adulthood (2015). Joint Commissioning in action. Available to download from: http://bit.ly/1du8oSU

[13] Together for Short Lives (2015). Jointly commissioning palliative care for children and young people aged 0 – 25 - including short breaks. Available to download at: www.togetherforshortlives.org.uk/jointcommissioning

44. CCGs should take account of the relatively high proportion of young people with life-limiting conditions who are eligible for NHS children's continuing care and subsequently continuing healthcare - and have a right to a personal health budget. The Care Act 2014 statutory guide and the Children and Young People's Continuing Care National Framework[14] both set out how CCGs and local authorities should work together to ensure a smooth transition for young people from children's continuing care to continuing healthcare.

45. Local areas **must** also offer personal budgets to children and young person aged 0 – 25 who have an EHC plan. Section 3.36 of the SEND Code of Practice[15] states that local authorities and CCGs have a statutory duty to consider the extent to which children and young people's needs could be met more effectively by integrating services and aligning or pooling budgets in order to offer greater value for money - and improve outcomes and/or better integrating services for children and young people with SEN or disabilities.

The extent to which budgets are currently integrated for children and young people with life-shortening conditions

46. As medical interventions improve, the number of children and young people with life-shortening conditions is growing. Unfortunately, as need and demand for support is increasing, CCG awareness and understanding of this population remains low[16]. We have found that only 19% of local authorities say they commission children's palliative care. This means that a staggering 4 out of 5 local authorities are failing to plan and fund care for seriously ill children and young people. We welcome the fact that a majority (93%) of CCGs say they commission children's palliative care. However, it is shocking that seriously ill children and young people are being forgotten or ignored by nearly one in 10 CCGs.

47. This is partly explained by the small geographic areas that CCGs cover, meaning that there may only be a small number of children for which services are required. The relatively small number of children also means that they do not register as a priority for many CCGs who are simply unaware of their needs and the complexity of their conditions.

48. We therefore think that the new sustainability and transformation plan (STPs) approach could help bring local health and care systems together over a wider geographic area. We would like the new footprint areas to commission children's palliative care over areas which create the economies of scale needed - and as recommended by the 2011 Independent Palliative Care Funding Review[17], commissioned by the coalition government. We are keen to ensure we do not lose the opportunity for the new STPs to include the highly effective palliative care offered by a range of providers including children's hospices, NHS community children's nursing teams and others.

49. There is a responsibility and accountability vacuum for commissioning children's palliative care; some CCGs and local authorities do not understand what they should be

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[14] Department for Health. 2016. Children and young people's continuing care national framework. Available to download from: http://bit.ly/2doRfyy

[15] Department for Education (2014). Special educational needs and disability code of practice: 0 to 25 years. Available to download from: http://bit.ly/1kOCi5i

[16] Together for Short Lives. 2016. Commissioning map of children's palliative care. Available to download from: www.togetherforshortlives.org.uk/datamap

[17] Craft A and Killen S (2007). Palliative care services for children and young people in England: an independent review for the Secretary of State for Health. Available to download from: bit.ly/YHZjsA.

commissioning: Six CCGs (4%) wrongly told us that NHS England are responsible for directly commissioning children's palliative care. While NHS England should directly commission specialised children's palliative care, including managing complex symptoms and prescribing unlicensed medicines, CCGs and local authorities are responsible for commissioning general children's palliative care. 32% of local authorities said we should ask the local CCG instead when we asked them if they commission children's palliative care, despite the vital role that local authorities should play commissioning short breaks and some equipment and emotional and psychological support services.

The extent to which care and support is being jointly commissioned for children and young people with life-shortening conditions

50. In December 2015 and January 2016, we held two masterclasses which aimed to help health and social care commissioners and providers to learn about jointly commissioning palliative care services for children aged 0-25, including short breaks. The event brought commissioners together to discuss and learn about successful joint commissioning and hear about cases in which joint commissioning has improved outcomes for children and young people.

51. Overall, while our delegates reported that joint commissioning of short breaks is being inconsistently implemented across England, there appears to some common traits of successful models which commissioners should seek to adopt as they fulfil their new duties under the Children and Families Act 2014.

52. Over the course of both masterclasses, we found that commissioners and providers are often **unable to determine the local demand for children's palliative care**. This is because of a lack of understanding in what this term means and difficulties in identifying children with life-shortening conditions. The lack of a register of children who need palliative care and barriers to sharing data about children also hinder work to identify those who are seriously ill. Those local areas which feel that they are successfully determining demand attribute this to common systems to store and share data - and their efforts to include the range of providers accessed by seriously ill children in multi-agency review meetings. The Education, Health and Care (EHC) planning process is reported as being helpful in some examples. Short breaks for children with life-shortening conditions are being offered by a range of statutory and voluntary sector providers across England.

53. Both good and bad practice was reported by delegates in applying the different stages of the joint commissioning cycle. Delegates told us that successful partnerships are created **when agencies communicate well with other** - and are clear about who funds and provides different services. Although good joint commissioning models and successful partnerships do not appear to depend on pooled budgets, some regarded a **lack of pooling as a barrier**. Other barriers included agencies not being willing to co-operate and/or having conflicting commissioning priorities.

54. Delegates shared a range of views and experiences of jointly planning children's palliative care. They reported that this is done well when it is timely and leads to agreed shared strategies, outcomes and budgets. **Joint groups to plan and review strategies and operations** seem to be a common trait of a well-planned local children's palliative care service. Making sure that plans are informed by the needs and wishes of children, young people and their families is crucial.

55. Planning challenges were identified where commissioning organisations do not have a lead responsible for commissioning children's palliative care. **A lack of data about the**

cost-effectiveness of commissioning children's palliative care and poor links between commissioners and voluntary sector children's palliative care providers were cited as barriers.

56. Other positive aspects of a joint approach include **robust training and mentoring** - and reciprocal training arrangements between different providers. Locally agreed and adopted pathways of care are also seen as helpful. Overall, delegates were enthused by the examples of good practice which they learnt about during the sessions and expressed a willingness to try to apply these in their own local areas.

57. While different successful joint commissioning models are being used in some local areas, we believe that all have the same common traits of:

    - good communications between commissioners, professionals and provider organisations
    - agreed joint commissioning strategies and funding arrangements (whether budgets are pooled or not)
    - making sure that the needs and wishes of children and families inform the joint commissioning approach.

The extent to which personal budgets are being used to integrate care for children and young people with life-shortening conditions

58. As part of our Department for Education-funded project to engage children's palliative care in the special educational needs and disability (SEND) reforms in England, Together for Short Lives hosted a personal budgets workshop in March 2016. Delegates included commissioners and providers from health, education, social care, local authorities and children's palliative care providers. We found that:

    - Commissioners and service providers are taking a proactive approach to personal budgets, attending courses and training sessions to share best practice.
    - In some areas, commissioners have robust systems and panels in place to holistically assess the needs of each individual and to conduct financial risk assessments.
    - There remain wide regional disparities in the number of personal budgets in place and knowledge of personal budgets among commissioners.
    - Engaging with commissioners can be difficult for service providers as their catchment area can include multiple CCGs and local authorities. This problem is compounded by high staff turnover at local authorities, which means that service providers have to regularly liaise with new commissioners.
    - Young people and their families need additional help with the administrative burden of managing their own personal budget. This includes areas such as human resources and payroll services.
    - Families want more non-clinical assistance in areas such as maintaining their home. They need commissioners to recognise that this type of support enables them to take care of their own children.

- Commissioners, service providers and service users all need better information and support regarding personal budgets. This should set out what each party can and can't do using a personal budget and where they can access additional support or advice.

The changes required at national and local levels to make sure that truly integrated budgets for the NHS and social care smoothly

Joint commissioning

59. Together for Short Lives believes that:

- CCGs and local authorities should implement Together for Short Lives' guide to jointly commissioning palliative care for children and young people aged 0 – 25.

- The government and NHS England should communicate commissioning responsibilities more clearly to CCGs and local authorities.

- Government, NHS England, CCGs and local authorities should work with Together for Short Lives to better understand numbers and needs.

- The government and NHS England should hold CCGs and local authorities to account for the way they commission children's palliative care.

- Parliamentarians and the public should press commissioners to do better for children with life-shortening conditions.

Personal budgets

60. Together for Short Lives believes that:

- The government should fund a designated website or staffed phone line to enable young people, their families, service providers and commissioners to access up to date and accurate information around personal budgets and to signpost them towards further support if necessary.

- Commissioners should broaden their offer of support to those with a personal budget, using expertise from within local authorities to offer further support in areas such as human resources and payroll.

- Children's palliative care providers should continue to proactively communicate with one another through their existing networks to share best practice when engaging with commissioners and demonstrating their value.

b. How can local organisations be incentivised to work together?

61. Together for Short Lives believes that, in addition to being held to account by government, NHS England and regulators in implementing their joint commissioning duties, commissioners should be offered incentives.

62. We believe that NHS organisations and local authorities should jointly commission networks of providers to provide holistic pathways or models of care and achieve defined outcomes. We believe that financial incentives could be offered to commissioners by the government and NHS England whereby they would receive extra money for achieving

better outcomes for defined population groups. These groups could include children and young people with life-shortening conditions.

c. How can the balance between (a) hospital and community services and (b) mental and physical health and care services be improved?

63. We believe that this could be done by commissioning better physical and mental health and wellbeing outcomes from networks of providers rather than activity from individual services. Commissioners can also play an important role by specifying in agreements with networks that people with long-term conditions must be allowed to choose how and where they receive their care. This way, networks will need to include providers which can offer care in hospitals, the community and at home - and who can address the physical and mental health of people with long-term conditions.

Prevention and public engagement

6. What are the practical changes required to enable the NHS to shift to a more preventative rather than acute treatment service?

a. What are the key elements of a public health policy that would enhance a population's health and wellbeing and increase years of good health?

64. Local community support is fundamental to children's palliative care. We believe that communities have a vital role to play in supporting children with life-shortening conditions to lead ordinary lives and should be enabled to do so. To do this, a better understanding of childhood death and dying is needed so that diverse communities are better able to be involved with and support children, young people and families.

65. We are concerned that professional development of palliative care in the UK, combined with societal change, has, in part, diminished communities' ability to manage death, dying, loss and grief.

66. A community based approach is embedded in most areas of healthcare with the notable exception of palliative care. The greatest successes in overcoming public health challenges in recent years have been achieved through a community response. For example, in HIV and smoking, community responses have helped to prevent harmful behaviour and make it less prevalent. The challenge is to apply a community engagement response to children's palliative care.

67. Communities become more effectively and sustainably engaged when they are empowered and enabled to act themselves without external support intervening.

68. Community engagement in palliative care has traditionally focused on adult services and has recognised a spectrum of activity:

    1. **Informing**: organisation provides information to the community.

    2. **Consulting**: organisation gathers views from the community.

    3. **Co-producing:** community has a role in determining how their views are used.

    4. **Collaborating:** partnership between the community and organisation.

5. **Empowering**: a community has the power to develop their own solutions to issues facing them.

69. Together for Short Lives is working with the children's palliative care sector to encourage it to explore a community approach to children's palliative care and to strategically develop and invest in volunteering. We aim to:

- develop new models and approaches with community based organisation to enable communities to better support children and families to live ordinary lives
- encourage use of the models in practice by working with services to engage with their local communities
- work with services to support their service users to be able to make best use of community services and facilities
- support services in the strategic development of their volunteers to improve the care and support offered to children and their families.

b. What should be the role of the State, the individual and local and regional bodies in an enhanced prevention and public health strategy; and what are the key changes required to the present arrangements to support this?

70. We welcome Public Health England's commitment[18] to work in collaboration with the voluntary and community sector and others to support local approaches to improve health and reduce health inequalities for communities. We ask that Public Health England work with us to make sure that:

- providers of children's palliative care use the new models and approaches to engage with communities
- children and families are better supported by their local communities
- more volunteers become involved in delivering of services, particularly in roles that work directly with children and families
- The public health workforce is appropriately skilled to support babies, children and young people with life-shortening conditions.

c. Is there a mismatch between the funding and delivery of public health and prevention, compared with the amount of money spent on treatment? How can public health funding be brought more in line with the anticipated need, for instance a period of protection or ring-fencing?

N/A

d. Should the UK Government legislate for greater industry responsibility to safeguard national health, for example the sugar tax? If so how?

N/A

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[18] Public Health England. 2016. Strategic plan for the next four years: better outcomes by 2020. Available to download from: http://bit.ly/1ty25ql

e. By what means can providers be incentivised to keep people healthier for longer therefore requiring a lower level of overall care?

71. As we state in paragraph 51, we believe that this could be done by commissioning better physical and mental health and wellbeing outcomes from networks of providers rather than activity from individual services.

f. What are the barriers to taking on received knowledge about healthy places to live and work?

N/A

g. How could technology play a greater role in enhancing prevention and public health?

7. What are the best ways to engage the public in talking about what they want from a health service?

72. We believe that CCGs and local authorities should involve parent carers and young people in jointly commissioning services for disabled children and young people with local authorities.

73. For example, commissioners should work with parent carers and young people to determine who is eligible and who would benefit from personal health budgets within their local area; this could include children and young people with life-shortening conditions.

74. Parent carers and young people should be able to suggest services to include in local offers. They should be able to review and comment on local offers and expect to receive a response from CCGs and local authorities following their suggestions.

75. Parent carers and young people could potentially be invited to train commissioners.

76. CCGs could be asked to publish their strategies for engaging parent carers and young people.

77. NHS England could assure these participation strategies to check that CCGs are broadly engaging with the right groups.

Digitisation of services, Big Data and informatics

8. How can new technologies be used to ensure the sustainability of the NHS?

a. What is the role of technology such as telecare and telehealth, wearable technologies and genetic and genome medicine in reducing costs and managing demand?

78. Telecare and telehealth can help maintain contact between children with life-shortening conditions, families and their care teams who can sometimes be a considerable way away from their tertiary consultants. It can be particularly helpful in caring for children and young people with life-shortening conditions, some of which can rare and will need the care of a specialist tertiary consultant.

79. Wearable technologies can give children and young people freedom to live life without being tethered to life-sustaining technology. This helps them to achieve the outcomes they want from their lives, including accessing education and leisure activities.

80. Genome developments may fundamentally change the life-expectancy of a proportion of children and young people with life-shortening conditions such as Duchenne muscular dystrophy, metabolic conditions and cystic fibrosis.

b. What is the role of ‘Big Data’ in reducing costs and managing demand?

81. As we set out in our response to question 1, worryingly, the number of children and young people with life-shortening conditions is not being monitored. As a result, the UK Government, the NHS and local councils are failing to plan services and budget enough money to meet the needs of children and young people with life-shortening conditions. The complex care they need from multiple agencies and professionals is not joined up enough and families are having to fight to get the services they need. Gaps in services also mean that children and young people are being admitted to acute care settings unnecessarily when their conditions could be managed in the community or in children’s hospice settings.

82. ***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.***

c. What are the barriers to industrial roll out of new technologies and the use of ‘Big Data’?

83. In terms of gathering more data about children and young people with life-shortening conditions, we believe that the evidence base underpinning children’s palliative care needs to be expanded and be made robust. Challenges faced by researchers aiming to recruit children with life-shortening conditions and their families are numerous[19], including:

    - small sample sizes

    - limited funding

    - difficulties with research ethics committees

    - the unpredictable nature of the illnesses

    - society’s perceptions of the potential physical and psychological burden for participants and their families.

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[19] Beecham, E., Hudson, B.F., Oostendorp, L., Candy, B., Jones, L., Vickerstaff, V., Lakhanpaul, M., Stone, P., Chambers, L., Hall, D., Hall, K., Ganeshamoorthy, T., Comac, M., Bluebond-Langner, M. (2016). A call for increased paediatric palliative care research: Identifying barriers. *Palliative Medicine,* pii: 0269216316648087).

84. Even when participants are successfully recruited, the lack of detailed, standardised reporting of how recruitment was achieved hinders our ability to decipher the applicability of research to our own populations of interest.

d. How can healthcare providers be incentivised to take up new technologies?

85. We believe that commissioners should specify the use of new technologies in contracts and agreements. There is also a role for government and statutory bodies to produce and disseminate guidance and to share examples of best practice with both commissioners and providers. Government should also consider seed funding pilot programmes to test and produce evidence about the use of new technologies.

e. Where is investment in technology and informatics most needed?

86. As we set out above, there is a pressing need for investment in better understanding the numbers and needs of children and young people with life-shortening conditions.