

Championing Children and Young People in England

Parliamentary Briefing: The Health and Social Care Bill 2011

March 2011



Office of the Children's Commissioner

The Office of the Children's Commissioner is a national organisation led by the Children's Commissioner for England, Dr Maggie Atkinson. The post of Children's Commissioner for England was established by the Children Act 2004. The United Nations Convention on the Rights of the Child (UNCRC) underpins and frames all of our work.

The Children's Commissioner has a duty to promote the views and interests of all children in England, in particular those whose voices are least likely to be heard, to the people who make decisions about their lives. She also has a duty to speak on behalf of all children in the UK on non-devolved issues which include immigration, for the whole of the UK, and youth justice, for England and Wales. One of the Children's Commissioner's key functions is encouraging organisations that provide services for children always to operate from the child's perspective.



Executive Summary

This briefing considers the possible impact of the Health and Social Care Bill 2011 on children's rights outlined in the United Nations Convention on the Rights of the Child.¹

The Office of the Children's Commissioner has assessed that the Bill has the potential to improve health outcomes for children in a number of areas, including helping realise children's right to participate in decisions affecting them through Local HealthWatch and HealthWatch England.

However, we share the concerns expressed by a number of the Royal Colleges, including the Royal College of Paediatrics and Child Health (RCPCH) that:

- the increased fragmentation of the NHS and the introduction of full price competition may both tend to undermine children's right to health;
- the reforms risk undermining partnership working across children's services and may fracture continuity of care, particularly for children with long term conditions or specialist or complex healthcare needs.²

We therefore urge parliamentarians and the Government:

- to ensure that children are a priority group for the NHS, both locally and nationally, by requiring health and wellbeing boards to have specific regard to the health and wellbeing of children;
- to ensure that both GP consortia and the NHS Commissioning Board are focussed on improving the quality of care to children, including primary care services to all children and specialist services to children with specific needs and vulnerable children, including children in care, youth justice settings and asylum seeking children;
- to ensure that GP commissioning consortia should have access to training and expertise to commission child health services;
- to ensure that the NHS Commissioning Board be given a clear remit to commission high quality services for children with rare disorders and other complex needs, and vulnerable children.
- to ensure that all bodies have a senior staff member with responsibility for ensuring high quality health outcomes for children.
- to require directors of children's services to be members of health and well-being boards.

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¹ UN Committee on the Rights of the Child (2008) Concluding Observations. UNCRC. See: http://www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC.C.GBR.CO.4.pdf ² RCPCH response to the Bill, January 2011. See: www.rcpch.ac.uk/doc.aspx?id Resource=8280, [accessed 21 February 2011].



- to require joint strategic needs assessments (JSNAs) to address current and future health and well-being needs of their population, which must of course include children's health.
- to place an explicit duty on Healthwatch England and Local Healthwatch to involve children in the development of services and decisions about their care.

Introduction

This briefing considers the major reforms to the NHS proposed in the Health and Social Care Bill 2011. It focuses on the possible impact on children's rights, particularly those set out in the United Nations Convention on the Rights of the Child (UNCRC). The key rights engaged by the Bill are:

Article 2:	The right to enjoy	v all human rights	, without discrimination

Article 3: That the best interests of the child must be a primary

consideration

Article 6: The right to life and to develop "to the maximum extent

possible"

Article 12: The right for children to participate and express their views

Article 16: The right to private and family life

Article 19: The right to protection from child maltreatment

Article 22: If a child is a refugee or seeking refuge, the government

must ensure they have the same rights as any other child

Article 23: The right for disabled children to enjoy a 'full and decent

life' and their right to 'special care', including health care

Article 24: The right to enjoy 'the highest attainable standard of health'

and to be able to access suitable health facilities

Article 33: The Government must protect children from the use of

illegal drugs

Article 34: Governments must protect children from sexual abuse and

exploitation

Article 39: Children neglected, abused or exploited must receive

special help to help them recover their health dignity and

self-respect.

Article 4 of the UNCRC states that the Government must take "all appropriate legislative, administrative and other measures" to ensure the realisation of rights protected under the UNCRC, and must also apply "the maximum extent of their available resources" to this purpose.



Concerns in relation to poor health outcomes for children are set out in the most recent UK report from the UN Committee on the Rights of the Child (October 2008). The Committee stated as follows:

"...Despite the State Party's efforts to tackle inequalities in access to health services through, inter alia, substantial investments, inequalities remain a problem, as demonstrated by the widening gap in infant mortality between the most and least well off groups."

The Committee called for these inequalities to be addressed through "a coordinated approach across all government departments and greater coordination between health policies and those aimed at reducing income inequality and poverty." The Committee also called for:

- additional resources to meet the needs of children with mental health problems
- intensified efforts to improve reproductive health services
- greater support for children to reduce substance abuse
- better training for health staff in relation to the specific needs of disabled children.

However, we are unaware that a specific budget has been allocated to the implementation of the UNCRC or that any action has been taken to address the recommendation for a clear central health budget for children proposed by Sir Ian Kennedy in September 2010.³

Children's health - the background

Realising a child's right to health requires the best quality health services to be available. Children are heavy users of health services. A child under two will visit their GP practice an average of six times a year, and children and young people constitute around 40% of each GP's workload.⁴ An increasing number of children and young people, including disabled children and children with life-limiting conditions, will need to access secondary and tertiary health services. Around 100,000 children in England with complex care needs will require support from a wide range of services.⁵

Department for Education and Skills, 2007.

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³ State of Children's Rights in England 2010, p9. See Sir Ian Kennedy's paper 'Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs', Department of Health, 2010.

⁴ Achieving equity and excellence for children, Department of Health, 2010, p24 at 4.16. ⁵ 'Aiming High for Disabled Children: Better Support for Families', HM Treasury and



A report by the Every Disabled Matters Campaign shows that disabled children use NHS services significantly more than other children, yet they and their families consistently report poor experiences of both universal and specialist health services. A young disabled person talks about lack of access to therapeutic services saying:

"I went to a mainstream secondary school. I did not get to see a physio or OT [occupational therapist] regularly. This is because I didn't go to a special school for disabled people. I think health, education and social services need to work more closely together". 6

We are conducting our own research around children and young people's views of using GPs' services. Initial findings show that there are issues children and young people would not feel comfortable talking to GPs about. When asked what they would not want to talk to a GP about, young people said:

"It's hard talking about eating disorders to strangers and people you feel may judge you, specifically after negative experiences with doctors in the past. I have been called psychotic..."

"Anything that is personal, for example, irregular periods, skin deformity, things like that. Reason being, he makes me feel stupid and it feels like my appointment is being rushed and I'm just a number"

"Mental health - they are very insensitive about this. When I moved to the area and registered with this GP, I was on a prescription psychiatric medication, and as soon as my GP found out he told me to stop taking it... He didn't ask my opinion or give any advice on withdrawal, and never followed it up."

The Bill - key issues for children

We have chosen to focus the analysis below on the following four areas:

- 1. Structural reforms
- 2. Public health and promoting positive outcomes
- 3. HealthWatch
- 4. National Institute of Clinical Excellences (NICE) standards

This is not because other aspects of the Bill are not important to children, but because we consider that these areas are those with the greatest potential impact on children's rights.

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⁶ 'Disabled children and health: Campaign briefing from the Every Disabled Child Matters campaign', See: http://www.ncb.org.uk/edcm/edcm_disabled_children_and_health.pdf [accessed 14 March 2011]



1. Structural Reforms

The main structural reforms created by the Health and Social Care Bill 2011 are set out in Part 1, "The Health Service in England". These extensive reforms include the establishment of a new NHS Commissioning Board, the abolition of primary care trusts (PCTs) and strategic health authorities and their replacement with GP commissioning consortia as the primary bodies with responsibility for local health services. There is also a far greater role for local authorities in the promotion of public health, working with the Secretary of State for Health.

The following aspects of the structural reforms contained within Part 1 of the Bill clearly have the potential to improve health outcomes for children:

- GP commissioning consortia may be closer to individual children and families than primary care trusts and may be able to commission packages of care with greater sensitivity to individual needs.
- The specific focus on reducing inequalities has the potential to lead to a greater focus on children's health outcomes.
- The focus on public health has the potential to lead to improvement in areas such as substance misuse identified by the Committee to be particular problems in relation to children.
- Each GP commissioning consortium must produce a commissioning plan each year (clause 22) which must "in particular explain how the consortium proposes to discharge its duties to seek continuous improvement in the quality of services".
- There is a specific new duty on local authorities to help deliver and sustain good health among the prison population (clause 25). Given the concerns about all outcomes, including health outcomes, for children in custody this duty may benefit this particularly vulnerable group of children.
- The requirement on directors of public health to publish annual reports on the health of their local population (clause 27) gives an opportunity for children's health outcomes to be subject to ongoing review in every local area – albeit that there is no specific requirement for directors to consider children's health outcomes.

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⁷ See Explanatory Notes at para 274.



However, we would wish to highlight the following specific concerns about these proposed structural reforms:

- As set out above, many children and young people currently have negative experiences of engaging with their GP practices. Given the central role for GP commissioning consortia, the ability to work effectively with children and their families with a range of needs must be an essential element of the training programme which must accompany these reforms. A further concern is that valuable relationships between children and families and their GP may be undermined if GPs are responsible for ensuring that their consortium's referral budget is not breached.
- Given the existing time pressures on GPs, it is unclear how and to what extent GPs themselves will be involved in the commissioning of specialist health services for children, or if this will continue to be done by managers. This raises the question as to what practical benefit for patients (including children) the transition from primary care trusts to GP commissioning consortia will entail.
- The introduction of full price competition within the NHS has led to concerns that the duty to promote quality in children's health services will be undermined by an incompatible duty to achieve the best price for a service. The RCPCH has stated that "Market-based competition in health without expert collaborative commissioning will undermine links between professionals, leach expertise, reduce service availability and increase waits. There must be safeguards in the Bill to ensure that services for children, which may not be lucrative enough for competitive market improvement, do not suffer." We share these concerns.
- None of the duties on any of the relevant bodies (for example that established by clause 19 in relation to the NHS Commissioning Board) explicitly mention children and young people. It is vital that a clear message is sent out that the duties to reduce inequalities and help patients make choices apply just as much to children as adults.
- The detail of which services will be prioritised by the NHS Commissioning Board will be set out in the 'mandate' to be published by the secretary of state each financial year (clause 19). Furthermore, the specialised services for rare conditions which the Board must commission will be set out in regulations. It is vital that the mandate and regulations make clear that the Board must commission sufficient specialist health services to meet the needs of children with complex health needs.

⁹ See Clause 11 and Explanatory Notes at para 133.

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⁸ RCPCH response to the Health and Social Care Bill, January 2011. See: www.rcpch.ac.uk/doc.aspx?id Resource=8280 [accessed 21 February 2011].



- A key concern of families whose children have complex health needs is that services for these children are properly integrated across agencies. Already this task is made harder when the boundaries of the local authority and the primary care trust do not align. This is also a particular problem for care leavers whose corporate parent is the local authority. 10 There is serious concern that the fragmenting of the local health service into an unknown number of GP commissioning consortia will make this problem worse, to the detriment of the health and wellbeing of some of the most vulnerable children. For example, the Royal College of Nursing has expressed concern that "fragmentation across the NHS could result in unexplained variations in service, a reduction in collaboration and less sharing of good practice."11
- The very significant changes to the way in which mental health services are commissioned and provided (clauses 30-37) must not undermine the recent and vital focus on improving child and adolescent mental health (CAMHS) services.
- The processes for determining whether the NHS or local authorities should lead on providing care for children with complex needs ('continuing care') are already far from clear. There is an opportunity, not currently in the Bill, to specify the requirements on GP commissioning consortia in relation to assessment and provision of services for children with complex health needs.
- Currently, transition from child to adult services is very poorly managed in many areas, with particular difficulties with respect to the transition from paediatric to adult health services. Again, the Bill could include how the new structures can improve this process.

In relation to GP commissioning consortia, the equality impact assessment¹² notes a concern that consortia may have "insufficient knowledge of the range of services for vulnerable children". The mitigation for this risk is said to be the power for consortia to enter into partnership arrangements with local authorities. We are concerned that in the absence of central direction or guidance from the secretary of state, this power will be insufficient to ensure that all GP commissioning consortia have adequate understanding of child health issues to meet the health needs of children and families. We therefore propose that the legislation should:

ensure that children are a priority group for the NHS, both locally and nationally, by requiring health and wellbeing boards to have specific regard to the health and wellbeing of children;

¹⁰ See the NCB Briefing for Second Reading of the Bill, 31 January 2011.

¹¹ RCN response to the Bill, cited in House of Commons Library Research Paper 11/11, p55. ¹² Health and Social Care Bill 2011, Equality Impact Assessments. See: http://www.dh.gov.uk/prod consum dh/groups/dh digitalassets/documents/digitalasset/dh 123 634.pdf, page EIA24 [accessed 20 February 2011].



- ensure that both GP consortia and the NHS Commissioning Board are focussed on improving the quality of care to children, including primary care services to all children and specialist services to children with specific needs and vulnerable children, including children in care, youth justice settings and asylum seeking children;
- ensure that GP commissioning consortia should have access to training and expertise to commission child health services.
- ensure that both GP consortia and the NHS Commissioning Board are focussed on improving the quality of care to children, including primary care services to all children and specialist services to children with specific needs and vulnerable children, including children in care, youth justice settings and asylum seeking children;
- ensure that all health bodies have a senior staff member with responsibility for ensuring high quality health outcomes for children.

2. Public health and promoting positive outcomes

In addition to those duties on the Secretary of State outlined above, the Bill makes proposals (in Parts 1 and 5) in relation to public health and the promotion of positive health outcomes. Key proposals include the establishment of directors of public health within local authorities and the requirement for local authorities and GP commissioning consortia to prepare joint strategic needs assessments (JSNAs).

The following aspects of parts of the Bill clearly have the potential to improve health outcomes for children:

- The requirement for directors of children's services to be members of health and well-being boards (clause 178).
- The requirement for joint strategic needs assessments (JSNAs) to address current and future health and well-being needs of their population, which must of course include children's health (clause 176).

However, we would wish to highlight the following specific concerns about several parts of the Bill in relation to children:

- There is nothing in the Bill which explicitly requires health and well-being boards to prioritise the health needs of children.
- There is not any specific requirement for child health to be a priority in joint health and well-being strategies.
- Health and well-being boards have a duty to encourage joint working across agencies but no powers to compel it.



We therefore propose that:

- Children should be clearly signalled as a priority group for the NHS, both locally and nationally, by requiring health and well-being boards to have specific regard to the health and well being of children in their decisionmaking.
- There should be a strong direction to health and well-Being boards from the Secretary of State and the NHS Commissioning Board as to the central importance of improving outcomes for children. In relation to public health, it is essential that the guidance to be issued to directors by the Secretary of State makes it clear that children's public health is a key priority.

3. HealthWatch

The context in which the Bill proposes to improve public engagement with the NHS is one in which it is widely acknowledged that children's views have been marginalised for too long. The Bill's equality impact assessment notes (in its section on 'Input to decision-making') that "One area for improvement is increasing the influence of children and young people." The equality impact assessment notes further that there is "significant scope to better focus advocacy services on...providing help for children" and that "advocacy for complaints does not appear to be adequately focussed on children."

The proposals on public engagement are found in Chapter 1 of Part 5 of the Bill. They include the establishment of Local and National HealthWatch ('HealthWatch England') to represent the views of the public in relation to the NHS Commissioning Board and GP commissioning consortia. Further, local authorities rather than the Secretary of State must make provision for independent advocacy services in relation to complaints (clause 170). These may be commissioned from Local HealthWatch or another provider.¹⁶

This part of the Bill has the potential to:

- help realise children's rights to participate and to have decisions taken in their best interests through proper engagement with them by Local HealthWatch and HealthWatch England
- improve advocacy services by transferring responsibility to local areas.

¹³ Health and Social Care Bill 2011, Equality Impact Assessments, pEIA73 at para D28.

¹⁴ Health and Social Care Bill 2011, Equality Impact Assessments, pEIA74 at para D32.

¹⁵ Health and Social Care Bill 2011, Equality Impact Assessments, pEIA79 at para D53.

¹⁶ See Explanatory Notes at para 922.



However, we would wish to highlight the following specific concerns about these proposed reforms:

- Children's participation will only be a reality if all HealthWatch organisations make children a priority and adopt best practice in participation.
- Improvements in advocacy services will only happen if sufficient specialist advocacy to assist children to make effective complaints is available in every local area.

We therefore propose that the Bill should:

• place an explicit duty on Healthwatch England and Local Healthwatch to involve children in the development of services and decisions about their care.

4. National Institute for Health and Clinical Excellence standards

The role of the National Institute for Health and Clinical Excellence (NICE) is dealt with in Part 8 of the Bill. Importantly, a new NICE function is proposed to develop 'quality standards' on being so commissioned by the NHS Commissioning Board (clause 218). The Secretary of State and the Board must have regard to these standards in discharging their health improvement duties. The standards will have statutory force once approved by the Secretary of State or the Board. Board.

There is obvious potential for NICE quality standards to improve the standard of child health services. This would be assisted by a specific duty imposed on NICE through the Bill to have due regard to the interests of children in developing its quality standards. This would make children a priority both in terms of general health standards and in terms of ensuring that NICE focuses on the need for specific quality standards in relation to child health.

In a system where decision-making is being devolved down to local areas, NICE quality standards and guidance are essential in ensuring that minimum standards are adhered to. In order for the Bill to deliver improvements to children's health it will be necessary for quality standards and guidance to address the issues that matter to children – and for all relevant bodies to be required to act upon the standards and guidance.

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¹⁷ Being the duties contained in clause 2 and clause 19 respectively; see Explanatory Notes at para 1141.

¹⁸ See Explanatory Notes at para 1141.



Conclusion

It is beyond doubt that this Bill will have a very significant impact on children's health services and children's rights, and much of the essential detail will be left to secondary legislation and guidance. Few of the currently proposed outcome standards relate to children's services and there are no outcome standards defined yet for children with developmental disorders and disabilities.¹⁹

If the Bill is to deliver improvements on child health it is vital that children are a priority across all directions and guidance issued to local bodies – including health and well-being boards, GP commissioning consortia and Local HealthWatch. The recent review by Sir Ian Kennedy demonstrates that children will not automatically become an NHS priority but that child health must be set as a priority both nationally and locally. If this happens, then there is certainly the potential that the Bill could lead to the better realisation of children's right to health – and the delivery of the requirement under the UNCRC that the "maximum available resources" are allocated to this task.

If, however, children are not placed at the centre of these reforms then the devolution of power to localities is likely to result only in an unacceptable increase in the 'postcode lottery' of children's health and social care services which currently exists. As the RCPCH rightly states, "Clear minimum standards of care and expertise in commissioning for children must be in place" if this Bill is to deliver on the universal commitment to improving children's health.²⁰

For more information

For further information regarding the Office of the Children's Commissioners response to the Health and Social Care Bill 2011, and our broader work in the area of health, please contact:

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RCPCH response to the Bill, January 2011. See:
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