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30 NOV 2011

Dear all,

Thank you for your letter of 24th October in which you request a meeting to discuss the opportunities provided by the proposed NHS reforms to improve services for children with disabilities.

I am, of course, delighted to discuss this important subject with you and was looking forward to meeting with you this Thursday. As you are aware, I have unfortunately had to postpone that meeting due to Parliamentary business but have asked officials to rearrange for a convenient time in the near future.

I thought it would be helpful in advance of meeting you to respond to the specific recommendations that your campaign, jointly with the Children's Trust Tadworth, make regarding the potential for the proposed NHS reforms to improve provision for children and young people. I would be grateful if you would take this as a response to similar letters sent to Ministerial colleagues and senior officials in the Department of Health.

Can I say at the outset how much I appreciate the extremely important work that the organisations who are part of the EDCM campaign and all their staff do in order to promote and improve the availability and quality of services for children and young people with disabilities. I am convinced that the campaign has had and will continue to have a significant impact in improving the life chances of these children and young people.

In terms of the recommendations made in the shared message between EDCM and the Children's Trust Tadworth, I will respond to these in the order you raise them.

1. The Health and Social Care Bill should require the Secretary of State to set priorities for child health as part of his Mandate to the NHS Commissioning Board

As we have made clear, the proposals ensure that children's health is built in explicitly and clearly throughout the new system, including through the mandate.

A significant focus of the mandate will be on the NHS Outcomes Framework - it is against that that the Secretary of State will hold the NHS Commissioning Board (NHSCB) to account, and on that basis that the NHSCB will performance manage Clinical Commissioning Groups (CCGs).

The NHS Outcomes Framework includes measurable outcomes to demonstrate improvement in critical areas relating to children and young people. The Public Health Outcomes Framework, to support all parts of the public health system will focus on improving outcomes across the lifecourse, with an emphasis on tackling health inequalities.

I believe that together these frameworks set a firm direction for children's health and healthcare. However, there is more to do and, as our data improves, we will want to work with clinicians and others, such as EDCM, to ensure we have the best possible suite of measures to promote improvement.

2. As a matter of urgency, the Department for Health should set out a clear vision for the way in which the reformed system will meet the needs of disabled children and children with complex health needs

We know the NHS as it works now does not get everything right for children – Sir Ian Kennedy in his report of last year 'Getting it right for children and young people' emphasised this. The quality of health care for children is variable and the outcomes for too many children are poor compared with other countries. With some 12 million children and young people in England, representing some 22% of the population, it is vital that they command our attention. They are our future, and the NHS must do better for them.

We have ambitious policy goals for children and young people – the right start to life in the foundation years, improved support for mental health and well-being, better joined up support for children and young people with disabilities and complex health needs, improved health in adolescence. In addition, the NHS must continue to play its part in keeping children safe as well as meeting the needs of sick children. Therefore, our proposals

recognise the importance of serving the needs of children and young people well.

That is the ambition behind our health reforms. We want to move to a service where the use of evidenced based treatment is adopted uniformly and across the lifecourse, and where the focus on promoting good health is of equal importance to caring for those who are ill. We want to ensure that children, young people and their families are always involved in decisions about their care, and that there is informed and expert knowledge underpinning the commissioning of integrated health services across primary, secondary and tertiary care.

The success of the reforms will be measured through improved health outcomes for children.

This is the vision we have and we are convinced that the proposed NHS reforms will release the commitment and expertise of those involved in this area to deliver it, while at the same time ensuring that there are strong and robust accountability mechanisms in place, locally and nationally.

3. An overarching Clinical Network for disabled children's health should be created in order to address longstanding issues, including barriers to commissioning specialist health care services

We believe that for some areas of care, clinical networks will have a crucial role in supporting the NHS Commissioning Board and clinical commissioning groups to design pathways of care and shape services, based on a wide-range of multi-disciplinary input.

Proposals for the role of clinical networks will be developed after the completion of a review of clinical networks, which is engaging with a wide range of stakeholders to assess how the functions and range of networks can most effectively support commissioners. The role of clinical networks and the new clinical senates is being developed in a review led by Dr Kathy McLean, who chaired the Future Forum workstream on clinical advice and leadership.

As part of this review, the need for a clinical network for children and young people will be considered, as will the future development of child protection clinical networks (on which the RCPCH and DH issued a joint report in April 2010).

4. Health and Wellbeing Board early implementers should be asked to test and report on integrated working for the delivery of services for disabled children which includes all relevant partners – e.g. education services

We very much recognise that if we are to optimise the potential to improve the life chances of children with disabilities, integrated working is crucial.

The Learning Network for the Health and Wellbeing Board early implementer programme includes a learning set on joint working to improve services for children and young people. This work is just getting underway, having been launched some two weeks ago, but there is a real energy and enthusiasm to develop and share innovative ways of delivering transformational change,

The outputs from this programme, taken with the work of those early implementing Clinical Commissioning Groups who are focussing on children and young people's issues will be shared across the country and will be extremely informative in supporting effective commissioning.

In addition, as you are aware, 20 pathfinders covering 31 Local Authorities and PCT Clusters have been appointed to test the ambition of the Government's Green Paper 'Support and Aspiration - A new approach to SEN' published in March 2011. This will include testing various elements to improve the current system including a new single assessment process with a single education, health and care plan along with the option of a personal budget. The pilots will run initially for 18 months.

5. Careful consideration should be given to the impact of current reforms on the commissioning of specialist health services for children and young people with high-cost, low-incidence conditions

A fundamental principle of the proposed NHS reforms is that services are commissioned in the most effective way.

For the majority of clinical interventions, commissioning at Clinical Commissioning Group level will be the most effective, although we acknowledge that for some services, a collaborative or in a small number of cases, a national approach may be appropriate.

There is work currently underway to consider which services are appropriate for commissioning at a national level through the National Commissioning Board.

It is through this mechanism that any service provision for high cost low incidence conditions for children and young people will be considered.

6. Information and support should be provided to disabled children, young people and their families to ensure that they understand the way in which the changing health system will affect them.

The Government has asked the NHS Future Forum to continue its conversations with professionals, service users and the public, including parents, about how to modernise the NHS. As part of this process, it has produced information materials that can be used by local groups to consider how these changes will affect them locally. The emerging Clinical Commissioning Groups and Health and Wellbeing implementer sites will have a key role to play in any such discussions.

We recognise that for specific groups, more tailored information may be required. Where this is identified as being the case, we will consider how best this should be done.

You may be aware that Sheila Shribman, National Clinical Director for children, young people and maternity chairs the "Health needs of children and young people with disabilities" group, which has a wide mix of members from different organisations. At their meeting last week, they heard a presentation on the health reforms and agreed to work with officials outside of the main meetings to address specific issues that need to be worked through further, for example on the integration of services. This is to ensure we get it absolutely right for this group of children and young people. This work will continue for as long as necessary.

In conclusion, I hope that this response reassures you that this Government is determined that these NHS reforms are much more ambitious than simply seeking to maintain the current level and quality of provision for children and young people with disabilities and instead, are ambitious in setting out the way forward for significant improvements for this group.

I look forward to meeting with representatives of EDCM in the near future to discuss these issues further. Again, I am so sorry to have had to postpone
with every good wish, Thursday's meeting.

Yours sincerely,
Earl Howe
EARL HOWE

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