

Care Quality Commission reviews in 2009/10 Consultation response from Action for Children

Action for Children welcomes the opportunity to comment on the proposals for periodic and special reviews of healthcare for 2009/10. Action for Children supports the vision of the Care Quality Commission (CQC) of *“high – quality health and social care that supports people to live healthy and independent lives, empowers individuals, families and carers in making informed decisions about their own care, and is responsive to individual needs”*.

Action for Children has only responded to those questions which relate to our direct work with children and young people.

Action for Children¹ – working with disabled children and young people

Action for Children is one of the largest voluntary sector providers of services for disabled children and young people in the UK. We have been providing services to disabled children for over 20 years. A significant number of the children using our services have multiple and complex impairments, which are often with associated health care needs or life limiting illnesses.

Action for Children is committed to working in partnership with other agencies, particularly health care, to achieve the best outcomes for children and young people.

We are committed to participation, ensuring that the wishes of the children and young people we work with (even where expressed non-verbally) are recognised and responded to. We work hard to ensure that disabled children and young people have a say in their lives.

Action for Children – raising the emotional wellbeing of children and young people

Action for Children continues to highlight the importance of emotional wellbeing through our Growing Strong campaign. We believe that emotional wellbeing, is instrumental in helping a child realise their full potential in life.

Developing qualities such as self-confidence and resilience equips a child with the emotional skills and inner belief to make the most of opportunities, and overcome any challenges, that they may have in the future.

Child Adolescent Mental Health Services (CAMHS) have a key role to play in supporting vulnerable young people and their families, particularly children who present challenging behaviour which restricts their opportunities socially and educationally.

Action for Children – a member of the Every Disabled Child Matters (EDCM) campaign coalition

As a member of the coalition we are signed up to their submitted response and the issues raised, including the background information:

¹ Action for Children helps nearly 170,000 children, young people and their families through nearly 450 projects across the UK.

Disabled children's access to healthcare – an overview of the evidence

Unfortunately, the evidence suggests that disabled children and their families have poor experiences of health services. Parents report that **universal** health services are inaccessible and access to **specialist** services is variable across the country.

Most recently, the **Healthcare Commission's report** on the 'State of Healthcare 2008' states that 'Children and young people with complex needs, including children with disabilities or those in situations that make them vulnerable, do not always get the attention and care from healthcare services that they need.'

An investigation by the **Disability Rights Commission**² revealed 'an inadequate response from the health services and governments in England and Wales to the major physical health inequalities experienced by some of the most socially excluded citizens: those with learning disabilities and/or mental health problems.' This included disabled children and young people. The investigation found children and young people in particular is the experienced 'diagnostic overshadowing' – that is reports of physical ill health being viewed as part of the mental health problem or learning disability – and so not investigated or treated.

Families also experience a postcode lottery in accessing specialist health services. Submissions to the Parliamentary Hearings on Services for Disabled Children³ expressed a high level of dissatisfaction with the services that disabled children and their families receive from health, social care and education services. Parents and professionals described health services as follows:

Good:	parents 16 %, professionals 19%
Adequate:	parents 36%, professionals 46%
Poor:	parents 48 %, professionals 35%

Information taken from EDCM Consultation response: Care Quality Commission reviews in 2009/10

Response to consultation questions

Consultation question 7 – Do you support a single, integrated report on the state of health and adult social care?

Action for Children, agrees with the EDCM campaigns concerns around how the work of the CQC will be co-ordinated with other regulators, including Ofsted, the regulators of children's social care and education services. This will be of particular significance for children's domiciliary care services which will be regulated and inspected by the CQC.

As a major provider of services for disabled children we understand that it is essential for both health and social care services to work together, especially in the cases of children with complex health needs, if they are to meet the real needs of children and their families.

We support the EDCM's position that both commissioners and providers of healthcare need to work together with their local authority partners, particularly in the context of Children's Trusts.

² Equal Treatment: Closing the Gap A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems

³ *Parliamentary Hearings on Services for Disabled Children* (2006) at www.edcm.org.uk/parliamentary

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In addition, we agree it would be helpful if the CQC can explain how it will work with Ofsted to report on whether a joined-up service is being delivered.

Consultation question 9 – From the potential topics for special reviews, which would you consider to be the highest priority?

1. Action for Children would like to see a special review into **the health and social care for families with disabled children and young people.**

Action for Children believes that there is a real urgency to carry out this review, believing that it is both required due to the poor experiences disabled children and young people have of healthcare and timely due to the Aiming High for Disabled Children programme and the Children Health Strategy – *Healthy lives, brighter futures* initiatives for disabled children.

2. Action for Children would like to see a special review into **Child and adolescent mental health services – a review of the care pathway**

Action for Children responded to the CAMHS Review – *Next Steps to Improving the Emotional Well-Being and Mental Health of Children and Young People*. Call for Evidence

In our response to the call for evidence Action for Children identified five key areas where we perceived a need for change in current CAHMS practice:

- a. A clearer understanding within mental health services of the value of early intervention at tiers 1 and 2
- b. The adoption of a social care approach at lower tiers
- c. An evaluation of current working relationships outside of the health sector
- d. The development of mental health services outside of a traditional medical framework
- e. Better planning across agency boundaries.

We would like clarification about this potential review and how it would fit into the CAHMS review.

Consultation question 10 – What specific issues would you want us to address for any of these topics and how would we best do this?

For the review into **the health and social care for families with disabled children and young people**, we would echo the request made by EDCM for the following issues that need to be examined:

- The specific issue of **joint working** between health and children's social care. Children who have both social care and specialist healthcare needs often end up stuck in the middle of an argument between the local authority and PCT over which agency will fund their care.
- Access to **universal health services** for disabled children and young people, including those with learning disabilities.
- The **commissioning** of specialist services for children with complex health and palliative care needs. There is a need for an improved system of commissioning to meet the needs of this small but high-cost group of children.

In addition, we would like the role of the voluntary sector to be taken into consideration in the commissioning of services. The unique contribution of the voluntary sector adds value to service provision and should be looked into when reviewing the health and social care for families with disabled children and young people

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For further information please contact Emma Scowcroft, Action for Children Policy Officer on 020 7704 7000 or emma.scowcroft@actionforchildren.org.uk

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