

Disabled children and young people: 21 years of policy

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Landing from Mars and looking at 21 years of children's policy in the UK, one could be forgiven for wondering whether disabled children are children at all. Whatever they are currently called (and never has a group of children had to change their name so frequently: handicapped children, children who are disabled, disabled children, children with disabilities, children with special needs, children with complex needs, children with additional needs) this group of children has occupied a range of confusing and conflicted positions in terms of government policy and guidance: often forgotten or tagged on as an afterthought, sometimes caught up by mistake in general initiatives, occasionally given high priority for brief periods, and subject to intermittent counting frenzies.

The general direction of travel is towards increased visibility, and in the last few years towards increased priority and greater clarity, although children are not necessarily being made visible or prioritised in ways that are helpful.

At a very basic level, confusion about which children should be defined as disabled has muddled our thinking and diverted attention from more important issues. Defining and recording childhood disability has proven very problematic, with attempts to create registers of disabled children hitting serious implementation issues, partly because of confusion about definitions, and partly because parents feared the association with child protection registers.

The Children Act 1989 required local authorities to identify the extent to which there are children in

need within their area¹ and to maintain a register of disabled children within their area.² Quality Protects (1999–2004) aimed to transform children's services in line with the Children Act 1989 and improve the wellbeing of children in need. Given that under the Act disabled children were automatically defined as children in need, it seemed reasonable to expect that Quality Protects would include objectives specifically relevant for disabled children. However, the only specific objective was to count them again.³

Despite several decades of counting activity, there are still wide variations in the way childhood disability is defined and recorded in England and we still are not able to estimate with any confidence the incidence or prevalence of childhood disability.⁴

Children's chances of being defined as disabled vary widely according to where they live: there is no consensus on what should be included in local definitions of disability. For example, a child in England with an autistic spectrum disorder has an 88 per cent chance of being defined as disabled, but this reduces to 55 per cent with dyspraxia and 53 per cent with ADHD. When disability definitions bump into categorisations of special educational need (SEN) the odds become even more random, with children with a statement of SEN having a 70 per cent chance of being defined as disabled, reducing to 41 per cent for children on school action plus.⁵

This would be funny if it wasn't absorbing such enormous amounts of time, energy and resources, and determining children's eligibility for support and services.

It seems that Scotland and Wales may be clearer about the numbers of disabled children: Scotland has 33,000 disabled children, of which 14,000 (or 42%) have a statement. This seems to result from the application of the Standards in Scotland's Schools Act 2000 and the Education (Additional Support for Learning (Scotland)) Act 2004.

The need to offer disabled children the same services as other children

Disabled children, being high users of services, are particularly vulnerable to the effects of change and reorganisation, and there has been constant movement of policy goalposts and often the playing field itself. Bounced around between generic and specialist services, children's and adults' services, health, education, social services and children's trusts, disabled children and their families are particularly vulnerable to the swinging of these pendulums.

Twenty-one years ago, a lot of children's policy was seen as irrelevant for disabled children, who were notable only for their absence from the mainstream. Local authority services for disabled children, including social work, were usually part of adult provision and separate from mainstream children's services.

The Children Act 1989 automatically defined disabled children as 'children in need'. This was welcomed by some as a positive step and criticised by others as unnecessary and unhelpful. The 'children first' approach of the Children Act, although well intentioned, created some confusion because some people finished the sentence thus: 'disabled children are children first so we'll just treat them like other children'. The renewed opportunity to deny children's additional needs set things back several years.

Guidance to the Children Act⁶ clearly stated that disabled children should have access to the same range of services as other children, but despite this commitment, following the Children Act some policy initiatives ignored disabled children altogether. For example, many area child protection committees hurriedly added appendices to their procedures in the early 1990s when they realised they had forgotten to consider the needs of one of the most vulnerable groups of children. Fifteen years on, disabled children remain under-represented on child protection registers, while research suggests they face a significantly increased risk of all kinds of abuse.

Disabled children were sometimes unintentionally caught up in generic children's policy. For example, the

introduction of the looked-after children's regulations was rapidly rethought when it became clear that disabled children using respite care would be subject to the rigorous reviewing process. This remains hotly debated, and an unknown number of disabled children remain looked after by the state but not technically looked after, because they are using respite care or are in hospital or residential education.

Similar processes went on in relation to disability legislation and guidance, aspects of which apply to children more by default than design. For example, the Disability Living Allowance in 1992, the Disability Discrimination Act in 1995, the Carers (Recognition and Services) Act 1995, and Direct Payments in 1996 were all introduced primarily with disabled adults in mind and required substantial revision as the implications for disabled children became clear. The Disability Discrimination Act was not implemented in schools or colleges until it was 10 years old and Direct Payments were only extended to disabled children after five years.

Disabled children and their families are now entitled to assessment under a baffling array of legislation and guidance: the Chronically Sick and Disabled Persons Act 1970; the Disabled Persons (Services, Consultation and Representation) Act 1986; the Children Act 1989 (which contains a power but no duty to assess unless it is suspected a child is at risk of significant harm); the NHS and Community Care Act 1990; the Carers (Recognition and Services) Act 1995; and The Carers and Disabled Children's Act 2000. The Framework for the Assessment of Children in Need and their Families (1999) was one of the first to include specific practice guidance on assessing disabled children. Unfortunately, this was published separately from the main guidance so many practitioners still don't know it is there.

Major policy developments in recent years

The first eight years of the 21st century have seen major policy developments affecting disabled children, a much clearer sense of direction and, recently, significant new resources. For the first time there is some clarity about what ought to be happening for this group of children.

The Special Educational Needs (SEN) and Disability Act 2001 strengthened entitlement to mainstream education and protection from discrimination, and the new Disability Equality Duty (2006) required all public sector organisations (including schools) to ensure that disabled children are fairly treated. The five-year strategy for SEN, called Removing Barriers

to Achievement, identifies action to improve early intervention and embed inclusive practice in schools and early years settings.⁷

The 2004 National Service Framework for Children, Young People and Maternity Services, in particular Standard 8, sets clear standards for service provision for disabled children and young people.⁸

The Prime Minister's Strategy Unit report, *Improving the life chances of disabled people*, published in January 2005, set out the government's strategy for disabled people and included some 60 recommendations for improving disabled people's lives. It focused on four key themes: early years, the transition from childhood into adulthood, employment and independent living. The Office for Disability Issues (ODI) was launched in December 2005 to drive this strategy forward and report publicly on the progress being made. This marked a real step change in the way that government thinks about the impact of its policies and services on the lives of disabled people, by incorporating a social model perspective: that is, the belief that people are disabled not by their impairments but by the way society responds to them or, in many cases, fails to respond to their needs and aspirations. The report set out a clear and ambitious vision for government: that by 2025 disabled people should have the same opportunities and choices as everyone else; should be respected as equal members of society; and should be able to participate as equals in every aspect of family and community life.

Every Child Matters provides a positive outcomes framework for all children, and the government recently noted that disabled children – who often need support from a range of services – should be benefiting 'even more than most' from the reforms of the Every Child Matters programme.⁹

However, this isn't entirely accurate: five years after the introduction of Every Child Matters, several major children's charities found it necessary to launch Every Disabled Child Matters, reflecting their continuing concerns about services, high levels of unmet need, duplicated assessments, poor information and fragmented, unco-ordinated provision.¹⁰ As highlighted in *Aiming High for Disabled Children: Better support for families*, 'across local authorities, disabled children and families are offered different levels and standards of care, those most in need are not always the most likely to get support, and parents and young people in some areas feel insufficiently empowered, informed, or involved'.¹¹

Three priority areas have now been identified: access and empowerment; responsive services and timely support; and improving quality and capacity.¹² Aiming High for Disabled Children (launched by the government in May 2007) sets out a 'core offer' to disabled children and their families, which will encompass minimum standards in five areas identified by research as playing a significant role in the delivery of responsive services. These areas are: clear information; transparent eligibility criteria and/or processes for accessing services; accessible feedback and complaints procedures; and participation by parents and children in shaping local policies and services. Aiming High for Disabled Children informed the government's spending plans for the three years to 2011.

At last, we have a plan: a properly resourced, long-term plan with explicit aims. Brilliant. Unfortunately the plan's first priority, to which £280 million of the new £430 million is committed, is to increase the availability of respite care. Although re-named 'short breaks', in the past this service has often been framed entirely around parents' entitlement to regular respite from their disabled child. This is a spectacularly unfortunate starting point from which to aim high for disabled children because it could perpetuate both the burden/tragedy perspective and also the separateness of these children's lives.

Aiming High for Disabled Children sets out to redefine and broaden our understanding of short breaks. Local commissioners will need to take up the challenge. It is not too late – Aiming High for Disabled Children could divert the resourcing of short breaks away from narrow respite and towards the resourcing of decent lives for disabled children. This would remove the 'burden' emphasis, with all that this carries with it. In addition, if disabled children are given skilled and robust support to make friends, go out, have fun and join in with life, their parents would automatically get regular short breaks, although this would not and should not be the primary function.

Creating more competent and inclusive communities offers another way forward: Wales, for example, is investing in personal care facilities aimed at disabled children in five major venues and in integrated play facilities as part of the social inclusion agenda.¹³

A lack of strategic direction

The lack of strategic direction has contributed to a high level of chaos and inequity and a culture of fighting for entitlements. It also means that people have the wrong arguments again and again: inclusion versus segregation; children's rights versus parents' needs; defining and redefining childhood disability.

As the government has recently noted, it has 'traditionally' been the case that disabled children are likely to have poorer outcomes across a range of indicators compared to their non-disabled peers, including lower educational attainment, poorer access to health services and therefore poorer health outcomes, more difficult transitions to adulthood, and poorer employment outcomes.¹⁴ Disabled children are also significantly over-represented in the populations of looked-after children¹⁵ and young offenders¹⁶ and research tells us that a significantly higher proportion of disabled children should have a child protection plan,¹⁷ although it appears that this is rarely the case.¹⁸

In 1998, the Labour Government pledged to halve child poverty by 2010 and end it by 2020. It is clear that these targets cannot be achieved without specific attention to children affected by disability and that services, including health, social services and education, are not only failing to mitigate poverty, they are often accelerating poverty. Families who are relatively financially secure descend into poverty when they have a disabled child.¹⁹ Children affected by disability are at greater risk of living in poverty, with over half of families with disabled children living in or at the margins of poverty.²⁰

Looking ahead: planning for and with disabled children

We know enough to do things differently. Disabled children have the same basic needs as other children. We do not need to start from a different position, but we do need to make sure that every time we plan for children we plan for all children, and we need to think disabled children into every local and national initiative, and not add them on afterwards. We also need to involve disabled children and young people in our thinking and planning: their voices are almost silent in these discussions.

It is crucial to remember that some of the most damaging aspects of the lives of disabled children are not an inevitable consequence of the child's condition or impairments. The five outcomes in Every Child Matters are relevant for all children, but are much harder to achieve for some children than others. We know that disabled children have the same 'ordinary' wishes and needs as other children (ie to live at home with their families, go to school, spend time with their friends, and participate in leisure and community activities with family and peers) but they face major barriers on all levels, so that getting these 'ordinary' things remains extraordinarily difficult.²¹

These are our five key recommendations to government:

- rethink the focus on 'respite' and short breaks, quickly, towards a focus on accessing basic rights and decent lives for disabled children
- monitor disability/SEN on all child protection registers to build an accurate national picture
- actively address disability issues in the child poverty strategy
- ensure disabled children are thought in, as routine, in all policy initiatives affecting all children
- develop basic skills in communicating and consulting with disabled children and make this a required competence for all professions in direct contact with children

Endnotes

1. The Children Act 1989 sch 2 para 1(1)
2. The Children Act 1989 sch 2 para 2(1)
3. Quality Protects 1999, objective 6.1
4. *Disabled children: numbers, characteristics and local service provision*, Mooney, A, Owen, C and Statham, J, Thomas Coram Research Unit, Institute of Education, University of London, 2008
5. *Can we count them? Disabled children and their households*, Read, Dr J, Spencer, Professor N and Blackburn, Dr C, University of Warwick, 2008
6. DH 1991a, para 1.6 Children Act Guidance: Children with Disabilities
7. Department for Education and Skills, 2004
8. Department of Health, 2004
9. HM Treasury, 2007
10. Audit Commission 2003 Review of Services for Disabled Children and their Families DWP, DoH, DfES, OPMD (2005), *Improving the Life Chances of Disabled People*, HMSO, London
Marchant, R, Lefevre, M, Luckock, B and Jones, M (2007) *The Social Care Needs of Children with Complex Health Care Needs*, Social Care Institute of Excellence, London
House of Commons Education and Skills Committee, 2007 *Special Educational Needs: Assessment and Funding*; Ofsted, 2004 *Special educational needs and disability: towards inclusive schools*
11. HM Treasury and Department for Education and Skills, 2007:14
HM Treasury/DfES 2007 *Aiming High for Children: Better support for Families* HMSO, London
12. HM Treasury and Department for Education and Skills, 2007 *ibid*
13. Personal care facilities and integrated play facilities in five major venues in Wales (as part of the social inclusion agenda) were announced by Jane Hutt, Children's Minister for Wales, and reported in the LLAIS newsletter Spring 2008 [www.learningdisabilitywales/org.uk/pdfs/disabled children](http://www.learningdisabilitywales/org.uk/pdfs/disabled%20children)
14. HM Treasury/DfES 2007 *Policy review of children and young people – A discussion paper*, HM Treasury and Department for Education and Skills, January 2007
15. Disabled children are disproportionately represented within the looked-after population, making up 10 per cent of all children in care, and only around five per cent of the overall population
16. See Herrington et al 2007 p14 for a recent summary of the research.
Herrington, V, Harvey, S, Hunter, G and Hough, M (2007) *Assessing the prevalence of learning disability among young adult offenders* in Feltham Institute for Criminal Policy Research, King's College London
17. A retrospective US study of 50,000 children found an unequivocal link between childhood maltreatment and disability, with disabled children being 3.4 times more likely to be abused – a 31 per cent prevalence rate against nine per cent for non-disabled children (Sullivan and Knutson, 2000). There is no comparative research in the UK. Sullivan, P and Knutson, J (2000) 'Maltreatment and Disabilities: a population-based epidemiological study' in *Child Abuse and Neglect* 24(10)
18. Two per cent of disabled children in need are on the child protection registers in England, in comparison with eight per cent of the general population of children in need (Cooke, 2000). Concerns about the abuse of disabled children are 50 per cent less likely to be case conferenced (Cooke and Standen, 2002).
Cooke, P (2000) *Final Report on Disabled Children and Abuse*, The Ann Craft Trust
Cooke, P and Standen, P (2002) 'Abused and Disabled Children: Hidden Needs...?', *Child Abuse Review*, 11: 1–18
19. *Ending child poverty – the disability dimension*, Disability Rights Commission, August 2006
20. *Poverty and social exclusion in Britain*, Gordon, D et al, Joseph Rowntree Foundation, 2000
21. Marchant, R, Lefevre, M, Luckock, B and Jones, M (2007) *The Social Care Needs of Children with Complex Health Care Needs*, Social Care Institute of Excellence, London

as long as it takes