



# **Children's Services in the UK – National policy issues around families and their disabled children**



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# A changing population of disabled children

- Using the broad DDA definition of disability, it is estimated that there are around 11 million disabled adults and 770,000 disabled children in the UK (about 7% of the population aged 0-16).
- Since 1975, children 0-16 have formed the fastest growing group of disabled people in the UK (from 476,000 in 1975 to 772,000 in 2002). This represents an increase of 62%. [Prime Minister's Strategy Unit Report, 2005]

# Why is the population changing?

- Improved neonatal care and associated survival of very low birth-weight babies or young children with very complex special needs.
- There is a marked (unexplained but much debated) increase in children and young people with Autistic Spectrum Disorders, ADHD and a range of mental health disorders. But issues about interface between disability related behaviour difficulties and the 'Respect' agenda!

# Behaviour matters!

- **Behaviour key concern for children and services** – University of California (2005) found a 300% increase in prescriptions for children under five with behavioural difficulties/disabilities.
- **Institute of Psychiatry** (Professor Stephen Scott, 2006) found that potentially severe behavioural difficulties identifiable as early as 2.3 but early intervention often not available.
- **Costs of behavioural disabilities:** Same study mirrors USA research, estimating that costs of severely disruptive behaviour can amount to £4-6,000 pa. Also linked to wider health issues – Scott found that two fifths of children in study were admitted to hospital for average stay of 8 days in previous year because of behaviour or accidents related to condition. High risk of depression or mental health problems in mothers.

# Issues of Social Exclusion

- Only 4% of disabled children currently receive support from social services
- The prevalence of severe disability increasing
- Up to 55% of disabled children live in poverty
- Evidence of lower educational attainment for disabled children – 60% of young disabled people 16-19 not in education, training nor employment [Youth Cohort Study, 2004]

# Care Matters – too many disabled children living/being educated away from home?

- Disabled children at greater risk of living away from home: c9400 children with disabilities or SEN in residential schools, c.1,500 in social care. (90% boys of 10 years or over).
- 4% increase in use of out of authority provision 2003-2005
- Behavioural, emotional or social difficulties (BESD) most common presenting reason for placement outside family home. **[CIN Survey, 2004/Pinney, 2005, Disabled Children in Residential Placements]**

# 'End Child Poverty' key Government objective – but families with a disabled child are more likely to be:


- Single parents (30% compared to 14% of general population)
- Working part-time (32% compared to 15%)
- 50% more likely to be in debt – families earn on average 17% less than other families.
- 50% more likely to live in temporary, poor or over-crowded accommodation
- 50% less likely to have holidays or 'treats'

**(Emerson and Hatton (2005), University of Lancaster)**

# A Changing Picture- Parents

- Increasing expectation on parents in relation to care and therapy needs
- Increasing expectations of services
- A strong policy message on parental involvement (and parental responsibility)
- But changing family structures and concerns that some parents have unacceptable levels of care.

# Key policies and areas for delivery

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- National Service Framework
  - Every Child Matters-Change for Children Programme
  - Children's Trusts
  - Improving the life chances of disabled people (PMSU, 2005) and Office of Disability Issues
  - DDA 2005: the Disability Equality Duty

# Common messages

- Integrated services and multi-agency partnerships
- Strategic Planning and JARS (Joint Annual Reviews): key roles for Directors of Children's Services and Lead Elected Members
- Pooled budgets/Health Act flexibilities

## Common principles – achieving the five outcomes for all children (and parents)

- Being healthy
- Being safe
- Enjoying and achieving
- Making a positive contribution
- Economic well-being

Strong focus on *outcomes*, ie 'life chances' and 'ordinary lives' (system change rather than single interventions)

# And new roles.....

- **Directors of Children's Services** (but issues around transition planning and relationship with Directors of Adult Services for 'new generation' of disabled children).
- **Personalised services** – Lead Professionals (some budget holding)– and Key Workers
- **Working towards common standards** – the Children's Workforce Development Council and Children's Workforce Network

# Strong focus on outcomes rather than short term interventions

- **Direct Payments and Individual budgets** (pilots under way)
- **The Early Support Programme (and new Early Years Foundation Stage)** – strategic approaches to early intervention
- **The Childcare Act 2006** – childcare in children's centres and extended schools positive developmental experiences for children, reliable support for employment and route out of poverty for parents.

# Steps for change- working together: The Children's Trust Concept

*'By 2008, local authorities are required to have in place arrangements that produce integrated working at all levels, from planning through to delivery, with a focus on improving outcomes. Local authorities may choose not to call this a 'children's trust', but the important point is that the way of working is in place and committed to'.*

# Working for operational change

- Integrated services, Common Assessment Framework and information sharing
  - Key working and Lead professionals
  - Children's Safeguarding Boards
- Active participation of disabled young people
- Parents – partners in policy-making
- Transition to adulthood

# Developing multi agency working

- **Integrated Services** [with development of roles of Lead Professional and Key Workers]
- **Common Assessment Framework** (with appropriate cross-referencing to other assessment arrangements)
- **New Commissioning Framework** for 'Health and Well-being'.

# The 'Parenting Agenda' cont...what do parents want?

- *'We need the services that all parents need – good childcare, the occasional break, decent homes, fun for our children – we need time for ourselves. And we sometimes need to work – childhood is not free in the 21st century!' Most of all, we want services which don't break us up into little pieces like Humpty Dumpty – and then fail to put us all together again! That's the challenge, getting an ordinary life without becoming a specimen for the professionals, no privacy, no life really.'*

# The Parents' Perspective – what works!

- *'The Early Support Programme – getting information and advice right from the start, being seen as part of the solution not the cause of the problem – and of course our wonderful Key Worker!'*
- *'Regular childcare with a childminder who was trained, confident and gave us all a breather – best of all she celebrated the small steps forward with us. We felt we had an ally!'*

# Family Support – the ‘big challenges’

- Need for greater clarity over local eligibility criteria and range of family support services – shortfalls in short breaks in every area.
- The Childcare Act 2006 – delivering sufficient appropriate childcare for disabled children and young people up to age 18.
- The Carers (Equal Opportunities) Act 2004 and Welfare Reform – is ‘work’ route out of family poverty when there is a disabled child?

# The opportunities....

- **The DDA 1995 and 2005 – the 'Disability Equality Duty'** and higher expectations of public services.
- **Transition planning** – recognition of the need for a more proactive system, putting young people and parents 'in control' and planning for long-term outcomes, *'careers not placements, ambitions not crisis management!'*

# More opportunities....

- **'Education, education, education'** – taking the inclusion debate forward, developing a skilled workforce – at every level – and strengthening the voice of pupils and parents across the school system.
- **The inclusion agenda:** real opportunities in extended schools, children's centres to improve 'life chances' of disabled children and address 'life chances' and longer-term outcomes.

# Taking the 'Every Child Matters' Agenda forward

- **New duty on local authorities** to promote cooperation between agencies
- **Joined up planning and commissioning** – Integrated Children and Young People's Plans (CYPP) based on analysis of local need
- **Integrated Inspection Framework** – Joint Area Reviews (JARS) *must* address looked after children and children and young people with disabilities/learning difficulties.

# In conclusion ...Delivering the NSF 'Gold' Standard

- 'Children and young people who are disabled or who have complex health needs should receive coordinated, high-quality child and family centred services which are based on assessed needs, which promote social inclusion and (where possible) enable disabled children and their families to live ordinary lives.'