14 June 2018

House of Commons Education Select Committee Inquiry into Special Educational Needs and Disability (SEND)

A written evidence submission from Together for Short Lives

Executive summary

- Perhaps more so than for any other population group, joined-up care and support is crucial for the 40,000 babies, children and young people in England with life-limiting and life-threatening conditions - and who need palliative care. We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. Because their conditions are often so complex, these families must typically liaise with around 30 different professionals from education, social care, health and other services.

- Together for Short Lives therefore supports the aspirations of the special educational needs and disability (SEND) system in England; we believe it has great potential to join-up assessments, plans and services across education, health and social care for children with life-limiting conditions.

- However, we do not believe that the government's vision for the SEND system is being realised for children with life-limiting conditions. Too few NHS clinical commissioning groups (CCGs) and local authorities are failing to meet their duty set out in the Children and Families Act 2014 to jointly commission services for disabled children. Too many education, health and care (EHC) plans do not sufficiently include the health and social care services that disabled children need.

- Our members, who include families of children with life-limiting conditions and professionals and services who provide palliative care, feel that the changes to SEND support have not substantially or adequately changed as a result of the reforms.

- We are members of the Disabled Children's Partnership and support its written evidence submission. We ask the committee recommends that the government:

    - makes disabled children a priority by providing ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families

    - review the way in which short breaks (respite) for disabled children and families are funded

    - clarify current rights and entitlements by co-producing with families guidance for local authorities and CCGs on their existing statutory obligations

    - hold local authorities and CCGs to greater account for the way in which they meet their duty to jointly commission care and support for disabled children

    - improve health and social care services for disabled children by providing an early intervention and family resilience fund

    - commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families; as part of this,

> Together for Short Lives would like a review to consider whether the system of single assessments and plans should be extended to all disabled children and young people up to the age of 25 - not just those with a SEN; it should also consider how the law can make sure that local areas set out what disabled children can expect from local services through a ‘duty to provide’ - and how an England-wide framework for local offers could be created.

Together for Short Lives’ response

About us

1. Together for Short Lives is the UK charity for children’s palliative care. We are here to support and empower families caring for seriously ill children, and to build a strong and sustainable children’s palliative care sector - so that no family is left behind.

2. Our submission to this inquiry is informed by feedback about the extent to which the SEND system is joining-up assessments, plans and support for children with life-limiting conditions, which we have sought from our members. Our members include families children with life-limiting conditions and the professionals and services who provide them with care and support.

3. We would be delighted to provide oral evidence to the committee should we be invited to do so.

About children with life-limiting conditions and the palliative care they need

4. The 40,000 babies, children and young people in England with life-limiting or life-threatening conditions need palliative care from the point at which their conditions are diagnosed or recognised - often at birth - until the end of their lives.

5. Between them, they have several hundred different conditions - some are well known, such as Duchenne muscular dystrophy and cancer; others are rarer and have no name until recognised in an individual child. Many children have a range of different needs and require complex, individualised health interventions to manage their conditions. Many also need additional social care and education support.

6. We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. These families routinely deal with over 30 professionals from education, social care, health and other services. Communication between agencies is generally inadequate, leaving families burdened with the stress of navigating their way through an uncoordinated system.

7. This experience is common among families of disabled children. However, for families whose children’s lives are likely to be short, time wasted navigating through the system in this way can be particularly distressing. As one parent has told us:

   “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”.

8. All the evidence suggests that the best outcomes for children with life-limiting conditions and families are achieved when there is effective partnership working between parents and services and care is co-ordinated around the needs of the family.

Assessment within the education and health care (EHC) plan

9. We have heard from families who say they feel frustrated by the system. They have said that frequently they are not consulted early enough in the process and that when they disagree with the EHC plan it is difficult to make the required changes.

10. We have heard of inconsistency in the way rules are applied between different areas, with families and children with life-limiting conditions experiencing different levels of engagement in assessment. There still seems to be pressure on parents to bridge these gaps themselves.

11. Some Together for Short Lives members within the voluntary sector feel that EHC plans still don't contain enough insight from health and social care. They feel that, while some good assessments are being done, they are predominantly focused on educational need and do not reflect a holistic view of the young person's need.

Joint working between health, education and social care

12. There appears to be geographical variation in the success of joint working. We are seeing patchy provision between geographical areas and many members mentioned social care as being particularly challenging to integrate.

13. CCGs and local authorities have a legal duty to jointly commission services for disabled children under the Children and Families Act 2014. Section three of the SEND Code of Practice sets out in detail what local areas must and should do to jointly commission services for children and young people aged 0 - 25 with SEND.

14. Despite this, in response to a series of freedom of information (FOI) requests issued by Together for Short Lives in 2017, only 68% of CCGs reported that they commission services for children with life-limiting and life-threatening conditions jointly with their local authorities[1]. Fewer than half (49%) of local authorities reported that they jointly commission these services with CCGs. Together for Short Lives has produced guidance for CCGs and local authorities on jointly commissioning palliative care for children and young people[2].

15. We are also concerned that local authorities are not meeting their statutory duty to assess the needs of parent carers (section 97 of the Children and Families Act).

16. The overall legal framework for health and social care for disabled children is complex. It stems from more than ten different acts of Parliament, regulations and guidance which have developed over the past 50 years. While the 2014 Children and Families Act made important changes to the law which we welcome, it did not remove this complexity. The joint commissioning duties were intended to address this, by ensuring that arrangements are in place to resolve disputes between agencies. Instead, we are increasingly seeing parents forced to take legal action to protect services and clarify legal responsibilities

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[1] Together for Short Lives. 2017. Commissioning children's palliative care in England: 2017 edition. https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/PolRes_Commissioning_children_s_palliative_care_in_England_-_2017_edition.pdf

[2] Together for Short Lives. 2015. Jointly commissioning children's palliative care. www.togetherforshortlives.org.uk/jointcommissioning

17. The Disabled Children's Partnership have gathered increasing evidence of cuts to services for disabled children and their families. A 2015 report[3], found that a majority (58%) of local authorities cut spending on short breaks between 2011/12 and 2015/16. This trend is continuing, and our members are seeing 'cost-shifting' between the health services and social care, with children and families falling between the cracks.

18. Ofsted and Care Quality Commission (CQC) joint inspections have also identified reductions in services such as short breaks. For example, Lancashire's report says "They struggle to identify any areas that have improved as a result of the implementation of the reforms. In fact, many described a reduction in services that were a strength in the past, such as access to short breaks". This same report identifies weak arrangements for joint commissioning.

Transition and provision for 18 - 25-year olds

19. One of our members, who works for a service which provides care and support for babies, children or young people with life-limiting and life-threatening conditions, told us that, while transition teams have developed successfully in some areas, "the issues in funding between children and adult services often counter this work as funding arrangements will not be put in place, and therefore agreements for placements and /or support made, until the young person is 18". This compromises the transition process and risks leaving young people isolated until care packages are agreed.

20. We are also concerned that young people between the ages of 18 and 25 who may move in and out of education, or leave education altogether, will not have access to a single EHC Plan and may lose access to support; this would include many young people who need palliative care who, owing to the complexity of their conditions, do not continue in education.

Choice in services

21. Overall, some families are still confused by the choices and do not feel fully informed about the options they have available.

22. One respondent (a professional providing care and support for babies, children or young people with life-limiting or life-threatening conditions) said more clinical resources are needed. For example: access to 24/7 nursing care when needed and provision of respite care; increased dietetics; therapy services; social work, community paediatricians and GPs with an interest. Funding pressures prevent any meaningful choice.

Personal budgets

23. We are conscious that, currently, children and young people with SEN may hold personal budgets relating to EHC plans, which may comprise a personal health budget, education and/or social care budget. The health and social care elements could also soon be held as an integrated personal budget, based on assessed needs and an agreed plan, if recent NHS England proposals are realised. Some disabled children will be eligible for a personal health budget and integrated budget, but not an EHC personal budget if they do not have a SEN. We are concerned that this could become increasingly confusing for families.

24. There are a series of specific barriers which we ask NHS England to work with us to overcome to offer families greater choice and control:

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[3] *Short breaks in 2015: An uncertain future* Every Disabled Child Matters, 2015

a. It is particularly important to address the regional disparity in the knowledge of personal budgets amongst commissioners:
  - Commissioners must recognise that parents often have the best understanding of their children’s needs – but require support to meet their needs.
  - It is key that those commissioning personal budgets understand how vital non-clinical assistance can be, allowing for sufficient provision within children’s personal budgets.

b. High staff turnover within clinical commissioning groups can lead to a frequent loss of knowledge and expertise.

c. The regional disparity in care provision also must be overcome for the increased use of personal budgets to be effective - currently there is a great regional disparity in care commissioning (www.togetherforshortlives.org.uk/commissioning2017):
  - Fewer than a third of CCGs have implemented the NICE guidelines on ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’
  - 63% of CCGs commission the provision of community paediatricians
  - The commissioning of out of hours community nursing, community paediatricians and equipment services is also subject to this postcode lottery, with 67%, 29% and 52% of CCGs commissioning these respectively
  - Almost half of CCGs are taking no action to implement the government’s end of life care commitment

d. Families and young people often feel frustration at the length of time it takes for personal budgets to be set up

25. There are also distinct challenges presented to the voluntary care sector (VCS) which will need to be mitigated for the increased usage of personal budgets to be beneficial:
    - VCS providers have little experience in marketing their services – therefore it will be important for guidance and assistance to be made available.
    - VCS providers and commissioners must have a close relationship to ensure accurate estimates of the cost of services.
    - It is often difficult for the VCS provider to determine their ‘local area’, resulting in interaction with multiple CCGs, who all have distinct processes, so a degree of regional standardisation utilising STPs may be beneficial

Recommendations

We ask that the committee recommends that the government takes the following action:

26. Make disabled children a priority by providing ministerial leadership to ensure a cross-departmental approach to improving outcomes for disabled children and their families.

27. Review the way in which short breaks (respite) for disabled children and families are funded.

28. Clarify current rights and entitlements by co-producing with families guidance for local authorities and CCGs on their existing statutory obligations.

29. Hold local authorities and CCGs to greater account for the way in which they meet their duty to jointly commission care and support for disabled children.

30. Improve health and social care services for disabled children by providing an early intervention and family resilience fund.

31. Commission a review of health and social care law, to strengthen and clarify rights and entitlements for disabled children and their families; as part of this, Together for Short Lives would like a review to consider whether the system of single assessments and plans should be extended to all disabled children and young people up to the age of 25 - not just those with a SEN. Integrated personal budgets could be offered to all those with an integrated plan.

32. A review should also consider how the law can make sure that local areas set out what disabled children can expect from local services through a ‘duty to provide’ - and how an England-wide framework for local offers could be created.

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