Child health: implications of the Health and Social Care Bill 2011

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A child and family's need for health and social care

Case illustration 1: complex needs

A child was born too early, at just over half way through her teenage mother's unplanned pregnancy. She has many complications from being born prematurely. She spent 6 months in intensive care, and survived despite several life-threatening illnesses in early weeks and months. She is now 8 years old, and has multiple health and learning difficulties. She has epilepsy, cerebral palsy and is wheelchair-dependent; she is partially sighted and is unable to feed or dress herself. Her mother finds it difficult to cope with her needs, and those of her two younger siblings.

This child and her family need a complex package of care that will include services from all parts of the health service interacting closely with eachother and with social and education services too. This package of care will change as she grows up. She will need acute care as all children do, from her GP, practice nurse and health visitor. She will need regular visits to a local general paediatrician. She will see a paediatric neurologist for her complex epilepsy, a paediatric neurosurgeon for her hydrocephalus, and a paediatric orthopaediac surgeon for her scoliosis; they work in two different specialist children's hospital in other areas. She will need physiotherapy to relieve the cramps, contractures, and limb pain she gets from being immobile. Speech and language therapists will try to help her learn to swallow safely. Occupational therapists will help teach her to manipulate a communication device. She needs special educational support, wheelchair services, and a paediatric dietician.

Her family may need adaptations to their housing to manage her wheelchair, advice on financial benefits and legal rights, and support from mental health professionals to support them through these difficult life circumstances, to prevent and treat depression, which is commoner in families where a child has a chronic disease.

Public health professionals will need to assess her needs, alongside other children's, in order to plan and monitor services across the community to ensure high quality services and efficient distribution of human and financial resources. They will plan and improve services to prevent other children being born prematurely to teenage mothers, undertake research to understand how better to prevent pre-term births, and work with social and education services to improve her life circumstances.

A child and family's experience of health and social care if the Health and Social Care Bill is implemented

Case illustration 1: complex needs

This child with cerebral palsy, scoliosis, visual impairment, learning difficulties and complex epilepsy will need services to manage her conditions, and their impact on her life, and the consequences for her family.

The services she needs will require multiple different providers across health, education, and social care who have to cooperate closely to ensure high quality and efficient care. Because there will be different providers competing with each other it will become more difficult to ensure a smooth carefully coordinated package of care for this child and family, than it was before the Health and Social Care Bill. For example bringing several professionals together to see the child in one place to minimize the number of separate appointments, would save money and improve the family's experience. But to do this, there has to be central coordination and an incentive to work together. By promoting competition rather than collaboration, the Bill makes a smooth patient pathway harder to achieve.

Services for children with long-term conditions, disabilities, and rare diseases will become more fragmented and parents will have to work harder to find the right care for their children.

This child's care is expensive. Clinical commissioning groups will "cherry pick" patients who are low users of health services which will severely disadvantage children with complex conditions and disabilities such as this girl, whose care is expensive and difficult to coordinate. This will worsen health inequalities for children.

Clinical commissioning groups can decide which services they will offer and which they will not – expensive uncommon services for small numbers of patients will be vulnerable. These same services can then be offered by private

providers, staffed by the very same GPs from the CCG who then gain financially from the loss of NHS-provided care.

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Case illustration 2: safeguarding and child protection

A 7 year old girl has autism and attention deficit hyperactivity disorder (ADHD). She is one of 4 children under the age of 8 living with a single mother who has no extended family nearby. The family live in a two bedroomed flat on the 8th floor in a deprived part of a large inner city. Because of her ADHD the child repeatedly tries to climb over the balcony, out of windows and let herself out the front door. There is no garden or nearby open space. The mother is depressed and struggling to meet the needs of her other 3 children. The school are concerned because the 7 year old frequently has bruises on her arms, arrives hungry and late most days.

Is the child being abused?

The child needs an urgent combined assessment by children's social care and health services to assess whether she's being maltreated or neglected. She has significant medical problems and her mother is unable to keep her safe. She has bruising to her arms which could due to "reasonable restraint" by her mother, or they could be deliberately inflicted by her mother or someone else. She in not getting to school on time and often arriving hungry, which may signal neglect or be indicative of the child's challenging behavior as autistic children are notoriously difficult to feed. There should be a full medical examination, a strategy meeting and possibly a Section 47 investigation led by children's social care.

The family need re-housing in a property which is safe for the child, with an adequate number of bedrooms and access to a safe outdoor space. She requires an appropriate school which can cope with her special needs and provides important extras such as an after-school club, breakfast club, and holiday schemes. She needs regular assessment and review by community paediatricians, a child development team, and child and adolescent mental health professionals working closely together. The family need input from social services, such as a family support worker who can advise, support, and provide practical help. It is of the utmost importance that all these workers communicate with eachother regularly and work as a team – ideally as a "team around the child".

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Case illustration 2: safeguarding and child protection

This child and her family need a complex package of care with carefully coordinated work from health, social, and education sectors. She needs

expensive time-consuming care, to prevent the substantial social and financial costs that would otherwise ensue.

Each part of the team looking after this child needs to be aware of, and working closely with, other organisations involved. This level of cooperation is essential to ensure the child's safety. If she turns up at school with bruises, and instead of being taken to the hospital that knows her, she is taken to the nearest hospital for assessment, it is vital that communication channels are fully open between those hospitals and all the rest of the team. Otherwise what could be a serious episode of abuse, perhaps heralding a more serious event, even death, could be missed.

The Health and Social Care Bill will not enable education, health, social and community services to provide the integrated patient-centred care envisaged by Professor Sir Ian Kennedy in his 2010 report on overcoming cultural barriers in the NHS.

This child needs an overview of her family's health needs looking across organizational and geographical boundaries. A seamless care plan will include primary care, social services, housing, Special Education Needs Co- ordinators (SENCO), Child and Adolescent Mental Health Services (CAMHS), education, community paediatricians, children's nurses, allied health professionals and the voluntary sector.

There is no provision in the Bill to ensure such an integrated care package is available.

Clinical commissioning groups have no financial incentive to commission the proactive preventative and supportive measures, for example at Children's Centres, that are needed to support this mother in meeting the needs of all 4 children and avoid the significant social and financial costs that failure to meet those needs may subsequently entail.

The 'choice mandate' will not confer this mother any advantage in meeting her children's needs, or in protecting them from neglect and abuse. Competition between providers favours large organisations delivering high volume low cost care. It does not drive service improvement for children with complex health and social needs. Small voluntary sector providers will be unlikely to compete successfully with larger providers. Many services for this family will be low on the priority list for commissioners, such as specialist community schemes for children with autism, psychologists and community nurses who can teach the mother coping strategies and parenting skills known to improve outcomes for children with ADHD more effectively than medication; school breakfast clubs, after school clubs and holiday schemes that could provide the extra support that makes the difference from this family reaching a crisis point .

Social services need to work with multiple health, social, and education agencies to monitor the children in this family who are at high risk of abuse or neglect. Competition brought in by this Bill will mean vital services being cut. Social

workers will be stretched more than they currently are, so the threshold for social worker intervention will inevitably be raised. Children will slip through the net as a result.

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Case illustration 3: child and adolescent mental health

A pregnant woman has anxiety attacks and when her baby boy is born she becomes depressed. He rarely sleeps and cries a great deal. She feels persecuted by the child, whose attachment to her is disorganized, putting him at high risk of maltreatment. By the time he gets to nursery class he can neither hold a pencil nor a conversation. His school years are not a happy time – borderline achievement and poor conduct results in multiple detentions and exclusions. By sixteen he is himself depressed, is lured into gang memberships and has had frequent contact with the police. His girlfriend is pregnant. He fails to attend counselling sessions which the local CAMHS has provided for him.

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Case illustration 3: child and adolescent mental health

The Health and Social Care Bill does not provide for early intervention for this boy and his mother. During pregnancy this woman may not ask for help but the needs of both herself and her unborn child must be attended to *right away*, by skilled assessments and interventions from midwives, psychologists, and social workers in a perinatal 'team around the fetus'. This is collaborative and preventive health that individualised competing clinical services could never provide.

The earlier the intervention the better, but at any stage of this child's life integrated social, educational, medical and psychological services must be available in order to minimise developmental harm, and significant costs to social services, education, and the criminal justice system.

The Health and Social Care Bill will not help these children and their families and will make their lives more difficult

- The removal of area-based population responsibilities renders the assessment of child health needs and planning of child health services significantly much more difficult. Who will take an overview of children's health needs looking across organizational and geographical boundaries? Who will ensure that primary care and the diverse range of community-based and specialist medical and allied health professional, social and educational services for children are planned, coordinated, and delivered in a

way that makes sense for the family, and makes the best use of health service resources?

Services for children with chronic conditions, disabilities, and rare diseases will become more fragmented and parents will have to work harder to find the right care for their children.

Children at risk of neglect and abuse will be put at heightened risk by the fragmentation of services that will be brought in by the new emphasis on competition in the NHS.

- Clinical Commissioning Groups will have the power to decide for themselves which services they will provide for their registered population. This will lead to CCGs "cherry picking" those patients who are low users of health services and will severely disadvantage children with complex conditions and disabilities whose care is expensive and difficult to coordinate.

  Children will attract little interest from competing providers. Children will be left behind in the new NHS that puts profits before patients.

- CCGs will control budgets and decide what they think are reasonable requirements for services for their patients. Low profit, expensive services are likely to be cut. On the other hand, profits generated by CCGs can be kept for GPs own salary and benefit. Moreover since services that CCGs decide not to provide can then be offered by private health care providers, an inevitable and damaging conflict of interest arises.

  Clinical Commissioning Groups can feather their own nests at the expense of services for children.

- Most of the conditions for which child and adolescent mental health services are sought are chronic. Therefore parents and other caregivers need integrated systems of care throughout childhood and adolescence. The notion of patient choice means far less to such families than having quality services that work together.

  Children and adolescents with mental health problems will have greater problems finding care that will support them in times of need.