

The changing framework for children with complex care needs

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The last government

- Did quite a lot to try and advance services for disabled children
- Much of it was large documents
- Some of it was translated into practical benefits:
 - short breaks
 - better information
 - more uniform standards for some conditions

National Service Framework



STANDARD 8
Children with
disability or complex
health needs



Standard 8

- Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, enable them and their families to live ordinary lives



Main themes

- Services promote social inclusion for disabled children and young people to enable them to participate in childhood, family and community activities
- Children and young people have increased access to hospital and primary health care services, therapy and equipment services and social services
 - Services are co-ordinated around the needs of the child and family: care pathways, team around the child
- Services provide early identification of health conditions, impairments and any social and physical barriers to inclusion through integrated diagnosis and assessment processes

- There is better early intervention and support to parents through the development of multi-agency packages of care
 - Direct payments
 - Key workers
- Palliative care is available for those who need it
 - Flexible
 - Sensitive
- Services have robust systems to safeguard disabled children and young people who are more vulnerable to abuse
- Multi-agency transition planning for adulthood





Main themes

- Early diagnosis
- Early intervention
- Participation
- Transition
- Partnership

Early recognition and intervention

- Right From the Start
 - Diagnosis
 - Breaking (bad) news
- Together From the Start
 - Working together in intervention
- Preschool
- And into school



Exemplar conditions: autism



Good practice markers

- Participation and inclusion
- Team around the child
- Early identification and action
- Appropriate team training
- Flexibility
- User involvement
- Improved child protection
- Transition
- Death/palliative care

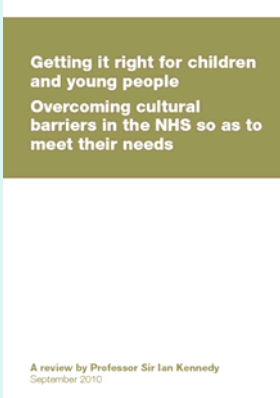
Size of the problem

- 700,000 in UK
- Severity/complexity rising
- 6,000 at home with assistive technology
- Each year 10 professionals, 20 hospital/clinic visits
- Barriers to community participation
 - Environment (accessible play and leisure)
 - Poverty (costs 3x able child, parental employment, benefits, direct payments)
 - Equipment (often multiple)
 - Ethnic background



But what happened?

- Children's Trusts never fully got off the ground
- In some senses working with local authorities is less joined up now than before
- PCTs didn't all sign up
- Difficult to extract funding for children from blocks
- Short break funds vanished
- Etc.



Getting it right for children and young people
Overcoming cultural barriers in the NHS so as to meet their needs

A review by Professor Sir Ian Kennedy
September 2010

Commissioned by Labour

- Cultural barriers prevent improvement in services for children and young people
- These originate from government
- Services vary widely across the country
- Many need significant improvement
- Some models of excellence could be more widely adopted
- Lower priority given to children's services

UNICEF study

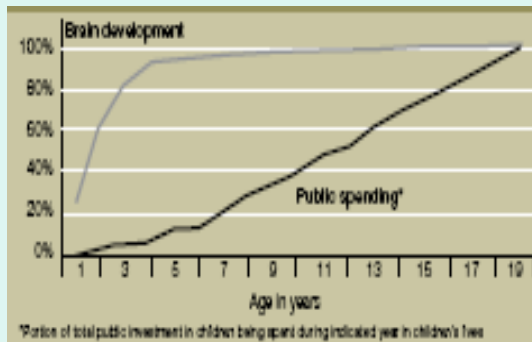
- Ranked UK bottom out of 25 industrialised countries for various measures of well-being enjoyed (or not) by children

Primary Care

- Many GPs have little or no experience of paediatrics
- A&E becomes the default option
- Not all A&E can deal well with children
- Networks of care built around children's hospital units
- GPs as the hub from which to navigate

Joined up services

- Lack of co-ordination between services
- Complexity of services
- NHS not a single system
- Let alone collaboration with other agencies
- 'Transition' means an abrupt change of service at an arbitrary 16 or 18
- Failure to share relevant information



Policy

- Policy comes from more than one government department and frustrates local co-operation
- Needs to be a holistic approach to overall welfare of children and young people
- One government roof
- Funding for children's service to be distinct
- Agree a common vision

Local partnership

- Holistic focus on children and YP
- Duty for local organisations to work together
- Appropriate ways of ensuring accountability to the public
- Emphasis on efficiency in service provision
- Children and YP should be actively involved
- Good leadership

Changing the NHS

- General Practice will take on a more proactive role as navigator of the system
- The hub of a network of services
- Dedicated information officer in every practice
- Initial and revalidation training should include care of children and YP
- More investment in early years
- Family nurse practitioner programme

Data

- Data sets
- Long term conditions, disability
- Outcomes and satisfaction

Care Quality Commission
Audit of services for disabled children

Transition

- Greater flexibility
- Greater continuity of care into early adulthood
- Continuity of care that ignores birthdays and concentrates on needs

Changing how people work

- People feel beleaguered
- The system must reconnect with its professionals
- Electronic patient records
- Common curriculum for all disciplines

EACD survey

The Tory response (RCPCH)

- More radical suggestions rejected:
 - Single government department
 - Local Partnership organisations
- Government does not want to deviate from the white paper



So what does the white paper say about disability?

- Coherent 24 hour service
- Feedback from children and families
- Shared decision making
 - No decision about me without me
- Via local HealthWatch
- Local Health and Wellbeing Boards
 - Should be the place of joined up multi-agency management
- HealthWatch England would be over-arching
 - Link with CQC: audit and outcome

Information Outcomes

- Better information for families
- Outreach services in Children's Centres
 - Health Visitors
- Need for clear outcome standards
- CQC survey coming up
 - Very much linked to patient experience
- BACD and other organisations asked to contribute
- Information sharing

Personal health budgets

- Aiming High
 - Pilot of individual budgets for disabled children and their families
 - Could be extended to include health
- Choice of any provider, choice of consultant led team, choice of GP practice and choice of treatment

Improving outcomes

- Money will follow the patient through transparent, comprehensive and stable payment systems across the NHS to promote high quality care, drive efficiency and support patient choice
 - BUT no specific tariffs for disability
- Providers will be paid according to their performance. Payment should reflect outcomes, not just activity, and provide an incentive for better quality

- National outcome goals: CQUIN
- Translated into a commissioning outcomes framework for GP consortia
- 5 outcome domains, including:
 - Prevention of premature death
 - Enhancing quality of life for people with long term conditions
 - Positive experience of care
- Quality standards developed by NICE

The bureaucracy

- GPs and their practice teams working in consortia
 - Local commissioning
- PCTs abolished 2013
- NHS commissioning board
 - National and regional specialised services
- Taskforce on Childhood and Families
- Public Health cabinet subcommittee
- DCFS now the DfE again
- Foundation Trusts
- LEAs with a strong enhanced strategic role
 - Joined up commissioning

- “We do not intend to set out centrally how local Children’s Trusts and Health and Wellbeing Boards would work together....up to local partners to decide”

Equity and Excellence: Liberating the NHS

Council for Disabled Children Response to the Health White Paper

October 2010

Council for Disabled Children Response to White Paper

- Local Health & Well-being Boards best placed to co-ordinate commissioning
- Consistency across agencies in a locality
- Good communication between local and specialised commissioners
- Accountability of local leaders to the public

Abolition of SHAs & PCTs

- Healthy lives, brighter futures
- EDCM
- SHAs & PCTs failed to deliver improved services
- PCTs slow to implement
- Designated funding hard to find locally
- Will anything change?

GP Consortia

- Training to provide universal health care for disabled children very limited
- Low patient numbers mean low on the job experience
- Little experience of specialist commissioning
- GP consortia may view provision of universal and specialist services for disabled children as a low priority
- Quality and Outcomes Framework: incentives

GP Consortia

- Some consortia develop specialist expertise
- Individual practices: 1 GP and 1 nurse with specialist knowledge
- Community nursing involvement
- GP role in transition?

Any willing provider

- How to assess quality?
- Needs of family not provider
- Small specialist providers not marginalised

Local health and well-being boards

- So far lack of progress engaging health in children's trusts
- Will this improve?
- Children's Trust guidance March 2010
- Children's services must not be lost in the wider agenda
- Another opportunity to align agencies

Remit should include:

- Community services such as school nurses, community paediatricians and children's centres
- Services for disabled children – joined up working between health and social care
- Power to steer local commissioning

HealthWatch

- Parent Carer Forums have been established in every local area
- National Parent Carer Forum Network under development
- Long term strategic participation of disabled children and their families
- How does shared decision making really work?

NHS information revolution

- Will it help in co-ordinating care?
- York Health Economics Consortium:
 - Lack of definitions in disability
 - Lack of recorded data
 - Limited information on local disabled populations and health needs
- Few outcome indicators relate to children
 - None specifically to disabled children



THE END