WRITTEN EVIDENCE SUBMITTED BY THE DISABLED CHILDREN’S PARTNERSHIP

1. The Disabled Children’s Partnership is a coalition of more than 70 charities campaigning for improved health and social care for disabled children and their families. We believe that disabled children, young people and their families should have access to the services they are entitled to, when they need them.

https://disabledchildrenspartnership.org.uk/about-us/

2. We were grateful to the Committee for the opportunity to give oral evidence to this inquiry. We were also grateful to be invited by the NAO to submit evidence to their study, and we welcomed their report.

Health and social care

3. The particular focus of the Disabled Children’s Partnership is on health and social care support. We have, therefore, focused our written evidence to those areas.

4. In order to give a full view of the value for money and effectiveness of public expenditure on children and young people with special educational needs or who are disabled, it is important that to consider the role of health and social care services; how effectively services work together; and how the incentives within the system – including accountability and funding mechanisms – drive behaviour.

5. Paragraph 1.22 of the Special Educational Needs and Disability Code of Practice says:

   If children and young people with SEN or disabilities are to achieve their ambitions and the best possible educational and other outcomes, including getting a job and living as independently as possible, local education, health and social care services should work together to ensure they get the right support.

6. We agree with this statement. However, in reality, this is not happening and the vision of the reform programme for integrated support is not being delivered. This is apparent at both strategic level – where joint commissioning arrangements are often in their infancy and not effective – and individual level, where too many Education Health and Care Plans do not sufficiently cover health and social care needs and provision.

7. Funding pressures on all parts of the system, including the high needs budget, social care and health services, mean that we are increasingly seeing commissioning decisions being driven by cost-cutting rather than a strategic assessment of the needs of the population. Education, social care and health services are all funded from different funding streams, and so services are incentivised to reduce their own costs even if that produces additional costs
elsewhere. The outcome is, sadly, that we are seeing increasing evidence of vital health and social care services being cut and declining in quality.

8. Poor joint working is also impacting on the quality of individual Education, Health and Care Plans. Too often, plans do not include a proper assessment of health and social care needs, and therefore risk leaving children and young people with unidentified needs and/or without the provision to meet those needs.

9. The failure to provide sufficient – and sufficient quality – health and social care support for disabled children has range of negative impacts on the health and wellbeing of the children, their siblings and their carers. Our recent survey\(^1\) of parent carers found that:

- only (4%) of parent carers feel they get the right support to safely care for their disabled children
- more than half (54%) of parent carers have been treated by a GP for depression, anxiety or stress (including suicidal thoughts)
- 53% of parent carers have been forced to give up a paid job to care for their disabled child
- 40% of parent carers have experienced relationship breakdown with a partner since diagnosis. 64% of those say a lack of support had a major impact on the breakdown of a relationship
- more than a third (37%) of parent carers say their disabled child has missed school or college because the staff or services are not available to support them
- a third (33%) of parent carers say their disabled child has been in unnecessary extra pain because the right equipment, doctor or health service hasn’t been available.

10. This failure to invest in support results in poor value for money, both in terms of poorer outcomes for children and young people, and in the need to make increasingly expensive placements and interventions further down the line. As recognised in the Long Term Plan for the NHS, services such as the Ealing Model have evidenced that an intensive multi-agency support approach prevents children being admitted into institutional care.

Conclusion

11. In conclusion, we consider it is vital to consider the impact of health and social care services as part of this inquiry. We welcome the National Audit Office’s recommendations, but – where appropriate – these should be broadened to cover health and social care. In particular, recommendations (a) [evidenced-based assessment of the cost of the system], (c) [review incentives in the funding and accountability systems] and (f) [investigate reasons for local variations] should encompass education, health and social care.

12. We have published a call to government to act on support for disabled children, by make them a priority, including by appointing a Minister for Disabled Children; clarifying and reviewing the rights and responsibilities within the system; and ensuring there is sufficient funding for services for disabled children and their families.²

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